Letter from the Director

Dear Friends,

Our ultimate goal in all encounters with our patients is to provide the highest level of care and achieve the best possible outcomes for them. The best way to do this as well as to provide hope to our patients is through discovery. Our focus is to advance our knowledge and work as best as we can to find answers and work towards treatments. Research helps our patients as well as our understanding of the disease. Thank you for all your support and help as we try to bring you the highest level of care possible.

Regards,

Dale J. Lange, M.D.
Director, ALS program at Hospital for Special Surgery

Share your story!

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

Meet Our Newest Members

Megan Parmenter

I am new to Dr. Lange’s research team, but not to the department. I am a certified clinical research professional (CCRP) with experience in neuropsychological testing. Prior to joining the team at HSS, I studied psychology at the College of the Holy Cross and worked in research roles at Yale University and Fairfield University. My ultimate goal is to obtain a doctorate degree in clinical psychology. I am a CT native but love New York sports and cuisine. Most weekends I can be found cheering for the Mets or trying out a new restaurant.

Aisha Sheikh

I am one of the new clinical research coordinators in the department. My professional background is in dance and Physical Therapy. As a Physical Therapist, my focus has always been on neurology, especially Cerebral Palsy, Parkinson’s disease, and Multiple sclerosis. I was born and raised in Copenhagen, Denmark where I attained my physical therapy license. I moved to New York City two years ago to complete a post professional Master’s degree in Pathokinesiology at NYU. I’m an enthusiastic runner, biker, and cross-fitter. In my free time, I enjoy photography, volunteering at homeless shelters around the city and travelling. I have lived in Japan, Sri Lanka, and Nepal.
The 68th Annual AAN Meeting took place on April 15-21, 2016, in Vancouver, BC. The AAN Annual Meeting is the world’s largest gathering of neurologists, bringing together more than 10,000 neurology professionals across the globe to network, discuss cutting-edge research, and take part in top-rated education programming across a wide variety of topics.

Amongst the many speakers was Dr. Lange, Chairman of Neurology at HSS and Director of the ALS program, regarding the results of our exciting clinical trial, use of Pyrimethamine in Familial ALS. This study was pioneered by Dr. Lange and conducted in 5 centers around the world, including 2 sites in Europe. The preliminary results showed that the primary aim of the study was reached, achieving a biological biomarker of SOD-1 reduction in Familial ALS. The next steps are to start a larger phase 2 study to evaluate the clinical efficacy in Familial ALS; recruitment will begin soon for this promising new trial. Stay tuned for more details!

**HOT TOPICS**

**American Academy of Neurology Meeting**

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**ALS Disability Insurance Access Act Introduced in Congress**

On May 10-11, 2016 in Washington, D.C., many advocates welcomed the introduction of a bill amending title II of the Social Security Act. If passed, this new legislation will waive the Social Security Disability Insurance (SSDI) five-month waiting period for people living with ALS. This bill will require payments to start the first month of which the individual is under a disability, in which the individual becomes entitled to the benefits.

The ALS Disability Insurance Access Act was introduced in the Senate by Senator Sheldon Whitehouse (D-RI) and in the House by Representatives Seth Moulton (D-MA) and Peter King (R-NY). The legislation was introduced during National ALS Advocacy Day.

“Those battling Lou Gehrig’s Disease shouldn’t have to wait to get benefits they’ve earned, especially given the unique challenges the disease poses for patients and their families,” said Whitehouse. “I’m proud to stand with the ALS community in introducing this legislation in the Senate.”

SSDI provides critical benefits and is a vital resource for ALS families who are unable to work and generate an income due to the disabling and fatal nature of the disease. Eligibility for SSDI enables people with ALS to immediately qualify for Medicare as Congress waived the 24-month Medicare waiting period for people with ALS in 2000, the only time the waiting period has ever been waived. However, under current law, people with ALS who qualify for SSDI must wait five months before beginning to receive both SSDI and Medicare.

“The cruel and unforgiving nature of ALS makes it imperative that we provide the best possible care for people living with the disease,” said Congressman Moulton. “I’m proud to introduce this bipartisan bill to provide critical SSDI benefits that people living with ALS and their families need and deserve.”

The ALS Disability Insurance Access Act would waive the five-month waiting period for people disabled with ALS and enable them to immediately begin to receive SSDI benefits and Medicare. The legislation builds on previous actions taken by Congress and the Social Security Administration that recognize the unique nature of ALS, a disease that progresses rapidly, is always disabling and is always fatal. SSA also has implemented a number of policies to expedite the review of ALS claims for SSDI and Supplemental Security Income benefits.

“Given the prognosis for those diagnosed with ALS, it defies common sense and decency to require these same individuals to wait for benefits they have paid for and most importantly deserve,” said King. Newhouse continued, “Congress originally justified the five-month waiting period by saying it allows time for temporary conditions

HOT TOPICS

LIFE-SAVING iPHONE FEATURE YOU PROBABLY DIDN’T NOTICE

Last fall, Apple created a new feature called the “Medical ID” which is stored in the iOS health app. While it’s often the feature most people have never heard of, it is also the one that could save your life. On your medical ID, you can fill out as much information as you want a medical provider to know, including allergies and your emergency contacts. Filling out your Medical ID to at least make your emergency contact accessible without needing to enter a passcode is important. It can be accessed from the iPhone’s emergency screen.

1) When you’re on your lock screen, it’s the “Emergency” on the bottom left

2) On the emergency screen, you can either place a call or tap the “Medical ID” screen on the bottom left.

There’s space to fill in your name, birthday, medical notes and emergency contacts. This information is available from the lock screen. Anyone who touches your phone can access this so make sure to fill in only what you are comfortable sharing.

To fill out your medical information:

3) Click on the Health app on your phone.

4) Click on the bottom right button to retrieve your Medical ID. Your iPhone doesn’t know any of this information until you fill it out. On your medical ID, you can fill out your conditions, allergies, and medications, along with any other notes you have. You can add multiple emergency contacts and fill out their relationship to you. You can also enter whether or not you are an organ donor, your blood type (if you know it) and your standard measurements.

If you don’t want any of this information to be seen from your lock screen, you can hide it from being shown when locked by unchecking the emergency access button that allows that. You can obtain information from your ID at any time. Apple does upload your medical ID to iCloud, but does not include it in your health data or share it with other apps.

SAVE THE DATE!

Myositis Awareness Day
September 21, 2016

Myositis Annual conference
early September, 2016 in New Orleans

Becker’s MD Annual conference
September 24, 2016 in Washington, D.C.

Limb Girdle Muscular Dystrophy Awareness day
September 30, 2016

World Multiple System Atrophy Day
October 3, 2016
RESEARCH: PROVIDING HOPE THROUGH DISCOVERY!

LIKE WHAT YOU SEE?  
YOU CAN JOIN THE FIGHT!

Our program is largely built based on support of donors. Your support gives us the foundation to provide the best patient care under the direction of leaders in the field in a multidisciplinary care model. We are dedicated to finding answers, treatments and therapies for neuromuscular disease.

If interested in donating and supporting our program Please contact Douglas Williams at 212-606-1046 or WilliamsDou@hss.edu

DALFAMPRIDINE FOR PLS — NEW ENROLLING STUDY

We are excited to announce that recruitment has begun for patients for a new clinical trial. The main purpose of this new trial is to determine if a drug named Dalfampridine can improve walking in PLS patients. Dalfampridine is an FDA-approved treatment to improve walking speed in people with multiple sclerosis. In PLS and upper motor predominant ALS we anticipate that Dalfampridine will have similar effect. It’s been shown to improve neuronal transmission and function in neurologic disorders of axonal and demyelinating pathology.

If you have been diagnosed with PLS and are interested in learning more about this study, please contact Shara Holzberg at 646-797-8657 or Holzbergs@hss.edu or Aisha Sheikh at 212-606-1569 or Sheikh@hss.edu.

CURRENTLY ENROLLING ONLINE STUDIES

We have two unique and important survey questionnaires that we hope will find answers to significant healthcare dilemmas or concerns you may face on a daily basis. While sexual function may not be directly affected by ALS, this study was designed to determine if you and your partner believe intimacy and/or your sexual relationships are affected by the 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.com/s/patientperspectiveintimacyquestionnaire
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.
ACTIVE STUDIES AT HSS

Phase III Ventilatory Investigation of Tirasemtiv and Assessment of Longitudinal Indices After Treatment in ALS patients
Evaluating the safety and effectiveness of Tirasemtiv’s for improving breathing, muscle weakness, and muscle fatigue in patients with ALS.

Safety of Caprylic Triglycerides in ALS: A Pilot Study
Determining if Axona (a medical food) is safe, tolerated and able to cause ketones to increase in the blood of patients with ALS.

Phase II Clinical Trial of Retigabine (Ezogabine) in ALS patients
Assessing the effects of Ezogabine (a potassium channel opener) on neuronal excitability in patients with ALS.

Triple Stimulation Technique (TST) in ALS Quantifying Upper Motor Neuron Function
Investigates the use of the Triple Stimulation Technique (TST) as an effective diagnostic tool and assesses TST identification of the presence of possible proximal conduction blocks in upper motor neuron function.

Driving forces behind driving habits and driving cessation in patients with ALS
Examining factors that are involved in the decision to stop or to continue driving amongst a cohort of PALS

Understanding quality of life and the impact of gastrostomy in patients with ALS
Assessing the perspectives of patients regarding their experiences and the impact that gastrostomy has on their quality of life

GET INVOLVED!!! Contact Shara, Aisha, Megan or Mona with any questions
On May 6, 2016 HSS held its 3rd annual Neuromuscular Disease Research Gala. Tradition continued at The Plaza Hotel where over 275 guests attended the event. Old friends and supporters welcomed new faces and new traditions, including cutting edge text-to-donate technology.

Guests from all walks of life joined us for this great evening including several patients and their families. A few were featured in the video that was presented, showing the many ways in which contributions to our program have enabled our research program to grow. Fundraising proceeds are dedicated to advances in clinical research and care of ALS.

Silent auction items were displayed in the cocktail-hour room, ranging from sports memorabilia to gift certificates and art. Attendees bid generously on silent and live auction items in support of the Department of Neurology’s neuromuscular disease research. Once the silent auction closed, Joe Piscopo led the crowd in bidding on more auction items ranging from vacations to Broadway’s Hamilton tickets to 2016’s Super Bowl. Through the generosity of attendees, we raised an all-time revenue record for this event which will allow us to do more to make a difference for the people we serve. The evening ended with entertainment by The Doo Wop Project, who kept us dancing and singing until the very end. Thank you to all our sponsors and especially to the Gala committee for making this night a success. Their commitment and support of the event is greatly appreciated. “It was a wonderful evening,” said Department Chair, Dr. Dale Lange. “We thank each and every person who supported us; your support enables us to give our patients hope through discovery.”

Link to the video: https://www.hss.edu/neurology.asp
WHAT’S NEW?

DEPARTMENT OF NEUROLOGY’S ALS PROGRAM RECOGNIZED AS A CERTIFIED NATIONAL CENTER BY THE ALS ASSOCIATION

On May 7, 2016, Dr. Lange was awarded a plaque for National Certification of HSS ALS clinic as a Certified Care Center at the annual ALS Association Greater New York Chapter Walk to Defeat ALS in Manhattan. The award was presented by Dorine Gordon, president and CEO of the ALS Association Greater New York Chapter, who recognized HSS as being “one of New York’s premiere treatment centers” for ALS.

Dr. Lange, chairman of the Department of Neurology and director and the ALS Program at HSS, works hard to treat patients with complex neuromuscular diseases, including Amyotrophic Lateral Sclerosis (ALS), weekly at the Department of Neurology. He leads a team of multi-disciplinary members, including neurologists, a neuromuscular fellow, a nurse practitioner, physical therapists, occupational therapists, speech therapists, dietician, research coordinators and respiratory therapists, who all play a vital role in the care of their patients. The hard and outstanding work of Dr. Lange and his team paid off when HSS was recently designated an ALS Association Certified Center of Excellence – one of only 49 recognized centers in the country! HSS has met all national standards of best practice care in the management of ALS and successfully completed a comprehensive site review, earning this distinguished designation.

If you are interested in more information about our ALS Clinic or Research Program please contact Dr. Dale Lange at 646-797-8917
Timely and proactive intervention for nutritional requirements, safe swallowing and feeding tube placement are some of the important issues in the management of ALS. Thirty percent of people with ALS (PALS) present with speech and/or swallowing impairments (bulbar-onset type) but 85% of PALS eventually demonstrate dysphagia [2,3]. Typical dysphagia symptoms may include: longer mealtimes often associated with fatigue when eating; weight loss; food getting stuck in the throat; difficulty swallowing pills; and difficulties swallowing saliva. With these difficulties, maintaining proper nutrition is often difficult, but it’s crucial.

PALS are highly susceptible to malnutrition due to two confounding factors:

1. **Hypermetabolism**: PALS have a higher metabolic resting rate (MRR) [4-8] and therefore, have increased energy needs which require more calories to maintain weight and nutrition.

2. **Reduced Caloric Intake**: Reduced oral intake of foods and liquids is common due to dysphagia; fatigue with eating and drinking; limb weakness impairing the ability to self-feed; and loss of appetite [1, 9-11].

A higher baseline MRR combined with reduced caloric intake creates the perfect storm for developing malnutrition and further muscle loss. It can become a vicious cycle of decreased eating, weight loss, malnutrition, and further muscle weakness. Research shows that a higher baseline body mass index (BMI) at diagnosis and maintenance of body weight during the disease are prognostic predictors of longer survival in PALS [9,10,12]. Therefore it’s important to make nutrition a top priority.

**PEG Use in ALS:**

One remedy to prevent malnutrition in PALS is placement of a feeding or percutaneous gastrostomy (PEG) tube. PEG placement in PALS is generally a well-tolerated, safe procedure and recommended by the American Academy of Neurology (AAN) and the European Federation of Neurological Societies [13]. Early and timely feeding tube placement can have a significant impact on maintaining one’s proper nutrition and hydration.

**Impact on Survival?**

Early PEG placement can help maintain nutrition and hydration before it becomes problematic. Several studies have documented that PALS who undergo PEG placement live, on average, approximately four months longer than PALS who do not undergo PEG placement [11,16,17]. Although these numbers may seem low, comparatively, this represents a 50% greater treatment effect than the use of Riluzole to treat ALS of 83 days. A 2014 retrospective study, done at the MDA/ALS Clinic at Houston Methodist Neurological Center reviewed 2172 cases between 1992 and 2014. Analysis determined that PEG placement was protective and increased survival, on average, by 107 days. Furthermore, it was noted that spinal onset PALS benefited most from PEG placement (+314 days). This data also showed a strong relationship between nutrition, wellbeing and quality of life. Therefore, considering early PEG placement to stay ‘ahead of the curve’, to prevent malnutrition and to ensure a ‘back up’ nutritional source if oral intake fails is key to meeting one's increased nutritional requirements. In addition, placement of a feeding tube allows for the administration of comfort measures (pain medications, hydration, etc.). But PEG placement is one of only a few interventions noted to significantly impact survival in this population. Data suggest that although effective treatments for PALS are lacking; attendance at a multidisciplinary clinic [18] and maintenance of adequate nutrition and weight [9,10] are also favorable prognostic indicators.

We acknowledge that placement of a feeding tube is a highly personal decision, based on a multitude of factors. While current data suggest that PEG placement is protective, we also understand that this treatment option is not for everyone. Our role is to ensure that PALS and caregivers understand the inherent risks of malnutrition and its impact on disease progression, current gastrostomy tube options and the associated outcomes with these interventions so an informed and educated decision can be made. Your clinic team is always available if you have additional questions. And check out our next page for food resources and dysphagia-friendly meal suggestions.
ASK THE EXPERTS

PREPARED FOOD RESOURCES

For those with meal prep difficulty, dysphagia or people who simply don’t like to cook, these options may be helpful!

Frozen meals from the grocery store:
Per our dietitian’s recommendations, these brands tend to have pretty good quality ingredients and also taste good.

- Amy’s
- Kashi
- Evol
- Organic Bistro

Slow Cooker Crock-Pot Options:
If you have limited use of your hands or find conventional ovens/stovetops difficult to use, this may be the option for you.


Meal delivery services:
- Meals on Wheels – http://www.mealsonwheelsamerica.org
- God’s Love We Deliver – https://www.glwd.org
- TopChef Meals – https://topchefmeals.com
- Fresh Direct and Pea Pod, which both deliver, also have prepared meals and snacks that are convenient.

Pre-made, dysphagia-friendly meals:
- Blossom Foods – www.blossomfoods.com; Owned and operated by an SLP who specializes in dysphagia
- Home Care Nutrition – www.homecarenutrition.com
- Smoothe Foods – www.smoothefoods.com

DYSPHAGIA COOKBOOKS

The Dysphagia Cookbook
This book is for anyone whose eating options are limited by chewing and swallowing difficulties. An unusual cookbook, it is filled with nutritious, great-tasting recipes that enhance the flavor, presentation, texture, aroma and color of food.
By: Elayne Achilles
Publisher: Cumberland House

Easy-to-Swallow, Easy-to-Chew Cookbook
This book offers over 150 tasty and nutritious recipes with simple instruction for tailoring food textures from very easy-to-chew to soft and smooth. All recipes contain nutritional information per serving.
By: Donna L. Weihofen, RD, Joanne Robbins, Ph.D. and Paula Sullivan, MS
Publisher: Wiley Publishers

Easy-to-Follow Recipes for People Who Have Chewing and Swallowing Problems
Part One highlights simple strategies for living with chewing and swallowing difficulties, offers guidelines for modifying recipes textures and to increase or decrease calories. Part Two offers over 150 recipes.
by Sandra Woodruff, RD, and Leah Gilbert-Henderson, PhD
People with Amyotrophic Lateral Sclerosis can experience muscle weakness, fatigue, and low endurance and stamina. The levels of weakness or low energy can vary from day to day or often times, hour by hour. Experiencing low energy frequently results in restrictions in doing the activities that people need to or want to do. Learning energy conservation strategies and techniques can help manage energy and thereby help to increase levels of independence, function, safety and quality of life.

Energy conservation refers to managing the body’s energy levels. We use the analogy of energy levels to having money in the bank. You wake up each day and have a certain amount of energy “in the bank”. How you spend your energy is up to you; there is only so much you can spend before your account runs low or in the “red”. Energy conservation is comparable to managing your bank account; you manage your energy by making deposits and withdrawals based on your needs for the day.

When you are experiencing fatigue or low endurance, do you listen to your energy levels and spend wisely on doing things that are important to you? Or, do you try to soldier on, regardless of how you are feeling, spending and depleting your energy? It is worth paying attention to energy levels and using strategies for conservation because when you do, you avoid unnecessary spending and end up having energy reserves to do the things that are most important to you.

When people experience weakness or fatigue, using energy-conservation techniques and strategies should be used. These techniques and strategies include balancing rest and activity, using supportive devices such as braces or splints, using assistive devices, or accepting help from another person. Here are some energy conservation strategies that may help.

**BRACES/SPLINTS:** Include the use of orthoses/braces when needed. These devices help conserve energy and increase safety. For example, if a person experiences weakness with ankle dorsiflexion, the ankle-foot orthoses (AFOs) could be helpful. The AFO is a light-weight splint worn on the lower leg and foot to provide support at the foot and ankle. The AFO holds the foot and ankle in the correct position to correct foot drop and to help prevent the foot from dropping. It helps compensate for muscle weakness (drop foot) and help to minimize abnormalities in walking and increase walking efficiency. Hand orthoses may be useful for people experiencing muscle weakness or muscle fatigue in the muscles of the hand or wrist. A volar cock-up splint may help improve a weak grasp in people with wrist extensor muscle weakness and an opponens splint could help improve grasp in people with thumb muscle weakness.

**ADAPTIVE EQUIPMENT:** The use of adaptive equipment can also be helpful in the efforts to conserve energy and increase independence. There are countless devices for all areas of self-care, leisure and work activities. Examples include lightweight and/or large-handled utensils, universal cuffs for holding tools such as utensils, zipper pulls, button hooks, shavers, tooth-brushes, floss holders, book easels, penholders, tilt-top over the bed tables, and adaptations for activities like gardening, golfing, and many types of adaptive sports.
**ASK THE EXPERTS**

**SIT** When possible, try to sit instead of stand when engaging in activity. For example, can you sit while showering? How about sitting down while preparing a meal or while folding laundry? Sitting instead of standing will give your lower body a rest and you will save up energy for other things.

**REST** Take frequent rest breaks throughout the day if possible. Rest before you become tired; this will help you avoid fatigue. Resting only when you are already fatigued is like drinking water only when you are already thirsty.

**RESTORE** Be sure to include activities each day that bring you joy and pleasure. This will add energy to your bank.

**DE-STRESS** Some stress is normal, but don’t overdo it. It can reduce energy and stamina.

**ORGANIZE** Think about your activities. Have what you need gathered together in one place and handy to get before you begin.

**PLAN, PACE, PRIORITIZE** Honor your energy level! Be aware of how you are feeling and plan accordingly. Review your day and list activities that you want to do and remember to include rest breaks. Schedule enough time for each task and alternate between heavy and light tasks and between physical and thinking activities. Decide what is most important to you to do. Allow people to help you when needed.

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**Beat the Heat: Tips to Keeping Cool this Summer**

Sometimes, warm temperatures can make some neurological symptoms worse. It can exacerbate symptoms in people with conditions that compromise one’s ability to regulate body temperature. While it does not cause further neurological damage, there are ways to manage heat sensitivity.

Here are some tips:

- **TALK TO YOUR DOCTOR.** Discuss your options. Certain activities may still be possible as long as you take precautions.

- **AVOID THE OUTDOORS WHEN IT’S REALLY HOT.** Create strategies that still allow you to enjoy the outdoors while lessening the risk of overheating. Schedule your day so that you’re not outside when the temperature is at its highest. If you love the beach, schedule your trip for early morning or late afternoon. Bring an umbrella and plenty of cold drinks — both of which will help regulate your core body temperature.

- **EXERCISE WISELY.** Avoid working out during the hottest part of the day and wear layers that you can peel off easily. If exercising indoors, keep a fan turned in your direction. Avoid activities where the room temperature is intentionally raised.

- **SEEK COOL PLACES.** Air-conditioned stores and cars are your best friend when out running errands.

- **DRESS APPROPRIATELY.** Choose light-colored and lightweight fabric when dressing to ward off heat. Wear a hat to shade you from the sun.

- **COOL YOUR BODY:** Put your feet in a bucket of ice or cool water. Fill a spray bottle with water and spritz yourself every so often. Place an ice pack, small bag of ice or cool washcloth on your neck. You could wear a cooling vest, which is a garment with pockets for ice packs. Cooling headbands, scarves and spine or ankle wraps are also on the market.

- **STAY HYDRATED.** Keep a cool bottle of water with you at all times and sip throughout the day.
Thank you for reading! Feedback is welcomed & greatly appreciated!
Sincerely, Your Team

CARE GIVER’S CORNER

Talk to Other Caregivers
Caregivers who share resources and their own personal experiences report less stress and fewer problems. Establish networks and support systems with other caregivers to share solutions to common problems and to talk with people who can understand first-hand what you are experiencing. Many of ALSA and MDA chapters run caregiver support groups. You can also talk to other caregivers via online forums such as:
www.thefamilycaregiver.org
www.wellspouse.org

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