

Meet Our Members: Zachary Lewis

Once a strong, busy and energetic man, Zachary Lewis was hit with a one-two punch of lupus and polymyositis that almost knocked him out. A long-time practitioner of martial arts, Zachary fought back ferociously.

You'll find his story in "The Burly Man," an honest chronicle of Zachary's struggle to understand and ultimately rise above his debilitating and mysterious symptoms. Zachary posts as "Burly Man" on Facebook, with insight, commentary, and links to information of interest to people with myositis. You can also follow him on Twitter.

Pain, weakness and uncertainty became constant companions to Zachary as he followed a path familiar to many with myositis, visiting doctor after doctor, taking test after test, landing in the emergency room in great pain, with dramatic symptoms and no explanation in sight. He had to leave a physically-demanding job he liked and was successful at, and was forced to rely on the support of a new wife and stepdaughter while struggling not to be a burden to them. True to his long-held beliefs, he also searched for ways to gain wisdom and find deepened relationships from personal hardship.

Zachary says it seemed automatic to him, given his background and philosophy, to take an extremely proactive approach to his painful physical condition. His choice as he saw it was never whether he would

aggressively confront his diseases — that was a given — but which approach he should choose to overcome the pain and multiple challenges of polymyositis along with the organ damage, sun sensitivity and temporary confusion of lupus.

Combining eastern and western thought, Zachary already had a fundamental philosophy in place, a system of thought and action that he had named "Weishendo." From his studies, he had learned to "adapt, change, assimilate, and transcend." Translated from Chinese, Weishendo means "the way of the active spirit." (WEI = active, Shen = spirit, DO = way or path.) Although this philosophy had been part of Zachary's life for years, it was truly tested by his fall from robust health.

Today, Zachary says, he shows improvement, although he has experienced a couple of setbacks caused by strenuous activity. He damaged his left rotator cuff and right and left elbows, injuries he credits to his

aggressive, trial-and-error rehabilitation program.

"I am constantly pushing myself to see just how much I can take mentally, and physically," Zachary writes from Los Angeles. The setbacks were temporary: despite the injuries, a recent appointment with his rheumatologist shows Zachary is gaining strength.

Another part of Zachary's strategy was to work closely with his physician to find the right balance of medications. He takes a number of drugs to control pain, combat inflammation and deal with the other symptoms of his two chronic diseases.

Zachary said he was glad to be able to stop taking prednisone. In the early days of his illness, where he sometimes barely clung to life, he took extremely high doses. Partly because of the prednisone and partly because he couldn't move around, Zachary — who had always prided himself on extreme physical fitness — gained more than 40 pounds shortly after his diagnosis. Tapering off that drug and experimenting with an exercise program has helped Zachary's return to strength.



"The Burly Man"

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Board Update

Outreach to veterans planned

Attention Veterans: The Myositis Association board of directors, after listening to concerns voiced at last year's Annual Patient Conference, has articulated the following as one of the strategic goals for the year 2013: "We will solicit and present resource material that will assist veterans and their families to maximize their benefits from the Veteran's Administration (VA). Resources will be made available on TMA's website and in at least one seminar at the Annual Patient Conference."

In order for the board of directors and TMA staff to meet this goal, we need your help. If you have had experience with the Veterans Administration, either good or bad, we would like to hear from you. If you

have advice for other veterans, we would like to collect that as well. The Annual Patient Conference staff and the Board of Directors are in the process of identifying suitable representatives from the VA, as well as "patient advocates" from the major veterans organizations (VFW, American Legion, etc.) to be available at the conference. If you have suggestions for content material, please let us know. The Myositis Association and its board of directors are firmly committed to assisting our veterans with myositis in any way we can – but we need to hear from you. We hope to see you in Louisville October 17-20, 2013! Please send your comments to TMA@myositis.org.



TMA Announcements

20th Anniversary!

For 20 years TMA has been serving the myositis community through research, patient/physician education, and support groups. Find out how you can be part of TMA's "20 for 20" campaign to help TMA continue to serve all myositis patients and their caregivers.



Mark your calendar

TMA's Annual Patient Conference:
October 17-20, 2013, Louisville, KY.
Register with TMA by May 31 to receive the lowest Conference registration rate. Call now: 1-800-821-7356.



Planned giving

It can be simple and does not need to cost you anything now. Help those living with myositis now and in the

future. Call TMA to find out how: 1-800-821-7356.



Research grant awarded

The Myositis Association announced recently an award of \$50,000 per year for two years to study the Effect of Creatine Supplementation on Muscle Function in Childhood Myositis. This award was made to Dr. Brian Feldman, Hospital for Sick Children, Toronto, Canada.



New online

Dr. Todd Levine talks about swallowing problems, a common concern for myositis patients, in a TMA video produced by myositis patient Mike Peck. Find the video at TMA's home page, www.myositis.org.



Over the past few months, TMA has presented a series of live discussions with experts on two of the drugs studied by members of TMA's medical advisory board members, and a discussion of the emotional difficulties myositis patients encounter. Following are excerpts. For the full transcripts, go to www.myositis.org; click on "community" and then "live discussion."

The first drug under discussion, rituximab, was tested in a multi-center study of adult and juvenile polymyositis and dermatomyositis patients. Dr. Chet Oddis, who led the study, took questions from TMA members.

The second drug, Acthar, has been approved for myositis for decades and has recently attracted new interest. Dr. Todd Levine found it helpful in DM and PM patients who didn't respond to conventional therapy, and conducted a small trial among his own patients.

Rituximab

Dr. Chet Oddis
University of Pittsburgh

To find the full "RIM" study, go to www.myositis.org; click "research," then "published research," then "PM and DM," then "2013."

I have used rituximab with methotrexate for several years with great results. I have recently quit taking the methotrexate on the advice of my rheumatologist since most symptoms have diminished. Will the rituximab work on its own?

Dr. Oddis: It may work on its own without the need for methotrexate, but some have reported that the concomitant use of methotrexate increases the effectiveness of rituximab. I think it is fine to administer the rituximab alone at the next infusion.

I have had four treatments of rituximab, spaced two weeks apart, with relapses between each. My last treatment was 18 months ago and I am currently without symptoms or adverse test readings. Should I consider a maintenance treatment or merely continue periodic testing until either symptoms or test results begin to worsen?

Dr. Oddis: We don't know the answer to this question. I don't usually give maintenance therapy and there is controversy, even in the rheumatoid arthritis literature, as to whether maintenance therapy is indicated. Since you have responded to the treatments, my opinion is to administer the rituximab at the first sign of relapse.

How has rituximab helped patients who have ILD?

Dr. Oddis: This is an important area to study and many of us are interested in ILD so we always want to know about new therapies in myositis-associated ILD. However, at this time we do not have enough data regarding the response of the lung to rituximab in the RIM Study patients. This may be looked at further in the RIM patients but there were only a few patients with significant ILD in the RIM Study.

I read that there seems to be a particularly strong effect of rituximab in those with anti-Jo-1 antibodies. Could you please discuss this further.

Dr. Oddis: The only thing that we can say now is that the presence of anti-Jo-1 autoantibodies predicted a beneficial response to rituximab, so if patients have this marker, then there is better chance of responding to the drug than if they did not have this marker in their blood. The impact of

this after the data is peer-reviewed is that this is the most common antibody marker in myositis, so it affects a lot of patients.

Is this drug good for people who have an overlap of dermatomyositis and lupus?

Dr. Oddis: I think it would be fine to consider using rituximab in this case but there is no specific data available.

I was a subject in the RIM study and had considerable improvement of DM symptoms after receiving rituximab in 2008. I was re-treated during a relapse in 2010 and my muscle strength improved again, but I had a severe skin reaction. Now that I won't be able to take rituximab again, I'm interested to know your expert opinion on current treatment options I should consider.

Dr. Oddis: First let me thank you for allowing us to enroll you in the study - we appreciate that. Other options include Cellcept for skin and there are many possibilities such as a combination of methotrexate and imuran and IVIG.

Would rituximab be recommended for treating my PM if I have been successfully treated thus far with methotrexate? I know that I could have potential liver side effects under current treatment. Are there any side effects possible with rituximab?

Dr. Oddis: Rituximab would not be indicated in your case since you have done well with methotrexate. I would stick with the methotrexate, as the side effects may actually be less.

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Does this drug help relieve the pain, itching and sores which are a result of the "derma" part of dermatomyositis?

Dr. Oddis: The skin response to rituximab has not been as encouraging to date.

If necessary, can rituximab treatment be combined with IVIG treatment?

Dr. Oddis: Not a common combination to be used except perhaps in children. And I doubt insurance will cover both.

TMA Member: Can you address why some insurance companies will not pay for rituximab?

Dr. Oddis: Unfortunately there is no good answer. This is a very expensive form of treatment.

When is it appropriate to consider using rituximab for treatment of PM and DM? Would it be used after trying normal treatments like prednisone, imuran, methotrexate, and IVIG? Or are there indications that would make rituximab the treatment of choice?

Dr. Oddis: It should only be considered after standard therapies fail, so it is more like a third line of treatment at this point.

How does rituximab work in myositis patients? Is this something that PM patients would have to take for the rest of their lives?

Dr. Oddis: It depletes one type of immune cell, the B cell. You would not necessarily continue this treatment the rest of your life.

I have had PM for five years, and am in remission except for resid-

ual interstitial lung disease which at times is quite debilitating. Prior treatments of rituximab always cleared this up. Should I consider a treatment for this reason alone?

Dr. Oddis: Yes, that is very interesting that your lung disease responded. I would consider this again.

How long after a rituximab infusion should a patient know if it has been effective or not?

Dr. Oddis: A bit unpredictable but probably within 3 months.



Acthar

*Dr. Todd Levine
Phoenix Neurology*

To find the full Acthar study, go to www.myositis.org; click "research," then "published research," then "PM and DM," then "2012."

If a patient is responding successfully to prednisone, what would be the advantage of switching to Acthar?

Dr. Levine: It is very hard to mess with success. I usually don't change a patient who is doing well unless side effects become an issue.

Are there plans to conduct an Acthar trial similar to the RIM trial for rituximab to find the most effective treatment for DM and PM patients?

Dr. Levine: There is a large national registry underway to study how patients respond to Acthar but at the moment, because of the time and expense of a study like RIM, I am unaware of any plans for a similarly-sized study with Acthar.

I have had PM for 13 years. My CPK numbers are good and

almost normal for the last three years, but my muscles are so weak that I can't walk up stairs or get up from the floor. Do you think Acthar may help me strengthen my muscles?

Dr. Levine: When a new drug becomes available it tends to be used in the toughest cases that are refractory to standard drugs. So it may be worth talking to your doctor about Acthar.

It appears that my insurance company does not want to pay for Acthar. Does the manufacturer have any programs to make the drug available? My physician believes it might be a good choice for me.

Dr. Levine: There are patient assistance programs run by the company. When I last heard, the company had given out more than \$250 million in free drugs.

How long does it take for Acthar to take effect in the body?

Dr. Levine: In the case series I published most patients felt an improvement after three months but this was only five patients. So it would need to be something that you work through with your doctor.

Can you discuss more recent patients' results with Acthar, especially since your prior study? Also, can you discuss if there is still a positive reception from insurers on the reimbursement front?

Dr. Levine: I have prescribed it to five other patients since the original five and the majority have done well and felt that it helped. Insurance companies have approved all of my patients, but that is because they have failed other therapies; in most cases, many other therapies. The drug company has a very good patient assis-

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Experts *from page 4.*

tance program to help get the drug covered by insurance

I just recently completed a 12 - week Acthar session. Is there a time frame between each session that is "normal" to wait before starting another one?

Dr. Levine: I don't believe there is anything set in stone. I have had some patients that I have treated continuously now for up to nine months and other patients who I treat for 12 weeks and then they do well and I have chosen to stop and see what happens. It is all individualized. Just like the disease is different in everyone, so is the therapy.

Why did you become interested in trying Acthar for your patients when few other doctors seemed to be using it for myositis?

Dr. Levine: It was a drug that was used by neurologists to treat multiple sclerosis patients who did not respond to steroids. So it seemed to make sense to try it in other autoimmune diseases where steroids had not worked. It was FDA approved. And I guess for my really difficult-to-treat patients I was running out of other options.

Are you or will you or any of the other doctors using Acthar try to gather their information and results to publish or make available to other doctors not yet using it?

Dr. Levine: Yes. The company has paid for and sponsored a registry that I initiated to try to do just this. If we can collect data on the patients who receive Acthar over the next two years, we will know much more about it then we do now and we will also help make other doctors aware of whether it works.

What criteria, tests and info do you gather to say that Acthar has been effective in your patients?

Dr. Levine: I primarily follow their muscle strength, so I am looking to see if they get stronger. In some of the DM patients the rash has also improved.



Adjusting to a new life with myositis

Psychotherapist, speaker and author Amy Wood, who is familiar with myositis and its problems because of a close family member, answered questions about fear, acceptance and finding meaning. The following is an edited version of the questions and answers. Find Dr. Wood's discussion in its entirety at www.myositis.org.

I feel like a shell of my former self, physically, mentally and emotionally. I am struggling with just coping and retaining some sense of purpose and usefulness as a father, husband and person. Any words of direction would be appreciated.

Amy Wood: The good news is that you are not alone, and there are answers. One challenge you are all facing is keeping up in a world that is going way too fast — a challenge for all adults, but especially for people with chronic illnesses like myositis. Keeping up in a world that is only going to get faster involves stepping away from all the pressures and distractions and creating your own standards, so that your goals are achievable. The other important piece is assessing your energy and resources on a regular basis, and adjusting your standards and strategies according to your unique situation as it fluctuates.

Is it better for a myositis patient to have a job or not, in terms of his or her psychological and spiritual health?

Amy Wood: The advantage of living in a world with so many options and distractions is that we are encouraged to do what is right for us, to make choices that resonate with who we are deep down. This means that you can decide what will work for you to make your life with myositis easier. Think about your resources, how much energy you have, what your options are, and then consider what you are most passionate about. Maybe a job would help to make your life better. Or maybe having a baby would help? Remember that it's entirely up to you, and only you know what will make your life more meaningful. The secret is to make room in your life to be still and quiet so that you can hear the wisdom of your inner voice. The answers are there.

What advice can you give when you have a complicated medical situation and friends ask about it? How do you help them to understand without giving so many details that it is too much for them to take in?

Amy Wood: If you feel that myositis is too much a focus in your life and you're tired of talking about it, you can let your friends know that you'd rather talk about something else. Try not to get irritated. Remember that people ask because they care.

I have DM and it is just now in a very active stage. I always have holidays here and, honestly, I just can't bear the thought of all the preparations to be made. It is difficult for me to even cook small meals when I am like this. How can I make changes in our holiday traditions without disappointing everyone?

Amy Wood: Remember -- especially during the holiday season -- that you can say "no" if you don't have the time or energy for something, or if you just plain don't want to do it.

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Experts *from page 5.*

Don't feel like you have to stick with traditions that no longer suit you. Make up new traditions that fit who you are now.

Often I do quite well in coping with my disease but for the past few months I have been angry all the time, even being mean to my family members at times and saying things I really don't mean. I am just so worn out with being weak and in pain and not having the life I imagined I would. Before I got IBM I was patient and easy-going and now I just can't seem to tolerate anything big or small that comes up. Please let me know what I can do to improve my outlook.

Amy Wood: It's normal to fall apart, to have meltdowns when you feel overwhelmed. You can't expect yourself to be calm and rational all the time, so forgive yourself if you have an outburst or in any way act irra-

tionally from time to time. Going forward, make sure to take excellent care of yourself and say no to what is just too much for you, so that emotions don't build up so much.

What emotional symptoms of patients with myositis and associated diseases warrant seeking psychiatric help? Sometimes all we need is people close to us to just listen to us, without blaming our life style for all our woes. This is why the myositis forums and support groups are a good outreach.

Amy Wood: It is normal for every adult to experience ups and downs with their emotions. But if you're feeling sad for a long time — say two weeks — and you can't shake it, you may be suffering from clinical depression and you may need professional help.

What is the psychology behind why comments from complete strangers can be the hardest thing to cope with? My dermato-

myositis has completely changed the way I look (among other things) so much that people don't recognize me. I have aged about 25 years. I often get mistaken for being the mother of friends my own age. While I and most of my friends have gotten used to the way I look, comments like "Do you want to use your pensioners card" and "You used to have a young girl working here" can send me unexpectedly into a tailspin. Any good coping strategies for this?

Amy Wood: Its easy to get upset when we are triggered by comments that remind us of our disease and what we have lost because of it. This is normal. All adults experience this in various ways. Life is about loss sometimes. If you accept that feeling sad in this situation is normal, you will be able to move on more quickly. Focusing on what is going well and what you have gained in your life also helps.

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ACCREDITATIONS



Facing the music

By Andrea Taylor Langworthy

Andrea Taylor Langworthy writes a periodic column for "The Outlook" about her experiences and observations as a patient. Andrea is a freelance writer who lives in Minnesota, where she leads the myositis support group. She writes a weekly column for the Rosemount "Town Pages" newspaper. She has IBM.

As my mother aged, I knew the day would come when I would have to tell her it was time to stop driving. Mom, a feisty little woman who was always on the go, loved to drive her blue-grey Oldsmobile Ciera and drive it well over the speed limit.

Mom died of a heart attack long before that dreaded conversation was necessary. She left each of us kids a bit of money, her worldly goods, and her love of being behind the wheel.

"You drive too fast," my husband told me not long after we began dating.

"It's hereditary," I answered. "Get used to it." I put on the blinker of my sporty red Grand Am and moved to the left lane of the Interstate to pass a truck. The car's V6 engine and big wide tires made me feel as if the road and I were long-time lovers.

The company demonstrator was one of the perks of being in the automobile business. Helping Mister and Ms. Customer decide between leather and cloth seats, an automatic or manual transmission, a light beige metallic or sage green exterior, was the perfect career for me. And a new car every 6,000 miles was as close to heaven as I might get.

During a downturn in the economy in the 1980s, my demo had been a four-door subcompact with a diesel engine. I drove a minivan when things improved and my children had places

to go with their friends. A two-seater sports car when the kids flew the coop. The model didn't matter, though. I just loved driving. My husband did not, so we deemed our marriage "perfect."

After my diagnosis of inclusion body myositis, I knew what was coming. I had been through it with my father. With a disease that attacks the upper legs and arms first, driving would become a challenge.

It took a number of years, but one day, without warning, I experienced difficulty lifting my foot off the accelerator and moving it to the brake. I must be tired, I thought. After all, I had spent the day walking customers around the inventory and retrieving cars and trucks for them to test drive. The next morning, I went to the garage and sat in my car. Over and over, I tested the time it took me to get my right foot from the gas pedal to the brake. Too long.

I devised a maneuver where my heel stayed on the floor and pivoted from right to left. It didn't require as much from the quadriceps muscles I had left. I practiced the action until I had it right and it worked for years. Until the afternoon I was behind a big white high-cube van on a city street.

The van's red brake lights went on the same second it came to an abrupt stop. In my panic, I lifted my foot from the accelerator. Instead of going to the brake as I told it to, the foot dropped to the floor like an anchor. White metal was coming at me so I threw the shift lever into park and turned off the engine.

Telling myself it would not have happened if I hadn't been engrossed in a Minnesota Public Radio broadcast, I turned off the radio and vowed it would stay in that position.

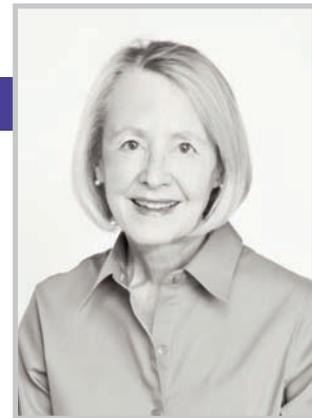
A year later, my husband and I picked up a friend at the airport. She had flown in for a visit because I was no longer working and she had enough airline miles for a free trip. My husband was driving — as he did most often then — and we all went to dinner at one of our favorite restaurants. Five days later, my friend packed her suitcase into the back of my car and I got behind the wheel of my newly leased Malibu. Five minutes from our destination, I had no power in my right leg.

"Concentrate," I repeated to myself as I looped onto the freeway, merged left towards the airport exit and finally, double-parked in the drop-off area. "Concentrate."

"Good-bye, I love you," we said to each other as she leaned towards the driver's seat to give me a hug. I waved until she was out of sight, then inched the car forward until I could slide into an empty spot along the curb. I calculated which would be the safest way home: the freeway with fewer stops or . . . no matter which way I went, it was freeway and then streets with lots of stop signs but 50 to 65 mile an hour speed limits.

"Please God," I prayed, "just help me get home."

The next morning, I convinced myself I needed to drive more; not less. Out of practice was the problem. I would go to the grocery store, Walgreen's, or Starbuck's every day. I would still be driving. With keys and a five-dollar bill in my hand, I left the



See Perspective page 13.

TMA support groups launch busy year

By CHARLIA SANCHEZ
TMA Member Services Coordinator

TMA support groups entered 2013 with a bang. Between January and March, 20 support groups hosted meetings, including two new support groups — one in Southwest Missouri and one in Wichita, Kansas — have formed. That's an excellent start to this year!

TMA welcomes new support group leaders Jerry King (Wichita), Donna Howell (Southwest Missouri) and Patricia Bedford (Philadelphia).

Groups offer support in a number of ways

Local support groups offer a variety of resources and information to their members. Some groups, including the Colorado and Southwest Florida groups, showed TMA's "Falls Prevention" video to members. This video is a starting place for a good discussion about what measures myositis patients should take to be both safe and mobile.

TMA's most recent video, "Dysphagia," featuring Dr. Todd Levine from the University of Arizona, is also available online, providing a lot of information and therapies for coping with this common symptom of myositis.

In addition to showing the Falls Prevention video, the Southwest Florida support group invited two exercise experts to speak to the group about safe exercises in a chair and for those who can stand. These presentations made for a great interactive meeting.

The Central Florida group also met and invited a speaker to discuss

mobility equipment with its members. The D.C., Maryland, Virginia and Delaware group discussed overcoming insurance challenges in an intimate setting, allowing for all attendees



to thoroughly discuss their experiences, difficulties and triumphs dealing with insurance companies.

Other meeting topics included independence, caregiving and general open forums.

Earlier this year, TMA hosted a KIT Leader conference call to provide an opportunity for open discussion, to share experiences and ideas about membership, meeting topics, and fundraising. The call covered many upcoming projects that require support group participation and collaboration. If you have any ideas for future support group meetings or a specific topic that you would like to know more about, don't hesitate to contact TMA's Member Services at 1-800-821-7356.

Time to grow

A recent initiative for the support groups is the support group leader mentor program for new and growing support groups. The program pairs

experienced leaders with others who are new and interested in expanding. Many leaders already reach out to one another for advice and guidance; however this program will offer a structured approach for correspondence and advice, depending on the participants' availability and interest in either mentoring or being mentored. If you are interested in starting or growing a support group in your area or in working with a new support group leader, contact Member Services at 1-800-821-7356 or tma@myositis.org for more information.

Educating health providers

Support group members should expect increased involvement from TMA's medical advisors as TMA continues to increase physician education nationwide. TMA's medical advisory board members will be active in their communities this year, giving presentations to local support groups and doctors who wish to learn more about myositis. Check with your support group to see if a medical advisory board member will be speaking at one of the meetings this year.

In addition to these informational presentations, TMA recently received funding from corporate supporter Questcor Pharmaceuticals to hold five "Lunch and Learn" seminars. These events will be held in conjunction with TMA support groups. Local physicians will be invited to attend sessions where TMA Medical Advisors discuss treatments for myositis and answer questions. These programs will be offered to select support groups in major

See Support next page.

Support *from previous page.*

cities where there are many myositis patients and doctors. TMA will collaborate with the support groups and fund the luncheon to attract doctors in the area who have an interest in myositis.

Stay connected

Did you know that TMA offers more than 40 support groups nationwide? Have you visited the support groups' page on our website? Visit www.myositis.org and type your zip code into the space on our homepage to find a local support group in your area.

Log into MyTMA to keep up with other members in your group and with events and meetings in your region.

Can't make it to the meeting? Check the KIT page on TMA's website to find your local group and see if there is a group newsletter or meeting minutes. If you want to keep in touch with a few members before the next meeting, call (1-800-821-7356) or email tma@myositis.org to set up a conference call. Contact other members on the community forum or on Facebook, and follow us on Twitter to stay connected to the myositis community 24/7.



Members *from cover.*

As for his other medications, he says, "I am slowly trying to get off of them with the help of my rheumatologist and urologist." At his last appointment, his laboratory results showed his medicine-exercise combination was having a positive effect. The results were the best since the start of Zachary's illness: proof, he says, that his research and hard work are paying off.

With great thought and effort,

www.myositis.org

Zachary came up with a diet and fitness plan that works for him. He's lost the prednisone weight and is down to 195 pounds, and has also gained back some of his former strength and flexibility.

Unable to return to his former job, Zachary spends his time as an advocate for explaining the difficulties and promoting the understanding of autoimmune disease. He runs his publication company, Weishendo Publications, from his home, and writes materials for people who suffer from autoimmune disease. He is the author of "The Principles & Philosophy of Weishendo" and "The Divine Spear & Intrinsic Staff of Weishendo," as well as "The Burly Man," the diary of his experiences with polymyositis.

Zachary also moderates an awareness group on Facebook called, R.A.I.D., which stands for "Raising Awareness of Auto-Immune Disease." He is the creator of several YouTube channels, one dedicated to Weishendo, and one to educating people about autoimmune disease.

Underlying his practical advice is his unique philosophy inspired by 20 years in the martial arts, but also tempered by his own personal suffering.

He has some advice for anyone struggling with chronic disease. "Find purpose in your life, and what you do each day," he says. "You have to tell yourself each day that you can defeat this disease. You will defeat anything it throws your way. Take control of it, and never let it shape or mold you into a finite structure. Seek out support groups, or others who share your illness, and inquire about what they have done to fight against it."

Zachary Lewis was chosen as "one of the 50 great writers you should be reading" by The Author's Show in 2012.

"The Burly Man" and other books by Zachary Lewis are available from

his online sites:

<http://www.lulu.com/weishendo>

<http://www.youtube.com/weishendo>

<http://www.youtube.com/polymyositis>

<http://www.facebook.com/weishendopublication>



Experts *from page 6.*

I am 27 years old I have been battling polymyositis for going on six years. Recently I found out that I need an endoscopic ultrasound and biopsy on a mass on my pancreas. I feel a bit defeated at yet another procedure. I put on a brave face for everyone on the outside but deep inside I feel very scared for the future. How do I overcome this terrible anxiety? I got sick right after graduating from college, and had to discontinue my educational plans. I feel stuck in one place. Sometimes I feel lonely in this but I know I am not. I have my mom and dad.

Amy Wood: Nobody wants to have a chronic illness but we make it worse for ourselves when we fight reality. The key is to make the most of what is working and accept that you are not perfect. And you will not be happy all the time, no matter what is going on in your life. And remember that you are unique and you get to determine your life path. You can't control many things in life. Life feels better when you let go of what you can't control and focus on what you can control.

Dr. Wood will be leading sessions at TMA's Annual Patient Conference in Louisville Oct 17 to 20. Find her award-winning book, "Life Your Way," at online booksellers or at Dr. Wood's web site, www.amywoodpsyd.com.



Current research of interest

Newer medications have lower shingles risk

The newest medications used to treat autoimmune diseases such as dermatomyositis and polymyositis don't seem to raise the risk of developing shingles, new research indicates.

There was some concern that anti-tumor necrosis factor (anti-TNF) drugs might increase the chances of a shingles infection because they work by suppressing a part of the immune system.

"We found there is no increased risk when using these drugs, which was reassuring," said Dr. Kevin Winthrop, associate professor of infectious disease and public health and preventive medicine at Oregon Health and Science University in Portland.

Results of a study by Winthrop were published in the March 6 issue of the *Journal of the American Medical Association*.

Shingles is a major concern for people with autoimmune conditions, particularly people who are older and more at risk for developing shingles in general. Shingles is caused when the same virus that causes chickenpox is reactivated.

Shingles typically starts with a burning or tingling pain, which is followed by the appearance of fluid-

filled blisters, and the pain can be intense.

Two classes of drugs used to treat myositis — the "biologic" anti-TNF drugs and a group of medications called non-biologic disease-modifying anti-rheumatic drugs (DMARDs) — are medications often used when prednisone does not work well, or to minimize prednisone side effects. Examples of biologics are adalimumab (Humira), etanercept (Enbrel), rituximab (Rituxan), infliximab (Remicade). A commonly used DMARD is methotrexate.



Winthrop and his colleagues reviewed data from

almost 60,000 people with various autoimmune conditions. More than 33,000 were taking biologic anti-TNF drugs, and almost 26,000 were on DMARDs. The study period ran from 1998 through 2008.

They found no significant increase in the risk of shingles based on the type of medicine people were taking, with the exception of a high dose of corticosteroids.

However, people taking more than 10 milligrams a day of corticosteroid medication had twice the odds of developing shingles.

Dr. Patience White, vice president of public health for the Arthritis Foundation, said the study's findings were good news.

"People worry a lot about taking

drugs, and this well-done study says this is another thing we don't have to worry about," said White, who also is a professor of medicine and pediatrics at the George Washington University School of Medicine and Health Sciences, in Washington, D.C. "Drug therapies, other than corticosteroids, don't increase the risk of getting [shingles]."

Both White and Winthrop said people, if possible, should get the shingles vaccine before they start taking medication for an autoimmune condition. The shingles vaccine is a live vaccine, so it's not recommended for people who are on any type of immune-system-altering drug.

Winthrop said that based on the latest findings, he suspects it would be OK to vaccinate people on the newer medications, but he added that a study would need to be done first to confirm that.



Aging research has implications for muscle disease

Dozens of drugs based on similar mechanisms have been found to slow aging, and may be available to the public soon, according to research led by David Sinclair of Harvard.

Sinclair's work, published in the journal *Science*, has proven that a single anti-aging enzyme in the body — known scientifically as SIRT1 — can prevent age-related diseases. The research also shows that SIRT1 is activated by 117 drugs, as well as low-calorie diets, exercise, and the antioxidant resveratrol, found in red wine.

Sinclair, a professor of genetics, said the discovery means that a whole new class of anti-aging drugs is becoming possible and could ulti-

mately prevent diseases caused by the aging process, including cancer, Alzheimer's disease, muscle wasting diseases and type 2 diabetes.

Although the drugs would be prescribed to treat one disease, they would actually prevent many diseases related to aging, Sinclair said in an interview with Newsmax.

He added: "We're finding that aging isn't the irreversible affliction that we thought it was. Some of us could live to 150, but we won't get there without more research."

According to the research, SIRT1 is activated naturally by calorie restriction and exercise, but can also be switched on by resveratrol — found in red wine, grape skins, peanuts, and berries — as well as drugs and supplements.

Although resveratrol has been studied for a decade, Sinclair's work is the first to identify the basic science

that explains how it confers health benefits. Past studies have suggested it may have promising implications for the treatment of cancer, cardiovascular disease, heart failure, type 2 diabetes, Alzheimer's, Parkinson's disease, fatty liver disease, cataracts, osteoporosis, muscle wasting, sleep disorders, and inflammatory diseases.

Sinclair's company was sold to GlaxoSmithKline (GSK), where Sinclair and other of the original researchers now work as scientific advisors. They're studying synthetic activators that are 100 times as potent as a single glass of red wine; the best three are in human trials, Sinclair noted.

"In the history of pharmaceuticals, there has never been a drug that tweaks an enzyme to make it run faster," said Sinclair, who is also a geneticist with the Department of Pharmacology at the University of South Wales, Australia.

While any drug would be strictly prescribed for certain conditions, Sinclair said oral medications could be developed to prevent aging, in the same way statin drugs are prescribed to prevent, instead of simply treat, cardiovascular disease.

In new research, led by Sinclair, overweight mice given synthetic resveratrol were able to run twice as far as slim mice and they lived 15 percent longer.

"Now we are looking at whether there are benefits for those who are already healthy," said Sinclair. "Things there are also looking promising."

The study was funded, in part, by the National Institutes of Health.



See Research next page.

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Research *from page 11.*

Case study: intensive aerobics helps PM patient improve

In a case study published in the December 2012 edition of *Neuromuscular Disorders*, Italian researchers described the experience of a 64-year-old woman affected by chronic polymyositis who had trouble walking, was losing muscle to fat, and had swollen thigh muscles.

She achieved significant clinical improvement after five weeks of intensive aerobic training, said the team who treated her at the University Hospital of Pisa. In particular the patient improved in motor performance tests, showed an improvement in the efficiency of oxidative metabolism and achieved a better quality of life.

Furthermore, analysis of CPK levels showed that the exercise protected her from muscle damage.

The researchers concluded that a specific intensive exercise program can be safely used with beneficial effects on muscle function in patients with chronic polymyositis.



Assisted living: one family's story

David Besnette thought the time was right for a website that gathered state-by-state guidelines and resources for assisted living. Besnette's web site also featured his flair for multimedia, as he interviewed experts in the regulation and delivery of assisted living care and incorporated videos into his site, along with commentary on matching specific cases with the best kind of assisted living provider for each individual family.

His website, www.assisted-living-directory.com, is a helpful resource for anyone exploring assisted living for themselves or someone they care

about, with advice about pitfalls, caregiving from afar, assessing the quality of care, and dealing with legal and financial issues.

Last year, David found out — in a very personal way — that even the most careful planning and research can be thwarted by a complex chronic disease like dermatomyositis. The patient was his mother-in-law, a strong and active woman who survived a battle with cancer and seemed well on her way to returning to her normal life.

A few months after the family celebrated her successful recovery with a trip to the beach, they found the woman they called "Mom" was struggling again.

David tells the story:

"It wasn't until a neighbor came by to check on her in the fall that she noticed that our mom couldn't raise her arms to open and close cupboards, or to adjust the blinds.

Mom, as it would turn out, had dermatomyositis.

Of course, standard protocol for this condition is plenty of meds that are very toxic, and very hard on your body. Mom started taking these, but she met with nasty side effects, fatigue and all the rest. Still, she remained stoic, insisting she could manage life on her own. We believed her.

As we neared the holidays, we were looking forward to seeing mom, but we were also anxious to get a first-hand assessment of her condition. However, we never made it to that

point. Again, a well-intentioned neighbor went to check on her, only to find mom 'scooching' on her back on the floor to get from room to room. She couldn't stand up anymore, and didn't bother to tell anyone. She went to the hospital that day, and never again returned home.

Once her coverage at the hospital ran out, she was transferred to a skilled nursing facility nearby that could handle her condition, and the feeding tube. This facility was not a 'choice' but was the default place that she had to go, as there were no other places in the area with the care available that she needed. She was an advanced case.

Mom wanted the option to move into an assisted living facility. Some friends of hers lived in a facility not too far away, and she wanted to move somewhere like that.

We began to research assisted living, either in her state, or perhaps nearer our family here in Colorado, or perhaps in Michigan where my wife's brother lives.

We struck out on every attempt, and almost universally got the same reply from all of them. "We can't accept a resident who is on a feeding tube." That was the answer across the

board. Many of them said that if we could get her off of her feeding tube, they would reconsider. We turned our attention to helping her regain her ability to eat, but that

never happened."

After her death, David looks back on how — even with all his vast knowledge of assisted living — he couldn't find the right place for his



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Hospital Fall Prevention Technology Now Affordable, Available for Home Use

As muscle weakness and pain from conditions such as myositis limit mobility, simple tasks such as standing and sitting in the bathroom becomes more difficult. Research studies have shown we also become more susceptible to painful, debilitating bathroom falls.

According to the Centers for Disease Control and Prevention (CDC), the simple activity of getting on and off the toilet is a leading cause of non-fatal injuries. In a recent study¹, the CDC estimated that in 2008 alone, 234,094 nonfatal bathroom injuries were treated in emergency rooms across the United States. The study noted that injury rates increased with age and attributed most injuries (81.1%) to falls.

"All persons, but especially older adults, should be aware of bathroom activities that are associated with a high risk of injury and of environmental modifications that might reduce that risk," the study advised.

One such environmental modification now available is the LiftSeat powered toilet lift. Initially developed for use by healthcare professionals in hospitals, rehabilitation centers and nursing homes, LiftSeat's patented technology is now available for the home to safely and smoothly raise and lower a person for toileting.

LiftSeat has proven especially useful in protecting persons with myositis or neuromuscular disorders including amyotrophic lateral sclerosis, multiple sclerosis, muscular dystrophy and rheumatoid arthritis.

LiftSeat helps prevent painful, debilitating bathroom falls that could force someone you care for to move from their home to the next level of care such as an assisted living facility or nursing home. Beyond the emotional impact of leaving home, the costs are significant. Studies estimate the national average of even a single month in assisted living is \$3,500.²

LiftSeat costs a fraction of even one month in assisted living, installs in seconds and is easy to use. For more information on a LiftSeat powered toilet lift for your home or the home of someone you care for, visit www.liftseat4home.com/107 or call (877) 665-4381.

1. Centers For Disease Control And Prevention. "Nonfatal Bathroom Injuries Among Persons Aged ≥15 Years - United States 2008" MMWR 2011;60: pp 729-733

2. The 2011 MetLife Market Survey of Nursing Home, Assisted Living, Adult Day Services, and Home Care Costs October 2011

mother-in-law when she needed it:

"I think that, as in our mom's case, knowing that she was on the quick decline, skilled nursing, or perhaps intensive, round-the-clock in-home care were the only real viable options."

I would submit though, for anyone going through a similar situation, to research options as far in advance as possible, and to ask pointed questions about things like feeding tubes, and what happens if mom (or dad or yourself, husband or wife) is placed into assisted living care, and they can no longer handle the care. Depending on the severity of the condition, assisted living may be a good option, especially if there are plenty of facilities to choose from in your area. In other cases, as in ours, it may not be realistic.

Ideally, so a loved-one isn't faced with multiple moves, finding a continuing care facility that offers a combination of assisted living and skilled nursing services under one roof would probably be the best arrangement.

We actually solicited the help of a certified senior care advisor, who, for us, was extremely helpful. Just having someone knowledgeable with state laws, as well as assisted living regulations, eligibility requirements, and who had a network of contacts in the industry - was invaluable to us during the process.

If you or a family member has experience with dermatomyositis and assisted living, David invites your comments on the site, www.assisted-living-directory.com.

Perspective from page 9.

house. At the stop sign a block away, I knew it was over. Not trusting myself to get around the block, I made a U-turn towards home. There were no tears left by the time my husband called to say he was on his way and offered to get dinner.

"How about a pizza?" I asked.

As he came in from the garage, I took the box from his hands and replaced it with my car keys. I suggested he turn in his company car and drive mine until the lease expired.

"You sure about this?" he asked.

I bobbed my head and then realized: A person is never out of tears.

Finding a myositis expert

TMA often hears from people who have alarming symptoms and are seeking a definitive diagnosis that will explain weakness, pain, loss of balance, skin rashes, trouble swallowing or combinations of several of these symptoms. More questions come from people who have already been diagnosed with polymyositis, dermatomyositis, juvenile dermatomyositis or inclusion-body myositis but — once diagnosed — can't find a physician familiar with their disease. Still others have had physicians retire or move and are seeking to replace them. Because myositis is such a rare disease, it's not always easy to find someone, even a specialist, who has seen a myositis patient.

Based on comments from members, TMA recommends that you use several approaches to find the best fit for you.

TMA's medical advisory board

TMA has an active, involved medical advisory board made up of neurologists, rheumatologists, and other specialists. They are recruited from the world's foremost authorities on myositis and serve without compensation. They advise the TMA board of directors on funding myositis research, answer questions from patients, and present sessions at TMA's Annual Patient Conference. If you live near the hospital, teaching school or medical practice of one of TMA's medical advisor's, call the office, explain your situation, and make an appointment. If the medical advisor is not able to see you within a reasonable time frame, ask for the name of another nearby specialist. You can find the names and

contact information for TMA's medical advisors by going to the home page, www.myositis.org, clicking on "about TMA" at the bottom right, then selecting "Medical Advisory Board" from the list to the right.

Heather Hughes, a registered nurse who was experiencing muscle weakness and was found to have many blood markers for myositis, including anti-Jo-1, talked about her experience. Heather didn't see any medical advisors



located near her home, so she emailed several across the country, asking their help in reaching some kind of treatment plan. "I will be honest in admitting that I really didn't expect a reply from them," Heather said. "However, to my surprise, I heard back from several." One of them called her that night at her home; several emailed answers to her very specific question, and one recommended a rheumatologist that he had personally trained and who had since relocated near Heather.

Ask TMA's members

TMA has several ways that you can interact with other members and find out about real-life experiences with their medical care team. Anyone visiting TMA's forums can be sure of receiving a warm welcome, along with hard-won advice from members about their own search and their present satisfaction with their own physicians. Facebook is also a good place to ask questions, and members are quick to respond if they can be helpful.

Find the appropriate forum by visiting TMA's home page at www.myositis.org; clicking on "Your Myositis Community" at the top, selecting "Community Forum," from the drop-down menu, then clicking the general or disease-specific forums. Submit a little information about yourself and your search, and you're likely to get many suggestions from people who live in your general area. TMA's Facebook and Twitter links are at the bottom right of the home page and will lead you to another community that will be quick to offer help.

Heather Hughes did both: "Within a day's time, I had names of doctors and support from other people who have dealt with similar frustrations."

Ask TMA

Not comfortable with social media? Email TMA at tma@myositis.org, and staff members can help you find someone in your area, either by posting for you or by finding the medical advisor closest to you.

Find a university health center

The website maintained by NIH for patients with genetic and rare diseases (www.rare-diseases.org) says you may want to consider contacting a doctor at a university health center in your area, since university health centers tend to have the latest technology and treatments. University health centers have doctors who are involved in clinical trials and who may work together with others to diagnose and treat patients.

MedlinePlus, a website designed by the National Library of Medicine to help you research your health questions, provides links to directories to help you find health professionals, services and facilities.

If you have further questions, call 1-888-205-2311 to speak with a GARD Information Specialist. Over time, most people will need care that's more specialized than a primary care doctor can provide, either for a difficult chronic problem (like osteoarthritis or intractable pain) — or because of a condition or test results that demand immediate attention (like a suspicious mammogram or blood in the urine).

Ask your primary care doctor

Primary care doctors generally make reasonable referrals, so the specialist your doctor recommends should be the default choice if you don't want to keep hunting, says a recent article on finding the right doctor in "US News Health." However, says author Angela Haupt, "a better tactic would be to ask your primary care doctor for the names of two specialists, and why he might recommend one over the other. Is it based on convenience or reputation? Especially when the referral could be for a serious medical problem, you can get right to the bottom-line opinion by asking: "Would you go to him? Would you send your mother to him?" Posing another question or two will tell you whether the specialist communicates well with primary care doctors; if so, your care will likely be better coordinated." This kind of communication between primary care doctors and specialists is important, since many myositis patients work out an agreement between the two doctors where one monitors day-to-day issues, and the other formulates the overall strategy for dealing with your disease.

"Say to the doctor, 'When you send people to this person, does he or she keep in touch with you?'" says Washington, D.C.-based family physician Kenny Lin, a blogger on family medicine for U.S. News. "And ask what other patients have said about the doctor."



Alternative Approach

Ancient practice promotes strength, balance, healing

It's an appealing notion: a treatment for chronic disease with no side effects, that also improves sleep, helps with general balance, lowers blood pressure and raises the quality of life.

Tai Chi, an ancient martial art, is so entrenched in China that its practice is visible in open spaces at the start and end of the day, with elders moving through a slow, synchronized routine with smooth, fluid motions that seem more gentle than martial.

You'll find the practice of Tai Chi gaining ground in gyms and fitness centers in this country, too, though you'll have to seek it out. That's what Clara Miller did. She's a dermatomyositis patient who has periodic flares and finds it hard to exercise because of muscle pain and weakness.

Believing she could do better, Clara joined a health club and took a tour. On the tour she saw a martial arts instructor leading a "Tai Chi for Arthritis" class. They were doing a motion (called a "form" in Tai Chi), where students were waving their hands in the air, and it looked to Clara like something she could do and enjoy.

Clara talked to the teacher about her disease and joined the class. "Of course, learning the form was much more difficult than I'd anticipated," she said, "but I enjoyed the class and my fellow students." She persevered, practiced every night, began taking other Tai Chi classes, and moved up in her practice to include more difficult forms.

Besides learning the graceful movements, she learned something about herself: "I realized that I really enjoyed all types of movement," she said. "Learning those precise steps and practicing shifting my weight from one foot to the other while breathing with each move made me feel great. My energy increased, and

I started to experience the integration of mind and body." Zachary Lewis (see page 1) considers his rhythmic, balanced martial-arts-inspired movements a cornerstone of his recovery from polymyositis.

Clara tracked her improved health by simply observing how she felt before and after her Tai Chi practice, but these results are hard to prove and hard to apply to the general population of people with muscle weakness. But after centuries of popularity in China, Tai Chi — along with meditation and yoga — has interested western researchers convinced of a strong mind-body connection in all kinds of disease. A number of studies have confirmed the benefits that practitioners report. And with its potential impact on the chronic diseases that burden our aging population, Tai Chi is attracting a great deal of attention as a possible low-cost complementary (meaning that it's used along with conventional medicine) treatment for everything from cancer to Parkinson's Disease.

An NIH-funded study, published last spring in the "New England Journal of Medicine," studied three popular forms of exercise — resistance training, stretching, and Tai Chi — and found that people with mild and moderate Parkinson's disease who practiced Tai Chi had the greatest improvements in balance and stability. Just as important, these patients had fewer falls than those doing the resistance training and stretching.

More than balance is affected. In 2008, a review of published research by NIH found Tai Chi reduced blood pressure in 22 (of 26) studies, and showed promise in stimulating the immune response, particularly to the virus that causes shingles.





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Physician education

Questcor Pharmaceuticals has provided funding to The Myositis Association to support our efforts to educate physicians about myositis. TMA will be initiating 3 activities in support of physician education – Visiting Professor program to educate medical students about myositis; Lunch and Learn seminars to educate established physician practices about myositis; and Physician’s Guide to Myositis to inform physicians about treatments appropriate for myositis.



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Looking to attend camp this summer? TMA has stipends for JM campers. To learn more, contact TMA@myositis.org or 1-800-821-7356.



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