Greetings from the Emory ALS Center Team,

Hopefully you were able to read our first newsletter in January. It was posted on our website and Facebook page.

You have been included in this newsletter as a new service that we are offering at the Emory ALS Center. You will receive our quarterly newsletter, notifications 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.

Spring started for us on March 27 at the A Round for ALS golf tournament at Chateau Elan. The inaugural event was a success and we are grateful to all the golfers, sponsors, and volunteers. Everyone was moved by the Silver Linings talk, presented by Phil Timp, one of our pALS from Bristol, VA. We hope to have an even larger crowd at next year's event.

May is ALS Awareness Month. There are many upcoming events, listed to the left, where you can show your support. Through this newsletter and our website, our goal is to provide regular communication, resources, and support as we partner together to Celebrate Life...Imagine a Cure.
Join us on **Saturday, May 4, 2013** at the Forsyth Conference Center in Cumming, GA for the **7th Annual FIESTA 15K/5K & Fun Run!** Cure for ALS has hosted this race since 2007 that has raised over $110,000. Our center receives 100% of the proceeds each year. The course is wheelchair friendly so run/walk/roll and join us to *Celebrate Life...Imagine a cure* at this annual fun, family event.

Online registration is open through May 2 and there is also race day registration. All event information can be found at [www.FiestaRunGA.com](http://www.FiestaRunGA.com)

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**Research News**

**Neuralstem Receives FDA Approval for Phase II Stem Cell Trial in ALS**

We have received approval from the Food and Drug Administration (FDA) to move ahead with Phase II of our stem cell trial. This phase will include increasing doses of stem cell injections into the spinal cord. The trial protocol can now be passed to the Emory Human Investigations for approval, after which we can begin enrolling patients in the trial. We will keep this website updated as to when patients may begin inquiring about participation. Thank you for your patience - we are excited to be moving forward with this important project.

[Read the entire news release here.](#)

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**Is Research Right for Me? Am I Right for Research?**

By Meraida Polak, RN, BSN

While most everyone is interested in results of research seeking causes and treatments for ALS, not everyone has the opportunity to personally participate in the process. Progress can only be made with the generosity of patients and families that choose to participate. But research is not for everyone. If the opportunity to participate in a research project arises, here are some of the things that you consider.

**There are two types of research that seek participants:**

1. Research that examines patients as they progress through the illness might include: surveys, observations over time and/or collection of blood, spinal fluid or tissue. This type of research provides no potential benefit to the participant other than the satisfaction of knowing that they helped move science forward. This may include a simple one-time donation of blood, or having blood and spinal fluid taken several times/year, or the donation of your tissue through autopsy after death.

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**Spring ALS Events**

**Tuesday, April 23, 2013 @ 7:00 PM**

**Book Signing Event**

Jimmy Carter
Presidential Library, 441 Freedom Pkwy. Atlanta 30307
2. Research with experimental treatment might be: a dietary plan, a pill, an injection, an infusion, an implant or a transplant. Treatment studies are divided into phases. Phase I studies seek to evaluate whether the treatment is harmful and if so, the treatment is abandoned. Phase II seeks to identify a hint that the treatment might work while testing to see what the best dose might be. Phase III determines if the treatment is effective. Phase IV studies look at drugs that have already been approved to learn more about the long-term risks, benefits, optimal use or to test the product in different populations of people.

Is it for me? Ask yourself:
How will I feel if my participation does not help me personally? Is it enough to know that I am helping others?

Am I prepared to accept risk and if so, how will I feel if I am harmed by my participation? All research poses a risk. Even a single donation of blood could result in bruising or discomfort. Experimental treatments have risks small and large up to even causing paralysis or death. And there are risks that no one even knows about yet! It is this participation where the risks are first identified. Continue reading the article here...

Bi-Level Ventilation/NIPPV

When the major muscle of respiration, the diaphragm, needs extra help, non-invasive positive pressure ventilation (NIPPV) is recommended. This is especially important in the reclined position. Commonly referred to by its trade name "BiPAP", NIPPV coordinates with the person's own breath pattern and increases the depth of the breath taken. A portion of the work necessary for a comfortable breath is relieved, thus providing an improvement in restful sleep and a decrease in daytime fatigue. NIPPV or bi-level (two levels) is generally worn during sleep. However, many people tolerate the machine quicker and easier if they begin wearing it during the day. Wearing the device while napping or watching a favorite TV show is often an opportune time to begin. Once a person is comfortable, they are encouraged to lengthen the time on the machine and finally to transition to nighttime use. Different masks often help make the
The new Macon group will meet on May 23 & June 27
Contact Crystal Jackson

June 15, 2013
ALS Braves Game
Turner Field

transition easier. A nasal mask or prongs for day and a full mask, if necessary, for night is often most comfortable. For severe claustrophobia, a mouthpiece may be successful for NIPPV introduction. By using the mouthpiece for very short periods of time, the patient can become acquainted with the alternating pressures of the machine and is relieved of the feeling of claustrophobia. NIPPV interfaces (masks) should not be an obstacle to wearing the device. Multiple companies manufacture a variety of masks. Patients have many options.

Link to the full Respiratory Brochure here.

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.

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.

Forward this email