



ALS Association
Fighting Lou Gehrig's Disease

The ALS Association Greater New York Chapter December 2008

Monthly Update

Serving Greater New York and Northern and Central New Jersey

116 John Street, Suite 1304, New York, NY 10038, 800-672-8857 f: 212-619-7409 www.als-ny.org

December Support Groups

SUFFOLK COUNTY, NY

December 2, 2008 6:00-8:00 PM

(1st Tuesday of every month)

Stony Brook University, Dept. of Neurology

179 Belle Meade Rd, E. Setauket

(631) 444-1970

Topic: Holiday Pot Luck

Facilitator: Theresa Imperato, RN - (631) 444-4623

NEW BRUNSWICK, NJ

December 6, 2008 1:00-3:00 PM

Note: This Is A Change in Usual Schedule

Robert Wood Johnson University Hospital

Medical Education Building, Rm 108A

180 Somerset Street, Follow signs to meeting.

Topic: Holiday Celebration

Facilitator: Debbie Schlossberg, LMSW

(732) 710-8832

Mary Ann Mertz, RN

NASSAU COUNTY, NY

December 7, 2008 2:00-4:00 PM

(1st Sunday of every month)

North Shore's Central General Hospital

888 Old Country Road, Plainview

Downstairs Meeting Room; (516) 719-3000

Topic: Holiday Pot Luck

Facilitators: Theresa Imperato, RN - (631) 444-4623

Jody Wiesel, PhD - (917) 699-9751

MANHATTAN, NY

December 16, 2008 6:00-8:00 PM

(3rd Tuesday of every month)

Phillips Ambulatory Care Center (Beth Israel)

10 Union Square East (Bet. 14th & 15th St.)

2nd Floor, Conference Room #1

Topic: Holiday Party

Facilitator: Jody Wiesel, PhD - (917) 699-9751

For more information about our Support Groups:

Goto the Patient Services section at

www.als-ny.org or call 800-672-8857.

CHAPTER TO HOLD FREE TELECONFERENCES EXPLAINING VETERAN'S BENEFITS FOR PALS & THEIR SURVIVING SPOUSES.



The decision to establish a presumption of service connection for ALS (amyotrophic lateral sclerosis) is a tremendous victory for veterans living with the disease and is the culmination of years of work by The ALS Association to expand benefits for those diagnosed with the fatal neurodegenerative disease.

It is absolutely critical that you apply for these benefits as soon as possible. Benefits will be retroactive to the date of your application, regardless of how long it may take to process the application.

To help people understand the new VA Benefits for Veteran PALS and their surviving spouses, we have arranged for Fred Gould, National Service Officer from the Paralyzed Veterans Association, to hold three FREE teleconferences on VA Benefits. He will discuss the new benefits and then open conference to participants' questions. We will also be accepting questions in advance to be addressed during the call.

There will be three separate teleconferences:

1) **Tuesday, December 9, 2008 (Register by 12/5/08)**

2) **Wednesday December 17, 2008 (Register by 12/15/08)**

3) **Wednesday January, 21, 2009 (Register by 1/19/09)**

All conferences will begin at 10:00AM.

Call Christine Dunn at 212-720-3044 to register. Instructions to call in will be provided at time of registration.

Why People with ALS (PALS) Who Served Are Eligible For Presumptive Disability Benefits From VA.

When specific conditions are diagnosed in a former service member of the U.S. military, the Veterans Administration (VA) presumes those disabilities were caused by military service and disability compensation may be awarded. In the case of ALS, the VA has made a connection between military service and the onset of the disease.

A study found Veterans who served in the Persian Gulf in 1990 and 1991 have a nearly twofold risk of Lou Gehrig's disease compared to veterans of the same era who did not serve in the Gulf. The incidence was especially high (2.7 times) among Air Force personnel who served in the conflict.

For more information and a list of Frequently Asked Questions & Answers about the new VA Benefits for veteran ALS patients please contact our Patient Services Department at 800-672-8857 or email them at patient_services@als-ny.org.

Holiday Gift Auction

Are you looking for the perfect gift this Holiday? We may already have it. Check out our Holiday Gift Auction on the web. Visit us at www.als-ny.org for more information.



The NY Chapter has a Lending Library available to all PALS.
We have books on CD or audio tape. If you would like to borrow books please contact Christine Dunn at the Chapter office or e/mail dunn@als-ny.org.





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VOLUNTEER NIGHT DECEMBER 18, 5-7 PM. Contact Christine @ 212-720-3044



FOCUS ON: A PALS Gift

When Dan Garry found out that Shawn O'Neil had ALS he asked his neighbor what his plans were. Shawn said he was going to "take it one day at a time."

The small community of houseboats that Dan and Shawn shared was like no other in Brooklyn and after Shawn's illness, it would never be the same again. While everyone had always been cordial, it wasn't until they had a cause to rally around that they became close.

"People would come out, pass each other and say hello," Dan said. "After Shawn's diagnosis we all became closer. The community formed a strong bond."

According to Dan, Shawn O'Neil, a contractor by trade, was a rather solitary person. Friendly but not open. Like many in the community he kept his personal details to himself and people rarely visited each others' homes.

"But the illness opened up his heart, his soul, his life," Dan said. "He was really very giving whether it was a word or food in his fridge when people came to visit. We learned from that."

If Shawn, who was battling ALS could be so positive and open, then perhaps everyone else could be too. Shawn's wish was to stay in his beautiful community as long as he could. He wanted to stay

on his boat, in his home. His neighbors made sure that he got his wish.

They rallied around Shawn and worked together to help support him. At first, they felt that they were giving Shawn a gift, by ensuring that he was able to live out his days in his beloved houseboat, but in the end, it seems that Shawn was giving more back than anyone ever thought possible.

"Everyone was touched by him," Dan said.

It could have been any illness, but this particular diagnosis of ALS allowed the neighbors to pitch in to help Shawn and in return they really got to know him, realizing that they were also getting to know each other. Along the way they all found a message in their shared plight.

"He taught us to let things go," Dan explained. "Don't get stuck in the details of life."

While Shawn was sick, the neighbors got together and renamed a street in their community, Shawn O'Neil Avenue. They were glad that Shawn was able to see that happen.

Shawn is gone now, but his memory lives on in all the people who met and cared for him. Every time they come home, they see the street sign with his name on it and are reminded of the gift that Shawn gave to them. Now people make time to invite their neighbors into their homes for dinner and to visit. Shawn's life changed the little houseboat community for the better.

"In retrospect it was a positive experience," Dan recalled. "I call it divine."

2008 HOLIDAY GIFT IDEAS FOR PALS

We surveyed PALS, caregivers, friends and family here at the Chapter, on the web, in our Facebook group, and everywhere we could think to come up with a list of suggested Holiday gifts for PALS and their families. If you know of someone who is shopping for an ALS patient this year and can use this list, pass it on.

With winter coming up some gifts are great for cold weather. **Microwave Heatable Gloves or Slippers** and/or a **Heated Blanket** allow PALS to self regulate their comfort (assuming they can operate the controls.) Speaking of cozying up, **Microwave Heatable Bean or Corn Bags** are great under the covers at the foot of the bed on cold nights. The bags are small material sacks of dried corn or beans. You heat them for 2 minutes and they stay hot for 1-2 hours. It would be very easy make them by sewing a couple of rectangles of material together and filling them with corn. If the corn dries out you can sprinkle the bag with water before heating.

On the theme of comfort and bedtime, **Satin or Slippery Material PJs** make a perfect gift because they allow for easier movement. With ease and accessibility in mind, **Athletic Pants with Leg Zip-**

pers or Snaps make them easy to remove without taking off UFO braces.

If you are particularly close to a PALS and want to do something nice that's not just giving a gift, **volunteering** to perform chores that a PALS may not be able to do anymore would be a great help, especially around the holidays. Offering to **decorate the house** or **help do the shopping**. Perhaps you can offer a day to **clean the home** or **do outside work** that can't be attended to easily. Offering to make up **Pre-Addressed, Stamped Envelopes/Cards** for PALS to send out for family birthdays and anniversaries is a thoughtful and much appreciated gift.

Is technology your bag? There are many tech gifts out there to help make PALS lives easier and more fun. How about an **Audiobook** either as an online download or on CD? Turning pages on a traditional book becomes a task for PALS but books on CD or computer engage the mind and help keep up spirits. Try Audible.com. Or you can purchase a **Switch-Adapted Flip Camcorder**. It's a popular and very easy to use compact flash memory camcorder. Look it up at <http://rjcooper.com/flip/>

Lastly, perhaps one of your friends or relatives with ALS just needs you to drop by this holiday season. Say hello and spend some time. It's worth more than anything you can purchase in the store.

*Happy Holidays from
The ALS Association Greater New York Chapter.*