

• INSIGHT INTO CHILDREN'S GLAUCOMA AND CATARACTS •

The Pediatric Glaucoma Patient Grows Up

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Children with glaucoma do eventually grow up. How well they see and what they are able to do depends to a large degree on what problem caused the glaucoma. In this article we will discuss how damage to the eye can occur during glaucoma. We will also talk about how the visual outcomes can vary widely, and some differences in treating an adult compared to a child with glaucoma.

Glaucoma that presents during infancy usually has the most effect on how a child will see as an adult. Infantile-onset glaucoma can interrupt the normal maturing of the brain, and cause poor vision due to amblyopia, also known as "lazy eye". What this means is the brain receives a blurred image during development. If the blurred image is not corrected in the first several years of life, poor vision out of one or both eyes may result permanently for life. In the adolescent or adult glaucoma patient, amblyopia can not be treated and it can not begin if it wasn't present before. It still may be necessary to change the glasses prescription periodically, but patching is no longer needed.

Glaucoma can cause poor vision in other ways as well. Uncontrolled glaucoma usually leads to progressive damage to the optic nerve, the connection of the visual impulses generated by the eye to the brain. Damage to the optic nerve can occur at any age, and once it occurs the damage is permanent. The goal of glaucoma treatment is to lower the intraocular pressure (the pressure inside the eyeball) to a level where there is no further damage to the optic nerve. Medications and surgery are used to lower the eye pressure. Patients who are

stabilized on medications for long periods as children generally remain stable on medications as adults but may still need further surgery. Different surgical approaches are used in adult patients. Rather than trying to repair the drain of the eye with goniotomy or trabeculotomy surgery, an alternative drain is created with trabeculectomy surgery, or a glaucoma drainage implant (i.e. tube [also called a seton or shunt] such as Molteno or Ahmed) is placed. In trabeculectomy surgery, a flap of tissue is created over an opening in the front part of the eye. Fluid flows from the inside of the eye to a pocket underneath the tissue that covers the white of the eye (conjunctiva) on the top of the eye called a filtering bleb. This lowers the pressure inside the eyeball. Alternatively, a drainage implant is the placement of a small tube in the eye which is connected to a rounded piece of specialized plastic located over the middle of the eye. A collection of fluid from inside the eye (bleb) forms over the rounded piece, lowering the eye pressure by shunting fluid from inside the eye. (See MORINformation issue Winter 2002 pp. 1-2) Other new surgeries continue to be developed such as viscocanulostomy, an operation where the drain which is formed surgically does not go all the way through into the eye but works by letting fluid seep out of the eye. Although trabeculectomy and tube surgery are also done in children, viscocanulostomy is an operation almost exclusively for adult patients.

Glaucoma can also damage the cornea (clear front window of the eye). This is more likely to happen with glaucoma which begins during infancy. The cornea can be damaged so that it

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stays permanently cloudy despite good control of the eye pressure. The cornea is the only part of the eye that can be transplanted, so it can be replaced by a donated cornea. If the cloudiness is present in young childhood then it is advisable to do the transplant then to allow for visual development to proceed. However, a child's immune system is quite strong, frequently making it difficult to keep a corneal transplant from clouding back over again due to the body rejecting the transplant.

Adult patients with a clear cornea usually continue to have a clear cornea unless the cells which control the clarity of the cornea are heavily damaged as a child. Adult patients usually have a better chance of maintaining a clear corneal transplant if such surgery is needed. Also, enlargement of the eye (buphthalmous) which occurs in infantile glaucoma no longer occurs in older children or adult patients with glaucoma.

If a child has a cloudy cornea due to a birth defect known as Peter's anomaly and also has glaucoma, the two problems are usually difficult to treat. Children with Peter's anomaly usually have the worst visual outcome as adults because so much is wrong with the eye at the beginning of life. They usually do not have vision which is good enough to measure on the eye chart, meaning that they are legally blind. That does not mean that they cannot see at all, and many of these children are still able to see well enough to walk around without bumping into things and see large objects. This is because they adapt to their low level of vision early in life. Inability to drive a car, need for mobility training in poorly lit environments, and need for Braille training in some children with severe corneal problems and

glaucoma are possible outcomes as adults.

One of the most common types of glaucoma which starts during infancy is primary congenital or infantile glaucoma. This type of glaucoma is caused by a birth defect in the drain of the eye (called the angle or trabecular meshwork), with the rest of the eye developing normally. If this glaucoma is detected early and responds well to surgery to re-open the drain of the eye, children with this disorder can develop normal or near normal vision. Some of the children may be quite nearsighted as glaucoma which occurs during infancy causes the eye to enlarge and makes the eye longer than normal. Glasses or contact lenses are used to correct the vision. Many of these children grow up to have 20/20 to 20/60 vision (at least in one eye), which is good enough to drive (in some jurisdictions), play sports, and do all the things that we consider normal activities as adults. However they must be watched lifelong as the glaucoma may come back and need further treatment in adulthood. Some children in this category respond poorly to treatment and can have a very poor visual outcome similar to a child with Peter's anomaly.

Children born with cataracts can develop glaucoma after the cataracts are removed. If the cataracts are recognized early and there are no other birth defects of the eyes, surgical removal and correction of the vision with glasses or contact lenses can lead to relatively good vision in many cases; even 20/20 in some cases. Glaucoma that occurs shortly after the cataract surgery can lead to worse long-term vision, as periods of corneal clouding and changes in the size of the eye lead to blurred vision and a lazy eye. If the glaucoma is not recognized, perma-

nent damage to the nerve with reduced vision can be the result. However, if the glaucoma is diagnosed early and successfully controlled, many of these children maintain useful vision into adulthood. Many of these children can read normal size print with their glasses or contact lenses and some are able to see well enough to obtain a driver's license. Glaucoma after cataract surgery in adults is much less common.

A variety of disorders can be associated with glaucoma that develops in childhood or early adulthood. School age children or young adults who develop glaucoma usually have good vision, but may lose a substantial amount of peripheral vision before they are diagnosed. Visual field tests measure peripheral vision, and are routinely used in older children and adults to ensure that the glaucoma is under control.

A 42 year old man with primary congenital glaucoma in both eyes returned to see me in the office recently. He has 20/400 vision (big E only) in one eye from a lazy eye (amblyopia) and 20/25 vision with his glasses in the other. He works as a swim coach and does not require any special accommodation or reading aids, nor does he require glaucoma medications.

In summary, children with glaucoma can have a variety of visual outcomes as adults. The vast majority of patients are not totally blind (unable to see light or dark) and many have good enough vision to be indistinguishable from people with healthy eyes. Early diagnosis and persistence with treatment are the key to your child maintaining the best possible vision as an adult. As adults, continued close follow-up remains essential.

Ask the Doctor

*My child is blind in one eye.
How will this affect her life?*

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When a child loses vision in one eye, there is virtually no effect on their life in terms of education or physical activity. A one-eyed child learns as well as their two-eyed peers. They play equally well in sports. In fact, there are several very famous professional athletes who demonstrate remarkable skills despite being blind in one eye since childhood. Of course these statements are made with the assumption that the remaining eye has normal vision. Children are remarkably adept at learning to live with normal vision in just one eye. Indeed, if you peered into a crowd of children it would be very hard to pick out the child who is functioning with just the vision in one eye. I would highly recommend not putting any restrictions on such children and allowing them to seek their own comfort level in terms of activities and interest.

However, with only one eye working, it is extremely important that this eye be protected from harm. Children should wear protective eyeglasses (see elsewhere in this issue) to protect their good eye from an accidental injury. These glasses have lenses which are made of break proof polycarbonate. The glasses should be worn even if the child does not need to wear glasses to see better. Children with only one good seeing eye should also

wear appropriate protective eyewear for sports. Every sport, especially those with racquets, balls, or contact, has appropriate protective eyewear. In Canada, every child who plays organized ice hockey must wear a full face shield. For baseball, there is a chin guard which attaches to a batting helmet that prevents a ball from entering between the top of the chin guard and the visor. In sports such as tennis, special sports goggles can be made even if an eyeglass prescription is required. The usual glasses that children wear are often not satisfactory for sports particularly if they have collapsible hinges, extreme flexibility, or wire frames. Consult with your eyeglass store to learn more about protective eyewear.

It is true that in some countries, there may be particular restrictions in certain professions on whether or not an individual can perform that profession with just one eye. In some jurisdictions there may be restrictions on military service, piloting aircraft, heavy industrial work, dental or medical practice, or even driving.

In North America, having lost vision in one eye as a child, assuming that the other eye remains normal or well-sighted, will not prevent a child from driving, playing sports (as long as protective eyewear is used), entering the medical profession, or many other activities.



What's new in patching?

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Amblyopia, or lazy eye, is one of the most difficult challenges that families face in trying to improve the eyesight of their child. Children require visual experience in each eye in order to develop the part of their brain that allows them to see. When the brain has a reason to prefer one eye over the other, the vision in the non preferred eye becomes less developed (amblyopia). Amblyopia from cataracts or glaucoma further lessens the visual potential of an eye that may already have vision damage. By patching the good eye or blurring it with atropine eye drops, the brain is forced to use the eye with lesser vision and the vision development will likely improve.

Much new research is going into the understanding of the treatment of amblyopia.¹ However, the major studies involve children whose amblyopia is caused by an unequal glasses prescription between the two eyes or a misalignment of the eyes (strabismus). Therefore, the study conclusions may not be directly applicable to children who have had cataract or glaucoma as the amblyopia in children with these eye diseases is of a different type. The studies on children without cataract or glaucoma are included here so that parents can understand more about amblyopia and the different treatments. The studies have mostly been done by a large consortium of pediatric ophthalmologists from North America called PEDIG.

Recent research has set out to answer several questions. In one study it was found that after six months the visual improvement with atropine drops was the same as that found with patching.²

However, patching achieved a faster improvement. Also, it should be noted that atropine might not work in children who have cataract or glaucoma. Atropine works by relaxing the lens of the eye. The lens is removed at cataract surgery. As a result, atropine has no structure to work on. Atropine also only works if the good eye can be blurred to vision worse than the bad eye. In children with cataracts and glaucoma, the bad eye is usually so blurry from amblyopia that the atropine can't make the good eye blurrier.

Another study found that with moderate amblyopia (vision of 20/40 to 20/80) two hours of patching per day had the same effect as six hours per day.³ In a study looking at children with more severe amblyopia, also called "dense" amblyopia, (vision 20/100 to 20/400) it was found that the visual improvement with six hours patching per day was the same as that achieved with almost full-time patching. However, patients with cataract or glaucoma must be treated separately as their patching requirements might be different.

Studies still underway are looking at the results of patching in older children and also the best method for stopping patching.

In summary, treatment of amblyopia is a very difficult challenge for families to contend with. However, it remains a very important part of the treatment of childhood eye conditions. It is possible to have completely successful eye surgery but the eye not to see well because of amblyopia. In these cases, the long hard road of amblyopia treatment is the only way to restore vision.

¹ Holmes JM, Beck RW, Repka MX. Amblyopia. *Current clinical studies. Ophthalmology Clinics of North America*. 2001;14(3):393-398.

² A comparison of atropine and patching treatments for moderate amblyopia by patient age, cause of amblyopia, depth of amblyopia, and other factors. *Ophthalmology*. Aug 2003;110(8):1632-1637; discussion 1637-1638.

³ Repka MX, Beck RW, Holmes JM, et al. A randomized trial of patching regimens for treatment of moderate amblyopia in children. *Archives of Ophthalmology*. 2003;121(5):603-611.

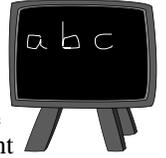
Editors note:

The full commentary of the Pediatric Eye Disease Investigator Group (PEDIG) can be found in *Pediatrics* Vol. 113 No. 6 June 2004 pages 1800-1802. Recent Advances in the Treatment of Amblyopia. Quinn, GE, Beck, RW, Holmes, JM and Repka MX.

For more information on alternatives to patching see *MORINformation* Jan 99 pages 2-3 and *MORINformation* Summer 2003 page 7.

For advice on coping with the struggles of patching see *The Patching Panel series in MORINformation* Winter 2001, Summer 2001, Winter 2002, Summer 2002, Winter 2003.

Visual Impairment in School Life



Life in High School

Monika Mistry
Grade 11

The simple thought of high school may be daunting to many students, regardless of whether or not they have a visual impairment. However, after spending three years in high school, I can honestly tell you that it's nothing to be afraid of. Personally, it has been an amazingly fun time and being visually impaired hasn't hindered me. Sure there are accommodations I need, however there are also many things I've gained as a result of being visually impaired.

Starting in grade nine is no easy task for the nerves, especially when you have this huge building in which to learn your way around. I still remember my first day. Most of the grade nine students, map in hand, were trying to find their way around the school. I had my map too, but I also had a little advantage that made me feel a lot more comfortable. In August, before school started, my orientation and mobility instructor and I had visited the school, noting the layout of the school in addition to important places. This advanced tour is a great way to make starting at a new school easier. It's also especially helpful to have a copy of your timetable ahead of time so you can figure out where your classes will be.

Another thing that makes the high school experience smoother for me is having a liaison with a guidance councilor. For me, the most beneficial aspect of this relationship is that I get placed with teachers who are most likely to help me make the accommodations I need. Before my courses start, the guidance councilor and I look at my schedule and choose teachers that will be most suitable and accommodating. This isn't to say that teachers should be easy, but some teachers are more understanding and mindful in helping make accommodations than others. For example, since I rely heavily on listening to the teacher, I'm usually placed with teachers who have clear voices. Having a connection to a guidance councilor is also helpful as you can go to them should any problems arise.

In regards to teachers, I've found it's crucial to let them know what accommodations I need. At the beginning of each course I introduce myself, my situation and my needs to each teacher. For example "Hi, I'm Monika, I have a visual

impairment. I would really appreciate it if you could give me a print copy of the notes you put on the board as well as say out loud whatever you write on the board..." At this time I would also give them a letter to introduce my itinerant vision teacher as well as to outline the assistance I require.

My itinerant teacher is a teacher from the School Board's Vision Program who helps me make accommodations and provides me with techniques that help me work more effectively. I also have an orientation and mobility instructor, an instructor from the School Board's Vision Program who teaches me techniques that allow me to travel as well as adapt to new environments, safely and comfortably. I've learnt various techniques, strategies and more, from traveling safely on the transit system, to crossing roads properly, to using a white cane.

While these teachers have helped me a lot, self-advocating for myself has been crucial. There are several accommodations I need and it is crucial that I'm able to tell the teacher what works for me and what doesn't. One of the obstacles I encounter is that I usually can't read what is written on the board. Therefore, I ask teachers to say out loud whatever they are writing on the board. Depending on each teacher and their teaching style, I may also ask for them to give me a print copy of the notes they write on the board. I also have a monocular that allows me to read material being put on the board as well as see demonstrations with greater clarity. In addition, I request my teachers kindly enlarge handouts for me or give them to me in advance so that I may enlarge them myself. Another accommodation I receive is that I am allowed to have extra time for quizzes and tests. Regardless of what I need, the most important factor is that I am able to speak for myself in telling others what I need.

I've found that telling teachers is a much easier task than telling peers. Especially in high school, where it seems like people are a lot more judgmental. In elementary school it took a little bit of courage, but I was able to make a presentation in front of the class explaining my visual condition and showing the aids I used. As I got older, instead of asking the teacher to allocate time for me to do a special presentation, I let the class know of my condition through class work assigned by the teacher. For example, in one class we had to present an interesting event from our life. I presented the events surrounding my birth, when my parents

discovered I had glaucoma and cataracts. In some classes I never found the right opportunity and so I never told the class. Fortunately this never became a problem for me.

Even though it doesn't cause any problems for me when people don't know about my visual condition, I can't deny that there are times in class when I've felt slightly awkward. For instance when teachers give me enlarged copies of notes or I'm allowed extra time for tests, I do feel self-conscious sometimes. I remember my first day of math class this year; I was very reluctant to use my monocular for fear of what other people would think. But of course I thought to myself, this is what I need to help me, if I don't use it I won't be able to be as successful and anyway it really shouldn't matter what other people think. A few weeks later I discovered that most people were completely amazed by my monocular and thought it was super cool.

Although not telling everyone in my class about my visual condition hasn't had any major set backs, I must say, I do feel slightly more comfortable when people are aware of my condition. This way people aren't wondering why I am allowed accommodations and why I get special enlarged copies of notes. Its just makes me feel more at ease, I would much rather people understand me and my condition than guess or assume. So although I don't randomly tell people about my visual impairment I do feel comfortable speaking about it and I encourage my peers to ask me questions.

Having a visual impairment may have caused a few awkward moments, but I rarely wish I was born without this condition. Although it has disadvantages, I have also gained so much. Specifically, in relation to school, I've learnt that it is crucial to respect and co-operate with your teachers to your highest potential. There are many things I request of my teachers and I realize that they go out of their way in order to fulfill my requests. As a result, I know I must do as much as I can to help them and make their work less stressful and complicated. If I was to be disrespectful and uncooperative, how could I ask them to help me? Being respectful and kind to your teachers has many more benefits than simply the accommodations they will make for you. It also makes you stand out as a student. Getting along with your teachers is so important and it will make the class more enjoyable too.

As you can see, surviving high school with a visual impairment is nothing to be worried about. Any obstacle that you encounter can always be triumphed and it will always bring a valuable lesson. This is very true for any problems, be they in the classroom or out of the classroom. I can attest to this as I am part of various extracurricular activities, including the Prefects, the Yearbook Committee and a committee that planned and led

a leadership conference. As well, outside of school I'm a Flight Sergeant in the Royal Canadian Air Cadet Program. From living with a visual impairment all my life, I feel I can be a real life example that having a visual impairment will only stop you as much as you let it. Live to the fullest and shine like a star, there is nothing to hold you back!

Informed Consent: What should I ask my doctor?

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When a physician recommends a procedure for a patient, a process ensues called informed consent. The physician has the obligation to inform the patient about the procedure and its risks/benefits and obtain the patient's consent to proceed with the procedure. In the case of children, the decision is usually made by their parents/guardians in the role of substitute decision makers. Some children are old enough to make their own decisions and depending on the jurisdiction, children of varying ages may be allowed to do so without the consent of their parents. For example, in Ontario, there is no official age of consent. It is up to the physician to determine whether or not the child is mature enough to understand the information presented and make their own decision. Some children are not mature enough to give full consent, yet they can understand the nature of the procedure and at least agree in basic principle. This is called assent. Some jurisdictions prefer that a child sign a form indicating their assent. In almost all jurisdictions, either the parent/guardian or the mature child must sign a consent form. This consent form is only valid in as much as it reflects documentation that the discussion and process of informed consent took place.

How much does the doctor have to tell the patient or their parents/guardians? The general principal of acceptability is that the information which a reasonable person would want to know before making a decision about the recommended procedure should be covered. Usually, this information includes

1. RISKS: the physician should discuss all minor risks that are common as well as all major risks that are known to occur which a reasonable person would likely want to know. For example, minor risks such as a slightly droopy eyelid after cataract surgery or a pupil that is not perfectly round, might be discussed. These complications of surgery do not affect vision, but do affect the patient's appearance and occur with enough regularity that they fall into the category of warranting discussion. Likewise, the risks of death or blindness from cataract or glaucoma surgery are extremely remote. However, most reasonable patients want to know about these risks.

2. REASON: the surgeon should explain why the procedure is being recommended as well as other alternatives. The surgeon should discuss why this particular alternative was chosen. The option of no treatment/intervention should also be discussed. In this discussion the patient will get some feeling for the balance of risks versus benefits.

3. WHAT: the surgeon should discuss how the procedure is done and the steps which surround the procedure (e.g. in-patient versus out-patient, if there is a patch after surgery, follow-up appointments). This should include a discussion regarding any discomfort or untoward effects that the patient might experience such as pain or eye drops after surgery.

4. WHO: the patient should be informed as to who is doing the surgery. In institutions where there are doctors in training, patients may want to know if there will be trainees involved in their care during the procedure.



Some researchers in bioethics and medicine have questioned whether or not patients can truly be informed. After all, the doctor has gone through years of medical school and further training to obtain a level of knowledge and skill that gives them the ability to do the recommended procedure and understand that it is indeed the correct thing to do. How can a patient be expected to have this command of the material in such a short time? In fact, there is some entrustment that goes on between patient and physician that allows, if not requires, the physician to take some charge of the decision-making in co-operation with the patient having attempted to obtain the best informed consent possible. The patient should be satisfied that they have indeed received all the information they would like to know. In today's electronic world, many patients will have information gleaned from the internet which might raise additional questions. If so, this information should be shared with the physician. It is perfectly acceptable, if not recommended, for patients to ask their physicians about specific concerns, risks, or circumstances surrounding the surgery. It is even acceptable for a patient to ask the surgeon how many times they have done the procedure. Second opinions may also be requested.

Going for eye surgery can be understandably frightening. Informed consent is a process by which the physician and patient (or their parent/guardian) work together to find a mutual understanding and agreement about the course of action. This type of teamwork will increase the chance of a successful outcome.

PROTECTIVE EYEWEAR FOR YOUNG ATHLETES

Extracted from the Policy Statement by the American Academy of Pediatrics Committee on Sports Medicine and Fitness, American Academy of Ophthalmology Eye Health and Public Information Task Force.

The full statement can be found in PEDIATRICS Vol. 113 No. 3 March 2004.

ABSTRACT. The American Academy of Pediatrics and American Academy of Ophthalmology strongly recommend protective eyewear for all participants in sports in which there is risk of eye injury. Protective eyewear should be mandatory for athletes who are functionally 1-eyed and for athletes whose ophthalmologist recommends eye protection after eye surgery or trauma.

The eye injury risk of a sport is proportional to the chance of the eye being impacted with sufficient energy to cause injury. The risk is not correlated with the classification of sports into collision, contact and non-contact categories. Instead the risk of injury to the unprotected player is roughly categorised as high risk, moderate risk, low risk and eye safe.

High Risk	Moderate Risk	Low Risk	Eye Safe
Small, fast projectiles: Air rifle BB gun Paintball Hard projectiles, sticks, close contact: Basketball Baseball/softball Cricket Lacrosse (men's & women's) Hockey (field & ice) Squash Racquetball Fencing Intentional injury: Boxing Full-contact martial arts	Tennis Badminton Soccer Volleyball Water polo Football Fishing Golf	Swimming Diving Skiing (snow & water) Non-contact martial arts Wrestling Bicycling	Track & field Gymnastics

All athletes and their parents should be made aware of the risks associated with participation in sports and the availability of a variety of certified sports eye protectors. Although eye protectors cannot eliminate the risk of injury, appropriate eye protectors have been found to reduce the risk of significant eye injury by at least 90% when fitted properly. It would be ideal if all children and adolescents wore appropriate eye protection for all eye-risk sports and recreational activities.

Physicians should strongly recommend that athletes who are functionally 1-eyed wear appropriate eye protection during all sports, recreational and work-related activities. Functionally 1-eyed athletes are those who have a best corrected visual acuity of worse than 20/40 in the poorer-seeing eye. If the better eye is injured, functionally 1-eyed athletes may be handicapped severely and unable to obtain a driver's license in many states.

Athletes who have had eye surgery or trauma to the eye may have weakened eye tissue that is more susceptible to injury. These athletes may need additional eye protection or may need to be restricted from certain sports; they should be evaluated and counseled by an ophthalmologist before sports participation.

PROTECTIVE EYEWEAR OPTIONS.

Eye protection and different brands of sports goggles vary significantly in both the way they fit and their capacity to protect the eye from injury. An experienced ophthalmologist, optometrist, optician, physician, or athletic trainer can help an athlete select appropriate protective gear that fits well and provides the maximum amount of protection. Sports programs should assist indigent athletes in evaluating and obtaining protective eyewear.

There are four basic types of eyewear. The two types that are satisfactory for eye-injury risk sports include

1. Safety sports eyewear that conforms to the requirements of the American Society for Testing and Materials (ASTM) standard F803 for selected sports (racket sports, baseball fielders, basketball, women's lacrosse, and field hockey).
2. Sports eyewear that is attached to a helmet or for sports in which ASTM standard F803 eyewear is inadequate. Those for which there are standard specifications include youth baseball batters and base runners (ASTM standard F910), paintball (ASTM standard 1776), skiing (ASTM standard 659), and ice hockey (ASTM standard F513). Other protectors with specific standards are



Joseph (5) wearing the protective goggles he chose for soccer. Other styles are available.

available for football and men's lacrosse.

The two types of eyewear that are not satisfactory for eye-injury risk sports include:

1. Streetwear (fashion) spectacles that conform to the requirements of the American National Standards Institute (ANSI) Standard Z80.3.
2. Safety eyewear that conforms to the requirements of ANSI standard Z87.1, which is mandated by Occupational Safety and Health Administration for industrial and educational safety eyewear.

Prescription or non-prescription (plano) lenses may be fabricated from any of several types of clear material, including polycarbonate. Polycarbonate

is the most shatter-resistant clear lens material and should be used for all safety eyewear.

An athlete who requires prescription spectacles has three options for eye protection:

- a) polycarbonate lenses in a sports frame that passes ASTM standard F803 for the specific sport;
- b) contact lenses plus an appropriate protector; or
- c) an over-the-glasses eyeguard that conforms to the specifications in ASTM standard F803 for sports in which an ASTM standard F803 protector is sufficient.

Functionally 1-eyed athletes and those who have had an eye injury must not participate in boxing or full-contact martial arts.

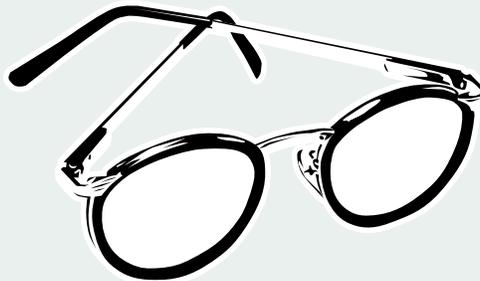
Athletes should replace sports eye protectors that are damaged or yellowed with age, because they may have become weakened and are, therefore, no longer protective.

Editors note: Safety Standards for protective eyewear are established by organisations elsewhere in the world including the Canadian Standards Association, the British Standards Institute, Standards Australia and Standards New Zealand. Others may also exist.

World View



UNITE FOR SIGHT DRIVE FOR EYEGLOSS DONATION 2004



Unite for Sight Canada is a registered charitable organization that is affiliated with Unite for Sight USA. The group organizes and directs local and international efforts to improve access to eye care. In its international effort to provide the gift of sight, Unite for Sight holds an eyeglass drive to collect used eyeglasses and sunglasses to donate to eye clinics in developing countries. Blindness affects 38 million people worldwide, and cataracts accounts for 40% of these cases. Wearing UV-protective sunglasses may help to prevent cataracts as well as macular degeneration, which is another leading cause of adult blindness.

Unite for Sight is seeking the donation of both prescription and non-prescription glasses and sunglasses for distribution to people in India and Ghana. Unite For Sight's Glasses Project will be distributing glasses and sunglasses, while also implementing health education programs that focus on the importance of wearing the donated glasses.

For information on donation of glasses please contact Shawna at uniteforsightcanada@hotmail.com

Kindest Regards,
Shawna Novak

Announcement - PGCFA award winner 2004



The annual PGCFA Award was announced at the annual international meeting of the American Association of Pediatric Ophthalmology and Strabismus. The award is now widely recognized and announced formally from podium in front of hundreds of pediatric ophthalmologists from around the world.

The winner for 2004 is Hess DB, Asrani SG, Bhide MG, Enyedi LB, Freedman SF: Macular volume and retinal nerve fiber layer analysis of normal and glaucomatous eyes in children using optical coherence tomography from the Duke University Eye Center.

Dr. Freedman (who was excused from the final review process when she was short listed as a finalist) is on the PGCFA Scientific Advisory Board.

The reviewers were

Dr. David Walton – Boston.

Dr. Terri Young - Children's Hospital of Philadelphia.

Dr. Edward Wilson – Charleston.

Dr. Ken Nischal - London, UK.

Sr. Steve Rubin - New York City.

These reviewers represent some of the “big” names in our field so I was very honoured to have them participate and volunteer their time.

The support of the PGCFA for pediatric glaucoma and cataract research via this award is greatly appreciated by all.

Thankyou

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JOINT CENTRE FOR BIOETHICS

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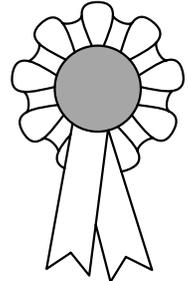
PGCFA award winning paper - Summary

TITLE OF PAPER:

Macular Volume and Retinal Nerve Fiber Layer Analysis of Normal and Glaucomatous Eyes in Children Using Optical Coherence Tomography

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The diagnosis of glaucoma in children can be quite challenging, especially when it comes to evaluating how much optic nerve damage has been produced by the glaucoma. Examination of the optic nerve by the ophthalmologist is the best, and in many cases, the only technique available for diagnosis of glaucoma-related optic nerve damage in children, since visual field testing (testing of peripheral vision) in young children is usually unreliable. Additional objective measurements of glaucoma damage in the pediatric glaucoma patient would be valuable. A recently developed technology called optical coherence tomography (OCT) can measure the thickness of different parts of the retina. In certain eye diseases, such as glaucoma, specific layers of the retina (especially the nerve fiber layer) get progressively thinner over time. Our study evaluates the utility of OCT as a method of assessing the thickness of the retina in two such areas, in children's eyes: 1) the nerve fiber layer near the optic nerve, and 2) the retina around the macula (the part of the retina responsible for the central “bull's eye” vision). Further, we evaluate the ability of this technology to differentiate in children between normal eyes and those eyes with glaucoma.

The results of this study show us that OCT can be used in the pediatric population. Children as young as 3 years old were able to sit for this test. It is a non-contact (no touching of the eyeball) and very patient-friendly test, similar to having a picture taken. The scan itself is totally painless and takes less than two seconds per scan to obtain. As well, there was a significant difference in retinal thickness measurements between eyes with glaucoma and those which were normal control eyes. This study is the first to report this particular application of OCT and is an important step in establishing it as a valuable additional tool in the evaluation of children with glaucoma. Long-term follow-up of eyes with pediatric glaucoma, and serial OCT measurements in these same eyes, will help assess the usefulness of this technology in monitoring glaucoma progression in children.



Every minute
a child goes blind
in our world.

CBMI Canada

Jennifer Grant, Donor Relations, CBMI Canada.

At this very moment, there are hundreds of thousands of children who shouldn't be living lives of blindness but they are. Most of these children live in third world countries... where blindness almost always means no schooling and crippling poverty. Half of all blind children die within two years of losing their sight.

Children go blind most often because of a lack of Vitamin A in their diets. Vitamin A is essential to all the mucous membranes in a child's developing body, but especially the eyes. Parents in the developing world often cannot grow the carrots or leafy green vegetables that are rich in Vitamin A. Even where these foods are available, many parents don't understand their importance to a child's health and sight. When a child who is already vitamin A deficient contracts a disease like measles or diarrhea, that child can go blind in a matter of days.

Thankfully for only 60 cents (including distribution), CBMI coworkers can give these children sight-saving Vitamin A capsules.

The terrible and highly contagious eye infection, trachoma, is another leading cause of global blindness. Children, the primary carriers of trachoma, will eventually go blind if they don't receive help. Trachoma is most often found in children living in crowded, unhygienic conditions, where families don't understand the importance of face-washing, latrines or proper garbage disposal.

Tragically, mothers, the primary care-givers for their infected youngsters, are

most at risk of trachoma blindness, as ongoing exposure causes them to contract and re-contrast the eye infection. Eventually, their eyelids turn under and the eyelashes cut the cornea, causing opaque scarring.

But for only \$1.00 a tube, infected children can be treated with antibiotic eye ointment and their trachoma cured.

Congenital cataracts also renders about 100,000 children in our world blind needlessly. Cataract surgery for babies and young children is a great deal more complicated than it is for adults. Cataracts in children is harder to diagnose, harder to treat, harder to follow up. Children's eyes, smaller and even more delicate than an adult's, behave differently during and after surgery. They require different surgical techniques, more sophisticated equipment and expensive general anesthetic.

Still, for approximately, \$200.00 Canadian, a child can have his or her cataract removed and an intraocular lens implanted. They can have their sight restored for life, virtually overnight.



Christian Blind Mission International is the world's leading agency preventing and curing blindness and enabling people with disabilities in developing countries, regardless of race, age, gender or religion. It has over 1,000 projects in over 100 nations, showing God's practical love to 10 million of the world's neediest people each year.

Madeline's story

Family Stories

When our daughter Madeline Erica was born on December 28, 2001, we were completely thrilled, as all new parents are, overwhelmed by the amount of love we felt for this tiny little person. The journey we had made to arrive at this moment made her all the more precious to us. We had tried unsuccessfully for over 4 years to have a baby. Those years were filled with many fertility treatments, all of which ended in heart sickening disappointment. Several thousand dollars and four years later, I had pretty much given up. I felt that my heart could not handle any more sadness or pain.

We decided to stop trying for a baby and go on a much needed vacation. As hard as it was to accept, we felt we must now face the reality that we were not meant to have children. Family had told us to appreciate that we would still have a rich full life, just one that may not include kids.

We went on a mini-vacation and relaxed more than we had in a very long time. Shortly after our return home, we booked a vacation to Las Vegas with friends. Then one day to my complete shock, I discovered I was pregnant! After all the treatments, we were pregnant without medical assistance. The Vegas vacation was cancelled – we decided we were not going to take any chances with this baby. To skip ahead... my pregnancy and delivery were great, no problems whatsoever.

We had no idea that anything was wrong with our perfect little angel for two months. We could not tell that anything was wrong with Madeline's vision. To look at her, she seemed perfectly normal, her eyes looked perfectly normal. Our family doctor noticed the abnormality in her right eye at her two-month check up. She told me that she wanted us to go see an ophthalmologist to confirm what she had seen and to try not to worry. She referred us to a local ophthalmologist who confirmed her suspicions – Madeline had a cataract.

The doctor allowed me to use his instrument and see for myself. The opacity was dead center in her eye. He referred us to The Hospital for Sick Children in Toronto, to which we are eternally grateful. Everyone there took such great care of us from the very beginning. Not knowing much of anything about cataracts, we just prayed it was nothing serious. I naively hoped that this was something that a prescription of medicine would just make go away. When we were first told that Madeline would have to have surgery, I panicked, fearing for our little girl. Then we were told that it wasn't just an issue of needing eye surgery – we also would need to learn how to put a contact lens in her eye and patch the

left eye every day for several years to encourage the vision development in her right eye. We were devastated. Yet somehow, the doctor made us see that this was something manageable. He patiently answered any question we could possibly think of and put us completely at ease. I don't think any other doctor could have made me feel more secure about the needed surgery than he did.

Madeline had her surgery when she was exactly 4 months old. For me, the hardest moment came when I had to hand over my sweet little angel to the OR nurses when it was time for surgery to begin. Everything went very well and all of the hospital staff was very kind to us. It seemed they truly understood how hard and emotional this all was.

Madeline did have a minor complication after her surgery – her eye had haemorrhaged and it was impacting her vision. The doctor assured us that this was quite common and that most of the time the blood would drain away, absorbed by the body without any need for intervention. He referred us to the retina specialists at to confirm his diagnosis. The retina specialist performed an ultrasound of her eye and felt that additional surgery would not be necessary. Sure enough, 5 weeks post surgery she was fine.

I will never forget how tough it was the first time we patched her. She seemed panicked and definitely appeared to me to not be able to see. The doctor assured us that she could see and to stick it out, as it were! Initially we patched her for all but 2 waking hours every day. I found that to be emotionally very difficult, like I was punishing her, because of the way she cried when the patch was on.

With time, it did get better. She became quite used to the patch, and didn't fight it...until she was about 9 months old. That was when I discovered her trying to eat it during naptime. After that, the patch came off while she slept. We then went through a very

rough 1-1/2 years of patching wars. The patching time had decreased to 2-4 hours/day.

Learning to put in and take out the contact lens was also tough for us. I myself am a contact lens wearer, and had hoped this would give me an advantage. I soon learned that doing it to someone else, especially a squirming infant was a completely different story. The doctor made time for us once again, and gave us further lessons to help us out.

We struggled through it, and lost 3 or 4 lenses in the first year, usually while Madeline was sleeping and we assumed rubbed it out of her eye. We did have many other times when we were lucky and found the lens – stuck to the carpet or a blanket. Not having any insurance coverage for the lenses or the patches made losing them an expensive and stressful incident. However over time, we came to accept that losing lenses will happen and to try not to worry about it quite so much.

Madeline continues to do extremely well. She was referred to another paediatric ophthalmologist for Madeline's care about one month after the cataract surgery. Last August we learned that her vision had dramatically improved and her prescription was changed to a significantly weaker lens. It was the BEST news anyone could have given us. Interestingly, we have not lost a lens since then. It seems as though it "sticks" to her eye better - the new lens is thinner, and somehow less likely to be rubbed off her the surface of her eye.

Madeline also had strabismus surgery this past January, just after her second birthday. The surgery went very well. We did not patch her for several weeks after the surgery while her eye healed, and I was very concerned that after such a long period of time, she would really fight the daily patching regime. She did fight it at first for about 2 weeks, but since then has been doing fantastically well. She does still pull it off, but far less than what she used to. Patch time has become much less stressful for me these days. I am sure that she will continue to go through co-operative and not-so co-operative phases, so I am enjoying this good phase while it lasts.

Madeline is a very curious, energetic and chatty 2 year-old who thankfully is developing normally in every way. I have been fortunate to stay home to raise her and every day I am thankful for this time that I am able to spend with her.

Andrea Osborn



The PGCFCA welcomes Andrea to the volunteer team, as she will be taking over as editor of MORINformation.

Recent Events

PGCFA Toronto Annual Education Day 2004

The annual education day in Toronto was held in April. There were several speakers covering interesting and relevant topics, which were much appreciated by the audience of parents and other relatives of children with glaucoma and cataracts. Some of the information will be reproduced in MORINformation.

This event has evolved over the years to become an extremely valuable resource for information and networking for parents in the southern Ontario region. We look forward to next year's education day as an opportunity to learn more about the care of our children and to meet others in similar situations to ourselves.

Thanks to the speakers, and all those who work hard to make this event happen, especially to Leslie Mowat.

Would you like to see an event like this take place in your part of the world? Contact the PGCFA for advice and support to make this happen.



Toronto Area Annual Family Picnic.

It was a sunny but breezy day for the annual family picnic, which took place at a conservation park just outside Toronto. With 10 families attending we shared fun, food and fellowship. The kids had a great time playing soccer and blowing bubbles

while the parents spent most of the time retrieving items blown off the picnic table. Boy those paper plates can really fly!

Many thanks to the Atwells once again for organising.

For details of future events keep an eye on the web site at www.pgcfca.org

Announcements

The PGCFA has a new central telephone number.

Contact us on (416) 444-4536.

We also have a new e-mail service for quick access to information about the PGCFA.
info@pgcfa.org

Brandan Cescolini Ophthalmology Research Fund

The Cescolini Family is establishing a long-term fundraising mission to support ophthalmology research. To find out more visit www.brandanseyereresearchfund.ca

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