

My Myositis[©]

This newsletter is compiled periodically and is provided for education and information to the members of the Greater Phoenix Area Myositis Support and Education Group. It is distributed electronically to interested parties both within and outside the group. It is not intended to provide, indicate or render any medical advice or professional service to the reader. Do not use this newsletter information to diagnose or treat a medical condition. Please consult your health care provider or primary care physician for your individual medical needs.

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Springtime in AZ - bring on the 90's!. It is our intent in this newsletter to keep you posted on the latest news on Myositis. We gather it from many different sources and point you to these sources to continue researching those items that interest you. We hope to give you some ideas, pose some questions, make you think and make you laugh as you live each day with one of these chronic illnesses – Dermatomyositis, Juvenile Myositis, Polymyositis or Inclusion Body Myositis. Your feedback and comments, both good and bad, are most welcome. We hereby solicit inputs, testimonies, opinions and coping ideas for publication. This is to be your newsletter not just an outlet for this very outspoken facilitator.

kajtlj 1 April 2008

CALENDAR OF EVENTS

5 APR 2008	MDA 5K WALK	- TEMPE
25 APR 2008	SUPPORT GROUP MEETING	- TUCSON
<u>21 MAY 2008</u>	<u>SUPPORT GROUP MEETING</u>	<u>- PHOENIX-RMH</u>
XX JUN 2008	TBD ACTIVITY	- PHOENIX
26 JUL 2008	SUPPORT GROUP MEETING	- TUCSON
<u>20 AUG 2008</u>	<u>SUPPORT GROUP MEETING</u>	<u>- PHOENIX-RMH</u>
XX AUG 2008	MDA EXECUTIVE LOCK-UP	- PHOENIX
1 SEP 2008	MDA TELETHON	- PHOENIX
18 SEP 2008	TMA CONFERENCE	- DENVER
24 OCT 2008	SUPPORT GROUP MEETING	- TUCSON
<u>19 NOV 2008</u>	<u>SUPPORT GROUP MEETING</u>	<u>- PHOENIX-RMH</u>
6 DEC 2008	MDA 2K WALK	- PRESCOTT
10 DEC 2008	CHRISTMAS PARTY	- TEMPE

The underlined events above are our normal quarterly support group meetings. They are sponsored by the MDA here in Phoenix and they have arranged with Ronald McDonald House (RMH) for the Windsor House conference room at their facility downtown. The MDA maintains member database and does our meeting notices. You must be registered with them to get the mailings and the Quest magazine. You are also asked to RSVP for each meeting so that we can get accurate headcounts for various purposes. Our contacts at the MDA are:

MARILYN HARDY mhardy@mdausa.org and

TRACI MCMILLAN tmcmillan@mdausa.org

They can be reached at 480 496-4530

MEETING MINUTES

Myositis Support & Education Group

20 Feb 290098 Phoenix, AZ - @ The Ronald McDonald House

Attendees:

10 Continuing Members (with Myo)

5 Continuing Spouses

4 Recent New Attendees (with Myo)

4 New Attendees (with Myo)

1 New Spouse/Significant

Marilyn Hardy – MDA

Bob Goldberg – TMA

Todd Levine, MD

Nicole Hank, RN



Todd Levine and Bob Goldberg (r)

Wow!! 28 people!! 18 people with Myositis!! A very full room!!

10:00AM

I convened the meeting promptly at 10 AM and introduced our first speaker.

Bob Goldberg, Executive Director of The Myositis Association (TMA) spoke for the first 45 minutes on many topics.

1. There are about 60 Myositis support groups around the USA tied to TMA.
2. TMA is continuing to fund many research grants and is optimistic of progress on the IBM front. (They have funded over \$3,000,000 in the past 5 years.)
3. \$20 in 2007 & \$15 in 2008 of your membership fees go to research.
4. There is a \$300,000 matching research challenge available in 2008
5. TMA recently approved \$170,000 for a Myositis patient registry.

6. TMA continues to focus on EDUCATION, ADVOCACY and RESEARCH.
7. The Fall 2008 Annual Myositis Conference is in Denver.
 Sept 18-21
 Denver Hyatt Regency Tech Center
 Conference Cost - \$150 (\$15 for hardship cases)
 Hotel Cost - \$129 per night
 Registration forms will be sent out around March 15
 Visit the TMA website at myositis.org for details
8. TMA has worked awareness for Myositis on a.) Good Morning America, 2.) Helpline, 3.) Discovery Health, 4.) NY Times and soon with the Wall Street Journal.
9. Fabio, "Crash" star and possibly Will Downing – spoke-persons for TMA
10. Bob lauded our Phoenix support group as one of the best in the country.

10:45 AM

We thanked Bob for coming through Phoenix to visit us. He introduced our next speaker. Dr. Todd Levine, a regular at our meetings, who recently became a member of the Medical Advisory Board for TMA and has been invited to speak at the fall conference.

Dr. Levine was asked to talk about any/all studies he is involved with for Myositis.

1. He is involved with the worldwide RIM (Rituxan In Myositis) study. Enrollment is still open until year end – they are looking for 225 patients with either PM or DM. Dr. Levine actually did the pilot study with Rituxan where 8 out of 9 patients saw improvement. This expanded RIM study involves the USA, Mexico, Israel, Europe and Canada. They first look for people with the Myositis specific anti-bodies (anti-Jo, etc) and patients may have to get a repeat muscle biopsy. They will be monitoring disease activity vs disease damage (?).
2. He is just getting started on a Medimmune study. He didn't give us much details but I Googled Medimmune and found that they are making a new MAB for RSV babies. I must call him and talk about this – is it being studied for Myositis? He did say that it was a cytokine blocker (vs the B cell killer, Rituxan): i.e., it will block the production of cytokines in the body. (More to follow!)
3. He then talked about a pilot study that he and Dr. Saperstein were trying to get going. He is looking at Lithium as a possible treatment for IBM. He noted that IBM is more frequently grouped with other nerve-degeneration diseases rather than the inflammatory Myopathies like PM & DM. He said that ALS, Alzheimers, Parkinsons and IBM should be grouped together for treatment studies. A Dr. LaFerla (sp) recently did a study on 12 patients with ALS (Lou Gehrig's Disease) and a TBD report has been issued. Dr. Levine points out that he has IRB approval of his proposal. The study will be 6 months long with a baseline and follow-up biopsy. He has applied for a grant from TMA!.

Bob Goldberg added that TMA is working with the MDA for a gene therapy trial for IBM. It is built on an Ohio State proposal using protein injections to promote muscle

growth. TMA has \$200,000, an individual has contributed a TBD amount and the MDA has been asked to participate. Wow!!

Bob and I got into a discussion on funding from NIH but differed in our beliefs.

11:30AM

We let the 4 new Myositis patients (2 DM, 1 PM & 1 IBM) introduce themselves and give us their testimonies. This is a very exciting part of our meetings. We continue to get new referrals from MDA, TMA and from Dr. Levine. Many thanks to you all.

We broke for lunch at noon. A 6 foot sub from Capistranos in Tempe with sides and water provided by the MDA comprised our gourmet repast this day. Eat something!

12:15PM

I reconvened the meeting and continued the “round the table” updates and testimonies from the remaining 14 others affected with this disease. Many continue to cope well with the help of their great care-partners, great doctors and the TMA/MDA people.

- Terri announced our annual outing to the Desert Botanical Gardens in Phoenix. It is on 12 March at 8:45AM at a cost of \$5 for the garden, wildflower and butterfly exhibits. Come one and all - friends, family et al. A flier will be sent out to all registered with the MDA– RSVP to Terri!
- Terri also announced our “Team Myositis” participation in the 8th Annual MDA 5K Walk at Tempe Town Lake. It is on 5 April at 7:45AM. You are invited to walk and raise funds for Myositis research at the MDA or simply make a donation to our team – make the checks out to the MDA! Terri signed up some walkers. We raised over \$3000 last year!
- Terri also announced that she (actually, our daughter, Amy) is selling Tupperware. She took some orders at the meeting.

There were a few notes in closing.

1. Many are interested in Naturopathic medicine. I have a nutritionist on call for our next meeting.
2. Some of us are interested in figuring out the Medicare maze. I will look for an expert for a future meeting.
3. We were referred to a website (myfamilyhistory.com) for a look at a medical family tree of sorts that is becoming a fad these days.
4. Our next meeting is on Wed, May 21, 2008 – same time and place!

kaj 3/4/08

Mar 18 2008, 11:47 AM EST - FROM TMA WEBSITE

Lithium chloride slows onset of skeletal muscle disorder

_University of California - Irvine _Study first to show biopolar drug could effectively treat inclusion body myositis

Irvine, Calif., March 18,

A new UC Irvine study finds that lithium chloride, a drug used to treat bipolar disorder, can slow the development of inclusion body myositis, a skeletal muscle disease that affects the elderly. In the study by scientists Frank LaFerla and Masashi Kitazawa, mice genetically engineered to have IBM demonstrated markedly better motor function six months after receiving daily doses of lithium chloride, compared with non-treated mice. The muscles in treated mice also had lower levels of a protein that the study linked to muscle inflammation associated with IBM. These data are the first to show that lithium chloride is a potential IBM therapy.

"Lithium chloride is an approved drug for treating humans. We already know it is safe and can be used by people," said LaFerla, professor of neurobiology and behavior at UCI and co-author of the study. "Given our findings, we believe a clinical trial that tests the effectiveness of lithium chloride on IBM patients should be conducted as soon as possible." Results of the study appear online this month in the journal *Annals of Neurology*.

IBM is the most common skeletal muscle disorder among people older than 50. People with IBM experience weakness, inflammation and atrophy of muscles in their fingers, wrists, forearms and quadriceps. There is no cure for IBM, nor is there an effective treatment, according to the National Institutes of Health.

LaFerla, a noted Alzheimer's disease researcher, began studying IBM about 10 years ago after learning the disorders have similar tissue characteristics. In the brain, a buildup of phosphorylated tau protein leads to the development of tangles, one of the two lesions that are hallmarks of Alzheimer's disease. High phospho-tau levels also are present in IBM, though patients do not experience dementia or memory loss. In a previous study, LaFerla found that lithium chloride reduced phospho-tau levels in mice genetically engineered to develop Alzheimer's disease. LaFerla and his research team then wondered: Could lithium chloride also reduce phospho-tau levels and symptoms in mice with IBM?

First, they sought to determine how the inflammation affects the skeletal muscle fibers. They injected the mice with a drug to trigger muscle inflammation, then put them on tiny treadmills to test their motor function. As expected, mice with inflammation could not keep up with the control mice, indicating reduced motor function. Examining their brain tissue, the scientists discovered the mice with muscle inflammation also had higher levels of phospho-tau.

Through additional testing, they discovered an enzyme called GSK-3 beta was responsible for increasing the tau phosphorylation. Previous studies have shown that same enzyme to cause tau buildup in the Alzheimer's brain.

Next, the scientists sought to block the accumulation of phospho-tau in the IBM mice with the goal of curbing motor function loss. In mice six months of age, one group was fed lithium chloride-laced food for six months, and a second group was fed regular food. At 12 months of age, mice in the first group performed on the treadmill as if they were six months of age, while mice in the second group had reduced motor function. Lithium chloride, the scientists found, blocked the GSK-3 beta enzyme that caused higher levels of phospho-tau.

"The older animals were performing as if they were younger animals," said Kitazawa, a postgraduate researcher of neurobiology and behavior at UCI and co-author of the study. "Lithium chloride was delaying their rate of decline."

The scientists then sought evidence that their results in mice might translate to humans with IBM. They performed tests on human muscle tissue samples and found the GSK-3 beta enzyme again played a role in the phosphorylation of tau. That was not the case, though, in patients with other muscle disorders. "This suggests that our IBM mouse model may have the same skeletal muscle mechanism as in human cases," LaFerla said. Researcher Dan Trinh of UCI also worked on this study, which was funded by the National Institutes of Health.

DO YOU HAVE IBM AND ARE YOU INTERESTED IN PARTICIPATING IN A CLINICAL TRIAL?

IBM is the most common acquired muscle disease occurring over the age of 50. The underlying cause remains unknown and there is currently no effective treatment. Pathological studies have revealed abnormal collections of proteins in the muscle cells from patients with IBM. These include proteins called phosphorylated tau (p-tau). A similar process appears to occur in Alzheimer disease, with accumulations of p-tau developing in brain cells. Lithium decreases the activity of the GSK, an enzyme that has a key role in the development of p-tau. Lithium and other GSK inhibitors have been shown to decrease the accumulation of p-tau in nerve cells in animal models of Alzheimer disease.

Dr. Todd Levine and Dr. David Saperstein are currently conducting a clinical pilot study to see if Lithium might be an effective treatment for IBM. During the course of the study you will be given two muscle biopsies, several questionnaires, EKGs, blood work, physical, neurological and strength testing exams, as well as Lithium 300mg/twice a day.

If this is something you are interested in or have any questions, please contact Nicole Hank at Phoenix Neurological Associates, LTD., at (602) 258-3354 ext 137.

QUIPS and QUOTES

The year is 1907, one hundred years ago.....

Theodore Roosevelt's ideas on IMMIGRANTS and being an AMERICAN in 1907.

"In the first place, we should insist that if the immigrant who comes here in good faith becomes an American and assimilates himself to us, he shall be treated on an **ex**act equality with everyone else, for it is an outrage to discriminate against any

such man because of creed, or birthplace, or origin. But this is predicated upon the person's becoming in every facet an American, and nothing but an American...There can be no divided allegiance here. Any man who says he is an American, but

something else also, isn't an American at all. We have room for but one flag, the American flag... We have room for but one language here, and that is the English language... and we have room for but one sole loyalty and that is a loyalty to the American people."

ATTENTION!!!
THE MYOSITS ASSOCIATION
ANNUAL CONFERENCE
18-21 SEPTEMBER 2008
DENVER

This is the premier annual event of TMA!

This is an event that you should not miss!

This is a very rewarding event for first-time attendees as well as those who have been before!

This event includes a panel of Myositis doctors presenting the latest findings on the cause, care, coping and cure of Myositis

This meeting includes many break-out sessions with opportunities to participate with others with the same disease as well as face-to-face Question & Answer sessions with the doctors.

The price is right: \$150 per member [good until 6/15/] and includes most meals. (There is a HARDSHIP price of \$15 {in commemoration of the 15th Anniversary of TMA} for those who cannot afford the regular cost of registration)

The lodging is right: \$129 per night at The Hyatt Regency Tech Center – Denver for nights from 9/15-9/24/2008.

The area is spectacular: Denver in the fall should be ideal; make plans to stay a few days in the area after the event.

Visit the TMA website (myositis.org) for registration for the conference, reservations at the hotel and further details as they develop.

AN OPEN LETTER

TO:

The Arthritis Foundation (AF)
The Muscular Dystrophy Association (MDA)
The Myositis Association (TMA)
and any other interested parties.....

FROM:

Ken Johnson

SUBJECT:

When will you find
the Cause and a Cure
for Myositis?

You don't look sick!
You don't look disabled!
Why are you taking so many dangerous drugs?
Why do they take blood samples so often?
What's a flare?
What is the name again of the disease you have?
How do you spell that?

Such is our life with Myositis!

I have had Myositis for 13 years now, almost as long as TMA has existed! The MDA has been around since 1950 and has spent millions of dollars on research for Duchenne MD, Becker MD and the 40 other diseases under their umbrella (including Myositis) and

still does not know the cause or cure for any of these diseases. The AF has been around since 1945 and has spent many millions of dollars on research on RA, OA and the 100 other diseases they have adopted (including Myositis) and have produced no cause or cure!

Those of us with Myositis continue to be guinea pigs, study pawns and victims of all types of treatments that could kill us but in the end, only mask the problems in a continuing life of biopsies, blood tests and new drug bombs. I see a non-ending cycle for these organizations, which are great at fundraising, but lack empathy for the patients. Their existence, their image, their overheads get more attentions than the patients they were created to serve. I challenge all of them to expose their percent of dollars raised that go directly to patient/member support! 50% - 60% - 70% - not good enough! I also challenge these big 3 - 501c's to expose your research expenditures and their "bang for the buck". That is an engineering term that is used to determine if your monies spent has produced anything tangible – other than journal papers and prestige for the researchers. Take the \$100,000 grant – at \$85 a minute – that allows about 20 hrs of research – about enough time to write a final report on obvious hypotheses.

We see our monies going to the giant monolithic insurance companies (for the ever-increasing premium costs), the high overhead drug companies (for their exorbitant drug costs), the well-perked doctors (who don't seem to have any samples these days) and the non-profits fundraisers (exploiting KIDS when more adults have MD than children) but see little in the way of progress towards cause and cure. Yes, I admit, treatments for all these diseases has improved such that masking the symptoms has progressed to the fine art of trial & error and/or drug effects cautions on the label/study/release forms. Prednisone remains the 1st line treatment in most cases with doctors knowing little more about it than patient tolerance and attestations on dosage and duration of treatment. All these drugs are off-label; i.e., we are

getting drugs developed for cancer, transplants, et cetera in that there are no drugs developed/available specifically for Myositis per se. The newer MAB drugs have revolutionized treatment today at the patients expense and the insurance company's whim but again, are we masking, maiming or mesmerizing the patient with false hope for a cure.

And where are we going with genetics? It is all well and good for the populace to know their genetic pre-disposition for certain diseases but that does little for the patient with a specific chronic illness to know that genes A, B and C are the reason you are in a wheelchair!! Lets get scientific about research! Lets put more quality, precision and better statistics into our goals for research! Lets gather data, monitor indicators from the onset and use a large enough sample to prove the efficacy of your conclusions. I expect to see a report one day that says that 8 out of 10 people with Myositis are married – therefore marriage causes the disease. Facetious conclusions akin to this are a waste of time and monies, \$100,000 at a time.

So, I suggest that the experts at TMA, the AF, the MDA, the FDA, NORD, Mayo, NIH, IMACS and any/all college medical school research groups be amassed under the Myositis umbrella and asked to focus on the data that exists. Wouldn't it be delightful if they all pooled their knowledge, their monies and their efforts on the cause and a cure for Myositis. Unless there is a unanimous agreed upon "statement of an objective" (akin to a man on the moon by the end of the decade) there will not be timely results. I included the IMACs project in the group in that it appeared to be an amassed group gathering data on Myositis, but in the 3-4 years since it's inception, I have not seen any conclusions that warrant immediate attention.

Myositis was thought of as a rare disease but the incidence of diagnoses has increased 50 fold since I was diagnosed in 1995. It was 5 in a million of the population then (and deemed fatal) and is

now 1 in 100,000! That should alarm somebody! That should wake up the research community! As a startling point, IBM is now the most common acquired muscle disease in those over 50 years old. And, as you may have read earlier in this newsletter, IBM maybe should be viewed under a neurological pretext (ALZ, PD & ALS) rather than an inflammatory Myopathy like PM and DM. One of the first sessions of my proposed multi-organizational amassing would be for just that purpose – separating the known, setting the focus and pointing out the direction of action with a stated objective of cause and cure.

Any responses I get will be published next quarter in this newsletter. I'm waiting with bated breath!

Addendum:

OK! I know there are a lot of good doctors out there trying their best in the name of Myositis. All of them -

from Engle/Askanas in Los Angeles,
to Miller/Plotz/Dalakas/Rider at the NIH,
to Mendell/Oddis/Amato on the TMA advisory board,
to Levine/Saperstein/Sivakumar here in Phoenix,
to Cwik/Stern at the MDA in Tucson,
to Bosch/Reed at Mayo
to the plethora of doctors in the medical school labs,

- are fine researchers each doing their thing! But just think what they could do if they were all a part of the same team, focused as I suggested above. Some day we “who don't look sick” will get the attention we need!

THE END

DESERT BOTANICAL GARDENS

Galvin Parkway in Phoenix

March 12, 2008

The following members of our support group (not everyone is in the picture below) were at the gardens and everyone had a great time. We met at 9AM, toured the Butterfly Exhibit, walked the garden paths, visited the Wildflower Gardens and stopped for lunch at Ullman Terrace on the south side of the place. The weather was spectacular, the butterflies were active, the gardens were beautiful, the food was delicious and the fraternizing was superb!

Lucy & Bud Ratcliff

Ed Glerup & Liz

Trisa Mason (and parents)

Terrell Smith

Marilyn Hardy

Amber Johnson w/Allison & Kenneth

Ken & Terri Johnson

Traci & Conner McMillan

Monique Claudio

Chyllia Dixon

Amy Rubink w/Emma



(Traci is taking the picture – thanks!)

IN THE NEWS

QUEST MAGAZINE (mda.org/publications)

Jan/Feb 2008, Vol. 15, No. 1 – pg 34 – a good article on muscle cell transplants

Jan/Feb 2008, Vol. 15, No. 1 - pg 18 – a research article on IBM as AI disease

Mar/Apr 2008, Vol. 15, No. 1 - - pg 28 – a good article on muscle diseases and breathing

ARTHRITIS TODAY MAGAZINE (arthritistoday.com)

Jan/Feb 2008, Vol. 22, No. 1 – pg 68 – How TV show “House” highlights AI diseases

Jan/Feb 2008, Vol. 22, No. 1 – 62 – a good chart on all the cortico-steroid drugs

Mar/Apr 2008, Vol. 22, No. 2 – 72 – a quick expose on the cox2 drugs like Vioxx

OUTLOOK MAGAZINE (myositis.org)

Winter 2007 – pg7/8 – a very good article on skin care with DM

I.G.LIVING MAGAZINE (igliving.com)

Feb/Mar 2008 Issue - This free magazine has a good story on IVIg re-inbursement that should interest many of you out there

AARP MAGAZINE (aarpmagazine.org)

Jan/Feb 2008, Vol. 51, No. 1B – pg 28 – a good article on the Mediterranean diet

Jan/Feb 2008, Vol. 51, No. 1B – pg 45 – an article on affordable housing Phoenix

Mar/Apr 2008, Vol. 51, No. 1C – pg 34 – a treatise on immune booster supplements

Myositis support/information websites

- | | |
|-------------------------------|--|
| 1. Arthritis Foundation | arthritis.org |
| 2. Muscular Dystrophy | mdausa.org |
| 3. Myositis Association | myositis.org |
| 4. Juvenile Myositis | curejm.com |
| 5. Jim Kilpatrick's blog | myositissupportgroup.org |
| 6. Nat'l Institutes of Health | nih.gov |

RECIPE CONTEST

from Terri Johnson (in the absence of other submittals)

TIRAMISU

INGREDIENTS:

8 large eggs, separated
1 pound Mascarpone (soft Italian cheese)
1 cup sugar
4 cups brewed espresso – cooled
1/3 cup favorite liqueur (coffee or rum or ???)
48 ladyfinger biscuits
1 cup heavy cream
1 tbsp sugar
Grated milk chocolate (for garnish)

DIRECTIONS

1. Whisk together yolks and mascarpone until smooth in a large bowl. Add 1 cup sugar and whisk until dissolved. Set aside!
2. In large bowl of electric mixer with whisk attachment, add egg whites; beat until soft peaks form. Fold egg whites into mascarpone mixture. Set aside!
3. Combine espresso and liqueur in medium bowl. Quickly dip half of the ladyfingers (one at a time) in the mixture and place in the bottom of a 9'by 13' glass baking dish. Evenly spread half the mascarpone mixture over ladyfingers; repeat layers with remaining ladyfingers.
4. In a large bowl whisk together heavy cream and 1 tbsp sugar until soft peaks form. Spread evenly over Tiramisu; garnish with grated chocolate.

Chill at least two hours but preferably overnight before serving.

PHOTO CONTEST - More pictures from the DBG



A rare black & blue butterfly



A very prickly situation!