

## Meet Our Members: John Kollar talks shop

### Retired facilities planner turns to avian architecture

John Kollar has approached his retirement with as much ingenuity and energy as he committed to all the stages of his life. Kollar was a drill instructor for the Army in the Vietnam era, studied art, and ultimately became an architect, working on huge commercial projects all over America. He did all of this while raising three children on his own and finding time to lead a scout troop and serve on city commissions. Kollar's motto in his own life and in raising his children has been "never say you can't," a philosophy that's served him well through an interesting and challenging life.

From a family of resourceful Midwesterners, Kollar was born at home, delivered by his grandfather, who also delivered Kollar's father and older son. All four men are John A. Kollars.

Kollar inherited more than his father's name. He also has the hereditary form of inclusion-body myositis that ultimately caused his father's death. Of the five children of John A. Kollar II, three of them inherited the disease, which progresses in much the same way as sporadic inclusion-body

myositis. His younger sister is Denise Antonucci, an active TMA member. Both Kollar and Antonucci are in a couple studies of familial IBM with the goal of learning how to alter the gene that causes it.



*John's whimsical bird bungalows.*

Kollar's disease was diagnosed in his 40s after his knees gave way while he was trying to keep up with his children. He had been an outdoorsman – a sailor, avid golfer and horseman. "Of course, it was on my mind that I might have what my father had," he said. A physician confirmed the diagnosis of hereditary inclusion-body myositis, and Kollar began to prepare for the disease to progress. "It happened so slowly that I always had a chance to get ready for the next step," he said. He has a push-up chair and a modified vehicle, and has altered his surroundings as needed.

About a year and a half ago, he

was fitted with special leg braces, and had a couple of sessions with an occupational therapist to learn how to use them. The braces have made a significant difference in his life, allowing him to walk longer without fatigue. The braces lock and unlock in a way that supports the knee while he's standing and allows flexibility when it's time to take a step.

He's on the board of the adult community where he lives and recently helped advocate for accessible showers for all the residents. Kollar, Antonucci and a number of family members and friends have conducted successful golf fundraisers in the Chicago area for TMA. "The first one raised \$40,000," Kollar said; "and the most recent raised \$62,000."

He's a new grandfather, and proud father of three grown and successful children. "They're too young to even show symptoms of the disease," he said. "Instead, they worry about me and what might happen in the future." He is extremely hopeful that gene therapy studies, particularly those led by Dr. Mendell at Nationwide Children's Hospital in Columbus, Ohio, will provide information that leads to intervention in the lives of his children and others who have either hereditary or sporadic forms of IBM.

Kollar takes a number of supplements recommended by his physician: CoQ10 and vitamins C and D and E. "These have given me new energy,"

*Continued, page 5*

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## MeetOurMembers

### TMA welcomes new board members

**James Kahl** serves as a caregiver for his wife, Judy, who has inclusion-body myositis. He and Judy live in Bonita Springs, Florida, and are active members of the Southwest Florida KIT group. Kahl, who received his undergraduate degree and his MBA from the University of Wisconsin, has had leadership roles in several major corporations. He was chairman of the board, chief executive officer and president of Berlitz when he retired in 2003. He also serves on church, non-profit and social boards.

**Graham Rogers**, of Charlotte, North Carolina, a polymyositis patient, graduated from the Naval Academy and served as a naval officer for seven years. In 1996 he received his MBA in Finance and Economics from the University of Chicago, Graduate School of Business. He currently leads Dixon Hughes' Intellectual Property Services practice and assists clients in placing an economic value on their intellectual property (i.e., patents, trademarks, and know-how). Rogers has done volunteer work in the Charlotte community, serving on the board of the Bridge, a program that provides high school dropouts, the unemployed and the underemployed with job training.

**W. C. (Augie) DeAugustinis**, an inclusion-body myositis patient,

retired from Delta Air Lines as a Captain in 2004. He also spent 20 years in the Naval Reserves as a pilot, retiring at the rank of Commander. DeAugustinis lives in Gainesville, Georgia, where he has been active in CONTACT Helpline, a non-profit, 24-hour crisis helpline, serving as a board member and as president of the board of directors.

**Dave Rudig**, an inclusion-body myositis patient since 2009, retired from HNTB Corporation in 2007. He was a Senior VP and the Chief Contracting Officer at the time of his retirement. He now operates Rudig Engineering, a sole-proprietorship forensic engineering consulting firm working with insurance carriers, local contractors and law firms. Dave and his wife, June, live in Menomonee Falls, Wisconsin, a suburb of Milwaukee. They have four adult children and nine grandchildren. Dave has served on the Greater Milwaukee Salvation Army Advisory Board and on various church and professional society committees over the years. While living in Sheboygan, Wisconsin, Dave served three 3-year elective terms on the Public School Board. He was Board President his last five years.



### MYOSITIS HORSES UPDATE

For those wondering what became of the "myositis horses," 2 of the 3 have raced. One never raced but was bred last year and will deliver a foal soon. The one that continues to race – though not particularly well – is appropriately named Myositis Survivor. Even though none has been very successful on the track, they have gotten the word "myositis" in front of a large number of people – about 3 million people either read the word "myositis" in the program or heard it over the racetrack's loudspeakers on the days when the "myositis horses" were racing.

## How does exercise influence disease?

TMA asked Medical Advisory Board Member Ingrid Lundberg and Physical Therapist Helene Alexanderson about the impact of exercise on polymyositis and dermatomyositis. Questions and answers are below.

**Research seems to show that exercise not only helps myositis patients stay flexible and protect their hearts, but also has some effect on the disease itself. Could you explain how this happens?**

**Drs. Lundberg and Alexanderson:** There are many studies on exercise in healthy individuals and in elderly populations that suggest regular physical activity improves performance and fitness and also has a beneficial effect on diabetes, hypertension, and risk of cardiovascular disease.

In some of these studies there is also evidence that long-term exercise reduces inflammation measured as C-reactive protein in blood tests. No such long-term studies have been performed in patients with chronic, inflammatory rheumatic diseases. We investigated muscle biopsies in one short-term exercise study in PM and DM where resistance exercise was performed for seven weeks. In this small study we found a lower degree of molecules involved in inflammation in muscle biopsies taken after 7 weeks of resistance exercise compared to before the exercise. This observation may indicate that, in patients with chronic, stable PM and DM, exercise may reduce inflammation in muscle tissue. Further studies are needed with larger groups of patients, with long-term follow-up to shed light on possible effects of exercise on inflammation in myositis as well as potential long-term effects on cardiovascular disease.

**What resistance exercises were used in your study? Did the par-**

**ticipants have to do them at a certain level to see results?**

**Drs. Lundberg and Alexanderson:** The participants performed muscular resistance training on the load of 10 voluntary repetitions maximum (the weight that can be lifted 10 times but not more.) This equals about 70% of maximal capacity. Exercises for each muscle group were repeated 10 times in three sets with a 90-second rest. The program included exercises for the shoulders, upper arm and back muscles, trunk muscles (sit-ups), quadriceps and calf muscles. The hour-long program also included a 10-minute warm-up on a stationary bicycle or a treadmill, and stretching, three days a week for seven weeks. In healthy muscle, about six weeks of exercise 2 to 3 times a week are required to increase muscle mass and strength. Seven weeks of exercise is a minimal length of time to see results, and larger effects would be expected with longer exercise.

**Because of insurance, most myositis patients have limited access to physical therapy. Could you give us some ideas about finding an appropriate exercise program?**

**Drs. Lundberg and Alexanderson:** We believe it is appropriate for many patients with myositis to go to a local gym or to do home exercise, but we recommend that they first see a physical therapist who can give instructions for an individual training program. For those who can see a physical therapist a few times a year, it would help to get baseline tests of muscle performance, and perhaps also a test of aerobic capacity at the first consultation, together with instructions concerning an initial training program for the home or local gym.

With follow-up visits, the therapist could see progress or detect worsen-

ing and adjust the training intensity accordingly. This is how we work in Sweden with patients in a stable, chronic phase of the disease. If visits with a physical therapist aren't possible, the health professional should instruct the patient in home-based exercise or every-day physical activity that can improve functional capacity. In Sweden we sometimes work with a personal trainer at a patient's local gym to develop an individual training program. One home exercise program has been published (see note at end).

**Is there any similar research for IBM patients?**

**Drs. Lundberg and Alexanderson:** The response to exercise in IBM is more uncertain than in PM and DM. Only a few studies have been performed, resulting in unchanged disease activity but with limited effects on muscle function. However, according to one recent study, a home-based exercise program of moderate intensity performed twice a day for 12 weeks did result in improved strength in affected muscle groups, along with improved functional capacity.

Another interesting case report shows improved quadriceps strength following vascular occlusion during moderate intensity muscular training. To our knowledge, only one study has used analysis of muscle biopsies to evaluate the safety of exercise in individuals with IBM. This study could only support the safety but not report on reduced inflammation, and there are no data on gene expression response to exercise in IBM.

*Find a discussion of the research on page 4, and an exercise program for myositis patients as well as further reading, on TMA's website at [www.myositis.org](http://www.myositis.org).*





### Unraveling Interstitial Lung Disease

Several decades ago, researchers first identified interstitial lung disease (ILD) as a complicating factor in myositis, and it still remains a poorly-understood feature of polymyositis, dermatomyositis, and amyopathic dermatomyositis (the form that affects the skin but not the muscle). In "Interstitial Lung Disease Associated With the Idiopathic Inflammatory Myopathies: What Progress Has Been Made in the Past 35 Years?" Drs. Geoffrey Connors, Lisa Christopher-Stine, Chester Oddis and Sonye Danoff discuss ILD.

All the authors have a long-time interest in myositis. Drs. Connors and Danoff are from the Division of Pulmonary and Critical Care at Johns Hopkins Department of Medicine, and are associated with the Myositis Center there. Dr. Christopher-Stine is one of the directors of the Center and a member of TMA's medical advisory board, and Dr. Oddis is from the Division of Rheumatology at the University of Pittsburgh Medical Center and also serves as a member of TMA's medical advisory board.

ILD is common in the three diseases researchers studied and, despite better treatments, it is responsible for a greater degree of illness as well as an increased risk of death in myositis patients who have it. The authors write that there are many questions about how the disease develops in connection with the myositis as well as how to best treat it.

This study is called a review because it reviews dozens of previous research articles rather than describing new research. Published in the journal, "Chest," it summarizes what we've learned over the decades and points out areas deserving further study.

#### What we've learned

- ILD is really a number of different pulmonary disorders that have different causes. Researchers typically classify them together because they eventually compromise the lungs, causing coughing, shortness of breath, and a decreased ability to exercise.

- ILD affects 200,000 to 500,000 people in the United States alone and accounts for 100,000 hospitalizations each year, with an annual mortality of 40,000 persons, comparable to the mortality rate for breast cancer.

- ILD affects as many as 35 to 40 percent of PM, DM and amyopathic dermatomyositis (ADM) patients (those with skin but not muscle symptoms), with varying degrees of severity. One follow-up study of 27 patients found ILD to be the leading cause of death in myositis patients over a span of 10 years.

- There are various theories about the reasons that ILD is associated with myositis, and all have some validity. ILD may be part of the same inflammatory process that causes the myositis, but since its progression varies so wildly, other factors are likely involved, including types of viruses and the immunogenetic profile of the patient.

- Researchers can now profile the myositis patients at greatest risk for ILD. For instance, several studies found that the majority of patients with antisynthetase syndrome also have ILD. However, we don't know whether the syndrome causes the ILD or is simply a marker for it.

#### Diagnosing ILD

- Pulmonary function testing (PFT) is an objective and minimally invasive procedure that can both uncover myositis-related ILD and predict the

response to treatment over time. Patients with ILD typically show less than 80% of the lung capacity predicted for their age and height, and a decrease in their body's ability to disperse carbon monoxide. This test can also measure whether the ILD is improving as the skin and muscle symptoms improve.

- High-resolution CT scanning of the thorax in addition to PFT is recommended by the authors, since it helps the physician to know whether lung capacity is reduced by the weakness caused by the myositis or by the ILD.

- Fiberoptic bronchoscopy can be helpful to rule out hidden infections, which can resemble interstitial lung disease. This is especially relevant for patients who are on immunosuppressive drugs for a long time, making them more susceptible to infections.

- Surgical biopsy is recommended by the authors only to clarify the diagnosis of ILD if there is clinical uncertainty.

#### Treating ILD

The authors summarize conventional treatments, but note that none of the studies available used a placebo group, and none were organized from the start to test the effectiveness of the particular treatment. To date, as has been the case for 35 years, corticosteroids are the main treatment for myositis-associated ILD. However, the authors point out, no treatment for myositis-related ILD has been sufficiently studied. Some brief observations from the authors:

- Corticosteroids have been prescribed for ILD in myositis patients right from the start. However, existing literature is from small case series of patients analyzed retrospectively, and for relatively short periods of time without a standard dosing schedule or

consistent definition. The studies show mixed results.

■ Azathioprine is the most common clinical agent used to allow patients to reduce the amount of steroids in the treatment of myositis-associated ILD. The authors could only find one case report of azathioprine as a successful adjunctive therapy. No prospective trials or large case series exist.

■ Methotrexate has become accepted in the treatment of myositis-associated ILD, but again the authors note no meaningful relevant research. They add that care must be taken with methotrexate because of its association with drug-related pneumonia.

Other drugs have been used in conjunction with steroids, especially in rapidly-progressing cases. New therapies, including the use of targeted immune modulators as well as the more experimental methods, require well-designed trials.

The authors express a hope that, since we now know more about the significant impact of ILD on the myositis patient and understand more about myositis sub-types most threatened by ILD, there will be trials aimed at finding more effective, more targeted and less toxic drugs.



## A profile of exercise in PM and DM

A group of researchers from Stockholm, Sweden and Washington, D.C., studied the clinical, histological and genetic profile of resistance exercise in polymyositis and dermatomyositis. The group included long-time myositis researchers Ingrid E. Lundberg and Helene Alexanderson of the Karolinska Institute and Kanneboyina Nagaraju of Children's National Medical Center. Lundberg and Nagaraju are on TMA's medical advisory board.

The authors note that, until recently, patients with DM and PM were advised to refrain from physical activ-

[www.myositis.org](http://www.myositis.org)

ity because of fears of exacerbation of muscle inflammation and disease progression. However, recent studies have shown that moderate exercise combined with medication can improve muscle performance without signs of increased muscle inflammation, suggesting that exercise represents an aid, rather than a threat, to recovery.

The researchers followed eight patients – five with DM and three with PM – who took part in a resistance exercise program at the Karolinska University Hospital in Stockholm. They ranged in age from 44 to 61 years, with disease courses that varied in length. All of them had been treated with prednisone and other drugs for more than a year, and all of them had seen some improvement. However, all also had persisting weakness.

Patients underwent a supervised resistance exercise training regimen with an intensity of 10 repetitions, of five muscle groups (deltoid, quadriceps, latissimus dorsi/biceps, gastrocnemius and trunk muscles).

Researchers measured the intensity of the exercise by gauging the oxygen intake. Disease activity was judged by standard clinical measurements and blood tests, and the results, both in increased strength and disease activity, after the exercise program were measured by a number of laboratory and strength tests.

Muscle strength increased, blood levels of creatinine kinase decreased and clinical disease activity improved. The authors found that a total of 41 genes involved in inflammation changed significantly, with 34 of the genes changed to reduce inflammation. The authors concluded that resistance training was an effective tool for reducing inflammation in myositis patients.

For more on PM, DM and exercise, see "Ask the Doctor," page 3.



## Kollar, cont'd from cover

Kollar said.

Kollar traveled extensively in his work as an architect and facilities planner. When his illness caused him to retire, he had time to pursue another of his interests. All his life he's been an avid woodworker, he said.

As part of his philosophy of helping his community, he designs and makes birdhouses for local charities, or personalizes them and gives them away to friends for gifts. Somehow, the word got out and people began calling him about his wonderful little houses. "It was a good way for me to combine my love of architecture and woodworking," Kollar said. "People even started coming to the house to ask about my birdhouses." One birdhouse, donated to charity, brought \$1,200 at auction.

Kollar wants to support medical research while also helping the disabled. "We're just as capable as anyone else, maybe more capable." He plans to employ disabled veterans like himself in a shop with benches exactly the right height for wheelchairs, with all the tools also mounted at the correct height. His contact with regional veterans' organizations convinced him that there is an eager labor force available for this work, and he's moving forward with plans for increased production, with proceeds to go to myositis research. Beautifully-made, intricate models of real houses, these upscale residences have secure perches, architectural details, bright, non-toxic colors and roomy interiors. They're perfect for gifts or to brighten a backyard as well as to provide shelter for birds.

Find more photos, and to keep up with Kollar's plans for employing the disabled, visit:  
[www.kollardesignstudios.com](http://www.kollardesignstudios.com).



## Blogger solves everyday problems; shares online

When Mike Shirk began his blog, "Life! Disabled," in September, 2010, he asked potential readers to note the emphasis. In his title, he punctuates "life"

rather than "disabled," and that's been his philosophy ever since his diagnosis years ago.



Mike and Beth Shirk

"Despite having a difficult disabling illness, I still find a lot of pleasure in living," Shirk wrote. "Much of that pleasure stems from finding – and sharing – new ways to cope as my illness progresses. In this blog I will share some of the things inclusion-body myositis has taught me."

Shirk, who worked in advertising before his retirement, uses his considerable communication and organizational skills in his blog, as well as in his daily life, which now requires both planning ahead and dealing with unexpected obstacles. As he's made his transition to each stage of his disease, he's figured out ways to get on with his life -- modifying his house, inventing and making small tools, finding a new passion, investigating assistive devices, even learning to sew. His path became even more complicated when his wife, Beth, who had planned to be his caregiver, was found to have myotonic muscular dystrophy. She also has macular degeneration and breast cancer. Both the Shirks are now in wheelchairs.

If you are newly diagnosed, or even if you're a veteran at finding ways to function despite your muscle weakness, check in often with Shirk's "Life! Disabled" blog at

<http://Life!Disabled.com>. Some of Shirk's good ideas follow:

### The Hook

This was Shirk's first do-it-yourself assistive device. Like many IBM patients, his fingers were severely affected from the start. "Drawers, car doors, even cartons of soft drinks became more and more frustrating to deal with," Mike writes. "But even though my fingertips



were useless, there was still some strength where the fingers joined the palm." His solution was a plant hook, a four-inch length of wooden dowel and a little electrical tape. For a total cost of less than fifty cents, he can now pull a drawer open, pick up clothes and open car doors. "I have constructed dozens of these little tools," Shirk said. "I have them lying around in every room of the house, plus the van, and one is in my belly bag." The San Diego KIT support group has made these sturdy hooks and sold them at TMA's Annual Patient Conference.

### Off-the-shelf leg lifter

Wherever he can, Shirk makes use of inexpensive, easy-to-find materials.

"The lip of my shower is only 3" high – it might as well be 3 feet when it is time to transfer." Shirk found that one of his most difficult problems was lifting his legs over the lip when he was transferring. The same problem arises when he transfers to his bed – the legs remain difficult to pull up.



Simple inspiration: Shelf-liner becomes an assistive device!

Shirk used scissors to cut shelf liner – the lightweight rubberized kind – into a narrow strip that works as a strap for leg lifting. He found this strip to be lightweight and strong, and it doesn't slip either off his leg or out of his hands. "One roll can provide 3 or 4 straps," he said. "I keep one by the bed and another in the bathroom. The others are spares, because they will wear out after a year or so. I also use it to finish getting into bed. I simply loop it around my leg, just above the knee, and then pull my leg into bed."

### The gravity transfer

"When your legs are weak or paralyzed and you try to stand or walk, gravity is your enemy. But when you are using a wheelchair or scooter, gravity can become your friend. One of the ways I have maintained my independence despite being unable to stand or walk is by using gravity. I have a wheelchair with an elevating seat. In addition, I have a hospital bed that elevates (the Invacare 'full electric' model). With an elevating seat, gravity does most of the work of getting you into the bed."

Make sure each place where you will transfer is about halfway between the lowest and highest positions of your scooter or wheelchair seat, Shirk says. For example, if you have a

wheelchair that's 20 inches high at its lowest seat position and 26 inches high at its highest position, your bed, toilet seat, and shower seat should be about 23 inches high, Shirk said. "This would allow you to slide

from your elevated chair to the bed and then slide from the bed onto the lowered chair when you are ready."



For transferring, Shirk strongly recommends the “UltraSlick” board, available in the 30-inch size from Amazon, or in different sizes from mobility catalogues and suppliers. “If you are trying to slide on the board when you are not dressed, be sure to wedge a towel part way under so that you can have it between you and the board,” Shirk said. “Bare skin, especially wet bare skin, on an UltraSlick board will probably stick like glue and you may need help getting free.”

### The accessible bathroom

When the Shirks moved to their present residence, they knew right away that it would be necessary to remodel the bathroom.

Shirk started out by listing all the functions typically performed in the bath-

room, keeping in mind that it would be necessary to close the door behind him, get his chair close enough to the sink to brush his teeth and spit into the bowl, and transfer sideways onto a toilet or shower seat. He removed the existing sink and surrounding cabinets and replaced the sink with a suspended model from Kohler.

Although Shirk was still able to stand while holding tightly onto something stationary, he knew that wouldn't last long. He designed the toilet and shower seat to be high enough that he could slide from them into his wheelchair at its lowest level. Since he can elevate his wheelchair seat, he can reach either the shower seat or the toilet by raising the wheelchair high enough to slide downhill.

He predicted that even sliding downhill would eventually become too difficult, so he had an overhead lift

system installed in the ceiling of the bathroom. The problem here was the shower curtain rod. There needed to be a water barrier, of course, so Shirk installed some hooks and latches that allowed his curtain to be stretched across the shower without the rod.

Shirk also elevated his toilet by 4 inches, using a Toilevator, and added a BioBidet 1000 seat, which provides fresh water for cleaning and an air flow for drying, right from the seat. Many IBM patients find that weak fingers make conventional hygiene difficult, and use some kind of bidet arrangement for cleanliness.

### Technology

Shirk explains in his blog that his illness caused him to turn from his active life to painting in watercolors, and some of his gorgeous work is featured in links from the blog. As his fingers weakened, though, he found it hard to do the preliminary sketches

that formed the basis for his finished work. He found that, using an iPad with a stylus, he could still sketch. He's explored other uses, too, and recommends the iPad to those who are disabled. He writes his blog and other correspondence using the Dragon voice recognition system that came free. “Without it, doing this kind of writing would be very difficult if not impossible, because my fingers can no longer bend or be controlled,” he says. He also uses it to take reading material with him from the Apple iBook store, and copies documents he wants to read later.

“It is a highly portable computer, a library, a music studio, a weather station, a radio, a movie theater, a bus or travel planner, and the list goes on. In fact there are now millions of little applications designed for use on the iPad, many of which are ideal for the

physically disabled. Just recently I used its inclinometer to determine that our community's sidewalks had driveway openings too steep for wheelchairs or scooters to safely cross.”

Shirk plans to discuss in detail some of the ways the iPad and different applications available for it help him, in later blog posts. Find these and other great ideas and inspiration at Life! Disabled.com.



## OnTheJob

### Disability and success

If you're at least 18, still employed, and have significantly-reduced mobility, your experience may help others with physical challenges remain in the work force.

Researchers at Washington University in St. Louis are conducting a web-based survey of people with severe disabilities who have been in their jobs for more than two years. The study will help employers and rehabilitation specialists understand how people with impaired mobility manage their day-to-day tasks, what their employer does to help them succeed, and what other resources they use to do their jobs successfully.

The survey is posted on the internet so it can include the greatest number of disabled workers possible. Those who are eligible will take it twice over the course of four to six weeks. It takes an hour to complete, is completely confidential, and those who complete it will be paid for their time. The survey is designed so there will be no way to know how each respondent answered the survey questions.

To find out if you are eligible, go to <https://emc.wustl.edu/DEscr/DEscrlog.in.html>



## TMA ambassador program reaches out

TMA's support groups are networks of comfort, understanding and education for people coping with myositis. At meetings, members share advice, experiences, and inspiration. Whether you're doing well or not-so-well, support group members are there to help.

Since myositis is such a rare disease, the larger cities are more likely to have a sizeable, active group. The greater challenge is to find support in rural and sparsely-inhabited areas of the country. These are the areas that lack support groups because people with myositis often are hundreds of miles away.

Myositis patients in rural areas have difficulty even finding doctors knowledgeable about myositis, much less another person close enough to visit and talk with. Do we tell the person in Idaho, Wyoming or Utah, "Sorry, we have no support group in your area," and leave it at that? No. Luckily, there are a few volunteers across the country who serve as TMA's ambassadors.

Ambassadors are available for those who need someone to talk to, but who don't live near anyone else with myositis. Ambassadors always have the same disease – and are usually the same gender – so they can relate to the person they will be speaking with. Ambassadors make contact through phone calls and email,

and offer their personal experiences and resources to help someone in need.

Being an ambassador isn't difficult. TMA generally requires that an ambassador be someone who has been diagnosed for at least two years with ample knowledge about myositis, and with a desire and the time to help others. If you would like to volunteer for the role of ambassador, please let TMA know. Email [tma@myositis.org](mailto:tma@myositis.org).

### **South Carolina members have special holiday meeting**

Medical Advisory Board Member, Dr. Robert Wortmann, offered to talk with the South Carolina KIT members while vacationing over the holidays in Hilton Head, South Carolina. The group met informally for lunch at the home of KIT leader Dannie Haines on December 30. Dr. Jerry Mendell, a second member of TMA's medical advisory board visiting the area, also joined the group. Dr. Mendell discussed the progress of his research. Both physicians answered a variety of questions posed by those present.

### **SW Florida KIT has largest turnout ever**

Sixty members, family and friends came to the quarterly meeting of the Southwest Florida support group on February 5. One reason for the great turnout was to hear the speaker, psychologist Andrew White, who flew in

from chilly Colorado to a balmy 75-degree Florida. Andrew was able to condense all three of the presentations he normally delivers at TMA Annual Patient Conferences into two 90-minute sessions. Even members who had heard him at Conferences reported that it was great to hear his message, and those who had never heard him were grateful for the insights into dealing with their diseases, either as patients or family members and friends.

### **Minnesota group plans full year of activities**

Daniel Seftick, leader of the Minnesota support group, published the support group's newsletter in early March, outlining a full program for 2011 that includes a question-and-answer session with Dr. Steven Ytterberg of the Mayo Clinic (a member of TMA's medical advisory board) in March, and talks by other health professionals in June and September. The support group's year concludes with the December meeting, which combines a social and business meeting with dinner. The Minnesota newsletter also contains some great advice about setting personal goals and encourages membership renewal and fund-raising activities. For a copy of the Minnesota newsletter, email [TMA@myositis.org](mailto:TMA@myositis.org).



## News&Announcements

### Annual Conference in Las Vegas!

Further your knowledge and form new friendships at TMA's Annual Patient Conference. Join us September 15-18, 2011, at the Fabulous Flamingo in Las Vegas, NV.

For more information or to register, call 1-800-821-7356, or visit [www.myositis.org](http://www.myositis.org).