### **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.

# Revenue

Individuals 29.2%

Foundations 69.1% Corporations 1.6%

# Research network & family education 37.8% Research grants administrative 4.7%

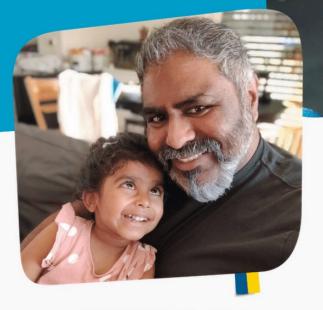
### Leadership

### **Board of Directors**

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

### Staff

Amanda Johnson, Chief Development Officer



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

arrefoundation.org

# 2021 Annual Report



### 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.



- 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



