

GETTING STARTED/PARENT CHECKLIST:

Prepared by The Childhood Glaucoma Research Network (CGRN) (Rev. 03/12)

Available at www.gl-foundation.org

Facing the diagnosis of childhood glaucoma can be shocking and upsetting, and is filled with many unknowns. This checklist is organized to help parents:

- **PREPARE to advocate** for the health, vision, and learning needs of your child, and to
- **ADOPT constructive ways** to face the challenges of raising a child with glaucoma
The good news is there are many types of doctors and specialists that can help you understand glaucoma and related issues. Sometimes it's hard to know who can help, and what questions to ask. There are resources in the website to help you to break this down. The more information you have, the more capable you will be to make decisions that will have a long-term impact.
- Through the highs and lows, **REMEMBER** that in today's world, *with attentive treatment from an experienced doctor, many children with glaucoma do not lose significant sight and your child may function normally in every way.*

STEP 1: Seek Care from an Ophthalmologist that Specializes in Treating Glaucoma in Children and Follow-up As Directed by the Physician

(See "Meet the CGRN" section of website to learn about members of the Childhood Glaucoma Research Network; also see articles in the "After the Diagnosis" section called "Choosing an Eye Doctor" and "What to Expect at the Eye Doctor's Office")

This may be a pediatric ophthalmologist and/or a glaucoma specialist who will treat the glaucoma, & manage the condition **and related issues** (e.g., amblyopia) as your child grows. Your ophthalmologist should also perform tests to evaluate your child's vision.

One of the most common causes of vision decrease in children with glaucoma is amblyopia. You must be under the care of a doctor who can check vision & manage treatment for amblyopia (lazy eye).

- Childhood glaucoma is a chronic condition, **IT IS VITAL TO FOLLOW-UP WITH YOUR CHILDHOOD GLAUCOMA DOCTOR(S) AS ADVISED.**
- Ask questions if you don't understand something.
- Don't be afraid to change doctors or ask for a second opinion if you are unhappy with the care you are receiving.

If your child has low vision or vision problems (e.g. light sensitivity), you should ask for a referral to a pediatric low vision specialist. (See vision impairment resources on website).

If you have questions or concerns about insurance or financial issues, or if you need assistance with transportation to a distant specialty care center, you can ask for a referral to a social worker who can connect you with supportive services, if needed. Also refer to the website for articles related to "obstacles to care".

If your child has co-existing medical conditions, you will seek care from other specialists as well. Be sure to keep your child's pediatrician involved, as he/she is the "quarterback" in making sure everything about your child is looked after.

STEP 2: Learn as much as you can about childhood glaucoma and related issues (such as vision and development if your child has vision impairment).

(see "Learn About Childhood Glaucoma", & "After the Diagnosis" sections on website. **Another excellent website about childhood glaucoma is www.pgcfa.org.** Be sure to sign up for their newsletter. To learn about Vision impairment, see related section on website.

STEP 3: Keep good records of health care interventions, phone calls, etc.

(see "After the Diagnosis" section of website for helpful forms and tips)

Good communication is vital. You are your child's best advocate and no one understands his/her needs better than you. Keeping a binder/notebook that records the history and course over time of your child's eye care is extremely valuable.

STEP 4: Seek Constructive Ways to Cope with Stress, and Connect with Others.

(see "After the Diagnosis", "Everyday Wisdom", "Connect with Others", & "My Story" sections) Childhood glaucoma is a chronic condition that requires lifelong care, and can be overwhelming at times for parents/families. Over time, families learn to adopt effective strategies, and find that there are very good resources available to help with issues related to managing medications, surgery, vision problems, financial burdens, and family stress. With the right services and support, children with glaucoma, including those with significant vision loss, lead very successful lives.

One parent shared this advice: "Childhood glaucoma is not a race, it's a marathon. Pace yourself – don't look too far down the track. Focus on the now and not on the questions no one can answer. Celebrate the wins, no matter how small."

- Acknowledge your feelings (e.g., fear, anxiety, doubt, feeling overwhelmed, anger)
- Connect with others who have a child with glaucoma. (www.pgcfa.org, www.congenitalglaucomanetwork.com, www.glaucoma-foundation.org)
- Rely on your support system (e.g. family, friends).
- Remember to make time for important family relationships (e.g. marriage, siblings).

STEP 5: If your Child has Vision Impairment or a Disability, Learn the Law and What Services are Available to Help Your Child.

- Seek out Early Intervention (Preschool-aged children) or an Individualized Education Plan (School-aged children)

(see "Success at School" and "Managing Vision Problems" section on website)

Services available vary by country, check with your eye doctor or school to learn more.

STEP 6: Partner with Your Child's School (when they reach that age)

(See "Success at School" section of website)

- Be proactive in facilitating communication between your doctors, teachers, vision specialists (if any), and other care providers.
- Help the teacher learn what glaucoma is, and any issues they need to be aware of. (see "Teacher Meeting Guide" on the website)
- If there are any vision challenges, help the teacher get to know ways to help your child use his/her vision effectively.
- Trust your instincts, and speak up if you feel your child needs more help.