

**I. CHESTER COUNTY COMMUNITY FOUNDATION
GRANT PROPOSAL SUMMARY SHEET**

One page only. This page will be shared electronically with Grant Committee Members & Fund Advisors.

*Note: If Philanthropy Network of Greater Philadelphia's Common Grant Application is used, the Community Foundation's **Summary Sheet MUST accompany application.***

To obtain an electronic version of this application, visit www.chescocf.org

Contact Information

Organization Name: ALS Association Greater Phila. Chap

Date 9/12/18

Executive Director Name: Marta Rubin Kiesling

Address: 321 Norristown Road, Suite 260; Ambler PA 19002

Executive Director E-mail:
Marta@alsphiladelphia.org

Phone: 215-643-5434

Board of Directors Chair Name:
Christina Martin

Website: www.alsphiladelphia.org

Primary Contact Name:
Donna Cleary

Year Incorporated: 1977

Primary Contact E-mail:
donna@alsphiladelphia.org

Has your nonprofit ever applied to the Community Foundation?

Yes No Not Sure

Has your nonprofit ever received funding from the Community Foundation? Yes No
Not Sure

Donor Advised Fund(s) Fund for Chester County Don't know/Not sure

Field/s of Interest:

Arts, Culture & Humanities

Environment/Animal Welfare

Education

Health

Human Services

Religion

Organization Information:

Geographic Area Served (If not all of Chester County, specify primary Chester County regions served):

Eastern half of PA (which includes all of Chester County), south and central New Jersey and Delaware

Organization History, Goals, Key Achievements and Distinctiveness

This year marks 79 years since “the Iron Man of Baseball” Lou Gehrig made his famous speech at Yankee Stadium declaring that even though he’d been dealt a tough break, he still considered himself “...the luckiest man on the face of the earth”. That tough break was being diagnosed with Amyotrophic Lateral Sclerosis, now more commonly known as Lou Gehrig’s Disease or ALS. A fatal, progressive neuromuscular disorder that affects the brain and spinal cord, ALS causes eventual paralysis of all voluntary muscles. As symptoms progress, an individual loses the ability to walk, talk, swallow and finally, breathe. Most are totally aware of their surroundings as they become a prisoner in their own body.

Despite the notoriety Mr. Gehrig brought to the disease, there was little support available for people living with ALS until 1975. Felice Weiner, whose mother lost her battle with ALS was frustrated at the lack of resources available and was inspired to create an organization that could help families. By 1977, with two support groups, the Greater Philadelphia Chapter was born. Led by several prominent families and many committed volunteers, the Chapter is now one of the largest in the nation providing a multitude of services for people living with ALS (PALS); funding research initiatives and leading advocacy efforts at the state and national levels of government.

We are proud to share that many of the volunteers who helped shape the Chapter continue their commitment today. Ms. Weiner served as a board member until she succumbed to the disease in 2015. In 1984, Ellyn Phillips became President and has kept that position since and remains relentless in her efforts to advance research initiatives and expand services.

Encompassing the eastern half of Pennsylvania, south and central New Jersey and all of Delaware, annually, the Chapter serves approximately 1,200 families, the number fluctuates determined by the number of patients who pass away and are newly diagnosed. As of September 11, there are 345 patient families living in Southeastern Pennsylvania in the counties of Bucks (58), Chester (43) Delaware (33), Montgomery (76), Northampton (26) and Philadelphia (107), representing 30% of our population. Fifty-three of these individuals are military veterans: Bucks (8), Chester (7), Delaware (4), Montgomery (7), Northampton (8) and Philadelphia (16). Tragically, and as yet for unknown reasons, military veterans are twice as likely as the general population to be diagnosed with ALS. Funds requested for this grant, will focus on care and support primarily for the ALS patient population who live in Chester County.

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.

Funding Request Key Initiatives

Through a comprehensive Care Services Program, Advocacy, and Research, The ALS Association brings help and hope to families living with ALS. The following description details the Chapter’s very important mission of these three key initiatives.

Specific Needs – Furthering the ALS Association Mission Care Services Program

People with ALS are our first priority in everything we do. In most cases, services are provided free of charge and in all cases, the needs of the patient come first. Programs are offered to help patient families sustain the highest quality of life as the disease progresses. They include: (1) Patient Care Clinics: The Greater Philadelphia Chapter is proud to support eight interdisciplinary centers for the diagnosis and treatment of ALS. Each Center provides specialized ALS care in a hospital setting, with patients seeing up to a dozen specialists in a single visit. Patients are typically seen 3-4 times per year; (2) The Howard I. Abrams In-Home Care Program: As the disease progresses, ALS patients lose the ability to take care of their most basic needs and eventually require 24-hour care. To help ease the burden of care and the financial stress, The Howard I. Abrams In-Home Care Program offers up to 12 hours of regular weekly custodial care for patients living at home by a home health aide free of charge; (3) Assistive Technology Program: When speech is no longer possible, the Chapter provides loaned devices to enable patients to communicate such as iPads, Lightwriters and Eyegaze systems; (4) Durable Medical Equipment Loan Program (DME): Various pieces of medical equipment are loaned to patients throughout the course of their disease such as wheelchairs, Hoyer lifts, and breathing machines; (5) Wheel Chair

Accessible Van Transportation Program: The Chapter has three wheelchair-accessible vans to transport patients and their caregivers to medical appointments, clinic visits and family events. Two vans are ventilator accessible. Patients living outside a 60-mile radius of the Chapter Office are provided transportation through contracted community providers; (6) Home Accessibility Solutions: The Chapter provides equipment such as stair glides and ramps to those with accessibility needs; (7) Support Groups: A variety of groups for patients and caregivers including newly diagnosed, bereavement and caregiving sessions are offered throughout our territory. Numerous in-person visits throughout the year, as well as one ALS teleconference help families to cope with the disease; (8) Education for Patients, Caregivers, & Healthcare Workers: The Chapter is dedicated to providing patients and their families with the necessary information to understand and cope with the disease. Additionally, workshops are offered for healthcare workers to enable them to give appropriate care specific to a person with ALS; (9) Recreational Programs: The Chapter organizes 3-4 annual outings for patients and their families at various locations such as amusement parks, arboreta, and zoos; (10) Visiting Volunteer Program: The Chapter's 16-year program provides trained volunteers to visit patient families offering companionship to people living with ALS throughout our entire geography; (11) Additional Field Support: The Chapter's team of Nurses, Social Workers and Mental Health Counselors also provide patients, to varying degrees, with counseling and education on a variety of issues affecting people with ALS such as: home safety, coughing assistance, fall prevention, sleep medications, range-of-motion exercises, pain management, in-home care, and depression.

Advocacy

Advocacy is an important way to draw awareness and resources to people affected by ALS. The Chapter's ongoing state and national advocacy efforts involving patients, family members, Board members, and staff have made great strides in the fight against ALS. At the federal level, The ALS Association gained the passage of legislation to fund the National ALS Registry. Data collected from the Registry is providing vital information for research initiatives. For the first time in 2017 and again in 2018, thanks to aggressive efforts, the Chapter received funding support through government funding from Delaware, New Jersey and Pennsylvania.

Research

Research is vigorously promoted and funded by The ALS Association using a collaborative approach to find treatments and a cure. In addition to engaging in clinical trials at the Penn State ALS Hershey Medical Center in Hershey, PA and the Jefferson Weinberg ALS Center in Philadelphia, PA, the Chapter works in conjunction with the ALS Association to promote research initiatives. Since the Ice Bucket Challenge social media fundraising effort in 2014, the ALS Association's research collaborations have grown globally greatly accelerating the discovery of new treatments for ALS. Most recently in March, the collaboration announced another new gene, KIF5A. It is the fifth ALS gene discovered since the Ice Bucket Challenge joining other genes, C21orf2, TUBA4A, TBK1, and NEK1, which ranks among the most common genetic factors associated with ALS. To date, over 25 ALS genes have been discovered, however, advancements progressed exponentially thanks to the significant funds raised through the Ice Bucket Challenge in 2014. This was the greatest amount of support raised at any time in the ALS Association's history.

Need for Funding

One thing that distinguishes ALS from many other diseases is that patients, even temporarily, simply do not get better. At an unpredictable rate, each day brings more loss. For families impacted, a diagnosis of ALS brings with it enormous emotional, psychological, practical, and financial implications. Spouses sometimes have no choice but to quit working to care for their loved one, sending a ripple effect throughout the entire family. Our care services provide the emotional, physical and financial support they so desperately need. Furthermore, it is vital to continue to promote awareness of this terrible disease, while also working to find a cure.

Having no endowment funds or fee for service revenue, The ALS Association relies solely on fundraised and contributed dollars each year to provide care services, fund research and support operations. While there is a modest reserve fund for emergencies, we begin each fiscal year on February 1st at \$0, and work diligently to achieve our revenue budget through seven annual Walks to Defeat ALS[®], special events, annual appeals, private foundation grants and individual gifts. In order to maintain services provided to ALS patients and their families throughout our extensive geography, the Chapter is turning more toward foundation and corporate funding sources in the local

communities in which we serve patients. A grant of \$7,500 from the Chester County Community Foundation in support of the patients residing in Chester and surrounding PA Counties who receive care and support services from the Chapter will strengthen our organization, and provide flexibility by enabling that portion of the Chapter's unrestricted event revenue to be applied to other important patient programs.

How impact and results will be demonstrated

Once a diagnosis of ALS is established either through a Chapter ALS clinic or the patient's personal medical team, a patient registers with the Chapter. At that time, our entire professional and certified staff and a multitude of programs and services are available to assist patient families through the challenges of the disease. Various strategies are at work to provide the programs.

During ALS clinic visits and/or home visits, patients are evaluated regarding care management. The certified staff member will make care recommendations for equipment and medication changes, in-home care needs or other support services. Often at Chapter Resource gatherings, staff interactions with patients and families may bring attention to certain patient equipment or in-home care needs at which time a staff member can make a referral for the appropriate program. Insurance case managers will also contact the Chapter recommending a patient's status and changing needs. Family members/caregivers make requests for assistance at which time our social workers and clinic staff will make suitable recommendations for a particular Chapter service. It is this close personal attention that helps patient families cope with this devastating disease as symptoms progress.

The Chapter's Care Services Committee meets quarterly to assess current programs and address any issues or needs as well as learn what programs need to be enhanced or added. Information used to make this important analysis is derived from the Care Services Medical Records database that contains records of every directive and care protocol issued for each patient, such as home visits, clinic visit information, dissemination of various equipment recommended and support assistance provided through emails, and or phone calls with the patient and family.

Furthermore, the Advocacy committee and Research committee review efforts made in these endeavors and make sure that dollars are expended carefully to accomplish goals established. This is done through direct participation in advocacy efforts as well as involvement in research committees on the National Association review board where research is conducted.

Lastly, quarterly budget reviews conducted by the board ensure that goals are being met and that we are fiscally efficient in our endeavors.