



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

It is truly an honor and privilege to serve the mission of the PA Fund as Founder and Director. This fall presents the perfect opportunity to celebrate the Fund's two-year anniversary and share with you the wonderful initiatives that the PA Fund participated in since the last newsletter.

With change in the air, the PA Fund, along with the extended lupus community, had some tremendous victories in the fight to create heightened awareness for the disease as well as the search to find better treatments for those suffering with this confounding and complex illness. I am beyond grateful for the continued support of generous individuals and corporations like you who allow the Fund to make this work possible.

As the year winds down, please make sure to visit the newly launched Lupus Research Alliance website where you can view all the activities that are scheduled before the New Year. To access the PA Fund on the new website, (www.lupusresearch.org), please go to the tab labeled "Get Involved" then tap "Other Ways to Donate" and you will find the tab for the PA Fund.



Thank you again for your continued support, and I wish you and your families an enjoyable holiday season.

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

Patti Allen
Founder and Director

Lupus Advocacy Conference and Hill Day – March, 2017

The lupus community had a tremendous victory last March as a result of our lobbying efforts in Washington, D.C. With PA Fund's co-sponsorship of this conference, we were able to include more lupus patients than ever before at our Annual Hill Day. With a group large enough to impress several Senators and House Representatives, our advocacy efforts were instrumental in securing an additional \$2 billion increase over 2016 for biomedical research conducted through the National Institutes of Health (NIH).

An additional \$2 million was also appropriated for the Office of Minority Health's National Lupus Outreach and Clinical Trial Education Program. This Lupus Program seeks to reduce disparities in lupus and includes a provider education program to provide medical professionals throughout the country with tools to better recognize, diagnose and treat lupus promptly and properly.

Another successful outcome of our group's lobbying efforts in Washington -- for the first time, the Department of Defense established an annual \$5 million Lupus Research Program! The program is now accepting grant applications; I am proud to be nominated by the Lupus Research Alliance to serve as a Consumer Reviewer, helping ensure that what matters most to patients is considered in the selection process.

Patient-Focused Drug Development (PFDD) Meeting - September 25, 2017

It was an honor to represent the PA Fund as an audience participant at the Patient-Focused Drug Development (PFDD) Meeting in the Washington, D.C. area this past September. The meeting gave people with lupus and their families a chance to be part of a history-making project, providing an opportunity to contribute to lupus drug development by sharing how the disease affects their daily lives as well as their thoughts on current and future treatments. This ground-breaking initiative was launched by the Lupus and Allied Diseases Association, the Lupus Foundation of America and the Lupus Research Alliance. The results from this meeting will be incorporated into a report and will inform Food and Drug Administration (FDA) officials as they make decisions about future lupus treatments.

Advancing Lupus Care through Research and Advocacy Conference - December 2, 2017

Presenting information about advances in treatment and the importance of advocacy, this conference has historically taken place in New York. Last spring, the conference was rolled out to the Boston area with great success, so much so that the event is going on the road again -- next stop Chicago on Saturday, December 2, 2017. The PA Fund is a proud co-sponsor of this event.

Scholarship Program for Lupus Advocacy Conference and Annual Hill Day -March, 2018

Due to the successful strides regarding our Annual Hill Day, the PA Fund is committed to increasing its budget for the Annual Lupus Advocacy Conference in Washington, D.C. this coming year. Plans are underway to implement a pilot scholarship program for those lupus patients, and their families, who might be interested in representing the community as a lupus advocate on the Hill next March. Individuals awarded a scholarship will have the opportunity to meet with their representatives to discuss their concerns surrounding the disease. Economy travel and hotel expenses for this trip will be paid for from the scholarship funds that are awarded to those individuals who apply and are accepted by the selection committee.

Mail-In & Online Donations

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