



Supporting patient advocacy and care for those with this life-threatening disease

**MISSION STATEMENT:**

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 and Director***

As the PA Fund embarks on its 4th anniversary, I would like to take a moment to celebrate and extend a heartfelt thanks for the generous support from individuals, foundations and corporations for donations of time and money, all of which 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 along with the inroads they have made 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 those suffering with this complex illness.

As the calendar inches towards summer, please remember that May is Lupus Awareness Month. To view a list of all events this month, or to donate to the PA Fund, please visit [www.lupusresearch.org](http://www.lupusresearch.org) and click on "get involved" and then click "other ways to donate" where you can access the PA Fund.

Wishing everyone a terrific summer season!

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

Patti Allen  
Founder and Director



*Patti Allen with Miah Andrade, one of the PA Fund 2019 Fund Scholarship recipients*

## ***Support Groups***

Support groups provide a vital and safe platform for lupus patients and their families. Members supply each other with help by coming together to share coping strategies as well as to help each other feel more empowered through the education of their disease and for a sense of community. The groups present relevant information relating to personal experiences as well as listening to and accepting others' experiences, providing sympathetic understanding and establishing social networks. Support groups are also instrumental in encouraging individuals to become advocates for lupus awareness. To give you the best insight into the vital role these groups serve, here's what just a few members had to say:

*"We bounce off each other and learn from each other. When we speak to our doctors, we are more informed. Family try but they can't really relate to what we're going through. They won't ever really understand. And we laugh together about our shared experience."* – Donnette

*"Information leads to living the best life possible. Sometimes it leads to better care. Sometimes it helps us find better treatments. Getting involved with the group helps balance my life."* – Sherilee

*"I just found out that other people in the group also have neuropathy related to their lupus. Then we share remedies – some people said walking barefoot helps while others told us what not to try. If I didn't have this support group, I would think I was the only one suffering from neuropathy!"* – Sylvia

## ***Lupus Advocacy Conference and Hill Day – March 2019***

The PA Fund Scholarship Program for the Lupus Research Alliance's Annual Advocacy Conference and Hill Day in Washington, DC, 2019, moved beyond its "pilot" phase. To ensure the program's viability, in 2019 it was co-sponsored by an important corporate grant. Fifteen scholarships were awarded to give the opportunity to attend this conference to individuals whose applications demonstrated a passionate interest in working on behalf of the national lupus community. This year a scholarship was awarded to one of the youngest lupus advocates ever. At 12, Miah Andrade is a tireless champion for creating an understanding of the disease; the scholarship afforded her the chance to travel to and from DC where her voice was heard by legislators on the state and federal level. Along with her mom, Elizabeth, Miah has been instrumental in expanding lupus awareness within her school and community. This May, Governor Phil Murphy approved their request for a State Proclamation designating May as Lupus Awareness Month in the State of New Jersey!



*Past and present scholarship winners.*

## ***Lupus Emergency Grant Program***

The PA Fund was excited to announce the launch of its Lupus Emergency Grant Program (LEGP) in February 2019. With the grant applications starting to come in, the program aims to address the immediate financial aid concerns of people with lupus struggling to handle day-to-day emergency living expenses. To learn more about LEGP and to view the program guidelines, eligibility requirements and application, please go to <https://www.surveymonkey.com/r/legp>.

## ***Mail-In & Online Donations***

Lupus Research Alliance • c/o Patti Allen – PA Fund  
 275 Madison Avenue, 10<sup>th</sup> Floor • New York, NY 10016  
 T: 646.884.6000/F: 212.545.1843 • Patti's Cell: 917.882.4227  
 For online donations, [click here](#) or go to: <http://bit.ly/DonatetoPAFund>