Winter Newsletter

On behalf of everyone on our team we want to thank you for your interest and support of the first edition of the Emory ALS Center newsletter. For sixteen years we have been dedicated to performing cutting edge research while providing comprehensive care for people and families with ALS and related motor neuron diseases, and the Emory ALS Center grown to be one of the premier centers for ALS care in the United States. The ability to deliver expert clinical care in an environment rich with opportunities for clinical and basic science research is what gets me and our team up in the morning.

We hope that this newsletter will keep you informed of what is happening in the ALS community, what is happening at our center, and how you can be more involved in education, awareness, and advocacy.

Best,
Jonathan D. Glass, MD

Research Update
We will be recruiting patients in the near future for two new clinical treatment trials:

- The **BENEFIT-ALS study** is looking at a new drug named tirasemtiv. This drug is not expected to change the course of ALS, but it is hoped that it will make muscles stronger temporarily. This is a phase 2 study and lasts about 20 weeks. Some of the criteria for participation include breathing at least 60% of predicted, and the ability to swallow tablets whole. To learn more about this study, visit www.clinicaltrials.gov and search "tirasemtiv"

- A **Novel Immunosupression Intervention for the treatment of ALS** (NIP-ALS) looks at the immunosuppression component of our stem cell trial. Treatment will last for 6 months but participants will be followed closely for three months before treatment and six months after. Information will be posted at www.clinicaltrials.gov soon.

Other updates:
• The phase I trial of Stem Cells in ALS is complete. While we were hoping to start the phase II in the next few weeks, the FDA has not yet given permission to move ahead.
• Sadly, in the last few months we have learned that both the ceftriaxone study and the dexpramipexole study proved that these treatments had no effect on ALS.
• While the results of the phase II NP001 study did not show a benefit, phase II studies are not designed to prove effectiveness. A phase III study is planned but we don’t know where or when. We expect it will be later this year.

SPEECH DEVICE ADAPTATIONS OR DONATIONS

It has come to our attention that many pALS have speech communication devices they are no longer able to use, due to disease progression and changes in mobility. Often with some simple adaptations, the device can be reconfigured to be accessed in a new way, restoring communication and computer access.

Also, some pALS or family members have devices that will no longer be used. These devices can be donated. They are extremely valuable to be loaned out to pALS with no insurance or those on hospice. Donated devices are also tax deductible.

If you have a speech communication device you are having trouble using, OR if you have one no longer in use you would like to donate, please contact Steve Parker at steer@staraac.com or 678-699-7480.

ALS Health Symposium - March 2, 2013

ALS in the Homefront is a health symposium coming to Georgia on Saturday, March 2, 2013.

Mary Beth Geise, RN is the presenter of this one day, "hands-on" event for pALS and caregivers. She introduces techniques not found in books or on the internet.

Caring for a family member or friend with ALS is not a one person job - it affects the entire family. Mary Beth's mission is to help the patient and their care team better understand the erratic progression of the disease. She helps to empower caregivers with tools and resources to stay one step ahead, assuring the best quality of life for the patient while maintaining their own sense of well being.

There is no fee to register but space is limited. CLICK HERE for information on how to reserve your spot.

How You Can Support Our Center

We consider you a partner in everything we do at the Emory ALS Center and ask for your support to provide cutting edge research and excellent patient care. There are many ways to help, whether it is with your time, your money, or your passion for the cause. Donations from fundraising events or direct giving go toward projects that will help improve the health and lives of those patients served by the Emory ALS Center, and potentially ALS patients around the world.

Event Giving
Participating in or supporting Emory ALS Center events are a great way to become
an involved partner. There are two events in the spring and 100% of the proceeds from both benefit our center. Please spread the word, invite your family and friends to participate, or come join us! If you would like to host an event, we are here to help. Give us a call to discuss ways in which you can host an event and raise awareness for the Emory ALS Center.

A ROUND FOR ALS - Wednesday, March 27, 2013
Chateau Elan Golf Club, Braselton, GA
Sponsorship and player packages are available offering outstanding opportunities for a company. Presenting, Eagle, Hole, and Beverage Sponsorships are available. Playing opportunities as well as corporate recognition on literature and on tournament day are offered. CLICK HERE for more information & to register.

7TH Annual FIESTA 5k/15k & Fun Run - Saturday, May 4, 2013
Forsyth Conference Center, Cumming, GA
Start a team - Join a team - or Register yourself. Past fundraising teams have come in shirts honoring their pALS as they've walked the 5k course together. The course is wheelchair friendly so run/walk/roll and join us to Celebrate Life...Imagine a Cure at this annual fun, family event. Visit FiestaRunGA.com for all event information and start your team today!

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.