

Impact Report

ALS
ASSOCIATION
Western Pennsylvania
Chapter

Fall 2017

cure4als.org



The mission of The ALS Association is to discover treatments and a cure for ALS, and to serve, advocate for, and empower people affected by ALS to live their lives to the fullest.



A letter from the President Christi Kolarcik, PhD

We can all agree that it would be difficult, if not impossible, to be grateful for ALS. This disease takes the people we love far too soon, and it does it cruelly; a relentless thief. However, in our shared fight against ALS, I can be grateful. Grateful for the dedication, strength, and love of the people in this community.

To paraphrase Jerry Rogers, one of our beloved PALS, we are “part of a community bound together by purpose in spite of the cards we’ve been dealt.” We share a commitment to serving, advocating for, and empowering people and families affected by ALS. And I am deeply

grateful to those that stand together to lead this charge.

We truly have an incredible staff, and I am honored to serve with a devoted group of board members. We have community partners willing to plunge into the inaugural CEO Soak™. We have energetic Walkers that worked to raise over \$500,000 for our 25th Anniversary Walk to Defeat ALS®. We have dedicated delegates that use their voices and stories to advocate for access to speech-generating devices and funding for ALS research. We have motivated community event hosts that push toward our shared vision of a world without ALS via their own

creative fundraisers. And, of course, we have our runners, skiers, and Erie and Johnstown walkers that come through year after year.

Passionate people are a staple in our community, so I can’t help but say thank you. Thank you, to Jerry, Blase, Joyce, and all of our PALS for the inspiration that you continually provide. Thank you, to our caregivers and families, for the compassion and selflessness that you epitomize. Thank you, to all of our partners, for your dedication to our critical mission. Thank you, each and every person in this community, for contributing to the love that binds us. I am grateful.

A Letter from the Executive Director Merritt Spier

I’m sure you have heard the term “great minds think alike.” Well, I have proof that they often do.

At the ALS Association Western PA Chapter, we have a wide range of compassionate, dedicated, mission driven minds – all of which are, in my opinion, great. And it’s not just those working at the Chapter, it’s those who sit on our board and advisory board, the army of volunteers who help us as well as the donors who support us.

What makes these great minds think alike? The passion to live in a world without ALS and the drive to put those living with ALS and their families FIRST. No important decisions are made without asking “is this going to be the

best decision for those living with ALS?” Despite many good ideas, suggestions and intentions, if the answer is no, we do not move forward. When we think alike, and all agree that the idea is best for those living with ALS, then we step into action and make it happen.

It’s powerful when great minds think alike and have a passion to serve to others. I believe it is what makes our Chapter so successful. And it is what drives us to do the most good for as many people as we can.

Please know that it is our great honor and privilege to do what we do for those who need it and want it. And be sure that there are some great minds thinking alike to make it all happen.



BOARD MEMBERS



Christi Kolarcik, PhD
Board President
ALS Connection:
ALS Researcher



Chris Bluemle
Vice President
ALS Connection:
Mother, Karen Bluemle



Keith Pisarcik, Esq.
Secretary
ALS Connection:
Mother-in-Law,
Angie Kazmeraski &
Grandfather, Richard
Pisarcik



Erin M. Fanok, CPA
Treasurer
ALS Connection:
Personal Interest



Paul Rockar, PT, DPT, MS
Fifth Voting Officer
ALS Connection:
Friend/Co-worker,
Richard Bowling



Susan Garland George
ALS Connection:
Husband, Fred George



John Meyer
ALS Connection:
Phi Delta Theta Brother:
Lou Gehrig's Fraternity



Daniel Potetz
ALS Connection:
Personal Interest



David Mongillo, Esq.
ALS Connection:
Father, David Mongillo



**Rebecca L. Renshaw,
PhD, MSL, COMS**
ALS Connection:
Father, Ronald Renshaw



Scott Steinkirchner
ALS Connection:
Mother, Dozzy
Steinkirchner



Eric Zydel
ALS Connection:
Wife, Mary Lou Zydel

Advisory Board

Nadav Baum
Mike Daniels

Rita Patchan Hirschfield
Grant B. Mason, Esq.

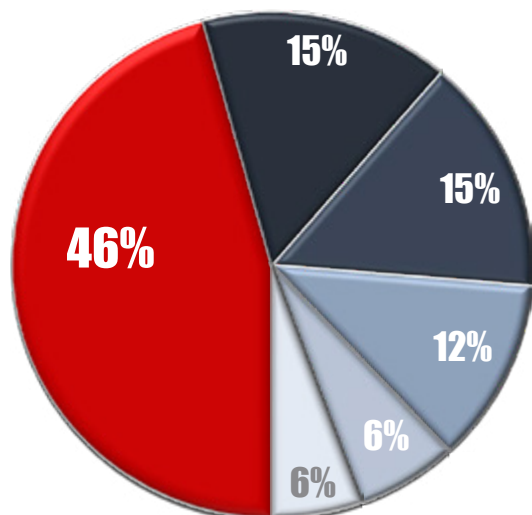
Norma Smith

We are proud to have 100% financial support from our board.

FINANCIALS FISCAL YEAR 2016/17

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, special events, and state funding. A complete list of donors 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.

Revenue

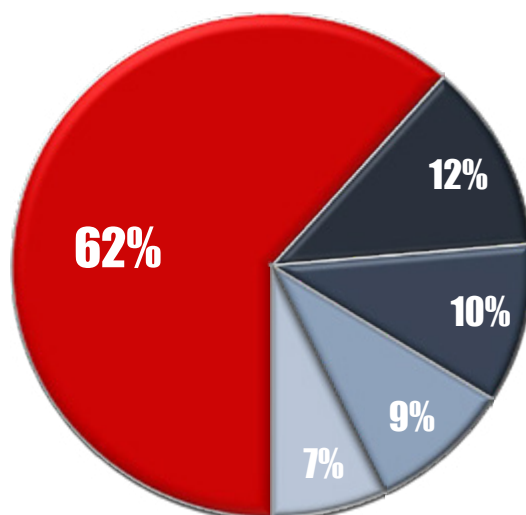


\$1,345,000

- Individual Gifts: Events, Honor/Memorial, United Way, Employee Giving (\$615,000)
- Government/State Grants via DOH (\$209,000)
- Corporate Giving (\$202,400)
- Planned Giving/Bequests (\$158,000)
- Foundation Support (\$85,000)
- Third Party Fundraising (\$75,600)

**Surplus of \$65,000 in revenue was used to enhance 2017/18 patient care programs.*

Expenses



\$1,280,000

- Patient & Community Services (\$787,000)
- Research & Advocacy (\$155,500)
- Fundraising & Development (\$131,000)
- Education & Support (\$115,000)
- Administration/General Operations (\$91,500)

Program Highlight: Home Visits



ALS is a journey no family should have to navigate alone. From care managers to occupational therapists, social workers to speech-language pathologists – The ALS Association's Care Services team is here to provide emotional support and guidance through coping with the diagnosis of ALS.

Our free, in home visits for people living with ALS allows for personal, one-on-one time with healthcare professionals. We can assist with applications and paperwork, help navigate the insurance system, find the best medical equipment for your current and future needs, and provide instruction for you and your caregiver. Home visits truly allow us to evaluate a person in their own environment and suggest the best course of action for the best care possible.

CARE SERVICES

IN ONE YEAR: **\$1,057,000**

spent on programs and services for people living with ALS and their caregivers.



118

New patients assisted

361

FAMILIES SERVED



237

Patients seen through multidisciplinary clinics



\$57,000

Given to support multidisciplinary clinics

LOAN CLOSET

123



Speech devices and computer access

95



Power wheelchairs and mobility equipment

203



Aids for daily living



42

Home modifications/ environmental controls



359

Home visits
*typically 1.5 hrs spent at each visit



4,662

Hours of respite care

“The ALS Association provided me with a ramp and a power wheelchair at no cost. I can’t describe how much joy it brings me to leave the house and go on a walk with my grandkids. In those moments, I have my independence back.”

-Ed G.

ADVOCACY



Advocacy Breaks Down Barriers

A group of ALS advocates storming the halls of the capitol, state or national, is a powerful sight. Each May, over 600 ALS advocates from all over the country converge on Capitol Hill to lobby for policies benefiting the ALS community. Each person, armed with their own personal story, comes ready to persuade our representatives to help people living with ALS.

In May of 2017, 13 advocates from the Western PA Chapter made the trip to DC to support four legislative priorities: waiving the five-month waiting period for Social Security for people living with ALS, providing continued access to complex rehabilitation technologies, passing the Steve Gleason Enduring Voices Act of 2017, and obtaining funding for the ALS Registry and Congressionally Directed Medical Research Programs (CDMRP). Our advocates bravely shared their emotional journeys and were successful in impacting each of these priorities.

Later that month, the Western PA Chapter advocates joined forces with the Greater Philadelphia Chapter to make a difference in Harrisburg. Advocates worked diligently to sustain \$500,000 in state funding for ALS patient care. State funding has allowed our chapters to provide increased respite care grants, assistive technology, and home modifications. These free services improve the quality of life for Pennsylvanians living with ALS and their caregivers.

Advocating for policies in favor of those living with ALS is one of The ALS Association's core mission priorities. To join us in Washington, D.C. or Harrisburg next year, please contact our office.



FDA FAST TRACKS RADICAVA TO TREAT ALS

For the first time in 22 years, the ALS community has seen a new drug. Radicava™ (edaravone), a treatment option for ALS, has shown to slow decline of physical function by 33% in Japanese trials. In a groundbreaking move by the FDA, Radicava was approved and fasttracked for the treatment of ALS in the United States.



In August of 2017, Western PA's own, Rene Fogarty, was the first ALS patient in the U.S. to receive an intravenous Radicava infusion. Dr. Sandeep Rana's team at the Allegheny Health Network ALS Certified Center of Excellence facilitated this first step.

Those interested in Radicava should discuss the treatment with their doctor. Mitsubishi Tanabe Pharma America, Inc. (makers of Radicava) have established "Searchlight Support" to assist patients in navigating insurance coverage.

The ALS Association Remains on the Cutting Edge of Global Research

The ALS Ice Bucket Challenge and the infusion of funds it generated has significantly impacted ALS research globally. Since 2014, The ALS Association has invested more than \$89 million in the most promising research projects. We proudly fund diverse, cutting-edge research through our competitive TREAT ALS™ global research program in laboratories around the world. In 2017, The ALS Association was the largest ALS research funder outside of the U.S. federal government in any single year.

With your help, The ALS Association funded more than 180 critical projects in eleven countries in the last year alone, in addition to nine global collaborative initiatives. Through collaborations with government, industry, academia, and other nonprofit organizations, The ALS Association aims to accelerate drug development so that people living with ALS receive treatments faster.



Mitsubishi Tanabe Pharma
America

Inspired by patients.
Grounded in science.



CEO SOAK: EXECUTIVES RAISE \$56,800

On Thursday, August 3rd, two dozen executives descended on PPG Place Plaza to get soaked by the fountains and raise money for the Chapter's patient care programs. The brainchild of Chapter advisory board member Mike Daniels, the inaugural CEO Soak was emceed by Pirates broadcast announcer Steve Blass and showcased the Pittsburgh business community's philanthropic spirit.

As Pirate's President Frank Coonelly, Senator Jay Costa, and Oxford Development's CEO Steve Guy stood side-by-side, the countdown began and the fountains turned on full-blast, drenching the good-natured line up. The noteworthy cast of characters and a packed house of employee spectators made this the most talked about charitable event in the city. We are excited to recruit even more executives for round two next summer!

26th Annual Jay Simon Golf Classic Supports Equipment Fund

The Norma Simon Fund provides equipment that is not covered by insurance to people living with ALS. The Annual Jay Simon Golf Classic has raised over \$269,000 for the fund in memory of Jay's mother, who lost her battle with ALS in 2000.

Save the Date: May 18, 2018! To receive an invitation contact Jay at (888)774-0990 or jsimon@hefren.com.



Golf FORE ALS

The 8th Annual Golf FORE ALS tournament was held on Sunday, June 4th at Olde Stonewall Golf Club in Ellwood City, PA. The tournament 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. The 2017 Golf FORE ALS event raised over \$20,000 with 100 golfers participating.

Chris and Joe are excited to continue to grow the Golf FORE ALS event in 2018. Registration and information for next year's outing will be available in early spring 2018. Thank you to all who attended in support of the Bluemle and Susan families and the Chapter's patient care programs!



Q & A WITH MIKE DANIELS

Q: How did you get involved with the ALSA WPA Chapter?

A: I was introduced to members of the board of directors at the Anne Lewis Advocacy & Humanitarian Award. After expressing interest, I took a position on the Chapter's advisory board.

Q: What do you do for a living?

A: I worked for Oxford Development Company for 37 years. Oxford is a very philanthropic company and I was raised in that culture. Since stepping back from my position as Senior Vice President of Oxford Realty Services on January 1st, I'm happy to remain affiliated with Oxford and their charitable vision in the community.

Q: What is your personal connection with ALS?

A: My sister Lola lived with ALS from 2009-2011 in rural Wisconsin. I often visited her and realized that the services and support systems where she lived are more challenging than they are in a major city. This is all coupled with my experiences as a caregiver for my son Patrick, who lived with Duchenne's muscular dystrophy and passed away in 2009. My wife Margaret and I started a fund at the Pittsburgh Foundation in Patrick's name and decided that one of the beneficiaries of that fund would be The ALS Association

Western PA Chapter, to honor my sister and support programs for individuals living with ALS and their caregivers.

Q: Where did your idea for the CEO Soak come from?

A: I was sitting in PPG Plaza one hot afternoon watching the fountains and saw a few businessmen in suits. I thought, "Wow, wouldn't they love to run through the fountain today like a kid?" This is when it hit me that this might be a good fundraiser. It was a "grown up" Ice Bucket Challenge.

Q: The inaugural CEO Soak was an immense success. What was your favorite part of Soak day?

A: After the event, everyone that participated was in a great mood and excited that they were involved. They all pledged to come back next year and increase their support.

Q: What are you most passionate about in your work with ALS?

A: I think a lot about research and a cure, but I'm really cognizant of the fact that most people living with ALS do not have the ability to meet the needs that they have day-to-day. I want to build upon the CEO Soak in the future and double or triple the amount raised to ensure that this event helps the Chapter meet these everyday needs and expand services for people living with ALS.

Planned Giving

In an era of instant-access online giving, it's easy to forget the importance of planning for your philanthropic future. By dedicating a planned gift to the Chapter, you can leave a lasting legacy of ALS patient care, research, and advocacy. While Mike & Margaret Daniels chose to support the Chapter through a charitable trust at the Pittsburgh Foundation, other planned giving options include gifts of stocks or bonds, wills and living trusts, charitable gift annuities, or beneficiary designations in your IRA or life insurance policies. Contact Julia Marsili at 412-821-3254 or julia@cure4als.org to discuss which opportunities might be right for you.



Daniel Finnegan chose to create a memorial fund for the Western PA Chapter to honor his wife Dawn, who passed away from ALS in 2015. Pictured is Dan and a plaque that will be dedicated to Ambridge Area School District where Dawn taught elementary school.

FUNDRAISING



Pittsburgh Marathon

\$53,325 raised | 93 participants



Ski to Defeat ALS

\$29,000 raised | 87 skiers



Erie Highmark Walk for a Healthy Community

\$30,558 raised | 225 walkers



Community Fundraisers

\$75,600 raised | 30+ events

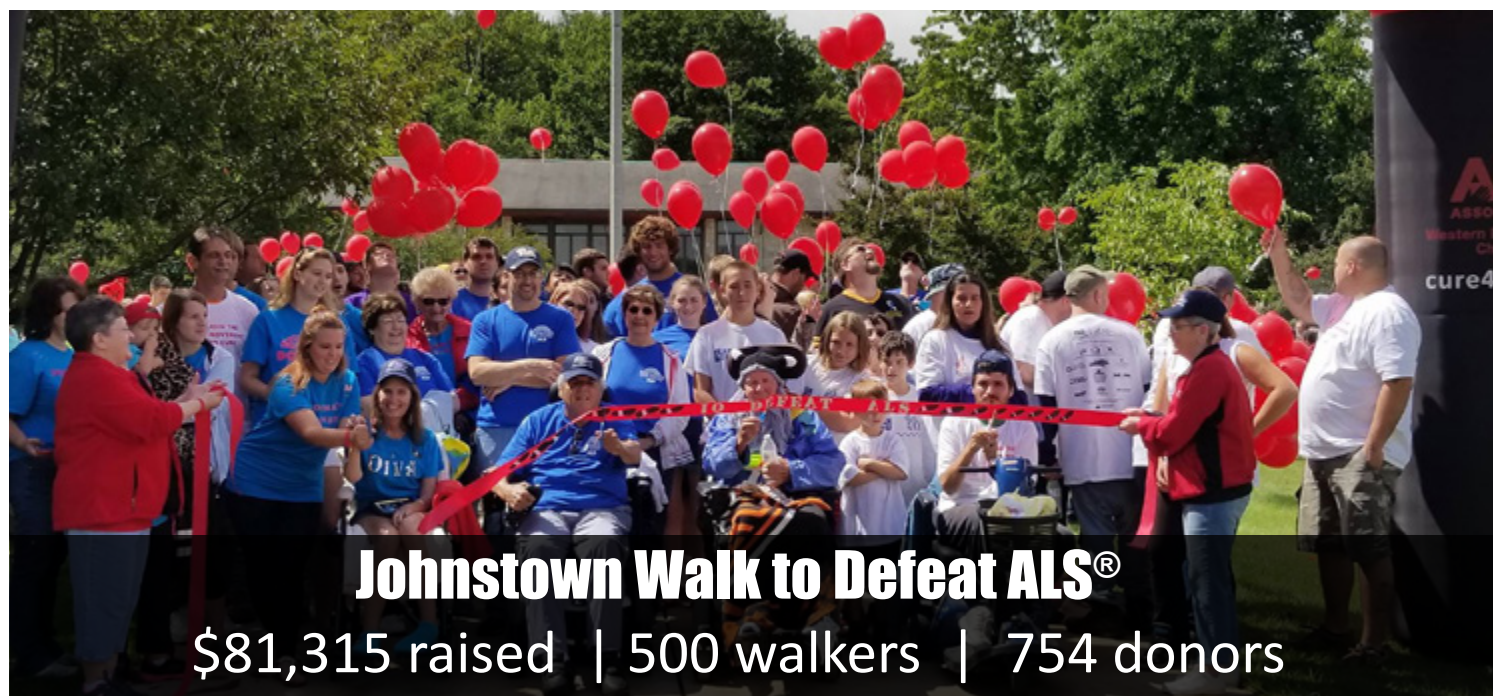


25th Anniversary Pittsburgh Walk to Defeat ALS®

\$505,840 raised | 2,600 walkers | 3,983 donors

TOP TEAMS

- | | |
|---|--------------------------------|
| 1 - Team Geniviva - The Iron City Horses (\$30,745) | 6 - ALS Kickers (\$12,931) |
| 2 - Camille's Crusaders (\$19,468) | 7 - Team YaYa (\$9,045) |
| 3 - Team Geroptimis (\$18,085) | 8 - Kelley Walk Team (\$8,820) |
| 4 - Carol's Crew (\$16,306) | 9 - David Calve (\$7,703) |
| 5 - Team Doerfler (\$13,754) | 10 - Captain's Crew (\$7,551) |



Johnstown Walk to Defeat ALS®

\$81,315 raised | 500 walkers | 754 donors

TOP TEAMS

- | | |
|--------------------------------|-----------------------------------|
| 1 - For Pete's Sake (\$7,385) | 6 - MAMA MAYAK (\$4,265) |
| 2 - Dozy's Daffodils (\$7,020) | 7 - A Mile for Max (\$3,550) |
| 3 - Pap's PALS (\$5,240) | 8 - The V Team (\$2,750) |
| 4 - Team Hoss (\$4,780) | 9 - Jack's Crew (\$2,672) |
| 5 - ALS Kickers (\$4,283) | 10 - Steve's ALStriders (\$2,525) |

FORGING PARTNERSHIPS

A Note from Michael Mascaro, Executive Vice President, Mascaro Construction

For the past 25 years, the ALS Association of Western Pennsylvania has been hosting a walk to raise awareness and bring the community together to fight this debilitating disease. This year's 25th Anniversary Walk to Defeat ALS® far exceeded expectations.

The walk was especially humbling for our family. It has been 24 years since my grandmother, Jean Mascaro, lost her battle with ALS. I remember it like it was yesterday. I was away at college when I received the call from my father. Although deeply saddened by her passing, we knew that she was in a better place.

What I most reflect on is the 19 years I was blessed to spend with my grandmother, not her two-plus-year battle with ALS. I find comfort in knowing happy and loving memories far outweigh the tragic cycle that follows diagnosis.

Although it is not always easy to understand, I believe everything happens for a reason. I believe my grandmother's passing was a sign for us to make a difference. A signal to ask – what can I do to make things better? What can we do, as a community, to help those in need? I believe that the Pittsburgh community bands together in moments of need more than any other area in the country.

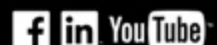
On Saturday, August 26, Pittsburgh proved that belief true as Point State Park blossomed with support. A crowd of 2,600 stood in solidarity with the common goal of fighting ALS. A record breaking fundraiser, a record-breaking crowd, and a beautiful, sunny day made for an amazing walk. From Janelle Hall's opening remarks to Dr. Kolarcik's passionate speech, each speaker spoke words of compassion and sincerity – and the crowd nodded in acceptance as if to say, "We are behind you."

What made this day even more special was I could share it with my oldest daughter. Although she didn't have an opportunity to spend time with her great-grandmother, this day gave her an opportunity to be a part of something bigger - a community who passionately fights for what is right and supports those who can't.

It is important to remember that as successful as the walk was, our fight does not stop here. We must continue to do the right thing as a community and remember the good we can do as a team. A long time ago, I heard something powerful that has never escaped me, "There are three things on a tombstone – a date, a dash, and a date. What people will always remember, and what defines us, is what we do during the dash."



Mascaro was honored to participate as the presenting sponsor for the record-breaking 25th Anniversary Walk to Defeat ALS.



www.mascaroconstruction.com

LOOKING FORWARD TO 2018

Johnstown Kick-Off Party
(Casino Night)
April 28, 2018
Stoystown American Legion

**Dick's Sporting Goods Pittsburgh
Marathon and Expo**
May 4-6, 2018

National Advocacy Meetings
April/May 2018 (TBA)
Washington, DC

Local Advocacy Day
April/May 2018 (TBA)
Harrisburg, PA

**Erie Highmark Walk for a
Healthy Community**
June 2, 2018
Presque Isle State Park - Erie, PA

Golf FORE ALS
June 3, 2018
Olde Stonewall Golf Course

Johnstown Walk to Defeat ALS®
July 28, 2018
University of Pittsburgh,
Johnstown Campus

Pittsburgh Walk to Defeat ALS®
August 25, 2018
Point State Park

Thank you Sponsors



Thank you Committee Members

Johnstown Walk to Defeat ALS®

Tricia Barron	Alexis Freoni	Shirley Mayak
Bobbi Benson	Jan Goodard	Carla Portash
Jeannette Brush	Debbie Larkin	Tim Spangler
Terri Englehart	Max Lawn	Sharon Squillario
Frannie Findley	Jeanine Lawn	Scott Steinkirchner

Pittsburgh Walk to Defeat ALS®

Peggy Borland	Keith Pisarcik
Jenni Franz	Colleen Schaefer
Mary Johnson	Amy Shaughnessy
Christi Kolarcik	Ally Warden

STAFF



Merritt Spier
Executive Director



Marie Folino
Director of Care Services



Julia Marsili
Director of Development



Kristi Marsili
Director of Marketing
and Fundraising Events



Amie Hackimer
Events Associate



Sandra Thompson
Care Services Associate



Catherine Frait
Care Services Case Aid



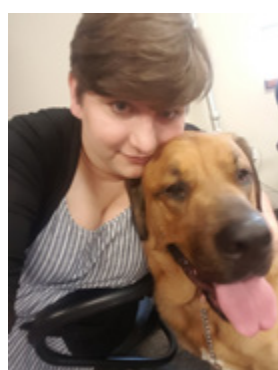
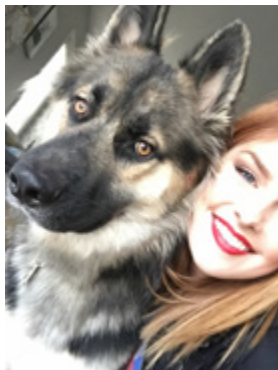
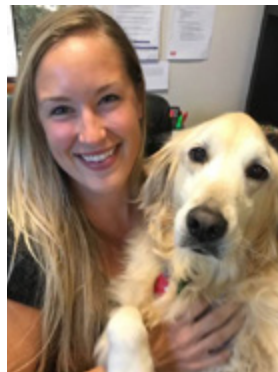
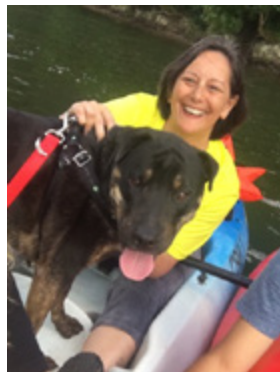
Kelsey Schooley
Development Associate

Contracted Workers

Meghan Chrobak, MSW
Leigh A. Ducoeur, MOT, OTR/L
Kaitlyn Graham, MS, CCC-SLP

Andrew Jinks MA, CCC-SLP
Mary Lattner-Lotz, PT
Amy Saraceno, MS, CCC-SLP

We are proud to have 100% financial support from our staff.



IN LOVING MEMORY

December 1, 2016 - October 29, 2017 (print date)

Tom Adamchik	Mae Gooden	Christine Rath
Colleen Allison	Sandra Hackett	Jerry Rogers
Alvin Altieri	Nancy Hall	Clinton Rudy
Dorothy Anna	Helena Hardy	Rose Sarp
Agnes Astemborski	Ronald Henderson	Howard Sarver
Linda Beatty	Deanna Hobba	Michaelyn Saxon
Bonnie Black	Lorraine Kollek	John Sepkovic
Raj Boehm	Barry Lavery	Greg Shank
Margaret Bruner	Jean Leonard	Maurice Singleton
Dennis Burke	Diane Mackrell	Laurie Slattery- Ferut
Barbara Chadbolt	Nancy Mansfield	Joe Staszak
Andrew Chough	Bernard Marcucci	Richard Streckeisen
Anna Clark	Mary Ann McKenna	Charles Tavel
Debbie Dainty	Joyce McNeal	Chuck Taylor
Robert Dax	Peter Mendicino	Julie Tencate
Linda Delbusso	Anne Meritzer	Gwendolyn Thomas
Tiffany Dobbin	Lanisha Mims	Gary Torretti
Jill Docherty	Leonard Mostowy	Joseph Triggs
John Engels	Gerard Neff	Blase Urban
Jennifer Entwistle	Charles Neverly	Ann Vannuki
Sandra Erdely	Richard O'Donnell	Peter Velissaris
David Finamore	John Ogurchak	Barb Verlich
Joanne Foryan	Shirley Osborne	Patricia Visokey
Ruth Fritch	Dilipkumar Patel	Dorothy Walker
Kenneth Gabert	John Pazur	John Woomer
Cindy Gaster	Mary Pino	
Myrtle Geeter	Franklin Piper	



**Western Pennsylvania
Chapter**

416 Lincoln Ave
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www.cure4als.org



"The Association gave us hope and comfort in a way that no else did. My Dad often said how hard you all worked and how much he loved how the organization **made us feel like part of a community bound together by purpose** in spite of the cards we've been dealt. We will never be able to thank you for everything you've done for us."

- Morgan Sava, in memory of Jerry Rogers