



## **Overview of Lupus ABC Inaugural Meeting April 16-17, 2023**

The Lupus Research Alliance is pleased to report that the Lupus Accelerating Breakthroughs Consortium (Lupus ABC) held its inaugural meeting on April 16-17 in Bethesda, Maryland. Lupus ABC is the first public-private partnership with the U.S. Food and Drug Administration (FDA) to focus specifically on advancing the development of safer and more effective treatments urgently needed for people with lupus. The goal of the Lupus ABC is to bring together people with lupus, federal agencies, medical societies, advocacy groups, industry, academic clinical researchers, and scientists, with the FDA, to overcome scientific hurdles in drug development that are beyond the capacity of any single entity. This meeting was an important first step in formally constituting the consortium and serves as a launching point for continued community outreach and engagement. In addition to an open plenary session, the first individual meetings of the two main governing committees of the consortium were held to set the strategy for the Lupus ABC – the Lupus Voices Council (LVC) and the Research Committee (RC).

### **Lupus Voices Council Session**

The Lupus Voices Council (LVC), is responsible for providing the Lupus ABC with the perspectives priorities and needs of individuals with lupus, including the symptoms and experiences that matter most, as well as identifying mechanisms for ensuring that the diversity of perspectives of the community are reflected in the Lupus ABC's efforts. The initial LVC panel is comprised of people with lupus and care partners with a broad range of experiences and expertise who have previously served on other advisory bodies. The LVC will be seeking nominations from the community to fill openings in the future.

The LVC members discussed a wide range of topics of interest to the lupus community including better diagnostics; impact of complementary, alternative and holistic approaches; better understanding of what causes lupus; improved treatment protocols; preventive therapies and minimizing flares; and a cure. They also provided feedback on potential projects that the Research Committee may undertake. The group expressed strong support for projects that improve clinical trial design as well as those that improve outcome measures, such as optimizing the value of patient reported outcomes.

### **Plenary Session**

A plenary meeting of the Lupus ABC was held during the morning of April 17 and set the tone for the day by noting the ambitious goals that were expected from Lupus ABC. Presentations were made by leaders in the lupus community, including Dr. Nikolay Nikolov, Director of the Division of Rheumatology and Transplant Medicine, Center for Drug Evaluation and Research, FDA. Lupus Research Alliance CEO Albert Roy; and LVC co-chairs Dr. Kelly McVearry and Veronica Vargas Lupo; Melissa West of the American Society of Nephrology, who formerly led the Kidney Health Initiative PPP, shared what she learned over the years of work with what is considered one of the most successful FDA PPPs.

### **Research Committee Discussion**

The Research Committee's initial meeting focused on discussing and prioritizing its initial projects. The Committee discussed several ideas including improving outcome measures for determining the effectiveness of lupus drugs in all types of lupus, including cutaneous lupus, as well as those that would improve how clinical trials in lupus are designed, including for adolescent and pediatric patients with lupus. The RC will be considering moving forward with one or more of these projects, as individual Working Groups, after formal evaluation of the projects' details is completed.

Lupus ABC committees will be meeting approximately quarterly with the next meeting to take place this summer, while Working Groups will convene monthly to advance the goals of the specific Lupus ABC projects. The lupus community will be kept abreast of Lupus ABC developments via its website; visit [LupusABC.org](https://LupusABC.org) for more background and updates about this public-private partnership.