THE OUTLOOK

The Myositis Association

FALL 2019
Quarterly Newsletter

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THE OUTLOOK

A quarterly publication of The Myositis Association

TMA's vision is a world without myositis

TMA's mission is to improve the lives of persons affected by myositis, fund innovative research, and increase myositis awareness and advocacy

Cover Photo used with permission of the International Alliance of Dermatology Patient Organizations
Tricha Shivas at the Global Skin Conference 2019

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Global skin conference 2019, Milan, Italy. Used with permission of the International Alliance of Dermatology Patient Organizations

Elevating TMA's mission around the world

By Mary McGowan, Executive Director

As you see in this issue of the OutLook, TMA has been busy spreading the word about myositis through participation in a wide variety of professional conferences and meetings around the world. TMA has exhibited and I have had the opportunity to speak at many of these gatherings.

Professional conferences provide great exposure for TMA and our efforts. More than just attending, TMA seeks opportunities to speak at national and international conferences as a way to raise awareness about myositis as a rare disease among groups with related interests, highlight who we are as an organization, and identify TMA as an expert in particular areas.

In June, for example, I had the opportunity to present at the Rare Disease Summit in Boston. Using our Women of Color and Myositis awareness campaign as an example, my presentation "*The Role of Disease Awareness Campaigns for Rare Diseases*" showcased TMA's expertise on best practices for launching and running such a national campaign. Not only was I able to speak before a large audience of industry experts and other rare disease organizations, but I was interviewed about my presentation, resulting in three published articles that expanded our reach to much larger audiences.

Exhibiting at conferences also provides exposure and an opportunity for TMA to educate clinicians. This year we exhibited at the American College of Rheumatology meeting and the National Hispanic Medical Association annual meeting, reaching thousands of physicians and healthcare providers with important information about myositis diseases and our research funding opportunities.

Global exposure is also achieved through participation in international conferences, such as the Global Conference on Myositis (GCOM) in Berlin and the Global Skin and RareDerm Forum in Milan. As you see in the photo on this issue's cover, TMA's Tricha Shivas, Director of Development and Strategic Partnerships, spoke up at the Global Skin conference, asking important questions about clinical research for myositis patients.

TMA members had the opportunity to have their voices heard at one of these meetings as well. We gathered nearly 80 questions from the TMA community and posed those questions to the international experts at GCOM. Responses to these important questions can be found starting on page 11, with the complete set of responses found on the TMA blog.

Nominating or receiving awards are other opportunities to elevate TMA's efforts. TMA nominated the International Myositis Assessment & Clinical Studies (IMACS) group for this year's Global Genes RARE Champion of Hope—Collaboration in Research award. IMACS was chosen, and TMA will be highlighted as the nominee for this prestigious award at the Global Genes RARE Patient Advocacy Summit, the largest gathering of rare disease patients, care partners, thought leaders, and other rare disease stakeholders from around the world. (See page 8 for more details.)

I personally find conferences to be inspirational, and I work to share that inspiration with coworkers and leadership of TMA. This inspiration provides new ways to think about advancing our mission, solving problems, and opening doors for partnering and collaborating with others.

As we enter the fall conference season, TMA will be planting the seeds for future collaborations and elevating the extraordinary work that we are all doing together in the fight for recognition of myositis diseases.

Cough as a clue to a serious disease

When a person shows up in the doctor's office with a cough, it's a symptom that may be caused by a number of things. It could be allergies, it could be pneumonia, it could be a cold. If that person has an inflammatory disease like myositis and they happen to be African American, there is a higher than normal likelihood that the cough could be something worse. It could be interstitial lung disease (ILD).

ILD is a condition that sometimes develops in people who have autoimmune diseases like myositis, because inflammation can affect the tissues that surround the tiny air sacs in the lung. In myositis, it's often associated with a condition known as antisynthetase syndrome. If it goes untreated, it can cause permanent scarring, making it difficult to breathe and get enough oxygen into the body.

TMA medical advisor and pulmonologist Dr. Sonye Danoff has spent her career studying ILD. She and her colleagues have found that race is a factor in disease severity and mortality for those with myositis and ILD.

"There is a genetic and an environmental component to all autoimmune diseases, and that certainly applies to myositis," Dr. Danoff says. "This is incredibly important, because there are so many studies showing that, for a variety of reasons, minority patients don't receive adequate healthcare."

Dr. Cheilonda Johnson, also a pulmonologist who specializes in ILD and autoimmune diseases, is exploring the question of why black race puts people at greater risk. Her focus is trying to understand what factors influence the development of myositis, why some people don't develop myositis, and what new treatments can be developed to more adequately treat myositis.

Her work has identified certain blood biomarkers called autoantibodies that are much more common in African American patients than in white patients. These markers, which occur only in people with myositis, include anti-PL-12 and anti-PL-7. Both of those autoantibodies are associated with antisynthetase syndrome.

One of the challenges with this, however, is that tests for myositis specific antibodies (MSAs) associated with antisynthetase syndrome often only include the anti-Jo-1 antibody. This is the most common antisynthetase antibody, but African Americans are more likely than Caucasians to have a non-Jo-1 antisynthetase antibody. That's why it's important to include all antisynthetase antibodies, especially PL-12 and PL-7, when testing for MSAs, so antisynthetase syndrome can be accurately diagnosed.

If you have myositis and you develop a cough or trouble breathing, it's important to take it seriously, especially if you are African American. Early diagnosis and treatment usually result in much better outcomes. It's also acceptable to ask your doctor to test you for autoantibodies, and to be sure that all antisynthetase antibodies are among the MSAs being tested.

Dr. Danoff and Dr. Johnson discussed these ideas in TMA's Myositis Awareness Month webinar "Women of Color and Myositis." A recording of this webinar can be found in the library section of TMA's website under webinars.

Noninterventional myositis research

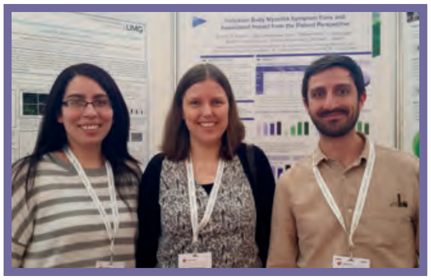
Natural history research and other observational studies are an important way for us to learn about rare diseases. Following is a list of "noninterventional" (meaning no treatment is being tested) studies currently being conducted for myositis diseases. More details are available on the TMA website on the Research page. The NCT number listed here can be used to search for the study on **ClinicalTrials.gov**.

Title of the study	Eligibility	More information
Environmental risk factors for antisynthetase syndrome	Adults and children with myositis, with or without antisynthetase	301-451-6031 NCT01276470
Environmental risk factors for myositis in military personnel	Military personnel diagnosed with myositis while in the service	301-451-6031 NCT01734369
Study of twins or siblings discordant for rheumatic disorders	Twins or siblings within 5 years, one of whom has RA, SLE, SSc, IIM	301-451-6273 NCT00055055
Studies in the natural history and pathogenesis of childhood-onset IIM	Adults and children with DM, PM, sIBM, and related conditions	301-451-6272 NCT00017914
Studies on the natural history and pathogenesis of PM, DM, and related disease	Adults and children, aged 16 or higher, with IIM (suspected or confirmed)	301-432-8434 NCT00001265

TMA raises its profile at meetings around the world

TMA staff have been extremely busy over the last few months attending scientific conferences, legislative and advocacy sessions, and patient engagement strategy forums to help raise awareness of myositis and to amplify our message and mission. In what follows, we give you a brief overview from a few of the recent meetings TMA attended.

The Global Conference on Myositis (GCOM)



TMA-funded fellows: Melissa Morales, Joanna Parkes, and Simon Rothwell

At the end of March in Berlin, Germany, two TMA staff members attended the third biennial Global Conference on Myositis (GCOM). TMA was proud to be a bronze sponsor of this premier international conference on inflammatory neuromuscular disorders. The conference featured more than 300 myositis medical experts from around the world sharing the latest scientific research, global patient organizations (including TMA) sharing the programs and resources they provide to their communities, and an opportunity for TMA to meet face-to-face with numerous drug developers and pharmaceutical companies to learn about their work in inflammatory myopathy and to encourage their interest and focus in research on myositis diseases. TMA was proud to have our Executive Director present at GCOM about our efforts and progress. We were also impressed by the number of presentations and posters featuring TMA-funded projects.

2019 World Orphan Drug Congress

TMA secured sponsorship to attend the 2019 World Orphan Drug Congress in Maryland in April. More than 1,500 attendees from 50 countries gathered to hear more than 300 speakers at 260 educational sessions. More than 100 exhibitors were also included. The main areas of focus for this conference were rare disease advocacy, growing patient advocacy and pharma partnerships through collaboration and innovation, and the challenges to access across the globe. TMA used this opportunity to continue to build and grow strong collaborations in the rare disease space, to meet with partners and regulators, and to learn more about the successes and challenges affecting the advancement of clinical trials and drug development from the industry and regulatory perspectives.

Dr. Christopher P. Austin, MD, director of the National Center for Advancing Translational Sciences (NCATS) at the National Institutes of Health, speaking at the 2019 World Orphan Drug Congress

FDA Meetings

TMA participated in several meetings with the FDA this year. The first was the FDA's Public Meeting on Patient Perspectives on the Impact of Rare Diseases and Bridging Commonalities, which took place on April 29th at the FDA's White Oak Campus. This meeting was an opportunity for the rare disease community to share with the FDA the challenges they face with the drug approval process, clinical trials, and access to treatments. The goal of the meeting was to identify the commonalities across the rare disease groups in order to help identify some immediate needs for the FDA's focus and attention.

Dr. Norman "Ned" Sharpless, MD, Acting Commissioner of Food and Drugs speaking at the Regan Udall Foundation for the FDA Annual Meeting.

On May 2, TMA attended the Annual Meeting of the Regan Udall Foundation for the FDA. This was a small gathering of fewer than 80 attendees together with the leadership of the FDA. It included a fireside chat with the FDA's acting commissioner, Norman "Ned" Sharpless, MD.

During these meetings, TMA interacted with other organizational leaders in the field, learned about shared challenges among rare disease organizations seeking new treatments, discussed partnership opportunities, and met with key regulators who wanted to learn more from patients and patient advocacy groups. As a result of these meetings TMA was able to secure speakers for the July 30th webinar with the FDA. Be sure to watch the recording of this webinar, which can be found in the library section of TMA's website under webinars.

Global Skin 2019 Conference and RareDERM Forum

US Delegates 2019 Global Skin Conference

This June, The Myositis Association was invited to participate in a truly unique and powerful patient organization-led global awareness project to address the underappreciated seriousness, challenges, and impact of skin diseases. Sponsored by the International Alliance of Dermatology Patient Organizations, the Global Skin 2019 Conference took place in Milan, Italy.

Thanks to a scholarship from the Alliance, two members of the TMA staff participated in a two-day working group focusing on rare dermatological diseases, called the RareDerm Forum. This exclusive group of 44 attendees from 12 different countries began to formulate ways that patient organizations and supporting stakeholders can help ensure a positive, measurable impact on the lives of those who live with skin disease.

This forum developed strategies for a global RareDERM network that will be implemented over the next three years. The aim is to build capacity among patient leaders to help raise awareness and increase action around the globe, and to create links between patient leaders and other key stakeholders internationally.

TMA also participated in the 2019 Global Skin Conference which is specifically designed for dermatology patient advocacy groups and patient leaders to focus on advocacy, science and research, and building strong, resilient organizations. This year's Global Skin Conference featured 60 skin conditions, 27 skin areas, 35 countries, and 140 delegates from around the world. During this Conference, TMA was a part of strategic discussions on how to raise the visibility

and understanding that skin diseases are about more than vanity, discussions on how to bring the patient's voice into the quality of life assessment tools used by medical providers around the globe, and strategy sessions for increasing drug developer interest in skin-related conditions.

Finally, TMA was part of a planning session for Global Patient-Initiated Research Project in Dermatological Diseases (GRIDD) to assess the impact dermatological diseases have on patients and communities as seen from the patients' perspective. The ultimate goal of this project will be to create a patient-reported outcome measure that is initiated by patient advocacy groups, patient leaders, and care partners.

Rare Disease Innovation and Partnering Summit

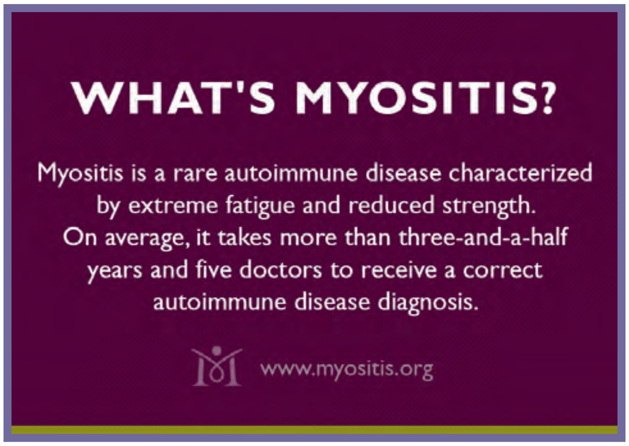
TMA Executive Director Mary McGowan speaking at the Rare Disease Innovation and Partnering Summit

TMA's Executive Director, Mary McGowan, was invited to present at the Rare Disease Innovation and Partnering Summit in Boston in June. This international conference featured more than 130 organizations coming together to discuss patient-driven progress, reimbursement, access, commercialization, and collaboration. Mary's presentation on best practices in patient engagement campaigns attracted more than 90 attendees, the majority of whom were from industry. During the session, Mary used the recent TMA's Women of Color and Myositis campaign, launched during this year's Myositis Awareness Month, as a model for a successful national campaign. This session received press coverage and a lot of positive feedback from a number corporate partners who were in attendance.

Matching grant makes the difference

TMA wishes to express its gratitude to Kezar Life Sciences for its support of the Myositis Awareness Month event at the San Francisco Giants baseball game on May 11. The game was dedicated to The Myositis Association, and TMA Ambassadors were on hand in the community club house throughout the game to help raise awareness, answer questions, and distribute TMA bracelets and literature. TMA was featured in a 30-second spot on the stadium's jumbotron, and Kezar generously offered a matching grant, helping to raise more than $14,000 for TMA programs and services and myositis research.

Myositis Awareness Month is a great success!



WHAT'S MYOSITIS?

Myositis is a rare autoimmune disease characterized by extreme fatigue and reduced strength. On average, it takes more than three-and-a-half years and five doctors to receive a correct autoimmune disease diagnosis.

www.myositis.org

TMA had lots of help in raising awareness about myositis across the country this year, and the results were a great success! More than ever before, TMA members were out in the world talking about the challenges they face living with a chronic muscle disease. Here are some of the results:

- TMA kicked off a special campaign on *Women of Color and Myositis* to raise awareness of the disproportionate impact this disease has on African American and Latina women. This campaign was guided by the expert advice of a special 11-member Patient Advisory Council.
- 16 newspaper articles, blog posts, and op-eds were published—more than ever before.
- Other media included a podcast interview, a live radio interview, and a television news story.
- Member Darlene Carruthers-Shelton persuaded the mayor of Nashville to issue a declaration of May as Myositis Awareness Month.
- For the third year in a row, member Vance Robinson toured California college baseball games with his First Pitch Campaign to raise awareness of IBM.

TMA nominates partner organization for award

National award presentations are an extraordinary opportunity to elevate TMA's efforts to bring awareness to myositis diseases. TMA was proud to nominate the International Myositis Assessment & Clinical Studies Group (IMACS) for the Global Genes RARE Champion of Hope – Collaboration in Research award.

TMA has collaborated with this body of international myositis researchers and clinicians since IMACS was formed 19 years ago. TMA has supported IMACS's annual meeting and collaborated on a number of research initiatives.

We are thrilled that Global Genes saw fit to award IMACS this prestigious award. This was a very competitive selection process with more than 100 advocates being nominated from their respective communities. TMA is elated by this opportunity to increase awareness of myositis, the hard work of myositis researchers, and the need for more funding and support as we work toward treatments and cures.

TMA has worked together with IMACS from the beginning

The award will be presented at the Global Genes Conference in September, and TMA will be highlighted as the nominee of this prestigious award.

Leaving the nest and learning to soar

The Pedano/Berretone family

When Joseph Berretone III went off to Duquesne University last fall, his mom, Monica Pedano, barely gave his myositis a second thought. He'd been diagnosed with juvenile dermatomyositis (JDM) as a toddler, but his disease had been in remission for ten years. He was healthy. He was strong. And he was doing what kids do: growing up and leaving home.

But it wasn't a good year for Joseph. While his JDM stayed in remission and he did well in school, he spent a good part of the year being sick.

"I was living in the dorms where there was always someone sick," Joseph said. "The first time I got sick, I came down with both strep throat and mono, and that triggered it all. It seemed like after that I wasn't able to fully recover."

Between not eating well because the cafeteria food didn't appeal, staying up late to study and go out with friends, and working and traveling with the football team as equipment manager, Joseph came down with nearly every infection that was going around the dorm. Since Joseph has a weakened immune system from a chronic autoimmune disease, these infections hit him harder, lasted longer, and even landed him in the hospital a few times.

"It was a nightmare," Monica says. "There were so many things we needed to think about that we never even considered. I wish somebody had prepared us and said, hey look, this is going to be tough. You need to watch out for this."

Dr. Richard Chung, an internist and pediatrician at Duke University School of Medicine, says it's not surprising that young people might have some difficulty when they take those first steps away from home and family support.

"The 18-to-22-year age range is a time of a lot of change on every level," Chung says.

In addition to moving away from the family unit to a more peer-oriented social and living situation, young people also typically begin to move toward financial and healthcare independence. This combined with the normal mental and emotional immaturity of young adults may make it difficult for them to think into the future and predict how their behavior today may affect their health tomorrow or next week.

(continued)

"We have a lot of examples of young people with chronic illnesses who do reasonably well through their 18th birthday and then dramatically fall off, not because their disease has evolved or their treatments have changed, but because the supports that have propped them up over time fall away," Chung explains.

Making the transition into adulthood doesn't have to be difficult, however. There are steps families can take to help their child move from dependence—where parents call for doctor appointments, fill out forms, keep track of medications, and pay attention to how well the child is eating and sleeping—to a more independent place where the young person takes responsibility for her or his own care. A more seamless transition requires coordination and planning among the healthcare team, the parents/family, and the young person. Preparing for this transition should also start as early as age 12, according to Chung.

The good news is there is help. **www.GotTransition.org** has a comprehensive set of resources aimed at parents, young people, and healthcare providers. Kids can take a quiz to see if they're ready to make the transition, and there are checklists of things to think about when making the move, suggestions for parents, and so much more.

TMA has other resources for families living with juvenile myositis. Find them on the support page of TMA's website under Living with Myositis.

> *To read more about Joseph Berretone and how he has faced the challenges of growing up with myositis, see the Summer 2015 issue of The OutLook in the Library section of our website under TMA Publications:*
> **http://bit.ly/32hpmio**

You asked for it: Responses to member questions from the experts at GCOM 2019

Before the March meeting of the Global Conference on Myositis (GCOM) in Berlin, Germany, TMA was invited to ask its members to submit questions they would like to pose to the researchers and clinicians gathered at this meeting. TMA members sent us nearly 80 questions, and we submitted them all to the program organizers, seeking answers. The following is a sampling of the questions and their responses. To see the complete list and the responses from the GCOM experts, please check out TMA's blog: **https://www.myositis.org/blog/**

1. *I am 26 years old and diagnosed one year ago with polymyositis in addition to interstitial lung disease (ILD).*
   a) *What should I expect in the future?*
   You should have an intensive myositis workup and adequate treatment with medications as soon as possible.
   b) *Will I keep feeling this continuous pain?*
   With therapy, symptoms should become better.
   c) *Will my joints be affected?*
   Joint involvement could happen if you develop an overlapping condition such as rheumatoid arthritis.
   d) *Will I have the chance to live like any other lady without difficulties, like having kids for instance?*
   Yes, you should be able to live a normal life and have children, but first your disease must be controlled.

2. *Is there any treatment or medication for IBM disease?*
   a. There is one clinical trial (arimoclomol) currently underway.
   b. Sometimes intravenous immunoglobulin (IVIg) is used to slow disease course.
   c. At this time, physiotherapy is the most helpful therapy.

3. *Are there certain things that trigger an episode with DM? If I knew, could I avoid the swelling and rash? I have suspected heat or sunshine. Perhaps antibiotics also.*
   a. Any infection can trigger a flare.
   b. Heat or sunshine might worsen the symptoms in some cases.
   c. Please avoid sun as it triggers the rash. When the rash is there, topical use of so called calcineurin inhibitors (e.g. pimecrolimus ointment) in addition to immunosuppressant therapy is helpful.

4. *Should cancer screening be routinely part of the protocol for dermatomyositis?*
   Yes, especially when certain antibodies are found in the blood (NXP-2 and TIF-1).

5. *Is there a new list of symptoms used to diagnose polymyositis?*
   No, polymyositis is still diagnosed based on a typical pattern of muscle weakness along with muscle biopsy and other tests. Some researchers, however, are trying to avoid using the diagnosis of PM, feeling the diagnosis can be more precise by testing autoantibodies and other factors.

6. *I understand exercise is very good for polymyositis patients. I also can feel the benefits of exercise sometimes. I am in pain most of the time, especially around my shoulders and neck area. Should I continue to exercise, or I am making more damage to the muscles and joints in this area?*

The recommended intensity and the form of exercise depend on the activity of your PM. If there is more disease inflammation and you need a higher dose of corticosteroids, you have to be more careful and exercise with less effort and use a mild to moderate aerobic exercise. If your disease is more stable and you need a low dose of corticosteroids, you can be more active, perhaps even with a resistance training.

7. *What exercises do you recommend for IBM?*
   Depending on the literature and my own experience, I recommend for IBM patients a combination of aerobic exercise and resistance training individually adapted. These exercise forms are very common and available. Overstrain should be avoided.

8. *Recently, my doctor suggested he check my blood with an ANA test. The result is I am positive for polymyositis. What is the difference between "myositis" and polymyositis?*
   a. Poly just means "more than one muscle affected." Polymyositis is one of several forms of myositis.
   b. There is no blood test saying you are positive for polymyositis. This is a diagnosis made by biopsy. I would recommend you consult a myositis specialist.

9. *I have been told I will need prednisone for one year. Does myositis go away in one year?*
   No, myositis usually does not go away in one year. Autoimmune myositis is chronic, and treatment is based on symptoms and other finding.

10. *Is restrictive lung disease seen as part of polymyositis or another type of myositis?*
    Different subtypes of interstitial lung diseases (ILD) can be associated with antisynthetase syndrome, and this causes lung restriction. ILD can occur with several forms of myositis as well as other autoimmune diseases.

11. *Has there been any evidence of myositis affecting either heart or bowel muscles?*
    Yes, myositis can affect both heart and bowel muscles.

12. *I have been diagnosed with dermatomyositis, and for a couple of years I have suffered from really painful calcinosis. Are there any treatment options for calcinosis?*
    Currently adequate immunosuppressive therapy is the best option. Unfortunately, this does not work well on calcinosis in many cases. It depends also on the size. For small (1-2mm) deposits, there are reports of successful use of a prescription containing sodium thiosulfate.

13. *How is remission of HMA Co reductase (HMGCR) autoantigen necrotizing myopathy defined? Where do my CK levels and other inflammatory markers need to be at to say I am in remission?*
    a. Anti-HMGCR myositis is thought to be autoantibody mediated. Remission is gauged by normal CK levels and no symptoms.
    b. Remission should be measured clinically. Biomarkers can be helpful, such as CK or autoantibody titers. In Anti-HMGCR myositis, CK levels often stay elevated, and titers can correlate with clinical improvement.

14. *I think I am right on the cutoff line for osteoporosis. What bone building formulas should I use for osteopenia?*
    Treatment is according to osteoporosis guidelines. For beginning osteoporosis, this includes vitamin D and calcium supplements.

15. *When a patient is pursuing a diagnosis of myositis, is there a recommended list of blood tests, including antibody tests, that should be undertaken?*
    We normally do CRP, CK, TSH, Na+, K+, Ca2+, ANA, anti-dsDNA (with typical symptoms for SLE), (pANCA, cANCA), myositis-associated antibodies, and myositis-specific antibodies.

Making each other aware during Myositis Awareness Month

by the TMA Southwest Florida Support Group

Members of TMA's Southwest Florida Support Group spent much of their Myositis Awareness Month meeting sharing tips and tricks with each other. We asked members—patients and care partners alike—to reflect on what helps them manage their myositis or what challenges they had for which they wish they had a little help. Here are some of the suggestions folks had to offer. As always, you should speak with your physician about any new or different treatment you are using.

Gadgets and garments:

- Install grab bars in the shower and bathroom.
- UPLIFT or Carex Upeasy seat assist are self-powered, portable lifting cushions that assist you up and down from an armchair or sofa.
- FUD (female urination device) is a funnel-like device that fits in your purse and lets you stand to do your business. They make even non-ADA toilets usable for the ladies. **Backpacker.com** has a review of a number of different FUD devices.
- Canes with various kinds of stability feet can be very helpful, but only if you use them!
- Grabbers. These come in many shapes and sizes and can be as simple as a pair of kitchen tongs to pick up a dropped TV remote or a commercial extension grabber to help reach to a tall shelf without standing on a chair or ladder.
- A round TUIT is a simple piece of round rubber that is very handy for opening jars.
- Sun-protective clothing, such as Solumbra or Coolibar, protects skin from sun damage (and DM patients from flares) without having to use sunscreen: (You still need to use sunscreen on your face and other exposed areas.)
- A portable oxygen concentrator (POC) is a portable respiratory therapy device that pulls oxygen from the air, rather than from an oxygen tank. This can be great for helping you stay active without getting short of breath.

Activities:

- Writing or journaling can help you put into words what living with myositis means to you. This can help immensely in coming to terms with this dreadful disease. (See the poem by Charlie Childes on page 15.
- Play or listen to music. Whether it's hard rock or new age, whatever you like will make you feel good. Even better: sing along!
- Water therapy or aerobics. This form of exercise is easy on joints, you don't have to worry about falling, and warm water feels good.
- The most creative something that helps is a timed cry. A member said when she starts to feel depressed, she sets her kitchen timer for 20 minutes, then allows herself to cry, feel sorry for herself, or just mope. When the timer goes off, the pity-party is over, and it's time to move on.

Other helpful hints:

- Answer the question "How are you?" with "I'm as good as I can be!"
- Walk backwards down the stairs…holding on to the railing of course.
- Home remedies for leg or foot cramps, especially at night:
  - Regularly take magnesium or potassium.
  - While you're having the cramp, take a sip of pickle juice, potato skins, tonic water, or yellow mustard.
  - Here's the weird one: sleep with a small bar of soap (any kind) under your bottom sheet.
- If you can no longer cut your own toenails, podiatrists or internist assistants will do it every six months. There's also the nail salon, even for men! (Just sayin'!)

And that's what it's all about folks. We do whatever it takes to get through our days, sometimes relying on the aids listed above, sometimes a higher power above. And sometimes it's a friend or loved one who is walking this journey with us. Our care partners are often THE most important 'aid' we have in our toolkit. Alleluia!

Patients with active DM or PM needed

Bristol-Myers Squibb is currently recruiting adults with active dermatomyositis or polymyositis for a clinical trial. The goal is to evaluate the effectiveness and safety of a study drug, called abatacept, in combination with standard medicines in improving symptoms of active myositis. The effectiveness of this combination therapy will be compared to standard therapy for myositis.

This clinical trial is underway and aims to enroll 150 patients over a three-year period. Multiple study sites are available throughout the US and abroad. Participants will first receive either abatacept, the study drug, or a placebo via a weekly injection under the skin for 24 weeks. Then, all study participants will receive abatacept for 28 weeks. More information on this clinical trial can be found at ***www.MyositisTrial.com****.*

My Myositis

By Charlie Childes

You make friends with Myositis by
heeding its call to consciousness,
by letting it change your life.
You slow down. You pay attention.
You stop doing things you don't really
want or need to do.
You prioritize. You pace yourself.
You respect your body.
You spend time with those whose
presence is healing.

You make friends with Myositis by noticing
the small miracles that occur daily:
the chorus of bird songs in the morning air,
the intoxicating fragrance of one pink rose,
the melody of raindrops, the heart-melting
sweetness of your grandchildren's smiles,
the eternality of an ocean wave,
the exquisite beauty of a setting sun, the presence of your
beloved—which, before Myositis, you may have overlooked
or been too "busy" to enjoy or appreciate.

You make friends with Myositis by letting love in.
You open your heart. You tell the truth.
You ask for help. You accept the profound
generosity of friends. You let whatever
you may have given, return itself to you.

You make friends with Myositis by allowing it to remind you
of what is actually important in life and what is less so,
by forging a relationship with it that fosters new insight,
by seeing the uninvited guest as an opportunity for learning and growth.

You make friends with Myositis by accepting
the myriad gifts and joys which life offers.
You don't waste time complaining about
things you cannot change
or which you wish were different.
You dance when you can, you weep when you must.
You notice what you have, instead of what you don't have.
You practice thankfulness and forgiveness.

You make friends with Myositis by not hiding
from it or hating it, but by acknowledging it,
accepting what it has to teach you
and continuing on your journey,
one step at a time.

The Myositis Association

2000 Duke Street, Suite 300
Alexandria, VA 22314

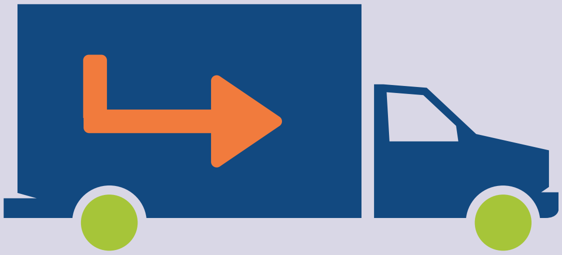
TMA's offices have moved!

As of July, we are now located across the street at:

2000 Duke Street, Suite 300
Alexandria, VA 22314

Other contact information including phone, e-mail, and web address remain unchanged.

WE'VE
MOVED



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