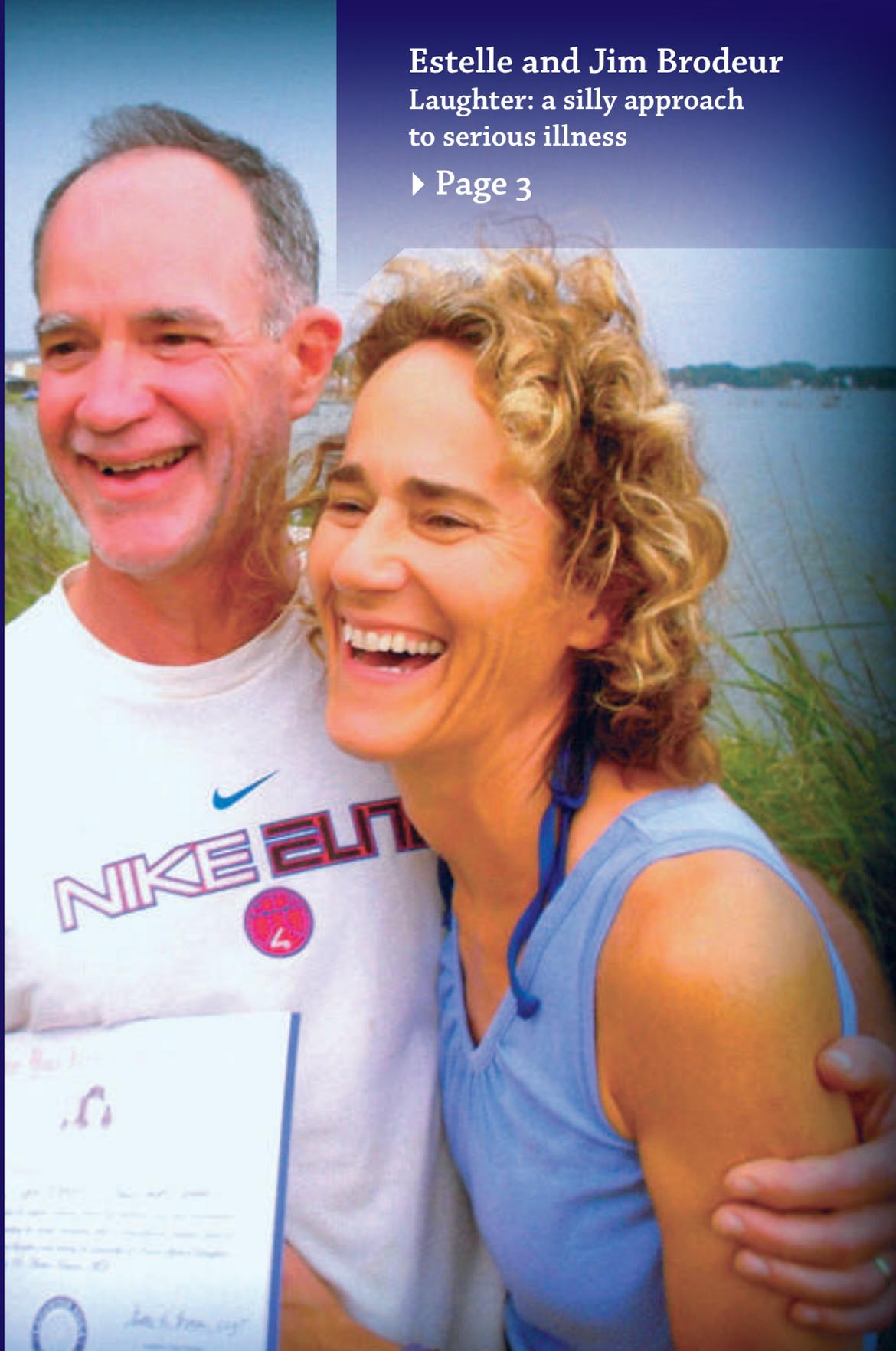


THE OUTLOOK



THE MYOSITIS ASSOCIATION

SPRING 2016
Quarterly Newsletter



Estelle and Jim Brodeur
Laughter: a silly approach
to serious illness

▶ Page 3

Meet Our Members | Page 5 | *Tanner Hunt: another side to IBM*

For the Caregiver | Page 7 | *Getting from here to there*

A Healing Path | Page 10 | *Grieving families find comfort in service*



Bob Goldberg, Executive Director

**The mission of
The Myositis Association is to:**

- *Increase program support to the myositis patient and caregiver community*
 - *Increase awareness of myositis throughout the general population with emphasis on the medical community*
 - *Increase funding for TMA operations and myositis-related research*
-
-

Dear reader,

Many of the articles in this issue of The OutLook focus on planning ahead — whether it is to plan for future equipment needs, a retirement community, or how you might honor the memory of a loved one who is no longer living. Planning is critical to coping and staying as healthy as possible with myositis.

Particularly for those with IBM, there is a need to plan for future expenses, and looking ahead can save you money and protect your health. I often say to those with IBM that the expression “better safe than sorry” is a motto that they need to live by. Taking precautions to prevent a fall and planning ahead for equipment that will be needed will spare you and your caregiver a lot of hassle and anxiety when the time comes for you to take that next step. The transitions that you go through will be much smoother if you have calculated the costs and made accommodation for what you will need in the future.

The Myositis Association Board of Directors recently examined the current strategic plan for the organization and made plans to put more emphasis on social media, greater use of videos, greater collaboration and organizational visibility, online improvements, greater physician outreach and more attention to physician education. We hope that you will notice more activity in these areas as we go forward.

If you have not planned to be at this year’s Annual Patient Conference in New Orleans, we hope you will consider if you can work it into your plans for this year. The Conference should have close to 500 myositis patients and their caregivers and I am certain that you will find a wealth of information and opportunities to speak with others who share your challenges. You are bound to leave the Conference more informed about your disease, how to cope with the disease and how best to plan for your future.

Okay, by now you have probably read enough about “planning,” so let’s do something that can help you today. Read the article on laughter in this issue on the opposite page. While there is nothing funny about myositis, you should try some of the suggestions for using laughter to make you feel better. It works. Try it — you will like it!

Have a fun and safe summer!

Published by: TMA, Inc.
THE MYOSITIS ASSOCIATION
 1737 King Street, Suite 600
 Alexandria, VA 22314
P: 800-821-7356
F: 703-535-6752
E: tma@myositis.org
W: www.myositis.org
 Bob Goldberg, *Executive Director*
 Theresa Reynolds Curry, *Editor*

BOARD OF DIRECTORS

Terry D. Anderson, *Chair*
 Dana P. Ascherman, M.D.,
Vice-Chair
 John C. Suttle, *Treasurer*

Renee Lantner, *Secretary*
 Doreen Cahoon
 Augie DeAugustinis
 Christopher Dotur
 Carol Hatfield
 Marvin Lauwasser
 John McClun
 Theresa Morris
 William Prall
 Carla Stevenson
 Pat Zenner

MEDICAL ADVISORY BOARD

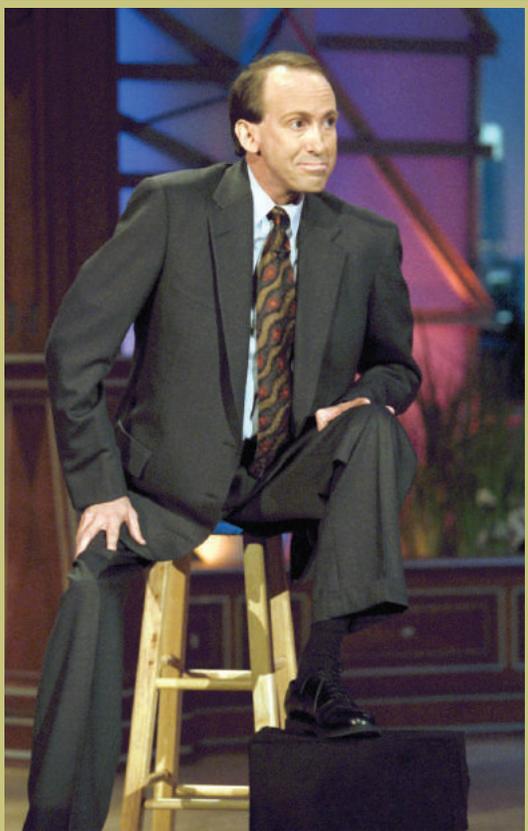
Dana P. Ascherman, M.D., *Chair*
 Andrew Mammen, M.D., Ph.D.,
Vice-Chair

Steven Ytterberg, M.D.,
Research Chair
 Christina Charles-Schoeman,
 M.D., *Nominating Chair*
 Rohit Aggarwal, M.D., M.S.
 Helene Alexanderson, Ph.D.
 Marianne de Visser, M.D.
 Mazen Dimachkie, M.D., FAAN
 Namita A. Goyal, M.D.
 Steven Greenberg, M.D.
 Wael Najib Jarjour, M.D.
 Thomas E. Lloyd, M.D., Ph.D.
 Susan Maillard MSC, MCSP, SRP
 Neil McHugh, M.D.
 Margherita Milone, M.D., Ph.D.

Kanneboyina Nagaraju,
 D.V.M., Ph.D.
 Chester V. Oddis, M.D.
 Ann Reed, M.D.
 Ruth Ann Vleugels, MPH, M.D.
 Conrad C. Weihl M.D., Ph.D.

STAFF

Theresa Curry,
Communications Manager
 Bob Goldberg,
Executive Director
 Aisha Morrow, *Operations Manager*
 Charlia Sanchez,
Member Services Manager



Brett Leake calls himself a sit-down comedian.

Brett Leake:

"I had to find a way to live an affirming, fulfilling, whole existence, and I found that through laughter."

Laughter: a silly approach to serious illness

By Linda Kobert

Brett Leake graduated from the College of William and Mary in 1982 with a business degree. He expected to get a job in finance: a stockbroker perhaps, or working in a bank. But he found himself looking for work during the worst economic downturn since World War II, and he couldn't find a job in his field anywhere. It didn't take long for him to realize that life was not working out the way he had planned.

Leake was familiar with the way life can say "no." As a high school sophomore, he was diagnosed with muscular dystrophy. Having to deal with this chronic, progressive disease that weakened his muscles and interfered with his movement meant he could no longer play baseball. He couldn't run on the beach either. Like many who must confront the similar reality of living with myositis, Leake's life was suddenly filled with "nos."

"I had to find a new version of 'yes' in my life," Leake said. "I had to find a way to live an affirming, fulfilling, whole existence, and I found that through laughter."

Leake discovered the affirming power of laughter one night when he and a friend went to a comedy club for the first time. There, in a dark room, surrounded by strangers, he sat and watched a man make a hundred people laugh for an hour-and-a-half. That night, a light went on in his head: finance was not the only avenue to a fulfilling existence. Even though he had never told a joke to an audience before, he decided to make humor his life and become a comedian.

Substance in a snicker

Laughing in the face of chronic illness is no joke. There's a growing scientific evidence to support that feeling of "yes!" that comes when we start to grin, then giggle, then guffaw.

"There's a physiology to laughter," said Estelle Brodeur, a certified life coach. "It's a great cardiovascular workout."

Laughter makes you breathe deeply, refreshing your body with oxygen. It also stimulates the vagus nerve, which slows the heart rate, lowers blood pressure, and contributes to relaxation.

"That's why laughing is such a powerful stress reducer," Brodeur said. "Laughter also increases lung capacity. It increases serotonin, the brain chemical responsible for joyful, positive emotions. It decreases physical pain. And it decreases inflammation."

Estelle and her husband Jim are laughter experts. Both are certified to teach a practice known as laughter yoga. Several times a week, they lead laughter clubs in the Richmond, Virginia area where people join them just for grins and giggles...literally. They also created space for myositis patients to be silly at TMA's 2015 Annual Patient Conference in Orlando to the delight of all those who attended.

Jim Brodeur, a rheumatologist, often prescribes laughter for his patients. He thinks it's funny how research now proves what everybody understands intuitively.

"We know that laughing feels good," he said, "and studies of people who laugh a lot show their stress system is less activated, they're healthier, they live longer, and when they do get sick, they bounce back faster. The more you look into it the more you find. It's hilarious."

Getting goofy gets results

Leake likes to look at laughter as a tool for problem-solving. It helps him be on the lookout for all those little things in life that don't make sense: an expiration date on aged cheese, for example; a black shirt that doesn't match black pants; getting junk mail on recycled paper.

"Humor taps a capacity within us that even we don't know is there," he said. "If we remain open to the things that don't make sense, then we allow our problem-solving self to find a new way to 'yes.'"

"Laughter will change your perspective," Jim Brodeur agreed. "It's ridiculous how after a long day at work you can laugh even when you don't feel like laughing, and everything changes."

Laughter also tickles the social side of our being. It's almost impossible, for example, to stand next to a person who is laughing and not start laughing yourself. It's contagious. Which is why laughter yoga sessions start with individuals introducing themselves as the whole group bursts out laughing.

"It's a very childlike, playful thing," Estelle said. "When we look into another's eyes and laugh, we feel like we're sharing the same experience."

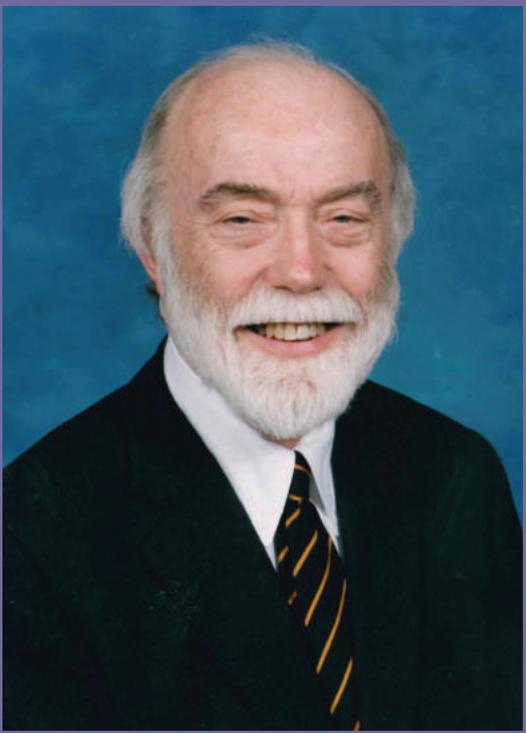
There are times, of course, when we might not feel up to our daily dose of delight. But the Brodeurs have seen many examples of clients who fake it until they make it.

"If you're not feeling so great, but you have a willingness to show up, that's what's important," Estelle said. "Even if you simply manage a little 'hee hee hee hee,' pretty soon you're laughing for real. You just can't help it."

"Laughter also helps us not take ourselves so seriously," Estelle said. "It helps us to not think so much. When you're really laughing you're not thinking about a whole lot, and that can be a great relief sometimes."

"...Studies of people who laugh a lot show their stress system is less activated, they're healthier, they live longer, and when they do get sick, they bounce back faster."

► Ready to start laughing? Find links to the Brodeur's presentation, "**You might as well laugh**" and the video, "**A dose of healthcare humor**" by comedian David Glickman on TMA's home page, www.myositis.org, under 2015 Annual Conference Videos.



Tanner Hunt

Tanner Hunt: another side to IBM

By *Charlia Sanchez*

Tanner Hunt, an inclusion-body myositis patient and TMA member, emailed TMA to share his experience. Hunt, a long-time patient, said his experience with IBM had been very different from the one he'd expected. He wanted to present another side of IBM and let other patients battling the same disease know that no two cases are the same.

Hunt's case has been marked by very slow progression. More than a decade ago, Hunt received his startling diagnosis. During a routine checkup, he discovered he had a CPK level of 740 (a normal count is between 20 and 200) and made an appointment at Baylor College of Medicine in Houston. There, neurologist Dr. Yadollah Harati said he would give Hunt the "good" news first: he did not have ALS.

Since he had no symptoms and no idea that ALS was even a possibility, Hunt had no time to feel much relief before Dr. Harati told him he had inclusion-body myositis.

After the doctor explained IBM: no treatment, no cure, gradual loss of mobility, Hunt feared the worst and expected to begin making the necessary changes in his life to prepare for imminent disability.

"I wondered whether I should drive directly to the nearest dealership that sold vans with disability accommodations and a rear wheelchair rack," he said.

At 79, Hunt reflects on his life since the IBM diagnosis and realizes that not much has changed. He never did purchase that accessible van and has yet to experience a fall.

Hunt continues to practice law full-time and is proud of his career of 54 years and counting. He lives in a two-story home with his wife in Beaumont, Texas, and performs necessary daily functions without assistance or any assistive devices.

Independent of a cane, walker, wheelchair or other mobility aid, Hunt has generally maintained his life despite his diagnosis.

Some things have changed. At one time he'd play handball and tennis four days a week, and occasionally run up to three miles, but he accepts that those days are now behind him.

"I wondered whether I should drive directly to the nearest dealership that sold vans with disability accommodations and a rear wheelchair rack."

At 79, Hunt reflects on his life since the IBM diagnosis and realizes that not much has changed. He never did purchase that accessible van and has yet to experience a fall.

"I can no longer play handball, tennis, or run, as I did before the diagnosis," he said, "but I probably wouldn't be doing those things anyway at 79."

However, he's not completely free of symptoms. Hunt compares his walk and posture to that of the late comedian Groucho Marx. He experiences arm weakness and moderate dysphagia and cannot make a fist, but those symptoms have not seemed to worsen much since shortly after his diagnosis.

Initially, doctors prescribed steroids, which helped his CPK level drop dramatically. He takes no treatment or medicine for myositis. He only takes daily vitamins, including Vitamins C and D, Metamucil and Centrum, all of which he took prior to his diagnosis.

Hunt follows a normal diet with practical adjustments such as chewing and swallowing small bites and drinking lots of water with meals. He enjoys a glass of wine or two.

Hunt's positive experience is one that falls within a wide range of possibilities. According to Dr. Andrew Mammen of the National Institute of Arthritis and Musculoskeletal and Skin Diseases and vice chair of TMA's medical advisory board, IBM has a variable rate of progression: "Some patients deteriorate quickly, others much more slowly."

Dr. Dana Ascherman of the University of Miami is chair of TMA's medical advisory board, and he agrees: "There is a continuum of severity in IBM, so that some patients naturally progress faster than others."

But both doctors mentioned the possibility of a misdiagnosis in Hunt's case, which is a common occurrence in the rare disease community. "We have seen oculopharyngeal muscular dystrophy misdiagnosed as IBM because both have dysphagia and red-rimmed vacuoles on biopsy," said Mammen. (Check out TMA's video, "Do I have the wrong diagnosis" on TMA's website under Annual Conference Videos.)

While Hunt realizes that the disease could get worse at any moment, he is most grateful for this extended period of mobility. He understands how fortunate he has been to have a remarkably slow progression, and advises newly-diagnosed patients to "take heart," as there could be another side to their IBM stories, too.

► **Questions about IBM? Join TMA for a live discussion by Dr. Andy Mammen June 16 at 3 pm. Find information about IBM diagnosis and treatment at "Learn about Myositis" on TMA's home page, www.myositis.org. Click on IBM. Find information about dysphagia, falls, traveling with a disability and IBM patient stories, also at www.myositis.org.**



Nancy Harber

Getting from here to there

By Nancy Harber

Nancy Harber, a registered nurse, was the long-time caregiver for Charlie Harber, an inclusion-body myositis patient. She serves as an informal consultant to patients and caregivers struggling with the challenges of myositis. Although her experience was specifically with IBM, many of her solutions will apply to other forms of myositis as well.

The first several years after Charlie's diagnosis presented little difficulty in mobility. Other than being careful and aware of his potential to fall, it was business as usual.

After a couple of years, he noticed an increasing sense of insecurity while walking. If he was inside the house near chairs or walking next to a rail, it was no problem. But out in the open he felt a real need for support.

A cane purchased at a pharmacy worked quite well for almost a year. Then he progressed to the standard three-sided walker, which basically gave him the support of four additional legs. While that increased his security, it didn't help with his loss of strength and energy when walking. Our next purchase was a walker with a seat. This made a big difference, not only in letting him sit down and rest if he was outside, but it also provided him with a good seat at restaurants and other businesses, one with two arms to help him push up.

Shortly after I retired, we planned a trip to Death Valley, California. Realizing that would be too strenuous for a walker, we rented a caregiver wheelchair, one without the large rolling wheels: made for me to push, not him.

Renting a chair is a good way to test the waters and see if this is for you. In our case, the lack of strength in Charlie's hands made it unrealistic for him to operate a wheelchair. Our experience made us realize it was time to consider an electric wheelchair.

Discussions with our physician confirmed that was the appropriate next step, and also that a special customized chair would be needed, as Charlie's height of 6 ft, 5 inches would make it impossible for him to get out of the normal height chair.

After an evaluation by a physical therapist, we ordered a chair that elevated 6-8 inches with a switch and was built to accommodate his height. Charlie was not yet on Medicare but our private insurance covered about half

the cost under the category of "durable medical equipment," and we paid the rest. Of course, acquiring an electric chair opens all kinds of challenges about transporting it — but that's a story for another time.

The point I want to share is this. Don't wait too long to make decisions about new equipment. I've mentioned before that we probably should make these purchases with an eye toward what will still work in three to five years. In retrospect, we could have eliminated the first standard walker and gone straight to the seated one earlier. But the standard one was given to us, so no money was wasted.

We were fortunate that Charlie only had a few falls over the years, and most of them involved him slipping off a chair or bed and having a soft landing. Anything that can help avoid breaking a bone, especially in a hand or arm needed so often to push and lift, is worth investing in.

I have had a number of people tell me they don't want to give up walking until it's absolutely necessary. I understand that, but keep in mind having a chair doesn't mean you can't still use a walker in the house. And remember once you decided to take that next step, it may be months before the chair arrives.

This journey is not an easy one for patient or caregiver, but fortunately we don't travel it alone and we have the advantage of people who have "been there, done that." Stay open to learning from the experiences of others, and then share that back with someone else just starting the journey. You really can get through this, and the ability to go out and move around opens up your world again. At one time, Charlie used to tell people that his world was shrinking as the disease progressed. However, with the help of some of the adaptive equipment we were able to acquire over the years, his world became a bigger and more exciting place again. Give it a try!



Karyn Rizzo

Assisted living: When, how, where

By *Karyn Rizzo*

Karyn Rizzo is the author of "Aging in America: Navigating our Healthcare System" and an occasional contributor to the "OutLook."

Many people, as they are aging, are determined that they will die at home. You often hear "I'm only leaving my home feet first, or "I'm sure I will die suddenly." The truth is that not everyone is going to have this experience.

The statistics show that 70% of Americans 65 years and older will eventually require help with the activities of daily living. These are eating, bathing, dressing, toileting, transferring (walking) and continence. If you have a chronic disease like myositis, the number goes up, plus you'll need extra help with pills, pain management, and trips to the doctor.

If you see the need for help in the future and are actively choosing a future healthcare center for yourself, you're likely to do better. You'll have a much better transition emotionally, a lower anxiety rate, and an extended life expectancy of three to five years.

Some people have the means and desire to stay at home with private-duty caregivers or a relative. However, many find this plan suddenly needs adjustments, especially when they realize home health doesn't always encourage socialization, a key component to aging gracefully. In fact, retirement community administrators identify an active social life as a strong motive for those seeking a group setting.

But too often, the impetus comes from outside, with the family suddenly realizing how much care their loved one actually requires, and they may begin the process of choosing a center, usually in panic mode and much against the elder's will. Given the personalities involved, this can result in a much more difficult transition than if their parents are able to choose for themselves.

Making the choice

In some states, there are advanced assisted living licenses that allow more assistance, such as "Limited Nursing" or "Extended Congregate Care" (ECC) licenses. These licenses allow them to provide more assistance as

the resident requires it. These centers are best as they allow their residents to "age in place," and most likely NOT need to go to a nursing home.

Many assisted living centers also offer day or respite care, usually costing around \$100-\$350 per day, a nice way for seniors to get familiar with their activities and meet the other residents.

Some also offer short-term respite stays, another way of exposing a person to the center without actually having to move in. The costs for assisted living centers vary based on the area and the amenities they offer.

Many are pet friendly, and will allow a dog or cat. Although they usually require that you be able to care for your pet, some places do offer pet care at a nominal charge.

Making the move

To "try out" a possible community, you can take advantage of a respite package, and this can be a weekend or longer. If you plan to sell your house and it needs repair, I've recommended using this time for renovating bathrooms or kitchens if needed, while you stay at a preferred center on a trial basis.

Sometimes it helps to ask your physician, religious leader, physical therapist or social worker to assist in this transition process, as it's hard to make big changes. Keeping yourself safe has to be the chief priority.

Most residents of assisted living centers say they now realize that they should have done this a long time before, and have reported they feel more energetic than before.

To order your copies of "Aging in America: Navigating our Healthcare System" go to: www.agingguidebook1.com or find one on Amazon, Kindle or Nook.

Paying for an elevated wheelchair seat:

Be creative when looking for funding

The following is a condensation of an article by mobility expert Mark E. Smith published in "New Mobility."

It's a crushing blow when you find the adaptation that might really help you is not covered by Medicare. But perhaps it's time to change the notion that Medicare is the most prevalent funder of assistive devices, says mobility expert Mark Smith. "With few exceptions, most complex rehab beneficiaries don't have Medicare as their primary insurer," Smith says. "Most have a state's Medicaid, private insurance, workers' compensation or veterans' benefits." Smith says to avoid unnecessary paperwork and stress, start with the insurance you actually have instead of trying to fit your more complex needs into Medicare policy.

You may not realize the full extent of your existing insurance, Smith says. He has found that Medicaid, workers' compensation and private insurance are more likely to look at the big picture of how you live your life, including getting around outside the home, rather than focusing on the more narrow interpretation of "activities of daily living" favored by Medicare.

Most complex rehab beneficiaries don't have Medicare as their primary insurer.

One issue of special interest to myositis patients is that of power seat elevation. Smith said that the idea that this is not covered simply because it's not covered by Medicare discourages people from seeking out this technology. "Some of us began looking into each state's Medicaid policy on power chair elevation," Smith said "To our amazement, 46 states have processes that allow beneficiaries to have power seat elevation considered for funding." Other insurers, both private and public, are taking a closer look at elevated seats as well.

Heartened by this knowledge, users and providers began to better explain the true importance of the elevated seats in the daily life of wheelchair users. Today, a market sampling confirmed a 65 percent approval rate nationwide, and it is still climbing. Medicaid's acceptance of power seat elevation as a necessary aid has an impact on other insurers, Smith concluded.

Mark Smith is an internationally recognized mobility expert and author of four books on the subject. He writes about his experiences in magazines and online: www.powerchairdiaries.com.

Why a power elevating wheelchair?

One of the biggest challenges for wheelchair users is to reach upper cupboards, upper shelves, cash machines and many other items standing people can do without a thought. Power wheelchairs with powered elevating seats help wheelchair users in daily living tasks that they would normally find difficult, if not impossible.

Power elevating wheelchair seats are not common options for wheelchair users and not every wheelchair manufacturer will offer them as options but many people find them a great help to making their lives more productive and independent. Despite their usefulness, power elevating seats are available only as optional equipment on power wheelchair bases.

Power wheelchairs with elevating seats are the best alternative available to a power stand-up wheelchairs. They are for people who are not able to support their weight, or find standing painful, but still want to be able to reach further than their seat in a wheelchair will let them.

Be aware that these chairs are not portable and will not fold, so most users of this category of wheelchair are transported while sitting in the wheelchair and loaded into vehicles using a van lift or ramp.

TMA has been pursuing, with the assistance of legal counsel, a hearing with the Center for Medicare and Medicaid Services to determine why elevating seats on power wheelchairs are not considered as durable medical equipment and covered by Medicare. To date, we have been unsuccessful, but will continue to try.

A healing path: Grieving families find comfort in service



Dana Worthington and Laurie Boyer

Dermatomyositis hit Tommy Worthington like a freight train. Tommy, a 39-year-old police officer in the peak of physical condition, saw some mild first symptoms in April 2012. By July, he was gone.

"To say my family and close friends were devastated by Tommy's death would be an understatement," said Laurie Boyer, Tommy's sister. Tommy was larger than life, she said, with a smile that lit up any room.

On the day he got sick, Tommy was 200 pounds of solid muscle, working out five days a week, remembers his wife, Dana: "At no point during his treatment did we think his passing away was even an option. Losing him never crossed our minds, nor was it mentioned by any medical staff."

Tommy's case — an especially serious one that included fast-progressing interstitial lung disease — put him in the hospital for weeks, surrounded by his large close family and his friends. No one could believe that the generous, outgoing man they loved was taken so cruelly and so quickly by a disease they'd never heard of before.

Dana and Laurie weren't alone in believing Tommy was special: While he was sick, he received such tremendous support from friends, family, community members and strangers that he was blown away, Dana said. "He had more cards, treats, private messages, notes, calls, and texts during that stay than any nurse or doctor had ever seen." Tommy promised, once he recovered, that he would repay the community. "He was going to volunteer more and help more and be involved much more than ever," Dana said.

How to mourn this remarkable man? Stunned and broken-hearted, Laurie and Dana supported each other after Tommy's death as they had in the hospital. Then, remembering Tommy's words and looking back on the experience of battling a rare disease with little information, they made the decision to start a foundation in his honor. Shaky at first — it was terribly difficult for either of them to talk about the tragedy behind their mission — they kept pushing forward and "Team Tommy" was born.

"We thought about the areas we wanted to focus on: providing financial support to families, raising awareness of the myositis diseases and funding research," Laurie said. "We reached out to TMA and learned that there were no organizations in the US at that time providing financial assistance to families who have a family member with myositis, and it reaffirmed that we were heading down the right path."

Four months after Tommy's death, the new Team Tommy held its first official fundraiser, a pub crawl to celebrate Tommy's 40th birthday.

Both women admit they had dark days and moments of despair, but they kept on, believing that doing something positive in Tommy's honor is what he wanted. In 2013, they were ready to include others who were grieving the loss of Tommy, and they formed a board of directors.



Team Tommy at TMA's 2015 Annual Patient Conference



Tommy Worthington

Team Tommy myositis patients have hosted health fairs, spoken on radio and TV shows, manned information booths at events, created a physician awareness letter-writing campaign, and sought out proclamations to raise awareness about myositis. They've provided funds to myositis patients and families for steps that encourage better outcomes.

After an amazingly successful couple of years, the women see that their hard work has helped them as well: "Our work establishing the Team Tommy Foundation helped us to grieve because it allowed us to share Tommy with everyone we met along the way," Laurie said. "At the beginning it was very difficult to not get choked up talking about Tommy and his journey. However, as time has passed, my heart is slowly healing because I feel proud knowing that we are carrying out his wishes and helping others."

Dana agrees: "While it was, and at times still is, difficult to tell Tommy's story, the Team Tommy Foundation gave me a new purpose. If I couldn't help my husband, perhaps in some way I could help someone else out there struggling to cope with myositis. Staying busy in such a meaningful way allowed my grieving to become subsidiary to the mission of Team Tommy.

She believes her actions, even in the immediate aftermath of the tragedy, were the right ones for her: "Because of that, because I am here and finding happiness again through the people we are helping and through the love that surrounds me, I would not change a thing."

Dana adds some advice for anyone struggling with the loss of a loved one, or even the loss of your health: "Allow yourself to grieve, but find every way possible to not let it take over you. Let your family, friends and community help, even if you feel that is admitting weakness or that you are becoming a burden. Be a burden! Be weak, be vulnerable, JUST BE!! Eventually, that darkness will subside and your light will shine again."



Jack Weinsheimer holding his daughter, Doreen Cahoon

A yearly tribute

Doreen Cahoon, a TMA board member, along with several family members, volunteers at every Annual Patient Conference. For them, it's a yearly tribute to their father, who died of inclusion-body myositis.

Doreen's dad, Jack Weinsheimer, lived with IBM for almost 30 years. "In the beginning stages, it was hard for dad to get up off of the ground or floor if he had been sitting or kneeling," she said.

Jack's IBM worsened over three decades to the point where he had to be in a wheelchair and had to use a lift chair, lift toilet, and a feeding tube. A life-long tinkerer, Jack looked upon his needs as a challenge: "Dad was a do-it-yourself kind of man," Doreen said, "He could fix anything and actually created devices to help him get through the day as his disease progressed."

"We always tried to keep Dad home and as happy and comfortable as possible," Doreen said. "I would tell people dealing with IBM to always be on the look-out for any new product that will help the patient keep their dignity and the ability to do things for themselves as long as possible."

In his later years with IBM, Jack enjoyed watching movies and TV shows and, unfortunately, he had hours and hours to watch them," Doreen remembers.

Jack's family found it very difficult: "Watching someone go from being a vibrant, active person to needing a feeding tube and close to around-the-clock aides was very hard," Doreen said. In the end, Jack ended up in the hospital on a ventilator. "Those days in the hospital were so sad, as he could not even talk to any of us." After Jack died, Doreen reached out to The Myositis Association, which had been Jack's key source of information — and decided to go to the TMA conference in Las Vegas.

"I asked my siblings to come along with me. We all went and it was the first time we talked with other people who looked like dad, or understood as caregivers what we had all been through."

"We all agreed that going to the conference and meeting all of the myositis patients and families was very healing for all of us," Doreen said. Doreen's family is now familiar to TMA staff and members, and they are among the best volunteers at each Annual Patient Conference.

TMA is always looking for volunteers for the Annual Patient Conference. If you're coming to the 2016 Annual Patient Conference in New Orleans and would like to volunteer, email TMA@myositis.org.

Celebrate with TMA!

May is Myositis Awareness Month

Many of you, especially those who belong to a myositis support group, have been planning events scheduled this month to draw community attention to Myositis Awareness Month.

But if you're just now getting started, it's not too late! TMA has posted some ideas for observing the month on its website, www.myositis.org. Look for "Myositis Awareness Month" in the drop-down menu under "get involved" on the home page. We've collected some ideas for approaching the media, advocating for special issues of importance to myositis patients, educating your community, and getting your physicians involved. You'll also find examples of what TMA members are doing, with tournaments, walk-a-thons, information booths and other gatherings.

Don't forget to use social media in May

Write a blog about your personal journey with myositis and share it on your social media accounts (Facebook, Twitter, Instagram, etc), tagging TMA and using

hashtags below. In addition, read blogs written by others and share their blog on your social media. Contact the author and offer to be a resource.

Ask any businesses that support you, especially one that may furnish the place where your support group meets, to post notices of your meeting on their social media channels. Contact local hospitals to post support group events on their online calendars and social media.

Encourage friends, family members, and all support group members to follow TMA on Facebook and Twitter. Link your support group social media pages to TMA's.

Create your own myositis video, post to YouTube and share it on Facebook and Twitter. Don't forget to send TMA a link!

Share and re-tweet Myositis Awareness content in the month of May and throughout the year. You never know if your post will reach someone who hasn't yet heard of myositis or is struggling with symptoms and seeking a diagnosis. Myositis awareness could help a new patient or family!

TMA is glad to provide support with brochures, wrist bands, myositis awareness car magnets, and other materials. Just let us know what you need: TMA@myositis.org.

We'd like to hear from you about your successful event, publication or fundraiser, along with photos, clippings and/or videos.

f Facebook
@Myositis
www.facebook.com/Myositis

t Twitter
@TheMyositisAssc
www.twitter.com/TheMyositisAssc

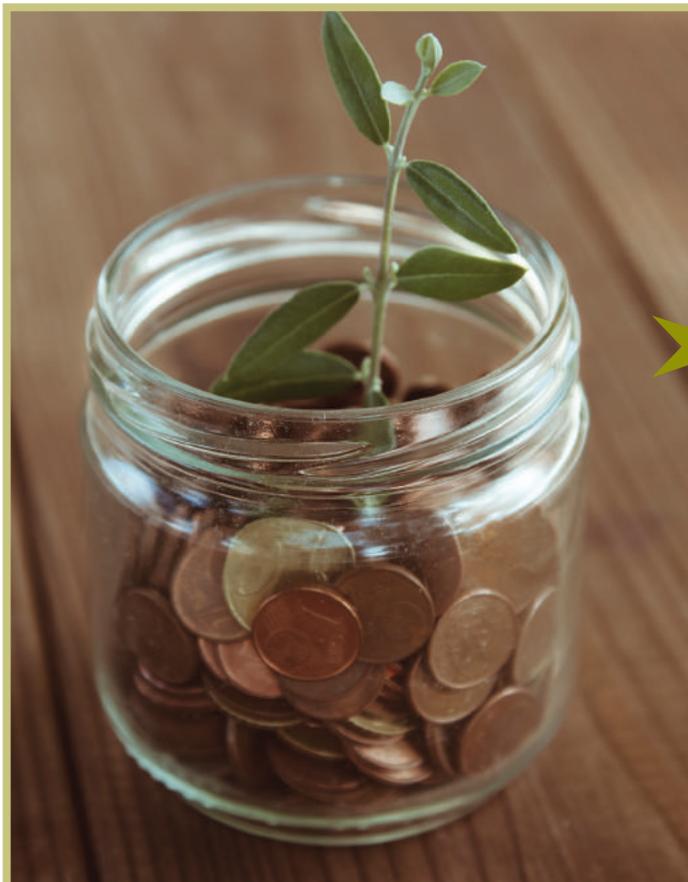
g Website
www.myositis.org

Hashtags
#MyMyositis
#KnowMyositis
#MyositisAwareness

Research Review: a myositis research toolkit

The Myositis Association supports, reports and funds research into the inflammatory myopathies. As soon as we know that a trial is recruiting patients, we let our members know in a variety of ways. TMA staff is always glad to answer your questions about research, and we also offer tools that will help you understand what's happening in TMA's research program and in other current myositis research. Unless otherwise noted, the following resources are available on TMA's website. Look for the drop-down menu under "Explore Research" on the home page.

- ✚ **Find lay summaries** of projects funded by TMA by visiting "TMA Grants & Fellowships" under "Explore Research."
- ✚ **Find out what research** TMA's medical advisors are conducting. They talk about current research interests in a video collected under TMA's 2015 Conference presentations, linked from "In the Spotlight" from TMA's home page.
- ✚ **Find out what myositis trials are open** and recruiting at www.clinicaltrials.gov. Search by using "myositis" or your specific form of myositis as the key word.
- ✚ **TMA catalogues** peer-reviewed research reports. From "Explore Research" on TMA's home page, go to "Published Research." Research is published by year and subject.
- ✚ **For candid discussions** of how patients in trials assess their progress and answer questions from other members, go to TMA's member forums, and find "Clinical Trials" on the home page under "Community Forum" under "Your Myositis Community." Be sure to click "View All" in the lower right to get to the "Clinical Trials" forum.



Leaving a Legacy

Fact | TMA recently received several large bequests

Result | TMA will be able to fund \$500,000 of myositis research this year

You can make a difference!

Remember to consider including TMA as a beneficiary of your estate, a life insurance policy, or an IRA.

Thank you!



Do you or a loved one suffer from myositis and have trouble getting on and off the toilet? LiftSeat can help.

LiftSeat reduces the risk of falls during toileting and can increase a person's independence by safely and securely lowering and lifting a person on and off the toilet.



Request a free info-kit at **liftseat4home.com** or call (877) 665-4381

LIFT YOUR LIFE TOWARD INDEPENDENCE



FREEDOM Chair

Battery-powered chair lift

- From sitting to standing in home, office, etc.
- Comfort and style for use anywhere



STAND AID

YouTube Product Videos on Our Website

Ask about our 30-Day Return Guarantee



POWER TOILET AID

Battery-powered toilet seat lift

- Perfect for those with muscle weakness
- Standard or mobile models available
- Lifts straight up; no forward push

- Manual or battery-powered lift >
- Rehab facility model with power height adjustment available
 - No transfer required! Stand while directly lifted from wheelchair
- Standing program provides many physical and psychological benefits*

For information and a FREE demo video **800-831-8580**
www.stand-aid.com sales@stand-aid.com



THE MYOSITIS ASSOCIATION

1737 King Street, Suite 600
Alexandria, VA 22314

Non-Profit Org.
U.S. Postage
PAID
Baltimore, MD
Permit No. 7175

REGISTER NOW FOR THE 2016 ANNUAL PATIENT CONFERENCE!

SEPTEMBER 1-4 | NEW ORLEANS, LA

📄 REGISTER ONLINE | www.myositis.org

📞 BY PHONE | 1-800-821-7356

✉ BY MAIL | The Myositis Association
1737 King Street, Ste 600
Alexandria, VA 22314

Be sure to check TMA's website (www.myositis.org)
for the most current agenda and conference updates.

CONFERENCE FEES:

Registration Per Person

By May 31	By August 1	After August 1
\$175	\$210	\$260

Refund Policy | Refund requests for TMA registration fees received in writing by July 10 will be issued a full refund; requests received after July 10 and by August 11 will be issued a 50% refund. No refunds after August 11.

HOTEL:

Hilton New Orleans Riverside

Two Poydras Street
New Orleans, LA 70130
Phone: 1-504-561-0500

www.hiltonneworleansriverside.com

TMA Group Rate Per Night: \$119

Rate applies 8/28-9/7/16

Rate unavailable after August 11!

