MORINformation
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• INSIGHT INTO CHILDREN'S GLAUCOMA AND CATARACTS •

STRABISMUS AND AMBLYOPIA

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1. Normal Vision with Two Eyes

A child born with normal vision has the capacity for clear focussing by both eyes as well as parallel (straight) positions of the two eyes. In addition, when the child wishes to look in different directions the two eyes move in tandem so that their lines of sight remain parallel to each other at all times. The sightlines will remain parallel as long as the eye muscles that move the eyes are in balance.

When both eyes see well and move in tandem the images seen by the two eyes are unified into one clear image by the brain. This process also leads to vision in 3 dimensions, known as stereovision. As long as the brain receives equal stimulation from the two eyes it will influence the eye muscles to remain in balance.

Any problems that upset the balance in the eye muscles or compromise the vision in one or both eyes can lead to loss of stereovision and to disruption of the normal alignment of the eyes. A child's visual system is especially sensitive to such problems, as it is not fully developed until age 8 or 9 years.

2. Strabismus

Strabismus is the medical term for eyes that are not straight. An eye can turn in either the horizontal or vertical direction. If the eye turns inward it is often called a "crossed eye" and the medical term for this is esotropia. If the eye turns outward it is sometimes called a "wall-eye" and the medical term for this is exotropia. Finally, if one eye is higher than the other eye the medical term is hypertropia. An eye can drift at an oblique angle such that it is misaligned in both the horizontal and vertical directions at the same time.

Strabismus has many different causes. Children can be born with strabismus, and the parents will notice that the eyes are crossing within the first few weeks of life. More commonly, however, strabismus develops several months or years after birth either as a result of problems with the focussing mechanism of the eyes or as a result of disorders in the eyes themselves.

a) Strabismus due to focussing problems

If a child is very far-sighted, a condition known as hyperopia, the eyes must focus more strongly than usual in order to create a clear image. This excessive focussing stimulates the eyes to cross because there is a link between the focussing mechanism and the messages to the eye muscles that turn the eyes toward the nose.

Alternatively, if the two eyes do not focus equally then the image from one eye may be blurred. As a result, the eye that sees the blurry image may wander because the brain will turn off the awareness of that eye. It may no longer send the signals to the eye muscles to keep the eyes straight.

For either of these conditions the initial treatment is glasses to help the focussing of the eyes. In some cases patching of the better eye is also needed to equalize the vision in the two eyes. If these measures do not lead to a straighter eye then eye muscle surgery is performed in order to put the eye muscles back into balance.

b) Strabismus due to disorders within the eyes

A problem such as glaucoma or cataract can reduce the vision in an eye to the point that the brain ignores the image from that eye and concentrates only with the good eye. The eye with poor vision may then begin to wander since the brain no longer sends signals to its eye muscles to keep it aligned with the fellow eye.

The treatment of these conditions involves treating the disease affecting the vision. For example, if the eye has a cataract the lens has to be removed as soon as possible. If the eye has glaucoma then either medications or surgery are often needed to control the pressure in the eyes. Contact lenses or glasses, and often patching of the good eye, are needed in order to restore the vision in the abnormal eye. If these measures do not lead to a straighter eye then eye muscle surgery will put the eyes into a more normal alignment.

3. Amblyopia

When one eye is not focussing equally with the other eye or when one eye is not straight (strabismus) then the brain can turn off its awareness of the image in the eye. In a child, if this process remains untreated for several weeks the vision in that eye can slowly worsen. This condition is known as a 'lazy eye', and the medical term for this is amblyopia. By contrast, if unequal focussing or strabismus develops in an adult the vision in the eye rarely deteriorates.

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Medical News

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When a child's eye develops cataract or glaucoma the loss of clarity of the image can lead to amblyopia in addition to the loss of vision from the disease itself. Therefore, treating the cataract or glaucoma problem may not, by itself, restore good vision. Treatment for amblyopia, such as patching, may also be needed.

4. Association between Strabismus and Amblyopia

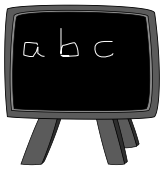
In a child, amblyopia is often associated with strabismus. Both problems involve disruption of the visual signals that normally come into the brain equally from the two eyes.

Strabismus, or a misalignment of an eye, causes the eye to lose focus on a target. As a result, the brain may ignore the signals coming from that eye and this can lead to amblyopia of that eye. Conversely, if an eye develops amblyopia then the brain will receive less visual input from that eye compared to the fellow eye. As a result, it may reduce the intensity of messages it sends to the eye muscles of that eye and this may lead to strabismus.

Fortunately, if amblyopia and strabismus are diagnosed and treated in childhood then the chance for recovery of vision and alignment are very good. Thus, it is important for family doctors and pediatricians to check the eyes for signs of strabismus, amblyopia, cataract, and glaucoma during all routine visits starting immediately after birth.

New Series

Visual Impairment in School Life



Supporting Students Who Are Visually Impaired in the School System. Assessing the Needs of Your Child.

Lenir Sommerville, Specialist Teacher of the Blind; Toronto District School Board, Vision Program
Dr. Carol Farrenkopf, Vision Program Consultant; Toronto District School Board, Vision Program

When you have a child of school age who is visually impaired, locating the appropriate support in school can be overwhelming. To help you figure out what's available for your child, there are several steps you need to take. Keep in mind that every District School Board is different. For specific information related to obtaining services in your board, it is best that you begin by contacting the Special Education Department. From there, you will eventually locate the right person to whom the referral can be made. Listed below is some general information and steps-to-follow that will make the process smoother. Although the authors of this article are from Ontario, Canada, the information outlined below is general enough that it should apply to most school districts in North America.

1. Obtain a Medical Eye Examination Report

In order to obtain vision support in the school system for a child, a medical eye examination report is essential to making a referral. To qualify for support, the report should indicate, aside from the name of the eye condition/diagnosis, the following:

- A visual acuity of 20/70 or less in the better eye after best correction OR
- A significant visual field restriction

Typically, children whose visual acuity is worse than 20/70 or who have a severe visual field restriction (i.e. they have pinhole vision or blind spots) meet the medical criteria for a referral to the Special Education Department, Vision Services. If your child does not meet the medical criteria, he/she can still be referred, but support within the classroom may or may not occur. It is up to the discretion of individual school board as to how much support to provide, if any.

2. Contact the District School Board, Special Education Department

Once you have the medical documentation, contact your local District School Board and ask to speak with someone in the Special Education Department. From there, ask to speak with someone who is in charge of the educational support to children who are visually impaired. Depending on the size of the school district, there may or may not be Itinerant Vision Teachers (specially certified teachers that travel from school to school who are trained to work with children who are visually impaired) employed by the school board.

If the school board does not have specially trained teachers to work with children who are visually impaired, they will likely contact the closest school for the blind. Some schools for the blind employ resource teachers of the blind that travel throughout the province/state that conduct assessments on children who are visually impaired and may provide support to classroom teachers.

3. Completion of a Functional Vision Assessment (FVA)

Functional vision is a term that describes how a child uses his/her vision. In the case where a child has no vision, a Functional Tactile Assessment is conducted to determine the appropriateness of braille (or some other medium) as a reading and writing tool. The FVA looks at how a child uses his/her vision to accomplish tasks within the classroom and school environment. Areas addressed in the FVA include the child's

- ability to perceive colour
- need for large print to read comfortably
- ability to move about the classroom
- ability to print neatly
- ability to see details within pictures.

Once the FVA is complete, the assessors will make recommendations regarding the level of support needed for the child by a qualified teacher of students who are visually impaired. The recommendations of the FVA will differ from student-to-student, as each child has different needs. In some cases, support may be substantial (i.e. several hours per week of one-to-one intensive instruction) or it may be minimal (i.e. one or two visits per year to monitor the student's level of visual functioning). Additional recommendations may be made that include some of the following:

- Use of an alternative reading and writing medium (large print, braille, taped material, digital material, adaptive tactile/visual communication system)
- Use of adaptive technology (e.g. computer with speech output or braille display, closed circuit television, laptop computer, notetaker etc.)
- Use of low vision aids that have already been prescribed (e.g. monocular telescope, magnifier) within the classroom
- Simple classroom accommodations (i.e. preferential seating, extra time to complete tests/exams, larger work space, task lighting, slant board/reading stand, high contrast materials, concrete materials, and verbal directions)

4. Determine your Child's Options

All children have a right to attend a regular school, however the intention of

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school boards is to find the most appropriate placement for the child. That placement may be in the child's local school with support from specialist teachers, a special program at a school further from home, or a segregated classroom/school. Depending on where you live, your local school may or may not have the services necessary to meet your child's needs. In Ontario, Canada, children who are visually impaired typically attend their local schools and receive Itinerant Vision Teacher support or a Resource Teacher from the Provincial School for the Blind. Admission to a school for the blind is typically dependent upon an assessment by their specially trained staff.

5. Identification and Placement Meeting

Children who are visually impaired that will require an intense level of support will need to be identified as requiring Special Education support for vision. This identification meeting is held by the school board and the results of the FVA and medical documentation are typically presented. It is at this meeting that the child's placement is usually determined. Once again, the placement is dependent upon the services available in that particular school board or suitability to attend a school for the blind. As a parent, you have various rights that you should be informed of that are specific to each province/state regarding identification and placement recommendations. If you disagree with the recommendations made at this meeting, you should contact your local school board to find out what your rights are.

In the next issue: Typical Classroom Accommodations for Children who are Visually Impaired

Pharmacy Corner

Recent Developments in Drugs for the Treatment of Glaucoma

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Medical treatment for glaucoma a decade ago was really quite simple – there were a limited number of drugs in just a few different classes, so the options for medication use were fairly limited. The good news was that most ophthalmologists knew which drugs were available and how to use them. The bad news was that some pediatric patients did not have adequate control of their eye pressures even on "maximum tolerated therapy", that is the most medication that was available or able to be tolerated due to side effects (some of which were severe).

In the last decade, the number of commercially available medications to lower eye pressure has increased dramatically. This means that there are increased options for treating children (and adults) with glaucoma, however, it is more complicated than ever to determine the best strategy for using the available medications to treat any given child's eye(s). It is also sometimes hard to decide when an eye is on "maximum medical therapy" since there are so many drugs to choose from!

Pharmacy Corner articles in the past three years have featured a variety of medications for glaucoma, including Pilocarpine, Propine, Xalatan, Iopidine, Alphagan, Trusopt and others. To put these articles and newer drugs in perspective, let's begin by making a list of most of the commonly available drugs used to lower the eye pressure in patients with glaucoma. Keep in mind that while each of these drugs has been extensively tested in adults with glaucoma, most information about the effectiveness and side effects of these drugs in children comes from the experience of ophthalmologists who treat children with glaucoma, and from those children themselves. In the past few years, the U.S. Food and Drug Administration has begun to encourage pharmaceutical companies to test the safety and effectiveness of their drugs specifically in children. Several of the commonly used glaucoma drugs are currently being tested, but no published results are yet available.

There are five major classes or types of drugs available to treat glaucoma. Below each class is a list of the major commercial drugs in that class:

1. Carbonic Anhydrase Inhibitors: These drugs lower the eye pressure by decreasing the amount of fluid that the eye makes.

a) Oral (pills or liquid by mouth) – acetazolamide (Diamox), methazolamide (Neptazane)

b) Eye Drops – dorzolamide (Trusopt), brinzolamide (Azopt)

2. Miotics: These drugs lower the eye pressure by increasing the flow of fluid out through the normal drain of the eye (the trabecular meshwork). pilocarpine, phospholine iodide

3. Alpha Adrenergic stimulants: These drugs lower eye pressure by decreasing production of eye fluid as well as by increasing the outflow of the fluid from the eye.

a) Older drugs, less effective with more side effects: dipivefrin (Propine), epinephrine

b) Newer drugs, alpha 2 stimulants: brimonidine (Alphagan)—BEWARE of using of this drug in infants and very small or underweight children, apraclonidine (Iopidine)

4. Beta Adrenergic blockers:These drugs lower eye pressure by decreasing production of eye fluid.

a) Nonselective drugs: timolol (Timoptic) levobunolol (Betagan), carteolol (Ocupress) – BEWARE of using in children with asthma

b) Selective drugs (perhaps safer for patients with a tendency for asthma): betaxolol (Betoptic S)

5. Prostaglandin-like drugs : These are the newest class of eye drops for glaucoma. (See also the Pharmacy Corner article from the January 1999 issue on Xalatan).

latanoprost (Xalatan), bimatoprost (Lumigan), travoprost (Travatan), unoprostone (Rescula)

Let's focus on the 5th drug class – the Prostaglandin-like drugs. All four of the drugs in this class are chemically related to naturally occurring substances in the body called prostaglandins. There are many prostaglandins made in the human body, having a variety of different functions. Xalatan (the first drug for glaucoma in this class) and its 'cousins' all lower the eye pressure primarily by allowing the aqueous humor fluid to get out of the eye through a pathway, called the uveoscleral pathway, that is an alternative to the usual trabecular meshwork.

The prostaglandin drugs are very easy to use, because they work best when given as one drop in the eye(s) once daily at bedtime. They can be used together with most of the other commonly used glaucoma medications, although there is some data to suggest that it may not be wise to use them together with the miotic drugs (e.g. pilocarpine) because they may counteract one another to some degree.

Although adults often have large eye pressure reductions on these drugs, many children, unfortunately, do not seem to respond as well. Xalatan works very well to lower the eye pressure in children with juvenile open angle glaucoma, but not as

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well in children with other types of glaucoma such as congenital or aphakic glaucoma. There is even less information on the use of the newer prostaglandin-like drugs bimatoprost, travoprost and unoprostone. Even though there are only subtle differences among these drugs, there are occasionally children who have a good eye pressure reduction on one of them, even when another drug in the same class did not work.

In general the prostaglandin drugs have been quite safe to use. Few systemic (involving the whole body) side effects have been reported. Specific caution is recommended in eyes with uveitis (inflammation) and aphakia (after removal of a cataract), because studies of the prostaglandin-like drugs in adult eyes have shown rare problems in these eyes (increase in inflammation, and swelling in the retina and choroid in the back of the eye). More common side effects include mild redness of the white of the eye after using the drops, and an increase in the length and thickness of the eyelashes of the treated eye(s). In addition, these drugs have been shown to increase the pigment in the pigment-containing cells of the iris, so that certain eyes (especially those with a hazel or blue-brown color) may get darker when treated with prostaglandin-like drugs.

Medications are playing a more important role in the treatment of pediatric glaucoma than ever before in our history! As with any medications, use of the newer prostaglandin-like drugs should only be undertaken together with your ophthalmologist. The ultimate place for these new drugs in the armamentarium against pediatric glaucoma will become clearer in the years ahead. Future drugs for glaucoma may even include drops or systemic medications that help protect the optic nerve itself against the damage caused by high eye pressure!

PATCHING PANEL

Q: How do we handle patching our 4-year-old, especially at school?

By school age a child can really start to take ownership of the management of their patching. Give your child choices – albeit within limits – of when during the day patching will be done for example "You can patch from breakfast till school time AND home time till dinner, or from breakfast till the lunch bell – you choose".

Teach your child the vocabulary to explain the reason for patching and whenever the need arises let your child to the talking. A couple of long words from a 4 year-old gets a reaction they really enjoy! It earns them respect, which in turn builds self-respect.

If you are going to patch at school go together to explain patching to each new teacher, and ask if your child can explain it to the class, perhaps at the first 'show & tell' lesson.

LM

One thing that definitely worked for us was complete and total honesty. We told Robert that we understood patching would be uncomfortable at first and he wouldn't want to do it. We explained that it was necessary to strengthen a weak eye muscle and the better he was at keeping the patch on the quicker his eye would strengthen and the patching would be finished. We told him that people (especially adults) were very silly when they said hurtful things like "Oh poor boy! What happened to his eye", and that adults need to be told what the patch is for as much as children. Robert was responsible for putting his patch on and off and with this sense of control came self-esteem.

Robert was never teased, in fact several of his friends were jealous of his patch and I feel that our open and direct approach to the idea of patching had a lot to do with it.

MW

We had to patch Victoria when she was 5 and 6 years of age. For a period of time in grade one, it was necessary to patch her during some school hours (1.5 hours at the end of the school day). The most difficult part of patching at an older age was that Victoria was particularly sensitive to comments from other children. She also found it frustrating to do her schoolwork and homework with the patch on. There was nothing that we could really do with regards to the vision challenge of completing schoolwork, but I would simply remind myself and sometimes Victoria, that this was really good exercise for her weak eye. With regards to comments from other children, we took a box of patches to school, and let the children in Victoria's class each decorate a patch, which stayed at school. When the children were decorating the patches we explained why Victoria wore a patch and that it was exercising her weak eye. The children were enthusiastic to see when Victoria would wear the patch that they had decorated and she enjoyed the positive attention with regards to the patch. This really helped for a while, until Victoria eventually decided that she simply wanted to wear plain patches and no longer wished to decorate them. We did go through really difficult phases of patch pulling (especially at school) but the teachers were really supportive and enforced that the patch be worn.

I hope that some of these experiences are helpful.

JO

Ryan was patched at school. I had to educate the teacher and check daily on how long he had managed to be patched every day. I would try to make up whatever time was missed after school. Bribery works well at this age. If he kept it on for a certain amount of time he would get a treat, e.g. play, watch TV, candy- whatever works. It was definitely a challenge.

AC

When Chris was patched at this age it was very important for his caregivers to be vigilant to stop the peeking. When he started school, we wanted school to be a positive experience so he only patched at home. He put his patch on as soon as he got home and could take it off when Daddy got home. We told him "You can take the patch off when..." a certain event occurred e.g. dinner or daddy coming home, so he would know how long he would have to wait. Kids can relate better to an event rather than a time span.

DA

News

PGCFA Award for Research in Pediatric Glaucoma and Cataracts

Alex V. Levin, M.D., MHSc, FRCSC

The Pediatric Glaucoma and Cataract Family Association has established an award of $500.00 (US) for the best paper or poster in the area of cataract and / or glaucoma presented at the annual meeting of the American Association of Pediatric Ophthalmology and Strabismus; the premier medical scientific meeting in the field. The award is designed to recognize and promote research in pediatric glaucoma and cataract while at the same time letting the AAPOS membership know about the PGCFA. The PGCFA is very grateful that AAPOS is working with them to make it happen. In addition, the first author or their designate will be invited, all expenses paid to a maximum of $2000.00 (US), to present their work at the following PGCFA Annual Education Meeting either in Toronto or for 2003, in Boston.

This was the first year that the PGCFA made this award. All papers and posters accepted for presentation at AAPOS in the fields of cataract and glaucoma were eligible. The Award Selection Committee included the 3 member Scientific Advisory Board of the PGCFA (Drs. David Walton [Boston], Sharon Freedman [Durham], and Alex Levin [Toronto]) along with Drs. Michael Repka ([Baltimore] Chair, AAPOS Program Committee and Terry Young ([Philadelphia] AAPOS Research Committee). They reviewed all of the abstracts, masked to the identity of the authors, for these papers and posters and selected 6 finalists for the award. The finalists were then invited to submit a full manuscript reporting their work. Five of the finalists did so. The Award Selection Committee was modified to ensure that none of the members were authors of those papers. Drs Monte del Monte [Ann Arbor] and Edward Wilson [Charleston] were therefore added and two members excused.

The winner of the award, a group of researchers in the area of pediatric cataract, reports their findings below. A member of the group will be presenting their work at the PGCFA Meeting in Boston on April 12, 2003.

The PGCFA looks forward to making this award again in 2003.

PGCFA Award Winning Paper 2002

Relationship Between Eye Growth and Vision in Aphakic Children

David R. Weakley, MD[1], Eileen E. Birch, PhD[2], Scott K. McClatchey, MD[3], Joost Felius, PhD[4], Marshall M. Parks, MD[4], David R. Stager Jr., MD[4],

[1]University of Texas Southwestern Medical Center, Dallas, Texas

[2]Retina Foundation of the Southwest, Dallas, Texas

[3]Naval Medical Center, San Diego, California

[4]Center for Pediatric Ophthalmology and Adult Strabismus, Dallas, Texas

Intraocular lens (IOL) implantation after pediatric cataract surgery is occurring at increasingly younger ages. Thus, it is important to determine what factors may influence eye growth in order to improve the accuracy of IOL calculations.

In normal children, the eye tends to get longer over time. This may be particularly true after cataract surgery. This elongation of the eye results in nearsightedness, which must be corrected by glasses or contact lenses.

We examined the relationship between the change in eye growth (glasses or contact lens power) and vision in 44 children with unilateral and 41 children with bilateral cataracts wearing contact lenses or aphakic glasses. All children had surgery before age one year and were followed for a minimum of 3 years, although the average follow-up was almost 8 years. We did not include eyes that had glaucoma since glaucoma itself can have a significant effect on the eye growth.

Eyes with better vision tended to be those that did not grow too long over time. The correlation was strongest in children with cataract in only one eye. This suggests that part of the change in eye growth and the development of nearsightedness is due to how well vision develops. In general, this means that children who see better are the ones who have eyes that do not get too long. The refraction (glasses or contact lens power needed) in eyes of children with vision of 20/60 or worse changed 50% more each year, on average, than eyes that developed vision of 20/60 or better.

Thus, excessive eye growth may indicate vision is not developing properly and more aggressive amblyopia therapy is necessary. Additionally, as more experience is gained with IOL implantation in very young children these findings should help determine how much eye growth is normal and improve the accuracy of intraocular lens selection.

Notice

Advance Notice!

The Annual General Meeting (AGM) and Education Day for the Pediatric Glaucoma and Cataract Family Association will take place in Toronto at The Hospital for Sick Children on Saturday, November 16 from 9:30 a.m. until 3:30 p.m. and is open to the public. The day will feature a series of presentations from doctors and health care professionals on a variety of subjects related to pediatric glaucoma, pediatric cataract, and vision in childhood. Registration begins at 9:00 a.m. followed by the AGM, lunch, coffee and muffins. Confirmed speakers to date include pediatric ophthalmologists Drs. Alex Levin and Stephen Kraft, and HSC Ophthalmology Social Worker Alissa Ulster.

Registration is $10.00 per person or $20.00 per family. Cheques payable to PGCFA, can be sent to Leslie Mowat, 9 Muirhead Crescent, Brantford, Ontario N3R 7S5, or pay by Visa on the website www.pgcfa.org

For more information or registration please contact Leslie Mowat (519) 753-8840 or lesliemowat@rogers.com.

World View

WORLD EYE MISSION

Dr. Jeevak Lal *Albion, Michigan*

The world is going blind. World Health Organization statistics are very clear about this. Despite significant efforts and some successes, the number of people suffering from preventable blindness is rising. As may be imagined, much of this grief is heaped upon the poor. Their burdens are already so unbearable.

Hands can be rung in despair. Or something can be done. A few years ago, out of desperation and frustration, World Eye Mission was cobbled together. It is a very small charitable organization. It has absolutely no allusions about how little it can really achieve. Its goals are modest and basic: to offer a modicum of eye care to poor and under-served countries while providing sustainable long-term improvements in the quality of care.

Rather than send teams to perform reams of cataract operations and then leave the operated patients without adequate post-op care, WEM opted for a different tack: sponsoring visits to developing countries by distinguished academic, university-based ophthalmologists. Professors have been sent to Haiti, the Dominican Republic, Venezuela, Bulgaria and Guatemala. By sharing knowledge and skills with colleagues and residents-in-training, WEM's professors help local ophthalmologists take better care of their patients. The effort is low-cost and according to an earlier professor, "gives a lot of bang for the buck."

WEM also has direct help projects in Trinidad and St. Lucia. There is a possibility of a tie-up with a hospital in India that cares for Tibetan refugees. A possible link with the University of the West Indies in Jamaica is also being explored.

At WEM, no salaries are paid. Expenses are cut to the bone. Volunteers do all the work. The efforts are funded by the generosity of others.

WEM's guiding philosophy is that the world's poor deserve more than free handouts and "quick fix" missions. Rather, we believe they deserve the gracing touch of the world's finest physicians and teachers. We will try to remain true to our beliefs.

Book Review

My Baby Brother's Eyes

By Jane Jones
Illustrated by Julie Coté
ISBN 0-9730302-0-8

Jane Jones M.A. is a Registered Clinical Counselor in the province of British Columbia, Canada. This book was inspired when her son was born with congenital cataracts, which necessitated several surgeries and hospital procedures. Her search for literature to support her older child's experience of her baby brother's many hospital visits turned up nothing written for children. It is her hope and wish that this book might help other young children and their parents.

The book is written from the point of view of the older sibling of a child requiring eye surgeries. The main theme is of comfort and reassurance. She is told that her brother's eye problems are not her fault, she can help by playing with him and that everything possible is being done to make him better. The story and illustrations have a personal and honest touch.

Liz McManus

"This book addresses the issues a family faces when a child is born with an eye problem. It is beautifully written and illustrated and is bound to help and comfort anyone who may be confronted with this difficult situation."

Dr C.J. Lyons, Head of Ophthalmology
British Columbia Children's Hospital, Vancouver, BC

Copies of this book are available directly from the author at 590, Cumberland Place, Nanaimo, BC V9T 4S5, Canada or 4048 Gage Road, Montreal, Quebec, H3Y 1R5, Canada. You can contact the author by telephone on 250 751 8141 or by e-mail at jsj@islandnet.com

Recent Events

Toronto Family picnic.

The Toronto group held their 3rd annual family picnic on June 15th 2002. The poor weather did not stop the fun and 6 families came out for an afternoon of games, food and fellowship.

If you would like to organise a similar event in your part of the world but are wondering how to get started please contact me using the reply card or through the web site on www.pgcfa.org.

Liz McManus

Busy Beaver's Fund raising success.

My son's boy scout's beaver group (the Oshawa 59th) collected spare change to be donated to a charity. The kids spent an evening painting and decorating collection jars from bottles, then took the jars home. At final count, the 6 year-olds collected $36.13. I printed a "Certificate of Appreciation" from the PGCFA and presented it to the beaver leader. The kids learned that they can help others by giving their time and effort, and about being generous with money.

Ian Hubling.

The PGCFA is a charity funded entirely by voluntary donation and we appreciate all donations, large or small

Family Stories

Megan, Age 13

At five days old it didn't bother me going to Duke Eye Center, but at thirteen, sometimes I wish it would all go away. I was born with cataracts and by the age of eight, I was diagnosed with glaucoma. Sometimes, I wonder what it would be like not to have to worry about my eyes.

I guess I will just have to play the cards I have been dealt. I've learned that the only control I have is my attitude. You can't be courageous until you have been afraid. You can't be patient until you have been tried. Most of all you have to believe in yourself before you can go forward.

Each time I face surgery, I become a little more courageous and patient.

The faith that I have in myself and in God is what really gets me through.

I always try to have a positive attitude on whatever problem I face, and that's what keeps me going forward into life, my life.

The Gendron family is from the province of Quebec and usually speaks French. Their story appears here in both English and French.

Pierre's Story

My name is Pierre Gendron. I am 2 years, 3 months old. I was born with a congenital cataract in my left eye. At 2 months old I needed surgery to remove the cataract. The operation was done at the Ste-Justine Hospital of Montreal. Since 3 months old I wear an extremely strong contact lens of +26 diopters. My parents must put in and take out my contact lens every day. I also wear an eye patch on my right eye 5 hours per day, 7 days per week. This is because my left eye is 'lazy' and must establish visual connections with my brain. So I must do the occlusion until I get good vision.

Later the ophthalmologist will put a lens implant into my left eye, which will be a relief to us. Each time a contact lens is lost it costs my parents $165, which is no small matter. I ate my first contact lens when I was a baby!

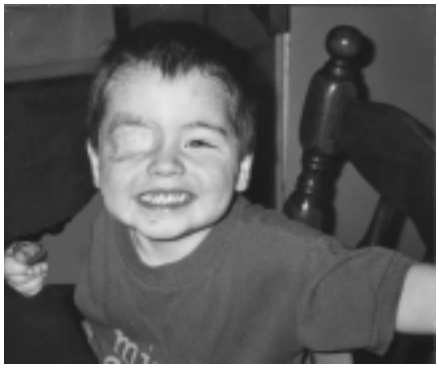
In December 1999 my first child was born. We were proud of our newborn baby. But a few days after his birth my husband and I discovered a white spot in his left pupil. The pediatrician confirmed that our son had a congenital cataract. We were flabbergasted!

Many questions went through our minds. Why did this happen to us? Nobody around us had this congenital disease and my pregnancy went so well. Did I eat or do something wrong? No, it's congenital.

At that time we knew nothing about congenital cataract, and in fact the team of doctors who followed me during my pregnancy had only seen this condition in medical books. When we heard that my son was going to be operated on to remove the cataract, I was shattered. I was afraid of the operation because of the general anesthesia. A 2-month old baby looks so frail. Then there would be a procedure to follow to make it possible for Pierre to see from his left eye. Now that we know more about cataracts we feel more secure. The occlusion and contact lens have become a routine. In fact, looking back we realise now that we were lucky that the cataract was discovered in time.

At the Ste-Justine Hospital the operation was successfully carried out by the ophthalmologist Dr. Maryam Aroichane. After the operation she told us "Pierre got through it like a champion". She has followed my son regularly since that day.

I was wondering about the years to come. I confess I was thinking that it would be less difficult after the operation, that nothing else would have to be done. But in fact it was just the beginning.



Pierre has been wearing the contact lens since he was 3 months old. The first year he lost many lenses and it cost us a lot of money. Since his birth we have needed to buy 7 contact lenses. The first was lost when Pierre ate it, and the others lost during naptime. A piece of advice: remove the lens during naptime. If we had known this, I'm sure we wouldn't have lost so many.

I think that Pierre is a really responsible child, and we ask him to remove the patch himself after 5 hours of occlusion. Around his first birthday he used to remove the patch all the time. We would then patiently put on another patch and try to explain to him that this was absolutely necessary. Now he cooperates very well, and I really admire him for his understanding. I think that the occlusion is giving good results, as Pierre can easily find his way around with the patch on.

We are anxious about the fact that he could develop glaucoma. His cataract gives him a higher probability of developing other eye diseases like glaucoma. In fact, up to 30% of operated patients develop glaucoma in the 5 years following cataract surgery. But it can appear sooner or much later or maybe never. That is why Dr. Aroichane measures the pressure of his eyes during the checkups to make sure everything is ok.

We have been a bit discouraged from time to time. But every time, something has happened that proved to us that we were on the right track. The trick is not to skip a single step.

When he is 4 or 5 years old, Pierre will have an intra-ocular lens placed in his left eye. We are eagerly waiting for this moment: removing and inserting the lens and making sure the lens is not falling out will then be over.

One thing makes me worry: when he starts school, how will the other kids accept him with his patch on? When a kid is different from the others it can sometimes give an opportunity for the others to laugh at him. I want a normal life for my son. However, Pierre is already going 2 days a week to a day nursery and everything is going well. It's a part of Pierre's life, and after the explanation of why he is wearing the patch the other kids don't pay any more attention to this.

In August 2001 Étienne, my second son, was born. During my pregnancy I was thinking a lot about the possibility that he too could be suffering from a cataract. Fortunately his two eyes are not affected by cataracts. We were so happy but at the same time we were prepared in case this happened to him.

My two sons are precious to me. One thing I can say to someone who lives through the same thing is that kids who have a disease, whatever it may be, are really engaging and marvelous. Just make them participate in any way they can in the treatment of their disease and it will be great.

A message to my son.

You know Pierre, we are doing everything

we can, in collaboration with your ophthalmologist, to make your left eye see. But you help us so much by the way you are happy. I love you so much.

Your Mother.

Melanie Gagnon, Pierre's mother.

Mon nom est Pierre Gendron, j'ai 2 ans et 3 mois. Je suis né avec une cataracte congénitale à l'œil gauche. À 2 mois, je me suis fait opérer à l'Hôpital Ste-Justine de Montréal. Je porte un verre de contact de force +26 dioptries, que maman et papa doivent mettre le matin et enlever le soir et ce, depuis que j'ai 3 mois. Je porte un pansement occlusif sur mon œil droit 5 heures par jour, 7 jours par semaine. Ceci, parce que mon œil gauche est 'paresseux' et qu'il doit établir des connections visuelles avec mon cerveau. Je devrai faire l'occlusion de mon œil jusqu'à ce que j'ai atteint une bonne vision.

Plus tard, je pourrai me faire greffer une lentille intra-oculaire, ce qui sera un soulagement pour mes parents. Il en coûte 165$ pour remplacer le verre chaque fois que j'en perds un. Inutile de vous dire que ce n'est pas une mince affaire. J'en ai même mangé un une fois! Pierre.

Pierre est né en décembre 1999. Notre premier bébé et notre fierté. Une seule ombre au tableau, il y a une tache blanche que l'on peut apercevoir dans la pupille de son œil gauche.

Une pédiatre nous confirme que c'est une cataracte congénitale. Pour mon conjoint et moi ça a été un choc. Mon si petit bébé, qu'est-ce qui a pu causer ça? Est-ce que j'ai fait ou mangé quelque chose qui a pu causer cela? Toutes ces questions je me les suis posées. En fait, cette maladie étant congénitale, il n'y avait aucune relation avec ce que j'avais pu faire ou manger durant ma grossesse.

Après tout, quand la grossesse s'est bien déroulée, comment [un] bébé peut-il naître avec une anomalie? Cest ce que nous nous demandions. Nous ne connaissions rien de la cataracte congénitale et l'équipe de médecins de l'Estrie, au Québec, qui m'a suivie tout au long de ma grossesse, ne connaissait ce problème que pour l'avoir vu dans les livres de médecine. Quand nous avons appris qu'il serait endormi et opéré afin d'enlever la cataracte, alors qu'il avait seulement 2 mois, je me souviens que j'étais effondrée. Il y aurait ensuite une démarche à entreprendre afin que Pierre puisse voir de son œil gauche. Nous en connaissons maintenant davantage sur la cataracte de mon fils et c'est plus sécurisant. La routine de l'occlusion et du verre fait partie de tous les jours. En fait, avec le recul nous réalisons que nous avons été chanceux que la cataracte soit découverte à temps.

Pierre a été opéré à l'Hôpital Ste-Justine de Montréal. C'est l'ophtalmologiste Dr Maryam Aroichane qui a opéré notre bébé. Très enthousiaste, elle est venue nous rassurer après l'opération que tout avait bien été. Je me souviens, elle m'avait dit « Pierre a fait ça comme un champion ». Depuis, elle rencontre Pierre régulièrement afin d'assurer un suivi.

Je crois que j'avais peur des années qui allaient suivre. J'avoue, j'aurais aimé que l'opération terminée, tout soit réglé. Mais en fait tout ne faisait que commencer.

Pierre a commencé à porter son verre à 3 mois de vie. La première année est jusqu'à maintenant celle qui aura coûté le plus cher monétairement. Le verre de contact que notre fils porte coûte cher et nous en avons commandé 7 jusqu'à maintenant. Pierre en a mangé un, et puis il en a perdu plusieurs à l'heure du dodo. Un petit conseil: il est préférable d'enlever le verre avant le dodo et de le remettre après. Si nous l'avions su, cela aurait évité d'en perdre plusieurs, j'en suis persuadée.

Pierre est à mon avis un enfant très responsable et nous lui demandons d'enlever lui-même son pansement quand la période de 5 heures est terminée. Il y a eu une période où il l'enlevait à tout moment. Nous le lui recollions patiemment en lui expliquant qu'il n'avait pas le choix. Maintenant ça va très bien. Je l'admire beaucoup pour sa compréhension et sa collaboration. Je crois bien que l'occlusion donne de bon résultats puisqu'il s'oriente bien pendant l'occlusion.

Il y a aussi une crainte qu'il soit atteint de glaucome, puisqu'il y a une plus grande probabilité qu'il développe cette maladie en étant opéré pour une cataracte congénitale. En fait, jusqu'à 30 pourcent des patients opérés le développent dans les 5 premières années suivant l'opération. Mais il est aussi possible qu'il développe du glaucome plus tôt ou plus tard, ou peut-être jamais. C'est pourquoi l'ophtalmologiste, Dr Aroichane, vérifie la pression de son œil gauche lors de rendez-vous et veille à sa bonne santé oculaire.

Par moment, nous avons eu des périodes de découragement, mais il arrivait toujours des événements qui nous ont aidés à continuer la démarche. Il ne faut surtout pas sauter les étapes.

Vers l'âge de 4 ou 5 ans, une lentille intra-oculaire sera placée dans son œil gauche. Nous avons hâte de ce moment-là, car il n'y aura plus de verre de contact à mettre, à enlever et à surveiller pour qu'il soit bien en place dans son œil.

J'appréhende un peu son entrée à l'école. Les enfants qui sont différent des autres font quelques fois rire d'eux. Mais en même temps, si je me réfère à la garderie où Pierre va 2 jours par semaine, les autres enfants sont habitués à voir Pierre porter son pansement. Alors il n'y a pas de problème, il s'intègre très bien aux autres enfants. Alors inutile de trop s'en faire pour l'instant.

Nous avons eu notre deuxième fils, Étienne, en août 2001 et heureusement ses deux yeux sont intacts. Pendant ma grossesse j'y ai beaucoup pensé. S'il avait eu une cataracte je sais que nous aurions été un peu déçus, mais nous avions les outils pour faire face à l'éventualité.

Mes enfants sont ce que j'ai de plus important. Je crois que les enfants qui naissent avec une anomalie ou une maladie, quelle qu'elle soit, sont des enfants très attachants et particulièrement épatants. Il faut les faire participer et leur montrer qu'ils sont aussi impliqués dans la voie de la réhabilitation de leur handicap ou maladie.

Un petit mot pour mon fils.

Tu sais Pierre, nous ferons tout ce qu'il est possible en collaboration avec ton ophtalmologiste pour que ton œil gauche puisse récupérer de la force. Toi, tu nous aides déjà beaucoup en nous montrant à quel point tu es pleinement heureux!

Je t'aime, Maman.

Mélanie Gagnon, Maman.

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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.