

## **Childhood Glaucoma Research Network – Mission Statement and Guiding Principles**

### **Who are the members of CGRN?**

The CGRN is an international organization of ophthalmologists who share a mutual interest in childhood glaucoma. CGRN membership currently includes over 85 ophthalmologists from North and South America, Europe, Asia, Australia, Africa and the Middle East. Most of the world's largest eye research centers are members of CGRN. This collaboration among eye research centers across the world increases the number of children who participate in studies and reduces the research time it takes to reach valuable conclusions.

### **What is the Mission of the CGRN?**

The mission of the CGRN is to serve as a catalyst to bring together ophthalmologists with a mutual interest in childhood glaucoma to leverage each member's unique expertise and understanding of pediatric eye disease and glaucoma to promote progress in research and improve care of childhood glaucoma. To achieve this mission the CGRN will

- Collaborate to complete projects that will define optimal care, and conduct research and educational efforts that will translate to prevention and better diagnosis and treatment of childhood glaucoma
- Investigate and define methods to improve quality of life in children with glaucoma
- Promote an organizational culture that is based on shared consensus about the best way to collaborate on projects that will advance the care of childhood glaucoma
- Form external partnerships to provide funding and infrastructure for CGRN research

### **What are the Guiding Principles of CGRN?**

- The network will support studies with the potential to provide evidence upon which to base effective patient care and educational projects with the potential to advance the care of children with glaucoma.
- Trust. This collaboration is based on a sense of mutual trust and respect among the participating groups. Members may disagree with each other but that should not erode the fundamental sense of trust and respect.
- Leadership. The CGRN is led by a leadership committee that consists of 5 of the founding members who helped defined the principles that guide the CGRN. Beginning in 2013, the CGRN will be led by a democratically elected Executive Committee.
- Transparency. The selection and execution of CGRN projects will be transparent and will clearly articulate governance, protocol/project development plans, publication policies, etc. The CGRN is strongly committed to data sharing and dissemination of results.
- Confidentiality. Findings and results generated by the collaborative efforts of the group will be treated on a confidential basis and cannot be used in grant applications, manuscripts, presentations (talks or posters), or discussion with the media without the prior consent of the CGRN members involved.
- Open communication among members. All decisions and activities will be conducted in an open way. This will be accomplished through clear, frequent and open communication, either by phone, email or in person meetings.

### **Publication and Presentation Policy**

- A CGRN study publication is one which contains details of the design, methods, or results of the CGRN study, and is written by investigators from a CGRN study. Any paper classified as a CGRN study publication must be approved by the Exec. Committee prior to submission for publication. Similarly, any presentation made on behalf of a CGRN study must be approved by the Exec. Committee. All papers of the CGRN study will be published with acknowledgement of the CGRN.

## Childhood Glaucoma Research Network – Organizational Structure and Leadership

### How is the CGRN Organized?

The CGRN has a strategic plan for developing the network into a sustainable, effective international organization. The plan addresses the funding, planning and execution of CGRN collaborative projects. There are currently 3 projects being performed by CGRN, funded by GL Foundation, University of Minnesota, Minnesota Lions Club, and Glaucoma Research Network. CGRN facilitates development of a cohesive scientific and educational agenda through its Executive Committee and through steering committees focused on specific projects and protocols. CGRN leaders continue to explore ways to build synergistic relationships with external organizations to fund CGRN research. Annual meetings at ARVO and AAO and other scientific conferences, as well as routine teleconferences further enhance the communication and collaboration of CGRN members and provide opportunities for education and mentoring.

### CGRN Executive Committee and Project Specific Steering Committees:

Currently, five of the founding CGRN members who have worked together to define the principles that guide the CGRN provide leadership. Each of these members will be offered a permanent position on the CGRN Executive Committee. Beginning in 2013, nominations for new members of the CGRN Executive Committee will be accepted, and new members will serve 2-year terms. Alana Grajewski serves as the current Network Chairperson, and her term will end on June 30, 2014.

The CGRN Executive Committee is tasked with making decisions about the overall operation of the network and collaborative research and educational projects to be conducted. Once a project has been approved, the Executive Committee will select a steering committee to oversee the conduct of the particular study or project. Specific duties of these committees are described below.

### CGRN Executive Committee Duties:

- Defining the strategic plan for developing CGRN into a sustainable, effective global network
- Identifying network goals related to clinical research & education of providers and caregivers
- Soliciting ideas for new projects from members
- Prioritizing research studies and/or educational projects that should be developed
- Selection of steering committee members for each research study/educational project
- Recruiting members into the CGRN, and suggesting partnerships that will benefit CGRN
- Identifying ways to fund selected projects, including representing CGRN in forming partnerships and negotiating alliances with external organizations

### Protocol/Project Steering Committee Duties:

Steering Committees will be selected by the Executive Committee and will be made up of members who propose the work and therefore have the most interest in seeing it succeed.

Note about studies funded under the CGRN/GRN Partnership: This Protocol Committee will report to the GRN and adhere to GRN participation agreement to design and implement the study.

Specific responsibilities of steering committee members could include:

- Conducting protocol review calls with investigators at the commencement and pivotal points
- Addressing day-to-day questions from investigators
- Considering changes or modifications in the protocol as may be necessary or desirable
- Advising and assisting the coordinating center on operational matters
- Reviewing monitoring reports, contacting investigators as needed to review protocol deviations
- Serving as the writing committee for primary protocol manuscripts
- Assisting the coordinating center in the study close-out procedures

## **Childhood Glaucoma Research Network – Background Information**

### **What is the Organizational Background of the CGRN?**

The CGRN was organized in 2011 to bring together thought leaders from leading eye centers around the world to leverage each member's unique expertise and understanding of pediatric eye disease and glaucoma to promote progress in research and improve care of childhood glaucoma. Initial work in creating the CGRN was led by the voluntary efforts of a number of pediatric glaucoma specialists in the US and UK. Dr. Alana Grajewski, glaucoma specialist from the University of Minnesota and Bascom Palmer Eye Institute, organized the group and established financial support from the GL Foundation for Children with Glaucoma, the University of Minnesota Department of Ophthalmology and Visual Neurosciences and the Minnesota Lions Vision Foundation. In the first 12 months, the CGRN successfully proposed a new international classification system to serve as the foundation for future research, and advised on the creation of an educational website for parents. As a result, the CGRN quickly gained significant support and momentum. The CGRN aims for members to work together to capitalize on opportunities, to be proactive in developing a scientific agenda, and to work with potential funding sources to create alliances that will support CGRN collaborative research.

### **Why was the CGRN Formed?**

If left untreated, childhood glaucoma causes blindness. As childhood glaucoma usually affects both eyes, this permanent vision loss is absolute. With early diagnosis and effective treatment, these children can achieve vision, even normal or near normal vision, but the evidence base to guide therapeutic intervention and recommend clinical guidelines is based on limited clinical experience within individual centers.

Childhood glaucoma is a rare and chronic disorder. This poses a significant research challenge because individual eye centers across the world do not have enough patients to accomplish critical studies. As a result, many questions about the disease remain unanswered: How did the disease start? What are the long-term outcomes? How can vision loss be prevented? No figure is known for the prevalence of all types of glaucoma in children. While current data is unreliable, most pediatric glaucoma specialists believe the incidence of primary congenital glaucoma is an overall average of 1 in 10,000 – 1 in 20,000 births. In certain ethnic groups and countries the rate is much higher. In children born with congenital cataracts the risk of glaucoma is likely greater than 80% before the child reaches adulthood.

A Network of ophthalmologists who share a mutual interest in childhood glaucoma will complete the necessary clinical research more rapidly and most effectively, and will more efficiently apply their results to help treat children. Similar research networks have dramatically advanced the treatment currently available for both childhood cancer and cystic fibrosis. Children with cancer who are treated in a participating center with network protocols now have a 58% chance of 4-year disease-free survival, compared to less than 19% for children treated outside the network with non-network protocols. This dramatic improvement in treatment is a direct result of careful clinical studies and trials within the collaborative research organization.