

# THE OUTLOOK



THE MYOSITIS ASSOCIATION



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**SUMMER** 2017  
Quarterly Newsletter

# THE OUTLOOK

A quarterly publication of The Myositis Association

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*Cover Photo*  
 IBM patient Martin Jarry running in the Ottawa 10K race wearing a Dermoskeleton suit

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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*

What About Me? It's All About Me! The Entitlement Generation.

Sound familiar? These are phrases sometimes used to describe the millennial generation that grew up in a different era from many of you. Whether fair or not to characterize young people in this way, the irony is that those who live with myositis are the ones who truly deserve to think along these lines.

Not only is myositis a lonely disease for many, it is also a disease that so limits those who have it that at times they are fully entitled to think of themselves first. This is not an attitude that many of us want to display publicly, but the reality is that to survive it is sometimes necessary to think like this. We all hope that we can be charitable toward others and not put ourselves first, but there are times when it is justified.

In this issue of *The Outlook* you will find articles about issues bigger than just you: research, awareness, physician education, physician appointments, nutrition, and more. But as you read and think about these topics, each is really intended to help YOU. There are suggestions for what you might want to do for yourself, and there are examples of what is being done for you and all the others who have myositis.

Do not be hesitant to put these into very personal terms of “what does this mean to me?” You are entitled to ask yourself that and act accordingly. Your myositis journey is a struggle that only you can fully appreciate and understand, and you know better than anyone else what you need to manage your disease.

Do not be afraid to assert yourself and make your wishes and needs known to those around you who might be able to help.

The Myositis Association is here for you, and you should not hesitate to let us know how we can better serve your needs.

We want to hear from you!

## Currently significant clinical trials

Name	Type of Drug	Company/Research Group	Eligible	Protocol
Abatacept (Orencia)	Modified antibody - interferes w T-cell activity - approved for RA	Bristol-Myers Squibb	Active DM/PM/NM/JDM (over 18), overlap	SubQ injection weekly + current treatment x 24 wks + 28 wks extension
Arimoclomol	Believed to stimulate normal cellular protein repair pathway	Mazen Dimachkie, MD, University of Kansas	sIBM	2 pills x 3/day, 8 visits over 2 years
Belimumab	Human monoclonal antibody that inhibits B-cell activating factor - approved for ALS	GlaxoSmithKline Galina Marder, MD, Northwell Health	Active DM/PM	Infusion x 36 weeks + 28 week extension
Bimagrumab/BYM338	Human monoclonal antibody	Novartis	sIBM	
IMO-8400	Toll-like receptor antagonist	Idera Pharmaceuticals	Adults w DM w active, treatment-resistant skin & muscle disease	SubQ injection weekly x 24 weeks
IVIg (Octagam 10%)	Immunoglobulin	Octapharma	DM	IV infusion every 4 weeks x 16 weeks + 24-week extension
Tocilizumab (Actemra)	Humanized monoclonal antibody - approved for RA and JRA	University of Pittsburgh and Genentech	Refractory adult PM and DM	IV infusion every 4 weeks x 6 doses
Tofacitinib (Xeljanz)	Janus kinase (JAK) inhibitor - approved for RA	Johns Hopkins and Pfizer	Adults w DM w active, treatment-resistant disease	1 pill daily x 12 weeks + 4 week extension

Study Sites	Recruitment Status	Expected Completion	Details	More information ClinicalTrials.gov ID #
78 sites in US, Australia, S. America, Asia, Europe	RECRUITING 150 patients needed	Data June 2020 Study June 2021	Phase III randomized, double-blind trial comparing drug + std treatment with std treatment alone	BMSStudyConnect.com NCT02971683
University of Kansas plus 9 other sites in the US; and the University College in London	NOT RECRUITING YET - 150 patients needed	Data & study December 2021	Phase II randomized, placebo-controlled	LHERBELIN@kumc.edu NCT02753530
Sites in Long Island, NY, Phoenix, AZ, and UC Irvine, CA	RECRUITING 60 patients needed	Enrollment completion December 2018	Double-blind, placebo-controlled trial to test effectiveness and safety as compared with std of care	Preeya Nandkumar pnandkumar@nshs.edu NCT02347891
	Extension study active but not recruiting	Data & study February 2017		NCT02573467
21 sites recruiting in US and Europe	RECRUITING 36 patients needed	Data & study August 2017	Phase II randomized, double-blind, placebo-controlled, trial for safety and effectiveness	<a href="https://ideraclinicaltrials.com/rare-disease/dermatomyositis/">https://ideraclinicaltrials.com/rare-disease/dermatomyositis/</a> NCT02612857
6 sites currently recruiting; 30 sites expected	RECRUITING 94 patients needed	Data & study March 2019	Phase III double-blind, randomized, placebo-controlled trial testing safety and effectiveness	Cheryl.bell@octapharma.com NCT02728752
7 sites in US	RECRUITING 40 patients (need 10 more)	Data Sept 2017 Study April 2018	Phase II, double-blind, randomized, placebo-controlled trial to determine effectiveness	Diane Koontz 412-383-8674 dik4@pitt.edu NCT02043548
Johns Hopkins	RECRUITING 10 patients needed	Data Dec 2017 Study Dec 2018	Open-label trial for safety and effectiveness	Julie Paik, MD 410-550-1741 NCT03002649

# The world of myositis research



*Global Conference on Myositis 2017*

It was just a happy coincidence that, during Myositis Awareness Month in May, myositis experts from around the world gathered in Potomac, Maryland for the Global Conference on Myositis. This meeting, only the second of its kind in history, attracted more than 300 people from 22 countries, all of whom have an interest in understanding this rare disease and finding new, more effective treatments.

Researchers shared a wide range of their latest findings with other scientists. Among these was Dr. Lisa Christopher-Stine, who directs the Myositis Center at Johns Hopkins University. She discussed

ways in which patient-reported outcomes offer a better way to evaluate therapies. Dr. Olivier Benveniste, a new TMA Medical Advisory Board member from France, talked about prognosis in adult myositis. And Swedish researcher Dr. Ingrid Lundberg, who recently received a TMA research grant, discussed autoimmune reactions that target muscles.

TMA staff and myositis patients participated in the meeting, reminding researchers what patients want: to provide input on trial design, to be kept informed about upcoming trials, and for researchers to remain focused on the grand prize: a cure.

## **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](http://www.MyositisTrial.com).*



*Sheraton San Diego Hotel and Marina*

## California here we come!

TMA's 2017 Annual Patient Conference is just around the corner, taking place at the Sheraton San Diego Hotel and Marina on September 7-10. There's lots to look forward to, with several new topics and more sessions that offer an interactive experience.

TMA's exercise experts, for example, have reconfigured their presentations, offering interactive exercise classes specifically geared to patients with IBM and those with DM or PM. These

classes will be limited to 20 participants each, and introductory sessions will be offered on Thursday for those planning to attend one of these classes.

This year, we will offer an additional focus for those with antisynthetase syndrome. Get Acquainted sessions include a separate gathering for those with AS syndrome. And we've added AS syndrome to the Saturday Q&A sessions.

Lots of new topics will be scattered throughout the Conference. Some of these include workshops on finding emotional support for both patients and those who care for them. A session titled "Truth in advertising" will discuss the validity of questionable therapeutic claims. And a session on clinical trials will help you understand how trials are designed and how you can best participate in them.

New this year: Friday evening has been designated "Feel Good Friday." Rather than offering the usual instructive presentations, breakout sessions during this time will focus on self care. Attendees can relax and participate in activities that have been shown to have healing effects. Whether you do a little singing, create some art, write your story, or laugh your heart out, these sessions are all about feeling good.

### **ProDERM A clinical research study**

#### ***Are you affected by dermatomyositis?***

*If you are between 18 and 79 years of age and diagnosed with dermatomyositis, you may be interested in the ProDERM clinical research study.*

*ProDERM is a clinical research study that will evaluate the effectiveness of an investigational drug for the treatment of dermatomyositis.*

*To find out more, please contact the study team, or talk to your doctor.*

#### **Contact details:**

*Cheryl Bell, Clinical Study Manager [cheryl.bell@octapharma.com](mailto:cheryl.bell@octapharma.com)*

# Myositis Awareness Month 2017

While there can never be enough activity to support Myositis Awareness Month and the patients having to live with myositis, this year's events included some truly unique activities.

Martin Jarry, a retired police officer from Canada, ran in a 10K race held in Ottawa on May 27. The really exciting and unique aspect of Martin's participation was that he wore an electronic mobility device often referred to as an exoskeleton. Martin has inclusion body myositis, and the Deromoskeleton suit helped his knees and legs to move in a motion that allowed him to run, albeit not as fast as he might have been able to previously. This exciting new technology will be on display at TMA's Annual Patient Conference in September.

Vance Robinson, a Californian who has IBM, came up with another unique activity in support of Myositis Awareness Month. He contacted several colleges, asking if he could throw out the first pitch at one of their baseball games in May. Vance received positive responses from five colleges in California. When he walked to the mound with his cane, the public address announcer talked about the disease that Vance has to live with and told the fans at the ballpark how they could find more information about myositis. Vance's appearance at one of the games led to him being invited to a concert held on the White House lawn in May where thousands heard him speak about his disease.

Thermo Fisher Scientific, based in Houston, Texas, held a month-long celebration in honor of one of their beloved employees who had myositis and died earlier this year. Odie Warf worked for the company for four decades and was a unique individual—not just for her rare disease, but for her warm and charming personality, which made her a favorite among the company's employees. During May, Thermo Fisher held weekly raffles, silent auctions, posted a display celebrating Odie's life, and hosted educational sessions at lunchtime for employees to come by and learn about myositis.

TMA's Southwest Florida support group held two myositis awareness events in May. The first was a dinner at a local restaurant on May 4, where



*Martin Jarry crosses the finish line*

physicians, invited through the county medical society, heard from a rheumatologist about myositis and how to treat those with this rare disease. The SW FL support group followed this up with a patient event for its members two days later to celebrate Myositis Awareness and learn more from a myositis expert.

Mallinckrodt, the company that manufactures Acthar, the only medication approved by the FDA for a myositis disease, held a special event on May 11 at their Hampton, New Jersey facility, inviting employees to stop by at lunch and learn more about myositis. Employees received special Myositis Awareness baseball caps, and the event included displays about myositis, educational materials, and snacks. Mallinckrodt has been hosting a special Myositis Awareness event for its employees for several consecutive years now.

Radio and TV coverage was considerable at several of these awareness events, in addition to newspaper articles appearing around the country about local residents who have myositis. TMA members also posted widely on social media about their personal challenges with the disease.

It takes a little creative thinking and initiative to make these sorts of awareness activities happen. But sometimes all it takes is a simple phone call to the athletic department at your local college to ask if you can throw out the first pitch at a baseball game.

To all those who did something to raise awareness of myositis during the month of May, we say THANK YOU!



MYOSITIS AWARENESS  
MONTH

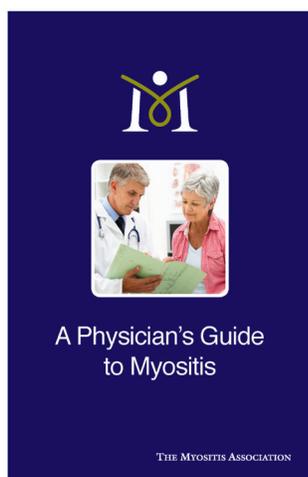
Vance Robinson supports  
Myositis Awareness Month



Rose Ryan, Dr. Rossitza Chichkova, Barb Kluding, Donna DeFant, Linda Sabatino, Marianne Moyer



Thermo Fisher Scientific honored the life of  
Odie Warf during the month of May



## Hot off the press

TMA's *Physician's Guide to Myositis* has been completely revised and updated to reflect the latest understanding of all forms of the disease. Directed at physicians who may not be familiar with myositis, the *Physician's Guide*

provides an overview of the symptoms, diagnosis, and treatment. It also provides the latest

understanding of disease-causing processes, clinical features associated with autoantibodies, complicating conditions, and more.

During Myositis Awareness Month in May, TMA members were sent a copy of the *Physician's Guide* and asked to share the publication with their health care provider. The hope is that by extending the latest information about myositis diseases to physicians and other health care providers they will be better equipped to diagnose and treat myositis patients effectively.

TMA members may request additional hard copies of the *Physician's Guide* by emailing [TMA@myositis.org](mailto:TMA@myositis.org). An electronic version is also available at [www.myositis.org](http://www.myositis.org).

# Finding support on the TMA Community Forum

by Fiona Ratkoff



The first time I saw the word dermatomyositis, I was in the hospital because I had problems walking. The doctors told me they thought I had an autoimmune disease, so I looked up autoimmune diseases on Wikipedia and read

everything. I remember seeing something about lung problems and dermatomyositis and thinking, “No, I can’t have that. I have to be optimistic.”

The second time I encountered the word, it was from the mouth of a medical student. I was in the same hospital bed a few days later. I could barely move my arms and legs and was wondering whether my heart might be affected too. I asked the student, “What do they think I have?” In a whisper, he said, “Dermatomyositis,” and he left the room. I looked at my husband and said, “What?” Again I went to Wikipedia and realized that they thought I had what I’d hoped I didn’t. I was crushed.

The first months with the disease, I was so exhausted I slept 18 hours a day. I couldn’t walk and couldn’t read. I trusted my doctors completely and followed their advice to the letter. But four months after the initial boost from the prednisone they were treating me with, I could barely walk again.

I decided to take my health into my own hands and started doing research on the internet. I spent several months reading all the official medical research. I wanted to be sure that what I read was true and wouldn’t trust any other sources.

Through this research, one of the things I realized was the important role of autoantibodies. I was having a very hard time with my doctor who thought I didn’t have DM, so I ordered him to

check me for all the myositis autoantibodies. The tests came back positive for MDA5 (Melanoma Differentiation-Associated protein 5).

Having MDA5 was the second shock of this disease. I had read about it but had dismissed it, because it was said to be prevalent in Asia. So again, I read all the research I could find on the internet about MDA5.

I did all this alone. I live in France, far away from my family in the US. My husband was very supportive. My two teenage daughters were perfectly nice, considering how our family life had been overwhelmed by my disease. But I didn’t want to impose my disease on those closest to me. I wanted to exchange ideas with other myositis patients who understood what this disease is like in all its little details and major despairs.

That’s when I discovered the TMA website, where I found videos from their Annual Patient Conferences. I watched all these videos, followed the advice, and took notes. But I was still very much alone.

Then one day, I registered to participate on the TMA Community Forum. Life changed from being very solitary to one in which I was able to share what I was living. I realized that some new patients were going through what I had for the previous two years, and based on posts written by more experienced myositis patients, I decided to contribute actively to the Forum.

I try to be as welcoming as possible in a setting where the only exchanges are through written words. I try to be reassuring and informative and give hope. The Forum is a place where there is proof that we can get better. It isn’t easy, but I’m not alone, and there are several other active members who are very generous with their time and expertise. I am not a doctor, but if I write something that isn’t accurate, a fellow member will politely correct me; I’m grateful for their remarks.

We are all struggling with this disease and trying to get better. There are so many aspects of myositis that affect us in our everyday lives that it is impossible to know everything, and every one of us lives his or her disease with different symptoms, medication, and access to help. So it is impossible to write anything that is true for everyone. But

by telling others what I am living, they can relate to what we are all going through. In the end, the disease touches us each in different ways, but we all have a lot in common.

After a few weeks posting on the TMA Forum, I realized that I was gaining as much from the site as I was helping others. Writing about what I had read made me realize I had some kind of mastery and understanding of this disease. My DM no longer controlled me. I was beginning to gain some control over what I was going through.

What's more, there were many aspects of the disease that were never dealt with in the medical literature, details that might seem irrelevant to doctors but that were not to me: itching, the need for sun protection, relationships with my children, my diet. My posts were friendly, funny, and informative. It was a pleasure to get to know people going through the same thing as I was. Participating in the Forum became a daily routine with my morning and evening tea.

And so I began to learn even more about my disease than what I had read in the medical research. I learned a lot, and I was reassured. I had doubted the expertise of my doctor, who still denied I had DM and MDA5, in spite of my interstitial lung disease (ILD) and the positive autoantibody test. But thanks to the Forum, I realized other myositis friends who had

ILD were taking the same medications as me, so I was less stressed about whether I was being treated properly.

My DM has progressively become part of my new me. It doesn't define me more than being a mother, wife, daughter, sister, woman, friend, or co-worker, but it is an important part of me all the same. Thanks to the Forum, I have met wonderful people and made long-lasting friendships.

If there is any advice I could give to others touched by myositis, it would be do not hesitate to contribute to TMA's Community Forum. The simplest topics can become the most discussed. Whether you are newly diagnosed, know nothing of the disease, and are overwhelmed by all the information, or whether you are an expert, those of us who participate in the Forum are grateful for everyone's willingness to share.

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*Fiona Ratkoff was diagnosed with DM, MDA-5, and ILD in August 2014, but she proudly declares she can now hike three hours in the mountains with no pain. She is a frequent and supportive presence on the TMA Community Forum, which is accessible to all readers. To comment or post, it is necessary to register on the Forum website. <https://tmaadministrator.discussion.community/categories>*

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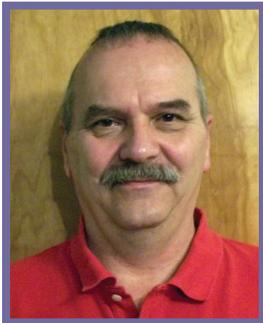
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*At TMA, we often hear from patients who have discovered for themselves a path to healing that strays beyond the mainstream. While some of these paths may seem remarkable and implausible, it's hard to argue with success. Although TMA urges all patients to follow the advice of responsible health care practitioners, we also urge you to take charge of your own health and healing. And if that happens to take an alternative form, as long as it doesn't cause more harm than good, we're happy to share these stories too.*

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## You are what you eat: My story of treatment, healing, recovery, and restoration



by Jerry Young

Most of us remember the day when our doctor gave us the diagnosis. Polymyositis was something I had never heard of. My rheumatologist said it was treatable, but not reversible. My doctors

admitted there is very little known about it. What they did know is that it has no cure, and decline was inevitable.

This did not sit well with me. I have been active all my life, and sitting around getting worse was not acceptable. I had lost about 70% of my muscle mass. I was told I would never go back to work and I would soon be in a wheelchair. My throat was nearly closed, and my doctor said I would have to have a feeding tube if I continued to lose weight. I thought, there are two things I can do: sit back and watch life go by, or fight in uncharted territory. What I know now is that attitude and determination played a huge part in having victory over this debilitating disease.

Even before I was diagnosed, I had thought that I should eat healthier. I was a sugar addict with a habit so bad I hid candy everywhere. I believe this habit amplified my polymyositis, and if I wanted to recover I had to make massive changes. And so the diet began. I went full organic and GMO (genetically modified organism) free. I also cut out all sugars, preservatives, additives, and anything artificial.

I experimented with foods and eliminated the ones that would set me back. Some things like pork, beef, and bread I knew were a problem almost instantly, because I could feel my throat close during the meal. I started to eat a lot of pineapple because I read several things on the internet about the benefits of pineapple, and that was one of the first foods I could swallow without warm water to help it get down.

My daughter studied nutrition for years, so she is my best resource. I also spend hours researching on the internet. I keep a daily journal and record any progress or negative effects. With the exception of wild-caught fish and organically raised chicken, I will eat nothing that does not come out of the ground grown organically.

We have all heard “You are what you eat.” This is true. We are sustained through nutrition, and the better the nutrition, the better it provides health and energy. Good nutrition means getting the right amount of nutrients from healthy foods without adding poisons that the body will have to try to process.

Our bodies are not designed to process poisons like pesticides, herbicides, artificial flavors, artificial colors, preservatives, or other chemicals. When we remove these poisons, the body can function better, and its natural ability to heal is amplified. The way to really allow nutrition to heal is to have a pure diet. When we go organic and GMO free, the body's immune system does not have to fight off as many foreign substances and can begin to heal.

My healing was beyond anything anyone ever expected. Four years after I was released from the hospital with the news that I was handicapped, I began playing kickball once a week. I am not the fastest, I am not the strongest player, but I can run, kick, catch, and enjoy activity again.

About a year ago, the company I work for had a benefits fair where someone did strength testing. In a company with over one hundred employees, I was the fourth strongest! It was just five years ago now that I couldn't even lift my foot high enough to get into a bathtub or lift my hands higher than my ears.

I've had such drastic improvement that I wanted to get the word out so others can benefit from my experience. I started posting on the myositis Facebook sites, but there would always be a naysayer with comments like, "Diet does not help." This was not useful. So in order to help those who truly want to give the healthy diet a chance, I started the group "Myositis, Healing through a Healthy Diet." It's a safe, friendly site where we encourage and share diet helps with each other.

There are several diets that people follow. I say find the one that helps you get healthier. Keep in mind

myositis is an inflammatory disease, so we need an anti-inflammatory diet. If you are not sure just what to eat for a clean diet, try eating five varieties of vegetables and three varieties of fruit every day.

I have said from the beginning ten steps forward and nine steps back is still progress. It takes a long time for nutritional healing to take place. Patience and persistence is required. Yes, organic and GMO-free food may be more expensive, but what price would you put on your health? This is what I have learned so far and would like to share.

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*Jerry Young is the administrator for the closed Facebook group "Myositis, Healing through a Healthy Diet." He lives in Pittsburgh, Pennsylvania.*

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*Jerry Young encourages everyone to read more about healthy diets. Here are some of the sites he uses:*

-  A respected source for health information: <http://www.healthline.com/>
-  Breaking science news: <http://www.bioexplorer.net/>
-  Information about GMOs and health: <http://responsibletechnology.org/>
-  Ten inflammatory foods to avoid: <https://theconsciouslife.com/top-10-inflammatory-foods-to-avoid.htm>
-  Organic foods: <http://www.mayoclinic.org/healthy-lifestyle/nutrition-and-healthy-eating/in-depth/organic-food/art-20043880>



## Leaving a Legacy

When one's days are over, they are remembered and not forgotten by family and those who knew them. You can be remembered by those close to you and an even larger "family"—those who follow you in having to live with myositis. Please consider including TMA as a beneficiary of your estate, a life insurance policy, or an IRA.

Your "myositis family" will appreciate you thinking of them, and they, too, will not forget you.

***You can make a difference!***

Thank you!



## Do I really need to see a physician?

by Nancy Harber

*“Why should we continue to see a physician when every time we go, there is nothing*

*new? The person with myositis I am caring for is a little weaker, but the physician has no real suggestions to offer and there is nothing on the horizon that would indicate a change is coming. It’s depressing to keep being told there is nothing more available for us.”*

It is discouraging when nothing seems to get any better and no one has any new ideas. People with inclusion body myositis probably get the most discouraged, because they see the least amount of encouraging news. Still, I always urge people with myositis and their caregivers to stay in contact with their physician. Whether you have IBM, polymyositis, or dermatomyositis, you are dealing with a chronic disease, and all chronic diseases should be monitored from time to time.

There are two aspects to seeing a physician to consider. If you are primarily seeing a specialist for your myositis challenges, s/he may prefer to not manage other aspects of your health, such as cardiac issues, pulmonary problems, blood pressure changes, anemia, dietary needs, and flu shots. As we all get older, our bodies can begin to wear down and may need a “tune-up” from time to time. If your specialist is willing to serve as your primary physician, great. If not, I urge you to consider establishing a regular relationship with a primary care physician (not a specialist) who can monitor your overall health.

Another factor to consider is that having myositis means that at one time your immune system went “sort of crazy” and began to attack your body instead of protecting it. We are not always sure what else beside muscles might have been affected, but it’s a

good idea to have someone keeping an eye on the rest of you. And I suspect that caregivers could use another ear to hear you and to make suggestions from time to time.

Even though you may feel that your specialist doesn’t have anything new to offer right now, we continue to hope that this will change. With PM and DM, it certainly has over the years and we’ve seen some encouraging progress. The medical experts who will first hear of new approaches on the way are the specialists who treat these diseases, so it is important you stay in touch with them. They also can help you obtain special equipment or devices to make life easier.

Establishing a relationship with a physician assures that there is someone who knows your “entire picture.” Should a crisis occur and you need serious medical intervention or even hospitalization, it’s most helpful to have someone who can step in and help explain your unique situation and needs.

When my husband Charlie, who passed away several years ago, was dealing with IBM, we worked with two regular physicians. His neurologist cared for the IBM, checked for changes in muscle strength, and wrote prescriptions for needed equipment. His primary care physician, an internist/endocrinologist, managed his other autoimmune diseases, kept his routine meds on a schedule, made sure he got adequate nutrition with his dysphagia, and took care of general health issues.

Frankly, I would not have wanted to go through those twelve years without both physicians. Even if they didn’t have *all* the answers, they had more than we did and were of tremendous help to both of us. So even if your doctors don’t have all the answers now, make them a part of your life with myositis. And should another challenge start to develop, they will be in the best position to pick up on those changes and start some intervention before you really get into trouble.

*Nancy Harber’s husband Charlie, who passed away several years ago, had IBM. As a registered nurse and 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.*

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