FEBRUARY SUPPORT GROUPS

LOWER HUDSON VALLEY, NY
Tuesday, Feb. 2nd - 6 to 8 pm
Ambulatory Surgery Center
Building C, 1st Floor, Suite 130
200 Westage Business Center
Fishkill, NY 12524
Contacts: Helen Mayer, RN, (845) 520-0952
Nancy Brenner, LCSW, (914) 406-3513
Topic: Open Discussion
Next month’s support group meets: March 1st

SUFFOLK COUNTY, NY
Tuesday, Feb. 2nd - 6 to 8 pm
Stony Brook University
Department of Neurology
179 N. Belle Meade Road
East Setauket, NY 11733
Contacts: Cindy Keyser-Posner, LMSW, (631) 416-2767
Theresa Imperato, RN, (516) 946-5467
Topic: Open Discussion
Next month’s support group meets: March 1st

NASSAU COUNTY, NY
Sunday, Feb. 7th - 2 to 4 pm
North Shore LIJ - Plainview Hospital
888 Old Country Road
Plainview, NY 11803 (Downstairs)
Contacts: Cindy Keyser-Posner, LMSW, (631) 416-2767
Theresa Imperato, RN, (516) 946-5467
Topic: Open Discussion
Next month’s support group meets: March 6th

WESTCHESTER, NY
Tuesday, Feb. 9th - 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: Open Discussion
Next month’s support group meets: March 8th

MANHATTAN, NY
Tuesday, Feb. 16th - 6 to 8 pm
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 Fl. Conf. Room
Contact: Jody Wiesel, PhD, (917) 699-9751
Topic: Research Updates for the ALS Community
Speaker: Tracy Sandy-Ali, BA, CCRC, LPN, Patient Services Manager
Next month’s support group meets: March 15th

NORTHERN NJ
Thursday, Feb. 4th - 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: Open Discussion
Next month’s support group meets: March 3rd

CENTRAL NJ
Saturday, Feb. 20th - 1:30 to 3:30 pm
Robert Wood Johnson Fitness & Wellness Center
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: Tips for Accessing the Computer and Other Assistive Technology Hints
Speaker: Ben Lieam, MSW, Assistive Technology Specialist
Next month’s support group meets: March 19th

TELEPHONE SUPPORT GROUPS
Patient group: Every Friday - 2:30 to 3:30 pm
Caregivers group: Every Friday - 4 to 5 pm
Topics include: Open discussions or Meditation and Guided Imagery for Stress Reduction.
A new telephone support group has been formed for patients newly diagnosed with ALS. Call for info.
Contact: Sue Zimmerman, LCSW, (212) 720-3050

2016 Walk Dates
New York City - Sat., May 7, 2016
Jersey Shore - Sun., May 22, 2016
Northern NJ - Sun., June 5, 2016
Westchester, NY - Sun., June 26, 2016
Long Island - Sat., Sept. 17, 2016
Central NJ - Sun., Oct. 9, 2016
Hudson Valley, NY - Sun., Oct. 16, 2016

REGISTER AT WWW.ALSWALKS.ORG STARTING FEB. 1st!
LONG ISLAND PALS ACCEPTED AS RESEARCH AMBASSADOR AT ANNUAL NEALS CONFERENCE

As a retired optometrist from Long Island, Frank Verdone has a clear understanding of the science behind clinical trials that may help to find a cure for ALS. As a person living with ALS, the 55-year old former long distance runner has enthusiastically volunteered to be trained as a NEALS Research Ambassador to educate others about the latest ALS clinical trials and inspire PALS to participate in them.

When Theresa Imperato, RN, Nurse Coordinator at the ALSA Certified Center at Stony Brook University Hospital, got an announcement that NEALS was seeking Research Ambassadors, she thought of Frank because of his medical background and interest in current research. "He wants to find a cure if not for himself but also for those diagnosed in the near future," Theresa said. Frank has also participated in ALS studies so he has first-hand experience with clinical research.

As a result, Frank was accepted into the program and attended the 14th Annual NEALS Consortium Conference last November. The ALS Clinical Research Learning Institute, sponsored by the ALS Association’s TREAT ALS initiative, is an intensive two day program dedicated to educating attendees on clinical research and therapy development and empowering them to be advocates for ALS clinical research. ALS Association Chief Scientist Dr. Lucie Bruijn was also in attendance. "We brought this information back to our support groups to explain why clinical trials are so necessary and to try to get patients involved," said Frank, who was one of 34 Research Ambassadors from all over the country including one couple from Canada and one from Puerto Rico. Of those, 15 were PALS who take on the role permanently.

Frank’s wife, Mary, accompanied him to the NEALS meeting where she learned how much work is being done in the field, how compassionate the researchers are, and that there is hope for an effective treatment in the near future. Frank noted that meeting other patients and caregivers was a comfort to them; to know that they were not alone in the fight for a cure.

Frank is a dedicated advocate for the Greater New York Chapter and a natural fit as Ambassador because he finds inspiration in educating people about ALS. He often visits local school districts to talk about ALS and the story of Lou Gehrig. "These are life lessons for all children at any age," Frank said. "After our presentation, principals and teachers always comment on how this is the best presentation they have ever heard and students are compelled to run fundraisers for our cause afterwards."

In addition to advocacy work, Frank keeps very busy. He attends the Chapter’s monthly support group and ALS clinic at Stony Brook University Hospital. "I find the support groups to be a wealth of information," he said. "And all of the medical providers and staff at the clinic provide us with the best care." Frank serves on the board of Long Island based Ride For Life. He and his family started Team FrankV in his honor to raise awareness and funds for the Long Island Walk to Defeat ALS.

For more information about becoming an ALS advocate please contact Jeanne Traugot, Director of Development, at (212) 720-3051 or jtraugot@als-ny.org.