

MAY IS



MYOSITIS AWARENESS
MONTH



THE MYOSITIS ASSOCIATION

AL, MS, FL NW KIT MAY 2019 Newsletter

*Our August KIT will
take place wherever
you happen to be on*

*August 22 from
1:00 pm – 2:00 pm*

Guest Speakers:

EACH OF YOU!

*We're going to
ZOOM*

our meeting!

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We express our sadness in sharing news of the passing earlier in the month of Charles, such a kind gentleman and conscientious caregiver to his wife Doris. They added so much to our gatherings and he will certainly be missed. We send to her and her family our condolences and prayers and hope that she finds comfort in friendships and can continue to join us.

Sacred Heart Hospital Pensacola proved to be an excellent venue for our gathering May 23 rd. Pat did an outstanding job making the arrangements for our meeting. We were on the ground level so access was very convenient and they even have Valet parking. We enjoyed lunch with a wide variety of great choices in the cafeteria and there was even a Wendy's and Subway to choose from as well. Our numbers were small with Sandra, Larry and Pat, Roy and Madge attending. Over lunch we discussed our disappointment that the hospital did not give approval for our display table in the lobby to publicize TMA and Myositis Awareness Month. We also noted the limited turn-out for the event and brainstormed how to help increase our attendance. We decided to try the ZOOM teleconference program for our next meeting. In the interim materials on TMA will be mailed to clinics and doctors' offices in our KIT area along with a letter requesting the materials be made available to all their Myositis and Necrotizing Myopathy patients. After lunch we adjourned to the meeting room a short distance away for our presentation from Dr. Dmytrenko.

Program:

Dr. George Dmytrenko, MD, PhD, Neurologist is board certified in medical neurology, electro-diagnostic medicine, clinical neurophysiology and neuromuscular medicine. After completing a doctorate in anatomy at Tulane University, he earned his medical degree from the Medical College of Pennsylvania. He completed a residency in neurology at Washington University School of Medicine, as well as electro-myographic training at Mayo Clinic and a fellowship in neuromuscular disorders at Washington University School of Medicine.

Dr. Dmytrenko held teaching positions for seven years as research instructor in neurology at Washington University School of Medicine. Dr. Dmytrenko has been in private neurologic practice in Pensacola, Florida since 1992 and is the medical director of the Sacred Heart Neuro-diagnostics Center.

During his tenure at Sacred Heart Dr. Dmytrenko said they treated patients of all ages. Infants with Hypotonia or Floppy Baby Syndrome (most often cerebral palsy or mental retardation rather than neuromuscular disorders), adolescents and adults presenting with muscle weakness, frequent falls, limited range of motion in extremities, difficulty climbing stairs, shortness of breath, etc. Diagnoses ranged from all forms of Myositis, Rheumatoid Arthritis, Lupus, Myasthenia Gravis, and Guillian-barre syndrome. Out of one hundred patients, he would have two PM patients or about one or two a month.

After his many years in practice Dr. Dmytrenko and his wife have decided to retire later this month dividing their time between their home in Pensacola and their small farm in South Carolina. We were honored that he took the time from his busy schedule, made more so by his pending retirement, to speak to us.

After Dr. Dmytrenko's remarks he took questions from us, one of which was 'How do we get our information into doctor's offices?' He advised asking for the Office Manager or Charge Nurse in primarily Neurology and Rheumatology offices to request permission to leave printed materials from TMA and our local KIT and then follow-up in a few days with a phone call to that person. We will take his advice and started with his office there at Sacred Heart. Materials were delivered to his Office Manager within minutes. 😊

He spoke highly of his replacement, Dr. Sidney Mallenbaum for those in our area seeking a Neurologist. A graduate of University of North Carolina Chapel Hill School of Medicine in 1986, Dr. Mallenbaum comes to Sacred Heart Pensacola from his practice in Roanoke, VA.

NEWS from TMA

A new analysis recently released by TMA shows that nonwhite women are twice as likely to die than white women with the disease, and they are four times more likely to die than white men with the disease. In childbearing years (ages 15-34), mortality in nonwhite women is 3.5 times higher than in Caucasian women. Because more women than men are diagnosed with polymyositis and dermatomyositis, and women of color are an underserved community that is at highest risk, we have created a *factsheet* and a patient story video as part of a special focus this year on *Women of Color and Myositis* for *Myositis Awareness Month*. Go to www.myositis.org and click on *Myositis Awareness Month*, then scroll down to *Get the Facts About Women of Color and Myositis*. Click the start button in the picture for the video and the *Download the Fact Sheet* to view the fact sheet.

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ZOOM ZOOM ZOOM ZOOM

Coming Thursday August 22nd:

We're going to ZOOM our meeting!! For those who have tried 'Facetime', it is similar but with a group rather than just two people.

Instructions for participating in a ZOOM meeting were included with the February Newsletter so hopefully you still have those on hand. However, a reminder about how to join the meeting and the specific time and login information will be sent prior to August 15th. As a reminder, the host and each participants picture will show in windows on your screen and with a 'click' you can request to speak. The host recognizes speakers individually so we do not talk over each other as in phone conference calls.

Our goal using ZOOM is to bring our wide-spread KIT together. TMA has grouped all of Alabama, all of Mississippi and the Northwest Florida Panhandle into our KIT so meeting face to face is a challenge. Let's try to overcome the obstacle of distance with a well-attended ZOOM meeting.

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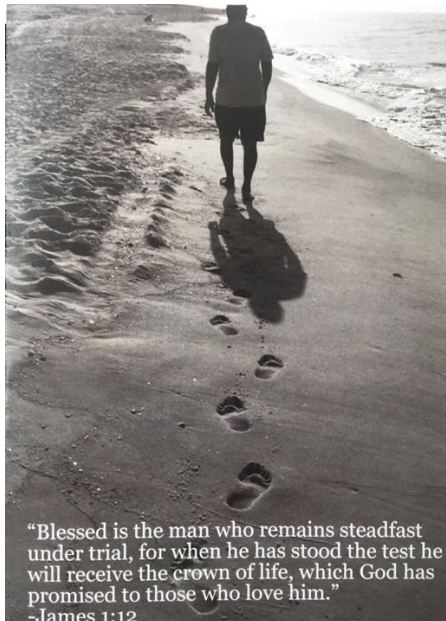
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EXERCISE, once thought to possibly be detrimental to remaining "good" muscles in Myositis patients is now heralded as one of the best things we can do for ourselves. The number of sessions about exercise at the annual TMA conferences continues

to increase to include and encourage patients with all forms of Myositis to KEEP MOVING. With this in mind the photo below illustrates how Mary, one of our KIT members refuses to give in to the progression of her diagnosis. Here she stops for a moment of silence at the **All Wars Memorial** while participating in the annual 4.4-mile *Gate to Gate Run* at Eglin Air Force Base, FL held each Memorial Day. She vows to keep ‘running’ as long as possible and says she actually runs better than walks. We admire Mary’s tenacity to Keep Moving! She is a worthy role model!



♡ In Memory of Charles ♡



Please contact me if you have any questions about our KIT, this meeting, TMA, the 2019 TMA Conference, MYO-Connect or any other subject you would like to address regarding our group.

Madge Chambers, leader

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