Greetings from the Emory ALS Center Team,

You can tell it has been a busy summer when the newsletter comes in July instead of June! Our team has been busy attending ALS meetings and conferences, working on studies and research in our laboratory, and caring for pALS in the clinic. You’ll find many pieces of information in this issue. The Research News focuses on Project MinE and the recent New Amsterdam City Swim; the patient centered article is on Government Benefits and how to navigate the process. It is time to sign up for the Terance Mathis Celebrity Golf Classic so be sure to read about the event and tell your friends to come out and play.

Last summer the ALS Ice Bucket Challenge took the world by storm. Never before had we heard ALS being talked about daily as people from all walks of life poured buckets of ice water over their heads to raise awareness and fund for ALS research. Many of you donated to the Emory ALS Center and we are grateful for your support. This is not a one-time phenomenon - as he accepted an award in May founder Pat Quinn stated, "Every August until a cure." So get your buckets ready and your technology powered to record your videos! You can post them on our Facebook page or send them to Karen Duffy so we can share them. On the left side below, next to the Research New section, is a link where you can make your donations. We need to continue to give ALS a voice so let the ice water dumping begin!

Every August Until A Cure!

Your donations from ice bucket challenges last year made a large impact on our center last year; we are so grateful. CLICK HERE to make your 2015#ALSIceBucketChallenge donation.

Research News

Project MinE is a genetic research program that aims to map the full DNA profiles of at least 15,000 people with ALS and compare them with 7,500 control subjects (people without ALS or a family history of ALS). The program originated in the Netherlands and includes researchers from 15 countries, including The United Kingdom, Portugal, Ireland, Spain and Belgium. Our center is the US site and Dr. Glass is the lead investigator in the U.S. All Emory ALS patients are invited to participate by providing a blood sample for DNA, and (optionally) a
small skin sample to create stem cells for further research. We will also be looking for "controls" who want to participate in this research.

Dr. Glass discusses Project MinE

On June 21, 2015 the New Amsterdam City Swim took place in New York City and raised over $400,000 for Project MinE! The event began three years ago in the Netherlands when 14 friends decided to participate in an ALS charity swim across the Hellespont River in Turkey. They were so inspired by the charity swim in Turkey that 5 of the 14 friends along with their partner House of Sports organized the first official "Amsterdam City Swim" on September 9, 2012 for the benefit of ALS research.

Over 1,100 swimmers jumped into the canals of Amsterdam, swimming 2km, and together raised more than $922,000! In the two subsequent years, the event has both attracted more swimmers and raised more funds for ALS, totaling more than $6 million. All of the money raised was donated to ALS research, making this the largest fundraising swim event in the Netherlands.

In 2014, the Amsterdam City Swim committed to going global and sought New York City as the first major swim host location outside the Netherlands. This US event has been named the 'New Amsterdam City Swim'. Did you know that New York used to be called "New Amsterdam" when the Dutch established the city in 1626?
Here is the story that led 400+ swimmers to #JumpIn NYC

**Photos from Shoot Out ALS**

Teams receiving instruction before heading out to the course

Waiting on results

Meraida Polak organizing set up for blood sampling for research

Who knows....maybe there will be a JumpIn swim in Georgia one day!

**Making Sense of Government Benefits**

By Holly Doe, RN

Understanding & applying for government benefits can be confusing and frustrating to say the least. We at the ALS clinic encourage all our patients to apply though. The benefits can be well worth it!

This short article is not a substitute for speaking directly with an employee of the department of social services (typically in the county where you live) but is a quick overview of what I have learned over the past few years.

The US government offers monthly payments for qualified disabled patients as well as medical insurance for qualified disabled patients. Brief descriptions below.

**Social Security Disability Insurance (SSDI)**

Social Security Disability Insurance (SSDI) provides monthly cash benefits and Medicare entitlement (aka medical insurance) to those blind or disabled individuals who have paid sufficient FICA and Medicare taxes on their earnings to meet certain insured status requirements. Spouses and children of SSDI recipients may also be eligible for cash...
benefits.

The most common reason patients get denied for these benefits is that you have not worked enough, therefore not contributed enough taxes, in the recent past, or total throughout your working career.

You cannot be actively working during the application process but I have been told you can be on FMLA (Family & Medical Leave), short or long term leave from your job.

Supplemental Security Income (SSI)
Supplemental Security Income (SSI) provides cash to meet basic needs for food, clothing and shelter to those age 65 and over, blind, or disabled who have little or no income. Individuals and their children may be eligible for SSI even if they have never worked or have an insufficient insured status for SSDI.

The income & asset threshold is very low, and that is the main reason patients don't qualify for this benefit.

Each individual who applies for SSDI (usually eligible if you have worked for 10+ years full time & paid FICA taxes) is also screened for SSI benefits. SSI payments (for lower income patients with few assets) may be available during the usual 5-month waiting period before SSDI cash benefits begin. Those eligible for SSI may also be automatically eligible for Medicaid benefits. CLICK HERE TO CONTINUE READING THE ENTIRE ARTICLE... and much more information on Medicaid and Medicare.
will be provided and there will be fun contests on the course. An awards reception will follow the round.

**CLICK HERE** for more information and to register.

Raise a Glass to Kick ALS's A$$ and the SnakeGap Time Trials raised $7,000 for Emory ALS Center

Many thanks to Becky Kidd, James Rodatus, Doug Moore & the Secret Sauce Band, and Famous Pub

Photos from the **FIESTA 5k/15k Challenge** which raised $25,000

And they're off! The Lovett Family
Karen Duffy, Dr. Glass, Meraida Polak

Margaret Pepe getting her 5k award from Brian Duffy

Jane & Mark Scudder remembering Jane's mom

Byron Grogan relaxes after winning the 15k distance race

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.