



August 2016



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SW Florida Myositis K.I.T.

Our Meeting, August 6, 2016

We had 35 in attendance, including two first-timers and a partner.

Highlights of our Meeting



Dr. David Sax

Our speaker was local Dermatologist, Dr. David Sax who reminded us that while those with Dermatomyositis certainly need to keep a close watch on their skin issues, the rest of us (myositis patient or not) must be careful as well. The last page of this newsletter contains the notes I took during his talk. I asked him to send me his Powerpoint slides but have not yet received them. We thank Donna DeFant for arranging for Dr. Sax to join us.

It was very satisfying to see the Sarasota Herald Tribune publish Marianne's letter to the editor about the value of support groups; our KIT and TMA in particular. As a result, two new members joined our KIT after reading about us.



Marion & Roger Marquis

We welcomed **Marion Marquis** (DM) and her husband **Roger**, and **Linda Bruns** (DM). The Marquis' live in Bradenton and Linda lives in Sarasota. I keep wondering; this is a *rare* disease?! And we can't talk about highlights without acknowledging that August is our anniversary month and you know what that meant! CAKE! We celebrated our **ninth** anniversary with some impromptu memories by our members and a lot of yummy chocolate. We've come a long way from our first meeting August 18, 2007.



Linda Bruns

TMA's 2016 Patient Conference Registration is Still Open

We hope you plan to attend the 2016 Conference in New Orleans. In case you are wondering, the flooding in LA is not in the NOLA area so you don't need to bring your water wings. But if you would like to do your good deed for the day, TMA will be collecting donations of new or gently used clothing, bedding and toys for flood victims. PLEASE do not bring food! Even in the midst of the challenges we myositis patients face, it's always a good feeling to help others who have it even worse.

Our KIT's display for the Thursday evening reception is shaping up nicely. If you have a few minutes while you're enjoying your wine and cheese, please stop by not only our table but other KITs' as well. If you see something that looks like a good idea at another KIT, make a note; we're always looking to improve!

BTW, if you attend and happen to run into Dr. Steve Ytterberg who spoke to our KIT last February, be sure to thank him. He didn't bill us for his expenses so now we have some extra cash for our next big name speaker!

If you won't be joining us in NOLA, remember that our November 5 meeting will be 'reports' by members who did attend. We'll be sharing what we saw, heard and learned. One more conference note: for the past few conferences a group of us have met for dinner usually in the conference hotel. We're not sure at this time how many of our KIT (or our friends) will be in NOLA but **Andrea Sledjeski** will post an invitation on the Conference Message board asking your interest in a Saturday dinner. If you want to join us, please sign up by noon on Saturday. The hotel's main restaurant does not take reservations but said we could call them that day with a headcount. See you then!

Keeping In Touch With Our Members...

Several members are going through some difficult times now. Please keep in touch with them through calls, e-mails, cards and prayers. Think how much a call would mean if it was you. And if you hear of someone else we should know about, please contact Marianne or Barb so we can Keep in Touch!

Jim Butler (IBM) (jbutlers@gmail.com 239-590-6878) recently received a new aortic valve. Donna reports that it was a minimally invasive procedure. He's done remarkably well and is getting stronger every day.

Tony Ungaro (IBM) (tonyhbl@aol.com 941-379-7803) has had a double challenge. In addition to some G.I. issues, his wife Cynthia has had serious lung problems. He probably won't be able to attend meetings any more but wants to *Keep in Touch*.

Patches Bryan, (IBM) (pbryan@greystonehcm.com 813-956-8838) continues to manage her IBM and pancreatic cancer. Chemo got in the way of her attending the August meeting but we're betting she'll be back in November!

Keeping In Touch, Sadly...

John Schell, (IBM) (schelljh37@comcast.net 352-314-8953) passed away in July. The contact information here is so you can call or e-mail Sherry, his wife of 57 years! She's doing as well as can be expected. His celebration of life service was on August 13 and was attended by over 150 people. Both the SW and Central Florida KITs were well represented. It truly was a beautiful occasion with many wonderful memories of a great man. Here's one quick example. His granddaughter told about several years ago when the family was planning a trip to Universal Studios. She was sad because she wanted to ride the big roller coaster and knew she did not meet the minimum height requirement. John took her by the hand; they went to the mall and he bought her two new pairs of shoes. One pair was comfy to walk around the park and one would elevate her to the minimum height to ride the coaster. Needless to say, there was a lot of laughter and a few tears as she told how this was her favorite memory of John.

Marty Kartegner (IBM) (tenmilliongirl@yahoo.com) died in June, from complications from a fall. Carol and he only attended one of our KIT meetings but they fit right in and we are sorry we didn't get to know them better.

Our KIT sends a card to the family and makes a donation to TMA when we lose one of our KIT family members. TMA now provides special envelopes with "In memory of..." in case you'd like to make an individual donation as well. Let me know if you want an envelope or contact TMA.

What *Could* Our KIT do with \$50,000?

In our last newsletter, we published an article with a similar headline. Now, three months later, we have a good chance to actually receive donations through the Sarasota Community Foundation Giving Challenge. Please read this article and then note that our social event for September will be tied into this event.

Those of us living in the Manatee/Sarasota County area have probably heard of and even participated in "Giving Partners". It is a 24 hour on-line event to raise awareness and money for local non-profits.

You will receive a separate e-mail explaining how you can help both our KIT and TMA. The 24 hours begin at noon on Tuesday September 20 and end at noon on the 21st. During that time period, we're asking you and your friends and neighbors to log on and make a donation.

Here's the amazing part. The Patterson Foundation which is huge in local philanthropy has pledged to match each dollar donated with an additional two dollars. As for where the money will go, here's the short version.

We have an agreement with TMA that any money donated this day will go directly to TMA. They are a 501 (c) 3 and we want people to know this is a legitimate non-profit fundraiser. However, when a donation is made (there is a \$25 minimum), up to \$100 will be matched by the Patterson Foundation to the tune of \$200. And that \$200 will come directly to our KIT! This means for a \$100 donation from you or someone who loves and supports you, \$100 will go to TMA and \$200 will go to our KIT. This is clearly a "win-win" for both TMA and our KIT. Here's how our KIT would like to spend it.

1. We'd like to help our members attend the 2017 conference. Generally, this means about \$1,000 per person. TMA's financial aid provides for conference registration and hotel and we'd like to do the same for some of our KIT members and their caregivers. Individuals will be responsible for transportation costs. The 'contest' will be developed and administered by a group of our KIT members. More on this to come...
2. We would like to initiate a campaign; not just in May but through the year, to raise myositis awareness in the medical community here in Southwest Florida.
3. Our meeting room is currently adequate for the group that we expect for each of our regular meetings. An exception is in February when we meet at Mixon's. In addition, if we hold another Myositis Awareness event next May, we will need money for a room, speaker, etc.
4. TMA and KIT leaders are serious about researching how to make our meetings electronically available to our home-bound members. Who knows what this may eventually cost but many of us feel it would be a very worthwhile expense!

So where can we get this money? Look for an e-mail around September 6. That's two weeks before the event. But today is NOT TOO EARLY to start thinking about where you will be and what you will be doing during those 24 hours so you can access the Giving Challenge website and donate. Also, it's not too early to start telling friends and relations to support YOU by making a donation as well. Remember the 2:1 match! And here's an invitation of where you might want to be...

Quarterly Social Event NOT on a Saturday This Time!

Some of our KIT members have expressed interest in holding an event that is not on a Saturday. Meetings, Awareness Events and Pot-Luck meals have previously been on Saturdays and that's hard for some working people or those with childcare issues. So can you guess the date for our next gathering of the KIT? ***It's Tuesday, September 20 starting at noon!*** Camille and Ray Lesoine have once again offered their lovely and very accessible home to us so we can celebrate the Giving Challenge together! And for those of us not as technically skilled as we'd like, there will be computers and tablets there to help us log on and donate. Since the Giving Challenge starts at noon on Tuesday, that's when the party starts. Bring an appetizer or other finger food to share and we'll nibble the day away! This Open House will actually be from noon till nine! This is an amazing offer from the Lesoines and it provides plenty of time for you to drop by, donate and dig in! We'll provide beverages and table settings. You bring yourself, your dish to share and a willingness to consider donating to the best cause we can imagine!

You will receive an invitation to this Open House so we have an idea of how many people to expect and about when you plan to arrive. By having this almost all day, you'll be able to come after work or an appointment or any time that suits you. Some of us will be there for the full nine hours. And while we are there, we'll be watching the Giving Challenge Leaderboard to see how donations are rolling in! Put this date on your calendar. **Tuesday, September 20 from noon to nine at the Lesoines.**

If you'd like to check out the Giving Challenge website beforehand, you may do so but remember that the Myositis and other non-profit names will not be active until a day or two before the 20th. But just by going to the site and looking at their amazing history and commitment, you will see what an extraordinary opportunity this is; for TMA and our KIT to raise myositis awareness in our community. Go to www.GivingPartnerChallenge.org,

You do not have to donate to come to this open house! Our KIT family loves any opportunity to gather together for fellowship and fun. So please plan to come to the Lesoine's on Sept 20!

Speaking of Our KIT and Our Amazing Events...

Did you read the latest version of Outlook, The Myositis Association Newsletter? There is an article about what some KITs did to celebrate and recognize Myositis Awareness in May. Our KIT (page 16) was written up very nicely. Thanks to all who helped make that day so successful.

Short Note about KIT meeting food and drink...

When we meet at the Sarasota Hospital Healthfit, we normally order lunch from Chick-fil-a. They are close, deliver for free, donate our morning coffee and are nice people to work with. We know we can't please all the people all the time but we are trying to be sensitive to needs like dysphagia, weak hands and those with food allergies like gluten or preferences against meat. Therefore, we try to provide some of everything. In addition, since soft drinks, even the sugar-free ones, aren't exactly the healthiest beverage alternative so we decided for several reasons to only offer water with lunch. It's easy to buy and bring, isn't fattening and won't rot your teeth or kill lab rats plus, it's inexpensive.

KIT Embroidered Shirts

Just a quick note: I bought some inexpensive tee and golf shirts for John and me and took them to the Red Barn. The lady there was very nice but swamped. She said it would take five days to do my six shirts.

Notes From Dr. Sax's Presentation at our KIT Meeting, August 6

He began with a review of Dermatomyositis (DM) and what may cause it. There may be a possible malignant cancer trigger (sometimes seen before the DM appears). Virus or other infectious agent can trigger excessive immune system reactions. There is often a genetic predisposition to cause DM or other auto-immune disease. There can be gene markers, and autoimmune antibodies are seen in as many as 95% of patients.

He showed many pictures of typical DM rashes on the face, chest and shoulders including purple eyelids and these are exacerbated by exposure to UV light. Gottron's Papules appear on knuckles, not fingers and are usually red and scaly. Also on the hands, cuticles are often ragged and display 'looped' blood vessels

He mentioned calcinosis cutis but said there is not much to help it. (We have members who can attest to that!) Mechanics' hands appear in 30-40% of DM patients who may also have antisynthetase syndrome

It resembles eczema on the hands, is symmetric, doesn't itch and usually affects the thumb, index and middle fingers.

Systemic issues include skin involvement without muscle weakness, Interstitial Lung Disease and complications like cardiac, arthritic, renal and GI systems affected. Malignancy can be present in 10% to 50% of patients; this is called Myositis Associated Cancer and is not caused by the DM or immune suppressant drugs. Cancers seen can include: ovarian, colon, breast, and lung. There is a new test called the *Dermatomyositis Skin Sensitivity Index* that measures the skin's level of involvement.

Treatments include: prednisone, methotrexate, imuran, IVIG and anti-TNF (Tumor Necrosis Factor) meds like remicade, enbrel, and interferon. Topical corticosteroids, plus retinoid (?) and biologics are also used.

He then talked about 'collagen vascular diseases', another skin concern Purpura or bruising can be caused by prednisone or aging. It can be mitigated by Vitamin K cream or Dermend.

Skin cancer is a big issue in Florida and for those of us who spent our youth in the sunshine. Basal cancer cells are the most common result although squamous cells are also seen. Melanoma is rarer but can be more deadly.

He reminded us of how to self-check any spots on our bodies:

A-stands for asymmetric edges of the spot

B-stands for is examining if the border of the spot is indistinct

C-reminds us that the color of a melanoma is often black and another color. Two-tone is not good.

D-if the diameter of the spot is larger than a pencil eraser it should be seen by a doctor

E- is now a concern; stands for evolving; that is, is the spot evolving or changing and if the answer is yes, have it seen.

Our members asked many questions and Dr. Sax did a great job of fielding them. He spoke for over an hour and we were grateful for his presentation. If I receive his Powerpoint slides, I will offer them to the KIT in a future newsletter or e-mail.

Note to DM patients: Ideara Pharmaceuticals is recruiting for a trial. If you are interested, go to the "explore research" section of TMA's webs

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