

SUMMER 2007
Volume XXIII : Issue IV



< Representatives from the Western PA/West Virginia chapter participated in the 2007 ALS Advocacy Day, May 15, 2007 in Washington, D.C.. FULL STORY, PAGE 2

the ALS press

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inside > President's Letter page 4 Resource Group Listing page 6

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Advocacy > ISSUES

By Dr. Sarah W. Wood

FEDERAL ADVOCACY

The ALS Association's 10th Annual National Advocacy Day and Public Policy Conference was held on May 14-16, 2007, in Washington, DC. There were over 600 total attendees, including over 100 patients who participated, along with 20 delegates from the Western Pennsylvania-West Virginia Chapter. This year for the first time, there were delegates from all 50 states attending. This was truly a national grassroots event!

Our delegates met with 12 of our 13 Congress members or their aides. As part of the "I Took the Extra Step" Campaign, we delivered nearly 700 letters collected by patients, Chapter board members, and friends to our members of Congress, urging them to support our cause.

This year, one of our chief priorities is the passage of a bill authorizing the establishment of a national registry for ALS. By instituting this nationwide registry, it would enable us to better identify and serve ALS patients. It would also help researchers identify potential causes of ALS, such as environmental triggers. These triggers are thought to contribute to the disease in susceptible people. So far, we have obtained significant bipartisan support for the bills in both houses of Congress, as well as the support of President Bush.



In the House of Representatives, HR 2295 has 235 cosponsors as of 6/13/07. This includes eight of our 10 members of Congress (Altmire, Capito, Doyle, English, Murtha, T. Murphy, Peterson, and Rahall). Representatives Shuster and Mollohan are not signed on as cosponsors. This is a clear majority and counting! In the Senate, S 1382 has 27 cosponsors as of 6/13/07. So far, none of our Pennsylvania or West Virginia Senators has signed on as a cosponsor, so we still have some work to do locally.

These lists are updated weekly, and hopefully our support will continue to grow. You can go to our Chapter web site at: www.cure4als.org to sign up to be an ALSA advocate: just click on Public Policy to sign up, look up your legislator, and to learn more about our ongoing advocacy efforts.

STATE ADVOCACY

The Western Pennsylvania and the Greater Philadelphia Chapters of The

ALS Association have been working on a new State Advocacy initiative to secure an \$800,000 line item in the Pennsylvania State Budget to enhance and expand patient and family services throughout the Commonwealth.

Our initiative, being lead by Senator Jane C. Orié (R-40) in the State Senate and Representative Josh Shapiro (D-153) in the State House of Representatives, has received an incredible amount of support. Thanks to everyone in our community for reaching out to their Members to help push this initiative forward. We were able to get such high ranking legislators to champion our cause because of our advocates sharing their personal story with them. We have advanced this far because of your hard work!

Please don't let up. Keep reaching out to your Members of the Legislature on behalf of all those battling ALS. Please use the following link to learn the name of your State Senator and Representative. Just type in your zip code and you will be taken to a page with all the contact information for your State Legislators. <http://capwiz.com/alsa/dbq/officials/>

If you have any questions about this effort, please contact Michael Bernarding at Michael@cure4als.org or 800-967-9296 or 412-261-5940.

Network of Clinical Investigators Stands Ready for ALS Trials

Research

>UPDATE From The ALS Association's
National Office

[Quick Summary: A network of clinical investigators is in place and ready to coordinate clinical testing of promising compounds for ALS, once these are identified.]

The ALS Association, through its TREAT ALS initiative, has put in place a partnership with the North East ALS Consortium (NEALS) to provide a network of clinical investigators that will be ready to test promising compounds in patients with ALS (amyotrophic lateral sclerosis, also known as Lou Gehrig's disease) and provide opportunities for training of newer investigators to participate in clinical trials for ALS.

TREAT ALS (Translational Research Advancing Therapy for ALS) is a drug discovery program and clinical trials process that accelerates discovery and testing of clinical candidates. The TREAT ALS/NEALS Clinical Trials Network will expedite multi-center trials of compounds identified through the TREAT ALS drug discovery program or any other compounds that appear to hold promise for the disease.

The network will facilitate training of ALS centers including centers certified by The Association, and the existing trials network of NEALS will provide rapid

translation of promising laboratory results into clinical trials. The ability to partner effectively with government, industry, and contract research organizations (CROs) is a key aspect of the TREAT ALS/NEALS Clinical Trials Network.

"Having a clinical trials investigator network in place is an important part of the TREAT ALS program, and we are pleased that the NEALS group is able to lend their expertise to train other centers. This will accelerate trials of ALS candidate treatments," said Lucie Bruijn, Ph.D., science director and vice president of The ALS Association.

Bruijn added, "Through TREAT ALS several biotech companies have approached The ALS Association for support in the development of novel compounds or ideas for drug development in ALS. With this new partnership, leaders in the field can provide the necessary expertise to help move these opportunities forward."

NEALS Consortium (www.alsconsortium.org)

This group of academic investigators, formed in 1995, has extensive experience in ALS clinical trials with 65 clinical

centers in North America that participate. Co-chairs are Merit Cudkowicz, M.D., and Jeremy Shefner, M.D., Ph.D., both experts at caring for ALS patients and leaders in design and methods for trials of compounds in neurodegenerative disorders. The eight members of the NEALS executive committee are elected biannually from among the investigator members and meet regularly. A scientific advisory board is in place whose members are actively involved in the study of ALS disease mechanisms and treatment development.

"NEALS has several meetings each year where members review possible therapies to test, and this provides opportunity to collaborate on research studies," noted Cudkowicz. The ALS Association's support of NEALS and partnership in a clinical trial network is "innovative and timely." She added, "This support will allow training of new ALS trial sites and improve access for people with ALS to new therapies throughout the U.S. It will speed up the development of new therapies by improving efficiency. We look forward to continuing to work closely with The Association and the TREAT ALS initiative."

See RESEARCH, page 12



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The new logo of The ALS Association—a hand touching a vibrant red-letter “A”—visually represents The Association’s unending, heartfelt pledge to fight on every front to cure ALS and improve life for those living with Lou Gehrig’s Disease. The visual identity reflects The ALS Association’s three focused areas of expertise and commitment: research to find new treatments and a cure, advocacy at the highest levels of government, and comprehensive care and support services for all people living with Lou Gehrig’s Disease.

President’s >LETTER

As I start my term as President of the Western Pennsylvania-West Virginia Chapter of the ALS Association, I want to thank the Board of Directors for their help and support, and I look forward to working with them. I also want to thank Sarah Wood for her leadership over the past six years. She has worked tirelessly to make our Chapter the organization it is today. I can’t thank our hardworking staff enough for all of their effort on behalf of ALS.

I have been involved with this chapter for over 25 years. Many people have asked me why I have stayed active for so long. My answer is that I have seen the help that we have been able to provide to our PALS and their families and without us, they could not secure these services. Not only do we provide this support, but through our National Office we are able to fund research to find the cause of ALS, discover treatments and eventually a cure for this devastating disease.

Our Chapter faces some challenges and many opportunities in the coming years. We know that there are many PALS that we are not reaching. We know that there are services that we cannot provide due to our limited staff. We need to expand our public awareness and develop the resources to increase our patient services staff.

We do not receive any Federal, State or local government funding. All of our operating funds are donated by you, our supporters. Without your generosity, we could not function. We need your help on an ongoing basis. Every memorial contribution, Walk donation, and event attendance keeps this Chapter running. We all have to step up to the plate and work as hard as we can to battle this disease. Thank you.

—Robert Kelley,
Board President

ALS Race Across America

On May 13, 2007 Team LOCO (Lou Gehrig's Outdoor Cycling Organization), a group of three young men began their travel across America in order to spread awareness of the urgency to find a treatment and cure for ALS. The tour began in Ocean City, Maryland and will end in July, in Los Angeles, California. During this expedition, Team LOCO will be taking part in numerous events sponsored by various chapters of the ALS Association in efforts to increase awareness of the disease as well as to raise funds in support of



Zach, Anthony, and Ryan biking across America.

See RACE, page 6

Mt. Lebanon High School Students Making a Difference

"Lean on me, when you're not strong, and I'll be your friend, I'll help you carry on."

When 16-year-old Katie Giarla of Mt. Lebanon came to her friends for support after her father, Bill Giarla, was diagnosed with ALS over two years ago, Julie Dumbaugh and Emily Sreisleben expressed their support for the family by hosting a birthday party honoring the Giarla's.

The joint party celebrating the girls 16th birthday was held at the Crown Plaza in Upper Saint Clair. In each invitation, the girls placed a donation envelope and asked that guests bring a donation in honor of the Giarla's for the ALS Association instead of a gift. With nearly 125 guests in attendance, a total of \$4,000 was raised and donated to the ALS Association in honor of Bill Giarla and his family.



Emily Sreisleben and Julie Dumbaugh celebrate their sweet 16.

Since her father's diagnosis, Katie has wanted to host a formal event to raise money; however, it was only made possible with the help and support of her friends. The three girls have been best friends since playing soccer together in 5th grade and have always had each other to lean on in times of need. After seeing the effects and progression that ALS

has had personally knew, Julie and Emily were determined to help in any way they could. Julie offers, "This has motivated me to pursue more projects and fundraisers to help The Association. I know that Emily and I made the right decision by giving money to The Association. There isn't anywhere else I would have rather given it to."

Soon after the fundraising event, Bill Giarla entered into rest on June 4, 2007, after a long battle with ALS. Although this was the first fundraising event Katie and her friends hosted, they have hopes of continuing to raise money by designing t-shirts and hosting other events in the future to continue to contribute to The Association and other families struggling with the effects of ALS.

Tribute Funds Make Impact on Association

On May 3, 2007, the staff of Ernst & Young, Manhattan office presented Jerry Grese with a check in honor of Jerry's brother, Joe, who was diagnosed with ALS last December. Through the ALS Association, Western Pennsylvania-West Virginia Chapter, arrangements were made to present Jerry and his family with the donation to this Chapter in their honor the night of his retirement. The retirement party was held at the Scaletta restaurant in New York City.

Jerry Grese worked for Ernst & Young for over 20 years, however, decided to retire after hearing the news of his brother's diagnosis. The Grese family often enjoys family golf outings, football games, etc., and Jerry explained, "As long as I'm around, Joe is not going to sit in the house." Jerry has made it his mission to not let Joe become confined to his bed at home. The Ernst & Young staff wanted to do something to honor Jerry's

contribution to the company and help his family with the struggle they are facing.

Tony Sirianni, a partner in Jerry's firm, took the bull by the horns and headed the "Joe and Jerry Grese Tribute Fund." Mr. Sirianni has known Jerry since 1994 and wanted to do something in honor of Jerry's hard work through out his years at Ernst & Young. After the tribute fund was set up, Sirianni stated, "The energy and willingness of the staff to donate was amazing. The tribute fund created a real excitement and buzz around the office." Also, to provide incentive and have a little fun, a silent auction was held with the winner receiving a very special Jerry Grese autographed memento. Overall, thanks to the efforts of



Tony Sirianni presents the check to Mr. and Mrs. Jerry Grease

Ernst & Young and many individual contributors, a total of \$49,886.00 was raised through the Joe and Jerry Grese Tribute Fund.

If you are interested in starting a tribute fund in honor or in memory of a loved one, please contact Tiffany Cramer, Special Events Manager at 800-967-9296 or Tiffany@cure4als.org.

RACE, from page 5

nationally driven cutting-edge ALS research and community-based patient service programs. To date Team LOCO has raised over \$20,000 and hopes to continue to raise substantial funds throughout their 45 day journey.

Team LOCO is an organization put together in honor of Gordon Miller who was diagnosed with ALS last year. Throughout Miller's life he has positively affected many peoples lives as a son, brother, father,

husband, uncle, and friend. In this time of need, Gordon's family and friends are showing their love and support by sponsoring Team LOCO in the ALS Race Across America.

Ryan Dagen of Lancaster, Pennsylvania, a nephew of Gordan Miller is the inspiration of team LOCO's conception. It is his goal that through the teams' efforts the ALS Association will take steps towards the improvement of life and research for those afflicted by ALS. Anthony Pietromonaco and

Zach Hall, both from Pittsburgh, Pennsylvania, are the additional members of Team LOCO that will be making this courageous journey. Like Dagen, Anthony Pietromonaco is also dedicating this excursion to his uncle who was recently diagnosed with ALS. All three boys are enthusiastic about their journey and have high hopes for the outcome of LOCO's efforts. For more information on Team LOCO and the ALS Race Across America visit <http://www.alsraceacrossamerica.com>.

The ALS Association
Western PA–West Virginia Chapter

Resource Group >LISTING

Pittsburgh Resource Group

Facilitator: Linda Talmon

Location: Panera Bread at The Galleria,
1500 Washington Road, Pittsburgh, PA

Greensburg Resource Group

Facilitator: Linda Talmon

Location: Hoss's Restaurant, Route 119,
Greensburg, PA

Please call Linda at 412.261.5940 or email
her at linda@cure4als.org for the dates and
times of the Pittsburgh and Greensburg
Resource Groups.

Johnstown Resource Group

Facilitator: Janet Goodard

Location: John P. Murtha Neuroscience
and Pain Institute, 1450 Scalp Ave.,
Johnstown, PA 15904

Time: 4–5:30pm

July 11

August 8

September

October 10

November 14

December 12

Janet Goodard,
RN, BC, BSN, CCAP
1450 Scalp Av., Suite 120
Johnstown, PA 15904
814.269.5288

VISIONARIES PLEASE APPLY

Leave A Legacy of Hope



We're looking for a few far-sighted people to
help us create a **legacy of hope**.

Please consider joining The Lou Gehrig Legacy
Society by including ALSA in your will or trust or
by making a gift that returns income for life.



For more information on how you can leave
a **legacy of hope**, please contact our chapter office
or visit us online at: www.alsa.org/giftplanning

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> We extend our sympathies to the
loved ones of the following people who
lost their battle with ALS

Rose Andrejwski
Lois Atkinson
Ursula Barrett
Thelma Callender
Thelma Clicquennoi
Mary Davis
William Dickinson
James Drumheller
Booker Dunmore
Dana Fischer
Debra Grimm
Regis Heyl
Robert Hixson
Richard King
Thomas Kuhn
Ed Lasher
Carl Lydic

Michael Masi
Judith Matthews
Mary Matty
Thomas Poydence
Seretta Reed
Delores Ritson
Larry Rush
Rita Sabruno
Julia Saia
Ronald Snyder
Shirley Stewart
Evelyn Stout
Martha Valla
Helen Vallencourt
Anne Veronese
Hazel Webb-Davidson
Mike Williams

Drive it Home 4 a Cure!

On Friday, June 8, 2007, The ALS Association held their summer fundraiser, *Drive it Home 4 a Cure!* at the Bobby Rahal Volvo.Jaguar. Land Rover.Aston Martin Dealership in Warrendale, PA. Over 230 guests were in attendance, raising over \$35,000 for the ALS Association.

Drive it Home 4 a Cure! featured wine selections from Laird wine and spirits, beer provided by Penn Brewery and vodka provided by White Diamond Vodka. The event also featured the Haute Summer Styles Fashion Show featuring some of Pittsburgh's finest retailers and boutiques. Guests gathered around the catwalk as they previewed exclusive summer fashions, hair styles and make up by Philip Pelusi. The fashion show was precluded by the ALS Association presenting two awards; one to Jay Simon in grateful appreciation for his many years of dedication to fighting Lou Gehrig's disease. Annually, the Jay Simon Golf Classic is held to raise funds for the Norma L. Simon ALS Patient Equipment Fund. The second award was presented to Dr. Sarah W. Wood the first recipient to receive the Dr. Sarah W. Wood advocacy award in appreciation for her visionary leadership and outstanding service.

Overall, the ALS Association raised more money on these auctions than expected. The event was sponsored by BPU Investments, Oxford Development, National City and Highmark Blue Cross Blue Shield.



PHOTOS: COURTESY ROBERT LUTZ PHOTOGRAPHY



THE NADAV BAUM GROUP AT



Board President, Robert Kelley (left), presents Jay Simon (right) with his award.

National City

Wexford Post Office
DELI & CATERING

RESEARCH, *from page 3*

Promising Pipeline

NEALS has pipelines of compounds through contacts with biotechnology companies, and through the collaboration of NEALS members who are prominent basic scientists with labs focused on drug discovery, NEALS investigators have also validated many outcome measures and pioneered streamlined and efficient new clinical trial designs. NEALS has an established coordination and data management center and has built and validated a state-of-the-art electronic data capture and trial management system. Many centers certified by The Association are already members of NEALS.

Shefner said, "As more drugs pass through the pipeline and require clinical evaluation, it will be critical to have sufficient trained clinical sites that can participate

in trials. The NEALS collaboration with The Association will provide a mechanism to train new sites and will provide the infrastructure necessary to rapidly design and implement clinical trials."

"NEALS has a history of inclusiveness," Shefner added, "and we look forward to welcoming many new sites to our group and to including them in future trials. In addition to enhancing training, this initiative will aid in further development of high quality data acquisition and management and will ensure that all study measures are accurately and reliably performed. I believe that the Treat ALS/ NEALS Clinical Trial Initiative will be a significant benefit to the ALS community."

New Steering Committee under TREAT ALS

The Association will establish a steering committee to advise on

trials to be conducted through this new network and will work with NEALS on design of trials, selection of participating sites, and training appropriate for each trial. Funding will support these activities, through the TREAT ALS initiative.

Participation will not be limited to centers already certified by The Association. Two clinical trials are already under consideration as pilot studies for the TREAT ALS Clinical Trials Network. Any promising clinical trial can be funded independent of or take advantage of this new resource to expedite discovery of effective ALS therapy.

Refer to the The ALS Association's Web site under the research tab for further information about TREAT ALS.

GOLF CLASSIC, *from page 11*

allowed the net funds raised to go "over the top." Thank you, ladies!

History of the Jay Simon Golf Classic

In 1992, Jay organized the first golf outing to create a means to gather friends, family, and business associates once a year as a way to stay in touch and enjoy a great time together on the golf course. From 1992 through 1999, the purpose of the

outing was simply "for the benefit of a darn good time."

Then, in 2001, with the passing of his Mom, Norma Simon, from ALS ("Lou Gehrig's" disease), the outing added a purpose. Through the ALS Association of Western PA/West Virginia Chapter, a fund was established in honor of Norma L. Simon to provide equipment that is not covered by insurance to families who have been stricken by this horrible disease. The annual golf outing is now used to support this fund.

Save the date!

The 17th Annual Jay Simon Golf Classic will be held on Friday, May 16, 2008. To be placed on the invitation mailing list, contact Jay at (412)258-1020 or jsimon@hefren.com. To make a donation to the Norma L. Simon ALS Patient Equipment Fund, please make the check payable to the ALS Association and send to Jay's attention at P.O. Box 383 Bradford Woods, PA 15015.

Join The ALS Association's Community of HopeSM



Become a Community of HopeSM Champion – and lead the fight against ALS

Community of HopeSM Tribute Funds are set up by individuals who want to build awareness and support for The ALS Association through their own network of friends, family and co-workers.

When you create your own Tribute Fund, you become a Community of HopeSM Champion and a recognized leader within our community.

As a Community of HopeSM Champion, you will have your own Tribute Fund web page.

Share memories online
A Tribute Fund web page is a place where family and friends can come together to share their favorite memories and stay connected. Visitors to the website can view online photo albums, leave messages and make donations.



As a Community of HopeSM Champion, you can update the site quickly and easily – whenever you want – with new information or photographs.

Celebrate your happiest moments
Whether it's a graduation, wedding or new birth, your Tribute Fund provides a unique and meaningful way to celebrate those special occasions. Invite your guests to visit your site both before and after the event and to make a donation as an alternative to giving a gift.



Raise funds for The ALS Association
Increasing public awareness of ALS is gratifying enough, but your Tribute Fund will also provide a convenient way for visitors to make donations to The ALS Association. All donations received through your website are acknowledged to your Tribute Fund.



To honor ... remember ... and celebrate ...

It's easy to get started
We offer easy-to-use step-by-step guidelines for creating your own site online, but if you prefer, we can create the site for you based on your input.

The screenshot shows a web page titled "Amanda Watson - ALS Advocate" under the heading "REASON FOR HOPE". The page includes a photo of Amanda Watson, a "Spreading Awareness" section with text about her diagnosis and advocacy, an "About Amanda" section, and several call-to-action buttons: "ADD Information About Honoree", "ADD Photos & CREATE Photo Album", "EASY to Find Donation Button", and "CREATE a Guestbook". A sidebar on the right contains navigation links like "ABOUT ALS", "ABOUT ALSA", "PARENTS & FAMILY SERVICES", "PUBLIC POLICY", "HOW YOU CAN HELP", "IN THE NEWS", "RESEARCH", and "REGISTER ACCOUNT".



Save These > DATES

Thursday, July 26, 2007
Walk to D'Feet ALS® Kick-off Event

Saturday, July 28, 2007
**ALS Night at the New Castle Thunder
(minor league football)**

Saturday, August 11, 2007
Johnstown Walk to D'Feet ALS®

Saturday, September 15, 2007
Pittsburgh Walk to D'Feet ALS®

Saturday, October 20, 2007
Pittsburgh Symposium

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Fighting Lou Gehrig's Disease



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