

My Myositis[©]

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Well, Happy New Year to you all. 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 15 January 2008

CALENDAR OF EVENTS

25 JAN 2008	SUPPORT GROUP MEETING - TUCSON
<u>20 FEB 2008</u>	<u>SUPPORT GROUP MEETING - PHOENIX</u>
12 MAR 2008	BOTANICAL GARDENS - PHOENIX
5 APR 2008	MDA 5K WALK - TEMPE
25 APR 2008	SUPPORT GROUP MEETING - TUCSON
<u>21 MAY 2008</u>	<u>SUPPORT GROUP MEETING - PHOENIX</u>
XX JUN 2008	TBD ACTIVITY - PHOENIX
26 JUL 2008	SUPPORT GROUP MEETING - TUCSON
<u>20 AUG 2008</u>	<u>SUPPORT GROUP MEETING - PHOENIX</u>
XX AUG 2008	MDA TELETHON 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 - PHOENIX</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 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

Ken's Resolutions for 2008

Before I get into the details of this newsletter, (Believe me, I have a lot of good, new information for you to read!) I thought I would give you some insight into my character from this point on. I turn 65 this year and feel as though I have reached the age where I no longer need to conform to the standards of those who haven't reached this milestone. As you may know, Terri & I have been retracing the Lewis & Clark trail for the past few years and have become interested in the man who charged Lewis & Clark with their duties. That is Thomas Jefferson and we think that we should "Become Jefferson's People". Now, that is the title of a book written by Clay S. Jenkinson, a writer we met on one of our L&C treks. As he finishes the book he has a chapter on the practical means to adopt in wanting to become a Jeffersonian. They seem appropriate as New Year resolutions and go like this:

1. Turn off your television. In fact, give it away!
2. Learn another politically or culturally correct foreign language.
3. Take up a musical instrument and become good enough to entertain friends.
4. Get and stay healthy – avoid excesses of food and drink.
5. Write long, lucid letters to friends and family.
6. Take an active role in your civic/community/volunteer life.
7. Love your family more than the world.
8. Build/buy your dream house. Take up a craft!
9. Hold splendid parties with the emphasis on graciousness and intelligent conversation.
10. Grow something and ingest it with vigor.
11. Be a champion of education; drive your off-springs to excellence, argue passionately.
12. Surround yourself with good books with plenty of time to read and, finally.....
13. Sit bathed in natural illumination with a glass of the best wine you can afford and read for hours knowing that reading/knowledge is the highest purpose of mankind.

In concert with many of our other founding fathers, I would also add praise and thanks to the Lord daily for allowing you to wake each morning and touch the floor!

Jefferson was an odd duck and I know Jeffersonianism is not for everyone. – kaj 1/9/08

QUIPS & QUOTES

VICTORIA MARKS, choreographer to “Dancing to Music”, a show recently in Phoenix in which people in wheelchairs move to music, is quoted as saying to the AZ Rep –

“ Who is to say what’s disabled! Disabled? - In what way? Who isn’t disabled? All of us can do some things and can’t do other things! Disability starts to exist, not as opposed to ability, but as a continuum! “

JAY LENO, of late show fame, was recently heard to say-

“With hurricanes, tornados, fires out of control, mud slides, flooding, severe thunderstorms tearing up the country from one end to another, and with the threat of bird flu and terrorist attacks, are we sure this is a good time to take God out of the Pledge of Allegiance?”

RECENT CONTACTS:

1. Ron Hutson	Laveen	ronhut4@yahoo.com
2. Sandra Sawicke	Tucson	sjsawicke@cox.net
3. Sabrina Moscoso	Ecuador	sabri.guti@hotmail.com
4. Barbara Ledbetter	Globe	torina@theriver.com
5. Jackie Green	LV, NV	jackie_green@touro.edu

WILL DOWNING

Who is Will Downing? Some of you may know, but I didn't so I asked my friends at the MDA what they knew about him. Here is a short bio from his 'My Space' page for you to read and after you have read it I will tell you why he is featured here in this newsletter.

Downing enrolled in the famed performing arts high school Erasmus Hall High School in Brooklyn, New York. The high school had one of the strongest performing arts programs in the city and included among its alumni singers Barbra Streisand and Stephanie Mills, and record company executives Clive Davis, who founded Arista Records, and Kedar Massenburg, who later became president of Motown Records. Downing, who eventually recorded for Motown, graduated with Massenburg in the class of 1981. Downing then attended college at Virginia Union University in Richmond, Virginia. In the mid-1980's he moved back to New York City worked on albums by Jennifer Holiday, Kool & the Gang, Billy Ocean, and others. Later he went on to singing with Arthur Baker's group, Wally Jump Junior, Downing then used Baker as a producer after he signed with Island Records.

In 1988 Downing signed a recording contract with 4th & Broadway Records, and his first solo album, Will Downing, was released that same year. The critics singled out Downing's version of the John Coltrane classic jazz piece A Love Supreme as one of its highlights. It reached No. 4 on the Billboard Charts.. Downing stayed with 4th & Broadway for just one album and switched to Island Records for his second release, Come Together As One, in 1989. Like his first album, Come Together As One was a pop- and dance-oriented collection of R&B songs that also reflected Downing's love of jazz.

Switching labels to Mercury Records for his fourth outing, 1993's Love's the Place to Be, Downing scored his best-selling album to date with about 235,000 copies sold in the United States and over 300,000 copies in Great Britain. He remained with Mercury for two more albums, Moods in 1995 and Invitation Only in 1997, both of which sold well to Downing's core fan base. The CD "All the Man You Need" received a Grammy Awards nomination for Best Traditional R&B Album in 2000. In 2002 he received the International Association of African-American Music Diamond Award.

In December of 2006 Will Downing was diagnosed with Polymyositis. Lucy & Betsy both pointed out a Dec 2007 article in the AZ Rep with some details on the past year for Mr. Downing. Even though he is in a wheelchair he has been working/recording and his album "After Tonight" topped the R&B charts in November. He said the CD was good therapy instead of sitting around and feeling sorry for himself. He is quoted as saying that he wakes up every day and says "Make the best of your circumstances." He notes that his treatment is 5-6 shots of ??? every day and he feels like a pincushion. He also says that learning to live with the disease has been a difficult process but he plans to resume touring this year. MDA! TMA AF! I suggest you get in touch with this guy!

CONGRATULATIONS, CHYLLIA!!



This is a picture of Chyllia Dixon (second from left) - a fairly new member of the support group - taken at the CureJM 10K walk in WDC this past year. Chyllia and her Mom participated with many others who are affected by juvenile myositis (JM). The walk was part of the annual Marine Corps marathon held in October of 2007. Here is her email to me after her trip to WDC.

I had a wonderful time in DC. It was touching to meet so many young children affected with myositis. Some are very sick and some are on their way back to a normal life. Many were able to share their war stories and show off scars to their new friends. CureJM honored me at the dinner with a CureJM Hero award for support and guidance for families battling JM. Probably the best award I could ever receive!

My mom and I were able to finish the 10K together. We walked most of the way and I enjoyed spending quality time as we trotted down the closed freeway. I finished in 2502nd place and was more than happy with my accomplishment. My goal was to finish. My finish line photo (above) shows I have a huge smile on my face.

I flew back to Phoenix on Oct 28th and was sitting in my first day of nursing school on the 29th. So far, school is going well and I've already had the opportunity to educate a few future nurses about myositis. I guess I didn't realize I'd be teaching my classmates about it because we have to do a history and physical and do a variety of assessments with each other. As all myositians know, myositis affects every body system so I've always got a quirk or oddity to report.

She also attended the annual CureJM conference and sent me some comments that you can find on the next page. Way to go, Chyllia! Phoenix MDA 5K in April is coming up fast!! Look for the details later in the newsletter.

CureJM Annual Conference in WDC in October 2007

Here is an email from Chyllia just after the conference. Here are Some tid-bits that were shared.

Dr Pachman indicated that those who go untreated for 2-4 months or longer may find that the CPK levels begin to normalize even with active disease. And they are also more likely to have trouble with bone density.

Nailfold capillaries are a good indicator of whether or not a patient will be able to absorb oral medications (specifically prednisone). The more "tangled" they are, the less medications will be absorbed in the small intestine. IV medications tend to work better in those cases. Dr Wedderburn (sp?) from the UK said they are starting to train doctors to use otoscopes and a jelly substance to look at cuticles since many myositis doctors do not

have the specialized cameras.

All four of the doctors and researchers emphasized the importance of sunscreen and suggested a "total block" cream. I believe it is not available in the US but you can order it and have it shipped from Canada. They also mentioned protective clothing and said RIT has a product you can add to your wash that will add protection to your every-day clothing.

Doctors and researchers have been working together to develop an assessment tool for myositis called the IMACC. It includes labwork, manual muscle testing, nailfold capillary exams, MRI's as well as patient and doctor scorings. One

area getting worse does not necessarily indicate a flare but when you look at the big picture, you can see a downward or upward trend. As part of the IMACC assessment they are determining a "definition of worsening" and "definition of improvement." Their hope is that a patient would receive the same IMACC score if examined by several different doctors.

It was also mentioned that exercise will NOT cause a flare.

Dr Miller discussed the role genetics play in autoimmune disorders and (in my own words) said autoimmune disorders involve multiple genes so it's a complex issue but they are working on it.

I read this email and immediately sent a note to TMA to get some more detail on two of the items in the report.

1. Nailfold capillary test and the

2. IMACs project

I have yet to get a response from TMA but did Google the first item and got the information presented on the next page. I will call Dr. Miller about IMACs soon!

Nailfold Capillaries

Diagnosis and/or monitoring of DERMATOMYOSITIS from the various symptoms coupled with blood tests is relatively straight forward, but determining the activity/severity of the disease and/or value of the treatments is more difficult.

One technique that is being explored involves studying the condition of the capillaries in the nail-fold - the skin overlapping the fingernail at its base.

Looking at nailfold capillaries is a technique used for many of the auto-immune diseases similar and sometimes, overlapping, with DM like Raynaud's Syndrome, Systemic Sclerosis, Scleroderma and Rheumatoid Arthritis.

There are three techniques that I have read about that are increasing in accuracy as the complexity/cost of the equipment used increases.

- a. The first is the simple application of a jelly substance on the fingernails and using an otoscope (the instrument that doctors use in looking in your ears/nose/throat) to look at the capillaries under the fingernail. (Mentioned in Chyllia's email.)
- b. The second is a test whereby the doctor puts a drop of oil on the patient's nailfolds, (the skin at the base of the fingernail). The doctor then examines the nailfolds under a microscope to look for abnormalities of the tiny blood vessels called capillaries
- c. The third, very scientific technique is where a video camera is coupled to a microscope and the capillary dimensions are measured by hand from a single video frame. At the magnification used (x200 - x600), capillaries one blood cell thick can be seen. The red blood cells pass through these fine capillaries in single file with the white blood cells appearing as gaps in the string of red cells. This, coupled with subtle changes in focus mean that not all of the capillary network is visible at any one instant, and so rather than work from a single frame, they intend to integrate the information over successive frames. This will form a composite image from which the capillary dimensions will be measured automatically by a computer system.

I believe the literature says that the size of these small blood vessels is a direct indicator of the presence of an auto-immune disease and also, an indicator of the effectiveness of the treatment of the patient. It seems to me that periodic looks at these capillaries is just as important as the periodic blood tests that we all are familiar with. This work is being done by doctors studying Raynauds and it seems prudent that Myositis doctors and those groups associated with the support for patients with Myositis should closely follow the progress of this approach to treatment efficacy.

kaj 1/14/08

IN THE NEWS

I have decided on a new approach to items I have read in the many periodicals I receive. I am going to give you the date and reference information so that you can research the data at your leisure, but will also provide a brief summary of the article to peak your interest.

Rheumatology News, Volume 6, Issue 11, November 2007 This is an article written on a speech that Dr. Chet Oddis gave at Harvard Medical School earlier last year. An item of interest is as follows. He is talking about a PM patient who is not responding to treatment and told the audience that he has devised a simple test to distinguish PM from IBM. Ask the patient to form a circle with the thumb and forefinger on either hand. If the resultant circle is round, note PM! If the resultant circle is more oval than round, note IBM!

Rheumatology News, Volume 6, Issue 11, November 2007 There is a good treatise on the off-label use of the Biologic Agents that I talk to you all frequently about in our meetings. They separate out the TNF alpha blockers (Remicade and Enbrel and Humira for example) and their uses; Rituxan and its use for DM patients; Abatacept, know as Orencia, an alternative to the TNF alpha blockers and Anakinra, the fairly new interleukin-1 blocking agent.

Arthritis Today, Volume 21, Number November-December 2007 This issue, as a primer for New Year resolutions, features many articles on diet and exercise – their suggestion is to call it movement, not exercise. The focused article on Dorothy Hamil (ex-Olympian with arthritis), is titled “The Joy of Movement”!

AARP - The Magazine, 50, Number 6B, November-December 2007 As the Arthritis Today's year end issue, the focus is on diet and exercise. There is also a great article entitled “Caregiver 911” with the subtitle of “Caring for the Caregiver.” Remember, we call them care partners, but sometimes forget that they need some attention when caring for an ailing partner, family member or friend. Good read!

AARP Bulletin, Volume 49, Number 1, January-February 2008 In this companion rag to The Magazine, there is a story on page 20 called “Ties That Bind” that points the finger at doctors about being courted (gifts, trips, pens, free samples) by the pharmaceutical companies, i.e., swayed by the sales people to prescribe their product whereby the doctor may loose sight of the patient's best interest.

Quest Magazine, Volume 14, Number 6 November – December 2007 I really liked the article on page 48 called “Canes, Crutches and Walkers”. It points out that the signs that assistive devices may be needed could be poor balance, unsteadiness, leg weakness, trunk weakness, slower than usual pace and, most importantly, falls.

Outlook Extra, Fall 2007 This is TMA's extra issue of their “The Outlook” publication . This issue features the fall conference held in Seattle. It serves up excerpts from many of the presenters as well as many of the Q&A exchanges with these doctors. Many of the presenters at the conference have posted their Power Point slides on the TMA website at myositis.org.

HIPAA FOR DUMMIES

Anna Sogard from Accredo sent me this article as a result of the many questions from our last meeting on insurance coverage in general, and coverage in specific relative to IVIg. Many were concerned about loosing their coverage for various reasons and this treatise directly from the HIPAA book should help.

The Health Insurance Portability and Accountability Act (HIPAA) offers protections for millions of American workers that improve portability and continuity of health insurance coverage.

HIPAA Protects Workers And Their Families By:

Limiting exclusions for preexisting medical conditions (known as preexisting conditions).

Providing credit against maximum preexisting condition exclusion periods for prior health coverage and a process for providing certificates showing periods of prior coverage to a new group health plan or health insurance issuer.

Providing new rights that allow individuals to enroll for health coverage when they lose other health coverage, get married or add a new dependent.

Prohibiting discrimination in enrollment and in premiums charged to employees and their dependents based on health status-related factors.

Guaranteeing availability of health insurance coverage for small employers and renew-ability of health insurance coverage for both small and large employers.

Preserving the states' role in regulating health insurance, including the states' authority to provide greater protections than those available under federal law.

Preexisting Condition Exclusions:

The law defines a preexisting condition as one for which medical advice, diagnosis, care, or treatment was recommended or received during the 6-month period prior to an individual's enrollment date (which is the earlier of the first day of health coverage or the first day of any waiting period for coverage).

Group health plans and issuers may not exclude an individual's preexisting medical condition from coverage for more than 12 months (18 months for late enrollees) after an individual's enrollment date.

Under HIPAA, a new employer's plan must give individuals credit for the length of time they had prior continuous health coverage, without a break in coverage of 63 days or more, thereby reducing

or eliminating the 12-month exclusion period (18 months for late enrollees).

Creditable Coverage:

Includes prior coverage under another group health plan, an individual health insurance policy, COBRA, Medicaid, Medicare, CHAMPUS, the Indian Health Service, a state health benefits risk pool, FEHBP, the Peace Corps Act, or a public health plan.

Certificates Of Creditable Coverage:

Certificates of creditable coverage must be provided automatically and free of charge by the plan or issuer when an individual loses coverage under the plan, becomes entitled to elect COBRA continuation coverage or exhausts COBRA continuation coverage. A certificate must also be provided free of charge upon request while you have health coverage or anytime within 24 months after your coverage ends.

Certificates of creditable coverage should contain information about the length of time you or your dependents had coverage as well as the length of any waiting period for coverage that applied to you or your dependents.

For plan years beginning on or after July 1, 2005, certificates of creditable coverage should also include an educational statement that describes individuals' HIPAA portability rights. A new model certificate is available on EBSAs Web site.

If a certificate is not received, or the information on the certificate is wrong, you should contact your prior plan or issuer. You have a right to show prior creditable coverage with other evidence - like pay stubs, explanation of benefits, letters from a doctor - if you cannot get a certificate.

Special Enrollment Rights

Are provided for individuals who lose their coverage in certain situations, including on separation, divorce, death, termination of employment and reduction in hours. Special enrollment rights also are provided if employer contributions toward the other coverage terminates.

Are provided for employees, their spouses and new dependents upon marriage, birth, adoption or placement for adoption.

Discrimination Prohibitions

Ensure that individuals are not excluded from coverage, denied benefits, or charged more for coverage offered by a plan or issuer, based on health status-related factors.

NATIONAL HEALTH CARE

With all the politicians trying to espouse their solutions to the rising cost of health care, I thought it might be appropriate to compare the U.S. with Canada in this area. I'm using the numbers supplied in a Nov 2007 AZ Rep article entitled "Canadian health care system may be cure for U.S. " Now, we have Medicaid & Medicare for the poor and the elderly, but those in all other categories must depend on private insurance for their coverage. Here is how we stack us against Canada.

	CANADA	UNITED STATES
LIFE EXPECTANCY (yrs)	80	78
INFANT MORTALITY (%)	5	7
DOCTORS/1000 PEOPLE	22	24
NURSES/1000 PEOPLE	10	8
POPULATION (MILLION)	33	300
INSURED (%)	100	86
TAXES (% OF INCOME)	32	26
PER PERSON EXPENDITURES	\$4548	\$7498
GOV'T SHARE (%)	70	45
HEALTH CARE (% GDP)	9.2	15.2
ADMINISTRATOR	Gov't	Gov't/Private
PRESCRIPTION DRUGS	Cheaper	Expensive

Bottom Line! You decide. It appears to me that if we taxed people more, the per person expenditures might come down. And with the additional taxes, the government might be able to pick up a larger share of the health care costs. And if the government would just open up Medicare to all ages (as President Bartlett on "West Wing" suggested) we would have national health care. But, who wants more taxes! Oh, well!

Turkey Soup

Recipe from

Traci McMillan

Chandler, AZ

1/4 diced onion

2 cloves garlic

1 tsp. cumin

1/2 tsp. salt

1/2 tsp. chili powder

1/8 tsp. ground red pepper

1 can chicken broth

Chopped fresh cilantro

1 can stewed tomatoes

1 can Mexican corn

1 can black beans

1-2 cups of Turkey

This meal is perfect for the crock pot. I usually quadruple the recipe! (3 growing boys) And I add hominy and other kinds of beans and really make it spicier.

Scalloped Corn

Recipe from

Terri Johnson

Tempe, AZ

1 can Cream style corn (17 oz)

1 c. milk

1 egg, well beaten

1 c. cracker crumbs

1/4 cup onions, chopped fine

3 tbsp. pimentos, chopped

3/4 tsp. salt

Pepper to taste

1/2 c. buttered cracker crumbs (topping)

Heat corn with milk. Gradually stir in egg. Add next four ingredients and pepper. Mix well. Pour into 8" round baking dish. Top with buttered crumbs. And bake at 350 for 20-30 minutes until brown.

Frozen kernel corn can be added to recipe for a heartier dish

Enter the newsletter RECIPE CONTEST. Send your input to Terri at kenandterri@msn.com Do it now!