

## Thoughts from a young caregiver

By Paul Hile

*Paul Hile became a major caregiver for his now wife, Grace, when he was 19, before they were married and after she was diagnosed with dermatomyositis. He explained the needs of young caregivers in an article in Read the Spirit ([www.readthespirit.com/caregivers/young-caregivers-facing-challenges-of-understanding-compassion](http://www.readthespirit.com/caregivers/young-caregivers-facing-challenges-of-understanding-compassion)) and we asked him to tell a little more of his story for The OutLook.*

Grace became ill only two months after she and I began to date, at the age of 19. Just before the diagnosis, we had concluded our first year of college, and we were on the way to her home in Illinois to spend some time with her family before our May term began. I was going to meet a majority of her family for the first time. We ended up getting in a fairly serious car accident, hitting a deer on the highway at about 70 mph. We were in the emergency room for several hours and returned to her house early the next morning. In the following weeks after the accident, as I began to feel better from the whiplash, Grace continued to feel tired, sore, and stiff, and that's when we knew something was wrong.

As you can imagine, those months without a diagnosis were pretty difficult. I am originally from Michigan and after our May term, when Grace returned to her home in Illinois, I returned to my home in southeast Michigan to work for the summer. I spent all my paychecks that summer on

train tickets and traveled to Grace's house almost every other week. I worked at a professional baseball park and every other week the team traveled to play elsewhere so I had that time off.

At the worst of the disease, we had to help Grace in and out of cars, up and down the stairs, with showers, and getting up from the couch. One evening,

Grace and I went to watch the sun set on the Mississippi River (she lives a few minutes from it) and after standing for a few minutes her legs just gave out on her and she fell. I should add, that before this diagnosis, Grace was a serious athlete. She competed in high school athletics at the varsity level in several sports. She had completed a triathlon the summer before college. She practiced yoga daily. She ate well. She seemed VERY healthy.

We were really fortunate to have lots of help from Grace's family as we planned the wedding. We also had a long engagement, which helped reduce the stress of planning everything. Still, Grace was in the midst of a relapse the

day of our wedding (though we didn't know it) and it was difficult for her to stand all day in heels and muster the energy for all of the various activities.

Becoming a caregiver at the age of 19 is something I did not expect nor was I prepared for. Of course, I wasn't her primary caregiver early on, but Grace's family allowed me to be with her through it all and I can never repay them for that. When I was 17 my mother was diagnosed with brain cancer and I was able to see my father care for my mother with incredible love and dedication. I was the child in that case, and likely was shielded from some of the more vulnerable moments, but I knew this: you didn't abandon the person you loved, just

because that person became sick. Still, being the child of someone who requires care is much different than being a spouse, at least in my case.

I made a lot of dumb mistakes early on. I was selfish and frustrated and had to learn very quickly that there was something happening in my life bigger than me. Similarly, I learned quickly that I can't just forget about my own health. There was a period of time where I wasn't really taking care of myself and that certainly didn't help anything. When I learned to listen to Grace, to actually listen to her fears and concerns, things became easier for her. That's what she needed most: someone



*"This is our life, and I wouldn't change it for the world."*

*See Caregiver on page 6.*

Published by: TMA, Inc.

## THE MYOSITIS ASSOCIATION

1737 King Street, Suite 600  
Alexandria, VA 22314

P: 800-821-7356 E: [tma@myositis.org](mailto:tma@myositis.org)  
F: 703-535-6752 W: [www.myositis.org](http://www.myositis.org)

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Editor: Theresa Reynolds Curry

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## LiveDiscussion

### Specialists tackle your questions online

*TMA has presented several "live discussions" in recent months. For the complete transcripts, go to [www.myositis.org](http://www.myositis.org), and click on "Live Discussion" under "Your Myositis Community."*

*Dr. Victoria Werth, a dermatologist specializing in autoimmune skin diseases and former member of TMA's medical advisory board, took questions in July. Following are some of the key discussion points.*

#### Your questions about skin

- Why does rash persist when muscles improve?
- What are natural treatments for DM?
- Does the sun cause a flare of both the muscle and skin disease?
- Is there anything I can do to alleviate the terrible itching on my scalp?
- Can IBM or PM skin conditions mimic DM?
- Why are my fingers affected so badly?
- Are there new treatments for DM?
- How can I treat the skin sensitivity and thinning that comes from my medications?
- How can I continue to enjoy life if I can't go out in the sun?
- What about using coconut oil on my skin?
- Why do my cuticles grow so quickly?
- Why do my fingertips hurt and feel cold so severely?
- Can I have both PM and DM?
- What can I use if my DM doesn't respond to any of the conventional drugs?

- What can I do for dry, cracking lips?
- What about bath soaks, vinegar or bleach for the rash?
- What vitamins or supplements might help?
- Why does my skin tear, bleed or bruise at the slightest touch?

Drs. Jerry Mendell and Brian Kaspar, investigators in the follistatin gene therapy trial for inclusion-body myositis now underway at Nationwide Children's Hospital, participated in a live discussion in June, addressing some of these questions from you:

#### Your questions about follistatin gene therapy

- What is follistatin?
- What are its side effects?
- How long did it take to see improvement?
- How do I get accepted into the study?
- If follistatin is approved, will it be covered by Medicare?
- If new muscles grow after treatment, will they also be affected by IBM?
- What were the benefits of follistatin?
- Does follistatin only affect muscles where it was injected?
- How do you measure improved muscle strength for purposes of the trial?
- Can follistatin be used even for those with advanced IBM?
- When will the trial results be available?



## Messages from the Executive Director

*A new feature of The Outlook, "The Corner Office," reports on TMA activities that may be of interest, and invites your involvement.*

### Advocacy

Advocacy is a word that many people outside of Washington, DC probably do not fully understand. It means having someone looking out for your interests and making policymakers at the national, state or local levels of government aware of your concerns. TMA moved its offices to Washington, DC 10 years ago so it could be a better advocate for those who have myositis.

An issue that TMA is currently working on (advocating for you on) is trying to get those who oversee the Medicare program to provide coverage for the seat elevating feature on a power wheelchair. We know that many of those with IBM in particular need this feature on their chair. Medicare has not in the past covered this feature because Medicare's interpretation of the regulations regarding durable medical equipment (DME) determined that elevating seats are not eligible for coverage. TMA disagrees with this interpretation of the rules regarding DME and has presented the new Medicare Administrator (just confirmed by the Senate several weeks ago) with an appeal from TMA signed onto by 30 other health charities. We also had a meeting with the Deputy Administrator of Medicare and several of his staff about this issue.

The request is currently under review and we are hopeful that we might be able to persuade Administrator Marilyn Tavenner that elevating seats ought to be covered for those who cannot raise or lower themselves due to damage to their quadriceps or other muscle disorders.

Advocacy is most effective when policymakers hear from the "grass-

roots." If this issue is important to you, a heartfelt message mailed or emailed to those involved in this decision will help the cause. Please email [Marilyn.Tavenner@cms.hhs.gov](mailto:Marilyn.Tavenner@cms.hhs.gov), [Jonathan.Blum@cms.hhs.gov](mailto:Jonathan.Blum@cms.hhs.gov), and [Laurence.Wilson@cms.hhs.gov](mailto:Laurence.Wilson@cms.hhs.gov), or you can snail mail each of them at the address below:

Centers for Medicare and Medicaid Services  
Department of Health and Human Services  
Hubert H. Humphrey Building  
200 Independence Avenue, SW  
Washington, DC 20201

We will keep you informed of the status of this request.

### 20th Anniversary

By now you probably know that TMA is celebrating its 20th Anniversary this year. For those who are attending the Annual Patient Conference in Louisville this October, there will be some special events celebrating TMA's 20 years, including an Anniversary Dinner Celebration at the Muhammad Ali Events Center. The Anniversary Dinner will feature a performance by Marquita Lister, a world renown opera singer who also has polymyositis. For information about tickets, contact [TMA@myositis.org](mailto:TMA@myositis.org) or 1-800-821-7356.

Whether you are coming to the Annual Conference or not, we want to invite you to participate in the activities honoring TMA's 20 years. We are holding an art contest and an essay contest related to the 20th Anniversary. To enter, submit an essay of 20 words or less as to what myositis has meant to you, or send a piece of art with a theme related to myositis. These contests are meant to be fun while also giving TMA members a chance to express themselves about the disease. Recognition to the winners will be provided following the Annual Conference. Entries for the essay contest should be emailed to [TMA@myositis.org](mailto:TMA@myositis.org) by October 8 or

mailed to TMA's Alexandria, VA office. Entries for the art contest should be shipped to TMA's Alexandria office by October 1 or, if you are attending the Annual Conference this year, you can bring your art contest entry to Louisville.

Another way you can join in recognizing TMA's 20th Anniversary is through our "20 for 20" Campaign. We are asking TMA members to ask 20 of their friends or relatives to give TMA \$20 in recognition of 20 years of service to the myositis community. So far, 75 people have joined in this campaign. To participate, email us at [TMA@myositis.org](mailto:TMA@myositis.org) or call 1-800-821-7356. We will send you 20 cards that are the size of a business card which you can hand to a friend or relative. One side of the card tells them how to donate and the other side gives them information about the myositis diseases. It is a great way to create awareness of myositis and raise money for TMA at the same time. We set a goal of raising \$50,000 from this campaign. If all 75 people participating so far raise the full \$400 (\$20 from 20 friends), we are already at \$30,000 and the \$50,000 goal is within reach. Please join in this effort if you are not participating already!

### Questions/Concerns/Suggestions

Nobody is perfect and TMA does the best it can with its limited funds. We welcome and encourage questions, concerns or suggestions from our members. If you need to get something off your chest or just have an idea that you think we need to know about, feel free to write to us either through email to [TMA@myositis.org](mailto:TMA@myositis.org) or snail mail to our Alexandria, VA address. We want to hear from you. We can always do better and your feedback and suggestions will help us to improve!



## What are the pros and cons of polymyositis and dermatomyositis drugs?

New drugs — and new drug combinations — are available to myositis patients, usually after being successfully used to treat people with rheumatoid arthritis. The benefits of treatment outweigh the side effects most of the time, but it is also helpful to know what to expect from the different drugs you are prescribed.

Medications for myositis are prescribed for a number of reasons: to manage the inflammation, pain, and complications, as well as to stop or slow the progression of the disease.

Updated treatment guidelines by the American College of Rheumatology, published in the journal *Arthritis Care & Research*, say that early aggressive treatment is the best way to minimize damage and to maintain quality of life. Doctors now have more drugs to use, and they are using them earlier, and in more combinations.

### Disease-modifying anti-rheumatic drugs (DMARDs)

Some physicians who treat people with myositis say that everyone should be started on at least one DMARD at the beginning of treatment and that people with more disease activity and signs of poor prognosis should be started on or considered for two or more DMARDs.

The guidelines for rheumatoid arthritis say that if you are started on one DMARD and you are not doing well after three months, you should have another DMARD added. Commonly used DMARDs for myositis include methotrexate (Rheumatrex and Trexall) and hydroxychloroquine sulfate (Plaquenil).

**Pros:** DMARDs not only help control symptoms, they can also minimize damage and stave off future complications.

**Cons:** Doctors must monitor your blood work and symptoms closely while you're taking DMARDs.

Benefits of DMARDs may take weeks or months to take effect. Possible side effects of methotrexate can include liver damage, lung damage, and a decreased ability to fight off infections. Side effects of hydroxychloroquine can include eye damage. Because of an increased risk for infection while taking a DMARD, the new guidelines suggest getting vaccinated for pneumococcus, influenza, hepatitis B, human papillomavirus (HPV), and herpes zoster (shingles) before starting treatment. If you are already on a DMARD, talk to your doctor about what vaccines you may need.

### Biologics

These newer drugs turn down your body's immune response. They can reduce pain and swelling as well as long-term damage. The two basic types are called anti-tumor necrosis factor inhibitors (anti-TNF) drugs and non-TNF drugs.

Anti-TNF medications work by blocking the effects of TNF—a protein that encourages inflammation and revs up the immune system—thereby decreasing the inflammation that is a hallmark of rheumatoid arthritis and myositis.

Guidelines recommend starting an anti-TNF drug with or without methotrexate if you have high disease activity and poor prognostic features. If you have been started on DMARD therapy and you have moderate to high disease activity after three months, your doctor may add or switch to an anti-TNF.

If you are taking an anti-TNF already and you are not doing well after three months, your doctor may switch to another anti-TNF or to a non-TNF biologic. Anti-TNF drugs used in myositis include etanercept (Enbrel) and infliximab (Remicade). Rituximab (Rituxan) is a non-TNF biologic used for myositis.

**Pros:** Biologic medications are effective in controlling symptoms and pre-

venting complications. These medications act quickly, and you may start to feel the effects after the first or second treatment.

**Cons:** They can cause several potentially life-threatening side effects. Because these drugs interfere with the immune system, they increase your risk for infection, including tuberculosis. Additionally, some of these medications have been linked to the development of lymphoma, a cancer of the white blood cells. Biologics are given by injection, and one of the most common side effects is burning, itching, and swelling at the site of the injection. Because biologics turn down your immune system, the new guidelines recommend that if you take a biologic, you should be screened for tuberculosis. You should not take a biologic if you have untreated chronic hepatitis B, have had a cancer tumor in the past five years, or if you have severe heart failure. Vaccination recommendations for biologics are similar to those for DMARDs, so you should talk to your doctor about them.

### Corticosteroids

Corticosteroid drugs help fight inflammation and depress your immune response. Steroid drugs include prednisone and methylprednisolone (Medrol). Steroids are used to control symptoms, but they do not alter the course of the disease in the same way that DMARDs or biologics do.

**Pros:** They can be given by mouth or intravenously, and are inexpensive and effective. Because steroids act quickly, they can be used while waiting for other drugs like DMARDs to take effect. They are also useful for a sudden flare of symptoms.

**Cons:** The length of steroid use is limited because these drugs can lead to a host of side effects, including weight gain, high blood pressure, elevated blood sugar, osteoporosis, and mood disturbances.



## What is the status of inclusion-body myositis treatments?

*TMA is often asked about drugs for inclusion-body myositis, which presently has no effective treatment. Drugs used to treat poly- and dermatomyositis are not effective for IBM, but in some cases are tried briefly. Following is an updated summary, adapted from articles by Dr. Michael P. Collins for Medscape and by Drs. Mazen M. Dimachkie and Richard J. Barohn for Seminars in Neurology, of some of the drugs that have been tried; and some under study, with future promise.*

### **Steroids and immunosuppressive and immunomodulatory drugs**

For years, anecdotal reports have documented the failure of patients with IBM to respond to steroids, methotrexate, azathioprine, and cyclophosphamide. Subsequent clinical studies of various immunosuppressive or immunomodulatory therapies have been disappointing. Some individual responses, functional improvement, or mild regional improvement in strength are documented in case studies, but sustained remission and improvement in whole-body strength have not been demonstrated.

A long-term observational study of a large cohort of patients in Paris and Oxford found that immunosuppressive treatments do not help in inclusion body myositis and could even slightly hasten disability. A study of high-dose prednisone in eight patients showed no improvement in strength or functional disability scores despite a decrease in CPK and inflammatory cell infiltration. After treatment, muscle biopsy samples showed more muscle wasting and a greater presence of amyloids, suggesting that other factors in addition to inflammation play a role in disease propagation.

A randomized, controlled study of oxandrolone in 19 patients reported a regional improvement in upper

extremity strength, but only borderline improvement in whole-body strength.

A randomized, controlled study of methotrexate in 44 patients showed no improvement in strength despite a significant decrease in CPK levels.

### **IVIG**

An early small, uncontrolled study reported improvement in strength in four patients following intravenous immunoglobulin (IVIG) treatment. However, subsequent larger and placebo-controlled studies failed to duplicate these results, although several studies suggest some benefit in patients with severe dysphagia.

### **Beta interferon-1a**

Beta interferon-1a at standard and high-dose regimens were found to be well tolerated but produced no significant improvement in muscle strength or muscle mass.

### **TNF blocker**

A pilot trial of etanercept (Enbrel), a tumor necrosis factor alpha blocker, did not show significant benefit in composite muscle strength scores after six months. However, with 12 months of treatment, slight improvement in grip strength was noted. A double-blinded, randomized, placebo-controlled study is currently underway to measure the efficacy of etanercept treatment in patients with IBM.

### **Alemtuzumab**

A study of alemtuzumab, a T-cell-depleting monoclonal antibody, involved 13 patients who underwent infusion for four days. It reported slowed disease progression, improvement of strength in some patients, and reduction in inflammation. This preliminary study holds promise for future studies.

### **Follistatin**

Follistatin has been shown to produce a dramatic increase in muscle mass in animals. These results are promising for future gene therapy trials to improve muscle mass in patients with neuromuscular disease, and are underway at Nationwide Childrens' Hospital, partially funded by TMA, and are now proceeding using a higher dose than before. (see "Follistatin Gene Therapy," page 2).

### **Arimoclomol**

Arimoclomol, a heat shock protein (HSP) co-inducer may slow down the process of protein misfolding and aggregation. A study of its safety and efficacy conducted jointly by investigators in London and in Kansas City has concluded, with researchers finding the drug worthy of further study.

### **Lithium**

Several investigators have conducted small trials of lithium chloride. The theory was that this treatment might promote clearance of misfolded proteins in IBM. The results have not yet been published.

Other therapies include coenzyme Q10, carnitine, and antioxidants. They may provide benefit to some patients, but, to date, none of these has been studied in a controlled clinical trial.

### **Bimagrumab**

In August, the FDA granted "breakthrough therapy designation" for BYM338 (bimagrumab) to Novartis for inclusion body myositis. Bimagrumab showed promise in a study of IBM patients. If approved, it will be the first-ever therapy for IBM.



## Everyday ideas from TMA members

*We never forget that the best sources of ideas for coping with myositis are you, our TMA members. Recently, you've weighed in on comfortable clothes and gardening tools.*

### For comfortable, functional, attractive clothes while in a wheelchair:

- Due to UV sensitivity, Beth Spicer loves the "Coolibar" line of clothing—comfortable and with a 50+UPF. Check them out at [www.coolibar.com](http://www.coolibar.com), or through Amazon. Coolibar offers clothing of all kinds, swimwear and sun hats, too.
- For a special event, Cynthia Childrey-Hameen likes to wear a comfortable dress with flats.
- Several of you mentioned the "Travelers" line featured at Chico's, wrinkle-free and basic, so simple pieces can be dressed up with accessories.
- Oi Ping Li Park finds that wearing loose-fitting cotton clothing is best during the day and less likely to rub or pinch the skin than synthetics. "Wear a top and trousers or a skirt for the ladies," she said, as dresses can pull when you move about in the wheelchair.
- Finally, Kathy Baker recommends "A sincere smile and no whining are great looks, no matter what position you're in."

### For gardeners with myositis:

- Laurene Lambertino Urquizo uses five-gallon painter's buckets with holes drilled at the bottom and sits on a plastic outdoor chair to tend them.
- Eddie Smith's daughter made a herb planter from old pallets, filling the space between slats with soil and herbs, then turning it on its end to make it a comfortable height.
- Missi Cooper-Frowein can't get down to tend raised beds, so she uses large containers. That's Leslie Buchanan's solution, too.
- Jill Phelps spends hours gardening and landscaping, using a small garden cart on wheels with a foam cushion. "Small tools are kept underneath," she says. "My thighs are weak from years of DM and prednisone, so getting up is the hard part but I'm able to accomplish a lot. My husband picks up all my piles, thank goodness." Jill has narrowed her garden beds to be able to reach from all sides.
- Valerie Nash loves her garden kneeler. "It helps you get up—my favorite!"
- Nicole Bolger writes: "Our landscape designer suggested we use large (like 3x3 foot) pavers instead of smaller pavers to avoid buckling that could cause trips or falls, and to use crushed fine gravel instead of pea gravel in our paths to avoid shifting ground hazards. If you're going to grow potted plants, fill half the pot with plastic bottles (or styrofoam) instead of soil to keep them light and moveable. Great for drainage too!" The Bolgers planted an anti-inflammatory veggie trug. Find it here: <http://myositisco.wordpress.com/?s=garden>.

## Caregiver, continued from Cover.

to listen without judgement, without prejudice, without exception.

We found out very quickly that there were--and would always be--people who didn't believe Grace was sick. Professors, friends, even members of her own family accused her of making up her illness, of embellishing her struggles just to get sympathy. But that was the last thing Grace wanted. She didn't want people to doubt her, or try and relate to her, she just wanted people to listen to her.

The friends and family that have been most helpful are those who actually listened. They were those who believed her, who didn't give her a hard time when she went to bed early, cancelled plans, or changed her diet and lifestyle around. The people who helped her most were the ones who sat down in front of her and said: "So tell me how you've been feeling?" "Tell me what it's like?" "Tell me what I can do?"

Of course, her parents have been incredible. They've gone out of their way to help her these past few years, and I suspect they don't really know how much love and appreciation Grace has for them. They love her and support her in ways I cannot even understand. I can't imagine what it's like to have to watch your child go through something like this. Similarly, my parents have welcomed her since day one, have loved her as if she is one of their own. Love like that goes a long way when you're sick.

To be completely honest, I still don't necessarily think of myself as a caregiver. I've helped Grace in ways other boyfriends and husbands haven't had to, sure, but she's my wife and the love of my life and I don't really know anything different with her. This is our life and I wouldn't change it for the world.



### Yoga student finds healing and peace

By Kathryn Nevard

I am in my weekly yoga class and lying in Savasana, the “dead body pose” and can’t move. My vertebrae feel like they are on fire, and my neck is similar to a ton of bricks to lift. There is pain in my chest wall and spine, and every breath I take feels like my lungs are deteriorating. I slowly sit up in prayer and look at myself in the mirror. I notice my skin flushed and red, my hands red with what looks like mosquito bites on my knuckles, and my eyes swollen and sore. Something is wrong. I am about to turn 30 and have been practicing yoga for 15 years. This shouldn’t be happening.

This is how my journey with dermatomyositis started. It’s February 2012, and I am at the gym. I did my normal routine of yoga, run, and sauna. Except today was not so normal. I went into the sauna and came out with my skin red and a butterfly rash around my eyes. I couldn’t run because I was too tired. Throughout the next two weeks my symptoms worsened: facial swelling, inability to swallow, chronic fatigue, body rashes, and worst of all, loss of muscle function in my upper body. Unable to move from bed and numerous emergency room and doctor visits later, I was diagnosed with dermatomyositis (DM).

When DM made its shattering appearance into my life, I tried very hard to hold everything together, to keep the pieces of my life in place. However, I became scared of many things; side effects of medications, inability to move again or even swallow food. I knew things were going to change, and I had to learn to accept this.

The first few months were a struggle, but I slowly started to accept my disease. Instead of being frightened by

my treatments and side effects, I approached DM with curiosity. Besides resting at home, I slowly started to garden and cook again. When I was in pain, I stopped. Unable to raise my arms to wash my hair, I cut it all off and embraced the “new me.”

I started my home yoga practice and the first few days were painful and difficult. When I tried to touch my toes, I couldn’t, when I sat, my back hurt, When I laid down, I was in pain. I cried, but I was determined. I felt as though I hadn’t been active my entire life and this was my first time moving my muscles. As time passed, I noticed small improvements. Those small improvements kept me going. I kept clear of yoga studios, and practiced daily at home, at my own pace, without any distractions.

During this time I also started to understand and become aware of my body and the connection to the mind. If I was too tired or sore to exercise my body, I exercised my mind. Bringing my mind to inner peace and letting go was a challenge, but I sat and meditated when I physically couldn’t move. When my mind became at peace, my pain slowly subsided. I felt content and calmer. I changed my nutrition program and eliminated foods that are prone to cause inflammation, like caffeine, alcohol, gluten and wheat. Within a week, my joint pain subsided. I learned to let food become helpful,

not harmful, to helping my healing.

After three months of starting to understand my new body and my disease, I had to confront an additional challenge. My right leg became infected from my muscle biopsy. Three surgeries and one month later, I returned from the hospital, still fighting DM. I was also learning to walk again. I didn’t go to physical therapy: I knew what I had to do. I moved, I stretched, and I meditated. I worked with my partner at home on small movements and he uttered the words to me daily “You will get there.” He was right. No one ever ran a marathon without putting one foot in front of the other, and I can’t recover without moving one small muscle at a time.

I am still on my medications, but my main treatment is my practice. I am aware of my body, the muscles and their functions. I am stronger physically and mentally than before being diagnosed. Today I flow through my warrior sequence; I shed tears of knowing I have become that warrior. For maybe this disease is not my enemy, but my own personal lesson in awakening.

As time continues to pass, I know I can always find healing with my mind and breath. Conquering our mind is the first step to healing our bodies. We must dig deep and find the strength that lies within us and helps us move. Whatever place our body is in for that day, that is where we begin, and slowly, in time, improvements will come. Work with your body and the disease, not against it. When you accept it, healing will arise.

*Kathryn will be teaching “early-bird” sessions at the Annual Patient Conference in Louisville on the benefits of yoga and meditation.*



Yoga headstands have many benefits.



### TMA support groups in full swing

By Charlia Sanchez, TMA Member Services Coordinator

Our KITS have been bustling this summer as TMA drums up support for the 2013 Annual Patient Conference and celebrates its 20th Anniversary.

A new support group in Raleigh, North Carolina, led by Vicky Baldock, launched in June and is gearing up for its second meeting in August. We would also like to extend our gratitude to Craig Cotter for stepping up as the newest KIT Leader in the Los Angeles area following the death of former KIT Leader, Richard Gay. TMA also has been in touch with members about reviving the support community in the Houston, Texas area as well as starting a new group north of Los Angeles. At the end of July, TMA hosted two conference calls with KIT Leaders to discuss the status of our support groups, opportunities, ideas, and areas to improve.

The support community is an integral part of helping our members stay connected and up to date with the latest information about myositis and TMA. Interested in starting a support group, or looking for support in your area? Call 1-800-821-7356 or email [tma@myositis.org](mailto:tma@myositis.org).



### Annual Patient Conference scholarships

We are pleased to announce that through the generosity of TMA members, we were able to award financial assistance to 12 TMA members this year so they can attend the Annual Patient Conference in Louisville this October. TMA will be providing Conference registration and hotel room for three nights to each of these individuals and their spouse or caregiver. This is the second year that TMA has offered scholarships, and we now have enabled 41 myositis patients to attend the Annual Conference who would not have been able to attend otherwise. Thank you to all who have supported this program and we look forward to offering scholarships again next year!



### 20 for 20 Anniversary Campaign

It is not too late to join the 20 for 20 Anniversary Campaign. Nearly 100 TMA members have now asked 20 friends and relatives to donate \$20 to TMA in honor of its 20th Anniversary. For more information, email [TMA@myositis.org](mailto:TMA@myositis.org) or call 1-800-821-7356.