NorthWest Florida Panhandle KIT May 2017 Newsletter

Myositis Awareness Month

As our contribution to May is Myositis Awareness Month the NORTHWEST FLORIDA PANHANDLE KIT hosted an information table in the lobby of the Musculo-Skeletal Center of the Medical Center Clinic in Pensacola from 9:30 – 3:00, May 24th to help get the word out to the general public about Myositis. This building houses a broad spectrum of clinics and our display garnered quite a bit of iinterest from folks as they passed in and out of the building.

Undr a large “Myositis Awareness” banner a “You Are Not Alone” poster was displayed with tear-off slips about TMA as well as cards with contact information for the Northwest Florida Panhandle KIT. Available to those who stopped by were copies of **Myositis 101** and the **Physicians Guide to Myositis** as well as car magnets, bracelets and the various pamphlets about the different forms of Myositis. Pictures provided by TMA were displayed illustrating the many difficulties patients have performing simple daily tasks like brushing their hair, tying shoes, cooking and climbing stairs. While we held our meeting in a conference room downstairs from 12:00 to 1:45, a member’s spouse was kind enough to “man the table” for us.

Dr. Nancy K. Morris, MD, Internal Medicine, Rheumatology, in the Rheumatology clinic of Medical Center Clinic, 8333 N Davis Hy, Pensacola, FL was the featured guest speaker at our meeting at 1:00 p. m.

The meeting began at noon with introductions of all present, especially our newest KIT member, Tammi who was diagnosed in 2010 with DM and lives in Spanish Fort, AL. We were fortunate to have Tammi's mother and her daughter, a student at University of Alabama accompany her to our meeting. We had a total of fourteen present, six of whom had read in the Pensacola newspaper of our meeting that Dr. Morris was to be our guest speaker, so came to hear her presentation. We were delighted to see such a positive response to our news articles. We also gave a big welcome to Sandra who has been unable to make our previous meetings although she has been a member since day one. Larry and Pat provided a variety of yummy refreshments that we enjoyed during our "meeting" portion of the day so we would be ready to receive Dr. Morris at one o'clock.

For those unfamiliar with The Myositis Association and KITs, a brief description of both was given. Particulars about our Northwest Florida Panhandle KIT were explained to those potential members present. i.e. Such as our geographic challenge of covering such a large area that we presently move our quarterly meetings so that the same members are not left to drive such a long distance to **every** meeting. Since our last meeting we have added new members from Gulfport, MS, Mobile, AL, Spanish Fort (Tammi) and Fort Walton Beach and we have two others in Pensacola who are interested in joining. Our KIT now reaches over 300 miles from Gulfport to Tallahassee! We are so proud to have all these folks joining us and look forward to great things as they add their contributions to how we function and what we accomplish as a KIT. Welcome all. A plan for a meeting in August was suggested, and will be planned in detail via emails. We welcomed Dr. Morris into the group at one o'clock.

Dr. Nancy K. Morris obtained her medical degree in 1989 from Tufts University School of Medicine, Boston, Massachusetts. She completed her internship and residency training at Mary Imogene Bassett Hospital, Columbia Presbyterian Hospital Affiliate, in Cooperstown, New York, and a fellowship in Rheumatology at Bowman Gray School of Medicine, North Carolina Baptist Hospital, Winston-Salem, North Carolina. Dr. Morris is board certified in Rheumatology and Internal Medicine. She is affiliated with West Florida Hospital in Pensacola.

She began her presentation by passing out an outline of what she would cover and a copy is included with this document. As the outline illustrates, her presentation was very thorough covering Classification, Etiology, Risk Factors, Prognosis and Treatments. She stated that she had found Scleroderma and Polymyositis the toughest to treat and that although classified as an inflammatory myopathy, IBM shows minimal inflammation and is the most common myopathy in patients older than 50 years with 80% of IBM patients being 50 years old or older at onset. A few trials are in process, but there is presently no effective drug for IBM.

Although there is no cure for Myositis, treatment is initiated to reduce inflammation and prevent muscle weakness from progressing. Treatment is complicated by the rarity of this disease and the scarcity of large randomized clinical trials. Because drug companies cannot expect large financial gains by producing medications for such a small portion of the population there is little incentive for them to conduct clinical trials directed at these myopathies.

Following her presentation she took questions from the group and one answer that stood out to us is that having one of these myopathies does not predispose our children to the same result. All in attendance were extremely impressed by the knowledge illustrated in her presentation and as a patient of Dr. Morris since moving to Florida in 2014, I feel very fortunate to be under her care. I am truly grateful to her for giving her time and talents to speak to our group.

News From TMA

Since 2002 The Myositis Association began funding research into better treatments and in search of a cure for Myositis and to date has funded more than 50 research awards to deserving scientists for a total of more than **$6,000,000!! THANK YOU TMA!!!**

Look for news of an August meeting

Nancy K. Morris

Rheumatology

Medical Center Clinic

May 24, 2017

Polymyositis

Idiopathic inflammatory muscle disease

- symmetric proximal weakness
  - elevated muscle enzymes
  - characteristic EMG and muscle biopsy finding

CLASSIFICATION

1. Primary idiopathic polymyositis
2. primary idiopathic dermatomyositis
3. polymyositis or dermatomyositis associated with malignancy
4. childhood polymyositis or dermatomyositis
5. polymyositis or dermatomyositis associated with CTD
6. inclusion body myositis (IBM)
7. miscellaneous (eosinophilic myositis, (NAM necrotizing autoimmune myopathy)

Although classified as an inflammatory myopathy, IBM shows minimal inflammation and is the most common myopathy in patients >50 years old. Presents as asymmetric, distal weakness with distinctive inclusion bodies on biopsy.

Incidence in USA=0.5 per million. Blacks > whites. Females > males. Age 45-60 yo. 80% IBM patients are 50 yo or older at onset.

ETIOLOGY

- Polymyositis is an immune-mediated syndrome which can occur alone or in association with viral infections, malignancies, CTD, medications, coxsackie, hepatitis B, influenza. Adenovirus and HIV have been implicated.
- T-lymphocyte mediated process directed against muscle antigens. CD8-T-cells invade and destroy muscle fibers.
- Myositis associated antibodies are present in 20-50% of patients. These antibodies include anti PM/Scl, anti Ku, Jo-1, anti M1-2, anti SRP, anti PL12, anti PL7.

RISK FACTORS

- HLA genes A, B8, DR3
- Preceding viral infections
- Medications such as hydroxychloroquine, colchicine, hydralazine, dilantin, ACE inhibitors, statins

PROGNOSIS

Although most patients respond to treatment, residual weakness occurs in 30% of patients. Poor prognosis factors include

- advanced age
- female
- African American
- ILD
- +Jo1, +SRP antibodies
- associated malignancy
- delayed treatment
- cardiac or pulmonary involvement

PROGNOSIS continued

5 year survival rate is >80%. Long term complications are often associated with malignancy or pulmonary complications.

There is clearly reason to be hopeful with regard to treatment options as clinical trials evolve and additional, more specific treatment options become available.

TREATMENT

Although there is no cure, treatment is initiated to reduce inflammation and prevent muscle weakness from progressing.

- corticosteroids
- anti inflammatories
- immunosuppressants (MTX, Imuran, CellCept, Arava)
- IVIG
- Rituximab (B-lymphocyte directed therapy)
- anti TNF inhibitors
- Abatacept
- Alemtuzumab (anti CD 52)
- Tolcilizumab (anti IL 6)
- Anakinra (anti IL 1)
- exercise training

Refractory disease fails to repond to steroids and at least 2 other immunosuppressants.

Treatment is complicated by the rarity of this disease and the scarcity of large randomized clinical trials.

Establishment of (IMACS)

Standardized treatment response criteria has helped investigators to evaluate and compare clinical trials in a more rigorous fashion.