

The Advocate

2016

Advocacy Newsletter



Creating awareness: From the beginning

In 2001, two Massachusetts mothers planned a community walk, designed to raise funds for myositis research and also to educate the community about the rare disease their daughters shared. "If you say 'cancer,' everyone responds," said Janet Goodell. "But say 'myositis' and you just get a blank look. No one understands what you mean."

Goodell is the mother of a dermatomyositis patient, and she had a history of organizing local events for a cause. She was also a community nurse, and educating people about various conditions was second nature to her. To draw attention to myositis, she and her friends designed some whimsical posters around the theme, "Muscling out myositis," with stick figures taking impossibly giant steps, a graphic reminiscent of the "Keep on trucking" posters illustrating the famous Grateful Dead song.

As part of her campaign, Goodell prevailed upon the Governor of Massachusetts to declare September 21 "Myositis Awareness Day." The idea grew and by September 21, 2002, there were events in California, Virginia and Pennsylvania, along with "Myositis Awareness Day" proclamations at the state and local levels. In the following years, TMA members used their considerable creativity to plan walks, competitions and media coverage. One member designed a "myositis cookbook" and others asked for donations to TMA instead of birthday gifts. People brought materials to their doctors' offices. One especially ambitious family member convinced other family members and friends to climb Mt. Kilimanjaro to raise awareness of the disease.

Several years later, TMA was successful in getting the U.S. House of Representatives to pass House Resolution 974 recognizing Myositis Awareness. TMA members, staff and board members talked about myositis on Capitol Hill. Fabio, the famous model and actor, joined them via video to tell the story of a family friend in Italy with inclusion-body myositis. Fifty-three members of Congress were co-sponsors of the resolution that passed on September 25, 2006. Every year, TMA members and support groups continue to plan special events for "Myositis Awareness" to interest their neighbors and local media in learning more about the disease.

This publication is designed as a guide for anyone interested in drawing attention to the need for more education and support for myositis patients and the pressing need for better treatments and a cure.

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Why the need for awareness?

In 1996, the American Autoimmune Related Diseases Association (AARDA) began to track the number of years it takes and the number of doctors a patient sees from the onset of symptoms to proper diagnosis. According to the most recent analysis, patients report it takes more than three-and-a-half years and nearly five doctors to receive a correct autoimmune disease diagnosis. Myositis patients are part of this larger group and many -- including frantic parents of drastically weakened children -- find that a great deal of damage is done during this wait. For example, members of a TMA support group in Virginia rallied to help a family whose mother had finally received a myositis diagnosis after several years of serious symptoms. By email and phone, TMA's mid-Atlantic support group recommended specialists in the Richmond area, and the grateful family transferred the hospitalized woman to an appropriate teaching hospital. Sadly, the relatively young woman died soon after the transfer. In an email to TMA, the daughter said, "If only we had known about The Myositis Association, its support groups and its medical advisory board, I believe the outcome would have been very different." Any effort that increases awareness among family doctors, allied health professionals and the general public increases the chances of positive patient outcomes.

As alarming as the thought of the three-and-a-half-year wait for a correct diagnosis may be, it's actually better than the results of the first AARDA survey that found it took five years and six doctors to get a diagnosis. "This results in patients suffering needlessly and often sustaining more severe, irreversible organ damage," said AARDA board member Dr. Stanley Finger.

Many factors figure into this gap between symptoms and treatment. In a survey of family physicians, AARDA found:

- 64 percent of family physicians stated they are "uncomfortable" or "stressed" when diagnosing autoimmune disease in patients.
- 73 percent do not believe they received adequate training in diagnosing and treating autoimmune diseases.
- 57 percent reported they had only one or two lectures on autoimmune disease in medical school.

The Institute of Medicine reports that the U.S. is behind other countries in research into the process involved in autoimmune disease.

With 50 million Americans suffering from autoimmune disease, and its position among the top ten causes of death for women and female children, this situation is a sad one for patients with complicated symptoms that do not fit with diseases that are better recognized and understood.

Advocacy changes lives

Advocacy is one of those words that can mean many things to different people. But, in terms of advocacy for patients suffering from a rare disease, it means having your voice heard through an association representing the patients' interests or by individuals advocating for their own interests and those others who find themselves in a similar predicament.

Individual advocacy

TMA Board of Directors member and active duty U.S. Air Force pilot Chris Dotur has been working for appropriate government recognition of inclusion-body myositis. Major Dotur, who has a hereditary form of IBM, was facing the end of both his flying and military careers. Dotur was in a "Medical Evaluation Board" for two years, a process where the military determines a person's disability and discharge conditions.

Knowing that other military veterans with myositis would benefit from his experience, Major Dotur challenged the bureaucratic classification of his disease, which did not adequately acknowledge the disease severity and its impact on his life. Dotur and his legal team used an argument to compel Veteran's Affairs to compare his disease to ALS (Lou Gehrig's disease) and increase the rating. Veterans Affairs finally agreed with the legal argument and awarded him 100% disability, with extra compensation and benefits.

Dotur, who is also active in TMA's outreach to veterans with myositis, passed on his story to help other myositis patients who are veterans, and to inform patients and doctors interacting with the U.S. government. His success establishes a modicum of precedence for myositis diseases in the context of Veterans Administration ratings.

Collaborative advocacy

It would be difficult to overestimate the influence of well-organized patient advocacy groups. Collaborations

between rare disease organizations have effectively impacted the government bodies that have oversight for medical research and regulatory processes. These collaborations have played a significant role in the adoption of public policies affecting patients, available research funding, and other factors affecting medical research and drug development.

Some of the significant results of these collaborative efforts were the adoption of the Orphan Drug Act; subsequent legislation providing for the designation of "breakthrough therapy" to ensure patients have accelerated access to treatments; and the establishment, in 2002, of the Office of Rare Diseases at the National Institutes of Health.

Educate your community

Taking part in a civic meeting or event is a great way to build a relationship with businessmen and local politicians and to raise the profile of your myositis group. Groups like the Rotary, Kiwanis, Ruritan, Elks and Lions generally meet regularly in your community or district throughout the year and provide an opportunity at every meeting for speakers of interest.

Tips for preparing to speak

- Determine the purpose and tone of the event. Find out what the overall agenda of the meeting will focus on, who else is

expected to participate or make a presentation, and the anticipated "tone" of the meeting. This will help you to prepare your remarks and delivery style.

- Use your network. Bring some other myositis patients, if appropriate, and let your associates within the group know that you will be presenting, so everyone will show up.
- Be prepared with accurate, timely, and relevant information, and leave some time for questions.
- If the group awards scholarships or yearly grants, apply for a scholarship for a student with myositis or a grant that will help with your community education efforts. Once a group invests money in an organization, they are likely to become more interested and involved.



TMA advocates for you

Lobbying

To effectively advocate for the interests of those with myositis, TMA works with Congress and federal agencies to make sure the voices of myositis patients are heard. The results of these efforts have been that TMA succeeded in getting Congress to provide funding for a myositis patient registry which was completed in 2013 and now serves as a resource for researchers looking for candidates for clinical trials. TMA also persuaded Congress to provide funds for a study to identify potential environmental triggers of myositis. These successful efforts in lobbying Congress are examples of just one form of advocacy.

State Capitol – Room 1116
P.O. Box 94604
Lincoln, NE 68509

RE: LB 322 – STRONGLY SUPPORT

Dear Senator,

The Myositis Association, representing patients who suffer from the crippling, incurable neuromuscular disease myositis, thank you for introducing LB 322, which ensures that Nebraskans have access to reasonable prescription drug benefits without having to pay outrageous amounts of money for these life-saving treatments. The efforts of health plans to create specialty tiers that require payment by patients of a sizable percentage of prescription drug costs can bankrupt patients of even moderate income. They are being asked to pay thousands of dollars monthly for these treatments.

Because specialty drugs are generally classified in Tier 4, the highest and most expensive tier, insurers are abandoning the traditional arrangement that had patients paying a fixed amount of \$10, \$20 or \$30 as a co-pay for a prescription, and instead are charging patients so much that patients essentially are being denied access to vital, life-saving medications.

Insurance is a means by which health risk is spread across a pool of payers. Yet to single out those needing expensive medications and charging them an exorbitant amount for the drug, negates the very reason they have been paying for insurance in the first place – to be protected from severe financial hardship should they become ill.

Senator, we need your leadership to see that this practice is restricted or eliminated in Nebraska so that patients are not left with the choice of either forgoing desperately needed medications or becoming bankrupt without any further means to afford the treatment keeping them alive.

Please do what you can to help!

Appreciatively,
Your signature

Regulatory advocacy

Federal and state agencies, or regulatory bodies, can greatly influence the care received by patients and reimbursement for medical services. As an advocate for the myositis community of patients and physicians, TMA has established relationships with federal agencies such as the Centers for Medicare and Medicaid Services, National Institutes of Health, Food and Drug Administration, and Department of Health and Human Services. TMA's advocacy with these agencies has been to encourage more federal research dollars going toward myositis research, appropriate reimbursement of treatments for myositis such as intravenous immunoglobulin (IVIG), Medicare coverage of devices needed by myositis patients such as elevating seats on power wheelchairs, etc. Additionally, TMA has hosted events on Capitol Hill in Washington, DC to educate Congress about myositis and how legislators need to serve their constituents who have myositis.

Grassroots lobbying

Members of Congress want to hear from constituents in their congressional district or their state. State insurance commissioners need to know from myositis patients how state programs and insurers in the state are serving the myositis community. And, nothing has more impact with these policymakers than hearing directly from their constituents, the “grassroots.” That is where individuals with myositis can help TMA better advocate and better serve the entire myositis community.

In a representative democracy, your legislators are elected to represent all of their constituents, including those with diseases few people have ever heard of. Your voice needs to be heard, not just for you, but for all those now and in the future who have myositis. Grassroots lobbying by myositis patients has so far resulted in nearly 50 states, counties and cities passing proclamations recognizing myositis awareness day. These proclamations have been accompanied by public ceremonies where news media were notified and provided coverage of the

“Nothing has more impact with these policymakers than hearing directly from their constituents, the grassroots.”

issuance of the proclamation. While there was not a specific, tangible benefit other than a piece of paper recognizing myositis, these activities and events raised awareness of the disease and drew attention to the fact that those suffering from a rare disease are as important as those living with common diseases, such as cancer and diabetes, which everyone has heard of.

United States House of Representatives
Rayburn House Office Building
Washington, DC 20515

Dear Congressman:

I live on (insert street) in the town of (insert town) in your congressional district. I am writing to ask for your support for XXX. Myositis is an autoimmune disease that causes inflammation of the muscles. I have been diagnosed with myositis since (insert year) and have been affected by it in numerous ways on a daily basis.

(Paragraph by Individual)

By funding XXX, you will enable there to be a better understanding of the disease and facilitate research advancements into all forms of myositis. This is critical to improve diagnosing and treating myositis.

Because my disease is so rare, few people are aware of it or care enough to help support research into this disease. As a constituent, I am asking that you take an interest in this disease so that I and others with this disease can remain productive members of society.

With your help, we can discover better treatments and ultimately a cure for this devastating neuromuscular disease.

Sincerely,

Your signature

Dear Members of Congress,

Unless you have a family member or a friend with myositis, a rare autoimmune disease, most likely you've never heard of it. Myositis is a neuromuscular disease that weakens and destroys muscle, often resulting in the need for a wheelchair or other assistive devices. Its onset can be subtle or sudden. Because it's constantly being misdiagnosed or overlooked, it is not even known for sure how many people have myositis.

The Myositis Association is a small organization, filling a critical need for myositis patients who look to it for information and support. With the financial support of our members, TMA has funded its own research program and awarded myositis-specific research grants and fellowships in the past two years.

The cost to society of autoimmune disease is becoming clearer. A recent study revealed that autoimmune diseases are a leading cause of death. Among adult women, autoimmune disease is the seventh leading cause of death - excluding accidents and homicides.

Although The Myositis Association doesn't have celebrity spokespersons among its members, TMA has many heroes. They are everyday people who suffer terribly but remain hopeful that a cure and the cause of myositis will soon be discovered.

Enclosed you will find information about The Myositis Association and autoimmune disease. Please take the time to review this information and consider how you can help in the fight against myositis. For additional information, or should you have any questions, please call 1-800-821-7356.

Sincerely,

Your signature

On these pages are sample letters that can be used to communicate with those who can impact the services provided to myositis patients. These letters can be modified to your particular cause and are only examples of some of the types of letters that can be used to communicate with legislators, regulators and policymakers.

Find Your Representative

Not sure of your congressional district or who your member is? Find your district and representatives, with links to your member's website and contact page using only your zip code at:

www.house.gov/representatives/find/assist

Call, write, email, visit: let your voice be heard!

Fundraising informs the public

Although fundraising is not ordinarily thought of as advocacy, the process of fundraising sensitizes and informs the public about rare diseases such as myositis in addition to raising much needed funds for patient and physician education, support groups and research.

Team Tommy Foundation starts a movement in Florida

Founders of the Team Tommy Foundation, Dana Worthington and Laurie Boyer, are the wife and sister of the late Tommy Worthington, a deputy and detective with the St. Lucie County Sheriff's Department (Florida) who lost his battle with dermatomyositis and interstitial lung disease in 2012. After being diagnosed, Tommy was transferred to the University of Miami Hospital for specialized care. Unfortunately, Tommy died five weeks after being hospitalized. Dana and Laurie were determined to honor his wishes and co-founded Team Tommy Foundation. The money raised by the Foundation has assisted families with medical expenses, eased financial burdens, and enabled others to attend TMA's Annual Patient Conference.

Tread for Sully sheds light on myositis in Boston area

In April 2012, Matthew G. Sullivan IV died from dermatomyositis. His sister, Beth Trout, organized an event in his memory with a unique twist: the Raynham Athletic Club sponsored a 24-hour treadmill run on the front lawn of their building, lovingly entitled Tread for Sully. The event raised funds to help bring awareness to the devastation caused by myositis and to aid in research for a cure.

Houston TMA member organizes community fundraiser through Kroger

Rose Mary Istre, leader of the Houston, Texas support group, was diagnosed with dermatomyositis more than 25 years ago. Since she became a TMA member, she has supported efforts to spread awareness about the disease. "We empowered ourselves with a fundraising

project that most everyone could join in," said Istre. Patients, family, friends and caregivers all go grocery shopping and Kroger offers a community service program for organizations to receive a portion of the proceeds from all purchases made throughout the year at Kroger. Istre said she always has myositis information with her when she shops and chooses a long line at the grocery store to engage waiting customers in conversation about myositis and to ask if they would help our cause. "Everyone I spoke to was happy to help," she said.

Franklin family

Every year for the past 11 years, members of the Franklin family have hosted fundraising events to benefit The Myositis Association. A family tradition, nearly all 8 children and many grandchildren take part in events to honor Madge Franklin and her battle against inclusion-body myositis. Their events range from sports contests, to the annual Miles for Myositis run, to milestone anniversary dinners, to special birthday dinners. It is a family effort that involves nearly 30 members of the family. The Franklin family focuses on spreading the word about myositis and having fun as a family as they raise money and get together with friends, business acquaintances and others wanting to help.

Dagmar Slaven's walk in the park

Each year, in Braintree, Massachusetts, members of Dagmar Slaven's family gather to walk a trail through the quiet wooded Pond Meadow Park. It is a small family gathering that includes extended family and friends wanting to join together and show their support for Dagmar who has been battling inclusion-body myositis since 1989. Though confined to a wheelchair, Dagmar makes the trek each year to the park and proudly greets family and friends. Her daughter records the event and afterward produces a beautiful video keepsake capturing memorable moments from the Walk set to music.





Raising awareness

Creating public awareness of rare diseases is critical to bringing attention to these diseases. Public events are particularly helpful in drawing attention to your cause.

Baseball announcer informs the public he has inclusion-body myositis

When San Francisco Giants baseball announcer Mike Krukow revealed in a newspaper article in 2014 that he had inclusion-body myositis, TMA was swamped with calls and emails of concern. The impact of a public icon announcing that he had a rare disease was evident and is another example of how one event can increase awareness of a disease dramatically. The next baseball season the Giants had a special day at the stadium to honor Krukow and increase public awareness of the disease. As Krukow stood at home plate with his family before the game sharing his experience over the ballpark's public address system, tens of thousands of Bay area fans learned for the first time what myositis is.

IBM patient inspired by TMA conference spreads awareness in Long Island

Salvador Negron, IV, an IBM patient hailing from Long Island, NY, attended TMA's Annual Patient Conference in 2013. After meeting many other patients, doctors and myositis experts, Sal decided he would take this experience and make a difference back home. With his inspiration and energy -- and with his co-leader, Melissa Marconi -- the Long Island Support Group hosted a very successful First Annual Valentine's Day Dinner Dance fundraiser at Bella Verde Restaurant in Brentwood, NY. He plans to continue myositis awareness efforts on Long Island by hosting a summer event as well.

Baltimore area support group walks 'n rolls to promote research

Each October, the MD, DE, DC, Northern VA Support Group, conducts a 5k Run, Walk n' Roll to raise awareness and funds for myositis research. Support group leader, Jenny Silverberg, with the help of several volunteers, enlists the area's myositis community to participate in this fun fundraiser, with funds raised to benefit myositis research through TMA and the Johns Hopkins Myositis Center.

Pedano Family and Sabia Family hold golf outings for awareness

The family of Joseph Pedano, a young boy who has had juvenile dermatomyositis since he was two years old, has held a golf outing in the Philadelphia area for more than 10 consecutive years. It is a family event that annually draws many business associates and friends to gather, enjoy a round of golf and an awards dinner afterwards to raise funds for juvenile myositis research. The family of Madeline Sabia who died in 2010 and had inclusion-body myositis has held a golf outing in Stamford, CT several times since Madeline passed away, to rally the close-knit Stamford community and remember Madeline. Each of these events are enjoyable afternoons and evenings for the participants, but more importantly, they raise awareness of myositis and remind the public of the ongoing need for more research and support for those suffering from the disease.

Tools and tactics for raising awareness

The following is a listing of some of the many ways that myositis patients and families can seek publicity about myositis, whether for Myositis Awareness, a human interest story, or simply a support group meeting.

Getting attention

While the plight of a small number of people with a rare disease doesn't appear to be earthshaking news, getting publicity for myositis-related events isn't that difficult, particularly if you live in a small town, a well-established suburb, or a rural area. You may be surprised to find television, radio and newspaper reporters are very interested in human interest features such as a person with a rare disease. Often, the way you present your story and the relationships you establish with reporters will be the key to success. The following pointers should help:

Start small

Think locally. Although TMA and its members have tried for years to draw the attention of national talk show hosts, your best bet for coverage is right in your own hometown. Editors and news directors like sources they can reach immediately as deadlines loom. In fact, many editors of even big-city newspapers and regional news shows pride themselves on their good local stories. Most media outlets

today have a way to submit a story idea online. And it's still possible in many towns and small cities to pick up the phone or drop into the newspaper office.

Look for alternatives

Find the neighborhood or alternative newspapers and television shows that cover stories like yours. Find news shows that target a certain audience. For instance, a farmer with inclusion-body myositis was featured in a "Down on the Farm" episode on his local public television station that later was shown nationally. Hospitals today often have their own publications designed to draw support from local officials and patrons. Find out who produces the one published by your hospital and pitch your story. If you have an active support group, make sure the hospital includes it in its online or print listing of patient resources.

Don't overlook the obvious

Radio and television stations need public service announcements to keep their licenses. They'll be able to turn your



news release into a short announcement. Ask them to interview you or other KIT support group members on the air for a longer story, or provide live coverage for your event.

Use every opportunity for wider publicity

When you're sponsoring a specific event, such as a myositis awareness walk, offer for you or others at the event to be interviewed for a story about your experience with myositis. Editors will want to explain what myositis is and how it affects people along with their coverage of the event.

Work with reporters

It's a good sign if an editor assigns a reporter to your story. It means that you've succeeded in catching the interest of a professional print or broadcast journalist. When the photographer or cameramen show up at your event, your best bet for coverage is to have something interesting visually as part of your event, and you should mention it in your news release.

Often your best chance at publicity is through the reporter rather than the editor of the local news show or newspaper. Take a look at who does human interest and health stories. In many small cities, it's the weatherman on television, or a specially-designated feature writer on the newspaper staff. Approach that person as well as the editor.

Prepare for media coverage

If you are to be interviewed at an event, work to present your position or statement as early in the event as you are able, as the media is more likely to attend and cover the first part of the event. Keep your presentation brief. Limit your statement to three clear and concise points. Provide persuasive facts to assist participants to understand and remember your points. Practice your statement to ensure you are comfortable and convincing when sharing your points with a larger audience. Provide written copies of your statement to the media. If you are speaking spontaneously, have something more formal available so the media can add to your statement before it's aired. Sometimes the person with the most information gets the longest coverage.

Follow up

Following up on your news release is important, but make sure you do it in a professional way. Don't send your release to more than one journalist at the same publication without letting each know. If there are rival newspapers or television stations in your area, it's okay to send them the same short news release, but don't arrange a news conference and invite them both, or work on the same kind of feature with two different newspapers. If two rivals become interested in your story as a result of your news release, be truthful about it

and work with the reporters to find different angles. Don't flood media outlets with faxes or emails.

If following up by phone, make sure it has not been too long since you sent out your news release. Should the journalist not recall receiving the release, ask if you can send it again. If leaving a phone message, make it short, non-accusatory, and with all the appropriate details.

Above all, try to form lasting relationships with your city media. They'll respect you if you submit timely calendar items, do your homework on longer features, provide interesting visuals, and tell them well ahead of time if you want live coverage. If you're disappointed in the response, do not call the publisher and advertisers to complain. Nothing alienates an editor more than questioning his or her news judgment. Continue to suggest newsworthy ideas, and you'll eventually get good results.

Use social media

Write a blog about your personal journey with myositis and share it on your social media accounts (Facebook, Twitter, Instagram, etc), tagging TMA and using hashtags below. In addition, read blogs written by others and share their blog on your social media.

Ask any businesses that support you, especially one that may furnish the place where your support group meets, to post notices of your meeting on their social media channels. Contact local hospitals to post support group events on their online calendars and social media.

Encourage friends, family members, and all support group members to follow TMA on Facebook and Twitter. Link your support group social media pages to TMA's.

Share and re-tweet Myositis Awareness content in the month of May and throughout the year. You never know if your post will 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!

Facebook: [facebook.com/Myositis](https://www.facebook.com/Myositis) | @myositis

Twitter: twitter.com/TheMyositisAssc | @TheMyositisAssc

Hashtags: #MyositisAwareness #MyMyositis #KnowMyositis

Use TMA's website

TMA sponsors several forums through its website as well as ways to directly post calendar events. Make sure to use these for your group's Myositis Awareness events as well as your regular meetings. Have an especially effective idea or interesting story? It may be of interest to TMA's membership, either through the support group network or TMA's quarterly newsletter, OutLook.

Creative advocacy and awareness

Visiting professors series

Besides informally mentoring residents and medical students at their own institutions, TMA's medical advisors participate in TMA's "Visiting Professor Series," traveling to medical schools and academic health centers to educate residents and medical students about myositis. This series has been well-accepted in the medical community, with more than 30 medical schools requesting a TMA medical advisor to present at their institution.



Racing for myositis?

A few years ago, TMA asked several horse farms in Kentucky to include the word "myositis" in the names of racehorses to bring attention to our disease. Airdrie Stud's owner, Governor Brereton Jones, readily offered to help and included the word "myositis" in the names of three of his horses - Stop Myositis, Myositis Survivor, and Myositis Dan. Although none of them made it to the Kentucky Derby, each has drawn attention to our rare disease. Racing fans at the racetrack and at home watching on TV or on their computer heard the word myositis several times during each race. It is estimated that nearly 10 million people in the U.S. heard or read the word myositis mentioned when they were racing!

Strength in numbers

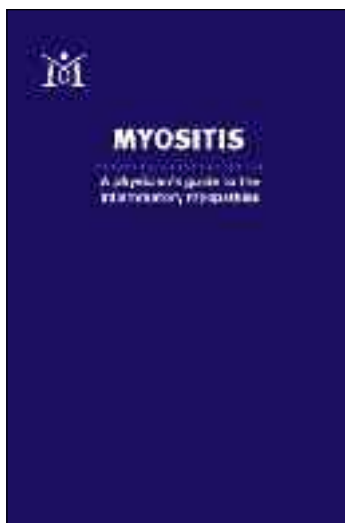
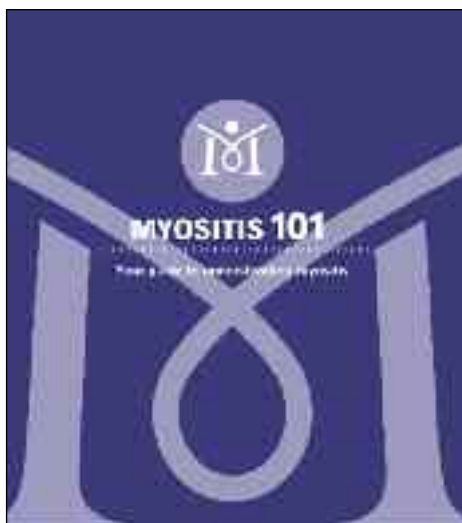
One important way that patients, families and medical professionals can raise awareness is to spread the word about the public health significance of rare diseases. Since it's discouraging for myositis patients to remember the grim days of their own diagnostic delay (see page 2), it's understandable that they may want to put the whole problem behind them. But everyone familiar with myositis has a role to play, and some of the following facts may help:

- **Rare diseases are 1 in 10.** Anyone who has mentioned that to friends can expect a surprised reaction. Ten percent of Americans have rare diseases? There's good reason to think that most family doctors would be just as surprised. Understandably, doctors-in-training are taught to focus their diagnostic efforts on common diseases rather than rare ones. The medical school adage, "When you hear hoof beats, think horses, not zebras", makes sense unless you are a zebra.

- **The numbers add up.** It's the size of the problem that seems to escape public notice. The National Organization for Rare Disorders (NORD) tells us that the number of people with rare disease is roughly the same as the number with asthma. There are almost 30 million of us — one on every crowded elevator, four on every full bus. We are roughly equal to the population of Canada. There are six times as many rare disease patients as there are patients with Alzheimer's. For every person with HIV or AIDS, there are 30 people with a rare disease, but this is the most telling statistic by far: rare disease patients outnumber cancer patients 2 to 1. There are so many rare disease patients that the average doctor sees at least two to three on every working day. They are as common as diabetics.

- **What you can do.** We've explained throughout this special advocacy newsletter about ways to raise awareness of myositis among policymakers and the community at large. The most effective single way, however, for you to make a difference, is to help TMA reach every myositis patient. Share our posts on Facebook, talk about us in your visits to your family doctor and specialists, leave materials every place that undiagnosed or new patients might be found, and publicize your support group as widely as possible in your community. With every myositis patient on board, we will truly make a difference. For more ideas or materials, always feel free to email TMA at tma@myositis.org.

Educate



Start here

Ready to start educating your community, local and national policymakers and health professional organizations about myositis? Don't forget to check TMA's website for resources before you begin.

Go to www.myositis.org for materials, including:

- **Myositis 101.** Help new patients, family physicians, caregivers and the community-at-large to learn the facts about a complicated and poorly-understood disease. TMA has published an introductory brochure that will help your audience understand the symptoms, treatment and complications of myositis. For your free copy, or to arrange for more than one copy for an awareness campaign, email TMA@myositis.org or call 1-800-821-7356.
- **Myositis: A Physician's Guide to the Inflammatory Myopathies.** This guide, written and reviewed by international myositis experts, contains up-to-date information on diagnosing and treating all forms of myositis. For free copies, email TMA@myositis.org or call 1-800-821-7356.
- **Advancing the World's Understanding of Myositis.** TMA's research program has approved nearly 50 grants and fellowships, totaling over \$5 million, since TMA began funding research in 2002. Review a copy online at www.myositis.org under "Research" or to receive a free copy, email TMA@myositis.org or call 1-800-821-7356.

Become a card-carrying myositis advocate

TMA now offers members a convenient way to educate friends and associates about myositis with personalized information cards you can use in the same manner as you would a business card.

The front side of the card displays your name, phone number and email address along with contact information for TMA. The reverse side has a brief, plain language description of either DM, PM, or IBM. You select which disease description you want. These cards can be used as an informal business card that also directs people to the TMA website, where they can learn more about myositis.



A UPS Store in Gainesville, GA produces these cards for TMA. For \$25 you will receive 100 personalized information cards. Shipping is included in the \$25 price. To order your custom cards, contact UPS by email at store6134@theupsstore.com or call 770-297-9944.

“Never doubt that a small group of thoughtful, committed citizens can change the world. Indeed, it's the only thing that ever has.”

—Margaret Mead

The Advocate

www.myositis.org

**Speak Up, Advocate and Create
Awareness of Myositis**

