

# Advocacy



## ***Greater Philadelphia Chapter***

### **Become an ALS Advocate!**

ALS Advocacy is an important way to draw awareness and resources to the people affected by Lou Gehrig's Disease.

Whatever your connection is to the disease, as an ALS Advocate, you can help change the laws and policies that affect thousands of persons with ALS and their families.

## Your Voice Counts!

---

The ALS Association is fighting on every front to find a treatment and cure for ALS— and that includes working with government officials on the state and national levels to draw awareness and resources to the people affected by this disease.

**But we can't do it alone.** We need YOU— patients, spouses, caregivers, family members and friends to help us put a face on ALS.

You do not need to have government connections— just desire to share your story with your legislators.

Read on for real stories of ALS Advocates in our region, and how they have made a difference through ALS Advocacy.

## Wes Rose

*Glenside, Pennsylvania*

---

One of the frustrating things about being diagnosed with ALS is the feeling that there's nothing that can be done about it. However, I've found that participating in advocacy can be a way to do something about a situation that nothing can be done about. **Through state and national advocacy efforts, I've been able to make a tangible difference in the fight against ALS.** By taking the ALS message in person to both state and federal legislators, we have been able to increase our legislators' awareness about ALS.

Indeed, our message has not fallen on deaf ears: we've been able to secure funds from the Pennsylvania state legislature for both the Greater Philadelphia and Western Pennsylvania chapters of the ALS Association. In addition, our efforts have resulted in the passage of federal legislature to fund the National ALS Registry. So for me, participating in advocacy efforts has definitely allowed me to expand my fight against ALS.



*Wes Rose (center) with Pennsylvania State Rep. Josh Shapiro, is joined by his father Ray on his left and ALS advocate Mike Kilpatrick to his right.*

## Jayne Cawthern

Boalsburg, Pennsylvania

---



*The Cawthern Family*

Seven years ago, my life changed forever when my husband and I heard the words that no one should have to hear: “It’s ALS.” Tom was only 50 years old, and he was the father of our six children. The disease progressed much too quickly, and in less than a year he was gone.

From the moment of diagnosis, the staff and volunteers of the Philadelphia ALS Association became our resources, supporters, friends, and extended family members. How can you begin to thank such wonderful, dedicated people? How can you help find a treatment and cure for this horrendous disease? Our family became involved with ALS advocacy.

**Advocacy doesn’t require skill or a huge time commitment. The only knowledge you need is the personal experience you have had living with the disease.** Age is not important. My teenage daughter, who was only nine years old when her father died, has been one of the most effective advocates I’ve seen. Whether we just answer our friends’ questions about ALS, write letters to the editor of our local newspaper, send e-mails to our state and federal legislators, or attend state and national ALS Advocacy Days

once a year, we feel that we are contributing in ways that are just as valuable as monetary donations would be. We are also remembering and memorializing my husband in a personally rewarding and positive way.

Our advocacy experience has become the one good thing resulting from Tom's death. It has brought our family closer together, with a common goal, no matter how far apart we may be geographically. We have met some of the most interesting and wonderful people in the country, many of whom have become friends. Talking about our experiences with them, and listening to their stories, has been more therapeutic than years of grief therapy. The commitment and dedication of the ALS staff members, volunteers, and celebrity spokespeople have motivated us to express our own passion about ALS research and funding. We have discovered that legislators and their aides are interested in hearing our story, whether we tell it through letters, e-mails, over the telephone, or in person.

**Advocacy may seem intimidating at first, but once you have faced a diagnosis of ALS, nothing can ever truly frighten you again.** Advocacy gives you the power to fight for treatment and a cure, and it provides a reassuring feeling of accomplishment ... and hope.

## Keith Canady

Wilmington, Delaware

---



*Keith and Ann Canady at  
Advocacy Day*

It's hard to explain how I felt when the neurologist first told me that he suspected that I had ALS... shock, fear, despair are some words that come to mind. But, out of this difficult time came a curiosity to find out as much about ALS as I possibly could. This meant spending hours on the internet searching websites, communicating with other people living with ALS, and becoming better informed. My wife and I attended a 'newly diagnosed' session at the Greater Philadelphia Chapter

and began attending Delaware Resource Group Meetings. Somewhere along the way, my focus changed from *having* ALS to *living* with ALS.

Through my visits to the ALS Center in Philadelphia, I learned about ALS Advocacy Day held in Washington, DC each year in May and knew that it was something that I would be interested in supporting. When I applied for Medicare and Social Security benefits, I soon realized that through ALS Advocacy I had already benefited with the 24-month Medicare waiver for ALS patients and the presumptive disability ruling for Social Security.

We attended our first Advocacy Day and Public Policy Conference in 2005 and were hooked.

Being the 'face of ALS' to our Congressman and

**“It is truly empowering to help our elected officials understand how Lou Gehrig’s Disease impacts people living with ALS and their families.”**

Senators has been a really positive experience for me and my wife. We’ve had the opportunity to support the ALS Registry Act , increased federal funding for ALS specific research through the

National Institutes of Health and increased funding for research through the Department of Defense.

It is truly empowering to help our elected officials understand how Lou Gehrig’s Disease impacts people with ALS and their families. There’s nothing like navigating a small office in a motorized wheelchair and bumping into furniture and legislative aides alike to drive home a point!!! Above all, our experience with ALS Advocacy has enabled us to meet people who are engaged in the same effort that we are – making the lives of those with ALS better and actively supporting the search for effective treatments and a cure.

# Kathryn and Gerry Voit

*Cheltenham, Pennsylvania*

---

The first year we went to D.C. for Advocacy Day it was an act of faith. We had no idea of what we could do. What a learning and enriching experience it turned out to be.

**“We are keenly aware of how uplifting it has been to meet with ALS people from all over our country, joined in an incredible effort to clearly present our special needs to Congressional representatives.”**

First, we are keenly aware of how uplifting it has been to meet with ALS people from all over our country, joined in an incredible effort to clearly present our special needs to Congressional representatives. No matter how cynical

you might be about our ability to have any impact, you first notice that the Senators, Representatives and their staffs with whom you meet do listen and try to understand.

Part of that is due to the excellent preparation work the National ALS staff does in preparing the visitors to the Hill with clear positions to discuss and solid backup material to carry along. One great asset that the Greater Philadelphia Chapter provides is the number of people with ALS, caregivers and volunteers who attend, so





*Kathryn and Gerry share a moment at the annual Candlelight Vigil during ALS Advocacy Days*

newcomers are in experienced company.

We have been so gifted to be able to attend Advocacy Day over the last 7 or 8 years and have witnessed the success that has grown out of these efforts. Not only is Congress listening but has acted on a number of the ideas advocated which have been significant in our efforts to overcome ALS.

In addition, there is so much to learn from the countrywide ALS community. Many times we are convinced that we take a lot more from Advocacy than we bring to it. The fact that we have returned year after year suggests it is of value, and we certainly advocate being advocates.

## Stephen Potter

*Cheltenham, Pennsylvania*

---

As a patient with ALS, attending advocacy days in Washington, DC is important to my wife Charlotte and me on many levels.



*Steve and Charlotte Potter*

There is a day of seminars and meetings to learn about important issues that affect all ALS patients and their families. Many of us are particularly interested to find out about the exciting advances in

research. Last year we listened to a panel of experts from all over the world discuss recent research and answer questions from the audience. There is a meeting for first time attendees so that they can learn what to expect when they have their meetings on Capitol Hill. Breakout sessions are also held on other subjects of interest.

Last year we also had a chance to help research by volunteering to give blood for DNA testing. On Tuesday we get the opportunity to meet with our elected officials and their staffs. We discuss ways to support the fight against ALS. All of the patients and

caregivers break down into small groups with a member of the ALS Association and meet with our local congressmen and senators. We share how ALS has affected our lives and ask them to support pending

legislation to help our cause.

**“Spending a day moving between the offices on Capitol Hill is an excellent way to get to know more people involved with the fight against ALS.”**

There is time to get to know and to socialize with other members in the ALS community. Last year we had a group dinner at the hotel, a candlelight vigil, and

an ice cream social. These events are well attended by patients, family members, and those who work for the ALS Association. Spending a day moving between the offices on Capitol Hill is an excellent way to get to know more people involved with the fight against ALS. It is good to know that we are not alone and there are so many people working every day in the effort to find a cure and to treat ALS patients.

You can also find time to explore Washington, DC. There are many sites to see and Washington is beautiful in early May.

Charlotte and I plan to be at advocacy days this year and every year. We hope that more patients will be able to attend. We look forward to seeing you there.

## Mary McConaghy

*Philadelphia, Pennsylvania*

---



*Mary with her family*

After being diagnosed with ALS in December of 2010, I attended my first Advocacy last spring and had an amazing experience! First, I learned so much from the medical people who spoke about the rapidly expanding and promising research that is fi-

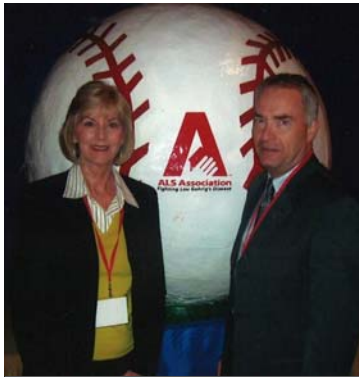
nally happening; their commitment to figuring out this disease and coming up with effective treatments, and doing so as fast as possible, was heartening. And then, I was empowered by the experience of going with others to congressional offices to advocate for ALS. It was fascinating to learn so much about how government works and gratifying to realize that I was having an impact on getting research money for ALS.

And throughout all these activities, **I was moved by the kindness and solidarity of the ALS community - patients and their families, medical caregivers and researchers; I heard so many stories and made so many friends.** And everything was so well-organized that I was never left wondering or lost or hungry. Gaining knowledge, making a difference, and building relationships with good people all committed to the same purpose - that's what Advocacy was for me.

## Arlene Gordon

*Downingtown, Pennsylvania*

---



*Arlene and Jeff Gordon at the Advocacy Day Conference.*

My first trip to the National Advocacy Convention in Washington, DC was in May of 2008, nine months after I was given the confirmed diagnosis of ALS. What struck me most during those nine months, was how little progress has been made in finding a cause and therefore a cure for this debilitating disease.

So I was compelled to get involved in advocacy for ALS. I went to Washington to let our Congressional representatives hear about my experience as an ALS patient. Getting additional funding for research and also the National ALS Registry, will provide much needed research data that will help all ALS patients. **Our representatives were very receptive to our needs, and willing to help in our efforts.**

I am one of the “ESP” patients- extra slow progressor , and feel very fortunate to be able to continue my life with some minor adjustments! My husband Jeff, daughter Deanna, and I have gone to DC as advocates for those PALS who are not able to make the trip. It is an empowering experience to be there with other people managing life with ALS and their families, and to know that your actions can have a positive impact on finding a cure for this difficult disease!

# Maureen McPeak

*Carlisle, Pennsylvania*

---

What does helping with Advocacy work for the ALS Association mean to me? Having gone through the experience of losing a loved one to ALS, I am happy and honored to do anything I can to help people with ALS and their families and I believe participating in advocacy work does that. Help can show itself in many ways – whether it is spending a day with a person with ALS in Washington DC for Advocacy Day to help share their experience or being an understanding listener when a family member is expressing their story, or being on a Walk to Defeat ALS® team – all of these ways matter.

**Being involved with Advocacy work for the ALS Association gives me the opportunity to give back to an organization that was a lifeline when my best friend struggled with her battle with ALS.** Not only were they very caring, compassionate and understanding, but they were able to anticipate her needs and help to meet those needs. The Greater Philadelphia Chapter was there in her time of need and I think I should help in any way possible when they have a time of need.

Advocacy work provides an opportunity to increase awareness about ALS and hopefully funding to continue the necessary research to find a cause and a cure for this disease. I am proud to be a volunteer for the ALS Association and am honored to help with Advocacy work in any way possible.

## Sally and Tom McLaughlin

*Newark, Delaware*

---

Sally and I have travelled to Washington DC to participate in ALS advocacy days every year since 2004— when she was diagnosed with ALS. It is an exciting time when you sit down with staff members from the offices of your own state's Congressmen. I know we make an impact as hundreds of us descend on Capitol Hill with walkers, canes, scooters, wheelchairs, communication devices and more.

As we tell our stories and request their support for specific legislation, I know that we make a difference. You can write hundreds of letters but it doesn't compare to a face to face meeting. With all the challenges of ALS, **Sally and I both have felt empowered participating in the advocacy process.** We have seen that we can impact legislation. Already Congress has passed a bill authorizing the creation of a National ALS Registry and a bill providing VA benefits to those who served in the military- both bills we lobbied for. We were so excited to hear they had passed!



*Sally and Tom with then Senator Joe Biden, at ALS Advocacy Day 2006*

*\*Sally passed away in 2009 but Tom continues to advocate in her memory.*



**Greater Philadelphia  
Chapter**

**The ALS Association  
Greater Philadelphia Chapter**  
321 Norristown Road, Suite 260  
Ambler, PA 19002

215-643-5434  
fax: 215-643-9307  
[www.alsphiladelphia.org](http://www.alsphiladelphia.org)

***Printing provided by Conlin's Digital Print and Copy Center***