

# Neuromuscular News

Volume 1, Issue II | April 2015

## IN THIS ISSUE

### Special points of interest:

- Patient spotlight!
- Research Updates
- Clinician Tips

### Share your story!

If interested in writing in our patient blog, sharing your experiences and thoughts, please contact Mona or Shara.

“Attending a Multidisciplinary care Clinics improves length and quality of life of patients with neuromuscular disease”  
**Van den Berg et al.**  
**Neurology,**  
**Oct 2005.**

## Letter from the Director

Dear Friends,

I am happy to bring you our second quarterly Newsletter. This issue contains information for caregivers, an entry from a patient, and updates in our work and continued research into Neuromuscular diseases. As always, our mission is to bring the best possible care to our patients, and to tailor this Newsletter to what you feel is area of need or interest. We hope you find this newsletter informative and entertaining, and we welcome your comments. We are continuing our efforts in clinical and basic science research here for breakthrough diagnostic and treatment options for our neuromuscular patients, with over 15 active clinical trials as well as genetic research and development. We are very excited and hopeful for the upcoming project and the future. Stay tuned!

Dale J. Lange, M.D.

[Director, Neuromuscular program at Hospital for Special Surgery](#)



## May is ALS Advocacy Month

- 2015 National ALS Advocacy Day and Public Policy Conference is Sunday May 10 — Tuesday May 12 in Washington DC.
- Please join us for LUNCH as we invite your elected officials to join you to learn more about life with ALS and discuss how current Medicare rules are effecting you. Please share your personal story and how ALS has impacted your life, while impressing upon your elected official how the Capped Rental policy is impacting your life and have further state funding will benefit all ALS patients throughout the states of New York, New Jersey and Connecticut.

If interested, please RSVP to [Holzbergs@hss.edu](mailto:Holzbergs@hss.edu). We hope to see you there .

# WHAT'S YOUR STORY?

## Patient Spotlight

by Fern Cohen

When I was first diagnosed with ALS in January of 2004, it seemed like almost nobody knew anything about the disease. Suddenly -- particularly in the last nine months -- ALS awareness has reached a level I never dreamed of. More money has been raised in the last year, than in all the years I have been an ALS warrior. In 2004, ALS was referred to as a rare "orphan disease" with no more promise of a cure or even an effective treatment, than 60+ years earlier, when Lou Gehrig gave his famous "luckiest man" speech at Yankee Stadium. Stephen Hawking, the Oxford-educated physicist was the only other celebrity I knew of, with the disease. There seemed to be a lot of ignorance about the disease, and almost no visibility. Where were the people with ALS hiding out, I wondered. I soon learned that ALS was considered a rare "orphan disease".

Most people go through their whole lives never knowing anyone with ALS. But with new advances in patient care, there are more ALS warriors surpassing the two-to-five year prognosis. Slowly, I heard about more high-profile people coming out of the shadows and talking about ALS. Talk-show host Nancy O'Dell watched her mother deal with ALS, the Baltimore Ravens' OJ Brigance got the diagnosis in 2007 and formed the "Brigance Brigade" to raise funds for ALS research. There was Steve Gleason of the New Orleans Saints and baseball player Jim "Catfish" Hunter. But still, I don't think any of us imagined what would happen in the summer of 2014.

I first heard about an ice bucket on Facebook. One of my closest friends asked in her update "Have you done the ice bucket challenge for ALS?"

I asked her "What's this ice bucket thing?" Soon, there were videos of people with icy water thrown on their heads. First, there were videos of everyday people who knew someone with ALS. Then the celebrities like Ellen Degeneres and David Spade, who raised mega-bucks for ALS

***Suddenly — particularly in the last nine months — ALS awareness has reached a level I never dreamed of.***

research. The last count topped \$100 million donated to various ALS charities.

Next, British actor Eddie Redmayne played the part of Stephen Hawking -- the most famous ALS patient alive -- in the biopic "The Theory of Everything". In his acceptance speech at the Academy Awards, he dedicated his gold statuette, in front of millions of viewers, to everyone around the world battling ALS.

Then one Saturday, I decided to check out a new FOX series everyone was talking about. I sat watching seven episodes of "Empire" on a freezing day, because the main character received a diagnosis of ALS in the second episode. I already plan to write a letter challenging the accuracy of a plot line. This is a major step: a main character of a network series, battling ALS. It's a level of awareness I never imagined would happen and it makes me optimistic that more money will pour in for research, and the path to a cure or more effective treatments, will be smoother.

**Want more??** Follow Fern on Twitter @ISitStillShutUp And read her blog "Forced to Sit Still and Shut Up" about living with ALS/MND <http://fernals.blogspot.com>

# RESEARCH NEWS

## HSS Hosts 6th Annual ALS Conference

Mona Shahbazi, NP

Together with the ALS Association, HSS held its 6th annual 3-day conference focusing on advances in Neuromuscular disease, with March 14th being dedicated to advances and care of ALS. Over 100 patients and physicians attended the conference which highlighted renowned speakers from across the country, discussing current and upcoming clinical trials including advances in Stem Cell Therapy in ALS. Conference also highlighted interactive workshops including Genetics, Trauma in ALS, Diaphragm pacing, Speech, Swallowing and Nutrition, Physical therapy and Palliative care.



If you are interested in attending this conference or viewing it via live web stream in the future please contact Mona.

## GET INVOLVED!!!!

We have two unique and important survey questionnaires that with your help we hope to find answers to significant healthcare dilemmas or concerns faced you on a daily basis.

Contact Lindsay or Shara or Mona with any questions:

We are conducting a study that involves an online survey asking both patients and their caregivers about their experiences in our clinic and how well present and future concerns are being met. It is our goal at HSS to not only deliver optimal care to our patients, but also to ensure that your needs, as a patient or caregiver, are being met as well.

**Multidisciplinary Clinic Survey:** <https://cs.createsurvey.com/publish/survey?a=yIzCjK>

While sexual function may not be directly affected by ALS, this study was designed to determine if you believe intimacy and/or your sexual relationships are affected by a diagnosis and symptoms of ALS. Surveys will take approximately 10 minutes each. Thank you in advance for your participation. Your feedback is very important!

**PALS:** <https://www.surveymonkey.comspatientperspectiveintimacyquestionnaire>

**PARTNERS:** <https://www.surveymonkey.com/s/partnerperspectiveintimacyquestionnaire>

All responses to these questionnaires will be kept confidential and there will be nothing identifying you to your responses.

# Clinician Tips

Lauren Langford, LCSW

One can easily become overwhelmed when caring for a sick family member or friend. As cliché and impossible as it may sound, you can't take care of anyone else unless you first take care of yourself, even if it's difficult to find the time. Here are a few tips to try and incorporate into your daily routine.

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can't take  
care of anyone  
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- **GET PLENTY OF REST** Try to get a full 8 hours of sleep every day even if it means napping while your loved one is sleeping.
- **STICK TO A HEALTHY DIET** A healthy diet includes fruits, vegetables and plenty of water.
- **ASK FOR HELP** Relinquish some control in the care of a loved one. This can be difficult, but it will give you a much needed break. Even if it is 30 min a day- allow yourself time to go to the gym or take a nap. Take up the offer from a neighbor, friend or family member. Take advantage if there is someone asking to help.
- **SEEK SUPPORT** Go to a caregiver support group, see a therapist or talk to a friend. It's important to acknowledge your feelings with all the changes going on and to deal with your own emotions over watching a loved one go through an illness.

Always keep in mind as challenging as this can be, you have been given invaluable time with someone you love and cherish. Embrace the experience and learn to find meaning in the simple moments of your days together, while taking each new phase of caregiving one step at a time.

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Thank you for reading! Feedback is welcomed & appreciated!  
Sincerely, Your Team

If you are interested in more information about our ALS Research Program, or supporting our work, please contact Dr. Dale Lange at 646-797-8917

## Meet Your Clinic Team

**Dale J. Lange, MD,**  
Attending Neurologist  
Program Director

**Mona Shahbazi, NP, MSN**  
Assistant Program Director

**Alex Shtilbans, MD**  
Attending Neurologist

**Dora Leung, MD**  
Attending Neurologist

**Lauren Langford, LCSW**  
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**Leah Pilossoph, RN**  
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**Laura Manfredo, PT**  
Physical Therapist

**Gioia Ciani, CMT, MS, OTR/L**  
Occupational Therapist

**Lorene Janowski, OTR/L, MS**  
Occupational Therapist

**Jessica Cording, RD**  
Dietician

**Karen Yanelli, DPT**  
Physical Therapist