

# Spring & Summer 2008

## CALENDAR OF EVENTS

<b>May</b>			
<p><b>10th</b> Michael Bartone Scrum for Six Rugby Tournament West Marlborough PA</p> <p><b>10th</b> Three Arches Ladies Tea Party Three Arches Historic Home, 335 Trenton Road, Fairless Hills PA</p> <p><b>11th -13th</b> ALS Advocacy Days and Public Policy Conference Washington, DC</p> <p><b>17th</b> Seaside Board... Walk to Defeat ALS™ Hiering Ave. and the Boardwalk Seaside Heights, NJ</p>	<p><b>21st</b> ALS Charity Auction &amp; Autograph Party with the Lakewood BlueClaws Lakewood, NJ</p> <p><b>31st</b> Battle to Strike Out ALS Benefit Rugby Match West Chester, PA</p>	<p><b>20th &amp; 21st</b> Billy Lake Basketball Marathon Monsignor Bonner High School Drexel Hill, PA</p> <p><b>21st</b> 10th Annual ALS Express Bike Ride Four start points in NJ, end point in Wildwood, NJ</p>	
<b>June</b>		<b>July</b>	
<p><b>14th</b> Harrisburg Walk to Defeat ALS™ Riverfront Park, Harrisburg, PA</p> <p><b>19th</b> Auntie Anne's Golf Outing Hershey, PA</p>	<p><b>28th</b> 19th Annual Phillies Phestival Citizens Bank Park Philadelphia, PA</p>		

FOR MORE INFORMATION ON ALL OUR EVENTS, VISIT [WWW.ALSPHILADELPHIA.ORG](http://WWW.ALSPHILADELPHIA.ORG).

This Issue We

THANK & SALUTE

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**Our mission** is to lead the fight to cure and treat ALS through global, cutting-edge research, and to empower people with Lou Gehrig's Disease and their families to live fuller lives by providing them with compassionate care and support.



# GREATER PHILADELPHIA CHAPTER

# news

Spring 2008

## Save the Date!

### 19th Annual Phillies Phestival

**Monday, July 28, 2008**

5 pm, Live Auction 8 pm  
Citizens Bank Park – Rain or Shine  
Tickets on sale in June - Call the Phillies at 215-463-1000  
Admission - \$20

This year, the gates at Citizens Bank Park swing wide open at 5:00 PM for the 19th annual Phillies Phestival, the autograph party and auction to benefit ALS.

The event features the 2008 players and management signing autographs, Jimmy Rollins and Cole Hamels in photo booths, live and silent auctions and family games and entertainment. Come out to support the Chapter and the team while getting autographs from 2007 and 2006 National League MVPs Jimmy Rollins and Ryan



*PALS Barbara Levonbuck loved meeting pitcher Cole Hamels at last year's event.*

Howard, along with Pat Burrell, Jamie Moyer, Kyle Kendrick, Carlos Ruiz, Pedro Feliz, So Taguchi, Chase Utley, Coach Charlie Manuel and more.

Please visit the Chapter website [www.alsphiladelphia.org](http://www.alsphiladelphia.org), or check [Phillies.com](http://Phillies.com) for the most up to date information, including special guests and amazing auction items. Admission is \$20. The live auction which includes incredible sports memorabilia begins at 8 pm.

The Greater Philadelphia Chapter is proud to be the Phillies principal charity. In 2007, our record-shattering year, \$720,056 was raised for the Chapter through Phillies Charities Inc. The team helps the Chapter throughout the year by participating in our Annual luncheon, visiting the ALS Center at Penn, and representation at other special events when their schedules allow.



*John Weber, the team's vice president for sales and ticket operations pauses from the action with PALS Shelbie Oppenheimer, her daughter, Isabel and aide*

### PENNSYLVANIA ADVOCACY DAY



Over 30 advocates joined us on a blustery day in Harrisburg for our Third Annual Pennsylvania Advocacy Day at the state capitol. Representative Bryan Cutler, who lost both his parents to ALS, welcomed the group to the capitol before our advocates went on to met with their representatives and senators. Advocates also accepted a \$25,000 check for a grant to fund Assistive Technology equipment. The grant was sponsored by Rep. Josh Shapiro, Rep. Bryan Cutler, and Rep. Rick Taylor.

The Pennsylvania Advocacy Day is just a first step in our efforts to secure funding for ALS programs through the state this year. Look for more updates and requests to contact your legislators this Spring. For more information about our state advocacy efforts, contact the Chapter at [alsassoc@alsphiladelphia.org](mailto:alsassoc@alsphiladelphia.org) or 215-643-5434.✻

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## Board Chair's Message **BENJAMIN OHRENSTEIN**



February 11th was a bone chilling, windswept, bitterly cold morning – at least it was in Harrisburg. Walking approximately two blocks from a parking garage, in football field type open space, to the Pennsylvania State Capitol Building, was an experience that I knew I could have done without. The security guards at the entrance to the Capitol were unusually polite and patient and obviously well aware of the difficulty that day of what it meant just trying to put your hands in your pockets to take out the ice cold change and other metal in order to pass through the security entrance checkpoint. But, once through, you immediately entered the main rotunda of this absolutely beautiful building and there, that morning, you were almost immediately met by a group of some of the most warm-hearted, excited (as well as exciting), caring people, you would ever want to be with – volunteers from both The Greater Philadelphia Chapter and The Western Pennsylvania Chapter of The ALS Association. It was enough to make you promptly forget that you were an icicle at that moment.

We were all in Harrisburg that day to participate in our state ALS Awareness Day and, specifically, to meet with our state legislators to help educate them about the nature and cruelty of ALS and to seek their help in obtaining for the first time funding from the Commonwealth of Pennsylvania to help in strengthening our existing patient service programs and to reach into under served and rural areas throughout Pennsylvania in order to provide much needed services to ALS patients and their families who presently are going without.

We all first met as a group with members of the advocacy staffs from both Chapters and from National, who briefed us on and reviewed with us the message that we were to share with our legislators. The advocacy staffs were terrific and prepared us well for our meetings (and, with that in mind, I should tell you that our Chapter is blessed to have Jenny Ruth as our Communications Manager, who did an outstanding job in coordinating it all for The Greater Philadelphia Chapter). We then went on our appointed rounds to meet with our State Senators and Representatives, and their staff members. I was fortunate enough to be paired with Jeff Faull for two of my meetings. Jeff is a relatively young, personable, articulate, patient who so far is progressing fairly slowly, and is able to walk and talk without any apparent difficulty.

**We were all in Harrisburg that day... to meet with our state legislators to help educate them about the nature and cruelty of ALS and to seek their help in obtaining, for the first time, funding from the Commonwealth of Pennsylvania...**

Specifically we are asking the Legislature to support and include a line item in the sum of \$800,000 in the 2008-2009 state budget, the funds to be allocated between the two Pennsylvania Chapters for use throughout the state. In general terms we found that as a group we were well received. My experience was that they were generous in the amount of time they permitted us to spend with them, they appeared to be listening, they asked good questions, and for the most part they gave good responses. For instance, Jeff and I spent more than a half an hour with his State Senator, John Gordner. Senator Gordner indicated that he had a good friend who was an ALS patient and that as a result he was personally familiar with the disease. He was very warm to Jeff and though he, of course, could not promise that we would be successful in obtaining the line item, he promised that he would help. In turn, we made it gently clear that we would do all we could to see that he kept his promise.

## E.D.'s Musings **JIM PINCIOTTI, EXECUTIVE DIRECTOR**



team-work [teem-wurk] –noun

1. cooperative or coordinated effort on the part of a group of persons acting together as a team or in the interests of a common cause.

2. work done with a team.

The dictionary cannot fully describe the nuances of a word, especially one as ubiquitous as "teamwork". We at the Greater Philadelphia Chapter are blessed with a wonderful and powerful team. Part of that team is made up of the other ALS Association Chapters.

Each year the National ALS Association gets together for a Leadership and Clinical Care conference. It is a wonderful opportunity for members of all ALS Association Chapters to meet and discuss issues related to patient care as well as topics of importance to Chapter leaders.

In January, the Chapter was fortunate to have twenty people at the conference, including seven members from our Pennsylvania Hospital and Hershey Medical Center Clinic teams. Everyone that attended found the information

extremely valuable and the networking opportunities bountiful.

This year we were introduced to a new spokesperson for the Association. Angela Lansbury of "Murder She Wrote" fame has enthusiastically joined our efforts in the fight against ALS. Miss Lansbury has filmed a Public Service Announcement that will soon be airing nationwide to help raise awareness about ALS.

Dr. Lucie Bruijn, Science Director and Vice President of The ALS Association, led a very informative session on research. It is obvious from the presentation that there is currently more effort being directed in more avenues than ever before. It is encouraging as well as daunting to realize that we must continue to find more funds from public as well as private sources in order to bring the work from the research bench to the people with ALS that need it. We applaud and thank all that have helped us throughout the years to increase the Greater Philadelphia Chapter's role in Research funding. We need to keep the pressure on.

On the last evening of the Conference, the annual awards banquet is held. This year the Greater Philadelphia Chapter was proud to receive four awards including

awards for Excellence in Advocacy, For Excellence in Brand Identity and Public Awareness, and Excellence in Education in Patient Services. We were also one of eleven Chapters to receive the "Iron Horse" award for exceeding financial targets. I hope you can see that we are recognized by the national organization for our expertise and dedicated hard work for PALS.

This fight against ALS is a nearly overwhelming one and requires a large team to be successful. It is comforting to know that there are forty-one Chapters across the country that are members of the team. It is wonderful to have the resources and network of talented and committed individuals to share ideas and best practices. We are fortunate to be able to participate in the Annual Conference.

In a larger sense, we are fortunate to have all of our team members working together to support our families and to sponsor research. Just as on any sports team, each position is necessary for success and the more skilled the players, the more successful the team. Each of you plays a vital role - you are skilled, valued and vital teammates. Thanks for all you do to make a difference.

Our day in Harrisburg was an extremely positive experience, however, it represented only the first step in a lengthy budget process. We need YOUR continued help over the next few months to keep the issue of ALS funding alive and well before all of our state legislators. Please be in touch with your legislators. Tell them your personal stories, who you are and why you, your family, and your friends will be grateful to them if they champion our cause and support our request. It is of great importance that you do so, particularly in this economy. Please let us know at the Chapter level what we can do to help you help us all.

And, oh, yes, when I left the Capitol building that afternoon I was pleased to realize that it no longer felt bitterly cold to me. ❁

## Greater Philadelphia Chapter Receives Four Awards

The Greater Philadelphia Chapter was the proud recipient of four awards at the National ALS Association Leadership Conference in January 2007:

- Excellence in Brand Identity and Public Awareness
- Excellence in State Advocacy
- Excellence in Innovation for Patient Services for our educational ALS in-service video for healthcare workers
- Iron Horse Award for Outstanding Achievement in Revenue Development and Expense Management

## You Should Not Take Lithium Just Yet



Leo McCluskey,  
MD



Mary Kelley,  
MSN, RN, CRNP

A recent article in the *Proceedings of the National Academy of Science* (Fornai, F., et al. Lithium delays progression of amyotrophic lateral sclerosis. PNAS 105(6): 2052-2057. 2008) reported the results of a small clinical trial in which a group of 16 individuals with ALS (8 males, 8 females) were randomly selected to receive lithium carbonate (Li) at 150 mg twice a day along with Rilutek 50 mg twice a day. This group was compared to a group of 28 individuals with ALS (12 males, 16 females) selected to receive Rilutek 50 mg twice a day. Both groups had 7 bulbar onset patients. The average age of the Li group was about 67 years old vs. 71 years old for the Rilutek only group (control group). Li levels were monitored by a physician so Li dosing could be adjusted between 300 and 450 milligrams per day in order to achieve a safe and therapeutic plasma level.

The subjects were assessed at baseline and every 3 months for a total of 15 months. The primary endpoint was survival. The secondary endpoints were the ALS Functional Rating Score Revised (ALS-FRS-R), the Norris ALS scale, quality of life (using the SF-36), quantitative manual muscle strength (MRC scale) and the forced vital capacity (FVC). At the start of the study the two groups had similar baseline values for these measurements. The FVC's at the start of the study were

similar (79%-99% in the Li treated group and 81%-101% in the control group). Over 15 months there were no deaths in the Li treated group; 29% of the control group died. Compared to the control group the Li treated group also demonstrated significantly less decline in the FVC, ALS-FRS-R, Norris scale and MRC scale over the 15 months of the study. These results led the authors to conclude that Li delays ALS progression in human patients.

So why not take Li now? These compelling results need to be confirmed in a larger study before Li should be recommended to all ALS patients. Of particular concern is that Li is a very toxic drug that has a very

“When you consider the entire picture, ALS patients are at a significant risk of developing Li toxicity that in some cases may produce only troubling symptoms.”

narrow therapeutic window. What does this mean? The blood level at which Li is effective and largely safe is very narrow and even a slight elevation of the blood level of Li can result in significant toxicity. Li toxicity may result from an accidental or purposeful overdose of the medication. Li toxicity can also be caused by dehydration caused by inadequate intake of fluids or the loss of bodily fluids that can arise because of vomiting, diarrhea, excessive sweating and use of diuretics or water pills. Li toxicity can also be

caused by the use of medications that may cause a rise in the blood level of Li. (Table 1). The potential side effects of Li range from mild and common to more severe and rare. (Table 2)

When you consider the entire picture, ALS patients are at a significant risk of developing Li toxicity that in some cases may produce only troubling symptoms in addition to the symptoms of ALS, but that in other cases may produce severe symptoms that may actually increase their level of disability. The side effects of Li (Table 2) can make some of the symptoms of ALS, such as weakness, imbalance and slurred speech, worse. Li side effects are more common in the elderly. Since the average age of onset of ALS is about 60 years old this is of particular importance for ALS patients. Given the typical age of onset of ALS it is also likely that many individuals may also suffer from other conditions such as heart disease, other vascular disease and kidney disease that may require the use of some of the medications such as ACE inhibitors and diuretics that may induce Li toxicity (Table 1). Some of the medications to avoid when taking Li are commonly used to treat some of the symptoms of ALS. Selective Serotonin Reuptake Inhibitors (SSRIs) such as Zoloft® and Prozac® are commonly prescribed for depression in ALS and are also used frequently to treat the symptoms of pseudobulbar affect (inappropriate laughing/crying). Pain medications such as the non-steroidal anti-inflammatory medications (NSAIDs) like Motrin® and Naprosyn® are used often in ALS. Dehydration that can result in Li toxicity may be a particular concern in some ALS patients. Those patients with

(Continued on page 9)

## Research Update

### THE ALS ASSOCIATION WORKS WITH INVESTIGATORS ON FOLLOW UP STUDY OF LITHIUM FOR TREATING ALS

[Quick Summary: An Italian study of 44 people reports that a 15-month trial found that daily doses of the drug lithium, used to treat bipolar disorder, significantly slowed the progression of ALS in patients also taking riluzole, the only FDA-approved drug for the treatment of Lou Gehrig's disease.]

The ALS Association is working with investigators and funding organizations to plan a follow up clinical study of lithium as a treatment for ALS.

The 15-month trial conducted on 44 people with amyotrophic lateral sclerosis, commonly known as Lou Gehrig's disease, reported that the progressive neurodegenerative disease was slowed significantly in patients receiving daily doses of lithium along with riluzole, the only drug approved by the U.S. Food & Drug Administration for the treatment of ALS.

Francesco Fornai at the University of Pisa (Italy) with colleagues at the University of Novara (Italy) and the Santa Lucia Foundation in Rome, demonstrated that lithium was neuroprotective and increased survival in the mouse model of ALS. These promising results led to the clinical study.

“The results of the study are very encouraging, however the number of patients in this trial is small, and a larger trial

would be needed to confirm that lithium is beneficial in ALS,” said Lucie Bruijn, Ph.D., science director and vice president of The ALS Association. Lithium has known benefit in bipolar disease and is currently being explored in other neurological disorders. The increasing numbers of studies aimed at understanding the biological mechanisms that may be involved in the neuroprotective effect of this agent and the pharmacological data that is available make this an attractive compound to pursue in further studies.

“It will be important to determine the appropriate dose and whether the beneficial effects are due to lithium or the combination of lithium and riluzole as all participants were also taking riluzole,” Bruijn said.

“The safety of administering lithium to people with ALS has not been carefully explored, and if lithium is helpful for ALS, the optimum dose would need to be determined,” Bruijn said. Lithium is toxic at higher doses and careful monitoring of blood levels of lithium as well as laboratory blood tests of kidney and liver function need to be performed. Clinicians caution that lithium may interact with other medications

The ALS Association urges people with ALS to consult their primary care physician and discourages the use of lithium before appropriate trials have been coordinated. The Association is working to expedite these studies and will keep the community informed. ❁

## New Board Members Elected

The Greater Philadelphia Chapter is proud to announce the recent election of two new members to the Board of Overseers.

**Ellen Farber Kurtzman** is Executive Director of the Farber Family Foundation. The Foundation is primarily involved in supporting research efforts in the Neurosciences and providing general support in health, education, Jewish and cultural programs in the Philadelphia area. She is also on the Governing Board of the Farber Institute for Neuroscience of Thomas Jefferson University. Ms. Kurtzman serves as the Treasurer of Security on Campus, Inc., a Philadelphia based National not-profit organization which focuses on college campus safety issues and is on the Board of Directors of the Abramson Center for Jewish Life and The Polisher Institute.

**Wes Rose** is an Assistant Professor of Biology at Arcadia University in Glenside, Pennsylvania, where he teaches Cell

Biology, Microbiology, and Immunobiology. His research examines the mechanisms of immune-mediated clearance of viruses from the central nervous system. Wes earned his B.A. in Biology from Franklin and Marshall College, his M.S. in Biomedical Chemistry from Thomas Jefferson University, and his Ph.D. in Biology from the University of Pennsylvania. Since being diagnosed with ALS in May 2005, he has become active in ALS advocacy at the state and national levels. He has also participated in the Greater Philadelphia Walk to Defeat ALS as the captain of team Absolutely Living Strong!!, which has raised over \$90,000 during the past three years. Wes and his wife Kelly, a family physician, live in Glenside, PA with their two sons, ages 6 and 3. ❁

# 2008 ALS Advocacy Day

## HELP US CONTINUE TO TURN HOPE INTO ACTION

Advocates from across the country will gather in Washington, DC on May 11-13 for The ALS Association's eleventh annual National ALS Advocacy Day and Public Policy Conference. The conference provides an opportunity for the ALS community to join together, share their experiences, and learn the latest information about ALS research and advocacy. The conference also empowers the ALS community, helping to turn their hopes into action.

This year's conference will begin on Sunday afternoon, May 11, with the 5th annual Candlelight Vigil taking place later that evening. The conference will continue with educational breakout sessions on public policy issues of significant importance to the ALS community on Monday, May 12, and conclude with our day on the Hill on Tuesday, May 13. The

2008 Advocacy Day is your opportunity to bring your ALS story to Washington, and advocate for increased awareness and support.

For more information about the 2008 National ALS Advocacy Day and Public Policy Conference, visit [www.alsa.org/policy](http://www.alsa.org/policy) or contact Julie McKeever at 215-643-5434 ext. 26 or [julie@alsphiladelphia.org](mailto:julie@alsphiladelphia.org). ❁

**SAVE THE DATE: 2008**

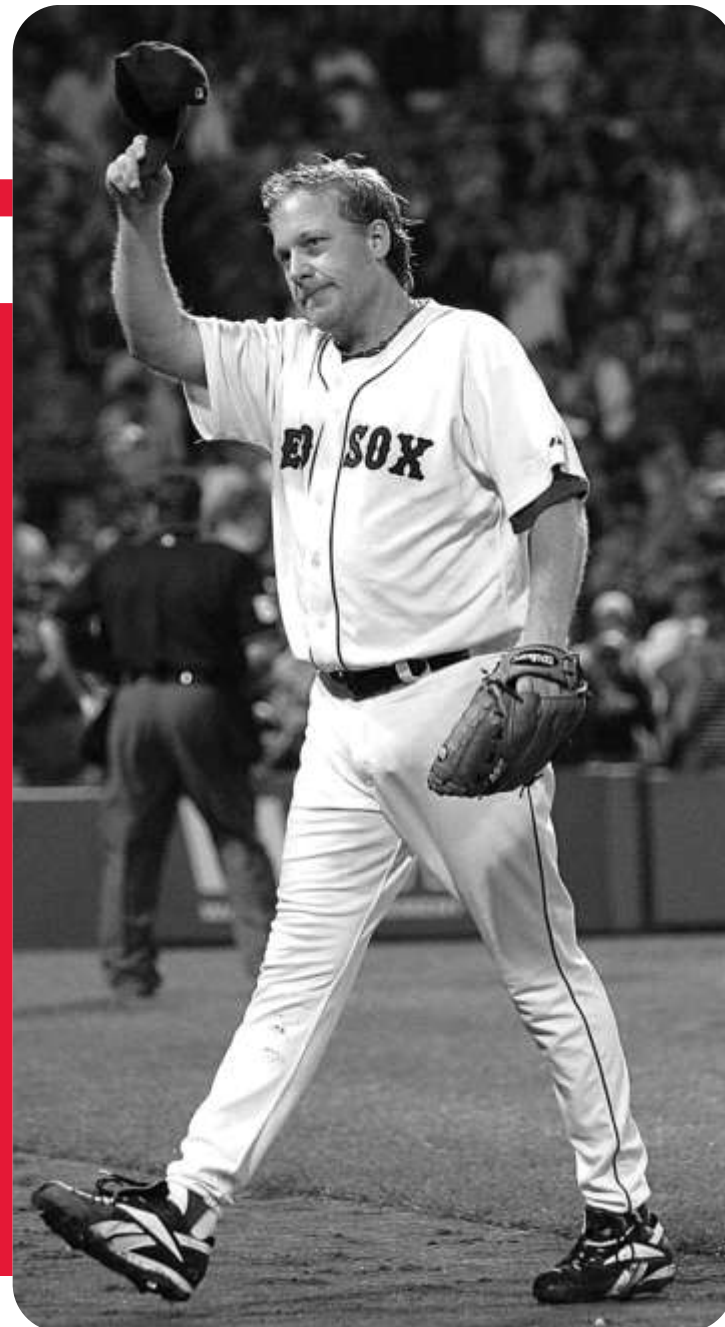
ALS Advocacy Days  
in Washington, DC  
will be held on  
May 11-13, 2008.

### Curt's Pitch

We have reached "The Final Innings" for our Curt's Pitch Program. With Curt's last year of major league pitching upon us it's your last chance to be a part of the Curt's Pitch Program to Strike Out ALS!

The 2008 season of Curt's Pitch for ALS has been thrown a curve. Due to his shoulder injury, Curt Schilling will be unable to pitch for the better part of the first half of the season. This will not prevent the 2008 season from being a success! Curt and Shonda have decided that this year, each chapter of The ALS Association that employs the Curt's Pitch program, will benefit based on the performance of pitchers local to each respective chapter. For the Greater Philadelphia Chapter, the Schillings have chosen to donate based on Cole Hamels' statistics during the 2008 season.

Please see our website at [www.alsphiladelphia.org](http://www.alsphiladelphia.org) to make your donation or contact April Haas at [april@alsphiladelphia.org](mailto:april@alsphiladelphia.org) with any questions or to receive a brochure!



Periodically in this Newsletter we will profile a new member of The Lou Gehrig Legacy Society, which is a special group of donors who have included The ALS Association in their long-term plans through a bequest, life-income gift, or other planned gift arrangement.

In this issue we are pleased to introduce new Society members, Jennifer & Helen Rimerman.

### Remembering the Chapter in Your Will Can be a Family Affair

One summer day in 2005, Jennifer Rimerman noticed something different about the sound of her father's footsteps coming down the hall, and by autumn it was thought that her dad, Morton W. Rimerman, might have Parkinson's disease. But Helen Rimerman, Morton's wife of 46 years, sensed that it was something else. "He just didn't have many Parkinson's symptoms," Helen recalls, and so the family kept searching for answers. On December 5, 2005, Morton visited the ALS Clinical Care Center at Pennsylvania Hospital in Philadelphia, a day that would forever change the Rimerman family's lives. Morton was diagnosed as having Lou Gehrig's Disease.

"They're the greatest group of people that you hope to never have to meet," was how Morton affectionately described the care team at the ALS clinic to friends.

A retired PECO Energy Company executive, Morton led an extremely active life. He served on the boards of several non-profit organizations as a way to give back to the community, and enjoyed many hobbies including woodworking, chair caning, and furniture making. Unfortunately, Morton's ALS progressed very rapidly. He lost his battle to the disease on Valentine's Day 2006 at the age of 76, only 8 months after the initial onset of symptoms.



According to Jennifer, Morton was a highly detail-oriented person who had given careful consideration to his estate plans throughout his adult life. By contrast, eighteen months after her father's death, Jennifer was involved as the only next of kin in an aunt's will that was written in

1939. Through this experience, Jennifer learned how a lack of proper planning and updating one's will can be damaging, which motivated her and Helen to look at their own estate plans with fresh eyes.

Jennifer and Helen knew that they wanted to leave something to The ALS Association out of appreciation for the many free



Jennifer Rimerman (center) and her mother, Helen, with the late Morton W. Rimerman.

services that Morton received from the Chapter including in-home care, loaned medical equipment, counseling, and of course his visits to the ALS clinic. However, they also wanted to provide for each other, first, before making any charitable distributions through their respective estates. The solution was relatively simple. In each case, The ALS Association is named as a secondary beneficiary in their wills. In Helen's will, Jennifer is named as the primary beneficiary with The ALS Association listed in the second position, and likewise with Jennifer's will.

"We are a small family and felt completely lost when my father was diagnosed with ALS," Jennifer remembered. "The Greater Philadelphia Chapter was there for us every step of the way throughout my dad's illness and became like extended family," she added. "In thinking about our estate plans, it was very natural for us to include the Chapter. After all, family comes first!" ❁

For more information about planned giving, contact Jeff Cline at 215-643-5434 ext. 16 or [jeff@alsphiladelphia.org](mailto:jeff@alsphiladelphia.org).

## Patient Profile: Jeffrey Faull



### IN THE BEGINNING...

Jeff Faull describes the first sensations of ALS as a sudden total loss of fine motor movement while performing the delicate task of threading a nut onto a bolt on the crawler at the Kennedy Space Center. "We were installing a temperature monitoring system in September 2005 and my left hand just wouldn't cooperate. I thought it was a pinched nerve. So, I'd ask my co-worker to crack my back and an hour later I was dandy. That went on for about a year and a half."

But, that was just the beginning for Jeff and his family. "During my employer, SKF's (a supplier of products, solutions and services in rolling bearings, seals, mechatronics, services and lubrications systems) business meeting in Charlotte, NC, I couldn't hold the plate at the buffet. My hand was so weakened."

This former eight-year US Navy Veteran was about to begin the most difficult mission of his life – when asked by his family doctor, "Do you have any idea what could be wrong?" I replied, "Yes, this could be ALS." Spoken like a true matter-of-fact man from Mifflinburg, PA. "I eventually found Dr. Zach Simmons at the ALS Center in Hershey and he confirmed the diagnosis."

"I have been aboard the USS Theodore Roosevelt for two Mediterranean missions – I was there for Operation Allied Force during the Kosovo crisis and Southern Watch (immediately after Desert Storm). I was a nuclear electronics technician/reactor operator. And

with each mission, I was leaving my loving wife Tammy, whom I married a month before boot camp, and my two daughters, Breanna and Tiffany who are now 12 and 14. I left the military in September 2000 to be with my family."

"The only problem was the Veterans Administration did not have the programs in place to help Vets like me, who basically risked their lives for their country, when something like ALS strikes."



### MY NEW MISSION...

"That's why I am on The ALS Association's Veterans Issues Team. I am assisting the Team in compiling a guide to benefits for veterans with ALS. My main goal is to see ALS services covered immediately upon diagnosis. Right now veterans have to show symptoms within a year of discharge. If you show symptoms more than 14 months after you're discharged, you won't receive presumptive service connection. Look at Multiple Sclerosis – there is a seven year presumptive connection. For ALS it's one year. I'm doing my best to become an advocate. I've been to Pennsylvania ALS Advocacy Day in

Harrisburg and will meet my congressman Carney and Senators Specter and Casey in Washington in May."

### HATE THOSE ZIP LOC BAGS...

"I'm one of the lucky ones as my progression in the last year and a half has been rather slow and I can still work out of my home. I just received a promotion in January. But, Zip Loc Bags – that's another story. I simply cannot open them. I know my arms are getting weaker, but I have great hope. Right now, I have two main goals, both stemming from the years I gave to my country.

1. Making sure ALS services are covered by the VA immediately upon diagnosis, thus streamlining Veterans' benefits.

2. Implementing my website [advocate4ALS.org](http://advocate4ALS.org) - Advocating and educating the public about this disease is a job in and of itself and as such it is the only focus of this site. "

In addition to these two projects, Jeff is working on the chapter's new "Walk in a Box" for the Mifflinburg area. If you can help out with this volunteer-driven Walk to Defeat ALS™ please contact him at [Jeff.Faull@gmail.com](mailto:Jeff.Faull@gmail.com).

Jeff is accustomed to overcoming obstacles. With his experience in the Navy, problem-solving skills at work, and a loving family behind him, he is ready for the challenge. ❁

## Community of Hope Funds to Honor & Remember Become a Champion for a Cure in 2008



People who are affected by ALS are not alone. The 350,000 people worldwide who suffer from Lou Gehrig's disease - and those who have lost loved ones - need to know they are part of a bigger community -- The ALS Association's Community of Hope<sup>SM</sup>.

Make 2008 an historic year in the fight against ALS by starting your own Community of Hope<sup>SM</sup> Fund today! People who create a Community of Hope<sup>SM</sup> Fund are called Champions. As a Champion you will have your own Hope Fund web page to honor someone's fight against ALS, spread the word about Lou Gehrig's Disease, and raise funds to support critical patient services programs and ALS research.

Imagine the joy of seeing a Hope Fund created in honor of someone special— or in memory of a loved one who has passed away. Whether it is reading the online guest book, receiving emails when donations are made, or looking through online photo albums, lasting memories will be created for those touched by your on-line Hope Fund.

Visit the Community of Hope<sup>SM</sup> Champion Center on the Greater Philadelphia Chapter's website at [www.alsphiladelphia.org](http://www.alsphiladelphia.org) and learn, first hand, that building a Hope Fund is as easy as 1-2-3.

For more information contact Roxanne Walter, Manager of Sponsor Relations, 215-643-5434, ext. 43. ❁

## You Should Not Take Lithium Just Yet

*Continued from page 4*

swallowing difficulty may have trouble drinking enough liquids to maintain hydration. Patients with mobility issues that make getting to the bathroom difficult if not impossible may purposefully restrict their fluid intake and thereby become dehydrated.

I hope, as I know you do, that Li will turn out to be an effective drug to retard the progression of ALS. Only a larger controlled clinical trial will give us the answer and evidence needed to recommend Li for all ALS patients. The ALSA Center at Penn is currently involved in a worldwide effort to make this happen. Until the results of such a study do prove that Li is effective, you should avoid taking this potentially dangerous medication. ALSA and the MDA have issued warnings in this regard.

If you do decide to take Li please do so only under the careful guidance of a physician who is well informed regarding the dosing, drug interactions and potential toxicities of this drug. You should inform your ALS physician

as well since the use of this drug may impact your symptoms and overall management.

### Table 1: A Partial List of Drugs That Should be Avoided When Taking Lithium

Haloperidol (Haldol); Nonsteroidal anti-inflammatory drugs (NSAID) such as ibuprofen (Motrin, Advil, Nuprin, others), ketoprofen (Orudis, Oruvail, Orudis KT), naproxen (Aleve, Anaprox, Naprosyn, others), indomethacin (Indocin), oxaprozin (Daypro), piroxicam (Feldene), nabumetone (Relafen), and others; Diuretics (water pill) such as hydrochlorothiazide (HCTZ, HydroDiuril, others), furosemide (Lasix), triamterene (Dyazide, Dyrenium, Maxzide); Angiotensin-converting-enzyme inhibitors (ACE inhibitor) such as benazepril (Lotensin), lisinopril (Zestril, Prinivil), fosinopril (Monopril), captopril (Capoten), enalapril (Vasotec), quinapril (Accupril), and ramipril (Altace); Calcium channel blockers such as diltiazem (Cardizem, Dilacor XR) or verapamil (Calan, Isoptin, Verelan); Selective serotonin reuptake inhibitor (SSRI) such as fluoxetine (Prozac, Sarafem), fluvoxamine (Luvox), sertraline (Zoloft), paroxetine (Paxil), or citalopram (Celexa); Carbamazepine

(Tegretol); Metronidazole (Flagyl); Theophylline (Theo-Dur, Theo-Bid, Theolair, Elixophyllin, Slo-Phyllin, others).

### Table 2: Potential Side Effects of Lithium

#### Most common:

Increased thirst, increased frequency and urgency to pass urine, muscle twitches, skin rash, tremor, stomach bloating, full feeling, trembling of the hands, diarrhea, drowsiness, loss of appetite, muscle weakness, nausea, vomiting, slurred speech, reduced kidney function.

#### Most severe:

Parkinson-like disorder, blurred vision, clumsiness or loss of balance, confusion, hallucinations, coma, fever, muscle rigidity, dizziness, seizures, severe tremor, cardiovascular collapse.

#### Rare or uncommon:

Difficulty speaking or swallowing, fainting, hair loss, hoarseness, slow or fast irregular heart beat, painful coldness or blue discoloration of fingers or toes, underactive thyroid gland causing rough, dry skin, sensitivity to cold, weight gain, goiter, fatigue/weakness. ❁

## Baltics or Bust for the Lodishes!

Len and Susan Lodish are at it again! For the 13th consecutive year, this amazing couple will be setting out on their bicycle built for two to raise money for ALS. This year the Lodishes are heading across the Atlantic to ride in the Baltic republics of Estonia, Latvia, and Lithuania from June 8 to June 25. Since the inception of their ride, the Lodishes have raised well in excess of a half million dollars for ALS research and patient services.

The impetus for the ride began in 1996 after Len's cousin, Dr. Jules Lodish of Bethesda, MD, was diagnosed with ALS. That year the Lodishes rode from California to Delaware, and since then have challenged themselves with trips up and down the east and west coasts of the United States, across the Midwest and New England, through Scandinavia, Argentina, Uruguay, Germany, Austria and Hungary, Australia, China, and Israel.

In keeping with a tradition started three years ago, the Lodishes have once again agreed to match any funds raised over \$100,000.

Visit [www.alsphiladelphia.org](http://www.alsphiladelphia.org) to make a donation today.



## Upcoming Walks To Defeat ALS™

### 2008 Seaside Boardwalk Walk to Defeat ALS™

Saturday, May 17, 2008  
Hiering Avenue and the Boardwalk  
Seaside Heights, NJ

**Registration:** 9:00 a.m.  
**Walk Starts:** 10:00 a.m.

For more information please contact Allison Walker at 215-643-5434 ext. 27 or [Allison@alsphiladelphia.org](mailto:Allison@alsphiladelphia.org).

### 2008 Harrisburg Walk to Defeat ALS™

Saturday, June 14, 2008  
Riverfront Park  
Harrisburg PA

**Registration:** 9:00 a.m.  
**Walk Starts:** 10:00 a.m.

Last year's walk welcomed 1500 walkers and raised over \$226,000. This year's goal is to raise \$250,000. For more information or to start a team please go online to [www.alsphiladelphia.org](http://www.alsphiladelphia.org) or contact Marianne Mancini at 215-643-5434 or [marianne@alsphiladelphia.org](mailto:marianne@alsphiladelphia.org)

## Save the Date for our Fall Walks!

More information and online registration at [www.alsphiladelphia.org](http://www.alsphiladelphia.org)

### 2008 Rehoboth Walk to Defeat ALS™

Saturday, September 13  
Rehoboth Beach, DE

### 2008 Ocean City Boardwalk Walk to Defeat ALS™

Saturday, September 27  
Ocean City, NJ

### 2008 Lehigh Valley Walk to Defeat ALS™

Saturday, October 11  
Lehigh Valley College  
Saucon Valley, PA

### 2008 Greater Philadelphia Walk to Defeat ALS™

presented by Thriftway/Shop N Bag  
November 2008  
Citizens Bank Park  
Philadelphia, PA

## How to find free money for The ALS Association

Are you leaving money on the table by not having your donation to The ALS Association matched by your employer?

A corporate matching gifts program is the easiest way for a company to support its employees' charitable contributions and increase the impact of your gift. These programs allow employees to make contributions to the organizations they are most passionate about, while increasing their donations through corporate matching. This means it's easy for you to double or sometimes triple your tax deductible gift to The ALS Association. Employer matching gifts may also be available to you if you are the spouse of an employee, a retired employee or the spouse/widow/widower of a retiree.

**How to find out if your company matches your charitable donations:**

- Contact your human resources manager or community initiatives director.

- Check your company's intranet website. Many companies have an online form and process.
- Learn what the matching gifts program guidelines are. Many require a minimum donation within a specific time frame for the matching gift request to be completed. For example, minimum \$25.00 donation with \$5,000 matched per employee per year.

Throughout the year, remember to submit your Walk to Defeat ALS, Hot Chocolate, other events or general donations to have them matched by your employer. With very little effort you too can find and take advantage of free money to support the programs and services of the Greater Philadelphia Chapter. Take the time to find out if your employer has a matching gifts program. You will be glad you did . . . and so will we!

## WE THANK OUR WALK SPONSORS

Presenting Sponsor of the Greater Philadelphia Walk to Defeat ALS™ - THRIFTWAY/ SHOP N BAG

AmRamp  
Auntie Anne's  
Bayada Nurses  
Capital Health System  
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Momentum Female Fitness Center

Neutrik, USA, Inc.  
Phantom Entertainment  
Kelly and Al Slipakoff  
St. Mary's Medical Center  
The River 97.3  
Wakefern Food Corporation  
WOBM

## Our sponsors help make our Walks to Defeat ALS a success!

To learn more about the benefits of becoming a walk sponsor, please contact Allison Walker, Marianne Mancini, or Julie McKeever at 215-643-5434 or toll-free 1-877-GEHRIG-1.



## Hot Chocolate: Take a Bite Out of Chocolate, March 13, 2008

Guests take a moment to pose for a picture before sampling the chocolate treats.



This year more than 400 guests attended the event and helped to raise more than \$57,000. Ben 95.7 Host, Joey Fortman, served as the emcee of the evening.

**PALS Denise Naylor and her husband, Cliff, enjoy chocolate martinis in front of the Shark Exhibit in Currents – the Ballroom at Adventure Aquarium.**



In addition to the great food and fantastic venue, the event featured a Silent Auction that included trips to Punta Cana (courtesy of Cheapcaribbean.com) and St. Thomas (courtesy of Bolongo Bay Beach Resort) as well as a tour of

Daily News Live (courtesy of Michael Barkann) and many more exciting items.

**Event co-chairs Gila and Orit Aviram spearheaded the evening.**

Special thanks to all committee members who helped to make this year's event such a success: Lauren Albert, Rachel Ben-Ari, Ted and Lauren Collins, Heath Davis, Eric Frank, Larry and Jill Kaplan, Dawn McEleney, Kathryn Meloni, Esq., Heather Pecharo, David and Robin Ricci, Kelly Rose, Gwenn Rubin, John Whitner, Elyse Willey and Lauren Stevenson Yacina.



Chocolate covered strawberries courtesy of Loews Philadelphia Hotel were just one of the many treats guests sampled. Other treats included two chocolate fountains from Pastry Pleasures, a Turkey Hill Dairy ice cream bar, worldclass, gourmet hot chocolate from Sazon Restaurant and Café, chocolate treats from the Hershey Company, Astor Chocolates, Ann Hemyng Candy, Inc., Zitner's Fine Confections, Blasius Chocolate Factory, Bayards Candy, Gertrude Hawk, Betty the Caterer, Tastykake, Just Born, Inc., Crazy Susan's Cookie Company, The Bakery House, Wegmans and Starbucks. Guests were also treated to Chocolate Martinis courtesy of Pravda Vodka and Glam Restaurant and Lounge.



**Guests take a break from chocolate to enjoy the Shark Exhibit at Adventure Aquarium.** Sponsors for the evening's festivities included American Advertising Company, American Flux and Metal, BEN FM 95.7, The Ben-Ari Family, The David Cutler Group, David Michael & Company, Fairmount Printers, The Hershey Company, Kaplin Stewart Meloff Reiter & Stein, P.C., Susan A. Katz, KPMG, LLP, Carol Lupo, CIMA and UBS Financial Services, Pravda, Pulmonology Associates, Anne P. Rudoler, Rudoler & DeRosa, LLC, Social Philly.com, Turkey Hill Dairy and Mr. and Mrs. David Twing



Dan Quinn and Patti Lake Quinn – The Chapter's All-Stars

On February 1, the 16th annual **Billy Lake Memorial Beef & Beer** to Fight ALS raised \$8,000 for ALS research and sponsorship of the Phillies Phestival. Dan Quinn and Patti Lake Quinn and their family and friends work tirelessly each year for the Chapter. This event, held at the Knights of Columbus, Mater Dei in Newtown Square, PA was no exception. A great silent auction and music provided by the incredible O'Fenders contributed to the festivities.



## Upcoming EVENTS

### 3 Arches Tea Party

Ladies Tea Party to benefit The ALS Association. Join in on the Hawaiian Tea-Ki Hut themed Tea Party on May 10th. With lunch and a Silent Auction it's sure to be a fun filled afternoon. Please visit their website for more information at [www.threearches.info](http://www.threearches.info)

### Battle to Strike Out ALS

The Philadelphia Fight Rugby League Club, Kildare's Irish Pub and the ALS Association, Greater Philadelphia Chapter present:

**"Battle to Strike Out ALS"**

**1:00 pm**

**Saturday May 21, 2008**

**Farrell Stadium on the campus of West Chester University, West Chester, PA.**

Come see perennial AMNRL powers the Philadelphia Fight and Jacksonville Axemen clash in Rugby League action in the opening game of the 2008 AMNRL season. If you like football, you are going to love Rugby League! For more information, please visit [www.fightrugby.com](http://www.fightrugby.com)

### ALS Charity Auction and Autograph Party with the Lakewood BlueClaws

**Wednesday, May 21st**

**Location to be announced**

**5:00 and 7:00 p.m. seatings**

### 17th Annual Billy Lake Basketball Marathon

Hundreds of area basketball players will take to the court on Saturday, June 21 at the 17th Annual Billy Lake Memorial Basketball Marathon at Monsignor Bonner High School in Drexel Hill, PA to raise money for the Billy Lake Memorial ALS Research Fund. The event has raised \$300,000 through the years. A celebrity team of local personalities and reporters will be on hand to battle the Lake Team and you are invited to watch them play from 11 am to noon. For more information about the event, visit [www.billylake.com](http://www.billylake.com).

### Young Friends of the ALS Association

**"The human race has one really effective weapon, and that is laughter."** –Mark Twain  
Well on Thursday, January 31st, the Young Friends laughed so hard their cheeks hurt! More than 30 Young Friends of The ALS Association came out to Helium Comedy Club for Happy Hour and a show. A great time was had by all! Don't forget to check out the Young Friends on our website and on myspace.com.



### 10th Annual ALS Express Bike Ride

Join us on Saturday June 21, 2008 for the 10th Annual ALS Express Bike Ride presented by The Eileen Frank ALS Foundation!

Visit their website at [www.als-express.org](http://www.als-express.org) for more information and to register your team or yourself TODAY!

# Patient Services **EVENTS**



Nurse Sue Walsb at the new ALS Clinic facility

## News from South Central

The Penn State Hershey ALS Clinic recently moved to its new home in the New East Campus Outpatient Health Campus Outpatient Facilities! The new facility is located on the campus of the Hershey Medical Center at 30 Hope Drive. Driving directions can be found on our chapter web site at the Hershey clinic link. The move to this new facility will allow us to provide ALS clinic appointments every Wednesday to a larger number of patients and their families.

The increase in space will also allow us to provide communication assessments in the ALS clinic. We also have a new conference room available for our ALS support group and other patient meetings on the first floor adjacent to the ALS clinic. When you come to our new site it is best to use Entrance B.

Judy Lyter, RN, MS, LPC who has been our mental health counselor and support group facilitator joined the chapter as full time employee in February. We are grateful to have her expertise available to our patients and families. Judy will continue to see patients in our ALS clinic and be available for consultation by phone or home visits. Her contact information is Judy@alsphiladelphia.org or 717-566-1700.

The Harrisburg Walk to Defeat ALS is June 14-- join us in supporting our patients and families in South Central.

## Memorial Service

**For our Families, Honoring our PALS**

The Chapter's annual Memorial Service was held in late March, at the Mainline Unitarian Church in Devon, Pennsylvania.

The event brought together family, friends, Chapter staff and board members to honor loved ones who have passed away from ALS. Holly Bennett, new Philadelphia Chapter Board member, gave an inspirational message. Jeanne Johnson, Director of Administration, is also a talented soprano and, along with pianist Linda Pennington, provided the music for the service. In what has become a much-anticipated event, the 2007 Memory Quilt was unveiled, as designed and quilted by Alisa Brownlee, the Philadelphia Chapter's Assistive Technology Specialist. The quilt is made of individually-crafted blocks, contributed by family, friends, and staff, honoring loved ones who passed away in the last year. If you would like to view the memory quilts, check in at the Chapter's web site ([www.alsphiladelphia.org](http://www.alsphiladelphia.org)). The new 2007 quilt will be hung at the Chapter offices in Ambler after traveling to be shown at selected ALS education and awareness events. The Memorial Service is an important event for the staff at the Philadelphia Chapter, and we were honored to have the opportunity to share in the Memorial service with so many of our family members.

## Paula Rich to Retire

Paula Rich, the Chapter's Nurse Coordinator in northeast and north-central Pennsylvania, will retire in June after over 13 years of working with people with ALS, and 40 years in nursing. Paula started work with the Chapter in 1995 on a contract basis, and two years later was hired on as a Chapter employee. Her dedication to our patients and commitment to our mission have helped hundreds of people over the years.

She plans to spend her retirement gardening, traveling with her husband, and maybe even helping out the Chapter with some special projects. We thank Paula for her service and wish her a wonderful retirement.



Paula Rich, Regional Nurse Coordinator, will retire in June.

## PROFESSIONAL STAFF

<b>EXECUTIVE DIRECTOR</b> James V. Pinciotti	<b>STAFF NURSE</b> Christine D'Angelo, RN, BSN	<b>DATABASE SPECIALIST</b> Alexandra Komarovskaia
<b>DIRECTOR OF PATIENT SERVICES</b> Brenda Edelman, LCSW, BCD	<b>SOCIAL WORKERS</b> Wendy Barnes, MSW, LSW Shelley S. Hill, MSW, LCSW Susan Schwartz, ACSW, LSW	<b>MANAGER OF SPONSOR RELATIONS</b> Roxanne Walter
<b>DIRECTOR OF ADMINISTRATION</b> Jeanne A. Johnson	<b>EVENTS MANAGER</b> Allison Walker	<b>ADMINISTRATIVE STAFF</b> Nilda Mallatratt Patient Services Assistant
<b>CHIEF DEVELOPMENT OFFICER</b> Jeff Cline	<b>EVENTS COORDINATORS</b> Julie Morrison McKeever Marianne Mancini Stacy Simon	<b>Mary Sharp</b> Receptionist/Office Assistant
<b>MENTAL HEALTH NURSES</b> Jennifer Klapper, APRN, BC Judy Lyter, RN, MS, LPC Connie Eriksson, RN, MSN, CS	<b>EVENTS ASSISTANT</b> April Haas	<b>Maryann Vagnoni</b> Executive Assistant
<b>ASSISTIVE TECHNOLOGY SPECIALIST</b> Alisa Brownlee, ATP	<b>DEVELOPMENT COORDINATOR</b> Joan Borowsky	<b>TRANSPORTATION VAN DRIVERS</b> John Conner Thomas R. Mitchell Gerry Neal
<b>COMMUNICATIONS MANAGER</b> Jenny Ruth	<b>SENIOR INFORMATION TECHNOLOGY MANAGER</b> Nora Isaac	<b>FINANCE STAFF</b> Erin Farrell Accounts Payable Coordinator
<b>REGIONAL NURSE COORDINATORS</b> Gail Houseman, RN, APRN, MSN Paula Rich, RN, MSN Sue Walsh, RN, MSN, CS	<b>DATABASE COORDINATOR</b> Heather Pecharo	

## Resource Groups

This is a general listing of our Resource Groups. We warmly invite people with ALS, and their families and friends, to attend. Please call the contact person for each group to confirm actual dates, or you may request to be placed on the Resource Group mailing list. This mailing is distributed monthly and lists upcoming dates, times, and other important information. Also, be sure to RSVP to the facilitator, if specifically requested.

### Bereavement - Ambler, PA

Info. and RSVP:  
Jennifer Klapper,  
(215) 726-8724

### Caregivers and Family Members - Ambler, PA

Info. and RSVP:  
Karen Dawson-Haines,  
(215) 487-4519

### Delaware - Wilmington, DE

Info: Wendy Strowhauer, RN  
(302) 547-8482

### For Women Only (Women with ALS)

Info: Jennifer Klapper,  
215-726-8724

### Harrisburg - Hershey, PA

Info: Judy Lyter,  
RN, MS, LPC  
717-566-1700

### Lehigh Valley - Allentown, PA

Info.: Wendy Barnes,  
(610) 282-5904

### Men as Caregivers

Info: Brenda Edelman,  
215-643-5434 ext. 20.

### North East - White Haven, PA

Info. and RSVP:  
Peggy Slusser,  
PhD, RN, CS,  
(570) 793-3906

### South Jersey- Egg Harbor Township, NJ

Info.: Stephanie Hand-Kowchak, MSW, LSW  
(609) 457-9261

### Trenton - Lawrenceville, NJ

Info.: Cathe Frierman,  
(609) 394-3556

### Monmouth/ Ocean County- Red Bank, NJ

Info: Patricia Schaeffer, RN  
(732) 450-2677

**Volunteers**  
We Couldn't Do It Without Them!



## IN MEMORIAM

- Louis Anderson
- Mary Bear
- Aloysius Berger
- Leslie Brida
- Nancy Burkett
- Paul Campbell
- Wayne Cassel
- Clement Chambers
- James Cipriano
- Russell Cox
- Loretta Damico
- Russell Denner
- Melvin Dickinson
- John Eby
- Dana Friedman
- Frederick Gossin
- Coralee Gratkowski
- Margaret Hahn
- Walter Howard
- Patricia Hulse
- Paula Jenkins
- John Lambert
- Jeanne Leeds
- Karen Malinoff
- Sharon Marino
- Robert McAllister
- Dolores Morgan
- Karen Neiheiser
- Sylvia Nicoletti
- Michael Regan
- Lorin Reynolds
- Dorothy Roller
- Fortunata Romanini
- Jerry Ross
- Anthony Sacchetti
- Linda Scamuffa
- David Schumacher
- Ryan Shupp
- Patricia Simmons
- Janet Spear
- William Stoner
- William K. Thompson
- Elizabeth Tinnelly
- Nancy Voegelé