



## Make Your Voice Heard on Lupus Drug Development

The national lupus patient advocacy community is excited to announce that **people with lupus will have the chance to be part of a history-making project** that includes a meeting called **Lupus: Patient Voices** on September 25 in the Washington, D.C. area. This very important effort is a tremendous opportunity for individuals with lupus to contribute to lupus drug development by sharing how the disease affects their daily lives and their thoughts on current and future treatments.

**If you have lupus or are the parent of a child with lupus**, we urge you to **make your voice heard by sharing your lupus experience** and what matters most to you when it comes to lupus drugs. By donating your time and input to this incredible project you will inform Food and Drug Administration (FDA) officials as they make decisions about future lupus treatments. **Please join your fellow lupus activists from all across the nation and take action to help make a difference in the lives of those with lupus!**

Learn more at [www.lupuspfdd.org](http://www.lupuspfdd.org) a website dedicated to this important initiative. **ACT NOW** and visit the site **TODAY** to learn how you can participate including:

- **Tell your lupus story** by taking the online survey and **you will have the chance to share your unique perspective** with the FDA and drug companies on living with lupus, what concerns you most, and your views on new treatments. The survey will collect information to assist in the planning of the September 25 meeting and in the development of a report to the FDA afterwards. **The impact of the survey** and the report **depends on you** telling your story. **Your contributions are critical!**
- **Take part in the actual meeting** by attending **in person or** joining **virtually** through the online webcast. The Lupus Patient-Focused Drug Development (PFDD) Meeting will be held Monday, September 25 at the College Park Marriott Hotel and Conference Center in Hyattsville, MD (just outside of Washington, D.C.) and includes **opportunities for people with lupus to provide input** on patient panels and during facilitated discussions and an open comment period. **Your voice matters!**

The Lupus PFDD Meeting is being organized by the Lupus and Allied Diseases Association, the Lupus Foundation of America, and the Lupus Research Alliance. Here's what they have to say about this historical event:

"For far too long individuals with lupus have suffered greatly from the lack of adequate treatments, but through the PFFD project they now have the extraordinary opportunity to sit at the table, share their unique viewpoints, and be heard by the FDA," said Kathleen A. Arntsen, Lupus and Allied Diseases Association President and CEO. "We are thrilled to be part of this remarkable and long overdue initiative and we strongly urge anyone living with this debilitating disease to act now by taking the survey to help advance new therapies in lupus."

"The Lupus Patient Focused Drug Development Meeting is an incredible opportunity for people with lupus to change the way new treatments are discovered, tested and approved and to bring those treatments to patients as fast as possible," said Sandra C. Raymond, Lupus Foundation of America President and CEO. "The lupus community has united to support this critical effort

and we encourage all people with lupus to participate and share their story so that we can continue to make a difference in the fight against this cruel disease.”

“The PFDD program demonstrates that the FDA is actively listening to patient concerns and priorities in considering how best to evaluate potential new drugs and diagnostic tools,” said Margaret G. Dowd, Lupus Research Alliance Co-CEO and Co-President. Kenneth M. Farber, Co-CEO and Co-President of the Lupus Research Alliance added, “We are proud to collaborate with the lupus community nationwide to support the FDA’s commitment and urge everyone to answer the call for feedback with the patient survey as a first important step.”

**Your input as a person with lupus is extremely valuable and important to the success of this project.** Please do not miss out on this amazing and unique opportunity to be a powerful lupus activist and to help drive lupus drug development forward with your voice. We encourage every person with lupus to **take action now by completing the survey** even if you are unable to participate in the meeting. We greatly appreciate your time and efforts.

To learn more about the project and take the survey, please visit our website:  
[www.lupuspfdd.org](http://www.lupuspfdd.org)