



# Los Angeles Myositis Support Group

Newsletter  
May 2006

**Time to Enjoy Spring!**



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.

## Kim's Story

*By Kim Chung Ha, LA KIT Member, IBM*



These last few months have indeed been busy, and I wanted to share my story with you. I hope everyone has been well.

Over the Christmas holiday season, I purchased a handicapped-accessible van with the in-floor ramp. Initially, before I made the investment, I had purchased a collapsible electric scooter that could be broken down and stored in the trunk of a sedan. However, I wanted the option of being transported around with greater ease and convenience. After researching various dealerships which catered to modified minivans, I purchased

mine from Advanced Mobility Works in Van Nuys which has a large selection, competitive prices, and good customer service ([www.advanced-mobility.com](http://www.advanced-mobility.com)). Please note that no sales tax is charged for the conversion value of the vehicle, which is quite substantial (usually half of the van's price). I love my van and would be happy to show it to others who are thinking about buying one.

On the medical front, these last few years, I have struggled with a high cholesterol problem despite watching what I eat. I was taking Lipitor for awhile, but experienced muscle weakening which is one side effect of the medicine. I stopped taking it for several months and briefly took niacin. *(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

**May 7, 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.

## May Program

We have no formal presentation for this meeting. Come and visit with us and share recommendations for successfully living with myositis.

## Kim's Story, cont'd

However, it was causing stomach upset and other problems, so I'm back on Lipitor despite the muscle weakness because it is less risky than more life-threatening conditions such as heart disease or a stroke. I am also taking Altace to reduce my high blood pressure problem. Initially, I took Benicar which was causing dizziness and upset stomach, but stopped taking it shortly thereafter. Altace seems to be treating my condition with no side effects.

In combination with my medicine, I eat a low-fat diet that is high in whole-grain fibers such as millet, red rice, and oatmeal and take multivitamins to maintain my energy level. I also use a massager for my back and legs to improve circulation, which is particularly important since I'm sitting in my electric wheelchair or lying down for long periods of time. Music is also a great stress reliever.

Recently, I discovered a great website called Disabled Online ([www.disabledonline.com](http://www.disabledonline.com)), which is devoted to helping disabled people with helpful resources that pertain to legal matters, education, home & living, employment, recreation, travel, etc.

Finally, for those who are interested, the Abilities Expo will be held at the Anaheim Convention Center June 16-18, 2006 where the latest advances in mobility equipment (scooters, wheelchairs, cars and vans, home modifications) will be exhibited. For more information, please check out their website: <http://soc.abilitiesexpo.com>.

Take care and I'll see you at the next KIT meeting!

## Christa's Success Story

Christa Bennett: 28 years old, diagnosed DM on 9/15/03 after the birth of my son. I am a strong supporter of the Antibiotic Protocol. I went from not being able to walk to now riding ATV's in the desert-  
-There is life after Dermatomyositis!

Ask me about it at [bennett520@sbcglobal.net](mailto:bennett520@sbcglobal.net)



## The Untold Story—DM and Relentless Skin Itching

*By Richard Gay and Vickie Jahaske*

The skin rash of DM is very well known to myositis patients, but not so well-known, and of much worse consequences, is the itching that sometimes, but rarely, comes with this rash. Your editor had this itching for 14 years associated with his JDM. It is like being in a prison without a door or lock. Nothing works to make it stop. Vickie's description below of the skin itching matches my experience to the letter (what a dubious distinction for both of us)! I don't know of anything that really stops the itching because I think it comes from internal forces, not just dry skin. I can remember all kinds of special soaps, creams, the whole works and nothing helped. I think it is important to recognize that this disease lingers for many years. I strongly discourage false expectations of rapid remission. I think people need to read about successful approaches for dealing with DM over the very long term. I received a letter from a TMA member, Ken, who is having very serious skin problems with his DM. Another member, Eileen, and her friend Vickie, responded to Ken's letter. Vickie's letter is included here. This is a beautiful letter to Ken with good observations and recommendations.

Dear Ken,

My name is Vickie Jahaske. I was born in 1964 (makes me 42) and raised in Chicago, but have been in Arizona for 14 years (Tucson). I've been married 20 years to my high school sweetheart, Mike, have two gorgeous children (Kyle, age 15 and Kate, age 8), and an overweight pug dog. Besides that, I have been trying to heal from dermatomyositis since 1987. Eileen, an acquaintance of yours and Richard's, gave me your name and info and asked that I write to you.

I am sorry to hear that you are doing poorly and feel miserable. Some times are better than others. The rash with the DM is bad for me, my face and back have a dark red rash which doctors have told me is the worse they've ever seen (I won't fight you for the distinction ;-). The rash makes my skin feel tender and burning, but by far the worse for me is a non-stop itch of the rash. Nothing in 19 years has helped that itch. I've lost my hair due to constant itching of the scalp and scarring alopecia. I scratch my scalp and back until they bleed and so they are covered with scabs and scars. I do not, however, have the pain in the extremities that you describe.

You can imagine that in the past 19 years I have tried quite a few treatments, prescription and natural. By far the best response I had was from Rituxan. I would run, not walk, to try Rituxan again. Unfortunately my body developed an absolutely-unheard-of-never-before-seen-or-documented antibody to Rituxan and the Rituxan stopped working. Now if my body is so damn smart to figure out an antibody to Rituxan why can't it stop the DM!!!!!!!!!!!!!! The Rituxan was the first drug to begin to clear up my rash. I advise you to try the Rituxan. I have been on a cortisone Rx since 1987. Also, I've been off and on the IVIG. It does help and I would try the IVIG second to Rituxan. I am thinking of trying Enbrel soon, though I've heard of others with DM using Enbrel without any great success. Methotrexate used to work well for my muscle pain and weakness, then stopped working and caused liver and white blood cell count problems. I did try blood thinners with a naturopathic doctor, but they didn't seem to help one way or the other. Your doctors are good and on top of the research.

I once spent many months at a naturopathic clinic in Dallas, Texas with Dr. William Rea. I can save you many thousands of dollars by urging you try a combination of exercise, dry-heat sauna and massage. It seems to me that sauna might help with the extremities and night sweats. I try to sauna three times a week. I use a portable sauna that is wonderful and stay in for 20 minutes (<http://www.finnleo.com/>). I also take daily pancreatic enzymes that help keep the muscle lab tests in the normal range ([www.nutricology.com](http://www.nutricology.com)). Others have had relief using acupuncture. If money was no issue, I'd definitely be trying an oral version of IVIG (see <http://www.protein-therapeutics.com/about.shtml>).

Here's a few good articles about DM and treatment choices (though your doctors have made good suggestions):

<http://www.mdausa.org/publications/Quest/q106beast.cfm>  
<http://www.mdausa.org/publications/Quest/q111fire.cfm>

Yep, this disease stinks. Big time. Each day I have to decide if I will say "my life could be better" or "my life could be worse." I'm grateful I can walk and feed myself. When I go out with make up and a wig, I guess I look normal (I call it smoke and mirrors). I think Richard hit the nail on the head about the struggle being both physical and spiritual. Again, I am so sorry for what you are suffering with. I hope I've helped in some small way. Feel free to write back with any questions. Take care, Vickie



## Lettrice's Story

Hi, my name is Lettrice Cathey-Lawrence, LA Myositis KIT member. I have had dermatomyositis for 15 years now and I often experience numbness, no energy, unexplainable weight gain, extreme pain & muscle spasms, difficulty climbing stairs or standing for long periods of time, sensitivity to sunlight, calcium deposits, light headiness. After years of struggling, I have been taken off of the prednisone and methotrexate for awhile. I am being monitored by a specialist monthly, because I am off of some of my medications and they want to make sure my CPK levels don't elevate. I also, have been given permission by my doctors to take only pain meds and vitamins. I am still fighting to clean my system, because it is still so full toxins due to the many years of taking toxic medications in order cope with myositis. However, I still take some pain medications and many different vitamins. I have just discovered that whole foods, cutting starches and sugar are extremely important when there is a disease like myositis invading the body. I want to tell you all about whole food farmacy... I just started trying their products. My brother Andre Cathey(4089001) is a salesperson for that company and he has allowed me to try many of the products. I have more energy since I have tried many of the snacks and the coffee. It is all natural! Just take a look at the site, if nothing else:

<http://cathey.wholefoodfarmacy.com/2005/shop.asp>

I must say that I was very disappointed that the Ricky Bell Memorial Fundraiser for April 14th was

cancelled. It should have been supported by everyone, but it wasn't. However there will always be other fundraisers. I practiced endlessly and was truly ready to perform and give of myself for that fundraiser, like many of the performers but we just realized that the cancellation was the only sensible thing to do at the time. "Everything happens for a reason."

In the future, my goal is to have a fundraiser before the end of the year, featuring local talent that can raise a tremendous amount of funds for Myositis research. I am going to pitch that idea in a future meeting and make it accommodating for everyone financially and make sure that handicap areas are set up for those who are unable to walk far distances. "I believe music is a good avenue for a possible next fundraiser." I will give my talent, time and possibly find the place to have the event, but I need help from



The Lawrence Wedding

everyone to make this happen. In the past, I have hosted and planned fundraisers and put all the work in and ended up bedridden, so I learned to pace myself and be smarter. As myositis patients, it is good that we all want to give back and help to make the world more knowledgeable about our illness. In the meantime, I will continue to strive to find other ways to fight this disease and remain positive. That does play a good part in recovery or at least stabilizing the disease some.

I have overcome cancer, had three surgeries, two car accidents, a miscarriage, almost died at least three or four times now... and I have learned to be more patient. Patience, avoiding stress, lots of love, REST and pacing yourself are the keys to fighting this disease. Sometimes, it seems to take over and there are days when you are sick and can do nothing about it. On those days of feeling sick, just read,

pray, talk on the phone with your loved ones (only people who know the right things to say or will uplift your spirit), watch a positive movie, surround yourself around positive people or even try to get out of bed and do something you love to do (within reason). That is the only thing that helps! Never feel sorry for yourself; crying does help... However, always see the good side of things even when the negative is present. Most of all love yourself and the body you are in, even though it is weary... I thank God I am still here, that I am celebrating two years of bliss with my husband on April 16, 2006, that my family and friends are well and surviving and that I have not lost my mind! :-). It is important to have a sense a humor and to keep your sanity intact. P.S. "Be well all of you and may the peace of God remain with you and your family forever." --Lettrice

## Words of Inspiration

*By Victoria Sanchez, LA KIT Member*

To get a little relief from stiffness and strengthen my joints I have help from a super Pilate Instructor once a week and for the past four weeks I have been going to another type of treatment once a week to an Acupuncturist & Herbalist because I very much want to get off of pills if I can? Maybe not all doctor's pills but I can sure hope! Water exercise I believe is the best, but I don't have the luxury since my working hours will not permit. And if all fails good friends and a sense of humor can't go wrong! Have a great day. Victoria Sanchez

I was given this inspiration message from a friend written by Leo Buscaglia: The majority of us lead quiet unheralded lives as we pass through this world. There will most likely be no ticker-tape parades for us, no monuments created in our honor. But that does not lessen our possible impact, for there are scores of people waiting for someone just like us to come along; people who will appreciate our compassion, our encouragement, who will need our unique talents. Someone who will live a happier life merely because we took the time to share what we had to give. Too often we underestimate the power of a touch, a smile, a kind word, a listening ear, an honest compliment or the smallest act of caring, all of which have the potential to turn a life around. It's overwhelming to consider the continuous opportunities there are to make our love felt. -Born for love

## New IVig Magazine

By Kit-Bacon Gressitt, Nu-FACTOR

I'm eager to let you all know about a new magazine we are launching, called **I.G. Living!**, for patients treated with immune globulin (see the description below). We are looking for writers within the various patient communities -- including myositis, neuropathy, Guillain-Barre syndrome and primary immune deficiencies -- to do some freelance work for the magazine. If you know of anyone in your group with writing skills, I'd love to hear from her or him, along with some writing samples.

Please give me a buzz if you have any questions:  
W: 800-843, 7447 x 1143 or C: 760-522-1064.

Kit-Bacon Gressitt

VP of Marketing

800-843-7477 x 1143

[www.fffenterprises.com](http://www.fffenterprises.com)

NuFACTOR and its parent company FFF Enterprises are very pleased to announce the launch of a new magazine for patients treated with immune globulin, **I.G. Living!**

**I.G. Living!** is the only magazine dedicated to bringing healthcare product, community and reimbursement news, along with community perspectives, directly to immune globulin consumers and their healthcare providers.

Launching its first bimonthly issue in February-March 2006, **I.G. Living!** will be distributed for free to patients and their physicians' offices, including practices in immunology, neurology and hematology-oncology.

The following are some stories you'll find in our first issue:

- How Safe Is the U.S. Biopharmaceutical Supply Channel – and Why You Should Care
- On Your Own: Transitioning Teens
- I.G. Administration: What's Best for You?
- PID Parenting
- I.G. Clinical Trials: Evaluating Participation
- Legislators of the Year Awards
- Managing the Healthcare Reimbursement Maze

As a leading distributor of immune globulin, we are acutely aware of the need for a responsible source of information about the full spectrum of issues affecting patients who rely on immune globulin for their health. We would like to hear your suggestions about the stories that would be most valuable to you.

NuFACTOR and FFF are dedicated to providing a responsible source of information about the full spectrum of issues affecting patients who rely on immune globulin for their health, and we hope you will join us in this effort.

**You can sign up for your free subscription to I.G. Living! at [www.igliving.com](http://www.igliving.com).** We look forward to your becoming a regular reader!

## Get the Most Bang for Your Doctor Visit Bucks

By Kit-Bacon Gressitt, Nu-FACTOR

Managing a chronic disease can be challenging, but there are some things you can do to make it easier, and making the most of your doctor appointments is one of them.

### How to Prepare for Your Appointment

1. You are your own best advocate. This is your job, not your physician's. You know best what ails you and what questions and concerns you have about your treatment. Take yourself seriously – be your own ardent advocate at every appointment.
2. Keep a diary of your health – and illnesses – and bring it with you to every appointment.
3. The average time a doctor spends with a patient is less than 15 minutes. Take a little time before your appointment to make sure you know what you want to achieve during it.
4. Make a list of your questions and concerns, and remember to bring them with you – along with a pen or pencil so you can make note of your physician's responses.
5. Make a list of all the symptoms and problems that you are experiencing so you can review them with your doctor.
6. Make a list of all medications you are currently taking, including over-the-counter products, herbal supplements, etc., and share the list with your physician.
7. If your doctor ordered any labs or tests at your last appointment, be sure to have them done well in advance of the next appointment so the results will be available to discuss.
8. Bring your own medical records file with you – particularly if you see other healthcare providers. This may prove a good resource during the appointment.

9. Bring the names and contact information for any other practitioners you are seeing.
10. Bring your infusion log to review with your doctor, and your insurance information for proper billing.
11. If you have a co-payment, bring your checkbook.
12. Be early to the appointment. Many offices have the nurse do a triage prior to your seeing the doctor, so you may end up having more time with the doctor, if she or he is not already running late.
13. If you want to discuss a possible new treatment with your physician, bring articles or other information about it to back up the discussion.

### **Try the Buddy System**

It's a good idea to bring someone to the appointment with you. He or she can listen and take notes to help you remember what the doctor has said. Even your

own list of questions can fail you if you don't feel well or the questions are not addressed in the order you've written them. Take advantage of your support system, and bring a buddy with you.

Perhaps most important, remember that your body needs the same commitment you would give anyone else you love. If you are not receiving the information or care you need, be firmly and politely persistent – maybe try a little humor – but don't give up. You wouldn't be passive if your child or mate were ill, so take an active role in pursuing the quality of healthcare you deserve – the best there is!

# # #

## **Why are myositis and other autoimmune diseases becoming more common these days?**

*By Dr. Fred Miller*

*National Institutes of Health*

This question intrigues Dr. Fred Miller and his colleagues, Drs. Lisa Rider and Mark Gourley, who are part of the clinical unit called the Environmental Autoimmunity Group (EAG), established by the National Institute of Environmental Health Sciences at the National Institutes of Health (NIH) in Bethesda, Maryland. The goal of the EAG is to understand the possible environmental and genetic causes for adult and juvenile myositis and other autoimmune diseases. While the causes of autoimmune diseases are not known, most researchers now believe that they develop after one or more environmental exposures occur in genetically susceptible persons. Although much work has been done to define the genes that predispose to myositis and other autoimmune diseases, relatively few studies have addressed the role of the environment, says Dr. Fred Miller. People in the United States are being exposed to many new chemicals in foods, air and water, as well as new infections, medications, and different kinds of stresses than they were just a few decades ago and it is possible that some of these new exposures might be related to the increased frequency of certain diseases.

Another problem that Miller and his colleagues believe is making it difficult to make progress in this area is that each autoimmune disease, as defined today, is likely made up of many different conditions and considering them as one single disease is like lumping apples and oranges together. The EAG is trying to separate the apples from the oranges in a number of these studies. Dr. Lisa Rider, who is a pediatric rheumatologist, says that although there are some differences in how children and adults present with autoimmune diseases, there are many similarities between childhood and adult onset autoimmune diseases and by studying children along with adults, a better understanding of both can be achieved.

The diseases of particular interest to the EAG are called systemic autoimmune diseases, which are illnesses in which many parts of the body may be affected. The major diseases in this category are myositis, rheumatoid arthritis, juvenile rheumatoid arthritis, lupus, and scleroderma. All of these illnesses can develop in either adults or children. The EAG has begun a number of studies carefully evaluating families in which two brothers or two sisters are within 4 years of age, but only one has developed a systemic autoimmune disease within the last 4 years. They are asking, through a number of questionnaires and blood tests, to try to determine why one brother or sister developed disease and the other did not. The study involves both adult- and childhood-onset illness, and persons can be enrolled in the study either at the NIH Clinical Center in Bethesda, Maryland or in their local doctors' offices. To learn more about these studies and determine if you might be eligible, please call 1-800-411-1222 or visit the EAG website at <http://dir.niehs.nih.gov/clinical>