

Impact Report

February 1, 2020 - January 31, 2021

Honoring ALS Healthcare Heroes



WHATEVER IT TAKES

ALS Greater
Philadelphia
Chapter
ASSOCIATION

Message from our Executive Director



Dear Valued Contributors,

The COVID-19 pandemic has changed many things. Here is another.

This is the Annual Impact Report for the Chapter's Fiscal Year-end '21, which runs from February 1, 2020, to January 31, 2021. Indeed, the donor listings in the back of this publication reflect contributions received during that time period.

However, because so many of our events and activities in 2020 were held virtually, we have decided to include some articles and photos of events held this year. Thus, we are bending the rules just a bit and hope you understand.

After somewhat rocky months due to the pandemic, things at the Chapter have mostly returned to normal. Our nurses and social workers are once again visiting patients in their homes (observing COVID protocols, of course) and all our eight regional ALS Centers and Clinics are seeing patients in person based on their own institutional guidelines. Plus, after a suspension of more than a year, the Chapter is once again transporting patients in our two handicap accessible vehicles.

People who know that I work for the ALS Association sometimes ask me, "How is your organization making out during COVID? Has it impacted donations and fundraising?" My answer is always the same. "People who have been impacted by this disease can't not support us. Our cause is simply part of who they are." Evidence of that fills the back pages of this report.

Yes, the last two years have been challenging, but thanks to faithful and generous and caring people like you, we made it through, and the skies are brightening. You have sustained us. On behalf of our Board and staff, but most importantly the people with ALS and their families we are privileged to serve, THANK YOU!

As always, I would love to hear from you and invite you to contact me directly at 215-664-4127 or jeff@alsphiladelphia.org.

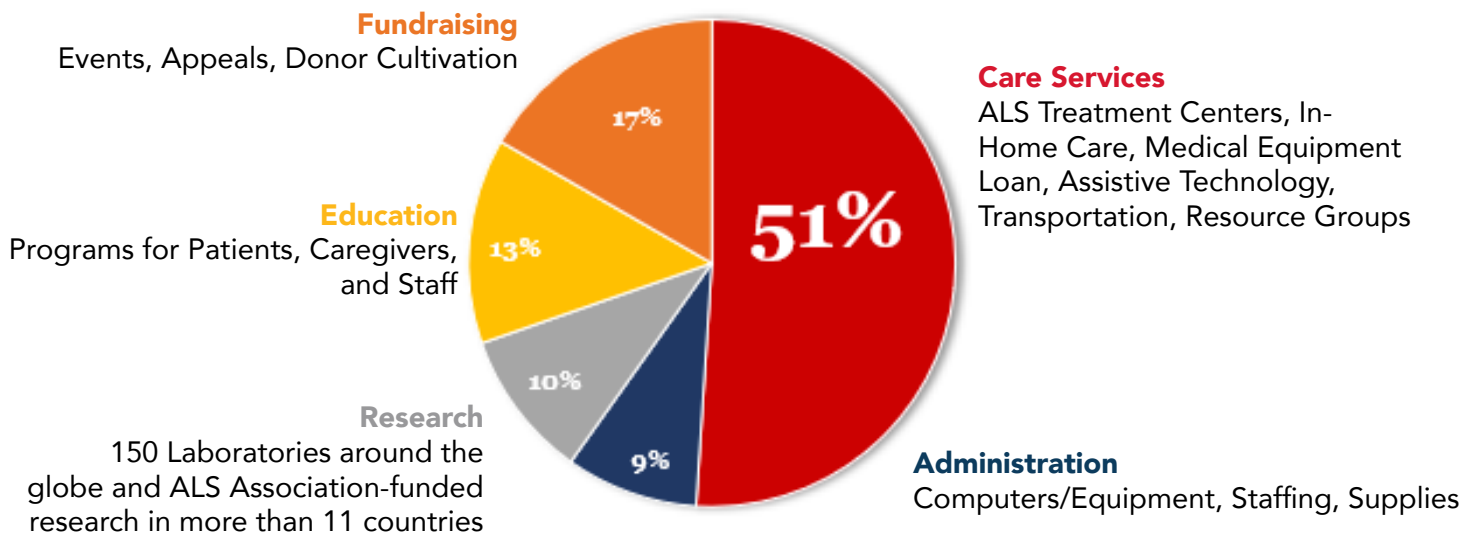
With Sincere Appreciation,

Jeffrey W. Cline
Executive Director

Research, Care, Education - The Cornerstones of Your Chapter

Your Gifts are an investment in doing *Whatever It Takes* to defeat ALS

Where Your Dollars Go



Donor Profile: **The Kirk Family** “Countin’ on a Miracle”



Maryanne and Roger at the Annual Roger Kirk ALS Golf Outing in 2013

WHY WE GIVE

ALS affects the whole family. The fight is all of ours, and thanks to donors like the Kirk family, we will win it together.

After Roger Kirk was diagnosed with ALS in 2013, there was no hesitation that his family was going to fight alongside him. “Roger never stopped trying to make the most of each day. He repeatedly said that although our family’s fundraising efforts through the Roger Kirk Golf Outing and our Walk to Defeat ALS Team ‘Kirkin’ It’ would not save his life, they will have a direct impact on and possibly save the lives of others,” said his wife, Maryanne.

In 2015, Roger, a dynamic, loving father, husband, grandfather, brother, colleague, and devoted friend who never missed a chance to enjoy life (and play a round of golf), lost his two-year battle with ALS.

“The Chapter helped our family with their compassion and vast knowledge of what we needed throughout Roger’s short ALS journey.”
Maryanne Kirk

Maryanne, their five children, and extended family never looked back. They looked forward. Forward to a world where ALS is something that only exists in the past.

The Kirks felt fortunate to have had support from so many people. Everyone had a role in caring for Roger. Additionally, family members and longtime employees united in running CNI Sales, the IT company Roger founded in 1994. But, just as importantly, the help the Kirks received from our Chapter was invaluable.

The ALS Association was a constant resource for the family. The Chapter’s ALS Treatment Centers, Loaner Closet from which Roger received a walker, manual wheelchair, and motorized wheelchair, Assistive Technology program that provided tools to help Roger communicate, and compassionate care were extraordinarily helpful. “If we were unsure of what to do as the disease progressed, The ALS Association was the first step,” noted Maryanne.

“Our family has embraced the need to help ALS families and help find a cure for this disease by getting involved in fundraising,” said Diana Kirk, the youngest of Roger’s five children.

The golf outing, now in its ninth year, is not only a day to honor Roger (coincidentally at the Old York Road Country Club where he belonged,) but also a way friends and loved ones do all they can to raise money for The ALS Association. Additionally, each year, the Kirk’s Walk to Defeat ALS team is one of the most spirited and highest grossing. Their presence continues to be a tremendous beacon of hope.

In the past eight years, team Kirkin’ It has raised over \$650,000 through their Walk to Defeat ALS Team and the Roger Kirk Golf Outing.

“We have a window to make an impact in this world and obviously Roger did that, and then some. Roger put up a brave fight and never stopped trying to make the most of each day. We will continue his fight. That’s why we give,” said Maryanne.

The Chapter is eternally gratefully for families like the Kirks who have formed the framework of The ALS Association Greater Philadelphia Chapter for over 44 years.



Team Kirkin’ It had a huge presence at the 2014 Philadelphia Walk to Defeat ALS at Citizens Bank Park and continues to participate each year.

Progress in Care Services

Honoring the Promise

Throughout 2021, the Chapter delivered a full range of care services programs to enhance the quality of life for individuals and families impacted by ALS. We are unique in that no other ALS organization in our region serves patients in such a comprehensive way.

In 2021, your support enabled:



8,951 hours of care delivered to 117 people with ALS through the Howard I. Abrams In-Home Care Program.



More than **166** Assistive Technology Interventions provided by the Scott A. Mackler, M.D., Ph.D., Assistive Technology Program.



257 pieces of equipment provided to 204 unique users by the Marjorie Shimer Durable Medical Equipment program. A total of 38 ramps and stair glides were provided.



Due to COVID, the Mike Kilpartic ALS Transportation Program program was suspended and the number of rides is significantly lower than we typically provide.



1,219 patient visits either through telemedicine or in-person at all 8 treatment centers.



124 support/resource groups offered for patients, family members and/or caregivers throughout the Chapter region.



15 in-service programs were held for ALS healthcare professionals.

Honoring Our Healthcare Heroes

Your Care Team "Doing Whatever it Takes"

None of us could have predicted the challenges we would face over past two years. Despite the pandemic and its effect on every aspect of life, the care we provide to ALS families is strong, having taken advantage of extraordinary opportunities to grow and innovate.



Here are just a few of the highlights of what your Chapter has supported:

- **COVID-19** is consistently monitored and ALS families are kept up to date with health and safety information.
- **Eight distinguished ALS Treatment Centers** continue to offer exceptional care either through telemedicine, or in-person in Southeastern PA, South Central PA, North Central PA, Central/Southern NJ, and Delaware.
- **The Help & Hope Symposium** was offered online in both 2020 and 2021 and featured exciting presentations. A "Meet the Experts Panel Discussion" shared critical information to improve the quality of life for those living with ALS. Each year, three top ALS researchers provided first-hand knowledge of some of the most significant advances in ALS research today. All videos can be seen on our Chapter's YouTube pages @alsphiladelphia.
- **Care professionals** continued to provide in-home care, durable medical equipment, and assistive technology.
- Your Chapter supported patient and family activities such as visiting Longwood Gardens and Knoebels Amusement Resort.
- As many as 12 Resource Groups met online and several returned to in-person or hybrid models.

Your donations enable the Chapter to provide compassionate care at our eight multidisciplinary ALS Treatment Centers throughout the region. People with ALS can be seen by a myriad of specialists in one visit or through telemedicine.



Progress in Advocacy



ADVOCACY IMPACT

With the support of over 40,000 ALS advocates, we secure resources to support treatment and research for the entire ALS community. Our nationwide network of 39 chapters and two service areas are essential to our efforts at the federal, state and local levels in advancing our 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.

Here are recent successes in ALS advocacy!



Protected access to noninvasive ventilators (NIV) for Medicare beneficiaries with ALS by fighting the Centers for Medicare and Medicaid Services (CMS) decision to add NIV to the competitive bidding program.



Ended the SSDI 5-month waiting period for people living with ALS by spearheading successful efforts to pass and enact into law the bipartisan ALS Disability Insurance Access Act.



Engaged the ALS community in a campaign to **bring AMX0035 to people living with ALS as quickly as possible** by collecting over 50,000 signatures on a petition to FDA and Amylyx.



Boosted funding for the ALS Research Program at the Department of Defense (DOD) from \$20 to \$40 million in 2020 to support the creation of more clinical trials that will lead to the discovery of treatments and a cure.



Joined with other leading patient organizations in the fight to **preserve protections for pre-existing conditions for people with ALS** under all insurance plans, including Medicare, Medicaid, and private insurance.



Ensured \$10 million in continued funding for the National ALS Registry and Biorepository to identify genetic and environmental factors for ALS, provide support to researchers to find treatments and a cure, and promote access to clinical trials.



Supported over **630 meetings with members of Congress and over 500 calls to Congress** during the 2020 Virtual Advocacy Fly-In and National ALS Virtual Advocacy Conference. **Empowered more than 40,000 ALS advocates** through 20 action alerts – resulting in over 85,000 advocacy messages to Congress.



Supported increases in funding for the National Institutes of Health, resulting in increased funding for ALS research from \$83 million in fiscal year 2018 to \$105 million in fiscal year 2019.



The ALS Association Core Values: **COMPASSION. INTEGRITY. URGENCY.**

ALS.org

02/11/21

Your Voice Matters — Advocacy

You can lead us closer to a world without ALS by joining our dedicated network of advocates throughout Pennsylvania, New Jersey, and Delaware. As an ALS advocate, you can help change the laws and policies that affect thousands of people living with ALS and their families.

The last decade has been a decade of progress for ALS advocacy, ensuring passage of legislation to improve access to research and securing millions of dollars in funding for ALS care from state governments in Pennsylvania, New Jersey, and Delaware. These outcomes were achieved because of the compelling stories our advocates continue to share through letters and visits with lawmakers.



In 2020, our chapter received more than \$1 million in combined state funding for ALS care services in PA, NJ, and DE.

To participate in ALS advocacy, please contact Tony@alsphiladelphia.org.

National Advocacy Goals for 2021



- Accelerate Development, Approval and Access to Effective New Treatments
- Increase Federal Funding for ALS Research
- Permanently Extend Access to Telehealth for People Living with ALS
- Provide High-Quality, Affordable, and Accessible Health Care
- Increase Veterans Benefits for People with ALS and their Families

“Be involved. The more people who participate in advocacy, the better off it is for the entire ALS community. Make calls, write letters, visit your legislators (when possible.) Everything matters.”

Lura Sawyer, ALS Advocate



Progress in Research



ADVANCES IN ALS RESEARCH

The ALS Association is the largest private funder of ALS research in the world. We advance ALS science by building research infrastructure and funding individual research projects and engaging the patient community in the search for treatments and a cure.

The ALS Association is proud to provide funding for these exciting innovations:



Healey Center establishes first platform trial

\$3M Helped support the Healey Platform Trial to speed up drug development by **reducing the cost of research by 30%** and **decreasing the trial time by 50%**.

Starting a new effort to stop ALS as soon as possible

Starting a new effort to stop ALS even before people get sick by funding the **first ever development of genetic testing and counseling guidelines** for ALS to help with ALS and their families identify and **manage their genetic risk** and **guide treatment decisions** on emerging gene-based therapies. We are also partnering with CDC on a workshop to problem-solve and translate research about ALS causes into preventive approaches and treatments to **reduce risk of ALS**.



Continuing the search during a global pandemic

By committing over **\$5.4M of funding for 24 new projects** spanning diverse areas of research such as biology, therapeutics, biomarkers, infrastructure, and clinical trials. The Association managed **over 162 active projects** with a **multiyear commitment of over \$55M**.

Investing in infrastructure and data access accelerates ALS research.



With over **\$1.2M** for the PRO-ACT (Pooled Resource Open-Access ALS Clinical Trials) database which is the **world's largest ALS clinical data repository**. Since its launch in 2012, over 900 researchers from 68 countries in both for-profit and non-profit sectors, have obtained access and analyzed these datasets resulting in 32 scientific publications.



Bringing effective treatments closer to approval

Including AMX0035 from Amylyx Pharmaceuticals that was **shown to extend life and slow disease progression**, and continued progress on Tofersen, a genetic therapy for SOD1-ALS in late phase trials, along with progress on biomarker research.

Finding out what matters most to people with ALS and their caregivers



Since launching, over **1,450 people have participated in the ALS Focus**. These surveys bring the perspectives and needs of people with ALS and caregivers to the forefront of program and policy decision making. To join, visit www.als.org/research/als-focus.

The Iron Horse Club

We are proud to share The Iron Horse Club which recognizes individuals and organizations that have donated consecutively in each of the last five years and \$500 or more this year. These loyal contributors provide the means by which The Greater Philadelphia Chapter can carry out its mission of offering help and hope to those living with ALS.

20 or More Years

Ms. Margaret A. Barry
and Mr. Jeffrey L. Abrams

BDO USA, LLP

Billy Lake Memorial ALS Foundation

Joan and Ted Borowsky

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*Denotes deceased at time of publication

Named Funds to Honor and Remember

Named Funds create a lasting tribute for loved ones with ALS and are a permanent part of The Greater Philadelphia Chapter. Each Named Fund has a page on the Chapter's website and is included on a recognition plaque in the Ambler, PA headquarters office. Funds supporting the ALS Association Certified Treatment Center of Excellence at Penn State Health Milton S. Hershey Medical Center are also recognized on a separate plaque at that location.

The Ashley Fund

The James E. Beck Memorial Fund

The Walter J. Benn Memorial Fund

The Eric Berg Fund

The Dennis Bierley Memorial Fund

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The Tony J. Vracarich Fund

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The Brian C. White Memorial Fund

The Ronald and Sherry Wenger Fund

Funds Established in FY 2021

Named Funds offer individual donors or families a way to express love for their Fund honoree that is also an expression of support for the Chapter. Since its inception in 2008, the Named Fund Program has generated more than \$3 million in donations to 56 Funds.

We are pleased to announce the establishment of three new Named Funds.



The Sergeant Major's Fund

Established by Bob and Pamela Fontello as an avenue to support ALS Clinic patients at Hershey Medical Center with a special focus on veterans battling ALS.



The Tony J. Vracarich Fund

Established by Tony, a veteran of the U.S Marine Corps, in gratitude for the Greater Philadelphia Chapter's services. This fund supports the ALS Association's general mission.



The Beth Strum Memorial Fund

Established by the Strum Family to benefit the Greater Philadelphia Chapter's Care Services Program for people with ALS and their families.

For more information about the Named Fund Program, please contact Donna Cleary, Director of Development at 215-664-4133 or Donna@alsphiladelphia.org.

The Legacy Society

The Legacy Society recognizes individuals who have included the ALS Association in their estate plans through a bequest in a will or trust, charitable gift annuity, beneficiary designation in a retirement plan or insurance policy, or other deferred gift.

Jeffrey L. Abrams
Rhoda Albom *
Seth Andrews *
Daniel Arden
Anna Arnold *
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Ron and Carol Baner *
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Constance Beurle *
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Gifts *Remained strong throughout the COVID-19 pandemic and invested in the future.*

HERO

\$500,000 and Above

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INSPIRATION

\$100,000 - \$499,999

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*Denotes deceased at time of publication

Financial Report

Statement of Activities

Fiscal Year Ended January 31, 2021

	2021		
	Without Donor Restrictions	With Donor Restrictions	Total
REVENUES AND OTHER SUPPORT			
Contributions and Special Events	\$ 3,298,497	\$ 748,687	\$ 4,047,184
Government Grants	-	850,392	850,392
Interest Income	23,376	-	23,376
Change in Beneficial Interest in Perpetual Trust	-	14,330	14,330
Total Revenues	3,321,873	1,613,409	4,935,282
Net Assets Released from Restrictions	1,508,768	(1,508,768)	-
TOTAL REVENUES AND OTHER SUPPORT	4,830,641	104,641	4,935,282
EXPENSES			
Program			
Education	635,374	-	653,374
Care Services	2,780,071	-	2,780,071
Research	820,349	-	820,349
Total Program Expenses	4,235,794	-	4,235,794
Management and General	464,871	-	464,871
Fundraising	765,666	-	765,666
TOTAL EXPENSES	5,466,331	-	5,466,331
CHANGE IN NET ASSETS	(635,690)	104,641	(531,049)
NET ASSETS - Beginning of Year	3,426,554	1,112,038	4,538,592
NET ASSETS - End of Year	\$ 2,790,864	\$ 1,216,679	\$ 4,007,543

Financial Report

Statement of Financial Position

Fiscal Year Ended January 31, 2021

ASSETS

CURRENT ASSETS

Cash and Cash Equivalents	\$ 2,963,353	\$ 379,347	\$ 3,342,700
Pledges Receivable, Net	137,509	96,667	234,176
Grants Receivable	315,982	221,067	537,049
Other Receivables	50,764	-	50,764
Prepaid Expenses	65,820	-	65,820

TOTAL CURRENT ASSETS

3,533,428	697,081	4,230,509
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PROPERTY, PLANT, AND EQUIPMENT

Patient Transport Vehicles	112,899	-	112,899
Computers and Equipment	543,719	27,840	571,559
	656,618	27,840	684,458
Less: Accumulated Depreciation	631,648	27,840	659,488

NET PROPERTY, PLANT, AND EQUIPMENT

24,970	-	24,970
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OTHER ASSETS

Pledges Receivable, Net	137,516	32,797	170,313
Beneficial Interest in Perpetual Trust	-	486,801	486,801

TOTAL OTHER ASSETS

137,516	519,598	657,114
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TOTAL ASSETS

\$ 3,695,914	\$ 1,216,679	\$ 4,912,593
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LIABILITIES AND NET ASSETS

CURRENT LIABILITIES

Accounts Payable and Accrued Liabilities	\$ 570,117	-	\$ 570,117
TOTAL CURRENT LIABILITIES	570,117	-	570,117

OTHER LIABILITIES

Conditional Contribution - Paycheck Protection Program	305,895	-	305,895
Deferred Rent	29,038	-	29,038

TOTAL OTHER LIABILITIES

334,933	-	334,933
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TOTAL LIABILITIES

905,050	-	905,050
---------	---	---------

NET ASSETS

2,790,864	1,216,679	4,007,543
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TOTAL LIABILITIES AND NET ASSETS

\$ 3,695,914	\$ 1,216,679	\$ 4,912,593
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Our Mission

To discover treatments and a cure for ALS, and to serve, advocate for, and empower people with ALS to live their lives to the fullest.

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321 Norristown Road, Suite 260, Ambler, PA 19002