MISSION: 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.
cure4als.org
A LETTER FROM THE PRESIDENT: Christi Kolarcik, PhD

The beautiful change of seasons remind us of the inevitable change that life brings, and The ALS Association has certainly experienced its share of change this past year. At the National level, we welcomed Calaneet Balas as CEO last December. Calaneet has worked hard in her new role, implementing the positive changes necessary to achieve our strategic goals and re-focusing us on our critical mission.

In Western PA, we bid a very fond “happy retirement” to Merritt Spier. Merritt served as our Executive Director for six years, leading the Chapter to substantial and sustained growth.

In September, Ryan Reczek joined the Chapter as our new Executive Director. Intelligent, energetic, compassionate, and hard-working, Ryan brings with him significant experience and dedication. In addition, we welcomed April Smith to our Care Services team.

The changes did not stop with our staff. One of our devoted Board Members, Rebecca Renshaw, embarked on a new professional journey that moved her out of the area. Two committed partners, Michael Daniels and John Letizia, joined our Board of Directors, bringing their professional experience and passion for helping those living with ALS.

We are grateful for and proud of how our Chapter has grown as a direct result of the people involved; their dedicated service and commitment has become a staple of our ALS family. Although the saying “the only constant in life is change” may be true, I know of at least one exception. The love for and dedication to our community and to our mission – to serve, advocate for, and empower people living with ALS – will never waver. We will be here as the seasons changes and as the daily challenges you face change. We will continue to serve our ALS family until the outcome that we all work, hope, and pray for becomes reality: a world without ALS.

A LETTER FROM THE EXECUTIVE DIRECTOR: Ryan Reczek

I want to start this letter by saying what an honor and privilege it is for me to join The ALS Association Western Pennsylvania Chapter. I officially started as the Executive Director at the end of September. However, in August I had the opportunity to participate in the Pittsburgh Walk to Defeat ALS® along with more than 2,400 other supporters. It was obvious from the moment I arrived at the Walk that I had made the right choice to join the organization. I was not just taking a new job, I was now part of a community and family.

I want to take this opportunity to thank my predecessor, Merritt Spier. During Merritt’s tenure she played an instrumental role in growing the Chapter and its ability to reach thousands of families impacted by ALS. Merritt leaves a foundation of success upon which the staff team and I hope to build upon for many years to come.

Finally, I want to share a few incredible Chapter accomplishments. It has been a remarkable year all around. The Chapter reached 97% of people in western Pennsylvania living with ALS - one of the highest percentages in the country. Additionally, we had a record breaking year for walks and were able to secure more funding for those living with ALS through advocacy. Overall, the state of the Chapter is excellent, and I am excited to be joining you all in this journey.
The ALS Association Western PA Chapter does not bill insurance companies or charge any fees for services. All Chapter programs and services are made possible through the generosity of individual giving, foundation grants, corporate sponsorships, special events, and state funding. For a copy of the Chapter’s Form 990 and most recent audit, please contact the office.

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

**REVENUE**

- Individual Gifts: Events, Honor/Memorial, United Way, Employee Giving ($697,159) (56%)
- Government/State Grants via DOH ($244,329) (20%)
- Corporate Giving ($164,981) (13%)
- Planned Giving/Bequests ($10,282) (7%)
- Foundation Support ($39,950) (.05%)
- Third Party Fundraising ($88,947) (1%)
- Miscellaneous ($4,006) (3%)

**EXPENSES**

- Patient & Community Services ($855,488) (64%)
- Research & Advocacy ($137,174) (10%)
- Fundraising & Support ($142,533) (11%)
- Education & Support ($108,583) (8%)
- Admin/General Operations ($86,870) (7%)

**BOARD OF DIRECTORS**

- Christi Kolarick, Ph.D.
  Board President
  ALS Connection: ALS Researcher
- Christopher J. 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
- David Mongillo, Esq.
  Fifth Voting Officer
  ALS Connection: Father, David Mongillo
- Michael Daniels
  ALS Connection: Sister, Lola (Daniels)
  La Count
- 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
- John J. Letizia, ATP
  ALS Connection: President - Laurel Medical Solutions
- Scott Steinkirchner
  ALS Connection: Mother, Dorothy Steinkirchner
- Eric Zydel
  ALS Connection: Wife, Mary Lou Zydel

**ADVISORY BOARD**

- Nadav Baum
- Rita Patchan Hirschfield
- Grant B. Mason, Esq.
- Paul Rockar, PT, DPT, MS
- Norma Smith
People with ALS come first in everything we do. The ALS Association is dedicated to providing people with ALS, their families, and friends with the critical information, support, and resources necessary to live a full life and better meet daily challenges. In 2017, The ALS Association Western PA Chapter was able to provide the following services.

$1,101,245 total spent on programs and services for people living with ALS and their caregivers

106 new patients served this year

339 total families served

150 patients seen through multidisciplinary ALS clinics

452 pieces of equipment given from our loan closet

$48,126 total given to support multidisciplinary ALS clinics

113 speech devices/computer access

432 power wheelchairs and mobility equipment supplied

223 aids for daily living/environmental controls provided

5,826 hours of respite care granted

43 home modifications completed

159 wheelchair accessible transportation trips provided
The dedication and selfless efforts that ALS caregivers make 24 hours a day – 365 days a year – are essential to the care of a person with ALS. The ALS Association Western PA Chapter recognizes the importance of this support system. The Chapter provides caregivers with the tools they need to better care for themselves, while empowering them to be better caregivers to their loved one. The ALS Association offers the following programs to support caregivers:

**Respite/Home Care Grant Program:** Professional in-home care is just as important to the caregiver as it is the person with ALS. This program provides short term funding for respite care workers to be brought into the home of a person living with ALS. In home care allows a caregiver to step out of the house feeling confident that their loved one is being attended to properly. With the addition of professional help, the caregiver can take time for themselves to catch up on other tasks, recharge, and regroup.

**Caregiver Support Groups:** The ALS Association offers a monthly caregiver support meeting, where caregivers can come together to learn, ask, share, and grow with other ALS caregivers that understand their situation and emotions.

**Powerful Tools for Caregivers Class:** A few times each year, the Chapter offers a self-care education program for family caregivers. Through this six-week class, caregivers cover topics like stress management, effective communication, self-care, guilt/anger/depression management, and problem solving. At the conclusion of the class, participants leave with their own copy of “The Caregiver Helpbook”, confidence, and a network of support.

**Care Connection:** Often when friends and family learn about someone’s ALS diagnosis, they want to help. The ALS Association can assist in organizing this network of volunteers through the Care Connection Program. This program guides caregivers through the most effective approaches to organizing help and training volunteers. The Care Connection uses a website – lotsahelpinghands.com – that allows volunteers to sign in and see the community calendar where tasks have been posted.

**Caregiver Appreciation Weekend:** Each November, The ALS Association Western PA Chapter hosts a Caregiver Appreciation Weekend which provides caregivers with a relaxing break to replenish their minds and bodies. This get-away weekend is a great opportunity to meet other caregivers and informally support one another. While the caregiver is at the retreat, The ALS Association provides respite care for the loved one at home.

**PROGRAM HIGHLIGHT:**
**Respite/Home Care Grants and Support for Caregivers**

Special thank you to Interim Healthcare for sponsoring Caregiver Appreciation Weekend.
Stephen and Misha Comninos are an example of a couple truly LIVING with ALS. With the help of a loving family and an understanding employer, Stephen and Misha maintain their quality of life through the use of Technology.

Technology like smart home hubs and Bluetooth enabled devices are often used to play music or order groceries in your average household. In the Comninos home, this tech is not a luxury, but a necessity.

Thanks to smart home technology, Misha can work full-time while Stephen is safe, comfortable, and independent in their home. Using his speech generating device and smart home technology, Stephen can turn on the lights, change the TV channel, and even see who is at the door. From her smart phone, Misha is able to check in on Stephen using a camera system, affording her peace of mind at any point in the day.

Stephen and Misha also have their independence back during meal time using the Obi Feeding Device. Stephen activates his Obi with a simple switch to select a feeding dish and deliver the food right to his mouth. While Stephen eats at his own pace, Misha has the opportunity to enjoy her own meal as well.

These pieces of technology are all loaned to the Comninos family from The ALS Association Western PA Chapter’s loan closet. In partnership with medical equipment suppliers and facilities, the Chapter provides equipment free of charge for those living with ALS. The loan closet offers a wide range of items from adaptive equipment to help with daily care to power wheelchairs, speech generating devices, and smart home systems.

Your support helps to ensure that equipment and technology are available for families like Stephen and Misha. Your gift helps those living with ALS stay in their homes and continue to do the little things that are often taken for granted. Please make a gift today to help families continue to truly LIVE with ALS.
**Smart Home Technology**

The ALS Association Western PA Chapter can assist families in making their home a “Smart Home”.

**Smart Plugs/Smart Lightbulbs**
Allows Stephen to control the lights and any devices plugged into a smart plug. TV controls are also accessible including volume, changing the channel, on/off.

**Smoke/Carbon Monoxide Detector**
Alerts both Stephen and Misha via an app if there is an issue.

**Smart Thermostat**
Allows Stephen to independently adjust the temperature from an app.

**Front Door Opener**
Allows Stephen to independently open the door for his guests and aids.

**Front Door Lock**
Allows Stephen to lock/unlock the door through an app.

**Smart Home Hub**
Is the conduit between Stephen’s speech device and the smart home tech.

**Indoor Cameras**
Allows Misha to have eyes on Stephen at all times.

**Motorized Curtains/Blinds**
Allows Stephen to raise or lower the blinds through an app, giving him more control of light and privacy.

**Front Door Video Camera Doorbell**
Sends an alert through an app to Stephen and Misha when someone comes to the door.

**Smart Plugs/Smart Lightbulbs**
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**Computer Access Controls**

The Smart Home Technology system is an incredible advancement for people living with ALS that can access and utilize a computer or speech device. If a person does not have full use of their hands or arms, The ALS Association Western PA Chapter can provide various tools through the equipment loan closet to find a solution.

**Trackball Mouse**
A variation of a traditional computer mouse that is easily controlled by minimal movement of a rotating ball.
Cost: $30.00 - $75.00

**Switches**
Can be placed nearly anywhere to utilize small movements to activate controls.
Cost: $50.00 - $100.00

**Voice Activation**
Uses vocal commands/voice recognition to control the computer.
Cost: $150.00 - $300.00

**Sip and Puff Switch**
Switch activated with either a “sip” or “puff” of the lips to move the cursor.
Cost: $400.00 - $500.00

**Head Mouse**
Hands free mouse alternative where cursor is moved through slight head movement.
Cost: $1,000.00

**Quha Zono Mouse**
Lightweight wireless device that can be worn in a variety of ways to move cursor.
Cost: $1,000.00

**Eye Gaze**
Sensor attached to a computer monitor to read eye movement. The cursor is moved through eyeblink or dwell.
Cost: $2,000.00 - $4,000.00
Pittsburgh Marathon  
$36,492 raised | 75 participants

Erie Highmark Walk for a Healthy Community  
$29,231 raised | 200 walkers

CEO Soak  
$50,904 raised  
21 Participating CEOs

Community Events  
$39,174 raised  
Golf FORE ALS  
$20,000 raised  
Jay Simon Golf Classic  
$16,000 raised
Johnstown Walk to Defeat ALS®
$101,477 raised | 595 walkers | 737 donors

1. Dozy’s Daffodils – $14,733
2. For Pete’s Sake – $7,975
3. Team Hoss – $5,575
4. MAMA MAYAK – $4,140
5. ALStriders for Clara – $3,510
6. Pap’s PALS – $3,406
7. Jack’s Crew – $3,150
8. Donna’s Divas – $3,115
9. A Mile for Max – $3,091
10. The V Team – $2,410

Pittsburgh Walk to Defeat ALS®
$509,579 raised | 2,400 walkers | 3,558 donors

1. Cindy’s Corner – $45,775
2. Team Geniviva – The Iron City Horses - $30,905
3. Team Doerfler – $22,282
5. David Calve – $11,348
6. Kelley Walk Team – $9,920
7. The Go-Getters for Bob Letters – $9,096
8. Carol’s Crew – $8,365
9. Team YaYa – $6,730
10. University of Pittsburgh Brain Institute – $6,230

Congratulations
Johnstown’s
FIRST $100,000 Walk!
Each spring, dedicated supporters advocate for ALS focused legislation and funding on national and local scales. Advocates, armed with their personal stories, come ready to persuade our representatives to become champions of the ALS community and help those living with this disease.

In late May 2018, advocates from the Western PA Chapter joined forces with the Greater Philadelphia Chapter to meet with Harrisburg lawmakers and ask for an increase in Pennsylvania state funding. The results were cause for celebration. Our hard-working advocates successfully secured an increase from $500,000 to $750,000 in the state budget, to be split between the two Chapters. This increase in funding will support the Chapter’s respite care grants, equipment loan programs, and funding for local ALS multidisciplinary clinics.

Earlier in the month, 17 Western PA Chapter advocates, including three individuals living with ALS, visited Washington, D.C. to advocate for federal research funding and ALS-focused policies. Advocates bravely told their stories and left everything on the table, urging their congressmen to support commonsense spending bills and legislation that will move us closer to finding new treatments and a cure, as well as bettering the lives of those living with ALS.

Advocating for those living with ALS is one of The ALS Association’s core mission priorities. To join the ALS advocates in Spring 2019 as they advocate in Washington, D.C. and Harrisburg, please contact the Chapter office.
Dr. Sandeep Rana, Medical Director of the ALS Certified Center of Excellence at Allegheny Health Network, has designed and produced a custom fit 3D printed BiPAP mask to improve breathing for ALS patients.

**Q: Can you tell us about yourself and your medical specialties?**

**A:** I am a fellowship-trained, board-certified neuromuscular specialist with a special interest in ALS. I also treat patients with myasthenia gravis, peripheral neuropathies, polymyositis and other neuromuscular disorders.

**Q: What is a BiPAP machine and why might a person living with ALS use one?**

**A:** BiPAP machines blow air into the lungs and are used when respiratory muscle weakness affects the ability to adequately draw air into the lungs. In advanced stages of ALS, we often use a BiPAP to improve oxygenation, particularly at night, which improves the quality of sleep.

**Q: Can you explain your inspiration behind the custom-fit 3D printed BiPAP mask?**

**A:** We found that many patients were not using their BiPAP because it is uncomfortable. This led us to work with the Carnegie Mellon University biomedical division to come up with a customized 3D printed mask that fits the unique facial contours of a patient, cutting down on air leakage and adding to overall comfort.

**Q: How did your design finally come to fruition?**

**A:** We received a grant from The ALS Association Western PA Chapter that allowed us to complete the first set of testing. We also received an additional grant from Highmark that will help move the mask toward FDA approval.

**Q: How does a patient get a mask? Is it covered by insurance?**

**A:** Until the mask is FDA approved, they will only be available through our clinic on a case-by-case basis. We are still perfecting the printing technique and it will be a couple of years before enough data is collected to get FDA approval. Our hope is that once the masks are FDA approved, the costs will be covered by insurance.

**Q: Can you give us some insight on the other project you are working on that will benefit ALS patients?**

**A:** Project Uplift is our newest endeavor where a licensed psychologist teaches mindfulness techniques to caregivers via teleconference. Our goal is to help caregivers withstand the stress of caring for someone living with ALS.
“Victory is always possible for the person who refuses to stop fighting.”

- Napoleon Hill

We will continue to fight to find a cure for ALS.
LOOKING FORWARD TO 2019

Johnstown Walk Kick-off Party (Casino Night)
Spring 2019
Stoystown American Legion

State Advocacy Day
Spring 2019
Harrisburg, PA

Pittsburgh Walk Kick-off Party
Spring 2019
Clark Bar and Grill/
Pittsburgh Pirates Game

ALS Kids 5K
April 28, 2019
North Park Boathouse

Dick’s Pittsburgh Marathon
May 5, 2019
Downtown Pittsburgh

28th Annual Jay Simon Golf Classic
May 17, 2019
More info: jsimon@hefren.com

Erie Highmark Walk for a Healthy Community
June 1, 2019
Presque Isle State Park

Golf FORE ALS
June 2, 2019
Olde Stonewall Golf Course

National Advocacy Conference
June 9 – June 11, 2019
Washington, DC

CEO Soak
June 20th, 2019
PPG Place Plaza

Johnstown Walk to Defeat ALS®
July 27, 2019
University of Pittsburgh,
Johnstown Campus

Pittsburgh Walk to Defeat ALS
September 14, 2019
Point State Park

RAISE FUNDS TO FIGHT ALS
Help create a world without ALS by getting involved in the way that best suits YOU!
When you fundraise with friends and family you take us closer to discovering a cure.

THANK YOU COMMITTEE MEMBERS

Johnstown Walk to Defeat ALS®
Tricia Barron
Bobbi Benson
Terri Englehart
Frannie Findley
Alexis Freoni
Jan Goodard
Debbie Larkin
Max Lawn
Jeanine Lawn
Jase Lawn
Shirley Mayak
Carla Portash
Jenny Portash
Jeremy Portash
Tim Spangler
Sharon Squillario
Scott Steinkirchner

Pittsburgh Walk to Defeat ALS®
Theresa Adamchik
Marie Folino
Jenni Franz
Laura Gidas
Mary Johnson
Christi Kolarcik
Keith Pisarcik
Amanda Rudd
Morgan Sava
Colleen Schaefer
Sandi Svaranowic
Randa Triggs
Ally Warden
STAFF

Ryan Reczek
Executive Director

Marie Folino, MSW, LSW
Director of Care Services

Julia Marsili
Director of Development

Kristi Marsili
Director of Marketing and Fundraising Events

Meghan Chrobak, MSW
Social Worker

Amie Hackimer
Events Manager

Kelsey Schooley
Development Associate

April Smith
Care Services Associate

Sandra Thompson
Care Services Associate

CONTRACTED EMPLOYEES
Leigh A. Ducoeur, MOT, OTR/L
Kaitlyn Graham, MS, CCC-SLP
Kathy Hagerty, OTR/L
Andrew Jinks MA, CCC-S
Amy Saraceno, MS, CCC-SLP

WE ARE PROUD TO HAVE 100% FINANCIAL SUPPORT FROM OUR STAFF.
IN LOVING MEMORY

October 31, 2017 - October 31, 2018 (print date)

Vernon Adams
Joe Adams
Thomas Baker
Nicolina Baker
Lawrence Barcosky
Elizabeth Beaumont
David Bell
Donald Berezanich
Michael Bond
David Bowser
Thomas Braithwaite
Jay Briggs
Judith Castano
Daniel Chess
Donald Cimarolli
Joseph Cioc
Iva Clark
Marvin Compher
Linda Covert
Elmer Covert
Diana Custer
Elyssa D’Antonio
Gaynale Davis
Jane Deblasio
James Dougherty
Richard Falchetti
Diane Galamore
John Geniviva
Tom Gigliotti
Lori Gould
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Corey Haas
Gregory Haluschak
Michaelene Hawley
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Cassandra Weikert
Donna Weimer
Dana Weller
Brian White
Tom Wilson
Mary Wilson
Dorothy Wittman
Elizabeth Wright
Barbara Young
Peter Yurtin
Florence Zatkoff
Together we are
#TeamChallengeALS

Join the team.
cure4als.org