

date	event	location
9/8/2006	Michael Bartone Memorial Golf Tournament	Arrowhead Golf Course, Douglassville, PA
9/9/2006	Michael Bartone Annual Dinner Dance	Saint Anthony's Lodge, Downingtown, PA
9/9/2006	Berks ALS Fundraising Event: Deanna Reuben and Friends "Classical, Broadway, and All That Jazz"	Women's Club Center for the Arts, 140 N. 5th Street, Reading, PA
9/10/2006	Elmwood Zoo	1661 Harding Boulevard, Norristown, PA
9/12/2006 and 9/19/2006	Newly Diagnosed Seminar: Philadelphia Region	1st Floor Conference Center, 401 Plymouth Road, Plymouth Meeting, PA
9/12/2006 and 9/19/2006	Newly Diagnosed Seminar: Harrisburg Region	Hershey Medical Clinic, Main Hospital, Dining Room A&B, 500 University Drive, Hershey, PA
9/17/2006	Couture for a Cure	King of Prussia Mall, King of Prussia, PA
9/23/2006	Sam Bonita Memorial Golf Tournament	Rolling Pines (formerly Willow Hill) Golf Course, Berwick, PA
9/28/2006	Friends of John Fineran present the 7th Annual John Fineran Golf Classic	Ramblewood Country Club, Mt. Laurel, NJ
9/30/2006	5th Annual Ocean City Board... Walk to D'Feet ALS®	Ocean City, NJ
10/4/2006	"For One More Day" Lunch and Conversation with Mitch Albom	Hilton Hotel, 4200 City Avenue, Philadelphia, PA
10/13/2006	6th Annual KAK Cup Golf Outing	Makefield Highlands Golf Course, Yardley, PA
10/20/2006	Research Update	Hilton Hotel, 4200 City Avenue, Philadelphia, PA
10/21/2006	4th Annual Lehigh Valley Walk to D'Feet ALS®	Lehigh Valley College, 2809 Saucon Valley Road, Center Valley, PA
10/29/2006	13th Annual Nurturing the Nurturer	The ACE Center, Lafayette Hill, PA
10/29/2006	7th Annual Scott Mackler 5K Run/Walk	Temple Beth El, 301 Possum Park Rd., Newark, DE
11/3/2006	13th Annual Curt Schilling ALS Golf Outing	Meadowlands Country Club and Whitmarsh Country Club
11/11/2006	5th Annual Greater Philadelphia Walk to D'Feet ALS®	Valley Forge Military Academy and College, Wayne, PA
12/1/2006	Annual Luncheon	Marriott Hotel, 1201 Market Street, Philadelphia, PA
12/3/2006	Patient and Family Holiday Party	Radisson Hotel, Trevese, PA

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

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ALS Association (Lou Gehrig's disease)
 Greater Philadelphia Chapter
 321 Norristown Road, Suite 260
 Ambler, PA 19002-2755

phone 1-877-GEHRIG-1
www.alsphiladelphia.org

The mission of The ALS Association, Greater Philadelphia Chapter, is to help people live with ALS, to advocate for ALS patients and caregivers and to support research into the cause, cure and treatment of ALS.

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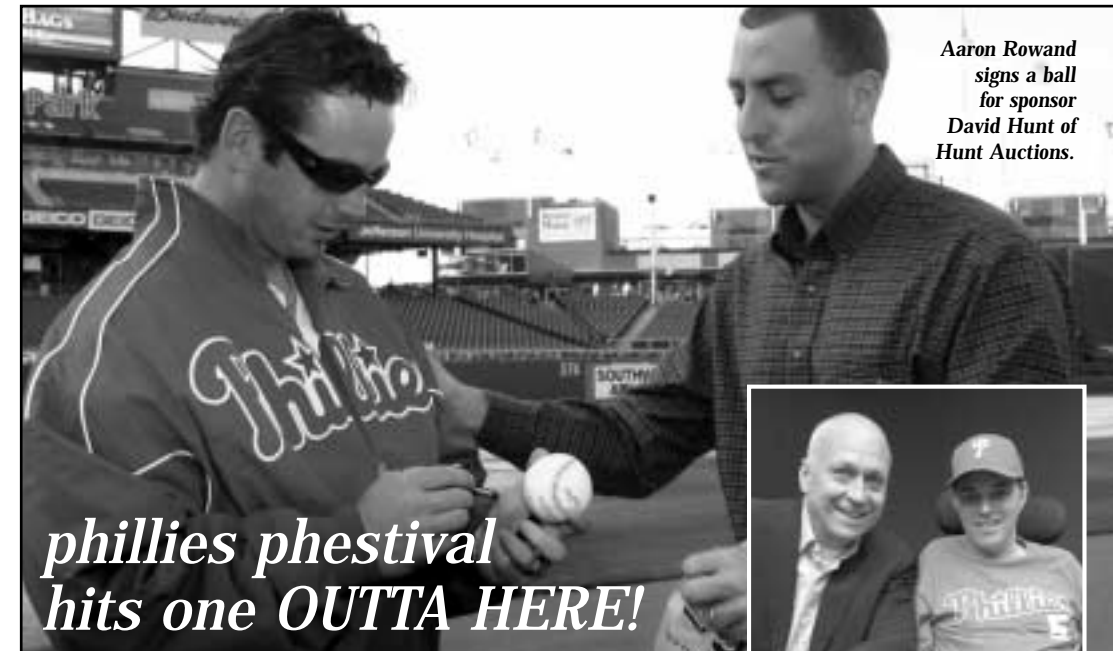
couture for a cure

Walk the red carpet for ALS at the Couture for a Cure Gala and Auction, a fabulous night of fashion and excitement planned for Sunday, September 17. The glamour begins 7 p.m. in the Plaza at the King of Prussia Mall, in King of Prussia, PA. This incredible event will feature an auction of dress forms decorated by high-end fashion designers including Joan Calabrese, Jessica McClintock, Grace Ann Agostino, Frank Agostino, Heatherette, Lilly Pulitzer,

(Continued on page 3)



greater philadelphia chapter
news
 summer 2006



Aaron Rowand signs a ball for sponsor David Hunt of Hunt Auctions.

phillies phestival hits one OUTTA HERE!

In 22 years as the team's principal charity, \$8.7 million has been raised for our chapter.

A record total of \$671,955 was raised at the May 22nd Phillies Phestival for ALS, surpassing last year's tally by over \$37,000. The use of Pat Burrell's suite and a set of jerseys signed by Hank Aaron, Jerry Rice, Wayne Gretzky and Kareem Abdul-Jabbar each received a bid of \$5,500 in the live auction, the top bid of the evening. The live auction raised \$76,400 and the silent auction raised a record \$37,545. The Program Book, chaired by Marcy Cardonick, raised a new high of \$171,186.

The 2006 Phillies squad and coaching staff, as well as the broadcast crew and the players' and coaches' wives, were on hand to lend their support during the event and live auction. This year's special guest was Iron Man Cal Ripken, Jr.

Smith Barney marked its 11th year as the Grand Slam Sponsor of the event. All-Star Sponsor Comcast SportsNet broadcast Daily News Live from the ballpark and several Ballpark Partners contributed a portion of their proceeds to the night's grand total. Home Run Sponsors included Corporate Synergies, Ron and Evie Krancer, Schiffrin & Barroway, LLP, Southwest and UFCW Local 1776.



Special guest, Cal Ripken, Jr. shares a moment with PALS Keith Canady of Newark, DE.

Lunch & Conversation with Author
Mitch Albom
author of Tuesdays with Morrie
 ...see page 13.

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president's report ellyn c. phillips

donation to exploration

Omaha, Nebraska is a charming city in the Midwest that is home to Mutual of Omaha, Omaha Steaks, ConAgra, Boys Town, the Phillips Family (my brother-in-law Eric, his wife Julie and their four kids) and Conor Oberst of the rock group Bright Eyes. Five of Fortune's 500 reside in Omaha.

And, it is in Omaha, with a staff of less than 2 dozen people that Warren Buffett runs his wildly successful company, Berkshire Hathaway. Mr. Buffett made the news recently when he announced that he would be transferring a large portion of his enormous wealth—approximately \$40 billion to the Bill and Melinda Gates Foundation. Rather than try to duplicate what the Gates Foundation was doing, Mr. Buffett acknowledged that the structure was already in place and that the goals of working on world health, scientific research and education were ones he shared. He welcomed partnering with the Gates Foundation.

Shortly after announcing his gift, The New York Times profiled Buffett's three adult children, who described their father as a "regular person." Susan said that she still calls him Daddy and lives just 10 blocks away. She remembers a normal childhood and that her father sang "Somewhere Over the Rainbow" as he rocked her to sleep. Susan, Howard and Peter Buffett were not upset that their father did not leave them the bulk of his holdings. Mr. Buffett had let them know throughout their adult years that his good fortune would be used to do good for others. Of course, the Buffett children are not soon to be applying for welfare either! Each already has a foundation which will receive \$1 billion from their father.

I love this story because charity is our Chapter's business. I always am interested in philanthropy and how donors select causes. We need people with attitudes like Warren Buffett. While 99.999% of us don't have the means of Mr. Buffett, we should all try to think and act like him. How much money do you really need? Curt Schilling often says he gets paid a "stupid amount" of money to play baseball. He and Shonda are very generous to The ALS Association and many other not-for-profits, including The SHADE Foundation which they established when Shonda learned she had melanoma.

But you don't have to have the means of Bill Gates, Warren Buffett or Curt Schilling to donate to our Chapter. And, as trite as it may sound, every dollar does make a difference. So, please ask yourself, if you can contribute more to our cause. You will be "our Warren Buffett" in the fight against ALS.

If it is Summer, I must be on my annual pilgrimage to Maine and my visit to The Jackson Laboratory in Bar Harbor. At JAX, as it is called, our Chapter has been supporting the SOD1 mouse colony and research conducted by Greg Cox, PhD. Over the years, Dr. Cox has become a "star" in ALS research. He recently assumed the position of Chair of The National ALS Association's Scientific Review Committee. While at JAX, I met with Drs Kevin Seburn and Rob Burgess. Dr. Seburn is an electrophysiologist with equipment that looks as if he could launch the Space Shuttle Discovery. Dr. Burgess is the first recipient of the Alan L. Phillips Discovery Award, named after my late husband and funded by my parents, Malvina and Morton Charlestein. Dr. Burgess is using the funding to explore a theory which is a bit "off kilter", "outside of the box," with his study entitled "Mitochondrial Involvement in SOD1 Mediated Neuron Loss." This is exactly the purpose of the Discovery Program which is designed to help researchers explore ideas that aren't traditional but if proven could open up new avenues for exploration.

It was exciting to speak with these three researchers and observe the synergy between them. Dollars, dedication, ideas and intelligence are ingredients needed to find the answer to ALS.

The Board Chair Message by Benjamin Ohrenstein will now alternate issues with the President's Report.

jim pinciotti, executive director e.d.'s musings



One of the important strategies that the Chapter has undertaken in the past two years is to expand awareness of our programs and services throughout our service area. As you probably know, The Greater Philadelphia Chapter serves eastern Pennsylvania, central and southern New Jersey and the state of Delaware. I am proud to say that all of the services and resources of the Chapter are available to the entire service area. However, in some places, we are not as well known, and ALS families and health care providers are not as aware of all that we have to offer.

There are many ways to reach out to these places and people, and we are using several of them. Our Patient Services team is expanding the geography in which they conduct in-service presentations. These presentations are generally made to healthcare organizations to educate them about the disease, about the best practice parameters to use in serving people with ALS and about the Chapter. We make nearly 40 presentations a year, and we have made them in Harrisburg, PA; up-state Pennsylvania; Smyrna, Delaware; Egg Harbor, NJ; and everywhere in between.

We also hold fundraising and awareness raising events throughout our territory. We hold an Autograph

Party and Auction in Scranton, PA with the Red Barons triple-A, minor league baseball team and recently had an event in Williamsport, PA with the Crosscutters baseball team (thanks to our good friends George and Joan Wolfe for developing this idea and chairing the event). We also hold our signature event, the Walk to D'Feet ALS® in six locations around the service area. Many of the events that occur are the result of caring, dedicated folks that live in an area and want to help get the word out. If this sounds like something you would like to do, contact the Chapter and we can put your event on our website calendar of events.

Finally, we have Chapter staff located around the territory. This includes south-central PA as well as north-central PA. Our newest satellite office is located in Red Bank, NJ, serving Monmouth and Ocean counties, in cooperation with a local foundation, The Joan Dancy and PALS Support Group. This will allow us to reach even more families with our resources and services.

I can promise you that, until the need is gone, our Chapter will continue to provide the programs and services that are so necessary to our PALS' quality of life, and we will continue to employ strategies to make every ALS family aware of them. If you can help, let us know.

couture for a cure (Continued from page 1)

Nicole Miller, Paula Hian, Angel Sanchez and more. Don't know Manolo from Mizrahi? No problem. The auction will feature something for everyone, with items from celebrities such as Bette Midler, Curt and Shonda Schilling, Regis Philbin, Paris Hilton, and the Phillies, as well as area businesses like Neiman Marcus and Robertson's Flowers.

Purchase a form as artwork for your home, or as memorabilia of your favorite celebrity. Ticket prices begin at \$125, which includes fine food, drinks, and access to this unique event. Sponsorships are also available.



Visit www.alsphiladelphia.org or call 215.643.5434 to ORDER TICKETS TODAY!

is exercise *beneficial* for the individual with ALS?



zachary simmons, M.D., Professor of Neurology, Penn State University Director, ALS Clinic, Penn State Hershey Medical Center

Due to an editing error, the final paragraph of Dr. Simmons' article was inadvertently deleted from our Spring 2006 edition. The article is reprinted below in its entirety.

Most patients with ALS want to do as much as possible to help themselves, particularly in view of the limited efficacy of current treatments for ALS. One of the most common questions I am asked by patients with ALS and their families is whether physical therapy or exercise will be helpful. As with so many other topics related to ALS, the answer is less clear than we would like, resulting in some uncertainty as to whether exercise should be recommended in ALS, and if so, how vigorous it should be. A brief examination of some of the data and studies to date may help shed some light on the topic.

Why should anyone even question the value of exercise in ALS? The concerns arise from studies that have investigated whether a history of athletic activities or other vigorous physical activities in one's lifetime produces an increased risk of developing ALS. The evidence here is conflicting. Some studies have found that individuals who developed motor neuron diseases were more likely than others to have been thin, to have been varsity athletes in school, or to have performed heavy physical labor as part of their jobs. However, other studies have not found any association between participation in sports or heavy physical labor and the subsequent development of ALS. Certainly the benefits of physical activity are clear with respect to the heart, bones, and overall general health, and the risk that performing such activities will lead to ALS is not at all

clear. Even if such activities increase the probability of ALS, the risk of developing ALS is still low. It's clear that we do not understand most of the factors that cause individuals to develop ALS, and there is simply no sense at this point in recommending to individuals that they avoid exercise to reduce their chance of developing ALS.

But what about the individual who already has ALS? Should he or she be encouraged to exercise? In an attempt to answer this question, one can look to studies done in patients with other neuromuscular

disorders, which generally support the benefits of moderate exercise. For example, a study of 8 patients with facioscapulohumeral (FSH) muscular dystrophy revealed that low-intensity aerobic training produced improvements in maximal oxygen uptake and maximal workload with no signs of muscle damage, and also led to an improvement in performing activities of daily living. There is probably no benefit to exercising to the point of exhaustion, however, at least based on knowledge gained from other neuromuscular diseases. One study of 10 patients with slowly-progressive neuromuscular diseases (not ALS or other motor neuron diseases) monitored the effects of high-resistance exercise at a near-maximal effort, and found gains in some measures, losses in others. The authors concluded that a high-resistance exercise program may offer no advantages over moderate resistance training, and may have some negative effects.

Moving on to motor neuron diseases, animal studies have generally shown no harmful effects of exercise in motor neuron disease. These have been conducted on mice who have been given a human gene that causes them to

develop motor neuron disease (SOD1 transgenic mice). A lifetime of vigorous exercise in these mice did not lead to differences in disease onset, progression, or survival compared to less active mice. There are a few studies in humans which have attempted to assess whether exercise is of benefit in ALS. In one study, a moderate exercise program for 15 minutes, twice daily, had short-term

benefits in producing a slower rate of decline in measures of strength and spasticity, but did not improve muscle strength. Another study revealed some improvements in function and a slower clinical course in those who exercised

regularly. Respiratory muscle training has been shown to produce some improvement in measurements of respiratory function over a 3 month period. Overall, it appears that moderate exercise can be beneficial in muscles that are not profoundly weak, but that extremely vigorous physical activity to the point of exhaustion should be avoided, particularly in very weak muscles. Currently, we believe that moderate exercise is a reasonable recommendation in ALS.

At our ALS center, we are attempting to clarify the value of exercise in ALS. A study will soon be starting under the direction of Dr. Kevin Scott to assess the effects of strength training in individuals with ALS. Persons interested in this study will be taught a series of exercises to perform regularly at home, and will have measurements of their strength, function, and quality of life performed at our center monthly over several months. In the future, we hope to undertake a study of aerobic exercise as well. We are hopeful that studies such as this will permit us to provide clearer answers to questions that so many of our patients ask about physical therapy and exercise.

At our ALS center, we are attempting to clarify the value of exercise in ALS.

advocacy day 2006



Advocates from the Greater Philadelphia Chapter and the Greater New York Chapter meet with Senator Robert Menendez of New Jersey.

On May 15-17, 2006, ALS advocates from across the country once again united in Washington, DC for The ALS Association's annual National ALS Advocacy Day and Public Policy Conference. The Greater Philadelphia Chapter sent over 55 delegates, including 11 PALS, to this empowering event, which is the single largest gathering of the ALS community in the country. They joined hundreds of representatives from the ALS community to share the ALS message with Members of Congress.

By all accounts, Advocacy Day 2006 was a tremendous success. For the first time, advocates were able to deliver our message to all 535 Members of Congress. In fact, since our Hill visits, over 130 Members of Congress have joined as cosponsors of the ALS Registry Act, an unprecedented show of support so soon after Advocacy Day! As of late June, 191 House Members and 43 Senators had cosponsored the bill. Clearly our advocacy is making a difference.

In their meetings, advocates shared the real life impacts of the disease, its toll on families and the urgent need for Congress to act. Importantly, advocates also educated their Senators and Representatives about the increased rate of ALS in military veterans, a subject that clearly seized Members' attention on both sides of the Capitol. And advocates called on Members to support funding for ALS research at the Department of Defense and to pass the ALS Registry Act (H.R. 4033/S. 1353), legislation that would establish a national ALS registry at the Centers for Disease Control and Prevention (additional information on ALSA's priority issues is available at <http://www.alsa.org/policy/priorities.cfm>).

Judging by the response from advocates and Members of Congress alike, our advocacy is making a difference! This year's Advocacy Day and Public Policy Conference demonstrates once again how The ALS Association is lighting the way for a treatment and cure.

SAVE THE DATE! 2007 Advocacy Events:

- Please join us for the 2007 National ALS Advocacy Day and Public Policy Conference, which will take place in Washington, DC May 14-16, 2007. Scholarships are available through the Chapter for patients who need assistance coordinating transportation or an aide while in Washington.
- Look for more information about state advocacy days in the next edition of ALS News.

research update — from ALSA's national office

Enrollment Begins in The ALS Association's TREAT ALS Combination Trial

roberta friedman, Ph.D., ALSA research department information coordinator

Patients with ALS can now volunteer to participate in a trial of combined, investigational therapies funded through the new initiative of The ALS Association TREAT ALS (Translational Research Advancing Therapy for ALS). Twenty centers are participating in this Phase II trial which seeks which combination might be effective in amyotrophic lateral sclerosis (ALS, also called Lou Gehrig's disease).

TREAT ALS is a drug discovery program and clinical trials process that accelerates discovery and testing of clinical candidates.

Each of the combinations to be tested has prolonged survival in rodent models of the disease to a greater degree than any of the compounds used alone. If neither combination turns out to provide beneficial effects in ALS, the study investigators will be able to decide this by enrolling just 120 patients. This streamlined trial should therefore serve as a model for future studies to speed decisions about clinical candidates for ALS.

If one or both should produce a slower decline in function compared to a historic control group, further testing will proceed under an expanded, Phase III protocol with a placebo control.

"This study provides an excellent example of how TREAT ALS seeks to hasten the pace of clinical discovery in ALS," said Lucie Bruijn, Ph.D., The Association's science director and vice president.

Minocycline plus creatine and celecoxib plus creatine are the only two drug combinations so far shown by published reports to have additive effects in the mouse model of the disease. Since each of these is an already marketed compound, safety in people as well as beneficial effects in animal models of ALS is already known.

(Continued on page 6)

boeing employees community fund awards \$8600 grant to purchase speakerphones

People with ALS in our region will have an easier way to keep in touch with friends and family thanks to an \$8600 grant from the Boeing Employees Community Fund. The grant was awarded to the Greater Philadelphia Chapter for the purchase of 20 remote controlled speaker phones to loan to patients.

These special phones have features that allow people who have lost dexterity in

their hands and arms to stay in touch with the world, hands-free. If the phone rings, the patient can answer it from across the room, simply by saying "hello." In addition, a wireless remote allows patients to make and receive calls without assistance.

For patients who can still talk, but who do not have the dexterity to dial the phone, these speakerphones are an invaluable tool to maintain



independence and stay in touch with the outside world.

The Chapter loans the phones to patients through the Scott A. Mackler, MD, PhD, Assistive Technology Program. With the purchase of these 20 additional phones, many patients currently on a waiting list for the device will receive them immediately.

two men race for ALS



Shawn Callahan (right) ran the Boston Marathon in honor of his uncle Earl Nau, who suffers from ALS.

The Boston Marathon took place this year on April 17. With parts of the 26.2 mile race discouragingly named eartbreak Hill, Hell's Alley and The

Haunted Mile, it is no surprise that the race is an intense one. But despite the potentially daunting course, two men ran it with hope. Shawn Callahan and Michael Brown ran for ALS.

Both men ran the race for a family member with ALS: Callahan for his uncle Earl Nau, and Brown in memory of his mother, Sylvia Brown.

Shawn Callahan said of the experience, "The support I have received from family, friends and colleagues has been tremendous. It has made my campaign easier and [their] goodness and generosity will go a long way in the fight against ALS."

research update — from ALSA's national office (Continued from page 5)

Despite the lack of definitive cause for most cases of ALS, multiple processes have been shown to promote nerve cell death. These drugs to be tested affect different aspects of the processes that may lead to the demise of motor neurons, including the inflammation that appears during the disease.

Markers of disease progression that the investigators will use include the ALS Functional Rating Scale and a measure of respiratory function. These surrogate markers will assess how patients progress with the treatments. Comparison to historic controls from prior trials will also streamline and accelerate the study—all patients volunteering will receive drugs and not a placebo. The only other drug patients are allowed to use while on the trial is riluzole, the sole approved treatment for ALS. Trial participants will have had ALS onset within the past

5 years. Breathing capacity must be at a certain level to participate: Forced Vital Capacity (FVC) must be above 60%.

There is no cure for ALS. It is only through well-designed clinical trials that more effective treatments will be found. Clinical trials are entirely dependent upon the participation of patients with ALS.

For more information about the trial contact:

Carolyn Doorish, Project Coordinator
e-mail: cd2141@columbia.edu
phone: (212) 305-2027

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a look at the chapter's new planned giving web page

Featured in the next several issues of this Newsletter will be components of the Chapter's new Planned Giving web page that is linked from our homepage at www.alsphiladelphia.org. The site helps visitors better understand various planned gift vehicles that are available, and the financial benefits of making such a gift from the donor's perspective.

In this issue we will focus on the simplest and most common form of planned gift – the bequest. By clicking on the **Gift Plans** section of the site, and then clicking on **Bequests**, the following information is available:

Bequests

A gift to The ALS Association in your will or revocable trust proclaims your confidence that we will continue to pursue our mission and make a difference in the lives of future generations. A bequest:

- is easy to arrange,
- does not affect your assets or cash flow during your lifetime, and
- is revocable.

You Can Make Your Bequest in Several Ways:

The following language may aid you and your attorney in preparing a bequest to the Greater Philadelphia Chapter:

Specific Bequest - "I bequeath \$ _____, (or the following described property such as shares of stock _____) to The ALS Association, Greater Philadelphia Chapter, a non-profit corporation located in Ambler, Pennsylvania."

Residuary Bequest - "I bequeath (_____ %) of the residue of my estate to ALS Association, Greater Philadelphia Chapter, a non-profit corporation located in Ambler, Pennsylvania."

Contingent Bequest - "If (name of beneficiary) does not survive me or is unable to inherit this bequest, I direct that it be paid to ALS Association, Greater Philadelphia Chapter, a non-profit corporation located in Ambler, Pennsylvania."

Your Bequest Can Be Used by Us in Two Ways:

A bequest can be directed to a specific program or purpose of the ALS Association, Greater Philadelphia Chapter, or you can direct that it be applied to our general resources for the need that we believe is most pressing at the time it is received.

For additional information about planned giving, or to request a confidential personal gift illustration, please contact the Chapter's Chief Development Officer, Jeff Cline, at 215-643-5434 or by e-mail at jeff@alsphiladelphia.org.

a patient earmarks his bequest to help others

Jim and
Jackie
Gahan



Grateful
for the
exceptional

care Jim received from the entire team at the ALS Center at Pennsylvania Hospital in Philadelphia, Jim and Jackie Gahan of Lakewood, NJ decided to leave a portion of Jim's estate to The Greater Philadelphia Chapter. Mr. Gahan's generous bequest has now been received and was earmarked to support the Center.

"My husband was diagnosed with ALS in 1998," said Jackie. "He was first treated at other facilities but was not truly satisfied with his care until we attended the ALS Center in 2001. The difference was like night and day for Jim," she added. "It means everything to feel that you are the most important person in the world to your doctor. That is honestly how we felt about Drs. Elman and McCluskey and the whole team of clinicians and Chapter staff that cared for us at the Center. Jim wanted his gift to truly help people with ALS in the same manner as he had received it. I know that we made the right decision."

nurturing the nurturer offers respite for caregivers

When ALS strikes, it affects all aspects of family life. Our Chapter's mission is to meet the needs of not only ALS patients, but also family members and caregivers touched by the disease. In recognition of the toll ALS takes on family caregivers, the Chapter is proud to host Nurturing the Nurturer, an annual day for caregivers at the ACE Center in Lafayette Hill, PA.

This unique event offers caregivers an opportunity to be pampered in a relaxing atmosphere, and to meet and share experiences with others in similar situations.

Gerry Voit, whose wife, Kathryn, has ALS, estimates that he has attended Caregiver's Day six of the past eight years. "I've tried most of the activities over the years—from massages, to swimming, to riding bikes," he says "But the best part is making connections with others, and having a chance to share experiences."



The day begins with break-out groups geared toward the caregiver's relationship with the patient. Special sessions are planned for husbands, wives, children, and other family members, to introduce caregivers to others facing the same challenges.

After a gourmet meal in the ACE Center's cafeteria, attendees can enjoy massages, manicures, pedicures, craft classes, and cake-decorating classes. Participants are also encouraged to make use of the swimming pool, bike paths, and work out facilities available at the ACE Center.

The Chapter has temporary respite programs available to coordinate and fund home health care during the event, if the patient can not be left alone. This year's event is planned for Sunday, October 29, from 10 a.m. to 4 p.m. Lunch is included, and the entire day is free to family caregivers. Contact Alisa Brownlee at 215-631-1877 or alisa@alsphiladelphia.org for more information.

To support the programs, services, and research of the Greater Philadelphia Chapter of the ALS Association, including events like Caregiver's Day, please use the enclosed envelope to make a gift today.

middle school hosts annual ALS awareness day

This spring Grover Middle School held its fourth annual ALS Awareness Day in West Windsor, New Jersey. The idea stemmed from an assignment from seventh grade science teacher, Shirley Allen, who asked her students to make presentations about the disease of their choice. One student did a particularly standout report on ALS, and the school decided to make ALS Awareness Day an annual occasion.

The students watched the movie, "Tuesday's With Morrie," about a college professor with ALS, and participated in a question and answer period with local ALS patient Mike Thomson. Following Thomson's presentation, the daughter of an ALS patient read a story that she had

written chronicling her mother's battle with the disease.

For the weeks following ALS Awareness Day, a fundraising booth was set up in the school's lunch room. Also, a Bowl-A-Thon was planned to raise even more money for the disease. Over the four years of the school's participation in ALS fundraising, it has raised over \$15,000 dollars!

One student, Ben Menahem was moved to write a poem about ALS, entitled, "A Poem, An Overview, A Tribute," which concluded by saying, "So do not drown in sorrow, but continue to live and to fight. Because once all is said and done, and the race is over we'll be there. We'll be together, with no pain."



Sue and Mike Thomson (right and center) shared their ALS experience with teachers and students as part of Grover Middle School's ALS Awareness Day

drew mccorkell & frank lindecamp
friends united by ALS

On most Saturdays you will find Drew McCorkell and Frank Lindecamp enjoying breakfast at the Butcher Block in Spring City, PA. The two men are regulars there, and the waitresses know what they want before they even sit down. Like old friends, they discuss everything from history to politics to entertainment to family. But Drew and Frank are new friends, united by their shared experience with ALS.

Frank, 74, has been living with ALS for 18 years. Thirty-four-year-old Drew lost his mother to ALS three years ago. As his mother's primary caregiver, he appreciated people who came to visit her during her illness. That appreciation led him to become a visiting volunteer to Frank nearly 2 years ago.

"Frank is a firecracker!" Drew says. "His mind is clear, his opinions are strong, and his spirit is vibrant. He teaches me a lot about life, and I'm wiser for knowing him."

Frank is similarly enthusiastic about Drew. Frank describes him as a "nice, church-going boy. Everyone in my family loves him. They say he is 'too sweet to be true!'"

The two have become fast friends. After their weekly breakfast, they run errands like food shopping, getting ice cream, or visiting friends. Drew adds that Frank often brings back snacks and small gifts for other residents at the Veteran's Center where he lives "just because he knows it will brighten their day," Drew says. "Maybe that's why they voted for him to be President of the Resident's Association."

The pair has attended ALS-sponsored events such as Longwood Gardens and the trip to the Philadelphia Zoo. Drew has also accompanied Frank to family outings such as a wedding, and barbecues.



Frank (Left) and Drew enjoy a day at the Zoo

As a dedicated middle school teacher for children with learning disabilities, Drew has even incorporated his ALS experience into the lesson plan. He introduced one of his students to Frank, and those two are now pen-pals. In addition to the time he spends with Frank, Drew also volunteers with the youth ministry at Hopewell Church.

Before his ALS diagnosis, Frank worked his whole life in the hospitality industry, where he says his "claims to fame" were serving then-President Dwight Eisenhower at a charity golf outing, and serving the Queen of England during her visit to Philadelphia for America's Bicentennial.

Frank has a chatty manner and says he retains a lot of "Jeopardy"-type trivia. This becomes evident as he speaks, as his conversations veer from his favorite president (Harry Truman) to his dedication to playing the lottery (if he hits the Powerball, he plans to give a portion to ALS) to his schooldays with Wilt Chamberlain (who still owes Frank 29 cents for doughnuts).

"Frank is acutely aware of the world around him and faces all of life's challenges with honesty and passion," says Drew. "I am grateful for the time I get to spend with him."

The Greater Philadelphia Chapter's visiting volunteer program matches volunteers with a personal experience with ALS to patients who would like visitors. For more information, contact Gail Houseman at 215-643-5434 or gail@alsphiladelphia.org.

upcoming walks



Fifth Annual Ocean City Board...Walk to D'Feet ALS®

Presented by CertainTeed Corp and ShopRite and their Customers.

Saturday, September 30, 2006
6th Street and the Boardwalk
Registration 9:00 am
Walk Starts 10:00 am

Make a weekend of it and join us at the shore as we walk the boards to D'Feet ALS! For more information about walking or forming a team contact, Julie McKeever at 1-877-GEHRIG 1 or email julie@alsphiladelphia.org.

*Registered walkers who raise \$25 or more will receive unlimited rides at Playland from 1-3pm the day of the walk.

Fourth Annual Lehigh Valley Walk to D'Feet ALS®

Saturday, October 21, 2006
Registration: 9:00 – 10:00 am
Walk Starts: 10:00 am
Lehigh Valley College
2809 Saucon Valley Road
Center Valley, PA

For more information about forming a team or joining the Walk committee, contact Allison Walker at 1-877-GEHRIG 1 or e-mail at Allison@alsphiladelphia.org.

Make a Difference
at a Walk to D'Feet ALS®!
Form a team, join a team,
or make a donation at
<http://walk.alsphiladelphia.org>, and
do your part to "D'Feet" ALS!



Farley's Faithkeepers walk in memory of Tom Farley, a teacher, administrator and nationally honored soccer coach.

New Jersey Schools Walk to D'Feet ALS®

When Cathy Cowan joined the Seaside Board...Walk to D'Feet ALS® committee she wanted to get schools involved in the Walk. Cathy walks in memory of her brother Tom Farley, a teacher, administrator and award winning soccer coach and felt that by reaching out to the schools of Monmouth, Middlesex and Ocean Counties she would truly honor her brother. Thanks to the support of the Superintendents of Ocean, Monmouth and Middlesex counties, last year five schools held shadow walks, sold bracelets and paper feet, held dress down days and walked. In 2006, 19 schools held shadow walks, sold bracelets and paper feet, held dress down days and walked raising an impressive \$6,766. In addition to raising funds for the Walk, students also learned about ALS, read Tuesdays with Morrie and helped to create awareness about ALS and The ALS Association. The New Jersey school participation is truly a fitting tribute to Cathy's brother.

Fifth Annual Greater Philadelphia Walk to D'Feet ALS®

Saturday, November 11, 2006
Registration: 10:00 – 11:00 am
Walk Starts: 11:00 am
Valley Forge Military Academy and College
1001 Eagle Road
Wayne, PA

For more information about forming a team or joining the Walk committee, contact Allison Walker at 1-877-GEHRIG 1 or e-mail at Allison@alsphiladelphia.org.

Third Annual Bucks County Walk to D'Feet ALS®

Oxford Valley Mall – April 21, 2007
More details coming soon!

We are actively looking for new committee members! Please contact julie@alsphiladelphia.org or 215-643-5434 ext 26 to join the fun!

recent walks

Sixth Annual Harrisburg Walk to D'Feet ALS®

It was a day to surpass records! Not only did more than 77 teams turn out for the 6th Annual Harrisburg Walk to D'Feet ALS®, they raised a Harrisburg record of over \$233,000, bringing that walks 6 year total to well over \$1,000,000! Congratulations to top fundraising teams, Pam's Pals, Big Daddy's Bunch, Gordie's Groupies and ABC 27/Guys and Dolls Walking for Mike. More than 1,500 people came together and created an energy that filled the air! A special thank you goes out to Leighann Moll, this year's walk chair, the committee, ABC 27, The River 97.3, Phantom Entertainment, My Gym and all the wonderful volunteers who helped make this day happen.

Fourth Annual Seaside Board...Walk to D'Feet ALS®

Almost 750 people joined us as we walked the boards of Seaside Heights and Seaside Park, NJ at the Fourth Annual Seaside Board...Walk to D'Feet ALS® on Saturday, May 20th. This year's Walk was the most successful yet as 51 teams helped us to raise over \$139,000. Top fundraising teams included Rube's Team, Kerrie's CUREsaders, Farley's Faithkeepers, Carlson's Roughriders and Angel Annie. The highest corporate fundraising team was The Ritz Carlton, Philadelphia and Mike Rubbinaccio was the highest individual fundraiser. Once again walkers were treated to a special appearance by cast members from the HBO series, The Sopranos. Vince Curatola, Robert Iler, Max Casella, Carl Capotorto and Jeff Marchetti signed autographs, posed for pictures and charmed walkers. Special thanks to our committee, led by Cathy Cowan and Mike Rubbinaccio, WOBN 92.7 for their continued support of the Walk, team captains, Seaside Heights and Seaside Park, corporate sponsors and our volunteers. Looking forward to seeing you at next year's Walk.



State Representative Jerry Nailor (right), ABC27's Chuck Rhodes (left), and "Jammer" Ruhland cut the ribbon at the Harrisburg Walk to D'Feet ALS.



Walk chairs, Cathy Cowan and Mike Rubbinaccio join committee member Vincent Cantone, Liana Rubbinaccio, Maria Maruca, Executive Director of the Seaside Heights Business Improvement District, Point Pleasant Mayor Martin Konkus and Seaside Heights Councilwoman Joyce Camera at the ribbon cutting ceremony to start the Walk.

we THANK our walk sponsors

CertainTeed Corp., Presenting Sponsor of the Ocean City Board...Walk to D'Feet ALS®, ShopRite and Their Customers, Presenting Sponsor of the Ocean City Board...Walk to D'Feet ALS® Neutrik USA, Platinum Sponsor of the Seaside Board...Walk to D'Feet ALS®

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Our sponsors help make our Walks to D'Feet ALS® a success!

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

A Victory For All On The Court!

Hundreds of area basketball players took to the court on Saturday, June 24 at the 15th Annual Billy Lake Memorial Basketball Marathon at Monsignor Bonner High School in Drexel Hill, PA. More than \$28,000 was raised for the Billy Lake Memorial ALS Research Fund. The event has raised well over \$280,000 during the last 15 years. 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.



A game between a celebrity team of local personalities, and the Lake Team is an annual highlight of the event. Thank you to all our celebrity participants!

4th Annual Michael Bartone Memorial Rugby Tournament Scrum for Number 6

On May 6, 2006, eight rugby teams competed in this tournament in memory of Michael Bartone including the Brandywine Old Boys. Many of the players on the Brandywine Old Boys team were teammates of Michael Bartone. The all day rugby event raised more than \$12,000 for the Michael Bartone Memorial Foundation.



ALS Express

Someone turned off the faucet just long enough for over 400 riders to make their trek to Wildwood, without getting wet, during the 7th Annual ALS Express Bike Ride on Saturday June 24th. Riders made their way from 70, 45 and 20 mile

start points throughout New Jersey ending up in Wildwood for a day of fun at Morey's Piers. This year's event raised \$120,000. A special thank you to this year's sponsor, ShopRite, spokeswoman Orien Reid and to The Eileen Frank ALS Foundation for organizing such a fabulous event! Check out the ride website at www.als-express.org!

6th Annual Gene Gladfelter Memorial Mile

June 10th was a beautiful day in York, PA for the 6th Annual Gene Gladfelter Memorial Mile. Participants turned out in force and raised over \$6,000 this year! A special thank you to Steve Harlacher and The Shiloh United Church of Christ.

Larry Goodwin Memorial Golf Tournament

On June 3rd, 45 golfers turned out for The 1st Annual Larry Goodwin Memorial Golf Tournament. Spirits were high as the outing raised over \$1535 for The ALS Association! A special thank you to organizers Melissa and Fred Menke for all their hard work.

ALS Charity Auction and Autograph Party with the Lakewood BlueClaws

Finnigan's in Lakewood, NJ was once again the site of the ALS Charity Auction and Autograph Party with the Lakewood BlueClaws. The 2006 BlueClaws team and coaching staff waited tables and tended bar for two sold out dinner seatings of BlueClaws fans and supporters of the ALS Association. When not waiting tables, players bowled with fans and signed autographs. A silent auction filled with sports memorabilia and tickets to events helped to make the night fun for everyone. Special thanks to the staff of the Lakewood BlueClaws and Finnigan's for helping to raise \$9,229 at this year's event.



Team members from the Lakewood BlueClaws pose for a picture before waiting tables at this annual event.



"For One More Day": Lunch and Conversation with Author Mitch Albom

Join nationally renowned author and journalist Mitch Albom at a lunch and conversation with the author on Wednesday, October 4, 2006. This event is your opportunity to meet Mitch and hear his perspective on his third book, which follows the story of Charley, who, after years of regret for leaving his mother on the day of her death, has an opportunity to spend one "last day" with her. The event will be held at the Hilton Hotel, 4200 City Avenue, Philadelphia. Albom is the award-winning author of "Tuesdays with Morrie" and "The Five People You Meet in Heaven." Tickets are \$100 per person, and include an autographed copy of "For One More Day."

Sponsorships are available by contacting Maryann Vagnoni at 215-643-5434.

ALS Research Update

Scientists are making exciting advances in ALS research. Join Lucie Bruijn, PhD, Science Director for the national ALS Association, for an update on the latest research news. The Research Update will be held at the Hilton Philadelphia City Avenue, on Friday, October 20, at 1:30 p.m. Patients, family members, caregivers, and donors are invited to attend. The update will be presented in layman's terms and is free to anyone who is interested in ALS research.

For more information or to RSVP, contact Nilda Mallatratt at 215-643-5434 or nilda@alsphiladelphia.org.

Mackler 5K Run/Walk

The 7th Annual Scott Mackler 5K Run/Walk will take place on October 29, 2006 at Temple Beth El, 301 Possum Park Road, Newark, DE. The race will start at 12:30pm with registration starting at 11:00am. Registration is \$20 before October 25th and \$25 the day of. Tee shirts are given to the first 500 registered runners and walkers and a fabulous post race buffet for all registrants. Awards will be presented to the overall male and female and top 2 in the following 5 year age groups 14 under to 65 and over, plus the top 3 male and female walkers.



For more information contact Joe Sontowski at 302-633-1208 or email Ljoekool@aol.com.

Berks ALS Fundraising Event: Deanna Reuben and Friends "Classical, Broadway, and all that Jazz"

Join us for an exciting evening with Deanna Reuben and special guests on Saturday, September 9. The fun begins at 8 p.m. at the Women's Club Center for the Arts, 140 N. 5th Street, Reading, PA. Other musicians include Marty Mellinger, pianist; Gary Floyd, vocalist; "Doc" Mulligan, trombone; Larry McKenna, saxophone; Keith Mohler, bass; and Dave Santana, drums.

Your \$50 ticket includes complimentary wine/champagne and dessert. Watch for our raffle for a fabulous trip!

For more information or to purchase tickets, contact Deanna Reuben, 610-478-9330.

golf, golf, & more golf

Friends of John Fineran present the 7th Annual John Fineran Golf Classic

THURSDAY, SEPTEMBER 28, 2006
Ramblewood Country Club, Mt. Laurel, NJ.

7:00 a.m. or 1:00 p.m. tee off. \$100 per golfer, \$400 per foursome. Includes greens fees, cart, lunch and dinner, and silent and Chinese auctions.

Contact Anne Coles
609-267-6700 x6257 or awcoles@cvs.com

Sammy Bonita Golf Outing

SATURDAY, SEPTEMBER 23, 2006
Rolling Pines Golf Club, Berwyn, PA

Contact Richard Brozena at 570-735-5297

6th Annual Kak Cup Golf Tournament

FRIDAY, OCT. 13, 2006
Makefield Highlands Golf Course, Yardley, PA.

Shotgun start at 1:00 pm. \$150.00 per golfer, \$600.00 per foursome (includes greens fees, cart, beverages, dinner, raffle and silent auction) \$50.00 per person for dinner only.

For more information contact Cyndee Ward at 215-428-3754 or info@kakcup.org

13th Annual Curt Schilling #38 ALS Golf Outing



FRIDAY, NOV. 3, 2006
Whitemarsh Valley Country Club and Meadowlands Country Club.

\$350/golfer includes dinner and fabulous silent and live auctions with priceless sports memorabilia and more!

Contact Julie McKeever at julie@alsphiladelphia.org or 215-643-5434 xt. 26.

elmwood zoo

The Patient Services Fall Recreational Event will be a trip to the Elmwood Zoo in Norristown, PA, on Sunday, September 10. Look for more information in the mail soon! For questions or to RSVP, contact Nilda Mallatratt at 215-643-5434 ext. 13 or nilda@alsphiladelphia.org.

morey's piers

On Saturday, June 24 the Patient Services department sponsored a trip to Morey's Piers in Wildwood, NJ. The day provided PALS and family members with lots of fun at the waterpark and amusement rides. Attendees also enjoyed a picnic lunch.



(Left)
Longwood Gardens
Over 135 people attended the Chapter's 14th annual trip to Longwood Gardens in May. Here, Rose and Ronald Johnson are joined by Chapter President Ellyn Phillips at Longwood.

(Right)
Robert Davis, who has transported patients for nine years as a van driver for the Chapter, has retired as of August 1, 2006. We wish Robert the best of luck in his retirement!



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

Caregivers and Family Members- Ambler, PA

Info. and RSVP:
Karen Dawson-Haines,
(215) 951-8263

Delaware - Wilmington, DE

Info.: Liz Hoff, LSW
(856) 566-0709

Harrisburg - Hershey, PA

Info.: Judy Lyter,
(717) 657-5352

Lehigh Valley - Allentown, PA

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

North Central - Danville, PA

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

Philadelphia - Bala Cynwyd, PA

Info.: Karen Dawson-Haines
(215) 951-8263

South Jersey- Egg Harbor Township, NJ

Info.: Stephanie Hand-Kowchak, MSW, LSW
(609) 909-3509

Trenton - Lawrenceville, NJ

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

NEW LISTING

Monmouth/ Ocean County- Red Bank, NJ

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



Lodish Bike Ride

Susan and Leonard Lodish's 11th annual tandem bike ride for ALS was a success! This year they rode through Israel, raising nearly \$100,000 for the fight against ALS, with more donations still coming in. The Lodishes ride in honor of Len's cousin, Dr. Jules Lodish of Bethesda, MD.

VOLUNTEERS NEEDED!

The ALS Association needs volunteers for many roles, which include helping at Chapter events, assisting in the Chapter office and visiting people who are coping with ALS.

If you are interested in becoming a Chapter volunteer, please contact:
the Chapter at 215-643-5434 or
toll-free at 1-877-GEHRIG-1

Volunteers, We Couldn't Do It Without Them!



VOLUNTEERS

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Jeanne A. Johnson

CHIEF DEVELOPMENT OFFICER
Jeff Cline

NURSE COUNSELOR
Jennifer Klapper, APRN, BC

ASSISTIVE TECHNOLOGY
SPECIALIST
Alisa Brownlee, ATP

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COORDINATORS
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Paula Rich, RN, MSN
Patricia Schaeffer, RN
Sue Walsh, RN, MSN, CS

STAFF NURSE
Christine D'Angelo, RN, BSN

SOCIAL WORKERS
Wendy Barnes, MSW, LSW
Shelley S. Hill, MSW, LCSW
Susan Schwartz, ACSW, LSW

EVENT MANAGER
Allison Walker

EVENT COORDINATOR
Julie Morrison McKeever

EVENT SPECIALIST
Marianne Mancini

DEVELOPMENT COORDINATOR
Joan Borowsky

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MANAGER
Nora Isaac

TECHNICAL SUPPORT ANALYST
Andrew Gohde

ADMINISTRATIVE STAFF
Nilda Mallatratt,
Patient Services Assistant

Mary Sharp
Receptionist/ Office Assistant

Maryann Vagnoni
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TRANSPORTATION VAN DRIVERS
John Conner
Thomas R. Mitchell

FINANCE STAFF
Janel Cullinan
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Erin Farrell
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