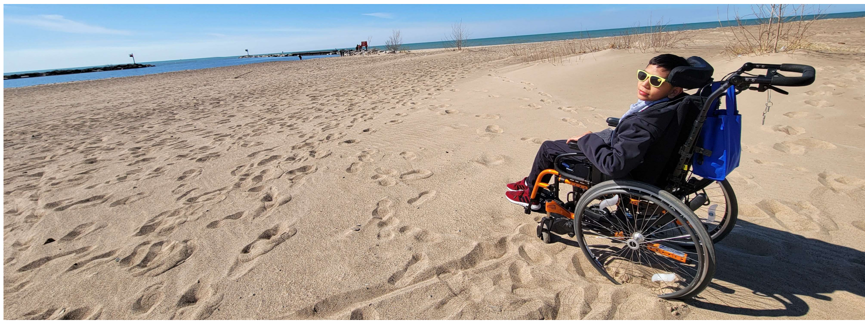
Dear Yaya Foundation Family & Friends,

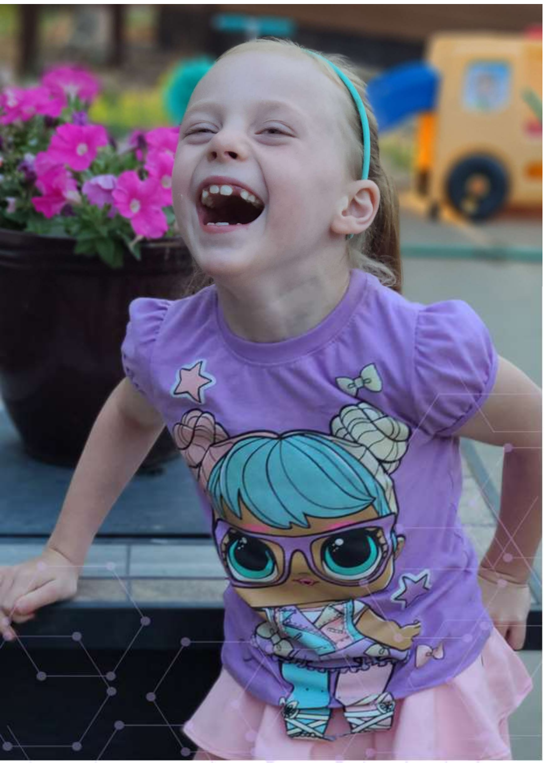
2021 has been a year of action fueled by hope – your hope, and our hope that one day, every person with 4H Leukodystrophy will have the chance to live a long, healthy life.

This year, the Yaya Foundation put hope in motion and invested in bringing researchers together to accelerate the pace of therapy discovery while connecting families with vital educational resources and emotional support. We've authored a strategic research roadmap and made progress on our journey to find a treatment and, ultimately, a cure. This past year, we

- Awarded our first-ever research grant to fund a gene therapy proof of concept in partnership with a leading 4H Leukodystrophy researcher and the President of the American Society of Gene & Cell Therapy,
- Launched a data collection program to advance what we know about 4H Leukodystrophy in which more than 50 affected families from 11 different countries have participated in less than five months, and
- Kicked off a Scientific Seminar series with global engagement from #4HLCN collaborative network, attracting new researchers from other fields.

The Yaya Foundation fights for people affected by 4H Leukodystrophy by accelerating therapy development, delivering cutting edge disease information, and connecting affected families to one another.





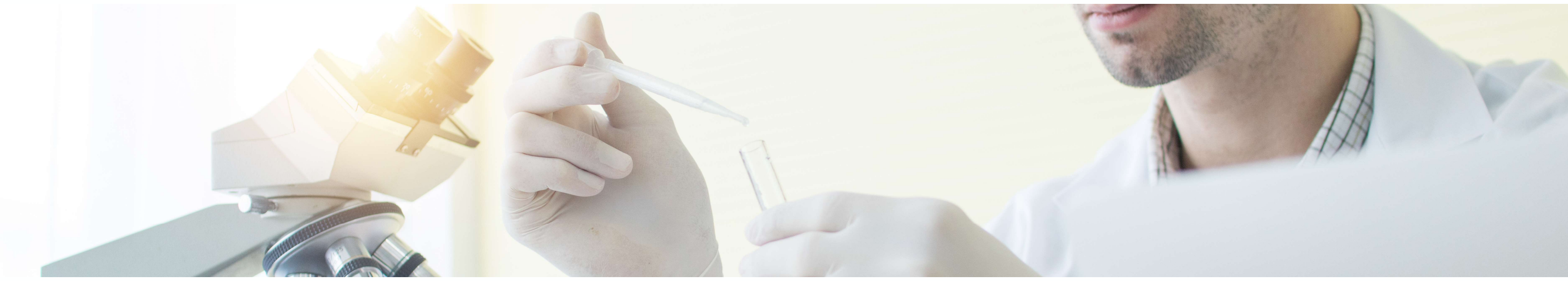
In 2021, we

- Hosted bi-monthly **#4HLFamilies calls**, increasing global engagement with expert guests such as Dr. Nicole Wolf and Dr. Genevieve Bernard,
- Created a first-ever disease overview for Newly Diagnosed families, including input from families and reviewed by Dr. Genevieve Bernard,
- Hired two **genetic counseling graduate student interns** to build family support materials with critical insight from families,
- **Connected several families to expert care**, where families were otherwise receiving standard care from providers who lacked meaningful knowledge of 4H Leukodystrophy, and
- Launched a new website with new capabilities for researchers and affected families like a curated and organized 4H research library, more family stories that show how amazing our community is, and fundraising opportunities so anyone and everyone can act on their hope!

YAYA
FOUNDATION

"Action is hope. There is no hope without action."

- Ray Bradbury, Author

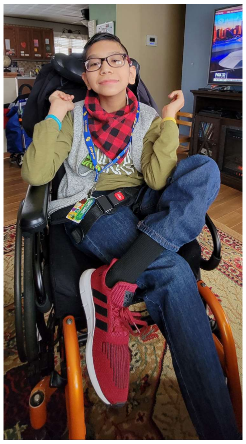


Yes, action is hope! The Yaya Foundation and our 4H Leukodystrophy family employ that hope each day with passion, commitment, innovation, leadership, and drive because we believe that all people deserve to live their lives to their fullest ability, free of rare disease.

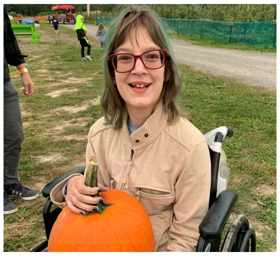
We are grateful for your support and all the hope you have demonstrated with your contributions in the past. Today, we launch our year-end fundraising campaign and are raising $100,000 between now and the close of 2021. Please donate to the Yaya Foundation – **your gift compels us and our critical work.** With urgent focus and strategic collaboration, we believe that we can rid our global community of the effects of 4H Leukodystrophy.

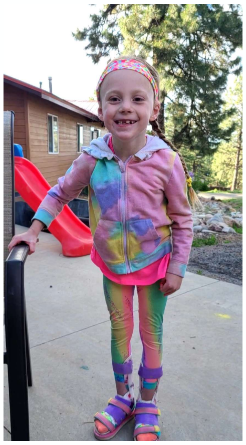
In gratitude,

Ron Garber
Father of Yaya
Co-Founder of the Yaya Foundation



Your Generosity
=
Hope For…





DONATE

Consider supporting us for
GIVINGTUESDAY
November 30th