2021 financials

This was our first year with a paid staff person who coordinates programming, events, communication, and fundraising.

We also paid out Year 2 of our research grant commitments made in 2020.

Leadership

Board of Directors
Laura Badmaev, Founder/Chair
Daniel Ordower, Treasurer
Julie Lopez
Melissa Richards
Mike Salad

Staff
Amanda Johnson, Chief Development Officer

Revenue
- Individuals 29.2%
- Corporations 1.6%
- Foundations 69.1%

Expense
- Research network & family education 37.8%
- Research grants 57.5%
- General & administrative 4.7%

ARRE Foundation
P.O. Box 4662
Portland, ME 04112 U.S.A.

2021 Annual Report

arrefoundation.org
Laying the groundwork

We hired our first staff person to accelerate our work, built partnerships with organizations that can help us achieve our goals faster, and positioned ourselves to launch a significant project to develop our Research Roadmap in 2022.

Our Research Roadmap will establish research priorities based on family input, guide our future research investments, and catalyze scientific work on the projects that will lead us toward life-improving treatments as quickly and efficiently as possible.

Pillars of our strategic plan
- Invest in and drive ASXL research
- Improve the clinical care and management of those with ASXL syndromes
- Educate, empower, and connect the community of families, medical professionals, and researchers

2021 highlights

Community support
Volunteers raised over $28,000 to support our work using Facebook Fundraisers, including 18 campaigns for GivingTuesday

A big grant
Received a $50,000 grant as a top applicant for the Chan Zuckerberg Initiative's Rare As One program

Research progress
Launched the "Ask a Researcher" online series for families to learn about the research grants we fund

Building networks
Hosted the 2021 ASXL Family Conference and ASXL Research Symposium virtually