HOTlanta greetings from the Emory ALS Center Team,

Summer has definitely arrived in Atlanta! As you read through this edition of our newsletter, we hope you are staying cool, whether you are in Georgia or anywhere across the country or the world. Thank you to the hundreds of people who came to run/walk, volunteer, sponsor, or donate to the 10th annual FIESTA 5k/15k Challenge. You will want to make sure to read the recap of the event and see the great pictures below. The next big event is the Terance Mathis Celebrity Golf Classic in September. Details are below and you can link to online registration and other information.

Our Research section of this issue is a recent article with the findings of the ALS stem cell transplant trial. You can always stay up to date with clinical trials and clinical research being done at Emory ALS Center by checking the Research & Trials page of our website. Our Clinic Nurse, Holly Doe, often fields questions about disability benefits - who qualifies, what is covered, how to obtain help. She's written a great article in this issue that you will want to read and print a copy to have on hand.

The ALS Association Georgia Chapter is hosting its annual Educational Symposium - Living for Today, Learning for Tomorrow - on Saturday, July 23, 2016. It is coming up quickly so make sure to CLICK HERE for all information and to register.

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

It's time to register for the 4th annual Terance Mathis Celebrity Golf Classic! We expect another sold out event so make sure to confirm sponsorship or register your group now.

The tournament will be held at St. Marlo Country Club in Duluth, GA. Groups of 3 players will be teamed with a celebrity team captain and fun contests and other
surprises will take place throughout the day.

NEW THIS YEAR - Helicopter Ball Drop!!  This is for ANYONE, whether you can come to play or not. Purchase a golf ball for $10 for the chance to win $500 - balls will be dropped from a helicopter and closest to the hole wins. Buy more than one to increase your chance of winning.

CLICK HERE for all information, to register, and to purchase helicopter ball.

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**Study Shows Risky Stem Cell Procedure for ALS May Be Done Safely**

Source: The Verge - By Alessandra Potenza on June 29, 2016

A complicated procedure for transplanting human stem cells into the spinal cord of patients with a fatal neurodegenerative disease may be done safely, new research shows. Although it’s unclear whether the stem cell treatment can actually slow down the progression of amyotrophic lateral sclerosis (ALS), or Lou Gehrig’s disease, researchers are hopeful that one day the procedure could be used to develop a new life-saving therapy.

This is not the first time that stem cells - cells that can develop into many different cell types - have been injected into the spinal cord of patients. But in today’s study, published in the journal, Neurology, researchers at three different clinical centers have injected increasing doses of stem cells in a controlled way - and have shown that patients can tolerate the procedure.

"We met our goal of proving that this is a way to safely provide this kind of therapy and now [it] can be tested in a larger trial to see if it will actually change the course of disease," says Jonathan Glass, one of the study authors and the leader of the Emory ALS Center at Emory University. "We're quite excited about it."

ALS is a fatal disorder in which motor neurons degenerate, causing patients to incrementally lose their ability to breathe and swallow, eventually leading to their death. Only one medication, called Riluzole, can slow down the progression of ALS, but it can't cure the disease. That's why stem cells are so appealing for treating the disease - they may be able to make motor neurons in the spinal cord live longer; study, neural stem cells injected into the spinal cords of rats with ALS delayed the onset of the disease and extended the rats' lifespan by 17 days. "There's a certain sense that stem cell therapies might be a way to move forward in these otherwise untreatable disorders," says Glass.

But injecting stem cells in the spinal cord is extremely dangerous. The slightest error could leave patients paralyzed and post-surgery complications can lead to death. That's why today's study focused on refining the injection procedure and assessing its safety. The fact that it was conducted at three clinical centers mean that it's teachable, and could be performed widely in the future. "Here all it takes is one error and you leave someone paralyzed from the neck down," says Jeffrey Rothstein, a professor of neurology at Johns Hopkins School of Medicine, who wasn't involved in the study. "Those safety errors can be very big."

The researchers injected the cells into the spinal cords of 15 people with ALS. The patients received between 2 million and 16 million stem cells in 10 to 40 injections, in either one or two surgeries. Two patients had serious complications, including spinal cord swelling and severe pain. Others developed side effects to the immunosuppressant medications given so that the bodies wouldn't reject the transplanted cells. But overall the procedure was found to be safe.

"It's an important step," says Lucie Bruijn, chief scientist at the ALS Association, who did not take part in the study. (Some of the study authors, however, receive funding from the ALS Association.) "Every time we do something and these people have sacrificed and taken the risk, we learn something. And in this case, what is important was to be able to increase the dosing because we don't know what dosing is going to be the correct one, and to know that it was safe to put it both in the lumbar and the cervical region."
The study cautions that the procedure was only tried on 15 patients - an incredibly small number. Most studies testing drugs for ALS and other chronic neurological diseases require from 800 to 1,200 patients, says Rothstein. The small number of patients also didn't allow the researchers to assess whether the stem cells were effective in slowing the disease. The study did not have a control group, so the researchers used three historical control groups from previous studies to see whether the treatment affected the disease at all. No changes in how ALS progressed were found. "The trial wasn't designed, and really wasn't powered, to test whether it was effective," Glass says.

However dangerous, the procedure needs to be tested further, because ALS patients are in dire need of new therapies, experts say. "ALS remains a progressive fatal disease," Holli Horak, an associate professor of neurology at University of Arizona, who did not take part in the study, wrote in an email, "so it is important to continue to explore novel treatments and therapeutics with the hope of providing relief or even a cure."

Disability Benefits In A Nutshell
By Holly Doe, RN

Please note this is a VERY general overview & available benefits are always evaluated on a case-by-case basis for each applicant.

With a diagnosis of ALS am I eligible for disability?
Yes: If you have been diagnosed with ALS you should qualify for Social Security disability benefits as ALS is considered a presumptive disability. The applicant must meet specific criteria but most PALS meet these. You do have to stop working to apply for disability benefits. You can be using short or long term disability benefits though.

Disability benefits include: Medicare & SSDI. Medicaid & SSI.
Medicare & Medicaid are social health insurance programs. SSDI & SSI are financial benefits. Medicaid is not the same as Medicare. SSI & SSDI are not the same either.

Medicare & Medicaid: the health insurance benefits:
Medicare: is a federal program that provides health coverage earlier than retirement age if you have a severe disability. You must be a qualified worker. Typically this means you have paid into the social security system for at least ten years. You likely are eligible for SSDI benefits also.

Medicaid: is a state and federal program that provides health coverage if you have a very low income. You likely are eligible for SSI benefits also.

* Note - If you are eligible for both Medicare & Medicaid, you can have both and they will provide you with very good health coverage.

The disability benefits (monthly $$):
Social Security disability insurance (SSDI, associated with Medicare qualified PALS): is typically available to any person who has paid into the Social Security system for at least ten years (qualified workers). The Medicare health insurance benefit that is associated with SSDI, has a 5 month waiting period. This starts from the date you are DEEMED disabled. This is often the date you were diagnosed with the disease. SSDI monetary benefits may be retroactive to your disability date but check with your disability contact person.

SSDI Provides Access to Medicare health insurance.

Social Security insurance (SSI, associated with Medicaid qualified PALS): is funded by general tax revenues, not by taxes taken from individual workers' paychecks. SSI has very strict financial requirements. These benefits typically are retroactive to the date you are DEEMED disabled as well, but check with your disability contact person.

SSI Beneficiaries Typically Receive Medicaid.

* Note - Typically the dependent children of recipients of SSI & SSDI are eligible for some benefits also.
PALS should also have **expedited approvals** for your disability claim. This is called a **TERI** case and should always be mentioned while you are applying.

To apply for disability benefits, call the Social Security Administration's at (800) 772-1213, online at [www.ssa.gov](http://www.ssa.gov), or visit your local Social Security office.

**Medicare eligible PALS, there are different parts you need to be aware of:**

**Very briefly:**

A= hospital insurance (free)
B= medical/outpatient insurance ($ premium)
D= pharmacy/medication, insurance ($ premium)
C= not a separate benefit, but a policy that allows private health insurance companies to provide Medicare benefits known as Medicare Advantage Plans. These are NOT supplemental plans but replace original/regular Medicare.

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**Luckily there is free help navigating this complicated system!!**

One resource is [MyGeorgiaCares.org](http://MyGeorgiaCares.org) provides resources including the state SHIP program (state health insurance assistance program) that will provide free one on one counseling & explain all of your options regarding Medicare & many other issues. They can be reached at (800) 669-8387 or online [HERE](http://HERE).

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**10th Annual FIESTA 5k/15k A Big Success**

In perfect weather conditions, over 650 participants gathered to #runLOCO4ALS at the 10th Annual **FIESTA 5k/15k Challenge** on April 30, 2016. The event, which brought runners and walkers from all across Georgia and the southeast, took place at Fowler Park in Cumming, GA and raised $36,000 for the Emory ALS Center. Eleven teams of individual fundraisers raised more then any of the previous years of the online campaign, raising $24,469 of the total funds.

The top fundraiser was **Allison Farkas**, Allison’s team, **Beat ALS for Greg**, traveled from North Carolina to run in the race and honor her dad, **Greg Hatcher**. The total raised from the Beat ALS for Greg team was $14,332.
Dr. Glass and ALS clinic volunteer, Jane Scudder

ADVA Optical Networking water station volunteers

Esther Glass and Doris Noel, mothers of Dr. Glass and Karen Duffy
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.