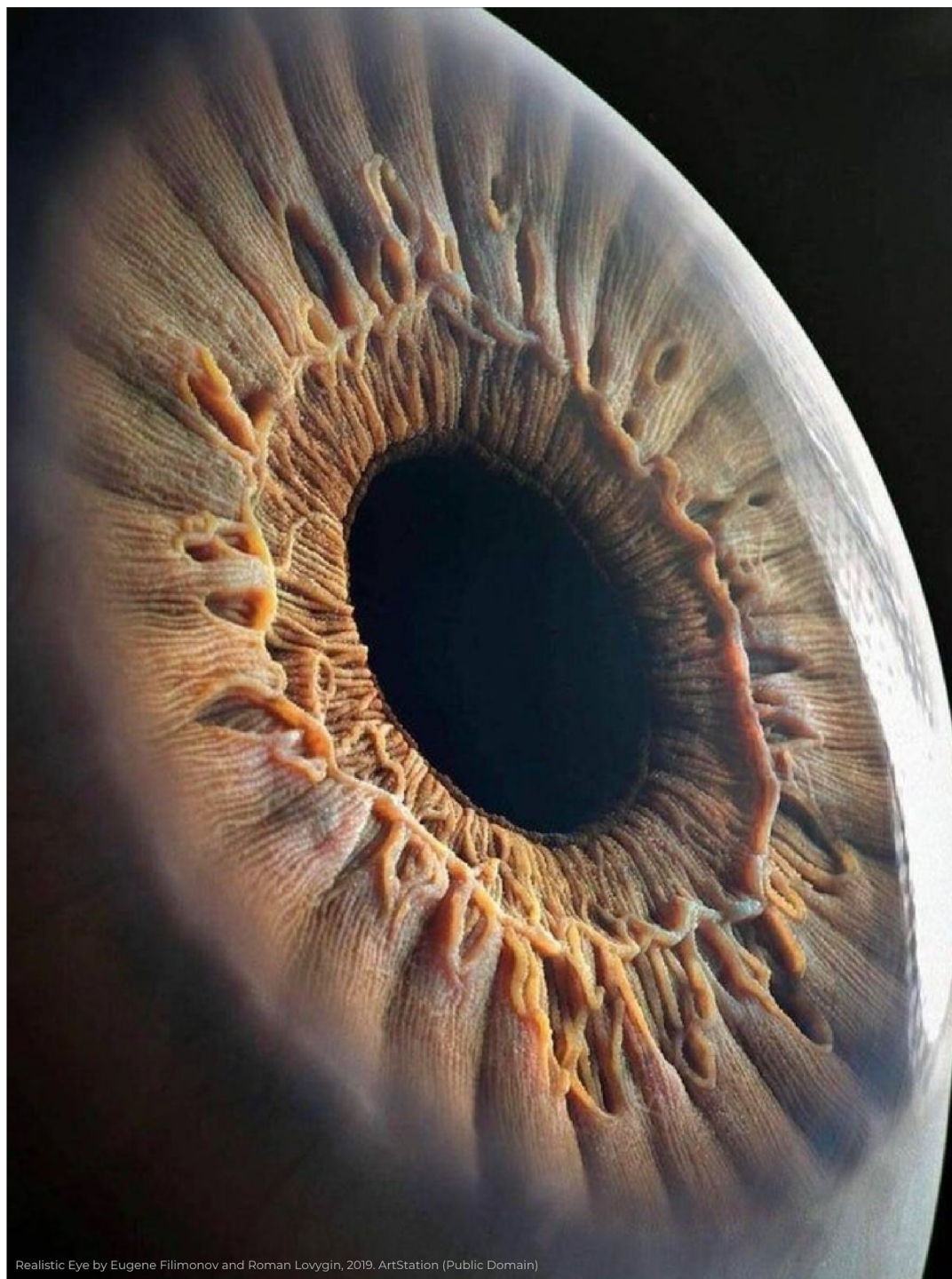


2023|

ROBISON HARLEY CGRN INTERNATIONAL PEDIATRIC GLAUCOMA REGISTRY



Realistic Eye by Eugene Fillimonov and Roman Lovygin, 2019, ArtStation (Public Domain)





New Sites

Helen DeVos Children's Hospital, USA



CHU Sainte-Justine, Canada



Updates

The registry now houses over 900 cases of pediatric glaucoma from over 20 sites internationally! We also have over 15 sites currently in the process of joining. We are always looking to add more sites from all across the world. Please reach out to me if you or someone you know is interested in joining!

The Registry is an international centralized secure de-identified website database of childhood glaucoma hosted at the University of Rochester, with the intent of fostering research on pediatric glaucoma. Patient data can be entered from anywhere in the world and any site worldwide is welcome to join. There is no charge to join. After entering 10 patients, individual sites have access to the entire registry for their IRB approved research. Researchers retain all authorship on any papers arising from the data. It is a "win-win" for all!



Registry Coordinator

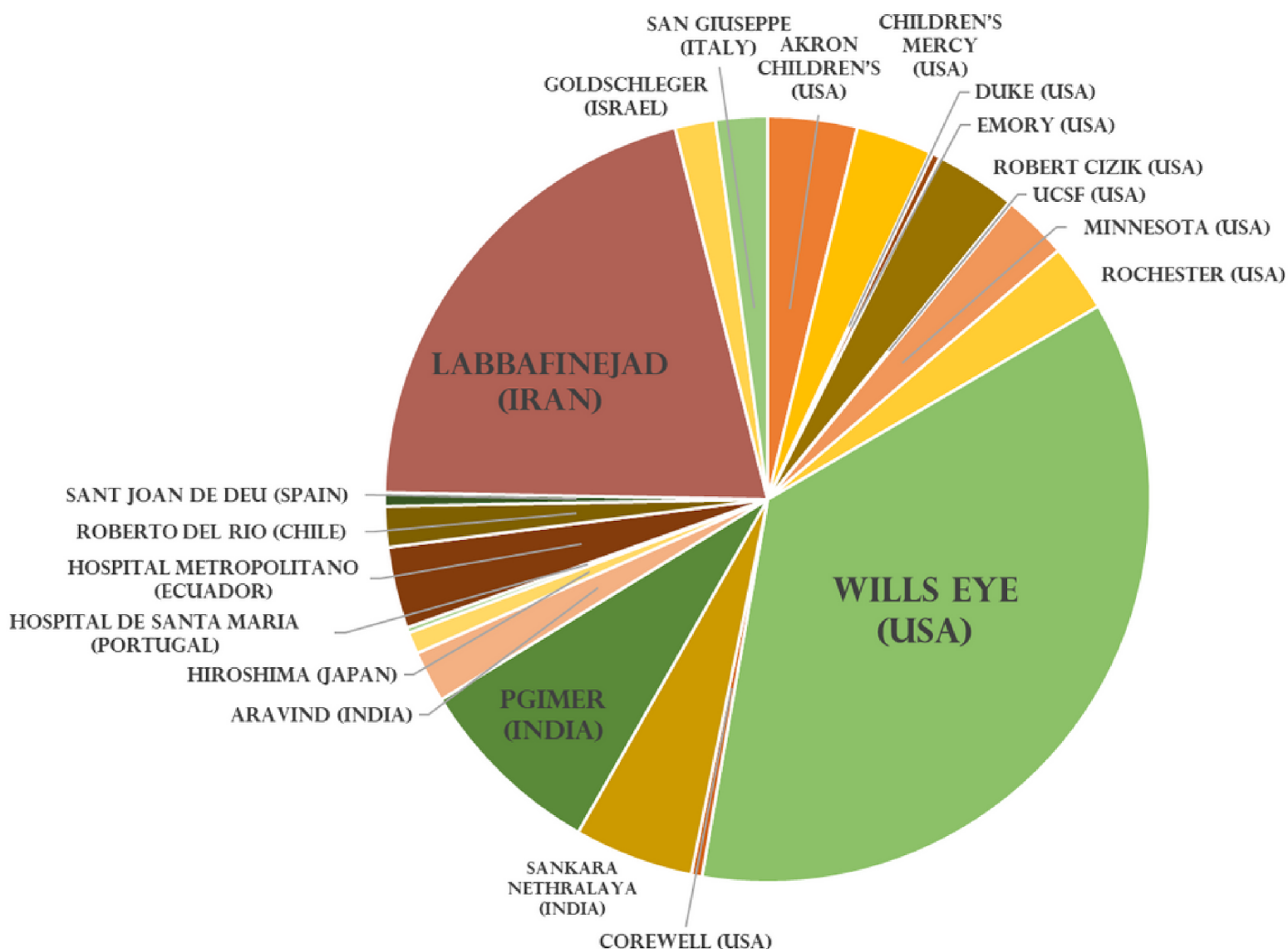
Kinza Abbas

Hello, my name is Kinza and I am the new registry coordinator. I am excited and honored to join this effort on behalf of all the patients and families affected by pediatric glaucoma!

As an introduction, I was born and raised in New Jersey. I am obtaining my medical degree from Geisinger Commonwealth School of Medicine in Pennsylvania. Before medical school, I studied cell biology, neuroscience and psychology at Rutgers University, New Jersey. In my free time, I enjoy painting, reading, hiking, visiting museums and exploring new places. The picture above was taken at the Grand Canyon during winter, which was a beautiful sight!

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BREAKDOWN OF DATA ENTRY BY SITE



The Robison D. Harley, MD Childhood Glaucoma Research Network (CGRN) International Pediatric Glaucoma Registry: The First 872 cases

Stephanie R. Beldick, MD, MSc, Adam Rockter, BS, Alex V. Levin, MD, MHSc

The University of Rochester will be reporting on the initial epidemiologic data entered in the registry, describing unique phenotypes between countries by exploring differences in family history, disease presentation and glaucoma type. This report has been presented at the Canadian Ophthalmological Society and is currently in the process of being submitted!

Please reach out by email if you are interested in investigating the registry data for studies at your sites!

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