Greetings from the Emory ALS Center Team,

There is a lot of news in this spring issue. You'll enjoy the pictures and recap of winter fundraisers, and can choose from many upcoming events in which to participate - fundraisers supporting our center and other events focusing on ALS Advocacy. The Research News section is full of information on clinical trials and a great announcement regarding Dr. Glass. Our patient tips section shares advice about the Cough Assist. It can be an intimidating piece of equipment but with education and instruction you will have confidence if you are ready or may be needing one in the near future.

The National ALS Advocacy Day & Public Policy Conference is May 10-12, 2015 in Washington D.C. Three members of our Emory ALS Center team will be joining pALS and advocates from Georgia. If you are interested in attending you can find information HERE.

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

Congratulations to Dr. Glass!

The Northeast ALS Consortium (NEALS) is an international, independent, non-profit group of researchers who collaboratively conduct clinical research in ALS and other motor neuron diseases. Their mission is to translate scientific advances into new treatments for people with ALS and motor neuron...
Prize4Life
National ALS Registry
ALS Untangled

PUT THESE DATES ON YOUR CALENDAR:

May 2, 2015
9th Annual FIESTA 5k/15k Challenge—benefiting Emory ALS Center
Cumming, GA
CLICK HERE

May, 24, 2015
ALS-MDA ALS Awariness Day at the Braves Game
Turner Field, Atlanta, GA
CLICK HERE

June 27, 2015
ALS Educational Symposium-Living for Today/Learning for Tomorrow
Cobb Energy Centre, Atlanta
CLICK HERE

September 14, 2015
Terance Mathis Celebrity Golf Classic—benefiting Emory ALS Center
Alpharetta Athletic Club, Alpharetta, GA
CLICK HERE

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

Winter Events Raise Nearly $16,000

Prize4Life
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Reflecting on his election Dr. Glass shares, "To the NEALS community: I am excited to step up as one of the co-chairs of NEALS, helping to lead this important organization forward as we address the needs of our patients and their families. NEALS is committed to improving care and driving the search for new therapies that slow or stop the progression of ALS. My goal as co-chair is to strengthen an already very strong organization by encouraging active participation by our member NEALS centers in clinical trials and in clinical research. I will also work closely with the NEALS executive and scientific advisory boards to promote therapeutic ideas that can be developed into trials and then treatments for ALS. The science is certainly exciting, and I think we are potentially on the cusp of moving past "just Riluzole" to a new era of therapeutic interventions, reducing disability and prolonging life in our patients. NEALS will be at the center of these discoveries - we're all in this together."

Update on Clinical Trials

Stem Cell Trial:
We are in between the completion of Phase II and the next phase of the trial. The next phase will be directed at evaluating the ability of stem cell transplantation to slow the course of ALS. We hope to begin by the end of the summer, however we are not currently recruiting, nor do we know all of the eligibility criteria.

Project MinE: Project MinE is a genetic research program that aims to map the full DNA profiles of at least 15,000 people with ALS and
We send a big THANK YOU to the Marist School Basketball Program, Becky Kidd, and Mountain Biking Team-5 Smooth Stones for the funds they raised for our center! The Marist School Basketball team had a Shoot-a-Thon on January 25th. Athletes obtained pledges and donations and participated in several games for a fun afternoon of competition, fellowship, and ALS awareness. The hard work from these student athletes resulted in $9,000 raised!

On January 30 one of our patients, Becky Kidd, hosted an evening of gratitude and fun to celebrate the Emory ALS Clinic Team. Raise a Glass to Kick ALS's A$$ took place at the Famous Pub in Atlanta. Fellow pALS James Rodatus kicked off the evening with his stand-up comedy routine. Local band, Secret Sauce entertained throughout the evening and had everyone on the dance floor most of the night. There were raffle drawings for great prizes and the evening raised $4,000 for the ALS clinic.

New Amsterdam City Swim Event Raises Funds for Project MinE

The first edition of the New Amsterdam City Swim (NACS) will take place in New York City on Sunday, June 21, 2015.

This unique and impactful ALS charity swim event will take place in the Hudson River.

The 1 mile (1500 meter) swim course starts at Hudson River Park's Pier 45 in Greenwich Village and finishes at Hudson River Park's Pier 26 in Tribeca. The swim originated as a small charity swim three years ago in Amsterdam. It is now the most popular charity swim in the Netherlands. In 2014, more than 3,000 enthusiastic swimmers jumped in the Amsterdam canals and raised $2.5 million for ALS research. Whether you are a swimmer or supporter, all are welcome at the inaugural U.S. event -Jump in!

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.
Fundraisers such as these help us provide the best care for our patients and families in the clinic, and also in the laboratory where we search for causes, treatments, and cures.

Photos from Raise a Glass to Kick ALS's A**

Host, Becky Kidd welcomes the crowd.

Dr. Glass toasts the team.

Comic James Rodatus made us laugh.

CLICK HERE for more information for the New Amsterdam City Swim.

Biomarkers: This study collects biofluid samples for the banking and usage in ALS research. Through comparison of these samples, the researchers hope to learn more about the underlying cause of ALS, as well as find unique biological markers, which could be used to develop new therapies.

The Cough Assist

The cough assist is a two stage device used for both hyperinflation (a deep breath similar to a sigh or a yawn) and expectoration (strong forced exhalation simulating or supplementing a cough).

Due to weakened respiratory muscles and declining FVC (forced vital capacity) associated with ALS/MND (motor neuron disease), the patient feels the urge and desire to "take a deep breath", but is physically unable. With the help of the cough assist, the patient can expand the lungs and airways. Even though there are often no secretions expelled, the benefit of the maneuver is good pulmonary hygiene. The cough maintains clearance of secretions.

Happy by products of the cough assist treatment can be a decrease in gas, a bowel movement, or improved digestion if used prior to a meal.
The machine itself is often seen as intimidating, however, with proper instruction, for both the patient and the caregiver, the ease of use will emerge and patient compliance and appreciation will increase.

There are many tricks which have been found to make the use of the machine easier. We suggest beginning with experiencing the inspiratory phase first. Begin with lower levels of pressure, and increasing the pressure as the technique becomes easier and more natural. Second, add the expiratory phase, again, begin with lower pressures, and gradually increase the pressures as the patient and caregiver's confidence increases.

Finally, put both phases together for the big deep breath and cough. Don't forget the machine can always be used for inspiration only any time a deep breath is desired or when a more severe episode of shortness of breath is experienced.

Who Might You See at Friday Clinic?

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 multidisciplinary clinic:

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

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.

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

Shoot Out ALS - Sporting Clay Tournament - April 23, 2015
Blalock Lakes Sporting Club, Newnan, GA
Jointly hosted by ALS Association Georgia Chapter and MDA - All funds raised benefit Emory ALS Center.

CLICK HERE for information.

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Saturday, May 2, 2015

We will hit the streets in two weeks for this 9th annual race. Choose from 15k or 5k distances, or signup to do the Fun Run! Runners, walkers, wheelchairs - all are welcome and you will have a "LOCO" time. All funds raised benefit Emory ALS Center.

CLICK HERE for information, to register or donate today.

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Monday, September 14, 2015

Registration is OPEN for sponsors and players for our 3rd annual golf tournament. Hosted by former Atlanta Falcon, All-American and Pro Bowl wide receiver, Terance Mathis. Golfers in threesomes will be grouped with celebrity team captains from the NFL, MLB, and other sports from the Atlanta area. Lunch 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.

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.