



Lupus ends with Us!



Lupus: Patient Voices Report Released Today

We are pleased to announce the release of ***Lupus: Patient Voices***, a comprehensive report based on input from the Externally-led Lupus Patient-Focused Drug Development (PFDD) Meeting and pre-meeting survey conducted last fall. This report includes data and personal accounts from people with lupus on symptoms, daily disease impacts, current treatments, and views on clinical trials. **The report has been shared directly with the Food and Drug Administration (FDA) to help advance treatments for lupus.**

The Lupus PFDD Initiative began over two years ago when the FDA responded favorably to a letter of intent to host an externally-led PFDD meeting submitted by the lupus community. Last summer, **over 2,100 people completed a survey** about their experiences with lupus, yielding important data about disease symptoms and treatments. On September 25, 2017, **over 300 people with lupus and their representatives attended** the Lupus PFDD Meeting in Hyattsville, MD and **nearly 300 more participated** via a live webcast. The meeting presentations, facilitated discussions, and post-meeting comments informed the content of the ***Lupus: Patient Voices Report***.

This report is considered patient experience data, meaning that it can be used by the FDA during the review and approval process of new drugs for lupus. We hope that this **report will help the FDA to better understand the perspectives and experiences of people with lupus and advance superior treatments** for this devastating disease.

We are grateful to everyone who helped to make this report possible including the many **lupus groups** across the country, **researchers, clinicians, the FDA, our biopharmaceutical sponsors**, and, most of all, **people with lupus and their loved ones. Thank you!**

[READ THE FULL REPORT HERE](#)

The ***Lupus: Patient Voices*** Report and the Lupus PFDD Meeting are the result of a collaboration by the Lupus and Allied Diseases Association, the Lupus Foundation of America, and the Lupus Research Alliance. To learn more about the Lupus PFDD Initiative, please visit **lupuspfdd.org**

