The Myositis Association

THE OUTLOOK

SPRING 2008

For the inflammatory myopathies

Matching Research Challenge Nets $400,000

The 2007 Matching Research Challenge proved very successful. The Challenge, offered by an anonymous TMA member, inspired more than 350 people to contribute last year as well as several new campaigns to raise funds.

The member who offered to match $500,000 in research donations in 2007 hoped this would provide TMA with an additional $1 million for research. He would still like to see TMA reach that goal and has generously agreed to extend the Challenge into 2008.

He is offering to match up to $300,000 this year and hopes that at the end of 2008 TMA will have another $600,000 to fund promising myositis research. Because of the expense of research and his desire to raise money quickly, he will only match donations of $150 or more but will match 2:1 any donation of $15,000 or more – your gift of $15,000 will yield a total of $45,000 more for myositis research!

Also, since there have been exciting developments in the applicability of gene therapy to myositis, the donor has requested that $200,000 of his money contributed in 2008 be directed toward gene therapy research which has promise to benefit all forms of myositis.

Help TMA meet the goal of raising $1 million by contributing to the Matching Research Challenge. To do so, mail in a check along with a note that the donation is for the Matching Research Challenge. Or, you can use a credit card to contribute by calling TMA at 1-800-821-7356 or going online to www.myositis.org.

TMA: 15 years later

Break out the fancy glasses and propose a toast. TMA is celebrating its 15th (crystal) Anniversary, marking a decade and a half of tremendous significance and progress for people with myositis. Those who have received our mailings already know that TMA is doing a lot with the number "15" during its international celebration, which will go on through the year and culminate with the Annual Conference in Denver on September 18-21.

Some of the Anniversary events have been revealed; others will unfold throughout the spring and summer, finishing with some additional surprises at the Conference, which is expected to be the biggest in TMA's history. Some key Anniversary events so far:

$15 of all TMA full memberships - both renewals and new members - will go towards myositis research. Renew today, and help TMA in its mission to find better treatments and a cure for myositis. This Anniversary research initiative is expected to raise more than $25,000 for the grants and fellowships TMA's board of directors awards to promising veteran and new scientists each year. For more news on TMA's current research program, see pages 4 and 5.

To make the Annual Conference - and the spectacular 15th Anniversary-Myositis Day celebration -- affordable for all, TMA has set a special Anniversary rate during 2008 only. If you have always wanted to attend but couldn't quite afford it, TMA offers a $15 registration fee. That's four days of information, celebration and support, and includes Conference breakfasts, lunch and the 15th Anniversary reception.

Many of you can afford the standard Conference fee, and regularly attend. For you, TMA offers a registration fee of $150 - lower than last year's and available anytime until June 15. By now you should have received a Conference brochure, register now to make this deadline.

When you register you'll be automatically entered into our Anniversary lottery. The 15th, 150th, 200th, 250th, and 300th person to register will have their registration refunded. They will be our guests and attend for free.

Keep-in-Touch (KIT) support group members will have a chance for more TMA "lucky 15" surprises. Groups who have more 15 or more members attending the Conference will get a $15 gift card for each member in their KIT that are TMA members. See more details on this incentive, page 8.

15th Anniversary

Research, Education, Advocacy, Support

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New directors bring de and diversity to TMA's

The Myositis Association began 2008 by saying goodbye to three dedicated board members. Terms ended for Board Chairman Janet Schuler, long-time TMA member and caregiver for her husband, Dan; Janice Goodell, who introduced myositis awareness day in 2001 with her annual walk in Massachusetts; and Dr. Chet Oddis, a TMA medical advisor who served as the medical advisors' representative on the board of directors.

At TMA's annual research review in Washington, DC, Executive Director Bob Goldberg thanked the departing members, saying all three were known for their activism and accessibility.

Dr. Oddis will remain on TMA's Medical Advisory Board. Dr. Lawrence Phillips, former chairman of the MAB's Research Committee, will replace Dr. Oddis as liaison to the Board of Directors.

Returning to the board are two former members: retired San Diego accountant **Earl Klein**; and Charlotte accountant **Richard Bullard**, both IBM patients.

TMA added five more board members, chosen for their diverse experience, skills and interests:

Keli Roberts is a personal trainer and fitness instructor in Tujunga, California, and teaches at the Equinox Fitness Club in Pasadena. She is a gold-certified personal trainer and group fitness instructor, having received certification for each at the American Council on Exercise. She is also certified by the American College of Sports Medicine as a Health and Fitness Instructor and is AAFA certified. She has served on the boards of for the Nautilus Institute and *Fitness Magazine*. Keli is a champion bicyclist when her disease allows. As a polymyositis patient, Keli brings personal experience as well as physiological and fitness expertise to the Board.

As an advocate for myositis patients, **Mary Jane Delauder** brings firsthand experience to her board appointment. Delauder, who lives in Florida, has an impressive nursing background. She earned her AAS from County College of Morris Nursing Program in 1983. She has served in oncology and psychiatric units as an occupational nurse, and is an RN in psychiatric case management. She sees herself as a "recipient" of her IBM diagnosis and participated in a Campath clinical trial at NIH. She says she has "real life experiences with regard to the challenges, trials and tribulations of the myositis patient," experiences that will help her be an effective board member.

Madeline Franklin lives in Baltimore, Maryland. She has IBM, but her disease does not stop her involvement in the community. Since the '80s, she has served continuously on boards and in clubs, including the Mother Seton House, the Town & Country Garden Club, The Friends School of Baltimore, the Maryland Historical Society, and St. Joseph's Medical Center in Baltimore. Her goal on the board is to increase public awareness and outreach to the myositis community. As a board member, she plans to encourage fundraising and other support in the search to find a cure for myositis.

In his own words, **John Gallagher** sees his IBM diagnosis as something that hasn't demeaned his life and acknowledges he has "positive opportunities still in front of me." Gallagher, who has an engineering background, retired from Eastman Kodak in 2001. While employed with Kodak, he served in increasingly responsible positions, including vice president and chief operating officer of Kodak's Office Imaging Division.

See ***TMA Board of DIrectors**, page 7*

Why celebrate?

In 1993, when Betty Curry started the Inclusion Body Myositis Association (which later grew to include the other forms of myositis and changed its name), it was an all-volunteer operation in the basement of her Harrisonburg, Virginia home. By any measures, the world then was a completely different place for myositis patients than it is today Mapping of the human genome was in its early stages, and coincidentally was being led at NIH by Betty's Shenandoah Valley neighbor, Francis Collins.

Many rheumatologists maintained that "DM is simply PM with a rash," and patients, even those in remission, were counseled to avoid exercise. Few IBM patients were correctly diagnosed. Most of the early IBM members reported they had been originally told they had ALS (Lou Gehrig's Disease), or polymyositis.

The organization changed its name twice, sponsored conferences and support groups, funded research and moved to Washington, DC. The effect of the collective efforts of hundreds of myositis patients can't be measured objectively: there are as many stories as there are members. But it is possible to note some of the milestones in myositis history during those 15 years.

1993

"The OutLook" newsletter, still published quarterly, was established to educate patients and families.

1994

The Board of Directors met in person for the first time, in Washington, DC.

1995

The first Conference for patients was scheduled; and the first internet presence, hosted by a neurology practice, demonstrates the growing power of the world wide web.

1996

IBMA changed its name to the Myositis Association of America. Rheumatologists and dermatologists familiar with other forms of myositis joined the Medical Advisory Board

1997

MAA grew substantially and supported its own web site. For the first time, the Annual Conference included juvenile myositis patients and families.

1998

The JM "Messenger" was published, and the first JM support group was formed.

1999

Support groups grew in number and size and began public advocacy for myositis and other rare diseases.

2000

MAA's board of directors made a commitment to funding myositis research.

2001

The first myositis awareness day was established in Massachusetts; September 21 was adopted as the day for this observance. A $1.6 million bequest began MAA's research program in earnest.

2002

MAA changed its name to The Myositis Association, to reflect a growing international membership and medical collaboration. The first round of TMA-sponsored research was awarded for a total of $1 million. Research has been funded every year since and now approaches $3 million.

2003

Work began on "Myositis and You," a complete compilation of information and resources for the Juvenile Myositis community. Scientists at NIH finished mapping the human genome and shortly afterwards identified the genetic profile of hereditary IBM. The TMA office moved to Washington, DC.

2004

After a series of international consensus workshops over nearly ten years, the International Myositis Assessment and Clinical Studies Group (IMACS) validated the preliminary definitions of improvement for adult and juvenile myositis. This very important accomplishment makes objective measurement in drug trials possible.

2005

An historic symposium brought together the best international minds to discuss IBM in a collaborative, interdisciplinary manner. The following January, *Neurology* published a 60-page supplement with the proceedings distributed to 22,000 neurologists worldwide. A TMA member sponsored the first face-to-face meeting of the Medical Advisory Board, an event that has continued each year thereafter.

2006

The U.S. House of Representatives passed a resolution designating September 21 as National Myositis Awareness Day. TMA published "Myositis and You."

2007

Myositis was "discovered" as a "mystery" disease, with unprecedented coverage in broadcast and print media. Medical advisors noted the growing importance of myositis-associated antibodies in predicting outcomes; and continue to find relationships between myositis and cancer. A multi-center trial of the potential myositis drug rituximab began.

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UPDATES ON TMA RESEARCH

TMA's Board of Directors approves DM research fellowship, IBM grant

Every year, TMA brings its medical advisors, board members and researchers together for a unique two-day session devoted to discussion and approval of research proposals, and updates on ongoing and completed research. This face-to-face meeting of those at the forefront of myositis research is made possible by the generosity of one of TMA's members, and fosters a spirit of innovation and collaboration.

This is TMA's sixth year of funding research, and with the award of a new fellowship and research grant the organization has now funded 26 projects for a total of nearly $3 million. On the recommendation of its medical advisors, TMA's board of directors met in mid-January and made two research awards this year.

Dr. Eun-Ha Kang, a postdoctoral associate in the Division of Rheumatology and Clinical Immunology, Department of Medicine at the University of Pittsburgh School of Medicine was awarded a fellowship of $100,000 over two years for the project "Characterization of CD4+CD8+ double positive T Cells in DM."

Dr. Mirabella Massimiliano, coordinator of the Inflammatory Myopathies Outpatients Clinic and Chief of the Laboratory for Diagnosis and Research on Inflammatory Myopathies, Stem Cells and Muscle Regeneration at the Catholic University's Department of Neuroscience in Rome, Italy was awarded $100,000 over two years for the project, "Exploring a stem cell-based muscle regenerative therapy for Inclusion-Body Myositis: preclinical studies on ex vivo treatment and in vivo bioimaging of IBM mesoangioblasts."

Recruitment complete for in tive new IBM brace study

Terry Oh, MD, an assistant professor of physical medicine and rehabilitation at Mayo Clinic in Rochester, Minnesota, is studying whether "Stance Control Orthosis" is effective for people with IBM and knee instability funded through a TMA research grant. She is midway through a two-year study examining the effectiveness of a new brace designed to prevent falls in those with IBM.

The new brace design, called "Stance Control Orthosis," seems ideal for people with IBM and knee instability, Dr. Oh said. Those who will wear the new brace are representative of the IBM community as a whole. There are seven men and one woman, ages 42-74; and all have had problems with falling. One of them has fallen more than 100 times in the past year. Half of them presently use a cane for balance. One man fell before the test began and had so many complications he couldn't continue in the study. All the participants will wear the brace on their left leg.

The recruits will wear the brace for six months and then return for a follow-up visit. They will go through a number of evaluations both before and after they are fitted for the brace, and researchers will judge the effect of the brace on each person's gait, the relationship between how changes in their gait affects their life, and how well they manage with the brace.

Once these answers are established, researchers will question whether using a brace in one leg is adequate to prevent falls and maintain activity; and whether braces on two legs would be more or less helpful. They'll also see how helpful the brace is for climbing stairs; whether users, once accustomed to the brace, can continue activities such as golf.

Research tracks muscle changes mice and monkey models

Drs. Brian Kaspar, PhD, and Jerry Mendell, MD, both of the Columbus Children's Research Institute, have successfully enlarged and strengthened the quadriceps muscle in mice by using a common virus to carry a follistatin gene into the quadriceps muscle. Follistatin is the substance that blocks myostatin, which is associated with loss of muscle mass. Drs. Kaspar and Mendell are at the midpoint of their research to test whether such gene therapy might be used to help IBM patients who lose muscle mass and strength. Dr. Mendell reported on the trial's progress at TMA's January meeting of its Medical Advisory Board. Some of the tests of the treated monkeys and mice have shown noticeable increases in muscle size and strength. This animal research is intended to be a preliminary step towards a human trial.

Two-year research on molecular pathogenesis of IBM concludes

Hanns Lochmueller, MD, and Sabine Krause, MD, PhD of the Friedrich-Baur Institute at the Ludwig-Maximilians-University in Munich, concluded their study of the molecular pathogenesis of sporadic and hereditary IBM. Dr. Krause reported their findings at the January research meeting. The study, which was funded at $164,000 over two years, built on some of the recently-discovered information about the genes of patients with hereditary IBM. An earlier fellowship by Dr. Krause concluded that normal muscle expresses GNE - a gene that codes for an enzyme involved in several cellular processes - in two compartments of the cell. Drs. Lochmueller and Strauss studied both types of IBM to better understand the function and malfunction of the GNE gene in hopes of discovering new avenues for therapy. The researchers looked at a series of 50 outcomes in both sporadic and hereditary IBM over two years.

Ask the doctor

Can a cholesterol-rich diet IBM in rabbits?

Some IBM patients were interested in a report published in the January edition of the online version of the American Journal of Physiology. A team of scientists from the University of North Dakota explored the relationship between cholesterol and IBM, a puzzling and indirect connection that's also been cited in Alzheimer's disease. Elements of this relationship have been studied for years by Dr. Valerie Askanas and others.

In the Grand Forks study, rabbits were fed cholesterol-enriched diets to see if they would show human-like IBM features. In the skeletal muscle of one-third of the female rabbits on this diet, researchers found features of IBM, including IBM's signature vacuolated muscle fibers, increased numbers of inflammatory cells, and a number of other changes consistent with IBM in humans. The researchers believed they had found an important new model with which to study IBM.

TMA's advisors say

After reviewing the paper, several myositis experts pointed out that the vacuoles the authors claim may not be real IBM vacuoles but are likely freezing artifacts generated during muscle sample processing and, therefore, the conclusions may not be accurate.

Dr. Kanneboyina Nagaraju, the director of the Murine Drug Testing Facility at The Research Center for Genetic Medicine at Children's National Medical Center explains the freezing process: "Normally, muscle samples collected from experimental animals or patient tissues need to be frozen immediately in isopentane chilled to -150 degrees Celsius by liquid nitrogen. The frozen tissue is generally stored at -70 freezers until cut into small sections for staining and visualization under microscope. The ice crystal formation occurs in the muscle tissue for reasons such as slow freezing over several minutes at higher temperatures, improper storage, repeated freezing and thawing. For examples, ice crystal growth rarely occurs at -150, very slowly at-70, relatively slowly at -40 and quickly at -20. Ice crystal growth results in the vacuoles in muscle fiber and degrades the quality of frozen sections if adequate precautions are not taken while handling the frozen muscle tissue."

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TMA Board Member is 'be doctor'

Dr. Lawrence H. Phillips II, Director of the Neuromuscular Diseases section of the Department of Neurology at the University of Virginia, has been named to the list of Best Doctors in America by Best Doctors, Inc. He has also been named Editor and Chief of Muscle & Nerve, the official journal of The American Association of Neuromuscular & Electrodiagnostic Medicine. "Best Doctors" are chosen through a comprehensive peer-review survey that asks: "If you or a loved one needed a doctor in your specialty, to whom would you refer them?" The database represents the top 3 to 5 percent of physicians in more than 400 medical subspecialties.

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Experts join TMA Medica Advisory Board

Dr. Robert L. Wortmann, Professor of Medicine at Dartmouth Hitchcock Medical Center in Lebanon, New Hampshire, assumed the chairmanship of TMA's Medical Advisory Board, replacing Dr. Richard Barohn in 2008.

TMA also added six new medical advisors to its medical advisory board: one dermatologist, three rheumatologists and two neurologists, bringing the number of advisors to 20.

Robert Cooper, M.D., Rheumatology

Dr. Cooper delivers lectures to family doctors and patient special interest groups on rheumatological problems as well as mentoring final year medical students. He is a consultant and Honorary Senior Lecturer in Rheumatology at Hope Hospital and Manchester University in the United Kingdom. He went to medical school at The University of Manchester.

Brian Feldman, M.D., Pediatric Rheumatology

Dr. Feldman is the Acting Head for the Division of Rheumatology at the Hospital for Sick Children. He is the Senior Scientist for the Health Sciences Program at the Hospital For Sick Children Research Institute. Feldman is a professor at the University of Toronto for the Institute of Medical Science and the Graduate Department of Public Health Sciences. He received his MD at the University of Western Ontario.

David Fiorentino, M.D., Dermatology

Dr. Fiorentino did his undergraduate work at Stanford. Both his masters and Ph.D are from Stanford University Medical School. His residency was done at Stanford, where he currently teaches as Assistant Professor of Medicine. He also currently works at Lucile Packard Children's Hospital and Palo Alto Veteran's Hospital. In March, 2007, Dr. Fiorentino has been named to the list of "Best Doctors in America" by a survey of his peers.

Gerald Jan David Hengstman, M.D., Neurology

Dr. Hengstman is a Clinical Neurologist in the Department of Neurology at Radboud University. His emphasis is in neuromuscular dis-

*See **TMA Medical Advisors** page 7.*

Myositis veterans encourage others to plan ahead

IBM patients share experiences with bathroom devices

Linda Metz, an IBM patient from Southern New Jersey, began her story on TMA's bulletin board (on TMA's website at www.myositis.org), and later elaborated on her search for bathroom independence for the OutLook. Her moral: in retrospect, she said, she should have spent less time and money on pieces of equipment that turned out to be good for only temporary assistance, and focused on the big picture. "Our mistake was not really understanding how disabled I was to become," she said. "Therefore, we purchased equipment that did not work in the long term."

Her story struck a chord with other members. Her progression through a number of arrangements is a common theme with TMA's members, especially those with IBM.

"Initially I used a toilet safety frame which worked for a while, but even with the addition of a plastic high toilet seat it became too difficult to get up," Metz said. Her husband installed a handicapped toilet over a toilevator, which was also successful for a time.

When these aids weren't quite enough as her arms got weaker, a "butt booster" and a "tuss push" were added.

"This was no small investment, especially the tuss push," Metz said. She remembers it cost about $700.00 and met her needs for a while. As she lost strength and stability, she needed more than the tuss push could offer to stay steady on her feet. Like other IBM patients, she found many devices that lift also tend to pitch forward, requiring muscles she didn't have to stop herself from falling forward.

Metz now uses a toilet lift called a "Mobile Carianna," an electric-powered lift made by Apex (www.worldwideseating.com) that has carried her successfully up and down for a very long period of time. It wasn't inexpensive - Metz said it cost about $1300 - but she feels confident it will meet her needs for years. The mobile model is a smaller version of the Apexlift Carianna, and is recommended for smaller bathrooms, or it can be used as a bedside commode. The seat lifts Metz high enough to stand, pivot with the aid of a pole and re-seat herself in her Jazzy 1103 (a power wheelchair). "The unit is very strong and stable," Metz said, "so I feel safe and secure each time I use the toilet."

The poles are called "super pole grab assist bars" and are available from medical suppliers. Find out more at www.healthcraftproducts.com. "We would have been smart to make most of these purchases initially," Metz said, "save the money we spent on the in-between products, and not have a basement of toilet lifts looking for homes."

Short bathroom tips

- Dianne Shaw, wife of an IBM patient, also has a basement full of discarded devices and wishes she had bought the automated lift immediately. She ultimately got a Papi Lift from Clarke Medical (www.clarkemedical.com) with a battery backup. This lift is also designed to fold up and transport when traveling.

- To shower, Jack, an IBM patient, uses a roll-in shower chair with big wheelchair wheels and a Rubbermaid bedside commode (one source: www.medsupplyco.com), recommending this one for cleanliness, strength and adjustable height. Some models may also be used over an existing toilet.

- Metz has found, and other members agree, that it's easier for the IBM patient to wear clothing that's easily removed, especially as their arm muscles get weaker.

- Jan Schuler, former TMA board chair, and wife and caregiver for an IBM patient, installed a bidet so her husband would be able to clean himself. She recommends the Toto 300 (www.totousa.com) which is easy to install and use.

- Special hinges save the day when bathroom doorways need to be widened for wheelchairs. It's possible to gain several inches simply by remounting the door.

Lifts help patients and caregi throughout the house

Members use both the Hoyer lift (a portable floor lift) and permanent ceiling tracks which are stationery. Linda Metz has ceiling tracks in both her bedroom and bathroom, and these have eliminated the need for her to re-do her bathroom or take out the tub. The lift sets her in the tub and on the toilet. "These are best for me," she says, "since I don't travel anymore." She does have one portable (Hoyer) lift so that if she falls down in a place where there are no fixed rails, her husband can wheel the lift to where she has fallen.

There are different types of slings to use with lifts. Many members prefer the "whole body sling" for the security it offers. Lifts are available both with and without power assistance, and at a huge range of prices. TMA members have recommended Apex as a source for medical products: http://www.apexmedical.com/.

On the road with a lift

The Hoyer Pro Stand Aid 300 used by many IBM patients has an anti-slip footboard, adjustable padded knee supports, and large caster wheels for easy rolling. It comes with medium and large long-back slings. This model is a little easier on the caregiver because it uses a sling that goes around the user's back, so it does not require any manual lifting of the patient when getting ready for transfer.

This lift is operated by a hand control and powered by a rechargeable battery pack that gives an audible warning signal when the battery is low. There's also an emergency lowering feature if the battery should wear out while the patient is in the lifted position. Sally, an IBM caregiver, says this has been especially easy for her to use.

Brad Bent gives some ideas for traveling with a lift. Bent takes his "Pro" on trips, separating the base from the mast, and leaving the mast fully extended to fit easily in his van. He packs a three-foot portable ramp, and when they get to the motel, they remove the base, slide the mast into its slot, and lay the portable ramp over the base, stacking the luggage on to get it into the room.

A good night's sleep

The ordinary hospital beds paid for by Medicare are not recommended by members with IBM, because the positions available do not really address the needs of myositis patients. Some members have been able to get Medicare to pay for a bed called the "Flex-a-Bed" (www.flexabed.com), They prefer the model called the "high-low" bed. Some who decided on a lift by their bed have found they do not need a different bed, but use the lift to transfer into the chair. Others say the combination of the flexabed and the bedside lift is the most workable.

Another member uses a "hi-lo bed" (Valiant series from Transfer Master, www.transfermaster.com) but adds that she cannot get out of it unassisted and also uses a lift.

* * *

TMA Board of Directors,

continued from page 2

His position took him all over the world, and he is a frequent traveler in his retirement. As both a patient and an avid traveler, Gallagher's interests are finding a cure for myositis and also increasing the information and resources available to international myositis patients. He has an interest in extending the use of technology to cost-effectively link members to each other and to sources of experience and knowledge.

Stephen Nichols is a passionate advocate for myositis patients, awareness, fundraising, and the Association as a whole. He serves as a KIT leader in the San Francisco/Sacramento areas. He served on TMA's Program and Services Committee and continues to develop programs to enhance TMA and serve its members. At the 2007 Seattle meeting, his KIT group had 10 members in attendance. While at the conference, he facilitated the DM "Get Acquainted" session and donated a painting for auction. For Myositis Awareness Day last year, he worked with his local paper on a front-page article for the Health section. He brings diversity, zeal, and knowledge to his new role, and plans to continue his active participation in board activities, special events, and meetings.

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TMA Medical Advisors,

continued from page 5

eases and neuroimmunology. Hengstman is part of the Myositis Study Group in Nijmegen, The Netherlands. He received both his MD and PhD from Radboud University Medical School.

Todd Levine, M.D., Neurology

Dr. Levine is the Co-Director of Samaritan Peripheral Neuropathy Center, Director of Samaritan Stroke Clinic, Director of Samaritan ALS Clinic and Director of Neurophysiology at Good Samaritan Hospital as well as Assistant Professor of Clinical Neurology at the University of Arizona. He is on the Medical Board of Directors for the Neuropathy Action Foundation. Levine has his M.D. from Duke University.

Steven Ytterberg, M.D., Rheumatology

Dr. Ytterberg is a consultant at the Mayo Clinic and the Associate Professor at the Mayo Clinic College of Medicine. He is on the American Board of Internal Medicine, Subspecialty Board on Rheumatology. His M.D. is from Jefferson Medical College.

To make room on the Medical Advisory Board for the members above, six current Medical Advisors who contributed greatly to the growth of TMA's research program during the past several years, reached the limit of six consecutive years of serving on the Board. TMA is indebted to each of them and looks forward to some of them returning to the Medical Advisory Board in the years ahead.

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SHOP TO SUPPORT TMA

Have you visited TMA's online marketplace recently? If not, you're missing out! In addition to valuable health resources like the books, *Myositis and You*, *Living with Myositis*, *Coping with Prednisone*, and more, TMA offers awareness and gift items as well.

Purchase myositis ribbon magnets for your car, order handblown glass hummingbird feeders as gifts for your friends, and know that all of the money you spend goes to support The Myositis Association.

Enjoy giving!

TMA welcomes new staff

Alyson Casey is the new office assistant for The Myositis Association. She joins TMA staff after spending time in Anchorage, Alaska, as a volunteer at a shelter for abused women. Casey was born and raised in Washington, D.C and graduated from Marymount University in 2005. After her Alaska experience, Casey wanted to continue her career in a non-profit setting. "I have the pleasure of working with people who strive to make a difference and working daily towards finding the cure for this debilitating disease," she says. "I'm excited to be on board and working with all of you."

Quineesa Smith is TMA's new member services manager, and some members have met her already through email and telephone calls. "In any case, I'm excited to be a part of TMA and its amazing group of members and volunteer leaders," Smith says. "I've worked with nonprofits for more than eight years now." She's worked with large associations like the American Red Cross and smaller associations more like TMA. "My hope is to bring a blend of what I've learned over the years to TMA, and do my best to assist you when and where needed," she said. Smith can be reached by email at quineesa@myositis.org and by phone at (800) 821-7356 ext. 502.

"A wonderful opportunity lies ahead of us," Smith says, "and if we work together, I believe we can accomplish some phenomenal goals for TMA, myositis research, and helping to find a cure!"

Support groups gear up

By Quineesa Smith

As I write this we are looking for new and better things for TMA's KIT groups. Groups are experiencing growth, increased public awareness, and even the good fortune to have medical professionals give presentations at meetings.

The TMA staff will be conducting quarterly conference calls with KIT representatives. The calls provide the opportunity to discuss effective group meeting organization, see what's working and what's not working, learn from fellow KIT representatives, and ensure that we are all working toward the goal of making all the KIT groups good… better… BEST!

This year, some KIT groups have new leaders, while some KITs still need group leaders. Those groups needing leaders will (if not already) be contacted by me to seek new candidates. So if you're interested in leading your group, call or send an email to let me know.

There's also been interest in starting new groups, as they've been paired with another state and now are ready to burgeon off on their own. We are definitely looking forward to the extension of our KIT support group network.

As myositis is a disease that is highly unpredictable, TMA understands that the duties of being a KIT representative can sometimes become too much. Dealing with doctor visits, treatments, and physical therapy, while trying to maintain your home, family, and for some, a job, can take its toll. So, if you're a KIT rep who's presently experiencing some difficulty maintaining your group, please let me know. It may be that you need a brief hiatus from your duties or you may feel you need to resign.

KIT rep positions are purely voluntary and accepted with the assumption that your health will allow you the time and opportunity to serve. All service to TMA is always appreciated.

What's your KIT planning for Myositis Awareness Day? Any special ways you plan to acknowledge the 15th Anniversary of TMA? Do you have any contacts with your local media? Have any ideas for a cool fundraiser?

As some of you move into your second or third meetings of the year, these are some of the questions you should begin to ask yourself. As you think of them, write your ideas down and then take them with you to your next KIT meeting.

Some activities other KIT groups are coordinating are motorcycle rides, restaurant or movie-theater nights, (where a portion of the night's proceeds are donated), telethons with local radio stations, golf tournaments, and other events. And don't forget to let the media know what you're doing and why!

If your group would like to do something, but not sure what, contact TMA. Planning to attend the Annual Conference in Denver? This year's special incentive to the KIT groups is a $15 gift card to Barnes and Noble, Best Buy, Borders, or Bed Bath and Beyond. To get this nice little addition, you'll need to have at least 15 TMA members of your KIT group in attendance. Also, a special hardship registration fee of $15 is available for those unable to afford the regular registration fee of $150. Get your calendars and mark the dates September 18-21, and plan to be with us in Denver.