



Myositis Newsletter



THE MYOSITIS ASSOCIATION

Georgia Myositis Support Group Newsletter

Volume 19, Issue 1

~Next Meeting~

February 9th, 2019

Please note: **DIFFERENT TIME!!!!**

Gwinnett Library, Five Forks Branch

2780 Five Forks Trickum Road, SW

Lawrenceville, GA 30044

1:30pm-400pm

We are meeting after lunch.

Reservations are a must!

Have questions? Call 678.386.2435

or email CheryleMiller@comcast.net

Reservations form will be emailed by February 1st

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|          |
|----------|
| 2019     |
| Meetings |
| February |
| April    |
| July     |
| October  |

**New Members**

**In November**

Andrea Harris

Renee Brown

Mike & Dianne Paul

~

Welcome, y'all!

### *Our Agenda*

*1:30 pm Welcome & Update*

*2:00 pm Speaker (TBA)*

*3:00pm-4:00pm Breakout Sessions*



#### Inside this issue:

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## Gary Fischer

was the raffle winner of the

## fitbit flex 2

*Congratulations, Gary!*

Many thanks to those who bought raffle tickets to support our group.

We earned \$105!!!

Plus a huge thank you to Gail Edwards, who made the raffle possible.

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# Rare Disease Day

## Thursday, February 28, 2019

Rare Disease Day is an observance held on the last day of February to raise awareness for rare diseases and improve access to treatment and medical representation for individuals with rare diseases and their families.

TMA will be participating in Rare Disease Week on Capitol Hill Feb 24th-Feb28th. For more information: [www.Myositis.org](http://www.Myositis.org)

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## Products That Benefit / Ladies Edition

Ladies, Do you have difficulty getting up  
from a low toilet seat?  
Pee Standing Up!

### Venus to Mars Silicone Urination Device

A Portable Female Urinal that lets you pee standing up. Reusable womans pee funnel, for travel, camping and outdoor activities.

\$11.45 at [Amazon.com](https://www.amazon.com)



### Venus by Sanigirl Disposable Sanitary Funnels

Package of 10

**\$8.99 Amazon.com**



- SaniGirl Sanitary Funnels (Female Urination Devices) are disposable & recyclable.
- Comes in a sleek re-closable 10 pack. Ready to just pop open. Convenient, simple & easy to use.
- Great unique ergo design that prevents splashing & backflow & enables a better seal against skin.
- Quality paperboard with a water repellent & leakproof barrier. No overflow. No mess. You Stay Clean  
Compact and can easily fold & fit in a pocket. Flat & discreet. Fits anywhere.





## Prepare for the unexpected ...A Hospital Ready Bag

Soon after my diagnosis of polymyositis, an ER visit turned into a hospital stay. After being up all night with me, Frank went home to shower and gather up a few items for me. After *numerous* phone calls of, “I can’t find it, what drawer did you say it’s in?” I quickly realized that I needed to keep a bag filled and ready with items to help make my hospital stay more pleasant and to keep Frank from having to repeat his scavenger hunt for each hospital visit. My Hospital Bag has served me well for over 12 years.

I use an old Caboodle makeup box that I keep ready to go on a shelf in my closet. In the first photo you can see I have a note stuck to the top for anything I need to throw in at the last minute.

The bottom photo shows how my box opens like a tacklebox and even has a mirror on top. I have filled it with things I may need during my stay. In addition to my normal toiletries, I also keep earplugs and an eye mask to block out the sounds and lights. Other items you might want to include are: eyedrops, eyeglass wipes, chapstick. I keep a puzzle book for sleepless nights and a set of earphones, so I can listen to music on my phone. I also keep a small photo of my granddaughter.

You can customize your box with things that make your stay more comfortable.

Amazon sells new Caboodle boxes, but you could also get one second hand from ebay or a thrift shop.

I hope I don’t need mine again for a long time, but at least it’s ready to go.

~Cheryle



*Pixies's Perspective*

**Scott Morrison of Brightstar Care**  
Support Group Meeting Nov 10, 2018

I start by listing some important sites, so that you won't have to read through the text again later to find them. My advice to you is, keep the list somewhere and use the links when needed.

[www.naipcatlanta.org](http://www.naipcatlanta.org) – Greater Atlanta Chapter of National Aging in Place Council Information to assist you to confidently stay in your own home for as long as you choose

[www.ageinplace.org](http://www.ageinplace.org) – Tools to help you plan to stay in your home.

[www.brightstarcare.com](http://www.brightstarcare.com) - private home care and medical staffing. Scott Is President and owner at one of the locations near Atlanta

[www.myphr.com](http://www.myphr.com) - Personal Health Care Record form to give to doctors at appointments and at hospitals, have copies available for relatives!

[www.stopfalls.com](http://www.stopfalls.com) - advice for home modification

[www.aging.georgia.gov](http://www.aging.georgia.gov) - Department of Human Services, Division of Aging Services

[www.georgialegalaid.org](http://www.georgialegalaid.org) - free and low cost aid, information on Georgia Advance Directive for Healthcare - It now replaces any living will.

[www.healthcare.gov](http://www.healthcare.gov) - information about preventive health services and health plans. ADL's – "Activities of Daily Living", dressing, eating etc, things that need physically touching the patient.  
IADL's – "Instrumentals Activities of Daily Living"; household chores and tasks like driving.

[www.affordablemedicareolutions.com](http://www.affordablemedicareolutions.com) – An Insurance Broker that can evaluate your insurance plans and options. 770.945.5261

[www.gatfl.gatech.edu](http://www.gatfl.gatech.edu) - Tools for Life, Georgia Tech has some 9,000 assistive devices which they can loan out for no or minimal charge including phone apps, also some at Cobb Senior Center

[www.fodac.org](http://www.fodac.org)-Friends of Disabled Adults and Children – Located in Tucker, they have a huge depository of Assistive Devices. No Cost/Low Cost Wheelchairs and Medical Equipment. They accept donated items for their thrift store and there is a small museum too!

The amazing amount of information included in these sites, along with the wonderfully useful information provided by Scott, does not have to be absorbed all at once. Each one of us is at a different stage or level of need now and may transition to other stages in the future. The important message is that there are compassionate, caring and knowledgeable people in organizations all around us who will respond if we know where to look. The sites are free, most of the advice is free and even some equipment can be found refurbished or loaned out. There is a checklist you can download from the NAIPC site above to help with planning and organizing.



Pixies Perspective, continued

**PLANNING FOR THE FUTURE**

**Finances** - your health insurance does not pay for ADLs, only therapies like wound care or post surgical care for a set number of visits. Medicaid has some different rules (and your assets must be less than \$2000 per month income). (if your assets are in a trust, they can't be touched after 5 years) Please check with a lawyer who specializes in elder care. Veterans have complex rules which are different. There are benefits for veteran and spouse whose income is low enough to qualify.

**Preventive healthcare** - considerations - checkups, including eyes; what are you eligible for with your insurance? Scott is also a Certified Senior Advisor - there may be others in your area Have your doc check your medication list often; get the new Shingrix vaccine for shingles; live close to medical care facilities and stores.

**Preparation**

Print copies of your Personal Health Care Record for every appointment and for relatives; have a hospital bag packed for personal needs (book, sleep mask, hand cream...) Include an updated list of your Doctors and their specialties and phone numbers.

Let relatives know what your end of life plans are. Doctor's orders are often needed for a DNR (Do Not Resuscitate) order but your family will be comfortable knowing that is your wish.

Evaluate your driving skills, check out adult daycare options, stay active and social

Have a check-in-system in place - example - a daily call or neighbors see your porch light turn on each night.

**Safety Deposit Box** If you keep your or a relative's important papers in a safety deposit box be sure to keep an authorization for access or a copy of the Durable Power of Attorney or POLST at home somewhere safe, as well as a copy the Healthcare Advanced Directive (Five Wishes).

**Home modifications** - get an evaluation with a certified senior home modification specialist,

Use latest technology to alert for falls etc, check with Tools For Life on the list at the top.

Have good lighting everywhere

**Companion care**, such as what is offered by **BrightStar** is personal care and skilled nursing (the highest level of care) all over metro Atlanta. Georgia requires only a local background check but Scott includes National checks for his employees. This company is also Joint Commission Certified, just like hospitals are for rules and regulation. Brightstar has a 'competency lab' setup to test potential hires for knowledge about every type of care from bed lifts to oxygen and injections. No one gets to even get a chance for the testing if Scott determines the person does not wash his or her hands properly! They also must have at least a year's experience as a certified nursing assistant. Employees are bonded and insured and have worker compensation coverage. Clients are also guaranteed a 'compatible' caregiver so you can choose another if desired - for example Scott asks what a client's favorite foods and activities are to make a good match.

Please forgive the lack of paragraphs - I wanted to include as much of Scott's experience, expertise and wisdom as I possibly could. Scott Morrison is a wonderful resource and we are so very lucky Cheryle knows him and has managed to find a time in his schedule that matched our support group meeting. You can reach Scott at 770.542.9544 or email him at [scott.morrison@brightstarcare.com](mailto:scott.morrison@brightstarcare.com)

~Pixie



Support Group Newsletter

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THE MYOSITIS ASSOCIATION

[www.myositis.org](http://www.myositis.org)



*“Toughness  
is in the soul  
and the spirit  
Not in muscles.”*

*Alex Karras*



A note from Cheryle

I'm sorry about the change in our meeting time for the February meeting. I had hoped that by switching between the two library locations that we would be able to secure the dates and times that we need, but availability is often very scarce. Added to that, the difficulty sometimes of securing and coordinating speakers with our limited dates, is a bit frustrating. Please bear with me. I will continue to do the best I can, for all of us.

I think we all will be very happy later this year, to move our meetings to our permanent home at Covenant Presbyterian.

A Happy New Year to all ~ Cheryle

