Committee Approves $7.5 Million for the ALS Research

This year’s advocacy conference, which was held May 8-11 drew more than 900 ALS advocates to Washington, DC. We had one unified goal: to urge Congress to step up the fight for a treatment and cure.

The empowering three-day event included people touched by ALS from all walks of life and from nearly every state in the country who joined together in the nation’s capital to make a difference. And that’s exactly what they did! Just three days after advocates met with members of Congress, the House of Representatives passed legislation to provide $7.5 million in funding for the ALS Research Program at the Department of Defense, a 17% increase over last year! And we more than doubled the number of cosponsors of the MODDERN Cures Act, legislation that would stimulate and expedite the development of new treatments for ALS. These accomplishments are swift and significant -- two adjectives not typically associated with Washington these days. However, the quick results prove that people with ALS -- indeed, all people touched by the disease -- have the power to make a difference. And that power lies in their personal stories, which move members of Congress to action. You can read more at http://www.alsa.org/news.

State Approves $350K Line Item for Patient Care

The ALS Association Western Pennsylvania Chapter and the ALS Association Greater Philadelphia Chapter partner each year in Harrisburg for a full day of visits with our district representatives and hold a press conference to maintain and grow our line item funding in the state budget for patient care. Our efforts resulted in line item funding of $300,000 for patient care in 2012/2013. And, this year’s meetings in Harrisburg resulted in a budget increase for patient care of $350,000. These dollars are split evenly across this state for medical equipment, wheelchairs, in-home care, home modifications and speech generating devices.
Being able to serve and help people in need is a life changing experience. Those of us working at The ALS Association Western Pennsylvania Chapter are blessed and fortunate to have the opportunity to work in a career that allows us to help others and improve their quality of life. But while the lessons we learn from those we serve are as valuable as what we are able to do for them, the hardest part of the job is probably the desire to do more. Unfortunately we must work within our financial means and do the best with what we have. Mr. Fred Rogers was a friend of mine and I used to work with him when I was employed at WQED-TV. He used to say, “The greatest gift you ever give is your honest self.”

In our jobs with the Chapter, the entire staff strives to show those we serve that we are honestly listening to their needs, sincerely reveling in their joys and that we genuinely want to help them with their challenges - whatever those may be. Caring for people with ALS and their families is our first priority and everyone in our office will drop anything at a moment’s notice to provide for someone in need. The interactions we have with our patients living with ALS and family members as well as the interactions we have with family and friends who have lost loved ones to ALS, are the most important and most rewarding parts of our jobs. It’s where we most often learn that giving of our honest selves has sometimes been more valuable than supplying a wheelchair or providing transportation.

Through our interactions with patients, families and caregivers, we have learned more about what’s important in life, more about being kind and compassionate, more about cherishing every moment, and more about living in the present. We have been given the greatest gift because we have been given the “honest selves” of all those we serve.

As the Executive Director of this Chapter, I feel as though every day is a life lesson and I am mindful that every day is a gift. Yes, some days are difficult, but somehow it balances out. For every sad moment there is an inspirational one. For every person we lose to ALS there is a person that still needs our help. We will never be daunted by the emotion of working for people living with ALS because the disease never daunts them. They lift us up, they give us hope, they inspire us and make us want to be our “honest selves.”

State Approves $350K Line Item for Patient Care (continued)

Thanks to our advocates who:
- speak out for those who have lost their voice.
- stand up for those who no longer can walk.
- fight for those who are weak from battling ALS.

There is still so much to be done and many more dollars are needed to fight this dreaded disease. While national research continues to seek a treatment and a cure, the Chapters continue to help those living with the disease today and our advocacy efforts make a huge difference in improving their quality of life.
Letter from the President

As we approach the end of 2013 and I reflect back on another successful and challenging year at the ALS Association Western Pennsylvania Chapter, gratitude (as it often does) overwhelms me. I am grateful for so many things related to our Chapter and our cause. As I am sure I’ve said many times before, we are very proud of the work that we do and the service that we provide to ALS patients and their families in the 31 counties we serve. When I think about what we do and the community of which we are an integral part, I don’t need to wonder why we are successful in helping ALS patients and their families.

Yes, we have had another successful year on the fundraising front, although we are always looking to do more. We are also continuing to expand our reach and scope of services so that ALS patients and their families can focus on the most important things, such as themselves, their families and friends, and their quality of life. In one of my favorite quotes, Ralph Waldo Emerson says, “… to know even one life has breathed easier because you have lived. This is to have succeeded”. This is an area in which I believe we excel, and we don’t excel in this area because we have some magic formula. We excel in this area because of relationships.

The Merriam-Webster Dictionary defines a relationship as “connecting or binding participants.” We are all connected by this horrific disease in a way that is awe-inspiring to me. Many of these relationships exist as a result of pure courage. ALS patients have such so much to do, so much to think about, so much to deal with, and yet continually they give of themselves, in addition to waging a daily war on ALS, by sharing their lives and their stories in an effort to raise money and awareness. Many of these relationships are developed through genuine caring. There are so many people, from our staff to our Board and our volunteers who give of themselves throughout the year to spread the word, further our mission and enhance the lives of those living with ALS. All of these relationships are borne of selflessness, with so many people extending themselves and opening their hearts. We are all connected in this way and these connections provide us with strength, resiliency and hope. I am so very grateful that these connections exist and I am honored to be part of this brave and relentless community. I know that I have breathed easier because of so many of you.

As we move into 2014, I continue to be extremely optimistic about our future. I wish that we were a little closer to a treatment and a cure and I know we will get there someday. In the meantime, I am proud of the organization that we are, the work that we do and the relationships that we build and maintain. As an organization, we are grateful to be able to contribute to the ALS community efforts that ultimately improve the lives of ALS patients and their families in western Pennsylvania.

Veterans with ALS Recognized

The Pittsburgh Penguins hosted military veterans at the November 13th morning practice including two veterans with ALS. They received personalized jerseys, watched practice and attended a game. The ALS Association counts on our military, who are twice as likely to die from ALS, to speak up and advocate for state and federal funding. We thank Ken Elliott, a Vietnam veteran, for his active advocacy efforts.

Pictured to the left:
First Photo: Jeff Zatkoff, Robert Beiswenger, Debbie Beiswenger.
Second Photo: Ken Elliott
Third Photo: Joe Vitale and Michael Testa.
There are many compelling reasons why people support our cause. Providing care for people currently living with ALS or funding research for a cure are just two good examples. And when you decide to make a donation to The ALS Association, you can choose to support the local Chapter – in this case the Western Pennsylvania Chapter or you can choose to give to the National ALS Association located in Washington, D.C. The choice makes a difference in how your dollars will be spent, so below are some clarification and facts regarding donations.

1) In very simplistic terms, when you donate to the Western Pennsylvania Chapter, your money is used to support and administer direct patient care for people currently living with ALS. When you donate to the National ALS Association (in Washington, D.C.) your money is used to support the administration of research, advocacy, and disease awareness. This money does not pay for actual clinical research, but for the administration of over $19 million in research dollars as well as the massive undertaking of advocating our nation’s capital for research dollars.

2) Donors who would like to give to ALS research and want to be assured that their money is directly funding actual research in the lab, need only specify that in writing when sending in a donation. Donations that specifically request be used for ALS research, go DIRECTLY into research projects.

3) The local Western Pennsylvania Chapter accepts donations for research and we are here to assure you that dollars specifically designated as such will be used toward research for treatments and a cure for ALS. Donating to research through the local Chapter is a win-win situation for everyone involved. The donor is assured that their money is directly supporting research. The local chapter benefits by getting a “revenue share credit” – literally a deduction in the 13.6% we are required to give to the National Office on a quarterly basis and the National ALS Association gets your full donation and applies it directly to ALS medical research.

Below is a pie chart that shows the various research projects currently funded through The ALS Association. Remember, you can give to research by donating to the local Chapter and specifying that your donation be applied to research only. You can even specify a specific research project.
Board Member Highlight- Dr. Kolarcik

Dr. Christi Kolarcik has been a Board Member of the ALS Association Western Pennsylvania Chapter since 2011. She chairs the Strategic Planning Task Force and has, for years, been the Chair of our annual Walk to Defeat ALS®. If that isn’t enough, she is a Postdoctoral Research Associate at the University of Pittsburgh, Department of Bioengineering, and an accomplished neuroscientist who has led multiple projects aimed at understanding the mechanisms underlying ALS and improving the biocompatibility of brain-machine interface devices. She is a wife and mother of three beautiful children. In this article, we’ve put the spotlight on Christi to find out a little more about her and her passion to help those with ALS.

Q: How did you first get involved with the ALS Association?
A: I came to the University of Pittsburgh as a graduate student in 2004 and I joined the laboratory of Robert Bowser in 2005. In September of 2005 I attended my first ALS Walk, which was also the last one to take place in North Park. Shortly after the walk, I contacted the Chapter and asked to be involved in the Walk committee and the rest is history.

Q: And now, besides being Chair of the Walk Committee, you are also the Chair of the Strategic Planning Task Force. Why do you think a strategic plan is important for our organization?
A: I think it’s important for us to really make focused, active decisions about where we are going and what we want to accomplish and to always assess how well we are doing in terms of serving our patients and their families. At the end of the day, serving our patients and families is THE MOST important thing. That’s what we are here to do, so not losing sight of that mission, I think a strategic plan really helps us to keep that at the heart of everything we do.

Q: What are you most passionate about when it comes to our Chapter?
A: As a researcher, my biggest passion is seeing research used in a way, or applied in a way, that can help patients and their families. That’s what I get excited about. Over the years patients and families have come to me and asked “What’s going on with research? How are things going or what new findings did you come up with in the past six months to a year?” And those things really drive me inside and outside the lab. So it’s nice to see that there is hope in the future possibilities of research and what research has the potential to provide.

Q: What would people be surprised to know about you?
A: I’m not very good at keeping secrets (she laughs.) But, people always seem surprised when I tell them that I’m an ice hockey coach for my son’s youth hockey team. That gets the most “REALLY?” responses. I love hockey, I started learning when my son started learning, I took a class at Schenley Park and I’ve stayed involved. Eventually it’s going to get to the point that he’s far better than me (actually that happened a long time ago) or to the point where I don’t think I have much to add in terms of his development. I love coaching and I love the game. I think I’m one of the only female ice hockey coaches in our organization. I’ll walk into a rink and hear, “Look, there’s a girl coach.”

Q: What is your greatest hope for this disease and the people who suffer from it?
A: With anybody I think it’s a cure. And maybe not even a cure, but with so many disease, like cancer, that were once death sentences, are now treated like a chronic condition. You have a flare up, you get a treatment, you get better and go home. That would be great to see for patients and their families that we serve with ALS. It also would be equally nice to see some things that could improve quality of life NOW. We’re very much aware of people that are affected right now and need something to help them right now. I don’t want people to have to wait. Some assistive technologies are great. Basically anything to improve their quality of life, to make their time living with the disease as fulfilled as it can be.

Q: As a Board Member, what are you most proud of in terms of our Chapter?
A: I really think it’s the people. From our Board to our staff to our patients and their families. Every time I interact with any of them I am so fulfilled. It’s such a wonderful experience and you really can’t put a price on the interactions that you have. And the fact that we are really a community, we are like a big family and that’s something you can’t pretend or fake, it’s just very real. A very rewarding feeling and I am so happy to be a part of it.
Every year the ALS Association Western Pennsylvania Chapter hosts an event that is solely dedicated to providing education focused on ways to improve the quality of life for those living with ALS. On October 19, 2013, the Living with ALS Educational Symposium featured presentations on “smart” technology and emerging breakthroughs in harnessing brain waves to move robotic arms.

The first speaker was Dr. Wei Wang, MD, PhD, an associate professor for the Department of Physical Medicine and Rehabilitation at the University of Pittsburgh. Dr. Wang’s engaging presentation concentrated on his research with Brain Computer Interfaces (BCI) that utilize brain signals to control external devices. Still in development, BCI systems generally include hardware and software that interface with the human body using variably-invasive methods. While traditional assistive technology devices depend on small but reliable muscle movements, patients with ALS lose this ability as the disease progresses. Research is proving that BCI’s detect brain signals to provide a path of control for devices that does not depend on muscle movement. For patients with ALS, there could be significant opportunities for BCIs to have a positive impact on quality of life. As BCI research progresses, the devices could give patients with ALS the power to interact with and control their surroundings by measuring brainwaves and thoughts. In general, BCI technology could lead to greater independence, improved productivity and enhanced quality of life for patients with ALS.

The second presentation was given by Carson Turner from Progressive Mobility and Medical, Inc. and Paula Voithoffer from Pride Mobility. To demonstrate how a person living with ALS can control their environment with very little muscle movement, they set up a “mock-living room.” Within the space was a TV, iPad, various smart phones, a recliner, computer, light switches, an automated door, lamps, a fan and even an area rug for a homey touch. Each of the items on display could be turned on, off, opened and closed and simply operated with the slightest muscle movement using a “smart button” attached to an electric wheelchair. These “smart buttons” can be adapted to anticipate the smallest muscle movements in order for a patient to easily control their environment. Attendees at the event were able to experiment with the buttons and see how they might use them on their own personal wheelchairs.

The third presenter was Kaitlyn Graham, MA, CCC-SLP, a speech language pathologist. Kaitlyn gave a very interesting presentation about the latest advancements in speech generating devices including new technology and eye-gaze systems that are more intuitive to the user than the current standard. From DynaVox, to Tobii to iPad applications, Kaitlyn gave a powerful overview of how speech generating devices are adaptable to today’s changing technology and increasingly more “user” friendly for persons living with ALS.
In Memoriam
From November 21, 2012 - November 21, 2013

Sharon Akmal
Patricia Anderson
Mary Jane Bearer
Thomas Bell
Sally Black
Daniel Blobner
John Bojarski
Scott Bolvin
Charles Borland
Robert Bower
Judith Burek
Josephine Butch
Connie Comer
Donald Cunliffe
Bonnie Dahm
Albert Darby
Walter Dolan
Lynn Finegan
Martin Fitzpatrick
Anna Forsythe
John Freas
Larry Fulmer
John Garczynski
Roy Glass
Hattie Hawkins
Anna Hooks
John Hunter
Elaine Jamison
Alberto Jasso
Joe Kelyman
John Kiss
Bonnie Lynn
Larry Mandella
William Martin
Bernice McClain
Charles Miles
Kathleen Milheizer
James Miller
Janet Millspaw
Rita Moses
Thomas Nale
Joan Nolan
William Ott
Ryan Palashoff
Rita Palmer
Agnes Pfeffercorn
Robert Piper
Linda Poydence
William Puz
Lorraine Rees
Joyce Reiter
Scott Reitz
Dustan Rhodes
Lauren Rossi
Janet Shean
Ruth Shively
John Shively
Jeffrey Smith
Carol Steele
Gerald Tamiya
Kathryn Tibbens
Theresa Vasselo
Tina Venderlic
Deborah Voshall
Mattie Ward
Betty Lou Weber
Ruth Weldon
Jayne Wesolowski
William Whigham
Raymond Witkowski

Do I know enough about my ALS treatment options?

"I noticed I’m not sleeping as well as I used to and my breathing capacity has declined. I’m always looking for options that might help me. Should I ask my doctor about the diaphragm pacing treatment?"

"I know that with FDA approval, it’s no longer experimental. We should watch the informational videos at synapsebiomedical.com.

Then let’s contact one of the select centers that support the treatment to find out more. We shouldn’t be guessing."

NeuRx® Diaphragm Pacing Treatment for ALS
Breathe easier. Sleep better. Live Longer.

Learn more at synapsebiomedical.com
The new location for the Pittsburgh Walk to Defeat ALS® received great praise for its spacious accommodations and outstanding backdrop. It was a beautiful day and participants commented that it “felt more like a community” at Point State Park because you could see the large number of people there to support the cause. We look forward to growing into this new venue and hopefully making this a $1 million dollar walk! Total as of 11/20/13: $415,888.75

A special thank you and congratulations to our top teams:
1 - Cleveland Brothers ($27,025.00)
2 - Bugatti ($21,745.00)
3 - Knopp Biosciences ($14,291.00)
4 - ALS Kickers ($12,011.62)
5 - Sandy & Edgar 4 ALS ($10,925.00)
6 - HT Stands Up for ALS! ($10,618.00)
7 - Nutty Buddies ($10,273.00)
8 - Pappy’s protectors ($8,263.00)
9 - Carla & Al’s PALS ($7,385.00)
10 - Charlene’s Angels ($7,365.00)
Johnstown ~ August 3, 2013

Through the rain and clouds, Johnstown shone brighter than ever on August 3, 2013! With the highest attendance in event history (483 walkers) Johnstown walkers not only hit goal on Walk Day but exceeded it and reached the highest fundraising total for this event ever! The basket raffle was a huge success as well as the newly added balloon release. We would like to thank our hardworking committee and a special thanks to the Steinkirchner family for donating the lunch buffet. Total as of 11/20/13: $69,237.06

Erie Highmark Walk for a Healthy Community
June 8, 2013

This was our second year participating in the Highmark Walk for a Healthy Community in Erie and it has proven successful once again! Presque Isle Park was filled with 28 charities and 2,140 walkers. The ALS Association was supported by 200 of those walkers and raised $15,296! Through this event we are able to connect with new families in the Erie area that may not have known about our Chapter or our services. Thank you to everyone that supported this event, and special thanks to Highmark for underwriting the walk costs.
In Our Community

Letter from Hefren-Tillotson, Inc.

In 2011, our beloved coworker and friend, Neil Alexander, received the devastating diagnosis of ALS. The employees and families of Hefren-Tillotson immediately rallied around Neil with support and prayers, and thus began our involvement with the ALS Association of Western Pennsylvania. The passion and dedication of the “HT Stands Up for ALS!” walk team has grown stronger every year since then, driven by the example set by Neil and his family as they deal with this overwhelming disease. Our walk shirts say it all “Hero… Teammate… Friend… Neil Alexander”.

This year, we were thrilled to see the Hefren-Tillotson team continue to grow, with over 125 people of all ages (and even some of our favorite pets) completing the walk. Point State Park is a fantastic new venue for the walk – easily accessible and plenty of room for the growing amount of walkers. The Point allows people on both sides of the river to witness the magnitude and importance of this event. We were blessed with a gorgeous, sunny morning and warm temperatures. And of course, no view could be more striking than our beautiful city of Pittsburgh.

Neil, Suzanne, Abby and Patrick Alexander have been inspirations for everyone who knows them, finding ways to turn the news of Neil’s disease into opportunities that make positive differences in the lives of many. Through their foundation, LiveLikeLou.org, and their involvement with the ALS Association, they have raised awareness of the needs of those with ALS in our community. They have also supported families dealing with ALS through several programs and have made grants for critical research.

The ALS walk is one important way for Hefren-Tillotson and Neil’s family and friends to collectively show our support and affection for the Alexander family and to raise money for the ALS Association. And the work of the ALS Association is so critical to Neil and so many others as they face a future with ALS.
On June 13th the Anne Lewis Humanitarian Award was presented to Pennsylvania Representative Bryan Cutler in recognition of his advocacy and humanitarian efforts on behalf of ALS patients. The event supports the Anne Lewis Humanitarian Fund, established in 2010 to increase ALS awareness and to generate funds for patient care. Previous recipients of the award have included Anne Lewis and Knopp Biosciences.

Our 2013 honoree, Representative Bryan Cutler, incredibly and tragically lost both of his parents to ALS. They were diagnosed just one year apart. Two years following diagnosis, Bryan’s father passed away. His mother battled ALS for nine years, finally succumbing in 1999.

Rep. Cutler has been a steadfast advocate for ALS patients ever since. He understands the financial hardships that accompany the disease and the value of keeping patients in their homes. He has tirelessly advocated on behalf of veterans, who are twice as likely to get ALS and Bryan’s efforts in Harrisburg were vital in securing the line item for ALS patient care.

Thanks to Anne Lewis and Bryan Cutler as well as many dedicated heroes living with ALS, the state funding along with donations from individuals, corporations and foundations supports our multidisciplinary clinics, in-home care programs, and devices such as wheelchairs and speech technology. All of this not only helps treat the symptoms of ALS, but it also makes sure that the people who are living with this disease can live their lives with dignity, comfort and have the opportunity to spend more precious moments with their families.

Sharing a personal story of ALS is emotional and difficult. It is an act of bravery and selflessness - yet our advocates do it every year and some even more than that. There are few people that can face the challenges of ALS and turn the experience into a positive one, working with purpose, action and getting results. Anne Lewis is one of those people. Bryan Cutler is one of these people. Our patients living with ALS are all members of this elite group of champions and every day heroes.

Rep. Cutler has helped to prove that our voices matter, that our voices are heard, and that by acting with our hearts and our spirits with vigor and determination we are changing lives.

This event raised $80,000 for patient care in 2013.

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**The Anne Lewis Humanitarian Award 2013**

Attention all runners! It is with great excitement that we announce that the ALS Association Western Pennsylvania Chapter will be participating for the first time in the 2014 Pittsburgh Marathon!

After you register for the race at [http://www.pittsburghmarathon.com](http://www.pittsburghmarathon.com), you will have access to our fundraising page where you can create your own fundraising campaign. Keep a look out on our website for the direct link to our fundraising page and other race day updates.

If you are interested in being a part of the our Pittsburgh Marathon Committee, duties include fundraising strategies, advertising, runner recruitment and event day logistics, please contact Kristi Marsili at 412.821.3254 or kristi@cure4als.org.

Registration for the marathon and weekend signature race events is now open!
Thank You

End of year gifts accepted by mail and online until midnight, December 31, 2013.

Our Chapter does not bill insurance companies or charge any fees for services. All of our programs and services are made possible through the generosity of individual giving, foundation grants, corporate sponsorships as well as funds raised through special events and a small amount of state funding. Due to the tremendous number of donors to the Walk to Defeat ALS®, we are unable to list them in this newsletter. A complete list can be found on our website at www.cure4als.org.

For a copy of the Chapter’s Form 990 and most recent audit, please visit www.PittsburghGives.org/nonprofits

Contributions received from November 1, 2012 – November 30, 2013

Thank You
Many thanks to our Johnstown Walk Committee and Chairmen Christi Kolarick & Colleen Schaefer.

Many thanks to our Pittsburgh Walk Committee and Chairmen Christi Kolarick & Colleen Schaefer.

Thank you to our Corporate Recruitment Committee: Neil and Suzanne Alexander Sandra and Edgar Snyder Christina and Christopher Brussalis
National President and CEO to Retire

In 2012 the Western Pennsylvania Chapter was honored to have Jane Gilbert, ALS Association President and CEO, visit our fine city for the 20th anniversary of our Pittsburgh Walk to Defeat ALS®. While the rain came down on all of us, Ms. Gilbert enjoyed her experience and even got to meet Pittsburgh Pirate legend and color commentator, Mr. Steve Blass.

In July 2013, Jane Gilbert notified the Association of her intention to retire. She has given the Board and The Association Chapters a year’s notice.

When she accepted the position to lead The ALS Association in 2009, it was clear that this would be the final challenge of her 45-year tenure in the professional world. Ms. Gilbert states that, “My work with The Association has offered me the most rewarding experiences of my career, and I am incredibly thankful to have had this opportunity. I am very proud of what we have accomplished, and I feel that I will be leaving The Association in a stable and productive place.”

Even though Ms. Gilbert is retiring from the workforce, she fully intends to stay committed to The Association's mission as a volunteer, an annual donor and as a member of the Legacy Society.

The National Board of Trustees is currently conducting an executive search for Jane Gilbert’s replacement. She will be missed, but thanks to her continued volunteer efforts, she will never be far away.

Who’s in our Office?

Merritt Holland Spier
Executive Director

Marie Folino
Director of Care Services

Kristi Marsili
Director of Marketing and Fundraising Events

Sandra Thompson
Care Services Associate

Michele Mehal
Office Manager

Let’s Get Social

www.Facebook.com/ALSWPA
@TheALSWPA
https://alsawpa.shutterfly.com
http://www.pinterest.com/alsawpa/

“My work with The Association has offered me the most rewarding experiences of my career, and I am incredibly thankful to have had this opportunity.”
Pittsburgh Marathon
May 4, 2014

National Advocacy Meetings
May 7-9, 2014

Local Advocacy Day
May 2014 (TBD)

Johnstown Team Month
Starting June 2014

Erie Highmark Walk for a Healthy Community
June 7, 2013

Pittsburgh Walk Kickoff
July 24, 2014

Johnstown Walk to Defeat ALS®
August 2, 2014

Pittsburgh Team Week
August 3-10, 2014

Pittsburgh Walk to Defeat ALS®
September 6, 2014

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