



GREATER PHILADELPHIA CHAPTER news

Spring 2009

OUTTA HERE! PHILLIES PHESTIVAL

Monday, June 22, 2009 5:00 pm,
Live Auction 8 pm

THE PHILLIES & THE ALS ASSOCIATION,
GREATER PHILADELPHIA CHAPTER
CELEBRATE 25 YEARS TOGETHER

Citizens Bank Park- Rain or Shine
Tickets on Sale May 6 –
Call the Phillies @ 215-463-1000
Admission \$25

After 25 years as the team's principal charity, The ALS Association, Greater Philadelphia Chapter can proudly say - WORLD CHAMPION Phillies! This year's Phestival promises to be the most exciting yet as thousands of enthusiastic fans rush to Citizens Bank Park for autographs of their favorite Phillie stars and bid on fabulous sports memorabilia in the live and silent auctions.

The 2009 event features players and management signing autographs, photo booths featuring the World Series

Trophies from 1980 and 2008, Charlie Manuel and Brad Lidge. Please visit the chapter website alsphiladelphia.org or check www.Phillies.com for the most current information including special guests and up-to-the-minute auction items.

Help us top our record breaking 2008 total of \$758,540 – in the last 24 years, the team has raised \$10.1 million for the Chapter's programs and services. ❁

Left to right: Dave Montgomery (Phillies General Partner and President) Michael Strieb (PALS) with his son, Alex, and Lyn Montgomery of Phillies Charities Inc.

PHESTIVAL PROGRAM BOOK

You can help make the Phestival a success in 2009! A program book is distributed to all who attend and is an integral part of the Phestival. Your ads are needed. Please consider purchasing an ad ranging in size from a friends listing of \$75 to a full page color ad at \$1200. You can also help by soliciting ads from friends and local businesses. It's easy...you can go on-line at www.alsphiladelphia.org or call the chapter-- 215-643-5434 for assistance.

The ad book
deadline is
May 15, 2009.



New Gene Mutation Discovery by ALS Association Consortium is Major Research Breakthrough

In one of the most significant breakthroughs in the recent history of ALS research, a consortium of scientists organized and funded by The ALS Association has discovered a new gene, ALS6 (Fused in Sarcoma), responsible for about 5 percent of the cases of inherited ALS. The discovery will provide important clues to the causes of inherited ALS, which accounts for 10 percent of all cases, and sporadic ALS, which occurs in individuals with no family history of the disease and accounts for the other 90 percent of cases diagnosed.

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FROM THE **Executive Director**



I am often asked about the programs and services provided by the Chapter and specifically the cost of these programs. In light of the current economic situation, I thought it may be valuable to address this topic. By far our largest program as far as expenditures is the Abrams In-home Care Program. This program is named for Howard I. Abrams, a PALS whose vision and financial contribution initiated this program in 1995. Since Howard's death in 1996, Howard's son Jeff, and daughter-in-law, Margaret, continue to support this essential program. Last year the chapter spent \$735,542 for 14,904 in-home visits totaling 37,902 hours of care. This does not include all of the hours spent by Wendy Barnes managing the program, negotiating with the agencies, arranging and scheduling the visits. It also does not include any of the administrative time needed to process all of the paperwork involved in the program.

The program that the most PALS take advantage of is our Centers of Excellence, also known as our ALS Clinics. These marvelous, multi-disciplinary clinics are the hub of patient care and are staffed by collaborative teams of professionals from the Chapter and the medical institutions at which they are housed. Whether a family attends an ALS clinic at the Geisinger Medical Center or Lehigh Valley Hospital; or one of the ALS Certified Centers at the Penn State Hershey Medical Center, or Pennsylvania Hospital, they are assured of high quality, ALS specific care. The neurologists directing these

clinics are ALS Specialists with expertise and experience second to none and all of the staff specializes in ALS as well. In 2008, the Chapter spent over \$720,000 providing care at these vital institutions.

Of course the Chapter also has many other services and programs such as monthly resource group meetings, transportation, equipment loan, in-service presentations, educational and recreational programs. All of these are provided at no cost to PALS and their families. We also sponsor a significant amount of ALS research through our national office. Last year, the

Chapter spent over \$4 million on Patient and Family Services, Research and Education. All are paid for with fund-raised dollars through the generosity of our donors. Without them, none of this would be possible. We are particularly grateful to our patient families and friends who so often remember The ALS Association with their gifts, it is a very special way to honor a loved one.

We are also grateful to our good friends, the

Philadelphia Phillies. Each year the Phestival gets bigger and better. Our event sponsors, business supporters, individual givers all are vital and deserving of our thanks. But no one person, company or group can do it alone. It takes all of us, working together, to enable The ALS Association to provide the care that is so greatly needed. I know that the times are tough, but I implore you not to forget that people living with ALS have it even tougher. Without The ALS Association, there are very few places to turn, and the Chapter cannot do it without your help. God Bless 🌸

“ We are particularly grateful to our patient families and friends who so often remember The ALS Association with their gifts...”

Jane H. Gilbert

Appointed President and Chief Executive Officer of The National ALS Association

Jane H. Gilbert has been appointed president and chief executive officer of The ALS Association by the National Board of Trustees. She replaces Gary Leo, who retired as the organization's leader earlier this year.

Gilbert joins The Association after serving as the senior vice president for chapter operations for the American Red Cross in Washington, D.C. In that post, which she occupied from 2005-2008, Gilbert was responsible for eight service areas and 760 chapters, leading a professional team of more than 350 full-time employees, managing a budget of \$900 million and directing the administration of more than \$30 million in chapter grants.

"We are very fortunate to have found a professional of the highest caliber in Jane Gilbert," said Allen L. Finkelstein, chairperson of The Association's National Board of Trustees. "She has an extraordinary record as a proven and widely respected leader and her accomplishments in fundraising, operations and strategic planning are strengths that will be critical in our drive to conquer Lou Gehrig's Disease."

As president and CEO of The Association, Gilbert has responsibility for the strategic direction and operations of the organization which directs the largest privately-funded research program into ALS and a national network of 42 chapters that deliver an array of services to people living with ALS. At the national level, Gilbert will oversee The Association's activities in research, advocacy, finance, development, community services, patient services, communications and operations.

"The ALS Association is a recognized leader in the fight against ALS, and as the new president and CEO, I will make

sure that we earn that distinction everyday," Gilbert said. "My most important priorities are to intensify our aggressive focus on finding new treatments and a cure for ALS while we rededicate ourselves each day to providing the best and most compassionate care for people with ALS across our nation."

"I will lead this effort with a sense of urgency because people with ALS cannot wait; their survival rate is only two to five years from the time of diagnosis," continued Gilbert. "I view the fight against ALS as an emergency that requires an all-encompassing response that will not cease until a cure is found."

Prior to her American Red Cross position in Washington, D.C., Gilbert was the service area executive of the Mid-Atlantic Service Area for the American Red Cross. Before the American Red Cross, Gilbert was the director of development for the Boys & Girls Clubs of Omaha.

Gilbert holds a master's degree in business from the University of Nebraska and a bachelor's degree in communications and speech from Southern Methodist University in Texas. ❁



Chapter Welcomes Three New Board Members

We are pleased to announce three new members of our Board of Overseers. Holly Bennett, Ted Collins, and Sheila Boyle Lessin officially joined our Board in January.

Holly Bennett serves as the Lehigh Valley Walk Chair for the ALS Association's Greater Philadelphia Chapter. She has served in this capacity since 2003. An experienced project manager and higher education administrator, Bennett is active in the Greater Lehigh Valley Chamber of Commerce, the Leadership Lehigh Valley initiative, and the Pennsylvania Library Association. She has participated in the highly selective education institute at Harvard University, served on the American Library Association's national publication committee, and awarded the President's Volunteer Service Award in 2007. She lives in Nazareth, is married to Rob and has two small children, Sydney and Nicholas.

Ted Collins is a Major in the United States Army Reserve currently stationed at Fort Dix in the role of government contract law attorney. He originally became involved with our chapter in 2002 after his father, William J. Collins, Jr., contracted ALS and passed away. Ted lives in Doylestown with his wife Lauren and his two children: Evan (2) and Claire (8 months).

Sheila Boyle Lessin has been involved with ALS patients since she was a child. Her late father, Christopher Boyle helped ALS patients with electronics communication devices and made devices that enhanced the comfort or leisure of patients. Over the years Sheila has stayed in touch with the ALS Association and was asked to join the board in 2008. Sheila has an MBA in International Business and is employed by Strategic Diagnostics, an antibody manufacturer, for the Life Science Industry. ❁

Become a Young Friend of The ALS Association

The Young Friends of the ALS Association is a dynamic group of individuals over 21 years of age who are dedicated to furthering the goals of The ALS Association, Greater Philadelphia Chapter. This membership group and volunteer committee will meet on a monthly basis to enjoy happy hours, tours and cultural activities all while raising funds and awareness for The ALS Association.

To become a member of the Young Friends or to find out more about the group, visit www.alsphiladelphia.org and click on How You Can Help and then Become A Young Friend.

Have a Facebook page? Become a Fan of The Young Friends by searching for "The Young Friends of The ALS Association."

The Young Friends Group is a fun and meaningful way to get involved and make a difference in the life of someone living with ALS. The membership fee of \$30 per year entitles members to the following:

- ALS Association Newsletter
- invitations to special events
- invitations to monthly happy hours at chosen location
- discount at fee based Young Friends events
- discount to the ALS Association's Annual Hot Chocolate event.

Spring Cleaning?

Sell your unwanted items on eBay to benefit our Chapter

We all know that one man's trash can be another's treasure, but did you know that you can turn your unwanted items into funds for the ALS Association?

The ALS Association, Greater Philadelphia Chapter is part of eBay's Giving Works program. Giving Works makes it easy for you to sell items on eBay and donate 10% to 100% of the final sale price to support our work.

ENJOY THE BENEFITS!

Your eBay listing will benefit from several unique program features that have been proven to attract more buyers and raise awareness of our cause such as the eBay Giving Works ribbon and enhanced searchability.

Your listings will automatically include information about ALS and our Chapter, and you'll receive a tax-receipt for your donation.

HOW TO USE EBAY GIVING WORKS

1. Click "Customize your listing"
2. Look for the "eBay Giving Works" field (Click "Add or Remove Options" if you don't see it) in the Sell Your Item form in the "Choose how you'd like to sell your item" area

3. Choose "Select a new nonprofit"

4. In the pop-up window that appears, type "The ALS Association, Greater Philadelphia Chapter" in the "Nonprofit Name or Keyword" field

5. Select The ALS Association, Greater Philadelphia Chapter and a percentage of the sale price (10-100%) you wish to donate to us (please note: there is a \$5 minimum donation if your item sells)

It's as simple as that! If your item sells, our organization will receive the percentage you selected to donate. It's giving back without giving your gift back.

Have questions? Please visit www.alsphiladelphia.org to learn more.



2009 ALS Advocacy Day

Help Us Continue to Turn Hope into Action

Advocates from across the country will gather in Washington, DC on May 10-12 for The ALS Association's twelfth 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 with an opening session on Sunday afternoon, May 10. The conference will continue with educational breakout sessions about public policy issues of significant importance to the ALS community on Monday, May 11, and conclude with our day on the Hill on Tuesday, May 12. The 2009 Advocacy Day is your opportunity to bring your ALS story to Washington, and advocate for increased awareness and support.

Register online for the 2009 National ALS Advocacy Day and Public Policy Conference at <http://www.alsa.org/policy/alsday.cfm>.



Pennsylvania Advocacy Day

Advocates from across the state joined us on a beautiful day in Harrisburg for our Fourth 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 meet with their representatives and senators. The goal of the day was to educate representatives about the needs of ALS patients and families in the state, and to garner support for state funding of programs for people with ALS.

The Pennsylvania Advocacy Day is just a first step in our efforts to secure funding. Look for more updates and requests to contact your legislators this Spring. For more information about our state advocacy efforts, contact the Chapter at 215-643-5434.

Planning Your Own ALS Event

We can't do it alone! The ALS Staff depends on people like you to help spread the word about ALS and to raise funds to help support PALS and their families all over the Philadelphia region. You can easily start your own fundraising event for The ALS Association, Greater Philadelphia Chapter. It can be a onetime event or something that is ongoing. Whatever you decide to do, be creative and make it your own! Whether it's a golf outing, a silent auction, a 5K run or a bake sale the staff here at the chapter office can help by providing ideas, brochures, signs and a raffle item or a speaker when available!

Planning your own event can be a great way to include family, friends, co-workers and members of your community in your fight against ALS. We can also include your event on our Event Calendar and our monthly E-Newsletter to help spread the word! If you are interested in starting your own event to benefit The ALS Association, Greater Philadelphia Chapter please contact April Haas at april@alsphiladelphia.org or 215-643-5434 ext. 42.

New Gene Mutation Discovery (Continued from cover)

“This is a momentous discovery in furthering our understanding of ALS,” said Lucie Bruijn, Ph.D., senior vice president of Research and Development at The ALS Association. “A new gene provides a new piece of the puzzle we can use to shed light on why ALS develops, and where to focus our efforts on creating new treatments and finding a cure.”

The results of this groundbreaking research are published in the Friday, February 27 issue of the prestigious journal *Science*. The project was led by Tom Kwiatkowski M.D., Ph.D., at Massachusetts General Hospital, and Robert Brown, M.D., of the University of Massachusetts School of Medicine, and ALS Association-funded researchers Caroline Vance, Ph.D., and Christopher Shaw, M.D., of Kings College in London. The project was supported by a consortium of leading ALS researchers from around the world, formed as part of The Association’s Gene Identification Project. Their success reflects an unprecedented effort to accelerate the search for genetic mutations linked to all forms of ALS.

Dr. Brown noted, “We are particularly delighted because our trans-Atlantic consortium has pursued the chromosome 16 gene for more than six years. The ALS Association has been an all-important partner in this search. This discovery should lead to new cell and animal models of ALS, which will accelerate drug development.”

“Global partnerships between investigators and funding agencies, such as the Motor Neuron Disease Association in the United Kingdom, are crucial to making these kinds of breakthroughs,” Dr. Bruijn commented. “This finding has opened up a whole new avenue of research and has the potential to uncover a common mechanism for most forms of ALS.”

The gene mutations were first identified by Dr. Kwiatkowski and were immediately confirmed by Dr. Vance, who also demonstrated abnormal accumulations of the mutant protein in cells cultured in the laboratory and the motor neurons of people carrying FUS mutations.

The gene, called FUS (“fused in sarcoma”), normally carries out multiple functions within motor neurons. These include regulating how gene messages (called messenger RNAs) are created, modified, and transported in order to build proteins. Some of these same functions also are performed

by another gene called TARDPB encoding the protein TDP43, and mutations in the TDP-43 gene were recently linked to ALS as well.

“The fact that these two genes help perform the same function suggests that problems in this function may be critical in the development of ALS,” Dr. Bruijn said. “More research into exactly how these two genes work could ultimately lead to new treatments that are effective in slowing or stopping the progression of ALS and extending the lives of people with the disease.”

The mutations in the ALS6 gene were identified by detailed genetic sequencing in several families with an inherited form of ALS (familial ALS). Normally, the ALS6 protein works in the cell’s nucleus, but the mutations caused it to instead cluster outside the nucleus. Further work will be needed to determine precisely how this leads to ALS. With the gene in hand, scientists will be able to create cell and animal models containing the mutated gene, to examine in detail how the mutation operates and how it causes ALS.

“This suggests there may be a common mechanism underlying motor neuron degeneration,” according to Dr. Shaw. Motor neurons are nerve cells in the brain and spinal cord that control muscles. Motor neurons degenerate in ALS.

This is the second ALS-causing gene to be discovered in the past 12 months. SOD1, discovered in 1993, accounts for 20 percent of inherited cases of the disease. Mutations in the TARDP gene account for another four to five percent. The only well-defined causes of ALS are genetic. In both inherited and sporadic ALS, the disease symptoms and pathology are the same.

The possibility that ALS may be caused by several factors is the rationale for The Association’s policy of funding multiple genetic projects around the world and encouraging these leading geneticists to work together and share information to help locate disease-linked genes for faster, more accurate scientific results. By funding research on a global level, The Association helps put together “genetic pieces” of the ALS puzzle.

“Through our support of research such as this study, The ALS Association is committed to finding the causes of ALS, and using that knowledge to develop a cure as rapidly as possible,” Dr. Bruijn said. “We will build on the discovery of this new gene to carry that effort forward. ❁

“A new gene provides a new piece of the puzzle we can use to shed light on why ALS develops”

HELP FOR TODAY, HOPE FOR TOMORROW Major Gifts Campaign

The Chapter's Major Gift campaign was launched in November of 2008 with the goal of raising \$5 million by 2011. We are more than halfway to our goal! Visit www.alsphiladelphia.org for more information about the campaign.

Named Funds to Honor & Remember Now Available!

Named Funds offer a way for family members, friends, colleagues, foundations, or corporations to permanently honor or remember a person whose life has been impacted by Lou Gehrig's Disease. A Named Fund may be established with a gift of \$25,000 or more and falls into two categories:

- Restricted Named Fund – supports a specific interest of the donor(s) within the overall context of the Chapter's mission (research, patient services, advocacy, and education).
- Unrestricted Named Fund – supports the overall mission of the Chapter.

THINGS TO KNOW ABOUT NAMED FUNDS:

- Individuals and families or other groups may combine gifts made over time to meet the minimum amount. Once a Named Fund is established, gifts may be designated to the Fund at any time.

- Families may choose to let others know of the plan to establish a Named Fund and invite their support using special cards available from the Chapter. To encourage gifts to the Fund on an ongoing basis, cards can also be used to mark key anniversary dates related to the honoree such as a birthday, date of death, or the Fund's establishment.
- Named Funds become part of the Chapter's permanent record, assuring that the name of the honoree will be forever linked to the Greater Philadelphia Chapter's unique history and heritage in the fight against ALS.
- Each Named Fund will be featured on the Chapter's website and will be listed in the Chapter's Annual Report with descriptive information about the honoree and the Fund's purpose.
- Named Funds established as part of the Major Gifts Campaign will be included in a planned campaign recognition display that will be mounted in the Chapter's headquarters office.

Please contact Jeff Cline, Chief Development Officer, at 215-643-5434 or jeff@alsphiladelphia.org if you have questions about or interest in establishing a Named Fund.



Lou Gehrig Legacy Society welcomes new members

The Lou Gehrig Legacy Society recognizes 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 welcome and introduce new Society members, Lisa and Jay Bolick.

After learning of her ALS diagnosis in April of 2006, Lisa and Jay Bolick decided to relocate from their home in Wilmington, NC to Emmaus, PA for two reasons -- to be closer to family and friends, and because they had learned about the comprehensive care and free services offered to ALS families by the Greater Philadelphia Chapter. Through the Chapter's Cox Fund for Accessibility, ramping has been installed at their home to help maintain

Lisa's mobility in her wheelchair. The family also receives support through the Chapter's Howard I. Abrams In-Home Care Program, which provides patients with personal care services while giving family caregivers a much-needed break.

As an expression of their gratitude for how much the Chapter's support has helped them, Lisa and Jay have both included the Chapter in their estate plans by making a percentage bequest through their wills. Jay states, "Knowing what other families will be facing with this disease, Lisa and I have both decided to leave 50% of our estates to the Greater Philadelphia Chapter."



If you would like to learn more about how to make a bequest to The ALS Association please visit the Chapter's informative planned giving website at

<http://alsphiladelphia.planyourlegacy.org/> or call Jeff Cline, Chief Development Officer, at 215-643-5434.

VOLUNTEER PROFILE: Sandy Hanson



For over 20 years, Sandy Hanson has been a friend and invaluable resource for ALS families in Lancaster and Reading. As the Chapter's unofficial contact in the area, Sandy ran a support group for many years. As the patients were no longer able to travel to the group, she began visiting them in their homes. She is now an "official" member of the Chapter's corps of Visiting Volunteers, and is matched with two local women whom she regularly visits.

Her dedication to the cause comes from personal experience. Sandy lost her husband, Tom, to ALS in the 1970s. "After Tom's death, I realized just how much I had appreciated having someone to talk to who understood what Tom and I were going through, and I determined to try to 'be there' for families that were struggling with the disease as we had struggled."

Sandy has spent nearly three decades "being there" for families in Berks and Lancaster Counties. In addition to visiting patients, she also served on the Chapter's Board of Directors for several years and participated in many chapter events, from Phillies games to luncheons to caregiver workshops.



She's been an active Visiting Volunteer for the past three years, has had 4 on-going matches with PALS in the Reading area. Sandy has been visiting Despina Grimes for approximately 2 years. Despina's husband, Robert reports that Sandy is more than a friendly visitor, but a true friend. He states, "I can't think of enough positive adjectives to describe her," and says she will often come to their home bearing flowers or something yummy to eat.

She also sees another woman in the area every two weeks to take her to the hairdresser,

and on alternate weeks they visit or go for rides to see the spring flowers or have lunch.

When not helping people with ALS, Sandy keeps busy as the President of the Friends of Exeter Community Library, and also serves on the Board of Trustees for the Friends of the Berks County Public Libraries.

"I would certainly recommend the Visiting Volunteer program to others. Of course it is heartbreaking to see good people struggling with such a horrible disease, but each and every one of the patients I have seen and continue to see is such an inspiration. I come away from every visit with admiration for their spirit and determination," Sandy says.

Though now retired, Sandy was an elementary school teacher and librarian for twenty-eight years. She recalls one Halloween when the schools decided to skip the typical Halloween parade and dress as scientists, heroes, and historical figures instead. "It was a perfect opportunity to explain the difference between heroes and celebrities," she says. When asked if she had any heroes of her own, Sandy replied "I visit folks who knew that there was no cure for the disease they had, but who got up each day and went on were their lives; they were- and are- MY heroes and heroines." ❁

The Chapter's Visiting Volunteer program matches volunteers with compatible people with ALS, for friendly visits and companionship.

Currently the Chapter has over 24 active visiting volunteers, matched with 30 patients. Visiting volunteers should be willing to maintain their relationship over time, and an orientation

is required. For more information, contact Gail Houseman at 215-643-5434 or gail@alsphiladelphia.org.

2009 Hot Chocolate Event

The energy was electric, the sharks were on their best behavior and chocolate flowed from every corner of the room at our 2009 Hot Chocolate event at Adventure Aquarium! In its fifth year the event hosted more vendors and even more chocolate than ever before. This year VIP guests were treated to a champagne bar, butlered hors d'oeuvres, a raw bar, exhibits like Touch a Shark and Critter Talk with Aquarium staff, a wine sampling by TV and Radio Wine-tertainer, Phillip Silverstone and amazing CHOCOLATE. Not to be outdone, the Chocolate



Tasting took place in Currents~The Ballroom at Adventure Aquarium and the Shark Realm.

Attendee favorites like the chocolate martini bars, chocolate fountains, and ice cream bar were a hit as well as this year's new favorite – the made to order s'mores station. The evening was made possible by the generous contributions of our sponsors: Adventure Aquarium, Cooper Electric Supply Company, Globus Medical Inc., Kaplin Stewart Reiter Meloff & Stein, P.C., The Legal Intelligencer and Pulmonology Associates at Lankenau and Paoli Hospitals. Special thanks to our event chairs, Larry and Jill Kaplan and the dedicated committee who helped make this year so successful. ❄️



PAST events

Lake Beef & Beer Friday, February 6, 2009

The Billy Lake Beef and Beer for ALS celebrated its 15th year of auctions, music, dancing, great food, drink and company on February 6 at the Knights of Columbus Mater Dei in Newtown Square, PA. It was easily the most successful ever as \$11,000 was raised for ALS research in memory of Billy Lake, a courageous young dad from Havertown, PA who lost his life to ALS in 1992. Congratulations to Patti and Dan Quinn and all of their friends and family who contributed to this meaningful evening. Pictured here are The O'Fenders, a group of talented attorneys and musicians who each year provide the fabulous music that brings out the best in everyone.



4 on 4 Basketball Tournament March 2009

In its 9th year, 4 on 4 for a Cure is a "March Madness" style basketball tournament that now raises money for The Chapter. Hundreds of students from Colonial Middle School in Plymouth Meeting, PA participate in the tournament which features a sixth, seventh and eighth grade contest. The final four for each grade compete on a fourth tournament day to determine the 1st, 2nd and 3rd place teams. This great event was organized by Matt Doroshow, in honor of his father, Jay.

Pictured above, Colonial Middle School 7th grader Victoria Lipson wrestles for the ball with fellow 7th grader Jamie Dumoff during the 7th grade Final Four of the 2009 4 on 4 For a Cure Tournament.

Gambone Steel Golf Outing Monday, Sept. 22, 2008

Gambone Steel Co, Inc. sponsored a golf tournament at Plymouth Country Club on September 22, 2008. The event attracted 100 golfers and 250 guests for dinner, and raised \$5000 for the fight against ALS. The outing was held in memory of Sal Gambone, who died from ALS on November 26 2006.

right: Relatives and friends surround a photo of Sal Gambone.



Walk to Defeat ALS™



Can't make one of the scheduled Walks to Defeat ALS™ this year? Do what Connie and Joe Stark did and take it on the road. The Starks couldn't make the 2008 Greater Philadelphia Walk to Defeat ALS™ because they were in India on Walk day so they walked there. The Starks walk to support Connie's cousin, Kathryn Voit and her husband Gerry. The Voits team, Kathryn's Krew has taken part in the Greater Philadelphia Walk every year since the first Walk. Connie and Joe Stark are pictured here holding their Walk to Defeat sign in front of the Little Taj Mahal. To find out more about holding your own virtual walk, contact the chapter office at 215-643-5434.

Upcoming Walks to Defeat ALS™

2009 Seaside Boardwalk Walk to Defeat ALS™

Saturday, May 16, 2009

Registration: 9:00 - 10:00 a.m.

Walk Starts: 10:00 a.m.

Hiering Avenue and the Boardwalk, Seaside Heights, NJ
Contact Allison Walker at allison@alsphiladelphia.org or 215-643-5434.

2009 Harrisburg Walk to Defeat ALS™

Saturday, June 6, 2009

Registration: 9:00 - 10:00 a.m.

Walk Starts: 10:00 a.m.

Riverfront Park/ City Island, Harrisburg, PA

Contact Marianne Mancini at marianne@alsphiladelphia.org or call 215-643-5434.

Get Involved!

Many of you may have participated in a Walk to Defeat ALS™ at one time or another, as a team captain, walker, volunteer, or donor. However, we are asking you to become more involved this year! You can do this by joining the committee for the walk in which you participate. Every walk has a small walk committee that comes together, gathers donors, solicits sponsors, and organizes the "finished product" you see-- the event day itself! The walk committee is an integral part; without them the walk would not happen. Please consider taking this extra step. Another way to help is by organizing your walk team or by helping your team reach its goal if you are already a part of a team. Some ways to do this are through organizing fundraisers or selling paper feet. For more fundraising ideas, call your walk coordinator.

We Thank OUR WALK SPONSORS

Presenting Sponsor of the Lehigh Valley Walk to Defeat ALS™ – **ORE Rental/Linden Foundation**

Auntie Anne's Training
Department

Bayada Nurses

Central Medical Equipment, Co.

Centre Pathology Associates

Clyde Stumpf & Sons

CVM Autopark Dodge
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& Company, CPA

G.R. Sponaugle & Sons

Griswold Special Care, Inc.

Hershey Company

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Resorts Entertainment Group

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Lehigh Valley Dairy Farms

Maxim Healthcare Services

Momentum Fitness Center

Neutrik USA, Inc

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St. Mary Medical Center

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

To learn more about the benefits of becoming a walk sponsor, please contact **Roxanne Walter**, at 215-643-5434 or toll-free 1-877-GEHRIG-1.

UPCOMING events



ALS Charity Auction and Autograph Party with the Lakewood BlueClaws Wednesday, May 27, 2009

Wednesday, May 27th 6:30 pm
FirstEnergyPark
Lakewood, NJ

Meet your favorite Lakewood BlueClaws player as the whole team comes out to serve you dinner to benefit The ALS Association. This fun evening also includes a great silent auction, a tip contest (so make sure to give your favorite player a big tip) and raffles.

For more information call 732-901-7000.

The Philadelphia Fight Rugby League 2nd Annual "Battle to Strike Out ALS" Saturday, July 25, 2009



Charity Rugby League Match-
A.A Garthwaite Stadium
Conshohocken PA 5:00 pm

Eagletag Youth Flag-Rugby Game before Main Event Raffle Prizes!! Benefit Concert after the game at Kildares in Manayunk. Featuring local band: Bryn Mawr

For more information and directions please visit the Philadelphia Fight Rugby League's website at www.FightRugby.com

A Summer Evening in Bucks County

Wednesday, June 3, 2009

PALS Bob Wilderman and his friends are one of our many Third Party Event organizers who, with a little assistance from the chapter, can do some amazing things and plan some fantastic events. Please join Bob and his friends from 6:30 to 9:30 pm on Wednesday June 3rd, 2009 for a night of cocktails, finger foods, and fabulous items in our live and silent auctions, while we enjoy the historic grounds of the Pearl S. Buck House in tranquil Perkasio, Pennsylvania. General Admission is \$60 and price per couple is \$100.

Please RSVP to the chapter office at 215-643-5434 or for more information please visit our website at www.alsphiladelphia.org. Kindly respond by May 25th.



Celebrities Score at Annual Lake Basketball Marathon Saturday, June 13, 2009

Hundreds of area basketball players will take to the court on Saturday, June 13 at the 18th 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. Billy Lake was a Havertown, PA, resident who succumbed to ALS in April 1992. His family and friends created this marathon as a tribute to his courage. Their never-ending spirit and dedication to the ALS cause is beyond compare.

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. Participants will include Michael Barkann of Comcast SportsNet, Dave Warren, of NBC 10; Don Bell of cbs3; Casey Boy from WMMR, Phil Martelli of St. Josephs University; ALS advocates Bruce Berkowitz, Jason Bacani and Jeff Fox, and several great volunteers from the Delaware County Times.

New players are always welcome – call Joan Borowsky at 215-643-5434 or e-mail Joan at joan@alsphiladelphia.org to sign up.

Beef & Beer to Defeat ALS Saturday, May 23, 2009

7pm-11pm at the Fraternal Order of Eagles #74
415 Philadelphia Pike, Wilimington, Delaware

For more information contact Kerri McCall at kerri.mccall@cigna.com or call the Chapter Office at 215-643-5434.

11th Annual ALS Express Saturday, June 20, 2009

Join us for the 11th Annual ALS Express Bike Ride on Saturday, June 20, 2009!

The ALS Express is a non-competitive bike-a-thon that's fun for people of all ages and riding abilities. You will join hundreds of cyclists for a ride through scenic southern NJ. There are 4 start points, one for every level of experience! Enjoy the support of wonderful volunteers who cheer-on the riders and help provide a worry-free cycling experience. Upon arrival at the end-point in Wildwood, NJ, the summertime fun begins! No other charity bike ride in the area offers an exceptional endpoint like this! Each rider receives two complimentary passes to Morey's Piers Amusement & Water Parks.

For more information and to register go to www.als-express.org or call 215-643-5434 xt 26. Start training today!



14th Annual Lodish Bike Ride August 14 through August 29, 2009

"To know Malaysia is to love Malaysia" ...find out just how true the country's slogan is when you support Len and Susan Lodish on their annual tandem bicycle trip to raise money for ALS. The Lodishes ride in memory of Len's cousin, Dr.

Jules Lodish, who lost his life to ALS last year. The couple leaves on August 14th and returns on August 29. This year's ride promises to be one of their most extraordinary as Malaysia is a land of extreme contrasts. Towering skyscrapers look down upon wooden houses built on stilts, and five-star hotels sit several meters away from ancient reefs.

Join their adventures and fundraising efforts by visiting our website at www.alsphiladelphia.org. Please support their incredible stamina with your gift.



ALS Awareness Night & Jersey Auction with the Scranton/ Wilkes-Barre Yankees Saturday, August 29, 2009

On August 29th, the Scranton/Wilkes-Barre Yankees will once again host an ALS Awareness night which will include both a silent and jersey auction. While the Yankees are taking on the Pawtucket Red Sox, we will be auctioning off game worn, autographed jerseys from each player. In addition to the jersey auction there will be a great silent auction which will include sports memorabilia from past and current major and minor league players. Both auctions will begin when the gates open and end starting at 8pm. Last year's event raised over \$12,000!

We hope you can join us! Tickets can be purchased by calling the Yankees at 570-969-2255.

Veterans with ALS and Their Families

Please contact your social worker (Susan Schwartz at 215-750-0270 or Shelley Hill at 717-761-4266) when you are notified of your service connected compensation award. We are interested in compiling information that will help us know how long this process takes and the ratings our VALS are receiving. If you have applied as a surviving spouse we are most interested in hearing from you as well. You will be helping us encourage all of our veteran families to go through the application process when they know that it does work.

Thanks in advance—we look forward to hearing from you.

Why Do I Want To Attend A Support Group?

Do the positives of attending outweigh the fears?

By Judy Lyter, RN, MS, LPC Nurse Counselor

As a support group facilitator when I invite patients and families to attend a support group, I frequently hear, “I don’t want to see what is in my future.” ALS can have different effects on individuals and does not have the same effect on each person, although often there are similarities. Once you meet individuals in the group you soon don’t dwell on their “equipment” or “physical changes” but see and hear that the person shares a common bond with you. The validation of each of you facing ALS by the other is what develops this unique bond.

Support groups help you to connect to others giving you an opportunity to network and learn through others’ experiences. An educational component helps you to stay abreast of new research and opportunities. Most find they have a new group of “friends.” Some, in fact, connect between monthly support group meetings by phone, internet, or visits. They recognize that these “new” friends understand and are not in need of a lot of explanation or expectations. These new friends share changes and ask each other questions about experiences. The loved one and/or caregiver also feel the support. It becomes “another family.”

The invitation, “try it, you might like it!”

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

A five-session series is available for people who have lost someone to ALS in the past 2 years.
Info. & RSVP: Jennifer Klapper
(215) 726-8724

Caregivers and Family Members- Ambler, PA

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

Brick, NJ

Info. & RSVP: Patricia Schaeffer, RN
(732) 239-4724 or
Kathy Valentino, LCSW
609-433-6333

Delaware - Wilmington, DE

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

Harrisburg - Hershey, PA

Info. & RSVP: Judy Lyter, LPC, RN
(717) 566-1700

Lehigh Valley - Allentown, PA

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

North East - White Haven, PA

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

South Jersey- Egg Harbor Township, NJ

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

For Women Only (Women with ALS)- Ambler, PA

Info. & RSVP: Jennifer Klapper, RN, CNS-BC
215-726-8724

Trenton - Lawrenceville, NJ

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

Monmouth/ Ocean County- Red Bank, NJ

Info: Patricia Schaeffer, RN
(732) 239-4724 or
Kathy Valentino, LCSW
609-433-6333

Men as Caregivers- Ambler, PA

Info. & RSVP: Brenda Edelman, LCSW, BCD
215-643-5434

Lancaster, PA

Info. & RSVP: Judy Lyter, LPC, RN
717-566-1700

NEW! Delaware Caregivers Group- Milford, DE

Info. & RSVP: Larry Ganster,
800-838-9800 ext. 4136

Please go to www.alsphiladelphia.org - Patient and Family Services for additional information about all Resource Groups.

The ALS Association Teams With Major League Baseball In '4 ALS' Awareness Initiative

"4 ALS Awareness" to Commemorate the 70th Anniversary of Lou Gehrig's Farewell Speech on July 4th, 2009

Major League Baseball will raise awareness and financial support for organizations leading the fight against ALS (Amyotrophic Lateral Sclerosis), otherwise known as "Lou Gehrig's Disease," with a new charitable campaign, "4♦ALS Awareness," Baseball Commissioner Allan H. (Bud) Selig announced today.

MLB is working with four leading organizations - The ALS Association, ALS TDI, MDA/Augie's Quest and Project A.L.S. - whose primary goal is to find a cure for ALS. The initiative will culminate on July 4, 2009, which is the 70th anniversary of Lou Gehrig's famous farewell speech at Yankee Stadium. ALS destroys the nerve cells controlling muscles, ultimately causing complete paralysis. Average life expectancy is three to five years after diagnosis.

"We are honored and pleased to have the opportunity to join these four important organizations in an attempt to make progress in the fight against ALS, a disease that is associated with one of the greatest players in baseball history," said Selig. "Lou Gehrig displayed tremendous courage and strength in the face of a debilitating illness, and his speech 70 years ago still stands as one of the defining moments in baseball history."

On July 4, 2009, each home team will host an on-field reading of Gehrig's Farewell speech during the 7th Inning Stretch. All players will wear a "4?ALS" patch on their chest and MLB will promote the effort in a variety of ways, including in-stadium promotions. In addition, MLB.com will conduct an online auction to raise funds for the cause, and Major League Baseball will continue to work with the four organizations to identify additional opportunities to raise funds and awareness. ❁

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 John Batz
 Suresh Bhut
 William Booker
 Mary Brooks
 Mary Ann Brown
 Marie Burton
 Verlena Dawson
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 Diane DiRenzo
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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.

Spring & Summer 2009 CALENDAR OF EVENTS

May	June
<p>9th Scrum for Six Downingtown, PA</p> <p>10th - 12th National ALS Advocacy Days Washington, DC</p> <p>16th Seaside Boardwalk to Defeat ALS™ Hiering Avenue and the Boardwalk Seaside Heights, NJ</p> <p>27th Lakewood BlueClaws Celebrity Waiter Event Lakewood, NJ</p>	<p>3rd ALS Fundraiser at Pearl S. Buck House Downingtown, PA</p> <p>6th Harrisburg Walk to Defeat ALS™ City Island Harrisburg, PA</p> <p>12th & 13th Billy Lake Basketball Marathon Monsignor Bonner High School Drexel Hill, PA</p> <p>20th ALS Express Wildwood, NJ</p>

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FOR MORE INFORMATION ON ALL OUR EVENTS, VISIT WWW.ALSPHILADELPHIA.ORG.