



# Myositis Newsletter



THE MYOSITIS ASSOCIATION

## Georgia Myositis Support Group Newsletter

*Next Meeting ~ April 16, 2016*

*Reservation and lunch order form including details and directions, will be e-mailed soon*

Volume 16, Issue 2  
Spring 2016

<b>2016</b>
<b>Meeting Dates</b>
<b>April 16</b>
<b>July 23</b>
<b>October 15</b>



**Dr Rachel Derr, MD, PhD**

***Rescheduled***

### “Endocrinology 101”

Dr Derr will be covering the basics of Endocrinology. Join us for an interesting discussion on our body’s endocrine system. Jot down the questions you may have on steroids and their effect on the adrenal glands. She will also cover the thyroid, gland, diabetes, hormones and metabolism. *Remember, Knowledge is Power!* The more we know, the better we can battle our disease!

### ***New Members***

We had 4 new members attend in February

- Lizzette Nixon**
- John Levandoski**
- Buddy Burnett**
- Faye Waggoner**

### **Blanket Raffle**



In October we will be raffling this warm, double-sided blanket as our 2016 Fundraiser. Tickets will go on sale at our April meeting.

A big thank you to Augie and Leslie for providing the blanket for our raffle.



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## Myositis Awareness Month, May 2016

Exact date to be determined.

### **Picnic in the Park**



As of this year, we will be celebrating **Myositis Awareness Month** rather than just one day.

We voted to hold a picnic and are forming a committee to pull it all together.

### **PLEASE HELP!!!**

We need a few volunteers, so that it isn't too big of an project for any one person. We can do most of our planning by conference call, so that we don't have to have a physical meeting.

Email [CheryleMiller@comcast.net](mailto:CheryleMiller@comcast.net)

or call Cheryle 678.386.2435

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When something bad happens, you have three choices.

You can ....

Let it define you,

Let it destroy you,

Or let it strengthen you.

-unknown





## Products that Benefit

### iBungee Laces



**IBungee cord-lock holds laces securely and adjusts instantly. The special bungee lace allows users to slip shoes on and off like a loafer. Fits all shoes and is available in brown, black or white and in three lengths, 30, 34 & 38 inches. \$8.10 pair**

**PattersonMedical.com**

**Or call 866.402.8720**

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### Hair Dryer Holder



**Hands Free Hairdryer Holder by Jumbl Includes 3 suction cups to hold your hair-dryer securely to mirror, tile, smooth door or other non porous surface. \$9.99**

**smileAmazon.com**

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**Sign up for [SmileAmazon.com](http://SmileAmazon.com).**

**When you sign up (it's free), choose Myositis Association of America as your charity and every time you shop SmileAmazon.com, some profit will go to the Myositis Association to help fight Myositis.**





## Helpful Information and Websites

### Patient Assistance Programs for help with the costs of Medicines, health insurance premiums or copayments:

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#### Needy Meds

**NeedyMeds.org** Help with cost of medications , Drug discount Card  
Dr Rich Sagall at 978.281.6666 or email richsagall@needymeds.org

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#### Acthar Support & Access Program (ASAP)

**Acthar.com** Provides assistance with insurance authorization and copayments for patients taking Acthar.  
888.435.2284

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#### Good Days from Chronic Disease Fund

**Patientsandpros.cdfund.org** Helps support both patients and their medical professionals in finding financial assistance. Patient information 877.968.7233

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## Caregivers

#### Well Spouse Association

**Wellspouse.org** Peer to peer support organization for spousal caregivers– husbands, wives or partners. 800.838.0879

**Caregiver Action Network** formerly National Family Caregivers Association Help for caregivers.

**Caregiveractions.org** 202.454.3970 or info@caregiveraction.org

**We now have a Breakout Session for caregivers at our meetings!!**





February 2016 Support Group Meeting Presentation

**Nutrition by Ofelia Mutia, MS, RDN, LD**

Ofelia Mutia, is a Registered Dietitian Nutritionist. She believes it is her 'mission in life to help others'. Our support group experienced her passionate, cheerful and positive personality, while we learned practical information along with details about how nutrition works in the body.

Ofelia has recently retired from working at the VA. She previously worked as a registered dietitian for people with head and neck cancers. She is now a consultant and still works with veterans.

She explained that our bodies are like our cars - we need gasoline daily as well as moderate amounts of oil, brake fluid, water etc. Complex carbohydrates are like the gas, proteins are like oil and fluids, minerals and vitamins in food are like the spark plugs, rest, exercise meditation and water are like the other components of a functioning system.

**Positive Nutritional Elements**

**Antioxidants** are natural substances or compounds in food that protect cells from the damaging effects of free radicals. **Free radicals** (see below) are byproducts of what we have eaten. They are normal unless you have too many. To keep your body balanced Ofelia suggested we get nutritional **phytochemicals** like vitamin C and A and get things like selenium and zinc from superfoods. These include all the colorful fresh unprocessed fruits and vegetables in the store!

We also need **phytoestrogens** to provide antioxidants. These would include flax seed, miso paste, soy protein, yogurt, tofu, sesame seeds, folate and tempeh. **Polyphenols** come from fruits like apples, grapes and berries, vegetables, grains and good oils like canola and extra virgin olive oil. These foods protect our bodies from developing cancer cells, from the harmful effects of UV rays of the sun and rapid aging of the cells.

**Nutrition Foes**

**Free radicals** are a natural byproduct of converting food into energy. Too many free radicals changes the transmission mechanism of nutrients in and out of cells. Antioxidants and free radicals have to maintain a balance in the body to create normal cell function. An excess can be caused by smoking, chemicals in the environment, radiation, ozone depletion, some drugs (both Rx and recreational) processed foods and stress.

**Repair Plan**

**Complex carbs** like whole wheat are good for you and necessary for nutrition. Simple carbs contain no vitamins and minerals or protein. **Proteins** from lean meat and nuts and beans produce necessary hormones (like estrogen and insulin) which help transport food into cells. They produce enzymes necessary for breaking down food for processing in the cells. **Fats** are also necessary for cell transport and essential fatty acids and suppression of hunger.

**Fiber** lowers cholesterol and blood sugar. We all need avocados, seeds, nuts of any kind, margarine, chia seeds and canola and olive oil for healthy nutrition.

**General advice**

When you change the form of food - like charcoal grilling, adding preservatives and chemicals - it also changes the chemical structure of the food. Avoid sodium and check food labels. Add ginger, turmeric and cinnamon (powdered forms are OK) to food for flavor and health. Don't watch TV while eating because your brain will not notice overeating. Check with your doctor to see if you are deficient in folate or vitamin D. Do lots of research because new things are discovered all the time and advice changes all the time. Try the National Institutes of Health website for example.

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February 2016 Support Group Meeting

**Dysphagia Advice**

Symptoms - coughing during a meal, feeling like food is stuck in the throat or chest, trouble with certain types of food (such as soft, dry, lumpy).

Advice. Even if food needs to be blended or soft make it colorful and add spices for flavor. Drink water before and during meals to hydrate the esophagus. Avoid dry food like crackers. For extra nutrition add yogurt or use a blender for vegetables and add them to soups. Mold the food into shapes (using unflavored gelatin if possible).

If you use Ensure or Boost try making a smoothie with  
1 packet Carnation Instant Breakfast

1 banana

some ginger powder

1 can of nutrition product

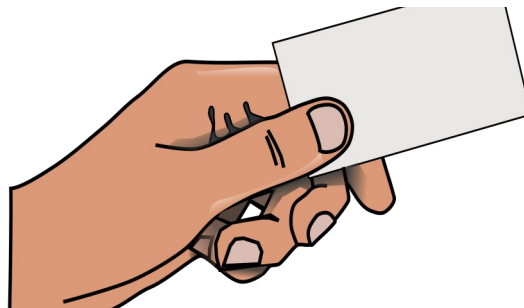
P.S. have someone else open the can of nutrition in another room if the immediate smell is too much for you

I hope those of you who were unable to attend this rescheduled meeting have gotten some of the flavor (ha ha) of this presentation. It was a happy and fruitful (did it again!) meeting. I hope the information helps keep you - mentally and physically - as healthy and hopeful as you can possibly be. One day at a time! —Pixie

**Contact Ofelia at 770.835.5954 or at ueatrite@trekfit.com**



**Doctors Business Cards**



We have started keeping a database of rheumatologists, neurologists and physical therapists. This will be especially helpful for newly diagnosed members and also for those who aren't completely satisfied with their current doctor. If you have a really good primary doctor and would like to share his or her information as well, pick up an extra business card or two and bring them to our next meeting, or email the information to Cheryle.

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## NOT TO DO LIST

1. **DO NOT say “yes” to an activity if your body is saying “no.”** You will regret it.
  
2. **DO NOT call yourself names or otherwise speak unkindly to yourself.** Never talk to you self in a manner you wouldn't use to talk to a loved one in need.
  
3. **DO NOT try a treatment just because someone said it cured him or her.** Do your research, consult with those whom you trust, and consider your pocketbook.
  
4. **DO NOT wait until the last minute to get ready for something.** When getting ready (showering and dressing for an appointment, picking up the house for visitors) try doubling the amount of time you think it will take.
  
5. **DO NOT strive for a spotless living environment.** DO NOT feel bad or criticize yourself for not striving for spotlessness. That would be engaging in unkind self-talk and it's already on your Not-To-Do list.
  
6. **DO NOT “shop ‘til you drop.** That's for healthy people.
  
7. **DO NOT wear uncomfortable clothes.** Your body is already struggling.
  
8. **DO NOT think about pleasures from your pre-illness life, freeze them in time, and assume they'd be as much fun today.** Even if you aren't sick or in pain, life is in constant flux. Among the healthy, relationships change, job conditions change, bodies change. Pleasures from the past might not bring you joy today.

--Taken from Toni Bernhard, JD, author of, 'How to be Sick'; 'How to Wake Up'; and 'How to Live with Chronic Pain and Illness, a Mindful Guide'





## New Orleans September 1st-4th, 2016

*Annual Patient Conference*

Cheryle Miller  
301 Cannon Farm Road, SW  
Oxford, GA 30054

Cheryle 678.386.2435  
Pixie 832.262.8646  
CheryleMiller@comcast.net



THE MYOSITIS ASSOCIATION

[www.myositis.org](http://www.myositis.org)



## Resilience and Recovery



Special thanks to the Volunteers who donated items for our meeting

**A big “Thank You” to:**

**John and Melissa Carel  
Pixie Allison  
and  
Veronica Gamble**

