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.

FULL STORY > Page 2
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...
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
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 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!
All of our Walks are over and we are still counting the donations. To date the Walks have raised:

<table>
<thead>
<tr>
<th>Location</th>
<th>Amount</th>
</tr>
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<tbody>
<tr>
<td>Johnstown, PA</td>
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</tr>
<tr>
<td>Charleston, WV</td>
<td>$12,121</td>
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<tr>
<td>Pittsburgh, PA</td>
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We hope to see you all at one of next year’s Walks!
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.
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 Marlovis 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.
We would like to apologize for omitting donations in the previous newsletter and have included the corrections below. Thank you!

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ALS ASSOCIATION > WESTERN PA–WEST VIRGINIA CHAPTER > 9
I n 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.

We would like to thank the following vendors:

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Svetz Orthotics & Prosthetics, Inc.
Trinity Hospice
Wheelchairs and More
Windber Hospice

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
John Scumaci
Bobby Dickens
Mary Lou Zydel
Margaret Sowolla
Thomas Arnone
Richard Smith
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Ralph Davis
Shirley Bennett
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.
In an effort to save money we will no longer be sending a newsletter via the USPS. We will be posting the newsletter on our Web site for you to view. If you would like to be emailed when the newsletter is posted on our website please email Michelle@cure4als.org and let her know.