

# THE CAROLINAS' MYOSITIS GROUP

Newsletter for May 2020

## 2020 Meeting Schedule

July 11: details TBA  
October 10: details TBA

All meetings are on a Saturday from 12:00-2:00 at Pineville Methodist Church Fellowship Hall  
110, Polk Street  
Pineville

## Online Resources:

<https://www.myositis.org/>

<https://www.myositis.org/myositis-library/tma-publications/>

<https://understandingmyositis.org/events/>

<https://www.mda.org/services/resources>

<https://www.facebook.com/groups/inclusionbodymyositis/>

<https://www.facebook.com/groups/myositissupport/>

<https://www.facebook.com/groups/1031853126906347/>

## May Online Meeting

Attendance: 20 on Zoom

Special presentation by speaker Amber Ward, MDA Occupational Therapist

Amber Ward is an Occupational Therapist at the Muscular Dystrophy Association in Charlotte, NC. Amber has a wealth of knowledge on assisting disabled patients with simple and inexpensive ideas to aid in the day to day living. Amber has experience helping patients with all forms of Myositis, ALS and other Myopathy disorders.

## On Home Management:

- If you are having a home built, be proactive on the design to have modifications built in. (walk in shower, eliminate stairs, wide door, etc....) One member on the call had an Occupational Therapist that specialized in home modifications involved with the design of the home.
- If you have a preexisting home with stairs, have a ramp installed. Ranch homes would be ideal. Also consider both exits on a home in case of a fire blocking your primary exit.
- If you struggle to bring in groceries, put them into a into a back pack that can be mounted on a power chair or rollator walker.
- Need a phone in your pocket at all times or a device around your neck for falls/assistance.
- Bathroom nightlight is useful for the middle of the night bathroom events, always keep path to bathroom clear.
- Consider doorway openings for wheelchairs, etc. Can use offset hinges (swing clear hinges). These can be purchased at Lowes or Home Depot.
- Grab bars - many different kinds not all "institutional" looking- many fit with decor in room.

- Bathing- Portable Shower System, shower seats on a track if you do not have a walk in shower that can be used over tubs, can renovate with different type of tub/shower - NC Architecture has plans, or you can use easy access showers at a YMCA; if you need more assistance for brainstorming ideas for your home, call Home Health Therapy, can save time and money.
- Toilet- Toilevator (Amazon) or raised toilet seats.
- It's important to work with your Doctor and Therapist to help you get medical devices in order so insurance will pay for it. MDA has "Closet" full of items/devices/equipment they lend out so you can try it out before you purchase.
- Beds- If your bed is too high, there are 1/2 size box springs and If your bed is too low, there are risers or can use two box springs or a combination; Randy recommends an adjustable height home bed assist handle (bed cane). A Super Pole- installs between any floor and ceiling by turning a jack screw, and the pressure created is strong enough to support up to 300 lbs. Great for near the bed to assist getting up .
- Cushions to elevate seating- For sturdy ones, look for foam or boat cushions and place something more "cushy" on top of those.
- Chores around house- great to use a rolling cart to place all your supplies on to reduce trips. i.e. putting away dishes, groceries, laundry basket. Also, putting a cafeteria tray on top of Rollator seat keeps items from rolling off. Needle-nose pliers- helps with opening packaging, buttons, zippers, etc.
- Turning over in bed— silk/satin sheets or pj's, cotton cloth strap tied to bed rails on either side with strap going across the top of the bed (under pillows) aids in rolling yourself over.
- Other tools: Grip/Strap wrenches, screwdrivers (provide leverage to open pop-tops, grip tape, Dycem (non-slip or rubbery material to help open jars or hold objects firmly, etc.
- Dog Leash- helps to close/open a door if you are in a wheelchair

### **On Leisure:**


- Many hobbies/leisure activities have adaptations so you can continue to do what you love....i.e. golf, gardening, knitting, crocheting, writing, etc. Try Googling it and see what you can find.
- Universal Cuff- helps you hold an eating utensil, toothbrush, hairbrush, pen, marker, etc.
- Driving- there is a lot of equipment available to have added to your vehicle: hand controls, spinner knob, grips attached to steering wheel, etc., etc. The first step is an outpatient OT evaluation. Then they will use the results of that and match to the equipment you would need in order to drive safely.



### **IBM Patient Video Support session, May 2020, 5 PM ET**

May 29 @ 5:00 pm - 6:30 pm EDT

Inclusion body myositis patients, join us for real-time video support, the last Friday of the month at 5 PM Eastern. Join us on May, 29, 2020, at 5 PM Eastern Time.



Telemedicine – Is it right for the Myositis Community

**May 28 4:00pm Eastern Time (US and Canada)**

Description: Join Dr. Namita Goyal, Associate Clinical Professor, Director Neuromuscular Medicine Fellowship Program, Department of Neurology, University of California Irvine, Dr. Tahseen Mozaffar, Dr. Tahseen Mozaffar, Professor of Neurology, Orthopedic Surgery and Pathology and Interim Chair of the Department of Neurology at University of California, and Dr. Lisa Christopher-Stine, Associate Professor of Medicine and Neurology and the Director of the Johns Hopkins Myositis Center for webinar on what has worked and what are the limitations of telemedicine.



### **Myositis Patient Video Support June 3, 2020 – 7 PM ET**

June 3 @ 7:00 pm - 8:30 pm EDT

Myositis patients, join us for real-time video support, the first Wednesday of each month at 7 PM Eastern. Join us on June 3, 2020, at 7 PM Eastern time.