



SW Florida Myositis KIT Newsletter

We Care, So Come and Share!

Published Quarterly

February-March, 2011 Edition

News of what happened at our February 5, 2011 Meeting
And a Special Report about our Weekend with Fabio, March 19 and 20, 2011
Our next meeting will be Saturday, May 7, 2011 – Learn about travel challenges for Myositis patients!

KIT Meeting, Saturday, February 5, 2011

There were 60 attendees at this meeting and we welcomed first timers: Don and Linda Broughton and guests Chris Alonso, Angelica Cruz, Erin Craig and Cindy Clay.

We were honored to have a very special speaker; Andrew White who has Polymyositis and is a family counseling specialist. Andrew delivered three presentations: The Emotional Aspects of Having a Chronic Disease, The Emotional Aspects of Being Caregiver for Someone with a Chronic Disease, and Maintaining Intimacy When You Have a Chronic Disease. All three were very interesting not only to those of us with Myositis, but to our family and friends as well. Because this was our largest turnout ever, we moved from our usual meeting room to the lobby area of the Healthplex. Big thanks to all who helped us set up and remove the furniture.

The other important topic at the meeting was our upcoming weekend of fundraising events and visit from Fabio. More on that below.

The sad note to this meeting is that we shared that our KIT lost one of our dearest members, Jean Fleming who died just a week before the meeting. In addition, Dolly Souder passed on in December. Both ladies had IBM.

Up, Up and Away at our May 7 Meeting

Does your summer include plans to travel? Are you flying, driving or cruising? Are you ready to deal with locales that don't understand what travelers with disabilities have to face? Regardless of your answers to these questions, there will probably be something of interest for Myositis patients and their traveling companions at our May meeting. We will have a panel discussion with several of our members who have recently experienced some challenges abroad, and a travel agent who will provide tips to handle these issues. Please join us as we armchair explore! As always, friends and relatives are welcome to join us.

March 19 and 20—Parties and Poker Run Weekend

What a weekend this was! Let's get right to the bottom lines. It was fun! It was a success!

Saturday the 19th we hosted a cocktail party at the Gulf Drive Chickee Hut on Bradenton Beach. While turnout was less than we expected, we still had a lively crowd. Of course our special guest, Fabio, made the evening memorable for all. He is a true gentleman who posed for dozens of pictures taken by local photographer Jack Elka and of course, dozens of camera phones.

Saturday the 19th five lucky ladies joined Fabio for a special dinner at the Beach Bistro. Between the five of them, they contributed \$1,250 to our fundraising efforts.

Sunday the 20th was our motorcycle poker run. About 70 riders and drivers participated. Fabio rode a motorcycle donated by Rossiter's Harley Davidson. There were photo ops with Fabio on a motorcycle, taken by our very own KIT members, Camille and Ray Lesoine.

Sunday the 20th at Popi's III in north Palmetto the ride ended with a barbecue attended by over 100 riders, KIT members and friends. The silent and Chinese auctions and live music by Marc Anthony Roman made it a festive and fun afternoon. At the barbecue we drew the winning raffle ticket for the beautiful gold and diamond pin that was donated by Suncoast Gem Labs. (The raffle raised over \$1,800).

And here's the big news of how successful we were. Checks are still coming in (that's good news) but so far our net for the weekend was just over \$12,200. Add to that the pledge from an anonymous donor, for a matching \$10,000 and financially we were certainly a success. (The \$12,200 will be split 50% to TMA's general programs and 50% to general research. The matching \$10,000 will be restricted to IBM research only).

Here's another major success...before the events, we were featured in articles in The Bradenton Herald, The Herald Tribune and The Islander. After the events, each of these three publications also ran stories about what occurred and in addition, we were featured in stories on both local cable channels. Of course the main reason we got the publicity was Fabio. But the result was that thousands of people who had previously never heard of Myositis or TMA, now have! It's kind of like that ad on TV: Our net for the events: \$22,200. Awareness raised: Priceless!

For those who don't know, Fabio approached TMA in 2006 to volunteer to help us raise funds and awareness. His father's best friend has Myositis. As a result Fabio has been very generous in his efforts to support TMA. We are very grateful to him for coming to Florida to help us; we could not have done it without him!

There are so many people to thank. The committee of five ladies; Bonner, Donna, Barb, Rose and Marianne are grateful to all our KIT members and friends who volunteered to help at one or more events. Then there are all the family members and friends who either contributed or bought raffle tickets or auction items. And to everyone who attended, we hope you had a good time, enjoyed meeting Fabio and will remember the events.

Now that the dust has settled, and the thank yous have been offered, it's time to document the promise we made to a few members. That is that this concludes our one and only fundraising effort for 2011. We've said it before but it bears repeating. Our KIT is NOT just about fundraising. We are "about" what the tagline of our logo says, "We care, So Come and Share". Our support group puts the lion's share of it's energy into supporting one another, whether by attending meetings, sending cards and e-mails or making calls. We do this just to Keep In Touch and that is why our KIT is so successful. By any measure, our success is a reflection of our people and how we support each other. Our fundraising efforts have been an off-shoot of our caring. In the three and a half years of our existence, we've raised almost \$50,000. Much of this was sent to TMA and restricted to use in research. This is because we all want to see answers to our questions about these diseases. The rest of our donations went directly to TMA for their programs and services to members. We did this because of what TMA does to support us; like maintaining their website which brings us new members and holding their annual patient conference. This conference brings together hundreds of people from all over the world. So I hope you agree that raising this money is the least we can do to live our tag-line. Thank you all for your support and caring. Love from Marianne.

**We hope to see you May 7. The e-mail invitation will be coming out soon.
If you are one of our 'Snowbird' members, travel safely as you head north and we'll see you in the fall!**