



FY23 Year in Review - (7/1/22-6/30/23)

Fundraising/Financial:

Total Raised \$ 141,229

How we are making an impact with our donations:

- Awarded \$5714 in Back to School Bucks to 23 families
- Awarded \$8782 in Family Assistance Awards to four families
- Awarded \$4601 in Conference Travel scholarships to two families

Activity:

1) Support/Education Activity:

Dispersed funds through our Back to School Bucks program to 23 families

Dispersed funds through our Family Assistance Program to 4 families

Held an in person (and live streamed) CLOVES Family and Scientific Engagement Conference on June 3, 2023 with over 120 attendees.

Dispersed 23 children's books to families all over the world



2) Rare As One Network Activity/Collaborative Research Network :

Hosted the PIK3CA Related Conditions Research Roundtable - every other month - with basic and preclinical researchers. This group is moderated by Ralitsa Madsen of Dundee Lab.

Created a portal on Open Science Framework for our Research Roundtable to share resources, network and collaborate.

We are working on launching a new patient registry, the IAMRARE registry, with the National Organization of Rare Diseases (NORD). Launch date is Fall 2023.

We have continued working with AllStripes on their PROS natural history study.

We created, in collaboration with Scientists, [an educational video about iPSC lines](#) and their importance in disease models.

We funded one research project in FY23 through the Rare As One Grant:

\$100,000 research donation to the University of Edinburgh – Patton Lab – to develop zebrafish models of CLOVES.