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The Myositis Association

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Dear friends:

2013 was a very good year for The Myositis Association and those who have to live with this dreadful disease. There was much progress made on the research front for all forms of myositis. We eagerly look forward to the results of the gene therapy trial for IBM and the upcoming testing of the Novartis drug BYM338 for IBM. Acthar and Rituximab were used more frequently in 2013 for DM and PM as well as juvenile myositis.

TMA partnered with the National Institutes of Health and Yale University to collect data for myositis patient registries, and reports on these findings will be forthcoming.

TMA also helped two pharmaceutical companies collect data on the impact of myositis on patients as the companies consider whether to pursue research into treatments for myositis.

We celebrated TMA's 20th Anniversary, and many of you participated in the "20 for 20" Anniversary Campaign, which raised more than $100,000 for TMA.

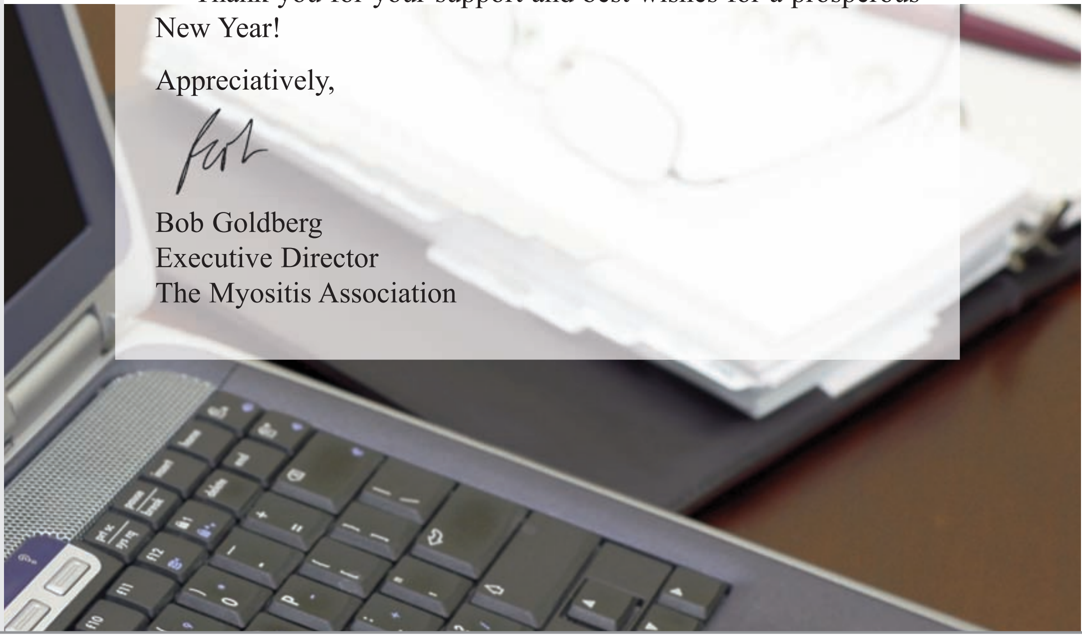
We published a report on the 34 research grants and fellowships that TMA has funded over the past 10 years, and we just announced three more funding awards for myositis research at the Mayo Clinic and Washington University, and for a fellowship at Hospital de la Santa Creu i Sant Pau in Barcelona, Spain. This brings to $4.5 million the total amount of funding for myositis research now provided by TMA.

All of this would not have been possible without the loyal support of TMA's members and others concerned about myositis. We plan to work even harder in 2014 to better serve those who have to live with this disease.

Thank you for your support and best wishes for a prosperous New Year!

Appreciatively,

Bob Goldberg
Executive Director
The Myositis Association



Jenni Stanton

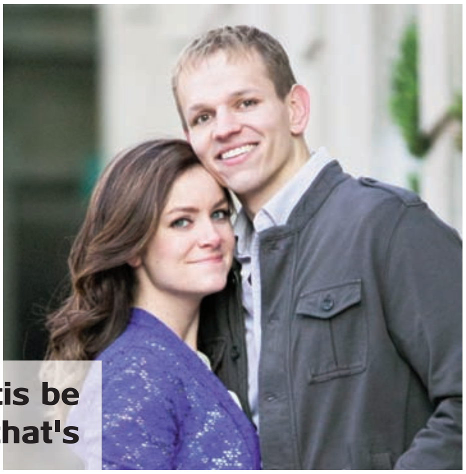
Three years ago, Jenni Stanton noticed a rash on her knuckles, a rash that was misdiagnosed as psoriasis. Her diagnosis seemed accurate since autoimmune diseases run in her family and the localized rash was Jenni's only symptom.

The 24-year-old woman went on with life as normal and there were no further symptoms through the spring and summer. Jenni moved to Des Moines and began preparing for her wedding to her fiancé Mike the following June. Suddenly, in October, she became very, very sick. All at once she had severe aches, fatigue and muscle weakness. Like others with active dermatomyositis, Jenni was horrified to discover that over the course of a few weeks her ability to climb stairs, brush her hair or even raise her arms rapidly diminished. "At first it seemed like a bad virus," Jenni said, "but it only got worse." Her knuckles were still involved and a matching heliotrope rash spread across her face. Everyday activities became increasingly more difficult. She remembers that she even dreaded wedding dress shopping, since the act of putting on the heavy dresses seemed overwhelmingly exhausting.

" I won't let dermatomyositis be the most important thing that's ever happened to me."

Finally, in January 2012 – a year after her first skin symptom – Jenni was diagnosed by a rheumatologist after an EMG and muscle biopsy. Luckily, the 40 mg. of prednisone prescribed for Jenni took immediate effect. "It was the difference between night and day," Jenni recalls. She felt more awake, stronger, and could do more. "I only missed a few days of work (Jenni works full time for a company that assists non-profits), and in a way, that helped," she said. "This may not be true for everyone, but having to be out and about, really pushing myself, kept me stronger."

However, Jenni also felt the full side effects of the prednisone, including weight gain, a moon face, fat redistribution, hair loss, acne and depression; and a constant gnawing hunger. "I was starving, no matter how much I ate," she recalls. The radical change in Jenni's appearance was especially disturbing because of her upcoming wedding. "I decided," she said, "that I'd just have to accept that my appearance was out of my control; that I would have to look the way I looked and give up my thoughts of the "perfect" wedding." Jenni focused on the things that were most important to her – enjoying the day with family and friends. "I ended up having a blast," she said.



Besides planning her wedding, Jenni had been involved in a huge project at work, one that required her to be the master of ceremonies at an event for 100 people. Trying to act "normal" took its toll. "I would just come home from work and fall into bed," she said. She also found that each time she tapered the prednisone — and because of the side effects she wanted to do this as soon as possible — she would spend a week or so feeling worse, then somehow adjust to the smaller dose. She's down to a tiny maintenance dose of prednisone now, and also takes methotrexate and plaquenil.

Jenni has some advice for other young people struggling with myositis:

- Find support. Jenni's mother (who has fibromyalgia) and a friend with multiple sclerosis gave Jenni many tips on coping with reduced strength and increased fatigue, and provided moral support and understanding.
- Learn all you can. "I'm a big nerd," Jenni said: "I read everything I could, joined TMA right away, and made sure I knew all about the drugs used for myositis before the doctor prescribed them. That way, I was a better partner to my doctor." Jenni acknowledges that the information can be quite scary, but still useful.
- Be honest with your friends and family. "My birthday came and friends began planning a big night out," she said. "I had to set them straight and say, 'Look, I just can't do this now.'"
- Narrow your focus. Jenni knew that she wanted to keep working, and she focused on that, eliminating the tasks in her life that were not as important. Similarly, Jenni approaches each day with a realistic knowledge about what's possible for her. She goes grocery shopping on slow days, and tries to work in physical activity in small doses.
- Find the right balance in sharing about your disease. Jenni found out that it's hard to know how your illness will influence other people's perspective of you. For example, people at work who knew about her

See Members, page 11.

Perseverance helps in navigating disability claims

by Molly Clark

In some circumstances, myositis is severely disabling and can prevent you from working. The resulting loss of income can be financially devastating. If you find yourself in this situation, you may be eligible to receive Social Security Disability benefits. Disability benefits can help make up for lost income and cover the cost of daily necessities. The following explains the options available to you, and will prepare you to begin the application process.

Disability Benefit Programs

The Social Security Administration (SSA) offers two different types of disability benefits. Each of these programs has different eligibility requirements. Be sure to research these programs and select the program that you find most appropriate for your case.

Social Security Disability Insurance (SSDI) – This benefit is offered to disabled workers and their family members. Eligibility for SSDI is contingent upon the amount of "work credits" applicants have acquired over the course of their career. Work credits are used by the SSA to measure a person's work history and Social Security tax contributions. Visit the following page to determine whether or not you have enough work credits to qualify for SSDI: http://www.disability-benefits-help.org/ssdi/qualify-for-ssdi.

Supplemental Security Income (SSI) – This benefit is intended to help disabled individuals who earn very little income. To qualify for SSI, applicants must fall within the financial parameters set by the SSA. Because SSI has no work or age requirements, this program is often the best fit for children or adults with limited work history. To learn more about qualifying for SSI benefits, visit the following page: http://www.socialsecurity.gov/ssi/text-eligibility-ussi.htm.

Is myositis a disability?

To qualify for either disability program, you must have a disability. While this may seem self-explanatory, the term disability can be interpreted in many different ways. For this reason, the SSA has established an official set of requirements to determine whether or not a person is disabled:

- Individuals must have a physical or mental condition that prevents them from engaging in substantial gainful activity (SGA). In 2014, SGA is defined as earning $1,070 or more in one month; and
- The individual's condition must last—or must be expected to last—at least one year, or result in death.

As you may have noticed, these criteria exclude any conditions that are less advanced or less severe. This means that not all individuals with myositis will be eligible to receive disability benefits. If you do not meet the above criteria, you will not qualify for Social Security Disability. If you do meet these criteria, you will be evaluated further based on specific medical requirements.

SSD Medical Requirements

When assessing your eligibility for disability benefits, the SSA will evaluate your specific condition and symptoms based on criteria found in the official manual of disabling conditions, commonly referred to as the "Blue Book." The Blue Book is broken up into many different sections, each pertaining to a specific condition or group of conditions.

Adults with myositis will be evaluated under Blue Book listing 14.05—Polymyositis and Dermatomyositis. To meet this listing and qualify for disability benefits, you must provide medical evidence of the following:

- Pelvic or shoulder muscle weakness that keeps you from walking or moving effectively; or
- Impaired swallowing with aspiration due to muscle weakness; or
- Diffuse calcinosis with limitation of joint mobility or intestinal motility.

Children younger than 18 with myositis will be evaluated under Blue Book listing 114.05—Polymyositis and Dermatomyositis. This listing is slightly different than the adult listing and requires the following:

- Pelvic or shoulder muscle weakness that keeps you from walking or moving effectively; or
- Impaired swallowing with aspiration due to muscle weakness; or
- Diffuse calcinosis with limitation of joint mobility or intestinal motility; or
- Child must display a combination of cognitive and communicative deficits, decreased motor development, emotional impairments, impaired social interaction, or developmental delays.

Be sure to look into the Blue Book listing that applies to your — or your child's — condition. If an applicant has a separate form of myositis, such as inclusion-body myositis, that is not mentioned by name in the Blue Book, he or she can still qualify if their symptoms match those required by the Blue Book listing.

Application process

Before you begin the initial application process, it is extremely important to gather the necessary documentation to support your claim. This should include medical records such as:

- Record of your diagnosis
- History of hospitalizations
- Lab results
- Findings of physical and mental examinations
- History of your treatments and their effects
- Written statements from your treating physicians

You may also be required to provide employment records and financial statements. For a complete list of necessary documentation, visit the Adult Disability Checklist or the Child Disability Checklist.

Once they have collected all necessary information, adults can submit their initial application online or in person at their local Social Security office. Children under the age of 18 will be required to attend an interview with an SSA representative.

When completing the application paperwork, it is important that you answer each question in as much detail as possible. Your answers should give the SSA a thorough understanding of your condition and the limitations that it causes you. It is important to note that missing, incomplete, or inaccurate information can cause your claim to be delayed or even denied.

Receiving a decision

On average, it takes approximately 3-5 months to receive a decision regarding an SSDI or SSI application. Unfortunately, more than 60% of applications are denied in the initial stage. If this happens to you, do not panic or give up. You are allowed to appeal the SSA's decision within 60 days of receiving your notice of denial.

The appeals process will provide you the opportunity to strengthen your claim and increase your chances of approval. It is encouraging to note that many more applicants are approved during appeals proceedings than after the initial application submission.

For more information about applying for Social Security Disability with myositis, visit the following page: http://www.disability-benefits-help.org/disabling-conditions/polymyositis-and-social-security-disability.

See Disability, page 7.

A page for veterans

In December, TMA developed a new "Veterans" page on its website at www.myositis.org, with important links to The Veteran's Administration and other appropriate sites. Below is the story of Ray Lesoine, edited here for space. To learn about programs for veterans, please go to the "Find Support" section of TMA's website at www.myositis.org and click on "Support for Veterans." There is also a new forum page under "community" and a Facebook page for veterans to share comments and stories at www.facebook.com/myositis.veterans.

Ray served in the Navy during the Vietnam war, and his service included a cruise to Vietnam. This is an important distinction, Ray found out, since anyone who stepped foot in the country is presumed to have been exposed to Agent Orange. Ray currently receives service-connected disability benefits for heart disease and diabetes, diseases that the VA presumes to be caused by Agent Orange. Myositis — with causes still unknown — is not included in this category.

Ray has IBM and is in a power chair full time. He had no idea, he said, that he was eligible for any medical or pension benefits, until a friend who works for the VA advised Ray to apply for medical benefits.

Ray went through several classifications after filing his first claim in April, 2012, but finally he applied for and was approved as a "Catastrophically Disabled Veteran," a designation given to veterans with a severely disabling injury or disease that permanently takes away their ability to carry out the activities of daily living. The disability must be severe enough to require personal or mechanical assistance to navigate in their home. This designation removes co-pays, and now all Ray's medical care and medications are covered 100% by the VA.

In addition to appointments, screening, lab work and shots, the VA has supplied Ray with equipment at no cost to help deal with IBM: a medical alert system, transfer board, Invacare Patient Lift, hospital bed, two hearing aids, a portable toilet and a cushion for his power chair. They also repaired his power chair and van wheelchair lift. (They did not supply his chair or van.)

Ray's only complaints were the lack of communication between departments, and the inability to get appointments in a hurry. Some orders fell through the cracks and had to be reordered, and some fairly urgent conditions had to wait. Ray presently has applied for home assistance, which would help with hired caregivers for respite for Ray's wife, Camille.

Ray found out that the VA also has programs in place for adapting vans for power wheelchairs, for the wheelchair user to enter, exit and be safely docked although, he says, the program won't cover power doors or automatic docking. Transportation and home modification grants are available, both dependent on degree of disability.

Ray also filed for compensation and pension and qualified because of his heart disease and diabetes. Since the cause of IBM is unknown, it does not qualify as a service-related disability, but may help veterans who have other chronic illnesses in addition to IBM. Ray urges veterans to volunteer for the clinical trial, "Environmental Risk Factors for the Development of Myositis in Military Personnel, (see page xxx) "studying people who developed myositis during their active service to determine if chemical exposure is a possible cause." Find out how to join by going to TMA's website, www.myositis.org and clicking on "highlighted trials" under "clnical trials" under "understanding research."

Ray has some recommendations:

- Be patient! Ray found the average time to process a claim was 272 days
- Talk to a Veterans Service Organization (VSO). Find them through your county government or through national and local veteran advocacy groups. Find a list in the veterans section of TMA's web site, www.myositis.org.
- File for major items. A man at the VA told Ray that he has had vets, usually thru a VSO, that filed for 50+ items. That greatly increases the time required to process a claim.
- Even if you do not have a service-connected disease, file for medical help. There is a yearly income maximum based on family income.

Annual Patient Conference 2013

In response to member requests, TMA will be providing more links to the valuable information shared at the conference, arranging it by subject matter as well as by conference year or day. For now, find topics listed below by going to TMA's home page, and selecting TMA 2013 Annual Patient Conference Recap.

Understanding myositis

TMA Twenty Years Later: Progress in understanding myositis - Dr. Fred Miller, National Institutes of Environmental Health Sciences

Finding reliable information on the Internet - Bill Simeral, PM patient

Myositis: Clues from the environment - Dr. Fred Miller, National Institutes of Environmental Health Sciences

Myositis 101 - TMA Medical Advisory Board Member Dr. Chet Oddis, University of Pittsburgh

Myositis auto-antibodies - TMA Medical Advisory Board Member Dr. Mark Gourley of the National Institutes of Health

Cancer, heart disease, dysphagia: Screenings and risks for DM and PM patients - TMA Medical Advisory Board Member Dr. Dana Ascherman, University of Miami

The role of genetics in IBM: The purpose and continuation of the St. Louis Study - Dr. Conrad Weihl, Washington University School of Medicine

Current research interests of TMA's medical advisory board (video)

Treatment

Evolving uses of IVIG - Dr. Rossitza I. Chichkova, University of South Florida

IVIG: Questions and answers about home infusion - Susan Artabasy, regional IV manager, Walgreens; and Tracey Lynn Englert, Kentucky IV manager, Walgreens

Myositis treatment: How and why? - TMA Medical Advisory Board Member Dr. Chet Oddis, University of Pittsburgh

PM/DM Drugs - Dr. Martin Brown, University of Louisville Neuromuscular Center

Anti-inflammatories, diet, exercise: a TMA-funded research project - Dr. Paul Murphy, University of Kentucky

Coping

Driving assessment and rehabilitation - Suzanne Farnan-Maddux, driving rehab specialist at Frazier Rehab Institute, Louisville, Kentucky

A new age for mobility - Dr. Mary Ellen Buning, professor, University of Louisville

Nutrition for inflammatory disease - Dr. Renee Lantner, TMA Board of Directors (video)

The effects of exercise on children with myositis: how the results might be applied to adults -TMA Medical Advisory Board Member Sue Maillard, Great Ormond Street Hospital.

Mobility, home adaptation and other programs for veterans with myositis - Stanley Kerr, Chief of Prosthetics for the Department of Veterans Affairs

Computer adaptations; apps for accessibility - Mary Ellen Buning, Ph.D, Frazier Rehab

Chronic disease in a fast-moving world - Dr. Amy Wood, author and psychologist

Screening for and managing lung disease - TMA Medical Advisory Board Member Dr. Chet Oddis, University of Pittsburgh

Finding strength through faith - TMA Board Chairman Augie DeAugustinis

Nutrition for inflammatory disease - Dr. Renee Lantner, TMA Board of Directors (Powerpoint)

Disability, from page 5

Returning to the workforce

If you already receive disability benefits but wish to return to the workforce, the SSA has established a network of supports to ease your transition back into the working world:

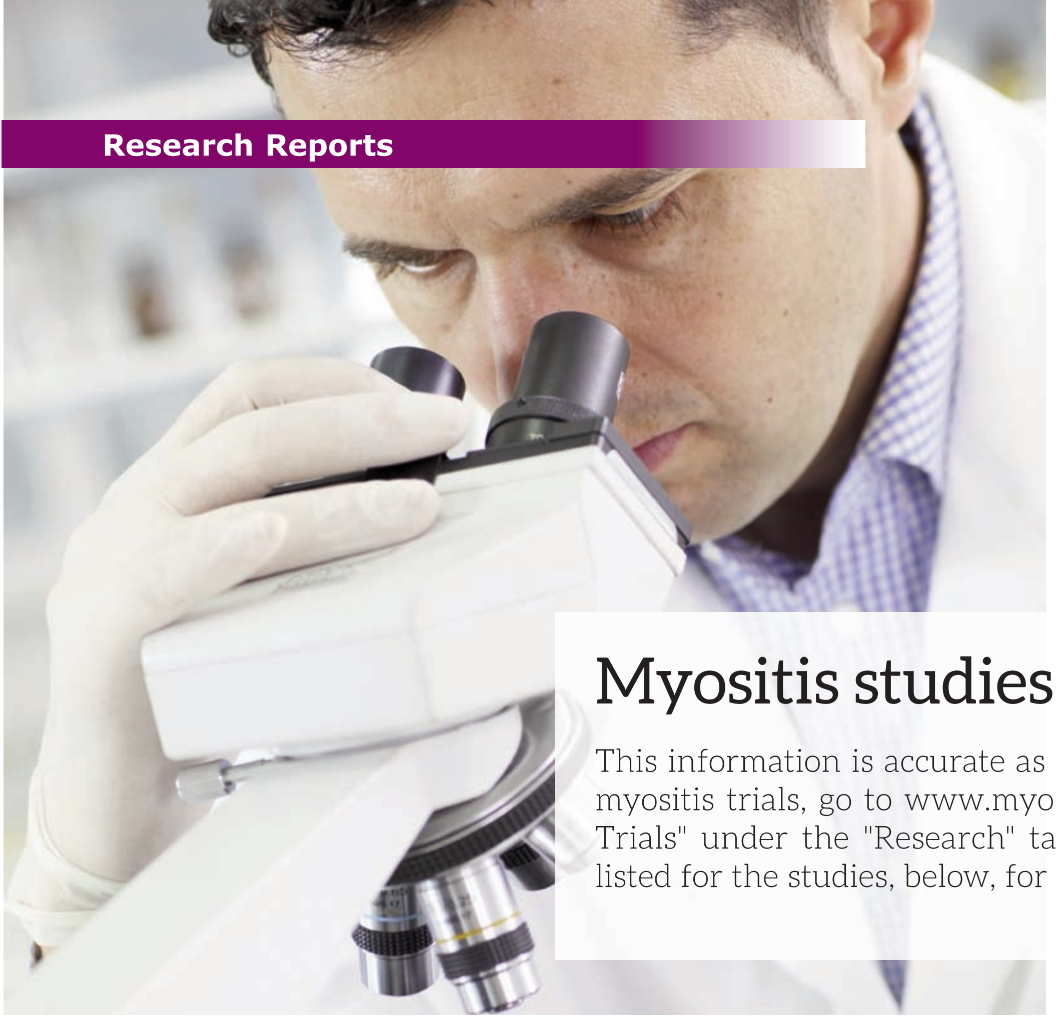
Ticket to Work - This program is a voluntary program intended to help disability recipients return to work. This program provides individualized assistance, continued Medicare or Medicaid benefits, and flexible work schedules. Through the Ticket to Work program, individuals will continue to receive benefit payments while attempting to return to work.

Trial Work Period - This incentive allows SSDI recipients to attempt to return to work for at least nine months without disruption of their benefits.

Expedited Reinstatement - Expedited reinstatement will help an individual qualify for and receive benefits sooner after a failed work attempt.

Protection from Medical Continuing Disability Reviews - This protects an individual from the SSA's continuing disability reviews while he or she attempts to return to work.

Molly Clarke is a writer for the Social Security Disability Help Blog, where she works to promote disability awareness and assist individuals throughout the Social Security Disability application process. For more information about disability benefits or returning to work, visit the Social Security Disability Help Blog, or contact Molly at mac@ssd-help.org.



Myositis studies now recruiting

This information is accurate as of press time. To keep up with myositis trials, go to www.myositis.org and find "Highlighted Trials" under the "Research" tab, or call the phone numbers listed for the studies, below, for updated information.

Novartis

BYM338: Novartis is enlisting sites to test its drug for inclusion-body myositis. Recruitment has begun in Houston, Texas and Phoenix, Arizona. Other sites selected but not recruiting as yet are in Orange, California; Miami, Florida; Kansas City, Kansas; Baltimore, Maryland; Boston, Massachusetts; Columbus, Ohio; Portland, Oregon; and Dallas, Texas. In addition, there are five sites in Italy and one in Denmark. Others will be added. Patients and their physicians may call Novartis Pharmaceuticals at 1-888-669-6682 to request information. Information is also updated on the clinical trials website, www.clinicaltrials.gov.

NIH

The NIH Twin-Sib Study: risk factors and mechanisms for the development of systemic autoimmune diseases in adults and children. This study evaluates same-gender siblings within four years of age where one has been diagnosed within the last four years with rheumatoid arthritis, polyarticular juvenile idiopathic arthritis, lupus, systemic sclerosis or polymyositis, dermatomyositis or inclusion-body myositis, and the other has no autoimmune disease.

The MYORISK Study: to determine if those with myositis, and particularly those with anti-synthetase syndrome (myositis with frequent interstitial lung disease and arthritis), have experienced different environmental exposures before disease onset from other polymyositis/dermatomyositis patients and healthy controls. Adult or juvenile polymyositis/dermatomyositis patients diagnosed within the last two years are eligible for enrollment.

The Myositis in Military Personnel Study: compares those who developed any form of myositis during U.S. active duty service, with matched persons who did not develop an autoimmune disease during active duty to assess factors that might have led to the development of their myositis.

The above studies involve a single visit to the NIH Clinical Center in Bethesda, MD, the NIEHS Clinical Research Unit in Research Triangle Park, NC, a collaborating center, or a local physician's office to complete patient, family and physician questionnaires and a blood draw. MYORISK patients will also collect a home dust sample. Patients may undergo a more thorough clinical evaluation if they enroll at the NIH Clinical Center. Compensation for enrollment will be $100 for each patient, and each participating physician will also be paid $100 for each patient they enroll, after completion of the study materials.

To participate in the NIH studies, call the NIH recruiting center toll-free at (800) 411-1222.

Identifying patients with cancer risk

Researchers from major universities in the U.S. — several of them TMA medical advisors — have developed specific tests to identify cancer biomarkers in patients with dermatomyositis, known to be associated with increased risk of malignancy. According to study findings published in the American College of Rheumatology journal, Arthritis & Rheumatism, antibodies against two specific proteins — along with patient age — predicted an increased likelihood of cancer.

The report said that most patients with dermatomyositis have auto-antibodies that cause distinct clinical disease features circulating in their bodies. Medical evidence suggests that these auto-antibodies in dermatomyositis patients stem from specific immune responses that shape various characteristics. In addition, up to 20% of those with dermatomyositis are at increased risk of malignancies.

“For the physician treating patients with dermatomyositis, identifying those at higher risk for cancer is a top priority,” said TMA Medical Advisor Dr. David Fiorentino from Stanford University in Redwood City, Cal. “Our team focused on creating specific tests to detect antibodies against two specific proteins and then testing if those antibodies can identify dermatomyositis patients at higher risk of cancer.”

The team used two advanced techniques to detect antibodies against TIF-1γ and NXP-2 proteins. Blood analysis was performed on 111 patients from Stanford University Dermatology Clinic and 102 patients from the Johns Hopkins University Myositis Center. Both groups were similar in gender and age at diagnosis.

Results show that 17% and 38% of subjects in the two cohorts combined had antibodies against NXP-2 and TIF-1γ, respectively. Using the specific assays, researchers found 83% of dermatomyositis patients with cancer had a reaction to NXP-2 or TIF-1γ. Further analysis indicates that cancer, older age, and male gender were linked to NXP-2 or TIF-1γ antibodies, with anti-NXP-2 specifically associated with cancer in men.

“Our findings confirm the link between cancer and age in dermatomyositis, with a sharp increase in frequency at roughly 60 years of age,” concludes Dr. Fiorentino. “By determining the presence or absence of NXP-2 and TIF-1γ antibodies, we believe that this will aid clinicians in identifying those with the highest cancer risk.”

Myositis and vaccines: the yearly debate

(Edited version of an article that first appeared in "The Rheumatologist")

Even physicians sometimes wonder about appropriate vaccinations for their patients with autoimmune disease, mostly because these patients are likely to have a reduced immunologic response. “As someone who deals with very ill immunocompromised patients, I feel strongly that some immunologic protection is better than none,” Camille N. Kotton said in a session on that subject at a meeting of the American College of Rheumatology.

Dr. Kotton routinely vaccinates patients in the transplant service of Massachusetts General Hospital, “You may not always be able to prevent disease,” she noted, “but the disease we do see may be significantly attenuated.”

This is important, she said, because patients with rheumatic diseases have twice the risk of infection than those in the general population. She also acknowledged the issue of whether vaccines might precipitate or worsen rheumatologic disease, but added there is not enough evidence at present to convince her.

In its recommendations, the ACR says that patients should be given the influenza vaccine, whether or not they are on biologic or nonbiologic disease-modifying antirheumatic drugs (DMARDS). The pneumonia vaccine is also recommended by the ACR for patients using leflunomide, methotrexate, or sulfsalazine. The hepatitis B vaccine is recommended for some patients, including those on leflunomide, methotrexate, and biologic agents.

However, the ACR recommendations clearly state that all live vaccinations should be avoided in those who are receiving biologic DMARDs. Shingles vaccine; varicella; and measles, mumps, and rubella vaccines are generally not given to immunosup-

See Vaccines, page 11

Lessons learned

by Andrea Taylor Langworthy

When I first joined The Myositis Association, I did it anonymously. It hadn't been that long since I was diagnosed with inclusion-body myositis and I wasn't ready to jump right in. Nor was I prepared to get to know anyone with the disease I inherited from my father. Watching Dad lose the ability to walk, drive, and swallow had been more than enough.

When I felt ready to connect, I contacted Dan Seftick, the coordinator of the Minnesota Keep-In-Touch group. I planned to attend the meetings but I was still working and that was all I could handle. Thankfully, Dan continued to keep me informed.

Early in 2012, Dan needed to step down after seven years at the KIT group's helm. He sent a mailing to members, telling them of his decision and asking if someone would take over the leadership. No one volunteered. Perhaps, like me, they feared it would be more than they could manage.

Some time later, TMA Executive Director Bob Goldberg asked if I would take on the group. "What do you think?" I asked my husband, reminding him that even though I was no longer working, I hadn't ever attended a meeting and probably wouldn't be strong enough to do so in the future.

I wrote a reply, saying I could plan the meetings and send information to those in the group but would need to find another member who could lead the sessions. I read the email to my husband before pressing "send."

"I'll do it," he said. "You handle the behind-the-scenes stuff and I'll facilitate the meetings." We talked about it for awhile and I turned back to the computer to formulate a new response.

After the idea was approved, I phoned Dan, the former leader. He explained the four yearly meetings held between March and the end of October. The first three have a speaker. The fourth is a social gathering with a meal.

The next weekend, my husband and I went through the box Dan had dropped off at my husband's work. "Wow!" I said, as I read newsletters, meeting notes and mailing lists. "He's left us with some big shoes to fill." My husband agreed and said it was lucky there are two of us. I worried two wouldn't be enough.

Things fell more easily into place that first year than I had anticipated. Dan gave me the contact information for a rheumatologist from the Mayo Clinic who had agreed to address the group. I heard from a member about a neurologist, also from Mayo, who was willing to do a presentation.

Another member called to tell me about Courage Center Saint Croix, a rehabilitation facility. The director offered us a meeting place where two occupational therapists would speak and afterwards, give us a tour.

Then, members offered to host the October meeting in the dining room of the cooperative building where they live. The person who does catering there would provide us with menu choices.

At the end of the year, my husband and I took stock and talked about taking a different, less mainstream, road the second year.

In March, a life coach who helps people deal with transitions and new beginnings spoke. June's meeting was led by a couple who engaged the group in a session of Laughter Yoga which had everyone, well, laughing.

September's meeting would be about meditation. An instructor at the University of Minnesota Center for Spirituality and Healing agreed to share her story and guide members in the practice.

The couple who hosted the social get-together the first year graciously offered to do so again.

After every meeting, before he leaves the parking lot, my husband calls from the car to tell me how it went, who was there, what was said. As much as he learns from the speakers, he says he learns from fellow members in the "catching up" time at the end of the sessions.

I, too, have absorbed a lot in the past two years from members and their spouses. Each person gives me something to think about, a new nugget of information about a disease I once thought I knew all about.

One woman, in her eighties, also has IBM. She told me about the exercise DVD she purchased from TMA. She does the workout every day. I bought the video and call her when I need inspiration.

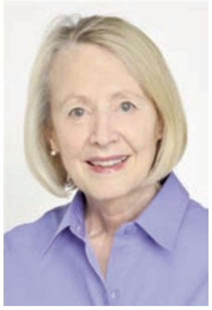
I've spoken with many men who have the disease, too. Most are well past the age my father was when he passed away. Their stories give me hope. So do those shared by members with other forms of myositis

The biggest lesson has been the importance of connecting with those who are in what my father would have called "the same boat."

If there is a KIT group in your area and you haven't joined it, please do. If there isn't one near you, think about starting one. You don't need to do anything fancy. Members of our group say the "catching up" part is their favorite.

If you're house-bound, connect with a group by phone or email. TMA will schedule a conference call if you want a group conversation. Another option is to go The Myositis Association's website (www.myositis.org) and be part of the Community Forum.

Whatever you do, don't remain anonymous. Reach out and Keep In Touch.



Andrea Taylor Langworthy writes a periodic column for The OutLook about her experiences and observations as a patient. Andrea is a freelance writer who lives in Minnesota, where she and her husband lead the myositis "Keep-In-Touch" support group. Andrea has inclusion-body myositis.

Members, from page 3

illness were very supportive. Jenni was hesitant to share details, though, because she didn't want people to feel sorry for her or assume she could not handle her workload. "I tended to downplay my disease," she said. "I am still not sure of exactly the right approach." The fact that this disease is rare makes it harder: "It's not like I can tell people the name and they'll understand my experiences."

- Choose a doctor you can trust. Jenni knew she'd have to make some important decisions and needed to be completely honest with her doctor about her hope to have a family and succeed at work. "I found it reassuring to be able to work towards my goals with my doctor," she said.

Now feeling much better, Jenni is glad she took the approach she did to handling her disease. She was recently promoted within her company and attributes this success to her drive to push beyond her sickness. She said, "I won't let dermatomyositis be the most important thing that ever happens to me."

Vaccines, from page 9

pressed patients, said Dr. Kotton. Another precaution: family members and others living intimately with immunosuppressed hosts should not be given the live influenza nasal vaccine. Although the oral polio vaccine is no longer given in the United States, patients traveling to countries where the live attenuated vaccine is still used should be counseled on risks.

Prevention of herpes zoster (shingles) is a special concern due to the elevated rates of the infection in patients with rheumatic disease, but patients should wait for at least one month after discontinuation of immunosuppressant therapy. Those receiving immune modulators, such as tumor necrosis factor–a blockers, should wait for a least a month after discontinuation of therapy; but those on short-term corticosteroids (fewer than 20 mg/day of prednisone or equivalent for less than 14 days), those given topical steroids, or those on long-term, alternate-day, low-dose treatment should check with their physicians. Also consider the zoster vaccine if you are on low doses of methotrexate (<0.4 mg/kg/week) or azathioprine (<3 mg/kg/day).

Take a seat for yoga

Jessica Rosenberg switched from a promising profession designing products for cosmetic beauty to one focusing on inner beauty. It was a good trade, she says. "If our culture put more emphasis on this, we would be a much happier and more compassionate world."

Long before she made the trade, Jes practiced yoga and studied other ways that breathwork, meditation and movement can affect health and happiness. From the start, she knew she wanted to be part of a healthy and mindful revolution that wasn't just for young athletes in spandex. "I wanted to make yoga available and helpful to everyone," she said.

To carry out this long-time dream, Jes looked at some unconventional ways to promote healthy practices, borrowing freely from a number of movement philosophies and yoga disciplines, achieving a balanced style that appeals to children and adults, whatever their ability level.

Jes's greatest pleasure lies in sharing, mentoring and spreading the benefits of yoga movement, breathing and philosophy. In 2001, she created "The Adventures of Super-Stretch," an interactive fitness program that includes a book series and family games developed to give children a physical means of expressing their exuberance in a healthy and happy way.

Jes is also the troop leader for "Gorilla Yogis," a kind of "pop-up" yoga program that puts the practice in unusual places, both to introduce yoga to those unfamiliar with it and to raise money for deserving non-profits. "I want people to know that you don't have to have special clothes; you don't have to be unusually flexible; you don't even have to be able to get down on the floor to experience the benefits of yoga."

As a veteran instructor, Jes teaches both beginning and advanced classes. She teaches instructors, including those who will lead yoga practice for people in nursing homes; and she creates materials for yoga practitioners of all kinds. Well aware of what yoga had accomplished in her own life, and what was possible for others, Jes got a more personal glimpse of its benefits when her mother, Barbara, was diagnosed with inclusion-body myositis and began to lose muscle strength and movement.

"When she found out about her disease, she also found out that muscles can eventually atrophy," Jes said. They worked out a system of seated exercise designed to keep Barbara's muscles long and viable.

The most important element is stretching, Jes said. "Stretches keep the hands working and open up the hips, keep the back muscles from tightening up." Proper deep breathing also increases mental clarity and opens up the chest.

Jes created an iBook on chair yoga, and her mother can follow it, doing one pose at a time. "It goes through everything, even sitting properly for good alignment," Jes said. Just as important, her mother can do it at home, alone, working along at her own pace.

"She can just do one pose at a time, if that's all she can manage," Jes said. The practice doesn't only promote flexibility, she said, but also helps people struggling with progressive chronic disease manage stress.

The "Chair Yoga Training Manual" by Jessica Rosenberg is available in electronic form through iBooks. Find Jes Rosenberg's "Introduction to Chair Yoga" on YouTube.

Hospital Fall Prevention Technology Now Affordable, Available for Home Use

As muscle weakness and pain from conditions such as myositis limit mobility, simple tasks such as standing and sitting in the bathroom becomes more difficult. Research studies have shown we also become more susceptible to painful, debilitating bathroom falls.

According to the Centers for Disease Control and Prevention (CDC), the simple activity of getting on and off the toilet is a leading cause of non-fatal injuries. In a recent study[1], the CDC estimated that in 2008 alone, 234,094 nonfatal bathroom injuries were treated in emergency rooms across the United States. The study noted that injury rates increased with age and attributed most injuries (81.1%) to falls.

"All persons, but especially older adults, should be aware of bathroom activities that are associated with a high risk of injury and of environmental modifications that might reduce that risk," the study advised.

One such environmental modification now available is the LiftSeat powered toilet lift. Initially developed for use by healthcare professionals in hospitals, rehabilitation centers and nursing homes, LiftSeat's patented technology is now available for the home to safely and smoothly raise and lower a person for toileting.

LiftSeat has proven especially useful in protecting persons with myositis or neuromuscular disorders including amyotrophic lateral sclerosis, multiple sclerosis, muscular dystrophy and rheumatoid arthritis.

LiftSeat helps prevent painful, debilitating bathroom falls that could force someone you care for to move from their home to the next level of care such as an assisted living facility or nursing home. Beyond the emotional impact of leaving home, the costs are significant. Studies estimate the national average of even a single month in assisted living is $3,500.[2]

LiftSeat costs a fraction of even one month in assisted living, installs in seconds and is easy to use. For more information on a LiftSeat powered toilet lift for your home or the home of someone you care for, visit www.liftseat4home.com/107 or call (877) 665-4381.

[1] Centers For Disease Control And Prevention. "Nonfatal Bathroom Injuries Among Persons Aged $\geq$15 Years – United States 2008" MMWR 2011;60: pp 729-733

[2] The 2011 MetLife Market Survey of Nursing Home, Assisted Living, Adult Day Services, and Home Care Costs October 2011

TMA support groups busy and growing

by Charlia Sanchez

Your myositis journey is unique. No two patients are alike and while experiences and symptoms may be similar, your individual stories are just that, yours. The entire idea of support groups is to let our members know that they are never alone.

TMA support groups provide the necessary space for our members to share, vent and learn about myositis. Whether it's coping with the disease, professional resources, handy tips or just fellowship with those who understand, support groups are about keeping in touch and strengthening yourself, your family and your peers with myositis. I strongly encourage all of our members and their families to get involved with their local support groups. We all go through bouts of frustration with several aspects of life. Some are easily resolved, and others such as myositis, require hope and faith to make it through. The relationships and connections made through support groups are essential to staying positive and helping not only yourself, but others as well.

At the 2013 Annual Patient Conference in Louisville, I witnessed the power of support groups. On the first day of the conference more than 50 members attended the "Successful Support Groups" session, either as current KIT Leaders or as members interested in leading. I was thrilled to see our members' enthusiasm and their commitment to not just maintaining, but improving the support community.

Two days later, we held a smaller afternoon support group session for those who could not attend the first, or who wanted to follow up the previous discussion. Suggestions and discussions focused on:

- Enhancing online features to make contacting other members easier
- Improving the support group search function
- Using online support group features
- Communication with TMA
- Announcing and promoting KIT meetings
- Involvement and participation from medical community
- Effective meeting structures, consistency and leadership
- Building your support community and member retention
- Co-leadership, facilitation, and defining member roles in the group
- Support group leader mentor and virtual support group programs

Following the conference, it was clearer to me than before that the support groups are an integral part of TMA and an invaluable asset for all of our members. We have an opportunity in this New Year to continue building our support community and finding new ways to expand our programs to everyone in need. In the first quarter of the year, we will set up our support group leader mentor program and share more information about a virtual KIT for members who cannot attend physical meetings.

Growing Interactions on the Web

As times are changing, TMA must keep up with the digital world by enlarging our support network online. In addition to our website and live discussions, we currently offer a "community forum" for members to post about all topics related to myositis. Many members use the forum to ask questions, share new developments, and discuss experiences. TMA also has a Facebook page and Twitter account for members who have profiles on those social networks.

Through Twitter, TMA frequently disseminates information about events, upcoming programs and information about research and the rare disease community. Our Facebook page, similar to the community forum, allows members to post myositis-related items of interest, share news and keep in touch virtually. TMA also posts pictures, videos, announcements and shares information with the entire myositis community. If you are looking for support and interactions beyond the live support group meeting, consider joining any or all of these communities to stay connected! Email charlia@myositis.org for more information.

Also, some support groups have their own Facebook pages and some even have their own websites. Feel free to join individual support group pages as well. All of these tools help to expand our network and make support more accessible to you.

2013 Highlights and Announcements

Last year, many members stepped up and helped grow the support community tremendously. As a result of their efforts, two new support groups formed: Central North Carolina and Mid-America (Wichita). In addition, other groups have been revived. These groups include Los Angeles, Northwest Region (Washington State and Oregon), Charlotte, North Carolina and Long Island, New York.

We currently have 42 KITS nationwide that have hosted nearly 100 meetings this year. More than 2,000 TMA members have expressed interest in the support group community and 1,200 members actively participate.

There are numerous ways to help us build our support groups. In 2013, the Georgia Support Group held a very well-attended meeting sponsored by Questcor Pharmaceuticals. The Colorado Support Group hosted Picnic in the Park, a Myositis Awareness Day Fundraiser. The Mid-Atlantic Support Group held its Annual Myositis 5k Halloween Run, Walk N' Roll Fundraiser. The Southwest Florida and Mid-America support groups both contributed handmade items to be displayed at the Annual Conference. These are just some of the ways our KITs stepped up to help TMA promote awareness, research, education and support. We appreciate all of our members' efforts and help supporting and growing our KITs.

Looking Forward

In this New Year, there is more work to be done expanding our KIT networks. We are hoping to continue this trend by finding new leaders and facilitators for groups in the Massachusetts/Rhode Island area, Houston and San Antonio areas and also in New Jersey.

Following the Annual Patient Conference, we received a great response from our Canadian members and are looking into extending our support efforts to our northern neighbor. Currently, a small support group meets in Ottawa, Ontario and we have members volunteering to build groups in Alberta and Mississauga.

On Saturday January 11, 2014, Alison Alexander hosted the first meeting for the new Charlotte, North Carolina Support Group at 2:00 PM at the Pineville United Methodist Church.

On Saturday February 15, 2014, the Long Island Support Group, led by Salvador Negron and Melissa Marconi, hosts the First Annual Valentine's Dinner Dance Fundraiser from 7 PM to 11 PM at the Bella Verde Restaurant in Brentwood, New York.

Contact TMA or visit www.myositis.org for more information about these and other upcoming events.

If you are looking for a support group in your area or are interested in starting a new group, please call 1-800-821-7356 or email tma@myositis.org.

Congratulations on 20 years from the place where it all started!

- San Diego KIT