

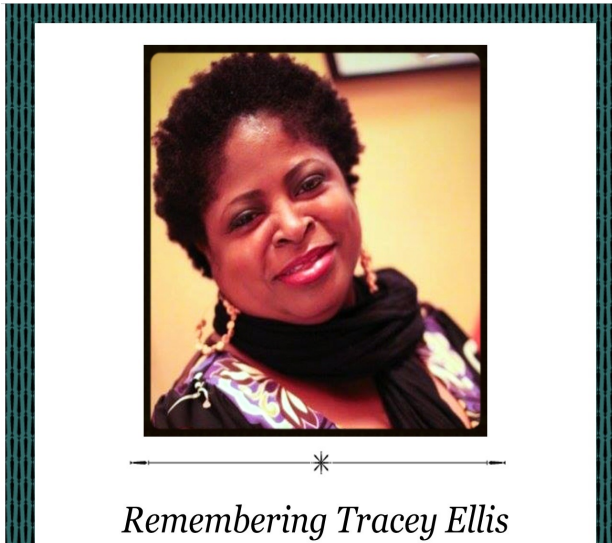


Myositis Newsletter



THE MYOSITIS ASSOCIATION

North Georgia / Atlanta Support Group



Remembering Tracey Ellis

This issue is dedicated to

Tracey Elaine Ellis

June 16, 1966 - May 21, 2015

With her diagnosis of Polymyositis with Anti-Synthetase Syndrome in May 2014, Tracey was a relatively new member to our group. She had a warm, friendly personality and positive attitude and to those of us who got to know her, will miss her immensely.

Tracey's doctors sent her to Alabama for a lung transplant, but due to complications, it just wasn't meant to be. Tracey's funeral on May 30 was a true celebration of her life.

She's breathing easy now....

Rest In Peace, Tracey.

2015
Remaining
Meeting Dates

August 8
November 14

Volume 15, Issue 2

Summer
2015

Welcome New Members

We had 3 new members attend in May

Fran Memberg, IBM

Walter Hutchins, PM

Judith Sandy-Samuel, whose niece,
Melissa, in Trinidad has PM

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Next Meeting August 8th -10:30am 'til 2:30pm

Two Presentations!

Since we hold only 4 meetings a year and some members travel from as far away as Augusta and Haysville, NC, we really want to pack as much value as possible into each meeting day. Whenever possible, we will offer two speakers, with two separate topics. One will present prior to lunch and one just after. The length of our meeting time has been expanded so that we will still have plenty of time for our breakout sessions.

Our first presenter will be **Jessica Frye, RN** of **Soleo Health**, a company that offers specialty infusion, specialty pharmacy and dedicated nursing services. Our second presenter will be **Donyetta Green** of **FODAC (Friends Of Disabled Adults and Children)** FODAC provides durable Medical equipment such as wheelchairs at little to no cost to the disabled.

Soleo Health is generously providing lunch. YOU MUST RSVP!!

to ensure we have enough food for everyone, we will need an accurate headcount.

To RSVP call or email Cheryle at 678.386.2435 or email: CheryleMiller@comcast.net by **August 5th**

More details will follow. Hope to see you there....

Doctors Business Cards

We have started keeping a database of rheumatologists, neurologists and physical therapists in our area. This will be especially helpful for newly diagnosed members and also for those who aren't completely satisfied with their current doctor. If you have a really good primary doctor and would like to share his or her information as well, pick up an extra business card or two and bring them to our next meeting.

2015 Annual Patient Conference September 10-13, Orlando, Florida

The Annual Patient Conference is being held once again in Orlando, Florida. If you have not been to the conference before, it is an enriching, educational experience. Enriching in the opportunity to meet and become friends with other myositis patients from all over the US. Additionally, there will be 85 educational sessions, many of them presented by members of **TMA's Medical Advisory Board**, covering many topics, to educate us on life with myositis, medications and treatments. The Medical Advisory Board will also report on research trials as well as information on new, upcoming trials.

Hotel: There are a limited number of rooms at the **Caribe Royale** at TMA's Group Room Rate is \$109 per night. **Conference Fees:** Registration **By August 9** \$195pp, **After August 9th** \$245pp .

For more information go to: www.myositis.org





Book Review:

You Bet Your Life! *The 10 Mistakes Every Patient Makes* by Trisha Torrey

This book is a guide for patients to take charge of their own healthcare. It gives a no-nonsense approach on how to become an empowered patient and teaches you how to bypass common mistakes that most patients make. It explains how the medical system works, what rights you have as a patient and helps you achieve safe, quality healthcare. The 10 mistakes are:

1. Thinking Your Healthcare is Focused on You, the Patient
2. Thinking Doctors Put Their Patients' Needs First
3. Not Confirming Your Diagnosis
4. Thinking You've Been Told About All Your Treatment Options
5. Thinking You Are Safe in the Hands of the Healthcare System
6. Not understanding the Reach or Risk of Medical Records
7. Spending Time in the Hospital Unless It's Absolutely Necessary
8. Using the Internet Without a Compass to Find Health Information
9. Believing All Medical Researchers are Searching For Cures
10. Letting the Media Determine Your Medical Choices.

Check this book out at your local library or purchase for \$15.00 at SmileAmazon.com, to find out the solutions Ms Torrey has for the 10 mistakes. It makes a good reference book to have on hand.

Products that Benefit

FUELGRIP

Fuelgrip is a universal fuel pump trigger clip that allows you to fill your vehicle without holding the trigger down. It slides easily over the trigger once fuel is flowing; you can store it around the fuel cap under the fuel cap cover. In the unlikely even of overfill, the fuelgrip is designed to be released immediately from the handle by simply pushing it and it will spring off. \$3.00 for one and three for \$7.00, plus \$5.90 shipping.

For more information, www.fuelgrip.com/buy-now-usa/4588327286



FISKAR'S PREMIER No. 8 EASY ACTION SCISSORS

Winner of the Arthritis Foundation's Ease-of Use Commendation and a perfect choice for people with limited hand strength. A spring -action design opens the blades after each cut, greatly reducing the effort needed for this basic motion. An ergonomically sculpted handle with Softgrip provides excellent control and comfort. Fiskar's has 11 models of Easy Action scissors to choose from. The one pictured, No.8, is priced at \$22.99 plus tax and shipping.

For more information, www2fiskars.com and type Easy Action Bent Scissors in the search





Myositis Awareness Day to become Myositis Awareness Month in 2016

September 20, 2015 will be the final Myositis Awareness Day. Starting May 2016, we will instead hold a Myositis Awareness Month. This will alleviate the conflict of dates with the Annual Patient Conference that sometimes occurs, and will give us the entire month to choose a date from, so that we can help promote awareness. Please share any ideas you may have, on how we can promote awareness in our community.

At the last meeting, we voted to hold a **Picnic in May 2016**. We need volunteers to form a small committee to organize the picnic. If interested, please contact Cheryle 678.386.2435.

On September 20 this year, the **San Francisco Giants** will hold a home plate ceremony to honor Giants Commentator, **Mike Krukow**, who has IBM.

Planned Giving

An good way to help fight Myositis for the future of our children and their children, is with Planned Giving. Read about it on TMA's website www.myositis.org On the Toolbar, go to Get Involved, then drop down to Planned Giving. There are several different methods to donate to support TMA upon ones demise. There are samples of gift language for your will or trust and there is also a sample codicil form that you can download. One form that would be particularly useful to have is **25 Estate Documents You Need To Put In One Place**.

Meet and Greet in Tifton, GA

Monday, July 27th at 10:30am at Mi-Lady Bakery

(see www.miladybakery.com for lunch menu-Dutch treat)

One of our members, **Sharon Moorman**, is starting a Meet and Greet get-together for those who live far south of Atlanta. If you live close to Tifton and would like to attend, Call Sharon at 912.381.8684 or email her: SharonMoorman@windstream.net

For now it will be a Meet and Greet, but hopefully someday as it grows, there will be enough members to become a much needed, second support group in Georgia.

Kudos to Sharon for reaching out and organizing this event!!!

Friendship is born at that moment when one
person says to another:

What! You too?

I thought I was the only one!

~ C.S. Lewis



North Georgia / Atlanta Support Group

Cheryle Miller
301 Cannon Farm Road
Oxford, GA 30054
CheryleMiller@comcast.net
Your Address Line 4

Questions on myositis?
Cheryle 678.386.2435
or
Pixie 832.262.8646



THE MYOSITIS ASSOCIATION

www.myositis.org



What to Expect, Traveling with Disabilities

The Transportation Security Administration, "TSA" as we know it, has answers and assistance for many of the questions that may arise when you are planning your trip. A help line , **TSA Cares 855.787.2227** is available Mon –Fri 8am –11pm, Weekends 9am-8pm. They suggest that you call at least 72 hours prior to your trip. You may request a **Passenger Support Specialist** to discuss your disability and explain to you how you will be screened.

www.TSA.gov/traveler-information/travelers-disabilities-and-medical-conditions

This part of the website gives specific information such as:

- ~What to expect with Ports, Catheters or other Medical Devices
- ~Have difficulty Walking or Standing
- ~Have difficulty Waiting in Line
- ~Uses Wheelchair or Scooter
- ~Cannot Remove Shoes

If you are traveling this summer, Bon Voyage!

Be an Ambassadors

Volunteer as a TMA Ambassador to reach out to individuals who are unable to attend a support group, either because there is no support group near to them or they are in such poor health that they cannot attend. Most people would love to get to know someone with their particular form of myositis. You choose if you want to be available to them by phone, email or both. If interested, call Charlia at 800.821.7356

Sometimes the best thing you can do is

not think,

not wonder,

not imagine,

not obsess.

Just breathe,

and have faith that everything will workout for the best.

