



# Los Angeles Myositis Support Group

Newsletter

September 2006

**Myositis Awareness Day 2006!**



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.

## Myositis Awareness Day 2006

*By Bob Goldberg, Executive Director, The Myositis Association*

On September 21st, The Myositis Association will be honoring Myositis Awareness Day with an event in Washington, DC on Capitol Hill. We are inviting all 535 Congressional offices to send a staff person to a luncheon briefing to learn more about myositis and the needs of those who have to live with this disease. Fabio, world famous male model and actor, will be talking about his close family friend who has IBM and the need for funding for myositis-related research.

We hope that the event in Washington will bring more attention to myositis from those in Congress as well as the news media.

It is also important that you do what you can in your community to educate others about myositis. We encourage Keep In Touch support groups and individual members of TMA to schedule events or activities on September 21 to bring attention to the disease and encourage the local media to cover myositis and those in your community that have myositis.

As we have in the past, we have press kits and other materials that you can share with local news media to encourage coverage of myositis on September 21. Also, we ask you to consider what you might do that day as a group of concerned patients, family members and caregivers to educate others about myositis. Please give this some thought. Gifts to The Myositis Association are tax-deductible and may be sent to The Myositis Association, 1233 20<sup>th</sup> Street, NW, Suite 402, Washington, DC 20036. *(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 6<sup>th</sup> St/Wilshire off-ramp from the Harbor Frwy, go ½ mile west)

### Next meeting

**Sept 10, 2006 1:30 – 3:30 PM**

Co-chairs:

June Colton, [junecolton@hotmail.com](mailto:junecolton@hotmail.com)

Richard Gay, [rgay@socal.rr.com](mailto:rgay@socal.rr.com)

Newsletter Editor: Richard Gay.

## September Program

We will have presentations from Ms Kim Pointer, a massage therapist, on the benefits of massage for muscle health, Mr Andre Cathey on specialized coffee products for good health, and a short DVD on custom bathroom modifications for the disabled. We will also have a celebration for Myositis Day. Come early and enjoy everything!

## Myositis Awareness Day, cont'd

We would love to have communities around the country honoring Myositis Awareness Day in addition to what will be occurring in Washington. Please let us know if you need materials, assistance or suggestions, and we will be glad to help however we can to make your event a success locally.

“Together We Will” has been a theme of TMA. And the assistance of others, such as Fabio, who doesn't have the disease but knows somebody who does, will go a long way to capturing the attention of the media and decision-makers who can help support those with myositis and make their lives more manageable. Thank you for all you do to help those with myositis!

### Christa's Dermatomyositis Story

*By Christa Bennett*

Dermatomyositis definitely has its shares of ups and downs. Sometimes it's all I can do to sleep all day. My pain and weakness fluctuates on almost a daily basis. I have found that the simplest things can cause my disease to flare, such as the weather, exercise, a virus, stress, menstrual cycle, diet, or even hair color. I continue to learn my boundaries and take care of my sensitive body, so I don't pay by spending a week in bed. My rashes are very painful, itchy and red, but I have found that liquid Bactine, and aloe help with the pain. I am down to 0.4cc's of Methotrexate per week, and my pain and weakness have increased. I will mention this change to my Dr. at my next appt.



Brandon August 2006

He is constantly tweaking my medications to keep my blood levels normal and my pain and weakness at bay. I have had DM nearly three years and have yet to be in remission. I am still on disability, take 13 prescription medications, and suffer from varying



Christa and Frank

degrees of pain and weakness daily. The key to my happiness has been “acceptance.” I pray, journal, and stay in gratitude for the things “I do” have. This mind-set really helps me feel normal and still live life to the fullest. I am only 28 years old and have a beautiful husband and baby boy. I am truly blessed, if I just look for the blessings...

I credit my wonderful life to God, Dr. Franco and all the support from the Arthritis Center of Riverside, my loving husband (and caretaker) Frank, my beautiful son Brandon, and my supportive family and friends...

Christa Bennett, 28 years old

Dermatomyositis diagnosed: August 15, 2003

[bennett520@sbcglobal.net](mailto:bennett520@sbcglobal.net)

## Register for Your Free Subscription to IG Living!

*IG Living* is the only magazine dedicated to patients who use immune globulin products and to their care providers. Subscribe at [www.igliving.com](http://www.igliving.com).

Regular features include such topics as product and manufacturer news, resources for healthy living, immune globulin treatment options, reimbursement, political advocacy and clinical trials.

*IG Living* is a community service provided by FFF Enterprises and its specialty pharmacy services division, NuFACTOR, [www.nufactor.com](http://www.nufactor.com).

**Hello coffee lovers,  
Is your coffee healthy? Ours is!**



*September Guest  
Andre Cathey*

**Yes, There will be samples!**

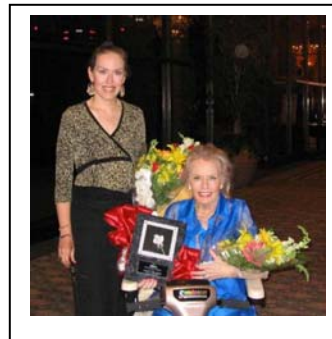
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To get your sample of Ganoderma Black Coffee  
send \$1 and additional \$.50 for each other sample  
you would like to try to:

Andre Cathey  
4005 Dublin Ave.  
Los Angeles, CA 90008  
323-242-5209

(Editor's Note: Andre's sister Lettrice is one of the  
members of our Los Angeles KIT group. Andre is  
well aware of the chronic problems faced by myositis  
patients.)



## **The IBM Corner**

*By June Colton*

From: Navanit

To: Richard Gay

Hello Richard:

I have a question for  
people with IBM: I have  
IBM, and all day long, I

feel tired, and very weak, energy wise. Is this common for  
people with IBM, or it is just me? How much can people  
with IBM usually walk ...a few feet, a quarter of a mile?  
Can you do minor exercises? I am also interested to know  
if any one tried any medicine that worked? Thanks.

Dear Navanit,

Richard forwarded your e-mail to me because I have  
IBM and he thought I might be able to answer some of  
your questions. I hope I will be able to help and at the  
same time give you some comfort.

I have had IBM for 25 years, and I just turned 76. Dr.  
W. King Engel of USC Neuromuscular Center in Los  
Angeles finally diagnosed me in March of 1993. I've had 5  
biopsies. Dr. Engel prescribed prednisone and when that  
didn't help, IVIG, which didn't help either. Vitamin  
supplements do aid in keeping one reasonably healthy and  
I take them daily. I believe exercise helps to keep one  
agile, maintains strength and flexibility and keeps one  
more mentally fit. Massaging the body helps, especially  
the legs, feet, arms, and hands. Stretching and Yoga are  
good also. You have to be careful not to overdo. You must  
listen to your body to see how you feel. Walking is  
excellent if you can do it safely. These are the things I do  
to counteract the IBM. You can try these and see if you  
feel better.

Now, let me answer some of your questions. You  
mentioned being tired. That is one of the common affects  
of IBM. Due to the disease muscles weaken, so  
accomplishing tasks takes longer and one has to work  
harder, which is tiring. Rest periods are helpful and  
drinking water is necessary, especially in hot weather.  
Getting enough sleep at night is very important. Do you  
feel rested when you awaken in the morning? Maybe you  
need a nap during the day. Protein helps build muscles, so  
you should be sure to have some at each meal. Perhaps it  
will help to lessen your feeling of weakness and give you  
more energy. Frankly, when I feel quite tired I have a diet  
Coke. It has caffeine and gives me a boost.

IBM also affects walking because leg muscles have  
weakened. I used to be a jogger and now I use a  
wheelchair inside and an electric scooter outside. I find  
that I am safer and less tired at the end of the day. But it  
was a gradual progression. IBM affects people differently.  
Some have more muscle loss in the legs and feet, while  
others loose it in their arms, hands, neck and even have

difficulty swallowing. Some folks can walk a mile, or less, a block or two, and now I can only walk with my 3 wheel walker, around the house a little...and certainly not outside because it's too risky. You have to be the best judge. You do not want to fall, which is what I was doing, so I use a wheelchair. I've heard that from others too.

To my knowledge there really isn't any medicine that helps IBM at this time. I mentioned the prednisone and the IVIG. It MAY help. You can ask your doctor what he suggests, and try it. I wish I could give you something more positive, but what I found that helps slow the progression is trying to stay in the best health possible with vitamins, healthy meals, exercising, enough rest, less stress and doing more things that make you happy. I should mention that there is an IBM KIT member who goes to Mexico weekly to receive injections, etc. She has gone there for years and although she has difficulty swallowing and using her hands, she can still walk with a cane and she can still drive her car! She will be at our next KIT meeting.

Navanit, I hope I have given you some insight here and not discouraged you about IBM. It is a problem disease and frankly, polymyositis and DM may be somewhat easier to treat. I assume that you have a good doctor, familiar with your disease. He needs to work with you and have a plan to keep you healthy as possible. Will you please let me know if I can be of further help and also let me know how you are doing? I hope you have family and friends to help you. My daughter lives with me and is a great help. Take good care of yourself.

With best wishes,  
June Colton

### **IBM and Prednisone**

Rich: Don't know that this is newsletter worthy but thought I would share my experience with medication. I have been on a relatively low dose of prednisone for my IBM (20mg every other day) since February. Initially it appeared to give me more energy for about a month but no apparent change in strength in my arms or legs. The side effect of insomnia has made it difficult to function at work each day, so I intend to inform my doctor next week that I want to discontinue the prednisone. Has anyone else had a similar experience??? Thanks. Sharon

Dear Sharon, Hi! Rich forwarded your e-mail to me because I have IBM, for 25 years now. He knew that at one time I too took prednisone, which was in 1993. Here are my experiences with it: Dr. Engel prescribed 5 mg. every other day to reduce the inflammation in my feet, legs, arms, etc. I only took 1/4 of that pill every other day & it threw off my thinking, my disposition, my serenity. I reduced the dosage, but it still had a bad affect on me. I realized I must be allergic to it. I talked to the doctor many times about this bad reaction. He tried to encourage me to continue with it, but it was affecting my life too much and

after a year or so, I just stopped taking it. I did have more energy using it however. My IBM is progressive and I use a wheelchair inside and a scooter when I go out. I like the front protection of a scooter, it seems.

Some can tolerate prednisone and some, like me, cannot. I have not taken any other medication for the IBM...Dr. Engel has never given me anything else. In fact, I only take vitamin supplements, daily. I hope this has helped Sharon. Please let me know if I can help anymore. I just have to live with the disease. I must mention that I do exercise daily. The legs & feet massaging I do every morning & at bedtime helps me so much. I am trying to find time and energy to do more stretching and yoga.

With best wishes,  
June Colton

## **Dermatomyositis – Case Study**

*By Matt Barba*

### **Matt Barba**

San Francisco, CA

43 year old male

DM since 2004

Treated at Stanford

Other Dx: sleep apnea, retinopathy, rosacea

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### **HISTORY & MEDICATION**

I developed symptoms in mid 2004 (face lesions), was initially misdiagnosed (August 2004) with discoid lupus. Began to develop fatigue and Grotton's papules at this time. Subsequently diagnosed (Dec 2004) with DM at Stanford. Began 2,000mg daily CellCept in January 2005, have been on this dose consistently since. After three months of CellCept therapy, muscles slowly started to gain strength, CPK level decreased slowly but consistently. I was invited to participate in a clinical trial at Stanford. Agreed to receive two infusions of the lymphoma drug, Rituxan (rituximab). After four months, began to notice improvement in muscle function and strength. The combination of CellCept and Rituxan have improved my muscles to about 90% of "normalcy". Rituxan is showing promising results for many inflammatory and rheumatic diseases, such as DM and arthritis. Today I have very good muscle strength and can do most anything. Fatigue level has drastically decreased thanks to these two drugs. I do, however, still have daily muscular discomfort (pain and soreness) primarily in the trunk, including upper back/shoulder blades. I take 600mg Motrin up to four times daily which mostly relieves these symptoms. I recently got a prescription for Baclofen (Lioresal), a muscle relaxant, which works well for the "knots" in my upper back, which are common, and quite distracting and uncomfortable.

However, baclofen does cause sleepiness, which I hope will decrease as my tolerance to the drug increases.

### **SKIN**

For scalp itching and flaking I use 3% salicylic acid shampoo as needed. It does help alleviate these symptoms. I also shampoo daily with tea tree oil shampoo & conditioner. I stopped using topical corticosteroids on the scalp when I was diagnosed with a macular (retina) disease. The eye doc (a retina specialist) told me that prednisone (and even topical steroids can worsen eye disease. He also said not to take plaquenil, as it too can worsen eye disease.

To alleviate the itching of the face, I apply pure coconut oil daily. This alleviates itching on contact! It also absorbs nicely into the skin, and is a very healthy product which can also diminish cracks and scales of the skin.

### **VITAMINS & NUTRITION**

I think it's VERY important to not only eat a healthy, balanced diet, but to also take supplements. Persons with chronic illness require more than healthy individuals in terms of nutrients. Every day, consistently, I take B-Complex with Vitamin C, magnesium, Alpha Lipoic Acid, Vitamin E, Fish Oil gencaps, Flaxseed Oil gencaps, and Milk Thistle. I feel MUCH better today than pre-supplements. The magnesium and B-Complex have eliminated the tingling and numbness I had in my fingers. The muscle spasms in my left bicep have disappeared since taking these two supplements.

After contracting DM, I did much research about diet and nutrition, and realized that I needed many changes. I stopped eating refined sugar, refined flour products, reduced my alcohol consumption, drastically reduced coffee intake (down to one cup per day), started drinking green tea every day (3 or 4 cups daily), as well as many other herbal teas, such as licorice tea and mint tea. I stopped buying cereals with added sugar, no longer bought processed foods and frozen foods loaded with preservatives. I immediately stop eating ALL prepared foods, which are loaded with nasty, toxic chemicals and additives which promote ill health, including headaches, GI upset, lethargy, nervous system imbalance, memory loss, addiction, weight gain, insomnia, hypertension, etc., etc., etc. I read every label on every product before putting it in my grocery cart. If the following words appear on the label, I won't buy it:

- High fructose corn syrup
- Partially hydrogenated vegetable (or soy) oil

- MSG
- Autolyzed soy (or vegetable) protein [a form of MSG]
- Hydrolyzed soy (or vegetable) protein [a form of MSG]
- Any food coloring
- "Natural flavoring" [usually means MSG, but can be anything]

I loaded up on fresh fruit, particularly berries. I eat breakfast every day (high fiber, low fat cereal or eggs). I only use good oils (olive, canola, walnut, and coconut). I started eating legumes and beans, fish, salads, nuts, grains, etc. I stopped eating all junk food and fast food. I cook 90% of my meals at home, using no prepared ingredients, all fresh and homemade.

As a result, I feel MUCH better. My nervous system isn't assaulted, I feel more calm, get less headaches, more balanced, my memory has improved, and my focus is clearer. I think more persons with disabilities would benefit from eating better, and by taking daily supplements. Tea is much healthier than coffee. Refined sugar and prepared foods are extraordinarily harsh and adverse on the human body and mind.

### **OTHER IMPORTANT, HELPFUL TIPS**

I have discovered the healthy benefits of having a pleasant environment and ambiance. Some things I have incorporated into my life include:

- ❖ I listen to classical music
- ❖ I light unscented candles at night often
- ❖ Laugh more frequently.
- ❖ I also maintain a clutter-free home, which makes me feel much more at ease, and I can think more clearly.
- ❖ I avoid loud, noisy places and people.
- ❖ I don't go near anyone who smokes, and don't allow smoking in my home.
- ❖ I keep windows open often, fresh air is so important.
- ❖ I avoid using anything with artificial fragrances, such as low quality aromatherapy or candles with scents.
- ❖ I switched to natural, pure citrus oil room air fresheners.
- ❖ I placed lots of beautiful plants around the house (though not in my bedroom so they don't compete with me for oxygen at night).
- ❖ I bought 300 thread count Egyptian cotton bed linens, a down comforter, and wash my beddings often.

## **Polymyositis- Case Study**

*By Emmanuel "Manny" Genova*

Editor's Note: Manny Genova is currently only taking very small amounts of prescription medicines. I am reporting his story here for potential benefit to our members for his strategy to regain his strength.

Hello Richard,

My name is Emmanuel Genova and I was diagnosed of PM on July 1997. I was confined at the hospital for a week. My doctor told me I had PM, my CPK was 14000 and I would be very sick (but on that time I felt tired only and I thought it was not a big deal). Weeks later, I noticed I had troubled walking, lifting my arms, climbing on my bed and the worst, swallowing food. Then, I started to get scared. I thought I was going to die because I wasn't getting any progress. Week after week, I was getting worst so I lost almost 40 lbs in couple of months. In other words, I experienced the full blown symptoms of Polymyositis. I took prednisone 100mg per day and methotrexate 30mg per week and some vitamins. These drugs stabilized my symptoms slowly but still I had pains and was very weak.

Luckily, my mother knew someone in Arizona who had the same disease that I had. They also have a myositis group in Arizona. When I went there and saw the guy (his name is Kenneth Johnson), he said, "you will be just fine" and all I remember I had tears on my eyes. Anyway, we've been friends since then and I visited their group probably only 3 times because I lived in California. But, one of the group there (she was an old but very nice lady) had mentioned something about the way you eat. She meant you have to eat good food, relax, and enjoy your life.

Now, I will tell you what and how I did to make myself better (I hope it will benefit to others). First week November of 1997, that morning my wife blended some fresh fruits (yogurt, banana, kiwi, apple, ground flax seeds) then I took a nap. (I was not working and was temporarily disabled) hours later, I snacked some more fresh fruits. Lunch, I ate fresh and steamed vegetables like broccolis, carrots, sweet potatoes, small portion of turkey breast or chicken breast. Then I relax, or took nap. Hours later I snacked more fresh fruits sometimes combined with vegetables like carrots or broccoli (yes broccoli) then again I relax, or took nap. Dinner, I ate again steamed vegetables and turkey or chicken. I remember, every meal and

snack I ate, it took me an hour to finish because I had to eat slowly and drink slowly. So you see the pictures, everyday same pattern with different varieties of fresh fruit, vegetables and water.

Third week, Thanksgiving night, I was invited with my friend's house to have a dinner. I was sitting on a table; we were talking & laughing and I realized I could swallow my food in a normal way. I felt miracle inside my heart but I always knew I would be better and I was just waiting for that time. I am a Catholic and I admit I am not a religious person but honestly, the day I got better for the first time, I thank Him so much and ask him for my forgiveness.

It's been almost ten years now and so far I have only relapsed probably less than 5 times and the last relapse I had was six years ago.

Today, I am 99% better and my weight is normal. My wife and I ride bikes, we walk, and I do light weight lifting. I like to read nutritional magazines or books. I am not saying you will be better right away the way I did but all I know I tried to be very positive and have faith. I would probably not be there in your September meeting but I say to all my fellow myositis friends, I know how you feel, emotionally, physically, mentally and etc. but let me tell you that you can fight this horrible disease. Please take good care of yourself. I have so many stories about my disease but unfortunately it will take me all day long to write.

To Kenneth Johnson who is a MAA member of Arizona group, we lost our touch and I haven't heard from him. The emotional support that you gave to me is a big positive support to me. I sincerely will always thank him.

God bless,

Emmanuel "Manny" Genova

### **Helpful Hints**

*By Tom Hunt*

Rich,

I currently am undergoing the steroid infusion treatment for Dermatomyositis. Like for many persons undergoing such treatment, a benign side effect has been an oil discharge on my forehead, nose and cheeks.

At first I found myself washing my face very hour or so which, of course, is not a big deal, but bothersome. They, my wife Eleanor suggested using baby wipes, which sell under the brand name of "Handiwipes" or "Softwipes." I now carry two or three in my pocket in an air tight box, which makes it

possible for me to quickly clean my face no matter where I may be.

Solving minor problems often helps one to cope with big problems, such as my radically reduced muscle strength. And, by the way, my strength is returning ahead of schedule!

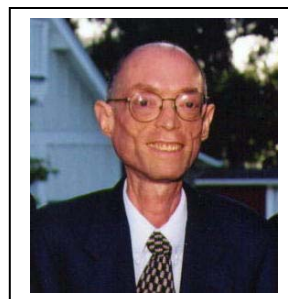
## **Cherry Juice Reduces Muscle Pain Induced By Exercise**

*Submitted by Rachael Nicometo*

Cherry juice can reduce muscle pain and damage induced by exercise, suggests a small study published ahead of print in the British Journal of Sports Medicine. Many approaches have been used to try and stave off muscle pain and damage after exercise, but few have been effective, say the authors. Fourteen volunteers were asked to either drink fresh cherry juice blended with commercial apple juice twice a day for three days before exercise and for four days afterwards, or to drink a dummy mixture containing no cherry juice. The blend comprised 12 oz of liquid, equivalent to the juice from 50 to 60 cherries. The fruit contains many antioxidant and anti-inflammatory agents. The exercise was classified as "eccentric," which refers to contractions in which the muscle is lengthened, such as in hill walking or weight lifting, or any type of exercise not previously done before. In this instance, the volunteers flexed and tensed one arm 20 times. Muscle tenderness, motion, and strength were assessed on each of the days before and after exercise, using standard pieces of equipment designed for the purpose. And the volunteers rated their own muscle soreness on a scale of 1 to 10. The whole process was repeated all over again two weeks later, with those who had taken the dummy mixture taking the cherry juice blend instead, and vice versa. The other arm was also used. There was a significant difference in the degree of muscle strength loss between those drinking the cherry juice blend and those taking the dummy mixture. This fell by 22 percentage points in those drinking the dummy mixture, but only by 4 percentage points in those drinking cherry juice. Muscle strength even improved slightly after 96 hours in those drinking cherry juice. The degree of soreness differed little between the two groups, but the average pain score was significantly less in those drinking cherry juice. Average pain scores came in at 3.2 for those drinking the dummy mixture and 2.4 for those drinking cherry juice. Pain also peaked at 24 hours for those drinking cherry

juice, but continued to increase for those on the dummy mixture for the subsequent 48 hours.

Editor's Note: Not all cherries are the same. For those who must watch their sugar intake, Michigan tart cherries with no sugar added are excellent. I have purchased dried tart cherries and concentrated cherry juice from Brownwood Acres Foods, (<http://www.brownwoodacres.com>). Their service is very fast and neither the juice nor the dried cherries raised my blood sugar. I cannot report any effect yet, positive or negative, on my muscle strength over the first three-week period.



## **Dermatomyositis, Statins, Cholesterol and Heart Disease—Are We at Higher Risk?**

*By Richard Gay*

I have now had dermatomyositis for 42 years, longer than almost anyone else in the United States (technically I have JDM, since I was 13 when diagnosed). This puts me on the leading edge of very long term effects of the disease. There is no data base of previous patients to forewarn me of potential illnesses associated with a 40-yr lifetime of JDM. Of recent interest to me is the correlation of unexpectedly high cholesterol with patients with DM. An informal survey of our KIT group indicated that cholesterol runs much higher than normal for almost all of our members. My own cholesterol has historically been in the 170-180 range, but most recently it has been about 220. This is despite the fact that I am very underweight, eat a well-controlled diet and have consistently followed a three-day-a-week exercise program for the last 28 years.

Due to my JDM I took prednisone for 17 years and I have had Type 2 diabetes for the last 14 years. The diabetes was diagnosed ten years after I stopped taking prednisone. My diabetes may be a delayed side effect of the prednisone, or an example of overlap of auto-immune diseases. I am able to control my blood sugar with diet, exercise, and oral medication. However, this does not mean that I am protected from the risk factors of diabetes. One of these risk factors is heart disease. My own doctor has told me that I will not likely die from DM, but could

die from heart disease. Even though my family has no history of heart disease, the combination of high cholesterol, DM, and diabetes puts me at risk. Therefore, it was prudent to perform standard tests for heart disease. One of these tests which I recently completed was an angiogram. In an angiogram, a catheter is inserted in an artery and fed towards the heart. A small amount of dye is injected which highlights the heart arteries on an x-ray image. It is considered the "Gold Standard" for heart diagnostics.

The angiogram itself took about 45 minutes followed by five hours of lying on a bed without getting up. The following day I felt fine with barely a slight sore spot on my leg. I was very surprised that the angiogram showed a complete blockage in my right artery and partial blockage in the center and left arteries. I have no chest pain and no shortness of breath. Cardiologists call this "silent ischemia" (ischemia means low blood flow). This angiogram was my fourth heart test in the last six months. I had an echo cardiogram but it does not show internal blockages in the arteries; the radioactive stress test showed some blockage but was not as detailed as an angiogram. The newest test by electron beam tomography, which Medicare does not reimburse (\$400 per test), actually showed my cardiac calcium to be in the 99<sup>th</sup> percentile on the high side. The recommendation would normally be to perform by-pass surgery for my situation. My cardiologist had experience with dermatomyositis and he didn't want to do by-pass surgery on me because of the dermatomyositis. He recommended using medication and gave me samples of Crestor, 10 mg, to take one a day. We talked about the possibility of muscle weakness induced by the statins, but we felt it was important to give it a try with the blockages showing up.

The side effects of the Crestor hit within days. Before I had the angiogram and started the Crestor I could do 21 minutes on the Stairmaster. Within four days I was really pushing just to finish 15 minutes on the Stairmaster. After that all I wanted to do was to lie in bed. I had no appetite at all and didn't feel like eating anything. My blood pressure dropped to 100/60 when it usually is around 130/80. My cardiologist said that I am a "terrible candidate for any kind of intervention" for my heart problem. I get internal bleeding from a daily aspirin and I get extreme muscle weakness and aches from the statins. I am a very high risk for any surgery from my

dermatomyositis. I have tried enteric coated aspirin many times with the same result (internal bleeding) each time. I think the problem is that the aspirin lowers my platelet count too much and the years of prednisone ruined the lining of my stomach. The cardiologist suggested trying to take aspirin or one of the statins just once every three days or even once a week because some or even a little is so much better than none.

So far I have been able to take a baby aspirin (81 mg) every other day. My strength took four weeks to fully return and I have been eating the tart cherries and cherry juice (see the story in this newsletter) without any increase in my blood sugar. The cardiologist said there is a diamond drill technique that pulverizes the plaque. He didn't want to do the balloon technique with me because I have a big piece of plaque followed by a large section of artery and he was afraid the balloon would push the plaque down into the artery rather than against the wall. Experience counts in cardiology just like everything else! Even if they do the diamond drill they would put a metal stent in afterwards and I have to be able to take aspirin after the stent is put in to stop the risk of thrombosis. No aspirin means no stent which means no diamond drill to pulverize the plaque deposits. I can continue to do the Stairmaster exercise but am not to do extreme exertion. I can also continue the weight-lifting I do. I don't have the muscle strength to do extreme exertion, so that is not likely to happen.

I have recounted my experience in this newsletter because I know of no direct data to forewarn DM patients that they are highly likely to have very bad muscle weakness from taking statins. The 10 mg size Crestor is a very small dose and my weakness from it was severe. Also, there are no studies that correlate DM with cholesterol and heart disease, but if our risk is much higher than normal, it is important for us to be learn of this. It can be a bit alarming to consider that I was already doing "all the right things" with a careful diet, consistently followed a dedicated exercise program, had a low stress-lifestyle, and still had some artery blockages. It may also be possible that the calcium metabolism of DM patients, especially adult JDM patients, may be abnormal due to JDM and thus contribute to plaque buildup. In the minimum, an electron beam tomography exam or similar heart diagnostic test may be worth considering for individuals with JDM and DM.