

# Childhood Glaucoma



**Christopher Wilmoth  
doesn't ever want  
to go blind.**



**Dr. Goldberg's pioneering  
research may prove  
that he won't.**

**“Glaucoma Research Foundation gives me hope that I will be able to keep my vision.”**

*Christopher Wilmoth*



Catherine Wilmoth’s son, Christopher, was diagnosed with glaucoma when he was 7 months old. Surgery and ongoing regular treatments saved Christopher’s sight in one eye; he’s legally blind in the other. Catherine says, “During his lifetime, perhaps there will be an intervention that will keep his disease from getting worse, so he can experience all the joys that we’ve had as his parents.”

# Childhood Glaucoma

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## **What is Childhood Glaucoma?**

### **A Team Effort**

Parents, family members, and health professionals are important members of the team involved in the care of a child with glaucoma. Successful management depends on the efforts of everyone to support the child during each phase of treatment and care. There are many challenges in facing a chronic disease like glaucoma. We hope this booklet will prove to be an additional resource to help your family with some of these challenges.

### **How Does the Eye Work?**

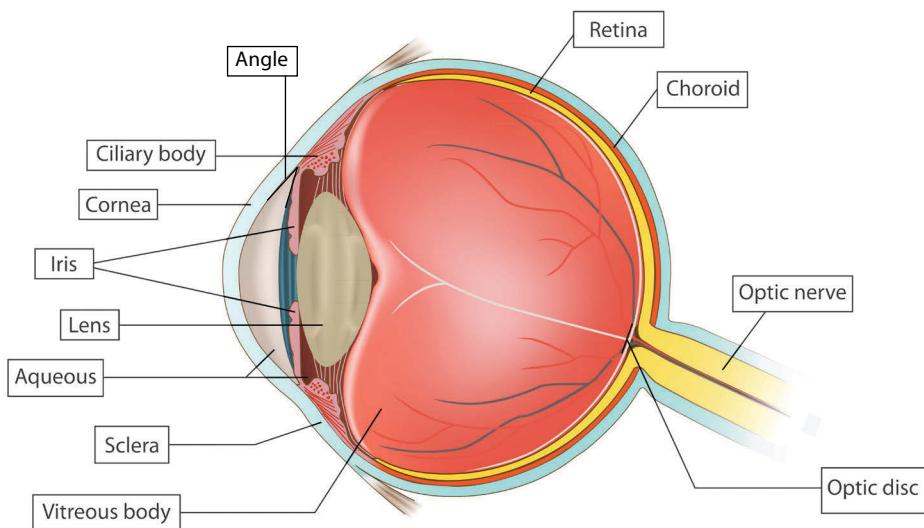
The first step in understanding glaucoma is to know how the eye works. The important parts of the eye are shown in the cross-section view to the right. The eye is round and protected by a tough, white wall called the sclera. Part of the white sclera can be seen in the front of the eye. The sclera is covered by a clear, delicate membrane called the conjunctiva.

At the front of the eye is the cornea. The cornea, in front of the iris, is the clear part of the eye's protective wall. It lets an image enter the eye. The iris is the colored part that shrinks and expands so the pupil can let just the right amount of light into the eye. The light passes through the lens to the retina at the back of the eye. Nerve fibers in the retina carry light and images to the brain through the optic nerve.

Inside the front part of the chamber is a clear fluid (called intraocular fluid or aqueous humor). The fluid nourishes the lens, iris and cornea, and it flows out of the eye through the trabecular meshwork (the eye's drainage canals).

The production, circulation and drainage of this fluid out of the eye is an ongoing process that is needed for the health of the eye. Fluid inside the eye is different from tears, which are produced outside the eye.

The eye pressure (intraocular pressure or IOP) depends on the rate of formation of fluid in the eye and drainage of fluid out of the eye. The eye's fluid system can be compared to a kitchen sink with the faucet turned on all the time. The ciliary body produces fluid like a faucet. The eye's drainage canals are like the drain and pipes connected to a sink. If a kitchen plumbing system is working, water from the faucet drains easily and quickly out of the sink. If the eye's fluid system is working, a constant amount of fluid is produced in the eye and then drained out to maintain a healthy pressure. The IOP can vary at different times of the day, but it stays within a normal range.



Glaucoma refers to a group of eye diseases with common features that may include elevated eye pressure, damage to the optic nerve, and potential vision loss. There are many types of glaucoma. Childhood glaucoma refers to the presence of glaucoma in a child. Congenital glaucoma is the common term used for a type of childhood glaucoma diagnosed in infancy or early childhood. It is also called infantile glaucoma when recognized in infants and it always includes high IOP.

In children there are two major types of glaucoma: congenital and juvenile. In addition to these two primary types, there are secondary forms either caused by trauma or by other diseases, such as juvenile idiopathic arthritis (JIA). All forms of childhood glaucoma are associated with high pressure in the eye. If the pressure remains too high for too long, there may be damage to the eye or the optic nerve. The type of damage depends on the age of the child. Up to age two or three, the eye may stretch and enlarge. In older children, only the optic nerve is affected; the increased eye pressure shows up as “cupping” (an enlargement of the optic nerve area that an eye doctor can detect in an eye exam).

There are many possible causes for childhood glaucoma. In all cases, blockage to the eye’s drainage system causes high IOP. In some cases, the cause is hereditary and inborn. In other cases, the glaucoma develops as a result of other diseases that affect the eye.

The physician will carefully examine your child and review other information in order to determine the specific cause of your child’s glaucoma. Finding the cause of the glaucoma helps in selecting the best treatment for your child.

- Primary congenital glaucoma occurs in 1 out of every 10,000 births in the U.S.
- Primary congenital glaucoma accounts for approximately 50% to 70% of all cases of congenital glaucoma.
- In diagnosed cases, about 2/3 of the patients are male. In about ¾ of all cases, the glaucoma affects both eyes (bilateral).

## What are the Different Types of Childhood Glaucoma?

Understanding the different types of glaucoma that can occur in children can be confusing. There are many terms used to describe the various types of glaucoma in children. The type of glaucoma and its severity are topics your eye doctor will discuss with you and consider in determining a treatment plan.

Childhood glaucoma can be classified in the following categories:

### Primary Childhood Glaucoma

If glaucoma cannot be attributed to any other cause, it is classified as primary. There are two categories of primary childhood glaucoma:

- **Primary Congenital Glaucoma (PCG).** Children with PCG have enlarged eyes and frequently have corneal clouding. It consists of three subtypes based on the age of the child at onset.
  1. Neonatal onset develops before 1 month of age;
  2. Infantile onset develops between 1 month and 24 months of age;
  3. Late onset develops after 24 months of age.
- **Juvenile Open Angle Glaucoma (JOAG).** This type of glaucoma develops after age 3 years, and is associated with normal sized eyes and the absence of corneal clouding.

### Secondary Childhood Glaucoma

Glaucoma is classified as secondary if it results from an ocular birth defect or a syndrome, an eye injury, or other disease such as juvenile inflammatory arthritis. There are four categories of secondary childhood glaucoma:

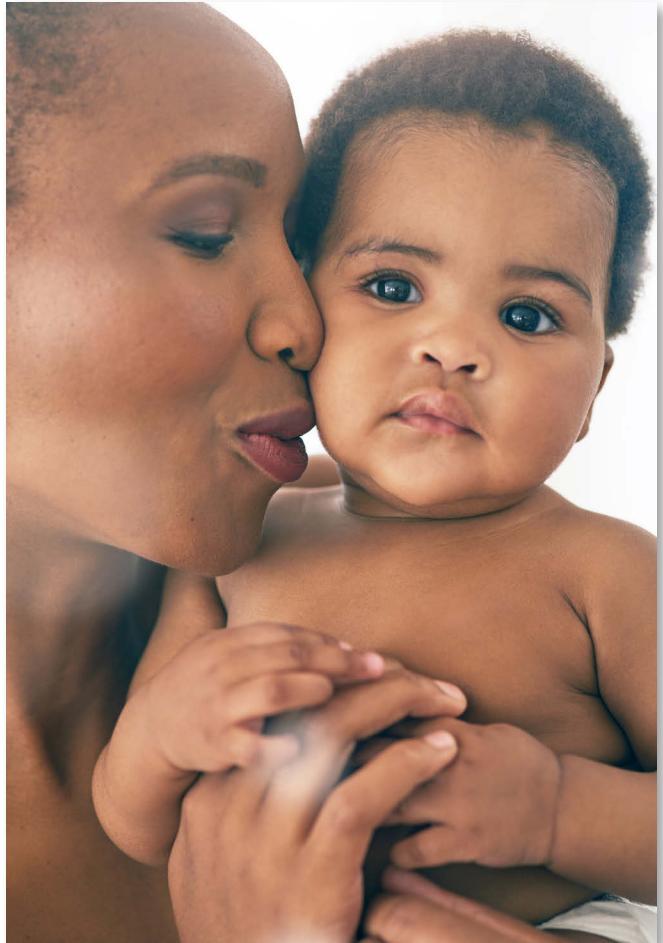
- **Glaucoma following Cataract Surgery.** Also called aphakic glaucoma, this refers to the type of glaucoma that can occur in children who've had cataract surgery.
- **Glaucoma Associated with Acquired Conditions.** This type of glaucoma occurs as a result of conditions such as ocular injury, inflammation or infection of the eye, or medication use (corticosteroids).
- **Glaucoma Associated with Non-Acquired Systemic Disease or Syndrome.** This type of glaucoma is associated with systemic conditions that are present at birth, such as Down syndrome, Marfan syndrome, and Sturge-Weber syndrome.
- **Glaucoma Associated with Non-Acquired Ocular Anomalies.** This type of glaucoma is associated with certain ocular conditions present at birth such as aniridia, Axenfeld-Rieger anomaly or Peters anomaly, among others.

(Source: The Childhood Glaucoma Research Network)

## Genetics of Childhood Glaucoma

Childhood glaucoma is often genetically determined. In most cases, the problem will not have been present in either parent, but there is a possibility that a sibling may be affected. The inheritance of childhood glaucomas varies and involves all the recognized patterns of transmission. When the type of glaucoma has been identified, your child's doctor will be able to discuss the genetic factors involved with specific conditions.

Molecular genetics, the study of genetic material, is a rapidly growing field that offers new opportunities to understand and classify the pediatric glaucomas. Currently, no treatments are based on information derived from molecular genetic testing. In the future, such information could become the basis for individualized glaucoma care.



## Recognizing Childhood Glaucoma

Childhood glaucoma is a serious and uncommon pediatric medical problem. Parents and doctors may be unfamiliar with the early signs of this disease. Recognition of the glaucoma may not occur promptly. Knowing the signs and symptoms of childhood glaucoma is also helpful in enabling parents to better monitor their child's progress.

## What are the Signs and Symptoms?

The symptoms of childhood glaucoma vary. In some cases, children will be asymptomatic; in other words, show no evident symptoms. In most cases, there will be a gradual onset of glaucoma related problems. Symptoms can include the development of light intolerance (photophobia), and be associated with corneal opacification (hazy gray cornea), epiphora (overflow of tears), and vision loss. Sometimes the child will hold their head in their hands to block the light from reaching their eyes.

A cloudy cornea is the earliest and most common sign of childhood glaucoma. The healthy cornea is transparent. The loss of this transparency is caused by edema, or swelling of tissue from excess fluid. This occurs in the corneal epithelium (outermost layer of the cornea) and in the corneal stroma (middle layer of the corneal tissue). Careful inspection of the cornea may also reveal defects in its inner layer, which is further proof of a raised eye pressure or IOP.

In most cases of glaucoma affecting children under three years of age, the cornea and eye enlarges. Review of early photographs of your child may reveal the presence of glaucoma months before the diagnosis was actually made.

In addition to eye problems, secondary systemic (body) symptoms may occur. These secondary symptoms are especially common with acute glaucoma. Examples include irritability, loss of appetite, and vomiting. These symptoms may be misunderstood before the glaucoma is recognized. Young children with glaucoma are often unhappy, fussy and poor eaters.

## How is it Diagnosed?

Glaucoma can occur in any age throughout childhood. Because of this, a doctor should be prepared to examine the infant or young child with the same thoroughness practiced with older children. A parent has an important role as well—to comfort, encourage, and sometimes, restrain a young child, if needed. As a parent, you can also help your child by providing the doctor with an accurate description of your child's symptoms and previous care.

Before developing a treatment plan, children with glaucoma or suspected glaucoma need a careful initial assessment. This will determine the presence of glaucoma and its type, the extent of the disease, and any other related problems. Your role as a parent is crucial in helping your child have a successful office eye examination. Often, especially in the very young child, an exam under anesthesia (EUA) will be needed to provide additional information.

## Office Examination

The examination often begins with an estimate of vision. The reactivity of the pupils to light is tested. Is there interest in or eye fixation when visually following toys? Is there any nystagmus (unsteady eye movement) present?

Is there abnormal avoidance of light? Older children should also have a Snellen visual acuity test (vision test with letters and images).

Inspection of the front of each eye is also important. The eye's corneal size is estimated and any asymmetric enlargement noted. Young children are examined using a loupe (a magnifying lens) and other hand-held instruments. For children three years and older, a slit lamp examination is usually possible. In children under three, an examination under anesthesia (EUA) is usually required for initial exam and possibly for follow ups where accurate measurements are needed. Asymmetric enlargement (the size of each eye is not the same) is more evident by inspection rather than by a formal measurement.

Corneal clarity and transparency are noted. If there is any corneal opacification, it may be spread out (diffuse), or it may be in only one local area. Corneal edema causes a loss of corneal luster, and reflections from the corneal surface are irregular.

Careful inspection of the iris will also be performed. With severe congenital glaucoma, abnormally large pupils are associated with abnormal irises.

The lens is usually normal in most cases of pediatric glaucoma. However, the lens will be examined for the presence of a cataract or lens dislocation.



**During an office examination, older children can be examined with conventional methods.**

“A good relationship with your eye doctor is the foundation of effective treatment.”

**Andrew Iwach, MD,**  
Associate Clinical Professor of Ophthalmology,  
University of California at San Francisco.



The back of the eye (fundus) is examined (ophthalmoscopy or funduscopy) to assess the condition of the optic nerve head, where glaucoma-related abnormalities are often seen. If the cornea is opaque or not clear the reliability of this examination may be limited, especially when a child is first evaluated.

During tonometry, the eye pressure is measured. This is an important part of the examination. Using a special instrument, this exam measures the eye pressure (IOP). Pressure readings at moments of maximum cooperation are the most reliable. In an older child, tonometry is done in the same way as with an adult. In a younger child, the parent often needs to assist the child and encourage cooperation in order to reliably measure the eye pressure. New devices such as the iCare tonometer have made it possible to get IOP measurements in very young children in the doctor's office.

Ultrasonography can add important additional information especially when there is a limited view to the back of each eye. This is a safe and easily performed procedure that uses ultrasound, or sound waves, to create a visual picture of the inner eye. The size of the eye can also be estimated at this time.

## **Examination Under Anesthesia (EUA)**

The operating room eye examination or examination under anesthesia (EUA) is an important part of the assessment for childhood glaucoma. The goal of this exam is to get more information to complement the office/clinic examination.

During the EUA, a gonioscopy is performed. Gonioscopy is an examination of the drainage system inside the eye. This will help your doctor to confirm the suspected type of glaucoma and to decide whether or not which type of corrective surgery would be helpful. This type of test is more reliable if performed under anesthesia, especially in young children.

Tonometry is also done during the EUA. The corneal diameter can be measured accurately at this time. Funduscopy will allow careful assessment of the optic discs for glaucoma related abnormalities.



# Treating Childhood Glaucoma

## How is Childhood Glaucoma Treated?

Both medical and surgical methods are used in treating childhood glaucoma.

### Medical Treatments

Medical treatments involve the use of medicines. They can come in the form of topical eyedrops and oral medications (e.g., pills or suspension liquids). These treatments help to either increase the exit of fluid from the eye or decrease the production of fluid inside the eye. These both result in lowering the eye pressure. Side effects of these drugs must be considered and evaluated.

In addition, parents should be carefully instructed in the administration of medicines, including any potential complications. If you have any questions or concerns, including how to put in your child's eyedrops, ask your doctor.

### Surgical Treatments

There are four main types of surgical procedures that are used to help control eye pressure: goniosurgery, filtration surgery, glaucoma implant surgery, and laser surgery. These surgical treatments can include: trabeculotomy, goniotomy, trabeculectomy, iridotomy, glaucoma implant surgery, cycloablation and, in extremely rare cases, enucleation.

A trabeculotomy and goniotomy involve an incision into the trabecular meshwork drainage system. This allows the fluid to better flow out of the eye, lowering the intraocular pressure (IOP). A goniotomy is an internal trabeculotomy procedure that is used in congenital glaucoma. Approximately 80% of children with primary congenital open angle glaucoma can be cured by trabeculotomy/goniotomy procedures. It is the only form of surgery unique to childhood glaucoma. An external trabeculotomy also involves an incision, but through an external approach. Both procedures aim to make the drainage system more porous so fluid can pass out of the eye.

Trabeculectomy involves the removal of part of the trabecular meshwork drainage system. This creates a drainage canal from the anterior chamber of the eye to the eye surface, under the conjunctiva. A small bleb (like a bubble) is formed on the surface of the eye. This is covered by the eyelid and is not very noticeable. By creating this new canal, the inner eye fluid can drain better. This surgery is needed when the glaucoma has been unresponsive to a goniotomy.

In an iridotomy, a small opening is made through the iris without removing any iris tissue. This helps the inner eye fluid drain from the posterior chamber to the anterior chamber of the eye. In most cases, a laser light beam is used to create this hole (laser iridotomy).

In some resistant cases of childhood glaucoma, placement of a glaucoma implant is an additional and important procedure. In glaucoma implant surgery a small silicone drainage tube is permanently placed in the anterior or posterior chamber and is connected to an external reservoir that helps absorb the exited aqueous humor.

In advanced or severe cases of glaucoma, a cycloablation surgery may be recommended. The goal of this type of surgery is to decrease the production of inner eye fluid, which in turn, lowers the inner eye pressure. This is done by destroying an area of the ciliary body. However, this surgery is only considered when the IOP continues to remain high, even with the maximum use of medications.

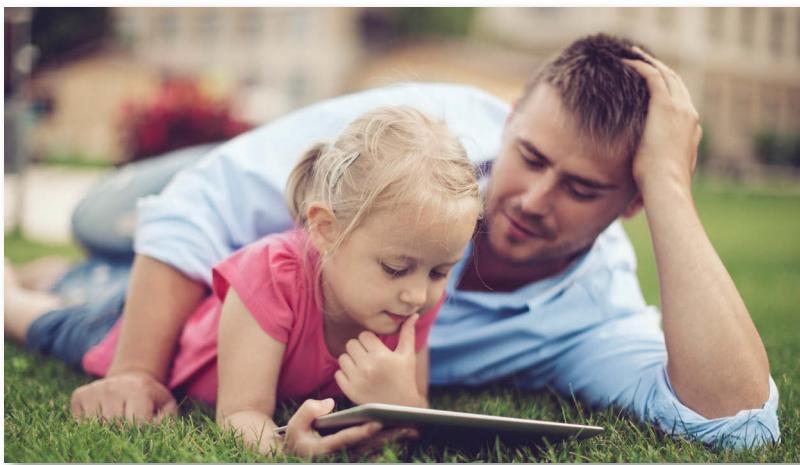
In rare cases, a blind eye becomes painful and/or disfigured. Enucleation, or removal of the eye, may be considered. This surgery usually involves the removal of the eyeball, leaving eye muscles and remaining orbital contents intact. An eye prosthesis will be fitted after surgery.

It is sometimes necessary to repeat some forms of glaucoma surgery in order to successfully control eye pressure. This can be difficult for your child and discouraging for parents. A child's physical and emotional needs must be considered by parents and by the health care team.

## **Preparing Your Child for Hospital Stays**

“We tried to prepare our son when he went to the hospital for surgery. For several weeks in advance we read books about other children in the hospital, and a day or so ahead we talked about him going to the hospital and what would happen there. Books that focused on hospital visits were very helpful. We started reading these kinds of books to our son when he was 21 months old, but they had more meaning to him when he was hospitalized at 26 months. We tried to relate the things that happened to him in the hospital to the things that happened in the books.”

—Susan and Schuyler Bailey, Berkeley, CA



## Helping Your Child to Cope with the Procedures

### For the Younger Child or Infant with Congenital Glaucoma

“I remember when my 12-day-old daughter was scheduled for surgery. ‘Nothing by mouth before surgery,’ the nurses said. But don’t they understand that my baby is tiny? How will I console her hungry cries? Will I have enough milk to satisfy her when she’s ready to nurse again?” If your child is an infant, try a pacifier—even for nursing babies—to help satisfy the need to suckle. Consulting a certification lactation consultant (“IBCLC”) before the surgery can help avoid breastfeeding problems that may occur as a result of using a pacifier and keep mother and baby on track. Talking to the lactation consultant prior to the surgery should be considered. Exclusively breastfed babies may reject a pacifier, leaving baby and parents even more upset unless the issue has been properly addressed beforehand. It is also important to note that breastmilk is considered a “clear liquid.” You can also have other family members help comfort your baby. It’s important to involve the whole family. And for the older child—make it a smorgasbord!

“Now, whenever our daughter is scheduled for a procedure under general anesthesia, we have a clear liquid smorgasbord. No kidding! Today, at six years old, Julia still looks forward to shopping with Daddy for her special smorgasbord.”

Make sure to check with your doctor regarding how many hours prior to a procedure your child can have clear liquids followed by no fluids. Then, offer an abundant variety. “Some of Julia’s favorites are chicken broth, beef broth, water-ice, and flavored gelatins molded into interesting shapes. It’s also a great idea to have the family share in this unique meal!”

[Note: Parents need to eat adequately to sustain themselves physically and emotionally. If there is no other adult to accompany you to the hospital, ask a nurse, or patient coordinator to give you a few minutes to take care of your own needs. You must be strong for yourself, your child and your family.]

### Other Coping Tips

Whether the procedure scheduled is an operation or an Exam Under Anesthesia (EUA), coping with instructions before the procedure can be difficult. In some cases an EUA may be planned, but if required, surgery may be performed at the same time so that additional anesthesia isn’t necessary.

1. Remember, your support and assistance with these procedures is in your child’s best interest.
2. Develop a support system, particularly among those who have experienced what your family is going through. They can give support, valuable ideas, an interested ear and an empathetic heart.

## Tips for Putting in Your Child's Eye Drops

Eye drops will help maintain the pressure in your child's eye at a healthy level. They are an important part of the routine for a child with glaucoma. Here are some steps and helpful hints for putting in your child's eye drops.

### You should always:

- Use drops the way your doctor tells you to use them.
- Be sure your doctor knows about any other drugs your child may be taking (including over the counter items like vitamins and aspirin) and about any allergies your child may have.
- Wash your hands before putting in your child's eye drops.
- Be careful not to let the tip of the dropper touch any part of your child's eye or face.
- Make sure the tip of the dropper stays clean. Do not lay it down on any surface.
- If you are putting in more than one drop or more than one type of eye drop, wait five minutes before putting the next drop in. This will keep the first drop from being washed out by the second before it has had time to work.

### Steps for putting in eye drops:

- Start by tilting your child's head backward. Have your child sit or stand with his/her head tilted back or have your child lie down. With your index finger placed on the soft spot just below the lower lid, gently pull down to form a pocket.
- Let a drop fall into the pocket.
- Slowly let go of the lower lid. Your child will most likely blink a few times naturally, but try not to let your child shut his/her eyes tight or squint. This may push the drops out of your child's eye.
- Gently press on the inside corner of your child's closed eyes with your index finger and thumb for two to three minutes. This will help keep any drops from getting into your child's system and keep them in his or her eye, where they are needed.
- Blot around your child's eyes to remove any excess.

It is very important for children with glaucoma to keep an eye drop schedule. Eye drops will lower the pressure in your child's eyes, but only for a certain period of time. This should be kept in mind when planning your child's eye drop schedule. When the pressure in your child's eye is too high, damage to the optic nerve is likely to occur. Every effort must be made to keep the pressure in your child's eyes at a healthy level, at all times, to fully protect his/her eyesight.

Always check with your doctor if you are not sure about any part of your child's eye drop routine. To be sure you're putting the drops in right, you may want to demonstrate the procedure for your doctor. You may need the help of another person to apply your child's eyedrops.





### Tips from Parents

"We give eyedrops at the same time everyday. Our son helps: he holds still, shakes the bottle, holds and returns the bottle lid and counts until he can rub his eyes."

"I give my daughter eyedrops in the same order each time. That way, I don't forget which one I just gave her."

"Younger kids love to count, and what better way to cope with short term discomfort than by doing something they love. Whether it's a pre-op finger-stick, stinging eyedrops or the little blue light of a tonometer, count with your child. For example, after eye drops are used, encourage them to press on the eyelids and count to 20."

"As an infant, we gently wrapped our daughter in a blanket. As a toddler, we let her practice putting eye drops in her dolls and teddy bears. We even let her practice on family members using hypo-tears."

"Have your child lie down. Give lots of praise when done willingly."

"Make it part of the typical routine: breakfast, eyedrops; lunch, drops; bath, drops."

# Living with Childhood Glaucoma

## Seeing Through Your Child's Eyes

Thousands of children with glaucoma can live full lives. That is the underlying goal of glaucoma management. While it may be true that vision lost cannot be restored, it is possible to optimize each child's remaining vision. It is also important to encourage your child's independence and participation in their own self-care.

Once glaucoma has been diagnosed and a treatment plan has been developed, one of the most meaningful actions parents can take is to learn how and what is seen by their child. This is another step in helping your child gain independence.

Begin by observing how your child responds to the variety of everyday lighting conditions, including full sunlight, shade, night conditions and moderate indoor lighting. In addition, it is helpful to observe how your child responds to objects of different colors (e.g. bright colors and various hues), different sizes and varied color contrasts. This helps build an understanding of preferences and areas of potential difficulty, giving you a more accurate picture of your child's visual abilities. Often, it is unknown at the time of diagnosis how much vision is already lost.

## How Does Glaucoma Affect Your Child's Vision?

It is also helpful to become aware of the rules of thumb about the functional implications of glaucoma. Functional implications refer to the way the surrounding environment is seen, which greatly influences how your child acts or reacts. As discussed earlier, some common vision problems in glaucoma

include photophobia, corneal clouding and visual field loss. Not every child with glaucoma will develop all, or even any, of these conditions. But it is important to anticipate potential problems and develop possible solutions.



**Sunglasses may be used to help ward off glare.**



**Ask your child, as they may have ideas about what works best.**

Photophobia is sensitivity to and discomfort from light. Frequently, a photophobic child will turn away from light or seek out the darker part of a room. Sometimes sunglasses can ease this sensitivity. Avoid sunglasses that are too dark as it may result in reduced vision. Brimmed hats, such as baseball caps, also provide protection from too much light.

Corneal clouding causes an irregular bending of light as it passes through the cornea. This can result in reduced acuity (detail vision) and an increase in glare. Glare causes discomfort in the eye. Glare can be caused by a direct light source within the field of vision (such as an oncoming car's headlights) or from reflected light off a surface into the eyes (such as light rays bouncing off snow or off water in a swimming pool). The use of polarized lenses may reduce glare.

There are two types of visual field problems found in glaucoma, peripheral (side) or central. In general, the loss of peripheral vision is more common in glaucoma. With a peripheral field loss, it may be helpful to teach your child to move away from an object in order to fit the complete image into their remaining central vision. Because of the eye's structure, a child with a peripheral field loss may have additional difficulties with seeing in dark or dim areas and in adapting to changes in lighting. With a central field loss, a child may benefit from the magnification of an object to increase the size of the viewed object, providing a more complete picture.



Physical characteristics of the environment will also affect vision. While these factors are external, they are equally important to your child's visual performance. These factors include lighting, contrast, color, distance and time. By adjusting the child's environment and teaching your child how to make minor changes, a child is given tools to help manage the glaucoma while also enhancing vision.

Appropriate lighting is critical to visual performance. Important factors include quality, type, direction, distance and position of the light source. Observe your child during different activities and experiment with different light sources. For example, flexible gooseneck lamps can be directed on the task and positioned to avoid glare. It is important to teach your child how to position the lamp on his/her own and how to avoid facing direct light sources.

Increasing contrast between an object and the background may make it easier for your child to see. Try minimizing the number of items around the object being viewed. Create an exaggerated contrast or difference between an object and its background. Black and white provide the greatest contrast, but other color combinations may be optimal, depending on the individual child.

To see an object better, sometimes its image needs to be made larger by adjusting the distance to the object, such as moving closer to the television. Another option may be to increase the size of the object, using bigger print or enlarging pictures. With help from a low vision specialist, your child can learn various skills to compensate using their remaining vision.

Detecting, recognizing and then acting upon an object requires more time for the visually impaired child. This can be especially difficult and time-consuming for the child with multiple impairments. The low vision child expends a lot of energy when using their eyes. Allow your child more time to do a visual task. Also, do not spend too much time on a visual activity without providing rest breaks.

## Managing Vision Problems

- Avoid direct light sources, such as looking into windows or lamps. Teach your child to position light sources from his or her back or side.
- Use opportunities in the child's daily routine to provide visual experiences. Be comfortable asking your child to use their vision at all times of the day.
- Children who are easily distracted may need a controlled teaching environment, which encourages focused attention. Auditory (sound), visual (sight), and olfactory (smell) stimuli need to be considered.
- Encourage your child to look at an object before handing it to him or her.
- Try a reading stand to raise reading and writing materials. This improved posture and lessens fatigue. Provide the correct amount of light for the task.
- Acquaint yourself with a low vision health care provider. Whenever possible, familiarize your child with the doctor's office before an appointment. This creates a comfortable atmosphere that will be helpful during the appointment.
- If you cannot find a low vision clinician, you may try a clinician with a pediatric specialty. Get referrals and resources to help in your search.

# Educational Issues

## Meeting Your Child's Educational Needs

As parents, it is important to work closely with your school staff and the educational system to insure that the needs of your child are met. Explore what resources are available in your area. In many communities throughout the country, special education funding and services are provided to meet the needs of visually impaired children.

Special education services for eligible children are available from birth to adulthood, beginning with Early Intervention. Early Intervention is a program designed to assess the needs of children and to implement services to help the child and support the family. Consult with a teacher of the visually impaired to better assess your child's needs and help the family develop a program that best fits the individual child. Early Intervention can also help the child make the transition to an integrated preschool program.

If your child qualifies, an Individual Education Plan (IEP) can be developed. Contact the special education director of your school district for further information. When developing an IEP, think about your child and what works with him/her at home. These adaptations and ideas may also work in a school



**Special education services for eligible children are available from birth to adulthood.**

environment. Implement these adaptations and ideas into the IEP plan. All the modifications that your child requires must be put into writing. Include whether prescription glasses are worn, if medications need to be taken, and if vision fluctuates under different conditions. The IEP ensures that your child's school knows and understands your child's special needs. While it may seem like an exhaustive list, the more information you offer, the more prepared the school system will be in providing support for your child.

## For Your Child in the Classroom

- To avoid glare, request that your child sit with his/her back to the windows or to bright lights.
- Educational materials should be presented against a simple background. Keep the work area uncluttered.
- Talk with the teacher about flexible seating, especially if visual props are used. For your child, that may mean moving closer to the front of the classroom.
- Encourage the use of materials with high contrast and bold writing.
- During outdoor playtime, teach your child to use sunglasses and hats. Even overcast days can cause glare in the eyes.
- To protect the eyes during activities, have our child wear protective goggles.
- Include ideas that enhance your child's learning style and ability. If needed use a Closed Circuit Television (CCTV) for enlarging print.
- If you have any area of concern, consult with an educator, an occupational therapist, or low vision specialist to evaluate your child's home and school environment. These evaluations can give you essential information about your child's areas of strength as well as areas that need support services.
- Develop a support system with family, friends, and community organizations that provide support groups.



**Talk with your child's teacher about the best place for him/her to sit in the classroom.**

# The Impact on the Family

## One Family's Story

Our first child Kelsey Marie was born, a healthy full term baby girl. Initially the appearance of her eyes concerned us. Three weeks after her birth the cornea became enlarged and had a cloudy appearance—an indication of glaucoma. We were referred to a pediatric ophthalmologist who confirmed the diagnosis of congenital glaucoma. She had elevated eye pressure that was controlled with eye drops and medication. At the young age of three months she required eye surgery, a procedure called goniotomy. The object of the goniotomy was to try to normalize and control the intraocular pressure. The surgery created a drainage canal for the excess fluid to drain. When this surgery is performed at such an early age, the chances that the canal will heal over are high. This causes the intraocular pressure to rise. Slowly over the next three months the pressure rose, prompting a second goniotomy. This was successful, however Kelsey still required medication and eye drops to control the pressure.

For the next six years, we went to the ophthalmologist for pressure checks every two months. Sometimes the pressure was okay, sometimes it was too high. The emotional roller coaster this put us on was very stressful. There was a lot of uncertainty. Questions like “When will the next surgery be?” and “Will it help?” never left my mind.

When Kelsey was 7 years old the pressure remained consistently high. Elevated intraocular pressure had increased, giving no choice except to have trabeculectomy surgery. This operation posed more risks for side effects than the first two procedures. The roller coaster continued. Just a few hours after



**Encourage the involvement and support of the whole family.**



**Networking with other families can provide a wealth of information about new approaches.**

this surgery, the intraocular pressure unexpectedly went very high. It was painful for Kelsey but she endured, earning the name Braveheart.

She was discharged from the hospital with intense follow up examinations and treatment. This involved four or five doctor appointments a day, then one every day for about three weeks. During this time, the pressure decreased too much and had to be monitored. The intraocular pressure remained low but satisfactory. We are very thankful for Kelsey's doctor. He has done an excellent job in the treatment of our daughter's glaucoma. Still we wonder what the future holds. "Will the glaucoma return? If so, when? How will we know? Will it eventually take her sight?"

We still live in a world that seems to revolve around her pressure checks. We somehow have to come to accept this circle of events as a type of routine. We know that as Kelsey grows and learns about glaucoma, she too will be more able to participate in the detection of symptoms.

Glaucoma is a disease that always has unanswered questions and unknowns. Raising children with glaucoma is a challenging journey, but with proper treatments and awareness, we look to the future.

## Relationships with Siblings

When you are a parent caring for your child who will have ongoing medical care, it takes extra time and energy from you and the rest of the family. It is important to spend time with your other children individually to make sure that their needs are also met. It is helpful to have open communication with your children in explaining and understanding the eye condition. Bring the siblings along occasionally for office or hospital visits to help them have compassion for what their brother or sister is experiencing. Including the siblings is important in the family's relationships with each other. The everyday interaction and activities between siblings is a wonderful natural way to encourage your child's development.



**Siblings—while needing support for their own pain and sadness—can play an integral role.**

## Looking Toward the Future

Your ability to cope with your child's glaucoma undoubtedly will vary from day to day. There may be times when you almost "forget" your child's glaucoma. You may be able to go great lengths of time easily living in the moment, and not worrying about the future. You'll likely have long stretches of time with only typical childhood worries.

Most children with glaucoma live full and active lives. Parents, siblings, teachers, and health care professionals are all important members of the team caring for your child's glaucoma. As your child grows older, continue to encourage his or her independence and participation in self-care. Although lost vision cannot be restored, it is possible to optimize each child's remaining vision—and preserving vision is the ultimate goal of glaucoma management.

## Gena Harper



### One Woman's Story

Gena Harper is Senior Vice President in Wealth Management at Morgan Stanley in Oakland, California. She is a nationally recognized advocate for glaucoma awareness, and she received the Kay Gallagher Award from the American Council on the Blind in 1998. Born with glaucoma, Gena is blind in one eye, and has very little sight in the other. She became a stockbroker at age 22, and today she has two children and is a highly respected financial advisor managing half a billion dollars. Despite the difficulties growing up legally blind, Gena's love of the outdoors led her to become an award-winning downhill skier, as well as a skilled rock climber, hiker, rafter, and sailboarder. Gena is pictured with her guide dog, Asia.



Dr. Goldberg's research laboratory is working with three other laboratories on the Catalyst for a Cure (CFC) Biomarker Initiative. His research is directed at neuroprotection and regeneration of retinal neurons.

### Jeffrey L. Goldberg, MD, PhD

Professor and Chair of Ophthalmology  
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## **How Glaucoma Research Foundation is Speeding the Cure**

Glaucoma is the leading cause of preventable blindness. Founded in 1978 in San Francisco, Glaucoma Research Foundation (GRF) works to prevent vision loss from glaucoma by investing in innovative research, education, and support with the ultimate goal of finding a cure.

### **Leading the Way In Glaucoma Research**

The Collaborative Normal Tension Glaucoma Study, funded by GRF, was the first controlled clinical trial to establish that lowering eye pressure preserves vision. Now, another major collaborative effort, Catalyst for a Cure, is redefining how glaucoma research is conducted and speeding the process of discovery. The Catalyst for a Cure research consortium brings together scientific investigators from university laboratories who are working to understand the genetic and neurologic development of the eye and find ways to intervene to stop glaucoma's progression.

In addition, GRF invests in Shaffer Grants—individual study grants awarded to researchers with promising new ideas to bring to the field of glaucoma which might otherwise be overlooked or go unexplored.

The Glaucoma Research Foundation, a 501(c)(3) non-profit organization, receives no government funds and is almost entirely supported through donations from private individuals—often patients like you.

**To make a secure donation online, please visit**

**[www.glaucoma.org/donate](http://www.glaucoma.org/donate).**

### **GRF Mission**

To prevent vision loss from glaucoma by investing in innovative research, education, and support with the ultimate goal of finding a cure.

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## Contributors

A special thank you to the families living with childhood glaucoma who contributed to this booklet, and to Susan La Venture of NAPVI, managing editor of the original document.

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GRF public education programs include the free newsletter, Gleams, free educational brochures about glaucoma, and this guide for parents of children with glaucoma and their families.

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This booklet is only a supplement to good medical care. Always consult a health professional prior to decisions regarding your child’s eyes.

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