Greetings from the Emory ALS Center Team,

We have had a very busy year and it’s only April! Our team is committed to providing you with the best clinical care while also working hard in ALS research with trials and studies. In February, 2014 the Emory ALS Center hosted the Southeast ALS Alliance (sALSa). Over two days in Atlanta, 32 sALSa professionals from 12 centers and clinics across the Southeast came together to share information and discuss topics such as ALS clinic management, patient care, respiratory management, and ALS research. Attendees at the two day meeting included neurologists, nurses, clinic coordinators, and allied health professionals supporting physical and occupational therapy, and speech/language specialists. Also in attendance were representatives from MDA and the ALS Association. Read more about sALSa here.

There is a lot of information for you in this issue. In the Research News section you’ll get an update on Phase II Stem Cell Trial in ALS. Navigating insurance with ALS can be frustrating but soliciting and working with a Case Manager can help you through the process. We hope the information in How to Prepare for Next Clinic Appointment is helpful.

The financial needs at the Emory ALS Center are great in both research and clinical care. Research drives the clinic -- and the clinical care of patients drives the research. Both are necessary to solve the mysteries of the disease and discover treatments and an eventual cure. Funds are needed for clinical trials and research studies, and also for staffing, therapy, and space needs in the ALS clinic. We hope that you will participate and support the upcoming events that directly benefit our center. We need you to get involved because YOU are part of our team!
Our Phase II Clinical trial of injection of neural stem cells into the spinal cords of patients with ALS is continuing on schedule. We are now completing surgeries on the fourth of five planned treatment groups, hoping to complete this phase of the trial by mid-summer. We have expanded the trial to include patients at the University of Michigan and Massachusetts General Hospital in Boston. The ability to demonstrate that this highly technical surgical procedure can be done at institutions other than Emory is a necessary step for developing stem cell transplantation as a potential treatment for patients with ALS.

This Phase II trial calls for increasing doses of stem cell injections into the spinal cord, both the number of cells and the number of injections. There are 5 treatment groups with 3 subjects per group who will receive injections either in the cervical (neck) spinal cord (groups 1-4), or in both the cervical and lumbar (low back) spinal cord through 2 sequential surgeries. The first patient underwent stem cell transplantation at Emory in early September, and since then an additional 10 subjects have successfully been transplanted among the three sites.

We will keep this website updated as to our progress, and we are excited to be moving forward with this important project.

**THIS STUDY IS FULLY ENROLLED AND NO LONGER RECRUITING SUBJECTS.**

For more information on the Stem Cell Trial click here.

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**Do you have a private insurance plan?**

**You should ask for a case manager to be assigned!!!**

**Utilize Your Insurance Case Management System** (unfortunately, Medicare & Medicaid do not offer these services)

Seeking the assistance of an insurance Case Manager (CM, usually a nurse) will gain you an advocate to help you understand the benefits and resources that can be provided.
Most all private insurance organizations have a Case Management department. Calling the insurance company and requesting case management is the first step in the process. The CM will work with the physician to provide the care that is needed and may uncover more care options.

Educating Your Case Manager
ALS patients and families find that they are constantly "training" others about ALS. Depending on the CM experience, you may need to educate them about the concept of planning and "staying ahead of the curve". If the CM is local, ask them to do a home visit to assess the situation. Make your case by listing all the care required and take pictures if appropriate to forward to them. Make the CM feel like a part of the team.

Skilled and Unskilled Home Care - Can It Be Paid for with ALS?
As the disease progresses the hands-on care required may fulfill criteria for skilled and unskilled care. A CM may be able to approve some additional unskilled and skilled coverage. Often this will require negotiation of your insurance benefits by a cooperative CM.

Use Case Management Lingo
Case Managers are solution seekers. The CM may have the flexibility that allows them to exchange one benefit for another. Ask if the plan allows for a substitution of benefits. One example might be converting the home health or SNF benefit into skilled in-home nursing hours.

Remind them that:

1. In-home care is less expensive than in an acute hospital or nursing home admission.
2. The goal is to avoid an inpatient hospitalization, emergency room visit or an expensive or serious complication.

What is the Case Management Goal?
It is encouraged and worthwhile for the person with ALS to engage in a relationship with their insurance Case Manager since they may be able to be flexible with the existing benefits.
Multidisciplinary clinic can be a long day for pALS and caregivers. 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 and we provide the best clinical care. You can help us in communicating questions, changes, and problems you are having before your scheduled appointment.

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.

Sometime during the week prior to your ALS clinic appointment, you will be contacted by Holly or Bonita, either by phone or email. You can also call in the week of clinic at 404-778-3444. Please make sure you let them know what changes have occurred since your last visit. Let them know of any concerns or questions you have and if you need to see any of the following: Speech, PT/OT, Dietician, Augmentative Communication Rep or other equipment providers.

Planning ahead will help us be prepared to meet your needs, and hopefully shorten the time you will be there. It's 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!

Join Us for These Events Supporting the Emory ALS Center

Saturday, May 3, 2014 is the FIESTA 5k/15k Challenge for ALS.

This is the 8th year for this event that directly benefits our center. The FIESTA 5k/15k Challenge features a 15K distance for long runners, a 5K distance for casual runners and walkers, and a Fun Run. Participants will receive a t-shirt (guaranteed to those registered by April 17, 2014). All 15k finishers will receive a medal, and awards will be presented in the 15k and 5k races to Overall, Masters, and Age Group winners.

Teams of fundraisers will gather to run or walk the 5K together, raising awareness for ALS and paying tribute to their loved ones living with, or who have died from the disease. This is your chance to share your ALS story with others, ask for their help in supporting the work we do at the Emory ALS Center.

Author, Mike Stephens, will be at packet pick up on May 2, 2014 from 4pm to 7pm for a book signing of "Don's Brother: A Hike of Hope on the Appalachian Trail." After his brother was diagnosed with ALS, Mike decided to honor Don with a 2,186 mile thru-hike of the Appalachian Trail. "Don's Brother" recounts Mike's journey and much more. A portion of every book sold is being donated to the Emory ALS Center. Books will also be on sale and available for signing on race day - before and after Mike, a lifelong runner, runs the FIESTA 5k!

CLICK HERE to register.

Can't join us on race day? Make a donation HERE.
SAVE THE DATE and check our website for upcoming information about a Cornhole & Kickball for ALS Day! Fun for all, whether you come out to play, volunteer, or just to support or spectate.

Make sure to check the How You Can Help page on our website for updated details and announcements.

Honor or Memorial Giving

Charitable giving helps bring positive change to medical research and patient care. In both these venues, progress requires funding for people to generate the ideas and do the work, and for materials and equipment that are essential for accomplishing our goals. You can celebrate the life of a loved one through honorary or memorial gifts. Donations can be made online or via direct mail. CLICK HERE to make your gift today.

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.