

mailing panel

## ALS Resource/Support Groups

A Resource group is a great way to meet other ALS patients, caregivers, family members and friends. You will also learn effective strategies and what community resources are available to help you live with ALS.

\* Please RSVP to Group Facilitator on or before morning of meeting \*

ACCESSIBLE TRANSPORTATION is available to meetings. Please call Linda Talmon, Patient Services Coordinator @ (800) 967.9296 to arrange transport.

### GREENSBURG RESOURCE GROUP

**Facilitator**  
Linda Talmon, LPN  
(412) 261.5940  
Linda@cure4als.org

**Location**  
Hoss's Restaurant  
Route 119  
Greensburg, PA 15601  
(724) 834.1515

**Time**  
1:30 p.m. to 4:00 p.m.

### JOHNSTOWN RESOURCE GROUP

**Facilitator**  
Jan Goodard, RN  
Please call Jan at  
(814) 269.5288  
with any questions

**Location**  
John P. Murtha  
Neuroscience and  
Pain Institute  
1450 Scalp Ave.,  
Suite 2400  
Johnstown, PA 15904

**Time**  
4:00 p.m. to 5:30 p.m.

**2007 Dates**  
Nov. 13th  
Dec. 11th

### NEW CASTLE RESOURCE GROUP

**Facilitator**  
Linda Talmon, LPN  
(412) 261.5940  
Linda@cure4als.org

**Location**  
Hoss's Steak & Seahouse  
\*\*Community Room\*\*  
2409 Wilmington Road  
New Castle, PA 16105  
(724) 654.0787

**Time**  
1:30 p.m. to 4:00 p.m.

### PITTSBURGH RESOURCE GROUP

**Facilitator**  
Linda Talmon, LPN  
(412) 261.5940  
Linda@cure4als.org

**Location**  
Hoss's Steak & Seahouse  
\*\*Community Room\*\*  
1101 Beaver Grade Road  
Coraopolis, PA 15108  
(412) 262.8857

**Time**  
1:30 p.m. to 4:00 p.m.

### WEST VIRGINIA RESOURCE GROUP

**Facilitators**  
Linda Talmon, LPN  
(412) 261.5940  
Linda@cure4als.org

**Location**  
Annie McCauley  
Medical Social Worker  
WVU Physician Office Center  
(304) 598.4806

**Time**  
12:00 p.m. to 1:00 p.m.

**Upcoming Dates:**  
Nov. 15th  
Dec. 20th



FIGHTING ON EVERY FRONT TO IMPROVE LIVING WITH ALS.™

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## Our Mission.

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.

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Linda@cure4als.org

\* denotes Director Emmeretis

## Letter from the Board President & Executive Director

As we enter this season of Thanksgiving, we would like to take this opportunity to express our deep and sincere gratitude to all those who help us fulfill our mission throughout the entire year. Our mission is challenging. Our ultimate goal, to eliminate ALS, at times seems like a daunting task. Nonetheless, we must, and will keep working. In order to see success, we need each and every one of you on our team.

This year, we partnered with the John P. Murtha Neuroscience Institute in Johnstown, PA and were able to open the doors on the first and only Multi-disciplinary ALS Clinic in the region. Together, we recruited Zachary Simmons, MD of the Penn State Hershey Medical Center to serve as the Medical Director of the Clinic. Now, people with ALS (PALS) from the West-Central Pennsylvania region have convenient access to exceptional care, with opportunities to participate in ALS research studies. We cannot express our gratitude and praise enough to our partners at the Conemaugh Health System/John P. Murtha Neuroscience Institute for their hard work, steadfast commitment, and most of all their never-ending compassion for all those we serve.

Also this year, we took our State Advocacy efforts to the next level. We worked fervently to partner with the state of Pennsylvania in order to enhance and expand our services across the state, especially to reach out to those people in rural and underserved regions. As we all know, this was a brutal year with State politics and budgeting. Nonetheless, we made great strides thanks to the amazing advocates, patients, family members, and friends who made the trip to Harrisburg in February, met with their Legislators in their district offices throughout the year, sent letters, and made phone calls. We are continuing this fight. We will not rest until we have all of the resources needed to serve each and every PALS in the state. We have already started planning for next year, so please contact us if you want to join the fight to enhance and expand services for all those battling ALS.

At the Federal Advocacy level, we have made great progress with the ALS Registry Act, which was recently passed by the U.S. House of Representatives and is now being considered by the U.S. Senate. Please sign up to be an ALS Advocate on our website, [www.cure4als.org](http://www.cure4als.org) and help keep this and other important pieces of legislation moving forward. In addition, the Department of Defense has established the first-ever "Amyotrophic Lateral Sclerosis Research Program" (ALSRP) and has directed \$5 million to fund the program in FY 2007 in addition to the other funding already supported by DOD. You can learn more about how The ALS Association has been the driving force behind these initiatives and many others at our website above.

All in all, we have had a great year and we owe it to all of you in our community who help us do it. We thank you for your generosity and service.

Together, we will create a world without ALS!

Warmest regards,




Robert Kelley  
Board President





Michael Bernarding  
Executive Director

### MEMORIES CAN LAST FOREVER

*Leave A Legacy of Hope*



You can create a tribute to someone you love and leave a **legacy of hope** for others. Join The Lou Gehrig Legacy Society by including ALSA in your will or trust.



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](http://www.alsa.org/giftplanning)

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PALS Gary Douthitt throws out the first pitch at The Altoona Curve game.

## An Outing with The Altoona Curve

Minor League baseball team The Altoona Curve is very proud of their involvement in the Central Pennsylvania community and consider their community activity the cornerstone to building fan support and creating goodwill throughout the

region. The Curve joined the fight against ALS this summer with a special game to raise money for The Association. On July 18, The ALS Association's Western PA-West Virginia Chapter staff joined nearly 400 ALS patients and supporters at Blair County Ballpark to cheer on The Curve against The Bowie Baysox. The Curve provided 500 tickets to The ALS Association for volunteers to sell. A portion of each ticket sale was donated to The ALS Association, raising over \$750.

Perhaps more important than the monetary donation that The Curve provided was the opportunity for an exciting outing for ALS supporters and patients. Many fans wore their Walk to D'Feet ALS® t-shirts to show their support for The Association and their efforts to find a cure for ALS. At the start of the game, Ron Shumaker and Gary Douthitt, two PALS (Persons with ALS), threw the first pitch. The event proved to be a great place to spend time with other ALS supporters and cheer on the team that made the night possible. The energy in the stadium that night drove The Curve to a 10-4 victory.

*informative*

## The ALS Association Announces \$ 3.5 Million Partnership with Cambria Biosciences to Accelerate Development of New Drugs for ALS

### Initial data from project presented at the Society for Neuroscience meeting

The ALS Association has awarded Cambria Biosciences a \$3.5 million contract to develop new drug compounds for treatment of Amyotrophic Lateral Sclerosis (ALS), also known as Lou Gehrig's disease. This partnership builds on previously funded efforts with Cambria to develop unique neuroprotective drug compounds that prevent cell death caused by misfolded proteins that aggregate together within the cell. Mutant copper-zinc superoxide dismutase, or SOD1, is a protein that is misfolded to form aggregates in the motor neurons of some people with inherited forms of ALS.

"With this award we will be able to set up a virtual mini-pharmaceutical company to pursue new ALS therapies. It is a real privilege to have the opportunity to collaborate on this project with scientists of the stature of Drs. Morimoto and Silverman," said Dr. Kirsch. The project team presented their results to-date at the international meeting of the Society for Neuroscience in San Diego on November 6 in a poster entitled, "Protein Aggregation and the Development of ALS Therapeutics," by R. Benmohamed and other researchers.

"This academic-industry partnership is an excellent step forward to achieving the goals of TREAT ALS to ensure accelerated drug discovery and the development of new compounds as clinical candidates for ALS," noted Dr. Lucie Buijn, science director and vice president for The ALS Association.

The study is a unique collaboration between Dr. Donald Kirsch, senior vice president for drug discovery at Cambria Biosciences, Dr. Richard Morimoto, an international expert in protein misfolding (which can cause cellular damage associated with neurodegenerative diseases) from Northwestern University and Dr. Richard Silverman, a leading medicinal chemist from Northwestern University.

The compounds will be optimized to produce the lowest toxicity, maximum potency and efficacy and favorable pharmacological properties, such as oral activity, to develop an investigational new drug to enter clinical testing. Cambria will retain intellectual property and commercialization rights on resulting drug candidates, and The ALS Association will be eligible to receive royalties from Cambria on net sales of any approved products.

Dr. Leo Liu, CEO of Cambria Biosciences, added: "This partnership further leverages Cambria's significant and ongoing commitment to develop medicines for underserved neurodegenerative diseases. We are very pleased to work

with The ALS Association and appreciate its support of our neurodegenerative disease drug discovery programs."

Currently there is only one Food and Drug Administration (FDA) approved compound on the market for ALS, Riluzole, with modest effects on disease progression. There is therefore an urgent need for the development of new compounds with properties more suitable for the treatment of neurodegenerative diseases. The compounds identified through this consortium effort act on a mechanism thought to be involved not only in ALS but other neurodegenerative disorders such as Parkinson's and Huntington's disease. Therefore the successful development of such compounds will have a major impact on currently untreatable neurodegenerative disorders.

### About Cambria Biosciences

Cambria Biosciences is an innovative biotechnology company building a product pipeline for serious neurological conditions such as Lou Gehrig's disease and epilepsy. Cambria employs its chemical genetics platform to discover and elucidate novel drug candidates with unprecedented mechanisms of action, internally and in partnership with other companies. Further information is available at [www.cambriabio.com](http://www.cambriabio.com). For more information about Cambria Biosciences, contact Doug MacDougall or Jennifer Greenleaf, MacDougall Biomedical Communications, at 508-647-0209.

TREAT ALS aims to move good ideas from the research arena more rapidly into the clinic for trials and then patient treatment. This initiative does not currently provide new therapies and is designed as a research initiative, not a short term treatment initiative.

The ALS Association periodically sends out Requests for Proposal (RFP) for investigators to design small pilot studies for clinical trials in ALS. TREAT ALS has already provided funding for several clinical projects. To keep current with the ALS field, read the monthly journal news reports at [www.cure4als.org](http://www.cure4als.org) and click the Research tab.



## Walk to D'Feet ALS® Kick-Off Party

*influential*

On Thursday, July 26, 2007, The ALS Association joined over 150 community members for their annual Walk to D'Feet ALS kick-off party at the Hard Rock Café in Station Square Pittsburgh. The kick-off party is an event designed to launch Corporate and Family Team fundraising for the Walk. At the kick-off, team captains and walkers received details for the September 15th Walk at the Pittsburgh Zoo and PPG Aquarium. New attendees learned how to organize a team of family, friends and co-workers to participate in the Walk, and everyone picked up Walk materials to aid in raising funds for local ALS patient services programs and international research projects.

Dr. Maria Simbra, an award-winning, Emmy-nominated medical journalist and medical reporter on KDKA-TV, welcomed the crowd. Dr. Simbra was joined by ALS Board President Bob Kelley, ALS Executive Director Michael Bernarding, ALS Special Events Manager Tiffany Cramer and 2007 Walk Chairman Bob Bowser. The event was also attended by one of the Pittsburgh Zoo's Polar Bears along with Pittsburgh Zoo staff.

A highlight of the evening's events was the raffle for a Hard Rock guitar signed by Brooks & Dunn and Sugarland. ALS supporter Eric Zydell won the prize. Eric has been involved with The Association since his wife Mary Lou was diagnosed in 2002. Mary Lou passed away last year; however, Eric and his family are still actively involved with The Association.

For more information on the Walk, please visit [www.cure4als.org](http://www.cure4als.org).

In cooperation with the Hard Rock Cafe, The ALS Association has created a limited-edition 10-year anniversary Walk pin. The pins can be purchased from the Hard Rock Café in Station Square or by calling (412) 481.7625. Support The Association and purchase one today - only 100 of the commemorative pins are available.

## Sympathies

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

Tamara Bradley	John Kaiser	Ron Sayles
Henry Foxhoven	Hazel Maslowski	Robert Schell
Cynthia Fulmer	Dolores Paullet	Carol Schmitt
David George	Marguerite Pawkovich	John Senock
Janet Geruschat	David Perry	Glen Siburt
William Giarla	Miriam Rossman	Linda Smith
Joe Iarussi	Betty Rotella	Gunter Stehr

# SHARE YOUR APPRECIATION

*Leave A Legacy of Hope*



If you have stock that has increased in value, consider sharing your appreciation by gifting it to ALSA. You can receive a deduction for its full value and create a legacy of hope for others.

EXAMPLE Why giving low-basis stock is better than giving cash		
	Cash Gift	Stock Gift
Gift Value	\$10,000	\$10,000
Capital Gains Tax Savings (15%)	\$0	(\$1,200)*
Income Tax Savings (33%)	(\$3,300)	(\$3,300)
Cost of Gift	\$6,700	\$5,500

\*Assume stock has a long-term capital gain of \$8,000.



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](http://www.alsa.org/giftplanning)

## JOHNSTOWN Walk to D'Feet ALS®

inspiring

On August 11, 2007, The Association held its 3rd annual Walk to D'Feet ALS® at the University of Pittsburgh at Johnstown. The otherwise tranquil Johnstown campus was soon alive with bustling participants eager to walk in support of The Association's mission to raise money for cutting-edge research and vital patient services for those affected by ALS.

Walkers gathered showing their team pride with creative t-shirts and posters. Even pets joined in the fun and supported their teams by wearing team t-shirts. Entertainment included music, clowns, The Altoona Curve and The Johnstown J-Hawks Mascots. At 11:00 am, the presentation began with a recognition of PALS in attendance.

Betty Hostettler, whose husband is living with ALS, uplifted the audience by singing "I Believe I Can Fly" followed by Kayleigh King, one of The Association's summer interns, who sang the National Anthem. Soon after, Bishop McCort High School's football team, walking for Pete Duranko, cut the red ribbon to officially start the one-mile walk around UPJ's campus.

Family, friends, and patients of all ages enjoyed the scenic route around the campus and then joined the ALS staff for a lunch of pizza, hot dogs and refreshments. Dessert included an assortment of homemade cookies, thanks to the hard work of Tricia Barron and her volunteers. The day concluded with raffles for various donated items.



Pete Duranko & The Bishop McCort Football Team Cutting the Ribbon at the 2007 Johnstown Walk to D'Feet ALS.

A special thanks to the Johnstown Walk committee volunteers for all their hard work in making the day a success.

Congratulations to team Mama Mayak for being the team to raise the most money. The team fundraised throughout the year and also held a softball tournament in August to help raise money and awareness. Most team members of Mama Mayak are now veterans of the Walk and are proud to walk each year in memory of Frank Mayak.

Thank you to all of our teams who participated. Your efforts succeeded our goal of \$60,000!

## PITTSBURGH Walk to D'Feet ALS®

inspiring

The Pittsburgh Walk to D'Feet ALS® was held at the Pittsburgh Zoo & PPG Aquarium on September 15, 2007. This year marked the 10th anniversary of The Association's Pittsburgh Walk, which is the largest fundraiser for The Association. Each year, the Pittsburgh Walk raises over \$200,000, which is donated to The Association's Western PA-West Virginia Chapter to help carry out their mission to lead the fight to cure and treat ALS and to empower people with Lou Gehrig's disease and their families to live fuller lives by providing them with compassionate care and support.

Much like those in Johnstown, Pittsburgh Walkers showed their spirit by displaying signs and home-made t-shirts to represent their teams. Face painters, stilt walkers, the Pirate Parrot, Froggy 98 Radio, and a steel drum band greeted guests as they arrived and provided entertainment for all Walk participants. At 9:15am walkers began their journey around the zoo and enjoyed watching the animals frolic in the cool morning air. Once all the Walkers made their way around the Zoo, everyone met for pizza and snacks.

This year, 23 new teams participated in the Walk for a total of 110 Walk teams.



Walkers of all ages attended the event.

The Association is thankful for all of the hard work and dedication put forth by the Pittsburgh Walk Committee volunteers, the Walk Team Captains and the donors on having yet another successful walk season.

Congratulations to the Triumphant T-Birds and Mimi's Marchers for being the two teams raising the most money. Members of the Triumphant T-Birds joined the Walk in 2006 in honor of Tammy Brode Bradley who was diagnosed with ALS in 2005. Tammy lost her battle to the disease on September 1, 2007, at the age of 43. This year, The T-Birds walked in her memory raising \$21,300, making them the first place team for the second year in a row. Mimi's Marchers should also be rewarded for coming in second place in fundraising and for having the largest Walk team. Walkers on this team walked in honor of Mimi Rossman who battled ALS for three years. Mimi lost her battle with ALS October 1, 2007.

The ALS Association Western PA-West Virginia Chapter would like to thank all donors and participants for continuing to make both the Johnstown and Pittsburgh Walk to D'Feet ALS® a huge success. This year's number of participants in both walks exceeded last year making this year's walk season one of the most successful thus far. The Walks would not be possible without support from our valued vendors.

