



Adult Polyglucosan Body Disease Natural History Study

We are pleased to announce the launch of the APBD Research Foundation and NORD Natural History Study (APBDRF-FAN), a collaborative effort between the APBD Research Foundation and the National Organization for Rare Disorders (NORD) to study Adult Polyglucosan Body Disease (APBD). The APBDRF was selected by NORD to create the APBDRF-FAN as part of a cooperative project between NORD and the U.S. Food and Drug Administration (FDA) that supports research on rare diseases and how they progress over time - natural history studies.

OVERVIEW OF RESEARCH STUDY

The APBDRF-FAN is more than a versatile online system that securely collects and stores data for medical research; it is a dynamic participant-driven resource that can empower and unite the APBD community through shared knowledge. Registry participants not only can complete surveys about their own disease experiences, but also can learn about other participants' experiences by viewing aggregated survey data. As the registry sponsor, the APBDRF will ensure that data privacy and confidentiality are strictly maintained. Participation in the APBDRF-FAN is free and voluntary, and participants may withdraw at any time.

COMMUNITY INVOLVEMENT

The APBDRF-FAN is a powerful opportunity for individuals with APBD and their family members to contribute directly to research that will enhance our understanding of APBD, thus facilitating the development of new diagnostic and treatment options. Participation is especially vital given the rarity of APBD - every patient experience is a unique and invaluable part of the natural history of APBD.

For further information or to join, please contact:
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About (Member Organization)

The APBD Research Foundation is dedicated to increasing public awareness and understanding of APBD, especially in the at-risk Ashkenazi Jewish Community and the medical community, which still remains largely unaware of the disease. The Foundation is also committed to supporting research studies that may lead to new treatment options and a cure. The research strategy of the Foundation is driven by its unparalleled Scientific Advisory Board, a multidisciplinary, international group of leading researchers and clinicians.

About NORD

NORD, a 501(c)(3) organization, is a patient advocacy organization dedicated to individuals with rare diseases and the organizations that serve them. NORD, along with its more than 250 patient organization members, is committed to the identification, treatment, and cure of rare disorders through programs of education, advocacy, research, and patient services.

