

# QUEST

MDA's Research & Health Magazine

**Getting from  
Here to There**  
Special transportation issue

**Focusing on  
Periodic Paralysis**

**Telethon 2009**

**Portable Wheelchair  
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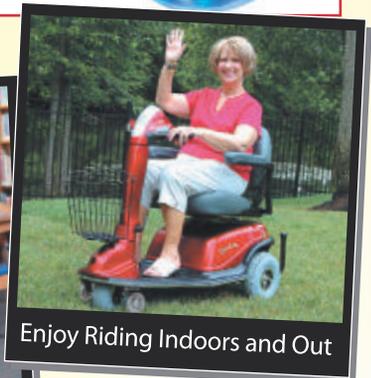
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# QUEST

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July-September 2009

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Despite the summer heat, at MDA it seems like it's just minutes until Labor Day and our biggest fundraising event of the year, the **Jerry Lewis MDA Telethon**. As you can imagine, planning for this mammoth, 21½-hour national event is quite an undertaking.

We know we can always count on the presence of our No. 1 volunteer, Jerry Lewis, who has never missed a show for "his kids" in 43 years, and whose dedication has made the Telethon a legend around the world.

Once again we'll be broadcasting live from the South Point Hotel in Las Vegas, which has graciously contributed its marvelous facilities to us for the past four years. We again will be benefiting from the talents of our wonderful volunteer celebrity co-hosts **Tom Bergeron, Jann Carl, Billy Gilman, Nancy O'Dell, Alison Sweeney** and **Ace Young**. This year, for the first time, former MDA National Goodwill Ambassador **Luke Christie** will join the national broadcast as the host of the youth segments, in his role as our new MDA National Youth Chairman.

To learn about some of the wonderful individuals and families who'll be profiled on this year's show, see the article on page 58.

We're betting that the Telethon will continue to achieve the ratings success it's shown in the past few years. Even as major network television viewership generally declines, the Telethon's ratings are healthy. Last year's show was watched by 22 million households, giving it an audience comparable to "Dancing with the Stars" (also hosted by MDA National Vice President Tom Bergeron), "Desperate Housewives" and the Academy Awards.

Although the Telethon is MDA's best-known fundraiser, we couldn't sustain our programs of research, services and education were it not for the work throughout the year of our national sponsors. These dedicated organizations and businesses are highlighted on the Telethon when they present facsimile checks representing their yearlong efforts in behalf of the Association.

Want to help us say thanks to them? Please look through this list of **MDA national sponsors** and then, in your own communities, support and acknowledge them — they mean so much to the fight against muscle disease:

Acosta; Burger King; CITGO; ClubCorp; DECA (an association of marketing students); Denny's; ERA Real Estate; Harley-Davidson Motor Company; Homebuilders; International Association of Fire Fighters; International Health, Racquet and Sports Club Association; Kappa Alpha Order; Kroger; Lowe's; National Association of Letter Carriers; National Child Care Association; Outback Steakhouse; Real Networks; Safeway; SUPERVALU; 7-Eleven Franchisees; 7UP; Tall Cedars; Valero and the Universal Cheerleaders Association.

Have a wonderful summer — we'll see you over the Labor Day weekend!

With best wishes,

  
Gerald C. Weinberg  
President & CEO



# QUEST

MDA's Magazine

MDA was founded in 1950 by adults with neuromuscular diseases and parents of children with these disorders. It's a voluntary health agency working to defeat neuromuscular diseases through worldwide research, advocacy, comprehensive services, and professional and public health education.

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## Surreal experience

Thank you for your great magazine! At first it made me emotional, but I figured out it helped put me in reality. I was diagnosed with *myasthenia gravis* two years ago.

I'm 55. I worked as a hairdresser for 35 years. [Every year] when I was a kid, my best friend and I went door-to-door and collected money for MDA. This was in the '60s. It got surreal for me when I became ill. I helped contribute to my own recovery! I just wanted to tell you my story and to thank you.

*Madelyn Young  
Portsmouth, Ohio*

## Paid family caregivers

I'm 50 [and] was diagnosed with FA [*Friedreich's ataxia*] when I was 25. I've been in a wheelchair for over 18 years.

I'm writing about family members being paid to be caregivers. My daughter is my caregiver and yes, the company she works for knows she's my daughter and pays her for her time. I'm not the only person who needs a caregiver and would love to have a family member get paid to help them.

I think our government should help all

In each issue, space allowing, Quest will run letters sent to MDA, National Chairman Jerry Lewis or to the magazine.

Write to: MDA Mailbag, Quest, MDA, 3300 E. Sunrise Drive, Tucson, AZ 85718-3299. Or e-mail letters to [publications@mdausa.org](mailto:publications@mdausa.org).

Letters must be signed and contain a daytime phone number, city and state, and be no more than 250 words. Letters may be edited for space.

If you have questions about your Quest subscription and are registered with MDA, contact your local MDA office by calling (800) 572-1717. If you're not registered with MDA, direct subscription questions to the national office at (520) 529-2000.

disabled people in every state. My e-mail is [teresa\\_fuller@sbcglobal.net](mailto:teresa_fuller@sbcglobal.net), so write me if you want to reply.

*Teresa Skyles  
Osage, Okla.*

## Great issue!

I have been happy to receive the Quest magazine over the years, but this one (March-June 2009) really was helpful.

1. "From Where I Sit" ("Am I Disabled or Aren't I Disabled?") is right up my alley! Most are not aware I have *myasthenia gravis*. They don't think about my dragging feet or dropping things. They think my raspy voice is a cold. They see my droopy eyelids as if I'm sleepy. I feel guilty when I know others have so much more difficulties. But I thank God that things aren't worse.

2. Doctors have encouraged me to exercise but I've wondered how much and what kind of exercise I should do. Tiring easily doesn't encourage me to exercise. This issue was a great help, including the topic of exercising the mind. Now I don't feel bad about spending a lot of time with puzzles and reading (when my eyes will let me). I feel like a slug around my busy-bee husband.

3. Caregiving is important to me, as well. My husband is a cancer survivor. I spent a long time being his caregiver. Thank you so much for this issue!

*Louise Cummings  
LaPorte, Ind.*

## Not inspirational

I am writing to you about the very disappointing article, "The Effect of Exercise on Different Muscle Diseases," (March-June 2009). My problem is that it is most certainly not inspirational and it just might be very disheartening for those with *CMT* [*Charcot-Marie-Tooth disease*].

## Looking Ahead in Quest

The fall issue of Quest (October-November-December) will include articles about:

- Accessible office spaces
- Holiday gift guide
- Retiring a service dog
- Innovative living arrangements

Be sure to check out the new Quest home page, Quest Magazine Online ([www.mda.org/questmagazineonline](http://www.mda.org/questmagazineonline)) for additional research and features found only online.

I was diagnosed with *CMT* at 12, and am now 65. Over 30 years ago, I was told not to exercise by a "specialist" in muscular dystrophy. Since then I have bicycled at a very high level, both mountain and road. I rode around Lake Superior, and this year after retiring, I downhill skied.

These sports did not come easily. Learning to ski with very deformed feet and very weak legs was the biggest challenge of my life. I underwent three major surgeries so that I could walk and perform better in the sports I chose.

These sports transformed my life. When I was a child and couldn't run with the other kids, and later as [an awkward] teenager, my self-esteem suffered. However, through much hard work, some pain and lots of luck, I have received the benefit and joys of these recreational sports.

My belief is that inspiration may actually make a huge difference. Certainly *CMT* is a very debilitating disease and can vary widely in its effect. Because I didn't listen to the doctors, and sought out ways to participate in sports at my level, I have had and hope to continue to enjoy an active and rewarding life.

*Van Schilling  
Edmonds, Wash*

## Be proud of yourself

Have you ever felt like you were all alone — like no one knew that you existed? Well, that was how I felt in high school. I have [myotonic muscular dystrophy](#). No matter how hard I tried to make it seem insignificant, I was defeated at every attempt.

My physical abilities were not up to par, but my emotions ran high. Oh how I hurt and wanted people to understand, and to treat me with dignity and respect. High school felt like a battlefield, knowing I was different, praying for God to make the pain go away. I had one true friend who understood that underneath my tough skin was a scared girl who couldn't understand why the world was so cruel just because she was disabled.

Nothing can change the past, but I had to change the future. Who's gonna stick up for me? Nobody but me. College changed my life. Everyone was different and it didn't matter if they liked you. It was the best feeling ever.

I learned to be myself. That's all I can do, look on the bright side and know there's a silver lining in the clouds of doubt. My advice is to remember you are bigger and stronger than what they say you are. You are better than that. Just be proud of yourself.

*Sarah Jefferson  
Union, Ill.*

*The following letters are in response to "The Quest for Fabulous Wheelchair Fashion" (March-June 2009).*

## AFO fashion sense

Fabulous Fashion? I wear AFOs [ankle-foot orthoses] and stopped watching "What Not to Wear" because of the incessant mocking of long skirts and clunky shoes.

There's no escaping the knee-high sock pulled up and over the calf strap. Nylons and tights catch and tear and you're left with runs in your hose.

The show touts knee-length skirts and walking shorts. HELLO to the sock cuffed over your AFO strap, which screams out "look at me!"

A length just below the knee means fabric gets hung up on the strap when walking and exposes the cuffed strap when sitting. A long skirt will cover at least this part of the embarrassment of wearing braces. If you can manage a few hours without ankle support, the "pointy toe shoe" (another of the show's mantras) is a hazard for foot-drop, even if they're ballet flats.

I have weak ankles and wide feet, made wider with AFOs. Where are the cute shoes that are low, wide and have the coverage to wrap around a brace?

It's hurtful to hear the show's hosts make fun of long skirts and sing the praise of pointy-toe heels for long, lean legs. You won't see AFOs and canes on the fashion runway.

*Ranel Gretebeck  
Oshkosh, Wis.*

## Fashion and MD

Your article missed some key points about clothing and [muscular dystrophy](#). Comfort, mobility and affordability are key issues beyond superficial looks. If you are not comfortable you will not feel very stylish.

The only pictures of the male model show him in a suit. This may be fashionable if you work at a financial institution, but that is not the majority of us.

The one useful tip the author mentioned was tailoring. This is a help only if you can afford it or have a friend do it. Tailoring that could have been mentioned to help people with neuromuscular diseases are as follows: longer zippers, or Velcro zippers (it makes dressing and toileting a whole lot easier), sew shut the pockets and cut them out. (Who wants to sit on them all day?)

Suits and fashion are not necessarily synonymous. One can be extremely professional and fashionable and still be dressed

comfortably. I spent many days at the California State Capitol talking to legislators and I never once wore a tie and was very respected by the legislators. As someone with muscular dystrophy, I had to consider being warm in the winter over the impracticality of a suit. I wore wool sweaters which are extremely warm and light. All my wool sweaters were unique and I received positive comments all the time.

Shoes are a definite issue when you are in a chair. My feet have been misshapen from my muscular dystrophy. I have always chosen shoes that are light and have little or no sole. Luckily for me, I have a friend who is a shoemaker. She makes my shoes out of buffalo or bull hide. I have a number of pairs ranging from plain to extremely colorful. I get comments constantly on my shoes.

The author placed an unreasonable amount of emphasis on not drawing attention to your feet. Tips for footwear should be: lightweight, easy to put on and take off and, once again, [appropriate for the] temperature. Crocs come in plain black and brown, are a magnitude lighter than any shoe or sneaker, and go on and off really easy. Black clogs are stylish for both men and women.

I do agree accessories can make the outfit. Jewelry that is chosen because it has meaning is always more fashionable than something purchased from under a glass counter.

Fashion is an individual trait. What feels fashionable for some would not feel fashionable for others. This is compounded when you throw in a neuromuscular disease. Ease of dressing, undressing, toileting, and temperature are just a few of the clothing traits that cannot be overlooked with muscular dystrophy. I believe this author ... missed the mark as far as fashion tips for people with muscular dystrophy.

*Dan Grover  
Chico, Calif. ☐*



## Jerry Lewis inducted into New Jersey Hall of Fame

On May 3, MDA National Chairman Jerry Lewis was among 13 prominent Americans honored by induction into the New Jersey Hall of Fame. The institution recognizes New Jersey natives and others with an affinity for the state who have achieved renown in such categories as arts and entertainment, sports, enterprise and others.

New Jersey Governor Jon Corzine said, "This group of Hall of Famers embodies the spirit of New Jersey, a combination of drive, determination and creativity that has led them to greatness." Lewis was born in Newark in 1926, and went on to become an actor, comedian, singer, director, producer, inventor and advocate for people with muscle diseases.

Other entertainment giants who joined Lewis as Hall of Fame 2009 inductees included Bud Abbott and Lou Costello, and Jon Bon Jovi. Representing other categories were basketball great Shaquille O'Neal, writer F. Scott Fitzgerald, communications pioneer Guglielmo Marconi, scientist Carl Sagan and poet Walt Whitman. Previous honorees have included Albert Einstein, Frank Sinatra, Yogi Berra and Buzz Aldrin.



## New MDA online community proves very popular

In April, MDA launched an online community, *myMDA*, where people

affected by [neuromuscular diseases](#) can socialize and exchange information. Organized under the motto "Strength in Community," *myMDA* members are people with muscle diseases, caregivers, volunteers, fundraisers, advocates, clinicians, researchers and MDA staff.

Features of the site include video and text messaging, video and text blogging, message boards and forums, photo and music video sharing, and chat rooms. Within two weeks of its launch, more than 1,500 individuals and 43 groups had registered on the site. Local MDA offices also have a presence. Groups, such as the [Duchenne muscular dystrophy](#) community and [MDA summer camp](#) community, offer a place to meet others with similar interests and concerns. The *myStory* section lets people describe their personal experiences with neuro-muscular disease. Join the community! Registration is free and open to those 18 or older. Go to [www.mda.org/myMDA](http://www.mda.org/myMDA) to register.

## Highlights of 2008 Telethon available on DVD

Every year, some of the top entertainers in the world appear on the [Jerry Lewis MDA Labor Day Telethon](#), helping raise funds for the Muscular Dystrophy Association. By popular demand, select performances from the 2008 Telethon are now available on a new compilation DVD, "The Best of 2008 Jerry Lewis MDA Telethon."

The new Telethon DVD features nearly 30 performances by a wide range of popular entertainers and musicians, including Jerry Lewis, Ace Young, Billy Gilman, Gloria Gaynor, Jack Jones, Maureen McGovern, Menudo, Neil Sedaka, Norm Crosby, ventriloquist Terry Fator, Tony Orlando, Tracy Lawrence, comedian George Wallace, Jimmy Wayne, Joshua Bell, Pat Monahan and Train, and Starship featuring Mickey Thomas — among

many others.

The 2008 Telethon DVD is available at [www.mda.org](http://www.mda.org) (click on Telethon) for \$15, or call (800) 572-1717.

## Familiar celebrities are authors, too

Two television celebrities who give of their time to MDA also have new books on the market.

**Nancy O'Dell:** The host of TV's "Access Hollywood," MDA's new ALS Ambassador and Telethon co-host Nancy O'Dell has written *Full of Life: Mom to Mom Tips I Wish Someone Had Told Me When I Was Pregnant* (Simon & Schuster). With warmth and humor, O'Dell candidly talks of her experiences in each stage of expectant motherhood, from pre-conception through delivery, and describes the intimidating but joyful first week at home with the new baby.



Nancy O'Dell



Tom Bergeron

**Tom Bergeron:** Also a Telethon co-host, Tom Bergeron hosts television's "Dancing with the Stars" and "America's Funniest Home Videos." Somehow he also has found time to pen *I'm Hosting as Fast as I Can* (HarperCollins Publishers). Although Bergeron is the picture of calm and cool on stage and on camera, his book describes (often hilariously) the incredible amount of motivation, inspiration and perseverance that was needed to achieve his unruffled demeanor. □



Luke Christie



Ben Cumbo



Lauren Carter photo: Bryn-Alan

## Former MDA National Goodwill Ambassadors still excelling

**M**DA National Goodwill Ambassadors don't stop being creative, talented, ambitious and caring when their terms of duty are over. Here are updates on the doings of a few former goodwill ambassadors:

### **Luke Christie, 2006, 2007:**

Christie, 15, of Due West, S.C., is an active member of Future Business Leaders of America, and recently was appointed to be the South Carolina representative to the national organization. In FBLA's statewide competition, Christie took first place in the job interview competition, and will participate in the national FBLA competition this summer. The energetic teen, who has [spinal muscular atrophy](#), is the MDA National Youth Chairman, replacing singer [Billy Gilman](#) in this role.

**Ben Cumbo, 1996, 1997:** Cumbo, who turned 22 in July, graduated from St. Mary's College in Maryland this spring with a major in sociology and a minor in religious studies, and plans to pursue graduate work in religious studies. Cumbo, who has [Duchenne muscular dystrophy](#), has written a book *King Me* (Trafford Publishing, 2007), and in 2007 worked as an intern for then-Senator Barack Obama.

**Lauren Carter, 2000:** Carter, who turned 18 in July, graduated in May from Morton Ranch High School in Katy, Texas. Carter was not only an honor student; she also was official chief of committees for her National Honor Society chapter; a vice president in Best Buddies, an international group that helps people with intellectual disabilities; and a teacher of a kindergarten Bible class. After a recent visit to Paris, Carter is now considering attending college there. She has [spinal muscular atrophy](#).

**Mattie J.T. Stepanek, 2002-2004:** Stepanek died in 2004, at age 13, due to the effects of [dysautonomic mitochondrial myopathy](#). But his spirit continues to have an effect on the world. His six "Heartsongs" poetry books, and a book of essays on peace that was published posthumously, have sold more than two million copies combined, and his message of peace continues to inspire peace efforts.

Now Mattie's mother, Jeni Stepanek, has inked an agreement with Dutton publishers to write the story of her son's remarkable life, which included many highs and lows, poverty and celebrity, close calls and not a few miracles.

**Messenger: The Legacy of Mattie J.T. Stepanek and Heartsongs** will include previously unpublished photos, poetry, essays and e-mail correspondence with such influential friends as Oprah Winfrey and former President Jimmy Carter. The book, due to be released in November, will have a foreword by Maya Angelou.

"Not a day goes by when I don't receive e-mails and letters saying that Mattie's poetry and speeches are not enough — people want to know about him directly and intimately," Stepanek said.



Mattie Stepanek

## Plugs and Patches Improve Muscle Health

Much attention has been paid to gene therapy and stem cell strategies for treating muscle diseases, but several less dramatic strategies also appear to hold potential, especially if used in conjunction with more definitive therapies to enhance their effectiveness.

One such new approach proposes stopping a leak of calcium inside muscle fibers affected by **Duchenne muscular dystrophy (DMD)**. Two others focus on repairing or shoring up the muscle-fiber membrane, a structure that's affected in many diseases, such as DMD, **Becker muscular dystrophy (BMD)**, some types of **limb-girdle muscular dystrophy**, and a type of **congenital muscular dystrophy (CMD)**.

### Plugging an internal leak

Investigators conducting experiments in mice with a disease resembling DMD have discovered that calcium can leak from internal storage areas in muscle fibers, and may be contributing to muscle degeneration. "Plugging" this leak could complement more definitive strategies, such as gene transfer, they say.

Andrew Marks at Columbia University in New York coordinated a team that included researchers from Montpellier (France) University and other institutions in Montpellier. They published their findings in the March 2009 issue of *Nature Medicine*.

The mice in these experiments lack the muscle protein dystrophin. In the mice — and in humans with DMD — a lack of dystrophin means a cluster of proteins nestled in a membrane surrounding each muscle fiber can't preserve the integrity of the membrane. Leaks and tears in the membrane occur and are accompanied by entry of excess calcium into muscle fibers.

Excess calcium entry into cells (which is not related to dietary intake of calcium) can cause multiple types of damage, and it's been assumed that it's responsible for some of the fiber degeneration seen in this form of MD.

However, until recently not much attention was paid to the release of calcium from internal storage areas in muscle fibers. A burst of calcium from inside the fiber is necessary for it to contract (see *In Focus: Periodic Paralysis*, page 45), but a continuous leak of calcium can be damaging.

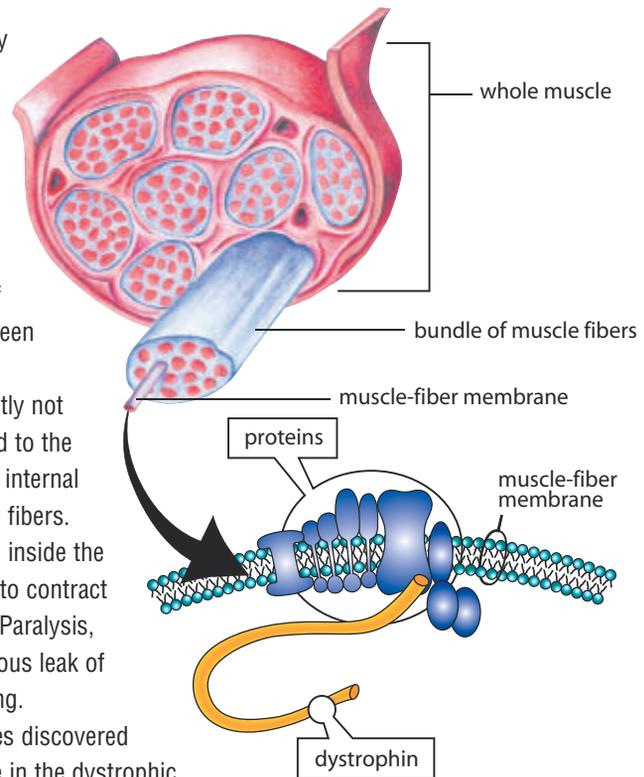
Marks and colleagues discovered internal calcium leakage in the dystrophic muscle that they say could contribute significantly to calcium-related damage in muscles and might be relatively amenable to preventive therapies.

When the researchers treated some of their mice, either orally or under the skin, with a compound called S107, they found it plugged the calcium leak without interfering with normal calcium release.

The treated mice developed better grip strength and tolerated downhill running better than their untreated counterparts, and biochemical and microscopic signs of muscle degeneration were much less severe than in the untreated group.

Improved exercise tolerance was seen after only one week of treatment, and improvement in the appearance of the muscle tissue after four weeks.

Investigators say therapeutic strategies for DMD that inhibit internal calcium leakage into the muscle fiber with a small molecule such as S107 could provide an additional way to help protect against muscle damage and improve function in this disease.



Repairing or reinforcing a fragile muscle-fiber membrane could be helpful in treating several muscular dystrophies.

### New membrane repair protein ID'd

Scientists in the United States and Japan say they've identified a previously unknown but crucial step in a natural muscle-cell repair process that could have implications for the treatment of **muscular dystrophies**, particularly those in which membrane defects are implicated.

Jianjie Ma of the Robert Wood Johnson Medical School in Piscataway, N.J. (part of the University of Medicine and Dentistry of New Jersey), with Hiroshi Takeshima of the Kyoto (Japan) University Graduate School of Pharmaceutical Sciences, and colleagues, have found that a muscle protein called mitsugumin 53 (MG53) is an essential component of the membrane repair machinery in muscle cells.

The researchers, who published their findings in the January 2009 issue of *Nature Cell Biology*, say the finding is relevant to both skeletal muscle fibers and

cardiac muscle cells.

Muscle-membrane repair, the researchers note, is required in response to exercise, injury, aging and a variety of muscle conditions. They describe a three-part repair process in which MG53 first senses damage to the membrane; MG53 steers vesicles (bubbles) carrying repair molecules to the damage site and holds them in place; and the vesicles fuse with the membrane, forming a repair patch.

Several years ago, MDA-supported researchers identified another protein, now called dysferlin, which participates in the membrane repair process. The researchers say future studies are needed to see whether MG53 and dysferlin are part of the same or different repair pathways.

### Laminin 111 protein may shore up membrane, reactivate muscle development program

A protein called laminin 111 had a marked therapeutic effect in dystrophin-deficient mice that have a DMD-like disease, say researchers at the University of Nevada School of Medicine.

Dean Burkin and colleagues, whose results were published online in Proceedings of the National Academy of Sciences on April 28, 2009, found systemic treatment with laminin 111 restored several aspects of muscle health and prevented exercise-related damage in these mice.

In their paper, Jachinta Rooney, Praveen Burpur and Burkin say laminin 111 is a “highly potent therapeutic agent” in the mouse model of DMD and could have applications for human muscle disease.

Earlier this year, Burkin and colleagues showed laminin 111 improved the muscle health of mice with an integrin-deficient form of congenital muscular dystrophy (CMD). (See [Research Updates, April-June 2009](#).)

When the investigators gave DMD mice a systemic injection of the laminin 111 protein and analyzed their tissues a month later, they were surprised to see laminin 111 throughout limb, diaphragm

and cardiac muscles. They had suspected the large size of the laminin molecule might prevent it from migrating far from the injection site.

More importantly, the laminin-treated mice showed signs that their muscle-cell membranes were intact. An enzyme called creatine kinase (CK) was not leaking from their muscle fibers into the circulation, a positive indication of membrane integrity. (Dystrophin-deficient muscles leak CK.)

And, when the muscles of laminin-treated DMD mice were examined after the mice ran downhill on a treadmill, they showed very little damage, while their untreated counterparts showed significant injury.

The laminin 111 protein normally is present in skeletal and cardiac muscles in mice and humans only during embryonic development. As tissues mature, it disappears and is replaced by other forms of laminin.

During development, it's located just outside the membrane that surrounds each muscle cell, in a gel-like substance called the extracellular matrix. While there, it increases production of a membrane protein called alpha 7 integrin, which is known to play a role in skeletal muscle regeneration and repair. (Burkin received MDA funding from 2000 to 2003 to study the role of integrin in alleviation of muscular dystrophy.)

Earlier research by Burkin and colleagues suggests the presence of the embryonic laminin protein may activate a muscle regeneration “program” like the one used to make muscle during early development. They believe it may have played additional roles in the DMD mice, such as directly reinforcing the muscle-fiber membrane.

### Success of exon skipping in dogs bodes well for human DMD treatment

Scientists at Children's National Medical Center in Washington, Carolinas Medical

Center in Charlotte, N.C., and the National Center of Neurology and Psychiatry in Tokyo, have successfully treated dogs with a disease closely resembling **Duchenne muscular dystrophy (DMD)**, using a molecular treatment strategy called exon skipping.

Exon skipping as a strategy for treating DMD is simultaneously under development in human subjects. Estimates are that 80 percent to 90 percent of boys with DMD could potentially benefit from



Eric Hoffman has MDA support to study muscular dystrophy therapeutics at Children's National Medical Center in Washington.

it. (Note: no single exon skipping drug will treat all mutations; compounds will be exon-specific.)

The investigators, who were supported in part by MDA, showed intravenous injections of a “cocktail” of

laboratory-developed compounds coaxed the muscle fibers of three DMD-affected dogs to produce functional dystrophin protein, the absence of which causes the disease.

“Many efforts have focused on treating dogs with muscular dystrophy, as it is widely expected that what works in the dogs will work in humans,” said Eric Hoffman, professor of pediatrics at Children's National Medical Center and an MDA grantee.

Exon skipping is a strategy that hides the error-containing exons (regions of a gene) from the cell's “view” in such a way that they're skipped over, and the remaining, correct instructions surrounding the region are spliced together. The spliced instructions allow for production of nearly normal, functional muscle protein that's free of genetic errors.

Two clinical trials, one in the Netherlands and the other in the United Kingdom, recently have shown that intramuscular injection of either of two

exon-skipping compounds appears safe in boys with DMD and that it can lead to production of dystrophin. (See “AVI BioPharma,” page 16.) These trials, which used compounds developed with MDA support, provide “proof of principle” for the strategy, but they only targeted a single muscle and weren’t designed to show functional benefit.

In contrast, the DMD dog experiments delivered exon-skipping compounds systemically, via intravenous injections, resulting in body-wide production of significant levels of dystrophin and improvement in the dogs’ functional abilities.

In addition, the human trials targeted only one exon, while the dog experiments targeted two consecutive exons.

In the experiments, for which results were published March 16, 2009, in *Annals of Neurology*, three dystrophin-deficient beagles each were given intravenous injections of a cocktail of exon-skipping compounds either weekly or every other week.

All three showed new dystrophin production in all examined muscles, although the degree of production varied. The average dystrophin protein production level was greatest in the dog given seven weekly doses of 200 milligrams per kilogram of the exon-skipping cocktail, causing dystrophin levels to rise from zero to 26 percent of normal.

Functional improvement was assessed by a 15-minute timed running test and by a combined functional score. All dogs that received the exon-skipping compounds ran faster after the treatment, while their untreated littermates became slower over the same period of time.

Scientists also saw marked improvements in the microscopic appearance of the muscle tissue in the treated dogs, as well as other measures of muscle health.

## Utrophin injections aid dystrophin-deficient mice

MDA grantee James Ervasti and colleagues at the University of Minnesota-Twin Cities in Minneapolis have found that the muscle protein utrophin conferred significant benefits when injected into mice lacking the dystrophin protein and showing a disease resembling **Duchenne muscular dystrophy (DMD)**.

Dystrophin is the muscle protein missing in people with DMD and partially absent in those with **Becker muscular dystrophy (BMD)**. The utrophin protein is very similar to dystrophin and is thought to partially compensate for dystrophin’s absence.

For people with DMD and BMD, the advantage of utrophin-based therapies over dystrophin-based therapies is that utrophin is highly unlikely to provoke an unwanted response from the immune system. Dystrophin can elicit an immune response from people whose immune systems haven’t previously been exposed to it, such as those with DMD and some people with BMD. However, people with DMD and BMD already make normal utrophin, so their immune systems are more tolerant of it.

Utrophin therapies have been explored in dystrophin-deficient mice as a strategy to treat DMD or BMD for several years, and they’ve shown promise. Until now, most of the experiments have involved either transferring extra utrophin genes (gene therapy) into the mice or boosting production of utrophin from their existing utrophin genes (gene upregulation). Both those strategies are viable and continue to be the subject of experimentation.

However, the experiments Ervasti and colleagues described online May 26, 2009, in *PLoS Medicine*, are the first to show benefit from the direct injection of utrophin protein (protein therapy) into DMD mice.

The investigators injected miniatur-

ized utrophin protein molecules (micro-utrophin) into the abdomens of DMD mice twice a week for three weeks, starting at 18 days after birth. They attached a cell-penetrating molecule called TAT to each utrophin protein molecule. (The investigators also tried using full-length utrophin molecules, but the micro-utrophins penetrated cells better.)

The TAT-micro-utrophin penetrated all the tissues the researchers examined. In addition, it aligned itself with the muscle-fiber membrane as part of a cluster of proteins in the way dystrophin normally would. Loss of the integrity of this cluster, and therefore of the muscle-fiber membrane itself, is a hallmark of DMD and to a lesser extent of BMD.

When compared with untreated mice, the mice that received utrophin protein injections had lower levels of a muscle enzyme called creatine kinase (CK) in their blood, which told the researchers that the muscle fibers in the treated mice were more intact and prevented CK leakage out into the bloodstream. The treated mice also showed fewer cellular signs of muscle degeneration than did their untreated counterparts, as well as better force production by the muscles and less susceptibility to contraction-related drops in force.

## Scientists prevent toxic protein clumps in flies with OPMD-like disease

Scientists in France and the Netherlands recently announced they’ve identified a promising new strategy that could potentially become a therapy for **oculopharyngeal muscular dystrophy (OPMD)**, a form of MD that primarily weakens the eyelid and throat muscles and also can affect limb muscles.

The strategy involves using an immune-system protein (antibody) derived from llamas that sticks to abnormally formed protein molecules in muscle cells and keeps them from form-

ing large, damaging clumps.

The experiments were conducted in fruit flies with the same genetic defect that causes human OPMD. The flies cannot hold their wings in a normal position.

Martine Simonelig at the Institut de Genetique Humaine in Paris coordinated a group that included MDA research grantee Silvere van der Maarel at Leiden (Netherlands) University Medical Center. The group announced its findings online March 3, 2009, in Human Molecular Genetics.

Llamas and related animals, such as camels and alpacas, produce single-chain antibodies, which are not found in humans, whose immune systems make antibodies that consist of two chains.

Unlike double-chain antibodies, these single-chain antibodies can easily be selected and modified to enter and function inside a cell nucleus, which is where the abnormal protein molecules are located in OPMD-affected cells. Antibodies that are expressed inside a cell are known as intrabodies.

After testing several llama intrabodies by introducing the DNA for them into the muscle cells of the fruit flies, the researchers chose one, dubbed 3F5, as the most effective in allowing the flies to assume their normal wing posture. They found the 3F5 intrabody didn't reduce the number of protein-containing clumps in the nucleus, but it markedly reduced the size of each clump, presumably reducing its toxicity to the cell.



Fruit flies with the same genetic defect that causes human OPMD benefited from treatment with "intrabodies."

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# CLINICAL TRIALS AND STUDIES



## LGMD gene therapy trial first to show promise beyond safety alone

Researchers supported by MDA and the [National Institutes of Health](#) say results of a gene therapy trial in three people with type 2D **limb-girdle muscular dystrophy (LGMD)** are the first to show promise beyond safety alone. This type of LGMD is due to a deficiency of the muscle protein alpha-sarcoglycan.

Neurologist Jerry Mendell, co-director of the MDA clinic and director of the Center for Gene Therapy at Nationwide Children's Hospital in Columbus, Ohio, received MDA support to coordinate the study team, which announced its results online April 16, 2009, in *Annals of Neurology*.

Although the primary goal of the small trial was to establish the safety of intramuscular injection of the alpha-sarcoglycan gene into a foot muscle, the investigators also evaluated how long gene activity persisted in the muscle, the level of alpha-sarcoglycan protein produced from the gene, and the response of the immune system to the gene.

No adverse events, such as rejection

of the therapy by the immune system, occurred during the trial, reassuring researchers of the likelihood that their approach is safe in people with this form of LGMD.

Moreover, all three trial participants produced four to five times the amount of alpha-sarcoglycan protein in the gene-injected foot muscle compared to the amount in the corresponding muscle on the other foot, which received a salt solution. This level of output from the transferred gene persisted at least until the date of the last evaluation, which was six weeks after injection in one participant, seven weeks in another, and 12 weeks in a third.

In each case, the alpha-sarcoglycan protein assumed its normal position in the membrane of the muscle fiber and restored the structure of a protein cluster that's normally found at that location but is missing in muscles that lack alpha-sarcoglycan. The cluster is crucial to the integrity of the muscle fibers.

The response of the immune system to the transferred gene and its carrier, a viral shell, was brief and minimal in all cases and did not interfere with gene activity.

No improvement in function was expected from this direct injection into a very small area. A delivery method that reaches a large muscle area will be necessary to improve function, the researchers say.

They also note that the study has potential relevance for other muscle diseases and for diseases in which muscle tissue can be used to secrete therapeutic proteins into the bloodstream.

## AVI BioPharma exon-skipping trial in DMD enters systemic-delivery phase

AVI BioPharma of Portland, Ore., has started the systemic (through the blood) delivery phase of its clinical trial of AVI4658 in **Duchenne muscular dystrophy (DMD)**. The trial is being conducted in the United Kingdom.

In January, the company announced that this laboratory-engineered molecule was safe and well tolerated when injected directly into a foot muscle in boys with DMD. More importantly, the molecule led to production of dystrophin, the necessary muscle protein missing in DMD, in all trial participants.

AVI BioPharma said the systemic-delivery phase of the trial now under way will test the safety and efficacy of administering AVI4658 intravenously into 16 boys with DMD. Systemic delivery is expected to reach several muscles and potentially could improve strength and function.

The 12-week study is being conducted in London and Newcastle Upon Tyne, United Kingdom. Francesco Muntoni at Imperial College London, who has MDA support to conduct research in another muscle disease, is the principal investigator. Support for this trial comes from AVI BioPharma and the British Medical Research Council.

AVI4658, a so-called antisense compound, is designed to cause muscle cells to skip over an error in a region (exon) of the gene for the dystrophin protein (see "Success of exon skipping," page 13).

In its Feb. 19, 2009, press release, AVI said the earlier results and preclinical research suggest that "by skipping [exon 51], a truncated but functional

form of the dystrophin protein is produced to ameliorate the disease process, potentially prolonging and improving the quality of life in these patients.”

## Prednisone dosing schedule affects behavior in DMD

A somewhat surprising result about moderate-dose, daily prednisone versus high-dose, weekend-only prednisone in boys with **Duchenne muscular dystrophy (DMD)** was obtained by a team of researchers from Children’s National Medical Center in Washington (CNMC) and the University of Pittsburgh.

The corticosteroid drug prednisone often is prescribed for boys with DMD because it has been shown to slow the decline of muscle strength.

The study, which was supported by MDA and the **National Institutes of Health**, was reported at the 61st annual meeting of the **American Academy of Neurology**, held in Seattle April 25-May 2, 2009.

The investigators found behavioral side effects associated with prednisone lessened over the course of a year in the daily prednisone group but stayed the same in the weekends-only prednisone group.

Twenty-eight boys with DMD were randomly assigned to receive 0.75 milligrams per kilogram of body weight of prednisone daily, while another 28 were randomly assigned to receive 10 milligrams per kilogram of prednisone weekly over two consecutive days (the weekend).

The investigators administered the Child Behavior Checklist (CBCL) rating scale at screening and after



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one, three, six, nine and 12 months.

Total behavioral problems at the start of the study were similar between the two treatment groups. One month into treatment, there were no changes in behavior within the weekend prednisone group and an improvement in total problems and attention in the daily prednisone group.

After a year, there were no significant differences within the weekend group. However, in the daily prednisone group, there were significant decreases in total problems, such as attention and aggression. The daily group also showed significantly fewer behavioral problems than the weekend group at one year.

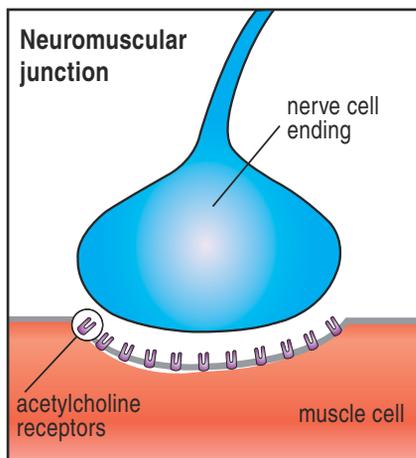
At the 2008 AAN meeting, researchers announced analyses of other aspects of this study. At that time, they said the effects on maintenance of strength were similar between the daily and weekend prednisone dosing schedules, but that the time required to rise from the floor was better in the daily group.

Growth retardation, another prednisone side effect, was less severe in the weekend prednisone group. The weight gain side effect was the same in the two treatment groups after one year.

## Myasthenia Gravis Studies

A variety of studies concerning **myasthenia gravis (MG)**, a disease in which the immune system mistakenly attacks specialized parts of the junction between nerve and muscle cells, were presented at the 61st annual meeting of the American Academy of Neurology, held in Seattle April 25-May 2, 2009.

Some studies examined alternatives to long-term, high-dose prednisone. Prednisone, a corticosteroid drug that suppresses parts of the immune system, is often prescribed for this type of MG, and is fairly effective at helping people maintain strength. However, it has many side effects, such as weight gain, high blood pressure, diabetes, bone loss and



The acetylcholine receptors, which receive signals from nerve cells, are the typical targets of the immune system in MG.

psychological problems, if taken for long periods of time at high doses.

## Mycophenolate mofetil allowed decreased prednisone dose

Michael Hehir at the University of Virginia Health System in Charlottesville, and colleagues, found a drug called mycophenolate mofetil (CellCept), when added to prednisone or substituted for prednisone, allowed people with MG to reduce or eliminate their prednisone intake during the second and third years of their therapy. There were 103 people in this study, all of whom had the type of autoimmune MG in which the acetylcholine receptors are the target of the immune system. These receptors are on the muscle fibers and receive signals from nerve fibers.

Those treated with mycophenolate mofetil alone began to improve between six months and a year after starting the drug. In the group taking mycophenolate mofetil and prednisone, the prednisone dose decreased after a year of mycophenolate mofetil. More than two years after starting mycophenolate mofetil, 53 percent of participants were off prednisone entirely, and 74.5 percent were taking less than 7.5 milligrams per day (a low dose).

## Methotrexate allowed reduction of prednisone dosage

Faisal Raja at the University of Kansas Medical Center in Kansas City, Kan., and colleagues, found that eight people with MG tolerated an immunosuppressant medication called methotrexate (Rhematrex, Trexall), and four were able to reduce their prednisone dosage after an average of 8.7 weeks after starting methotrexate.

No one experienced any methotrexate-related adverse events, but no one had an improvement in their functional scores.

In seven people, the acetylcholine receptor was the autoimmune target. In one, it was a protein called muscle-specific receptor tyrosine kinase, or MUSK, which is needed at the junction of nerve and muscle fibers.

## In ocular MG, prednisone reduced symptom spread

Another study, conducted by Mark Kupersmith at Roosevelt Hospital and the New York Eye and Ear Infirmary in New York, found prednisone appeared to prevent or at least delay the onset of generalized (all over the body) MG in people who only had ocular (eye-muscle) MG. It also controlled double vision resulting from ocular MG.

Eighty-seven people with ocular MG participated in this study, of whom 55 received prednisone and 32 did not.

Participants were followed for more than four years or until generalized MG developed. Generalized MG developed in seven (13 percent) of the 55 who took prednisone and in 16 (50 percent) of the 32 who did not. It typically appeared within a year in those not taking prednisone.

Double vision associated with ocular MG was present at the end of the study in 15 participants (27 percent) of the 55 who took prednisone and in 18 (57 percent) of the 32 who did not.

# RESEARCH ADMINISTRATION

## Two longtime MDA grantees receive prestigious award

On May 3, 2009, molecular biologist **Louis Kunkel** at Children's Hospital in Boston and Harvard University, and biophysicist Kevin Campbell at the University of Iowa, received the prestigious March of Dimes Prize in Developmental Biology. The prize includes a \$250,000 cash award.

Kunkel was on the MDA-supported research team that in 1986 identified the gene for dystrophin, the protein missing in **Duchenne muscular dystrophy (DMD)**.

Since then, his laboratory has been studying muscle stem cells and has been using dystrophin-deficient zebrafish to screen for small molecules that potentially can be developed into therapeutic agents. Much of this work has had MDA support. Kunkel now chairs MDA's Scientific Advisory Committee,

which recommends new projects for MDA funding.

Kevin Campbell headed teams that identified several of the proteins that interact with dystrophin in the muscle-fiber membrane. This research, much of which was MDA-supported, shed light on the functions and structure of dystrophin and the membrane itself and also clarified the role that other membrane-associated proteins play in causing **limb-girdle muscular dystrophies (LGMD)** and **congenital muscular dystrophies (CMD)**.

More recently, Campbell's laboratory has focused on the dystroglycan protein and its role in CMD; the role of sarcoglycan protein deficiency in skeletal and cardiac muscle abnormalities; and development of gene transfer for LGMD. Much of this work has been MDA-supported. Campbell also serves on MDA's Scientific Advisory Committee.

## Symposium honors two MDA-supported leaders in myositis research

On April 25, 2009, W. King Engel and Valerie Askanas, both neurologists and neuropathologists at the University of Southern California in Los Angeles, were honored at the USC International Neuromuscular Symposium. Engel and Askanas, who are married, co-direct the MDA clinic at Hospital of the Good Samaritan in Los Angeles, and Engel also directs the MDA/ALS Center at that institution.

Askanas has received support from MDA for many years for studies of **inclusion-body myositis (IBM)**. She and Engel are well known for having demonstrated that amyloid-beta and several other proteins form toxic clumps in the muscle fibers in this disease. All speakers at the symposium were former trainees of Engel and Askanas.

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# Scientists Continue to Explore Stem Cells



Stem cells — immature cells with the potential to develop into different tissue types — have been heralded as a major advance for developing treatments for a variety of diseases. That’s true for diseases of the nerves and muscles, where such cells could potentially be transplanted into the body and either support or replace a patient’s ailing cells. Although most experts believe it will be a few years before stem cells are used for this purpose, they say another usage of stem cells already is bearing fruit: studying how a genetic disease evolves by watching it develop as the stem cell matures.

President Barack Obama announced March 9, 2009, that he will lift Bush-era restraints on federal funding for stem cell research involving human embryos. Although federally funded researchers may now move beyond the limited number of embryo-derived cell lines authorized for research under the Bush administration, restrictions remain, the details of which are as yet unclear. (Stem cell research funded by private companies and organizations in the United States has never been subject to these restraints.) Obama asked the [National Institutes of Health](#) to develop new guide-

lines within four months.

Although opening up federal funding for all types of stem cell development likely will speed research in the field, recent developments have shown that stem cells also can be developed from non-embryonic sources. It remains to be seen which types of cells will be best for specific applications.

## Umbilical cord blood cells

Stem cells that are isolated from the umbilical cord blood of healthy babies then mixed in a lab dish with early-stage muscle cells (myoblasts) from people with **Duchenne muscular dystrophy (DMD)** or **Becker muscular dystrophy (BMD)**, can fuse. The resulting early-stage muscle fibers can produce dystrophin, researchers in Brazil have found. (Dystrophin is the protein that’s missing or deficient in DMD and BMD.)

Mayana Zatz of the Human Genome Research Center in Sao Paulo, Brazil, and colleagues published their findings Jan. 14, 2009, in the *Journal of Translational Medicine*.

The researchers say these very immature (“undifferentiated”) umbilical cord

stem cells, known as CD34-positive stem cells, are extremely flexible. They say the cells probably responded to chemical factors released by the dystrophic muscle cells that invited fusion and formation of muscle fibers.

## Stem cells that renew repair cells

This spring, MDA grantees Bradley Olwin at the University of Colorado-Boulder and Dawn Cornelison, now at the University of Missouri-Columbia, and colleagues, isolated a new type of skeletal-muscle stem cell in mice that appears to be particularly suited to repairing damaged muscle tissue.

The investigators, who published their findings March 6, 2009, in the journal *Cell Stem Cell*, say they believe these cells are the precursors of special muscle repair cells called “satellite cells.” Satellite cells reside near muscle fibers and move into them to compensate for damage when necessary.

The newly isolated cells are a subset of previously identified muscle precursors known as muscle SP (“side population”) cells, the researchers note. SP cells are “stemlike” in their ability to give rise to mature muscle fibers. However, in experiments in mice, relatively few of them have engrafted into existing muscle tissue after injection.

When Olwin and colleagues injected satellite SP cells into leg muscles in mice lacking dystrophin, they saw extensive muscle regeneration and replenishment of this protein.

“These cells are presumably poised to conduct repair operations when needed and can replenish the satellite cells as well as repair muscle,” Olwin said. He added that he’s encouraged at the large effect of one injection with a small number of cells.

Both Olwin and Cornelison have MDA support to continue working in this area.

## Nerve cells derived from skin cells

Recently, skin cells from a child with **spinal muscular atrophy (SMA)** and from an 82-year-old woman with **amyotrophic lateral sclerosis (ALS)** have been “reprogrammed” back to a stemlike state and then coaxed to develop into SMA-affected or ALS-affected nerve cells. (See [Research Updates, April 2009](#).)

This type of turning back the clock so that a mature cell can return to its stem cell origins and regain its ability to take a number of developmental paths is known as creating “induced pluripotent stem cells,” or iPS.

The technique has the advantage of not having to use human embryos to create this type of cell, as well as holding out the possibility of creating therapeutic cells from the cells of a patient, thus avoiding an unwanted immune response to donated cells.

So far, no one is sure of the extent to which iPS cells can actually become functioning specialized cells, such as motor neurons, the nerve cells affected in SMA and ALS. But scientists at the University of California-Los Angeles and the University of Rochester (N.Y.) say they’ve taken a step forward.

William Lowry and colleagues at UCLA, who published their findings online Feb. 23, 2009, in *Stem Cells Express*, say they’ve created fully functional human motor neurons from skin cells converted back to iPS cells. The motor neurons showed the typical electricity-like signaling functions of these nerve cells. In previous experiments, they say, these functions were not assessed.

## New way of deriving nerve cells from stem cells

Researchers at the Burnham Institute for Medical Research in La Jolla, Calif., and the University of California at Los Angeles, say they’ve developed immature nerve cells that are flexible enough to become multiple nervous-system cell types but committed enough not to become other types of cells or form tumors.

Alexey Terskikh at the Burnham Institute, with colleagues there and at UCLA, used two different human embryonic stem cell lines previously approved by the [National Institutes of Health](#) to produce “committed neural precursor cells” using a procedure they developed. They say the technique was equally successful in both cell lines.

Their procedure for deriving the partially specialized cells is different from that of other research groups in that they omit a “priming step” in which cells are cultured in serum or serum replacement.

With this new method, the investigators say, the embryonic stem cells rapidly developed into committed neural progenitors, generally after 10 to 14 days in culture.

Unlike neural progenitor cells cultured using certain other conditions, Terskikh’s cells appear to have limited proliferation capacity (ability to divide) and instead mature into nerve cells and related cells called glia.

The researchers consider this a good sign, because too much cell division can lead to damaging over-proliferation of cells and even result in tumor formation. Tumors have been a concern when considering transplantation of embryo-derived cells into patients.

When the researchers transplanted these neural precursor cells into the brains of mice, they found they migrated to different parts of the brain and took on the characteristics of cells in their surroundings. Importantly, the transplanted human cells didn’t over proliferate or

form tumors.

The investigators say they’ve described the molecular stages and pathways that normally occur as embryonic cells develop into nerve cells and have proposed genes that may play a role in the process but have not been previously recognized.

They say their cells can be best described as committed neural progenitor cells, which are on a path to becoming nerve cells but are still capable of becoming different types of nerve cells and don’t undergo dangerous proliferation or tumor formation.

## Stem cells made from skin cells without help from viruses

Two scientific teams describe virus-free methods for “reprogramming” skin cells from mice and humans so that they become stem cells, with the potential to mature into multiple cell types. Until now, most methods for doing this have required the use of viruses.

Andras Nagy at the University of Toronto and colleagues, and Keisuke Kaji at the University of Edinburgh (United Kingdom) and colleagues, each described their work online March 1, 2009, in the journal *Nature*.

They say the new approach to cellular reprogramming is technically simpler than earlier methods and allows a range of cell types, not just those with limited susceptibility to viral infection, to be used to create stem cells. In addition, it allows the complete and accurate removal of genes inserted to accomplish the reprogramming.

Virus-free delivery of genes that reprogram cells, and an effective way to remove these genes after reprogramming has occurred, have the potential to provide stem cells that could be used to treat disease, as well as study disease development and screen potentially therapeutic compounds, the researchers say.

# Getting From Here <sup>to</sup> There

Travel scooters  
Page 40



By scooter, van, bus, train or plane, people with disabilities are overcoming barriers and hitting the road.

Wheelchair-friendly roadside assistance  
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Accessible vehicles Q&A  
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When air travel goes bad  
Page 39





# Rolling Through Boston & Phoenix

by Jake Geller

Although not perfect, accessible public transportation in these two cities is improving.

What options are available, and how can riders improve public transit accessibility in their own towns?

Public transportation has provided me with a lifeline to pursue my education, jobs and social life. As a student and a working person who uses a wheelchair, I understand both the freedom and the frustration of traveling on Phoenix's Valley Metro and Boston's Mass Bay Transit Authority (MBTA) systems.

Thanks to the [Americans with Disabilities Act \(ADA\)](#), transit systems accessibility is required by law. When transit systems meet or exceed ADA requirements, public transportation is a breeze to use. But not all transit systems are created equal. Disability advocates have found they can fight poor service and win, and improve accessibility at the same time. Here are my experiences with public transportation in two major cities, and what can be done to improve it.

## Taking the bus

When I go to school or work, I ride the bus or light rail. So long as I know the schedule and route, it's relatively easy.

When the bus arrives, I make sure

the driver knows I want to get on. Then I roll to the wheelchair lift or ramp at the back door. Ramps are becoming more commonplace on newer buses, and are easier and quicker to navigate than the older lifts.

The first few rows are reserved for seniors and people with disabilities who don't use wheelchairs so they're closer to the door and driver. The wheelchair seats are near the back door. Once I roll on, the driver lifts the seat, and I park my chair in the spot. The driver then secures my chair using a four-point tie-down system that keeps it from moving more than a few inches. Within easy reach is a button with a different tone to alert the driver that a person in a wheelchair wants to get off.

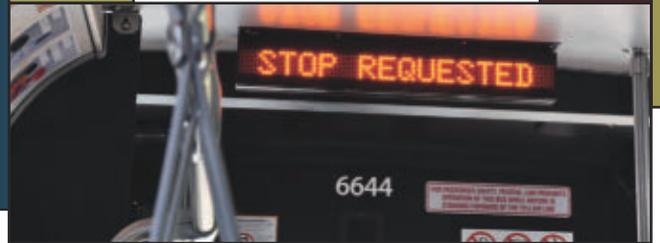
ADA guidelines require that bus drivers or automated recordings announce stops for those with visual impairments. Many buses in large urban areas have easy-to-read LED displays at the front with stop and transfer information, as well as additional seating areas for wheelchair users.

In Phoenix, passengers with disabilities would benefit from buses that run more frequently. In summer, 20 to 30 minutes (the average time between buses) can be a long time to broil in the Arizona heat reaching into the 100s. Round-the-clock service would help too. I know wheelchair users who have missed the last bus and had to spend the night





Author Geller finds the Valley Metro system very accessible, although the ticket machines are challenging for someone with limited arm mobility.



Photos by Gerald Byrnes

culture of the MBTA, thanks to the hiring of Gary Talbot, assistant general manager for system-wide accessibility for the MBTA. Talbot stopped treating the ADA requirements as something special, and made them part of good customer service. He was able to challenge people about the way things were done. For example, in the past, the accessibility training for drivers was done separately by an outside person. Talbot ensured that the training portion is now fully integrated with the rest of the in-house driver training.

“What I’ve been able to do is draw attention to things that needed to be changed,” Talbot says.

## Sharing a ride

When traveling by bus or light rail isn’t an option, I use paratransit. These shared vans provide door-to-door transportation for people with disabilities and those over 65.

The ADA requires this service for people with disabilities who live within three-quarters of a mile of a fixed route system, such as buses or trains. According to ADA rules, vans can arrive up to an hour before or after your desired pick-up time, and can take as much as twice the amount of time it would take to travel to your destination by bus. Paratransit operators can charge no more than twice the regular bus fare.

The convenience of paratransit is the door-to-door service. Its biggest drawback is the uncertainty of the pick-up time. In my case, a trip can take anywhere from 20 minutes (if the van travels straight to my destination) to two hours (if it stops for other passengers). I would sometimes arrive an hour early or

an hour late for class or work. At other times, I’d have to leave early because the van arrived before class was over.

In the Phoenix area, individual cities operate their own Dial-a-Rides. Riders can cross town borders only at specific transfer points. If you go from Phoenix to Tempe, for example, you have to transfer from the Phoenix to the Tempe paratransit van at a grocery store on the border between the two cities. When you schedule a ride, the company coordinates with the other Dial-a-Ride providers for the transfer.

The system usually works, but starting a new trip with the other provider can prolong your journey. I know people who have been stranded at transfer points for hours because of poor coordination.

## Welcoming the newest addition

With the launch of light rail in Phoenix in December 2008, people with disabilities have another way to travel around the Phoenix area. From the start, community members with disabilities helped plan how the system could meet or exceed ADA requirements. Planners also researched other communities with light rail and subway systems.

“A lot of thought went into this, making sure it’s as easy as can be,” says Amy Washburn, communications coordinator for Metro Light Rail.

Braille and low-glare displays on the ticket machines aid those with visual impairments. So does the amber lettering on the platform signs. Security officers on platforms and in the park-n-ride lots ensure public safety.

Audible warnings alert passengers

at a hotel.

While working in Boston during the summers of 1998 to 2001, I didn’t use the buses much, but when I did it was a trying experience. Either the bus drivers were not trained adequately or the lifts on the buses simply didn’t work. Drivers might not stop for me; if they did, they might not know how to use the lift. When drivers told me the lift didn’t work, sometimes I would be able to troubleshoot the problem and get on the bus, but many times the lift legitimately didn’t work.

I wasn’t the only one with this experience. In 2006, 11 MBTA riders with disabilities and the Boston Center for Independent Living won a lawsuit against the transit agency which resulted in better training for bus drivers and improvements in how buses and their lifts were maintained.

Not only did this lawsuit change bus operations, but it worked to change the

of an approaching train. Access is easy because the floors of the cars are the same height as the platform. The only area for improvement I found was that the card readers and ticket machines on platforms were hard-to-reach for somebody with limited arm mobility.

Wheelchairs don't have to be secured to the floor because the light rail makes gradual stops and starts. "A train takes two football fields to stop," Washburn says.

In Phoenix, light rail costs the same as the bus. With an all-day pass, you can ride both the light rail and the bus.

Since the system was designed with accessibility in mind, the light rail is easier to use than the bus or Dial-a-Ride. I can leave my home in Tempe, roll a half-mile to the light rail stop, get on the train and arrive in Phoenix for work in 35 minutes.

## When things don't work

There are many places where public transit hasn't lived up to the standards of the ADA, and there are several different approaches one can take before taking legal action, says Marilyn Golden of the [Disability Rights Education and Defense Fund](#). These include getting the disability community involved, writing a complaint to the [Federal Transit Administration](#), and asking the FTA for a compliance review.

But sometimes legal action is necessary, as in Boston. Taramattie Doucette, co-counsel in the case against the MBTA and senior lawyer at Greater Boston Legal Services, says the disability community "did everything they were supposed to

do" in attempting to improve transit system accessibility before filing suit.

Doucette says the disability community tried to find solutions by speaking with senators and congressmen, holding protests at major subway stops and even talking with top management at the MBTA. But the group was merely given lip service. "This is just common human decency," Doucette recalls thinking, angered by the disrespect to "people who just want to get to work and just want to get to school."

Doucette says that when the group had exhausted all other options, it decided legal action was the only alternative. "Nobody wanted a long protracted litigation on this matter. We just wanted to have it resolved."

She filed the first complaint with the FTA in July 2002. By 2003, she was in talks with the former MBTA general manager, Michael Mulhern. Doucette found these negotiations unhelpful and continued to prepare for a lawsuit against the MBTA, filing another complaint in federal court in 2005.

Two months later, Doucette found that the newly appointed MBTA general manager, Dan Grabauskas, was willing to listen, understood the issues and wanted to find a solution. Through a partnership with Grabauskas, the group was able to come to a settlement and start the process of improving the transit system in April 2006.

One result of the settlement was the hiring of Gary Talbot, assistant general manager for system-wide accessibility. Talbot says he used to be skeptical of lawsuits, thinking they only made money for lawyers. Now he thinks they can do a lot of good, if done right.

In the MBTA lawsuit, no one made any money. All the money was folded back into the transit system to improve accessibility. This set the stage for a fully accessible transit system in the future, he says, which will cost the MBTA a projected \$310 million, including \$122 million to upgrade the elevators in the subways.

"If it wasn't for the lawsuit and settlement, I wouldn't be here, my department wouldn't be here," Talbot says. "I don't believe that the 'T' [MBTA train system] would've made the progress we have already made to date."

At 18 years post-ADA, if some transit agencies still are not following the law, then disability advocates need to explore all their options, including lawsuits, Talbot says. He suggests asking transit agencies a simple question: "How many people with disabilities are professionals, not just advocates ... in leadership positions that report to the top level of the organization and are put into positions of authority to help make a difference?" The MBTA answered that question by hiring Talbot (who is paralyzed from the waist down and uses a wheelchair) and allowing him to make a positive change.

Phoenix's light rail cars have special areas for wheelchair riders adjacent to the doors for easy access.





*Jake Geller, 30, lives in the Phoenix area and has Duchenne*

*muscular dystrophy. Geller grew up and worked in the summers as a camp counselor and broadcasting intern in Boston. He is currently working for the Walter Cronkite School of Journalism and Mass Communication at Arizona State University in Phoenix as the coordinator for the National Center on Disability & Journalism, while finishing up his applied project for a master's of mass communication. Geller can be reached at [jgeller@asu.edu](mailto:jgeller@asu.edu).*

## Hope for the future

Experiencing public transportation in Boston and Phoenix has been both challenging and exciting. Having one of the oldest systems in the country, Boston is moving forward to make up for lost time, while Phoenix has started off right

from the start, designing its brand-new rail system to be fully accessible from the ground up.

These two cities bring hope for the future. Soon we won't need to discuss how to make things accessible because public transportation will be the lifeline for all people. □

*For accessible transportation resources, see InfoQuest, page 86.*

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Photo courtesy of Vantage Mobility International

# Accessible Vehicles Q&A

by Alyssa Quintero

Rear vs. side entry.  
Buying online.  
Buying used.

What do you need to know to get maximum benefit for minimum expense?

**G**ood information is the key to saving money and getting the most value for the dollar when making a big-ticket purchase like a wheelchair-accessible vehicle.

With that in mind, Quest consulted the experts for answers to some common questions facing consumers.

**Q** Can't I just go to the car dealer down the street? Why do I need a certified mobility dealer?

**A** Certified mobility dealers help consumers buy the right vehicle and adaptive equipment to meet their mobility needs now and *in the future*. Future planning is especially important for people with muscle diseases that get progressively worse over time.

"There are so many different products out there, and technology has improved so much. We just want to help people make the right decision," says Sam Cook, president of Superior Van & Mobility based in Louisville, Ky.

"Many times, consumers will go to a

car dealer and buy [a vehicle] that can't be modified or one that doesn't fit their needs. And once you buy a vehicle, normally it's very difficult to return it."

Cook serves as vice president of the board for the [National Mobility Equipment Dealers Association \(NMEDA\)](#), a nonprofit organization that provides consumer guidance and ensures quality and professionalism in the manufacturing and installation of mobility equipment. Members include mobility equipment dealers, manufacturers, driver rehabilitation specialists and other professionals.

NMEDA member-dealers must follow the safety standards established by the [National Highway Traffic Safety Administration \(NHTSA\)](#), in addition to NMEDA's own stringent guidelines.

Some dealers choose to enroll in [NMEDA's Quality Assurance Program \(QAP\)](#), which requires them to adhere to national motor vehicle safety standards, and use proven quality control practices to yield the highest level of performance and safety.

"The QAP dealer is audited by an outside engineering firm to verify that technicians have been trained, make sure

the dealer has insurance and make sure the facility is ADA-compliant,” Cook says. “It’s a voluntary program, so it means the QAP dealer is going above and beyond.”

To locate a NMEDA mobility equipment dealer in your area, visit [www.nmeda.org](http://www.nmeda.org), or call (800) 833-0427. QAP dealers have a QAP designation with their contact information.

Other reasons to seek out a certified mobility equipment dealer include:

They’re committed to “an easy buying process,” says Monique McGivney, marketing manager for Vantage Mobility International ([www.vantagemobility.com](http://www.vantagemobility.com)) based in Phoenix, Ariz., noting that many will bring the vehicle to you at home or work to test drive.

They specialize in assessing clients, explains Troy Schultz, the BraunAbility Corp.’s ([www.braunability.com](http://www.braunability.com)) lowered-floor minivan division manager. They determine what vehicle will best fit a buyer’s needs based on several factors, including the wheelchair size and person’s seated height.

They provide a link to qualified service and repair, says Cook, noting that it’s crucial to have an adapted vehicle serviced by a mobility dealer due to its special features.

It’s possible to buy an adapted vehicle without going through a dealer at all, and still receive expert guidance.

Some manufacturers of adapted vehicles sell directly to consumers, cutting costs by cutting out the middle man, says Scott Andrews, director of sales for Rollx Vans ([www.rollxvans.com](http://www.rollxvans.com)), based in Savage, Minn.

But expert assessment and “try before you buy” remain essentials for prospective buyers, with or without a dealer in the middle.

For example, Rollx, a NMEDA QAP-certified member, sends representatives to customers’ homes for assessment and test drives before they buy, and also to service any modified vehicles purchased from Rollx.



Investigate your options. It’s always advisable to test out different vehicles with you in your wheelchair, as well as family members and caregivers, to determine the best modified vehicle to meet your needs. Photo courtesy of BraunAbility

## Q Can I get a better price if I buy online rather than from a dealer?

As with any online shopping, the warning “buyer beware” rings true. Buying online without trying out different vehicles with different conversions can be a costly mistake.

Mobility Independent Transportation Systems (MITS) based in Largo, Fla., does a lot of online sales, says Pete Galietta, president of the NMEDA-member QAP dealership ([www.wheelchair-van.com](http://www.wheelchair-van.com)).

But, Galietta says, his clients aren’t shopping blind. Typically they already know what kind of vehicle they need and have specific recommendations from a driver evaluator or occupational therapist.

“If you’re not familiar with the product, you definitely shouldn’t buy it online,” Galietta said. “We’re not trying to assess your needs by e-mail or over the phone. That’s either already been done, or if they do contact us directly, we’ll steer them in the appropriate direction to a driving evaluator or local dealer.”

MITS has a questionnaire on its

Web site to help it understand a buyer’s needs. But, Galietta says, “If we’re not comfortable with what you’re asking us to provide, we just won’t provide it.”

Patrick Brent, marketing manager for Freedom Motors ([www.fminow.com](http://www.fminow.com)) based in Battle Creek, Mich., seconds the “buyer beware” warning.

“A mobility vehicle is probably the second-largest purchase after a house. You should see it, try it out, and make sure it’s something that will work for you. It’s horrible when people get something that they’re disappointed in.”

Every vehicle is a little bit different — such as in the dimensions, electrical and fuel systems, or suspension modifications, says Jim Probst, director of sales for Viewpoint Mobility ([www.viewpointmobility.com](http://www.viewpointmobility.com)) based in Kalamazoo, Mich. “If you go online and buy [based] on price, you’re not really looking at the total package.”

McGivney of Vantage Mobility adds that, while buying online can save money, consumers may miss out on the important local service contact that a mobility equipment dealer provides.

# When the going gets easy...



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Where do you want to sit? If you plan to drive from your wheelchair, then a side-entry conversion is what you'll need, unless you can transfer to the driver's seat (rear entry). With a rear-entry conversion, the wheelchair user typically is positioned in the back or between two mid-row captain's seats, while a side entry offers a wheelchair user multiple seating options in the driver, front passenger and middle sections. Photos courtesy of Viewpoint Mobility (left) and Rollx Vans (right).

## Q What are some common mistakes people make when buying a modified vehicle?

**A** Manufacturers and mobility dealers agree that one of the most common — and costly — mistakes is buying the vehicle first and then shopping for the conversion. Not all vehicles can be converted.

For example, Scott Andrews from Rollx notes that people who purchase a minivan from a traditional car dealership may hit a roadblock if it doesn't meet specific requirements to have the floor lowered for a rear- or side-entry conversion.

## Q What are some good questions to ask a dealer or manufacturer?

**A** Although buying a modified vehicle can be "a daunting experience," says VMI's Monique McGivney, it also can be "exciting and fun when you walk in armed with good questions and information."

Prior to getting an assessment from a mobility dealer, evaluate your needs and try answering the following questions:

- What vehicle will fit in my garage?
- What kind of parking issues will I encounter where I live?
- What is the size and weight of my wheelchair?
- What is my seated height in the wheelchair?
- How many people will ride in the vehicle?
- In what part of the vehicle do I want to sit?
- Will I be able to drive with hand controls?
- Do I want a full-size van, minivan or alternative vehicle?
- Do I want manual or power equipment?
- Will an in-floor ramp or fold-out ramp meet my needs?
- What is my budget, and do I have access to supplemental funding?

The first question mobility dealers usually ask a client is: "What is your seated height in the wheelchair?" From there, the dealer can advise whether a full-size or minivan is appropriate, and what kind of conversion is needed.

Be sure to ask the dealer about the warranty and how the vehicle can be serviced.

Furthermore, Freedom Motors' Patrick Brent encourages requesting a copy of the vehicle's crash-test data, to ensure you're getting a safe vehicle. If you ask and don't receive, be cautious.

## Q Which is better: rear entry or side entry?

**A** The most important difference between a rear- and side-entry conversion is that with a rear entry, wheelchair users can't drive from their wheelchairs nor can they ride in the front passenger seat. From there, the choice comes down to personal preference and budget.

In recent years, because of convenience and cost, there's been a shift toward rear-entry vehicles, says Freedom Motors' Patrick Brent. Rear entry involves a less-complicated conversion process and typically is less expensive than a side-entry conversion.

Many people prefer rear entry because they can park almost anywhere and not worry if the spot is wide enough to open



Side-entry conversions are available with your choice of two ramps – in-floor and fold-out. Power in-floor ramps (top left) slide under the door, while fold-out ramps (bottom left) are available in power and manual versions. Photos courtesy of Vantage Mobility International (top) and Rollx Vans (bottom)



But the market still tends to focus more on side-entry vehicles because they're more versatile, says MIT's Pete Galletta, who uses a power wheelchair and accessible van. For example, side entry allows someone with a progressively worsening condition to use the vehicle for a longer period of time. A wheelchair user can start out driving from

his or her chair, and then move to several other positions in the vehicle when no longer able to drive.

Side-entry conversions typically are more expensive than rear-entry because they're more intrusive and labor intensive. For example, with a minivan, the entire floor and frame must be removed and replaced with a lowered floor and new frame.

the ramp and roll out. Also, rear entry allows the consumer to maintain the mid-section seats in a minivan because the conversion doesn't affect that area.

Jim Probst of Viewpoint Mobility (which specializes in rear-entry conversions) says rear entry also is more reliable because the back hinged door has fewer moving parts, as compared to a side-entry door on slider tracks.

## Q What's the difference between a fold-out ramp and in-floor ramp?

A This decision comes down to aesthetics, convenience and cost. A fold-out ramp folds up into the vehicle and must be deployed whenever the door is opened.

The more expensive in-floor ramp slides under the floor, so there's no obstruction to the door, and other passengers can enter and exit without deploying the ramp. In-floor ramps only are available for side-entry minivan conversions, and there isn't a manual (unpowered) option.

In-floor ramps generally provide more room in the vehicle because there's nothing blocking the doorway. The ramp is "out of sight, out of mind," says VMI's Monique McGivney, and may last longer because it doesn't have to be deployed each time the side passenger door opens.

Fold-out ramps generally cost less than in-floor, and consumers can select from manual and power versions; a power fold-out ramp still costs less than an in-floor ramp. Some consumers prefer fold-out ramps because they can be used on any curb, especially if there's limited parking.



Power or manual rear-entry conversions are available only with fold-out ramps, offer parking flexibility, and cost less than a side-entry conversion. Photo courtesy of Viewpoint Mobility

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If a modified van isn't quite your style, then alternate vehicles with lowered-floor side- or rear-entry conversions, such as the Toyota Scion, can offer fuel- and cost-efficient options. Photos courtesy of Freedom Motors

Wheelchair users also tend to feel more comfortable with a fold-out ramp because it can be pushed out manually if the vehicle loses power or if there's an electrical computer malfunction, says Scott Andrews of Rollx.

If an in-floor ramp system breaks down or the vehicle loses power, a caregiver can use a hand crank to get the ramp down. McGivney notes that VMI's in-floor ramp systems have a backup system that bypasses the vehicle's battery and allows a caregiver to deploy the ramp even in a power failure.

But a lot of people just feel more secure knowing they can quickly deploy a fold-out ramp in case of an emergency. Troy Schultz says BraunAbility tends to sell more fold-out ramps primarily for this reason.

"Our system allows a person to open the door and push down the ramp, and it will slowly fall down so the person in the wheelchair can get out," Schultz says.

## Q I use a wheelchair, but a van or minivan just isn't "me." Are they my only options?

**A** You have some choices. Lowered-floor conversions with fold-out ramps can be done

on the Honda Element, Chrysler PT Cruiser and Toyota Scion. The side-entry conversion can be on the passenger side or driver's side, for people who drive from their wheelchairs.

"We've seen a lot of demand for those vehicles," says Patrick Brent, marketing manager for Freedom Motors. "There are many people who've always had vans and never had other options."

The Toyota Scion also can be modified with a manual rear entry, which is less expensive than an automatic side entry-conversion. (Rear-entry conversions aren't available for the Honda Element or PT Cruiser.)

The Scion with rear entry is "great for people looking for a more economical alternative," says Brent, because the entire package is less expensive than other modified new vehicles, and it's more fuel-efficient than a van. The downside to the rear entry is that a wheelchair user can't drive unless he or she can transfer into the driver's seat.

For those who prefer to keep their standard car rather than purchasing a modified vehicle — and who can make the transfer from a wheelchair to a car seat — the answer may be a turning seat. These power seats extend from a vehicle, and lower and raise to help people enter and exit more easily on their own or with assistance.

Turning seats can be used in a wide range of vehicles, from sedans to SUVs and pickup trucks. A way to transport the wheelchair (like a rear lift) also is needed.

The rate at which your disease symptoms are worsening is one thing to consider when looking at turning seats — is it likely you'll be able to transfer and ride in a car seat for many more years? Also, be sure to check with a mobility dealer to determine if your vehicle can accommodate a turning seat and a wheelchair lift.

To learn more, read "Turning Seats Can Enhance Mobility," July-August 2008, by going to [www.mda.org/QuestMagazineOnline](http://www.mda.org/QuestMagazineOnline), and clicking on "Quest Back Issues."

## Q Why are modified vehicles so darned expensive?

**A** A vehicle conversion can cost consumers upwards of \$20,000 — and that's just the cost for the conversion, not the vehicle. The total package can run between \$40,000 and \$60,000 — or more.

Besides the cost of the components, the reason it's so pricey is that basically the entire vehicle must be taken apart, the components installed, and then the

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| Criteria Description                           | Threshold Value | Driver Measured | Passeng Measure |
|--|-----------------|-----------------|-----------------|
| <b>CRASH TEST CERTIFIED</b>                    |                 |                 |                 |
| Head Injury Measurements:                      |                 |                 |                 |
| Head Injury Criterion - 36ms interval (HIC-36) | 100             | 473.00          | 347             |
| Head Injury Criterion - 15ms interval (HIC-15) | 700             | 361.00          | 236             |
| Neck Injury Measurements:                      |                 |                 |                 |
| Axial Tensile Force (N)                        | 4170            | 843             | 1213            |
| Axial Compressive Force (N)                    | -4000           | -523            | -229            |
| Nij (tension-flexion)                          | 1.00            | 0.27            | 0.13            |
| Nij (tension-extension)                        | 1.00            | 0.14            | 0.26            |
| Nij (compression-flexion)                      | 1.00            | 0.12            | 0.12            |
| Nij (compression-extension)                    | 1.00            | 0.11            | 0.15            |



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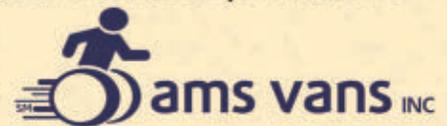
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on location - many of which are available for immediate delivery to anywhere within the continental United States. We can also convert your existing '99-present year Chrysler, Dodge, or VW minivan. In addition to pricing, selection, and superior service, AMS Vans, Inc. offers a product you can own with confidence. Our conversions are built and installed by a NMEDA QAP Member, RADCO Compliant, and have passed year 2010 FMVSS crash test certification with flying colors! The simple design keeps maintenance costs low while providing families with the functionality they need. AMS offers over 29 years in the mobility van industry, references across the country, the best conversion warranties in the business, nationwide maintenance and repair services, and an all-hours live emergency roadside assistance advisor. AMS Vans, Inc. is definitely the smart choice for your accessible transportation needs.

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whole thing put back together again.

Modified vehicles from certified manufacturers and dealers must meet NHTSA's Federal Motor Vehicle Safety Standards (FMVSS). That means all modified vehicles must be properly crash tested. (To learn more, visit [www.nhtsa.dot.gov](http://www.nhtsa.dot.gov) and <http://204.68.195.250/cars/rules/adaptive/>.)

Oliver Ramaker, director of business development for Liberty Motor Co. ([www.libertymotorco.com](http://www.libertymotorco.com)) based in Oakville, Ontario, Canada, explains, "It's quite a labor-intensive process because of the customization. When you make structural modifications to a vehicle, you have to go through all of the crash testing, and you have to show that the vehicle is compliant again, and those tests are very expensive."

For example, says Viewpoint Mobility's Jim Probst, lowering the floor in a minivan requires replacing or moving the fuel tank, meaning the lines must be altered. Once the conversion is finished, the vehicle still has to meet the original requirements for evaporative emissions, in addition to NHTSA requirements.

## Q How can I pay less?

**A** Consumers have some options. For example, a manual rear-entry conversion is less expensive than a powered side-entry conversion.

Many consumers cut costs by purchasing pre-owned vehicles with new conversions, typically saving around \$10,000 to \$12,000.

This offers the best of both worlds, says Diana Conte, vice president of business development for AMS Vans ([www.aavans.com](http://www.aavans.com)) in Norcross, Ga., which buys and converts about 800 used Dodge or Chrysler minivans a year.

The previous van owner already has absorbed the depreciation hit on a new van, which essentially occurs right after

you've driven off the dealer's lot, says Conte. But she warns against buying an already converted used van. Used adaptive components may have unknown problems and probably aren't under warranty.

Troy Schultz from BraunAbility, which manufactures both rear- and side-entry conversions, notes that buying used can be beneficial for first-time buyers who want to try out a vehicle for a few years before buying new. BraunAbility will warranty a new conversion on a used vehicle for three years or 36,000 miles, if purchased through a mobility dealer.

But if you plan to buy used, do some research and make sure the vehicle is structurally sound and able to handle the conversion process. Ask for a vehicle history (CARFAX) report, and get the vehicle inspected by a mobility dealer to ensure it can be modified.

It can be difficult to convert a vehicle with more than 20,000 miles, says mobility dealer Sam Cook, because "it doesn't work very well when you cut into the floor, and the gas and brake lines have corrosion."

VMI's Monique McGivney notes that VMI typically won't convert a van with more than 35,000 miles on the odometer because "it's got a lot of wear and tear on it, and since we add some weight to the vehicle and take the floor off, it needs to be as structurally secure as possible."

And of course it doesn't make sense to put a \$20,000 conversion on a vehicle that's depreciated in value to \$10,000



Don't make the mistake of buying a vehicle before shopping for the appropriate conversion. It pays to work with a certified mobility dealer to ensure you're getting the right modified vehicle. And, if you're buying a used vehicle to lessen the cost, consult with a dealer to make sure it can be modified with the appropriate conversion to suit your needs. Photo courtesy of AMS Vans.

because the conversion would outlive the vehicle.

## Q How do people manage to pay for it?

**A** In the past, many consumers used home equity loans to purchase a vehicle and adaptive equipment. But with home values decreasing, that option has evaporated for some families.

Many dealers and manufacturers work with lending institutions that offer extended-term financing, including 10-year loans, allowing consumers to make lower, more affordable monthly payments. The downside is that consumers are locked into the vehicle for 10 years, and end up paying more in interest.

"If you finance for 10 years, and you're not going to keep the vehicle for that amount of time, you're going to lose money when you try to sell or trade it because you haven't paid off much of the balance," says Viewpoint Mobility's Jim Probst.

When you buy a new vehicle, many

car manufacturers offer mobility reimbursement programs (up to \$1,000) to

help offset the cost for the purchase and installation of adaptive equipment. Visit the NMEDA Web site for the latest information about these programs at [www.nmeda.org/consumers/resources/rebates.aspx](http://www.nmeda.org/consumers/resources/rebates.aspx).

Some other options:

**Alternative Financing Programs (AFP)**, available in 33 states and U.S. territories, offer low-interest loans for modifications to vehicles used by people with disabilities. People on fixed incomes who don't qualify for traditional bank loans may find AFPs more receptive to their applications (<http://69.89.27.238/~resnaorg/AFTAP/state/RESNA.html>).

**State vocational rehabilitation agencies** may assist with costs if the vehicle helps you pursue educational goals, or become and stay employed

([www.jan.wvu.edu/cgi-win/TypeQuery.exe?902](http://www.jan.wvu.edu/cgi-win/TypeQuery.exe?902)).

**Home and Community Based Services (HCBS) waivers** can help state Medicaid recipients receive funding for assistive technology. The waiver programs vary from state to state, but some have approved funding for "other services" that include vehicle modifications ([www.cms.hhs.gov/MedicaidStWaivProgDemoPGI/](http://www.cms.hhs.gov/MedicaidStWaivProgDemoPGI/)).

**Burhill Financial Services**, based in Dayton, Ohio, offers mobility financing packages, generally with little or no down payment. The credit service organization partners with mobility dealers nationwide, and offers low-interest loans and leases, as well as long-term financing. For more information, visit [www.burhillfinancial.com/index-mobility.html](http://www.burhillfinancial.com/index-mobility.html), or contact Danielle Conley at (866) 521-0083 or [danielle@burhill.com](mailto:danielle@burhill.com).

For more information, check out these past Quest stories by going to

[www.mda.org/QuestMagazineOnline](http://www.mda.org/QuestMagazineOnline), and clicking on "Quest Back Issues." Or, call your local MDA office and request a printed copy.

- "Playing the Money Game: Funding Challenges and Options," May-June 2008
- "Funding Freedom: Tech Loans Provide Alternate Financing," May-June 2006 □

For a list of resources, visit *InfoQuest* on page 86.



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# Emergency Roadside Assistance for Wheelchair Users

“I use a power chair and wanted to let you know how much I appreciate your services,” reads a testimonial on the Web site of [ADA Nationwide Roadside Assistance](#), a membership-based emergency assistance service for people with disabilities.

“In August we took a road trip to Northern California to visit family. On I-5, about 30 miles from the nearest town, my van broke down. When I called ADA for help they arranged for a lift van to transport us to a hotel with an accessible room. Shortly thereafter a tow truck arrived to take care of my van. Thank you for being there for me!”

One in four people experience a roadside emergency each year. For people who require wheelchairs for mobility, this can be a particularly difficult situation.

ADA Nationwide Roadside Assistance, of Nuevo, Calif., was created to address this situation by providing emergency roadside assistance tailored both to the needs of people who use mobility devices, and their modified vehicles.

The service currently is the only national one of its kind in the U.S. focused on drivers and passengers with disabilities.

## Wheelchair-lift tow trucks

In 1999, Patricia Kosta, a veteran of the auto travel club industry, designed and

manufactured a wheelchair-accessible tow truck featuring a wheelchair lift to transport stranded wheelchair users. But Kosta quickly realized that it would take more than a few tow trucks to handle the needs of disabled travelers around the country.

And so she created ADA Nationwide. The membership-based, for-profit travel club works with more than 47,000 towing and road service providers around the country, to offer tow service for adapted vehicles, and accessible transit service for stranded drivers.

The company offers several services.

**Emergency lift service:** When a vehicle's lift ramp doesn't work, a service technician will be dispatched to assist with minor repairs or device override.

**Wheelchair battery service:** If a member's power chair loses power while they're away from home, ADA Nationwide will dispatch a service technician for battery replacement, repair or charging.

**Fuel delivery:** Out of gas? The company will deliver enough fuel to get you to a service station.

**Gas station service assistance:** When traveling, ADA Nationwide will locate a fueling station on your route to assist with pumping gas when you arrive.

**ADA Personal Assistant Hotline:** A toll-free number is staffed around the clock. Services include emergency travel and

medical assistance and concierge services, such as theater tickets and prescription deliveries.

## Coverage specifics

Members are covered whether riding in their own vehicle or someone else's, so long as they have their membership card with them.

In some cases, a member might have to initially pay for accessible transportation, and the company would reimburse 100 percent of the cost, up to the mileage limit, which varies according to the membership package. ADA Nationwide says it follows the industry standard of providing four tow transports a year.

Response time reportedly is within the industry standard of one hour; the company says its average wait time is 45 minutes.

Membership plans start at about \$140 a year for one person and one free associate member. More “associates” (other users in the household) can be added at a reduced rate, and receive all the same services, whether or not they have a disability.

For more information, call (800) 720-3132 or visit [www.americandriversalliance.com](http://www.americandriversalliance.com). □



# Who Ya Gonna Call When Air Travel Goes Bad?

by Bill Norman

Traveling by air can be a nightmare when a traveler's special needs run up against an inflexible, unsympathetic bureaucracy — as Julianna Dombrowski of Greenacres, Fla., found out the hard way.

In July last year, Dombrowski, 54, booked a Delta Airlines trip from West Palm Beach to visit family in Harrisburg, Pa., with a connecting flight in Atlanta.

At first it didn't seem problematic. Dombrowski, who has **limb-girdle muscular dystrophy**, can walk with care but requires a wheelchair ride in airports because she's easily knocked over in a crowd.

Problems developed when her flight was late getting to Atlanta. Things got worse when she realized she would have to exit the plane down a steep flight of steps more than 100 yards from the terminal.

Dombrowski had arranged for a wheelchair and attendant to meet her on arrival in Atlanta, but they hadn't shown up.

The Delta flight crew was anxious to fly on. Dombrowski said she wasn't moving until her wheelchair arrived. The Delta crew was not happy.

Finally, an attendant arrived with a manual wheelchair.

But neither the attendant nor crew were willing to help Dombrowski down the stairs.

"They all had the same line," she said. "It's not my job."

In desperation, she got down on her hands and knees and crawled backward down the steep steps.

Did she make her connecting flight? No. Her attendant wasn't willing to push her the additional distance to her gate. She wound up sitting in the terminal for nearly six hours waiting for another flight.

After more people determined it wasn't their job to help her, she broke down and began crying, winning some help for a badly needed trip to the restroom and a bite to eat.

Once safely in Harrisburg, she fired off an overnight letter to Delta. But before they contacted her, the news media picked up her story. Delta reached her in a hurry after that, but said they couldn't find her letter ... would she mind faxing them a copy of it?

Eventually, Delta apologized profusely and gave her \$300 toward a future flight, the cell phone number of an upper-level manager, and an invitation to help improve their customer service procedures.

## Who ya gonna call?

**Complaint Resolution Officers (CROs)** As Dombrowski learned, insist on speaking to a CRO. Each airline is required to have one available.

**U.S. Department of Transportation/  
Air Carrier Access Act hotline.** (800)

778-4838; <http://airconsumer.ost.dot.gov/ACAAComplaint.htm>; or Aviation Consumer Protection Division, U.S. Department of Transportation, Room 4107, 400 7th St. S.W., Washington, D.C., 20590.

**Avoid hassles** Before boarding, remind the gate or ticket counter agent about your needs at other airports. Ground agents are better able than flight attendants to arrange services at airports.

## Respiratory equipment alert

Attention air travelers using ventilators, respirators and other electronic respiratory assistive devices: Effective May 19, the **U.S. Department of Transportation (DOT)** requires such equipment to carry a manufacturer's label certifying it meets FAA standards for electromagnetic and radio frequency emissions. In addition, passengers may be required to have enough battery power to last 150 percent of the scheduled flight time. Commercial airlines can deny boarding if these requirements aren't met, or can refuse to allow the equipment to be used during the flight. For a label, contact your respiratory equipment manufacturer. For more about these regulations, contact the DOT (see above), or check out Quest Extra at [www.mda.org/questmagazineonline](http://www.mda.org/questmagazineonline). □



## Travel Scooters Offer an Easy Way to Go

by Bill Norman

Fold 'em up or  
break 'em down.

Toss 'em in the  
trunk — and go!

**E**lectric scooters are a great option for people who are partially ambulatory, whose muscle weakness is not progressing quickly, and who just want some help getting around.

But people with disabilities may not be best served by heavy scooters that can't readily be lifted, or that require a special vehicle or lift to transport them.

In this case, a more viable alternative may be a *travel or transport scooter*.

These are typically smaller-sized scooters that can be easily disassembled into several pieces and fit neatly inside a car trunk or airplane cargo hold. The heaviest piece usually weighs less than 40 pounds.

Travel/transport scooters generally aren't used as a full-time method of transportation, but for visits to the mall or grocery store, or on vacation where a portable transportation option is needed, says Pat O'Brien, marketing manager for the scooter manufacturer [Golden Technologies](#).

Depending on the rider's muscle weakness, a caregiver or friend may be required to handle disassembly, stor-

age in vehicles, removal and reassembly of a travel scooter.

### A tale of two scooters

Josh McDermott, 18, of Walden, N.Y., has a dual perspective on travel scooters because he uses two different three-wheel models, both products of



Josh McDermott on one of his rides.

**Pride Mobility.** McDermott, who has **limb-girdle muscular dystrophy**, can walk, with care.

He uses a Go-Go travel scooter to get around his high school campus and classrooms. “The only downside is that the scooter only gets 13 miles to a charge, and if you go up a hill, its range will drop to about half that,” he said.

McDermott’s 14-year-old brother Zach can easily disassemble and store the Go-Go, but when the family goes camping, McDermott moves up to a larger Legend scooter. Although it can’t be disassembled, this model “goes over rocks — some pretty good-sized ones — and good-sized hills.”

## What to look for

Most travel scooters break down into five or six parts. Depending on the manufacturer, a single part could weigh up to 60 pounds, which, for some

people, is a deal-killer. Potential buyers should be sure to check scooters’ “heaviest part” rating ahead of time.

In order to remain relatively light, travel scooters often skimp on amenities that would be standard on heavier scooters, such as suspension systems to smooth out the ride. The best way to determine if a scooter’s suspension is adequate is to take it for a test drive. If it proves too jarring, some models offer an optional suspension upgrade.

One of the more recent scooter options on the market is the **TravelScoot**. The diminutive rig takes weight reduction (35 pounds, with lithium-ion battery), disassembly (comparable to a two-wheel scooter) and compactness to new heights (it fits in the overhead bins on aircraft). Limitations include the fact that its maximum range is eight miles, and there’s no reverse gear.

## Three vs. four wheels

According to **Mobility Scooter Reviews**, 80 percent of all travel scooters sold are three-wheelers.

The main reason for three-wheelers’

popularity is their ability to get around in tight places, thanks to a shorter turning radius. This allows freer movement around the house and out shopping.

Three-wheel scooters can be used outdoors as well, but usually aren’t as stable as a four-wheeler on uneven sidewalks, rough roads or grass fields, said O’Brien. They also are prone to tipping over when turning quickly.

Conversely, four-wheelers aren’t as maneuverable inside, especially in tight places like bathrooms.

One manufacturer has devised a way around the tippiness issue.

The **Rascal Company’s** new three-



Two scooters from Golden Technologies — the Zip’r model, top, is disassembled and carried in a car’s trunk.



The TravelScoot, ready to roll (above) and collapsed to store (right).



wheel Balance scooters feature “self-centering stabilizer technology.” Two half-size stabilizer wheels on either side of the front wheel hang down about half an inch above the ground. If the rider takes a turn too sharply, centrifugal force aims the stabilizer wheels in exactly the same path as the front wheel, and the stabilizers drop down.

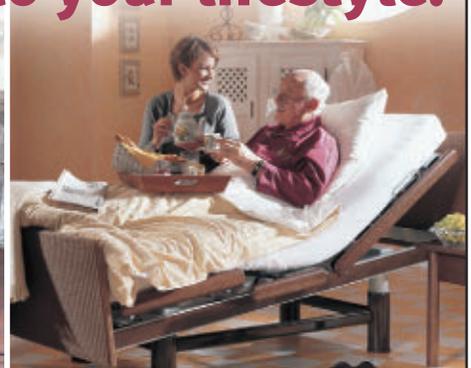
When the rider recovers from the turn, magnets above the stabilizer wheels pull them back up off the ground.

“Three-wheelers’ lack of stability scares some people off,” said Mike Flowers, Rascal’s chairman. “Our Balance scooters essentially become four-wheel scooters at any reasonable speed. It’s a solution to having to choose between the maneuverability and comfort of a three-wheeler and the stability and safety of a four.”



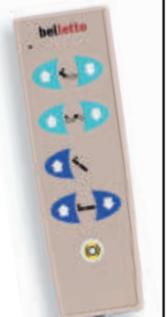
The Rascal Balance has a pair of stabilizer wheels to help correct for sharp turns.

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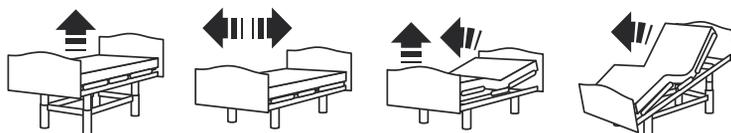


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Instead of conventional handlebars, Pride Mobility offers the Delta Tiller, a wrap-around steering mechanism.

## Other considerations

Other factors to consider when buying a travel scooter include:

**Weight capacity.** Travel/transport scooters have a comparatively lower weight capacity than heavier scooters, usually ranging from 250 to 300 pounds. Remember that the listed capacity is for the entire load, including the person and any cargo.

**Battery range.** Depending on their weight and battery power, scooters can travel from seven to 30 miles before the batteries need a recharge.

Some manufacturers offer a larger battery option to boost range and/or speed.

**Battery charger.** Most scooters

have an integral battery charger that can be simply plugged into a wall electrical outlet. Others have to be moved to where an off-board charger is located — a potential downside if power runs low somewhere away from the charger.

**Top speed.** Some travel models top out at three miles an hour, while others can do more than six.

**Steering mechanism.** Hand controls can be part of short stubby handlebars; a joystick that permits one-handed operation; or what Pride Mobility markets as its Delta Tiller, with wrap-around handles and a push-pull throttle lever that responds to finger pressure. Some tillers can be moved forward or backward into several different positions to make controls easier to reach.

**Seat options.** Travel scooters tend to have rather utilitarian seats, in the interest of keeping the total rig light-

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Merits offers scooters with three wheels, left, and four wheels. Three-wheeler advantages include easier entry and exit, and a smaller disassembled package to store.

weight. Options to look for include variable seats widths, low or high backs, or headrests. Some seats, like [Amigo's Travelmate](#), swivel a full 360 degrees. More comfortable aftermarket seats are available on some models.

**Leg room.** This can be a problem on scooters, especially the travel kind. Generally, three-wheelers tend to have more leg room than four-wheelers. But some models, like the four-wheeled Zip'r Xtra, offer an extra-length chassis that can comfortably accommodate taller riders.

**Tires.** Pneumatic (air-filled) tires usually offer a softer ride than solid rubber ones.

**Cargo room.** Because most travel scooters are bare bones units that can't accommodate much more than the mass of the rider, carrying things can be a challenge when shopping. Golden Technologies' LiTEWAY and Golden Tech scooters, among others, provide valuable storage capacity in the form of wire baskets affixed either beneath the seat or to the front of the tiller.

## When you're ready to buy

Once you've found your model, there are a few extra considerations before you buy.

**Merchant's reputation.** Mobility Scooter Reviews recommends that prospective scooter buyers look to see if the [Better Business Bureau \(BBB\)](#) logo is displayed on scooter sales companies' Web sites. If it is, visit BBB records (by clicking on the logo) to review a merchant's record of compliments and complaints, and whether it responded to complaints satisfactorily. Also check to see if the merchant has a 1-800 number and e-mail access that can be used to answer questions/resolve problems.

**Medicare reimbursement.** Mobility Scooter Reviews says only about 50 percent of the scooters on the market are eligible for Medicare reimbursement. Given that the price of higher-end scooters can approach \$2,000 (and some are twice or three times that

much), this may be a critical consideration.

**Refund policy.** Some firms have an "all sales final" policy when it comes to scooters. Others have a policy of refunding all or part of the purchase price within 30 days — but only if the scooter has not been used and still is in its original packaging. Carefully check this out in advance.

**Warranty.** Ditto for warranties. Some manufacturers warrant their products for one, two or three years, subject to limitations. Others offer a limited lifetime warranty. Know before you buy. □

*For travel scooter resources, see InfoQuest, page 86*

# Periodic Paralysis

## InFocus

### Dear Readers

This “In Focus” report is the third in a series of MDA comprehensive reports about the latest in [neuromuscular disease research](#) and management.

This report focuses on the [periodic paralyses](#), a group of disorders that result from malfunctions in so-called ion channels, microscopic tunnels that make possible high-speed movement of electrically charged particles across barriers inside cells and between cells and their surroundings.

When ion channels fail to open or close according to an exquisitely fine-tuned program, episodes of paralysis of the skeletal muscles and even temporary irregularities in the heart-beat can occur.

Throughout history, and unfortunately down to the present day, people who experience episodes of paralysis or weakness, interspersed with periods of normal functioning, have been met with suspicion by their peers and even their doctors. Individuals have been accused of faking their attacks to gain attention or shirk their responsibilities, and parents have been suspected of child abuse when their children displayed these mysterious symptoms.

Today, molecular biology has pinpointed the precise mechanisms that underlie the periodic paralyses, and drug trials to treat them are under way. There is much work to be done, but awareness of the diagnosis can provide significant reassurance and help in managing these conditions.

This special section (located in the center of Quest for easy removal) includes:

- *“Fast Facts” about periodic paralysis*
- *An update on state-of-the-art research and disease management, with first-person stories from families affected by periodic paralysis*
- *Information about genetic testing*

To learn more about periodic paralysis, visit [www.mda.org](http://www.mda.org) or call your [local MDA office](#) at (800) 572-1717.

### Fast Facts

MDA's three-year commitment for all [periodic paralysis](#) research as of March 2009 is \$1,938,367. The Association's allocation for research on [hyperkalemic and hypokalemic periodic paralysis](#) research since 1950 is \$8,125,341. MDA's allocation for the recently identified Andersen-Tawil syndrome is \$515,430 since 2001. MDA is currently funding 11 grants in the periodic paralyses.

The periodic paralyses are generally divided into hyperkalemic periodic paralysis, hypokalemic periodic paralysis and Andersen-Tawil syndrome. The first two are caused by genetic defects in high-speed tunnels in skeletal muscle fibers known as ion channels. The last is due to such defects in both skeletal and cardiac muscle.

All forms of periodic paralysis affect both sexes equally and are inherited in a dominant manner, meaning only one genetic flaw (mutation) from one parent can cause the disease.

#### Hyperkalemic periodic paralysis

Hyperkalemic PP usually begins early in childhood, with episodes of muscle weakness or paralysis lasting from 15 minutes to hours or even days. With time, some people develop permanent mild or moderate weakness that persists between bouts of severe weakness.

Some patients also experience episodes of myotonia, the inability to relax muscles completely.

The underlying cause is any of several genetic mutations in a gene on chromosome 17 that carries instructions for a sodium channel protein. The sodium channels in skeletal muscle can't close properly, permitting an excess of sodium ions to enter the muscle fibers.

#### Hypokalemic periodic paralysis

Hypokalemic PP can begin anywhere from early childhood to the 30s, with periodic attacks of severe weakness lasting hours to days. The frequency of attacks generally lessens in the 40s or 50s. Permanent weakness may persist between attacks, usually beginning in middle age and progressing slowly over years.

The most common underlying cause is any of several genetic mutations in a gene on chromosome 1 that carries instructions for a calcium channel protein in skeletal muscle fibers. When this channel fails to transmit a signal to a calcium storage area inside the cell, the muscle fiber can't contract. A minority of people have sodium channel mutations, but not the same ones that cause hyperkalemic periodic paralysis.

#### Andersen-Tawil syndrome

This syndrome usually begins in childhood or adolescence and is characterized by episodes of weakness of the skeletal muscles and irregular heartbeat in the cardiac muscle. Occasionally people may develop permanent weakness between episodes. Heartbeat irregularities can be serious enough to warrant treatment with medication or electronic devices. Widely spaced eyes, low-set ears and a small chin also are characteristic of this disorder.

The underlying cause of Andersen-Tawil syndrome is any of a number of genetic mutations in a chromosome 17 gene for a potassium ion channel present in both skeletal and cardiac muscle tissue. When these channels fail to open, the exit of potassium from muscle cells after they contract is impaired, and the cells can't “reset” to receive further contraction signals.

# InFocus:

## It's All in the Muscles, Not the Head

Individuals and families struggle to manage the periodic paralyses, a group of diseases that's too often misunderstood by teachers, employers and even health professionals.

by Margaret Wahl

People who know me know I lead an extremely active life," says Linda Feld of Longwood, Fla. "People don't see me as somebody on a scooter. I'm Linda, and I do all these things every day, and they know me for me. I tell people that [periodic paralysis](#) has become my friend. It's along for the ride, but it's not going to rule my life."

Feld, now 59 and a hospice volunteer, says her experience with the genetic disease she now knows as hypokalemic ("low potassium") periodic paralysis goes back to her earliest memories, at age 3 or 4.

"I would develop a limp [periodically]," she recalls. "We're talking the early 1950s, and not much was known about periodic paralysis. Even though my father was disabled, he didn't have a diagnosis."

An orthopedic specialist suspected her legs were of unequal length and prescribed a lift for her shoe and supportive footwear. "It was always very important to my parents that I wore really sturdy shoes. I wanted to be like the other kids and wear sneakers," Feld says.

"I was never good at gym in school. There was teasing by fellow classmates. I couldn't run fast. When I reached my teen years, I started having terrible muscle cramps. There was nothing that would alleviate the pain. The muscles became rock hard. It was not my whole body, always just a limb. Those cramps lasted 24 to 48 hours. Then they would start to subside, but the weakness took weeks to come back from. I missed big segments of school."

Feld finished high school and went on to college. When she was about 20, she

visited the MDA clinic at Yale University in New Haven, Conn., where a doctor suggested her condition might be periodic paralysis but wasn't sure.

She tried to work, but soon "it became more and more difficult to hold down a job. The weakness episodes would come on, and I couldn't get out of my desk chair at work. I'd be sitting there working and couldn't get up to go to the copy machine. It became impossible to hold a job."

As she aged, the paralysis episodes ceased, but were replaced by progressive and ultimately permanent weakness. (The lack of episodes and the permanent weakness made diagnosis even more elusive.) She tried breeding dogs, but the work of maintaining a kennel eventually proved too taxing.

Feld's sister, Sally, nine years younger, began following a similar pattern. "When she reached her teenage years, she started with terrible episodes of muscle cramping," Feld recalls. Sally was given an erroneous diagnosis of [limb-girdle muscular dystrophy](#).

Their father retired at age 55 because of continued weakness, including weakness of his respiratory muscles. A bad chest infection when he was 72 caused his doctor to recommend a tracheostomy, a surgical opening in the trachea, through which mucus would be suctioned out.

The family was unaware at the time that certain anesthetics, both gas and local, and muscle relaxants called "depolarizing" agents, frequently used during surgery, can cause long-lasting and severe weakness in people with periodic paralysis. Epinephrine, often

added to local anesthetics, also can cause problems. If the respiratory muscles are affected, respiratory insufficiency can result.

Feld's father became com-

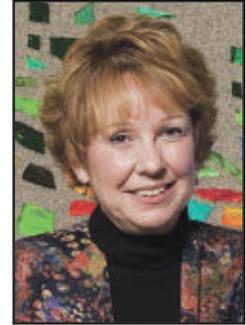
pletely paralyzed after the anesthesia he was given for the tracheostomy procedure and succumbed to a respiratory arrest a few days later.

Feld finally got a definitive diagnosis when she was 56 years old, through the laboratory of Frank Lehmann-Horn at Ulm University in Germany.

Lehmann-Horn, who received several MDA grants in the 1990s to study the periodic paralyses, was originally trained as an engineer, later becoming a medical doctor. He's widely regarded as an outstanding contributor to the study of ion channel physiology, having done more to describe its behavior in health and disease and to apply his findings to patient care than perhaps any other professional.

Feld says the disease has forced many compromises in her life. "I had to learn I could not be everything that everybody else was. I couldn't be the athlete, couldn't follow the crowd and do what they did. I couldn't go out and go drinking with them. Alcohol was a big trigger. I wish I had known earlier in life some of the things that work for people."

Today, she manages her disease with a medication called eplerenone (Inspra),



Linda Feld didn't get a definitive diagnosis until she was 56 years old.

which keeps her serum potassium levels up; potassium supplements as needed; and avoidance of certain activities, foods and medications.

Carbohydrates and salt bother her, as does repetitive muscle activity, like peeling potatoes. "I work with computers, and that doesn't bother me," she says. "But if I were to hold a potato and use a peeler to keep peeling that potato, my hand would become paralyzed."

Being cold can trigger an attack, as can corticosteroid medications (such as prednisone).

She's undergone a hip fracture repair and a hysterectomy with spinal instead of general anesthesia. "That was a piece of the puzzle that was extremely important to get," she says. "We have a very strict anesthesia protocol."

"I'm happy to be the vehicle to tell the story to as many people as possible, so that the children growing up today with this disease do not have to follow the same frustrating path I did," Feld says. She welcomes inquiries about periodic paralysis, especially the diagnosis odyssey, and can be reached at [lfeld@cfl.rr.com](mailto:lfeld@cfl.rr.com).

## Ion channels let muscle fibers contract, relax

**Periodic paralysis** results from any of a number of defects in microscopic tunnels (channels) in muscle cells, also known as muscle fibers. These channels allow electrically charged particles to move in and out of the cell in fractions of a second, or in some cases to sense and propagate an electrical charge in a cell. (See, "How Ion Channels Regulate Muscle Contraction," pages 48-49.)

Electrically charged particles of sodium, calcium, potassium and chloride are known as "ions." They're normally kept within very narrow ranges of concentration inside cells, in the fluid surrounding cells and in the bloodstream. Sodium, calcium and potassium particles carry positive charges, while chloride carries a

negative charge.

Ions have a special role to play in skeletal and cardiac muscle cells, where their concentrations rapidly change in response to signals from nerve cells. These changes, which allow muscles to contract and relax, are made possible by the sensing function and the extremely rapid opening and closing of ion channels.

## Channel problems can cause myotonia, weakness or paralysis

There are three major **periodic paralyses**: *hyperkalemic* (high potassium) periodic paralysis, *hypokalemic* (low potassium) periodic paralysis, and *Andersen-Tawil syndrome*, explains Louis Ptacek, a neurologist who specializes in the study and treatment of ion channel diseases at the University of California at San Francisco.

The first two affect only the channels in skeletal muscles. The last affects ion channels in both skeletal and cardiac muscles.

During the 1990s, when he was an MDA research grantee at the University of Utah, Ptacek played a major role in the identification of the genes underlying hyper- and hypokalemic periodic paralysis. More recently, he's received MDA support to study Andersen-Tawil syndrome at the University of California.

Although the first two periodic paralyses are named for their relationship to serum potassium levels (kalium is Latin for potassium), this can be misleading, Ptacek says.

People with periodic paralysis often have normal serum potassium levels when tested between attacks, and even often during an attack, contributing to the difficulty of diagnosing their disease. "The term 'kalemic' has to do with the ability to precipitate attacks," Ptacek says. "It does not have to do with whether serum potassium is high or low during an attack."

In general, people with hyperkalemic

PP are more likely to experience an attack of paralysis when their serum potassium is temporarily high, and those with hypokalemic PP are more likely to experience one when their serum potassium is temporarily low. (Normally, serum potassium levels are 3.5 to 5.0, measured in units called "milliequivalents" per liter.)

Most people have ion channels that work so effectively that they can quickly readjust for a transiently high or low blood potassium level, so that muscles stay poised to receive nerve signals that allow them to contract or relax. But in periodic paralysis, these ion channels, because of a genetic mutation, don't work the way they should. They may open or close too easily, or with difficulty; or they may stay open or closed too long. Or they may fail to transmit a signal to another part of the cell.

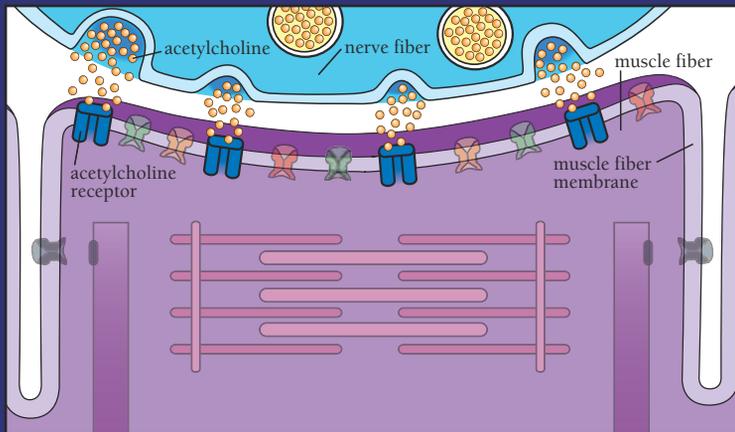
When serum potassium levels change in response to dietary intake, medications, cold temperatures, exercise, rest or anesthesia, the channels can't quickly adjust to compensate for the change. Patients then become temporarily paralyzed, although not necessarily throughout the body. A more localized attack may affect just part of the body, such as a leg or arm.

In some cases people also experience a tingling sensation. Pain or prolonged contraction (myotonia), sometimes with severe cramping and hardening of the muscles, is most likely to occur in hyperkalemic PP. Permanent weakness between attacks sometimes develops.

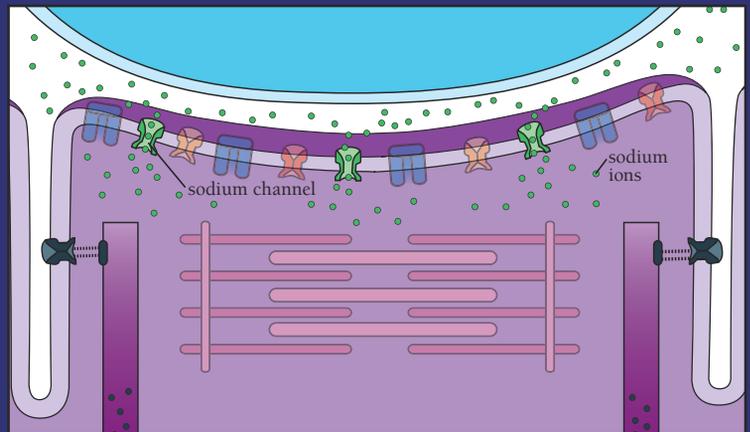
## 'Interesting and different'

Andersen-Tawil syndrome is a more dangerous condition than the other two forms of PP because of its potential to induce serious abnormalities in heart rhythm. Ellen Andersen at the University Hospital of Copenhagen (Denmark) is credited with the first description of this disorder back in 1971.

# How Ion Channels Regu



Acetylcholine leaves the nerve fiber and docks on receptors in the muscle membrane, causing that area of the muscle fiber to become slightly more positive (“depolarized”).



Sodium channels open in response to this small depolarization, permitting a huge flow of positively charged sodium ions to enter the muscle fiber. The depolarization is greatly amplified, and a brief electrical impulse (“action potential”) spreads throughout the fiber.

In the early 2000s, Rabi Tawil at the University of Rochester (N.Y.) led an effort to collect a large cohort of patients and refine the diagnostic criteria. Tawil is co-director of the [MDA clinic](#) at the University of Rochester Medical Center, where he conducted MDA-supported research on what would later become known as Andersen-Tawil syndrome. Ptacek and colleagues identified the underlying genetic and biochemical mechanisms.

“Andersen-Tawil syndrome is interesting and different,” Ptacek says. “It’s a complicated, multisystem disease. Like other periodic paralyses, it’s highly penetrant, which means that if you have the genetic mutation, you get the disease. But the variability of the disease is extremely high. It’s very different from one patient to another, even within the same family.”

Although doctors and patients have long noted that periodic paralysis could run in families, scientists did not begin to identify the precise genetic abnormalities involved until the 1990s.

All forms of periodic paralysis are inherited in an autosomal dominant fashion, which means the genetic defects are

not on the X chromosome and that one defect, inherited from one parent, is sufficient to cause the disease. But in many cases, the person with periodic paralysis knows of no family history of the condition. In these cases, it’s believed to be caused by a new genetic mutation, not one that’s been seen before in the family. (From that point on, however, it can be inherited by future generations.)

## A long and winding road led to hyperkalemic periodic paralysis diagnosis

Hyperkalemic PP stems from mutations in the sodium channels that sit on the surface of muscle fiber membranes. These channels normally respond to a signal from a nerve cell by opening briefly and allowing sodium ions to flow into the fiber.

Sodium ions carry a positive electrical charge, and when they enter a cell, they make it more positive, a phenomenon referred to as “depolarization.”

But mutations in the sodium channel gene cause these channels to malfunction when they’re in a high-potassium

environment, such as when foods high in potassium are ingested or when a person rests after exercising. Under these circumstances, the sodium channels fail to close right away, allowing sodium to continue leaking into the muscle fiber and keeping the muscle fiber (muscle cell) membrane depolarized.

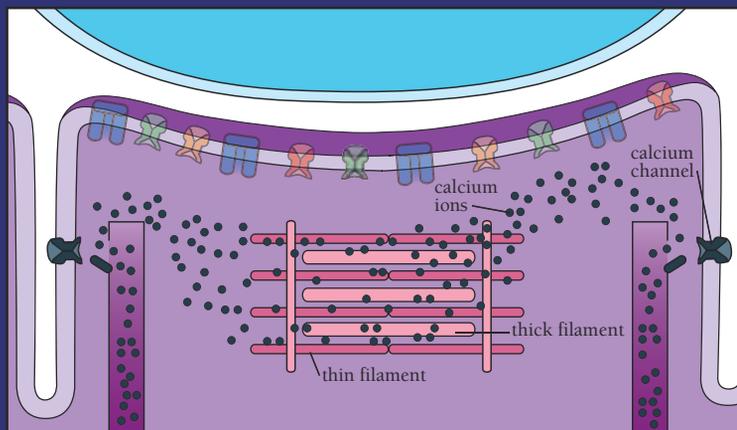
This depolarization may cause prolonged muscle contraction temporarily. However, weakness or paralysis soon occur, because a depolarized muscle fiber can’t receive new signals from a nerve cell.

“Too much potassium narrows the

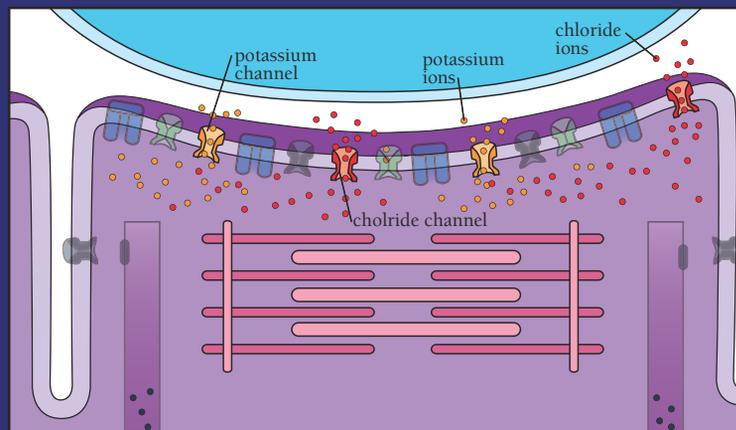


Before her periodic paralysis was diagnosed, the parents of Faith Couture (in front) were told their daughter might have seizures, growing pains, arthritis or multiple sclerosis.

# late Muscle Contraction



Depolarization of the muscle fiber is sensed by calcium channels and triggers the release of calcium ions from internal storage areas. This flood of released internal calcium is the chemical signal that causes the thick and thin filaments of the muscle fiber to slide past each other (contract).



The sodium channels spontaneously close, potassium channels open, and positively charged potassium ions exit the fiber. Chloride channels also stay open, and negatively charged chloride ions enter the fiber. All these actions cause the inside of the fiber to become more negative (“repolarized”). The muscle fiber returns to its resting state, calcium is pumped back into the internal storage vesicles, and the fiber is now ready to accept another surge of positively charged ions in response to stimulation from a nerve fiber. (When several muscle fibers are at rest, a muscle can relax.)

safety margin, and people with hyperkalemic periodic paralysis have less of a safety margin to begin with,” Ptacek says. “When you increase the extracellular potassium, it pushes them over a threshold where the cell remains depolarized.”

That’s what began happening to Faith Couture of Dayton, Ohio, when she was 2 years old. She’s now 9.

“It looked like she would play possum when anybody would get her out of the car,” says her mother, Enola. “But we started thinking, ‘she’s too young to do that.’ We watched how she reacted when we set her on the ground. She was like a blob of Jello. She would just collapse and start crying.”

Soon after the car episodes, Faith began waking up from naps unable to move, sweating and screaming. There was no family history of anything like what Faith was experiencing.

The pediatrician suggested the problem was “growing pains,” later revising his diagnoses to juvenile arthritis or multiple sclerosis. A referral to one neurologist resulted in a diagnosis of learning disability and speech impairment, while another neurologist told the Coutures,

“It’s in your daughter’s head. Get over it.”

Faith’s father was in the Air Force at the time, and the frequent moves around the country added complications to the diagnostic process.

“We’ve had so many misdiagnoses that if we hadn’t taken the initiative and been guided by two or three doctors, we probably would have gone with whatever we heard. We were told 19 times this was seizures.”

When Faith was 7, the family received orders to go to Ohio and ended up at Children’s Hospital in Dayton. There, a geneticist who had worked with Robert Griggs, a longtime MDA grantee at the University of Rochester, thought he knew what the problem was and recommended DNA testing.

“They took her blood two days before her eighth birthday,” Enola recalls. “When it came back a month later, it was like Christmas.” The diagnosis — **hyperkalemic periodic paralysis** — “wasn’t something we were extremely excited about,” Enola says, “but we were excited to know that we weren’t crazy.”

Faith’s episodes still aren’t well controlled, but her mother says they’re “still testing everything.”

Faith is in the extremely unusual situation of being steered away from most fruits and vegetables, which are high in potassium, and toward sugar, which can ward off an attack of paralysis. “For now we try to manage her diet and watch how much she has in fruits and vegetables,” her mother says. “The only problem we have with her is tomatoes. She’s a Southern child and loves tomatoes.”

Because some kidney diseases require a potassium-restricted diet, a good reference for the potassium content of foods, and a method to reduce the potassium in vegetables, is the National Kidney Foundation Web site at [www.kidney.org](http://www.kidney.org). (There are, however, marked differences between the management of kidney disease and periodic paralysis, even if they overlap in one area.) The potassium fact sheet can be found at [www.kidney.org/news/newsroom/fs\\_new/potassiumCKD.cfm](http://www.kidney.org/news/newsroom/fs_new/potassiumCKD.cfm); or you can contact the Foundation at (800) 622-9010.

Giving Faith some sugar to take to school has helped somewhat as well, says Enola. A Coke around 11 a.m. seems to have helped a little bit. “She’s not having [attacks] as frequently. We keep an eye on her.”

## Father, son and daughter struggle with hypokalemic PP

Carl Parker, 43, of Enon, Ohio, who has hypokalemic periodic paralysis, says his life has never been easy. But finding out

his children also are affected has been even harder than having the disease himself.

Parker's parents knew something was wrong fairly early, but they didn't know what. As in Faith Couture's family, no one else was affected.

"As a kid, I was very clumsy, but we didn't really know why," he recalls. In 1972, when he was 6 years old, he underwent a muscle biopsy at Children's Hospital in Columbus, Ohio (now Nationwide Children's). Neurologist Jerry Mendell, then a young physician

## The Periodic Paralysis

| Disorder                          | Hyperkalemic Periodic Paralysis   | Hypokalemic Periodic Paralysis   | Andersen-Tawil Syndrome  |
|-----------------------------------|---|--|--|
| Location of problem               | sodium channel  | calcium channel (most common)<br>sodium channel  | potassium channel  |
| Location of gene                  | chromosome 17   | chromosome 1<br>chromosome 17  | chromosome 17  |
| Inheritance pattern               | dominant  | dominant   | dominant   |
| Functional defect                 | channel does not close properly;<br>prolonged sodium leak into cell   | calcium channel on cell surface<br>does not transmit signal for interior calcium release   | channel does not open properly;<br>potassium can't leave cell  |
| Average age of onset              | before age 10   | age 5 to 35  | age 2 to 18  |
| Average duration of episodes      | 30 minutes to 4 hours   | 2 to 24 hours  | 1 to 36 hours  |
| Maximum weakness                  | mild to severe  | severe   | moderate   |
| Development of permanent weakness | may occur; increases with age   | may occur; increases with age  | may occur; increases with age  |
| Muscle pain                       | may occur in exercised muscles  | may occur in exercised muscles   | may occur in exercised muscles   |
| Episode triggers                  | high blood potassium; high potassium intake; fasting; cold temperatures; certain anesthetics; depolarizing muscle relaxants   | low blood potassium; high carbohydrate intake; rest after exercise; cold temperatures; certain anesthetics; depolarizing muscle relaxants  | high or low blood potassium, depending on exact genetic mutation; certain anesthetics; depolarizing muscle relaxants; other triggers consistent with either hyper- or hypokalemic PP   |
| Treatment                         | <ul style="list-style-type: none"> <li>hydrochlorothiazide, furosemide, acetazolamide or dichlorphenamide; glucose-insulin solution; inhaled albuterol; drugs that bind potassium</li> <li>carbohydrate intake, low-potassium diet</li> <li>frequent meals, warmth, keep moving</li> <li>avoid certain anesthetics and depolarizing muscle relaxants</li> </ul> | <ul style="list-style-type: none"> <li>potassium supplements, acetazolamide (can harm some patients), dichlorphenamide, spironolactone or eplerenone</li> <li>high-potassium, low-carbohydrate, low-sodium diet; warmth; keep moving</li> <li>avoid certain anesthetics and depolarizing muscle relaxants</li> </ul> | <ul style="list-style-type: none"> <li>cardiac medications such as beta blockers and anti-arrhythmics, implanted pacemaker-defibrillator</li> <li>acetazolamide or dichlorphenamide can help or harm</li> <li>high- or low-potassium diet, depending on mutation</li> <li>avoid certain anesthetics and depolarizing muscle relaxants</li> </ul> |

and now a longtime MDA research grantee at Ohio State University and Nationwide Children's, arranged for a muscle biopsy. The diagnosis came back "unknown," Parker says, but the tissue appeared to have bubbles called vacuoles. "They said it looked like a Milky Way candy bar," he says.

As his childhood progressed, Parker continued to be clumsy. "Some days I didn't function well. I had trouble getting up and down, couldn't run well and would fall down for no apparent reason. They tried high-top shoes. We went to different doctors, but they didn't understand the problem."

Then, at age 12, Parker experienced his first true attack of periodic paralysis. "My parents were out for the evening," he remembers. "I was sitting on the couch, eating popcorn and drinking a pop. I went to get up and I couldn't."

Parker's parents arrived home, and his father tried unsuccessfully to get him up and walking. "My legs didn't work, and my arms were weak. I could still move them a little bit. I could wrap my arms around my dad's neck," he remembers.

At Children's Hospital, Parker's serum potassium level was 1.8, which is very low, and he was started on potassium supplements. "That started a whole process of doctoring. We went through a whole gamut of potassium [types] to find the one that worked for me." Although Parker still didn't have a diagnosis, at least he had something that seemed treatable, if imperfectly.

Then, at 15, he experienced a major attack of paralysis. He was already in the local hospital undergoing intravenous treatment for an extremely low serum potassium level. Unfortunately, in addition to potassium, the IV contained glucose (sugar), which drives potassium from the bloodstream into cells.

When treating potassium deficiency in other conditions, that would be the goal. But in hypokalemic periodic paralysis, which Parker would soon learn was his

diagnosis, it triggers a paralysis attack by lowering serum potassium.

"Potassium travels into muscle cells when glucose goes in," Ptacek says. "If you drop a hypokalemic periodic paralysis patient's serum potassium level, you can precipitate an attack."

"It was the worst spell I ever had," Parker says. "They had pulled the door shut on my room that night. I was trying to yell, but I couldn't, and I couldn't reach the buzzer."

Parker was finally taken to Ohio State by ambulance, where they started treating him with oral potassium. Several hours later, his serum potassium level was back up, and the diagnosis became clear.

"They did a lot of tests. They finally got me medicated and got me going." Parker began taking oral potassium and acetazolamide.

Ptacek admits that the mechanism by which acetazolamide and other diuretics in the "carbonic anhydrase inhibitor" family actually work in periodic paralysis remains uncertain. Some experts believe they interact directly with ion channels, he says, while others believe their effects on the acidity of the serum are involved.

"The teenage years were very rough for me," Parker says. He had paralysis attacks every few days, often requiring a hospital stay.

Like other periodic paralysis patients, he soon learned that high-carbohydrate meals (such as the popcorn and soda he ingested the night of his first full-blown episode) trigger attacks. (Like intravenous glucose, these carbohydrates cause potassium to migrate from the serum into the cells, lowering serum potassium levels.) But the paralysis was still unpredictable.

"I could eat almost anything and not have an attack and then three days later have an attack," he says. He also found attacks could be triggered by excess



Cory Parker (left) had his first periodic paralysis episode at age 8, while his sister, Brittany (right), didn't have hers until age 19.

sodium and by cold temperatures.

"Until about 25, it was very rough. I had a lot of attacks. I always had a rough time holding jobs. It's hard to explain to people. I'm 6 feet 2, 290 pounds. I could tear the barn doors off a barn, but some days I can't get out of bed."

Parker has the type of hypokalemic PP caused by a mutation in a cell-surface calcium channel gene. (A minority of patients have hypokalemic PP caused by sodium channel mutations that are different from those that cause hyperkalemic PP.)

The surface calcium channels, unlike the other ion channels, don't play an important role in the movement of calcium into and out of the muscle fiber. Instead, their role is to sense changes in the electrical state (voltage) in the fiber and transmit signals to storage areas inside the fiber, from which calcium ions are then released, causing contraction of the fiber.

When the surface calcium channels malfunction in hypokalemic PP, this signaling doesn't happen, and the muscle fiber doesn't contract.

In 2002, Parker's DNA was tested at Lehmann-Horn's laboratory in Germany, the same lab that would later pinpoint Linda Feld's genetic abnormality, and he learned the precise mutation that affects his calcium channel gene.

Although his own attacks of paralysis have become less frequent, he now has a son and a daughter with the disease.

"From what we were told [in the 1980s], we thought it couldn't be geneti-

cally transferred,” Parker says. He and his wife, Rhonda, had a daughter, Brittany, in 1989, and a son, Cory, in 1991.

Cory had his first paralysis episode at the age of 8. Before then, nothing unusual had been noted. “We never saw any signs with Cory, growing up. He was never clumsy. He played soccer. Then this one day he had a bad attack.”

Now 18, Cory manages his episodes with potassium supplements and acetazolamide, as does Carl. And, like his father, he finds high-carbohydrate or high-sodium meals, especially late at night, must be avoided. A late-night taco and milkshake will almost invariably cause paralysis. Resting after exercise also can trigger an attack.

“He struggles as a young man, going to high school,” Carl says. “The teenager years are hard with this disorder. Usually he gets to school regularly. He goes in late two or three times a week. Usually he’ll be weak from the waist down, sometimes arms or legs, sometimes both. For him and me both, it can be just one leg, both legs, one arm or full body. You just never know what it’s going to be.”

And then came another blow. In January, Brittany, who had just turned 19, had her first paralysis attack. “Brittany never showed anything,” says her father. “She could run all day. She ran cross-country, played basketball and all kinds of sports. It was a very hard pill to swallow.”

Since then, she’s had some localized attacks, in an arm or leg or foot, but no full-fledged episodes. She has potassium supplements to use if needed, but, Carl says, they’re taking a wait-and-see attitude to see what her treatment will be.

## Genetic testing can bring relief, assist with management

Many laboratories in the United States and Europe now conduct genetic testing for the periodic paralyses. See [www.genetests.org](http://www.genetests.org) for a list. (Click on

Laboratory Directory and search by disease name.)

Frank Lehmann-Horn and Karin Jurkat-Rott conduct extensive genetic testing for all three types of PP (including Andersen-Tawil syndrome). Their laboratory is at Ulm University in Germany, but they also help U.S. patients. The Web address, with all pertinent information, is <http://physiologie.uni-ulm.de/angewandte-physiologie>. Contact Lehmann-Horn at [frank.lehmann-horn@uni-ulm.de](mailto:frank.lehmann-horn@uni-ulm.de).

“I traveled throughout the United States trying to find a diagnosis,” says Linda Feld. “I feel the [doctors] in the United States try to put people with periodic paralysis into too tiny a box. They have a very definite diagnosis in their mind. They describe the disease in very narrow terms, so it’s hard to fit the box they’re trying to put you into. Dr. Lehmann-Horn goes to the nth degree. He makes a box for the patient. If he doesn’t find your mutation, he does linkage analysis on the whole family.”

Linkage analysis is a technique in which the DNA of family members with and without a genetic disorder is compared in an effort to find the disease-associated difference.

A study of Feld’s family revealed they had a previously unknown mutation in the gene for the voltage-sensing calcium channel.

“I could never get a firm diagnosis from any physician until I was genetically identified by Dr. Lehmann-Horn in the fall of 2006 at age 56,” Feld says. “It was my new birthday. My diagnosis up to that point had included and excluded periodic paralysis several times, as well as many other diseases.

“Finding the mutation has made a huge difference in my life, because they were able to tell me what kind of drugs I could use to better manage the disease.” Feld now takes eplerenone (Inspra), a so-called potassium-sparing diuretic, a drug that increases water loss through

the kidneys but maintains or raises serum potassium levels. She also takes acetazolamide, although she’s reduced her dosage of that drug, and potassium supplements.

“I also learned that potassium is a really good friend of mine,” Feld says, “and that taking a lot of potassium is not a dangerous thing for somebody with hypokalemia. If I feel an arm muscle getting stiff, I take potassium and get rid of it.”

## MDA supports basic and clinical research

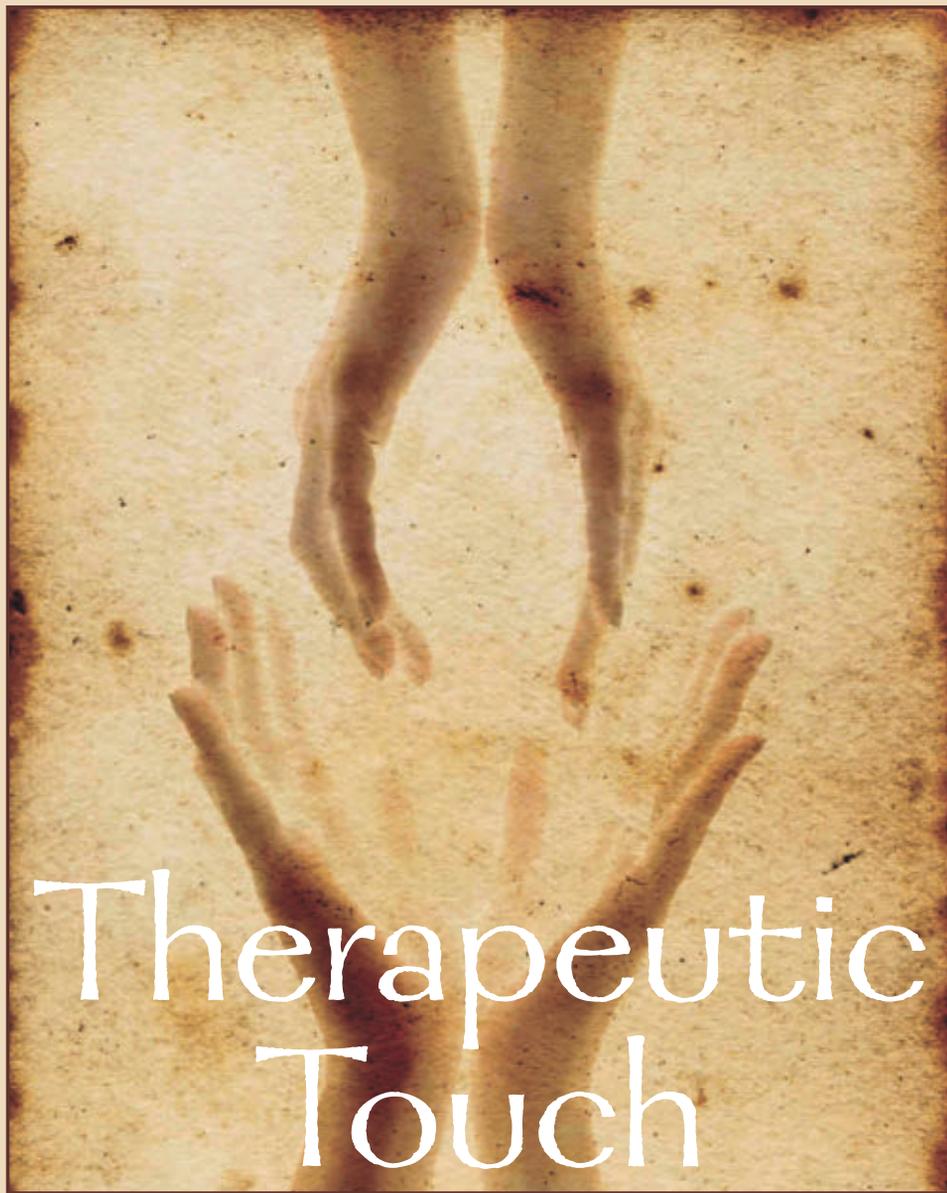
Today, MDA is allocating about \$2 million for studies related to periodic paralysis. Of immediate relevance to patients and families is a multicenter clinical trial comparing acetazolamide with another carbonic anhydrase inhibitor called dichlorphenamide for people with **hyper- or hypokalemic periodic paralysis**.

For more about this study, which is being funded by the National Institutes of Health with additional support from MDA, contact project coordinator Patty Smith at the University of Rochester (N.Y.) Medical Center, (585) 275-4339 or [patty\\_smith@urmc.rochester.edu](mailto:patty_smith@urmc.rochester.edu).

Other MDA-supported researchers are studying how mutations in genes for ion channels affect channel function and muscle contraction; creating mouse models of the periodic paralyses; and identifying the characteristics of Andersen-Tawil syndrome.

For updated information about clinical trials and studies in the periodic paralyses, see the clinical trials section of the MDA Web site at [www.mda.org/research/ctrials.aspx](http://www.mda.org/research/ctrials.aspx) and the National Institutes of Health clinical trials site at [www.clinicaltrials.gov](http://www.clinicaltrials.gov). □

*Editor’s note: As this article went to press, we learned that Carl Parker died abruptly following an appendectomy. The cause of death has not yet been determined.*



# Therapeutic Touch

## A caring touch can work wonders

by Donna G. Albrecht

“I guess I’d give anything to get physical affection,” says Carol\*, a former gymnast who lives in Nevada. She has had slowly progressive [ALS \(amyotrophic lateral sclerosis\)](#) over roughly two decades, but early in the disease her husband and caregiver became distant — “figured I’d die in a few years,” she says.

Carol’s problem is not uncommon. “From birth, all human beings need to be touched. We need and desire to be touched, to be reassured that someone is connected to us, cares for us, finds us acceptable or even desirable,” says Roberta Greenberg, a licensed social worker with the MDA Forbes Norris Clinic in San Francisco.

### Touch deprivation

People who have serious physical disabilities, like Carol, need physical signs of caring as much as anyone. However, there are times when many people with disabilities get the impression that their caregivers find them a burden to be borne, a set of chores to be done.

When [muscle diseases](#) progress to the point that people need caregiving, spouses sometimes stop being sexual, and the person with the disease may become withdrawn, angry, depressed. “They may feel worthless and despondent, but may not say anything openly for fear of more rejection,” says Greenberg.



Loving gestures boost mood and self-esteem.

Children also can suffer from lack of caring touch. There are many factors that affect parents' and family members' bond with a child with a disability. Parents may be mourning the loss of the healthy child they expected, learning how to cope with a new reality that includes a lot of medical appointments and equipment, and struggling to find appropriate child care providers and babysitters.

The effects of touch deprivation on a child can be profound, causing feelings of shame and worthlessness, states Dan Hughes, a therapist specializing in childhood trauma and attachment issues and author of *Building the Bonds of Attachment* (Jason Aronson; August 28, 2006).

Hughes notes, however, that "if the child had some unconditional acceptance and support at some point, it will give him the ability to see another perspective."

## Silence doesn't help

Part of the problem is that people who have serious disabilities and have uncaring (or even abusive) caregivers are likely to keep it to themselves out of a fear that they will be treated worse or be abandoned.

Often, they don't see any other options for themselves. Carol, the Nevada gymnast with *ALS*, moved into a hotel as her husband's verbal and emotional abuse escalated. "I thought I could do it on my own, living in a hotel," she says. But after two months of struggling to do everything alone, she moved back in with her husband. She felt her only other option was a nursing home.

Other times, people with disabilities may be ashamed to admit their situation. This can be true for anyone, regardless of age, intelligence or wealth. For example, over a period of a few years, world-renowned scientist Stephen Hawking, who has advanced *ALS*, was seen in a hospital for a broken arm, broken wrist, black eyes and gashes on his face. He also was left outside on a very hot day until he had heatstroke and had to be hospitalized.

Yet Hawking's response was "I firmly and wholeheartedly reject the allegations that I have been assaulted."

## What to do

If you're the care receiver and feel your caregiver is perfunctory and lacks warmth you need to: Find an [MDA support group](#) either online or locally; talk to your physician, who can direct you to resources; join a group that shares your interests (Carol joined a Bible study group where she gets lots of hugs); and call 911 if you fear you're in danger.

If you're the caregiver and find it dif-

ficult to bond with your care receiver: Consider therapy or a support group; arrange regular time off to care for your own needs; and schedule a sensory or esteem-building event for your care receiver every day — gentle hair brushing, a back rub, even a friendly game of checkers can help create a positive atmosphere and build a better relationship.

It doesn't have to be much. For example, when changing someone's shirt, give a quick hug when the shirt is in place. Or, if a hug is inappropriate, simply tell the person how attractive they look.

Little things can make a big difference. "Perfunctory caregiving can give your loved one the idea that they're unwanted or even repugnant," says Greenberg. □

*\*Name has been changed.*

*Donna G. Albrecht, Concord, Calif., is a frequent Quest contributor, and the author of seven books, including **Raising a Child Who Has a Physical Disability**. She raised two daughters with *SMA*.*

## Be sure kids have lots of physical experiences

It was a picture of a drum that opened my eyes to the fact that my daughter Katie's medical problems were keeping her from experiencing — and understanding — the world the way her peers did.

Katie, who had *SMA*, was three years old and being tested for some governmental program. When she couldn't identify the drum, it was a mark against her score. You can bet she had a drum by that night!

Everyone deserves to experience the world in a visceral way. Someone can spend all day describing how waves feel, but sitting on the sand (with a caregiver) at the edge of the beach while little waves come and go, gives a better understanding than any words can say.

Whether you are a care receiver or a caregiver, be aware of the environmental experiences that are all around you, and take advantage of them. Then the next time someone raves about the taste of just-picked berries, you'll know exactly what they mean. — **D. Albrecht**



# The International Heartsongs Project

## 'Palliative care' means more than 'end-of-life' care for children and families coping with muscle disease

by Amy Labbe

Families face complicated health care decisions when coping with a child's neuromuscular disease, and the best course of action isn't always clear. Often, the child's doctors are in uncharted territory too.

Now, MDA is trying to provide a road map through this confusing, emotional time by offering families and physicians enhanced "palliative care" services for the children it serves.

Although the term "palliative care" traditionally is associated with hospice or end-of-life care, it takes on new meaning when applied to children with muscle diseases, says MDA Vice President of Advocacy Annie Kennedy.

For these children, Kennedy says, "palliative care begins when a child receives a diagnosis, and continues throughout that child's life, regardless of any treatment received."

Pediatric palliative care seeks to address not only the child's comfort and quality of life, but also medical communication, decision making, access to resources, and the family's emotional needs.

Says Kennedy, "One of the greatest services MDA can provide is to connect the families we serve to valuable resources. We want to expand and extend



the palliative care services available to our families — focusing on 'quality of life,' not 'end of life.'"

### An international effort

While some fields, such as oncology (cancer care), do provide pediatric palliative care, it's a new idea in the care of children with muscle diseases.

But that's changing, not only in the U.S., but around the world.

MDA's palliative care program is part of the International Heartsongs Project, a collaboration among seven countries to improve services for children and families affected by pediatric neuromuscular diseases, particularly Duchenne muscular dystrophy (DMD) and type 1 spinal muscular atrophy (SMA1). The project was named in honor of former MDA National Goodwill Ambassador Mattie Stepanek (see page 57).

Heartsongs was conceived as an international project, funded by the Stavros Niarchos Foundation and co-directed by Gail Geller and Cynda Rushton from the Johns Hopkins Berman Institute of Bioethics.

The participating countries — Australia, Canada, Denmark, France, Greece, United Kingdom and the United States — all have active muscular dystrophy organizations with a readiness to integrate palliative care into their programs, says Geller.

The aim of the international project, she explains, is "to marry two worlds — the muscular dystrophy community and pediatric palliative care programs — by bringing together the active partnership and voices of interdisciplinary professionals, palliative care professionals, parents and children."

### Redefining palliative care

A palliative care program for children with muscular dystrophy, "says nothing about when, or even whether, the child will die," Geller says.

"It simply says that since there's a possibility the child might have a life-threatening or life-limiting experience, they can benefit from these services at any time, and these services ought to be woven into their overall care early on before it becomes a crisis issue."

Palliative care services include:

- managing pain and other symptoms;
- addressing quality-of-life issues, such as mobility, environment and rehabilitation;
- addressing the emotional and spiritual needs of families;
- educating adolescents about their disease, prognosis and treatment; and
- adding palliative care professionals to a

child's health care team.

People receive better care within such a model, says Petra Kaufmann, co-director of the MDA Clinic at Columbia University, N.Y., "not because of changed medications or standards, but because their care is better coordinated and better able to accommodate the needs of the entire family."

The goals of a palliative care program run parallel with the goals of seeking treatments and cures for muscle diseases.



Kaufmann, with artwork contributed by her patients.

## Heartsongs Art

In March, to mark the conclusion of the international project, the International Heartsongs Consortium met in Athens, Greece.

The Consortium gathered **neuromuscular-disease** professionals from the seven participating countries, as well as patient advocates and parents of affected individuals.

"Everyone shared the common experience of living with or caring for someone with a neuromuscular disease," says Petra Kaufmann, co-director of MDA's clinic at Columbia University in New York.

The group worked on developing recommendations for caregivers, policymakers and members of society on ways to support people in their journey with neuromuscular disease, starting at diagnosis.

On March 20, the final day of the summit, conferees gathered at the Megaro Cultural Centre to share thoughts. Joining them were people with neuromuscular diseases, parents, politicians, ambassadors, religious leaders, patient advocates and representatives from funding organizations, including MDA.

After the closing ceremony, the group toured **HeartSCAPE: Creative Arts Pathway to Expression**, an international exhibit featuring artwork made by people with neuromuscular diseases and their siblings from each of the seven countries.

"It's well understood that children's voices are often best captured through art," says International Heartsongs Project co-director Gail Geller. "We wanted to make sure the voices of children from every country were included in some way."

Among the pieces exhibited from the U.S. were works created in January at a special MDA-supported event for families, volunteers and art therapists at the Children's Hospital of New York, where children were encouraged to express themselves through art.

The HeartSCAPE artwork will become part of the permanent art collection of MDA Hellas, the Muscular Dystrophy Association of Greece. Artwork that didn't travel to Athens has been put on display at Columbia University, N.Y..

To see a selection of children's art from the exhibit, visit the *Quest Magazine Online* page at [www.mda.org/QuestMagazineOnline](http://www.mda.org/QuestMagazineOnline).

"The idea," Geller says, "is, while we're still hoping and fighting, and seeking a cure, there are still needs that these children and families have that perhaps are even beyond the health care system — such as social support and education — in which palliative care has a role to play."

## The heart of the matter

Palliative care programs address the unique, emotionally laden, complicated kinds of questions that arise when a child has a neuromuscular disease.

Parents may wonder:

*What should I tell my son with DMD about his disease? What information should I withhold?*

*What should I do if I don't agree with the plan of care my daughter's physician wants to pursue with regard to her SMA?*

*At what age should I let my son begin making his own health care decisions?*

Physicians rarely receive instruction on how to effectively communicate with chronically or terminally ill children and their families, or how to manage conflicting goals and values between children, siblings, parents and health care team members.

Doctors may wonder:

*What do I do when a mom insists that everything possible be done to prolong the life of her child, but her 16-year-old son doesn't want to undergo a tracheostomy?*

*What can I — or should I — do if I know a family has chosen not to tell a child his or her diagnosis or relay the seriousness of the illness?*

*What can I do if I notice signs that*



## What's in a Name?

The Heartsongs Project is named in honor of poet and peacemaker **Mattie J.T. Stepanek**, who served as MDA's National Goodwill Ambassador from 2002 until his death in 2004 at age "almost 14." Known for promoting peace and tolerance, Stepanek's six bestselling "Heartsongs" poetry books also explore the ways he coped with life with **dysautonomic mitochondrial myopathy**, the same disease that affects his mother and claimed the lives of his three older siblings.

*the sibling of one of my young patients is feeling sad or angry or somehow 'left out' because of a brother's or sister's muscle disease?*

Obviously, there are no simple answers to these questions and others like them. But a pediatric palliative care program can provide the training and tools necessary to help people consider and respond to such challenges in ways that work for each unique situation.

## MDA's program

As funder and a principal project leader for the United States Heartsongs delegation, MDA is moving forward with a pilot palliative care project at six **MDA clinics**.

Last year, each clinic participated in a three-day workshop on integrating palliative care practice into pediatric neuromuscular care. Then, each team created a comprehensive palliative care model for its facility.

Participating MDA clinics are: Children's Hospital Medical Center in Seattle; Children's National Medical Center in Washington, D.C.; Columbia University Medical Center in New York; Johns Hopkins University in Baltimore; Massachusetts General Hospital in Boston; and University of Virginia Hospital and Kluge Children's Rehabilitation Center in Charlottesville, N.C.

"This was something I'd had on my mind for many years," says Kaufmann, of the Columbia clinic. "We had a good multidisciplinary clinic, but had made less progress in pediatric palliative care."

The Heartsongs project "gave me the

framework and support, and also the motivation and inspiration to look out for partners at my own organization," she says.

Teams at each of the six clinics come up with methods and practices to meet their palliative care goals.

For example, one goal at the Columbia clinic — better communication with families — resulted in a team approach that includes the participation of a nurse-practitioner in meetings. In addition, the Columbia team created a follow-up plan for communicating with families that receive new diagnoses.

Brian Tseng, co-director at the MDA Clinic at Massachusetts General Hospital, says the Heartsongs project has inspired "far greater whole-family, whole-patient care approaches."

"It's the first time I've seen the concept of pediatric palliative care talked about in such an illuminating way," he says. "This isn't something we're taught in school, and it's not experienced in practice unless you happen to spend time with people who are passionate about it."

## Maintaining momentum

In Baltimore this January, the U.S. Heartsongs delegation, headed by MDA, brought together panels of experts — including patients, families and multidisciplinary clinic teams from the pilot-project clinics — for a "next steps" meeting.

Teams reported on progress, shared their best practices and learned from each other.

"There was so much to learn, so much

to share, so much to be exposed to from the different groups and centers," Tseng says.

Panel discussion topics included:

- reflections by young men with neuromuscular disease on their experiences as children within the neuromuscular clinic setting;
- recognizing that affected children often know something is wrong even if it's not explicitly discussed; and
- the care that physicians and other health care professionals should use when talking about "cures" and "treatments," to avoid fostering unrealistic expectations.

Progress has continued since that meeting. For example, Tseng's team at Massachusetts General has watched videos from the International Pediatric Palliative Care Initiative (IPPC) on such topics as: how to talk about diagnosis; comfort care; use of medications to stop pain; and how ethnicity and culture play into decision-making for both families and physicians.

"In a way, it's everyday stuff," Tseng says. "But you don't always stop to think about these things. Participating in the Heartsongs project has been one of the most enriching experiences I've ever had as a practicing physician."

The work has only just begun, notes Annie Kennedy.

"These resources exist but must be tailored to the needs and opportunities within our community. Now we must, on a grander scale, replicate the care networks these six clinics have built and implement this model in MDA clinics across the country." □

# Telethon 2009!

by Kathy Wechsler

This Labor Day weekend, stars will gather in Las Vegas for the 44th **Jerry Lewis MDA Telethon**. Broadcast live from the South Point Hotel, Casino & Spa, the legendary show will reach out to millions of viewers around the world.

**MDA National Chairman and Telethon star Jerry Lewis** and friends are pumped up for 21½ hours of top-notch entertainment, information about MDA's research and medical services and inspiring stories from families affected by muscular dystrophy and related diseases.

Returning as Telethon co-hosts are Television Personality **Jann Carl** of "Entertainment Tonight;" **Alison Sweeney** of the hit daytime drama "Days of Our Lives" and host of the reality series "The Biggest Loser;" **Nancy O'Dell** of "Access Hollywood;" and **Tom Bergeron**



Kayla Vittek and mom, Lisa



Jann Carl and Ace Young

of "America's Funniest Home Videos" and "Dancing with the Stars."

All four serve as MDA national vice presidents, a voluntary position.

## New MDA roles

O'Dell also recently accepted another advocacy role for MDA, to serve as the Association's National ALS Ambassador. O'Dell lost her mother in June 2008 to **ALS (amyotrophic lateral sclerosis, or Lou Gehrig's disease)**. She joins **MDA ALS Division co-chairs Augie and Lynne Nieto** in raising research funds and public awareness of ALS.

Also returning to the Telethon with a new MDA title is **Luke Christie**, the ebullient 16-year-old who served as 2006 and 2007 MDA National Goodwill Ambassador and 2008 Harley-Davidson MDA Goodwill Ambassador. Christie now



is MDA's National Youth Chairman, a role he inherited from his good friend, award-winning country music artist Billy Gilman. Christie, of Due West, S.C., has **type 2 spinal muscular atrophy (SMA2)**. He will host the youth segments of the Telethon.

Co-hosts **Billy Gilman** and "American Idol" finalist **Ace Young** also will perform on the show. In the past year, each accepted the role of MDA Celebrity Ambassador.



Alison Sweeney



Tom Bergeron

## Abbey returns

Anything but camera-shy, **Abbey Umali** of Redlands, Calif., returns to the national broadcast excited and ready for action. She'll be making several live appearances with her parents, Wendi and Joel.

The enthusiastic 10-year-old is affected by a form of **Charcot-Marie-Tooth disease**, and is in her second year as MDA's National Goodwill Ambassador, a role she



Vance Taylor, with daughters, Isabelle and Samantha

takes very seriously. Abbey and her parents spend the year traveling the country, spreading the word about MDA's missions of help and hope.

## The Nietos

The Telethon will welcome back **MDA ALS Division co-chairs Augie and Lynne Nieto** of Corona del Mar, Calif., for the fourth consecutive year. Augie Nieto received a diagnosis of **ALS** in 2005.

In addition to spreading the word of MDA's battle against ALS and encouraging ALS research efforts, the Nietos spearhead **MDA's Augie's Quest**, an initiative that raises funds to "fast-track" ALS research.

## Family profiles

This year's family profiles will feature four outgoing, committed and talented individuals and their families, who will discuss



Tyler Myers and dad, Brad

living with muscle disease and the importance in their lives of MDA's programs of research and services.

The youngest is 4-year-old Kayla Vittek from Rocklin, Calif. Kayla, who has **myotonic muscular dystrophy**, is ambulatory with leg braces and communicates using American Sign Language.

In addition to participating in horseback riding therapy once a week, Kayla loves to read, dance, listen to music and play basketball with her parents, Jeff and Lisa. The Vitteks are active with MDA, participating in fundraisers and volunteering at the local Sacramento Telethon each year.

Tyler Myers, 12, of Las Vegas, is affected by **Duchenne muscular dystrophy** and uses a power wheelchair for mobility. Talkative and outgoing, Tyler enjoys MDA summer camp, video and board games, swimming, and animals of all kinds.

Tyler, who served as the 2006 Las Vegas Goodwill Ambassador, is active with MDA, participating with his family in the Harley-Davidson "Ride for Dreams," Lock-Ups, Shamrocks kick-offs and golf tournaments. He appeared on the local Las Vegas Telethon broadcast in 2000 and 2008.

Caroline Pennell of Chesterfield, Va., loves art, the outdoors, swimming, boating, dancing and socializing with friends. Caroline, 14, has **limb-girdle muscular dystrophy (LGMD)**. She's ambulatory and sometimes uses a power wheelchair.

Caroline and her family are active participants in many local MDA events, such as Fill-the-Boot, Lock-Ups and Stride & Ride. She has been the local MDA Goodwill Ambassador, was profiled on the 2008 Richmond Telethon and was fea-



Caroline Pennell with mom, Robin

ured in a local video message for Lowe's, an MDA national sponsor.

Vance Taylor lives with his wife, Casey, and daughters, Isabelle, 4, and Samantha, 2, in Oxon Hill, Md. Taylor, 31, who has



Nancy O'Dell

LGMD and uses a power wheelchair, works at the Washington, D.C., lobbying firm Catalyst Partners.

Taylor, who co-hosted his local

Washington Telethon last year, regularly attends MDA summer camp to speak to teens about college, work, family and independent living. He also has accompanied Annie Kennedy, MDA's vice presi-

dent for **Advocacy**, on visits to Capitol Hill to lobby for issues of importance to the people served by MDA. □



Billy Gilman

## Tune in

Starting at 9 p.m. EDT on Sunday, Sept. 6 and ending 21½ jam-packed hours later, the Telethon can be viewed on MDA's 180 "**Love Network**" stations across the country or online at [www.mda.org](http://www.mda.org), with streaming video provided by RealNetworks. Check local listings for broadcast times in your area — and when it's done, don't be shy about sending a thank-you note to your local station for supporting this essential MDA fundraising event!



# Roundup

The Americans with Disabilities Act was signed 19 years ago this July. In our annual roundup, we look for signs of progress over the past year.

by Bill Norman

## 'Disability' gets a makeover in new ADA Amendment Act

On Jan. 1, the Americans with Disabilities Act Amendments Act of 2008 went into effect. The Act promises improvements in employment-related ADA protections, bringing the landmark disability civil rights legislation back into line with the original intentions of its creators 19 years ago.

As of this writing, regulations for the amendments haven't been fully spelled out, and court interpretations are yet to be written. But several important observations can be made.

### Disability redefined

Up until Jan. 1, the courts (including the U.S. Supreme Court) interpreted the term "disability" so narrowly that many people,

including those with significant disabilities, were denied ADA employment protections. One of the most important effects of the Amendments Act is that the focus now will be on whether job discrimination against a person occurred — not on the question of whether that person is disabled.

The basic definition of "disability" hasn't changed, but the meanings of some of the words in the ADA's definition have, such as in the part that defines disability as a condition that **"substantially limits one or more major life activities of an individual."**

Under the Amendment Act, the meaning of "substantially limits" has been relaxed so more people meet the standard, and the meaning of "major life activities" has been expanded.

Previously, "major life activities" included such things as speaking, reading, working, caring for oneself, standing and thinking. The courts often disallowed medical conditions (heart disease, sleep

disorders, diabetes) that affected primarily internal functions.

Now "major life activities" are considered to include major bodily functions such as bowel and bladder functions, and the neurological, respiratory and circulatory systems.

This change in definition impacts cases such as that of Larry Rohr, an employee of Salt River Project (SRP, a large Arizona power and water utility company). Rohr sued SRP in 2004, contending he had been pushed out of his job of 23 years when he asked for job assignment exemptions to accommodate treatment of his type 2 diabetes. In 2006, a lower court dismissed his claim, regarding his diabetes as a disease rather than a disability.

But in February a federal court sided with Rohr — diabetes is a disability.

Wrote the judges, "Diabetes is a physical impairment because it affects the digestive . . . systems, and eating is a major life

activity.”

Another change wrought by the ADA Amendment Act: “Mitigating measures” no longer will be considered in employment discrimination cases. In the past, people with disabilities might not have been considered disabled by the courts if they used something that mitigated (lessened) their symptoms and/or facilitated their performance on the job, such as seizure medication, a mobility device or hearing aids.

Now, the only measures that still will be considered as “mitigating” a disability (meaning the person will not be considered as disabled) are eyeglasses or contact lenses.

## Win some, lose some

A roundup of ADA court cases, enforcement actions and mediations over the past year reveals a mix of success, failure and uncertain outcomes.

## Florida pays \$1.4 million penalty for voting violations

The United States District Court in Florida sided with the [American Association of People with Disabilities](#), which contended that the polls in Jacksonville failed to provide accessible voting equipment.

The court held that the ADA does indeed apply to voting, and its decision, including a \$1.4 million award to plaintiffs, was upheld by the Circuit Court of Appeals.

## Retirement home restricts power chairs

In November, the [U.S. Department of Justice \(DOJ\)](#) filed suit in federal court against owners and managers of Rathbone Retirement Community in Evansville, Ind., alleging it discriminated against its residents by prohibiting their use of power wheelchairs and scooters in their apartments and in the common dining room.

DOJ wants Rathbone to cease discrimination of this type, to pay monetary dam-

ages to residents harmed by the policy and to pay a civil penalty to the government. DOJ got involved in the situation when two people filed discrimination complaints with the [U.S. Department of Housing and Urban Development \(HUD\)](#). HUD investigated, then turned the case over to DOJ for follow-up. The outcome is pending.

## Theaters exempt from some ADA rebuilds

AMC Entertainment, and probably other theater owners, got a break from the 9th U.S. Circuit Court of Appeals in December. AMC, which operates more than 100 indoor theaters around the country, had been sued by the U.S. Department of Justice, which said AMC had to retrofit many of its theaters so movie-going wheelchair users would have the same viewing angles of the screen as other patrons.

DOJ based its suit on standards of



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Appellate court sides with theater owner AMC in wheelchair viewing-angle suit.

movie theater design that had been set in 1991. The appellate court overruled the lower court, however, saying federal regulations did not, until 1998, make it clear that not only obstructions to viewing, but also viewing angles had to be considered for disabled movie patrons.

Since the regulations were not clear, the court ruled AMC couldn't be held accountable for not heeding them.

#### Care center excluded disabled child

A parent with a child who wears leg braces sought day care for the youngster at Push My Swing day care in Camden, S.C. The center accepted the family's application and a \$25 deposit check, but later denied the child admission because, it said, its

in part, to: not discriminate against any child on the basis of disability; not refuse to admit any child on the basis of disability (unless the child poses a "direct threat"); and not to use insurance coverage or lack thereof to justify exclusion of individuals with disabilities.

The center further agreed to maintain records at its offices of all admission inquiries on behalf of children with disabilities and the disposition of such inquiries for a period of three years following the inquiry.

#### College campus management company opts for accessibility

DOJ asserted that Education Management

insurance company would not cover her if she fell.

After DOJ got involved, the center officially denied it had discriminated against the family or violated any ADA regulations. However, in a subsequent settlement agreement, Push My Swing agreed,

Company (EDMC), headquartered in Pittsburgh, Pa., was in violation of ADA requirements at several college campuses EDMC operates in a multistate region. Violations of wheelchair accessibility requirements included doors and hallways that were too narrow; thresholds that were too high; excessively steep ramps; inaccessible restrooms; and drinking fountains with too-high spouts.

EDMC admitted no liability for the violations, but did reach a settlement agreement with DOJ. Its provisions included designating an ADA compliance officer; hiring an ADA consultant; and coming up with accessibility plans of action. The company is required, by Oct. 1, 2009, to ensure that its campus facilities are fully accessible to people with disabilities in all the violations areas described above. EDMC also must ensure access to parking and public telephones, and accessible seating in classrooms and auditoriums.

#### Retaliation against spouse doesn't fly

A husband and wife both worked for the Colorado Springs, Colo., police department when she filed an ADA claim against the city. The husband, Lance Lazoff, partici-



## Mediation works!

The bad news: Accessibility violations usually aren't fixed until somebody complains about them. The good news: Nearly 80 percent of these complaints are resolved through free, **DOJ-sponsored mediation**, in which the complainant and respondent sit down and work out a mutually agreeable solution with a neutral mediator.

Following are examples of successful mediation cases over the past year:

After a man with a mobility impairment complained that a Massachusetts country club was inaccessible, the club installed accessible parking, outside lighting, a lift at the entrance and an accessible bathroom.

A wheelchair user complained that a Texas gym didn't have accessible parking, exercise equipment or restrooms. Following

mediation, the gym installed a van-accessible parking space, remodeled restrooms and added a hand-operated exercise bike.

A California youth sports organization refused to modify its policy requiring every parent to volunteer at the snack bar during the season. After a disabled parent complained and mediation occurred, the organization agreed parents could volunteer for other supportive tasks, such as answering phones.

pated in the claim and assisted her. For his involvement, Lazoff said the department retaliated against him by denying him a promotion to sergeant. The EEOC (Equal Opportunity Employment Commission) investigated the matter, found that Lazoff's claims of retaliation were justified, and referred the case to DOJ after efforts at conciliation between the two parties proved fruitless.

Noting that the ADA specifically prohibits retaliation of the sort Lazoff experienced, DOJ worked out a consent decree with the city of Colorado Springs that included: Lazoff's promotion to sergeant at the earliest opportunity; retroactive seniority to sergeant extending back about four years; retroactive back pay to June 2008; payment of \$35,000 to Lazoff if he dropped his claims against the city; and retroactive contributions to Lazoff's pension account. The city, for its part, denied it had violated ADA regulations. □

## Resources

### Architectural and Transportation Barriers Compliance Board.

Works to enforce federal laws requiring disability access to federally funded buildings and facilities. Also sets guidelines and requirements for accessibility standards prescribed by federal agencies. [www.access-board.gov](http://www.access-board.gov) (202) 272-0080 or (202) 272-0082 (TTY)

### Disability and Business Technical Assistance Center. DBTAC is a national network of 10

regional ADA centers that provide information about ADA regulations and issues. Visit [www.adata.org](http://www.adata.org) to find the center nearest you.

### Equal Employment Opportunity Commission.

Complaints about violations of ADA employment policy should go to this agency. [www.eeoc.gov](http://www.eeoc.gov) (800) 669-4000 or (800) 669-6820 (TTY)

**Georgetown University Law Center.** Has developed an ADA Web site archive that is updated periodically. Included

are the ADA's legislative history, text of the law and details of congressional hearings. [www.law.georgetown.edu/archiveada/](http://www.law.georgetown.edu/archiveada/)

**U.S. Department of Justice Office on the Americans with Disabilities Act.** Civil Rights Division. Answers to frequently asked questions about disability rights and discrimination in employment. [www.usdoj.gov/crt/faq.php](http://www.usdoj.gov/crt/faq.php) (800) 514-0301 or (800) 514-0383 (TTY)

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The high number of recent property foreclosures, driven by an uncertain economy, is taking a particular toll on people with disabilities who rent homes, condos and apartments.

People with disabilities often require ground-floor dwellings and close proximity to medical services, equipment providers, caregivers and accessible means of transportation. These requirements — plus difficulties with finances — can make it doubly hard to quickly find and move to new lodgings.

Renters with disabilities may get some help from proposed and recently passed legislation protecting renters' rights in foreclosure cases. Renters themselves can take some preventative measures to avoid being caught in a foreclosure vise. But for people with disabilities, this is unquestionably a situation that needs to be fixed.

### Forced out

Steve and Susan Masarsky are an example of how things can go wrong. They had rented their two-bedroom apartment in Canyon Country, Calif., for three years. Susan, 50, has [myotonic muscular dystrophy \(MMD, also known as DM\)](#), uses a vent and spends most of her time on bed rest. Steve, 53, who has a history of heart problems, is her caregiver.

A few months ago, the Masarskys learned their landlord had defaulted on payments to the company that owned their apartment, so it was foreclosing on the

# Renters with Disabilities Hit Hard by the Foreclosure Hammer

by Bill Norman



property. The company gave the couple 60 days to vacate the premises. Then Steve lost his cashier's job at Wal-Mart.

"I told them it would be too hard for us to move because of Susan's health, her equipment and the medical services she needs," Steve said. "They didn't care. They said, 'How much will it take to get you to move?' Then they offered me \$100. It was insulting. I told them, 'I have two months rent right here in my hand. Why can't we stay?'"

The company that owned their place wouldn't relent on the demand that they move out, but it did raise its offer of "help," eventually to more than \$3,000.

After searching desperately among friends and relatives, the Masarskys finally found an in-law willing to rent them space in her home temporarily. Her spare room was accessible, barely, for Susan.

At least in the Masarskys' case, alter-

nate lodging was available, even if only for the short term. And the property owner eventually forked over enough money for them to make the transition. Others have not been so lucky.

Steve Masarsky says people in this situation need all the time they can get to find a new place to live. "I think there needs to be some kind of agency where disabled people can go to get help renting a place, with no money down," he said.

## Renters at risk

Nationwide, the foreclosure numbers are staggering. [RealtyTrac](#), a large online marketplace for foreclosure properties, said the number of foreclosure filings reported in the United States during 2008 increased by 81 percent over 2007 filings, and 225 percent over those in 2006. Rural areas seem to be getting hit as hard as urban areas.



The nonprofit [National Low Income Housing Coalition \(NLIHC\)](#) reports that renter households (36 million of them) make up one-third of U.S. households. In a special report released in December 2008, NLIHC said, "The current foreclosure crisis is affecting the entire housing market, including rental properties. Dependent on their landlord to inform them of a foreclosure, renters are most often at risk of being evicted with little notice."

The report goes on to note, "... it appears that as many as 40 percent of the families who have [lost] or could lose their homes due to foreclosure are renters."



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## A double bind

Alice Gunderson and her husband Ed, 70 (who has MMD), facilitate MDA's MMD support group in Southern California. They say many of the families are renters.

"Because [myotonic dystrophy](#) often occurs later in life, many people with it are no longer generating income with full-time jobs," she said. "That puts them in a double bind, financially, if a foreclosure happens."

Gunderson spoke with the husband of a woman with MMD who had promised her that he never would put her in an assisted living institution.

"But when the bank foreclosed on their apartment, he had no choice," Gunderson said. "He told me he would be willing to live on the street if that's what it took until he could find a new place for them to rent. He sounded suicidal."

It's often impossible for people with disabilities to quickly come up with the first month/last month rent and security deposit required by most landlords, as well as the cost of transferring utilities. If they're evicted, their credit reports get a black mark.

Steve Masarsky said when he and his wife were looking for new rental lodgings, each prospective landlord charged \$60 to do a credit rating check on the couple. Because of Susan Masarsky's health expenses, their credit rating wasn't good and most landlords refused to rent to them. That sequence of "\$60 refusals" repeated itself again and again.

## Apartments in short supply

One effect of the housing crisis is that the rental market is getting tighter. And in response to the scarcity of rentals, some landlords see an opportunity to boost rents even higher.

Others have taken advantage of their renters (or prospective renters) in even more egregious ways:

- accepting rent and security deposits when they have no intention of renting a property;
- accepting deposits when a property is already in foreclosure;
- accepting rents even after they have lost all legal right to a property;
- failing/refusing to refund security/damage deposits; and
- ceasing to pay utility bills, so even if renters are allowed to remain on the premises, they may have no water, electricity or heat.

Newspapers around the country are full of tales of renter abuse during foreclosures.

From the Chicago Reporter (July/August 2008): Even though Illinois law requires tenants be given 30 days to vacate foreclosed properties, some banks were telling renters they had to vacate immediately, because it's easier for them to sell empty buildings.

From the Phoenix [Arizona] Business Journal (Jan. 2009): Renters seldom take landlords to court because the amount they could win is likely smaller than the legal fees they would pay.

From the Boston Herald (Nov. 23, 2008): Banks often prefer to file eviction cases in district court where pro bono (free) legal assistance isn't as readily available as in lower courts.

## Fixing the problem

In response to these situations, legislation was introduced in Congress last year that would require landlords to give a minimum amount of notice to tenants that their rental premises are in foreclosure (the Protecting Tenants at Foreclosure Act of 2008, sponsored by John Kerry [D-Mass.] in the Senate and Keith Ellison [D-Minn.] in the House).

Both bills died in committee. Ellison has re-introduced his legislation; as of late April, Kerry's office was "still looking at" the issue of foreclosure to determine what action would be most appropriate.

In more than a dozen instances, individual states have passed or proposed similar minimum-notice-of-foreclosure requirements.

Arizona (2009): Minimum 30 days' notice; penalty for non-compliance of \$2,500 or six months in jail (pending).

California (2008): 60 days' notice before eviction (passed).

Massachusetts, Michigan, North Carolina (2008): Minimum 30 days' notice prior to foreclosure (passed).

Minnesota (2008): Minimum 60 days' notice (passed; legislature now working to add penalties).

The District of Columbia: The law permits renters to remain in their lodging even after foreclosure.

Both the [Federal National Mortgage Association](#) ("Fannie Mae") and [Federal Home Loan Mortgage Corporation](#) ("Freddie Mac") have announced they will not — at least for several months — evict renters from properties on which they are pursuing foreclosure, so long as rent payments are current.

In Cook County, Ill., (home of Chicago), the sheriff refuses to evict renters from foreclosed properties if they are current on their rent.

## What to do?

People with [muscle diseases](#) have plenty on their minds without having to perform preventative maintenance on potentially shady landlords. But time spent on advance



precautions can pay off.

To avoid renting from a landlord who is delinquent on mortgage payments, ask to see the monthly mortgage statements that the lender has sent to the landlord.

Check with the county recorder's office for default notices on a potential rental property.

Verify ownership of a rental property through the county assessor's office.

Look for warning signs, such as landlords who don't require a rental agreement, ask for rent payments in cash only, or who don't have an office. Look for signs of poor maintenance and neglect.

Is the rental price much lower than seems logical? Find out why.

Call the [Better Business Bureau \(BBB\)](#) to see if there have been complaints against the landlord.

If worse comes to worst, the [AARP](#) gives several suggestions to renters facing eviction due to foreclosure:

- Avoid "cash for keys" offers to leave the property immediately, since most aren't enough to cover the cost of moving to a new place.
- Keep paying your rent. Try to locate the new owners of your rental property (their names will be on any eviction notice), and offer to pay them rent. Keep copies of all correspondence related to the situation.
- Investigate the possibility of getting low- or no-cost legal assistance from attorneys in your community.
- In addition, go online to learn how your state's rental laws work, including how much minimum notice landlords are required to give renters facing eviction due to foreclosure.

### Hang in there

Until protective legislation is passed or the economic situation improves, times may be

tough for many renters with disabilities. In response, some are "getting creative."

Gunderson tells of a couple who were evicted from their rental but had no accessible vehicle in which to transport the wife, who has MMD, to new lodgings they'd found.

Pressured to move out quickly and at wit's end, the husband called 911 and said his wife was having chest pains. Shortly after, an ambulance arrived and took her to the hospital. After an overnight stay, she again got a ride in the ambulance — to their new rental unit.

"It wasn't ethical, and I knew it full well, but I was in a terrible dilemma," the husband said. "Finally, I just did it." □

*For more information and assistance, see InfoQuest, page 86.*

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## Portable Solutions

### Get your wheelchair where it needs to go

by Amy Labbe

Life often requires getting out and going places, many of which aren't wheelchair friendly. But with the right portable ramp or lift, getting from Point A to Point B can turn from logistical nightmare to smooth transition.

The benefits of portable wheelchair ramps include ease and versatility of use, and sizes that accommodate hassle-free storage and transportation. Most are lightweight, and can cost far less than permanent solutions.

Federally defined ramp standards and dimensions apply only to nonmovable, permanently installed ramps, says Alejandro Miyar, from the office of public affairs at the [U.S. Department of Justice](#). "Neither the [Access Board](#) nor the Department regulates the equipment sold as a 'movable ramp.'"

This means it's ultimately up to each individual to make a determination about what they want or need. First learn about your options and then analyze your situation to see what will work best for you.

### Small rises

"Threshold" or "transition" ramps are meant to bridge small transitions in height, such as door entries, raised landings, roll-in showers, sunken living rooms and other minor transitions. They're typically free-standing, though some come with hardware that allows for a more permanent installation.



Freelance writer Jan Blaustone of Nashville, Tenn., used a homemade ramp of this type that a friend fashioned for her out of a 4-foot by 4-foot piece of plywood.

Blaustone, who has [limb-girdle muscular dystrophy](#), says she carried the ramp around in the back of her van, using it to get over curbs.

"Ideally, a lighter-weight wood would have been better," Blaustone says, "but it was great to have — until I drove off one day and left it on the sidewalk!"

Threshold ramps, some of which can be had for less than \$100, typically come in 3/4-inch to 6-inch height, or *rise*, and commonly are made of anodized aluminum or rubber with an antislip surface.

### Greater heights

A number of ramps are designed to be used for accessing homes, offices and other buildings; they also may be used to

gain access to vans or some trucks and SUVs.

Some feature a single-piece design, while others fold up or come apart into one or more pieces, or roll up for easier use and storage.

These ramps may be as long as 7 feet. (You may find the same design in longer lengths, but that generally makes them less portable.) They range in price from \$150 to upwards of \$800.

Mike Neufeldt, who has [Emery-Dreifuss muscular dystrophy \(EDMD\)](#), is a communications specialist for Harley-Davidson Motor Company in Milwaukee. He uses a folding ramp that's compatible with his newer mid-wheel-drive power wheelchair.

Neufeldt's ramp is 7 feet long and weighs about 75 pounds, but it folds in half and breaks down into two 35-pound pieces for easier carrying. It has a weight-bearing capacity of up to 600 pounds.

Also piloting a mid-wheel-drive power wheelchair and requiring a portable ramp is Tom Bush of Oro Valley, Ariz., who has spinal muscular atrophy.

A ramp is a requirement with mid-wheel-drive chairs, says Bush, because they cannot be tilted back to go over “even one step or a curb.” Once the middle-drive wheels leave the ground, the chair no longer can move.

Bush’s ramp is a one-piece model made of lightweight aluminum, weighing about 20 pounds and measuring 3 feet wide by 2 feet long. He uses it primarily to enter and exit friends’ homes and some buildings, and also for interior barriers such as one-step sunken living rooms and for entering or exiting backyards and patios.

He notes that for single steps in the higher-height range, he sometimes backs his wheelchair down the ramp with

guidance from a companion. Also, depending on the surface, he says, “the ramp can slip off the step, so I usually ask someone to place their foot at the end of the ramp until the wheelchair’s front wheels are on the ramp.”

For up to three-step barriers, Bush uses his portable ramp “in conjunction with a six-foot ramp I store in my garage.”

Wheelchair repairers also make use of his portable ramp, Bush notes, raising up the front or rear of the chair to view the underside.

Bush stores the ramp in the storage space at the rear of his van and says his wife, Tina, “handles it without a problem.” In most cases, he notes “the wheelchair user will need the assistance of another person to safely transport and position



Roll-A-Ramp makes portable ramps that roll up for easy transport. Pictured is a 12-inch wide, 9-foot long channel ramp (used in pairs).

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their ramp.” For ease of portability, he recommends obtaining the lightest-weight ramp that will do the job.

A 4-foot-long suitcase ramp that folds up lengthwise and sports a handle for carrying is the portable ramp of choice for Sam Kahn, who has [EDMD](#) and is creative director for Namazu Studios in San Diego.

“It’s bulky and heavy and inconvenient,” says Kahn, who uses it mostly to visit friends and family, “but unfortunately it’s the only solution most of the time.”

Kahn says he only uses the ramp “on two steps at most,” due to the increased chance with steeper inclines of “the chair slipping and losing control.”

When traveling, Kahn says, the ramp fits neatly in the van’s storage space or in the back seat (strapped down).

Track wheelchair ramps (sometimes called channel ramps) are designed to line up with the wheels on each side of a wheelchair and often are used for loading wheelchairs and four-wheeled scooters into vans. Some are designed with a telescoping feature that allows their length to be adjusted.



Tom Bush’s one-piece ramp from [Prairie View Industries](#) helps him effectively navigate one-step barriers and stows easily in the back of his van.



wheelchair to give him extra support.

Channel ramps usually are not recommended for mid-wheel-drive chairs because, on most such chairs, the middle wheels are slightly offset from the front and rear wheels. If you have a mid-wheel drive, ensure each channel is wide enough for your wheel alignment.

These ramps usually are made of aluminum in order to be both strong and lightweight, and generally can be purchased (by the pair) for less than \$700.

Before he switched to a folding ramp, Neufeldt used a pair of telescoping ramps that were adjustable to approximately 5 feet in length and weighed about 10 pounds each.

The ramps were great for travel and getting into homes or buildings with one or two steps, Neufeldt says, explaining that, “the most important thing was to get them lined up properly.” If the tracks weren’t properly spaced, he adds, “the chair wouldn’t be able to make it up.”

Neufeldt also notes that the ramps had some “slippage” at times, making it important that someone hold on to the back of his



Multifold ramps fold along two axes, allowing for longer length while maintaining portability.

## How heavy, how high?

Before starting to shop, think about the expectations you have for your ramp.

“It’s hard to purchase one ramp for every occasion,” Blaustone says. “I’d



Suitcase ramps, such as this one from [Prairie View Industries](#), feature handles for easier transport.

Portable stairlifts, such as the Super-Trac from Garaventa Lift, make it possible for a caregiver to help the wheelchair user access areas where stairs normally would act as barriers.



ask myself, what is the main circumstance I need it for? Is it curbs or steps? For air travel or car travel? To use alone, or will I have someone to lift and/or assemble it?"

Check your wheelchair's instruction manual or the manufacturer's Web site for the weight of your chair, then add in your weight. Bariatric ramps with greater weight-bearing capacities are offered in many portable models.

If possible, measure the vertical height of the places you'll use the ramp the most. Then check your chair's specifications for its *maximum allowable incline*. This is the degree of slope your wheelchair can safely ascend and descend, a figure that determines the length of ramp you'll need. (The slope angle often can be steeper for an unoccupied chair.)

Choose a ramp that doesn't form an angle greater than your chair's maximum allowable incline. Failure to do so may result in injury to you and damage to your wheelchair.

Next, narrow down other critical factors like ease of portability and setup, and storage space in your vehicle. Compare prices, which can vary widely.

Then buy the ramp, and get up and go with a little added confidence that you can handle the "bumps" life may put in your way. □

For more resources, see *InfoQuest*, page 86

## Need a (Portable) Lift?

Although not as maneuverable and requiring more storage space than ramps, portable lifts may be just the thing in certain situations. They're easy to use but more expensive to own and much bulkier to transport.

As with portable ramp purchases, be sure to know precisely what you expect a lift to be able to do and communicate your specific needs and circumstances to the dealer or manufacturer.

Portable *vertical lifts* roll into place on wheels or casters and allow users to access raised platforms such as stages, decks or landings. Most models include a platform enclosed with panels or bars to lift a person and wheelchair straight up or down from one level to the next.

Vertical lift operation usually is powered via plug-in to a standard power source, but some models offer battery-backup power. Cost begins around \$5,500.

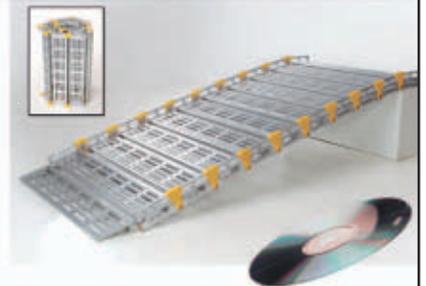
Portable *stairlifts* attach to the wheelchair itself or use a platform to enable a caregiver to move a person in a wheelchair up and down stairways. Some accommodate manual wheelchairs only; others are capable of moving power wheelchairs as well. These types of lifts rely on battery power. Cost starts at around \$7,000, and may run upwards of \$12,000.

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# Hospitable Historic Hotels



Formerly a railroad terminal and looking like a castle, the Union Station Marriott is an accessible landmark hotel in St. Louis.

by Barbara & Jim Twardowski

**O**ur love affair with historic hotels began on our honeymoon.

We spent four wonderful days walking through the New Orleans French Quarter where we admired the architecture, listened to jazz, and dined in world-famous restaurants. Each night, we returned to the Bienville House Hotel with its tropical courtyard, wrought iron balconies and Southern charm.

Over the years, our attraction to properties with character has never waned. But, as Barbara's neuromuscular disease

has progressed and she has come to rely on a power chair, staying in a historic hotel has become a challenge — many of them do not have accessible rooms. Often, it is impossible for a property to accommodate wheelchairs and doing so would destroy their historic integrity. For example, at the landmark Algonquin Hotel in New York City, the guest bathrooms are small and cannot provide

the 5-foot turning radius required for a wheelchair. Built in 1902, the hotel's elevator is just barely wide enough for a manual wheelchair.

We're always scouting for properties that are wheelchair friendly and are delighted when we find the rare hotel that indulges our passion for the past and meets Barbara's physical needs. Hotels that have undergone renovations in the last decade often have incorporated accessible design.

If you love history and are willing to make some compromises, there are many wonderful hotels that will transport you (and your wheelchair) to another era.

Here are three that we found to have good accessibility.

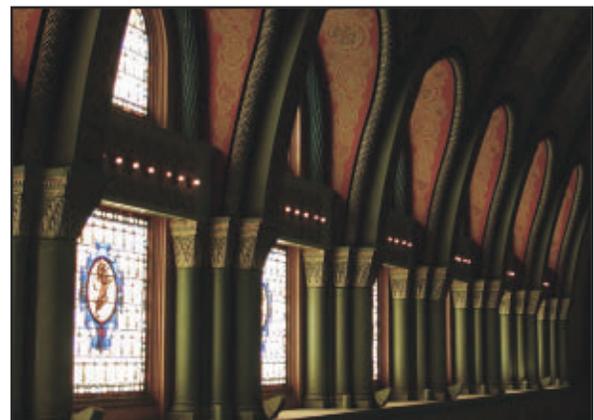
## St. Louis, Mo.

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Driving into downtown St. Louis, it's easy to spot the St. Louis Union Station Marriott (formerly the Hyatt Regency St. Louis). What was once the world's largest and busiest railroad terminal looks like a castle. One of the most popular attractions in the city, Union Station has barrel-vaulted ceilings that soar 65 feet with Tiffany stained glass accents. The lobby originally was the passenger wait-



Arched stained glass windows grace the Marriott's interior.

ing area. Visitors sip drinks while sitting on plush red velvet chairs surrounded by antique outdoor street lamps in the Grand Hall. Take your time exploring, and don't miss the mosaic tiled fish.

The landmark hotel has 517 rooms and 22 suites. Our room had two queen-size beds and a roll-in shower. The hotel was very accessible, with two onsite restaurants and a fitness center. Attached to the hotel are 11 acres of retail shopping — we didn't have to travel far to find souvenirs.

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the Mayflower Hotel opened in 1925. Calvin Coolidge's Inaugural Ball began a long tradition of presidents using the hotel for formal events. FBI Director J.

Edgar Hoover ate lunch at the Mayflower every day for 20 years. When Franklin Roosevelt was living in the hotel before his inauguration, he dictated his famous



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Luxurious bar in the historic Renaissance Mayflower.

speech, “We have nothing to fear, but fear itself.”

Located just four blocks from the White House, the Mayflower Hotel is the largest luxury hotel in the capital city, with 583 rooms and 74 suites. Our elegant eighth-floor room was very accessible, but it is the bathroom that we will always remember. The toilet was in one room and the shower in another. The huge space could have accommodated multiple wheelchair users.

Take the time to explore the hotel’s meeting rooms — the Chinese Room has a spectacular carved ceiling and the massive chandeliers throughout the Grand Promenade are stunning. You can have breakfast in the hotel’s café and work off a few calories in the onsite fitness center, or spend an afternoon exploring the Dupont Circle neighborhood.

## Memphis, Tenn.

*The Peabody Memphis*  
(901) 529-4000  
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Known as the birthplace of rock ‘n’ roll, **Memphis** is an iconic

American city. The Peabody Hotel is located downtown and within walking distance of the famous Beale Street. The hotel itself is home to one of the city’s most popular attractions — the March of the Peabody Ducks, a tradition that began 75 years ago.

Every morning at 11, an audience gathers in the hotel’s grand lobby to watch as the Duckmaster leads five mallard ducks from their home on the hotel roof — “Duck Palace” — down the elevator and out to the hotel’s marble fountain. The ducks parade on a red carpet to a John Phillip Sousa tune. The ceremony resumes at 5 p.m., when the mallards retire to their palace.

Originally built in 1925, the hotel completed a multimillion dollar renovation in 2005. Our 12th-floor room had a view of downtown and a variety of accessible features — some of which worked better than others. The raised bed made

transferring from a wheelchair difficult. The spacious bathroom with a wall-mounted television had a flimsy shower bench in the roll-in shower. The toilet had ample handrails, but was extremely low. The granite-topped bowl-shaped sink easily accommodated Barbara’s wheelchair.

The Peabody has three restaurants, two bars and an eclectic collection of retail shops on the ground floor offering everything from souvenir T-shirts to imported pearls. The accessible entrance to the hotel’s Capriccio Restaurant, an Italian steakhouse, requires going outside the hotel and walking around the block. The pool and athletic club are inaccessible by wheelchair because both require guests to climb stairs.

## Finding a historic hotel

The [Historic Hotels of America \(HHA\)](#) is a program of the National Trust for Historic Preservation. HHA identifies hotels that have “faithfully maintained their historic integrity, architecture and ambience.” Currently, there are 211 member hotels and resorts. The properties must be

located in buildings that are at least 50 years old, and they must be listed or be eligible for listing in the [National Register of Historic Places](#) or be recognized locally as having historic significance.

The member properties range from the eight-room American Hotel in New York to the 1,639-room Palmer Hotel in Illinois. The location of the hotels is as diverse as mountain wilderness and bustling metropolitan cities. Some of the hotels are owned by large hotel



Situated near famous Beale Street, the Peabody Hotel, originally built in 1925, received a major renovation in 2005.

chains and others have been in one family for generations.

Reservations made through HHA support the National Trust, a nonprofit, private membership organization that is dedicated to revitalizing America's communities and saving historic places. Rooms at member hotels can be reserved by visiting [www.historichotels.org](http://www.historichotels.org), calling (800) 678-8946, or calling the hotel's reservation number.

A description of member hotels can be viewed online at [www.historichotels.org](http://www.historichotels.org) or you can purchase a directory for \$5 by sending a check or money order to Preferred Hotel Group (HHA), 38999 Eagle Way, Chicago IL, 60678-1389. Several member hotels offer video tours of their properties on the HHA website at [www.historichotels.org/video\\_tour](http://www.historichotels.org/video_tour).

Not every historic hotel belongs to the HHA. Another way to find them is to conduct an Internet search using the name of the town you're visiting and "historic hotel."



The Peabody's Forest Room offers pure Southern elegance.

questions, because some areas of the hotel and some services may not be accessible. Questions we typically ask before booking a reservation include:

- Is your hotel wheelchair-accessible?
- Do wheelchair users need to use a different entrance? Where is it located?
- Do you have a guest room with a roll-in shower? Does the shower have a transfer bench?
- Are there grab bars in the bathroom?
- Are the hotel's restaurant and guest amenities (lounge, fitness center, etc.) wheelchair-accessible?
- What attractions are within walking distance of the hotel? □

*The Twardowskis are frequent Quest contributors. Barbara Twardowski has Charcot-Marie Tooth disease.*

## Checking accessibility

Once you've found a property, call the reservation desk and ask very specific

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## Ben the Book Saver

For Benjamin Carpenter, 14, of Brandon, Fla., reading is more than just an enjoyable hobby. It's a way for him to give back to the community, through his two nonprofit organizations, Ben's Mends and Ben's Mends Hearts.

"It was an easy choice to try to help others who may not have the same opportunities as I do and to help them escape from their troubles into a book or story," says Carpenter, who received a diagnosis of *spinal muscular atrophy* at age 2 and uses a power wheelchair.

Carpenter started Ben's Mends in 2007. The organization, which receives used and abused books from outside sources and repairs them with professional book supplies, has donated more than 3,000 refurbished books to other nonprofit organizations such as Tampa's Shriners Hospital for Children, the Veteran's



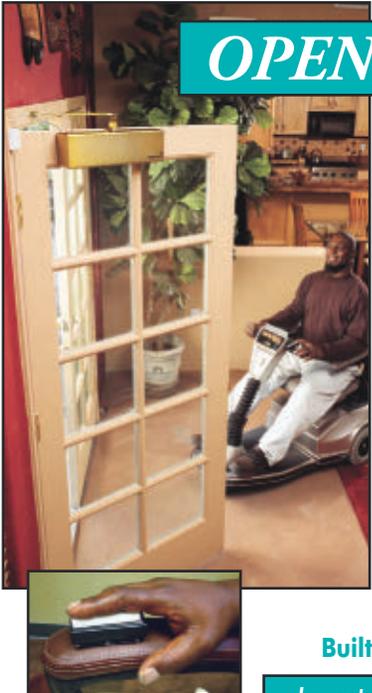
Ben, center, and a few of his friends.

Administration and an Alzheimer's disease care facility. Books also are mended and donated to Carpenter's former elementary and middle schools.

A soon-to-be freshman at King High School, Carpenter is involved in every aspect of Ben's Mends, from picking up

used books to repairing them to dropping off mended books. He's also in charge of fundraising and public awareness events to promote Ben's Mends. Volunteers (the number varies) are mostly his classmates.

Carpenter's second organization is still in its beginning stages. Ben's Mends



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Hearts will send volunteers into places such as retirement homes or homeless shelters to read books that have been mended to those who may not be able to read for themselves.

"I'm very proud of my organizations, and I think that they've been very successful so far," says Carpenter, who was one of 27 students nationwide chosen as "Nestle's Very Best in Youth" in 2007.

"Our motto for Ben's Mend's Hearts says it all: We want to change lives 'one story at a time,' and I think we've really made a difference to those who we've touched."

## Born to Invent

The inventor of the Zip-It drain cleaning tool, Gene Luoma of Duluth, Minn., is at it again. The challenges associated with having **facioscapulohumeral muscular dystrophy (FSHD)** only add fuel to his creative fire.

Built with accessibility in mind, featur-

ing wide doors and a ramp to accommodate his scooter, the floating Gazeboat is Luoma's latest invention. A 10-foot hexagon with a table and chairs on an 18-foot deck, the Gazeboat floats on 12 plastic foam-filled dock floats and has a trolling motor located under the table for convenience. Luoma, 66, also can operate the motor via wireless remote control while he's out on the deck fishing.

Another recent Luoma invention is the Verti-Grill, a vertical gas grill with upright grilling baskets that cooks both sides of the meat simultaneously.

When he's not inventing, Luoma is working on a new Web site with his son, Brian, 42, who also has FSHD. Through [www.gizmoplans.com](http://www.gizmoplans.com), people can buy



Gene, center, and his floating gazebo.

plans for all of the "stuff" Luoma has invented, designed and sold over the years. He hopes to sell the plans to the floating Gazeboat on his Web site.

Luoma, who has been inventing since he was 11 years old, has added a Web page to his site where other inventors can sell their own plans and drawings. □

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In 2001, Jack Orchard was diagnosed with ALS. He's been busy ever since, running a foundation and writing his autobiography, **Extra Hands - Grasping for a Meaningful Life**. Writing his book was "incredibly easy." Jack wrote in an e-mail, "When you lose your natural connections to other people and replace them with Eyegaze ... using it becomes almost as natural as using the capabilities you've lost." Jack uses his Eyegaze at least 12 hours a day.

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# Did Someone Say 'Recess'?

by Annie Kennedy

Who doesn't love recess? Remember those school days ... you sat



at your desk with your feet dangling from your chair, dreaming of the moment when the teacher would let you and your friends go to recess? Rain or shine, you got a well-deserved break from your daily routine, and you made the most of every second of it.

In elementary school, recess was about connecting with friends in a casual place, making new friends, learning about what your friends cared about, and getting the "scoop" on what was happening within the school. Well, even though we're now grownups, recess still exists and it isn't much different from what took place on the elementary school playground.

During the month of August, members of Congress leave their offices on Capitol Hill and head home to their own backyards for recess. That doesn't mean they all go on vacation. It means that they're home, visiting with their constituents and friends, learning about what matters to the people that they're elected to represent, and connecting in a more personal and casual way than they're able to do in Washington.

With this in mind, we're excited to announce that MDA will be conducting our inaugural "MDA Fly Out" this August and we'd love for you to participate.

This event is a new twist on a popular advocacy tool, the legislative "fly in," where members of an organization travel to Washington, D.C., and meet with their elected officials on Capitol Hill. In the "fly out," [MDA advocates](#) will meet with elected officials when they're home for the summer recess.



The MDA Fly Out will avoid the strain and expense of travel, but also allow local MDA advocates — families, sponsors, clinicians, researchers, volunteers and MDA staff — to give their representatives the "scoop" on issues of importance to people affected by [neuromuscular diseases](#).

Among other topics, MDA advocates will ask their representatives to support [several pieces of legislation](#), including:

The **Achieving a Better Life Experience (ABLE) Act** allows individuals with disabilities to create disability savings accounts that can accrue interest tax free.

The **Community Choice Act** expands choices in long-term care options.

The **Community Living Assistance Services and Supports (CLASS) Act** amends the Public Health Service Act to create a voluntary national disability insurance program.

The **SMA Treatment Acceleration Act** authorizes critical infrastructure and enhances key research efforts needed to expedite the fight against spinal muscular atrophy. In the previous Congress, similar legislation was introduced and received impressive support, thanks to the grassroots efforts of the SMA community.

To learn more about planned MDA Fly Out activities in your area this summer, contact your [local MDA office](#). And remember, there's plenty you can do to advocate

for important legislation right from the comfort of home.

Visit [MDA's Advocacy Web pages](#) to sign up to be an MDA advocate and receive e-mail alerts about important pending legislation. We've recently added an online tool that makes it even easier for you to "Take 5" — five minutes — for advocacy.

Our updated Web site enables you to monitor legislation and e-mail elected officials with just a few mouse clicks. Go to the MDA Advocacy page, [www.mda.org/advocacy](http://www.mda.org/advocacy), and click on "Current Congress" to find everything you need to learn about important legislation that affects the MDA community and other legislation; click on "Get Involved in Current Advocacy Campaigns" to e-mail your elected officials. Simply enter your zip code, and the system will identify your representatives, and provide an e-mail message about specific legislation. You may personalize your message for added impact.

We hope you'll give this new tool a try and encourage others to check it out too. Together, we can make an impact and change lives!

*Annie Kennedy is the MDA Vice President for Advocacy.*

# Pen Pals

Pen Pals is only available in the print edition of [Quest magazine](#). To obtain a copy of this issue, contact your [local MDA office](#) at (800) 572-1717.



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# 'Lightning Fast' Switch Increases Accuracy, Reduces Fatigue



Although single-switch scanning is considered a slow method for computer access, David Jayne is scanning faster and more accurately with the Impulse switch, which responds to slight muscle movements in his forehead.

## Wireless switch with Bluetooth technology responds to the faintest muscle movement

by Alyssa Quintero

As technology evolves, new adaptations for hands-free computer access tools help people with muscle diseases communicate, stay online and even drive a wheelchair — all with the slight movement of one working muscle.

### More than a switch

For longtime ALS survivors David Jayne and Jack Hurst, AbleNet's new Impulse computer-access device keeps them online and connected to the world.

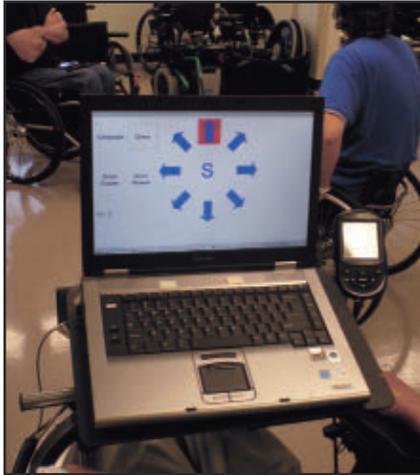
Manufactured by Neural Signals for AbleNet, the **Impulse switch** (\$2,100) is wireless and powered by Bluetooth technology. It uses an electrode to measure electromyography (EMG) impulses through small muscle contractions, providing a way to control computers and speech-generating devices with very small movements.

Used in conjunction with a Windows-based computer, Impulse detects and wirelessly transmits the EMG signal to a Bluetooth receiver. Specialized Impulse software then processes the muscle signal as a switch "click," which activates the communication software, such as **EZ Keys** (manufactured by Words+; retail price \$1,395), for complete computer control.

The switch can be used for 24 hours between charges, and the adjustable switch sensitivity makes it effective for

users who only can manage the slightest muscle movement.

Joe Wright, Neural Signals' vice president of product development, said the sensitivity of the switch to slight movements cuts down on user fatigue. The lack of wires makes it easier for caregivers to maneuver around the person.



Jayne uses the Impulse sensor to start scanning the wheelchair-driving software, which displays the drive function and a directional grid on his wheelchair-mounted laptop.

## Staying on course

Disability-rights activist David Jayne of Rex, Ga., uses a single-switch scanning computer system for communication, environmental controls and driving his wheelchair. (See "On My Command," *Quest*, May-June 2008, and "Keep On Keepin' On," *MDA/ALS Newsmagazine*, January 2008.)

(Single-switch scanning is used by people who have one reliable movement to activate a switch. The switch prompts the computer/communication software to scan a variety of options, briefly highlighting each. Once the desired option is highlighted, the user again activates the switch to make the selection.)

Previously, Jayne relied on a fiber optics switch attached to his eyeglasses to send commands to his laptop for communication access, environmental controls and driving his wheelchair.

Always in search of the most functional and cutting-edge developments in assis-

tive technology, Jayne was encouraged by fellow ALS survivor Jack Hurst to try the Impulse switch. Hurst, 71, of Marietta, Ga., has used the switch for more than a year, dating back to its early development and testing stages.

Jayne, 48, wasn't excited about changing access methods, but he consulted with Neural Signals to make the switch more functional with an easy setup; compatible with his computer/communication system, particularly his specialized wheelchair-driving software; and able to reboot his computer independently, something he could do with his fiber optics switch system. He's been very happy with the result.

"The switch is lightning fast," Jayne said via e-mail. "I am scanning faster and driving better than ever as a result of the switch. The adjustable sensitivity can be reduced to the point that sometimes it feels like I'm just thinking of moving the muscle.

"I'm doing everything faster, more accurately and with less effort than ever before."

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## A wireless world

Although eye-tracking technology (also called “eyegaze”) can be made to work faster by adjusting the settings, Jayne says he prefers the Impulse because he’s constantly changing lighting environments and is in direct sunlight. Light, or different light angles, can interfere with some eye-tracking systems.

Because his laptop controls virtually every aspect of his environment, Jayne demands a reliable system, and “eyegaze technology hasn’t advanced to meet my needs at this time.”

The Impulse sensor snaps onto a small, disposable electrode pad that sticks to the skin. It’s attached to the left side of Jayne’s forehead and is activated by electrical activity in the muscle there.

(The sensor can be attached to virtually any part of the body with a working muscle, and is commonly placed on the face, jaw, forehead, arm or leg. It’s advisable to work with an occupational or physical therapist to determine the appropriate spot.)

Jayne raises his eyebrows to activate the switch and begin scanning; when the desired option is highlighted, he raises his eyebrows again to make the selection.

For example, if Jayne wants to put his wheelchair in reverse, he raises his eyebrows to start scanning the driving software, and when the correct line of commands is highlighted, he raises his eyebrows again to scan each icon in that line. When the down arrow is highlighted, he raises his eyebrows and holds them in position until he’s backed up the desired distance.

## Highly responsive

Like Jayne, Jack Hurst uses the Impulse switch and EZ Keys for full computer access. Hurst, who spends at least eight hours a day on his computer, uses his jaw muscle to activate the switch and send wireless signals to his computer. He



AbleNet’s wireless Impulse switch uses Bluetooth technology to help provide computer access to people with limited movement. The device detects small muscle impulses and can be attached to virtually any part of the body, like the head or jaw.

bites down to start the scanning process, and when it reaches the desired letter or phrase, he bites down again to select the option.

“I use my jaw muscle because it’s not tiring or fatiguing at all; it doesn’t require a lot of force to activate, and it keeps my jaw strong,” Hurst said via e-mail.

Jayne said he appreciates the switch’s wireless feature “because there are no concerns about becoming disconnected by individuals who aren’t familiar with my equipment, and I thoroughly enjoy that my children and others can hug me without fear of disturbing my communication.”

Jayne said he didn’t realize how much effort he was expending to trigger the fiber optics switch.

“I was anticipating when to activate the switch ahead of time,” he said. “Now, I activate the switch the instant the desired icon is highlighted [via scanning]. Eliminating the need to anticipate, combined with the minimal effort to activate, has increased my scanning rate and accuracy significantly.”

The switch’s sensitivity can be



adjusted so low that it can be activated without any visible muscle movement, Jayne said, giving those who are almost completely paralyzed “hope of continued communication.” □

*For more information about the Impulse switch, visit [www.ablenetinc.com/impulse](http://www.ablenetinc.com/impulse), or call (800) 322-0956. The AbleNet site also features a three-minute video of David Jayne using the Impulse switch to drive his wheelchair, speak and help lead a business presentation. To learn more about the EZ Keys communication software, go to [www.words-plus.com](http://www.words-plus.com), or call (800) 869-8521.*

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The EasyStand Evolv line of youth and adult standers now offers a swing-away front option that lets caregivers swing away the knees and tray to gain full access to the front of the stander, making assisted transfers easier. The Swing Away Front is available in two configurations: H-Frame Tray and Shadow Tray. Retail price for the Swing Away Front for H Frame Tray is \$225, and \$175 for the Swing Away Front for Shadow Tray. Starting retail is \$2,775 for the sit-to-stand stander, which features a lifting design that mimics the body's natural pivot points. For information: **Altimate Medical**, (800) 342-8968, or [www.easystand.com](http://www.easystand.com).

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This foot mouse, or "slipper mouse," lets those with hand and arm weakness control a computer with their foot. Includes scroll roller, mouse clicks and a double-click button. Users rest their heel on the floor, using the toes to turn the roller to the left or right and scroll up or down. Programmable buttons allow users to define 10 shortcuts or functions (per program), and FOOTIME fits any size foot, with an elastic strap and hook-and-loop (Velcro) ends. It's compatible with most Windows and Mac operating systems; USB port required. Retail price for the FOOTIME Foot Mouse is \$200. For information: **Bili Inc.**, (626) 333-8718, or [www.bilila.com](http://www.bilila.com).



### Options for Electra-Ride Elite

Several new options are available for Bruno's Electra-Ride Elite straight-rail stairlift; these include an enlarged footrest, an automatic powered footrest, and a powered swivel seat. The powered footrest automatically flips up and out of the way when the seat is raised, and flips down when the seat is lowered. The powered swivel seat securely positions the rider to exit the unit. Manufacturer's suggested retail prices: enlarged footrest, \$420; automatic powered footrest, \$500; powered swivel seat, \$700; and \$4,100 for the Electra-Ride Elite stairlift. For information: **Bruno Independent Living Aids**, (262) 953-5501, or [www.bruno.com](http://www.bruno.com).



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### FreedomAlert



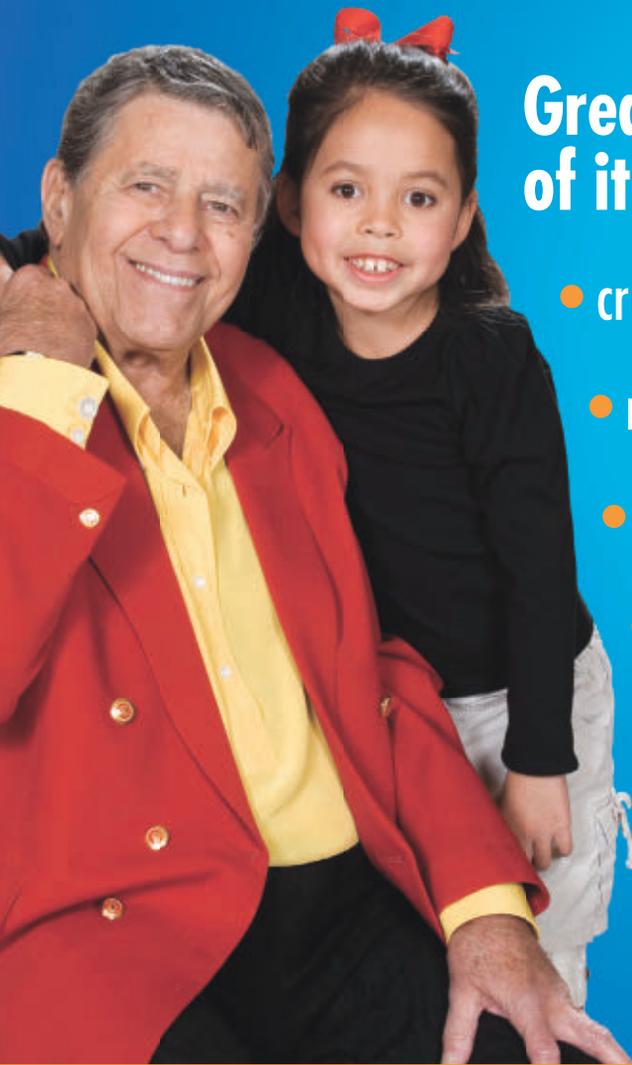
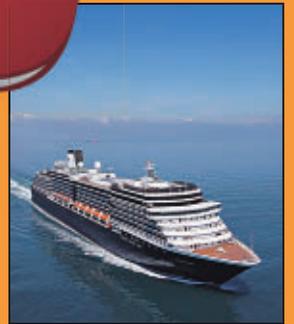
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## Mark your calendar

### MTM-CNM Family Conference

July 24-26, Houston  
(281) 997-3581  
www.mtm-cnm.com

Families affected by myotubular myopathy (MTM) and other centronuclear myopathies (CNM) will gather for fellowship and information on current research and treatments, with presentations by top researchers in this area.

### 2009 Independence Expo

Aug. 7-8, Orlando  
(800) 404-2898  
www.independenceexpo.org

Sponsored by the United Spinal Association, the expo will feature products, services, resources and workshops geared toward people with disabilities.

### Nemaline Myopathy Conference

Aug. 8-9, White Plains, N.Y.  
www.nemaline.org

People affected by nemaline myopathy, families, friends, caregivers, doctors, researchers and health care specialists will gather to share information and support.

### 2009 National Disability Sports Conference

Sept. 10-12, Kennesaw, Ga.  
www.blazesports.org

### U.S. Business Leadership Network Conference & Career Fair

Sept. 15-18, Landover, Md.  
(305) 519-4256

www.newworkforceconference.org

The conference, which features a national career fair, provides networking, education and resources related to employing people with disabilities and marketing to customers with disabilities.

### 2009 National Respite Conference

Sept. 24-25, Los Angeles  
(919) 490-5577  
www.archrespite.org

The conference is for caregivers and families.

### 2009 11th Annual Periodic Paralysis Association Conference

Oct. 9-11, Orlando, Fla.  
(407) 339-9499  
www.periodicparalysis.org  
Contact: lfeld@cfl.rr.com (Linda Feld)  
Experts in periodic paralysis, including physician-investigator and MDA grantee Stephen Cannon, will speak.

### Closing the Gap Conference on Assistive Technology

Oct. 15-17, Minneapolis  
(507) 248-3294  
www.closingthegap.com

The conference features product exhibits and more than 200 workshops.

## Resources

### Accessible public transportation

*(For more on accessible public transportation, see "Rolling Through Phoenix and Boston" page 23.)*

### ADA Accessibility Guidelines for Transportation Vehicles

www.access-board.gov/transit/index.htm

### Disability Rights Education and Defense Fund

(510) 644-2555  
www.dredf.org/transportation  
DREDF advocates for strong, comprehensive ADA transportation requirements and services, and provides in-depth training on ADA transportation.

### DOT Guidance Clarifies Paratransit Regulations

(888) 446-4511  
www.uic.edu/orgs/ada-greatlakes/adanews/003dotguidance.htm

### Federal Transit Administration Office of Civil Rights

(888) 446-4511  
www.fta.dot.gov/civilrights/civil\_rights\_2360.html  
FTA.ADAAssistance@dot.gov  
The Web site has complaint forms and technical information on the transportation provisions in the ADA.

### 2008 Public Transportation Factbook, American Public Transportation Association

www.apta.com/research/stats

## Accessible vehicles

*(See "Accessible Vehicles Q&A," page 27.)*

### Quest Articles

*To read the articles below, go to [www.mda.org/QuestMagazineOnline](http://www.mda.org/QuestMagazineOnline), and click on "Quest Back Issues." If you're not online, contact your local MDA office at (800) 572-1717, and ask that a copy be mailed to you.*

"Hand Controls Keep You on the Go,"  
July-August 2008

"InfoQuest: Hand Controls, Turning Seats & Funding Resources," July-August 2008

"Turning Seats Can Enhance Mobility,"  
July-August 2008

"Playing the Money Game: Funding Challenges and Options," May-June 2008

“Assistive Technology Funding Challenge,” January-February 2007

“Show Me the Money: Financing Options Can Make Van Buyers Good to Go,” July-August 2006

### Adaptive Driving Alliance

(623) 434-0722

[www.adamobility.com](http://www.adamobility.com)

The national group consists of vehicle modification dealers that are NMEDA Quality Assurance Program (QAP) certified and provide van conversions, hand controls, wheelchair lifts, scooter lifts, tie downs, conversion van rentals, para-transit and other adaptive equipment for disabled drivers and passengers.

### Association for Driver Rehabilitation Specialists (ADED)

(877) 529-1830

[www.driver-ed.org](http://www.driver-ed.org)

Database to locate Certified Driver Rehabilitation Specialists (CDRS) in your state.

### Disabled Dealer Magazine

[www.disableddealer.com](http://www.disableddealer.com)

Organized into eight regional publications, the online advertisements feature new and used mobility products, including used accessible vehicles. Visit the site for local contact information.

### National Mobility Equipment Dealers Association (NMEDA)

(Quality Assurance Program)

(800) 833-0427

[www.nmeda.org](http://www.nmeda.org)

Search the directory for NMEDA manufacturers and dealers in your area, and check out the section with details about mobility reimbursement/rebate programs.

### National Highway Traffic Safety Administration

(888) 327-4236

Go to [www.nhtsa.dot.gov](http://www.nhtsa.dot.gov), and enter the following titles in the search box:

“Adapting Motor Vehicles for People with Disabilities”

“Automotive Safety Issues for Persons with Disabilities”

“Hand Control Usage and Safety Assessment”

“Safety Issues for Vehicles Adapted for Use by Persons with Disabilities”

### Travel scooters

(For more on travel scooters, see story on page 40.)

### Amigo Mobility International

(800) 248-9131

[www.myamigo.com](http://www.myamigo.com)

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For example, according to the rate chart above, if you are single, age 75 and made a \$10,000 MDA CGA, then you will receive \$630 per year, every year, for the rest of your life. Some of your payments will be considered tax-free income, and if you itemize on your tax return, a portion of your MDA CGA qualifies as a tax deduction.

For more information go to [www.mdausa.planyourlegacy.org](http://www.mdausa.planyourlegacy.org).  
For a FREE, no-obligation, personalized MDA CGA proposal, call Dr. Rick Brown at (800) 223-6011.



Herb and Davida Aronoff, MDA donors for years, say, “The MDA Charitable Gift Annuity (CGA) is a great financial planning tool, because we’re supporting the important work of MDA, and receiving a great annuity rate at the same time — it’s a terrific way to both give and receive!”

### **Golden Technologies**

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www.goldentech.com

### **Mobility Scooter Reviews**

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www.mobility-scooter-reviews.com  
The site includes a comprehensive comparison table of scooter specifications from various manufacturers.

### **Pride Mobility Products**

(800) 800-8586  
www.pridemobility.com

### **The Rascal Co.**

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www.rascalscooters.com

### **Shoprider Mobility Products**

(310) 328-8866  
www.shoprider.com

### **TravelScoot**

(800) 342-2214  
www.travelscoot.com

### **Zip'r Mobility Solutions**

(800) 760-9107  
www.zipr.com

## **Renter resources**

*(See "Renters with Disabilities Hit Hard," page 64.)*

### **Federal Home Loan Mortgage Corporation ("Freddie Mac")**

(800) 373-3343  
www.freddiemac.com

### **Federal National Mortgage Association ("Fannie Mae")**

(800) 732-6643  
www.fanniemae.com/index.jhtml  
News about their current policies dealing with evictions of renters related to foreclosures.

### **National Housing Institute**

(973) 763-0333  
www.nhi.org  
Referrals to local tenant organizations.

### **Rental Protection Agency**

(801) 484-7368  
www.rentalprotectionagency.com  
Advises both landlords and tenants on consumer issues.

### **State bar associations**

Listed in telephone directories; may be able to provide referrals to local attorneys specializing in foreclosure and landlord-tenant issues.

### **U.S. Department of Housing & Urban Development (HUD)**

(202) 708-1112  
www.hud.gov  
Resources include lists of no-cost foreclosure-issue counselors and public housing agencies by state.

## **Lifts**

*(See "As the Wheel Turns: Portable Solutions," page 68.)*

### **Adaptive Engineering**

(800) 448-4652  
www.adaptivelifts.com

### **AmeriGlide**

(800) 790-1635  
www.ameriglide.com

### **Ascension**

(800) 459-0400  
www.wheelchairlift.com

### **Garaventa Lift**

(800) 663-6556  
www.garaventa.ca/pwl

### **ThyssenKrupp Access**

(800) 829-9760  
www.tkaccess.com/wheelchairlift\_PLP.asp

## **Ramps**

*(See "As the Wheel Turns: Portable Solutions," page 68.)*

### **AlumiRamp Inc.**

(800) 800-3864  
www.alumiramp.com

### **EZ-Access**

(877) 231-3487  
www.ezaccess.com

### **Handi-Ramp**

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www.handiramp.com  
Ramps and lifts

### **LiteRamp**

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www.literamp.com

### **MyPortableRamp.com**

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www.myportableramp.com

### **Prairie View Industries**

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www.pviramps.com

### **Ramp solutions**

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www.rampsolutions.net

### **Roll-A-Ramp**

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www.rollaramp.com

# MDA and Walgreens Fight the Flu



**For people with weakened respiratory muscles, the flu can be more than a minor inconvenience. It can be life-threatening.**

Weakened breathing muscles make it hard to keep lungs clear, allowing a "simple case of the flu" to evolve into a respiratory crisis.

This year, MDA has teamed with Walgreens to make flu shots easily available to people registered with the Association at nearly 7,000 Walgreens locations, including Take Care Clinics<sup>SM</sup>, throughout the flu season.

Contact your [local MDA office](#) to obtain a voucher good for a free flu shot at any participating Walgreens or Take Care Clinic<sup>SM</sup>.

Free flu shots also are available at any of [MDA's 220 clinics](#).

**For more information, contact your local MDA office by calling (800) 572-1717, or go to MDA's Web site at [www.mda.org](http://www.mda.org).**

To locate a participating Walgreens, visit [Walgreens.com/flu](http://Walgreens.com/flu) or call 800-WALGREENS (800-925-4733).

***You are encouraged to call your local Walgreens to schedule an appointment.***

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## Online News

Between issues of Quest, readers can stay informed of the latest research news through Quest Extra stories on the MDA Web site ([www.mda.org/QuestMagazineOnline](http://www.mda.org/QuestMagazineOnline)).

For those who missed them, below is a list of Quest Extra online stories (as of May 29) that were *not* included in this issue of Quest. If you would like to read any of these articles and don't have Internet access, call your [local MDA office](#) at (800) 572-1717 and ask that a printout be mailed to you.

### May 2009

#### Idebenone Not Effective

Idebenone failed to show a significant difference when compared to a placebo in [Friedreich's ataxia](#)

#### Fighting the Fire

Blocking a protein associated with inflammation and scarring helped mice with a [DMD](#)-like disease.

#### Survival Gene

A new study shows a small change in the [KIFAP3](#) gene lengthens [ALS](#) survival time.

#### Searching for Signs

Possible [ALS](#) "biomarkers" are discussed at American Academy of Neurology meeting.

#### Adding Insult to Injury

When [ALS](#)-affected nerve cells lose function, their closest neighbors can't protect them.

#### A Force for Good

Longtime disabilities advocate will serve on the Maryland State Independent Living Council ([VIDEO](#)).

### April 2009

#### Master Woodworker

Dale Taylor brings wood to life.

#### Doubts About EKGs

The widely used test may not screen reliably for heart problems in [DMD](#).

#### Here She Comes ...

Ms. Wheelchair Indiana, who has [SMA](#), is a veritable Superwoman. ([VIDEO](#))

### March 2009

#### A Streak on the Slopes

A former expert skier with [FSHD](#) now schusses the slopes on a bi-ski ([VIDEO](#)).

#### ALS Fatigue Fighter

Modafinil (aka [Provigil](#)) may reduce common fatigue and daytime sleepiness in [ALS](#).

## Now there's another option when considering a bathroom remodel



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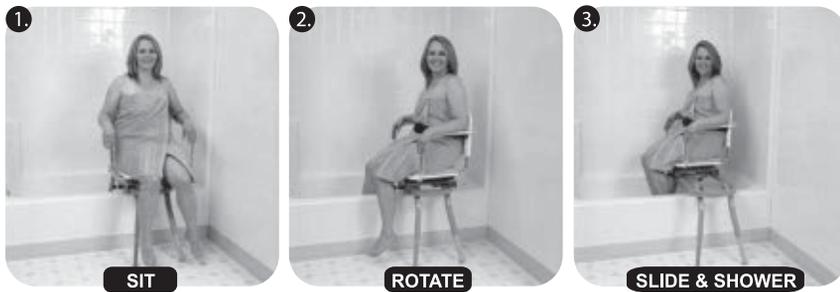
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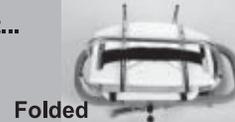
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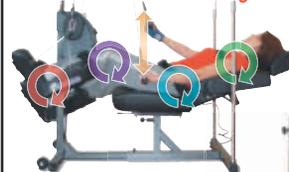
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# As If High School Weren't Tough Enough ...

## Even freshman orientation is more complicated for students with muscle diseases – and their parents

by Sabrina Low-DuMond

Imagine 800 middle school students arriving for freshman orientation at Trabuco Hills High School in Southern California.

All students are taking their first steps onto a campus four times the size of their current school, complete with swimming pool, tennis courts, a school store, vending machines and a gym with real wood flooring.

The school is adorned with adulations of “Distinguished School” and “Blue Ribbon” in larger-than-life signs. Rows of tables are set up for every sport and activity imaginable and high school students are handing out maps and selling chili, submarine sandwiches and home-baked goods to raise money for their respective sports teams. Each new and existing student is trying to look purposeful, yet bored.

It's all quite intimidating for the incoming freshman class of 2013.

### Be a sport

My husband, son and I are first directed toward the tables where every sport the school supports is trying to recruit new talent. Thirteen-year-old Zack, who has the metabolic muscle disorder called [Pompe disease](#), reads each sport aloud as if he's contemplating which one to sign up for.

I quicken my pace, hoping he'll follow my lead so that we don't spend too much time in this area that serves as a painful reminder of what he cannot do. His pace does not change; instead he looks at each table, all proudly arrayed with trophies and



Author Sabrina Low-Dumond and husband Don are pictured with two of their children, Zack, who has Pompe disease, and Madison.

staffed with suited-up athletes ready to answer our questions and hand out applications. We find our way out of Sports Alley seemingly unscathed.

I guess the good news for us is that when Zack was younger, we didn't have to invest thousands of dollars in equipment and lessons to find the one sport that would take him to the Olympics. Before Zack's diagnosis in 2007, he knew his muscles were significantly weaker than other boys his age. He just didn't know why. Having a diagnosis gave the disease a name, but he often still wonders why.

Our next stop is a short overview about Trabuco Hills High School. A very upbeat and confident student body president leads us in the Pledge of Allegiance. She then gives her words of wisdom on how to survive high school, which start with a strong recommendation of ... you guessed it, getting involved in sports!

I nervously glance over at my son, who appears to be smiling and waving at a girl from his art class. I follow his line of sight to see her smiling and waving back. Who cares about sports?

### Cheerfully clueless

We are then herded, by last name, to tables of counselors to have our questions answered about electives. Of the 15 electives available, eight of them are music related, which is not an option for Zack, given his weakened diaphragm muscles. This leaves keyboarding, animation, video production and computer-assisted drafting as his top four choices.

After a brief summary of how electives work, we power walk our way to the “D” table to find out what elective Zack can take, since he is exempt from physical education. A smiling and very informative counselor greets us when it's our turn. We show her the middle school's recommendation (which, by the way, is really not a recommendation as much as a mandate), and she happily explains that we don't need to choose an elective since Zack's course schedule is already complete. She takes her red Sharpie marker and puts a big red X across the electives we've chosen.

We explain that Zack is exempt from PE, given his [504 plan](#), and ask what he will do during that period. She says that he has to

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take an elective and looks down at her big red X over his list. Her mouth turns down at the corners, but a few seconds later she's happily optimistic again and quickly scribbles an "OK" in the same red Sharpie, making life all better. She cheerfully looks up and asks if we have any other questions. We take our marked-up course schedule and leave the table.

## Stairs and stares

It's now free time to tour the campus. Our family walks through campus trying to understand the general lay of the land. My husband and I try to keep the mood light and upbeat, but I can tell that Zack is feeling anxious.

His first concern is having enough time between periods to get to his next class. I remind him that his 504 plan allows for extra "travel time" between classes. His next concern is having a bottom locker, given how hard it is for him to stand up from the floor. I assure him that an arrangement can be made for him and make a mental note to ask the head counselor.

He looks up and makes the observation that there are a lot of stairs. To me, it looks like a run-of-the-mill flight of stairs. To Zack, it looks like a long flight of stairs with no landing, wide enough to fit 10 students shoulder to shoulder, with no railing down the middle. Again, we assure him he will have elevator access and not to worry.

I'm saddened by these thoughts that fill Zack's head and add to the already stressful situation of starting high school.

Differently-abled kids have the challenge of dealing with all the firsts of high schools, plus the added challenge of doing it in a way that doesn't bring attention to them — the challenge of making their special arrangements not obvious to anyone and, of course, the challenge of fitting into a "normal" world when their world is anything but normal.

Several kids say hello to Zack as we walk around campus and I can't help but wonder if all these kids will remain his friends when ninth grade begins. Each year, he seems to shed a few "friends" as the kids get promoted into higher popularity social circles where all bets are off and it's every man for himself.

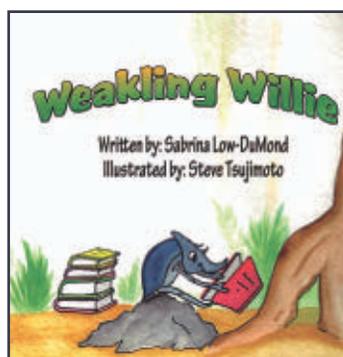
Zack has had the same circle of friends for several years. They don't know about the muscle disease he has. They know he's weak, they know he wears a body brace under his clothes and they know he can't play paint ball with them. This is how Zack wants it.

High school is tough. It's awkward, stressful, confusing and intimidating. As parents of a special-needs child, we have worries well beyond those which can be fathomed by parents of able-bodied students.

This is not a complaint. We are blessed beyond measure to have Zack in our lives. This is merely a snapshot inside our life, for one single event. Not unlike the hundreds of other single events where Zack experiences the milestones, goals, rites of passage and life situations of a growing boy, but with the added hardships and mental weight of doing this while coping with an inherited muscle-wasting disease.

Yes, high school is tough enough. □

*Sabrina Low-DuMond, of Foothill Ranch, Calif., is a stay-at-home mom. She and her husband, Don, have three children: Kyle, 25; Zack, 13; and Madison, 12. Low-DuMond recently authored a children's book about a rhinoceros beetle with weak muscles, called **Weakling Willie** (Publish America, May 2008).*



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