Los Angeles Myositis Support Group

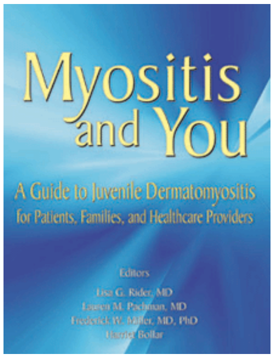
Newsletter

January 2007

Happy New Year!

Juvenile myositis book available February 2007

By Kathryn Spooner



Myositis and You

A Guide to Juvenile Dermatomyositis for Patients, Families, and Healthcare Providers

Editors

Lisa G. Rider, MD
Lauren M. Pachman, MD
Frederick W. Miller, MD, PhD
Harriet Bollar

WASHINGTON DC – The Myositis Association has published a book on childhood forms of myositis, the first of its kind to focus solely on this rare, chronic, and often disabling disease. Juvenile myositis (JM) affects 3,000 to 5,000 children in the United States. *Myositis and You: A Guide to Juvenile Dermatomyositis for Patients, Families, and Healthcare Providers* brought together more than 70 healthcare professionals who contributed to forty chapters covering various aspects of the disease. Dr. Lisa Rider (National Institutes of Health), Dr. Lauren Pachman (Children's Memorial Research Center), Dr. Frederick Miller (National Institutes of Health), and Harriet Bollar (Cure JM Foundation) served as editors and contributors. *Myositis and You* aims to help patients, families, and healthcare providers learn about juvenile myositis and explain it to children of different ages; find strategies to help children adjust physically and emotionally; and understand the choices for treatment and monitoring throughout the disease course. The book includes resources to support families fighting juvenile myositis. "Until now, there has been a notable absence of written material for parents and non-physicians dealing with this group of illnesses," says Suzanne Bowyer, Professor of Pediatrics and Director of the Section of Pediatric Rheumatology at Indiana University School of Medicine, and Chair of the Executive Committee, Pediatric Section, of the American College of Rheumatology. "*Myositis and You* has now arrived to address this need." *(Continued on next page)*

The Los Angeles Myositis Support Group meets bimonthly on Sunday in the Board Room on the first floor of Good Samaritan Hospital,
616 S. Witmer St., Los Angeles.
(Take the 6th St/Wilshire off-ramp from the Harbor Frwy, go ½ mile west)

Next meeting
January 21, 2007 1:30 – 3:30 PM

Co-chairs:
June Colton, junecolton@hotmail.com
Richard Gay, rgay@socal.rr.com
Newsletter Editor: Richard Gay.

January Program

We will have a guest speaker from who will discuss the dollars and cents of income taxes. Come hear Mr Joe Marra who is a CPA and retired IRS employee. He himself has muscular dystrophy.

New Myositis Book, cont'd

Juvenile myositis is a chronic neuromuscular disease distinguished by muscle weakness and often a skin rash. Many children have never been accurately diagnosed or properly treated. The Myositis Association is a patient support, education, and advocacy group that represents myositis patients here and on every continent. TMA has awarded more than $2 million in research grants and fellowships in the first four years of its research program, with more than $500,000 specific to juvenile myositis research. Information about juvenile myositis, TMA, and *Myositis and You* is on the TMA web site at www.myositis.org or by calling 1-800-821-7356.

Helpful Tips Obtaining a Wheelchair or Scooter from Medicare

By June Colton
Los Angeles KIT Co-Chair

It took about 8 months for me to get my electric scooter because I had been misinformed about the correct procedure when dealing with Medicare. I had to change suppliers who were dishonest. A friend suggested I deal with American Medical Supply in Sunland (818) 352-1614, Michael Duffy. They took care of everything and in a month they delivered the one I had selected. It is a Pride Go Go. Michael showed me everything I needed to know, such as disassembling it, its features, and maneuvering through the hallways and doorways. They will do repairs and bill Medicare. If I need a loaner, they will supply one. I am a happy driver, in the house and outside, and feel more independent once again.

To make your experience a better one than mine, here are a few suggestions for dealing with Medicare.

Phone Number: (800) Medicare, select Billing, Supplies, Durable Equipment

E-Mail: www.medicare.gov Billing, Supplies and the State in which you live, then Durable Equipment.

1. Visit suppliers who accept Medicare, to find the wheelchair or scooter that is best for you. Be aware of the following:
    a. Is it comfortable?
    b. Is it easy for you to operate?
    c. Look at the specifications to see if it is easy to take apart for vehicle travel. How far will it go on a full charge and what is the speed?

You need to know the turning radius, and the dimensions so it will go through doorways, isles, etc. Does the seat rotate (scooter)? Are the tires solid or air filled? (The solid ones don't leak.)

2. You need to be examined and evaluated by your doctor. Then he can write a prescription for your wheelchair or scooter. He must say that it will be used inside the home. Medicare doesn't authorize durable equipment for outdoor use, even though we may need to use it for that purpose. He needs to be specific and say that it should be motorized (if that's what you want) and that with your disease (such as advanced myositis, which is progressive) you cannot walk or stand. You have to be unable to get from here to there by yourself.

3. Give this prescription to your supplier, along with the exact equipment name and model number you want. He will submit this claim to Medicare for approval. Medicare has specific approved amounts they pay for equipment.

4. It may take a month for Medicare to approve. They will contact the supplier and the supplier will get the equipment.

5. Your will receive a call from the supplier (if you don't, be sure to call him) and he will make arrangements to deliver and demonstrate your new wheelchair or scooter. Or you can pick it up yourself if you choose.

6. Medicare will replace equipment very 5 years or sooner if the doctor says your condition has worsened and you need something else. Medicare will also pay for necessary repairs. Contact your supplier about this. If you need a loaner while your equipment is being repaired, your supplier should be able to accommodate you.

I hope this information, current as of this publication, has been useful. Medicare may change their rules annually. It's always good to know the rules before proceeding. It should make the experience a nice one. Happy traveling with your new equipment.

Member Wants to Know

Hi Richard: If you have a 'member wants to know' column, I have a few queries. 1. Has anyone had the gamma globulin infusion therapy and, if so, was it successful? 2. If you have arthritis and also DM – can you be confused by pain and weakening of muscles from arthritis v. myositis?

All the best,
Barbara W.
Please respond to Barbara at bar.bar@verizon.net

Update from Christa

By Christa Bennett

bennett520@sbcglobal.net

I am rapidly approaching my 4th year having Dermatomyositis. I continue to get better, thanks to the Antibiotic Protocol. Although I am not in remission, I pretty much have a regular life. I keep up with my young son and even volunteer and attend pre-school two days a week. My flare-ups come and go. Some days are good and some days are bad. I allow myself "down time" if I am having a tough day. It is not uncommon for me to sleep almost all day, on the days I do not feel well. Both my husband and my son are very understanding when I don't feel well and I am lucky that my husband helps pick up the slack, when I cannot get to the laundry, cleaning, etc.

When I was first diagnosed, I was very angry and sad about having this disease. I find today that "it is what it is." Some people get sick. It doesn't seem fair, but it happens. Like many of us, getting Dermatomyositis, was not part of the plan for my life. I had hoped to become an executive at my company and climb the corporate ladder. As a result of DM, I had to stop working and was forced to stay home. Since my son was just an infant at the time, I stepped into my new role as "stay-at-home-mom"--only with an autoimmune disease in tow. I had to ask for a lot of help in the beginning. My mother-in-law would have to come over almost every night to give my son a bath. My arms were too weak to lift him into the tub and I could not squat down on the floor and still get back up. I did a lot of crying early on. I did not like the feeling of my mind telling my body to do something and my body not being able to.

Things are different today. I am no longer on this quest to find out why I got sick. Today it doesn't matter. I live my life "one day at a time" and try to be grateful everyday. Having DM is not easy, but it is manageable and it does get better. If you have recently been diagnosed with Dermatomyositis and need to talk, please feel free to contact me. It is very hard for others to understand the plethora of emotions we go through when battling this disease. There is hope and I am a true believer in the Antibiotic Protocol. Thanks to Dr. Franco, Dr. Lallande, and the entire team from the Arthritis Center of Riverside, I am the healthiest I have been since my diagnosis almost four years ago, and for that I am grateful!

MCTD and Homeopathy

By Mukesh Gupta

I am suffering from MCTD (mixed connective tissue disease) and was cured by homeopathy. In the beginning I tried allopathy but all the steroids and chemo-therapies boomeranged. I was hospitalized due to drug induced diabetes reading 450 and above and also due to suppressed immunity got infected by PCP, CMV, a very bad liver profile, paralysis of my right foot, and so many things now do not remember. Ultimately I was recommended to a homeopathy doctor who took two years to bring me back to normal and completely off all drugs even steroids. I also do not take any homeopathy medicine for the last 6 years.

Thanks to God I am now living a very normal life

I will strongly advise all to go for homeopathy as it is completely harmless and unlike allopathy it is absolutely without any side effects.

Mukesh Gupta, mukesh@mukeshgupta.com

LIVE THE LIFE YOU LOVE

AND LOVE THE LIFE YOU LIVE

Latest News from Australia

By Anita Chalmers
KIT Chair Australia

Australian KIT members with IBM have participated in an sIBM research programme, which is being carried out by Doctors in Western Australia. We have decided to become an incorporated body and just are waiting confirmation that our new name will be The Myositis Association - Australia Inc. We hope that this step will help us become recognized here in Australia. It also helps me as the group will now be run by a committee. We now have 135 members. We started out with 12 in 2003. Let's hope that 2007 will be the year of the breakthrough in Myositis research. Happy new year to you and your group. All the best,
Anita

Sign Up for Free IG Living Subscription

I.G. Living is the only magazine dedicated to bringing healthcare information; immune globulin treatment information; community, reimbursement and product news; and resources for healthy living directly to immune globulin consumers and their healthcare providers.

Launched in February-March 2006, *I.G. Living* is distributed for free to patients and their physicians, including practices in immunology, neurology and hematology-oncology, and to infusion clinics.

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DM and Acupuncture

By Matt Barba

For Christmas I was given a gift certificate by a very good friend of mine for an acupuncture consultation and session. I had never had acupuncture, nor am I familiar with any Eastern medical therapies.

I've had DM for almost 3 years, and have been on Cellcept and Rituxan. These have been very beneficial for my muscles, I am very strong and don't suffer the fatigue I had for two years. However, I've had severe muscle tightness of the neck and back for many, many months.

I can honestly say that the 20-minute, 10-needle acupuncture session has done wonders for my neck and shoulder muscles. I am free of muscle tension and tightness of the neck and most of my back. This after SEVERAL months of daily, consistent doses of 600mg Motrin to cope with the ongoing muscle knots, tension, and stiffness of the neck and back.

The acupuncturist felt my neck and said, "Wow....I don't think I've ever worked on anyone with such muscle tightness". Today (two weeks later) I now have full range of motion of the neck, and haven't needed any Motrin. It's a great feeling and I'm truly thankful to my friend for giving me such a miraculous gift.

I strongly encourage everyone with myositis to seek out a qualified, recommended licensed acupuncturist. My friend utilized yelp.com to read reviews about this acupuncturist prior to buying the gift certificate for me. Her office was immaculate; she was professional, understanding, and efficient. Well worth the $90. Each subsequent session is $65. Good luck to you all.

Matt Barba
DM since 2004

Participate in New Research Study

By Rose Mary Istre
KIT Leader, Houston, Texas

Hi Rich,
It’s Rose Mary from the Houston KIT group. I, along, with University of Houston staff, have launched our research project investigating diet with regard to inflammation and mood in myositis patients. Our KIT group’s mentor, Dr Mavis Fujii supports the diet (as it is high in antioxidants and omega-3’s and does not eliminate any food group as to what is generally regarded as medically healthy) and is co-authoring the project. We are looking to enlarge our participant pool so, perhaps members of your group would like to participate I heard from one interested person a few months back, but she never sent me her postal mailing address. And I need to mail out the packets. Any help to find participants would be greatly appreciated.
Thank you for all you do. Rose Mary
Please contact Rose Mary at 281-997-6600 or her e-mail address Rosemarykay@sbcglobal.net

The Hazards of Falling

By Bob Cain
LA KIT Member with IBM

Hi Rich,

I took a page out of your book about 6 weeks ago. I fell in my garage. My car was being serviced, so I took my wife's car to pick up dinner. My procedure to get out of any car is to back out by extending my good leg on the pavement-locking my knee and pushing with my arms to an upright position. The garage floor was too smooth to gain traction, so I fell-landed on my good knee-bloodied my elbow and my rib cage landed on the door sill of the car. I have never felt so helpless! It took me 20 minutes to crawl and scoot on my butt to my front yard. Fortunately, my neighbor saw me and helped me up. Although I am OK now, I find myself more fearful of falling. This is bad, because I know I need to keep moving if I want to remain mobile.

Happy New Year,
Bob

Hi Bob,

Ouch!!!

I totally understand the helpless feeling of being flat on the ground and not being able to get up. I also crawl and scoot to a location that has potential for rescue. It gives one a true appreciation for the word miracle!

The fear of falling increases with every fall. It's been 13 months since my last fall (also in my garage). All you can do is to be extremely careful. I always allow extra time, even with the embarrassment of being very slow, because it is still much faster and much more comfortable than a fall. Even this morning, in the cold and wind, I asked a 78-yr old lady at the gym to hold my hand going out to my car just to be sure I would not fall.

You are absolutely right--we have to keep moving to remain mobile.

Rich

Focus on Proper Diet

By Harriet Riendeau, RLD
DM patient, New Hampshire

Hi Rich,

How's your world? We're doing just fine since Colorado got all the snow and left us with no snow here in New Hampshire! All the snow plowing folks are bored and lack of income but all the towns have held on to their salt and sand budget money! The bait and tackle people have all this bait because the waters are all open, no ice fishing! Our snowmobiles will just sit quietly in the basement, fine with us! I will share my personal story for your KIT newsletter. Harriet

My Personal Story

By Harriet Riendeau

It happened to me! To my family and friends I was a healthy athletic dietitian on active duty in the Army. I exercised, followed a low fat diet, and worked hard. Then, in 1992, I got sick and medically retired. The diagnosis: dermatomyositis. I had extreme weakness, difficulty holding my head up, getting up from a chair, stairs, extreme fatigue, shivering, and pain, difficulty swallowing and breathing. I was treated for years with high doses of prednisone, methotrexate, morphine and IVIG. The side effects: osteoporosis; weight gain; adrenal insufficiency; frequent infections including meningitis, e. coli, colds, and pneumonia, reflux, depression, anxiety, and hypersensitivity to smells and touch. I have known many doctors and learned how to be a patient. We know it is not common to have more than one family member with myositis, but my father, Oscar, had PM and passed away in 2002. My sister, Dallas, has fibromyalgia. In 2002, I went to a doctor specializing in family medicine, nutrition and anthroposophic medicine. I said "I eat pretty well." This doctor said "I doubt it". Nourishing Traditions got my attention. Just a few changes and I started healing from the side effects of medicine. It took time, some shifts in thinking, and awareness of my choices. In 2004, I participated in a Phase II clinical trial using Rituxan, which depletes CD20 and B cells. Currently, I am off prednisone, IVIG and all pain medications. I am reversing the osteoporosis. I still take methotrexate, but it's possible to wean off that this year. My last treatment of Rituxan was in January of 2005. I started my own business as a personal nutrition coach in 2006. I have a web site www.wheytogo.net.

What I Know Now--A Mother's View of JDM

By Genie Penn

In my 45th year I learned about life. I thought I understood it more than others, after all I am the daughter of Holocaust survivors. I have stood on the same train platform in Poland where my grandmother stood before she was loaded on to a train car to her death. I have stood on the grounds of the concentration camp in Poland and Austria where my father managed to cheat death. I have even stood inside a gas chamber. But none of these really taught me about life until I saw it through my 12 year old daughter's pain.

You see she was a normal, happy, smart, beautiful (aren't all daughters?), and full of life girl until the day in February 2006 when she complained that her back hurt. I listened to her complain for 2 weeks, thinking it was normal adolescent complaining. After all she had been lugging her middle school backpack for almost 5 months, something to get used to after being in elementary school. I gave in and decided to take her to her pediatrician.. The doctor listened intently and suggested that I get her a new backpack. She even took back x rays to make sure. About 2 weeks later we were back again. This time the doctor decided to run blood tests. I walked out of the office and felt like I would faint. Well the blood work came back normal except for one area, but the doctor was not too concerned and suggested we come back in a few weeks. From February to April I watched my sweet daughter deteriorate before my eyes. She cried each morning before school, she cried when I took her shopping. She began to walk haltingly; she could not climb the stairs leading to our house. She cried all the time. I would pick her up from school and watch her walk in pain to my car. Eventually she could barely walk. It was her spring break week and all she could do was lie on the couch. She could no longer dress herself, get out of bed by herself, lift her arms, use the bathroom by herself or do anything any normal active 12 year old could do.

Finally 2 months after her first back pains, she was diagnosed with a rare autoimmune disorder called Dermatomyositis. Her body had fought off a virus and then attacked its own muscles. It is so rare that most pediatricians will never see it in their practice. Yes, we were relieved it was not lupus, cancer or anything life threatening. But tell this to a 12 year old. She had been through a painful trauma that was only just the beginning. The next trauma would teach her and me about life. It began in the form of a little white pill that would save her but change her…It was Prednisone, better known as steroids. She was put on 75 mgs. the day she was diagnosed. Within one week she was walking better. At the same time she began to suffer the horrible side effects that no child should have to experience. My happy daughter became depressed, suffered from dark mood swings, grew dark hair, suffered from sweaty palms, and gained 20 pounds within one month. She developed the steroid moon face and belly. Through this whole experience she continued on with school, barely missing a day in her gifted magnet middle school. Some of the students were horrible to her, very mean, asking her if she "ate balloons for lunch". Each day she faced middle school with a courage I myself could not have mustered. Each day I picked her up from school and watched her hobble to my car, her face and body not the girl that looked like my daughter. Each day I sat and looked at the other young girls, who looked normal and trim, angry at god for doing this to my sweet, beautiful daughter. I missed her laughter, her smile, her company at the mall. Despite all this pain, she managed to get straight A's because she said it was the only thing she could do. She even came home one day and said that she would get a high achievement award. Then the following day she found out she would not be getting it because she had come late to homeroom a few times. Again I saw the pain in my daughter's eyes, and I quickly informed the school why she had come late so many times, because she could barely walk!

Slowly my daughter began to get better, the steroids reduced, the pain disappeared, her muscles began to function. She no longer needed help to get out of bed, I no longer had to put on her socks, shoes, clothes or help her out of bed. She learned how to cope with the insensitivity of other adolescents and became a more compassionate and stronger person. She intends to become a physician so that she can help others. At 12 years old she faced pain, trauma, depression, a major change in appearance, and the meanness of others. What she got in return was compassion, beauty, intelligence, strength, and a lesson about life. What I got from her taught me more then my UCLA education, my MBA degree, my visits to concentration camps, and my treks through Europe. So in my 45th year I thought I knew, but I did not.

Update from Genie Penn Jan 1, 2007
Richard, my daughter was tapered slowly, without problems, and has been totally off Prednisone now for about 10 days. All her tests have been normal and she was lucky because she responded so well to Prednisone. She did not have any other treatments or medications besides Prednisone. The Prednisone was as bad as experiencing the condition, but she is a stronger girl for her experience and will take it with her the rest of her life. It was the worst year of my life but I am thankful that the experience made me appreciate life more. She has a good Ped. Rhem. who will continue to watch her.
Genie Penn

Research grant for JM awarded

By Connie Radzwion
President, Cure JM Foundation

Hello Rich -

My name is Connie Radzwion, I am President of the Cure JM Foundation. My daughter Madeleine was diagnosed with JDM in 2004. She is now 7 and continues to struggle with the disease. Her case has been very complicated and she has GI involvement. I am writing in response to your call for the January KIT newsletter.

Cure JM Foundation recently approved a $1 million, three year grant, for a Program of Excellence for Juvenile Myositis Research, under the direction of Dr. Lauren Pachman at Children's Memorial Research Center in Chicago. This news should give every JDM patient and parent hope and encouragement.

Please let me know if I need to provide you with detailed information. I look forward to hearing from you.

Connie may be contacted at CGoldTX@aol.com

Looking for More Newsletters?

By Richard Gay
Co-Chair, Los Angeles KIT

If you liked this myositis newsletter and want to learn more or read all of our past newsletters (they started in Sept 2003), then you will be happy to learn that they are readily available on the Internet. The Los Angeles KIT group has a web site on Yahoo at http://health.groups.yahoo.com/group/LAKIT/
The web site requires registration, which is free of charge. After registering, click on Files and then on Newsletter Issues. The newsletters are in Adobe Reader (.pdf) format. Enjoy!

Fund-raising for JM Research

By Harriett Bollar
CoFounder & Chairman
Cure JM Foundation

Cure JM Foundation, www.curejm.org was honored as an official charity at the LaSalle Bank Chicago Marathon on October 22, 2006. JM families from all over the country participated in the marathon race to help raise money for myositis research. They were joined by several runners from a number European and South American countries who traveled to the U.S. to support this effort. The event raised over $ 210,000 for JM research and included a special dinner at DePaul University and a tour of the research facility at Children's Memorial Research Center in Chicago.

On January 21, 2007 Cure JM Foundation will be honored again as an official charity at the Carlsbad Marathon in North San Diego County. JM families on the West Coast are in training for this event and will be participating in special marathon events, including a JM party to be held on January 20 in Encinitas.

A New Baby in the Family

By Alistair and Barbara Hunter
LA KIT Members

Lots of excitement here as we have become Grandparents of a wonderful little boy named Ashton. Our daughter's water broke eight weeks early, but through her great attitude, great doctors and staff, and lots of prayer, he was delivered as a healthy little guy only six weeks early. He was in the NICU for a week. He is now about four months old and we have been going up to Santa Barbara every weekend to help out.
Best wishes and Happy New Year to all of the great LA Myositis folks. Keep us posted with the Newsletter, the Webpage, Meetings, and Activities.
Love, Barbara and Alistair Hunter

J. Edgar Dogg's Stun-Gun

By David Cramer

Los Angeles KIT Group Member

I think I may have made a mistake today.

It started when J. Edgar Dogg asked politely if he could use my credit card to make a reasonable small purchase on line. I of course asked what it was and how much it cost. He was a little vague about it but said it was electronic and sort of like a remote control. I try very hard not to be judgmental about such things and as it was fairly inexpensive I said yes. A few hours later I was on the computer and got an e-mail verifying that my order had been shipped. It was for an 80,000-volt stun gun. As you might imagine I was taken aback at this news and immediately thought there had been some sort of mistake made. Not so! This was the "Electronic Control" J. Edgar had ordered. Not wanting to seem overly suspicious but feeling a need for answers, I went looking for J. Dogg. I found him in the rec-room down in the basement shooting pool with one of his friends. (A rather nasty pit bull named Jason with a drool problem.) I told J. Edgar I needed clarification on what he had ordered on line. He readily admitted that the e-mail was accurate.

Not wanting to blow things out of proportion I decided to ignore the basic subterfuge he had employed in getting my consent to purchase the item and go straight to what need he had for such a thing. The fog got pretty heavy at this point as first he said such things had always fascinated him and he wanted to see how they worked. He then said it was for personnel protection from the bullies in the neighborhood and finally after several considerably more probing questions from me he admitted he wanted it to help him train the cat. I was as you might think a bit stunned by this last revelation and came back upstairs to consider the ramifications of such a thing. I could swear I heard suppressed giggles coming from the pit bull as I left.

After ruminating on the possible pitfalls of the developing situation for a while I have come to a conclusion. I am pretty sure J. Edgar Dogg is not telling me the truth about his intended use of this item. I say this because first of all, he has never shown any interest in electronic gadgets before, second he is the only bully in the neighborhood and last but not least…we don't have a cat.

I'll let you know how things progress.

Uncle Dave