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## Summer Newsletter

July 2013

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## Greetings from the Emory ALS Center Team,

*It has already been an active summer for ALS news - conferences, summits, media - all bring attention and awareness and it is good to hear people talking about ALS. As partners of the Emory ALS Center we encourage you to become involved. Engage in learning more about the disease, attend local conference or register for an online webinar; not only does that empower you, it helps us with our important task of taking care of people and families with ALS.*

*In this issue you'll read about a new study, led by Dr. Glass and Dr. Fournier, of medications that suppress the immune system in pALS, the National ALS Registry and why it is important for every person with ALS to register. You will also read ways you can support the Emory ALS Center. Our website is a comprehensive tool for you to stay up to date. If you have not visited our site, take a look [here](#) and make a habit of checking in regularly.*

PUT THESE DATES ON YOUR CALENDAR:

September 9, 2013  
**Terance Mathis Celebrity Golf Outing for ALS**, benefiting Emory ALS Center  
 Alpharetta Athletic Club  
[CLICK HERE](#)

September 21, 2013  
**Walk to Defeat ALS**  
 Atlanta, GA  
[CLICK HERE](#)

October 5, 2013  
**4th Annual Run for Jeremy 5k**, benefiting Emory ALS Center  
 Hamilton, GA  
[CLICK HERE](#)

## Research News

### Immunosuppression Trial for ALS

Patient recruitment and enrollment is expected to begin in July of 2013 for a study of medications that suppress the immune system in patients with Amyotrophic Lateral Sclerosis (ALS). In

a recent human stem cell transplantation study, one patient had improvement in his ALS symptoms shortly after receiving a stem cell transplant into his lower spinal cord.

The improvements occurred quickly and in areas of the body that are in different regions of the body from where the stem cells were given. The time course and location of the improvement are not expected if the benefits were from the stem cells themselves. Additionally, several patients in the neural stem cell trial seem to have slow disease progression as compared to the expectation from current understanding of typical disease course. Each patient in the stem cell trial was also given medications to suppress the immune system, similar to the medications given to patients with organ transplants. It is possible that the improvements are because of the immune suppressing medications. The purpose of this trial is to test the same immune suppression medications to determine if other patients with ALS show improvements like the patient in the stem cell trial.



October 18, 2013  
**MDA Night of Hope Gala**  
 Atlanta, GA  
[CLICK HERE](#)

October 19, 2013  
**Care in the Homefront-Empowering through Education**, with Mary Beth Geise, RN  
 Athens, GA  
 Contact [Terri Partain](#) or call 706-202-4441

October 26, 2013  
**Skydive for ALS**  
 Thomaston, GA  
[CLICK HERE](#)

**ALS Association Support Groups**  
[Click here for locations & dates.](#)  
 Contact [Crystal Jackson](#)

This study is led by Dr. Jonathan Glass and Dr. Christina Fournier. All patients in this trial will receive the same immune suppression medications. Study participants will be enrolled in the study for a total of 15 months. During this time, 14 in-person visits will be required. Participants will be followed for 3 months prior to treatment, undergo 6 months of immune suppressing treatment, then continue for 6 months of post-treatment follow up. During the 15 month period, participants will be monitored for clinical, laboratory, and safety parameters. Markers of the immune system will be checked in blood and spinal fluid periodically throughout the study. All patients in this trial will receive the same immune suppression medications. These medications make the immune system less responsive and lessen a person's natural immunity that protects against infections and even cancer. All medications used in this trial have been approved by the United States Food and Drug Administration (FDA) for suppressing the immune system. However, none of these medications are approved by the FDA for treating ALS, and none of these medications have been shown to help patients with ALS.

Up to 30 volunteers with ALS will take part in this research study at approximately 3 centers across the United States. We expect to enroll about 10 study volunteers at Emory University. Stay tuned to the Emory ALS center website for study updates.

### The Emory ALS Center is happy to be the recipient of funds raised from two events coming up this fall!

The **Terance Mathis Celebrity Golf Outing for ALS** is Monday, September 9, 2013 in Alpharetta. Organizers are looking for golfers, sponsors, and volunteers. Groups of three golfers will be paired with a celebrity team captain - former NFL players and other professional athletes and Atlanta celebrities. If golf isn't your thing you can make a reservation to attend the awards reception where former NFL player, Kevin Turner will share his ALS story.



The **4th Annual Run for Jeremy 5k** is Saturday, October 5, 2013 in Hamilton, GA. This is an event we look forward to each year as it honors one of our pALS, Jeremy Williams. This year's 5k race will be electronically timed and organizers have added a 1 Mile Fun Run to the agenda.

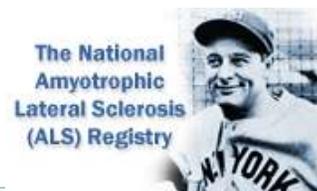


More information is available on the [events page of our website](#).

### The National ALS Registry

#### What is it?

The **National ALS Registry** is a program to collect, manage and analyze data about pALS that began enrollment in October of 2010. It was initially started after pALS lobbied congress to create a registry as a way for them to be counted. Since its inception, elements



have been created and distributed to pALS. "These segments greatly add to the power of the registry as they collect things like residential history, occupational history, physical activity history, toxic exposure history, etc. Eventually, if enough people complete these modules, we may be able to find some commonalities that are meaningful in pointing us to a cause," shares Meraida Polak, RN.



The **National ALS Registry** includes data from existing national databases and information provided by pALS who choose to participate - and that is the key - it is a voluntary program, but one that is of vital importance in helping scientists better understand who gets ALS.

#### **A valuable tool for researchers.**

The goals of the **National ALS Registry** are to determine how many new cases of ALS are identified each year in the U.S. and how many people are living with ALS at a given time. Additional objectives are to understand who has ALS, why people get it, and examine connections between ALS and other motor neuron diseases. Researchers can use ALS Registry data to look for disease pattern changes over time and try to identify any common risk factors among pALS. Information can also be used to improve care for people with ALS.

#### **Why should I register?**

Although other ALS registries exist, the National ALS Registry is the only one that attempts to identify every person with ALS in the U.S. In order for researchers to have the best information possible to discover commonality factors and connections between people with ALS, participation from every pALS is ideal.

Basic information is required when a pALS registers - age, gender, health, job, family histories, etc. Participants are not identified personally, and some fields are hidden to ensure security. Resources available through the ALS Registry are:

- Clinical trials information
- ALS clinic information
- Reports and journal articles
- Fact sheets

**If you have not already registered, please visit [www.cdc.gov/als](http://www.cdc.gov/als) today.** Your participation helps doctors and scientists trying to solve the mysteries of ALS. We hope you will be engaged in learning and participating in the process.

## **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.*

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Emory ALS Center | 101 Woodruff Circle, Suite 6000 | Atlanta | GA | 30322