



# PEDIATRIC RETINAL DISEASES

The Pediatric Retinal Research Foundation will focus all research initiatives and community programming on supporting the needs of children, young adults, families, and caregivers affected by the following rare retinal diseases:

Coats' Disease

Congenital X-linked Retinoschisis (CXLRS)

Familial Exuative Vitreoretinopathy (FEVR)

Norrie Disease

Persistent Fetal Vasculature Syndrome (PFVS)

Retinopathy of Prematurity (ROP)

Stickler Syndromes

Learn more at [PRRF.org](http://PRRF.org)

## CONTACT US

248-838-9102

[info@pediatricrrf.org](mailto:info@pediatricrrf.org)

PO Box 1926

Birmingham, MI 48012

 @PediatricRRF

 @Pediatric-RRF



Join the podcast team on social @ThroughOurEyes



**Support our mission. Donate today!**

[PRRF.org/donate](http://PRRF.org/donate)



## Volunteer with PRRF

As a small nonprofit, volunteers make all the difference to the success of achieving our mission. We simply couldn't do this important work without the drive and dedication of volunteers. Learn more about open opportunities at [PRRF.org/volunteer](http://PRRF.org/volunteer)



Supporting the community of families impacted by blinding pediatric retinal diseases and championing the quest for cures since 1990.

[PRRF.org](http://PRRF.org)

# RESEARCH INITIATIVES

The Pediatric Retinal Research Foundation (PRRF) is dedicated to investing in the advancement of translational research specific to rare pediatric retinal diseases. PRRF annually awards grants to researchers at Oakland University's Pediatric Retinal Research Lab (PRRL) for the pursuit of new therapies and cures for pediatric retinal diseases.

The PRRL, launched in 2011, is the only lab of its kind where researchers and clinicians collaborate to better understand rare pediatric retinal diseases.

# OPHTHALMIC BIOBANK

PRRF sponsored the first Ophthalmic Biobank in the world. The Biobank accepts tissue samples from retinal disease patients and their family members through Associated Retinal Consultants. The DNA samples are then sequenced at Oakland University's lab to aid researchers in learning more about the diseases, as well as help families understand the genetic and hereditary impact of the disease.



[Learn more at PRRF.org/Our-Research](https://www.prrf.org/Our-Research)

# COMMUNITY SUPPORT SERVICES



## Family Connection Conference

This annual free event, hosted by the Family Advisory Committee, brings together those affected by rare pediatric retinal diseases for research updates, connection with other families and an inspirational keynote.

## Through Our Eyes Podcast

Hosted by visually impaired young adults, the podcast shares what it's like to navigate high school, college, career, and beyond. Guests share their experiences and cover a wide range of topics providing actionable tips & strategies.

## Informational Resources

The PRRF website is robust with informational resources to help families and loved ones at any stage of their rare disease journey, including:

- Monthly blog posts & Client stories
- *Sightlines* eNewsletter
- Ask the Doc videos (and more)

# INFORMATION FOR PARENTS & CAREGIVERS

All of the following resources can be found on our website by visiting [PRRF.org](https://www.prrf.org).

- Active learning materials
- Educational support & advocacy
- Remote educational & emotional support
- Mobile assistive technologies for people with low vision & blindness
- Navigating college with visual impairments
- Employment resources for visually impaired
- Free access passes to national parks & federal recreational lands
- Camping for the blind & visually impaired
- And much more...

