

Kate and Deb: an Olympic story

The myositis community had two representatives -- both women with severe dermatomyositis -- running with the Olympic torch to the start of the summer games. Both of them count their moments as part of the ancient ritual to be among the most important and inspiring of their lives.

We met Kate Barnett in the spring 2012 issue of the *OutLook*. Kate had a case of dermatomyositis so severe that she was hospitalized until it was under control. She had to give up her job to take another, less physically demanding position with the same company.

She'd always been athletic and was already working out regularly to overcome the weakness caused by her struggle with dermatomyositis, so Kate didn't do a lot of training for the race, she said.

Kate's big day was June 12, and she ran with the torch in Aberdeen, Scotland:

Kate's run in Aberdeen

What a fab day, I have never felt so proud and emotional in all my life. My Mum and Dad managed to make it down (my Dad has just been diagnosed with prostate cancer which has

spread to his bones) and he was worried he might miss it.

I ran my 300 meters (about 1,000 feet) and was fairly out of breath at the end, I had to hold the torch with both hands as it was a bit top-heavy and weighs 800 grams (about two pounds), but I managed to wave at the crowd. I even made it onto the BBC Scottish lunch time news, and we now have a copy.

I wore my myositis T-shirt (Kate belongs to the UK Myositis Support Group) legally under my

Olympic one and managed to get some good photos of me in it. My work sent down a photographer, and he took some great shots.

And I also made sure my myositis badge was pinned to my official Olympic T-shirt all the time, good job no officials saw me as I think they would have made me take it off, and I even had my Union Jack knickers on...cheeky.

Even though my slot was at 7:27am, there were people out waving and cheering me on, even some in their nightwear! It was great to see all the children with homemade torches. And I have had to go around to a couple of local homes in my village with my torch and tracksuit so the kids can



Kate Barnett carried the Olympic torch in Scotland.



Deb Bliss ran with the torch in Coventry.

see me. It was lovely that for 15 minutes everybody I ran past was happy and smiling and just having a great time. My Mum and Dad had more than a tear in their eyes.

What an honor is all I can say, and the moment will stay with me forever.

I have kept my torch, which I bought for £199 (about \$300), it has 8,000 holes (one for each bearer) is 90 cm (about three feet) long and weighs 800g (not sure of the significance of the number 8). It is three-sided, as the Olympic games have come to the UK three times now.

As you will see from most of my photos I'm grinning like the cat that's got the cream!

Deb Bliss

Like Kate, Deb is a life-long athlete, and she credits much of her ability to bounce

back from several near-fatal flares to her physical conditioning. Before she was diagnosed with dermatomyositis, Deb worked in the physical fitness industry. She is now the national operations manager for the Mark Group, a company specializing in energy solutions. She organizes charitable events for her employer and, on her own, has managed to raise more than \$100,000 for deserving health-related charities.

See Olympic Story, page 3.

Published by: TMA, Inc.

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Do pennies count?

By Marianne Moyer, TMA Board of Directors Chair

Did you grow up like I did, believing “find a penny; pick it up and all the day you’ll have good luck?” Maybe it was my depression-era parents or maybe it was just that we were a frugal family but if we saw a penny on the sidewalk, we always picked it up.

Having myositis, it’s not as easy today to bend to pick up that penny but I do still believe in the value of every cent and I know many of you do as well. And in this case, I’m talking about pennies building up to make dollars to make a difference to TMA.

As I’ve traveled to meet with KITs around the country, one of the subjects of my talks has gotten a surprising amount of interest and that is the use of GoodSearch, GoodShop and GoodDining websites. If you ever use a search engine like Google, use www.goodsearch.com instead and each time you do, one penny will be donated to TMA. Not worth it you think? OK, try www.goodshop.com the next time you order anything online. Retailers like Amazon, hotels, airlines and other vendors donate between 1.5% and 8% of your purchase price to TMA and it doesn’t cost you anything but one extra click to get to GoodShop before you buy. Then, if you are like me and eat out frequently, go to www.gooddining.com and enter your zip code for a list of restaurants that will contribute up to 6% of your meal bill to TMA, again, at no cost to you. Please look into these three sites and let those pennies start rolling into dollars for TMA.

Other groups around the country are branching out into creative ways to make their pennies count. In Texas, Rose Mary Istre discovered that Kroger stores have a program that automatically contributes to TMA. All a customer has to do is have a barcoded letter and then, scanned once at checkout, Kroger sends a donation to TMA, based on purchases for a year. No cost to the customer and the pennies add up. If you live in Texas, contact Rose Mary at rosemaryistre@gmail.com for a copy of the letter.

TMA is now offering envelopes with the definition of myositis on the front. You can buy 100 envelopes from TMA for \$24, and each time you mail one, the recipient will be reminded of myositis and what it is.

Let’s not forget Augie DeAugustinis’ idea of the Myositis Information Cards. You order them through TMA’s website and hand them out to friends, family and especially your doctors, explaining your disease. The pack of 100 cards only costs you \$20 and each order generates a \$5 donation to TMA.

I’ll bet there are other great ideas out there that I haven’t mentioned. And for every one of them, I’m grateful. Not only for the pennies they generate for TMA, but just as importantly, for the fact that they demonstrate that our members are committed to helping TMA grow; even if it’s penny by penny.

Olympic Story, from cover.

Deb ran her 300 meters two weeks after Kate, along Leamington Road in Coventry.

Deb was told in 2000 that she would not walk again. More recently, in February 2012, she was rushed to the hospital with a suspected stroke, as her right side was paralyzed.

She suspected it was a flare, and that turned out to be the case. A new course of steroids gave her back her strength. Deb sometimes loses all strength in her hands, and had a bout of hand weakness right before the run. She was worried about carrying the torch.

Deb's story

Wow, wow, wow! I have never experienced anything like it. Awesome is not a big enough word.

I was lucky because I did my run on a Sunday at around 6:30, and the sun was shining. The crowds were around six deep on both sides and the atmosphere was truly amazing. Such a well organized event!

I was not nervous, just so excited. Watch the video, and see me skip, heel kick and run backwards.

I had been poorly on the Tuesday, Wednesday and Thursday before, but I would have still done it. My right hand became paralyzed on the coach whilst on route, but it came back in time and I was determined to hold the torch in it - and did!

Wave and smile was what we were asked to do - Cheshire cat more like! Great day - one I will remember for the rest of my life!

Watch Katie and Deb at the BBC website: www.bbc.co.uk/torchrelay. You can find them by name, or by the dates they ran along with links to their biographies, including their work for health-related charities.



Patient Perspective

Kicking and screaming

By Andrea Taylor Langworthy

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 leads the myositis support group. She writes a weekly column for the Rosemount "Town Pages" newspaper. She has IBM.

Despite my Pollyanna attitude that accepting my disease was simply mind over matter, I quickly learned acceptance can be hard to come by. Constantly, I repeated, "It is what it is," and constantly, I resisted making changes.

My husband did his best to help me. One day, knowing another cold, snowy, icy Minnesota winter would soon be upon us, he brought home an application for a handicapped parking permit.

Handicapped parking? I couldn't bear to look at the bald blue stick figure in the wheelchair. Who posed for the picture, anyway? Certainly not a middle-aged woman who looks pretty darn good for her years but has difficulty getting out of her car and walking.

I asked my hubby to put the paperwork in the basket on the kitchen counter. I would get to it in a while. A few weeks later, I moved the basket to the pantry where it and the application stayed all through winter and spring and well into summer.

"I want to send you for cane evaluation," the neurologist said.

"A cane?" I asked.

"How many falls are too many?" she countered. I had to admit my last crash landing scared me. Falling straight backward, my rear end, shoulders and head had bounced in



sequence on the floor of a public building. The cup of tea in my hand spilled all over the front of my new white tee shirt. Two good-looking, muscular young men offered to help me up as my friends chanted, "Her legs are weak; her legs are weak. Don't let go of her until she says you can."

"If the evaluator says you need a cane," I asked the doctor, "have you passed or failed?"

Either way, I was fitted for an ugly black metal cane with a shepherd's hook handle; very sturdy and utilitarian. The cane evaluator suggested a meeting with a physical therapist for pool therapy. Water? I hate to get my hair wet.

My mother had worked out in the pool. Sissy exercise, I used to tease her. My husband suggested taking the ugly, black metal cane to the pool where, he assured me, even an Olympic swimmer could slip. I gave in to the idea when a picture of me on a stretcher in my bright blue, one-piece, tank-type Speedo flashed in front of me.

"Can you teach me to exercise in the lap pool with one of those foam waistband things?" I asked the therapist after I had mastered leg exercises in the warm water shallow pool. She looked surprised. We had often laughed that I would keep the required appointments and never get wet again. But with a bright blue jogging belt that matched my swim suit strapped around my middle, I was soon running in the lap pool.

See *Kicking and Screaming*, page 4.

Tom Salliotte: Working for IBM research

Tom Salliotte is a 67 Year-old male patient with sIBM. Karen and Tom have two children, five grandchildren and a Yorkie named Fran.

My journey with sIBM began several years before I was diagnosed. We installed a fitness center in our home, thinking my muscle weakness was due to the aging process.

After several months and no results, my wife noticed that I was having difficulty going up and down stairs and even more difficulty getting up from a chair. I was also moving more slowly, and none of it made sense to us.

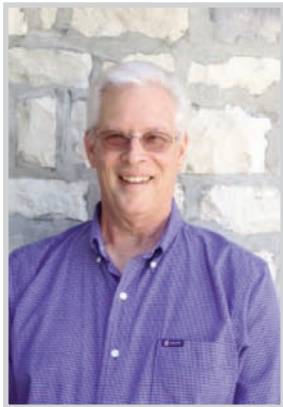
Finally, after a year and a half we met Dr. John Kissel of the Neurology department at Ohio State University in Columbus. Dr. Kissel diagnosed me with sIBM on February 24, 2009, following the completion of a muscle biopsy at the Nationwide Children's Hospital in Westerville, Ohio. I had been retired only nine months.

After being diagnosed with a rare and progressive disease, and with no treatment or cure available, we had a lot of questions and no answers as to what was happening to my body.

Several months later a close friend of ours attended a fundraiser. The person he knew won the marathon, and on the trophy was inscribed: Myositis Winner. He thought the name looked familiar and asked us if this was the name of my disease.

We were surprised, to say the least, and said, "Yes it is." Later that weekend, another name came up from that fundraiser and it just happened to be an active TMA board member. Now

we had met a person who was directly connected with TMA and things began to happen. We called the contact and she told us about a conference being held in Charlotte, NC in September, so we booked our hotel room and prepared for our trip.



Tom Salliotte

During the conference we heard Dr. Brian Kaspar's presentation on gene therapy research being conducted by Dr. Jerry Mendell and his team in Columbus. Many questions came to mind, but what really got our attention was the research results in the mice and more so with the monkeys! We could actually see that the muscles were larger as a result of the gene therapy.

It was mentioned that a possible clinical trial could begin in 2010 or 2011 and for us to follow the updates from the TMA website.

After we returned from the conference Dr. Brian Kaspar invited us to take a tour of the research lab. After several hours of touring the lab and discussing the new gene therapy research, we were really excited about the possibilities for some type of treatment in the future for IBM patients. Later, we were to meet Dr. Mendell as well as Dr. Kaspar.

We are very grateful for this work on behalf of myositis patients and thank the research team for its expertise, commitment and dedication to improving the quality of life for sIBM patients and those with other neuromuscular diseases. We are so impressed with Dr. Mendell that words alone cannot express how we feel.

On the drive home from the conference my wife and I agreed to start a myositis support group in our state. Since then we have completed two successful fundraisers with individual donations from support group members, family, friends and our church community totaling over \$12,000. It all goes directly toward IBM research.

We have approximately 20 members in our support group and we meet three times a year to discuss our different diseases, be they IBM, PM or DM. We have wonderful guest speakers at our meetings and we encourage each other to stay positive and never give up!



Kicking and screaming, from page 3.

My serotonin level escalated to euphoria. Are there pool marathons? I wondered. Could I live at the YMCA and never leave the water? I wasn't sure how that would go over with the board of directors but one thing was certain: I was hooked.

The idea of buying some cute swim shoes for my early morning pool runs tempted me until I realized I had all the accessories I needed. A handicap-accessible parking permit dangling from the rearview mirror of my car and the sturdy cane clutched tightly in my right hand.



Making the move to assisted living: solves problems, creates others

Making the decision

Many of you are familiar with Mike Shirk, a retired copywriter in San Diego and long-time TMA member. Mike has IBM, and we have followed with interest his retirement success with art, as well as his ingenious solutions for everyday living. Mike's blog, "Life! Disabled," (www.lifedisabled.com) is a wonderful source of information for those making adaptations to their homes. Over the past few years, Mike has made many changes to allow him to continue with his art and accommodate the almost complete loss of muscle strength in his legs, arms and fingers.

Mike's situation was complicated when Beth, his wife and caregiver, also became disabled. Both Shirks have been in wheelchairs for a long time, Mike for 12 years and Beth for six, and they treasured their home and the accessibility modifications that Mike had added to the house over this time. They managed, as Mike says, by each being able to do just enough for the other for them to get by, until both of their conditions declined rapidly. Many myositis patients who are alone, as well as those with aging spouses, find themselves facing a similar decision as the Shirks: whether or not to move to assisted living.

What will it cost?

Mike started with the financial angle. Could he afford to move?

"I discovered that, to obtain adequate care within our home, we would need to spend about as much as it would cost to get assisted living outside the home," Mike said.

This isn't true in all cases, especially where there is a great deal of family help.

But he realized that wasn't the only financial consideration. "If we

remained where we were and continued to spend considerably more money than we had coming in, we would eventually reach the point where we had exhausted our savings and then what? We could sell the home, but then we would hardly have enough resources to maintain us in any other location for more than a few years. On the other hand, if we moved and spent down our savings, we could retain our home and rent it, which would provide additional income during that time. Then, when the savings were depleted, we could sell the home and continue to live in the assisted living facility for several more years."

Money Magazine wrote a comprehensive article about the state of assisted-living facilities a few years ago (See box on following page). They found then that the average assisted-living complex charges more than \$3,000 a month for basic services. Some of the more costly places

charge as much as \$6,000, often in addition to a substantial entry fee, which can be as much as hundreds of thousands of dollars. For many, this fee is not deductible: newer plans allow you or your family to "sell back" the apartment if you leave or die.

Don't make the mistake of assuming that Medicare and Medicaid will cover your assisted living. If you are trying to work out a budget, you'll also need to realize that in most states, an assisted-living complex can raise its prices at any time, and with little notice.

The *Money* article attributes this to a clumsy business model, which calls for a quick turnover, meaning quickly re-selling the beds as people die or leave for skilled nursing care (the next level, appropriate for people who need full-time nursing supervision, which is covered by Medicaid once income guidelines are met). When filled with

What is continuing care?

A continuing-care community generally has three levels of long-term care on one campus, and residents have the ability to move between them.

Independent living offers residents the chance to live in their own apartment, townhouse or house. This allows them to move in while still healthy, and offers incentives for those not as mobile as they used to be: lectures, bike and walking paths, social events, and exercise classes.

Assisted living provides help with daily tasks such as bathing and dressing. This is an important level to examine if you expect to need it. Many facilities use this level for mid-level Alzheimer's patients, so someone whose mind is intact may find it a lonely place.

Nursing care offers skilled nursing care for those who need more than assistance with daily tasks, and is likely to serve as a temporary place for those in assisted living who need rehabilitation after an injury or surgery.

Because of the difficulties presented by this model, newer communities are coming up with different plans, building larger apartments to accommodate family caregivers and offering other forms of nursing care at the assisted living level.

people who need a lot of assistance, but who are relatively stable, assisted living complexes find it hard to pay expenses.

Many assisted living facilities have strict guidelines about staying in that level of care, and insist a patient who needs more move to a higher level, either in their facility or another. A newer model allows people in assisted living to live out their lives in the same place, bringing extra services to them and having staff act as case managers. The exception is dementia patients, who need less medical intervention but more protection, and are moved to a separate area with more security. (See "What is continuing care, previous page).

Sometimes, the eviction of a resident who needs more care is not the choice of the assisted-living complex. In Florida, for example, an assisted-living facility with a basic license isn't allowed to tend to a resident who is bedridden for more than seven con-

secutive days.

Money found that another strategy employed by assisted living places is to charge residents a monthly rate to cover a basic set of services and add charges for care not included in the basic list. Services that you might think are covered in your definition of "assisted living" like distributing medication, arranging doctor's visits and providing transportation are sometimes extra charges, so read the fine print carefully. One family member was astonished to learn that she had to hire a night nurse whenever her father needed medication at night, or if he needed assistance getting to the bathroom. This is true even in some places at the "nursing care" level.

The key is to ask well ahead of time, in the interview process, what's covered by your contract and what's not. If you have special needs, find out exactly what it will cost and get it in writing. An article by the Muscular Dystrophy Association included inter-

views with family members who were charged additional fees when aids found it hard to understand a resident because of dentures or a weak voice. If the facility charges for something as basic as that, you might consider looking further.

There may be other unexpected expenses, too. Some devices are covered by Medicare as long as the patient is not in skilled nursing care, the theory being that aids for independence are not so important once you have 24-hour care.

An understanding of the financial demands of long-term care is sometimes hard to come by, and more recent rules make it harder to transfer assets in order to qualify for Medicaid. You may want to discuss your decision with an attorney, medicaid officials, and a social worker who specializes in senior care. If you're not sure where to find people skilled in this area, free, knowledgeable help is offered at area agencies

RESOURCES

Assisted Living Facilities

www.assistedlivingfacilities.org

Assisted Living Federation of America

(703) 691-8100

www.alfa.org

Assisted Living Directory

(866) 967-9270

www.assisted-living-directory.com

National Center for Assisted Living

(202) 842-4444

www.ahcancal.org

Section 8 Made Simple: Using the Housing Choice Voucher Program to Assist People with Disabilities, by Ann O'Hara and Emily Cooper, Technical Assistance Collaborative, 2003 (Free PDF download)

(617) 266-5657

U.S. Department of Housing and Urban Development

(202) 708-1112

www.hud.gov/offices/ftheo/disabilities/pwd.cfm

Know Your Rights, Access Board

(800) 872-2253

www.access-board.gov

ADAPT

(303) 733-9324

www.adapt.org

An advocacy organization promoting supported communities for people with disabilities.

Americans with Disabilities Act Mediation Program

(U.S. Department of Justice)

(888) 528-1609

www.ada.gov/mediate.htm

Disabled Rights: American Disability Policy and the Fight for Equality, by Jacqueline Vaughn Switzer, Georgetown University Press, 2003

Independent Living Research

Utilization project (ILRU)

Directory of Statewide Independent Living Councils (SILC)

(713) 520-0232

www.ilru.org/html/publications/directory/index.html

National Council on Disability

(202) 272-2004

www.ncd.gov

National Council on Independent Living

(877) 525-3400

www.ncil.org

on aging (available in every state; check the phone book under "senior services"). Counselors there provide information on federal and state programs and nursing home residents' rights under the law. Counselors also have lists of facilities, questions families should ask, and criteria for comparing facilities.

Read the resident contract very carefully and have a lawyer look it over before you sign.



What to expect?

Continuing care communities normally charge an entry fee, and all of them charge a monthly fee. These vary widely, even in the same community, depending on the size of the apartment and the number of services.

If there is an up-front cost, it generally runs from \$20,000 to \$1 million. The average cost is \$250,000, according to the National Investment Center for the Seniors Housing and Care Industry (NIC). In most cases, no equity is purchased with this expense.

Some places offer a standard monthly fee (about \$3,000) that remains stable no matter what level of care you are in. Others depend on your needs, and range from about \$2,500 for independent living to \$7,000 to \$8,000 for skilled nursing care according to Genworth Financial. Some fees are tax-deductible. There's also likely to be an annual increase of 3-6% in the monthly fee.

Find the right home for your needs

Like hotels, restaurants and hospitals, there are good and bad assisted living homes, and there are some steps you can take to find the situation right for you. Again, we turn to Mike Shirk to see how he chose his present home, Huntington Manor.

Know what's essential for you.

Faced with a monumental change, Mike wanted to keep some things familiar. He wanted to remain within the same general community, to stay with Beth, and for both of them to continue their art work. They both used power wheelchairs, so they needed ample space in doorways and rooms, and more space for art supplies and tables. Mike found more than 700 possibilities in his county, but he knew he would be restricted to a space that was willing to install an overhead lift system, so his choices were limited to a larger home, one that was accustomed to dealing with non-ambulatory residents.

Here's how he made his choice: "There are several large assisted living facilities in the county, but they have fire code restrictions that prevent them from accepting non-ambulatory residents. Most have associated skilled nursing facilities, which is where they suggested I stay, but that would totally restrict my freedom and be very expensive.

Also, because our needs were different, the large facilities planned to put my wife and I into two separate buildings. After eliminating hundreds of facilities, we came upon Huntington Manor, just five miles east, in Poway, California. At 27 residents it was neither large nor small, which for our needs was just right. What really caught my eye was their statement that they accepted non-ambulatory patients. Huntington Manor specializes in caring for the frail elderly and has done all of the necessary legal groundwork to be able to accept up to 21 residents who are unable to bear weight. Also, for the first time, I found a facility owner who was willing, even eager, to let me install an overhead lift system in my room."

Look behind the curtain. Mike checked out the available references for his future home, but he went farther than that. Before he signed the contract, he dropped by Huntington Manor many times unannounced, to

gauge the attitude of the staff, the cleanliness of the surroundings, and the quality of the meals, all when they weren't expecting scrutiny. It's especially important to find out how the place is staffed at night, when many assisted living places cut corners.

Money points out that even the best assisted-living complexes tend to staff their facilities with mostly unskilled workers, most of them personal aides working for close to the minimum wage. The folks who distribute medication need as little as 16 hours of classroom instruction in some states to qualify for the job. Even in Virginia, which is known for its strict rules, the training requirement jumps to just 48 hours.

Family and friends can also serve as advocates, coming at random times to see you. A vocal, concerned family is the best possible incentive for the assisted-living or nursing complex to be careful of your care.

Consumer Reports found that non-profit and independent nursing homes do a better job than for-profit organizations, including big chains. Its experts concluded that planning ahead is the best way to find a good spot. It doesn't hurt to get on the waiting list at several assisted living and nursing homes that you like, even if you're not sure you will need one.

Note the challenges and try to compensate. Because his assisted-living place was designed for non-ambulatory patients, Mike knew that most of the residents would be very old and infirm. He knew that most likely he and Beth would need to find companionship elsewhere, and he said the owner was direct in pointing this out to him. One thing Mike is doing as he settles in is working on on-line materials for Huntington Manor, including a blog about resident activities, and a soon-to-be-unveiled blog about cooking for the elderly.



ResearchReport

Current research of interest

New approaches to treatment

In "New approaches to the assessment and treatment of the idiopathic inflammatory myopathies," published in the British Medical Journal, TMA founding medical advisory board member Fred Miller makes a systematic review of past research.

Miller reports that prednisone is still the first treatment choice, that methotrexate and azathioprine are the most commonly used corticosteroid-sparing agents, and that hydroxychloroquine, mycophenolate, cyclosporin, tacrolimus, cyclophosphamide, and IVIG benefit some patients who do not respond. Miller also sees promise in biological agents, especially Rituximab, which has been effective even in difficult cases.

Miller notes that few studies have assessed combination immunosuppressive treatment in myositis, and calls for more research in this promising area.

Regarding IBM, Miller acknowledges the importance of physical therapy and exercise in long-term care.

He writes that new treatments for other diseases and new international collaborations and standards for outcome assessments provide hope for new treatments and better outcomes.

Find the complete journal article at www.myositis.org.

Calcinosis study recruiting

The Departments of Dermatology and Rheumatology at the George Washington University Medical Faculty Associates are conducting a 24 week study involving laser and a topical medication called sodium thiosulfate for treating superficial calcinosis, or calcium deposits in the skin, in individuals with adult or juvenile dermatomyositis who have not responded to other treatments. Participants must be between the ages of 18-65 years, have stable disease which is mildly active or in remission, and have failed at least one therapy for superficial calcinosis. The study consists of 8-10 treatments of laser and topical medication during the course of the study. Assessments, questionnaires, blood testing, imaging, and an optional skin biopsy will be

performed. Participants will receive \$25.00 per visit. There is no charge for the treatment and diagnostic tests. For enrollment call 1-202-741-2230.

Acthar for dermatomyositis and polymyositis

Acthar (H.P. Acthar Gel) was approved by the FDA in 1952 for use in 42 different conditions, including dermatomyositis and polymyositis. It works by helping your body produce its own natural steroid hormones, and may be used when other medications do not relieve symptoms or produce too many side effects. Its maker, Questcor, has a free service that provides training to patients on how to inject themselves.

In a small study, TMA medical advisory board member Dr. Todd Levine found that all five patients treated with Acthar improved.

To learn if you might benefit from Acthar, please consult your healthcare provider. Questcor supplies information on Acthar at www.questcor.com or www.acthar.com.