The Myositis Association

THE OUTLOOK

For the inflammatory myopathies

MeetOurMember: Kate Barnett

Dermatomyositis patient prepares to carry Olympic torch

Kate Barnett was tough enough to work as an engineer on an oil rig in the North Sea and endure six rounds of chemotherapy and five weeks of radiation for breast cancer. Never for one moment did the 41-year-old native of Aberdeen, Scotland, believe she couldn't overcome her cancer. It was her experience with dermatomyositis, however, that really tested her, she said.

It was 2009, a month or so after finishing cancer treatment, and Kate was looking forward to going back to the North Sea.

"I started getting a red rash on my hands, then it progressed to my face and I began to have real problems walking. I was getting very tired," Kate said. "After five trips to the doctor, I went downhill so far that my GP sent me to the dermatology center, where by this time I was so ill I was admitted to Aberdeen Royal Infirmary."

Kate said she had never felt so sick: "I couldn't walk and had to be pushed about in my wheelchair, couldn't eat, swallow, dress, or hold a pen. And I really thought this was going to be it for the rest of my life. I have to admit I was very scared."

Kate was treated aggressively with steroids, then azathioprine was added. At the time it seemed like a wonder drug to Kate. She began to improve.

"With a lot of grim determination and hard work, I took up swimming, walking and just trying to get my body back into shape." Her fiancée worried, she said, concerned that she was doing way too much.

Photos courtesy Kate Barnett

With extreme effort, she made it back to work in April 2009, but she found she couldn't work offshore with the number of drugs she had to take. Now Kate works as a chemist for her company.

She receives IVIG every eight weeks, and just had her medication changed from azathioprine to methotrexate, which helped reduce the steroids dosage to 9mg. She goes to the gym three times a week, does Pilates and swims.

Her legs are too weak for frequent runs, but she managed to run a benefit race for breast cancer research just as she began radiation. Kate also won the Aberdeen Champion Awards for Charity, a contest sponsored by the local newspaper, where readers pick the winner.

Unbeknownst to Kate, her fiancée applied for her to carry the Olympic torch as it passed through Scotland on the way to London. In August, she received an e-mail telling her that she was selected for the second round, then found out in December that, pending security checks, she'd be one of the torchbearers running through northeast Scotland. On June 12, she'll be part of the team that runs from Aberdeen to Dundee, about 75 miles. Each runner travels only a short distance, she said.

Kate spends so much time at the gym that she probably won't have to train further for the run, but she worries about the weight of the torch: "I hope my arm muscles will be up to it."

The last time the Olympics were held in the UK was 1948. "I am so very proud to be part of this Olympic celebration," Kate said, "although I am sure there are many other people who deserve this honor more than me. I never would have thought, when I was first diagnosed with cancer and then DM, that it would lead to something as prestigious as this. It goes to show that the best of things can come from out of nowhere, and there is light at the end of the myositis tunnel."

More than 8,000 torchbearers will carry the Olympic torch across the UK between May 19 and July 27. Kate will find out in March where she will run, and keep us posted on her experience in future correspondence.

Find out more about the London Olympics and the torch at http://www.london2012.com/olympic-torch-relay.

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THE MYOSITIS ASSOCIATION
1737 King Street, Suite 600
Alexandria, VA 22314
P: 800-821-7356 E: tma@myositis.org
F: 703-535-6752 W: www.myositis.org

Executive Director: Bob Goldberg
Editors: Theresa Reynolds Curry

BoardofDirectors

New members join TMA Board and Medical Advisors

Four new directors join TMA's board

Terry D. Anderson, a caregiver who lives in Severna Park, Maryland, had a long and distinguished career with the United States Air Force, serving in Vietnam and later as a squadron leader in Europe and at the National Military Command Center at the Pentagon. For the last 20 years of his career, he served as an executive with Northrop Grumman Corporation, from which he retired in 2005.

Renee Lantner, MD, is a physician in private practice near Chicago, who is a dermatomyositis patient. She served her fellowship in allergy and immunology and her residency in pediatrics. She has taught at Loyola University Medical Center in the Departments of Medicine and Pediatrics, Division of Allergy and Immunology. She served as president for the Illinois Society for Allergy, Asthma and Immunology and for the Suburban Asthma Consortium.

William D. Prall, a Phoenix businessman, is an IBM caregiver. He is the president of Diamond Kitchen and Bath in Phoenix and has been involved in the start up, growth, management and leadership of a number of small businesses for the past 35 years. He graduated from Northern Michigan University with a degree in speech pathology and has also worked as a speech pathologist.

John Suttle, an IBM patient, is a California businessman and attorney with an MBA from the University of California at Berkeley and a law degree from Hastings College of the Law. He is the managing partner of Suttle & Company, a CPA firm; and the president of SuttleLaw, a law firm. He has served in leadership positions on a number of non-profit and civic boards helping educational, environmental and social causes.

TMA's medical advisory board adds new members

New myositis experts joining the medical advisory board in 2012 demonstrate the increasingly international and collaborative nature of The Myositis Association:

Dr. Andrew Mammen, a neurologist, is the co-director of the Johns Hopkins Myositis Center, and an assistant professor of neurology at Johns Hopkins. He sees patients with diseases affecting muscle and nerve and has a special interest in toxic myopathies and muscular dystrophy as well as myositis. His research focuses on muscle regeneration in myositis as well as the link between myositis and cancer. Dr. Mammen is the recipient of the 2007 Passano Physician Scientist Award.

Dr. Zarife Sahenk is a professor of Neurology, Department of Neurology, Ohio State University College of Medicine. She is also a professor of Neurology and Pediatrics, Columbus Children's Research Institute, Neuromuscular Program; and the director of Neuromuscular Pathology.

Dr. Christina Charles-Schoeman, a rheumatologist, received her medical degree from the UCLA School of Medicine, where she remained for training in both internal medicine and rheumatology. Dr. Charles-Schoeman has interests in rheumatoid arthritis and inflammatory myositis, and is an active investigator in multiple clinical trials of novel therapies for rheumatoid arthritis. She is the co-director of the UCLA Myositis Center.

What does the Board do anyway?

Someone once said that a speaker should never answer a question with "…that's a good question," because it implies that everyone else's question is not good. However, sometimes there is a question that really is good. At TMA's 2011 annual patient conference in Las Vegas, at the "Meet the Board" session, someone asked "…so what does TMA's board do, anyway?"

I say, "Good question!"

Your board had a very busy, productive and interactive year in 2011. And 2012 promises to be another much like it. First, let me tell you about who we are. We are a volunteer board and receive no compensation for our expenses or services. Each person on the Board either has a myositis disease or is close to someone who does. IBM, PM and DM are all represented.

We are geographically diverse and we'd like to be more ethnically diverse as well. Each year, three to five members' terms are up and they leave to be replaced with new candidates who have applied. A member may serve up to five consecutive years. Currently, there are 15 people on our Board. The four new members met the rest of the board for the first time in January, 2012.

We meet face to face, twice a year. The full board also meets via conference call at least three additional times; and each board committee meets by conference call at least four times. Some of us are on two or more committees so that could mean between eight and twenty-four calls in this coming year!

In 2011 we had three major accomplishments:

- The first is hopefully no longer news to you: that **we eliminated the requirement to pay dues**. This decision was not taken lightly and I appreciate that some of you have questioned if TMA can manage the reduced income from dues.

The answer is that after a great deal of research and consideration, we believe that many of our members will voluntarily provide donations equal to, or more than, what they had paid in dues. One reason for this is that we believe that people who receive TMA's services and support will want to ensure the continuation of that level of support for all myositis patients. To quote a letter we recently received from a myositis patient, "…we have no money to send at this time; we have canceled internet, cable, etc., just to make house payments. But we will continue to pray that those who are able to send money will make up the difference…"

- **We reaffirmed our board vision.** Our vision statement is simple; "We envision a world without myositis diseases." Then we engaged in lengthy processes to revise our mission statement to define how we will achieve that vision.

- **We reaffirmed our mission.**

The mission of The Myositis Association is to:

1. Provide support to myositis patients and their families

2. Provide connections between the Medical Advisory Board and the general medical and patient communities

3. Increase funding to support myositis research.

We have committees that target each one of these objectives. We've identified specific action items, timelines, responsible parties and project goals. In coming issues of the OutLook we will report to you on our progress in these areas. You should expect nothing less, since we work for you!

Finally, let me say that it's truly an honor to chair this board. Each individual board member, plus Bob Goldberg and his staff, is pledged to doing everything he or she can to live our vision and mission. I don't need to tell you that, since ten of our fifteen Board members have myositis, and the others are caring for someone who does, sometimes it's not easy. There are times when our muscles just don't want to type one more word and holding the phone to our ear for a conference call is exhausting. But you can count on the fact that we will do it, somehow, someway. Because, after all…we have a vision, and we plan to achieve it!

Please let us know how we are doing.

Marianne Moyer
TMA Board Chair

Keep up with myositis news

- Find News and Announcements in TMA's "Community" at www.myositis.org
- Find support at TMA@myositis.org
- Find us on Facebook http://www.facebook.com/pages/The-Myositis-Association/85879364090
- Follow us on Twitter www.twitter.com/themyositisassc

Milestone IBM gene transfer trial begins

Several IBM patients have let TMA know that they've been chosen for the landmark gene transfer study now underway at Nationwide Children's hospital in Ohio. In the interest of keeping people informed, we will feature firsthand reports about the trial, although we must keep the authors' names confidential. If you have been chosen and would like to write about your experience, please email TMA.

First-ever human patient "positive and hopeful"

On January 16, a 72-year-old male received the first gene transfer injections for IBM to be given to a human. He relates his experiences for the OutLook, and will be keeping TMA members updated as the trial progresses.

I am writing to you to share my experience with Phase I of the IBM Gene Transfer Trial in Columbus, Ohio at the Nationwide Children's Hospital, led by Dr. Jerry R. Mendell and coordinated by Dr. Xiomara Rosales. I have been married for 46 years and have three children and 11 grandchildren. Recently, I retired from my own business in the hospitality industry, and I am a member of my local myositis support group.

Approximately five years ago, I was diagnosed with IBM after a muscle biopsy at the Mayo Clinic in Rochester, Minnesota. Certainly, my symptoms began long before that.

In late November, 2010, I read about the gene transfer trial in the TMA newsletter. I called Nationwide Children's Hospital and asked for the office of Dr. Mendell and advised the staff that I would like to be considered as a candidate.

They invited me to visit Columbus for an interview, which was at my own expense. I was examined, interviewed and tested by Dr. Mendell and his team. They told me they would select nine people. They were preparing for FDA approval and would notify me with the results of this screening phase.

After waiting 11 months, I was told I was selected. Shortly thereafter, the FDA gave its approval for the Phase I trial, and I was to be the very first participant. I flew to Columbus for a lengthy meeting and examination with Dr. Mendell and many of his team members. I had the opportunity to ask many questions and express my concerns at being the first human in the trial. My questions were answered honestly and with sincerity. Still, I had much to think about before making my final decision.

At this time, I was given a 16-page packet of consent documents to read. I went over every detail and, in the end, felt very comfortable in signing on. I was very excited and enthusiastic about adding my contribution.

The next two days were spent taking tests: an MRI, chest Xray, echocardiogram, blood and urine tests, and a complete examination by the neuromuscular therapist.

The plan now was to return on January 16 for the injections, 12 in all, in my weakest leg. The sites were identified by ultrasound, and executed by an impressive team of experts. I watched the whole procedure on the ultrasound. It was painless!

Afterwards, I stayed overnight in the hospital, then was released to a hotel. The next day, there were more blood tests and leg measurements. The tests and measurements will continue until the completion of the trial. I flew home after this. The trial has limited funding, and pays for airfare and hotel accommodations only.

Dr. Mendell is called "the master" by many of his colleagues, and I concur. It was a great experience, and I never felt nervous. I look forward to my next six visits, and I remain positive and hopeful that this will not only help me, but others as well. This is a two-year study.

I salute Dr. Mendell for his commitment to this scientific endeavor to improve the quality of life for IBM patients and the children and adults with other neuromuscular diseases.

The following is from a male IBM patient about his reasons for wanting to be included in the trial.

Most of the people I have met with any type of myositis are research hounds who spend hours on the computer looking for as much information as they can to educate themselves about their illness. I was one of those people. I had been diagnosed with inclusion body myositis in 2008, and after confirmation of the disease, I dove headfirst into Google looking for everything I could about IBM.

I was looking for hope.

But everything I read painted the same picture—a slow, progressive dis-

ease with no known treatment or cure. Phooey! During my search I discovered The Myositis Association's website and read an article about some gene therapy research that was currently underway by Dr. Jerry Mendell in Columbus, Ohio.

In September 2009, while attending the TMA conference in Charlotte, N.C., I heard Dr. Brian Kaspar's presentation about the same project. He had a handout with a lot of medical jargon, but it also had pictures—before and after pictures of mouse legs. Who would have thought that someday I would be excited about pictures of mouse legs? The difference between the before and after shots was striking. This was all the result of the gene therapy research of Dr. Mendell and his team. That was encouraging.

Then I discovered that Dr. Kaspar was going to have a live discussion via the TMA website, in which he would talk all about the research project and take questions from his web audience. He described the completed clinical trials on mice and how successful they were, and how at this point they were just finishing up another clinical trial with non-human primates (monkeys). He also talked about the upcoming clinical trials for humans.

It was that bit of information that really tweaked my interest, and near the end of the online discussion, Dr. Kaspar invited anyone interested in participating in the trial to submit their name and some brief medical information. So I sent in my information, not really thinking that I had much chance of being selected. After all, they were only looking for 9 candidates from the entire world of IBM patients.

This happened in November, 2009. Dr. Kaspar was hopeful that the clinical trial for humans might begin around March, 2010. No such luck. One year, later I unexpectedly received an invitation to come up to Columbus, Ohio. My wife and I were very excited! Out of all of the possible candidates around the country, we actually were chosen to go to Ohio for pre-screening! Sure, they invited almost 200 people to participate, but that was still better odds than before.

Spring forward to December 2011, a full two years after hearing Dr. Kaspar describe the first glimmer of hope for IBM patients. On the morning of December 19, 2011, I received an email from the Columbus research team inviting me to participate, but they were very clear that everyone still needed to be screened again and that at any point someone could be eliminated. Sounds a bit like reality TV. I don't want to be eliminated. This is real life.

I received a 16-page consent form outlining the process and all of the things that could go wrong. It's filled with phrases like, "consequences are not known at this time"; "….could damage normal genes"; "…could put you at risk for developing cancer." Wow, that will make you think. They recommend discussing all of this with your family and your doctor. Good idea.

The decision to go forward was unanimous, but regardless of whether or not I make it all the way through, the medical world is moving one step closer to improving the quality of life for IBM patients everywhere. Hope lives on, indeed!

For information about inclusion in the trial, contact:

Xiomara Q. Rosales, M.D.
Neuromuscular Division
Center for Gene Therapy
The Research Institute
and Ohio State University
700 Children's Drive-WA3112
Phone: 614-722-6961
Fax: 614-355-7686
Email: rosalesx@ccri.net

ResearchReport

Join a myositis trial

Got siblings?

The National Institute of Environmental Health Sciences (NIEHS) in Bethesda, Maryland, is conducting a study for families with siblings or twins in which one sibling has developed an autoimmune disease and the other has not. The goal of this research study is to understand the genetic and environmental factors that may result in autoimmune diseases.

You may be eligible if you or your child has:

- Adult or juvenile myositis diagnosed within the last 4 years
- A sibling or twin of the same gender within four years of age without an autoimmune disease

Study facts:

- Both children and adults are eligible to participate
- The sibling pair is essential to participate (parents may also be included)
- You may enroll at your local doctor's office, the Clinical Center at the National Institutes of Health (NIH) in Bethesda, MD, or at the NIEHS Clinical Research Unit in Research Triangle Park, NC
- There is no charge for study-related evaluations and tests
- Compensation is available
- Patients remain under the care of their personal physicians while participating in this research study
- For more information, call: 1-800-411-1222 or TTY 1-866-411-1010

Refer to study # 03-E-0099, clinicaltrials.gov

NIEHS Environmental Autoimmunity Group at http://www.niehs.nih.gov/research/clinical/index.cfm.

New NIH rare disease program tackles hereditary IBM treatment

By Geoffrey Spencer

Associate Director of Communications, Division of Extramural Research, National Human Genome Research Institute

A dedicated group of researchers at the National Institutes of Health and their collaborators are in pursuit of a potential treatment for H-IBM and have started a study to better understand the disease.

It's been a long road and there are miles and miles still to go, but the researchers are hopeful that the potential treatment they've identified may one day make a difference to HIBM patients.

Unlike sporadic IBM, HIBM is usually identified when people are in their twenties or thirties. It gets progressively worse, upsetting the most productive times of a person's life. It can lead to severe disability within 10 - 15 years, confining many patients to a wheelchair. Currently, there is no effective treatment.

HIBM, also known as inclusion body myopathy type 2 (IBM2), distal myopathy with rimmed vacuoles (DMRV), Nonaka myopathy, or GNE myopathy, can result from mutations in a gene called GNE. GNE encodes the enzyme responsible for making a sugar called sialic acid. Research has shown that HIBM patients have lower levels of sialic acid on the surface of certain proteins important for muscle function.

In 2007, a mouse model of HIBM was developed by a group of researchers that included the Medical Genetics Branch at the National Human Genome Research Institute (NHGRI), part of the NIH.

The researchers administered a drug to the mice to replace the loss of sialic acid associated with HIBM, called ManNAc, an abbreviation for N-Acetylmannosamine. The market name of ManNac is DEX-M74. Some of the mice exhibited improved amounts of sialic acid. Later, Japanese researchers used ManNAc in another HIBM mouse model with similar positive results and improvement of muscle function.

The findings led to the start of a human clinical protocol in 2007 to treat HIBM patients with DEX-M74. Soon after, an investigational new drug (IND) application was filed with the U.S. Food and Drug Administration (FDA) in an effort to start human clinical trials. However, the FDA evaluated the effort and requested additional preclinical studies. Unfortunately, such studies are expensive and so the effort came to a halt due to lack of resources.

Along came the NIH Therapeutics for Rare and Neglected Diseases (TRND) program, which conducts preclinical drug development to advance new drugs for rare and neglected diseases. The HIBM project was selected by the program in 2010 and is currently conducting the preclinical studies required by the FDA. TRND plans to submit a response to the FDA clinical hold in summer 2012 so that a clinical trial can move forward. More information on the project is available at http://nctt.nih.gov/27544213.

"It is difficult to translate laboratory findings of potential treatments for rare disorders into clinical trials, said Marjan Huizing, Ph.D., an associate investigator in the Medical Genetics Branch at NHGRI who has been a researcher on the HIBM project since the beginning. "It is gratifying to know that our laboratory findings may be translated into a treatment for HIBM."

TRND, in collaboration with NHGRI, is also currently conducting a natural history study for patients with HIBM. Natural history studies are a critical piece of developing new therapies. The purpose of this research study is to understand the rate of disease progression in patients with HIBM, evaluate potential outcome measures for use in clinical trials and to educate patients about their condition. Natural history studies are a critical piece of developing new therapies.

For more information, visit http://hibmstudy.nhgri.nih.gov/about.html.

Find more information about HIBM at:

http://hibm.org/arm/about_hibm:living_with_hibm.

http://www.ndf-hibm.org/index.php?option=com_content&view=article&id=44&Itemid=66.

Is There Hope for a Treatment Soon?

Yes. Based on preliminary scientific findings, researchers believe it is less difficult to develop an intervention for HIBM than for other forms of myositis. This is because HIBM is associated with mutations on an enzyme that is expressed at low levels in skeletal muscle, but many other common muscle wasting conditions are caused by mutations on cellular structural proteins which are expressed at very high levels in muscle.

If you would like to speak with a physician at NIH regarding HIBM, you may call (818) 789-1044.

PatientPerspective

Experiences and observations of an IBM patient

By Andrea Taylor Langworthy

The open door

Growing up, I learned there was a ready truism for every situation. Wrestling with your conscience? "Right is right." Difficulty with a task? "If at first you don't succeed, try, try, try again." Looking for a solution? "Listen to your heart, that little voice inside you."

A favorite dictum, credited to Alexander Graham Bell, promises that when a door closes to us, if we just look around, we will see another has opened.

Nine years ago, when a friend announced she was moving, I asked, "What will I do every Wednesday for lunch?" That "little voice" said to take a writing class.

I perused a catalog of classes from a nearby literary center. Every Wednesday, at the exact time my friend and I had always gotten together, a beginning writing course was scheduled. I signed up.

From that first class — where I was certain everyone could see the blinking neon sign above my head proclaiming I was not a real writer and didn't belong — seven of us formed a writing group. We continued to meet at lunchtime every Wednesday.

The practice of writing and this group made it easier when the autoimmune disease I had been diagnosed with made it impossible for me to do my job — selling cars and trucks — during icy, snowy Minnesota winter months. It was then that I took more classes, bonded with the Twin Cities writing community, and began to dream of writing a weekly column for the local newspaper.

But, until now, I never wrote about myositis, an inherited condition robbing me of the ability to get out of a chair, into the cab of a truck, or maneuver through a crowded restaurant. Maybe it was because myositis was a disease that wouldn't concede to my favorite axiom, "mind over matter."

My father's story

It had been painful to watch my father struggle to get up the curb to the sidewalk. Not a new scenario but one that worried my sisters, brother and me. Walking up a flight of stairs was slow going for Dad, too. He assured us he was "just tired."

"Shouldn't you see a doctor?" my sister asked.

A specialist diagnosed polymyositis, an inflammatory auto-immune disease where the body attacks and destroys the proximal muscles — in the upper arms, thighs, throat and neck — those closest to the trunk. High doses of prednisone made his face swell up but didn't squelch the disease.

Eventually, Dad was given another diagnosis: inclusion body myositis, which affects the distal muscles, too. There was no cure.

My father was a hard-working attorney. When walking became difficult, falls frequent, and driving a car out of the question, he didn't stop practicing but brought the office home to two side-by-side condos that had a door cut into the wall that joined them. He would live in one and conduct business in the other.

Because he didn't want clients to know something was amiss, Dad didn't use a wheelchair or walker. Instead, he employed a grocery shopping cart. Holding on to the handle bar gave him the stability he needed but required both hands. He carried files and his coffee cup in the basket. We kids found the cart humorous, an eccentricity. Other household innovations followed: A bar height table was built for the dining room and surrounded with high stools. That was where Dad ate and often worked when he wasn't seeing clients. When he needed to get up, instead of struggling to hoist himself out of a chair of regular height, Dad just turned to the side, dropped his feet to the ground and was standing.

My father passed away in 1991, nearly 15 years after being diagnosed with IBM. He didn't die from the disease, but a combination of its effects and those of a stroke he had nearly two years before. After the stroke, Dad was confined to bed or a wheel chair and received nourishment through a feeding tube. Otherwise, he may have succumbed from dysphasia (weakness in the throat which can cause choking) or a fall, as many with IBM do.

Five years after he passed away, I had trouble walking up steps. Doctors said my legs were weak because I was a runner and worked long hours on my feet. It could not, they insisted, be what my father had. "Buy support hose," they all said, as though it was written on page one of every medical book.

Three years later, I was diagnosed with polymyositis. When the drugs didn't work, a second muscle biopsy confirmed IBM. There still is no cure. But finally, I understand Dad's shopping cart. Eccentric? Humorous? No, just proof that necessity is the mother of invention.

Andrea Taylor Langworthy is a freelance writer who lives in Minnesota with her husband.

KeepInTouch

Common myths about support groups

Don't let misconceptions prevent you from forming valuable connections

By Quineesa Smith
TMA Member Services Manager

By now you should be aware that TMA has support groups around the country. Those who participate in these groups find them very helpful, so it's often perplexing as to why more people do not come to meetings.

Since myositis is so rare, many patients say how isolated they feel with this disease. They're unlikely to meet anyone else who has it in the course of their normal life. Yet, many of these same people choose to remain isolated.

Are you apprehensive about attending meetings? Are there support-group myths that keep you at home? We'd like to debunk some of these myths, in the hope that many more will join TMA's support group network.

Myth #1 – "I'm not a people person, and I don't want to openly share my story with others."

No one has to do anything they do not want to do at a support group meeting. You can sit and listen, or share your story and personal experiences with myositis. Many think that meetings are just a time to visit with others -- and certainly, some of that is involved -- but many meetings have speakers on topics that specifically address your needs. Medical professionals, including doctors, come and speak about treatments, coping, exercise, diet – you name it. It's definitely not a bunch of people listening to similar stories and feeling sorry for each other. Group members comfort and empower one another to live a healthy lifestyle with myositis.

Myth #2 – "Someone may tell my personal business to others if I go and share."

FALSE! Confidentiality is paramount within our support groups and is taken very seriously by all involved. There may even be a confidentiality agreement that must be signed by group members and kept on record. You'll find support group members are comfortable that whatever they share stays within the group. If you have concerns about confidentiality, talk to the support group leader before becoming involved, to ensure your concerns are addressed.

Myth #3 – "Support group meetings are going to be boring."

Support group meetings have come a long way. You're going to find many meetings incorporate games, breakout sessions, snacks, lunch, raffles, even entertainment. Whatever you want in a support group meeting, you should share it with your group's leader. Maybe a meeting could be offsite at a pool for some aquatherapy sessions, or maybe the meeting could be a movie and lunch date. Instead of wondering when the meeting is going to be over, you'll be wondering when the next meeting will be.

Myth #4 – "My myositis isn't as advanced as some in the group, and I don't want to seem as though I'm showing off."

No better time to attend a meeting! Stay involved to stay healthy. You're still an integral part of the group; you are still another person coping with this rare disease. There's no one who is going to judge you and your current physical condition. Those with myositis celebrate others in every stage of this disease. Some people will be walking, some may have a walker or a scooter – but everyone has a sincere desire to learn more to help educate themselves and others about myositis.

Myth #5 – "The group doesn't meet close to me, and it's such a long drive. That's why I don't go to meetings."

Two words – conference call. Groups can have a conference call either during their meeting, or a separate conference call for those physically unable to attend. Don't let distance keep you from joining. If you live far away, you can consider driving down the day before a meeting and staying overnight, or ask your group's leader to set up a conference call for you and others to participate. Often, this will be your only contact with others who have myositis, so if you want to be involved, we will find a way to make it possible for you.

If you're not involved in your local support group, give it some thought, and explore why you haven't joined yet. Joining is easy. Just go to www.myositis.org and My TMA and elect to be a part of the support group. Then attend a meeting and see what it's all about. Don't knock it until you've tried it!

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