

# 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 Greater Philadelphia's Common Grant Application is used, the CCCF's Summary Sheet **MUST** accompany application. To obtain an electronic version of this application, visit [www.chescocf.org](http://www.chescocf.org)

Date: 5/11/15

## Contact Information:

Organization Name: ALS Association Greater Philadelphia Chapter  
Address: 321 Norristown Road, Suite 260  
Ambler, PA 19002  
Phone: 215-664-4133  
Website: www.alsphiladelphia.org

Contact Name: Donna M. Cleary  
Contact Title: Annual Giving Manager  
Contact E-mail: donna@alsphiladelphia.org  
Fax: 215-643-9307  
Year Incorporated: 1977

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 Pennsylvania including all of Chester County, south and central New Jersey and Delaware

**Describe Population Served and Annual Number of People Served:** A multitude of programs and services are offered to any individual diagnosed with ALS and who is registered with our Chapter. Currently there are 961 patients registered; 320 live in the southeastern PA counties of Bucks (55), Chester (40), Delaware (50), Montgomery (63), Northampton(24) and Philadelphia (88).

**Mission:** Our mission is to lead the fight to treat and cure ALS through global research and nationwide advocacy while also empowering people with Lou Gehrig's Disease and their families to live fuller lives by providing them with compassionate care and support.

**Proposal Summary:** Relying solely on fundraised dollars, The Chapter provides patient families the appropriate equipment and care services to help manage the challenges of the disease. In most cases, services are provided free of charge and in all cases, the needs of the patient come first. With no endowment funds or fee for service revenue, the Chapter begins each fiscal year at \$0. It is our hope that the Chester County Community Foundation will partner with the ALS Association to help subsidize our important mission.

## If Capacity Building Proposal:

Mission, Vision & Strategy  Governance & Leadership  Strategic Relationships  
 Fundraising & Development  Operations  Other: \_\_\_\_\_

**Annual Budget** \$ 5,814,342 21 # of Full-Time Equivalent Paid Staff  
77.2 % of budget for program expenses 44 # of Board Volunteers  
6.5 % of budget for administrative expenses 200 # of Active Non-Board Volunteers  
16.3 % of budget for fundraising expenses 10,000 # of Volunteer Hours

100 % total

Top 3-5 funding sources: **Phillies Charities through Phillies Phestival event; The Donald B. and Dorothy L. Stabler Foundation; The Julius and Ray Charlestein Foundation**

Grant Amount Requested from CCCF: \$ 5,000

GRANT APPLICATION

TO THE

**CHESTER COUNTY**  
**COMMUNITY FOUNDATION**



Submitted by  
Donna M. Cleary  
Annual Giving Manager  
321 Norristown Road  
Ambler, PA 19002  
215-664-4133

## **1. ORGANIZATION HISTORY, GOALS, KEY ACHIEVEMENTS AND DISTINCTIVENESS**

Amyotrophic Lateral Sclerosis, better known as Lou Gehrig's Disease or ALS, is a devastating progressive neurodegenerative disease that knows no racial, ethnic or socioeconomic boundaries. Every 90 minutes someone new is told that they have ALS. In approximately two to five years from diagnosis the degeneration of motor neurons in the brain and spinal cord will lead to muscle weakness and rob the patient of the ability to walk, talk, swallow and finally, breathe. ALS patients lose the capacity to take care of themselves in the most basic ways resulting in an immense need for custodial care and support services.

The year 2014 marked the 75th anniversary of Lou Gehrig's famous speech declaring "he is the luckiest man alive" as he told his fans that he was retiring because the symptoms of ALS would no longer let him play. He passed away two years later from the disease. Since that time and despite recent promising research, science has not been able to develop a treatment or cure. Another tragic fact is that military veterans are twice as likely to be diagnosed with ALS.

Even though Lou Gehrig's reputation brought attention to the disease, there was little support available for people living with ALS (PALS) for many years. That was, until 1975 when Felice Weiner's mother lost her battle with ALS. Ms. Weiner, frustrated at the lack of resources was inspired to create an organization that would provide the critically needed support for patient families. Through her vision and perseverance, two years later, in 1977, the Greater Philadelphia Chapter was born. Since that time, thanks to the dedication of several prominent families and many committed volunteers the Chapter has grown to be one of the largest in the nation, providing more services for PALS than any other Chapter. One particular devoted individual is our current President, Ellyn Phillips, who has been with the Chapter for over 30 years. Ellyn lost her husband to ALS when he was just 38 years old and the father of their three-year old daughter who is now 33 years old. Both Ellyn and her daughter continue to be committed to the fight against ALS.

The ALS Association is the **only** non-profit organization fighting Lou Gehrig's Disease on every front. Our mission is to lead the fight to treat and cure ALS through global research and nationwide advocacy while also empowering people with Lou Gehrig's Disease and their families to live fuller lives by providing them with compassionate care and support.

Encompassing the eastern half of Pennsylvania, south and central New Jersey and Delaware, the Greater Philadelphia Chapter serves approximately 900 – 950 patient families annually. Of this segment of our population, there are 320 patient families living in Southeastern Pennsylvania in the counties of Bucks (55), Chester (40) Delaware (50), Montgomery (63) and Philadelphia (88), representing one-third of our population. Forty-nine of these individuals are military veterans: Bucks (7), (Chester (11), Delaware (7), Montgomery (9), Northampton (5) and Philadelphia (10). Funds requested for this grant, will focus on care and support primarily for the ALS patient population who live in Chester County.

## **2. FUNDING REQUEST**

### **• Key Initiatives**

Through a comprehensive Patient Services Program, Advocacy, and Research, The ALS Association brings help and hope to families living with ALS. The Patient Services Program provides a multitude of services to help individuals living with ALS sustain the highest quality of life during the progression of the disease. Through our Advocacy Program, we connect elected leaders with patients and families who share personal stories in an effort to gain support that will help secure funding for research and subsidize programs. Research is vigorously promoted and funded using a collaborative approach to find treatments and a cure.

### **• Specific Needs to be addressed - Patient Care 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. Representing 48% of our organization's total expenses, The Greater Philadelphia Chapter provides the appropriate aids and supports to help patient families meet the many challenges they face throughout their journey with ALS. All programs are managed by the Chapter's Patient Services Staff of nurses, social workers, behavioral health counselors and an assistive technology specialist. Programs include: (1) Hospital-based clinical care and symptom management through two Certified Centers of Excellence Pennsylvania Hospital in Philadelphia, PA, Hershey Medical Center in Hershey PA, and two Recognized Clinical Care Centers) Lehigh Valley Medical Center in Allentown, PA and Geisinger Bloomsburg Hospital in Bloomsburg, PA; (2) Comprehensive case management by RNs, licensed social workers and counselors; (3) In-home personal care for up to 12 hours per week and respite care up to 60 hours a year; (4) Loaned durable medical equipment and assistive communication devices ; (5) Home accessibility and safety solutions (6) Support groups, education, and recreation programs and (7) handicapped-accessible and ventilator equipped van transportation.

### **• Need**

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.

Living with ALS can cost as much as \$250,000 a year. Many of these costs are not covered by medical insurance or, if they are, the cost of the co-pay can still make care unaffordable. The Chapter alleviates some of the financial burden families' face through our programs and services offering them at no cost. Last year, the Chapter expenses for Chester County patients totaled over \$80,000.

- **Organizational Impact**

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<sup>®</sup>, special events, annual appeals, private foundation grants and individual gifts. It is imperative that we seek additional revenue streams to continue to offer ALS patient families the programs they so vitally need. The Chapter humbly requests a grant in the amount of \$5,000 that would help subsidize 6% of the care expenses anticipated for Chester County ALS patient families in 2015.

- **Overall strategies to implement the Patient Services Program**

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.

Additionally, our website provides a vast amount of information to ALS patient families. The site lists all Chapter programs and services, as well as valuable links to available resources needed for patients and their families to make informed decisions about care. It additionally provides location information about clinical trials, and various community resources including local ALS support groups.

Lastly, communication through monthly patient newsletters, emails and event flyers provide patient families information about ongoing Chapter programs including resource groups such as Caregivers Skills Day and bereavement sessions.

- **Why it is important to fund this now**

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 \$5,000 from the Chester County Community Foundation in support of the patients residing in Chester County PA 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.

### **3. How impact and results will be demonstrated**

The Chapter's Patient Services Committee meets quarterly to assess current programs and address any issues or needs. This year, the committee has assigned a special task force to fully evaluate the Program using evidenced based methodology. Additionally, patient medical data is evaluated quarterly through reporting modules that greatly assist in determining future care protocols for all patients. These combined endeavors ensure that the Chapter is providing and delivering services effectively and efficiently to help patient families sustain the highest quality of life while managing the effects of the Disease.

### **4. Patient Story (identity changed to protect privacy)**

Barbara Miller is a 57 year old woman who lives in Chester County. An active individual and a competitive runner, she lost the ability to write virtually overnight. False diagnoses of Parkinson's disease and kidney cancer were made, and were eventually cured through treatments; however, Barbara's symptoms of debilitation and muscular degeneration remained. Finally two years later, a final diagnosis of ALS was determined. As ALS is a disease of exclusion, unfortunately Barbara's experience is not unusual. Sometimes by the time patients are introduced to our chapter because of late diagnosis, they are well into their disease and in need of many services right away.

Today, Barbara's ALS symptoms have progressed and she is totally paralyzed below the neck, has lost her ability to speak, and is on a ventilator. Her mind remains sharp. She finds comfort through visitors and prayer partners throughout the week. The ALS Association Greater Philadelphia has provided Barbara and her family with medical assistance and support, durable medical equipment, such as wheelchairs, and lifts, and the essential MegaBee with which she communicates as she bravely copes with the challenges of the Disease.