Los Angeles Myositis Support Group

Newsletter

November 2006

Donate to The Myositis Association!

This newsletter is a service of the Los Angeles myositis support group. It is a means of sharing experience and information related to polymyositis, dermatomyositis and inclusion body myositis. It is not a source of medical advice or diagnosis. Please see your own doctor for specific medical treatment.

JDM and the Triumphal Healing Power of Music

By Dr Richard Gay
Co-Chair Los Angeles KIT
(This article is dedicated to Laura.)

Daydream Believer

Oh, I could hide 'neath the wings
Of the bluebird as she sings.
The six o'clock alarm would never ring.
But it rings and I rise,
Wipe the sleep out of my eyes.
My shavin' razor's cold and it stings.
Cheer up, Sleepy Jean.
Oh, what can it mean.
To a daydream believer
And a homecoming queen?

Words and Music By John Stewart
1967 #1 Song by The Monkees, arranged by Peter Tork

The enticing words and music of The Monkees 1967 hit Daydream Believer are an invitation to an imaginary world in which we are asleep but almost awake, daydreams come true and anyone who just wishes intently enough can become a homecoming queen. For any of us, healthy or with myositis, it only takes one time to hear this song to fall in love with the music and lyrics. After all, the song was a number one hit for four weeks in 1967. It doesn't matter what John Stewart originally meant by these lyrics, *(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
November 12, 2006 1:30 – 3:30 PM

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

November Program

We will have a guest speaker from the staff of Good Samaritan Hospital,

Ms Socorro Hernandez.

She is a clinical dietician and will give us guidance on nutrition and healthy food choices. What a way to get ready for the holidays! See you at our KIT meeting.

JDM and Healing Music, cont'd

or what were the circumstances surrounding him when he wrote it, what matters to us is how we want our own daydreams to materialize, and we want something just as wonderful as the experience of any homecoming queen, with glamour, fun, excitement, admiration, fond memories, no worries or cares: a fairly tale world of release from bad conditions better than the songs and dreams of Cinderella or Sleeping Beauty or enchanted princes (think of the enchanting climax of Beauty and the Beast).

But Daydream Believer had a much more powerful meaning to me in 1967. By 1967 I was 17 years old, and had fought the auto-immune disease juvenile dermatomyositis (JDM) for three years. I was one of the fortunate kids who survived the initial mortality rate of 50% at that time, but this required a large daily dose of prednisone which suppresses the immune system but also brings its associated severe side effects. I experienced the trauma of a disease similar to severe muscular dystrophy: rapid loss of muscle strength, inability to swallow, muscle contractures in my hands, arms and legs. I spent three months at home before I was strong enough to go back to school. I had tried imuran as an experimental treatment for JDM and immediately had severe liver jaundice as a side effect which took two weeks of intense therapy to cure. I wore a very awkward bad brace during all my waking hours from osteoporosis, a side effect of prednisone for the JDM, and it required assistance from another person just to put it on each morning. Just think of a heavy slab of rubber pushed against your back in the 100 degree summer sun with a metal bar at your throat and another pressed against the bottom of your stomach. That was the back brace. I had skin rash and itching over my legs, scalp and back so severe that I lost an hour each day to scratching all over. I saw all my teenage friends growing bigger and stronger almost without making any effort while I exercised with weights and never grew any muscle mass or increased in strength. This was due to the JDM and the fact that prednisone suppresses growth hormone in kids. My doctor had originally said that my JDM should "burn itself out within a couple of years" and yet I was three years into it with no sign of remission and there was no hope of remission. I saw my healthy talented friends in high school trying various illegal recreational drugs just for the fun of it and I thought "How foolish can you be. You have no idea what real drugs can do to you." I was very grateful just to be alive and still active in school.

In today's world it is possible to sit comfortably at our office desk with just a computer at hand and access to the Internet and pages of detailed information are available with just a couple of mouse clicks. We can quickly learn details of juvenile dermatomyositis, treatments, experience of others with the disease, even technical medical research papers involving many aspects of the disease. We can go onto bulletin boards and have discussions with others who have the illness. Their experience provides a good road map to choose optimum treatment options and prepare us for side effects of medications before they happen. This doesn't mean that instant remission is available to all, but JDM mortality rates are now very low, and a lot of good information is quite readily available. In 1967 none of this existed. Any choice I made was done working blindly, with just my doctor's best guess and recommendation as a guide. I knew no one else who had this disease. Despite new medications JDM is still a serious disease today, 40 years later, just as it was in 1967. Only one-third of the kids with JDM will see drug-free remission (I must point out a remission of unknown duration), one-third will see a remission with long-term maintenance level drugs and their attendant side effects; and one-third will see a continuous fight and deterioration with the disease and perhaps control with strong drug regimens. The daydream of the happiness of the homecoming queen is the daydream of anyone with JDM and yet never to be held and always out of reach. But keep in mind, John Stewart's lyrics didn't say "daydreams;" he said "daydream believer". Wonderful things can happen to those who believe and are faithful.

After wearing the back brace daily for five years I was fortunate in 1969 when I participated in the first medical study that combined methotrexate with prednisone. This technique is now a standard treatment. Within a year I was able to reduce my prednisone dose in half, my backbones recovered some strength (this was thirty years before fosamax, actonel or any of the current treatments for osteoporosis), and I no longer had to wear my back brace. I thought I was in heaven! But this only alleviated one problem, a side effect of the medicine for the disease.

I still had a severe problem with the skin rash and itching and I could walk but anything like running was not possible. I still took daily doses of prednisone and methotrexate, which meant I faced a future of uncertain length filled with constant infections, cataracts, stomach ulcers, osteoporosis, and liver damage just from the side effects of the medications alone. I heard no stories or reports of anyone with long term JDM reducing their medications below maintenance level, and going completely off medication was totally out of the picture. There may have been others who had JDM and were able to go off their medications, but the disease is so rare, that it was not reported in the literature, and I had no way of knowing about them. Any decision I made regarding my medication levels and method for handing the disease would have to be done totally blind; obviously the safest approach would be to stay on a maintenance dose of medications and accept the problems of the side effects as a "cost" of staying alive.

One of the rare but extremely disruptive aspects of my JDM was the skin rash and itching. It came from within, and no external creams or salves could stop the itching. I tried everything available with no relief. The itching was just like being in a prison cell with no door or window or key to open the lock. It was impossible to go for 24 hours without spending an hour in rubbing and scratching all over. I was even told by a nurse that it would kill me if I could not stop it. Imagine to be told this when you know you have no control over the problem. It was like being at the bottom of a deep chasm with slippery walls and no way of getting out. After 14 years of dealing with the skin itching I was discouraged at ever finding a solution to the problem. However, in 1978 a miraculous breakthrough occurred. Whether it happened spontaneously, or the result of being prayed for at a small prayer meeting, my notes indicate that the itching started to diminish. Over a period of weeks it totally stopped! After 14 years it had stopped! It was gone! Fantastic! I felt like I wanted to shout from the highest mountain but no one would understand the magnitude of the event. I also felt like I had a new start on life. At the same time I made the decision to attempt to go completely off medications. This was not a simple task, because anyone who has taken prednisone for a significant time will no longer produce the natural hormone that prednisone replaces, so it takes many months to slowly reduce the dose. There is no guarantee that your adrenal gland will start working again, especially after 14 years. In addition, my muscle enzyme levels (CPK) were still in the upper 700-800, at least five times above normal. That meant my JDM was still active in some way. My doctor advised staying on the maintenance levels of prednisone and methotrexate, but he was willing to go along with my plan if I could show that my strength did not decrease. There was no data to guide me in accomplishing this task, so I took the logical approach that a following a consistent exercise program would be the best way to maintain and even improve my strength even while tapering off the medication.

I started the exercise program inside my apartment. It took at least three months of exercise just to lower the prednisone by 1 mg, and I started at 10 mg per day. This adventure would take years to achieve. I had a small collection of some of the best music ever written: Handel, Mozart, Beethoven, Bach, Dvorak, Tchaikovsky, Copland, Vivaldi, the Mormon Tabernacle Choir singing classic American songs, and others. These were recordings on 33 1/3 rpm records, and I had a turntable that would hold six records at a time. This was 1978, and music CD's were brand new, expensive and rare. That didn't matter because the power of the music was sufficient. Each exercise day I loaded up the turntable with records and started my exercises. What a gold mine of inspiration ready to be tapped! I was not the first person trying to do the impossible; these composers knew exactly what it was all about! Just listen to Tchaikovsky's Symphonies #4 and #5 as he builds up the momentum from movement to movement to triumphant climaxes. Or listen to Beethoven's piano concertos, especially the 5th, and his symphonies, with all their emotion and power. These composers knew what it meant to experience hardship and follow it with triumph. And they could capture that spirit in music, which speaks directly to the heart. I listened to Handel's Water Music suite over and over and never grew tired of it. I would listen to classic Americana songs, such as Shenandoah, which capture the longing for the impossible and it was the same thing I was trying to do. I listened to Copland's Appalachian Spring, with the glorious melody of Simple Gifts, surrounded by the peaceful beauty of the Appalachian countryside. My spirit had the right stuff to keep it going: Bach's Brandenburg Concertos, Christopher Parkening playing Bach's cantatas on the guitar; Pachelbel's Canon, Handel's

Messiah, this was the real thing with real spiritual power. I could not afford second best—these guys got it right. Consider how Vivaldi's Gloria speaks of a dynamic powerful God that lives and blesses us; there is nothing wimpy about it, just listen to the power expressed in the first attention-grabbing bars. I added more religious music to the stack, especially music from the St Louis Jesuits, which I consider the best contemporary religious music in the last 40 years. The music recognized exactly what I was trying to do, to achieve in a personal way the impossible, given that I had no prior knowledge that I could stop the medications at all. We cannot arrive at Easter Sunday unless we go through Good Friday first. As each month went by and I slowly lowered the prednisone levels, my strength actually increased. I went from jogging in place for 30 seconds until two years later I could go for over 25 minutes.

There was even more power for healing in this music than would first appear obvious. The years of itching and scratching had left my legs totally red and scarred. It would have been a big embarrassment to go to any gym and exercise. But composers like Tchaikovsky knew the experience, just listen to his symphony number six, he could say in music what it meant to have a problem seemingly beyond our control. Or consider Steven Foster's classic Americana songs of good times and struggle against overwhelming problems. This was the music I surrounded myself with; this is what kept me going. It took three years, and in October 1981 I went completely off all medications. For me this was a personal triumph, even though it had no meaning for others. I told my friends at work that I was jogging in place at home and they convinced me to start going to the company gym to exercise. By then the skin on my legs had somewhat healed and I started doing my jogging outside, four times a week. I was able to go for over thirty minutes, although it was a struggle, and for the next ten years I completed 5 K races once each month. Today I still continue my exercise program, and listen to music often. In addition, I had an angiogram in August this year which found that I had one completely blocked heart artery; I should have had a heart attack but did not. The angiogram showed that my heart had constructed new blood vessels from the other main arteries and this was why there was no heart attack. The blocked artery was the result of diabetes, one of the side effects of prednisone. The new arteries, well, one can only speculate that the exercise produced them. Another miracle.

In today's trendy world there is an inclination to search all over for some sort of hidden meditation or inspiration to soothe our spirit or motivate us. We neglect the accumulated genius of hundreds of years of powerful triumphal music which has been tested and found to work. It is called classical for a good reason. For me it was a lifesaver and a daydream come true.

November Speaker Socorro Hernandez

Our November guest speaker is Socorro Hernandez, married to a doctor who has a family practice. She graduated from U C Davis, got her Master's in Public Health from Loma Linda University. She did her internship at Good Samaritan, and now she is a Clinical Dietitian there. Prepare for the holidays by learning how to eat healthy and wisely.

THE IBM CORNER

Tips For Traveling

By June Colton

Vacations can be a time for fun, relaxation, rejuvenation, and learning. Here are a few tips to help you with your trip.

1. PLAN AHEAD: Make those reservations and receive confirmations regarding flights, cruises, trains, buses, shuttles (Prime Time 800 RED VANS), car rentals, guided tours, etc. Using the computer saves time and money.

2. INSURANCE: Travel insurance can be a wise investment. 17% of people who buy insurance use it. When booking your trip through a travel agent or cruise line you may have the option to add travel insurance at the time of booking, or it may be included in the price of your ticket. Consider insurance for: loss of life, dismemberment, accidents, medical, dental, trip cancellation, trip delay, lost, stolen, delayed baggage (including at hotels), emergency medical evacuation, and 24 hour emergency assistance. Your airline will insure for lost or delayed luggage. If you charge your flight to AMERICAN EXPRESS (800 645-5700) you will be

covered for loss of life. The cost is $4.99. Call them for details. ACCESS AMERICA (800 756-2639) has a vacation policy. GLOBAL TRAVEL SHIELD (800 332-4899) Call them for trip cancellation and trip delay coverage. CSA TRAVEL PROTECTION (800 873-9855), located in San Diego. They have good rates. WWW.INSUREMYTRIP.COM They will help you compare policies and prices.
HEALTH INSURANCE: Check with your insurance carrier to see if you will be covered on this trip.
HOMEOWNERS INSURANCE: Pay a small fee for adding personal property like jewelry, equipment, other valuables.
3. CHECK IN TIMES: Check to see how much in advance of departure time you need to check in. Be sure to reconfirm your departure times 1-2 days before leaving (even with shuttle service).
4. PASSPORT & DRIVER'S LICENSE: Are they current? The Auto Club will give you an out of the country Driver's Permit.
5. IMMUNIZATIONS: Check with the Health Department in your city or with your health insurance carrier to see if you need shots or medication for your destination. Whoever administers the shots will give you a statement and you will need to take this with you to show that you've had the immunizations.
6. MAKE COPIES: Passport, Driver's License, credit cards (take only a few, those that are most acceptable there), itinerary, medication & eye glass prescription, addresses & emails for your correspondence.
7. CURRENCY: TRAVELER'S CHECKS: A safe way to travel. Find out what kind and denomination will be accepted where you are traveling. Inquire where you may exchange the checks for the best rate. For example, if you are using AMERICAN EXPRESS CHECKS, are there AMEX offices where you will be traveling or will you use a bank? CASH: It's always accepted. Figure out how much you should take and in what denomination. Use a concealed money belt for these valuables.
8. TIPPING: What is the tipping policy?
9. WEATHER: Check weather report so you will know what to pack.
10. PACKING: Travel light. Take only what you will absolutely need. Pack days ahead of departure. Check with the airlines, etc. to find out their limits on weight and size of luggage. Make a list: clothing, cosmetics for both sexes, medications, extra eye glasses, equipment, postage stamps for U.S. mail, electrical conversion plug, electrical & duct tape, first aid kit, nutrition bars for snacking.
11. FOR HANDICAPPED FOLKS: Check to see that the airlines, ships, trains, buses, hotels, restaurants, restrooms are handicap accessible with ramps if necessary.
12. DEVELOP YOUR OWN TRAVEL WEBSITE: You can write about your travels while you are experiencing them. Your family and friends can log in, read about you and send their messages to you. For example, my daughter Laurel who is on vacation now in South America, set up her website: www.tripchick@wordpress.com and she has her itinerary on it and Laurel posts frequent reports about her adventures.
13. READ AHEAD: Bone up on the history, culture, landscape, food and entertainment of your destination. Do you need to take a Language Dictionary? A little advanced planning will make your trip easier and more carefree.

BON VOYAGE!

Campath Clinical Trial

By Sharon Pilgrim

Background

Eighteen years ago, as I was approaching the age of 50, I was newly re-married. Life was good!

Then I noticed I was having some problems. It was difficult going up the stairs. It was difficult getting out of a low chair. It was difficult getting up when I was down on the floor playing with my grandson. My rheumatologist did a series of tests, including a muscle biopsy. He said I had polymyositis. He explained poly means many, “myo” refers to the muscle and “itis” is inflammation of. Now I had a name for my illness.

I was put on the usual medications, prednisone, methotrexate, Immuran, etc. I had a severe reaction to Immuran and ended up in the hospital for 3 days. Nothing helped. I did not have flares or remissions. My CK level was always elevated above the high normal, but never more than 600. I continued the downward spiral of losing muscle strength, graduating to using a cane, a quad cane, a walker and now sometimes a scooter.
It was than thought I might have IBM instead of PM. I have had 3 more muscle biopsies confirming this.

Before I entered the protocol at NIH I was having trouble lifting my foot high enough to get my foot in our van. Also, my arms would get caught underneath me when I was sleeping and I had to use my other arm to pull my trapped arm free.

NIH protocol

In 2002 I went to NIH in Bethesda, MD to be part of a study headed up by Dr. Dalakas. The study title was Search on Immune Dysregulation and Disease Progression in Patients with Sporadic Inclusion Body Myositis (s-IBM). During this study, every couple of months I was examined by a Doctor, had my history compiled, went to re-hab for evaluation and had lab work done. When this study was completed, I went into the Campath Clinical Trial. I had the above mentioned tests done every couple of months, plus some additional tests. They did computerized muscle testing, swallow testing (I test just below average for a woman of my age) and functional testing. This is how well I could do some daily chores, such as making a grilled cheese sandwich or making toast and tea.

In December of 2004, I had my infusion of Campath. I was hospitalized for more than a week. Since my immune system was further comprised, I had to avoid crowds and being around sick people. My infusion was Monday, Wednesday, Friday and the following Monday. I had no trouble with the infusion, nor the antibiotics and anti-infection drugs they had me on. They followed me for a year after my infusion. I expect sometime they will call me back for a follow-up visit. I feel in that year, my muscle strength did not decline.

Now I am experiencing some problems again. Until a month ago, I could still lift my leg high enough to get into our van. Now my husband has to help me.

I would take Campath again in a heartbeat. Yes, even with IBM, life is good!

Please Donate to The Myositis Association

By Jan Schuler
Chair of the Board, TMA

My name is Jan Schuler and I am the Chair of the Board for The Myositis Association. I'd like to share some of the reasons why I am involved with TMA and why I am so passionate about its mission.

My husband, Dan, has inclusion-body myositis, and we are the proud parents of four sons, four daughters, and grandparents to eighteen grandchildren. Before my retirement, I was an economic developer, and prior to that, a Congressional aide. My husband and I were very active in community and church affairs. For several years, Dan had noticed some muscle weakness. But he and his physicians blamed it on excessive exercise, etc., until in 1995, he was diagnosed with myositis. We learned that this is a debilitating, progressive disease for which there is no effective treatment or cure. Since then, my family and I have watched a very active man, who had once been able to run marathons, go through various adjustments until he now has to have assistance for all daily functions. I must use a hoist to transfer him from the bed to a chair or to the toilet. He can no longer hold or grasp even lightweight items. His story is typical of those who have inclusion-body myositis.

Some families have to deal with one of the other debilitating forms of myositis -- polymyositis, dermatomyositis, or juvenile myositis. The loss of these potentially productive members of society affects us all. It is especially painful to watch a young mother with polymyositis or dermatomyositis making great efforts to continue to care for her family, or to watch a young child suffer with the disease, dealing with harsh drugs and infusions. (For more information about the myositis diseases and our work, go to the TMA website at **www.myositis.org**).

Because myositis is a rare disease, many physicians as well as the general population know little about it. Creating awareness is one of TMA's goals, and we were successful this year in getting Congress to proclaim a National Myositis Awareness Day. We will continue our advocacy efforts and work to promote more research into myositis. Together with our Medical Advisory Board, we review research applications and award funds for research. Unfortunately, without more funds, we will have to deny funding for worthwhile projects.

November is National Caregiver Month and, in honor of that, I am asking that you join me in taking care of those with myositis, by helping us in our daily fight against this disease. All of us owe much in our lives to those who have cared for us. In appreciation of this, won't you join me, my family, and the TMA family in our efforts to cure and eradicate this disease? Please read my note below about the Chairman's Campaign; this is an especially good time to make a donation! Thank you so much for thinking of others who have to live with this dreadful disease.

Gratefully,
Jan Schuler

The Chairman's Campaign

Dear Friend:

I am writing to you as Chair of the Board for The Myositis Association with an important message. For several years, members of my family have held various fundraisers to benefit TMA. Among these have been golf tournaments, walkathons, races, and holiday letters to friends. These have been a labor of love for my family, but I know many TMA members are not physically able to help in this way. Nevertheless, fundraisers are vital to fulfilling the mission of TMA and serving its members.

In order to raise more funds for the organization, I am being joined by other Board members and TMA members in issuing the 2006 Chairman's Campaign Challenge. We will match donations from TMA members up to $25,000. If we meet this challenge, we will have raised $50,000 for increased education and research. Just think, your $50 contribution becomes $100, or your $500 donation becomes $1000! To reach this $50,000 goal, we ask that you forward a message from me about this challenge to your family and friends, along with a personal comment from you. My message to be forwarded to others will be emailed to you in a separate email following this one.

Donating is made easy. Credit card contributions can be made by going to **www.myositis.org** and clicking on the "Donate" link at the top of the page. (Gifts of **stock and life income gifts** are also discussed on the website.) You can call us at 1-800-821-7356 to donate by credit card over the phone, or checks can be sent to The Myositis Association, 1233 20th Street, NW, Suite 402, Washington, DC 20036. Please note on your check or credit form that your contribution is part of the Chairman's Campaign, so we know to apply the available matching money.

Don't delay. Help us make this the best year yet in the fight for better treatments and a cure for these terrible diseases!

Gratefully,
Jan Schuler

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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.

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Join In New Research Study

By Rose Mary Istre
KIT Leader, Texas

Rich,

Hi, Hope you are having a great day today. Thank you for the opportunity to spread the word about my project in your newsletter.

I am beginning a research study through the University of Houston concerning chronic illness and nutrition. My doctor is overseeing the project since most of those in my support group are her patients. Patients are asked to implement a diet rich in antioxidants and omega-3's for a period of 6 weeks. The diet does not exclude any food groups and is generally accepted as medically healthy. I would like to enlarge my participant pool so please publish my contact information Rosemarykay@sbcglobal.net 281-997-6600 if there are those who would be interested in joining our study.

Coming to Terms with Lack of Independence

By June Colton
Co-Chair Los Angeles KIT

Richard, long time no hear. How are you doing? I've yet to attend a meeting and I'm sorry about that. I suppose part of that reason was that I wanted to be well. To maybe be an inspiration of hope. I don't ever want to see myself as a disease. The only way to escape that is to be well. I've been able to be under that radar by all appearance for many years until now. It's very disconcerting to me to have to admit that perhaps I've advanced into a level of physical disability. I'm having a hard time with it. I am 16 years into polymyositis. I did my first round of Rituxan last September. It seemed to me that I was cured. (a girl can dream). Six months later I was still doing well so I held off on another treatment. Than in June of this year I started feeling the symptoms of my illness creeping up on me. I also developed E Nodosum. I had never heard of that before. Tests confirmed my disease was back and I received for the second time Rituxan treatments. I had the treatments August 2nd and August 16th. I'm sad to say that to date I feel worse. A visit to the Dr. showed that my CPK's are still 2000! I did one bottle of IVIG. We want to give the Rituxan another month before we decide whether or not it worked. The IVIG is just to help until than. I don't know where we go from here or to question why it didn't work the second time. I just have here and now to hope that it will still kick in. The first time it took almost three months to work. So here I am barely walking, I don't remember ever being still weak and it's scary to think I won't come out of this. What will happen if Rituxan doesn't work? More important to me, how do I come to terms with losing my physical independence? Thanks Richard.
Sincerely, Dora

Dear Dora, Thank you for writing about your coping with Polymyositis. Some of our KIT members have this also and are trying different things to remain strong and independent. One takes prednisone, which Rich mentioned to you. Ask your doctor about this. There are side affects. I have IBM and cannot take this steroid because of the side affects.

I had the IVIG treatments but that did not help either. There isn't anything else available for me to take. I must tell you however, that what does really help me is to exercise. I cannot do very much because I am in a wheelchair now. I've had IBM for 25 years, and it's not inherited in my case. Dr. Engel thinks the cause was a virus of some kind. Who knows? I'm not sure how much you are able to move around, but here's what I do. Every morning (takes about 1/2 hr.) and evening (takes about 10 min.) I massage my toes, feet, ankles, legs & all the way to my hips, sitting down. That helps the blood circulate and it definitely reduces the swelling in my feet and ankles. They swell in the evening especially & that's why I also massage when I retire at night. In the morning the swelling has disappeared. Also I never have any pain in my legs, feet or toes. For upper body exercise I have a table model rowing machine I use. It elevates the heart rate as well as circulates the blood and my upper arms aren't really flabby. The exercises seem to stimulate my brain and I am in a better mood, more positive, have a bit more energy and can think more clearly. This helps me to feel more in control and independent I do have to face reality however. My daughter Laurel has to drive me where I need to go because I had to decline my driver's license several years ago due to the lack of strength in my feet and legs. I use an electric scooter when traveling outside. I feel more protected in a scooter than in a wheelchair. Do you have family, friends or neighbors who can help you when you need someone or something? I don't recall if you are still able to get around on your own, or if you are using a wheelchair, and I don't recall your age. I know you mentioned you have had Poly for 16 years...a long time. It can change your life, but if you have a Plan A & Plan B, it helps you cope and be more independent. I hope you will be able to attend our next KIT meeting on 11/12, 1:30-3:30 pm, at the Good Samaritan Hospital in Los Angeles. We will be sending you a notice about this soon. We will have a speaker talk about Vitamins and Nutrition, especially for our disease. Last year we had a very good physical therapist as guest speaker. He was very helpful. Take good care of yourself and again thank you for writing. We are here for you and our KIT friends. With best wishes,
June Colton (323) 256-8406
junecolton@hotmail.com

J. Dogg's Great Adventure

By David Cramer
Los Angeles KIT Group Member

Rich,
I don't know if you can use this but I wrote it and I have been dealing with Polymyositis for about ten years (diagnosed for four) so at least it comes from the right source. Yes, I am a member of the Los Angeles group, I just had to come to Alabama to have family around when I can't do things for myself. I find having a dog to be a great help when dealing with the disease as he gets me moving in the morning and makes me play with him so I do get some physical contact and affection every day.
David Cramer

J. Edgar Dogg is a 7-month-old puppy who lives in the woods of Alabama with a pet human that answers to the name "Uncle Dave." He likes Rap Music, TV (mostly Animal Planet,) dog food, chewing on carpet, chewing on wood, chewing on Uncle Dave (well, just gumming him really) and playing on the computer, particularly, chat rooms and e-mail.

This morning J. Dogg had a new idea for something interesting to do. He has been watching a lot of shows on TV about the wild animals of Africa. Being very smart but not as knowledgeable as he thinks he is, J. Edgar assumes Africa is nearby and he wants to go there and see it for himself. Part of the reason for this is Lions. He has seen a lot about lions lately and he thinks he bears a more than passing resemblance to them. He is after all a Shar Pei and his ancestors back in China were known as "Lion Dogs" so J. Dogg wants to visit his roots.

It would do no good to try and explain to him how many ways he is incorrect in these assumptions as 7 months in a puppy is equal to about 13 years old in a human. As we all know 13 year old boys are not known for accepting their limitations or being told they have it all wrong. That puberty thing hits them about the same as it does human boys. He's not going to be rational for several months unless I get him a little elective surgery… but we won't talk about that now.

So today J. Edgar Dogg will do something totally out of character for him and when he sees the front door open he bolts for freedom. Now under the best of conditions Uncle Dave is not what you would call spry, in fact he is pretty much the opposite of "spry." This means there is little he can do when J. Edgar heads out. So he hobbles out on the porch and watches as the Dogg runs off across the grass heading for the woods.

Run, Run young dogg, run like the wind… "Bonk!"

Did I mention the J. Dog is a little nearsighted? In the house he runs into things a lot, stationary objects, moving objects, doors, walls, pretty much everything. And now he has hit a tree, well a sapling really but it was wood and hard and he has bumped his head and is whimpering like a little baby.

Uncle Dave gets his cane and the leash and goes out across the grass to the edge of the woods where in J. Edgar's current condition even UD can corral the wayward pup. He leads him back to the house where there is a little trouble getting him inside as he is a little too wobbly to negotiate the steps by himself so Uncle Dave has to lift him up onto the porch and then climb the steps himself to get them back home. Once inside and unleashed J Dogg goes into his room and lays down on his bed to nurse his wounds, the bump on his head and the bigger wound on his ego. The grand visions of rejoining the pride pushed far back on his to-do list for the time being.

In a while he comes back out into the living room and starts playing with his rubber ball and when the front door is next opened he hides behind the easy chair until it is once again safely closed.

J. Edgar Dogg (as told to and witnessed by Uncle Dave)

Vitamin D for your muscles, too

By Dr. Tammi Shlotzhauer

It has long been understood that vitamin D is required in order to absorb calcium to help prevent osteoporosis. New research reveals that vitamin D is also needed for proper muscle functioning. Weakness, muscle aches and pain, as well as bone pain may be a sign of inadequate vitamin D reserves. These chronic and often progressive muscle symptoms may lead to a false diagnosis of fibromyalgia, polymyalgia rheumatica or other muscle condition. Most importantly, if not diagnosed, vitamin D deficiency cannot be treated appropriately. Very recent studies suggest that vitamin D may also have a role in the prevention of inflammatory or autoimmune diseases, but this area needs more study. Vitamin D is made available to the body through sunlight and through diet. Most vitamin D is made in your skin after exposure to UVB sunlight. Older people, those with darkly pigmented skin and people who live in sun-deprived places are at risk for developing vitamin D deficiency. Clearly we want to protect our skin from the damaging effects of UVB light, so this makes us all more dependent on dietary sources of vitamin D. These sources include dairy products, some cereals, oily fish, fortified orange juice and supplements. The two forms of vitamin D supplementation are D2 and the more potent and preferred D3. Check the label to see which kind your supplement contains. Vitamin D levels can be checked by a blood test. Leading researchers believe that we have set the "normal" test range for this vitamin too low and we should strive for higher blood levels to optimize muscle and other body functions. An informal analysis in my rheumatology practice revealed a majority of patients having insufficient levels of vitamin D, with people of color being almost uniformly effected. The dosing recommendations for vitamin D supplementation are varied and controversial because of fear that individuals will take too much of this fat-soluble vitamin. However, there is very little evidence that higher supplementation leads to toxicity. Current national guidelines range from 400 to 800 international units per day. Experts in vitamin D metabolism believe these dose ranges represent the very minimum required intake, with the goal for optimal functioning favoring higher doses. We will hopefully see new guidelines that reflect these expert recommendations.

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