Winter Newsletter
January 2015

Happy New Year from the Emory ALS Center Team,

As we start 2015 we first want to thank you for partnering with our center in 2014 in what was a breakthrough year for ALS Awareness and support for the Emory ALS Center. The Ice Bucket Challenge campaign was unprecedented. We are grateful, as are our research partners across the country and around the world, for the generous support.

You can read more about how our center is benefiting from the ice bucket campaign in the Research News section. Please read through the article about the National ALS Registry. It is important that EVERY patient go online to become a part of the registry as this a very useful tool for researchers.

It is only January but already the calendar is getting full with events for awareness, advocacy, and fundraising. In the Events section you will see information on events directly benefiting our center. Other events are listed in the left column, and first on the list is Georgia ALS Advocacy Day at our State Capitol on Tuesday, January 27, 2015. We hope many of you will be able to come at some point during the day to share your journey with ALS and help to educate the legislators about the disease and needs of patients and caregivers.

Get involved because YOU are part of our team! Make sure to check the How You Can Help page on our website for updated details and announcements.

Research News
Atlanta Magazine, January 2015

Last summer, as millions of people worldwide posted Facebook and YouTube videos of themselves taking part in the Ice Bucket Challenge in the name of raising funds and awareness for amyotrophic lateral sclerosis, or ALS, skeptics wondered if all that social media hype would translate into something tangible.
Short answer: Yes. The challenge raised $115 million for the ALS Association, which in October announced initial grants of almost $22 million to researchers, including Jonathan Glass, who directs the Emory ALS Center.

Glass is one of the U.S. investigators for Project MinE, an international genetic research program that will receive $1 million in funds raised by the challenge. Glass, the only local researcher involved with MinE, says he’d requested funds long before anyone posted ice bucket videos. "We had put a grant into [the ALS Association] back in May, before anybody had done the Ice Bucket Challenge," he says. "It's an enormous project that requires multiple countries, multiple investigators, and it's going to be very, very expensive."

Although Glass wasn't surprised his program got the funding, he was shocked at the success of the slushy fundraiser itself. "What was wonderful was that it was grassroots. What it's done is raise awareness for a disease that is relatively rare," he says. "In terms of a campaign, it was just extraordinary. We have money; we have awareness."

Of course, Glass and his team all performed the challenge. "Even my mother did it—and she's 87 years old."

Fast facts: Project MinE

- The project is working to map the DNA profiles of 15,000 people with ALS to compare with the profiles of 7,500 control subjects.
- 13% of the profiles-2,808 to be precise-had been collected by November 2014.
- The study's objective is to identify genes..."
ALS is a different story in each person living with it. Depending on your individual needs, here is a list of who you might see at your next visit to multi-disciplinary clinic:

Dr. Glass/Dr. Fournier
Research team members
Holly Doe, RN: Clinical Nurse
Bonita Yeshurun, LPN
Dawn Burroughs, Social Worker
RT (Respiratory Therapist)
PT (Physical Therapist)
Nutritionist
Orthotist
ALSA representative
MDA representative
Volunteers

PUT THESE DATES ON YOUR CALENDAR:

January 27, 2015
**Georgia ALS Advocacy Day**
Atlanta, GA

January 30, 2015
**Raise a Glass to Kick ALS’s A**
Atlanta, GA
CLICK HERE

Feb. 7 & March 7, 2015
**Snake Gap Time Trial Series-Team 5 Smooth Stones**
Dalton, GA
CLICK HERE

April 23, 2015
**Shoot Out ALS-Clay Sport Tournament**
Newnan, GA
Check website for info

The National ALS Registry
Your participation is needed!

**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

that may influence whether someone gets ALS, when an individual gets it, how quickly it manifests, and how the disease affects the body.

- The project originated in the Netherlands and includes researchers in multiple countries, such as Portugal, Belgium, and Ireland. The name MinE comes from "mining"
- 2,500 (or 1,950 Euros) is the cost to complete one DNA sequence
May 2, 2015
9th Annual FIESTA 5k/15k Challenge
Cumming, GA
CLICK HERE

ALS Association Support Groups
Click here for locations & dates.
Contact Anita Flowers

Follow Us On Facebook

Photos from the Run for Jeremy 2014

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 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.

Upcoming Events Supporting Emory ALS Center - Mark these on your calendars!

Friday, January 30, 2015
Hosted by Becky Kidd and team 5 Smooth Stones, "Raise a Glass to Kick ALS's ASS" will be Friday, January 30, 2015 at Famous Pub on N. Druid Hills Rd. in Atlanta. Join us for a night of live music by Secret Sauce and the stand-up comedy of James Rodatus, who is living with ALS, to entertain you while we honor the Emory ALS Clinic Team. The fun begins at 6:30pm and goes until ???
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.

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**Shoot Out ALS - Thursday, April 23, 2015**

An afternoon for sportsmen and women to shoot clays and celebrate new science in the fight to cure Lou Gehrig's disease. The location is at Blalock Lakes, a private sporting club & community in Newnan, GA. The event is being **jointly hosted by ALSA and MDA** - more information will be posted on **our website** as details come together!

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**Saturday, May 2, 2015**

**REGISTRATION IS OPEN** for this 9th annual road race that has become the traditional kick off of ALS Awareness Month. You can sign up to run, walk, and/or create a fundraising team. **CLICK HERE** for information, to register, donate, or start your team today.

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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.