

# ALS Press

The annual newsletter for The ALS Association Western Pennsylvania Chapter

Winter 2016

**ALS**  
ASSOCIATION

Western Pennsylvania  
Chapter

cure4als.org

## Small Change has Huge Impact

**\$115 million** was donated nationally through the ALS Ice Bucket Challenge during an 8-week period in 2014, to The ALS Association.

In addition, the Western PA Chapter benefitted from the Ice Bucket Challenge.

**\$600,000**



#everydropaddsup

Since August 2014:

**\$77 million** has been spent or committed to research because of the Ice Bucket Challenge, it costs \$2 billion to develop ONE new drug

### RESEARCH

**4**

new genes have been discovered in the last two years, which will help identify new therapies

**9**

global research collaborations were funded that have already resulted in 2 new antisense drugs, SOD1 and C9orf72, going into clinical trials in patients

**150**

active research projects were funded by The ALS Association since the Ice Bucket Challenge

**\$35,500**

was donated from the Western PA Chapter to the Live Like Lou Center for ALS Research at the University of Pittsburgh Brain Institute

NEK1, announced in July 2016, is now known to be among the most common ALS genes and an exciting new target for drug development

### PATIENT CARE

**2** new ALS certified centers within the VA Healthcare system (and expanding)



**100% increase** in funding to ALS Certified Treatment Centers of Excellence to enhance patient care; there are currently 51 centers nationally

#### NATIONAL

**15,000** patients per year are helped by The ALSA Chapters - National Association



**10,500** downloads of new resources that explain Medicare Home Health benefits for people with ALS

#### LOCAL

**8,400** hours of respite care = **\$225,800** spent on respite care locally in 2 years

**76** grants to patients

**\$250,000** spent on Direct Medical Equipment

wheelchair accessible transportation = **\$15,153**

**\$76,500**

total granted to the Johnstown Clinic and the Certified Center of Excellence at Allegheny General Hospital

**79** power and manual wheelchairs were loaned and 24 ramps were installed



### ADVOCACY

**\$7.5 MILLION**

for the ALS Research Program at the Department of Defense to study why veterans are twice as likely to develop the disease

**FIRST DRUG GUIDANCE**

submitted to the FDA to speed the development and approval of new ALS treatments

PA State funding for ALS patient care has increased to **\$500,000**



**30%** increase in funding to support the National ALS Registry

**\$20,500** granted for home modifications



**\$22,000** spent on outreach and education

Note: National numbers were provided by The ALS Association National Office. Local numbers were tallied using budget figures to date.

# Western PA Chapter

## Letter from the President - Christi Kolarcik, PhD

As I prepare to write this, my first article as the President of the Board of Directors, I am drawn to the idea of what it means to serve. Maybe it is because we have just elected those that will now represent (and serve) us for their respective terms as Senators, Congressmen, and President. Perhaps it is because we have just celebrated the sacrifices (and service) of our heroic veterans who are also over twice as likely to be diagnosed with ALS. It could be because I have just seen some of our patients and caregivers at the 3rd Annual Brewski Event and am keenly aware of the love (and level of service) that our caregivers exemplify. Regardless of the reason(s), this reflection has been valuable. We all have the opportunity and, hopefully you will agree the obligation, to serve others. Certainly, the ways in which we serve can vary, but, as Martin Luther King Jr. is quoted as saying, "Everybody can be great because anybody can serve...you only need a heart full of grace, a

soul generated by love."

I am incredibly fortunate to be part of a team that has committed to serving a community of people that feels like family. And I hope that each and every one of you never has reason to doubt our dedication, passion, and love for each and every member of this community. We will work tirelessly toward a future in which ALS no longer robs us of the moments and memories we wished to share with our loved ones, but, until that glorious day, we are here to lighten the load, to share the ups and downs, and to walk with you throughout your journey. For some of you, this may be your first newsletter, the early stages of dealing with the monster that is ALS. We are here for you. For those of you that are not new to this disease but are struggling with the "every day is a new challenge" reality. We are here for you. And for everyone that has a void left behind by the thief that is ALS, please, never doubt it. We are here



*In Photo: Christi Kolarcik, Joseph Schmitt, Jared, Reanna and Layla*

for you. Our Chapter staff and our Board of Directors are honored to serve the ALS community of Western Pennsylvania however, whenever, and for whatever the situation requires. For, as Albert Einstein said, "Only a life lived in the service to others is worth living."

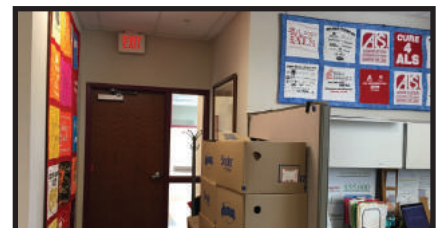
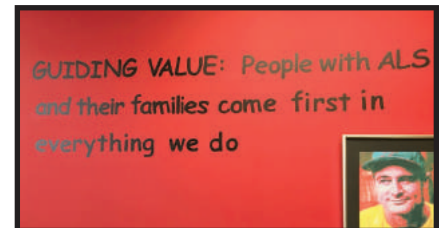
## Letter from the Executive Director - Merritt H. Spier

I was hired as the Executive Director of the Chapter on 11/28/2011, just after Thanksgiving. So November 28th marked my 5th Anniversary and I could not be more proud of our team and all that we do.

I am continually amazed by how much we accomplish with so little. Those of you who have visited us in Millvale know that our office is a tiny, open space, filled with medical equipment, photos and t-shirt quilts, awards, brochures, files, boxes and decorated cubicals. These pictures (right) are typical examples of what things look like on an average day. We have no sink to wash our lunch dishes, we take out our own garbage and vacuum our own floors, most furniture we got for free and we each have our own little space to work in but no privacy. We are a

small but mighty, close-knit group and I never hear a single complaint. Every day I am welcomed by a joyful staff of incredibly dedicated people who would do anything for patients and families living with ALS. And while there is nothing good about ALS, it is astounding to us how good, strong and heroic those living with ALS are. And they are our inspiration. Our guiding value is that patients and their families come first in everything that we do! This is on our office wall and we live by it – even when we are just trying to clean up.

Our physical environment is not what is important to us. Our focus is on the compassionate care we provide to those in need, and we will not stop until there is a treatment and a cure!



*"I am incredibly fortunate to be part of a team that has committed to serving a community of people that feels like family."*

*"And while there is nothing good about ALS, it is astounding to us how good, strong and heroic those living with ALS are."*



## Rebecca Renshaw - Board Member

**Q: You dedicate a lot of your time to the ALS Association Western PA Chapter, but what do you do for a living?**

A: I am the Education Director at the Western PA School for Blind Children. I oversee the educational programs for student's ages 3 years old to 10 years old. All of our students have a visual impairment and most have additional disabilities as well. I also am an adjunct professor at University of Pittsburgh and Salus University.

**Q: Tell us a little bit about your personal experience with ALS and why you joined the Chapter Board.**

A: My dad, Ronald Renshaw, was diagnosed with ALS in April 2013. We were extremely close all my life. He was not only my dad but one of my friends. He was truly one of my most favorite people to hang out with. He was genuinely kind and giving. He enjoyed cooking meals at his church for those less fortunate, donating his time to help someone with their computer issues, singing hymns, going for long walks, and playing with his grandchildren. I think that was one of the saddest parts of watching his progression with ALS – seeing him robbed of the very things he loved the most. The progression was rapid. Just 374 days after he was diagnosed, ALS took his life. Over the course of those 374 days, I watched my dad slowly lose his ability to talk, eat by mouth, walk, and eventually breathe.

My involvement with The ALS Association came in the fall of 2013, just a few months after he was diagnosed. I became a Board Member of the Western PA Chapter in Spring 2014 and continue to serve in honor of him.

**Q: In your first year with the Chapter we experienced the Ice Bucket Challenge. That August you were “in charge” of the Ice Bucket station at the Pittsburgh Walk. An amazing thing happened that day – what was it?**

A: At the height of the Ice Bucket Challenge craze, I attended my first official ALS Chapter event, The 2014 Pittsburgh Walk. It was a hard day for me since my dad had recently passed, but I was determined to be there. We had a lot of Walk teams take the Ice Bucket Challenge and I kept track of how many people did it that day. The final total was 374 ice bucket challenges, the same number of days my dad lived with ALS. He was clearly with me on that difficult day.

**Q: You were instrumental in getting our Chapter involved in The Pittsburgh Marathon, how did that come about?**

A: In the fall of 2013, I sent an email to ALS Association Western PA Chapter saying I wanted to run in the Pittsburgh Marathon and raise money for ALS. Prior to 2014 the ALS Association was not involved in the Pittsburgh Marathon at all. That email lead the Western PA Chapter pursuing charity involvement with the Pittsburgh Marathon and inviting me to serve on the race committee. That first year I ran the full marathon (my first ever) in honor of my dad. Sadly just 4 days after I ran that inaugural race, my dad passed away.

Before he passed I promised my dad I would continue to use my voice to tell his story and use my legs to raise money for a cure. Every year I continue to serve on our Pittsburgh Marathon race committee and run for Team Challenge ALS.

**Q: Our participation in The Pittsburgh Marathon has been a huge success for the Chapter. What is your goal for this coming year?**

A: In our inaugural year we had 17 runners and raised a little over \$12,000. In 2015, we had a little over 20 runners and raised more than \$16,000. In 2016, we well surpassed our previous records. We had 67 runners, had a goal of \$20,000 and actually raised over



*In Photo: Rebecca Renshaw, Jason Jacobetz, and Jaden Jacobetz*

\$47,000. Personally, I would like to see us to surpass 75 runners and \$50,000 in 2017!

**Q: What are you most looking forward to in your work as a Board Member with the ALS Association Western PA Chapter?**

A: I look forward to telling my dad's story and helping to find a cure. Whether it is contacting donors, talking to legislators, or running on the Marathon team – I do it all for my dad.

**Q: What other volunteer work do you do?**

A: I also serve as President of the Board for Penn Del AER, an organization for professionals in the field of visual impairment

**Q: What would people be surprised to know about you?**

A: That I once played drums in a band that performed in local Pittsburgh bars.

**Q: What's your favorite movie of all time?**

A: Elf and the Money Pit, because they both made me laugh really hard.

**Q: Any last words?**

A: I miss you dad!



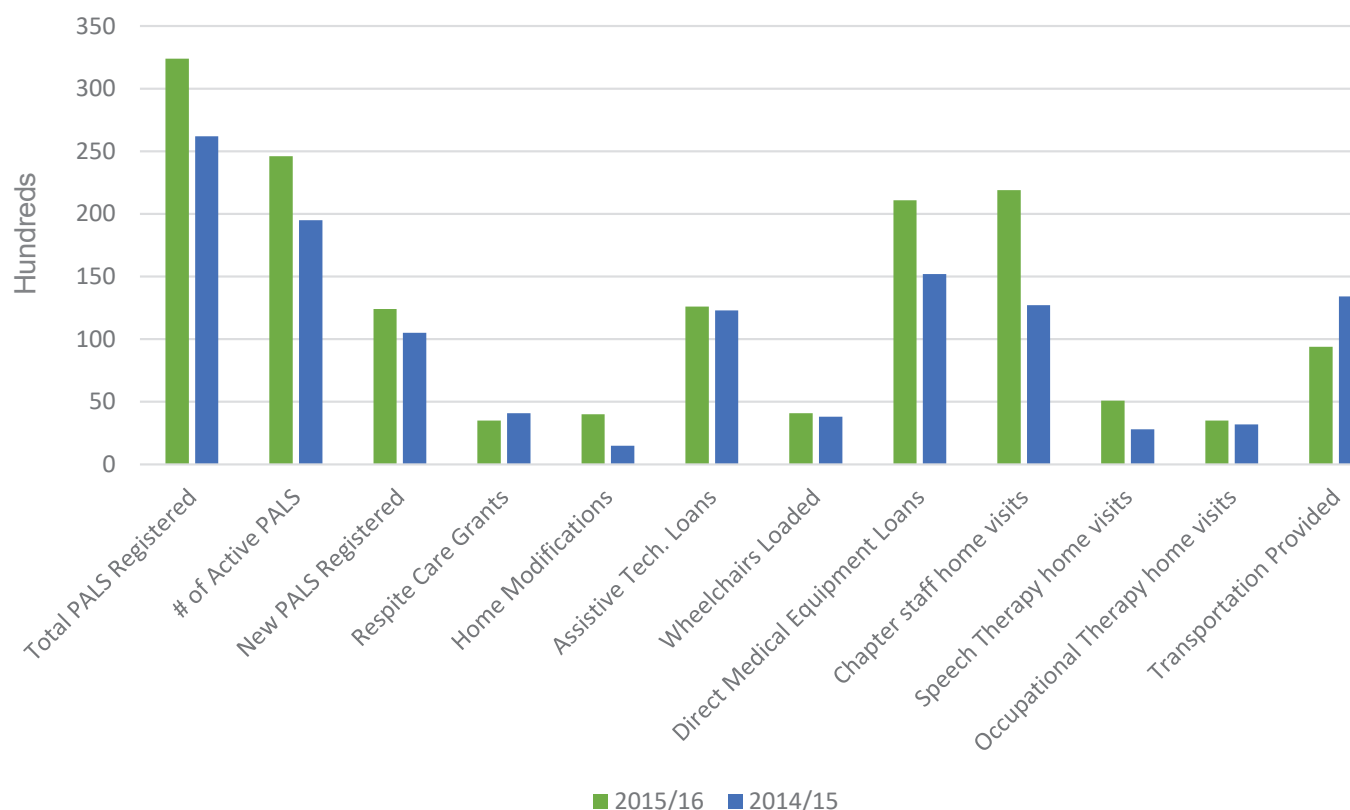
*“We had a lot of Walk teams take the Ice Bucket Challenge and I kept track of how many people did it that day. The final total was 374 ice bucket challenges, the same number of days my dad lived with ALS.”*

# Care Services

## Chapter Services Continue to Grow

Over the last year the chapter has, once again, seen an increase in the number of patients and families registered with our Chapter and with that, an increase in requests for our programs and services. We are proud to say that we have been able to provide each request, free of charge, and even handle some very unique circumstances quickly and easily.

Over 60% of the Chapter's annual budget is dedicated to direct care, services and programs for those living with ALS and their families. The chart below shows the growth in numbers between fiscal years 2014/15 and 2015/16.



## Highlight on Private Caregiver Training Program

Formal, professional caregivers must go through a rigorous training program that involves learning the proper techniques for repositioning, transferring, bathing, and dressing patients. However, these are the same tasks that family caregivers provide on a daily basis with little to no training whatsoever. Our Chapter is concerned that family caregivers do not know the most efficient way to do these tasks and could injure themselves or their loved ones in the process.

Our Private In-Home Caregiver Program won an ALSA National Innovation Award last year and is designed to focus on the day-to-day care such as bathing, dressing, and grooming, providing one-on-one training in the real world setting of the home with all its challenges.

We offer six different sessions that change with the progression of ALS and are conducted with a Bayada Home Care Registered Nurse. Please contact our care services department if you are interested in this free, in-home education.  
Email: [care@cure4als.org](mailto:care@cure4als.org) or call 412-821-3254.



*Mary Johnson advocates in D.C. for better care for ALS patients and their caregivers. Note: Mary has lost 12 family members to ALS.*





# Advocacy

## State Grants \$500,000 to ALS Patient Care

At any given time, over 1,000 Pennsylvanians are living with Amyotrophic Lateral Sclerosis (ALS). Almost all patient care services available to PA residents with ALS and their families are provided free of charge through The ALS Association's Greater Philadelphia and Western PA Chapters. The two chapters now serve more patients and families than ever before. In 2015/16 the Pennsylvania legislature approved a \$350,000 line item for ALS patient care after a LONG budget impasse that had us all sitting on the edge of our seats until December.

However, thanks to our dedicated advocates and our diligence in communicating with our local representatives, the 2016/17 state budget was passed – on time this year – with an increase for ALS patient care to \$500,000!

### **Why this line item funding must continue:**

- The ALS Association provides direct in-home care services, which allow people with ALS to stay in their homes longer instead of living in costly long term care facilities.

In Pennsylvania, the annual market value of the services family caregivers provide for “free” is estimated to be \$13.4 billion.

- The Chapters provide financial support to purchase, or directly loan, necessary medical equipment to patients and their families. The average cost savings generated from The Association's equipment loan program is approximately \$471 per person per year.

- State funding has made it possible for The ALS Association to provide patients with wheelchair ramps in and out of their homes, stair glides, lift chairs, bathroom modifications, adjustments to door handles, and electronic wheelchairs.

- The ALS Association, through state support, has increased the amount of respite care, assistive technology, and home modifications it is able to provide in Pennsylvania, improving the quality of life for



*Harrisburg Advocates*

people with ALS across the state.

Those of you who joined us in Harrisburg on May 18, 2016 – THANK YOU! You had a huge impact. As the state budget spends millions of dollars each year on long-term care costs, a line item of \$500,000 saves tax payers hundreds of thousands of dollars.

Please consider becoming an ALS advocate and join us this spring when we hope to increase the state line item for patient care once again. If you are interested, please call Julia Marsili at (412) 821-3254.

## National Advocacy is Another HUGE Success

May 8 through 10, 2016 in Washington, D.C. was an amazing and empowering opportunity for ALS advocates to use the power of their stories to influence legislators and making a difference in the fight against ALS on Capitol Hill.

Over 1,000 people attended the Public Policy Conference including 128 people living with ALS. The advocates participated in over 500 meetings with Members of Congress and their staff, telling their stories and urging legislators to act on behalf of the ALS community, specifically by waiving the 5-month waiting period for Social Security Disability benefits for people with ALS, enacting the Dormant Therapies Act, and ensuring access to complex rehab technologies.

### **Highlights:**

- Senators Sheldon Whitehouse (D-RI) and Tom Cotton (R-AR) introduced legislation in the Senate

(S. 2904) to waive the five-month waiting period for Social Security Disability benefits for people living with ALS. In the House of Representatives, Congressman Seth Moulton (D-MA) and Peter King (R-NY) introduced identical legislation (H.R. 5183).

- ALS advocate Lorri Carey was highlighted in a Medicines in Development report released in partnership with The ALS Association and PhRMA. The report detailed the promising treatments in the pipeline for rare diseases, such as 38 for neurological diseases, including ALS.

With results like these, it's clear our efforts are making a tremendous difference!



*In Photo: Back row L to R: Merritt Spier, Julia Marsili, Josh Sullivan, Mary Johnson, Barrett (baby) and mom Christi Kolarcik, Michael Shaughnesy, Amy Shaughnesy. Second row L to R: Emma Shaughnesy, Kristi Marsili, Sandra Thompson, Ida Langer, Sue George Front row L to R: Maeve Shaughnesy, PALS Joyce McNeal, Christy Simmers*

*State funding has made it possible for The ALS Association to provide patients with wheelchair ramps in and out of their homes, stair glides, lift chairs, bathroom modifications, adjustments to door handles, and electronic wheelchairs.*

*To become an ALS advocate and attend our events in D.C. and/or Harrisburg, please email Julia Marsili: [julia@cure4als.org](mailto:julia@cure4als.org).*



# Chapter Events

## Ski to Defeat ALS

Thank you to presenting sponsor, Allegheny Health Network, and all the skiers, snowboarders and donors that made the 2016 Ski to Defeat ALS a success. Doubling last year's attendance, we had 80 participants who helped raise more than \$44,000! With the addition of snowtubing, we hope to make 2017 our best year yet. Please join us on February 12, 2017 for the 3rd annual Ski to Defeat ALS. As PALS, Donna Boring, said, "Every person that participates helps one person living with ALS climb their own personal mountain to get the support and services they need to embrace life, not fear it."



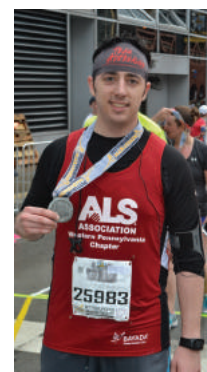
**Allegheny  
Health Network**



## Dick's Sporting Goods Pittsburgh Marathon

Team Challenge ALS has once again exceeded goals and expectations. With an earlier start this year The ALS Association's presence has grown from 25 runners in 2015 to 67 runners in 2016. More than half of the runners raised more than the minimum required and 13 runners entered the \$1,000+ fundraising club! With all efforts combined, Team Challenge ALS raised \$47,563, crushing their goal of \$20,000! The Chapter is extremely grateful for this dedicated group of runners and can only imagine what will be accomplished next year. Registration for the 2017 Dick's Sporting Goods Pittsburgh Marathon is open and Team Challenge ALS is accepting runners and fundraisers. Sign up early to be included in all the fundraising and recruitment incentives!

<https://www.crowdrise.com/ALSPitt2017/fundraiser/alsawpa>



## Highmark Walk for a Healthy Community

On Saturday, June 4, 2016 the Western PA Chapter participated in the Erie Highmark Walk for a Healthy Community, alongside 25 other charities. 107 walkers participated at Presque Isle State Park to raise awareness and funds for ALS. Bayada Home Health Care, Erie Otters, and Superior Toyota showed their support as our local sponsors. With the dedication and hard work of our walkers, sponsors, and donors, we were able to raise \$10,118! With all of these efforts, we were the third highest fundraising charity at the event again this year. We are looking forward to another great Walk next year on Saturday, June 3, 2017.



**BAYADA**  
Home Health Care



The ALS Association's presence has grown from 25 runners in 2015 to 67 runners in 2016. More than half of the runners raised more than the minimum required and 13 runners entered the \$1,000+ fundraising club!

We were the third highest fundraising charity at the event.





## 2016 Pittsburgh Walk to Defeat ALS®

Thank you to everyone that participated in the 2016 Pittsburgh Walk to Defeat ALS®. With about 2,000 walkers, we raised more than \$370,000 for patient care and research. Next year we look to have our biggest year yet as we celebrate our 25th anniversary walk with a reunion themed event.



### TOP TEAMS

Carol's Crew (\$23,132.58)  
Team Geroptimis (\$17,796.22)  
Team Father Dennis (\$10,066.52)  
Al's ALS Kickers (\$6,214.49)  
Knopp Biosciences (\$6,171.00)

Bowser's Mechanics (\$5,363.00)  
University of Pittsburgh  
Brain Institute (\$5,216.06)  
Clint Rudy's Team (\$5,200.00)  
Kelley Walk Team (\$4,975.00)  
Hope-1 ALS-0 (\$4,395.00)

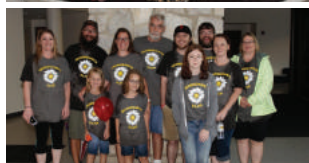


## 2016 Johnstown Walk to Defeat ALS®

It rained, it poured, but our spirits soared. On August 6, 2016 despite the epic down pour, more than 400 dedicated walkers marched on through the elements to support the Johnstown Walk to Defeat ALS®. Teams were huddled together as they enjoyed the free lunch provided by Wells Creek Station and several local pizza shops, while waiting for their chance to win one of the 100+ baskets in the infamous basket raffle. This community won't let anything get in their way of success, and for the 4th year in a row, they have surpassed their goal and raised \$80,800! Many thanks to emcee, Jack Michaels, for supporting this event and cause year after year.

### TOP TEAMS

Pap's PALS (\$7,026.00)  
For Pete's Sake (\$6,869.00)  
Dozy's Daffodils (\$5,881.00)  
MAMA MAYAK (\$5,537.73)  
Ice Bucket Wife (\$5,305.00)  
Team Hoss (\$4,636.95)  
Steve's ALStriders (\$3,125.10)  
A Mile for Max (\$2,412.00)  
Team Phyllis (\$2,395.00)  
The V Team (\$2,245.00)



The very first Walk to Defeat ALS® started here in Pittsburgh in 1992. It is now ALSA's national signature event and has raised more than \$262 million since 2000. August 2017 will mark the 25th Anniversary of the Pittsburgh Walk to Defeat ALS®. Please join us for this momentous occasion. To get involved please email Kristi Marsili: [kristi@cure4als.org](mailto:kristi@cure4als.org)



# *In Loving Memory*

*November 1, 2015 – November 2, 2016*

Jacqueline Anderson  
James Armbrust  
Raymond Augustine  
Regina Bailey  
Cynthia Barnhart  
Monica Blackwell  
Thomas Cain  
Susan Charney  
Barbara Chieppa  
Robert Clark  
Deborah Colello  
Donald Cook  
Ralph Covington  
Lloyd Cox  
Diane Daffin  
Maria Davidson  
Fred Deweese  
Timothy Edmundson  
Sandra Farina  
Thomas Faulkner  
Brenda Fleming  
Katherine Ford  
Albert Forgas  
Virginia Gleason  
Eileen Gordon

Robert Gress  
Gloria Hammond  
David Harouse  
Thomas Hayes  
Marie Held  
John Hensch  
Wanda Hess  
Margaret Hile  
Joseph Hrezo  
Larry Jacknin  
Punita Jani  
Michele Johnson  
Carol Johnston  
Bill Johnston  
Peter Jones  
Bonnie Karsten  
Gary Keefer  
Chris Kelly  
Arleen Kern  
Kenneth Kinder  
Margery Knipple  
James Knopsnyder  
Darcy Kosobucki  
Edward Kuhar  
Lee Larck

Thomas Large  
William Lentz  
Gregory Neil Lewis  
Joseph Linn  
Kenneth Loughman  
Steve Lowmaster  
Richard Mancuso  
Linda Mannion  
Carol McCandless  
Audrey McLaughlin  
Douglas McWherter  
Leah Mealy  
Margaret Mileski  
Alberta Miller  
Jesse Miller  
Sharon Mintmier  
Karen Morgan  
Nicola Morris  
Donald Mosites  
Robert Mumau  
Lewis Naylor  
Kelly Neal  
Clara Nossek  
Clara Pearce  
Martha Pohrer

Catherine Polito  
Rebecca Ribaric  
Diane Roney  
Miguel Roura  
Patricia Ruch  
Rebecca Sandreth  
John Saunders  
Barry Schell  
Carlos Seger  
Sidonia Simsic  
Duane Siple  
Carol Skinner  
Maria Steliga  
Catherine Straub  
Kevin Sullivan  
Frank Tabin  
Allan Tillander  
Carol Vince  
Sandra Weekley  
JoAnn Will  
Dwight Winck  
Eric Witherite  
Jim Zurcher

## *Thanking our Charitable Community*

We would like to thank the following for their support of our Chapter's work and helping us to provide free, critical services for ALS patients, caregivers and their families.

- **PNC Charitable Trusts**, for providing funds to support the Chapter's respite care and ramp programs.
- **LiveLikeLou.org, a fund of The Pittsburgh Foundation**, for partnering with the Chapter to provide patient care services and offer The Iron Horse Awards and scholarships. These funds provide memorable childhood experiences and college scholarships for children of families living with ALS. LiveLikeLou.org also supports the Holiday Gift Card program for ALS families in need.
- **William B. McLaughlin Charitable Trusts**, for providing grant funds to support power and manual wheelchair purchases and refurbishment for individuals living with ALS.
- **Pennsylvania's Initiative on Assistive Technology (PIAT)**, a program of the Institute on Disabilities at Temple University, for their support of the Chapter's assistive technology refurbishment programs.
- **The Elsie Hillman Foundation, Laurie E. Lust Foundation, Tippins Foundation, Woll Family Fund**, and various other family-run trusts for their generous gifts for patient care.





# We Care for Caregivers

## Caregiver Appreciation Weekend

The Western PA Chapters annual Caregiver Appreciation Event took place on November 5th and 6th at Seven Springs Mountain Resort. Sponsored by Interim Healthcare, this event allows caregivers and one guest to spend the night away from their care recipient so they may relax and bond with other ALS caregivers.



*"I haven't been away, alone, since last year this time. It is wonderful to have a time to look forward to." - Betty Hostetter, caregiver for her husband, David Hostetter.*

## Powerful Tools for Caregivers

Powerful Tools for Caregivers is an educational series designed to provide the caregiver with useful tools needed to take care of themselves. This program helps family caregivers reduce stress, improve self-confidence, communicate feelings better, balance their lives, increase their ability to make tough decisions and locate helpful resources. Classes consist of six sessions held once a week for six weeks.

## Support Group Information

### Frank Mayak Support Group (Johnstown)

The ALS Clinic at the John P. Murtha Neuroscience & Pain Institute hosts a free monthly support group for individuals with ALS, their families, caregivers and friends. This casual forum is a chance to find out about the latest clinical trials, learn new ways to ease the physical and emotional stress of ALS or just get together with special friends who truly understand what you're going through. Teleconferencing capabilities are available to those who are unable to attend but would like to participate.

### On-line Resource Group

Monthly on-line resource groups provide the opportunity for patients, caregivers, family and friends to participate in on-line educational programs on topics related to caring and living with ALS.

### Bereavement Support Groups

The Western Pennsylvania Chapter of the ALS Association has partnered with the Good Grief Center, a service of Ursuline Support Services, for Bereavement Support and offers a series of bereavement support groups. The group meets weekly for six weeks and provides education and support on how to effectively cope with and better handle the grieving process.

### Alternative Resource Group Options

Options are available for patients and caregivers who are interested in support groups in other areas of western Pennsylvania.



*Interested in any of these support groups?  
Please contact the Care Services Department at 412-821-3254.*

# Development

## *A Note from the Director of Development - Julia Marsili*

As my first year as Director of Development with the Chapter comes to a close, there is significant growth and tremendous achievements to look back on. The efforts of all Chapter employees have been a wonderful example as I became familiar with the organization's culture. Our fundraising events have shattered their goals, allowing us to provide the highest level of service to our patients and their families living with ALS.

The truth is, the Ice Bucket Challenge changed the way we operate as an organization forever. It brought more awareness and a lot more funding to this disease, but has also led to a substantial increase in patients registered with our Chapter over the past two years. This means that more patients than ever are learning about and accessing our services. It also means that we must find new ways to financially support these increasing needs. We never want to turn patients and their families away from services. Thanks to your generosity, we have met every need to date.

This year has been about exploring and implementing new ways to maintain and expand existing services. There are many ways to support the Chapter through both event and non-event sources. We hope to continue to build and diversify our fundraising to meet donors' needs and, most importantly, to meet the needs of every ALS patient and family member we serve. If you have any questions about donations or ways to support the Chapter, please do not hesitate to call me at (412) 821-3254 or email me at [julia@cure4als.org](mailto:julia@cure4als.org).

## *Giving Options*

Please consider supporting the Chapter through one of the following giving options:

### Planned Giving

Until ALS becomes a disease of the past, you can help us plan for the future of ALS patient care, research, and advocacy. Consider leaving a legacy of hope and care for those living with ALS through your estate or will. The Chapter can assist you in planning for bequests, IRAs, or gifts of stock directed to the programs that are most important to you.

### Sustainer Gifts

The Chapter's sustained giving program allows donors to make a monthly gift, helping the Chapter to account for patient care needs months in advance. You can make a sustaining gift using a credit or debit card or through automatic withdrawal from your bank account.

### Year-End Appeal

As the year comes to a close and we look back with gratitude for all we've been given, please consider helping to replenish the Chapter's annual fund by making a year-end contribution by December 31st. Your year-end gift will help the Chapter continue to provide the best in patient care while also supporting advocacy and global research efforts in 2017. You can make your gift online or by returning the enclosed donation envelope.

## *Join a Community of Hope*

The ALS Association's Community of Hope Fund allows loved ones of individuals living with ALS to raise awareness and money through an online fundraising platform. Community of Hope pages are customizable and users can add their personal touch to tell a story, rally others to join their cause, and collect donations.

In December 2015, the Sullivan Family started a Community of Hope Fund as a Christmas present to Kevin Sullivan, who was living with ALS. Sadly, Kevin passed away on December 29th, 2015. Family and friends rallied behind the fund, raising over \$35,000 in just over a month. Their incredible generosity in memory of Kevin helped to support the Chapter's ALS patient care programs and provide much-needed services to others as they battle this disease.

Consider building a fund to unite your personal community against ALS while honoring or memorializing someone you love. If you would like more information on creating or renewing an existing Community of Hope page, please contact Julia, Director of Development, at (412) 821-3254 or [julia@cure4als.org](mailto:julia@cure4als.org).



*The Shaughnessy Family Carol, Michael, Amy, Maeve and Emma: setting the fundraising bar very high.*



*Kevin and Susan Sullivan  
Community of Hope Page raises over \$35,000!*

Planned giving, sustained gifts, year-end giving... just a few ways to support the Chapter's patient care programs and global research.



## Live Like Lou Honored

On Wednesday, May 4th, 2016, The ALS Association Western Pennsylvania Chapter presented The Anne Lewis Advocacy & Humanitarian Award to Live Like Lou. The event was held at The Duquesne Club where Honorary Chairman, James C. Roddey, led a touching evening full of laughs, remembrance, and gratitude for the groundbreaking work happening in Pittsburgh to create a world without ALS. Speakers included Dr. Christi Kolarcik, President of the Board of The ALS Association Western PA Chapter, Dr. Christopher Donnelly, Assistant Professor of Neurobiology for the Live Like Lou Center for ALS Research, and Anne Lewis, Board Chair of Oxford Development Company. Accepting the award on behalf of Live Like Lou were Suzanne, Patrick and Abby Alexander in memory of their husband and father, Neil Alexander.

The Anne Lewis Advocacy & Humanitarian Award honors a deserving group, individual, or organization that demonstrates a steadfast commitment to improve access to quality care for those living with ALS and/or support research initiatives working to find a treatment and a cure.

The 2016 award recipient, Live Like Lou, was honored for their extensive partnership with the Chapter, helping to provide patient care and scholarships for children and young adults living in households impacted by ALS, as well as their vision and strategy behind the \$10 million Live Like Lou Center for ALS Research at the University of Pittsburgh Brain Institute. The Center focuses on developing new treatments, and, ultimately, a cure for ALS.

Thank you to the following sponsors who helped to make the presentation of The Anne Lewis Advocacy & Humanitarian Award possible.



*In photo: Anne Lewis, Suzanne, Abby and Patrick Alexander*

# Onward.

Honoring those with and without ALS.  
Cheer, challenge and charge ahead.



## HEFREN TILLOTSON

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*We would like to send a special thank you to Hefren-Tillotson for being the Presenting Sponsor of the Pittsburgh Walk to Defeat ALS® for the past five years.*

# Community Partners

## *ALS Kids - Change for Good*

Maeve Shaughnessy was born with a heart of gold. As she grew, so did her heart. When her grandmother, Carol Shaughnessy, was diagnosed with ALS in Dec., 2014, nobody was surprised when nine year old Maeve jumped to help.

Following Carol's diagnosis, Maeve, her sister and her cousins, formed Carol's Crew, a walk team for The 2015 Pittsburgh Walk to Defeat ALS®. Their goal was to raise money for The ALS Association Western PA Chapter patient care programs. Carol's Crew hit the ball out of the park raising a total of \$21,597. To help reach that goal, Maeve and her cohorts ran lemonade stands and held a school-based walk-a-thon.

But Maeve was far from done. In early 2016, she and her friend Sydney submitted a business plan as part of their school's extremely competitive Be the Boss program. Maeve and Sydney's idea was one of only two plans accepted and they call their business ALS Kids!

Their business model is to continue to raise money to support The Chapter's patient care programs and to send ALS patients a gift to raise their spirits. ALS Kids has a website, business cards, marketing materials and provides a small gift bag for every patient living with ALS. In the span of a few months, Maeve and Sydney handed out over 100 mason jars to collect loose change, raising over \$5,000 in coins alone.

Maeve has drawn on her network of connections to raise even more money for ALS Kids. She has sent letters to friends and family, she held a kids miniature golf tournament and she's put in countless volunteer hours to help the Chapter with other fundraising events.

As far as Maeve is concerned, the sky is the limit when it comes to helping individuals living with ALS. In May 2016, Maeve traveled with The Chapter to Washington, D.C. to visit lawmakers on Capitol Hill and share her grandma's story. The House and Senate leaders were impressed by Maeve's business skills and extremely moved by her story. It takes a very hard heart to say "no" to Maeve.

This year Carol's Crew raised an amazing \$23,032 for the Pittsburgh Walk and they aren't done yet. In April 2017, ALS Kids is holding a 5K for ALS, just another example of their on-going success.

For more information, visit [www.alskids.com](http://www.alskids.com) and watch a special YouTube news story about them at: <https://youtu.be/UUFbpoX4QIE>.



## *Kim Fleming - Hefren-Tillotson Inc.*



In 2011, Hefren-Tillotson's beloved coworker and friend, Neil Alexander, received the devastating diagnosis of ALS. The employees and families of Hefren-Tillotson rallied around Neil with support and prayers ever since, and this began Hefren-Tillotson's involvement with the ALS Association of Western Pennsylvania.

Sadly, in March 2015, Neil lost his battle with ALS, but his purpose lives on in his family, friends, and foundation, LiveLikeLou.org.

For the sixth year in a row, the Hefren-Tillotson family gathered to honor Neil and the Alexander family for the annual Walk to Defeat ALS®. Their team's t-shirts quoted Neil's philosophy "Leaving ALS Better Than We Found It... Onward!" Point State Park is a great venue for the ALS Walk, and the walkers were blessed with a gorgeous morning and warm temperatures.

Kim Fleming, Hefren-Tillotson's Chairman and CEO, said, "Neil has touched our lives, the lives of many in our community and so many others beyond this region, in ways that leave an impact that will last forever. His fierce determination to make a difference in the face of what would defeat most people has been an inspiration, and the work he began will not stop."

Neil did not let his illness define him, stating "I have never been hungry. I have never been lonely. I have never lived in fear. It's been a good life. I am lucky." With the support of everyone, Neil was able to enjoy his life and put his focus on helping others. I think we can say that Neil was and always will be an inspiration to all.

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. The work of the ALS Association is critical to those facing a future with ALS and for their families.

At only 11 years old, Maeve has formed her own business to raise money for ALS called "ALS Kids."



## 25th Annual Jay Simon Golf Classic Nets \$18,000 for The Norma L. Simon ALS Patient Equipment Fund!

The 25th Annual Jay Simon Golf Classic raised \$18,000 for the Norma L. Simon ALS Patient Equipment Fund. The outing was held on Friday, May 20, 2016 at the Beaver Valley Golf Club in Beaver Falls, Pennsylvania. Weather was ideal for the second consecutive year; 75 degrees, partly sunny, low humidity.

Twenty-three teams participated in the four-player scramble event. The Simon family, including Jay's father, Jack, and brothers, Jett, Jeff and Judd were in attendance as the four brothers played as a team for the fourth consecutive year. Sister, Janette Wilson, Atlanta, Georgia, was unable to enjoy the festivities.

Flight winners included teams led by Dave Faller, Derek Deakins, Jett Simon and Danny Baker. Skill Shot awardees were Mike Leopardo, Chad Restori, Mike Downey, Evan Ruhling and Andrew Riley.

As usual, all of the prizes and golfer gifts were contributed by generous donors. Thank you, Clint Hurdle and the Pittsburgh Pirates, Jeff Daltorio of Cutter and Buck, Bill Braasch-First Trust Portfolios, LLC and LC from Indian Lake!

### 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 2000, with the passing of his Mom, Norma Simon, from ALS, the outing added a purpose. Through the ALS Association of Western Pennsylvania, a fund was established in honor of Norma Simon to provide equipment that is not covered by insurance to families who have been stricken by this horrible disease. The annual golf outing raises money to support this fund.

The Jay Simon Golf Classic has cumulatively brought in over \$235,000 to the fund since its inception.

### Save the Date!

The 26th Annual Jay Simon Golf Classic will be held on Friday, May 19, 2017. To be placed on the invitation mailing list, contact Jay at (888)774-0990 or jsimon@hefren.com.

## Golf FORE ALS Hits Hole in One

The 7th Annual Golf FORE ALS tournament was held on Sunday, June 5th at Olde Stonewall Golf Club in Ellwood City, PA. The event was started by ALS Association Western PA Chapter Vice Chair, Chris Bluemle and friend Joe Susan in memory of their mothers, Karen Bluemle and Anne Marie Susan, who both passed away from ALS. Golf FORE ALS raises awareness and funds to support ALS patient care programs at the Chapter. This year's event raised almost \$42,000.

Chris and Joe attended school together at Baldwin High School. After losing touch, they were reunited 8 years ago at the Pittsburgh Walk to Defeat ALS®, discovering that both of their mothers battled with ALS. Chris stated, "Sadly, it took the loss of our mothers to bring us back together to form Golf FORE ALS. Now we strive to raise money and awareness for Lou Gehrig's disease."

Over 100 golfers enjoyed a continental breakfast, 18 holes on the beautiful course, and a buffet dinner and raffles. Registration and event information for the 2017 Golf FORE ALS outing can be found at [www.golfforeals.com](http://www.golfforeals.com) in spring 2017. Thank you to all who attended and showed your support for the Bluemle and Susan families while raising money for the Chapter!

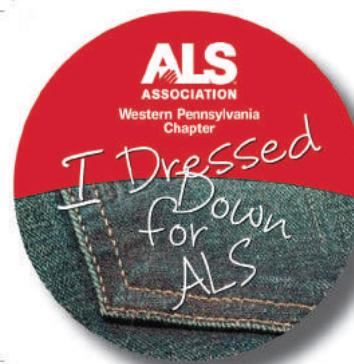
A special thanks to People's Gas for their generous sponsorship.

## Third Party Events Make a Huge Impact

Constituents in western Pennsylvania have been very ambitious this year hosting their own events to benefit The ALS Association Western PA Chapter. From chili-cookoffs, to LuLaRoe parties to 5K's and bike events, our community raised more than \$40,000 so far this year. If you are interested in hosting your own event next year, check out our One Dollar Difference website to create your own online platform to collect donations and registrations.



*In photo: Jett Simon, Judd Simon, Jack Simon, Jeff Simon, Jay Simon*



*If you would like to host your own fundraiser, give us a call. We are here to help every step of the way. Please contact Kristi Marsili.*

*Hosting a dress down day at your school or office? Ask for our stickers to let everyone know what cause you are supporting.*

# ALS Association Western

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University of Pittsburgh  
System Neuroscience Institute



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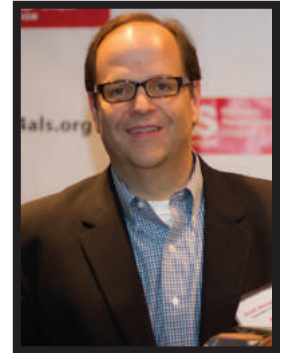
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Scott Steinkirchner  
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The ALS Association  
Western Pennsylvania  
Chapter is proud to  
report 100% financial  
support from our  
Board of Directors  
and staff.

## Many thanks to our Johnstown Walk Committee:

Tricia Barron  
Bobbi Benson  
Jeannette Brush  
Terri Englehart  
Frannie Findley  
Alexis Freoni  
Jan Goodard  
Debbie Larkin  
Max Lawn  
Jeanine Lawn  
Shirley Mayak  
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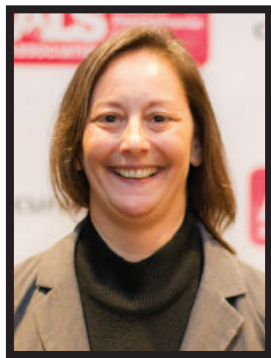
## Many thanks to our Pittsburgh Walk Committee:

Katlyn Andrulonis  
Peggy Borland  
Amie Hackimer  
Nathan Hyde  
Christi Kolarcik  
Keith Pisarcik  
Colleen Schaefer  
Sandy Shank  
Amy Shaughnessy  
Christy Simmers  
Josh Sullivan





# PA Chapter Class of 2017



Merritt Spier  
Executive Director

Marie Folino  
Director of Care Services

Julia Marsili  
Director of Development

Kristi Marsili  
Dir. of Marketing and  
Fundraising Events



Michele Mehal  
Development &  
Administrative Associate

Sandra Thompson  
Care Services Associate

Sonia Palmer  
Care Services Social  
Worker

Lauren Reinhard  
Event Associate



Catherine Friant  
Care Services Case Aid

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](http://www.cure4als.org).

For a copy of the Chapter's Form 990 and most recent audit, please contact us.



**Our Mission:**  
Leading the fight to treat and cure ALS through global research and nationwide advocacy while also empowering people with Lou Gehrig's Disease and their families to live fuller lives by providing them with compassionate care and support.

End of year gifts accepted by mail and online until midnight, December 31, 2016.



## Congratulations to our Chapter Award Recipients:

The Monessa Tinsley-Crabb Voice of Courage Award

*Mara Sweterlitsch*

The Rita G. Patchan Volunteer of the Year Award

*ALS Kids*

The Sarah W. Wood Advocate of the Year Award

*Mary Johnson*

The Robert F. Balint Above and Beyond Award

*Kim Fleming*

*Thank You*



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Pittsburgh, PA 15209  
Phone: 412.821.3254  
Fax: 412.821.3549  
[www.cure4als.org](http://www.cure4als.org)

### **Holiday Party**

12/10/16  
Sheraton at Station Square

### **Alex and Ani Charmed by Charity**

12/11/16  
Shady Side

### **Ski to Defeat ALS**

2/12/17  
Seven Springs Mount Resort

### **Johnstown Kick-Off Party**

5/6/17  
New Location - TBD

### **Local Advocacy Day**

TBD  
Harrisburg, PA

### **GNC Live Well Pittsburgh Health and Fitness Expo**

5/5 - 5/6  
David L. Lawrence Convention Center

*See you soon!*

### **Dick's Sporting Goods Pittsburgh Marathon**

5/7/17  
Point State Park

### **National Advocacy Meetings**

5/14 - 5/16  
Washington, DC

### **Erie Highmark Walk for a Healthy Community**

6/3/2017  
Presque Isle Park- Erie, PA

### **Johnstown Walk to Defeat ALS®**

7/29/17  
University of Pittsburgh, Johnstown Campus

### **25th Anniversary Pittsburgh Walk to Defeat ALS®**

8/26/17  
Point State Park