



To educate and support patients, along with their families, by increasing awareness of the disease and improving communication among healthcare providers and the general public.

### **A Note from the Founder**

Exciting news - it's "Lucky 7" time!

Thanks to you, the PA Fund will be celebrating its 7-year anniversary this summer. I'm honored to share with you the many strides the Fund has made over this time and since we were last in touch. First, these advances are only made possible by the generous contributions and ongoing support you've afforded the Fund's programs. I want to take this opportunity to extend my sincere gratitude for your incredible benevolence.

Your kindness has enabled these programs to expand their reach from local to national during these challenging times. Read on to pages 2 & 3 for more highlights on what the PA Fund has accomplished!

I am proud to announce two additions to the PA Fund's Advisory Board:

- Alison Lee, Technology and Marketing Advisor.
- David O'Neill, Financial Advisor.

It is a privilege to have their expertise on the Board and I'm grateful for their generous gift of time to champion our mission.



As many of you know, the PA Fund is a separate, restricted entity under the 501(c)3 non-profit Lupus Research Alliance (LRA). Your donations go directly to support the three programs highlighted on the following pages.

As the spring season unfolds, it is my hope you will continue to share your philanthropic spirit with the PA Fund. Please keep in mind May is Lupus Awareness month. As spring brings thoughts of warmth and light, may your thoughts during May include healing for Lupus!

A handwritten signature in black ink that reads "Patti Allen". The signature is written in a cursive, flowing style.

Patti Allen, Founder

## 1. Lupus Emergency Grant Program (LEGP) Reaches Milestone - Awards 100th Grant

Prior to the pandemic, this grant program was only available to the lupus community in the Tri-State area (NY, CT, NJ). In the fall of 2020, due to COVID, this program expanded its grant availability nationwide. The financial challenges the pandemic has presented to families and their budgets is staggering. The cost of day-to day basic living essentials has increased dramatically over the past two years.

In the first four months of 2022, the Program awarded its 100th grant. Almost three-fourths of the grants assist recipients with covering medical expenses, utility bills, and rent. The Fund was able to help a young woman with college tuition and a mom with the installation of a handicap ramp for her son.

National outreach efforts have resulted in increased number of applications. The Table below shows a summary of grant awards for the first two and half years and January through April 2022.

|                      | 2019* - 2021 | January to April 2022 | Total    |
|----------------------|--------------|-----------------------|----------|
| # Awards             | 76           | 40                    | 116      |
| Total Amount         | \$33,665     | \$18,626              | \$52,291 |
| Average Award Amount | \$443        | \$466                 | \$451    |

\*First grant awarded in August 2019

*"I accept the grant - thank you for everything this will really help my family and I catch back up".*

*Eliza P.*

## 2. Lupus Advocates Take it to the Hill

For the past 7 years, the PA Fund has sponsored the Lupus Research Alliance's (LRA) annual advocacy event. The 2022 Take it to the Hill Conference took place in March, on the virtual platform, vFairs. This sponsorship provided:

- Advocacy training for all participants from the LRA's DC-based consulting firm to prepare attendees for meetings with members of Congress.
- Education:
  - o Issues important for the funding the advancement of lupus research.
  - o How to advocate with legislators and tell their individual lupus stories to members of Congress.
- Panel discussions with seasoned advocates to provide peer-to-peer training.
- Opportunities for advocates to network with presenters and each other.

The virtual format allowed for greater participation and this year, over 130 advocates registered to take part in the event representing 27 states including Washington DC.

### **3. Support Groups Offer Emotional and Educational Support**

Two support groups a month are supported by the PA Fund for approximately 24 meetings throughout the year.

In 2020, an all-virtual format began, and participants have expressed gratitude for this change. Many have told us they would not be able to attend in-person meetings.

Carla Menezes, the Project Coordinator, works with each support group facilitator to arrange and run the groups. Topics presented and discussed include:

- Community resources.
- Managing one's illness.
- Coping with the emotional challenges lupus presents.

During the first quarter of 2022, six support groups were held with an average of five attendees per group.

### **Mailing Address and Online Donations**

Lupus Research Alliance c/o Patti Allen - PA Fund

270 Madison Avenue, Suite 300 • New York, NY 10016. For online donations, go to:

[\*\*http://bit.ly/DonatetoPAFund\*\*](http://bit.ly/DonatetoPAFund)