

Dear Friends,

On behalf of the Children's Hospital Boston Department of Neurology, it is our pleasure to invite you to our fourth Boston SMA Day. This one-day conference is intended to bring researchers and families together to share the most up to date information on Spinal Muscular Atrophy.

The conference is open to individuals with SMA of all ages and their families. We are very pleased with the success of prior conferences and hope this event will provide another opportunity for parents to learn from each other and for children and adults alike to meet other children and adults with the same condition. We encourage parents to bring their children as we have several exciting events planned to ensure they have a memorable day.

During the morning session, many of the top Boston researchers in SMA will be meeting to share their work with each other and try to collaborate on future research endeavors to get one step closer to a cure. They will then join you all for lunch to give researchers and families the opportunity to interact and ask questions of each other.

We loved the feedback we have received in previous years and have made sure to incorporate it into the planning of this event. We are excited to bring you this one-day conference that we hope will be even more educational than the last and another wonderful way to meet others in the SMA community. Boston has so many wonderful families and talented researchers that it is time to bring everyone together again.

Morning Agenda

9:45-10:15 Registration and Breakfast (provided)

10:15-10:25 Welcome
Hailly Butler, B.S.

10:25-10:45 Keynote
Tracy and Daryl Denelle

10:45-11:15 Research Overview
Basil T. Darras, M.D.

11:15-12:00 Sharing Your Experience (by type)
Moderated by Shuei Kozu, MSW

12:00-1:00 LUNCH (provided)

Afternoon Agenda

Session I—1:00-1:40

Respiratory Support and Management
Lauren Perlman, RT

Navigating the School System
Federation for Children with Special Needs

Session II—1:45-2:25

Nutritional Management
Stacey Tarrant, RN, LDN

Alternative Therapies
Aquatic Physical Therapy
Laura Diamond, MS, PT
Diamond Physical Therapy Associates, PC
www.diamondphysicaltherapy.com

Hippotherapy—Susan Farese, PT
www.challengeunlimited.org



Joey!

Session III—2:30-3:10

Orthopedic Care
Frederic Shapiro, M.D.

Augmentative Communication Options
Susanne S. Russell, MS, OTR/L
Alycia Berg, MS, CCC-SLP

3:30—4:30 Physical Therapy & Equipment Showcase

Janet Quigley, PT, PCS & Sue Riley, DPT, PCS

Showcase Presenters:

- Susan Farese, PT, Challenge Unlimited, Inc.
- Laura Diamond, MS, PT
Diamond Physical Therapy Associates, PC
www.diamondphysicaltherapy.com
- Peter Eastman, Hudson Home Healthcare
- Jackie Dobson of Solutions for Accessibility
- Susanne S. Russell, CHB Assistive Technology

Children's Activities

Activities for children will be available throughout the conference. This activity room will be monitored by nurses and administrative staff from the Neurology Department and general hospital volunteers.

Please note that any individuals with a trach should be accompanied by a private nurse. As we will not be in the hospital, all necessary equipment should be brought with you.

All children, including siblings, are welcomed at the conference. Please include the number of children and their ages in the RSVP, due April 15th.

Synopsis and Sponsors

This year, we will all convene together to discuss research efforts in the greater SMA community and here at Children's. The afternoon will be broken into three sessions, where you can decide which talk you would like to attend during each forty minute session.

Finally, at the end of the day, we will again join together to discuss physical therapy management and you will have the opportunity to try out equipment.

**Children's Hospital Boston
Neurology Foundation**



SMA Foundation

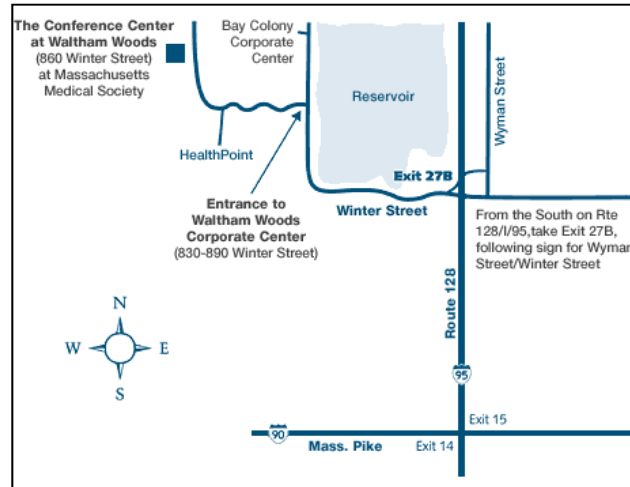


The Slaney Fund



Katie and Kate!

The Conference will take place at:
The Conference Center at Waltham Woods
860 Winter Street, Waltham, MA



Directions for All

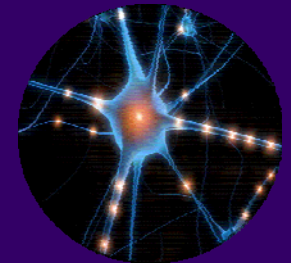
Remain in the far right lane through two sets of lights, passing the Doubletree Hotel on your left. Travel around the Cambridge Reservoir (on right) for approximately .5 mile (pass AstraZeneca on left). Turn left at the granite sign announcing HealthPoint and Waltham Woods Corporate Center. Travel up the hill following the green signs to Waltham Woods Corporate Center for approximately .3 mile to a second granite sign for Waltham Woods (860-890 Winter Street) on the left. Immediately after sign, turn left into the parking lot for the Massachusetts Medical Society. Park near the Conference Center entrance. Enter the lobby through the glass doors.

If you plan to attend please RSVP via email or telephone before April 15, 2010 to:

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Children's
Hospital
Boston
Neurology
Foundation
Presents:

**Boston SMA Day
2010**



**Date: May 01, 2010
Time: 10am - 4:30pm**
Located at The Conference
Center at Waltham Woods