

ALS Press

Winter 2015

In this issue:

Letter from the Executive Director	2
Letter from the President	2
Board Spotlight: Christopher Bluemle	3
Chapter Events	4
Walk to Defeat ALS®	5
In Memoriam	6
Three Men Changed ALS Forever	6
Care Services	7
Advocacy	8
Sponsor Highlights	9
Community Partners	11
Local Research	11
2015 PDGA World Championships	11
One Dollar Difference	11
Jay Simon Golf Classic	12
Ice Bucket Challenges	12
Nancy Frates Visits	13
Chapter Award Recipients	13
New Staff Welcomes	14
In the Office	14
Save the Dates	15

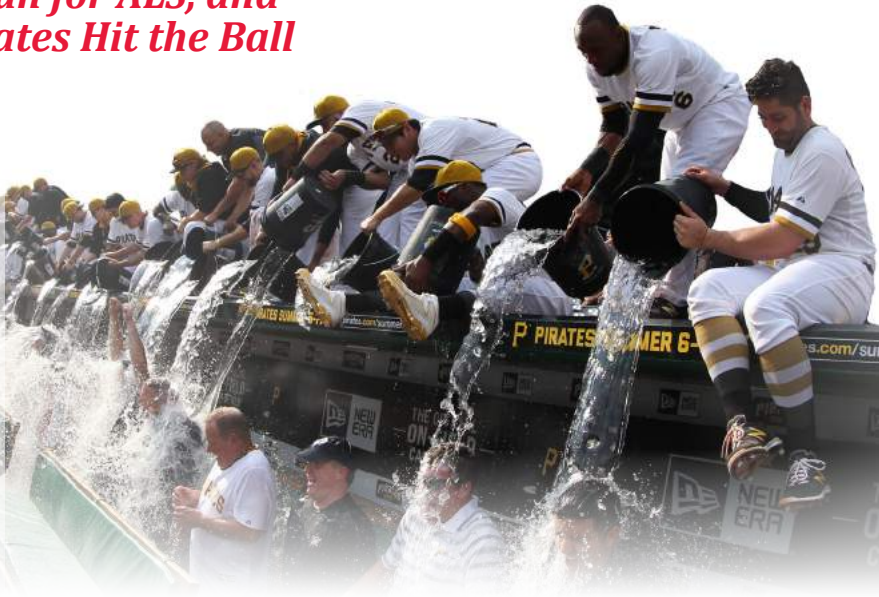
Our Mission:

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.



MLB Hits a Homerun for ALS, and the Pittsburgh Pirates Hit the Ball out of the Park!

Major League Baseball has long been an important ally in the fight against ALS. This year, however, MLB helped take that fight to the next level. MLB and its 30 clubs helped turn the Ice Bucket Challenge into an event benefiting ALS charities. Each day during August, a different ball club took the Challenge and passed it on to another club bringing awareness to the ALS Association's local chapters.



In addition, MLB gave the ALS Association a generous donation of \$100,000, which will be spent on collaborative efforts to accelerate care, treatments and a cure.

And speaking of collaboration, the Pittsburgh Pirates and Pirates Charities, in conjunction with ROOT SPORTS, held the eighth annual "Pirates Charities on ROOT SPORTS Auction" on August 4, 2015. The event raised a record \$715,000+ through the sale of over 3,000 VIP bags including autographed items and a special Ice Bucket Challenge T-Shirt.

The ALS Association Western Pennsylvania Chapter, the ALS Certified Center of Excellence at Allegheny Health Network and LiveLikeLou.org, all benefitted from the auction. Each charity was presented with a check for \$87,500 on the field at the game on October 4th, and Pirates Charities will use the rest for other worthy causes.

The auction took place live on the air during the ROOT SPORTS broadcast and featured stories on ALS which can be viewed on YouTube: <https://www.youtube.com/watch?v=ZzEJMXRxEr4>.

Live interviews with our PALS Duane Siple and Dr. Sandeep Rana, Medical Director of our ALS Certified Center of Excellence also took place.

But that wasn't all, fans had the opportunity to purchase a spot in the Pirates Team Ice Bucket Challenge – an event that included having a Pirates player douse you with a bucket of ice water during the Pirates Team Ice Bucket Challenge at PNC Park, a once-in-a-lifetime experience!

Thank you to the Pittsburgh Pirates and ROOT SPORTS for this amazing fundraiser.



Merritt Spier accepting check



VIP Bags



John Frates and members of the National ALS Association



Duane Siple and Family

Western PA Chapter

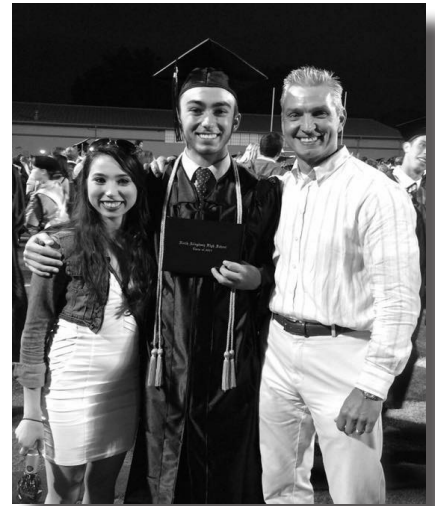
Letter from the President - Eric Zydel

In July of 2006, six months after my late wife Mary Lou lost her courageous battle with ALS, my kids and I were featured in North Hills Monthly Magazine article that outlined our efforts to raise money and awareness in support of our local ALS chapter. Courtney convinced her Girl Scout Troop to donate proceeds from cookie sales, Tyler was able to organize a bake sale at his school's spring choral concert, they both made the trip to DC for National Advocacy day and organized a forum for kids whose families were affected by ALS, and we were raising money for our Walk team that year. Courtney even traveled to Harrisburg to testify in front of the Pennsylvania House of Representatives Health and Human Services Committee urging them to fund ALS patient care and research. From the beginning, I couldn't imagine not utilizing what we learned through our experience to try and help. We were all in (and I'm so proud of them both)!

The article also stated that I was serving on the Board of the ALS Association Western Pennsylvania Chapter. The only problem was that I wasn't ... yet. Nudged by the article's inaccuracy (and perhaps

fate), I contacted the Chapter and was nominated and elected to the Board of Directors. Two years later I became Board President and have served in that capacity ever since. During my tenure I have had the honor and privilege to work with many incredibly gifted, dedicated and selfless individuals. I have watched our Chapter struggle and grow as we faced and overcame many challenges and obstacles, as organizations like ours sometimes do. I have had the immense satisfaction of seeing the breadth and depth of our Chapter services grow and ever increasingly impact the lives of those living with ALS in a very positive and tangible way. I have experienced the tremendous joy of hearing firsthand from our PALS how our work changes their lives. I have made many great friends, and lost many too. All in all, I have been tremendously blessed to be a part of this organization and the ALS community.

But, now it is time to move on. I will be relinquishing my position and my seat on the Board as of February 2016. My time serving on the Board has been a gift that I will always cherish. It is difficult to express how immensely grateful



(L-R) Courtney, Tyler and Eric Zydel

I am to have had the opportunity to serve the ALSAWPA. Ours is a world-class chapter providing extraordinarily valuable services for those who need and appreciate all that we do. I wish to thank our staff, our volunteers and our Board for all that they give, all that they do, and all that they have done for me. Lastly, I'd like to thank all of our PALS and their families for their support, courage and strength. You inspire me daily.

Though I'm leaving the Board, I'll never be far away and together we will continue to fight until we are living in a world without ALS.

Letter from the Executive Director - Merritt H. Spier

More than a year has passed since the 2014 Ice Bucket Challenge that generated \$220 million for ALS organizations all over the globe. Now people are asking, "What's standing in the way of a cure?" The short and unfortunate answer is that it costs \$2 billion dollars or more to bring ONE drug to market. And much is still unknown about what causes ALS.

The hopeful news is that The ALS Association has more than tripled annual spending on research. In 2015 alone the ALS Association distributed \$38 million in research grants and projects. Additionally, the ALS Association has spent \$23 million supporting clinics such as our ALS Certified Center of

Excellence at Allegheny General Hospital. And a new program will provide \$50,000 grants to groups developing novel approaches to assistive technology.

Our own Chapter responded to last year's increase in funding by developing a strategic plan that carefully plotted out ways to sustain the funds and add programs. We added grief counseling, private in-home caregiver training, and as you'll see in our care services report, we've reached ambitious goals in the number of services provided. We added a part time social worker and a social worker intern to reach more patients and we hired a Development Director to help us sustain and grow our



Merritt Spier

programs and services.

Patients and their families come first in everything that we do. We are dedicated to you in all ways and will continue to provide the highest level of service we possibly can to enhance the lives of all those living with ALS.

"My time serving on the Board has been a gift that I will always cherish"

"Patients and their families come first in everything that we do."

Board Spotlight

Christopher Bluemle

Q: Where are you employed and what's your title?

A: I work for Crown Castle. Crown Castle is one of the largest wireless infrastructure companies in the U.S., owning or controlling 40,000 cell phone towers and 15,000 miles of fiber. I am an Acquisition Manager within the Corporate Development & Strategy organization focused on mergers & acquisitions, as well as identifying future strategic initiatives.

Q: How did you first get involved in the chapter?

A: I became involved with the ALS Association in 2009 / 2010 shortly after my high school friend lost his mother to ALS in 2009. My mother, Karen, lost her fight in 2005. The tragic losses lead to the creation of Golf FORE ALS, an annual golf outing established to honor our lost mothers and raise funds & awareness for ALS and the ALS Association Western PA Chapter. Shortly after the golf outing was up and running I was asked to join the BOD here in western PA.

Q: You serve as a Board Member of the local Chapter board, a representative on the National Board of Representatives and on Committees within both boards. What would you say is your primary role at the Chapter overall?

A: I would have to say much of my time & focus centers around fundraising and development. I thoroughly enjoy working with my local chapter staff & Board, National office staff, as well as other National Board of Representative members & Trustees on developing new programs and procedures to help increase the brand awareness for our organization. In addition, collaboration with regards to identifying and establishing relationships with new sponsors has been very rewarding.

Q: As a member of the National Board of Representatives (BOR), can you explain the MAIN function of the BOR?

A: Each of the 39 ALS chapters

elects a representative to act as ambassador for their region. This agent, along with the spokesperson for each of the other chapters, meet a few times each year (in person & on calls) to get a better understanding of the state of the ALS Association as a whole – patient care updates, treatment / clinical trial updates, fundraising status, etc. However, one of the most important duties of the BOR is to recommend and ultimately vote on the National Board of Trustees for the ALS Association.

Q: What can you tell us about the ALS Association that has surprised you most in the last two years?

A: Quite honestly, I have not been surprised by anything at the ALS Association. I am constantly impressed by the people I meet and the work being done by the local chapters as well as the folks at National. The level of passion and dedication is sincere and never waivers – so I think that is why I am never truly surprised by anything at the Association. Amazed, excited, proud – but never surprised.

Q: What do you see in the future for the ALS Association and direction of Chapter work and national work?

A: I see amazing work continuing to be done. The increased funds & awareness as a result of the IBC has enabled local chapters to significantly increase their resources & offerings to directly impact the breadth of patient care & services. At the National level, we are seeing exciting & encouraging trials rolling out each and every month. Collaboration between local & national continues to expand to ensure that the people we serve – our PALS, who come first in all that we do – continue to receive the best in care & compassion.

Q: You have a family team for the Walk to Defeat ALS, but in addition you host of Golf FORE ALS event every spring and you started Ski to Defeat ALS last year- what do you do on your time off?

A: When not at work, or



Chris Bluemle and son, Caleb

dedicating time to ALS, I love spending time with my wife Alison and our 3 young children – Caleb (5), Paige (3) and Grayson (6 months). When I can find time I love to go golfing and skiing. That may have a little to do with me hosting an annual golf tournament and now a ski event. It is also no coincidence that skiing and golfing were two things my mother loved to do as well. That all being said – I truly enjoy all of the work around coordinating and pulling off these events. I love spreading the word of the amazing work we do at the ALS Association and am always appreciative of the opportunity to engage new and excited partners and sponsors for these events.

Q: What do you see as the Chapter's greatest successes?

A: In the past several years I have seen the chapter overcome some unfortunate obstacles and ultimately come out better off and further ahead. It is a reflection of the amazing staff and leadership on the Board to stay on track and always keep in mind our number one priority – the patients & families whom we serve.

Q: What is your hope for the Chapter in the coming year?

A: That we continue to fight each and every day to support our patients and their families to the best of our abilities.

Q: One last word?

A: Join me at the Ski to Defeat ALS event on Sunday, February 21 at Seven Springs. Register today at www.ski4als.org.

Favorite Color:
Blue

Casual or
Formal?
Casual

Given the
chance, would
you want to
be on a reality
show?
No

Dogs or Cats?
Dogs

What is one
thing about
you that
would surprise
people?
I stopped a
bank robber

Favorite
Movie?
Tombstone

Favorite movie
star?
Chris Farley

Favorite
pastime:
Skiing

Have you had a
hole-in-one in
golf?
No

Place you most
want to go?
Croatia

Place you
LOVE to go
again and
again?
Lake Ontario

Favorite Drink:
Beer

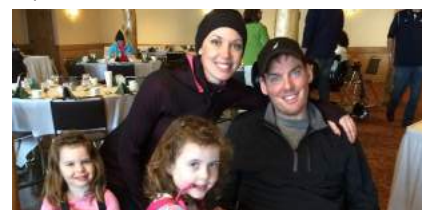
Favorite type
of music:
Country

Chapter Events

2015 Ski to Defeat ALS

On Sunday, February 1st, 2015, The ALS Association Western PA Chapter hosted their First Annual Ski to Defeat ALS fundraiser at Seven Springs Mountain Resort. With fresh snow falling, two of our chapter's own persons living with ALS: Pittsburgh firefighter, Matt Onyshko and Johnstown Diva, Donna Boring experienced the slopes with the assistance of Three Rivers Adaptive Sports. Matt, a seasoned skier and Donna, a first timer were both on the slopes for a good portion of the afternoon.

The Western PA Chapter is only the third chapter to host a ski event, next to Oregon and Colorado and we were very pleased with our turnout. We are also grateful to all those who sponsored and donated to the event. Between raffles and silent auction items in the Foggy Goggle, our fundraising efforts garnered \$36,403 for the Chapter. We could not have pulled this event off without the special support of Three Rivers Adaptive Sports and Allegheny Health Network. We are looking forward to the second annual event on February 21, 2016.



2015 Pittsburgh Marathon

On Sunday, May 3rd, nearly 40,000 runners flooded the streets of Pittsburgh for the Pittsburgh Marathon. People from all over the world attended the largest Pittsburgh Marathon to date, participating in the relay, half and full Marathon. For the first time, the ALS Association Western PA Chapter was an official charity with a great team! There were 24 runners who raised almost \$15,000! This beat last year's total and also surpassed our fundraising goal.

The runners who participated all wore red shirts with the chapter logo and on the back a special place to write the name of the loved one they were running for. It was easy to spot our runners in red and people showed plenty of support for everyone running on behalf of ALS. It was a perfect day to run for our cause and a huge thank you goes out to all of our participants and their fundraising efforts!



2015 Erie Highmark Walk

On Saturday, June 6, 2015 the Western PA Chapter participated alongside 25 other charities in the Erie Highmark Walk for a Healthy Community at Presque Isle State Park. 55 walkers participated for ALS, and with the help of our sponsors, we raised more than \$11,182! With this great effort our Chapter was the third highest fundraising charity at the event!



Legacy Sponsor



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WESTERN PA HEALTH MANAGEMENT SINCE 1968



UPMC
Centers for Rehab Services



LAMAR
OUTDOOR ADVERTISING

tobi dynavox



UPMC HEALTH PLAN
UPMC Senior Services



Top 5
Fundraisers:

Lynne
Hartnett

Jim Bluemle

Donna
Boring

Chris
Bluemle

David
Hay

Top 5
Marathon
Fundraisers:

Heather
Crago

Jason
Hoover

Dana Kozak

Brianna
Renshaw

Maile
Schewieger

Top 5
Erie Walk
Fundraisers:

Stacy
Schwalbendorf

Alison
Steadman

Peggy
Maloney

Cynthia
Glass

Kevin
Davis

Walk to Defeat ALS®

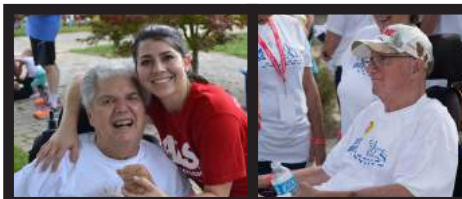
Johnstown

Not only did the Johnstown Walk hit a record high of \$90,000, surpassing the goal of \$67,000, but at the very end of the walk route the 600 plus participants of the walk gathered around hundreds of buckets of ice water to take a group Ice Bucket Challenge. The Richland Volunteer Fire Company came out to spray anyone who may have escaped the downpour of water.

The Johnstown community won the award for "most returning walkers" at this year's National Leadership Conference and has a very good chance of doing so again this year. It was an incredible day of family, friends and fundraising!

Johnstown Top Fundraising Teams

- 1.) Ice Bucket Wife (\$7,330.00)
- 2.) For Pete's Sake (\$7,225.00)
- 3.) Pap's PALS (\$6,712.00)
- 4.) Team Hoss (\$5,412.00)
- 5.) MAMA MAYAK (\$5,305.00)
- 6.) Siple's DASiples (\$4,600.00)
- 7.) Dozy's Daffodils (\$4,598.00)
- 8.) Donna's Divas (\$3,665.00)
- 9.) A Mile for Max (\$2,866.00)
- 10.) Team Phyllis (\$2,580.00)



Johnstown Top 10 Fundraisers:

Frannie Findley
Rebecca Johnston
Tricia Barron
Duane Siple
Scott Steinkirchner
Betty Hostetler
Donna Boring
Mary Kay Voytko
Sharon Squillario
Peggy Mumau

Pittsburgh

August 22, 2015 was a spectacular day. Perfect weather that was perfect for the Pittsburgh Walk to Defeat ALS at Point State Park. Although we did not reach our fundraising goal this year, there was no lack of team spirit and enthusiasm as 1,600 people walked for all those they love who live with ALS and those who have lost their battle with ALS. At the time of this newsletter printing the Pittsburgh Walk had raised \$369,427. Donations can still be made at: <http://web.alsa.org/pittsburgh>. Thank you for the hard work of all our participants, sponsors and team captains!

Pittsburgh Top Ten Fundraising Teams

- 1.) Cleveland Brothers (\$23,335.00)
- 2.) Carol's Crew (\$21,497.74)
- 3.) Team Father Dennis (\$17,117.00)
- 4.) Knopp Biosciences (\$8,339.00)
- 5.) Hope-1 ALS-0 (\$8,038.00)
- 6.) University of Pittsburgh Brain Institute (\$6,305.00)
- 7.) A.M.'s Army of Angels (\$6,235.00)
- 8.) Carla & Al's PALS (\$5,995.00)
- 9.) Pop Pop's Jumping Jaguars (\$5,840.00)
- 10.) The Hill Group (\$5,000)

Pittsburgh Top 10 Fundraisers:

Cleveland Brothers
Father Dennis
Carol Shaughnessy
Barbara Grosse
Chris Brussalis
Susan George
Ken Gilson
Jim Shields
Eric Zydel
David Mongillo



Top Fundraising Family Team: Carol's Crew

Team Week Winner: University of Pittsburgh Brain Institute



In Memoriam

November 1, 2014 – October 31, 2015

Neil Alexander
Leonard Aloise
Carol Anderson
Carl Anthony
Floyd Barr
Mike Braden
Matthew Bulvony
Louise Burky
Sharon Burnworth
Margaret Calano
Frank Camuso
Jim Capps
Eugene Casasanta
Bob Clear
Dennis Colamarino
Helena Dropcho
Suzanne Enright
Ruth Fink
Dawn Finnegan
Brian Fulton
Dolores Gallo
David Giltinan

Sandra Haines
Elaine Hauser
William Houser
Nancy Lea Jewett
Sammy Johnson
Vivian Kalberer
James Kolenda
Russell Kunselman
Martha Leporace
Barry Levin
Teresa Ludington
Anthony Luta
Kenneth Lynch
Thomas Martin
William McClaine
Adeline McNeal
John Nichols
Harold Parker
Doris Polansky
Zally Price
Donna Pruchnitzky
Mona Rice

Lee Roberts
Gloria Rosso
Burley Saylor
Sandra Schmidt
George Shames
David Shaner
Donald Shaw
Larry Smith
Stanley Stein
Arlene Stenglein
Michael Sullivan
Michael Swick
Paul Toth
Robert Uber
Louis Volk
Richard Way
Twila Wess
Diane White
Mary Wilson
Barbara Witosky
Kathleen Young



Three Men Changed ALS Forever

With the news of every death of someone within our ALS community, we suffer. Every individual and his/her family members has a special place in the hearts of our staff and our Board. While no one individual is more important than the other, some individuals have made a lasting impact in the world of ALS. Mr. Fred Rogers used to say that memories can be comforting and that it can be especially helpful to talk about your feelings. So, in the case of these three individuals, we felt compelled to share our feelings about the impact these three special men left on our community and celebrate the positive impact they made on us and on each and every person they met.

Michael Sullivan: Lived Differently



"Everyone knows they're going to die, but nobody believes it. If we did, we would do things differently." A quote from *Tuesdays With Morrie*.

One such individual who "did things differently" was Michael Sullivan...laid to rest on June 19, 2015. Perhaps the knowledge of his impending mortality inspired him to remake his life in a remarkable way.

Michael was an extraordinary human being, whose energy seemed only to increase as his disease progressed. He was generous, funny and compassionate, his dedication to the helping his fellow ALS sisters and brothers knew no bounds.

"I have been asked why I do medical trial studies," Michael would say. "Getting involved empowers me to fight ALS. It gives me hope. It's about being a part of something bigger than me. My enrollment in studies gives me purpose. This purpose driven life has been a catalyst for positive change in my thoughts. It will take great efforts to eliminate ALS but I have hope that we are a part of the cure for ALS." And Michael was part of the process for a cure.

Despite his struggle to walk in the later stages of his disease, Michael continued to make annual trips to Harrisburg and Washington, D.C., with the ALS Association for nine grueling years. Again and again, he recounted the emotionally exhausting story of his battle with ALS. And he played a pivotal role in helping to win line-item funding in the PA state budget for ALS patient care. In Washington, he expressed the critical need to fund research and to support the National ALS Registry. He fought for veterans with ALS, who now receive benefits without a waiting period, and pushed to get drugs that treat neurological diseases fast-tracked through the FDA.

Michael Sullivan's exemplary life lives on in our hearts as do his final public words on Capitol Hill in Washington, D.C. on May 12, 2015: "I'm here to share my story, so that you can do something to help those coming behind me. I will never give up hope."

Father Dennis: Lived Faithfully



Reverend Dennis Colamarino, pastor of Christ the Light of the World Parish in Duquesne, established a Walk to Defeat ALS® team and raised \$81,000 for the Chapter in 2014 and another \$17,000 in 2015! Father Dennis lived a life of faith and continued his ministry even in his final days with ALS. You may recall his memorable Ice Bucket Challenge video with Bishop Zubik. He said he decided to do the challenge because it's "something out of the ordinary for us uptight adults. It's fun and everyone has fun with it. And it's raising awareness and money for ALS."

Despite some reservations within other Catholic dioceses around the country about taking the Ice Bucket Challenge and drawing attention to ALS research, the Challenge was no problem for Father Dennis. He was teaching an important lesson: that ALS knows no boundaries, so why should we set boundaries to find a cure for this fatal disease? Father Dennis and his parishioners raised a lot of money for research and patient care. They continue to do so, because they understand that adult stem cell research is just one of the many projects showing hope for a cure and public funding does not support Embryonic stem cell research at the ALS Association.

Colamarino's godson and parishioner Adam Gilbert praised the priest. "Fr. Dennis was truly one of a kind! He was an inspiration for our parish and community. He embraced diversity and created a unique faith experience. All were welcome at Christ the Light of the World Parish. Above all else, he loved his family, his friends, and his faith. We will miss him dearly."

Get the facts about ALS research by visiting: <http://www.alsa.org/research/>

Neil Alexander: Lived Like Lou



Neil Alexander: father, husband, brother, son, ALS advocate, Board Member of the ALS Association Western PA Chapter, founder of LiveLikeLou.org and its associated research institute at the University of Pittsburgh Brain Institute. The list goes on and on. There is almost nobody in western Pennsylvania who didn't know him or hear of him. Prior to the Ice Bucket Challenge we would often say that Neil single handedly brought ALS out into the light – bringing badly needed attention to this dreaded disease by publically sharing his story through every possible media outlet and by documenting the relentless progression of the disease through photography.

But one of the most amazing things about Neil was the choice he made early after his diagnosis to live as Lou Gehrig lived. Neil, an avid baseball fan, studied the game, was a devoted Pittsburgh Pirates fan but admired and respected Lou Gehrig – the baseball legend who also died from ALS, giving it the name "Lou Gehrig's Disease." Neil wanted to live out the rest of his time on earth like Lou Gehrig, honoring the example he set for all people living with ALS. Described as quiet and unassuming, Gehrig's hardworking nature and ability to play through incredible pain certainly earned the respect of all who knew him, and earned him the nickname "The Iron Horse." Neil and his wife Suzanne fund the Iron Horse Awards and the LiveLikeLou.org Patient Care Fund through our Chapter, providing help and a sense of community support to families struggling with ALS. Letting them know that they are not alone in the fight against this disease.

Neil died at age 49 on March 24, 2015 but not before setting into motion the vision and the strategy to build the LiveLikeLou Center for ALS Research at the University of Pittsburgh's Brain Institute. Neil knew that a cure wasn't probably going to happen in his lifetime but wanted to "leave ALS better than I found it."

Neil's mantra was "Onward" – he never looked back. He lived like Lou and kept pushing through the pain with hope that others coming behind him might be the ones to see the day when a cure is found, maybe right here in Pittsburgh.

Tribute Gifts

The entire list of tribute names and donors from November 1, 2014 to October 31st, 2015 can be found on our website at the following link: <https://secure2.convio.net/alsa/site/SPageNavigator/TributeList.html>. If you do not have access to a computer and would like a paper copy we will print the list and mail it to you upon request. Simply call our office at (412) 821-3254. Thank you for your support and understanding.

Care Services

Chapter Wins Innovation Award

Last February at the ALS Association National Leadership Conference the Western Pennsylvania Chapter won a prestigious Chapter Innovation Award recognizing us as a trailblazing chapter actively developing and implementing new ideas and/or methods in the delivery of ALSA's mission priorities. The spirit of this

award is one of collaboration, sustainability and measurable impact. We received the award for our "Powerful Tools for Caregivers" course which is a 6 week class providing a wealth of self-care tools for non-professional caregivers. The Western PA Chapter is the only ALS Chapter out of 39 currently offering this course.



Christopher Bluemle, Merritt Spier and Barb Newhouse

Care Services Highlights From July 1, 2014 – June 30, 2015

The Chapter has seen significant growth since last year's Ice Bucket Challenge. We attribute much of it to increased awareness of our services and more people reaching out than ever before. To date we have been able to fulfill each request and we want to thank you for your support because YOU make it all possible. We also want to urge your continued support so we can sustain and grow our level of service. Here is proof of your dollars at work:

- A total of 262 people living with ALS were registered with our Chapter. We registered 105 new individuals and for comparison, we registered 91 new PALS the year before.

New Patients

105

- We loaned 38 power wheelchairs and the significant thing to consider when looking at this number is that the majority of these chairs were for individuals living in a nursing facility who would have no other option for mobility without our loan closet. As a comparison, in 2013/14 we loaned 17 power wheelchairs.

Wheelchairs

38

- We provided a personal touch to our patients and families in a variety of ways. Home visits are the best way for us to assess the needs of someone living with ALS and help us build lasting relationships with the patient and their family members. We provided:

- 127 Chapter staff home visits;
- 28 Speech Language Pathologist visits; and
- 32 Occupational Therapy visits.

Home Visits

187

- 41 families received a total of 5,221 free hours of respite/home care services. To demonstrate the increase over the past five years, in 2010 we provided only 1,030 hours.

Respite/Home Care Services Hours

5,221

- We provided 134 free trips for 32 patients to and from medical appointments and Chapter events – even during that epic Winter we had last year.

Transportations

134

- We provided 15 home modifications, 12 of which were wheelchair ramps for access into and out of the home. Only three years ago we had requests for just four.

Home Modifications

15

Interim Healthcare Continues to Sponsor Caregiver Appreciation

Each year the Chapter holds a Caregiver Appreciation Weekend at Seven Springs Resort and Spa that provides caregivers with a relaxing break to replenish their minds, spirits and bodies. It is a great opportunity to meet other caregivers and informally support one another. There is no set agenda except a group lunch as a way to mingle and meet one another, an optional group dinner, and optional breakfast. Everyone that attends receives a caregiver goody bag and a \$100 gift card to use at the spa or activities center.

We want to thank Interim Healthcare for sponsoring this event on an annual basis. This year they presented us with a check for \$6,000 to make it possible for us to accommodate the largest group of caregivers we've ever had attend the event!



Karen Pompe and Marie Folino

We are providing more care and support for people and families living with ALS than any time in the history of the Chapter.

Advocacy

President Barack Obama signed off on The Steve Gleason Act

In July 2015 The Steve Gleason Act officially became law when President Barack Obama signed off on the bill named for the former New Orleans Saints football player currently living with ALS.

Gleason, who was diagnosed with ALS in 2011 and became the driving force behind the law, which helps protect patient access to medically necessary Speech

Generating Devices (SGDs) for individuals with communication disabilities, including ALS. Specifically, the new law removes SGDs from the Medicare Durable Medical Equipment (DME) payment category as a “Capped Rental” and provides coverage of eye-tracking technology for patients who rely on this method to access and operate covered SGDs.

These amendments were effective beginning October 1, 2015.

Gleason has also tasked Microsoft Corporation to create a way to operate a power wheelchair via eye-gaze technology. The company has already unveiled a prototype and Gleason has called the new technology “liberating.”



Chris Brussalis - National Board of Trustees Advocacy Chair

21st Century Cures Act Passes in the House

Also in July 2015, the U.S. House of Representatives approved H.R. 6, the 21st Century Cures Act, helping to advance ALS research and accelerate the discovery and development of new treatments. The bill now sits in the Senate for consideration.

The new legislation would allow the FDA to cut out the third phase of some clinical trials if the pharmaceutical showed significant effectiveness in phase II — and get new medications to people who need them sooner. However, pharmaceuticals that have been fast-tracked by the FDA would still need to meet appropriate safety standards.

Thank you to everyone who took action by writing and calling your representative. Your outreach helped make a difference! But now that the bill has passed, it is important to follow up with your Senator on the 21st Century Cures Act and urge them to pass the bill as well. Let's get this done!

PALS Attended National Advocacy Days in Washington D.C. in Record Numbers

Advocates really do make a difference! This past year a record number of individuals living with ALS, along with their caregivers, family, friends and ALS Association staffers joined forces in Washington, D.C. to secure continued funding for The ALS Registry, for ALS research through the Department of Defense, to push

the 21st Century Cures Act and The Steve Gleason Act.

Not only was attendance for ALS Advocacy Days record breaking, so was the impact on Capitol Hill. To learn more about how effective ALS advocates are and to become an ALS advocate please visit <http://www.alsa.org/advocacy>.



State Advocates Campaign for \$500,000 Line Item in State Budget

The ALS Association Western Pennsylvania Chapter, in partnership with the Greater Philadelphia Chapter, once again made our annual pilgrimage to Harrisburg to request \$500,000 line item funding in the state budget for ALS patient care for 2016.

Our legislators welcomed us with open arms and applauded our efforts. They also gave us considerable verbal support for our nominal request and our group got an audience with the Governor.

Unfortunately at this time the current \$350,000 line item for ALS has been zeroed out while negotiations on the state budget

continue. Normally, by June 30 of each year, the Commonwealth must approve a budget that sets funding levels for the following fiscal year. When a budget has not been approved, the Commonwealth is prohibited from making many payments. This period, known as a budget impasse, continues until a budget is approved. With the amazing support – both verbal and written – that we received from our state legislators, we feel confident that ALS line item funding for 2016 will be approved. We are not cutting any services to patients due to the impasse.



Governor Wolf with our Advocacy Team



Harrisburg Advocacy Team

Microsoft is creating an eye-gaze power wheelchair.

Find your local Senator: opencongress.org

The PA budget is at an impasse. Please encourage your legislators to pass the budget with line item funding for ALS patient care.

Sponsor Highlights

This is the fourth year Hefren-Tillotson, Inc. has sponsored the Pittsburgh Walk at \$25,000.

To date, Hefren-Tillotson, Inc. and HT Stands up for ALS have raised \$178,097 for the Pittsburgh Walk to Defeat ALS®.

Legacy Sponsor: 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 their involvement with the ALS Association Western Pennsylvania Chapter.

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

To honor Neil and his family, the Hefren-Tillotson family gathered once again at Point State Park for the annual Walk to Defeat ALS®. Their team's t-shirts quoted Neil's philosophy "Leaving ALS Better Than We Found It... Onward!" All were blessed with a gorgeous, sunny morning and warm temperatures, and the Point is a wonderful venue for the ALS Walk.

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 life without being reminded of his disease. When the Alexander family found out about Neil's diagnosis, they decided to create a photo progression of him. He wore shirts representing different places and people who were important to him. 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 support and affection for the Alexander family and to raise money for the ALS Association. The work of the ALS Association is so critical to those facing a future with ALS.



Thank you to our Legacy sponsor.



HEFREN TILLOTSON

METICULOUS WEALTH MANAGEMENT SINCE 1948
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member SIPC

Cleveland Brothers Signs on as First Chapter Sponsor

An important part of running a successful business is giving back to the community in which you do business. Cleveland Brothers is a family-oriented business that not only meets the needs of its customers, but also takes a tremendous amount of pride in supporting the cause to help find a cure for ALS.

The need for a cure has a personal connection for Cleveland Brothers. One of the company's owners, Tom Kirchhoff, courageously battled ALS for over four years and recently passed away. Before last year's ALS Ice Bucket Challenge, the company declared, "WE WILL WIN!" During Tom's life, he applied those words to everything he did. As a business owner, athlete, father, and husband, he never gave up and continued being active in all aspects of his life.

In addition to donating, Cleveland Brothers also holds fundraising events such as charity auctions and motor cycle rides, participates as a team in the Walk to Defeat ALS®, and is a top fundraiser in the Pittsburgh Walk and Hershey Walk each year. Mary and Jay Cleveland have served as Co-Chairs of the Corporate Sponsorship Committee and have been instrumental in involving their employees, families and friends to support the cause. With all the participation and support from Cleveland Brothers employees, families and friends - all helping to create awareness for ALS - "WE WILL WIN!" will be realized!



Cleveland Brothers becomes first official Chapter Sponsor supporting all Chapter events.

Allegheny Health Network

The Allegheny Health Network (AHN), is the second-largest provider of healthcare in our region. AHN includes Allegheny General Hospital where our ALS Certified Center of Excellence is housed. The system also includes Forbes Hospice, Pittsburgh's first end-of-life and palliative care program.



(L-R) Kathleen K. McKenzie, Merritt Spier, Christy Simmers

AHN employs approximately 13,000 people with a medical staff of 2,726 including Dr. Rana, the medical director of the ALS Certified Center of Excellence and his wonderful team.

Last year AHN became the Presenting Sponsor of our annual Ski to Defeat ALS event at Seven Springs and has renewed their commitment for this year as well. We want to thank Kathleen K. McKenzie, Vice President of Community & Civic Affairs for seeing the value of our work to create a better quality of life for all those living with ALS. Not only are they the presenting sponsor of our annual Ski event, they became a new Bronze level sponsor of The Pittsburgh Walk to Defeat ALS this year as well.

Brewski Kicks Off Winter Event for ALS

The ALS Association Western PA Chapter Ski to Defeat ALS event will be held on Sunday, February 21 at Seven Springs. This is the second year for this event and guests gathered at The Beer Market on Federal Street to start 'brewing' up support for the big day at the Brewski kick off! Brew-SKI.... Get it?

Attendees enjoyed some delicious food from local restaurants and beers from over 50 draft and 500 bottle choices while snow enthusiasts learned all about the Ski to Defeat ALS details. Everyone received a commemorative pint glass to remember the fun night. You can find out more about the upcoming event at www.ski4als.org.



Community Partners

Local Research

The ALS Association Western PA Chapter is honored to be partnering with the University of Pittsburgh Brain Institute (UPBI) on some groundbreaking assistive technology efforts as well as ALS research. This past summer UPBI welcomed Christopher Donnelly, PhD, to the research team to lead the basic science efforts of the Live Like Lou Center for ALS Research, one of the Six Centers of Excellence within the UPBI. The goal of the Live Like Lou Center is to study the mechanisms underlying ALS to develop effective treatments and, eventually, a cure. Dr. Donnelly joined the faculty after completing his postdoctoral studies at Johns Hopkins University.

Research in the Donnelly lab utilizes induced pluripotent stem cells (iPSC) from patients with ALS. These cells are programmed to become neurons and glia, two of the cell types affected in ALS. These cells are then used to investigate which pathways go awry in ALS. Most recently, Dr. Donnelly and his collaborators identified a pathogenic mechanism that seemingly affects the majority of patients with ALS and might explain a universal phenomenon observed in the disease. Dr. Donnelly is collaborative in his work and passionate about ending ALS; we are grateful to have him in Pittsburgh and to be a partner in his efforts!

To learn more about the University of Pittsburgh Brain Institute, please visit: <http://www.braininstitute.pitt.edu>.



Dr. Chris Donnelly

2015 PDGA Professional Disc Golf World Championships



The 2015 PDGA Professional Disc Golf World Championships were held in the Pittsburgh, Pennsylvania metro area from August 1st to August 8th 2015.

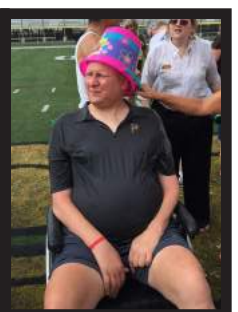
The host club for Pro Worlds, the Pittsburgh Flying Disc Society (PFDS), welcomed participants from all over the world to the City of Champions. PFDS has established and maintains multiple world-class courses throughout Western Pennsylvania. And has raised thousands of dollars for local area non-profit organizations since the club's founding in 1988.

This year the PFDS proudly joined with the PDGA and made the ALS Association Western Pennsylvania Chapter one of the official Charity Partners along with Butler County Tourism and VisitPittsburgh. The efforts of over 400 participants from 20 countries raised more than \$35,000 for the chapter to fund patient care. A HUGE thank you to J. Gary Dropcho for organizing this amazing event. Sadly J. Gary lost his mother to ALS just prior to the PDGA World Championship events.



One Dollar Difference makes a Difference!!

Hosting your own fundraiser is a great way to get you and your community involved. Using the One Dollar Difference online platform makes promoting, collecting funds and organizing your event a breeze. All funds collected through your fundraising site will go directly to the Chapter. Create your event now: <http://web.alsa.org/wpaODD>



23rd Annual Jay Simon Golf Classic has another great year for the Norma L. Simon ALS Patient Equipment Fund!

Jay founded the first golf outing in 1992 to simply “have a darn good time with friends and family.”

Then, in 2000, with the passing of his mom, Norma Simon, from ALS, the outing had added purpose. Through the ALS Association of Western Pennsylvania, a fund was established to provide equipment not covered by insurance to families who have been stricken by this horrible disease.

The Jay Simon Golf Classic has cumulatively brought in over \$219,000 to the fund since its inception. This year on May 15, the 24th Annual Jay Simon Golf Classic netted \$18,239 for the Norma L. Simon ALS Patient Equipment Fund.

Twenty-three teams participated in the event. The Simon family, including Jay’s father, Jack, and brothers, Jett, Jeff and Judd were all in attendance as the four brothers played as a team for the third consecutive year. Sister, Janette Wilson, came in from Atlanta to enjoy the festivities.

To recognize The 20 Year Club, green golf gloves were given to those golfers who have played at least twenty times throughout the history of the outing.

Flight winners, Skill Shots and Two SKINS were all recognized with special awards.

Again this year, all of the prizes and golfer gifts were contributed by donors.



L-R: Judd Simon, Jett Simon, Janette Wilson, Jack Simon, Jeff Simon, Jay Simon

Save the Date!

To be placed on the invitation mailing list for this golf outing, contact Jay at (888)774-0990 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 WPA” and send to Jay’s attention at 35 Laurel Road Bradford Woods, PA 15015.

Thank you..

Thank you to our community partners that participated in the Ice Bucket Challenge this year! Mascaro Construction, The National Aviary, the Pittsburgh Pirates and the Pittsburgh Penguins.



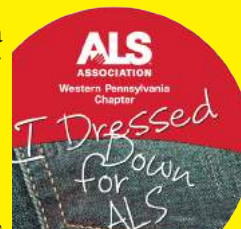
The Ice Bucket Challenge Goes to The Dogs!

This year one of the most unique Ice Bucket videos was arranged by Lucky Paws Pet Resort in Freedom, PA. The dogs and people lined up for the challenge and everyone with four and two legs got wet in the name of ALS, raising \$1,000 for the Chapter. Watch the video here: <https://youtu.be/O9nyG2jg03A>



Lucky Paws Resort

Need a fundraising idea for your walk or ski team to help raise money for Chapter events? Try a Dress Down Day and be sure to ask us for these great stickers you can use as an incentive for all your participants.



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

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Eric Zydel

Vice President

Christi Kolarcik, PhD

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Sarah W. Wood, ScD



Many thanks to our Johnstown Walk Committee:

Chairmen:

Sharon Squillario and Carla Portash

Committee Members:

Trisha Barron

Bobbi Benson

Jeannette Brush

Terri Englehart

Frannie Findley

Alexis Freoni

Jan Goodard

Debbie Larkin

Max Lawn

Jeanine Lawn

Shirley Mayak

Tim Spangler

Scott Steinkirchner

Many thanks to our Pittsburgh Walk Committee:

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Christi Kolarcik & Colleen Schaefer

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Peggy Borland

Ken Gilson

Amie Hackimer

Nate Hyde

Rachele Keller

Kristi Marsili

Melissa Oreowski

Jennifer Parco

Keith Pisarcik

Nadene Purcell

Christy Simmers

Courtney Zydel

The Mother of the Ice Bucket Challenge Visits Pittsburgh

After the viral sensation of the 2014 Ice Bucket Challenge, how could we not bring the mother of the Challenge -Nancy Frates -to Pittsburgh? Nancy is the mother of Pete Frates who, along with his friend Pat Quinn, founded the Ice Bucket Challenge. Both Pete and Pat are young athletes, newly married and suffering with ALS. This photo is Nancy and Pete on Pete's wedding day when he had to be helped down the aisle by



Nancy Frates and Pete Frates

his father and new bride, but he was determined to walk on his own. He is now in a wheelchair full time and on a vent. But as August 2014 came to a close and the Ice Bucket Challenge was peaking, Pete's wife gave birth to a baby girl and it was truly the perfect ending to what had been an amazing summer of attention and funding for ALS.



(L-R) John Frates, Anne and Craig Adams, Nancy Frates

Nancy serves on the National Board of Trustees of the ALS Association and this was her first trip to Pittsburgh. She agreed to come kick-start the Chapter's walk events and inspire people to invest in ALS for the long haul. The attendees were captivated as she spoke about the life changing experience for her family during the height of the Ice Bucket months, but more importantly she challenged us all to continue to fund and support the ALS Association every August until there is a cure.

At this event we also bid farewell to our celebrity Walk co-chairs for the past three years; Craig and Anne Adams. Craig was #27 for the Pittsburgh Penguins and son-in-law to Gov. Paul Cellucci of Massachusetts who died from ALS in 2013. Craig and Anne assisted our Chapter by raising money and awareness for ALS. They had attended every walk with many of their Penguin teammates and over the course of three years raised well over \$25,000 for our Chapter with the help of the Pittsburgh Penguins Wives Association. Our loss is Boston's gain and we were pleased to put the Frates and Adams families together to continue the fight against ALS.

Chapter Award Recipients

**Monessa Tinsley-Crab Voice of Courage Award
Vaughan Thomas**

**Rita G. Patchan Volunteer of the Year Award
Scott Steinkirchner**

**Sarah W. Wood Advocate of the year Award
Joyce McNeal**

**Robert F. Balint Above and Beyond Award
The Pittsburgh Pirates and ROOT SPORTS**

ALS Association Western PA Chapter Welcomes New Staff

The growing needs of our constituents has created a bit of a growth spurt at the Chapter in an effort to maintain and sustain the high standard of care and service we've been able to provide to those living with ALS and their families. Please help us welcome three new key members to our staff:



Sonia Palmer MSW, LSW
Social Worker

Email: sonia@cure4als.org

Sonia joined our Care Services Department in October as a part time licensed social worker. Sonia earned her Masters of Social Work from the University of Cincinnati, OH and has been working in care management, home health, hospice and social work since 1993. Sonia is conducting home visits and attending the ALS Clinic in Johnstown. Her coverage area includes the southwestern counties of Pennsylvania.



Lauren Reinhard
Events Associate

Email: events@cure4als.org

Lauren joined us at the beginning of October. Her desire to give back to the community and her passion for event planning started while she was attending California University of Pennsylvania, volunteering to create promotional events for the Athletic Department. She built sponsorship relationships and created fundraising events that ultimately fostered a desire to make a difference in her community and achieve goals that would directly benefit people in need. We are fortunate to have her talent and energy and she is a great addition to the fundraising events team.



Julia Marsili
Director of Development

Email: julia@cure4als.org

After an exhaustive and careful search, the Chapter has hired a Director of Development. This is a new position and part of the Chapter's long range strategic plan to sustain and grow the organization's programs and services. Julia is the former Executive Director of the Methodist Union of Social Agencies. She has a Masters of Public Administration from the University of Pittsburgh Graduate School of Public and International Affairs and a Bachelor of Arts from Chatham University. Julia started on November 16th and is eager to meet our friends, donors, patients, families and sponsors. Her responsibilities include engaging new donors, working on planned giving and major gifts as well as applying for foundation grants.

Oldies but Goodies in the Office...



Merritt Holland Spier
Executive Director

Michele Mehal
Development and
Administrative
Associate



Marie Folino
Director of
Care Services

Sandra Thompson
Care Services Associate



Kristi Marsili
Director of
Marketing
and Fundraising
Events

Christy Simmers
Development
and Advocacy
Coordinator



Thank You

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 contact us.

End of year gifts accepted by mail and online until midnight, December 31, 2015.

Contact us:
Merritt Spier:
merritt@cure4als.org

Michele Mehal:
michele@cure4als.org

Marie Folino:
marie@cure4als.org

Sandra Thompson:
sandra@cure4als.org

Kristi Marsili:
kristi@cure4als.org

Christy Simmers:
csimmers@cure4als.org



**Western Pennsylvania
Chapter**

*416 Lincoln Ave
Pittsburgh, PA 15209
Phone: 412.821.3254
Fax: 412.821.3549
www.cure4als.org*



See you soon!

Holiday Party - December 5, 2015

The Sheraton at Station Square

Ski to Defeat ALS - February 21, 2016

Seven Springs Mount Resort

Pittsburgh Marathon - April 29 - May 1, 2016

Downtown Pittsburgh

Johnstown Kick-Off Party - May 6, 2016

Wells Creek Station - Listie, PA

Local Advocacy Day - TBD

Harrisburg, PA

National Advocacy Meetings - May 8- 10, 2016

Washington, DC

**Erie Highmark Walk for a Healthy
Community - June 4, 2016**

Presque Isle Park- Erie, PA

Johnstown

Walk to Defeat ALS® - August 6, 2016

University of Pittsburgh, Johnstown Campus

Pittsburgh

Walk to Defeat ALS® - August 27, 2016

Point State Park