



Monthly Update

September 2015

Greater New York Chapter

Serving New York City, Long Island, Westchester County, Hudson Valley, and Northern & Central New Jersey
42 Broadway, Suite 1724, New York, NY 10004 • (212) 619-1400
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SEPTEMBER SUPPORT GROUPS

NASSAU COUNTY, NY

*This month's support group will not meet due to Labor Day Holiday Sept. 6th**
North Shore LIJ - Plainview Hospital
888 Old Country Rd., Plainview, NY 11803
(Downstairs)
Contact: Cindy Keyser-Posner, LMSW
(631) 416-2767
Next month's support group meets: Oct. 4th.

SUFFOLK COUNTY, NY

Tuesday, September 1st - 6 to 8 pm
Stony Brook University
Department of Neurology
179 N. Belle Meade Road
East Setauket, NY 11733
Contact: Cindy Keyser-Posner, LMSW
(631) 416-2767
Topic: Open Discussion
Next month's support group meets: Oct. 6th.

HUDSON VALLEY/FISHKILL, NY

Tuesday, September 1st - 6:30 to 8:30 pm
Ambulatory Surgery Center
Building C, 3rd Floor
200 Westage Business Center
Fishkill, NY 12524
Contacts: Helen Mayer, RN,
(845) 520-0952
Nancy Brenner, LCSW,
(914) 406-3513
Topic: Respiratory Issues in ALS
Speaker: Keith Llewelyn, RT from
Millennium Respiratory Services
Next month's support group meets: Oct. 6th.

WESTCHESTER, NY/WHITE PLAINS

Tuesday, September 8th- 6 to 8 pm
Burke Rehabilitation Center
785 Mamaroneck Avenue, Building 7
White Plains, NY 10601
Contacts: Helen Mayer, RN (845) 520-0952
Nancy Brenner, LCSW (914) 406-3513
Topic: Respiratory Issues in ALS
Speaker: Keith Llewelyn, RT from Millennium
Respiratory Services
Next month's support group meets: Oct. 6th.

NORTHERN NJ/SADDLE BROOK

Thursday, September 3rd - 7 to 9 pm
Kessler Institute for Rehabilitation
300 Market Street, Saddle Brook, NJ 07663
Contacts: Debbie Schlossberg, LMSW
(732) 710-8832
Mary Ann Mertz, RN, (908) 552-5573
Topic: Ask the Doctor
Speaker: Jerry M. Belsh, MD
Next month's support group meets: Oct. 1st.

CENTRAL NJ/NEW BRUNSWICK

Saturday, September 19th - 1 to 3 pm
Robert Wood Johnson Fitness & Wellness Ctr.
100 Kirkpatrick Street
New Brunswick, NJ 08901
Level 2, Community Education Room
Contacts: Debbie Schlossberg, LMSW
(732) 710-8832
Mary Ann Mertz, RN (908) 552-5573
Topic: Nutrition and ALS
Speaker: Anna Baratta, RD, MS
Next month's support group meets: Oct. 17th.

MANHATTAN, NY

*This month's support group will not meet due to Rosh Hashanah Sept. 15th**
Mt. Sinai Beth Israel Hospital
Phillips Ambulatory Care Center
10 Union Square East
(b/w 14th & 15th Sts.)
New York, NY 10003
Neurology Department
5th Floor Conference Room
Contact: Jody Wiesel, PhD, (917) 699-9751
Next month's support group meets: Oct. 20th.

TELEPHONE SUPPORT GROUPS

Patient group: Every Friday from 2:30 to 3:30 pm
Caregivers group: Every Friday from 4 to 5 pm
Contact: Sue Zimmerman, LCSW
(212) 720-3050.
Topics include: Open discussions or
Meditation and Guided Imagery for
Stress Reduction

Upcoming Events

Monday, September 14th - Sixth Annual Joe Pettinato Golf Classic at Pebble Creek Golf Club in Colts Neck NJ. For info and to register: Kristen Cocoman at Cocoman@als-ny.org or (212) 720-3048.

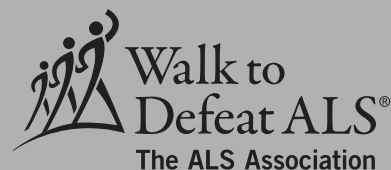
Saturday and Sunday, September 19th – 20th - Grab your friends and join Team Challenge ALS for the 2015 Vermont Spartan Sprint or Vermont Spartan Beast. For info and to register: Kristen Cocoman at Cocoman@als-ny.org or (212) 720-3048.

Saturday, September 19th - Long Island Walk to Defeat ALS at Eisenhower Park, East Meadow, Long Island. For info: Sarah Pattison at (212) 720-3042 or spattison@als-ny.org.

Saturday, September 19th - MLS Tennis Tournament for ALS at Armonk Tennis Club in Westchester, NY. For info and to register: Kristen Cocoman at Cocoman@als-ny.org or (212) 720-3048.

Sunday, September 27th - "Ask the Experts" Research Update. Long Island. Contact Kim Peters at (212) 720-3054 or kpeters@als-ny.org for info.

SIGN UP TODAY!



2015 Walk Dates

Long Island, NY
Saturday, Sept. 19

Hudson Valley, NY
Sunday, Oct. 18

www.ALSWALKS.ORG
(212) 720-3042



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Latest News To Be Presented at Ask the Experts ALS Research Update

On Sunday, September 27th the ALS Association Greater New York Chapter is presenting a day of lectures by leading scientists in the field of ALS research at Cold Spring Harbor Laboratory, in Cold Spring Harbor, NY. After an introduction by Greater New York Chapter President Dorine Gordon, ALS Association Chief Scientist Lucie Bruijn, PhD, MBA, will open up the Ask the Experts event with an overview of current research. There will be presentations on advances in three key areas of ALS research followed by a question and answer session.

Using Stem Cells to Treat and Model ALS by Clive Svendsen, PhD, Professor and Director, Vickar Family Foundation and Distinguished Chair in Regenerative Medicine Board of Governors, Regenerative Medicine Institute Cedars-Sinai Medical Center, Los Angeles, CA.

Dr. Svendsen is a global leader for stem cell research. In 2010, Dr. Svendsen received funding through The ALS Association's Sheila Essey Award for ALS Research to establish stem cell approaches for the treatment of ALS. Dr. Svendsen is also an investigator as part of ALS Accelerated Therapeutics (ALS ACT), a novel academic-industry partnership to accelerate treatments for people living with ALS, funded in part by The ALS Association from money raised by the ALS Ice Bucket Challenge.

Discovery & Development of an AAV Gene Therapy for ALS: an Industry Perspective by Dinah Sah, PhD, Senior Vice President of Neuroscience, Voyager Therapeutics, Inc., Cambridge, MA

Dr. Sah has more than 20 years of experience in research and drug development in the biotechnology industry, focused on neurodegenerative diseases. Earlier this summer, The ALS Association announced its support for 58 new research grants

totaling \$11,621,638 to find treatments and a cure for ALS. Among those awards were drug development contracts, milestone-driven awards designed to rapidly bring the most promising potential therapies closer to clinical trials. Dr. Sah, in collaboration with Joan Coates, Ph.D., University of Missouri, Columbia, Mo. received \$500,000 to develop AAV gene therapy targeting SOD1 for the treatment of ALS.

Clinical Trials Overview by Merit Cudkowicz, MD, Chief of Neurology, Massachusetts General Hospital, Boston, MA, Julieanne Dorn Professor of Neurology, Harvard Medical School.

Dr. Cudkowicz is an international leader of clinical therapeutics in ALS. She is co-founder and co-director of the Northeast ALS Consortium (NEALS) a clinical trials network of clinical sites throughout the U.S. and Canada dedicated to performing academic led clinical trials. At NEALS Dr. Cudkowicz acts as Coordinating Center Chair. There are two Coordinating Centers that are responsible for the management and conduct of NEALS-affiliated trials located at Massachusetts General Hospital and Barrow Neurological Institute. Dr. Merit Cudkowicz is also an investigator as a part of ALS ACT.

The Ask the Experts ALS Research Update presented by The ALS Association Greater New York Chapter will take place on Sunday, September 27, 2015 from 1:00 pm – 4:00 pm at Cold Spring Harbor Laboratory, 1 Bungtown Rd, Cold Spring Harbor, NY 11724 in the Hawkins Lecture Hall.

Anyone interested in the most up-to-date information available on ALS research is encouraged to attend this event. There is no cost but registration is required by Monday, September 21, 2015. Please RSVP to Kim Peters at kpeters@als-ny.org. If you have any questions please contact Kim at (212) 720-3054.