ALS Multidisciplinary Clinics give families like Brett and Jeannine direction in their ALS diagnosis. (page 5)
A LETTER FROM THE EXECUTIVE DIRECTOR: Ryan Reczek

This past year has been one of growth for The ALS Association Western Pennsylvania Chapter. In the spring we restructured our team, promoting Kristi Marsili to Director of Development. In this role, Kristi is still overseeing fundraising events, but has added management of all other fundraising activity to her duties. Kelsey Schooley was also promoted to a new role as the Director of Marketing and Advocacy. In her position, Kelsey is overseeing all communications, along with leading the Chapter’s public policy work. Additionally, Amie Hackimer was promoted to Development Manager and will continue to support events while expanding her duties as our corporate partner liaison. Furthering our growth, we welcomed Danielle Labruzzo as our Marketing and Advocacy Associate, Jena McEwen as our Development Associate, and Jim Gallagher as our Administrative Assistant.

We have seen great strides forward in the areas of research, advocacy, and care services this year. I invite you to read on and learn about ALS Association funded research, public policy wins in Harrisburg and Washington, DC, and new technology that is making life easier for people living with ALS. I also encourage you to read through our article highlighting ALS Association funded Multidisciplinary Clinics and how they help families like my friends, the Schoeneckers, navigate ALS.

Finally, I want to thank you for the warm welcome that I received as the new Executive Director over my first year. I look forward to serving our ALS community for many years to come.
The ALS Association Western Pennsylvania 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.

**REVENUE**

- Individual Gifts: Events, Honor/Memorial, United Way, Employee Giving ($832,902) - 29%
- Planned Giving/Bequests ($580,385) - 15%
- Government/State Grants via DOH ($211,167) - 10%
- Corporate Giving ($121,911) - 8%
- Third Party Fundraising ($110,322) - 7%
- Foundation Support ($98,000) - 6%
- Miscellaneous ($4,632) - 6%

**EXPENSES**

- Patient & Community Services ($916,496) - 43%
- Research & Advocacy ($239,545) - 11%
- Fundraising & Support ($149,484) - 6%
- Education & Public Awareness ($129,931) - 5%
- Admin/General Operations ($103,939) - 5%

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

**BOARD OF DIRECTORS**

- Christi Kolarcik, Ph.D.
  - President
  - ALS Connection: ALS Researcher

- Christopher Bluemle
  - Vice President
  - ALS Connection: Mother

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

- Erin Fanok, CPA
  - Treasurer
  - ALS Connection: Personal Interest

- David Mongillo, Esq.
  - Fifth Voting Officer
  - ALS Connection: Father

- Michael Daniels
  - ALS Connection: Sister

- Susan Garland George
  - ALS Connection: Husband

- John Letizia, ATP
  - ALS Connection: President - Laurel Medical Solutions

- John Meyer
  - ALS Connection: Phi Delta Theta Brother

- Daniel Potetz, CPA
  - ALS Connection: Personal Interest

- Amy Shaughnessy
  - ALS Connection: Mother-in-Law

- Chris Steinkirchner
  - ALS Connection: Mother

- Paul Rockar, PT, DPT, MS
  - ALS Connection: Friend/Co-worker

- Eric Zydel
  - ALS Connection: Wife

**ADVISORY BOARD**

- Nadav Baum
- Rita Patchan Hirschfield
- Grant B. Mason, Esq.
- Norma Smith
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.

LOOKING FORWARD TO 2020

Johnstown Walk Kick-off
Casino Night & Auction
Spring 2020

State Advocacy Day
Spring 2020
Harrisburg, PA

Pittsburgh Walk Kick-off
Spring 2020

Dick’s Pittsburgh Marathon
May 3, 2020
Downtown Pittsburgh

Erie Highmark Walk for a Healthy Community
May 30, 2020
Presque Isle State Park

National Advocacy Conference
May 31 – June 2, 2020
Washington, DC

CEO Soak
June 11, 2020
PPG Place Plaza

Johnstown Walk to Defeat ALS®
July 25, 2020
University of Pittsburgh, Johnstown Campus

Pittsburgh Walk to Defeat ALS®
September 12, 2020
Point State Park

PARTICIPATE

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
Jace Lawn
Jeanine Lawn
John Letizia
Shirley Mayak
Jack Michaels
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
Amber Letters
Keith Pisarcik
Amanda Rudd
Morgan Sava
Colleen Schaefer
Amy Shaughnessy
Sandi Svaranowic
Randa Triggs
Ally Warden
If you told me in early 2014 that people dumping icy water on their heads would change the course of ALS research, I wouldn’t have believed you.

However, later that year we experienced the game-changing, lighting-strike-type global phenomenon that was the ALS Ice Bucket Challenge (IBC). As a result of the IBC, $115 million was raised for The ALS Association in a matter of weeks. The decision was made that the majority of IBC funds would be directed to research. Five years later, we are unlocking the mysteries of ALS one research project at a time.

In 2015, The ALS Association increased research funding from $6 million to $19 million annually, committing over $89 million toward worldwide research collaborations over the last five years. Please visit The ALS Association Western Pennsylvania Chapter website (cure4als.org) and click on the IBC Progress button in the top left corner to find detailed information on research expenditures including clinical management, drug development, and assistive technology awards, as well as the projects and researchers that have been funded.

One of the most impactful results of IBC funds is the identification of new genetic causes of ALS. In 1993, the first genetic cause was identified. By 2011, five more genes had been identified. From 2014-2019, seven new genes have been discovered! These exciting developments provide novel insights into ALS as well as new models to study the disease.

Although the majority of ALS cases are not currently linked to a genetic abnormality, genetic cases help us categorize the “types” of ALS that exist. As treatments for each type of ALS are developed, we will chip away at the disease as a whole. I like to compare this to cancer because we treat each type of cancer differently, but understand the aspects common to all cancers. We believe we can do this for ALS, and studies using antisense technology to treat SOD1-linked ALS are the first step.

A second aspect of this portfolio is less tangible but still critically important. Funds from the IBC have and continue to encourage and support up-and-coming scientists working in ALS. This is most reflected in the Milton Safenowitz Postdoctoral Fellowship and the investigator-initiated Starter Awards. It cannot be understated how influential these grants can be, and I want to ensure you that your commitment to research is also a commitment to dedicated, intelligent scientists in the early stages of their careers.

I hope this glimpse into the research landscape brings you hope and an assurance that the urgent need for answers felt by the ALS community is not lost on researchers. As scientists, we want nothing more than to solve this puzzle for the people who we care about so deeply and who inspire us every day. Thank you for supporting our research efforts as our shared fight for a cure continues.
There is no map to navigate an ALS diagnosis. “When I was diagnosed, it felt like my wife and I were in a boat in the middle of the ocean and didn’t know which way to paddle,” said Brett Schoenecker, a person living with ALS. Shortly after Brett’s diagnosis he began working with an ALS Multidisciplinary Clinic and The ALS Association Western Pennsylvania Chapter. Brett continued, “the Clinic and The ALS Association became our compass, providing support and guidance. We’re no longer lost or alone.”

ALS Multidisciplinary Clinics bring together a team of healthcare professionals trained to address the needs of people living with ALS. In one clinic appointment a person will see a neurologist, respiratory therapist, and several other medical professionals. This collaborative approach drastically reduces the number of doctor visits for a patient and creates an integrated care plan to meet their unique needs.

The ALS Association provides funding to several ALS Multidisciplinary Clinics throughout western Pennsylvania and around the country. Most patients only pay to see a neurologist, which is typically covered by insurance. The Association’s support funds all other professionals who make up the clinic team, including a Chapter social worker.

“If we had to see each specialist at separate appointments, we would be spending thousands of dollars out of pocket. Attending the clinic not only saves us money but offers us more time to enjoy our lives together,” explained Jeannine Schoenecker, Brett’s wife.

The Chapter also offers support by covering the cost of wheelchair transportation, telemedicine, and follow-up home visits. At clinic and after, the Chapter guides the family through resources to implement clinic suggestions while filling gaps in their integrated care plan.

Collaborative care from ALS Multidisciplinary Clinics is proven to improve quality of life for people living with ALS and their families. Donations to The ALS Association Western Pennsylvania Chapter ensures necessary funding of these clinics and continued Chapter services to meet patient needs. Your support provides direction for families like the Schoeneckers, who may otherwise be lost on their ALS journey.

“Attending the clinic not only saves us money but offers us more time to enjoy our lives together.”
ALS Multidisciplinary Clinics provide people living with ALS access to multiple healthcare professionals in one visit. This collaborative approach provides patients with integrated care and guidance along their ALS journey. The ALS Association provides funding to support clinics in western Pennsylvania, drastically reducing out of pocket costs for an ALS family.

**NEUROLOGIST**
ALS expert and team leader that helps a patient navigate their ALS journey.

**DIETITIAN**
Helps a patient maintain proper nutrition and weight.

**NURSE**
Coordinates a patient's care plan and provides ongoing support.

**OCCUPATIONAL THERAPIST**
Recommends equipment to help a patient with independence and daily function.

**SPEECH LANGUAGE PATHOLOGIST**
Monitors a patient's swallowing and speech and helps overcome challenges.

**PHYSICAL THERAPIST**
Helps patients adjust to changes in physical mobility.

**ALS ASSOCIATION REPRESENTATIVE**
Social Worker that connects a patient with resources to fulfill clinic recommendations.

**RESPIRATORY THERAPIST**
Assesses a patient's breathing and educates on respiratory assistance.
FUNDRAISING

Pittsburgh Marathon
$35,000 raised | 53 participants

Erie Highmark Walk for a Healthy Community
$18,732 raised | 133 walkers

CEO Soak
$104,314 raised
36 Participating CEOs

Third Party Events
$110,322 raised
### Johnstown Walk to Defeat ALS®

**$120,556 raised | 622 walkers | 802 donors**

<table>
<thead>
<tr>
<th>TOP TEAMS</th>
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<tbody>
<tr>
<td>1. Dozy’s Daffodils – $15,470</td>
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<tr>
<td>2. For Pete’s Sake – $9,719</td>
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<tr>
<td>3. A Mile for Max – $6,225</td>
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<td>4. Team John – $5,587</td>
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<td>5. Team Hoss – $4,442</td>
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<td>6. MAMA MAYAK – $3,720</td>
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<td>7. ALStriders for Clara – $3,605</td>
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<td>8. Ronnie’s Rangers – $3,383</td>
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<td>9. Mike’s ALStars – $3,095</td>
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<td>10. Donna’s Divas – $2,827</td>
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### Pittsburgh Walk to Defeat ALS®

**$576,756 raised | 2,354 walkers | 4,425 donors**

**Numbers as of October 31, 2019**

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<td>5. Team Hoss – $4,442</td>
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<td>6. Scooter’s Bunch – $14,393</td>
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<td>7. Hugh’s Crew – $13,585</td>
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<td>8. Walk for Watters – $10,589</td>
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<tr>
<td>9. Miles for Melissa – $9,456</td>
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<td>10. Team YaYa – $8,365</td>
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Having seen the effects of ALS on my family for years, (taking my mother, my siblings, my cousin, two of my nieces, and my nephew) I officially became an ALS Advocate in 2007, the year my sister was diagnosed. Ten years later, I found out that I am the only person in my family who does not have a mutated gene associated with the familial form of ALS that affects 10% of cases. As a result, I no longer need to worry that I may have passed this cruel disease on to my daughters or grandsons. I do not take this fact lightly, and will continue to use my voice to advocate on behalf of loved ones I’ve lost until every breath leaves my body.

Becoming an ALS Advocate has taught me that I can make a difference. Together, we have secured more funding, and changed more laws than I ever imagined possible, and I truly believe this is a direct result of our diligent advocacy efforts! I get one day a year to visit D.C. to tell my story and make an emotional impact on our legislators. Our purpose is to connect our elected officials to the ALS community and help them understand why we need to do more. Taking care of a loved one who is dying from ALS is the hardest thing I will ever do. As an ALS Advocate, I feel that my loved ones have not suffered in vain, and that we are going to end this terrible disease and all the pain that comes with it for future families affected by ALS.

I won’t lie, advocating for a terminal illness is an emotional experience for everyone involved, but it is also a bonding experience unlike any other. I consider my fellow advocates and Chapter staff as an extension of my family. We laugh together, we cry together, and we are consistently reminded of the special connection that we share as advocates and members of the ALS community.

It’s important to remember that ALS can happen to anyone. Every 90 minutes someone is diagnosed while another loses their life to this devastating disease. The cure for ALS and other motor neuron diseases is on the horizon, but progress only comes when enough people are willing to advocate for change. We need you! Don’t wait, please visit cure4als.org to learn more about being an ALS Advocate.
It started with a bucket...

And ends with a cure.
People with ALS come first in everything we do. The ALS Association is dedicated to providing people with ALS and their loved ones with the critical information, support, and resources necessary to improve quality of life. In 2018, The ALS Association Western Pennsylvania Chapter provided the following services:

- **$1,285,972** total spent on programs and services for people living with ALS and their caregivers
- **115** new patients served this year
- **343** total families served
- **164** patients seen through multidisciplinary ALS clinics
- **481** pieces of equipment given from our loan closet
- **$50,230** total given to support multidisciplinary ALS clinics
- **102** speech devices/computer access equipment loaned
- **104** power wheelchairs and mobility equipment supplied
- **268** aids for daily living/environmental controls provided
- **5,110** hours of respite care granted
- **33** home modifications completed
- **125** wheelchair accessible transportation trips provided
Improving quality of life and increasing independence for those diagnosed with ALS is one of the primary goals of The ALS Association Western Pennsylvania Chapter.

Through programs like the Equipment Loan Closet, the Chapter provides durable medical equipment and assistive technologies to people living with ALS at no cost to the family. With the support of Mitsubishi Tanabe Pharma America, the Chapter recently created an ALS Tech Lab in the office conference room to showcase the technology available through the Loan Closet.

“We like to think of the Tech Lab as a Technology and Loan Closet Showroom,” said Chapter Executive Director, Ryan Reczek. “It is an interactive space where families can try out a variety of equipment and technologies that can assist people living with ALS.”

The ALS Tech Lab aims to open the eyes of ALS families to available technology and bring more assistive equipment into their homes. In the Tech Lab, individuals can test out 100+ pieces of technology and equipment. They can try everything from a smart home setup - including Alexa-controlled lighting, televisions, and outlets - to an Obi robotic feeding device or a simple thick handled spoon.

With the ALS Tech Lab, Chapter staff can now demonstrate how each component can work together in a real life setting to increase independence and improve a person’s quality of life. Patients and families can demo many types of assistive technology and decide what will work best for an individual now and in the future.

Marie Folino, Chapter Director of Care Services, explained, “No two people need or want the same technology and those needs change. The Tech Lab gives those who we serve an opportunity to test-drive equipment before incorporating it into their everyday life.”

The ALS Tech Lab provides a comfortable, hands-on environment for Chapter staff to share information about the Smart Home program, Equipment Loan Closet, and other Chapter Services. It is a one stop shop for durable medical equipment and assistive technology for people living with ALS in western Pennsylvania.

To schedule a time to visit the ALS Tech Lab, please call the Chapter office at 412-821-3254.

**ALS TECH LAB:**
Opening Eyes to Assistive Technology

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Special thank you to Mitsubishi Tanabe Pharma America for sponsoring the ALS Tech Lab.
IN LOVING MEMORY

Ryan Reczek
Executive Director

Marie Folino, MSW, LSW
Director of Care Services

Kristi Marsili
Director of Development

Kelsey Schooley
Director of Marketing and Advocacy

Meghan Chrobak, MSW
Social Worker

Amie Hackimer
Development Manager

Jena McEwen
Development Associate

Danielle LaBruzze
Marketing and Advocacy Associate

Sandra Thompson
Care Services Associate

April Smith
Care Services Associate

Jim Gallagher
Administrative Assistant

CONTRACTED EMPLOYEES

Leigh Ducoeur, MOT, OTR/L
Kate Graham, MS, CCC-SLP
Kathy Hagerty, OTR/L
Andrew Jinks, MA, CCC-S

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

October 31, 2018 - October 31, 2019 (print date)

Gerald Allen
David Allison
Adriann Arbeider
Al Arnal
Lyvonne Battle
Cynthia Behringer
Suelyn Bell
David Bell
Ruth Bender
Randel Bradshaw
Stanley Bradway
Gwendolyn Briggs
Sandra Brooks
Sandy Brown
Sharon Brown
Kathryn Cameron
Camille Cash
Kathy Cassella
Ronald Ciejrowski
Evelyn Chesnutt
James Churchill
John Conrad
Carl Daubenspeck
Richard Diener
Richard Doerfler
Douglas Dolby
Amy Doria
Diana Duttry
Rene Fogarty
Richard Fondrk
Patricia Foringer
Gary Foster
Jere Gallagher
Karen Gallagher
Andrew Gelesky
Wayne Gieraltowski
William Glenn
Donald Griffith
Patricia Guthrie
Roxanne Hensley
Susan Hess
Jovon Higgins
Kathryn Hilf
David Hostetler
Charles Hotaling
Debra Jonson
John Joyce
Ronald Kania
John Kapp
Joan Kavalir
Linda Ketterer
James Klapthor
James Knepper
Donald Lang
Stephen Laskey
Priscilla Lecker
Judith Leeper
Carol Lowry
Gregory Mace
John Marshall
Mary McDermott
Catherine McDonough
Cathy McElroy
Robert McWilliams
Wayne Miller
Diana Murray
Michael Muscatello
David Nolfi
Richard Ogurchock
Mark Panizzi
William Parkes
Teddy Parks
Alayne Payne
Annagrace Peluso
Royell Peterson
Brian Pfeiffer
Patricia Reardon
Thomas Recker
Lloyd Rohanna
Frank Romano
Timothy Rowan
Raymond Sauer
Dalia Scioscia
Thomas Scott
Jeff Secker
John Soffa
Irwin St. Clair
Connie Stemm
Mona Strong
Buddha Subba
Sylvia Tauber
Michael Testa
Ashok Vanjani
Linda Wade
Edmond Weckoski
Genevieve Wiesen
Donna Wiley
Barbara Womeldorf
Brian Woodward
Tim Zanot
Robert Ziegler

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