ALS ASSOCIATION
Fighting Lou Gehrig's Disease
Greater New York Chapter

Greater New York Chapter
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Traveling the Globe for the Walk to Defeat ALS

Cathy Standish was reading through her husband Fred's travelogue when she came up with an idea to honor her late husband. Fred was diagnosed with ALS in December of 2015 and unfortunately lost his battle last month. He left behind a wonderful travelogue documenting all the places he lived and worked throughout his career as a reporter for the Associated Press.

"Fred would take pictures of himself in the homes where he lived and at local landmarks. It's a log of every small bureau and town or city he worked," Cathy said.

Since Fred's diagnosis the travelogue has taken on new meaning. Cathy is determined to be a part of The ALS Association's Walk to Defeat ALS in every city her husband has lived and worked. This includes more than 20 cities across the US. They will then travel Greece, where Fred worked, for their own honorary "walk."

"I think he would be really happy with my plan, he would feel the travel log meant something and there was a reason for it. Through the travelogue we are bringing awareness and hope to the ALS community," Cathy said.

Fred and Cathy Standish

She said the decision to tackle nearly 2 dozen Walks to Defeat ALS was an easy one.

"I have a neighbor a couple doors down who also just lost a family member in NJ from ALS. ALS touches so many more people than we think. I think it touches everybody, it may be 6 degrees of separation, but I believe it affects everyone in some way," Cathy says.

Cathy says her motivation to keep going stems from the strong bond, love and respect she shared with Fred. She said even at the very end she did what she needed to help keep Fred's spirits up.

"I would do silly little things like disco lunch time when it was time for his tube feeding. I would play a horrible disco song because Fred hated disco. And certain things like that would make him laugh and I always tried the best I could to keep him up," Cathy said.

She admits it wasn't always easy helping Fred keep his fight, while also taking care of herself. Cathy says it's important to remember your own needs as well as your loved ones.

"Be kind to yourself, and have self-compassion. If you get in a fight it's ok. My husband and I had arguments over silly things like where to hang a picture. Just because you're a caretaker doesn't mean you're not their spouse anymore. Take time for yourself; every minute you can take time for yourself," Cathy said.

Fred spent time working for the Associated Press in New York so on her walk list is the New York City Walk to Defeat ALS on May 6th.

"I'm really looking forward to coming to NYC and feeling the energy of the city. I know amongst all the people there will be so much hope, and I will be so excited," Cathy said.

Registration is now open for all 7 of the Chapter's Walks to Defeat ALS. We look forward to seeing all of our amazing PALS, families, and supporters on walk day!

MARCH MONTHLY UPDATE

ALS ASSOCIATION
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Greater New York Chapter

Advocacy

Patient Services

Research

Awareness

Serving New York City, Long Island, Westchester County, Lower Hudson Valley, and Northern & Central New Jersey
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MARCH 2017 SUPPORT GROUPS

NASSAU COUNTY, NY
Sunday, March 5th, 2017 from 2:00 to 4:00 pm
Northwell Health - Plainview Hospital
888 Old Country Road
Plainview, NY 11803 (Downstairs)
Contact: Cindy Keyser-Posner, LMSW (631) 416-2767
Carol Bishop, RN, (631) 219-0947
Topic: Medicaid, Disability Benefits, Estate Planning and More
Speaker: Melissa Negrin-Wiener, Esq. - Partner, Genser Dubow Genser & Cona
Next month's support group meets: April 2nd, 2017

LOWER HUDSON VALLEY, NY
Tuesday, March 7th, 2017 from 6:00 to 8:00 pm
Ambulatory Surgery Center Bldg. C, 1st Fl.
Suite 130 (across from the elevator)
200 Westage Business Center
Fishkill, NY 12524
Contacts: Helen Mayer, RN, (845) 520-0952
Nancy Brenner, LCSW, (914) 406-3513
Topic: CPR-Helen Mayer, RN
Next month's support group meets: April 4th, 2017

SUFFOLK COUNTY, NY
Tuesday, March 7th, 2017 from 6:00 to 8:00 pm
Stony Brook University, Dept. of Neurology
179 N. Belle Mead Road
East Setauket, NY 11733
Contacts: Cindy Keyser-Posner, LMSW,
(631) 416-2767
Theresa Imperato, RN, (516) 946-5467
Topic: Medicaid, Disability Benefits, Estate Planning and More
Speaker: Melissa Negrin-Wiener, Esq. - Partner, Genser Dubow Genser & Cona
Next month's support group meets: April 4th, 2017

WESTCHESTER, NY/WHITE PLAINS
Tuesday, March 14th, 2017 from 6:00 to 8:00 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: CPR- Helen Mayer, RN
Next month's support group meets: April 11th, 2017

MANHATTAN, NY
Tuesday, March 21st, 2017 from 6:00 to 8:00 pm
Mt. Sinai Beth Israel Hospital
Phillips Ambulatory Care Center
10 Union Square East (b/w 14th & 15th Sts.)
New York, NY 10003
Neurology Dept., 5th Floor Conf. Room
Contact: Jody Wiesel, PhD, (917) 699-9751
Topic: Preparing for Homecare
Speaker: Mandy Blake, LMSW - Bayada Home Healthcare
Next month's support group meets: April 18th, 2017

NORTHERN NJ
Thursday, March 2nd, 2017 from 7:00 to 9:00 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: April 6th, 2017

CENTRAL NJ
Saturday, March 18th, 2017 from 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: Open Discussion
Next month's support group meets: April 15th, 2017

JAMES J PETERS BRONX VA MEDICAL CENTER
*** OPEN TO VETERANS ONLY**
Wednesday, March 8th, 2017 from 1:00 to 3:00 pm
130 West Kingsbridge Road
Bronx, NY 10468
1E - Dayroom SCI Unit
Contacts: Michelle McKenzie, LMSW (718) 644-1750
Carmen Rivas, RN (718) 584-9000 ext. 5405
April Jones, RN (718) 584-9000 ext. 5213
Topic: Open Discussion
Next month's support group meets: April 12th, 2017

TELEPHONE SUPPORT GROUPS
Patient group: Every Wednesday from 2:30 to 3:30 pm
Caregivers group: Every Wednesday from 4 to 5 pm
Contact: Susan Zimmerman, LCSW at 212-720-3050
Topics include: Open discussions and Meditation and Guided Imagery for Stress Reduction

SUMMER CAMPS FOR KIDS
If you are interested in summer camps for kids who are coping with a loved one with ALS of who are already bereaved, please call Sue Zimmerman, LCSW, Patient Services Coordinator at 212-720-3050 for information.

NATIONAL ALS REGISTRY
People living with Amyotrophic Lateral Sclerosis (Lou Gehrig's Disease) may self enroll in the ALS Registry via a secure on-line web portal at the Centers for Disease Control and Prevention: www.cdc.gov/als.

For more about the ALS Registry, contact Christine Dunn in the chapter office at (212) 720-3044 or dunn@als-ny.org. Chris can also help you with your enrollment.

2017 Walk Dates
New York City - Sat., May 6, 2017
Jersey Shore - Sun., May 21, 2017
North Jersey - Sun., June 4, 2017
Westchester, NY - Sun., June 25, 2017
Long Island - Sat., Sept. 16, 2017
Central Jersey - Sat., Oct. 7, 2017
Hudson Valley, NY - Sun., Oct. 15, 2017

REGISTER NOW AT WWW.ALSWALKS.ORG!