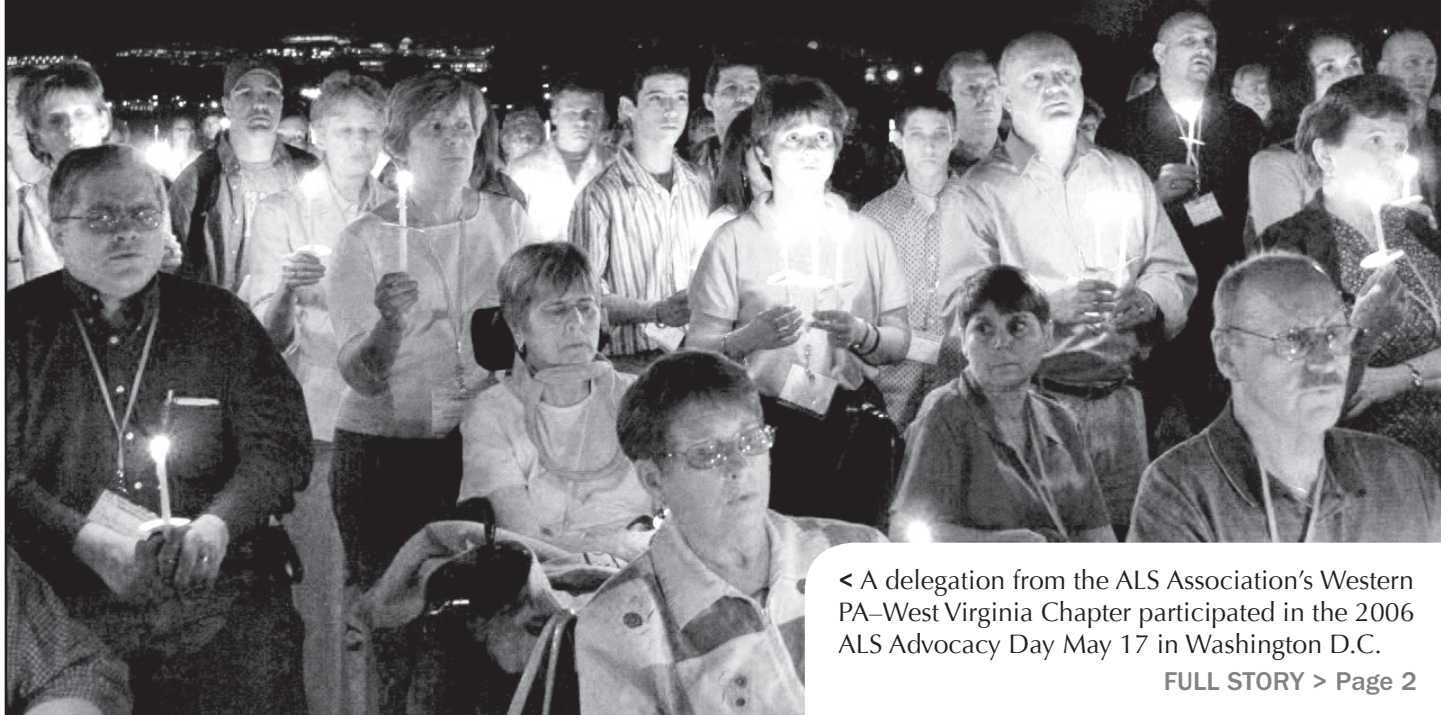


SUMMER/FALL 2006

Volume XXII : Issue II



< A delegation from the ALS Association's Western PA-West Virginia Chapter participated in the 2006 ALS Advocacy Day May 17 in Washington D.C.

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the ALS press

SERVING WESTERN PENNSYLVANIA AND WEST VIRGINIA

inside > *Walk to d'feet ALS*[®] page 5 Resource Group List page 6



2006 National Advocacy Day and Public Policy Conference

Advocacy

>ISSUES

By Dr. Sarah W. Wood

Advocacy Day 2006 was outstanding! Both attendees and Members of Congress on Capitol Hill have reported a wholehearted success! This year, advocates from more than 48 states attended the conference, including from states such as Alaska, Hawaii, North Dakota, and Utah where ALSA does not have a Chapter. Our own delegation from Western Pennsylvania and West Virginia included 19 advocates, the most we have ever had. In addition, more than 90 people with ALS (2 of them in our group), an Advocacy Day record, made the trip to Washington DC and delivered the ALS story to Members of Congress on Capitol Hill. We met with 12 of our 13 Members of Congress on May 17 and delivered 365 letters to them. These letters were signed by attendees at our three Living with ALS Symposia this spring, held in Johnstown and Pittsburgh, PA, and Charleston, WV.

This broad representation of the ALS community has made a difference in advancing this year's public policy priorities in Congress, as 258 Representatives and Senators have cosponsored the ALS Registry Act since Advocacy Day on May 17. Support for the bill nearly doubled in just one week, with a total of 209 cosponsors in the House and 49 in the Senate, as of Oct. 4. Six Representatives from our area have signed on: Shelley Moore Capito (WV-2), Mike Doyle (PA-14),

Alan Mollohan (WV-1), Tim Murphy (PA-18), John Murtha (PA-12), and Nick Rahall (WV-3) and Senator Santorum. We offer our sincere thanks to them for listening to our stories and acting on our requests.

In response to another priority issue, many Senators and Representatives have sent letters to the House and Senate Appropriations Committees urging the Chairmen to support including ALS as a disease to be studied as part of the Neurotoxin Exposure Treatment Research Program (NETRP) at the Department of Defense.

These are significant accomplishments that reflect the effectiveness of our advocacy

efforts and the important role that the entire ALS community plays in delivering our message to Capitol Hill. Clearly we are making a difference!

To view the latest list of cosponsors of the ALS Registry Act, visit the Advocacy Action Center (www.alsa.org/policy) and select the link to the ALS Registry Act in the Action Alert section of the site. Please encourage your Members of Congress to support these priorities, if they have not already done so.

If you are not sure what Congressional District you live in, go to the Advocacy Action Center and follow the steps for

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Front Row L to R: Miriam Rossman, Amy Murphy, Beth Cancilla, Back Row L to R: Paul Rossman, Linda Talmon, Rep. Tim Murphy, Mike Cancilla.

ALSA Funds Preclinical Project to Target Trophic Factors to Spinal Cord

By Roberta Friedman

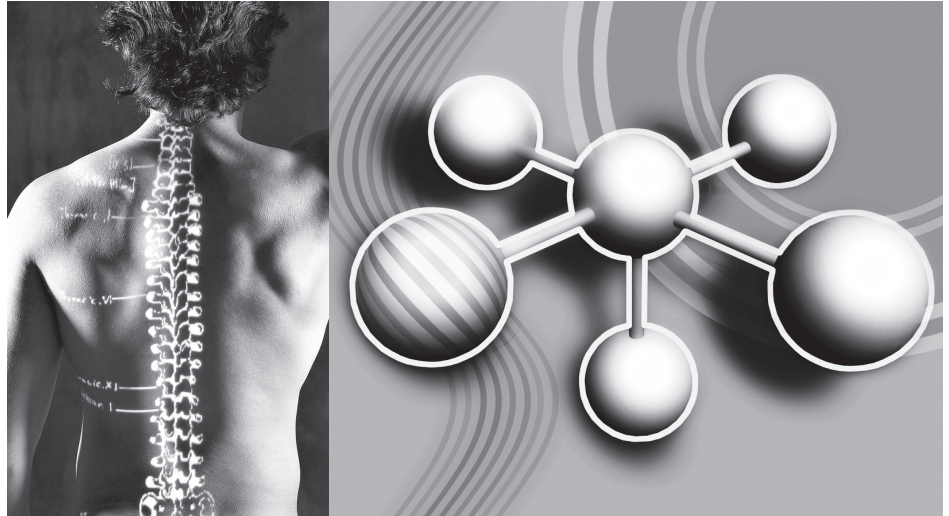
Research >UPDATE

The ALS Association (ALSA) announced funding of an ALSA-initiated project that aims to test feasibility of direct delivery to the spinal cord of the helping molecule, IGF-1, which shows promise in supporting motor neurons dying in the disease, amyotrophic lateral sclerosis (ALS, also known as Lou Gehrig's disease).

Cleveland Clinic investigator Nicholas Boulis, M.D., will be working with Eva Feldman, M.D., Ph.D., of the University of Michigan, and Raymond Bartus, Ph.D., Sr. Vice President, Clinical and Preclinical R&D and COO at Ceregene to show that the delivery strategy is safe and effective in rats and pigs, a prerequisite for human clinical testing.

Ceregene, Inc., of San Diego makes a viral vector that can carry the gene for IGF-1 into the body's cells. The project complements another ongoing investigation into the feasibility of viral vector delivery of IGF-1 into muscle also using the Ceregene compound.

"This new effort, involving injections into the spinal cord, represents a 'parallel approach' to try to assure as much trophic support for the motor neurons is achieved as is possible," Bartus said. "This effort is being initiated to maximize the probability of eventually moving a treatment



into human testing in ALS patients."

"It is possible that both approaches might be effective and also possible that one approach might be more appropriate for one type of patient and the other for another type of patient. Both approaches therefore will be evaluated," said Bartus.

Trophic factors such as IGF-1 (insulin-like growth factor-1) have shown some promising effects in pre-clinical models of ALS. However, clinical trials have yielded mixed results. The trophic factors do not readily enter the brain or spinal cord, so new strategies to get them to these target tissues are being pursued.

One way around the problem is to deliver them by microinjection directly into the spinal cord. The techniques are available to do so safely and have been adapted

from treatments to stimulate deep regions of the brain for pain control and movement disorders. Boulis, a neurosurgeon, will apply this approach to pigs, which have spinal cords of a size similar to humans. The collaborative project now funded will extend initial observations to ensure that the direct delivery is safe in pigs, and effective in the ALS model in rats, to allow clinical testing in ALS patients.

The vector will be delivered by a microinjector electrode placed in the part of the spinal cord that has the motor neurons. Findings in the SOD1 mouse show that this vector with the IGF-1 gene, injected into muscle, is able to improve survival.

Roberta Friedman is the ALSA Research Department Information Coordinator



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Local High School Student is a Dedicated ALSA Advocate



Jean Bartholomew is a 17 year old Taylor Allderdice high school student who has been active in the fight against ALS for many years. Jean has attended The ALS

Association's National Advocacy Day and Public Policy Conference for the past three years. This year

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finding your Representative. There are also photographs taken at the conference available for viewing and purchase at www.alsa.org/policy/alsday.cfm.

You can become an ALSA Advocate by signing up at www.alsa.org/policy/involved.cfm. As an ALSA Advocate, you will receive email Advocacy Updates and other information that will help you to raise awareness of ALS in Congress and make a difference in the fight for a treatment and cure for ALS. If you did not sign letters at one of our three symposia, be sure to send one now via this website. If your Representative is already a cosponsor, send him a thank you! And remember: these letters

change throughout the year, in response to activities on Capitol Hill, so you may need to send several messages.

Last but certainly not least, thank you to all who attended Advocacy Day 2006 and to those who sent letters: you helped make our Chapter part of this success story. You are playing a significant role in the fight against ALS!



From left: Sharon Hrezo, Linda Talmon, and Joe Hrezo.



All of our Walks are over and we are still counting the donations. To date the Walks have raised:

Johnstown, PA—\$53,503 • Charleston, WV—\$12,121 • Pittsburgh, PA—\$180,000

We would like to especially thank the Corporate Team Chair and the Presenting Sponsor of the Pittsburgh Walk

Paul Rockar, CEO
Centers for Rehab Services

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We hope to see you all at one of next year's Walks!

The ALS Association
Western PA–West Virginia Chapter

Resource Group >LISTING

The Forbes Regional Hospital and Allegheny General Hospital resource groups have changed. They are no longer at the previous locations. To find out the new locations, dates and times for these resource groups, please contact Linda Talmon at 412-261-5940 or 800-967-9296.

Johnstown Support Group

John P. Murtha Neuroscience Center
1450 Scalp Ave., Suite 2400
Johnstown, PA
Jan Goodard
814-269-5288

Second Tuesday of each month, 4–5 pm

June 13, 2006

July 11, 2006

August 8, 2006

September 12, 2006

October 10, 2006

November 14, 2006

December 12, 2006

West Virginia Area

Facilitator: Jackie Heintzman, RN
Please call to register 304-652-2420

Kanawha Valley Board of Realtors

2110 Kanawha Blvd. East
Charleston, WV

August 5, 2006

October 7, 2006

December 2, 2006

Ruby Memorial Hospital

Cafeteria Conference Room #6

July 9, 2006

September 10, 2006

November 5, 2006

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when our Chapter organized a State advocacy day in Harrisburg, Jean was there also too to speak for those affected by ALS. Advocating for people affected by ALS is very close to Jean's heart. Her father lost his battle with ALS when she was just 9 years old.

Jean was invited to present as part of a panel at this year's National ALS Advocacy Day and Public Policy Conference in Washington, DC. The topic was Year Round Advocacy and Jean spoke to a group of 100 people about an extensive, strategic letter writing campaign she developed. Jean focused on one issue and wrote a letter about the issue. She identified people—from classmates, to family friends, to influential leaders—to sign copies of the letter. When she attended advocacy day in 2005 she had 500 signed letters to personally deliver to Senators and Representatives.

Steve Gibson, Vice President, Government Relations and Public Affairs, said, "The letter writing campaign that Jean initiated is a perfect example of advocacy in action. By reaching out to her community and enlisting their support for our cause, she strengthened the voice of the ALS community and helped us deliver a powerful message to Congress that much more must be done in the fight against ALS. It is through these types of grassroots efforts that we can use advocacy to make a difference in the fight against ALS." To find out current legislative priorities you can visit our Advocacy website at <http://www.alsa.org/policy/>.

Jean is spending her senior year in Switzerland studying. After high school, she plans on attending George Washington University in Washington, DC. to study public policy advocacy.

For >SALE

ACCESSIBLE VANS

2000 Ford Econoline Van with wheelchair lift, 26,500 miles, 5.4L V8 Engine, new tires and brakes, \$17,500, Call 304-788-3897

Wheelchair Custom Ramp Van, 1997 IMS Dodge Caravan SE, 21,900 miles, Power Passenger Transfer Seat, New Battery, Keyless Entry, Perfect Condition, Purchased New, Asking \$14,900. Please Call 724-482-4103

1999 Chrysler Town & Country Limited. VMI conversion. Red. Power driver transfer seat. Remote start. Keyless entry. Magnetic entry. 45,000 miles. Asking \$16,500.00 or best offer. Call 724-459-6062

2004 Ford Windstar, VMI conversion. Side ramp. Hydraulic lift. 60,720 miles. Asking \$18,000.00 or best offer. Call 724-349-1761 or 412-289-2800

EQUIPMENT

Quickie customized wheelchair (designed for male, 6'1", 200lb), 2 headrests, cushion seat & gel cushion seat, hip & rib adductors, tray, battery charger, \$5000, Call 304-788-3897

Waverlygen Ceiling Lift (2002, excellent condition). Three different track sections. Pneumatic hand control. Charger included. Two lift slings. Asking \$3000.00 or best offer. Call 724-459-6062

Porch lift. (2001, excellent condition). Vertical platform lift. Automatic access ramp. Platform controls. Emergency stop switch. Platform safety switch. Asking \$1500.00 or best offer. Call 724-459-6062

Jazzy 1121 electric wheelchair. Tilts. Asking \$1500.00 or best offer. Call 724-349-1761 or 412-289-2800

2002 Permobil Chairman Entra, battery and charger, tilts, seat elevator, head control, hand control, and attendant control in back. Asking \$4000.00 or best offer. Call 724-459-6062

2 Bruno Stairglides. One is 7 steps and the second is 8 steps. Asking \$1,500 each. Please Call 814-942-5504

Fold-up Portable Ramp. All Aluminum with non-skid surface. Used One Month. Cost \$600. Will Sell for \$450. Call 412-766-7737.

Inflatable Bed Bath, never used, still in box. Hospital bed size. \$700 new, sell for \$450.00. 304-872-5111.

Permobil electric wheelchair, rechargeable battery, reclines and lifts, best offer. 412-364-8362.

Invacare Storm Electric Wheelchair, 24V rechargeable battery. Battery charger included. Top of the line. Ideal for larger person. Only used for three weeks. Completely adjustable back and bottom seat. Tilts/Reclines. 7 mi/hr. Price Negotiable. 724-547-3924

Ranger II Storm Series electric wheelchair, 3 yrs. old, great condition, battery with charger. \$2,000. 724-846-9803.

Jazzy electric wheelchair, red/gray. Price very negotiable. 724-743-1852 or 412-606-5856.

Tuff Care electric wheelchair, with charger. \$1200.00. 412-341-5736.

Rolling Shower Chair/Potty Chair. New, used only 2 weeks. Purchased at Dick's Homecare, Central, PA. \$1,000.00 or best offer. Daytime: 814-422-8024 ext. 240; or Evenings: 814-349-5644.

Rascal Scooter with battery, one year old. \$5,000 New. Sale Price: \$2,000.

Invacare Electric Wheelchair, automatic. Lift/tilt. Robo-cushions included. \$3,000 negotiable. 724-758-4866

Stairglide 15-Step, used only twice, \$2,000; Collapsible Manual Wheelchair & cushion, used 2 years, \$200; Victory Scooter & battery charger, \$3,500; Ramp 3'-4', \$175; Bath Chair, slides over tub, \$500. 724-986-0496

Jazzy 1120 Electric Wheelchair, 6 years old, perfect working condition, used once/month, includes battery charger, J-cushion seat, leg & back tilt. \$1,800; 412-487-5222

KCI "First Step" Tri-Cell Mattress \$250; Stair Glide: 14 feet, straight, \$600; Shoer Chair-PVC Shower Wheelchair, \$100, Hoyer Lift Hydraulic with Sling \$700, 412-487-5222

Jay Simon Golf Classic another big success for the Norma L. Simon ALS Patient Equipment Fund

The 15th Annual Jay Simon Golf Classic netted \$10,500 for the Norma L. Simon ALS Patient Equipment Fund. The outing was held on Friday, May 12, 2006 at Beaver Valley Golf Club in Beaver Falls, Pennsylvania.

Twenty-six teams participated in the four-player scramble event. The field consisted of players traveling from 11 states and two foreign countries. The Longest Domestic Traveler Award went to Mark Jenks of Seattle, Washington and the Longest International Traveler Award was given to Joe Marlovits of London, England.

Flight Winners included teams led by Fred Clerici, Mike Slevin, Bob Skerlec and Bill Blechman. Skill Shot awardees were John Marinaro, Don Belt, Pat Bailey, Kelley Chico, Eric Lenyk and Chris Kayafas.

Jay is the son of the late Norma Simon, who passed away from ALS on May 26, 2000. 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." Jay's mission was to have his outing be unique in that every dollar coming in also went back out to the golfers the same day.

Then, in 2000, with the news of his Mom's ALS diagnosis, the outing added a purpose. Through the ALS Association of Western Pennsylvania, the Norma L. Simon ALS Patient Equipment Fund was formed to provide equipment that is not covered by insurance for current ALS patients. The golf outing is used to support this fund.

Each year, golfers are asked to write two checks, the first for golf, and the second, a straight donation to the ALS fund. Once again, results were terrific. It was another record year for "From the Heart" sponsors...eleven donors made contributions of \$500 or more!

The 16th Annual Jay Simon Golf Classic will be held on Friday, May 18, 2007. 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.

EQUIPMENT LOAN CLOSET

The Equipment Loan Closet was established to assist families with needed equipment while awaiting insurance approval, or if such equipment is not covered by insurance. When no longer needed, we encourage families to return it to our Chapter for use by other PALS. We accept durable medical equipment and wheel chair donations for our loan program. Please note: new items continually are being donated; also, listed items may have been loaned to patients since this posting. Call Linda at 800-967-9296 to request an item and arrange for delivery. Exceptions to our loan closet have a contact number listed beside the individual item and all arrangements are made between the individuals.

STAIR GLIDE/STAIR LIFT
7-Step stairglide. Call 412-370-7461

AMBULATION
Non-wheeled walkers
4-wheeled walkers
2-wheeled walkers
Quad cane
Cane
Forearm crutches
SHOWER/BATH
Tub bench
Transfer bath bench

Shower chair
Slide shower bench
Bedside commodes

MISCELLANEOUS
Hospital bed, motorized head/foot controls
Long handle shoe horn
Grip utensils
Lift Chair

ELECTRIC WHEEL CHAIR
LOAN CLOSET

This program is designed to help ALS patients who are unable to obtain insurance coverage for an electric wheelchair. Our Chapter accepts electric wheelchairs that are donated in good condition. These electric wheelchairs are then refurbished and delivered to PALS in need.

REPAIRS/MODIFICATIONS

Our Chapter covers the cost of repairs/modifications to the wheelchairs in our loan closet. Like all of our Chapter Programs this service is made possible by the generous donations of individuals and sometimes may be subject to the availability of funds. The Walk to D'Feet ALS is our largest fundraiser of the year. Please visit our website to learn how you can help sustain our programming.

February 1–May 31, 2006

Contributions

>RECEIVED

We would like to apologize for omitting donations in the previous newsletter and have included the corrections below. Thank you!

In Memory Of

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2006 Living with ALS Symposia

In an effort to reach more of our community living with ALS, The ALS Association, Western PA-West Virginia Chapter, was honored to host three symposia this year.

The Johnstown, PA; Charleston, WV; and Pittsburgh, PA symposia were attended by over 250 people seeking information on current symptom management, potential treatments and therapies and resources.

We would like to thank our Presenting Sponsors: **Respironics, Sanofi-Aventis, Dynavox and Prentke-Romich** for their support in all three symposia.

Each symposium's morning session featured an ALS-neurologist who presented an

overview of ALS and symptom management. A multi-disciplinary panel then joined the ALS-neurologist to field questions from the audience. This panel included experts in the fields of: respiratory, speech, swallowing, physical therapy, occupational therapy, psychology, and legal issues.

The afternoon session for each symposium was filled with research updates. Johnstown, PA, hosted Dr. Bowser, who discussed his ALS Biomarker study. Charleston, WV, hosted both Dr. Laurie Gutmann (current clinical trials update) and Dr. James Bennett (who discussed the pramipexole study). The Pittsburgh, PA, symposium's research session featured three

presentations: Dr. Raymond Onders, who discussed his trial on diaphragmatic pacing; Dr. Bowser, who discussed his ALS Biomarker study; and, Mike Bozic, M.D., president and chief executive officer of Knopp Neurosciences, who discussed his company's role in the pramipexole study, which has a clinical site in Pittsburgh, PA. These three presenters also took questions from the audience.

*** Please contact ALSWP-WV for requests for taped copies of any symposium.

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

Charles Long
Joyce Siclari
Beverly Squire
Jack Menego
Bobby Glaspell
Robert Maxwell
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Ralph Davis
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Frank Cancilla
James Kingas
Floyd Ruffner
William Rebold
Tim Everline
George Bailey

The ALS Association Plays Ball at MLB FanFest

By Stephanie Seiffert

Major League Baseball's All-Star FanFest may be touted as "heaven on earth" for baseball fans, but it also hit a home run for the Western PA – West Virginia Chapter of The ALS Association.

Pittsburgh's FanFest drew record crowds to the David L. Lawrence Convention Center during its five-day run, July 7-11. According to mlb.com, over 106,000 people attended the event, making Pittsburgh's FanFest one of the top five in history (along with Baltimore, Boston, Philadelphia and Seattle).

Located in the All-Star Bazaar, amongst vendors and a flurry of FanFest guests, volunteers and staff from The ALS Association distributed information on the Western PA – West Virginia Chapter and on the upcoming Johnstown, Charleston and Pittsburgh locations of the annual Walk to D'Feet ALS®. Over 60 volunteers put in their time to cover the 50-plus hours of FanFest.

While FanFest operations ran smoothly, much work and planning had to be done ahead of time to secure a spot for The ALS Association's table. Natalie Brova, Special Events Associate for the chapter, said organizing volunteers became a challenge when more people wanted to help than could fit in the designated area.

"We actually had too many volunteers," Brova said. "They were calling after we already had a full schedule, wanting to help." Members of the chapter accommodated everyone by allowing some people to leave the booth and walk around, handing out brochures.

Visitors to FanFest proved to be very enthusiastic about The ALS Association and its mission.

"People who didn't know about ALS were curious to find out about it," said Melissa Fera, Chapter Development Coordinator, "and people who did know were excited to see us there."

Brova also said that those who knew someone affected by ALS took the opportunity to share their personal stories and those who did not were eager to help once they received information.

Volunteers and staff were able to experience everything FanFest had to offer, and each had a favorite aspect: Brova liked the All-Star Bazaar because of the

large number of people there and Fera enjoyed the auction, where she heard the story of a pastor who auctioned off a Babe Ruth autographed ball and bat to benefit his financially troubled church. Volunteer and ALS Association Board Member Bob Bowser, PhD, named the Steal Home Challenge as his favorite attraction, where participants competed against each other and against the clock in a 90-foot sprint.

All who participated in FanFest were able to recognize the rewards of the event.

"It allowed us to reach a different audience," Brova said. "We had friends and family of people who had ALS or had died from ALS who hadn't known we were here in Pittsburgh or didn't know about the Walk."

Fera appreciated the chance to connect with people who have been affected by ALS and Bowser said he enjoyed interacting with people.

Overall, all volunteers and staff agreed that The ALS Association's time at FanFest was a success; one more at-bat toward the ultimate grand slam of a cure for amyotrophic lateral sclerosis.



Amanda Mason (center) along with FanFest attendees.

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