Holiday 2019

Issue No. 8 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 general public.

A Note from the Founder and Director

As the year winds down and the festive season approaches, I know we're all busy making plans to celebrate the holidays. In this season of gratitude, I'd like to take a moment to extend my appreciation to you for giving hope to so many people with lupus through your generous donations, enabling the PA Fund programs to exist and thrive throughout 2019.

As the founder of the PA Fund, my passion for speaking up for and advocating on behalf of those lupus patients across all generations has personally been an honor. It's a privilege to be part of an organization that is bringing change to many lives, one person at a time. Talking to people with lupus about their struggles with the disease and their desire for a better quality of life and knowing that we are making a difference towards that goal, are some of the most fulfilling aspects of leading the PA Fund.

As the scope of the PA Fund continues to expand, your financial assistance in keeping these programs viable is even more critical. We face a daunting task: with millions worldwide suffering with lupus and associated diseases, we need your help now more than ever. Your donations have enabled the Fund to provide dayto-day emergency grant relief for those struggling with lupus-related expenses. You have also helped send ardent advocates to DC for the Lupus Research Alliance (LRA) Advocacy Day through the PA Fund Scholarship



ath all

Program - they successfully convinced members of the House to increase 2020 federal spending for much-needed medical advances for new treatment of lupus.

In closing, I want to wish you all as dedicated and caring supporters the very best this holiday season.

Lupus Emergency Grant Program

The PA Fund is excited to have launched our Lupus Emergency Grant Pilot Program and has already awarded several grants to people in need to cover day-to-day, lupus-related, emergency living expenses. Individuals were chosen based on a formal application and stringent review process by a multi-disciplinary grant committee. The grant monies cover expenses that address the immediate financial concerns of people living with lupus ranging from an overdue electric bill to unpaid physician bills and purchases of durable medical equipment to assist lupus patients in their daily struggle with this disease. The positive feedback from awardees has been overwhelming, demonstrating the importance of this program to individuals with limited resources to help navigate their illness. Here's what a sampling of grant beneficiaries had to say:

"This is great news, thank you so much! I accept the grant. I'm so very grateful as this grant will improve the quality of my life. It has been a blessing." Jessica

"I'm so thankful for your help in awarding me this grant to cover the balance of my rheumatologist's bill that my insurance company rejected." Bianca

Lupus Advocacy Conference and Hill Day - March 2020

For the Lupus Research Alliance's Annual Lupus Advocacy Conference and Hill Day, DC- March 2020, the LRA has collaborated with the PA Fund Scholarship Program on its application process by offering, in addition to the PA Fund scholarships, grants to people whose applications demonstrated a strong desire to advocate on behalf of the lupus community. Over 100 excellent applications were received -- a testament to our advocates' passion to educate their representatives about the urgent needs of people with lupus. Between the two sources of funding, the number of awards has doubled. This year one of the largest groups of lupus advocates will be able to join together on the Hill and tell Congressional decision-makers their daily life struggles with such a complex disease to illustrate why increased funding is critical for the research that can deliver better treatments and ultimately a cure.

Support Groups

Support groups continue to be a cornerstone of the PA Fund mission, providing a deep sense of community as well as a framework for social networking. Participants learn more about managing their illness and share their lupus journey not only with each other, but also to others who may not be able to get out for group meetings.

Several of the support groups are directed by a volunteer peer leader, Anne Zablotowicz. This year the PA Fund is extending an honorary PA Fund scholarship to Anne, affording her the opportunity to attend this year's Annual Advocacy Conference and Hill Day. This scholarship is a gesture of gratitude from the Fund for her enormous gift of time, care and commitment to helping others in need of guidance.



Support Group Holiday Party

Mail-In & Online Donations

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