

# MORINformation

WINTER 1996/97

## INSIGHT INTO CHILDREN'S GLAUCOMA

### from the chair...

This past year has been another eventful year for the PGFA. After the success of Sunset Blvd. and all the hard work put into it, we are now focused on our next project which is a "Parent's Handbook". A book which we hope will answer many questions that parents and children have when diagnosed with glaucoma. This booklet is in the developing stage. If you're in Dr. Levin's waiting room, look on the PGFA "Glaucoma News" bulletin board. There's a sheet asking for you to put down any questions you would like answered, that could be used in the handbook. This is a very exciting project and we welcome any suggestions or help you can offer to put this book together. The target date for this book is sometime in the fall, 1997. Watch the board and MORINformation newsletter for updates.

In May 1996 we hosted our 2nd Annual Conference at HSC. Our feature speakers, Dr. Yvonne Buys, Toronto Western Hospital and Leslie McKeen HSC were very informative and well received. Many parents stayed and networked which proved to be successful.

In September the Richmond Hill County Club hosted the **Unilever, R.H.C.C. Golf Tournament** which donated to "Marnie's Rainbow" and the Pediatric Glaucoma Family Association. An amazing "\$23,000" was raised and shared between our charities. A very special thank you to **Michael Silverman**, Tournament Organizer and to **Dr. Fred and Patty Weizenberg**. Their support of PGFA has been overwhelming. The tournament had a waiting list of participants!!



November 12, 1996 was the General Meeting of the Association. Discussion and plans were made for the Parent's Information Handbook. Elections were held and we are pleased to welcome new and returning members to the Board. Please feel free to contact any member for information or suggestions.

We also want to acknowledge the hard work and dedication that **JOANY VERSCHUUREN** has given to the PGFA. Joany is transferring to another division within Allergan. We wish you all the best Joany and **THANK YOU** for your many hours of commitment. We will miss your enthusiasm, knowledge and your support.

### 1997 PGFA BOARD

Leslie Mowat	Brian & Jane Worth
Thea Greenspan	Anne-Marie & John Mohler
Cheryl MacDonald	Anne & Frank Lenarduzzi
Edye Webster	Lucy Spivak
David Van	Alex Levin, MD

Advisors:	Seetha Pobran Peter McCormack, Allergan
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### Pediatric Glaucoma Family Association Advisory Board

#### Contact Address:

Pediatric Glaucoma Family Association  
c/o 6 Winsland Drive  
Etobicoke Ontario, M9B 6A2

Registered As A Canadian Charitable Organization  
Registration # 1037019-11

*Our spies have evidence, as you can see by the photo of a certain doctor, dentist, sportscaster and friends enjoying the golf tournament....rumour also has it a certain doctor is "mum" on his golf score.....!*

# Kid's Eye View

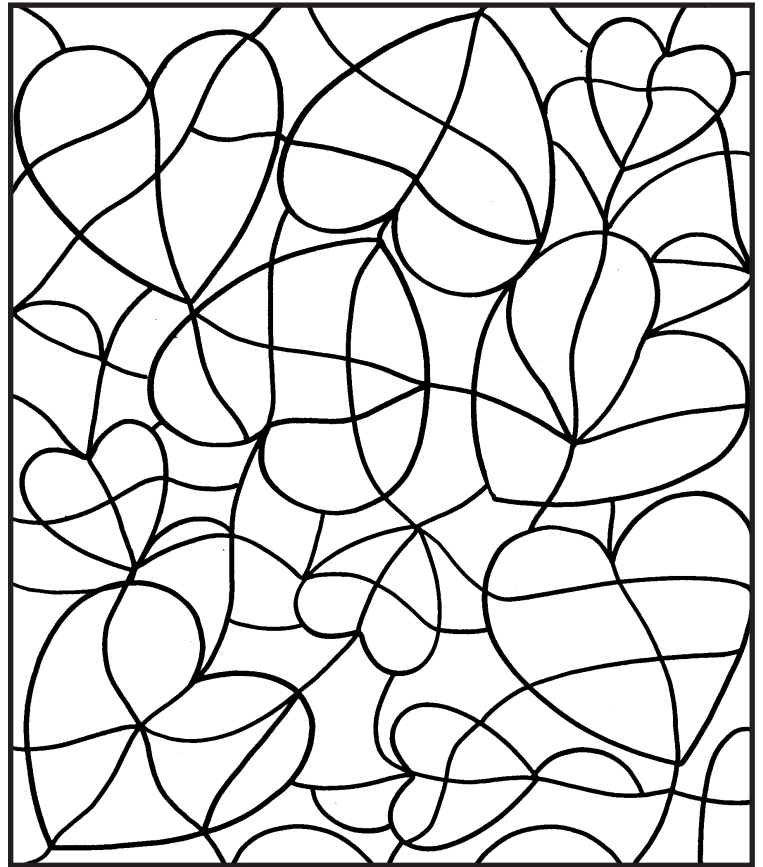


Gotta a question???  
Want an answer???  
Kids Column.....

featuring advice from  
*"Dear Iris"*

Watch the next Morinformation for  
more *"Dear Iris"*

**FIND AND COLOUR**  
FIND 10 VALENTINE HEARTS & COLOR THEM RED.



Write to: Kids Column  
c/o 6 Winsland Drive  
Etobicoke, ON M9B 6A2

*Dear Iris:*

Last week the new kid in my class kept bugging me about my glasses. He called me "4 Eyes" and "Nerd". He's not the kind of kid who listens to medical explanations. What should I do if he continues to tease me?  
Signed  
"4 Eyes"

*Dear Iris:*

I am a 12 year old girl with glaucoma in both eyes. While out for recess, my friend noticed that my pupils were the size of a pinpoint. We went to the washroom to check it out and sure enough she was right. I freaked! We called my mom to find out if this was okay. How come this happened to me.

Signed Ticked

*Dear 4 Eyes:*

The teasing usually stops when the new kid realizes they aren't getting a reaction from you or anyone else. The new kid is probably feeling insecure and doesn't know what's what. If the teasing persist and is bothering you tell your teacher. They will talk to the kid and hopefully the kid will stop.

*Dear Ticked:*

Don't worry it's probably just one of the side effects of Pilocarpine. The next time you get a new med, ask your doctor to give you a list of the possible side effects. If you don't understand ask questions until you do understand. Next time a friend notices you'll have all the answers.

**HEY KIDS!**

**GREAT PRIZE TO BE  
WON IF YOU ANSWER THE  
QUESTION AND SEND YOUR  
ANSWER TO OUR MAILING ADDRESS...**

- RANDOM DRAW
- FIRST CORRECT ANSWER WINS
- SEND YOUR ANSWER NOW!!!



DO YOU KNOW THE NAME OF THE GREATEST MINNESOTA TWINS PLAYER WHO RETIRED THIS YEAR AFTER AN OUTSTANDING CAREER IN BASEBALL??  
THIS PLAYER HAS GLAUCOMA.....  
CAN YOU NAME HIM?

Answer: \_\_\_\_\_

Your Name \_\_\_\_\_

Telephone # ( ) \_\_\_\_\_

### STURGE-WEBER SYNDROME RESEARCH PROJECT

Alex V. Levin, MD, FRCSC  
Narindra Armogan, MD

*The Hospital for Sick Children  
University of Toronto*

Sturge-Weber syndrome (SWS) is a congenital disorder characterized by a red facial birthmark (port wine mark), brain abnormalities and/or glaucoma. Not all patients get each feature.

Historically, Sturge-Weber syndrome glaucoma occurs during one or more of three distinct stages: infancy, childhood and early adulthood. In the infantile form, the primary problem is an abnormal drainage angle (trabecular meshwork), as in other forms of common infantile glaucoma. The childhood and early adult forms seem to develop because of an increased pressure in abnormal veins (episcleral veins) on the surface of the eye, unique to SWS, which make it hard for the eye fluid to drain.

Identifying a key role for episcleral venous pressure in Sturge-Weber glaucoma has been attributed to the work of Dr. Phelps in 1978. However, no one has ever challenged or tested his theory.

To date, the first arm of the study, which is funded by a grant from the Glaucoma Research Society, comparing glaucoma to non-glaucoma eyes in the same patient has been completed. The results do show statistically significant higher episcleral venous pressure in the eyes with glaucoma. These values when compared to established norms for episcleral venous pressure suggest that the episcleral venous pressure in the glaucomatous eye is significantly elevated, while the non-glaucomatous eye has episcleral venous pressures within the normal range. This validates the work of Phelps.

The second arm of the study will involve comparing the patients with a facial birthmark but no glaucoma to their eye on the side with no birthmark. Preliminary examination of this data suggest that there is no elevation in their blood vessel.

The preliminary conclusion that can be drawn from the data compiled so far is that the episcleral venous pressure in glaucomatous eyes of Sturge-Weber patients is abnormally high. This is the most likely cause of Sturge-Weber glaucoma in

childhood and early adult patients.

Knowing this information now allows us to plan methods of treatment specifically aimed at the glaucoma cause; for example, developing medications which decrease episcleral vein pressure. In addition, it may be possible to use measurement of episcleral vein pressure (which is just like taking eye pressure but with a different instrument) to identify those children with SWS who may be at risk for developing glaucoma.

### The Sturge-Weber Foundation (Canada) Inc.

#### What is the Sturge-Weber Foundation?

The Foundation is a charitable non-profit organization comprised of parents, individuals, and professional affected by or with SWS. The Sturge-Weber Foundation (SWF) was founded in 1987 by a persevering mother whose daughter was born with this rare and relatively unknown condition. Since then, the SWF has grown to include organizations in a least four countries and more than 900 members worldwide. In 1993 the SWF expanded to include Klippel-Trenaunay Weber and Port-Wine Stains.

The Foundation's primary goals are:

- to act as a clearinghouse of information to offer support to families and individuals with SWS
- to educate the public and medical professionals
- to facilitate and fund research on SWS and its related conditions

#### FOR FURTHER INFORMATION:

##### The Sturge-Weber Foundation (Canada) Inc.

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## Ask The Doctor

### Q. Will Diamox cause my child to have bedwetting?

**A.** Diamox (acetazolamide) is an oral medication used to decrease the production of fluid inside the eye which in turn will cause a lowering of the eye pressure. This medication is also known to be a diuretic: it stimulates increased production of urine. Increased frequency of urination is a common effect of Diamox and usually has no significant medical consequences in children. Usually, the medication is given four times daily with the dose adjusted to correspond with the child's weight. As such, the last dose is usually given before bedtime and in the occasional child, bedwetting (enuresis) may begin. If this is the case, with supervision from your physician, there are a few options. The dose of Diamox can be altered to three times daily by increasing each dose so that the total dose remains acceptable. One can also change the dose-body weight ratio for the child. Usually, the child is given somewhere between 15-30 mg per kilogram per day total dose. If a child is up on the higher end of this range and having bedwetting, one could decrease the total daily dose, while still keeping within this range, as long as the intraocular pressure continues to be well controlled. There is an extended release form of Diamox which only requires twice daily dosing but it unfortunately does not come in a small enough dosage to allow its use in preadolescent children: the same population that is most likely to have bedwetting occur. Lastly, one might consider switching to other medications. Neptazane (methazolamide) has a similar effect on intraocular pressure but causes less of an effect on urination. However, this medication in tablet form may be harder to break into smaller doses and there is not a commonly available liquid form. There is a new eyedrop on the market, Trusopt (dorzolamide) which is in the same class of drugs (carbonic anhydrase inhibitors) as Diamox and Neptazane but by placing it directly onto the eye, one does not get the systemic effects such as increased frequency of urination. It has been my experience, that this medication is sometimes not as efficacious as oral medications but in many children it does work well enough to keep them off the oral drugs.

Alex V. Levin, M.D., FRCSC  
The Hospital for Sick Children  
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### Newsletter Goals

- To promote The Quality of Life for Children with Glaucoma and Their Families By:
- Providing Resources & Education ...
- Providing Support ...
- Providing Information ...

## Family Stories

### THE MACDONALD STORY

My daughter Lauren is five years old. She was born with congenital Cataracts and Pervasive Developmental Delay (PDD). The cataracts were diagnosed at three months of age. The PDD was not diagnosed until she was two and a half years. Cataract surgery was performed by the late Dr. Morin who did an exceptional job. This fact was later confirmed by Dr. Levin on his first examination of Lauren's eyes. She wore contact lenses until she was three and a half years when we opted for glasses as she seemed very sensitive to the lenses.

In May of this year Dr. Levin did an EUA and found that glaucoma had developed in the right eye. It has since developed in the left eye as well. Betagan was the first drop prescribed for the right eye. It wasn't working well enough, so Iopidine was added and is also used in the left eye. This combination is working well and I pray the pressure stays under control. Any vision loss for Lauren would be devastating for her with the many learning difficulties she struggles with.

My daughter Sara and I were also born with congenital Cataracts. I have never had any problems with pressure and Sarah is fine so far. She is twenty-three months old and wears contact lens which she does quite well with. Sarah has no developmental delays. She is a typical toddler with all the joys and little challenges.

I would like to thank Dr. Levin for this wonderful care of my children. I would also like to thank all the staff at HSC. Your warmth and kindness is much appreciated, especially for Lauren and her special needs. The wagon rides and the freezies make a day at the hospital not so bad after all!

Cheryl MacDonald



**What special gift do you give to remember a special someone?**

A Birthday, Anniversary, or in Their Memory. Giving a donation to the Pediatric Glaucoma Family Association can be made at any time. Our commitment to help educate and support children with glaucoma is ongoing.

Donor Cards and Acknowledgment Letters are available. Donations can be made to the Pediatric Glaucoma Family Association c/o 6 Winsland Drive, Etobicoke, Ont. M9B 6A2. Tax receipts will be given.