

The Outlook

FALL 2014

Quarterly Newsletter

Meet our Members

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Dear TMA member,

2014 is turning out to be a milestone year for The Myositis Association. We are excited by the ongoing trials for inclusion-body myositis and the increased interest of the pharmaceutical industry in treatments for dermatomyositis and polymyositis as well. We have now established a Forum on our website to enable those in the two IBM trials to share their experience with those interested in learning how they are doing. Final results from the trials will not be known until the trials are concluded and the data is analyzed. But for now, through the Clinical Trials Forum, you can get some sense of how patients in these trials are doing.

September 21 is the annual Myositis Awareness Day, and TMA has a significant effort underway to increase public awareness of myositis and to improve physician knowledge of this disease. Through the generosity of Questcor Pharmaceuticals, TMA has funding this year to make a major push to educate the public and physicians. Nearly 2,000 physicians are receiving copies of Myositis 101, our new Physician's Guide to Myositis, TMA disease brochures for IBM, DM, PM and JDM, and a poster to be placed in their office to direct patients to TMA who are looking for support and information. We are also providing our 45 support groups in the U.S. with these same materials as well as car magnets, wristbands, an advocacy newsletter, and other items to distribute to patients and the public to raise the visibility of our disease.

And don't forget Myositis Dan, the thoroughbred racehorse running to bring attention to myositis! He is having a great season and has won several races already. It is estimated that 5-10 million people will hear or see the word myositis just from watching Dan's races.

TMA will also soon be surveying its members to learn from you what we can do to better serve the myositis community. The feedback from the survey will help to shape future activities of the organization and allocation of funds. Please be sure to take a few minutes to share your thoughts with us through the survey.

We are trying to do more than ever to promote education, awareness, support, research and advocacy. Your support and assistance is vital to our success!

Best regards,



Bob Goldberg
Executive Director
The Myositis Association

Trials, treatments, and discussions

BYM 338 trial continues

TMA has been following the BYM338 trial for sporadic inclusion-body myositis and, after hearing from a few of the physicians conducting the trials that more spots had opened up in the U.S., sent out a notice to all IBM patients in the database. We encourage you to find a study center near you by going to www.clinicaltrials.gov; scrolling down toward the bottom of the page and clicking on the line "Show 43 Study Locations" for a drop-down menu of sites around the world.

The site unfortunately does not seem to be updated. Some of the sites that say "Not yet recruiting" are full; others may have been given some additional slots. Meanwhile, sites have been added around the world. Novartis asks that everyone call its main number, 1-888-669-6682, if they have questions.

Remember to also visit the Community Forum page where those interested can informally ask questions of those who have been in a drug trial. Go to www.myositis.org, click "community," then "Community Forum."

Stem Cell Therapy

TMA's Medical Advisory Board recently issued the following:

"Recent years have witnessed an explosion of stem cell 'therapy centers' that purport to cure diseases, including many forms of myositis. Lately, The Myositis Association (TMA) has received a number of inquiries regarding fat-derived stem cell treatments. These stem cell therapy centers promise to cure a myriad of diseases by using patients' own fat derived 'stem cells'."

TMA's Medical Advisory Board cautions against the use of such treatments, since there is very little scientific data to validate the claims that these stem cell treatments provide a viable treatment option or cure. Furthermore, there are risks associated with these treatments including potentially exacerbating the inflammation and thus worsening the underlying muscle disease, promoting tumor and cancer growth, and unnecessary risks to patients from the stress of surgery and anesthesia. The scientific evidence that these fat-derived stem cells stop the progression of myositis is non-existent, and favorable reports are based on purely anecdotal experiences, which have not been validated. If these treatments are to be tested,

they should be examined in a strictly research environment through a properly designed randomized clinical experimental trial.

Until there is scientific evidence supporting using fat-derived stem cells as a treatment for myositis, the potential risks outweigh the potential benefits."

Prednisone, rituximab, exercise

TMA presents quarterly online "live discussions" with international experts from TMA's Medical Advisory Board. During the summer series, we heard from medical advisors about new research regarding prednisone, rituximab and exercise.

If you are new to TMA, check our website for news of upcoming discussions. Have a previous engagement at the time of a discussion that interests you? No problem. Simply leave your question in advance and it will be answered in turn. Transcripts of sessions are posted shortly after each live discussion. Watch for news of the fall live discussion series. We also remind you via Facebook and Twitter. If you have a suggestion for a live discussion topic, email tma@myositis.org.

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Creativity eases pain, improves concentration

Although we've known instinctively for years that the creative arts broaden horizons, encourage honest expression and give people with chronic illness an increased sense of purpose, it's only recently that scientists have had the tools to track this phenomenon. Reports from patients, caregivers and health professionals confirm that music calms people who have experienced trauma, both physical and mental; the satisfaction of painting or pursuing other visual arts reduces pain; and performance art creates a sense of accomplishment in those who can no longer be as active as they were previously. Many hospitals and rehabilitation centers include various forms of creativity in their "alternative medicine" offerings.

Lately, as the number of people with chronic illness grows, this idea has captured public attention. One of 2013's bestselling books was Lissa Rankin's "Mind Over Medicine: Scientific Proof That You Can Heal Yourself." Rankin believes in the body's ability to guide its own healing. Rankin, a doctor and artist, includes so much research about the benefits of creative expression in her book that creativity as a tool for health hardly seems "alternative" at all.

When TMA invited members to talk about their experience with a new creative passion — one either discovered after their diagnosis or pursued with

greater dedication in the absence of other activities — patients responded enthusiastically. "When I start painting, I forget about everything else," said Jill Hartley, a young dermatomyositis patient.

That intense focus might be exactly the point, say art therapists. Today, more than half of the major medical centers in America have art therapy for pain management, relaxation, healing and quality of life. Creating from your own imagination, whether it's visual art, music, dance, poetry, drama or storytelling, helps people find their place among the rest of humanity during what can be a terrifying journey.

Jessie Park, the coordinator of Sanford Arts at Sanford's Cancer Center in Sioux Falls, SD, says that for art to be effective, it must be fun and playful. "If people sit down and strive to create a masterpiece, frustration can set in. Most adults simply don't consider themselves artists," she said. "When you present fine art to people, the first thing they think of is the critical business of looking at art. That introduces vulnerability and even fear." She suggests that anyone just starting out resolve that what they do is for their own enjoyment, not to be judged by themselves or others.

Traci, a DM patient, 54, who also has lupus, just started painting. "I never thought I could paint!" she said. "It is

fun and it helps me take my mind off the pain." How did Traci get started? "I googled 'how to paint in oil?' I feel we never stop learning!"

Keecha, also a myositis patient, has taken up painting, but in acrylic. She is definitely following Park's advice to have fun. "My stuff is random and I'll incorporate mixed media into my paintings." Keecha has already sold a painting.

Not only are these TMA members connecting on TMA's Facebook page, they are also inviting each other to join groups so they can view each other's work, giving their new hobbies a social as well as artistic aspect.

Art therapists are quick to point out that "healing" doesn't always mean "curing." Some patients who know they are seriously ill create art as a kind of heirloom, to be treasured after their death. Others, who may need long periods of infusion as part of their treatment for myositis, find that they're unable to focus on reading or other forms of busy work, but drawing, painting, sketching or creative needlework makes the time pass more quickly and distracts them from treatment that reminds them all too visibly that they are not well.

And for those hospitalized for long periods of recovery, art makes a difference. Stress levels decline, blood pres-





sure stabilizes, and nurses report better communication and effective pain management with patients. Also changed are patients attitudes: families and nursing staff report a big difference in the days that involve creative effort of some kind.

"I didn't set out to get any kind of help or comfort from my hobbies," says Tom, an IBM patient. "But there are things all through my life that weren't planned, including my IBM. I've always believed we were born to be involved, to DO something. When it came to the point that this was all I could do, that's what I did." Tom makes metal sculptures and has found another pleasant pursuit for days when he is able to be more active. He used to enjoy scuba diving and had to give it up because of his disease. He developed an interest in searching for historic artifacts. With a metal detector, he started looking for buried treasure where long-ago raiders approached the beach near his home. "I've found some interesting artifacts," he said. "If they aren't collectible, they become part of a sculpture."

Myositis patients Deanna Cross, Ray Dunton, Zachary Lewis and Mike Shirk found creative expression in writing. Deanna wrote an autobiography that included her struggle with chronic disease, Mike (who also produced gorgeous watercolors after his diagnosis with IBM) collected dozens of practical tips for those facing a gradual loss of independence and published them; Zachary wrote about his sometimes difficult path to improved strength and focus; and Ray published a collection of original thoughtful poems and observations. All are available on Amazon.

Others with a love for literature now find even more comfort in books. Myositis patients like Trudi and Mary now have time to do all the reading they put off over the years. Mary has embarked on a study of classic literature. "I have found substantial inspiration in the words that suffering people have written over the years," she said. "Loss and redemption are common themes, and losses from chronic disease are no different than others. You learn how to adjust and go on."

Some of you have embraced hobbies with a practical as well as a creative element. Teresa turned to quilting, Paula to embroidery, Connie started quilting when she could no longer garden or ride her horse. "Having something that I am passionate about is very good for the soul," she says. Becki has been quilting (and sewing) for more than 30 years, 21 of them since her diagnosis with DM: "I'm so thankful that I have something I love to do while being somewhat sedentary." Karen has found she gets a sense of accomplishment from doing household projects, one small project at a time.

Other newly-discovered hobbies — while not generally classified as artistic — demand focus, energy and interest and provide the same benefits. Tammy reconditions old smaller furniture pieces in the hope of reselling them for a profit, and has found her creations in great demand. Rachael raises backyard chickens, mostly rare or endangered breeds. "This gives me peace of mind and is great physical therapy," she says.

Diarra was a chef, and now, with reduced energy, uses her culinary skills for home cooking and has also embraced a new skill, learning how to make stained glass. Janet always loved to bake and now has more time for it; David has found that cooking fulfills his creative side.

Some TMA members have embraced the performing arts. Michael had to trade in heavier instruments for a keyboard, but is still able to indulge his love for music; Crystal has become active in local theatre, finding that the physical activity involved also makes her stronger. Natalie tries to conserve her energy for

See Creativity, page 7.



Exercising in water provides pain relief, safety, and strength

Exercise in the water provides extra resistance and has benefits for everyone wanting to strengthen muscles. For myositis patients, there are extra benefits, says Sheralee Beebe, a veteran aqua therapist who works with myositis patients and has taught the water sessions at several of TMA's Annual Patient Conferences.

"I have seen people with severely weakened quadriceps muscles able to get conditioning in the water that would never be possible on land," she said. "They can actually get a full range of motion, while not worrying about falling." She has found that the buoyancy of the water is particularly helpful for those with bad knees, allowing them to both bend and put weight on the knees without undue pressure on the joint.

"I've found also that, by adding weights and supports, we can provide a good workout for people who really can't exercise in any other way," she said. For those who need assistance from a caregiver, there's another positive aspect, Beebe said: "This is a way to avoid a caregiver being injured if the patient loses his or her balance. If it happens in the water, the water bears the weight." Beebe has found that most myositis patients, even those who are severely disabled on land, can successfully exercise in the water without a caregiver taking an active part.

Many TMA members exercise in the water and find it helpful. Here are some of their stories:

Bruce Gibbs has IBM and goes weekly to a hydrotherapy pool for a 30-minute session and finds it strengthens his legs significantly. "In particular," he said, "one end of the pool has steps in the floor and I walk forward and backwards up and down them, something impossible to do in the air." After 30 minutes, he finds that he's not too tired.

Kathy Corso Baker has been doing aerobics in the water for 16 months. "The first thing I noticed was a smoother gait," she said. "After about a year, my strength and endurance has improved to about 90% of normal. I hope I never need to quit."

When **Maryann Parker** was first sick, she did physical therapy in the water, including leg lifts, squats and water walking. "I used to be a lap swimmer," she said, "so the physical therapist worked with me until I could swim ten laps, then released me and I continued to swim laps a few times a week. Prior to DM I could swim a mile, and as my strength got better I worked my way back up to a mile, but I found it was too much because I was exhausted the next day. Now I swim a half a mile two times a week and it works for me, and helps with strength and aches and pains."

Marianne Durkin has IBM, diagnosed in the spring of 2012, and has done pool-based exercises one to three times a week and kept up with land-based exercises, on the recommendations of a physical therapist. "I do a variety of pool-based exercises, both in formal classes (stretching, aerobics and yoga) and individual exercises." Her water movements include mimicking exercises on land: walking, bicycling and cross-country skiing movements, leg, hamstring quad stretches, toe and heel rising stretches, stair stepping and sit-to-stands. The pools she uses are therapy pools and have built in side benches, and ramps.

"All I can say is, that while I have had one IBM knee-collapse fall, I am still very mobile, walk without any assistance and continue to work full time. And I (and my physical therapists) chalk much of that up to the pool and land-based exercises. With the help of flotation devices and a good therapist and the right therapy pool, just about anyone can do some pool-based activity, even if they are wheelchair bound," she says.

Emily Filmore has dermatomyositis and does aquatic therapy once each week. "It was supposed to be twice a week," she said, "but it was making me too tired and weak to work my muscles that much. I do leg lifts, lunges, rowing, squats, toe and heel lifts, arm exercises with paddles, arm pulses, and 'bicycle riding' against the current. I tested much stronger today than I did when I started but we will continue to go slow and easy so I don't get damage."

**Find an aqua therapist near you.
Go to www.physicaltherapists.com.**



Finding help

Finding an aquatic specialist can be very challenging depending on where you live, says Beebe, noting that the popularity of aquatic therapy has gone up and down in history. "It was popular during the polio epidemic and again during the Vietnam war," she said, "and variable in between." Aquatic therapy is always quite popular in Europe and south America.

Your ability to find a therapist may depend somewhat on its popularity in the area where you live. Beebe gives a few pointers:

- Look for low-level aquatic group classes, arthritis classes, water walking groups, or seek private sessions with an aquatic therapy professional.
- Learn the levels of qualifications that serve the aquatic fitness and wellness world. The aquatic physical therapist (licensed), the aquatic rehab specialist (non-licensed), a personal trainer or medical exercise specialist with some water training, or an aquatic fitness instructor with additional training from agencies like the Arthritis Foundation, are all possibilities. The aquatic physical therapist is the most qualified and holds a medical license. This practitioner may be the easiest to find in hospitals, rehabilitation facilities and private clinics, and may take insurance and medicare. Some tips:
 - You can seek a non-licensed aquatic specialist with aquatic therapy certification from www.arti.org, or find an aquatic exercise instructor certified by AEA (<http://www.aeawave.com>).
 - Most certification companies list their certified instructors or list facilities where their instructors teach. Some companies provide a question and answer service on their web sites. Try www.atri.org, www.aqua4balance.com, www.aquaticnet.com, or www.aquatic-therapy-university.com.
 - Search for swim pools in your area (YMCA's), check with hospitals, municipal, county or regional swim pools, and private pools. Warm water pools are expanding for children's swim lessons with companies like Petit Baleen (little whale). These pools, if approached, may allow adults during off hours to fill unused pool time. Inquire what the water temperature is (85 to 90 degrees is nice) and what programs they have to serve less fit populations or special needs populations. Ask first if they have a stair entry or a hydraulic lift.
 - The Arthritis Foundation and MS Society have approved water fitness programs, may certify instructors in your area, and may have helpful information.

Creativity, from page 5

her singing on good days. Listen to her at www.starnow.co.uk/nataiegerschowitz.

Those in remission from the disease that once robbed them of their strength pursue physical activity with a new passion. Paul has finished his first half-marathon and now is training for a full marathon next year. Rey thought she could never get on a bike again but then found an adult trike which enables her to ride again. Bill works out, skis and golfs constantly; Anupa says, "Exercise and cycling have become my passion and I think what keeps me from having tremendous weakness and other issues. I have to constantly push myself harder to reach my goals and in turn my muscle weakness reverses."

Many of you have found comfort and connection in volunteering, most often in social media advocacy roles, promoting awareness or offering one-on-one encouragement. Most TMA members mentioned hobbies that keep them connected to other people, but evidently creativity helps in ways even when it doesn't involve social interaction.

That has been the case for Rachael, a severely disabled polymyositis patient who lives on a farm in rural Nebraska. "I was raised in a tradition where everyone contributes," she writes. "So it was not unusual for me, like my mother and grandmother, to make quilts and quilted artwork when I could no longer garden or drive the tractor. I forget about my sorrows when I piece a beautiful pattern together, and it also helps somehow when others admire my work. I'm a yearly winner in our county fair, and one of my quilts was auctioned for a Mennonite relief sale and was the top money maker. People need to be productive, whatever their abilities."

Too much information?

by Andrea Taylor Langworthy

My mother often said someone or another would be rolling over in his or her grave at the thought of this or that. Mom will be topsy-turvy at what I'm about to share with you — toilet troubles.

When I was diagnosed with inclusion-body myositis, I wasn't surprised. My father, who'd passed away eight years before, had the same disease. I had watched Dad struggle to climb stairs and rise from a chair; when I began to experience the same problems, I was ready for the verdict. What I wasn't prepared for, though, because Dad would never have talked about it, was the toilet challenge. That every time I plopped myself down, I would have to pray for enough strength to get up again.

Before long, my husband and I had an elevated toilet installed in the master bath. Eventually, that wasn't tall enough so we removed the seat and added a five-inch-high molded plastic one with side arm supports. We left the right arm in place but removed the other. That way, I could turn to the left and secure that foot under the vanity's overhang while I gripped the tank lid with my left hand and pushed myself up with my right.

Public restrooms were problematic until I remembered a trick my mother taught me in a filthy gas station bathroom along a highway: the art of stand-

ing with my knees bent and hovering. Thanks to handicap-accessible stalls and their assist bars, this balancing act still works. I tried it at a friend's once — using my hand to steady myself against a wall because there was nothing else to hold onto — but the floor's black and white ceramic tile stared up at me menacingly, daring me to take a fall. That's



when my husband and I decided we would have to meet friends at restaurants or invite them to our home.

You may wonder, and Mom would hope

you don't dare ask: What if I had to, well, you know, sit down on a public porcelain pot? Despite the ever-present supply of Pepto-Bismol tablets in my pockets, it happened. During a meeting, my stomach's gurgling and churning indicated the pretty pink pills had failed. I grabbed my cane, asked a friend to safeguard my tote bag and did my best to hurry from the room.

In the hall, I debated: unisex single bathroom to my immediate left or women's room downstairs with an accessible stall equipped with multiple assist bars on both sides of the toilet? The elevator filled with the cacophony of my tumultuous tummy. "Please don't let me embarrass myself at this world-renowned literary center," I prayed. "And please, may that stall be available."

I sat down knowing I might have to call my husband, who was running errands, to rescue me. A bit later, I huffed and puffed, pushed and pulled to get myself up. As I admitted defeat, I realized my cell phone was in the bag I had left with my friend.

Finally, a door opened. Shoes appeared on the floor to my right. I apologized to the woman for interrupting but before I could ask her to make a call for me, she was done and scurried out. A bit later, I heard my friend ask, "Are you in here?" I explained my dilemma. She offered assistance. But I'm sitting on the toilet," I whimpered.

"We all do it," she said.

I aimed my cane towards the door and tried to slide open the lock. When it didn't reach, I leaned further forward and nearly fell from my perch.

My friend dropped to the floor, slithered under the door like a snake and rose like a phoenix, a victorious smile across her face. We worked like teamsters to get me standing and she held me up until my legs stopped wobbling.

That was the last time my husband dropped me off anywhere. The choice that day, using the multi-stall women's rest room with the non-locking entrance door had been fortuitous. Had I opted for the unisex room with its bolt-type lock on the inside, I would have had a front row seat to the maintenance man dismantling the door.

The last few years, I have avoided large ladies' rooms in favor of single-style ones where my husband can accompany me. Now, it's not just the toilets that scare me. It's soap dis-

pensers designed for weight lifters. Doors with locks too stiff to open or close with weakening hands. Concussion-causing stone floors pooled with water because the hand towel dispenser is across the room.

The truth is, I've come full circle. The only bathroom where I feel safe, the only toilet I want to use, is the one in my home. The exact feeling I had as a small child when I refused to use any potty but the one in my family's second floor duplex.

Years ago, I never would have told this story. I was raised to believe that disclosing or discussing bathroom-related issues is akin to airing dirty laundry in public. But sharing our stories and sharing a laugh about being trapped on a toilet will keep us from crying, right? And we all know, if we start crying, we may never stop.



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

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ACCREDITATIONS



Support for siblings

Teenage and young adult siblings of those with chronic diseases are often overlooked, but may be affected more than it appears, a recent British study showed.

Eight siblings of children with rare diseases (none of them myositis) were included in a series of interviews, using visual prompts as well as questions to engage them. The results showed clearly that siblings are greatly affected emotionally, pragmatically and relationally by the ill health of a child in the family.

The researchers found that four key themes ran through the lives of the siblings: perceptions of the condition and its symptoms, impact on daily life, emotional consequences, and ways of coping. The siblings often had researched and observed to the extent that they had considerable knowledge of the condition. Many of them had taken on important roles in the family in providing companionship and even managing the symptoms and rehabilitation of their ill sibling.

Researchers also found that siblings were acutely aware — not only of the severity of the disease — but also of the importance of protecting parents from discovering how much they knew. Far from resenting the time invested by the parents and other family members in the ill child, siblings often came to view their own needs as being relatively less important. As a consequence, relationships outside the family had a tendency to suffer as everyone became caught up in the very pressing issues at home. Siblings often reported feeling isolated, but also expressed the feeling that they could not identify very well with peers — whether at school, in the neighborhood or among young adult friends — who had what they considered frivolous lives, unencumbered by the day-to-day necessities of caregiving.

Even those who had gone on to marry expressed having less patience with spouses demanding attention for what they saw as fairly unimportant matters. Some of them expressed "feeling guilty" for leaving the family, whether it was for marriage, college, or to establish a household of their own, and they reported returning home for visits as often as they could. On the other hand, the siblings did not express a lower level of happiness than the population at large. In fact, all eight expressed some gratitude for the experience of assuming adult responsibility at a fairly young age.

Researchers suggested that siblings of children or young adults with a chronic illness find ways to connect with other siblings in the same situation and recommended that parents be aware of this need for support. They also recommended that teachers at the pre-college level be informed of home situations that demanded attention from young family members among their students.



New additions to the support community

by Charlia Sanchez

The Myositis Association has been expanding its support network in several ways, and encouraging all local support groups to plan events for September 21, Myositis Awareness Day. This fall, be sure to join in the effort to reach more myositis patients and their families. Find out how your local support group plans to recognize Myositis Awareness Day by going to www.myositis.org and clicking "events." If a group near you is hosting an event, invite your family and friends. Share information with neighbors in your community so that you can spread awareness about this disease, or come up with your own unique event to draw attention to myositis. To locate the closest support group, email tma@myositis.org.

If there is no support group near you, TMA can help with our new "virtual support groups." TMA introduced this concept, with a series of disease-specific conference calls, last spring, and will offer the series again, beginning this fall. In the meantime, those who are without a nearby support group

can visit TMA's Community Forum and Facebook page to keep in touch with other myositis members and friends.

In addition to improving its virtual support offerings, TMA is establishing an organized support network in Canada. On TMA's website, you can now find a Myositis-Canada support group page in English, with a link to the French translation. There's also a translation of TMA's myositis brochure in French and there will be a Spanish translation available later this year.

Finally, do you have a suggestion for TMA? Is there anything about our current programs and services that you enjoy or would like to see changed? TMA has designed a Member Survey to help us improve service and respond to patient needs. The survey will be available online and in print. If you would like more information about this member survey, or to get a hard copy, call 1-800-821-7356.



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TMA, with the help of Questcor Pharmaceuticals, has published a special newsletter, "The Advocate." If you want some ideas for advocacy and publicizing myositis on Myositis Awareness Day or any day, email TMA, tma@myositis.org.



In memory Betty Curry, TMA's founder, dies



Just before The OutLook went to print, we learned that Betty Curry, TMA's founder, died August 9 in a Harrisonburg, VA retirement home. Betty was born in 1928 in Illinois.

She was a successful realtor, entrepreneur and artist before her diagnosis of inclusion-body myositis in 1993. She tackled the disease with the same energy and optimism that characterized all her endeavors. Her first step in establishing the non-profit that later became TMA was to publish the first issue of this newsletter from a tiny office in the basement of her Harrisonburg home, using a mailing list she pieced together from the National Institutes of Health and the National Organization for Rare Disorders.

Betty loved to tell stories about her enrollment in a clinical trial at NIH. Realizing that she would never find so many myositis patients in one place again, she went from room to room in a hospital gown and slippers to recruit the first members of the organization's board of directors.

While there, she also recruited the nonprofit's medical advisory board from the doctors running the trial.

No one could say no to Betty. Admirers described her as "a force of nature."

She persisted in her idea of a non-profit devoted solely to myositis and steered the organization through its early days. She expanded the medical advisory board, recruited friends and relatives to volunteer, searched out national and international experts and oversaw every detail until TMA had its own office and paid staff. She retired as executive director in 2000 and pursued other projects with the same energy and determination.

In keeping with Betty's philosophy, her family requests that her friends and admirers think of Betty the next time they believe they can't do something, and then go ahead and do it anyway.

Lindsey Funeral Home in Harrisonburg has set up a website for Betty's friends to remember her and leave messages for the family at www.lindseyharrisonburg.com.