



MYOSITIS SUPPORT GROUP *Newsletter*

Connected by Myositis and the Chesapeake Bay!

Washington, DC, Maryland, Northern Virginia, and Delaware | June 2016

NUTRITION ADVICE

Our May 7 meeting gave us an opportunity to hear Vickie Starr (RN, IgNC Vice President, Specialty Infusion Services) provided information on how to overcome the difficulty of swallowing, gave hints on getting the best nutrition, and provided advice on dealing with the insurance world. She was full of enthusiasm and really good ideas.

Vickie brought a delicious lemon chicken casserole and a tuna fish salad with bagel bites, all to reinforce the idea and importance of having moist food available for all meals. She promised us the recipe—stay tuned.

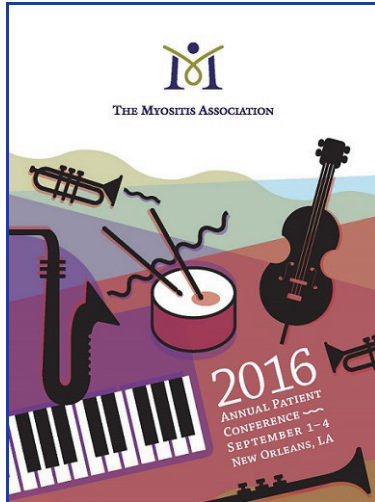
She recommended:

- **Soft foods** are easy to swallow
- **Moist foods** with fluids which will help with swallowing between bites.
- **Boost Protein** or **Ensure** drinks are high in protein (15 g) and have 26 vitamins and minerals including calcium and vitamin D and antioxidants; add to cakes, cookies, or brownies as the liquid.
- **Freeze fruit** to use in a smoothie in lieu of ice to avoid dilution. Soups and smoothies are a good way to get fluids and vegetables into your diet. Whole Foods has coconut milk popsicles (delicious).
- **Use a blender or Vitamix** to puree foods, make soups and dishes with great in-season vegetables (such as cauliflower soufflé).

- **Keep a journal of foods** to determine which ones work best.
- **Season foods with spices rich in antioxidants**, such as cinnamon, turmeric, and ginger.
- **Don't eat when you are stressed**; it creates anxiety and there is a greater chance of choking.
- **Maintain a well balanced diet.** Fruits, vegetables, whole grains, meat, fish, poultry, beans, nuts, seeds, and healthier fats.
- **Exercise.** There are many kinds of exercise you can do to remain active: laughter, yoga, tai chi, pool yoga, walking, pool exercise, yoga on YouTube.
- **Try things you like doing that make you happy.**
- **Keep a journal of medications** each day, how are you feeling, lab results, etc. Know what brand of IVIG or IGG you are taking.
- When traveling **use Travelocity to check on handicap accessible rooms** near the elevator.

Web sites that have a wealth of information:

www.myositis.org (myositis community, community forums, general discussions, IBM discussions)
www.ibmmyositis.com (Functional Rating Scale tells you where are you on the scale and provides a way to monitor progress.



2016 Annual Patient Conference

September 1–4, 2016
Hilton New Orleans Riverside
Two Poydras Street
New Orleans, LA 70130
504.561.0500

Book your room NOW!!
Group rate of \$119/night is available 8/28 through 9/7/16

TMA's Annual Patient Conference is about how to cope with myositis; how to come out of it stronger than ever; and how to find ways to lead a truly productive and satisfying life. You will hear from physicians, scientists, and other health professionals leading the charge to find better treatments for myositis. You will hear of the promising research underway now and what it may mean for those with any of the forms of myositis. And, you will hear stories of inspiration from other patients who have been in your shoes and know the challenges you are facing. Please join me in September.

May is Myositis Awareness Month

TMA is launching a 31-day campaign during the month of May to raise awareness of myositis!

Go to www.myositis.org to see how you can help.

The myositis website (www.myositis.org) also has **live discussions** on topics such as:

- Polymyositis
- Exercise for Myositis (to reduce inflammation, increase strength and flexibility)
- Lung Disease and Myositis
- Skin Care for Myositis
- Use of Prednisone

GIVEAWAY



Also disposable underwear in size small and extra large.

Call **Bitsy Anderson** at **410.987.8407** if you are interested in any of the above items.

Linda Spevack (spevack2jd@verizon.net) has the following items:

- 4 transfer/gait belts, various straps and harnesses for standing
- 2 sets of bed railings to aid getting out of bed
- 1 device to pull up to a chair to stand up
- 2 sets of silverware easy grab and hold (one never used)
- 3 easy-up cushions that can be adjusted for the user's weight
- 4 cups w/straw attached through the bottom so the cup does not have to be tilted
- Accordion shower door that pulls to one side to open the whole shower
- 2 nonelectric toilet seats (one never used, good for travel)
- 1 "tush push" electric toilet seat that can raise you to an almost standing position – best thing we ever used.

Our meetings to finish out the year are:

August 6, 12:00–3:00

November 5, 12:00–3:00

Our Lady of the Fields Catholic Church

1070 Cecil Avenue South

Millersville, MD 21146

Call Bitsy if you have any questions at 410.987.8407.



**IF YOU CAN'T FLY, RUN
IF YOU CAN'T RUN, WALK
IF YOU CAN'T WALK, CRAWL
BUT BY ALL MEANS KEEP MOVING
—Martin Luther King, Jr.**

MYOSITIS 5K



Run, Walk N' Roll

Saturday, October 15, 2016

Centennial Park, 10000 Route 108, Ellicott City, MD

Register or donate on-line at <http://getmeregistered.com/Myositis5K> or scan the QR code below!

NOTE: Register by Oct 1 to ensure T-shirt size.

8:00—Registration and packet pick-up

8:45—Welcome and warm-up activity

9:00—5K Run followed by walkers and rollers

12:00—Activities finish

Registration Fees:*

Adults—\$25.00 (\$30 after Oct 10)

Under 13—\$15.00

*A processing fee of \$2.48 will be added for online registrations.



Also available: Free massage therapy demos, silent auction, specialty information tables, instructor-led warm-up exercises, 50/50 drawing.





Please Help: Myositis is a rare, life-altering autoimmune disease that can cause muscle damage, pain, fatigue, weakness, and death. For many who suffer from the illness, it is a challenge to stand up, get out of bed, walk, or perform other simple daily activities. Some forms of the disease may also damage the skin and attack major organs of the body.

For more information please contact:

Jenny Leonard at 770.891.3966 or jennysilverb@yahoo.com

Bitsy Anderson at 410.987.8407 or terrybitsy@verizon.net

