Greetings from the Emory ALS Center Team,

It was a busy winter! We have several new trials and studies happening as we work toward figuring out this disease and how to stop it. We also enjoyed fundraisers that were festive and fun - we are grateful and honored to receive your gifts from events and donations. Make sure to read about the Roswell Ball and Raise a Glass to Kick ALS’s A$$.

In just a couple of weeks runners and walkers will hit the Big Creek Greenway in Cumming, GA for the 10th annual road race which benefits our center. There is still time to sign up for the FIESTA 5k/15k Challenge! Also check out the other upcoming events - some new challenges to step outside of your comfort zone. Please share with your friends and family.

Our research section has an article written by Dr. Fournier that answers some often asked questions about trials.

CONGRATULATIONS to Jane Bordeau, RN from our clinical research team for her nomination to this year’s Atlanta Journal Constitution Celebrating Nurses award. What a huge honor!

As always, our website and Facebook page are great ways to stay connected.

The 10th annual FIESTA 5k/15k Challenge for ALS will take place NEXT WEEK, on Saturday, April 30th.

Join us at Fowler Park in Cumming as runners and walkers hit the Big Creek Greenway for ALS.

There is still time to register to run, walk, sponsor, volunteer, or create a fundraising team. All proceeds benefit our center.
Why Participate in a Research Study that Does Not Offer any Treatment?
By Christina Fournier, MD

Several research studies taking place at Emory do not involve specific ALS treatments for the study participants. ALS patients who enroll in these studies provide information about themselves and their ALS symptoms and undergo clinical assessments, such as tests of muscle strength and measures of breathing. Participants also give samples of blood and sometimes other specimens including spinal fluid or a small piece of skin. These PALS do not receive any medication or treatment and therefore do not benefit directly from this type of research. However, these kinds of research studies are essential for scientists to learn more about ALS and are needed to develop a cure.

Some of these non-treatment studies are designed to discover ALS biomarkers. Biomarkers for ALS are molecules or structures in the body that can be measured as a marker of ALS disease activity. In order to develop a new drug to treat ALS, scientists need biomarkers of the ALS disease process to see if the treatment is working. Finding these kinds of biomarkers can speed up the discovery of ALS treatments by making clinical trials faster and more efficient.

Another goal is to develop individualized treatments for ALS by performing experiments directly on the cells of patients with ALS. Scientists can create stem cells from the blood or skin of ALS patients, and these stem cells can be turned into motor neurons or nerve cells. These cells can then be used for experiments to test new drugs and compounds for the treatment of ALS.

While the specifics of each non-treatment trial are different, all of these studies have the same goal of working towards finding a cure for ALS. If you are interested in participating in one or more of these studies, please contact a member of the Emory ALS team for more information.

Stay up to date at the Research & Trials page of our website.

Why Multidisciplinary Clinic?

The concept of multidisciplinary specialty clinics evolved in order to provide comprehensive coordinated care for patients with complex diseases. It can be a long day for pALS and caregivers and we are always trying to be more efficient to make your time at the clinic shorter, while also making sure that all your needs are taken care of as we provide the best clinical care. Our hope is that by coming to clinic you will be able to see many providers in one day, rather than having to schedule multiple appointments at several locations.

We are little biased but think that the Emory ALS Clinic Team is the finest you will find anywhere! The team consists of the following:
EMORY ALS CENTER STAFF

- Neurologists
- Nurse clinicians
- Clinical Research team

SUPPORTING EMORY THERAPY/REHAB EXPERTS

- Respiratory Therapy
- Physical Therapy
- Occupational Therapy
- Social Worker
- Dietician
- Speech & Language Pathologist

OTHER SUPPORT

- MDA representative
- ALSA representative
- Clinic volunteers

All patients will see: Neurologist, Attending Physician, Respiratory Therapy, Research Team Representative, Nurse, MDA, and ALSA. For some patients, once you see these each of these persons your visit will be complete. Others may need to see additional members of our clinic team.

CLICK HERE to meet the Emory ALS Center Clinic Team - make sure to go to the various provider pages listed on the left side of the page.

Planning ahead will help us be prepared to meet your needs, and hopefully shorten the time you will be there. You can help us in communicating questions, changes, and problems you are having before your scheduled appointment. It is also a good idea to bring a book or something to pass the time - of course our volunteers are also happy to visit with you as well!


The Ladies First Georgia Events will benefit Emory ALS Center

On June 11, 2016 another set of races will take place at the same location at the FIESTA 5k/15k Challenge. The 2nd annual Ladies First Half Marathon & 5k and the Ladies First Duathlon organizers have partnered with Cure for ALS and a portion of the event proceeds will be donated to our center.

Information for the Ladies First Half Marathon & 5k can be found HERE.
Make sure to use the code: ALS at check out to receive $5.00 off the entry fee and support Emory ALS Center.

MEN CAN RUN TOO so don't let the "ladies first" name fool you - Men who register will start the race a few minutes after the ladies begin.

Information for the Ladies First Duathlon is HERE.
Make sure to use the code: ALS at check
out to receive $5.00 off the entry fee and support Emory ALS Center. This is a run/bike/run race and a great opportunity to try out this type of event.

Swimmers - We have an event for you...in New York!

Swim in the Hudson River for ALS. On June 12, 2016, New York City will celebrate the second annual New Amsterdam City Swim. Jump in with and bring your family and friends to the Finish Festival. The festival includes food, drinks and live entertainment. This unique event benefits Project MinE, Emory ALS Center is the U. S. site for this program.

CLICK HERE for all information and registration.

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Winter Events Recap

On February 6, 2016 the inaugural Roswell Mardi Gras Ball - Bow Ties & Pearls was held at Country Club of Roswell. The event was hosted by Voila Salon in Roswell. CLICK HERE to read all about the great event that also honored Jan Giordano.

Voila Salon donates $29,000 to Emory ALS Center from Inaugural Roswell Mardi Gras Ball

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Raise a Glass to Kick ALS’s A$$ was held on February 19, 2016. This was the second year for the event, hosted by pALS, Becky Kidd. The event celebrated the Emory ALS Clinic Team
and the fundraising effort of the mountain bike team 5 Smooth Stones. Team 5 Smooth Stones participated in the Snake Gap Time Trial Series and another event in North Carolina, raising awareness for ALS and honoring their good friend, Becky. $4,960 was raised from the combined events. CLICK HERE to see the video presentation from the evening.

Team 5 Smooth Stones & Becky Kidd

Holly Doe and Jane Bordeaux

Kathleen Kaminski, Michelle Hammond-Susten, and Dr. Fournier
Dr. Glass pulling raffle winners

You have been included in this newsletter as a service we offer at the Emory ALS Center. You will receive our quarterly newsletter, notification of upcoming conferences, symposiums, and special events. If you prefer not to be on this list, please contact Karen Duffy to be removed. No other person on the list is able to view your address and your information will not be shared.

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