END OF YEAR CAMPAIGN

APBD
ADULT POLYGLUCOSAN BODY DISEASE
RESEARCH FOUNDATION

November 2022

Dear Name,

The APBD Research Foundation advocates for patients' unmet needs; develops supportive and collaborative networks of health professionals, researchers, and patients; and funds research.

As we approach year-end 2022, we aim to raise $50,000, with your help, to ensure we start 2023 strong. But without it, we risk cutting critical APBD programs. As we look back on the past year, we are so thankful for the steadfast support of our community members and donors like you. Our work is only possible because of your involvement, contributions, and generosity. We have come a long way and there is still so much more to accomplish.

Since its founding in 2005, the APBD Research Foundation was – and continues to be – the only patient advocacy and research organization dedicated to finding treatment options and a cure for this ultra-rare, neurodegenerative condition.

In 2022, we made significant advances, with patients' needs in mind:

- We raised $99,354 for critical research through UPenn's *Million Dollar Bike Ride*;
- We held international *APBD Scientific and Community Conference* which brought together over 140 attendees – scientists, clinicians, federal agency representatives, industry partners, patients, and family members;
- We hosted 24 *Patient and Caregiver Chats,* serving as a lifeline of support for patients and family members in need of connection, resources, and answers;
- We developed the *APBD and related GSD IV Clinical Care Guidelines* in collaboration with the Association for Glycogen Storage Diseases;
- We determined the global prevalence of APBD and other GBE1 diseases in partnership with the Rare Genomes Project;
- We capped our groundbreaking *2021 Listening Session with the FDA* with a published summary that put APBD on the radar of federal agencies; … and more!

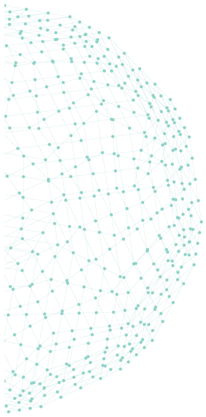
Over the past three years, we received two generous *Rare As One* grants from the Chan Zuckerberg Initiative (CZI). With the grant cycle coming to an end, your donation matters more than ever. We look to you – individuals, corporations, and foundations – to help us raise the funds needed to sustain and build from our recent successes.

Between now and December 31, 2022, we must raise $50,000. **Thanks to the generosity of anonymous donors, your gift will be matched dollar-for-dollar up to $25,000.** This year-end fundraising campaign will ensure we start 2023 strong and support the programs you and so many others rely on. As hard as we work, we need the continued support and commitment of our community to meet the match, reach our $50,000 goal, and succeed in our mission.

Please keep us fighting and being a beacon of hope.

Help us reach our goal of raising $70,000 by Dec. 31, 2022.

We cannot do it alone. Make your year-end donation today!



Looking forward, with hope, to 2023, we find ourselves positioned for breakthroughs with clinical trials, guidelines for clinical care, patient-driven programs, and so much more – all of which has been years in the making. Your support now fuels our quest for treatments and a cure for APBD.

We extend our warmest gratitude once again for your exceptional contributions to our mission-driven programs. On behalf of the entire APBD Research Foundation family, we hope to count on your support again this year.

With a full heart,

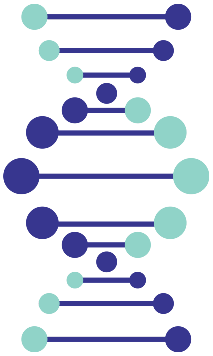
Emil Weiss

Jeff Levenson

Emil Weiss
Co-President

Jeff Levenson
Co-President

Our Mission:



We are the only US-based nonprofit supporting people with APBD. As the trusted APBD hub for medical providers, healthcare industry, and APBD families, we are the #1 source for patient information and support through our website, social media, e-newsletters, and patient and caregiver Chat events. Our mission is four-fold:

- Improve the diagnosis and treatment of APBD;
- Support affected individuals and families;
- Increase awareness of APBD among health professionals and the public;
- Facilitate the translation of research into treatments and a cure for APBD.