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• INSIGHT INTO CHILDREN'S GLAUCOMA AND CATARACTS •

Persistent Hyperplastic Primary Vitreous

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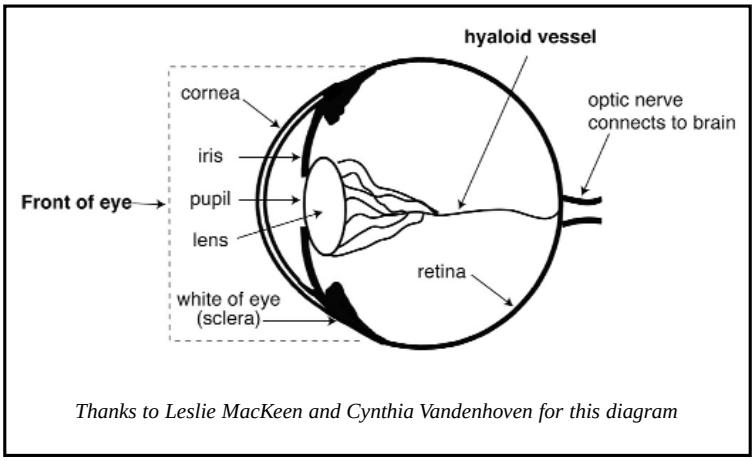

Thanks to Leslie MacKeen and Cynthia Vandenhoven for this diagram

During the development of the eye in the womb, there is a blood vessel which runs between the optic nerve and the back of the lens (see Figure). This blood vessel carries nutrients and oxygen to the developing parts of the front section of the eye. The blood vessel is known as the hyaloid vessel. The vessel, along with surrounding embryonic material, is also known as the primary vitreous. In the 3rd trimester (last third) of pregnancy, the hyaloid vessels are supposed to dissolve, as they are no longer needed. However, if the blood vessels do not disappear, this can result in a particular form of cataract involving the back part of the lens. The condition is known as Persistent Hyperplastic Primary Vitreous, or more commonly simply as PHPV. Recently, recognizing the many variations in which this abnormality can present, some ophthalmologists have recommended replacing this term with a more general designation: Persistent Fetal Circulation (PFC)1. For the purpose of this article, I will use the more familiar older terminology of PHPV.

PHPV is sometimes further divided into subtypes. Anterior PHPV occurs when the remnant vascular stalk is seen attached to the back of the lens but no longer extends back to the optic nerve. Posterior PHPV occurs when the remnant vascular stalk is seen arising off the optic nerve but not reaching the lens and therefore not usually causing cataract. Posterior PHPV may be associated with developmental abnormalities of the optic nerve or surrounding retina. The surrounding retina can be scarred or even detached. If there is significant involvement of the optic nerve and/or retina, good vision may not be possible. Most often, patients have some element of both Anterior and Posterior PHPV.

PHPV is often associated with a small eye (microphthalmia). In addition, the pupil often does not dilate well and there may be traction on the tissue behind the iris (ciliary processes). The front part of the eye (anterior chamber) may be shallower than normal leaving less space between the iris and the overlying cornea. This predisposes the child to glaucoma. The cataract may range from a tiny visually insignificant opacity on the back of the lens, to a wide spread vascularized plaque on the back of the lens, to varying degrees of opacity throughout the lens including the possibility of total white cataract.

When the cataract is significant, surgery is required to clear the visual axis so that visual rehabilitation may begin. However, surgery for PHPV is complicated by a higher rate of retinal detachment than seen with any other pediatric cataract surgery. Research published from our institution2 has shown that there may be abnormal tissue behind the lens which connects the remnant vascular system, lens, and retina. This may cause the retina to experience traction as the cataract surgery is performed. In addition, after cataract surgery, there is a significant chance that the pupil may close up due to scar tissue. These problems may be eliminated by insuring that the abnormal tissue behind the iris is excised at the time of cataract surgery. For that reason, PHPV surgery is sometimes performed by retinal surgeons rather than pediatric cataract surgeons. The surgeon may choose to remove the remnant vascular system within the eye and, if possible repair any damage to the retina resulting from the PHPV. Patients who have surgery for PHPV are also at higher risk for glaucoma as compared to other children with cataract. Some physicians believe that cataract should always be removed to prevent glaucoma but the risk remains even after surgery.

The cause of PHPV is unknown. It is almost always a disorder that affects one eye. When PHPV is found in both eyes, this may indicate a syndrome affecting other parts of the body as well. Appropriate pediatric evaluation is indicated. In addition, other congenital abnormalities of the retina can mimic PHPV and should be considered when both eyes are involved. Most likely, unilateral PHPV represents a "mistake" in the development of the eye. Making an eyeball is a complicated process and therefore it

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is not unreasonable to think that a simple error could occur. PHPV in one eye is not a genetic disorder. Therefore it should not be passed on by the affected children or to more than one child in a family. However, each family should consult a geneticist, eye geneticist, and/or genetic counselor for information specific to your own situation.

It was not too long ago that ophthalmologists believed that all patients with PHPV had a poor chance of recovering decent vision after cataract surgery. However, PHPV can be part of a more widespread developmental disorder of the eyeball that may limit vision. Late detection is also a problem as the brain may miss the chance to develop the vision normally. Yet, modern techniques have allowed us to achieve excellent vision in some children particularly when there are no other abnormalities of the eye and the disorder is diagnosed in the first few weeks of life. Since the cataract is present at the time of birth (and may worsen with age) patching of the good eye is absolutely essential to achieve visual rehabilitation. Placement of an intraocular lens implant (IOL) may not be advisable because the surgery is often being done in the first year of life, excision of the vascularized plaque on the back of the lens may leave little support for the IOL in the eye, and these eyes are already predisposed to complications which could be potentially aggravated by an IOL. Glasses, and particular contact lenses, are the usual treatments. Some children have experienced successful IOL implantation but there is no evidence yet that this improves the vision outcome.

Further Reading (Editor's tip: Ask your local hospital or medical school librarian to help you find these articles from the medical literature) for a more detailed review see

Goldberg MF: Persistent fetal vasculature (PFV): an integrated interpretation of signs and symptoms associated with persistent hyperplastic primary vitreous (PHPV). American Journal of Ophthalmology 1997:124(5):587-626

for more on the research done at our centre see

MacKeen LD, Nischal KK, Lam WC, Levin AV: High frequency ultrasound findings in persistent hyperplastic primary vitreous. Journal of the American Association of Pediatric Ophthalmology and Strabismus 2000;4(4):217-223

Glaucoma Surgery in Children

Choices and Considerations

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[Editor's note: also see our webpage www.pgcfa.org to view previous newsletter issues that contain articles about different forms of glaucoma surgery]

What types of glaucoma surgery are there?

There are several types of glaucoma surgery, which all share the common goal of trying to reduce the eye pressure to help prevent damage to the structures of the eye and vision from the glaucoma. To help remember them better, they can be categorised as 1) Angle surgery – this type of surgery helps to open the eye's own drainage system (also called the "angle" or the "trabecular meshwork") so that the fluid of the eye (the aqueous humor) can get from the inside to the outside of the eye through the natural drainage route); 2) Filtration or Drainage surgery – this type of surgery helps the aqueous humor within the front part of the eye to get out through new passageways, but does not use the eye's own drainage system; 3) Cycloablation or Cyclodestruction surgery – this type of surgery works to decrease the amount of aqueous humor that the eye makes, by treating the part of the eye (the ciliary processes) which make the fluid.

It is very important to understand that the best surgery for one child's eye at any given time, may be very different from the best surgery for another child's eye, or even the same child's eye at a later time. The choice of surgery is influenced by the type and severity of the glaucoma, any prior surgeries which the eye has had and how they worked, the age of the child, the personal experience and expertise of the surgeon, and sometimes also by how healthy the child is and how easily the child can be followed up by the surgeon or another pediatric eye specialist.

Angle Surgery: for which cases does it work, and how well?

Both goniotomy and trabeculotomy are surgeries designed to open the existing drainage structures. These surgeries are most successful in children with congenital or infantile glaucoma (glaucoma presenting very early in life usually without other serious abnormalities to the eye), as well as for children with glaucoma as a result of uveitis (inflammation in the front part of the eye) in association with juvenile rheumatoid arthritis, and sometimes in other forms of glaucoma as well. There are surgeons who have reported excellent success using goniotomy surgery also to help prevent glaucoma associated with aniridia in very selected patients, and some surgeons also favor goniotomy as their initial surgery in juvenile open angle glaucoma (but this is not universal).

The success of angle surgery to control glaucoma depends upon the type and severity and age of onset of the glaucoma: success rates as high as 80 % or even higher have been reported for infantile glaucoma presenting between the ages of 3 and 9-12 months, although conservative estimates probably would place the likelihood of successful control of glaucoma (with or without the additional use of medications) at about 70 %. As a treatment for glaucoma in the setting of uveitis (iritis) with or without juvenile arthritis, success of goniotomy is about 60 – 75 %, again often requiring medications to continue. Often more than one goniotomy or trabeculotomy is needed to control glaucoma, since these surgeries (except one specific modification of trabeculotomy) usually open only a portion (rather than the entire circumference) of the drainage system each time.

Filtration surgery: for which cases does it work and how does the surgeon choose which type of filtration surgery?

Filtration surgery comes in two basic types: trabeculectomy (and modifications) and glaucoma tube implant surgery. In trabeculectomy, the surgeon creates an opening in the outer coating of the white of the eye (the sclera), just near the limbus (the place where the clear cornea meets the white sclera), usually in the upper portion of the eye which is normally covered by the eyelid. The aqueous fluid then flows through this hole to form a small raised area (the bleb) under the outer overlying

covering of the eye (the conjunctiva). Sometimes the surgeon modifies this surgery to include the use of medications to help prevent scarring, such as mitomycin c, and 5-fluorouracil. This surgery can work very well to reduce eye pressure. The two major problems with trabeculectomy surgery include thickening or scarring of the bleb area over time so that the fluid can no longer drain and eye pressure rises again, and the possibility that the bleb tissue might get very thin over time and leak or become infected. If leakage of the bleb persists, and especially if infection occurs, there is a serious risk of damage to the structures of the eye if the problem is not quickly treated. This risk is especially high when mitomycin is used. The bleb may need to be revised or removed if serious infection or persistent leakage occurs, sometimes requiring a different glaucoma procedure to control the eye pressure thereafter.

Trabeculectomy is probably most suited to treat children who are slightly older, because these children seem to have fewer tendencies to scar or thicken their bleb sites, and also seem to be more reliable for examination to detect leaking or infection. Conversely, very young infants and those who have had cataract removal early in life, may be more at risk for scarring or infections and failure of this type of surgery. In older children who have not had cataract surgery, the success of trabeculectomy is quite high, ranging up to 75 % or higher, depending upon the specific published report. The success rate does decline slowly over time, as cases of bleb scarring and infection can continue to occur years after trabeculectomy. This type of surgery can be repeated, and can also be followed by Glaucoma Implant Surgery and/or Cycloablation Surgery (see below). There are also surgeons who prefer to combine trabeculectomy with trabeculotomy for difficult cases of congenital/infantile glaucoma, with some favourable reported success rates in these children.

Glaucoma Implant Surgery was discussed in detail in the Winter 2002 MORINformation newsletter. A glaucoma implant is a tiny tube connected to a round or oval plate (also called the reservoir), which can be used to direct the aqueous humor within the front part of the eye to a space just outside the eye. The fluid drains to the reservoir, which is usually attached to the sclera where the upper eyelid covers it, and under the outer conjunctival layer of the eye. Different types of implants are made with reservoirs of different sizes and shapes, and some also have a "valve", a small flow-regulator, separating the tube from the reservoir plate.

Glaucoma implant surgery is usually reserved for cases of glaucoma that have already been treated with medications and often, in the case of congenital glaucoma, with angle surgery (such as goniotomy or trabeculotomy). Many surgeons prefer to use a glaucoma implant if trabeculectomy surgery (above) has failed to control the glaucoma or before trabeculectomy especially in cases where trabeculectomy is likely to fail (e.g. iritis). Glaucoma implant surgery is also useful for treating glaucoma in eyes that have already had cataracts removed, because these cases sometimes don't do as well with trabeculectomy surgery. Glaucoma implant surgery is sometimes preferred over trabeculectomy in infants, because trabeculectomy has a reduced success rate in infants compared to older children, due to the high rate of bleb scarring that often occurs.

The published success rates of various glaucoma implants used in pediatric cases vary widely, from as low as 50 % to as high as about 90 % over time. It is reasonable to expect about a 60 – 70 % chance that the implant surgery will control the intraocular pressure in an eye, but to realize that additional glaucoma mediations (usually eye drops) will be needed in at least 50 % of eyes that receive a glaucoma implant. The long-term success rate is probably lower in very small children, due to their propensity to form thicker capsules over the implant reservoir, which allows the eye pressure to increase over time. In small children, there is also a substantial risk of needing to do another surgery related to the glaucoma implant, such as repositioning of the tube over time.

Comparing trabeculectomy with glaucoma implant surgery is a little bit like comparing apples and oranges, but we will try anyway! Pros and cons of trabeculectomy include a better chance of getting the eye pressure low enough to not need additional medications, with the disadvantage that this surgery carries a life-long risk of leak and infection, is contraindicated in some surgeons' opinions in eyes wearing soft or extended wear contact lenses, and does not work well in certain cases due to thin tissue or scarring. Pros and cons of glaucoma implant surgery include a lower risk of infection over time, and probably an increased success rate vs. trabeculectomy in selected cases such as infants and eyes after cataract removal; with the relative disadvantage of a generally higher eye pressure than after successful trabeculectomy, often requiring continued use of glaucoma medications.

Cycloablation or Cyclodestruction: When should it be considered?

There are three basic ways in which the ciliary processes of the eye can be treated to try to decrease the amount of aqueous humor fluid that the eye makes: 1)cyclocryotherapy; 2) transscleral laser cycloablation; and 3) endoscopic laser cycloablation. These three treatments are usually reserved for use in eyes that either have elevated eye pressure after attempted filtration surgery, or those in which filtration surgery is not possible or advisable due to the shape or other features of the eye. Some surgeons do select endoscopic laser cycloablation as the first surgical choice in children who have had cataracts removed, and in whom the eye pressure is too high despite the use of glaucoma medications.

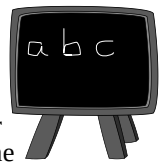
In cyclocryotherapy, a very cold probe is placed onto the outside of the eye, which, through the sclera and eye, freezes the tissues down into the level of the ciliary processes. This treatment is performed especially in eyes where the anatomy makes it difficult to perform other forms of cycloablation. It causes more inflammation in the eye and is more uncomfortable than the other two types of cycloablation. Transscleral laser cycloablation uses a laser (usually a diode or YAG type of laser) to direct energy directly through the outer sclera of the eye, to reach and destroy portions of the ciliary processes, without causing damage to the overlying tissues. Transscleral laser cycloablation causes less inflammation that cyclocryotherapy, but shares the disadvantage of being unable to always treat the ciliary processes adequately, because the treatment is placed from the outside of the eye without visualizing the target tissue to be treated. Finally, endoscopic diode laser can be used to treat the ciliary processes under direct visualization (see MORINformation January 1999), and may be more effective and with less inflammation than the other two techniques.

All cycloablation techniques sometimes require multiple retreatments, and have an overall effectiveness of not more than 50 %. The major risks of the procedures include phthisis (letting the eye pressure go too low from loss of fluid production by the eye), which is rare(especially with the laser techniques), blurred vision from possible edema or swelling in the retina, and rise in eye pressure over time after the treatments, requiring either additional treatment, or another glaucoma surgery to be used. These procedures can be used after almost any other glaucoma procedure described above, and are often reserved to use after other treatments have failed or only partly reduced the eye pressure.

Conclusions

The decision regarding which glaucoma surgery is best for any given child's eye, should be made by the family and the specific surgeon taking care of the child. It is important to know that there may not be just one "right" surgery for a given eye. There are risks and benefits to each type of glaucoma surgery, and it is best to fully discuss these with your surgeon prior to proceeding.

Visual Impairment in School Life



Classroom Accommodations

Dr. Carol Farrenkopf,
Vision Program Consultant;
Toronto District School Board, Vision Program

Meeting the needs of children who are visually impaired that are integrated into the regular classroom can be accomplished with some creativity, simple adaptations, and through the use of adaptive technology. Some students may only need a simple accommodation like sitting with their backs to the window, while others may require more extensive (and expensive) accommodation through a computer with a screen enlargement program. Accommodating students' needs and providing modifications to meet students' needs have very different educational implications. To understand the difference between these two terms, the definitions and examples have been included here.

Accommodation: Accommodations are things that school personnel can do to make the visual environment more accessible to the student who is visually impaired without making changes to the academic expectations/standards for the student. For example, the use of a closed circuit television (CCTV) enlarges regular size print to a size that is easiest for the child to see. Allowing the child to sit closer to the chalkboard may help the child see what the teacher is writing. Speaking aloud as the teacher writes may also help the child take down notes in his/her notebook. Providing task lighting, enlarged handouts, high contrast materials, black lined paper and pens, assigning only 10 questions instead of 20 questions for homework, and allowing extra time to complete tests are also examples of accommodation.

Modification: Modifications are changes that have been made to a child's educational program that are different from the regular stream. For example, a child who is in grade 6 but is using a grade 2 math textbook is on a modified math program. Children who spend part or all of their school day in a special education classroom are likely on a modified academic program. If the student is in high school and on a modified program, he/she may not obtain academic credits for some courses. However, this may vary from one school district to another.

Three Basic Principles for Teaching Children Who are Visually Impaired

Berthold Lowenfeld, a pioneer in the education of children who are visually impaired, identified three basic principles for teaching children who are visually impaired. Any teacher can apply these principles, not just teachers who have a child who is visually impaired in their classrooms.

1. Provide Concrete Experiences: Children who are visually impaired need to be able to touch and manipulate real objects in order to fully understand the properties of the objects. By using real objects and allowing the child to explore materials tactually and visually, children will gain a more global perspective of the objects. For example, a young child who is blind or who has low vision may not fully understand a story about Halloween because he/she has never carved a pumpkin before. By bringing a pumpkin into the classroom for the child to carve, the teacher has made the experience concrete or real for the child.

2. Encourage Learning by Doing: Children who are visually impaired should be allowed to participate in all aspects of real-life experiences, including all of the steps in a sequential activity. For example, a school trip to the pumpkin patch where children are able to pick a pumpkin, break it from the vine, bring it back to school, and then carve it would be an invaluable experience for the child. The child participated in all of the steps involved in the "pumpkin patch" experience, thereby making it a meaningful activity.

3. Unify the Experience: Often, children who are visually impaired are taught in "units" or "chunks" of information. For example, if the child is unable to trace or cut along a darkened line/shape, it is unlikely that he/she will be able to cut along the triangular outline of a pumpkin's eyes. Consequently, the child may engage in some pre-pumpkin cutting experiences/lessons that will enable him/her to cut the pumpkin's face. Eventually, the ability to cut along a line should be unified into the experience of cutting out the pumpkin's eyes to make the whole activity more meaningful.

Accommodations for Students with Low Vision

The following is a list of accommodation strategies and tools a student with low vision might use in the regular classroom. Not all students require the same accommodations—school personnel will help determine which of the accommodations below best suits the needs of your child.

- Large print textbooks and enlarged handouts
- Black-lined paper (instead of light blue lines) with regular-size spaces between the lines or wider spaces between the lines
- Black marker (instead of pencils or coloured pens)
- Thick white chalk or dustless chalk for use by the teacher
- Thick black markers for use by the teacher on white chart paper/white board instead of coloured markers
- Coloured overlays (plastic, non-glare sheets that change the colour of print material) [Editor Note: The use of coloured overlays, in particular to treat what has been called the Scotopic Sensitivity Syndrome, is controversial and not recommended by the American Academy of Ophthalmology, the American Academy of Pediatrics, or the American Association of Pediatric Ophthalmology and Strabismus]
- Slant board/book stand for reading and writing which helps reduce glare and changes the angle of print material so the student doesn't have to crane his/her neck over the desk
- Extra desk space and storage for materials
- Preferential seating, location depending on student's needs
- Task lighting to increase light and/or to reduce glare on work surfaces
- Time-and-a-half for tests, exams, and some assignments
- Taped materials if appropriate
- Partnering with peers to assist student with identifying what's on the chalkboard or overhead and other print material the student cannot see clearly
- Monocular or binocular telescope used to see in the distance
- Magnifier (dome-shaped, horizontal bar or floppy sheet-size) to enlarge materials up close)
- Closed circuit television (CCTV) to enlarge print materials and to write under
- Desktop/laptop computer with screen enlargement program and/or speech output, printer, scanner
- Orientation & Mobility training with or without a white cane

Accommodations for Students who are Totally or Functionally Blind

Students who are functionally blind rely primarily on their tactile and auditory senses for learning. School personnel may recommend some of the following accommodations for these children.

- Braille books and materials/handouts
- Braille writer (a manual one such as the Perkins or a computerized one such as the Mountbatten)
- Braille paper (8 _ x 11 or 11 x 11 inches)

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- Slate and stylus
- Tactile teaching materials (e.g., 3-D geometric shapes, tactile line maps, life-size models, miniatures of life-size objects, textured books, raised line graphs/tables)
- Books/materials on audiocassette (usually 4-track)
- Desktop/laptop computer with speech output and/or Braille display, print printer, Braille embosser (Braille printer), scanner
- Books and handouts/assignments on disk
- Portable notetaker with Braille display or speech output
- Personal organizer with speech input/output
- Orientation & Mobility training (white cane or dog guide)
- Sighted readers
- Partnering with peers to assist with accessing visual information in the environment
- Extra desk/storage space for computer, Braille books, tactile materials
- Preferential seating near the exit and power outlets
- Preferential locker position and specialized lock (key or tactile combination rather than the typical rotary combination lock)
- Time-and-a-half to complete tests/exams and assignments (double-time for math and science exams)
- Reasonable expectations and extension of deadlines to complete projects that require research ("skimming" Brailled/taped/digital material is time-consuming and can be difficult for some students)
- Extra instructional time to learn new concepts, especially technology-related, math, and science
- Teacher verbalizing what he/she writes on the chalkboard/overhead
- Teacher calling students by name rather than pointing
- Teacher providing copies of assignments on disk or hardcopy to be scanned ahead of time so student has a chance to have material in an accessible medium (i.e., Brailled by the Vision Teacher)

In the next issue, suggestions for making physical education classes accessible and safe for students whom are visually impaired.

Contact Lens Solutions and Care Systems

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The Toronto Western Hospital

Cleaning and disinfection of contact lenses is of almost equal importance to the fit. If there is a problem or complication as a result of improper care or non-compliance with the system, the lenses are unlikely to provide the comfort and vision for which they were prescribed. This holds true for both adults and kids who wear cosmetic or therapeutic contact lenses.

Contact lenses can be generally categorized as rigid, soft or silicone hydrogel based (see MORINformation winter 2001). Each material is compatible with certain solution care systems. The care system is prescribed so as to best clean and disinfect the lens while not causing irritation to the eye.

Contact lens care systems in use today are classed as cold disinfection meaning that some form of chemical, or combination of chemicals in the storage or cleaning solution act as an antibacterial agent. The active ingredient in the solution is the preservative which serves a double purpose; to prevent deterioration of the solution as well as to disinfect the lens. In the past heat was used to sterilize soft lenses but has not been promoted for several years due to the unreliability of the sterilizing units.

Disinfection

Multipurpose or 'all in one' solutions for soft lenses are commonly seen in the marketplace. Whilst these systems can be very effective and convenient, they are preserved, contain a cleaning agent and may cause some low level sensitivity or reaction. Itching, mild redness and dryness are typical symptoms of what is described as a low-level solution reaction. Multipurpose soft lens solutions are generally best when used in conjunction with disposable and frequent replacement soft lenses. 'No rub' versions of the all in one type are available but it must be noted that the amount of rinsing required is significantly increased over the rub, rinse and soak version of the same solutions. The cleaning properties of the all in one solutions are not effective enough for most wearers of conventional soft or silicone based lenses although they are compatible with the materials.

Oxidizing or hydrogen peroxide-based systems are effective in disinfecting soft lenses and do not use chemical preservatives. The solution must be neutralized with a catalytic tablet or disc in the case during storage prior to the lens being inserted. Peroxide will cause severe burning and redness if put in the eye without being neutralized. Peroxide systems will usually include a daily cleaner and saline rinse in addition to a weekly enzyme cleaner. The hydrogen peroxide based system may be used for any soft lens material. It is not used for rigid lenses, as it does not provide surface wetting for the material. Peroxide is not generally used for silicone based (e.g. Silsoft) lenses as it tends to make the surface of these lenses break down prematurely. The oxidization process of the peroxide system will cause a bleaching effect on tinted soft lenses causing the colour to fade.

Disinfection may also be achieved by using a 'cleaning' or 'starting' solution, which contains isopropyl alcohol. The lens is rubbed for a minimum of five seconds to clean debris from the surface while killing bacteria. The lens is then rinsed and stored in a saline solution that may be virtually preservative free. This type of system may also include enzymatic cleaning and can be used on all soft and silicone lenses.

It should be noted that the rubbing or cleaning step of any system is an integral part of the disinfection process. The physical cleaning of the lens removes most of the bacteria and contaminants thus making it easier for the disinfectant in the solution to be effective against those that remain on the lens surface.

Cleaning

All cleaning solutions are to be applied to the surface of the contact lens and rubbed for a minimum of ten to twenty seconds. As previously stated, this aids in the effectiveness of the disinfection agent of the soaking solution. Cleaning solution should be well rinsed from the lens surface prior to soaking or inserting. This includes all flexible and rigid lens materials and solution systems.

Enzyme cleaners may be used on any contact lens material. The enzyme breaks down protein that adheres to the lens reducing its comfort and optical quality. These enzyme cleaners are available in tablet form to be placed in the soft lens solution with the lens, and liquid form for rigid lenses. Most enzyme cleaning is performed on a weekly basis with an overnight soak. The lenses should be thoroughly rinsed after enzyme treatment to avoid any irritation that may be created by traces of the enzyme being in contact with the surface of the eye.

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PATCHING PANEL

Q: Does Patching work?

David's story

This is the story of how, through the three P's of vision therapy, Persistence, Prayers and Patching, David has achieved an outcome far exceeding the original prognosis.

My son David was diagnosed at 2 1/2 years old with a unilateral cataract. He had an eye problem from ten months of age, when one eye would drift away from the other. I raised it with the pediatrician on many visits, and through three different pediatricians, but they ALL assured me that there was nothing wrong with his eye, and he would grow out of it. At his 2-year check up with the pediatrician I took in a photo to demonstrate the eyes going in different directions. He agreed that there was a problem but, because it was deemed a "lazy eye", it was considered not urgent and we had to wait nearly 6 months to get into the ophthalmologist.

David was diagnosed as having a cataract and the pediatric ophthalmologist (PO) told me to patch every waking moment and return in a month and also to use atropine eye drops. The eye drops stung him, so I only used them once and then tried them on me. They were pretty bad and my vision didn't return to normal for several days. So I stopped them, until I could discuss it with the PO at a later date. The PO didn't offer any advice on how to patch a child or what it would be like. I soon found out. David would scream when I patched him and try to rip it off, so I had to hold his arms to stop him from doing that. I didn't realise that the poor boy was blind when patched and so was scared silly because he suddenly couldn't see. I just had to hold him, with his arms outstretched, against my chest, talking softly into his ear until he would stop screaming. As soon as I stopped that and put him down for a toilet break or a meal break he would remove that patch faster than lightning, and we would repeat the procedure until the end of the day. This carried on for a few weeks, until he began to see well enough to look around the room. Then I was able to sit down with him on the couch and hold his hands, while he watched videotapes (normally he was limited to 30 minutes a day so this was a real treat). Once he got the hang of seeing the TV, he started to leave his patch alone a bit. Then he could see further and could play with his toys, so I was able to stop holding his hands. Then he resumed normal play with his toys and started going outside again. Throughout all of this his monthly visits to the PO showed very minor improvement, and the only advice I got was to keep patching.

I asked the PO for some support or a web-site for vision issues and he came up with one web-site. He also told me not to worry too much as David had another eye anyway. He also said that David would never have a driver's license, let alone pass any medical examinations where eye sight was a requirement, such as pilot, military, ambulance driver, fireman etc. Not words I wanted to hear. Then he raised the issue of surgery "as patching isn't working". As this was about four months after I had first seen him I thought that was a bit premature. However we were moving house the next month so I thought that I would wait and see what the new PO thought. I had also just discovered the aphakic web support group and they were very, very helpful. They gave me the courage to go on with my convictions, which was that, in David's case, surgery should be the LAST option, not the next.

The new PO was completely different, and his vision therapist was very supportive and gave me a whole bunch of exercises to try with David starting for half an hour a day, while he was patched. I continued with that and David showed some improvement. The therapy was increased to an hour a day and David's vision continued to improve. The PO felt that we should wait and see what the therapy would do before considering surgery. Next visit showed further improvement and David's therapy was increased to two hours a day. We have continued that for the last 15 months and the improvement has been nothing short of miraculous. His vision is now 6/9 (20/30) in his cataract eye.

I am astounded at the progress he has made. In just under 2 years, David has gone from blind in one eye to having functional vision, better than I can see without my glasses and sometimes with my glasses! It has been difficult for him, and he has not always been a compliant patcher. But he has been very good about it, and I admire his resilience. David has come a long way, but it hasn't been an easy road. There have been days when I really wanted to give up, and days when I was so sick of people asking or teasing about his patch that I could have smacked them. It has been very frustrating some days, but we have muddled through and done it. But I have to say that without the support of the group, and the input of the new PO and his assistant, David's outcome would be completely different. So they all deserve some of the credit.

Margaret Maher

[Editor's Note: Although patching is a well accepted cornerstone of treatment, "vision therapy" is controversial. See the next issue of MORINformation for further discussion]

Taylor's story

My daughter Taylor had bilateral cataract surgery a year ago. She was 7 months old. We started patching right after the surgery. I would patch her as soon as she woke up and did it for four hours a day. At first I did not take her out because I didn't like the stares. She got such nice positive comments from people when it was just her glasses on. Then I got to the point where I had things to do, so we were out and about with the patch on. People are mostly just curious so I answered their questions, and usually everyone is quite nice.

Anyhow, in July of this year we were bumped up to 6 hours a day of patching. Her eye has improved greatly. She is going in for strabismus surgery soon, and the doctor feels that once surgery is done we might not have to patch anymore. I am thrilled! To actually hear that what I stuck to has done the job, makes me very happy. Taylor will be grateful in

the long run. So any parents who are struggling with the patches, hang in there and get it done. It's worth it!

Stick to a routine and the child gets used to it. As soon as she's dressed in the morning the patch goes on. She even shuts her eye for me. She will be 21 months on the 25th of September.

Vicky Sterling Mother of Eric - bilateral cataract surgery at age two. He is now 8 years old. Rebecca, aged five, has bilateral cataracts but has not needed them removed. Taylor, 21 months old, had bilateral cataract surgery, patching 6 hours a day and is soon in for strabismus repair.

Maggie's Story

Our youngest daughter, Maggie, was born with congenital glaucoma. She had her first surgery at 8 days and then a second at 4 weeks, neither of which was successful. Our glaucoma specialist sent us to Boston to see Dr. Walton. He did miracles for her. She ended up with Ahmed valves in both eyes. Once the glaucoma got under control, we had to deal with the scaring on the corneas. She had a corneal transplant in her left eye at about 4 months old. She had some scarring in her right eye, and still does, but it is not impairing her vision. We needed to patch the left eye because the right had a tendency to turn inward. We see a doctor about 3 hours away from home and he is the one who started her patching. We started with patching for half the day at about 10 months old. This was definitely a challenge. She didn't really care for it. We had to use all kinds of tape to keep it on. Gradually she did become used to it. I think she hated having the tape taken off more than wearing the patch. So it did become second nature for her. At each of her check ups the doctor noticed how she was starting to use both eyes together. Very encouraging! Slowly we were able to decrease the hours she had to wear the patch. We saw the doctor this past July and he has taken her off the patching. She is using both eyes together well, and her right eye isn't turning inward anymore. She has just turned 3 in August so it was about a year and a half struggle, but very worth it for the results we have seen. There is no guarantee that she will never need a transplant in her right eye for the scarring, but it is amazing what a simple thing like patching can do for children. We are just so excited about all the new technology there is out there for children with visual impairments, and extremely thankful for doctors like Dr. Walton who care so deeply for the children. We know that Maggie's struggle with glaucoma will continue for her life, but knowing the possibilities out there we can move ahead feeling totally confident that whatever gets thrown our way there are services for her.

Stacie Harrison

Joseph's story

The beginning of our story can be found in MORINformation, January 2000. In short, Joseph was born with a unilateral cataract, had surgery at 5 days old, contact lens and patching right after that. No complications, no issues – other than the prospect of 7 – 9 years of patching ahead of us. Gulp!

We patched pretty much exactly as prescribed, first half his waking time, later 85% of his waking time. I remember when Joseph was small and took frequent naps I kept a notebook and calculator with me so I could keep track of how long he'd been awake and figure out 85% of that. We patched on his birthday, we patched on Christmas day, and we kept the patch on for photographs and whatever else was going on. My view was that sight development doesn't stop just because it's December 25th!

We had a couple of rough periods at 9 months and around 18 months when he would take the patch off. With persistence and constant reinforcement as I have written about in previous editions of the Patching Panel series, we got though those phases with just a few gray hairs to show for it.

At around 2 _ years old we started to notice his 'good' eye turning inwards. The ophthalmologist advised us to stop patching for a couple of weeks and observe. Time went by without patching as over the next few months we went for frequent checkups and even returned to the pediatric ophthalmologist to be sure that we weren't missing anything. But the news was that Joseph has 6/6 (20/20) vision in both eyes and is using his eyes together.

We haven't patched for over a year now which still amazes me. We have been blessed with a number of things – a midwife who spotted the cataract at Joseph's birth and knew to refer us, a very skilled surgeon, and a very compliant little boy. I do believe in miracles, and thank God every day for Joseph and his sight.

Liz

Marilou's story

Our story began on the 28th February 2000 when our third child was born. An adorable and healthy baby girl was our gift after a normal but difficult 9 months, due to many viral and bacterial infections that I contracted during that pregnancy. None were known to be harmful to the baby but I have never been that sick in my life.

Seconds after Marilou was born, we noticed that her left eye looked white. The next day, she was referred to a pediatric ophthalmologist who diagnosed a corneal opacity known as Peter's anomaly with no known cause. She was treated with no success and had no visual input since birth in that eye. The eye began to turn in at around 3 months old. Some specialists were saying that if the eye wasn't stimulated before the age of three months, the brain would be unable to receive messages and no recovery of vision would be possible. Our cornea specialist was hoping to save the cornea with anti-inflammatory drops, but it wasn't possible and she had a cornea transplant at 5 months old. After several infections, we were able to begin the ...Patching...She was then 7 months old, 4 months too late as some would have said.

At the beginning she had no vision at all except that she seemed to turn her head toward light. We had to start to patch 4 hours a day. As soon as the patch was on, she would turn her head, close her eye and fall asleep until we took it off.

We tried several 'tricks' and the methods

continued on page 8

that I remember helping the most are these:

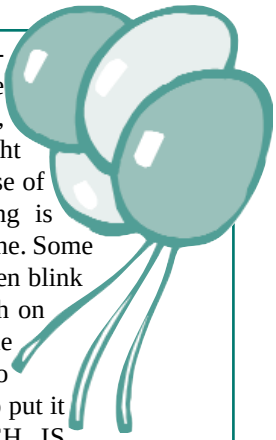
- I used to put her on my back in a baby carrier for the full time of the patching. I was doing my chores around the house and the movement seemed to keep her awake longer and was less stressful on her.
- We created a 'slide show' on the computer with a variety of shapes in black and white and contrasting colors. I used to sit her in front of the screen in a dark room and run the changing images in front of her eye once or twice a day for the first weeks. We still use it but more for fun than to develop vision although I am sure it still helps.
- We put the patch on during her naptime and she would wake up with it on. It was easier for her to wake up with little vision than to lose the good vision she had with the other eye.

ATTENTION - PATCHES ARE A CHOKING HAZARD AND KIDS HAVE A TENDANCY TO TAKE THEM OFF AND HIDE THEM IN THEIR MOUTHS. AS SOON AS A CHILD IS ABLE TO PULL THE PATCH OFF, HE NEEDS CONSTANT SUPERVISION WHEN WEARING IT.

- Never feel sorry for your child. He would be pitiful if you weren't doing a thing to help his vision. As long as you are helping him, he is a lucky child.
- Follow a regular routine. It is easier for your child and for you.
- Let the clock decide about the time to take it off. They can't make the clock change its mind!
- He takes it off...You put another one on. Never let him win at this game. One victory makes him confident that he can win the next time, even if you have to put a patch on only for a couple of minutes to prove your point. It seems hard, but kids are pretty quick at this game.
- We chose to have a patch-free day every week. For us it is on Sundays.
- Get the other members of your family involved. If they have the same attitude and speech as you on this subject, your child will feel more secure.

Three months after the beginning of the patching, Marilou coincidentally developed a cataract in her weaker eye that interfered with her vision. Its evolution was pretty fast and she had cataract surgery with IOL (intraocular lens implant) at 15 months old, and began to wear glasses. Because of this, her vision wasn't functional from 10 to 17 months of age.

We have been back to the patching since then and Marilou is now 2 1/2 years old. She wears her patch 4 hours a day. During the morning in summer, and during the afternoon in winter, due to the daylight hours, and also because of our schedule. Patching is now a part of her routine. Some periods she doesn't even blink when we put the patch on and then, for a couple of weeks, we have to restrain her in order to put it on, but THE PATCH IS PART OF HER LIFE.



Up to now, her vision has clearly improved. Even though you can tell that she doesn't see as well with that eye as with the other, she is functional with it when the good eye is patched. She runs in the yard, plays ball, looks at books, watches TV, goes up and down the stairs, avoids obstacles, uses her vision to find an object and that is only the beginning. She has not had a visual acuity test done yet, but judging by the way she functions her sight is already better than we were expecting. And we still have over four years of visual stimulation (patching) to do. By the time she turns 7, her vision should be much better!

Pascale

Patching Day at Nursery School

Pierre is now 2 years and 8 months old. I was wondering if he is conscious of his patch and that he is different to the other kids. So at the day nursery an educator proposed that we put a patch on the other 4 and 5 year-old kids. To my surprise Pierre didn't pay any attention to the other kids, but for them it was a great experience, to see like Pierre sees when he is wearing his patch. They enjoyed trying on the patch, but took it off after a few minutes. They told us that it is not easy to wear the patch, it itches and is uncomfortable. Also they realise they see better with their two eyes. Pierre has been wearing a patch since he was 3 months old; it is a routine and he doesn't know life any other way. The other kids of 4 and 5 are more aware of the reasons Pierre wears a patch and get on well with him.

It was a great experience. I think Pierre sees himself as a little boy, no different to the others. His patch is not an obstacle to happiness – a good conclusion!

Mélanie Gagnon, Mother of Pierre.
Pierre's story appears in MORINformation Summer 2002.

Notice

Boston Workshop 2003
for Parents of Children with Glaucoma.

Sponsored by: Pediatric Glaucoma and Cataract Family Association, Toronto, Canada, and the Children's Glaucoma Foundation, Boston Massachusetts.

Saturday April 12th 2003
9:00 AM to 5:00 PM
Shriver's Hospital for Children
51 Blossom Street
Boston, Massachusetts.

Program:

- Medical care of childhood glaucoma.
- Resources for children with visual loss secondary to glaucoma.
- Topics describing glaucoma surgery including goniotomy, trabeculectomy, glaucoma implants, new advances.
- Parent's needs.
- Parent's perspective on eye care – what has worked and failed.
- Litigation - yes or no?
- Panel questions and answers.

Speakers:

Sharon Freedman, MD, Duke University, North Carolina
Alex Levin, MD, Hospital for Sick Children, Toronto, Canada
Steven Kane, MD, Harkness Eye Institute, New York, NY
Beth Arnold, BA, Massachusetts Eye and Ear Infirmary, Boston
David Weakley, MD, Southwestern Medical Center, Texas
David S. Walton, MD, Harvard Medical School, Boston

Registration information

Please send the following information and registration fee by Monday March 10th to:

Ms. Karen L. Sicher
Children's Glaucoma Foundation
2 Longfellow Place, Suite 201
Boston, MA 02114 USA

- ❑ Name
- ❑ Institution or Affiliation
- ❑ Address
- ❑ Postal Code
- ❑ Telephone

Fees:

$50.00 (Cdn) or $40.00 (US) for single registration
$75.00 (Cdn) or $70.00 (US) for family registration of 2 or more people
Registration fee includes luncheon. Onsite registration add $10.00 US

Please make checks payable to: PGCFA-CGF Workshop 2003

For further information contact: Ms. Karen Sicher
tel. (617) 227-3013
Fax. (617) 227-4352
Childglau@attworldnet.att.net

Recent Events

Education day, Toronto November 16th 2002

Dawn Atwell

The 2002 education day was a huge success. Thank you to Alcon for sponsoring the day.

Sixty parents, children and health care professionals, attended the education sessions. Dr Levin discussed current and future directions of cataract and glaucoma management. Dr Kraft gave a talk on the importance of patching for the correction of amblyopia. He gave credit to the parents that are dealing with this on a day to day basis. A discussion was also held between parents on patching strategies that have worked for them. Alissa Ulster stressed the importance of getting support for parents and children who are dealing with these and other challenges. Ian Hubling gave us useful tips on how to search the internet for information. (find links on our web site www.pgcfa.org). Dawn Atwell told of her experiences explaining vision issues to classroom teachers and sports coaches. Nancy Cornish, a patient representative from the Hospital for Sick Children talked about the importance of clear communication when advocating for your child. Overall, it was a well-spent informative day. Well done and thank you to everyone involved.

World View

World Eye Surgeons Society (Worldeyes)

Dr Boon-Long Quah
MBBS, M.Med(Ophth), FRCS(Ed), FAMS
Pediatric Ophthalmology and Adult Strabismus
Singapore National Eye Centre

World Eye Surgeons Society (WORLDEYES) is an international movement of eye surgeons dedicated to the control of mass blindness in the developing countries worldwide, especially in Asia where millions are blind. The Society was conceived by Professor Arthur Lim from Singapore and registered in 1994. Its name was changed from World Cataract Surgeons Society (WORLDCATS) to WORLDEYES in 1998 to reflect its interest beyond cataract to include other major blinding conditions such as glaucoma, diabetic retinopathy, ocular trauma and corneal diseases requiring transplantation.

One of the major objectives of WORLDEYES is to promote quality assurance in eye surgery. It also hopes to promote training and skills transfer in surgical expertise to the developing countries. It has thus established five lens implant training centers in China and organised numerous training courses and international meetings.

WORLDEYES has currently over 1,000 volunteers that include surgeons, nurses and other ancillary staff from more than 90 countries all over the world.

WORLDEYES is targeting to increase its membership to more than 5000 members from 100 countries in the next 3 years. It aims to combat mass blindness and to perform one million cataract surgeries over the next 8 years.

The secretariat of WORLDEYES is based at the following address:
Singapore National Eye Centre
11 Third Hospital Avenue
Singapore 168751
Tel: (65) 62277255
Fax:(65) 62277291

History of the PGCFA

Leslie Mowat, Founding Member and Past Chairperson.

Inspired by Dr. Alex Levin the Pediatric Glaucoma Family Association was formed in November 1993 to fulfill a need for interaction and information between parents and children with glaucoma. Dr. Levin asked the first seven parents he had scheduled on a particular day if they would be interested. Each parent accepted and the PGFA was born.

The first meeting was held in the office of Dr. Levin at The Hospital for Sick Children in Toronto. The goal established was to promote the quality of life for children with glaucoma and their families by providing information, resources, education and support. The first item on the agenda was how the association could honour the memory of Dr. J. Donald Morin. Dr. Morin was Ophthalmologist-in-Chief at HSC until he passed away in June of 1993. He was an internationally acclaimed expert in pediatric glaucoma, had one of the largest pediatric glaucoma practices in the world and was loved by his patients. The first newsletter aptly named "MORINformation" was published the summer of 1994 and was sponsored by Allergan. In October 1994, the first open house and education evening for parents was held by the PGCFA at HSC. The largest undertaking was to host a fund raising event selling tickets to the show "Sunset Boulevard" on November 8, 1995. This event raised $65,000, which was used to purchase a fundus camera for the Ophthalmology Department at HSC in memory of Dr. Morin. A plaque commemorates this gift.

The focus of the Association changed as people became more aware of the PGFA. The mailing list for the newsletter grew, with people from countries all over the world requesting to be added. A Scientific Advisory Board (SAB) was established and met in October 1999. Dr. David Walton of the Massachusetts Eye and Ear Infirmary in Boston, Dr. Sharon Freedman of Duke University Eye Centre in Durnham, NC and Dr. Alex Levin comprise the SAB.

In January 2000, the PGFA expanded to include families of children with cataracts who were also in need of information, education and support. After all, cataract surgery is one of the most common causes of pediatric glaucoma so it was a natural match. With a committed and united constituency, more people could be helped. A family picnic was held near Toronto to celebrate and has become an annual event each June. The name was officially changed to become the Pediatric Glaucoma and Cataract Family Association in September 2000.

September of 2000 was an important time for the group. The PGCFA secured its own domain name pgcfa.org and developed a web site. This has given the Association a much higher profile. People from around the world access the site.

These milestones of the PGCFA comprise a brief overview of what has occurred. The Parents' Guide to Childhood Cataracts and Glaucoma, an exhaustive question and answer handbook, is a very important project for the association which is finally coming to reality and should be published in late 2003. Dr. Walton is holding an education day April 2003 in Boston and members of the Board will be attending. We continue to grow, thanks to the volunteers on the Board, parents and friends.

Financial Overview of the PGCFA

The PGCFA is an organisation run entirely by donations. The board feels very strongly against charging fees for services or membership dues as this might become an an issue for parents.

So where does our money come from?

- Corporate sponsorship, either by regular donation or as a 'one off'
- Donations from individuals
- Fund raising events organised by individuals and groups such as golf and euchre tournaments, scouts fund raising efforts etc
- On going fund raising schemes organised by the board such as the sale of greetings cards.

Of these the most significant in terms of dollars is the corporate donations, and the most significant in terms of emotional involvement is the organising of events by individuals and groups. We are very grateful for the generosity and efforts of all those who donate money to our cause. Without you we would be unable to continue our services.

What do we spend the money on?

- Outreach Services: newsletter typesetting, printing and postage; the annual education day in Toronto, web site operation
- Support for clinical research
- Purchase of medical equipment
- Annual prize money for a research paper within the field of pediatric glaucoma and cataracts, plus money towards expenses for the prize winner to travel to one of our education days
- Production of a book to be available to parents of newly diagnosed children.

At this point in time the work of our organisation is flourishing. We are reaching more people than ever with our global outreach. Through the newsletter and web site we are making a difference in the lives of hundreds of families affected by glaucoma and cataracts.

Unfortunately, as our success increases, so does our need for additional financial assistance. That is why we are asking for your help. A donation from you would not only help us to continue with the level of support you enjoy today, but would help us increase our effectiveness.

Donations can be made in several ways:

- By cheque payable to 'PGCFA' to the address on the reply card enclosed with your newsletter – 39 Freeman Road, Markham, Ontario, L3P 4E9.
- By credit card on the PGCFA web site through an organisation called CanadaHelps who will provide a charitable receipt by return e-mail, all major credit cards accepted
- By credit card on the PGCFA web site through a service called Paypal, all major credit cards accepted.

Instructions and links for donating can be found from any page on our web site at http://www.pgcfa.org. Thank you for your support. May the good work continue!

Ruthie's Story:

A Story Of Hope And Miracles And Doctors

Ruthie is my second child. She was born 5 weeks early. Our pediatrician came to the hospital and checked her out; said she was fine. She weighed only five pounds and I had to nurse her at the nurse's station because she initially turned blue because she couldn't swallow milk and breathe at the same time. We were released the next day.

After about two weeks of nursing I was still waiting for her to straighten out her eyes and look up at me. But she had severe strabismus and nystagmus, so at the next doctor's visit I mentioned my concern. The pediatrician said her eyes were slow to develop because she was 5 weeks behind normal children.

One month later, at the age of six weeks, Ruthie seemed worse than before. I told the doctor, my mother, and my husband that she was blind. They attributed this opinion to hysteria brought on by post-partum depression (which I did not have). At the age of ten weeks I took Ruthie and my four-year-old to a birthday party. There was a one-month-old baby there who was smiling and laughing and looking directly at his mother. I began to panic. If Ruthie's crossed-eyes and nystagmus were due to her prematurity, then surely she should be at least focusing as well as a baby six weeks younger than she. I took her back to the pediatrician on a Friday afternoon. They let me in only because I was completely hysterical on the phone.

So on a Friday afternoon at 5:00 the doctor looked at her eyes. She didn't follow the flashlight, she didn't look up, her head hung down and she had severe nystagmus. After 20 minutes of this, the doctor looked up at me with tears in his eyes. "Something is definitely wrong; she cannot see a thing. But now you will have to wait over the weekend to see a pediatric ophthalmologist." So there I am going down the elevator with my blind baby. The nightmare that nobody believed was now reality. My husband and I cried the entire weekend with the baby sleeping between us, as if we could somehow protect her from what was to come by keeping her safe. My thoughts went from "How will I explain the color of the sky?" to "What kind of life will she have?"

The pediatric ophthalmologist confirmed she was blind from completely opaque congenital cataracts. The lenses had to be surgically removed as soon as possible because usually this is caught at birth and done at the age of one month. The window of opportunity for infant sight development is over. We have a slight chance of sight recovery but "don't get your hopes up".

The right eye was done on October 11. The patch that was put on her eye was half the size of her whole face. I removed the patch after four days and she woke up at 3 a.m. to nurse. I turned on the light to look at her, and with that one eye she stared at me. She LOOKED at me. I knew then that all my talking to God and praying and doing good things in my life had paid off. I told the doctor about it and he said, "That is what you want to think but it is unlikely that she sees anything and it's too soon."

The other eye was done and patched. When the patch came off we were waiting for the eyeglasses. Every night I took Ruthie outside and walked around holding her. She would stare up at the streetlights and the moon. Just stare for minutes on end. I took her out every night to do this and every night she was mesmerized by the light. The doctor frowned at my optimism, almost laughing at me. The eyeglasses were put on her and we went back to see the doctor. The nystagmus was still as bad as ever and he proclaimed that there wasn't any sight. My mother was with me on that visit as the doctor explained how lucky we were to be living in Los Angeles where there were several excellent schools for blind children. My mother and I had a good cry and went home.

A couple of days later I noticed a change in the nystagmus. Instead of bouncing in circles her eyes were going back and forth only horizontally. I called the doctor. "It doesn't mean anything." My husband worked at UCLA in medical research and I used his computer to look up old medical journal articles using key words aphakia, nystagmus, blindness, whatever I could think of. One article popped up from 15 years earlier. It was about children with albinism who are born blind and have severe nystagmus. When their sight begins to develop their nystagmus becomes horizontal rather than circular. I printed the article out and brought it to the doctor. I was going to have my hope regardless of his pessimism. He was impressed. Can you get this article for me? I printed one out for him but I was angry that he didn't do his own research, that he made us ill for so long, that he had no hope for my daughter.

At five months Ruthie began her contact lenses in order to develop her peripheral vision. Her eyesight at the age of 7 months was 20/50 with the contact lenses. When Ruthie was 20 months old we moved to Atlanta and found an excellent pediatric ophthalmologist. We visited every six weeks. When she was three years old I found an article that said aphakic children have a 30% greater chance than other children of developing glaucoma between the ages of one and five. I told the doctor and said "Don't you think we should check for it?" Good idea, he said. Of course at that point when he checked for it her pressure was already up to 30 in one eye. So we went to the glaucoma specialist and started drops. When the doctor tried to dilate her eyes to check the optic nerve the right pupil would not dilate. Turned out this was a result of the initial lensectomy, a complication of that surgery. We started her on eye drops for the glaucoma and the doctor did the best he could to check the optic nerve with the very small opening of that pupil. So far there has been no damage to the optic nerve.

Of course we were hoping for the past couple of years to be able to have intraocular lenses put in her eyes so she wouldn't have to wear the aphakic eyeglasses. However, both the pediatric ophthalmologist and the glaucoma specialist have told us that this procedure will certainly exacerbate the eye pressure and possibly cause irreversible damage. She would subsequently have to have a shunt put in her eye to relieve the pressure, so we wait and wait and hope. If there were any other opinions out there regarding other possible options I would welcome any information.

Ruthie is now six years old. She has gone through all of the drops that exist for glaucoma. She is now on Cosopt twice a day and Xalatan at night. Her pressure at the last visit was the lowest it's ever been: 18. Up until last year she wore aphakic lenses with bifocal glasses for school. Now she refuses to wear contact lenses and wears her aphakic glasses with bifocals. She is a beautiful child and very self-confident. Nobody makes fun of her, and when they occasionally do say something about her bulging eyes through those thick glasses, she takes off her glasses and looks at them with her large black eyes and foot-long eyelashes and says: "Do they still look funny to you?" She gets straight A's in school, she is on the principal's honor roll, she plays the piano, she plays soccer, she is an excellent artist, she's funny, smart, curious, kind-hearted, a wonderful sister and a loving, playful daughter; the happiest child I have ever seen. Her eyesight with her aphakic glasses is 20/40. She is a miracle child.

The most important lessons I learned over the past six years are that you have to trust your parental instincts, that doctors are only people who can also make mistakes, and that miracles do happen.

-Debbie Sidell-one HAPPY mother!

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Family Stories

Jude's story

My son, Jude was born in December of 2000 a perfectly healthy baby boy. As the months went by we noticed his left eye would become red and swollen. Of course, we took him to the doctor who told us he had pink eye. When the symptoms continued we would be told he had everything from allergies to sensitive skin. Jude would cry excessively and never slept very contently. After five visits to our pediatrician, who had been practicing for over 20 years, I insisted on an appointment with an eye doctor. The appointment was made for six weeks away and I was very worried. Then the next day they called back and said the doctor at the eye center was concerned and could we bring Jude in the next week. I agreed and became more concerned. The next morning when Jude woke up he wouldn't open his eyes. After 30 minutes I probed his left eye and saw it was totally white.

I was stricken with fear and panic. I immediately called the eye center here in Roanoke VA and told them I was bringing my 4-month-old son in immediately! I loaded my other three children into the car and headed for the doctor's office. Immediately he was diagnosed with pediatric glaucoma. I was told his pressures were around 40 and his sight may have been lost totally in his left eye.

Pressures? Glaucoma? What in the World was happening to my perfect baby boy? Could he possibly have a blinding disease? The answer was yes. I was told to give Jude drops in his left eye as the right had not yet shown symptoms of elevated pressures, which I found should be around 10 not 40. I was referred to a leading specialist in the field, a wonderful and concerned Dr. Sharon Freedman of Duke University Eye Center. We saw her the following week where we were told to expect one of possibly many surgeries.

In the mean time Jude's eye was still white and he had to be placed on Diamox which served it's purpose in bringing down the pressure in the left eye but caused sickness and breathing difficulties.

When we got to Duke, Dr. Freedman explained to us what pediatric glaucoma was and how she would start to treat my baby. His first surgery was a goniotomy. The aftermath was traumatic for us as we saw our little lamb's eye patched for days. A few weeks later we were back and Jude was in trouble. He underwent a bilateral trabeculotomy after learning that indeed both eyes had been affected.

Two weeks later Jude underwent a third surgery, a bilateral goniotomy. That was in July of 2001.After that he remained on many drops which have gradually been reduced to his present medications of Trusopt twice a day and Timoptic once a day. His checkups are 3-4 months apart. When Jude was diagnosed his vision was found to be damaged, but recently when tested he found to actually have improved to a point where he doesn't even need glasses. We have been blessed to not have to use patching techniques, as his eyes are again healthy.

After one lost job for me and countless missed work days for my husband and long weeks at Duke we are finally able to stop and breath. During all that time I didn't think the horrors would ever end but they did. Somehow, through prayer, much support from our church family, and no doubt the determined Dr. Freedman, we can finally say that the worst is over. Jude has normal daily routines except for the drops twice a day, which he sometimes gets s fed up with, but overall I consider ours a success story.

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Rinsing

Saline is the only specific rinsing solution for contact lenses. Multipurpose solution may be used to rinse prior to insertion of the lens but it is also used for storage and disinfection. Saline is available as a mildly preserved or non-preserved preparation. Saline has no disinfecting ability and should not be used as such. Saline that is packaged in an aerosol container contains no preservatives and is excellent for patients who suffer from allergies to contact lens solution preservatives. Saline may be used to rinse the lens that has been stored in a solution for the purpose of disinfecting the lens or to rinse a cleaning solution off the lens prior to soaking. Tap water should never be used to rinse soft contact lenses due to the levels of bacteria and pathogens that are present. Rigid lens care systems may allow tap water to be used as a rinse after cleaning the lens but require a minimum soaking time of four hours in the storage/conditioning solution prior to lens wear. Saline can be used for rinsing rigid lenses to further reduce the chance of contamination of the lens.

Rigid lens solutions

The solutions used for storing and conditioning rigid lenses may not be used on soft lenses. Rigid lens solutions, like soft lens solutions, come in both multipurpose and multi-step forms. The decision as to which system is prescribed is based on the specific rigid lens material and the fitter's evaluation of the patient. While water could be used to rinse off cleaning solution prior to overnight storage, saline is recommended.

Compliance

You should always use the solutions and care system which have been prescribed. By changing to alternate solutions you may cause eye irritation, allergic reaction or damage to your lenses. Always consult with your contact lens fitter regarding a change in your contact lens system.

It is important to remember that contact lenses have a finite life. Younger patients deposit faster and more heavily than adults and their lenses will require more frequent replacement through normal wear. The general rule is that the younger the patient, the more frequently the lens will require replacement. This means that some lenses will require replacement as soon as four to six months in spite of excellent care and cleaning. Each case is individual and your contact lens fitter or eye doctor are the best sources of information regarding you or your child's contact lens fitting and management.

Contact us by e-mail through the web site at ***www.pgcfa.org*** or at our postal address at the office ***c/o Dr. Levin at The Hospital for Sick Children, 555 University Avenue, Department of Ophthalmology Suite # M158, Toronto, Ontario, M5G 1X8, Canada.***

Please contact us regarding anything you would like to see in the newsletter. We welcome new members to the Board or any of the subcommittees if you would like to get involved.

Thanks…. to all the contributors to this edition of MORINformation.