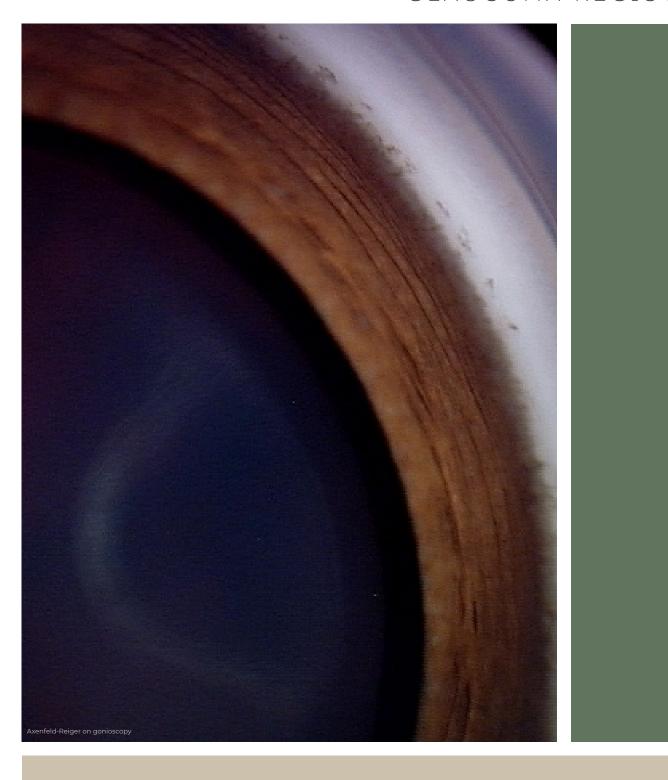
2024

ROBISON HARLEY CGRN INTERNATIONAL PEDIATRIC GLAUCOMA REGISTRY



Newsletter



New Sites

University of Pittsburgh, USA



<u>University College Hospital,</u> <u>Ibadan Nigeria</u>



<u>Chinese University of Hong.</u> <u>Kong, Hong Kong.</u>



LV Prasad Eye Institute (LVPEI), India



Introduction

The registry now houses over 1000 cases of pediatric glaucoma from over 25 sites internationally! We have many more sites joining and are always happy to welcome additional sites into our community. We are all committed to our mutual goal of helping children with glaucoma. Feel free to reach out to me if you have any questions or are interested in joining!

The Robison Harley Childhood Glaucoma Research Network (CGRN) International Pediatric Glaucoma Registry is a centralized database hosted at the University of Rochester to facilitate collaborative research worldwide. There is no charge to join, participate, or develop research from the Registry. The data is available to members for their use for research, under their own authorship. The data that is contributed is instrumental in driving research, refining treatment approaches, and ultimately improving the lives of children affected by glaucoma.



Registry Coordinator
Jacob Perkins

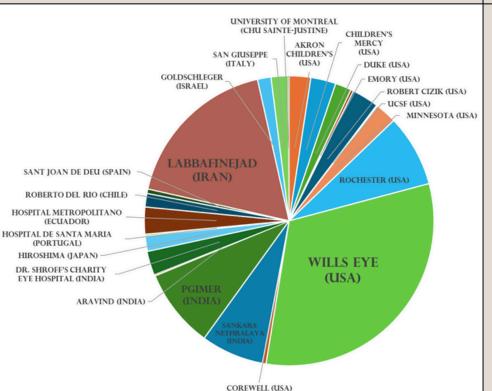
Hello Everyone,
My name is Jacob, and I am the
new registry coordinator. It is a
privilege to join this initiative
and I am excited for the
opportunity to improve the lives
of children with glaucoma!

Background: I was born and raised in Rochester, New York. I obtained my Medical Degree from the Jacobs School of Medicine and Biomedical Sciences, University at Buffalo. I have enjoyed working in Population Eye Health, Ocular Genetics, and Retinal Degeneration Research.

My hobbies include playing soccer, basketball, and volleyball. I have a passion for playing piano and exploring national parks (Favorite: Glacier National Park). Also, I am a huge Buffalo Bills (American Football) Fan!

Newsletter

BREAKDOWN OF DATA ENTRY BY SITE



UPDATES

New Registry Webpage

- All participating institutions listed at:
- https://www.urmc.rochester.edu/ eye-institute/research/pediatricglaucoma-registry.aspx

<u>First Publication Using Registry</u> **Data**

- Accepted to Ophthalmology Glaucoma and pending publication:
- Beldick SR, Rockter A, Beck AD, Levin AV: The Robison D. Harley, MD Childhood Glaucoma Research Network International Pediatric Glaucoma Registry: The First 872 Cases. [In Press] Ophthalmology Glaucoma

Site Highlight: Post Graduate Institute of Medical Education and Research (PGIMER), India

We are proud to recognize PGIMER as the 3rd highest registry contributor in 2024! Congratulations and thank you to the entire PGIMER team for their commitment to improving the treatment and lives of children with glaucoma! Here is a statement from the lead contact at PGIMER, Dr. Sushmita Kaushik, Professor of Ophthalmology:



"I have had a special interest in childhood glaucoma for many years. Once I realized childhood glaucoma was being lost in the crowds of adults, since they need much more than just intraocular pressure control, I set about organizing focused care of children within our Department's Glaucoma Service. I spearheaded the starting of a dedicated Pediatric Glaucoma Service at the Advanced Eye Center, PGIMER, in 2012, which has now grown into a separate dedicated Pediatric Glaucoma Clinic.

In the last 12 years we have contributed 31 publications including the description of distinct phenotypes of neonatal onset glaucoma, the characterization of genetic variants, establishing the role of oral propranolol in Sturge-Weber syndrome, demonstrating the utility of angle surgery in India, and describing rubella newborn glaucoma. I was honoured to have been conferred the Noel Rice Oration by the United Kingdom Pediatric Glaucoma Society in 2019 in recognition of the work done in childhood glaucoma. We formed the Indian Pediatric Glaucoma Society with Dr Sirisha Senthil and Dr Viney Gupta and spearheaded a Indian 15-center survey of childhood glaucoma. We are happy to have been invited to participate in the Registry. We believe it will add to the knowledge about varied phenotypes of various entities in different ethnicities and help in better characterization of disease."

DO YOU KNOW A SITE THAT WOULD LIKE TO JOIN OR THAT SEES A NUMBER OF CHILDREN WITH GLAUCOMA? LET US KNOW!

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