

THE OUTLOOK



THE MYOSITIS ASSOCIATION



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Quarterly Newsletter

THE OUTLOOK

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**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 TMA member,

Support for those who live with myositis is critical to helping the patient feel less isolated and less like they've been left to fend for themselves. TMA has 40 support groups around the US, and most major cities have a support group nearby. Not all of these groups meet in person; some keep in touch with each other by phone, email, or an occasional conference call.

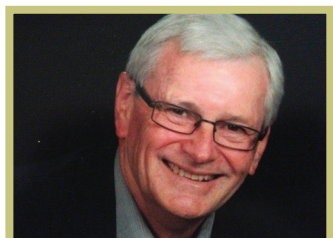
This year, TMA is making a major push to include more of our members in these groups. Some of you may feel like you do not want to see others who have the disease, and that is understandable. However, there are other ways to keep in touch with people who have your disease and share information. TMA can connect you by phone or email with someone else who has your form of myositis, or you can participate in a conference call of people who have the same disease as you. I hope that you will think about this and not dismiss it as something that is not for you but maybe for others. Many people who are skeptical at first discover that there is much practical, useful information they can learn from others, and support does not just mean emotional support.

For those who have been to a TMA Annual Patient Conference, you probably learned firsthand how much you can gain just from talking with others who also have myositis. If you have not been to an Annual Patient Conference, you ought to consider coming to the Conference in San Diego this September. As you will see in the stories of first-time attenders on pages 5-6 of this issue, the Conference can be very rewarding. Information about the Conference and how to register can be found on the back cover.

Finally, I want to let you know that as part of our effort to strengthen our support groups and grow the services we offer to TMA members, you will find inside this issue (page 13) a short piece on our newly hired Programs Services Director, Ruthann Devine. Ruthann is a nurse who has been very involved with patients and support groups over the last 30 years and brings to TMA much direct experience in working with people who have chronic autoimmune diseases, especially myositis. I know she will have an impact.

TMA welcomes new Directors

Please join TMA in welcoming two new board members.



Jim Mathews

Jim Mathews probably had IBM for 11 years before he was finally diagnosed in late 2015. An avid tennis player, he noticed he was

getting steadily slower on the tennis court and thought it was just the result of aging and bad knees. When his long-time doctor retired, his new internist started digging a little deeper into his symptoms and sent him to a neurologist who eventually diagnosed IBM.

Like many newly diagnosed patients, Mathews sought out any information he could find about myositis. He joined The Myositis Association, became active on the Community Forum, and immersed himself in materials from past Annual Patient Conferences and research articles posted on the TMA website.

"I'm a pharmacist (recently retired), so I have that medical background," Mathews says. "I went looking for any article I could find and devoured it. I understood most of it, but I was obsessed with learning as much as I could about the disease."

Learning that he has myositis has been a life-changing experience for Mathews, one that makes him want to be involved with the organization. He joined the TMA Board of Directors in January where he serves on both Professional Relations and Programs and Services Committees.

"Because of my medical background, being on the Professional Relations Committee is what I am best suited for," Mathews says. "I have dealt with physicians and dealt with research in the past. And I have been on boards at a state and national level, so I have that experience, though never before with a nonprofit."

Mathews lives with his wife of 47 years, Cathy. The couple have six children and 29 grandchildren (number 30 is on the way), all of whom live within a 35 minute drive of their home in Grand Haven, Michigan.



Roger Marken

When **Roger Marken** was diagnosed with IBM in 2012, he was overjoyed.

"I was originally diagnosed with ALS [amyotrophic lateral sclerosis, also known as Lou Gehrig's disease]," Marken explains. "It brought my whole world to a crashing halt. So when they told me 'You don't have ALS, you have IBM,' I was happy knowing I'm not going to die."

Still, Marken had a lot to learn about this rare disease. The self-described technology geek went online and discovered TMA, sought out his local KIT group, and participated in the two most recent Annual Patient Conferences. These experiences inspired Marken to take on a leadership role with the South Florida KIT group, where he's now working to stretch the group's reach through digital communications technology, allowing more members to participate, even if they can't drive to meetings.

Now that Marken has retired from his work as an internet solutions and infrastructure specialist, he wants to offer his expertise as a member of the TMA Board of Directors. As a member of the Board's Development Committee, he is eager to help find new sources of funding for the organization. With his background in technology, he also wants to develop connections with companies creating devices, such as the new exoskeleton technology, that can help myositis patients live a more normal life.

"I always want to give back to the community and overall to humanity," he says. "I have a great life. I have certain skills. I want to bring that to bear to help the functioning of this organization."

Marken lives in Highland Beach, Florida with his wife of 40 years, Maureen. They have two grown children, a daughter and a son.

Attending TMA's Annual Patient Conference for the first time

TMA's Annual Patient Conference will be held this year at the Sheraton San Diego Hotel and Marina. Each year, members look forward to attending the Conference where they can learn about their disease and how to manage it, as well as meet with other members who are sharing a similar experience. But there's a first time for every attendee, so we thought we'd highlight insights from folks who attended their first TMA Conference in New Orleans in 2016.



Mariah Abercrombie

Mariah Abercrombie knows how valuable patient education conferences can be. As a child, she was diagnosed with a rare gastrointestinal disorder, and has participated many times in these sorts of conferences in a variety of ways.

So when she was diagnosed with polymyositis two years ago, the first thing she did was go to the internet where she found The Myositis Association website and the announcement about the Annual Patient Conference in New Orleans.

"I really wanted to go, but I didn't think it was possible," Abercrombie says.

She had just quit her job as a social worker because of her PM, and she didn't have the money to spare. But she signed up for the TMA email list, and one of the announcements talked about a scholarship TMA offers for first-time attendees. She applied and was accepted.

"I would not have been able to go if I hadn't gotten the scholarship," she says. "I had just moved back to Las Vegas from Virginia. I'm back on disability and living with my mom, so it was very helpful."

The educational sessions were what attracted Abercrombie. She knows how important it is for people with rare diseases to understand as much as they can about their disease, because health care providers may not be as fluent with the details of conditions they don't see every day. And even though this was her first TMA conference, and even though she was newly diagnosed with myositis, Abercrombie already understands how important it is to be an advocate for yourself.

"Having a chronic illness requires a lot of advocating for yourself," Abercrombie says. "You have to come into your doctor's appointments with your questions written out. You have to understand a lot about what the doctor will be asking you about. And you have to arm yourself with knowledge."

Abercrombie, who is 34, also appreciated being able to share this experience with her mother.

"I feel very lucky that my family is very supportive," she says, "but sometimes they just don't get it. So to go there and to hear about my disease from the professionals and in a way that they can understand, it is really helpful for family members."

As someone who lives with a feeding tube herself and is dependent on total parenteral nutrition, Abercrombie hopes to attend TMA's 2017 Annual Conference in San Diego as a volunteer for the Oley Foundation, a nonprofit support organization for those living with home intravenous nutrition and tube feeding. She's eager to share her journey through both myositis and tube feeding with others who may face similar situations.

Sometimes [family members] just don't get it. So to go [to the Conference] and to hear about my disease from the professionals and in a way that they can understand it is really helpful.



*Givonna De Bruin and
Elodieanne Browning*

Givonna De Bruin's mother, Lyvonne, is thankful that she's had a full and active retirement after a career as a teacher. But five years ago, at the age of 81, she was diagnosed with sIBM.

As caregivers, Givonna, who works as a healthcare auditor, and her sister Elodieanne, a licensed practical nurse, wanted to learn about this unfamiliar disease so they could make their mom's life comfortable as her condition progresses. So among other things, they started watching videos from TMA's Annual Patient Conferences on the TMA website. This made them want to attend one of these informative Conferences.

Lyvonne had no interest in traveling to New Orleans, but her daughters were eager to find out all they could. So last year, as a birthday gift for both of her daughters, Lyvonne offered to pay for them to attend the TMA Conference.

The sisters enjoyed spending time together and exploring NOLA's music scene. And the conference gave them a lot to think about as they contemplate their mother's future. Neither had seen another sIBM patient before, so they learned a lot about what they can expect. There were also some disturbing moments.

"To be honest, I wasn't prepared for the emotional journey of the conference," Givonna says. "There were times when I had to leave sessions and go for a walk just to move through my emotional response."

Still, it was good to see how other patients managed, despite power wheelchairs and difficulty swallowing and having to use a lift to get out of bed. The sisters enjoyed both the patient sessions and those for caregivers. They loved hearing others' stories and experiences and comparing them with their own. And they were surprised and delighted to meet a number of other Canadians.

"What I found especially wonderful," Givonna says, "was feeling that there were hundreds like us who were caregivers without full knowledge of what our families were going through or what was ahead on the journey."

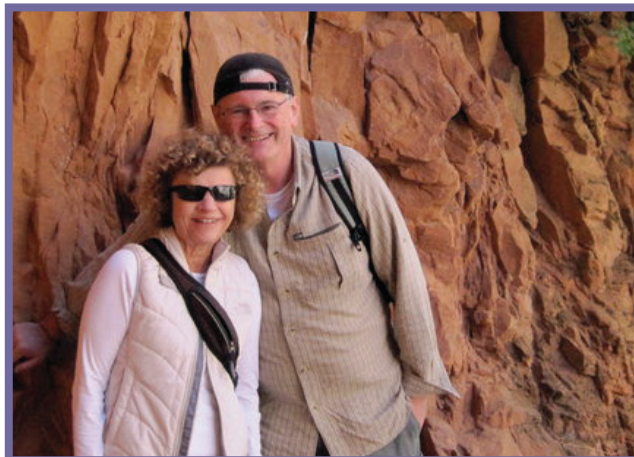
As a nurse in a long-term care facility, Elodieanne, was excited to return home and share the things she'd learned with the medical and nursing community she works with. It surprised her that Americans with myositis seemed to be much more knowledgeable about the disease than those in Canada, especially in the medical community.

"We only wish we had attended [the Conference] earlier when Mom first was diagnosed," Givonna says. "We could have been more encouraging as to exercise and nutrition, and would have saved all that time researching equipment."

Givonna encourages other Canadians to attend. TMA's Annual Patient Conference provides caregivers and patients access to a network of folks who understand what they are experiencing and can offer advice and support.

"It's a conference as much for the caregivers and families as it is for the patients," she says. "It was also an affordable holiday, a time for the two of us to connect and be sisters and not mothers/wives/daughters."

New TMA Board member **Jim Mathews** attended TMA's Annual Patient Conference for the first time last year, but he had already read the research of



Jim and Cathy Mathews

many TMA medical advisors. In fact, he had even watched many of their presentations from previous Conferences in the videos posted on the TMA website. And still he found all the sessions he chose to attend in New Orleans to be very informative.

"I learned something from every one," Mathews says. "I think all of our medical advisors are stellar, and all these guys—Dr. Greenberg, Dr. Mammen, Dr. Weihl—were right there, and I could ask them questions and get answers. To me, that was like being a kid in a candy store."

As a former college athlete, Mathews especially appreciated the presentations about exercise. From his reading, he understood that there was some disagreement within the medical community about the value of exercise for myositis patients. Some older research he'd read even suggested exercise was harmful for people like him. When he heard Dr. Helene Alexanderson's and Sue Maillard's talk on "What happens when you exercise," he was relieved.

"She gave me permission to push myself," Mathews says. "Now I feel like I can do something positive with this disease."

Mathews, who was diagnosed with IBM about a year-and-a-half ago, and his wife, Cathy, also enjoyed the chance to meet other people who have lived with this disease for longer than he. Cathy attended some of the caregiver sessions, which she found educational but also a bit scary. Getting to know other folks who, though they struggle, still have such high spirits was very reassuring.

"The inspiration that I got from talking to people, the tremendous knowledge from listening to the presentations...it was all good," Mathews says. "Having it in New Orleans was fun, too."

Mathews, who lives in Grand Haven, Michigan and joined the TMA Board of Directors in January, is looking forward to attending this year's Annual Conference in San Diego.



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Drawing a line in the sand

by Jim and Kim Bushmiller

Jim's story

It started 12 years ago on a brisk autumn evening. I was feeling manly. I needed a challenge. But where to find a challenge that was worthy of my caliber? Yes! My son! I asked him for a foot race to the car. We came to the starting line, and the race was on. I ran like Forest Gump.

The next morning, I woke up and my hip flexors were sore. I thought this was the price of battle. I didn't pay much attention to it. But over the next couple of weeks, the soreness did not go away. I started to become very tired, like I had the flu. Then all hell broke loose. I started experiencing pain in my legs and shoulders on a level I did not know existed. I needed help fast.

My wife, Kim, and I went to an emergency room where they ran blood tests. The next day they called an emergency appointment. They thought I had hepatitis. They ran more tests and still could not figure out what was wrong with me. I *knew* there was something wrong. Something serious. I was scared.

Finally, some smart doctor in the ER tested my CK level. It was off the charts. He referred me to a rheumatologist. We met with him the next day. I walked in with an attitude of, Okay, Doc. Give me some pills, and I will be on my way. Little did I know there was no pill. There is no cure for dermatomyositis.

Over the next few years, my life was a blur. I remember parts of it, but most of the time I was angry and scared. I lost my ability to swallow food. I couldn't even swallow my own saliva! I had to have a PEG tube inserted into my stomach so I could pour cans of nourishment into my stomach just to live. I lost 100 pounds. I lost my job. I lost my ability to walk. I was forced into a wheelchair—my most archenemy. I was in pain all the time. All I could do was sit and watch TV.



Jim and Kim Bushmiller

This was the lowest point of my life. I gave up. Kim got me up in the morning, set me in front of the TV, and left me with a portable urinal. I stayed there until she got home. When she was home, we would try to be "normal," but it wasn't working. I figured I was about a week away from dying.

During that week, Kim came to me and said, "I need you. I know that you do not want to live, but I need you to fight for us." That was the turning point. I started to fight. Hard. I drew a line in the sand and said *no more!* This disease has taken enough from me...NO MORE!

I wish I could report that I was cured, and my wife and I live on a tropical island sipping Mai Tais. We do not. My disease is mildly active, but now I struggle with severe calcinosis. I am turning into the elephant man. My body will not process calcium, so it deposits the calcium in my muscles and bones. I have bumps all over my body.

You might be thinking, "How do you not give up hope? This is hopeless?" Here is what I have learned:

- ✦ You have to fight. This is a war. The disease does not play fair or by the rules. Your mental attitude and positive outlook will determine your day, your week, and maybe your healing. You have to stay positive. This will not be easy.

- ✚ Take it day by day. There will be days when the disease will win. Let it. Relax. Do not fight that day. Do something fun. The disease may have won this battle, but it won't win the war.
- ✚ Never quit searching. Do not be satisfied with what one doctor says. Search the internet. Go to another doctor for another opinion. Last year I even went to the NIH (National Institutes of Health) in Washington, DC, where I spent a week with a team of doctors doing research with me. They gave me some good advice. And hopefully I have helped others.
- ✚ Focus on what you can do. You need to have fun in your life. I cannot run at all or walk without concentrating on what I am doing. So I found a new love: I can drive! Like the wind. In a very fast car. I may not be able to stand or work, but Kim helps me type. So I created a Facebook page (Gods411) where I interact with and encourage others. What have you always wanted to do in life? Make it happen today, even if your caregiver has to push you across the finish line.

Kim's story

I have been on this road for 12 years. During this time, I have wanted to yell, scream, cry, fix it, run away, and give up. I have become the breadwinner, chauffeur, nurse, cook, maid, masseuse, and cheerleader. During my journey, I have learned some things that may be helpful to other caregivers:

- ✚ Find your support. You need to find your own strength so you can carry on as a great caregiver. I have the Lord, and I pray and meditate daily.
- ✚ Be willing to lose a battle but not the war. Even though you may feel alone, frustrated, and weary, you can fight. You can do it!
- ✚ Cherish each day. There will be bad days when you want to run, but there will be good days too, and those are the ones to cherish.

To all who live with this disease, never forget that your physical body may not be the same, but you are still *you*. Always let your wonderful, quirky self shine forth to others.

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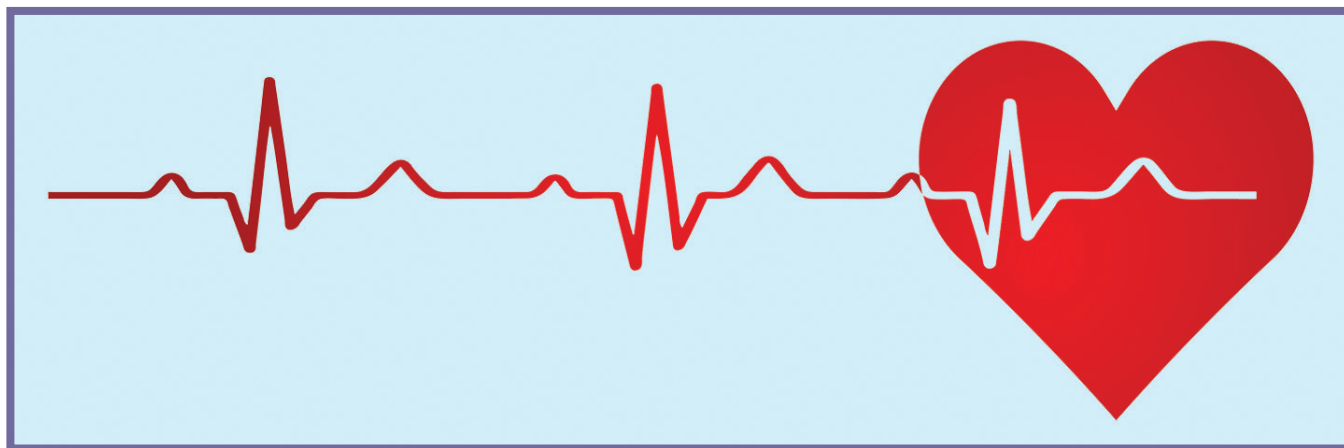
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Issues of the heart

The heart is a muscle, so it's no surprise that cardiac disease is yet another health problem that frequently troubles those with myositis. While patients may not realize symptoms such as shortness of breath, fatigue, indigestion, nausea, sweating, and rapid heartbeat can be heart related, undetected cardiovascular disease can lead to serious complications and even death.

In a recent TMA Live Discussion, TMA medical advisor Christina Charles-Schoeman, MD discussed the issue of heart disease and how it relates to myositis.



“As is true of other autoimmune inflammatory diseases, coronary artery disease (atherosclerosis) appears to be more prevalent in patients with myositis,”

Charles-Schoeman says. “Inflammation can also occur in the heart muscle in myositis patients. This can lead to fibrosis of the heart (damage), which can lead to arrhythmias (irregular heart beat), and poor heart function (also called heart failure).

Steroid medications, such as prednisone, can also contribute to coronary artery disease.

“But prednisone is very important in controlling the myositis itself, which also contributes to heart disease, Charles-Schoeman says. For this reason other

immunosuppressant agents are also used in myositis—cellcept, methotrexate, IVIg, and others—to limit the prednisone dosage.”

The most important way to avoid heart complications or treat them after they arise is to aggressively control the inflammation of myositis. Charles-Schoeman also recommends patients follow healthy heart guidelines: keep blood pressure within a normal range, maintain a healthy weight, don't smoke, and exercise regularly.

Individuals who know they have a cardiac condition—such as arrhythmias, heart failure, or coronary artery disease—should follow closely with a cardiologist. Charles-Schoeman recommends a thorough evaluation that may include an electrocardiogram (EKG), a cardiac stress test, perhaps an echocardiogram, a Holter monitor that can assess arrhythmias over a 24-hour period, and other tests.

Abnormal EKG findings

“Conduction abnormalities on EKG are the most commonly reported evidence of heart problems in patients with myositis,” Charles-Schoeman says.

Myositis can cause inflammation in the heart that leads to damage to the system in the heart that controls the heart's electrical signals that cause the heart to beat. This can result in conduction disorders, such as heart block, and arrhythmias, such as atrial fibrillation. And these can occur when the disease is active as well as in remission.

“Uncontrolled arrhythmias are not good for the heart” Charles-Schoeman says. “It is most important to control the myositis as best as possible.”

Those who experience symptoms such as lightheadedness, dizziness, fainting, low blood pressure, or slow pulse need to be evaluated and followed closely by a cardiologist.

Statin drugs and myositis

Statin medications, such as Crestor, Lipitor, and other lipid-lowering medications, have been prescribed increasingly in recent years to reduce cardiovascular disease and mortality in high-risk individuals. Many doctors now recommend these medications even for patients who have never demonstrated a cardiac risk.

One of the side effects of these drugs, however, is muscle pain and weakness. In the great majority of patients, this side effect goes away when they stop taking the medication. For some, however, especially those who test positive for anti-HMGCR antibodies, this myositis turns out to be a necrotizing myopathy that stays, even after the statin is stopped. This can be a concern for people who already have myositis as well as their physicians.

“Most doctors consider statins to be first line therapies for lowering cholesterol because of the great benefits they’ve shown in clinical trials,” Charles-Schoeman says. “While many doctors are fearful about using statins in patients with myositis, we found nearly 80% of myositis experts use statins in their myositis patients.”

When patients or physicians are uncomfortable with this therapy, however, other treatments can be considered. These include bile acid sequestrants, such as Questran, used for mild to moderate elevations in LDL, the “bad” cholesterol. Side effects of these drugs include nausea, bloating, cramping, as well as increased liver function tests.

Niacin is another alternative, although it is often poorly tolerated due to flushing (in 80% of patients) and itching. Ezetimibe (brand name Zetia) decreases cholesterol absorption in the intestine and has been studied mostly as an additive therapy to statins. And

PCSK9 inhibitors, such as Praluent, are injectable medications that have been recently approved for specific patients groups; they block the action of a particular protein thereby lowering LDL cholesterol levels.

For those who do have “statin” myositis, however, Charles-Schoeman says they should never take statins. “They need immune treatment for their myositis,” she says. “I treat several patients with this disease, and they have improved greatly with treatment. Luckily, this is a very rare disease and does not occur for the vast majority of patients taking statins.”



Exercise for the heart and the muscles

And finally, Charles-Schoeman stresses the

importance of exercise for both cardiovascular health and to improve myositis symptoms.

“Both the heart and skeletal muscles need exercise,” she says. “There is not a specific amount of time for this; it is different for each person. I find it very useful for my patients to start in a monitored cardio-pulmonary rehab program and then continue on their own.”

Dr. Charles-Schoeman, a member of TMA’s Medical Advisory Board, is a rheumatologist and associate professor of medicine at Ronald Reagan UCLA Medical Center in Los Angeles. She is an active investigator in multiple clinical trials involving novel therapies for myositis, and her research in this area includes the study of cardiovascular disease in myositis, including the use of cholesterol-lowering statin drugs and their association with myopathy.

Transcripts of this and other Live Discussions are available on the TMA website: <http://myositis.org/your-myositis-community/live-discussions>.



On the road again

by Nancy Harber

Nancy Harber's husband Charlie had inclusion body myositis (IBM). A registered nurse and an informal consultant, Nancy shares the wisdom she gained as Charlie's long-time caregiver with patients and caregivers struggling with the challenges of myositis. While her experience was specifically with IBM, many of her solutions apply to other forms of myositis as well.

When it comes to driving, the family car can pose some problems for people with myositis. One of the first issues my husband Charlie experienced was just getting in and out of the car. The seat height was too low, even though we could raise it. We found that the addition of a firm cushion helped raise the seat just enough to work. Now a hand-held device is available that hooks into the hardware on the open door to give you something firm to hold onto as you pull yourself up to standing.

Something else we explored but didn't purchase was a specially built passenger seat that can electrically slide out of the vehicle, turn sideways, and elevate, allowing the passenger to stand up outside the car.

Another device that can be added is hand-controlled brakes. If the individual with myositis is still driving but concerned about being able to step on the brake quickly, this is worth considering. We had a handbrake installed in our car on the steering wheel; it worked

with very little pressure. The nice thing about it was the foot brake was still operational, so Charlie used the handbrake and, when I drove, I used the foot pedal.

For those who use a standard wheelchair and can get in and out of the car without a problem, it's easy enough to fold the chair into the trunk or even the back seat of some cars. If you use an electric chair, you can purchase a platform lift that attaches to the rear of the car and load the chair with a remote control device.

When you are ready to think about a van, the high seat is an advantage, making it easier to get in and out of the vehicle without special modifications. When an electric chair entered our lives, we started with a Dodge van with no special ramps, but one that was modified by removing the seat behind the driver. Plates were installed in the floor to lock Charlie's chair in place along with an electronic lift that could move the chair into and out of the vehicle. As long as Charlie could stand and lean against the van, he could do this procedure alone. When that became difficult and I took over the driving, he simply transferred from the chair into the passenger seat, and I rolled the chair around to the other side and used the lift to put it into the van.

The most expensive option, but the one that will last a lifetime, is a van that "kneels" down low to the ground. The side door opens, and a ramp folds out so the person can simply roll in and out in the chair. Keep in mind that the cost of modifications made to any vehicle can usually, with a physician's prescription, be taken as a tax deduction. Used modified vans may also be available. We found one that was like new, had less than 20,000 miles on it, had been fully reconditioned, and cost about half the price of a new one.

One important thing caregivers should realize is that when you become the sole driver in the family, it will have a significant impact on your schedule. Charlie and I always compared our calendars weekly and scheduled accordingly. We both realized that his need to stay involved outside of the home was as important to both of us as my schedule of meetings, work, and activities. And we always made sure to maintain our usual social life. Still, it's good to pace yourself and avoid stretching yourself too thin. You still have lots of other tasks in your "job description" now!

Welcome to TMA's Programs Services Director

As a registered nurse working for specialty infusion companies for the past 28 years, Ruthann Devine has encountered many patients with autoimmune diseases, including myositis. Some of her favorite projects were presentations she's made to patient advocacy groups.

"I decided the best way to stay involved and passionate about my work was to participate in patient support group meetings," Devine says. "It keeps it real, because I'm talking to patients and families. And any time I can be actively involved in finding solutions for patients, I get excited, because I know I've made a difference."

As Programs Services Director, Ruthann will be visiting with TMA support groups, providing resources and doing whatever she can to enhance their efforts to support those living with myositis.



Ruthann Devine

"I want to raise the bar of what's possible," Devine says. "I want to be there as a resource for support group leaders so they feel like they have what they need to be the best leaders they can be."

"Ruthann brings a long history of commitment to improving the lives of people with chronic diseases," TMA Executive Director Bob Goldberg says. "I'm confident she will have a great impact on the services TMA is able to provide to patients and their caregivers."



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

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TMA-funded researcher discovers new target for treatment of DM



Xavier Suárez-Calvet, PhD

or even non-existent, but they have aggressive skin disease, often including ulcers, and rapidly progressive interstitial lung disease. They also have a poor prognosis.

Two years ago, TMA funded a research fellowship for Xavier Suárez-Calvet, PhD to conduct a research project that would identify new therapeutic targets in DM. Working with myositis expert Isabel Illa, MD, PhD at the Autonomous University of Barcelona, Suárez-Calvet recently completed this project, demonstrating a number of important results.

Among these findings is the recognition that immune response as well as the structure of diseased muscle fibers and blood vessels in MDA5-positive patients are strikingly different than those found in patients with classic DM, which likely accounts for differences in symptoms and response to treatment. This work provides new targets for clinical research to find treatments for this form of DM. These results were published in the *American Journal of Pathology* in March, 2016. The article is available on the TMA website here: <http://myositis.org/explore-research/published-research/dermatomyositispolymyositis>.

Skin disease is a major burden

This is not news to DM patients, but a recent report from the American Academy of Dermatology details the burden of all forms of skin disease in

the US and highlights the serious nature of these conditions. Findings include:

- ✚ Nearly 85 million Americans were treated for at least one skin condition in 2013.
- ✚ Direct cost of treating these conditions was \$75 billion.
- ✚ Patients with skin disease and their caregivers experienced \$11 billion in lost productivity.
- ✚ 50% of skin disease categories assessed resulted in mortality.
- ✚ There were more skin disease claims in 2013 than cardiovascular disease, diabetes, or end-stage renal disease.
- ✚ Patients spent \$10 billion on over-the-counter skin treatment products.

To read the whole report, see [http://www.jaad.org/article/S0190-9622\(17\)30017-8/pdf](http://www.jaad.org/article/S0190-9622(17)30017-8/pdf).

Tofacitinib for DM

Adults with active, treatment-refractory dermatomyositis are currently being recruited for an open-label clinical trial testing the safety and effectiveness of tofacitinib, a Janus kinase (JAK) inhibitor that blocks a key immune pathway in the cells. Refractory myositis is defined as active disease despite being on steroids for at least 12 weeks and at least one other first-line immunosuppressive agents (such as methotrexate, mycophenolate mofetil, or azathioprine).

Tofacitinib is approved by the Food and Drug Administration (FDA) for the treatment of rheumatoid arthritis. This pilot study will be conducted at Johns Hopkins University in partnership with the manufacturer Pfizer to determine if tofacitinib reduces the symptoms of DM in both skin and muscle. Subjects will take the oral medication once daily over a 12-week period and will need to attend up to nine study visits over six months. There is an optional treatment extension period of four weeks. All subjects will undergo follow-up assessments four weeks after stopping treatment.

For more information see <https://www.clinical-trials.gov/ct2/show/NCT03002649?term=dermatomyositis&rank=6%27> or call the principal investigator Julie Paik, MD at 410-550-1741.

Observational study of twins and sibs

Current evidence suggests that adult and juvenile forms of systemic rheumatic disorders, such as myositis, share many common clinical symptoms, immune responses, and genetic, hormonal, and environmental risk factors. They may even have similar causes. The National Institute of Environmental Health Sciences (NIEHS) is currently engaged in a study of families to better understand the impact of genetics and environmental exposures and other factors on the development of these disorders.

Families in which one sibling has developed a systemic rheumatic disease, including myositis, and the other has not, are eligible for this study. The siblings may or may not be twins, but must

be of the same gender and be within a 5-year age difference. Biological parents, or, in some cases, children, will also be included in the study. Normal, healthy volunteers will serve as control subjects. Participants of all ages are being sought.

A history and physical exam will be done, including completion of environmental exposure questionnaires. Participants may be asked for permission to have some of their blood and urine samples stored and to obtain previously collected blood or tissue biopsy specimens that are no longer needed for clinical care, for research purposes. They may also be asked to give additional blood or urine samples.

Participants will be followed every year for 5 years (either in person or by questionnaire) to evaluate any changes in their condition.

For more information, see <https://clinical-trials.gov/ct2/show/NCT00055055?term=twin+sib+myositis&rank=1> or contact the principal investigator, Frederick Miller, MD at 301-451-6273 or millerf@mail.nih.gov.

May is Myositis Awareness Month!

Tell someone about myositis!

Many of you have been planning events to draw community attention to this rare disease. But even if you're just now getting started, it's not too late! Here are some ideas for spreading the word:

- ✚ Tell a friend about your myositis journey.
- ✚ Download shareable Myositis Awareness Month images from www.myositis.org
- ✚ Write a blog about your personal journey with myositis. Tweet it. Post it to Facebook or Instagram. And be sure to share it with TMA.
- ✚ Encourage friends, family members, and support group members to follow TMA on Facebook and Twitter.
- ✚ Link your support group social media pages to TMA's.

- ✚ Give your physician the updated Physician's Guide to Myositis now available from TMA.

You never know when your post might 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, wristbands, myositis awareness car magnets, and other materials. Just let us know what you need: TMA@myositis.org

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(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
\$225	\$270	\$320

Refund Policy: Refund requests for TMA registration fees received in writing by July 24 will be issued a full refund; requests received after July 24 and by August 21 will be issued a 50% refund. No refunds after August 21.

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