

The CGRN is proudly sponsored by:

The University of Minnesota Center for Pediatric Glaucoma
The GL Foundation for Children with Glaucoma

Childhood Glaucoma Research Network Strategic Overview 2012

What is the CGRN?

The Childhood Glaucoma Research Network (CGRN) is comprised of clinicians and scientists who specialize in treating children with glaucoma. The CGRN connects doctors around the globe to leverage each member's unique expertise and understanding of pediatric eye disease and glaucoma in order to promote progress and advance research in the care of childhood glaucoma. CGRN members come from top institutions across the world. An advisory Committee composed of distinguished Pediatric Ophthalmologists and Glaucoma Specialists is responsible for oversight and execution of CGRN projects.

Our Mission:

The CGRN is dedicated to supporting research, education and process of care projects that result in high quality, evidence based care of children with glaucoma. Because the role of parents is also vital to successful outcomes, the CGRN also supports development of educational resources for parents.

Our Goals:

Quality of Care: To ensure high quality, evidence based care by providing guidance on diagnosis & treatment strategies in children with glaucoma.

Research: To support projects that increase the evidence base related to: 1) incidence and prevalence, 2) diagnosis, 3) treatment outcomes, and 4) quality of life related to childhood glaucoma.

Education: To provide an extensive set of resources for parents and caregivers so they are empowered and encouraged to take an active role in the care of their child with glaucoma, so they can advocate for their child and adopt constructive ways to face the challenges of raising a child with chronic disease.

CURRENT PROJECTS:

1) Childhood Glaucoma Standardization of Diagnosis Terminology

- *Terminology used to classify the types of childhood glaucoma is inconsistent*
 - *Proposing global definitions for glaucoma & glaucoma suspect; defining broad categories based on clinical features*
 - *Working together with ICD 11 revision committee to define common standard*
 - *CGRN plans to propose standards at ARVO 2012 & publish*

2) Central Coordinator for Childhood Glaucoma Registries

- *Registry projects are underway at Wills Eye and Moorfields. Others may develop in future.*
- *Goal - capture data records from all registries to provide larger numbers and global understanding of the incidence and prevalence of childhood glaucoma across the world*
- *This will help to determine what the best course of action is in treating different types of CG that occur in different regions of the world. This information is currently not available.*
 - *Identify a standards for data collection and coding*
 - *Establish and maintain a central server for standard form collection*
 - *Administrator of access and analysis of centralized data*

3) Development of the webSITE for Parents of Children with Glaucoma:

- *Parents share a major responsibility for the daily management of their child's condition*
- *Parents have reported great difficulty and frustration finding the information they need.*
 - *Information about Childhood Glaucoma – Overview of treatment and more*
 - *Managing Vision Problems – An integral part CG care in children with low vision*
 - *Social Services – Removing barriers to care*
 - *Parent to Parent: Tips, support, encouragement, and inspiration*

4) Seeking Partnerships to Co-Host Childhood Glaucoma Parent Day; to Create CG Educational Materials; and to Promote Awareness about CG

- *CGRN has begun preliminary discussions with large national and international glaucoma organizations to seek partners to:*
 - *Co-host Annual "Parent Day" Educational Event for Parents of Children with Glaucoma*
 - *Develop an Educational Webcast Series For Parents for the webSITE*
 - *Develop Childhood Glaucoma Awareness Campaign*

The CGRN is proudly sponsored by:

The University of Minnesota Center for Pediatric Glaucoma
The GL Foundation for Children with Glaucoma
