Friedreich Ataxia Patient Focused Drug Development (PFDD) Meeting.

Tell the FDA what is important to you in finding a treatment for Friedreich Ataxia

An upcoming Friedreich ataxia (FRDA) Patient Focused Drug Development (PFDD) meeting with the U.S. Food and Drug Administration (FDA) is your opportunity to tell FDA and drug developers about challenges and burdens you have experienced with FRDA, and share your thoughts about what is most important to you in evaluating potential new treatments for the disease.

The meeting, co-organized by the National Ataxia Foundation, Friedreich's Ataxia Research Alliance, and Muscular Dystrophy Association, marks the first-time patients and families affected by FRDA will be able to speak directly to the FDA and share their experiences in their own words.

Information captured at the meeting, summarizing input about the patient experience from people with FRDA across the country, will be published in a "Voice of the Patient" report and submitted to the FDA for inclusion in the framework used to evaluate future FRDA therapies.

There are several ways you can get involved:

- Attend the PDFF meeting in Bethesda, MD on June 2, from 8 a.m. – 12:30 p.m., at the College Park Marriott and Conference Center.
- If you cannot attend in-person, join online via streaming webcast and share your input on the specific panel questions, as well as demographic questions.
- Keep an eye out for future communications and surveys through which you may be able to contribute your thoughts.

No one can make the voice of the FRDA community heard more than those impacted by the disease. Your participation is critical to making sure our collective voice makes an impact. Don't miss out on the opportunity to make sure your input helps guide the development of successful, effective, meaningful treatments for FRDA. If you have questions, you may contact Sue Hagen at susan@ataxia.org.