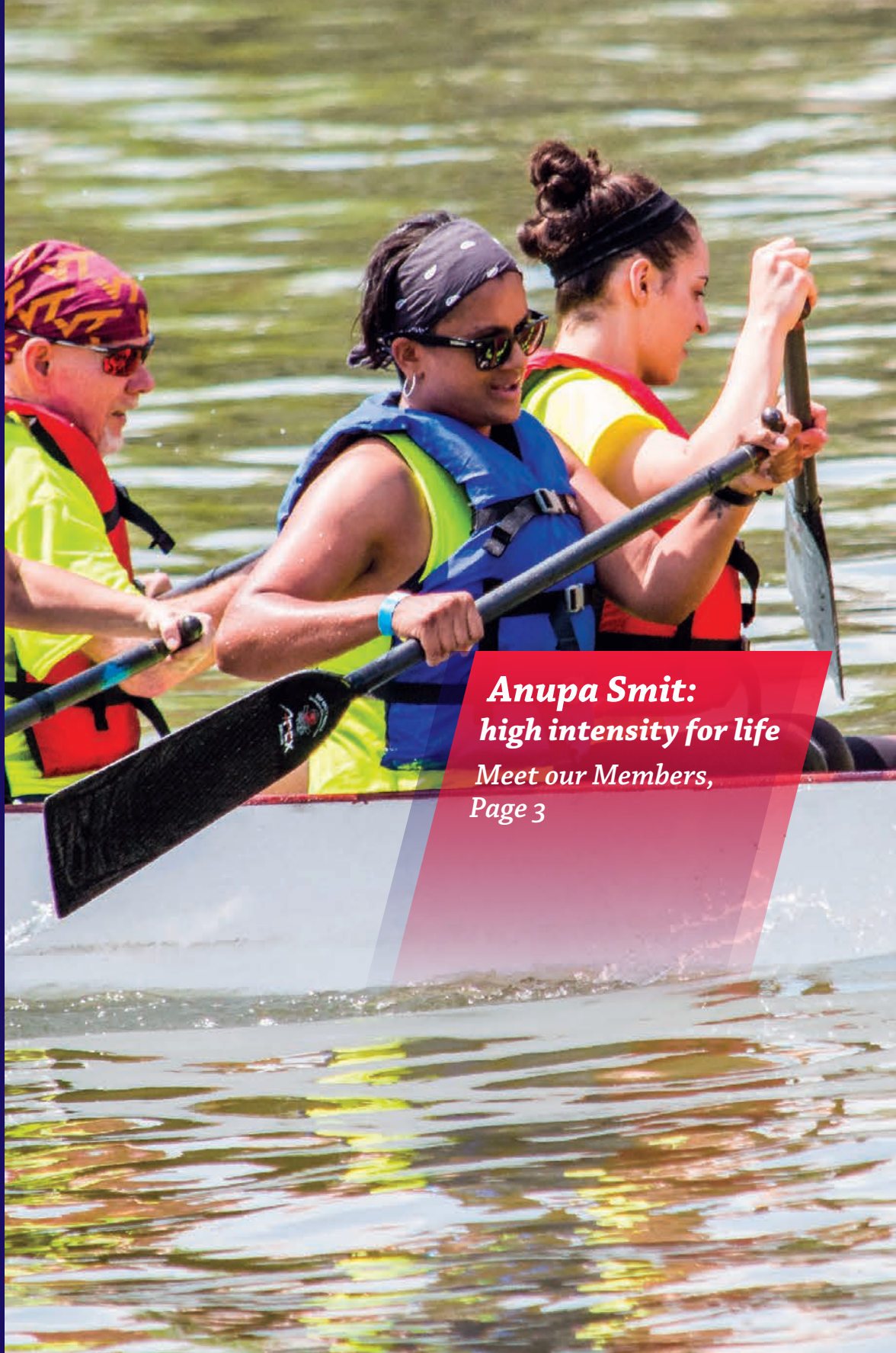


THE OUTLOOK



THE MYOSITIS ASSOCIATION



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WINTER 2016
Quarterly Newsletter



Bob Goldberg, Executive Director

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

- *Provide support to myositis patients and their families*
 - *Provide connections between the Medical Advisory Board and the general medical and patient community*
 - *Increase funding to support myositis research*
-
-

Dear reader,

Rare disease organizations are constantly fighting for the attention of the public to create awareness of their disease and to improve care for those who have to suffer from it. One of the ways to gain public attention and news media interest is to have a special day or month to honor those who live with the disease and to explain the need for more research and education.

TMA had the U.S. House of Representatives declare September 21 as National Myositis Awareness Day a decade ago, with over 100 members of Congress signing onto the resolution declaring September 21 as Myositis Awareness Day. Since then, TMA's support groups and individuals have conducted local events to raise awareness of myositis. However, since TMA's Annual Patient Conference is nearly always held in September, it has been increasingly difficult for our members to plan events around September 21 when many patients and their caregivers are just coming back from our four-day Annual Conference.

To address this dilemma, TMA's Board of Directors has chosen to move this special event to the month of May in 2016 and have the entire month be Myositis Awareness Month. We will be working with our support group leaders to plan more activities to raise awareness during the month. We will suggest new ways to honor those who live with myositis and will encourage creating media opportunities to grab the public's attention — even if it is just for one day during May. Every event incrementally helps to raise awareness of our disease.

If you have ideas for how we might increase public awareness, you are encouraged to share those ideas with TMA and your fellow myositis patients. I know that we all wish there were a nationally-known celebrity who could draw attention to our disease, but that has not yet happened. For someone to take up our cause, they need to have a direct connection to, or a passionate concern for, myositis. We will continue to seek out anyone who might be able to help in this regard. But, in the meantime, we count on you to do whatever you can to raise awareness in your community.

Thank you for your support in this effort!

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Anupa Smit

Anupa Smit: high intensity for life

By Linda Kobert

Three years ago, Anupa Smit had just started a rigorous indoor-cycling fitness class, trying to get back in shape after the birth of her third child. She was making good progress, pushing her aerobic workout to an hour-and-a-half. Then one day her legs just wouldn't go. She felt weak and couldn't keep up with the class. She couldn't even sustain the workout for ten minutes.

The 35-year-old paralegal from Wilmington, Delaware had a small rash on her face too, so she went to see her doctor who thought she might have Lyme's disease or maybe lupus. But the lab tests didn't add up. After a referral to a rheumatologist and more tests, the diagnosis was confirmed: dermatomyositis (DM). This diagnosis

of a life-altering autoimmune disease devastated Smit. She couldn't understand how someone like her, someone who watched her diet, paid attention to her stress levels, and exercised vigorously could develop such a condition. Worst of all, her doctors told her she'd have to cut back on those workouts. "They told me to really limit my exercise," Smit said.

"They said to be very careful, limit it to low impact and very light weight training. This was very disappointing to me, because one of my goals was to run a 5K race."

So while she adhered to her doctor's treatment recommendations, which included immune suppressants and intravenous immunoglobulin, Smit chose to continue

"You can't let it take over your life. I have three kids under ten years of age. I have a really busy life. There's no way I'm going to just stop living."

her exercise routine to the fullest extent possible. She found a trainer who understood her condition and was willing to work with her to balance the needs of her disease with her desire to remain physically strong and active.

Working out the workout controversy

Until recently, the idea of exercise for people with myositis was controversial. Conventional wisdom sug-

gested that vigorous exercise should be avoided, because it may trigger or amplify inflammation in muscles already inflamed by the disease.

But this notion was based on research in sports medicine, not in patients with myositis, according to Helene Alexanderson, RPT, associate professor of physiotherapy at the Karolinska Institutet in Stockholm, Sweden, and a member of TMA's medical advisory board.

"Our research group and others have shown that exercise adapted to disease activity and muscle weakness is both safe and beneficial in myositis," said Alexanderson, an expert in the physiology of exercise in patients with myositis. "There is even some evidence suggesting that resistance training or intensive exercise can reduce disease activity and inflammation in patients with established, low-active DM. Intensive aerobic exercise can also improve the aerobic capacity of the muscle." *(Continued on page 20)*

Practical solutions:

Creative minds of TMA members figure out how to do just about everything



Gadgets, strategies and assistive devices, both high and low-tech, maintain independence for those with myositis. Some of the ideas contributed by TMA members are ideal for anyone with aging or weak muscles: some are specifically well-suited for people with inclusion-body myositis or those in a flare with dermatomyositis or polymyositis.

Many of these were displayed and shared at TMA's 2015 Annual Patient Conference in Orlando in a session led by Camille and Ray Lesoine and assisted by TMA medical advisor Dr. Helene Alexanderson.

Over the 15 years of Ray's disease, the Lesoines researched, purchased and adapted many ideas for allowing Ray, who has IBM, to be as active as possible. "So we have lot of stuff," Camille said. "We know what works and what doesn't." Other suggestions come directly from members, both in the Conference session and through email or online forums.



Helene Alexanderson

For the hands and arms

Dr. Alexanderson introduced a couple of devices she uses in her exercise clinics in Stockholm. One, a claw lifting strap, fits on the wrist, with the fingers curving around the claw part, increasing the hand

strength needed to carry bags or open doors. It has an added benefit, says Alexanderson: "One of my patients who used it a lot actually found that it provided a bit of strengthening exercise for the fingers and he no longer needs it." The lifting straps, the same as those that weightlifters use, are available at sporting goods stores for about \$15, she said.

Another inexpensive, effective way to improve grip suggested by a conference attendee is provided by the small British company Gripeeze (www.gripeeze.com), which offers both gloves and mittens made of materials that help those with weak muscles maintain a good hold on items. The company also makes specialty gloves for activities like fishing.

Many myositis patients, both at the Conference and at home, use strong synthetic rope loops designed to use wrist strength rather than finger strength to lift bags and open doors. Simply loop one end around your wrist or the door or drawer in question and pull with the larger muscles of your arm. An IBM caregiver said that a rope attached to screws in the dryer door enabled his wife to get clean dry clothes out of the dryer when the built-in handle became too difficult. Various kinds of loops are sold by companies that specialize in products for arthritis; others were simply made from materials at hand.

Dr. Alexanderson talked about "servo gloves," gloves with built in sensors that react to the weight being lifted. "We found that the sensors were in the wrong place for myositis patients," she said. She's working with the manufacturers for better placement, and will let us know when the reconfigured gloves are available. She also demonstrated ring splints, simple ring-like devices made to hold fingers steady and avoid over-extension.

Dennis Chada suggests an online accessibility aids store, Gimpgear (*now changing its name to Broadened Horizons*) for eating and gripping aids.

Ray Lesoine continues to type with the aid of Dragon voice recognition software and to control television via a special remote provided free by his cable company. It has large, easy-to-press buttons and is available upon request.

At the time of the Conference, Ray had just received the Jaeco exo-skeleton arm. After several weeks of use following the Conference and an extended western trip, the Lesoines agree it has made a big difference in Ray's ability to feed himself, allowing him to eat while sitting up straight, rather than leaning back at an awkward angle to make use of gravity. "And it's easy to get on and off," Camille said. "So we can just take it with us." Find their model at www.jaecoorthopedic.com.

Other tools that compensate for weak hands and arms, from the Lesoines and others:

- ✚ Seven-inch tongs with silicone tips for eating.
- ✚ Cup holder that mounts on TOP of armrest. (*Avoid side-mounted cupholders*).
- ✚ Plastic wineglasses allow easier gripping for liquids at home, and you can request drinks served in goblets at restaurants.
- ✚ Cutlery with big plastic handles — Scanpan Spectrum (*available at Marshalls*).
- ✚ Toothbrush holder homemade with Sculpy clay.
- ✚ Dave McLaughlin found that he had an easier time starting his lawn mower with a replacement handle in the shape of a "D," much easier to hold onto than the standard "T" shaped handles. These handles are available at Amazon, Lowes and several other places.
- ✚ Dave also found that most spray nozzles were too difficult, and found one he can use with one hand, a Rust-Oleum product available at Home Depot: www.homedepot.com/p/Rust-Oleum-Stops-Rust-High-Performance-C.
- ✚ Greg Fountain was bothered by bruising of his hands and uses some specialty padded gloves — Linebacker gloves from Underarmor (www.underarmor.com/en-us/mens-ua-combat-iv-half-finger-foo) and Rock Climbing Gloves from Metolious (www.amazon.com/Metolious-Finger-Climbing-Gloves/dp/B0000E5N4R).
- ✚ Ray enjoys the recorded books offered without charge by the Library of Congress (www.loc.gov/nls/). Anyone who has difficulty holding a print book is eligible for this service.

Dennis Chada suggests an online accessibility aids store, Gimpgear (*now changing its name to Broadened Horizons*) for eating and gripping aids.

Ray Lesoine continues to type with the aid of Dragon voice recognition software and to control television via a special remote provided free by his cable company. It has large, easy-to-press buttons and is available upon request.

For those troubled by dysphagia, TMA has resources:

- ▶ **Video by Dr. Todd Levine**
(Link from front page under "Helpful Videos").
Or link directly: www.myositis.org/learn-about-myositis/helpful-videos/387.
- ▶ **Smoothie article, Spring 2015**
Go to "My TMA" at www.myositis.org, look for "TMA Publications," then click on "2015," then "Spring Outlook."

Getting up, getting around

The Lesoines like approaching each new challenge as an adventure, encouraging those with advanced IBM to continue to seek out ways to travel, learn and enjoy life. "I heard from someone who now thinks she must stay in bed because she can no longer walk," says Camille. "I think that is very sad." The Lesoines use an over-head lift and travel with it. Their choice is the Invacare Lift, "Reliant

450" which is battery operated for portability.

Mike Shirk, an IBM patient and — like Ray — a big man, has become an advocate for the use of lifts and has been working to make them acceptable in assisted living facilities. We all can benefit from his years of research. Rather than duplicating his work here, we direct you to his blog (lifedisabled.com) which gives a comprehensive account of his experience with lifts and advocacy.

He uses a lift by Prism Medical and offers a display of how it works for lifting, changing clothes and personal hygiene on his blog.

You'll also find a detailed account of Mike's journey both with ingenious homemade work-arounds, advanced technology, living with a disabled spouse and other topics in his book, *Rolling Back: Through a Life Disabled*, available at TMA's website (look for "Resources" in the bottom right, then click on "Store") of the homepage.

Other items that make hygiene easier for patients and caregivers:

- ✎ Female urinals (\$4.99 or so at amazon.com).
- ✎ "Travel Johns." Camille swears by these, purchasing them by the dozens. These are disposable, converting urine into a solid substance that can then be thrown in the trash. (Available through Amazon and medical supply houses.)
- ✎ Unscented baby wipes.
- ✎ Those using a portable bedside commode caution that it must be sturdy and have reliable brakes to avoid falls.
- ✎ John Schuiteman suggests installing a bidet for those who are mobile for easier cleanup.
- ✎ Those who use elevated toilet seats and push-up toilets suggest finding the most lift possible. For a power assist, many TMA members use StandAid (www.stand-aid.com).
- ✎ Another strategy is elevating the toilet from below (Toilevator has models, sold by almost all medical supply houses). Camille points out that your local custom auto body shop can help with any need for longer rods for support.



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- ◀ A surprise, low-tech but genius solution hit upon by TMA members is the use of non-stick, non-skid **texturized shelf paper to provide traction** while doing various tasks. Camille and Ray use it to hold Ray's feet in place while dressing and to help with transferring with a board; Marvin Lauwasser carries a couple of squares to provide a grip for rising from a chair. If the chair has no arms (such as a metal chair), he simply uses it on the chair back.
-

Wheelchairs and scooters

Fans of both electric wheelchairs and mobility scooters are well-represented among TMA's members, and many are on view at each Annual Patient Conference. If you are considering a purchase, here are some characteristics of each, summarized:

A power wheelchair is run by battery and an electric motor instead of using manual effort. The user drives the wheelchair by touching a button. It's useful for those with limited use of their hands and or who experience extreme fatigue using a manual wheelchair. Electric wheelchairs can go long distances, turn in tight spaces and endure tough terrain. Most electric wheelchairs are foldable and fit into closets, car trunks and SUVs, and can be used inside and outside.

A mobility scooter is obviously made to look more like a scooter. It has two or three wheels, swivel seat, handlebars and is run by chargeable

batteries. Those who use a mobility scooter need good balance and the capability of using both hands for steering. Scooters are larger than wheelchairs and are not foldable. They require specific equipment to move by car or a large van to transport. Mobility scooters are used by those who are able to walk a few steps, stand and sit upright without support.



Anyone in doubt about which choice is best at their stage of myositis should discuss their needs with an occupational therapist or mobility specialist. Ray Lesoine uses a Quantum Q6 Edge power chair with a 7" lift seat.

Many of those with myositis who use wheelchairs or scooters when out have strategies for getting around the more confined and familiar spaces of their homes. Karl Lange uses a Vela motorized office chair, Tango 100E (find a demonstration on YouTube, <https://m.youtube.com/watch?v=cSQsBfJIU4>).

TMA has published articles and collected information that may be helpful for those looking for a used power chair. Earl Klein discusses his experience in the Winter, 2012 edition of the Outlook; and Bob Massey writes about his experience in finding the right van for a power chair in the Summer, 2011 Outlook. Find electronic copies of the Outlook by going to the "Community" tab on TMA's homepage, then selecting "My TMA." Publications are listed in order of year.

The Lesoines travel in their Toyota Sienna XL with VMI conversion and a 14" drop. Camille has written about their travels out west and is glad to share

experience with anyone interested. She notes that the Invacare lift has front wheels that are 4.5" high, and that's usually the most clearance possible under hotel beds. "The lift is huge," she says, "and we always request a roll-in shower. It's a good storage place for the lift and shower chair." She also found that — although most hotel rooms now have platform beds that can't accommodate a lift — the hotel housekeepers (not the desk clerks) know which rooms have traditional open bed frames.

For the video of the complete Lesoine Conference presentation, reach 2015 Conference presentations through the TMA home page at www.myositis.org, then click on the video.

Electronic help is at hand

Speaking at the 2013 TMA Annual Patient Conference in Louisville, Kentucky, Mary Ellen Buning, an occupational therapist with a specialty in electronic assistive devices — told TMA members that now is the time to consider the idea of using technology to improve safety and comfort. "If you don't feel comfortable with running your household with your tablet or smartphone, chances are you have a friend (or a grandchild) who can help," she said. She gave an overview of assistance that can be controlled by IOS or android devices, including ideas for mounting and simplifying controls, ensuring safety and finding funding. Her presentation is available on TMA's website. Look for it under the 2013 Conference presentations.

A few resources for turning your home into a "smart home":

- ✦ www.smarthome.com
- ✦ www.atilange.com
- ✦ [www.atilange.com/ESW/Files/BASIC ELECTRONIC AIDS TO DAILY LIVING.pdf](http://www.atilange.com/ESW/Files/BASIC_ELECTRONIC_AIDS_TO_DAILY_LIVING.pdf)

Ray Lesoine with high-tech "bionic arm" and low-tech mini tongs.



In the article above we refer to documents available on TMA's website. Past editions of the OutLook are available as a benefit of TMA membership. It requires registration (it's free) to get to the "My TMA" section of the website. If you have trouble finding the complete newsletter articles or the 2015 Annual Patient Conference presentations online, please email TMA (TMA@myositis.org) for assistance or a print copy.



▶ Watch Emily Filmore's session at the 2015 Annual Patient Conference. [Link to Conference presentations from the homepage of TMA's website.](#)

Writing helps authors gain understanding

Emily Filmore:

"Writing returned me to my true self."

Having dermatomyositis and other illnesses since I was 19 years old meant I had no chance to develop an adult sense of "self" prior to becoming sick. I've lived most of my life under the cloud of doctor's appointments, rashes, weakness, pain, and fatigue. I've broken more promises than I've kept. I've slept more than average. I've had more than the normal number of absences from jobs, leading to an unstable career. I went to law school, but even though I did well, I was unable to practice law. I knew the rigor of a regular law practice would further impair my health. My husband and I are raising our beautiful daughter and nephew, but we still feel the pain from multiple miscarriages.

One could expect me to sit around and cry all day over the loss of a normal life; but I refuse to be defined by my diseases. I manage to find the gifts and graces in my life. I am determined to live a beautiful, happy life full of valuable experiences that work within my limitations.

As a woman in the 21st century, who has always been told that I can be, do and have everything, I found it difficult to give up my legal career. As much as I love my life, before I started writing I wondered how I would contribute to the world. Sure, being a mommy is important and I value that contribution, but I had always dreamed of how I would make my contribution to the whole of humanity. I wanted to "save the world!"

This is how writing brought me back to myself. First I started writing about my parenting experiences, then about spirituality, and finally about how my spirituality "saved" my life on numerous occasions (It enhanced my outlook on

the world, improved my own mental health, which in turn enriched my physical health.) Through writing, I was able to express my innermost fears, insecurities, wishes, and dreams, and amazingly, I found that when I expressed them, they helped others. Could this be the "macro" world contribution for which I had yearned?

Writing about my dermatomyositis was cathartic. I was able to examine every detail of my life with the attention of a scientist, the romanticism of a poet, the tenderness of a lover, and the elucidation of a teacher. I found that in turning this awful disease around and using it for the greater good, I have in fact helped myself. I have embraced a new and exciting reality, one in which my illness has no longer stolen my purpose, but has rather led me back to my life's true purpose and passion: inspiring and teaching others! In helping my fellow patients understand chronic illness doesn't have to lead to chronic unhappiness, I may be receiving the biggest gift of all, a return to my true self, the me that was meant to help, teach, and inspire others to be their best selves.

Emily Filmore has had dermatomyositis for 20 years and is author of [The Marvelous Transformation: Living Well with Autoimmune Disease](#). She spoke at The Myositis Association's 2015 Annual Patient Conference on the topic of how writing can help patients cope with their disease. You can buy her book at [EmilyFilmore.com](#). She lives in St. Louis, Missouri.



Dennis Bracety:

“Writing about my disease helped me put it in perspective.”

One of the main reasons why I chose to write about dermatomyositis was to bring some much needed awareness, through personal accounts, to this rare and extremely unfair disease. There are many people who suffer from autoimmune diseases today, many of whom have lost hope. Some just give up and accept their “new” life. Others choose to stay motivated and continue their fight. I never realized how blind I was before my diagnosis. What I failed to realize, or to see, was how many patients with autoimmune diseases that appear to be “normal” on the outside, are in a great deal of pain on the inside. These same people struggle to get out of bed in the morning, lose energy rapidly and can’t live an active lifestyle because of fatigue. So I thought to myself, “what can I do to help spread a message of courage, inspiration and perseverance?” I remember often lying in my hospital bed, continually

I thought to myself, “what can I do to help spread a message of courage, inspiration and perseverance?”

asking myself, “what’s next?” And I never found the answer. Doctors didn’t know my outcome. They could only speculate or give an educated guess as to my recovery. The term “practicing” medicine became more significant with every passing day. My family would search the internet for answers to the impossible questions of what, why or how? They would look for anything success-related, anything that would keep me motivated, often coming up empty. There were many times when I felt like a lab rat chasing cheese through an impossible maze. Fear of the unknown is very real.

The three lessons I’ve learned on this ongoing journey are: how to be your own patient advocate, finding a doctor, who not only listens, but believes in you, and probably the most important lesson I’ve learned was to never give up! You never know how strong you can be until you have no choice, I’ve always told myself. My stubborn, New York attitude, along with a tremendous support system and a sheer will to live, are the reasons why I was able to recover from DM. With continued treatment and education, I found it imperative to maintain focus on what is going on throughout.

*Dennis Bracety, now an active firefighter once again, wrote *The Fire Within: a Memoir of a Firefighter's Will to Live*. Find it on www.amazon.com.*

Other patient accounts share a common beginning; unique journeys

Debbie Bliss: *Life is Bliss*

Debbie had always been athletic and strong, so her diagnosis with DM as a young woman was a huge blow. Debbie worked hard towards her goal of restoring herself to her former level of fitness. She became one of two women with myositis who carried the Olympic torch through the UK in 2012. Debbie specifically wanted to provide encouragement to others with myositis in writing her book, and it worked. She heard from others in the area and helped them by sharing her experience. Through a radio program to promote her book, she heard from a local woman with myositis and cancer, and they became close friends. You can find *Life is Bliss* on www.amazon.com.

Beverly Boyarsky: *Dr. Bev'isms. A Photo Journey of Inspirational Thoughts*

Beverly had been a successful public relations professional when she began her long journey to a polymyositis diagnosis. Then came the hard struggle for a way to make the best of her new reality. She found inspiration from a source she hadn't counted on — herself. She would wake from sleep with healing thoughts and write them down to create this book that reinforces the power of gratitude and mindfulness. A skilled photographer, she accompanies her words with photos. She's touched the lives of other chronically ill people with what one reader calls “peaceful wisdom”. Find *Dr. Bev'isms* at www.amazon.com.

Zachary Lewis: *The Burly Man*

Zachary's search for spirituality and consistency was severely tested when he was diagnosed with lupus and polymyositis — two serious, incurable, autoimmune diseases — in one year. In addition to his illness, other adversities in his life piled up. Using his background in martial arts, focus and concentration, he built his philosophy of “adapt, change, assimilate, and ultimately transcend” a system of thought that helped him through the difficult times. His story and his practice have helped many with myositis, lupus and other chronic diseases. He spoke at the 2014 Annual Patient Conference in Reno. You can find his book at www.amazon.com.



TMA bookshelf

Books that offer a variety of solutions to common problems are available at the TMA store:

Mike Shirk:
*Rolling Back Through
a Life Disabled*

Mike's blog, 'Life!Disabled' has been a source of inspiration and information to those on their own journey with myositis. Mike faces every new and challenging event with courage and optimism (*see page 6*). He has great ideas about facing everyday struggles with muscle disease, coming up with one solution after another. He wrote the book, he says “to help people with myositis, especially those newly diagnosed, because this is not a common illness and coping with it is not a common skill.” Order from TMA's bookstore at www.myositis.org (*click on “resources,” then click on “store”*) or download free from www.amazon.com if you have a Kindle.

Jenny Fenton:
Living with Myositis

With humor, compassion and common sense, London dermatomyositis patient and TMA member Jenny Fenton wrote and edited this resource for everyone dealing with myositis. It's an accessible, realistic and sympathetic guide, and readers will find it lives up to her description. Jenny includes patients with every type of myositis and from both sides of the Atlantic — and also incorporates commentary and advice from experts about every aspect of the disease: emotional issues, practical challenges, complications, nutrition, exercise, prognosis and coping with drugs. Order from TMA's bookstore at www.myositis.org (*click on “resources,” then click on “store”*).

*When You're the
Caregiver/When You're
Ill or Incapacitated*

Written by James E. Miller, this book is actually two booklets in one. *When You're the Caregiver* outlines 12 things to do as the caregiver of someone who is ill or incapacitated, including discussion on communication and setting boundaries. *When You're Ill or Incapacitated* gives patients 12 things to remember in times of sickness, injury, or disability, including guidance on expressing your feelings and recognizing that your condition affects others as well. Order this book from www.myositis.org.

Coping with Prednisone

It's the drug that myositis patients love to hate. Approximately one million Americans per year take high doses of prednisone and related drugs (glucocorticoids) to treat serious illnesses and conditions ranging from asthma and rheumatoid arthritis to kidney disease and organ transplantation. While these medicines may have unpleasant, even devastating side effects, including gastrointestinal problems, intense mood swings, changes in hair and skin, and increased susceptibility to infection, they may also be the only treatment available for serious life-threatening illnesses. This classic, written by Eugenia Zukerman and Julie Ingelfinger, has helped countless people with inflammatory disorders. Order your copy from www.myositis.org.

The Chronic Illness Workbook

Joan Fennell addresses many of the issues that The Myositis Association members discuss every day on the online forums. She begins, appropriately, with the voices of chronic illness. One patient mentions the trauma and fear she felt with the sudden onset of the disease; one reports an exchange with a friend that ended with these words: “It's like the Joan I knew is dead. I don't recognize you anymore. It's like you're a completely different person.”

One of Fennell's main goals is to give people the skills to integrate their experience into a meaningful new life rather than hopelessly pursuing an unattainable former life. Because it's a workbook, there are lessons and charts, with lists to make and items to check off. She encourages readers to examine everything in their lives to determine what they can let slide and what they can't. One of her objectives is to make sure her readers focus their dwindling energy on the most important — rather than the least important — activities in their lives. Buy it at www.myositis.org.

The Dysphagia Cookbook

If you suffer from dysphagia, this is an all-purpose guide to preparing and serving food. General recommendations for swallowing, information on food consistency, handy tools and foods to have on hand, and suggestions for traveling and eating out supplement the recipes. The author marks each recipe with S (soft), G (ground/shredded/sliced) or P (pureed) to help you decide which recipes are most appropriate depending on the severity of your swallowing difficulties.

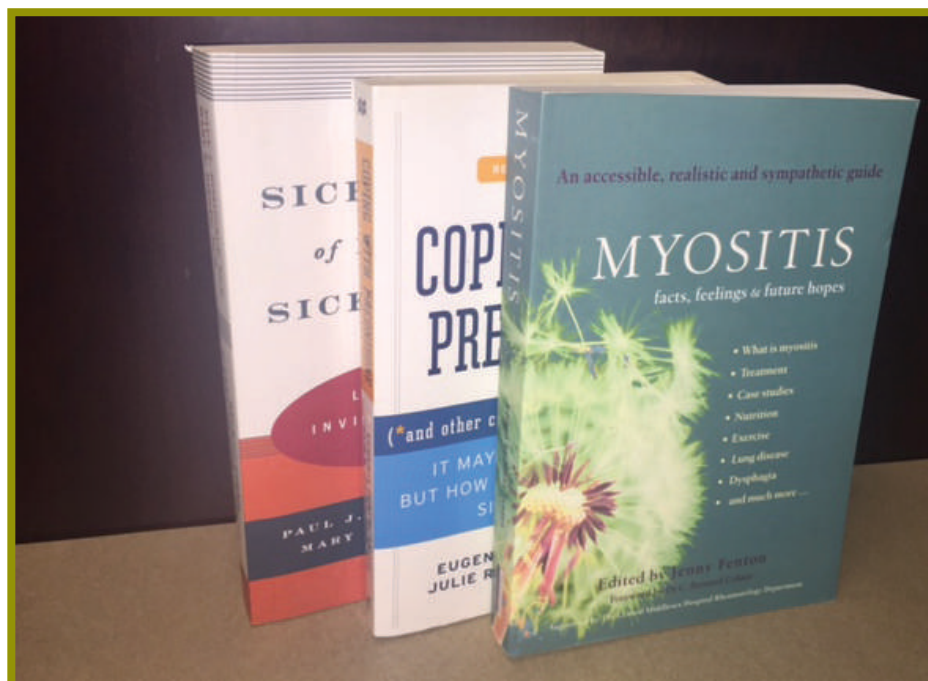
Written by Elayne Achilles, and with an introduction by long-time TMA medical Advisor Dr. Todd Levine, the cookbook is available at www.myositis.org.

Sick and Tired of Feeling Sick and Tired

Unlike a leg in a cast, invisible chronic illness has no observable symptoms, so people who suffer from chronic fatigue, chronic pain, and many other miseries often endure not only the ailment but also dismissive and negative reactions from others. This book offers hope and coping strategies to the thousands of people who suffer from invisible conditions. Drs. Donoghue and Siegel teach their readers how to communicate with loved ones and doctors in a way that meets their needs. Buy your copy at www.myositis.org.

Myositis 101

Patients who are informed, who seek out other patients, and who develop helpful ways of communicating with their doctors have better outcomes. Because the disease is so rare, TMA seeks to provide as much information — all from TMA's medical advisors — as possible to myositis patients so they can understand the challenges of their disease as well as the options for treating it. You'll find it at www.myositis.org.





Sooner rather than later for accessibility aids

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.

As I write this article, I am struck with both the sameness and the newness of what we face each day as we continue to cope with myositis. I remember the recent TMA conference in Orlando — certainly one of the best. I was privileged to participate in four of the workshops and the questions and comments took me back almost 20 years, to what Charlie and I struggled with. So much is still the same — how do I handle bathing, getting on and off the commode, in and out of bed? Is exercise good or bad for my muscles? And what can I do to help me swallow more easily?

And yet new things appeared in our shared conversations in Florida. Antibody testing, research clinical trials that just may hold some hope for IBM patients, and better equipment to make life a little easier for all.

The subject of equipment and technology has always been a challenge for all of us. When should we start thinking about wheelchairs, lifts or vans. Fortunately, many myositis patients won't have to face these challenges, but for many of us, especially those with IBM, some type of specialized equipment may be a necessity. I guess a piece of advice I would like to share is don't wait too long to make a move.

People often tell me they don't want to go to a walker or wheelchair until the last possible minute, for fear they will become too dependent and lose more strength. While I understand these concerns, there is a real potential for problems here. If we could predict the exact point at which we will need the additional help to avoid a fall, we could wait until the last minute. Since we can't, I worry about people putting themselves in harm's way. One little fall that results in a broken wrist or hand (to say nothing of a leg or hip) can be disastrous for someone with myositis who needs both hands to push up from a chair.

Charlie's first power chair stayed in our van for about six months before we brought it in the house and we planned it that way. In the house, he was fine with cane or walker, but when we went out, he not only faced uneven surfaces but also fatigue. Getting the chair opened up his world and we knew it was available to bring inside whenever he decided he needed it. Getting the chair a little early also gave us time to make some adaptations for the house, like a ramp up to the front door.

I usually suggest when people are planning to get some adaptive equipment, they think about what will be needed for the next 3-5 years, not just the next six months. Better to have a little more now for what's needed than not enough. Equipment is expensive and I always encourage people to look around before buying. In San Diego, our KIT support group is great about sharing equipment someone no longer needs and there are several medical supply houses that offer used items for sale. Check out your options sooner rather than later and don't put yourself at risk. New worlds can open up again with increased mobility.

▶ Watch a video on caregiving featuring Nancy Harber from TMA's Annual Patient Conference. Link to conference presentations from TMA's home page, www.myositis.org.



Caregiver relief: finding respite options

By Karyn Rizzo

*This is one in a series of occasional columns by Karyn Rizzo, author of *Aging in America*. Karyn writes about negotiating the confusing world of public and private insurance benefits. She spoke at TMA's 2015 Annual Patient Conference.*

So many caregivers find themselves running on empty; selflessly taking care of a loved one's every need in a very task oriented way to the point that they may not even realize the fatigue and resentment they are feeling.

There are many reasons to find respite care options, not simply to avoid burnout, but more importantly because healthy caregivers have healthier patients.

Where do I begin?

"START where you are, USE what you have, DO what you can."

— Arthur Ashe, Professional Tennis Player

The simplest in home respite options are to use family members, friends, church groups, students from health colleges, and volunteers. Many caregivers don't want to impose upon anyone, but be aware that many would like to help if they are asked.

Furthermore, sometimes the patient may get tired of receiving care from the primary caregiver, and both can get a much-needed break from each other. Make a list of simple tasks that can be offered to people when they ask "do you need anything?" and give them a specific answer: "I'd love to have help with the laundry, with a doctor's visit, or to pick up prescriptions."

There is a tool online that many families use to distribute tasks to multiple care providers called www.ecarediary.com. There is a message board, and the primary caregiver can put in tasks to help with, so that other family members can be notified and sign

up. In-home assistance can also come from Medicare home health providers such as physical therapists and nursing evaluators. Private duty home care agencies sometimes offer special packages that can be easily afforded.

In some states, Medicaid state aid includes weekly private duty care staff to provide some help with the activities of daily living, adult day care programs, and even assisted living financial assistance. To see if you qualify for Medicaid in your state, begin the process online at www.medicaid.org (enter state). In most cases, a case manager is assigned, and most interviews can be done over the phone, or at home.

Out of the home respite options include adult day centers, residential respite care, and caregiver support groups. Assisted living facilities often offer a 3-7 day "respite stay" program that can be free or reasonably priced, and will enable you to attend family events, or just to maintain a good life with work, caregiving and family in balance.

Some organizations that offer respite financial assistance are listed below:

American Association of People with Disabilities
www.aapd.com

ARCH National Respite Network
www.archrespite.org

Family Caregiver Alliance
www.caregiver.org

Hospice Foundation of America
www.hospicefoundation.org

National Day Services Association
www.nadsa.org

Mental Health America
www.nmha.org

National Alliance for Caregiving
www.caregiving.org

National Volunteer Caregiving Network
www.nvcnetwork.org

Retired military and their spouses often qualify for additional money to pay for care under the "Aid and Attendance" benefit, which can pay up to an additional \$2120 monthly to cover in-home private duty care-givers, adult day care programs, and assisted living. If there are liquid assets over \$80,000, (not including house or a car) then it's best to contact an elder law attorney who specializes in veteran benefits to submit the application. However, if there are no liquid assets, or less than \$80,000 (not including house or a car), then it's best to contact the local veteran service officers (free) through the National

Association of County Veteran Service Officers (www.nacvso.org).

There are many other benefits that may be available through the VA healthcare system, including mental health counseling, social services and widows' benefits. To begin the application, go online at www.va.gov. You will need the veteran's DD214, social security number, and date of birth to get started. Achieving balance as a caregiver is essential in maintaining outside relationships, and good physical, emotional and mental health.

Idera Pharmaceuticals opens new DM trial

For many DM patients, currently available treatments do not effectively control their disease and/or are not well tolerated. Researchers hope that new, more narrowly-targeted therapies will improve patient outcomes.

Such a therapy, IMO-8400, is being tested in a Phase Two, randomized, double-blind, placebo-controlled clinical trial to assess the safety, tolerability and efficacy in adult DM patients. Eligibility criteria include evidence of active skin and muscle involvement. Once enrolled, patients will be randomized to one of four groups to receive once-weekly subcutaneous injections of either placebo or IMO-8400 for a period of 24 weeks. Eventually, the study is expected to enroll approximately 48 patients and will be conducted at approximately 20 centers in the United States and United Kingdom. An Idera spokesman said that the only center openly enrolling at the time of publication is in Arizona. More will open shortly: keep track of where they are at www.clinicaltrials.gov. The identifier is NCT02612857. Or contact patientinfo@iderapharma.com or email tma@myositis.org.

Study confirms efficacy of combination drug treatment for JM

A large study of JM treatments with many collaborators (54 centers in 22 countries) enrolled 139 patients aged 18 years or younger with newly diagnosed juvenile dermatomyositis who had received no previous treatment and did not have either skin or stomach ulceration.

The study was partially funded by TMA, and published in the November 27 issue of The Lancet.

Investigators randomly allocated patients to prednisone alone or in combination with either cyclosporin or methotrexate. In this landmark study, the first of its kind, researchers found that combined treatment with prednisone and either cyclosporin or methotrexate was more effective than prednisone alone. The safety profile and steroid-sparing effect favored the combination of prednisone plus methotrexate. The full study, accompanied by an editorial, is available on TMA's website, www.myositis.org, under "Published Research/Juvenile Dermatomyositis/2015."



TMA is governed by a board of directors who volunteer their time and talents. They're involved in projects as well as in planning TMA's future direction. TMA's medical advisory board is also composed of volunteers, many of whom are from outside the U.S.

TMA is always seeking people interested in making a difference in the lives of myositis patients, and has been fortunate to have people of the highest quality willing to serve. Three new people joined the board of directors this year; and five health professionals joined the medical advisory board.

New members, TMA board of directors

CAROL W. HATFIELD OF JONESBORO, GEORGIA | has both an education and business background. As a volunteer, she has served on numerous boards focused on health and the local community. An IBM caregiver, she is interested in improving TMA's offerings to caregivers.

JOHN F. MCCLUN OF WILLISTON, FLORIDA | is an Army veteran. He has a long background in biomedical engineering and is an athlete who has volunteered for many community causes. He is interested in improving awareness of myositis and the public's understanding of the disease.

THERESA A. MORRIS, MPAS, PAC | of Savannah, Georgia, educates physician assistants at South University in Savannah, where she also serves as an assistant professor. She has served in a variety of volunteer and business leadership positions. Since her diagnosis with DM, she has made it a priority to educate health professionals about myositis.

New members, TMA medical advisory board

MARIANNE DE VISSER, MD | a neurologist, is a professor of neuromuscular diseases at the department of neurology at the Academic Medical Centre in Amsterdam, The Netherlands.

NAMITA GOYAL, MD | a neurologist, is an associate professor of neurology at the University of California, Irvine. She also directs the neuromuscular diagnostic lab.

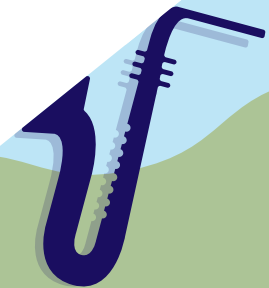
WAEI NAJIB JARJOUR, MD | a rheumatologist, is the director of the division of rheumatology-immunology and an associate professor of internal medicine at Ohio State University.

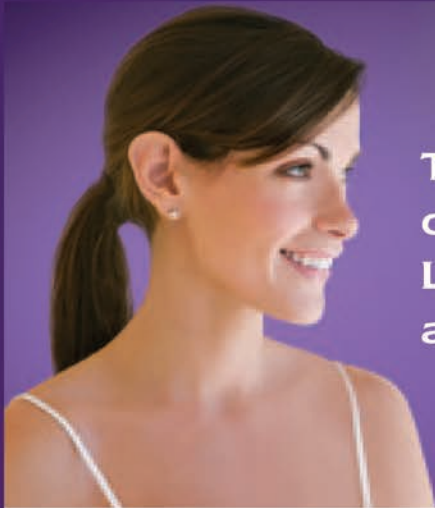
THOMAS E. LLOYD, MD, PHD | a neurologist, is an associate professor of neurology and neuroscience at The Johns Hopkins University School of Medicine.

CONRAD C. WEIHL, MD, PHD | a neurologist, is an associate professor of neurology in the neuromuscular division at Barnes-Jewish Hospital of Neurology in St. Louis Missouri.

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Lisa—28 years old, IG infusion patient
Photographer, favorite subject: her son

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Smit thrives on challenge and discipline

Not only has Smit maintained her fitness regimen, but on a daily basis she confronts her disease like a champion athlete, refusing to allow it to defeat her. “I’m a person who will not give up,” she said. “If there is a challenge in front of me, even if I’m doing it extremely slowly, I’m going to keep on trying.”

She may not be able to do 50 burpees like the rest of the people in her high-intensity interval training class, but with the help of her trainer, Smit realized that she can do enough of these squat-kick-squats to feel like she is challenging herself. And if she can’t do a full jump, well, she can step through the routine, pacing herself, and that’s okay.

Over time, Smit has made gains. She is stronger, her aerobic capacity is greater, and if she misses a day at the gym, she feels it. Even her doctor is coming around. Smit says her doctor is impressed by her progress and is starting to realize that maybe there is some benefit from exercising more than just a little.

“This disease will help you know your body really well,” Smit said. “I have this muscle weakness. That’s just there. So my goal is to try to stay ahead of it as much as I can. I have to push through and do it, even when I’m not feeling well.”

Staying on top of her disease includes eating a healthy diet too. This includes the usual good nutrition, such as increasing fiber and eating plenty of green, leafy vegetables like kale. But Smit is very sensitive to sugar and gluten, so she also has to pay close attention to what’s in what she eats, especially when someone else does the cooking.

“When you eat out, you don’t know what they put into the food,” she said. “There are times when I eat something and I can instantly feel the inflammation swelling in my hands.”

Smit says her commitment to doing whatever it takes to remain strong and healthy is just part of who she is.

“When I was first diagnosed, I read a lot of blogs by people with this disease,” she said. “It was terrifying. People had a really negative attitude toward it. But you have to think of this as a chronic illness that you have to figure out how to live with. You can’t let it take over your life. I have three kids under ten years of age. I have a really busy life. There’s no way I’m going to just stop living.”