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Advocacy Conference 2018, Washington D.C.

ADVOCACY

The Critical First Step

Advocacy can mean different things to different people. Some seek to make changes in policy and funding at state and federal levels by helping Congress and government agencies better understand what it means to live with lupus. For others, advocacy is a way to take action with respect to their own health.

Regardless of the motive, one thing is certain – the lupus community is highly motivated, extremely active, and tremendously successful! On a national level, our advocacy with Congress has resulted in an increased budget from the federal government for medical research, dedicated funds for lupus research specifically, and programs to address racial disparities in healthcare. On a state level, advocates have been very effective in gaining awareness for what remains a little-known disease.

Our hard work is being rewarded. The Lupus Research Alliance – with lupus advocates across the country – has fought for lupus research to be recognized as a federal priority, and we are seeing the fruits of our labor.

Strongly supported by our advocacy community, the National Institutes of Health (NIH) Action Plan for Lupus Research was updated in 2016 under the direction of the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS). This recent report updated the previous NIH strategic research plan driven by Lupus Research Alliance advocates.

Originally published in 2007, *The Future Directions of Lupus Research* guided the nation's investment in lupus research for nearly a decade.

“Advocacy helped motivate NIAMS to initiate the 2007 plan, which has evolved into the current comprehensive roadmap for the nation’s investment in lupus research going forward,” said Diane Gross, National Director of Advocacy and Programs for the Lupus Research Alliance. “This effort was designed to **dramatically improve our understanding of lupus and set priorities for the direction of lupus scientific exploration.**”

Another series of successes – in 2004, our advocates were able to get lupus included as one of many diseases eligible for funding through the Department of Defense Congressionally Directed Medical Research Programs (CDMRP). Our persistence has maintained that designation every year since. But even more impressive and important, our advocacy resulted in a new program created in 2017 that designates funding just for lupus – the Lupus Research Program allocated \$5 million in its first year under the CDMRP operated by the Army Medical Research and Materiel Command in Ft. Detrick, MD.

Based on the critical need for better treatments and the overwhelming response to the first call for grant proposals, our advocates effectively secured an additional \$5 million to continue the Lupus Research Program in 2018. Most recently, the federal budget was approved to allocate \$5 million for Year 3 in Fiscal Year 2019!

In addition, our yearly requests have elicited billions for biomedical research funded by the NIH.



Diane Gross

ADVOCACY ON THE PERSONAL LEVEL

“Advocacy has many forms, including taking action for one’s own health. It’s self-advocacy – even though many would not think of their actions this way,” explains Diane. “When patients hear that their insurance company is not going to pay for a medication and then they get on the phone to complain – what they are doing is self-advocacy.”

This is a point Diane always makes when she speaks to groups who want to become more involved in their own health and issues that affect the larger lupus community. “People soon realize that they are already advocates,” she continued.

Driving the point further, Diane asks: “Wouldn’t it be great if you showed up at the pharmacy and your medications were covered with no problem? Well, you can work toward making that difference.” Diane tells her audiences they can make their voice be heard ... that contacting state and federal legislators to tell their story can propel changes in legislation.



Dr. Betty Diamond

LUPUS INSIGHT PRIZE PRESENTED TO DR. BETTY DIAMOND

The 2018 Lupus Insight Prize was awarded to Betty Diamond, MD, for her groundbreaking work in lupus nephritis.

Through the Lupus Insight Prize, the Lupus Research Alliance awards \$100,000 in recognition of major insights and discoveries that can change scientific thinking and generate advances in the understanding, diagnosis, and treatment of lupus.

The Lupus Research Alliance congratulates Dr. Diamond on her tremendous contributions to lupus research.

PATIENT INVOLVEMENT

The Next Critical Step

Certainly, advocacy is absolutely necessary to generate funding for the National Institutes of Health (NIH) and other federal organizations, as well as for groups that support and conduct lupus research. But **patient involvement is also critical to opening pathways to discovery.**

“Just helping to raise money isn’t enough,” said Diane. “We need people to be part of research. There are more clinical trials in lupus than ever before, so there are a lot of opportunities for people to get involved – yet there is not enough patient participation, particularly among minority groups.”

Visit LupusTrials.org to learn more about clinical trials and explore studies that might be right for you.

The Lupus Research Alliance is working hard to inform the lupus community about clinical trials so potential new ways to diagnose and treat lupus can be tested and approved by the U.S. Food and Drug Administration (FDA).

For instance, to help ensure greater diversity among trial participants, the Lupus Research Alliance recently launched the Lupus Multi-Cultural Engagement Partnership with the National Minority Quality Forum. A full report of the group’s (NMQF) inaugural meeting will be released this fall to inform development of new strategies that can help increase enrollment of traditionally underrepresented populations in lupus clinical research.

This fall, the Alliance has partnered with the digital health company, Antidote, to better understand patient perspectives on medical research. We invited the lupus community to take part in a national survey.

In addition, the Lupus Research Alliance is a champion for the *NIH All of Us Research Program*, a large-scale effort to gather data from at least one million Americans “to improve health outcomes, identify new treatments for disease, and begin a

new era in preventive care and medical treatment.” **“The more we know about what makes each person unique, the more customized health care can become,”** notes Dr. Francis Collins, NIH Director.

Incorporating the patient perspective in the drug development process is also why the Lupus Research Alliance worked with the Lupus and Allied Diseases Association and the Lupus Foundation of America on a collaborative program called the Patient-Focused Drug Development (PFDD) Initiative to inform FDA officials reviewing potential new treatments about the needs of people with lupus.

Patient advocacy also impacts the pharmaceutical industry. Today, biopharmaceutical companies are working with advocacy groups more frequently and closely than ever to ensure that patient priorities are always considered as potential therapies are developed. This relationship is expected to greatly speed the therapeutic discovery process.

The Lupus Research Alliance is proud of our lupus community. **Together we have spoken out and together we have been heard.** Our greatest rewards have been the ground we have gained ... the bills that have passed ... and seeing people become empowered to step up and take action.



Kenneth M. Farber with NMQF President/CEO Dr. Gary A. Puckrein



Lupus PFDD Meeting Attendees

Lupus Patient-Focused Drug Development Meeting

The Lupus Research Alliance collaborated with the Lupus and Allied Diseases Association and the Lupus Foundation of America on a groundbreaking initiative in cooperation with the Food and Drug Administration's (FDA) externally-led Patient-Focused Drug Development (PFDD) program. The well-attended meeting hosted by the three groups supplemented by a national survey of people with lupus resulted in a comprehensive report, *Lupus: Patient Voices*, released this spring. With quantifiable results and personal accounts from people with lupus, the report has been shared with the FDA. The information meets the FDA criteria for patient experience data, meaning that the findings can be considered during the Agency's review and approval process of new drugs for lupus.

The FDA initiated the PFDD program as part of its commitment to "systematically obtain the patient perspective on specific diseases and their treatments."

Kenneth M. Farber, President and CEO of the Lupus Research Alliance, noted, "We are proud to have collaborated with the lupus community nationwide in supporting the FDA's commitment to hearing patient concerns and priorities. **This pioneering approach to providing the FDA with patient perspectives empowers patients with the knowledge that their words can open minds and guide policy.**"

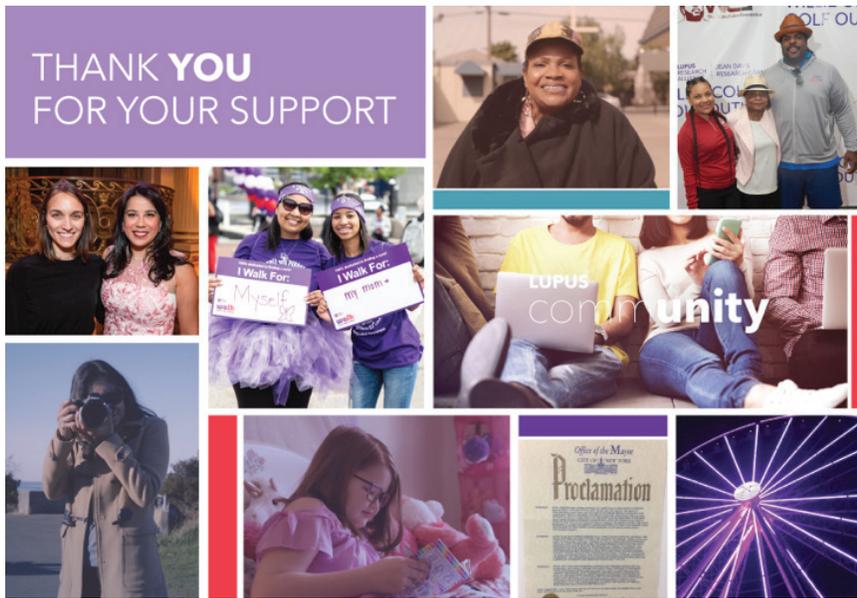
Serving Underserved Lupus Communities



The Lupus Research Alliance's Multi-cultural Outreach Task Force is out in full force to raise awareness among the African American communities, who face a higher risk of developing the disease, at health expos around the country, including the Essence Music Festival in New Orleans, LA this summer and Healthy Churches 2020 National Conference hosted by the Balm in Gilead this fall.

The Lupus Research Alliance is at these events to hand out educational materials and talk to attendees about lupus.

Celebrating Lupus Awareness Month



“For us, raising awareness about this awful disease isn’t limited to May. All year long, we are engaged in delivering discoveries that can transform lives. Because that is where real hope begins.”

Kenneth M. Farber, President and CEO

Lupus gained the attention it deserves throughout the month of May! Millions of people throughout America learned about the urgent need for lupus research through:

- Launch of Lupus Research Alliance **Community**
- Premiere of **Film Short Series** featuring 4 extraordinary lupus superstars
- **Walk with Us to Cure Lupus** events across the country
- **Willie Colon Golf Outing** fundraiser
- **9th Annual Lupus Handbag Luncheon & Silent Auction**
- First-ever grants awarded by the **Department of Defense**
- **Lupus Research Program** secured by Lupus Research Alliance advocates
- May proclaimed **Lupus Awareness Month** throughout the country!
- Broad presence on social media including **One Line, One Day** Campaign
- Featured in **PUMA** launch of **Defy Sneaker** with Selena Gomez
- **CBS Cares Public Service Announcement** airing on national TV
- Participation in educational events

Visit lupusresearch.org to make a donation, learn more about lupus and our funded lupus research, or find out about our *Walk with Us to Cure Lupus* program.



walk WITH US
TO CURE LUPUS

100% of all donations goes to support lupus research programs because the Lupus Research Alliance Board of Directors funds all administrative and fundraising costs.

For the latest, up-to-date information about lupus you can join our online community on



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