



Spring 2024/Issue No. 16

*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**

As the PA Fund embarks on its ninth anniversary, I would like to take a moment to celebrate and extend a heartfelt thanks for the generous support in time and money from individuals and corporations that have made the work of the Fund possible. The execution of the Fund's mission and ongoing support of its programs rely on these charitable gifts.

Please take a few moments to read about the strides the Fund has made in advancing these programs. The PA Fund has made tremendous inroads in supporting patient advocacy efforts by promoting lupus education and awareness as well as empowering lupus patients to publicly promote medical reform on behalf of all those suffering with this complex illness.

The PA Fund was honored with a lead article on the Lupus Research Alliance website last month. Take a look! ([lupusresearch.org/honoring-pa-fund](http://lupusresearch.org/honoring-pa-fund))

As the calendar inches towards summer, please remember May is Lupus Awareness Month. To view a list of awareness events this month, please visit [www.lupusresearch.org](http://www.lupusresearch.org) and click on "get involved".

Wishing everyone a terrific summer season!

Happy Spring,

A handwritten signature in black ink that reads "Patti Allen".



## Highlights for Spring, 2024

### **1. Lupus Advocates *Take It To The Hill***

As you know, your contributions to the PA Fund financially support the LRA's annual *Take It To The Hill event*, where hundreds of advocates from around the country use their voices to ask members of Congress to champion increased funding for improved lupus treatment.



#### ***Breaking News – March, 2024!!***

Congress passed and President Biden signed the 2024 spending bills, which include priorities that we requested last year. The 2024 budget includes:

- \$10 million for the Lupus Research Program within the Department of Defense.
- And the Agriculture-FDA bill includes a provision expressing support for FDA's engagement with industry and the lupus community to help develop promising treatments.

These huge strides forward would not have happened without your financial support!  
Thank you, thank you!

### **2. Lupus Emergency Grant Program (LEGP)**

*Delivered 2023 single-year milestone of \$114,500!*

We're excited to share that the LEGP has awarded a total of \$231,500 since its inception. This grant money has given vital relief to individuals with lupus literally struggling to make ends meet, particularly during these volatile economic times.

The top categories of expense relief from applicants remain the consistent from previous years.

- Medical (31%)
- Utilities (32%)
- Rent Arrears (18%)

*This is the Good News...*

*The Not-so-Good News:* As of December, 2023, we were forced to temporarily pause the Emergency Grant Program because the overwhelming demand for short-term financial relief exceeded available funds. All of the allocated funds earmarked for this program were **depleted in 2023**.

Please consider an immediate donation to help us begin a new chapter in the life of the Lupus Emergency Grant Program!

### **3. Support Groups = Emotional & Educational Support**

Support groups provide a vital and safe platform for lupus patients and their families. Members strengthen each other by coming together to share coping strategies and help each other feel more empowered by learning about their disease and gaining a sense of community.



These groups provide a safe space to share personal feelings and experiences which are essential for one's well-being. They provide coping strategies and current information about the disease. Support groups continue to meet one to two times a month, both in-person and virtually. The virtual platform allows individuals to attend who would otherwise not be able to do so.

### **Spring giving to the PA Fund**

Your continued support is needed to ensure these three programs continue to be available resources for the lupus community.

We ask that you consider earmarking a portion of your charitable donations to the PA Fund.

**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>

