

Spine Tingles

Newsletter of the Scoliosis Support Group of Qld Inc.

August, 2006

**Important
DATE!**

Annual General Meeting and Afternoon Tea

**37 Oleron Tce
PETRIE**

**Saturday 26 August 2006
2.00pm**

We ask our members to make an effort to attend the forthcoming Annual General Meeting. A well-attended AGM will ensure that the Support Group continues its work for another year.

We thank Loretta for her contribution to this newsletter and wish the family all the best for the children's progress.

In the light of Grace's experience with congenital scoliosis, it is a good time to revisit a book held in our library *What can I give you?* by Mary Mahony.

If you would like to attend and don't have transport, please contact us (see page 2).

A proxy form is included in this newsletter. If you are unable to attend the AGM, please mail your proxy form to arrive on or before Friday 25 August 2006. A completed proxy form counts as an attendance.



Scoliosis Support Group of Queensland Inc

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This newsletter is published
quarterly, normally before a social
gathering or meeting.

Warning:

Information published in this
newsletter represents views of the
authors and is not to be seen as a
recommendation or the views of the
Support Group. We aim to inform
our members of as many options as
possible. It is the responsibility of
individual patients to decide on their
treatment in consultation with their
doctor.

What Can I Give You?

by Mary Mahoney

This is a personal account of one family's struggle with their daughter's congenital scoliosis. Although the word "congenital" literally means "born with", this problem is not inherited in the genetic sense. Rather, something happens to the developing embryo at a very early stage. The effect of a spinal deformity in a young child can be devastating and cause great heartache for both the child and parents.

This book was first published in 1997 and has had a wide audience of readers. This is an updated version (2005) that follows the author's daughter, Erin, from her diagnosis at the age of fourteen months, into young adulthood. The medical update is the most current information regarding the treatment of congenital scoliosis. Understanding the many faces of this disorder is key to accepting the diagnosis and coping with treatment, which is usually lengthy and involving surgery at a very young age.

The difficulties experienced by this family and carefully described in this book are worthwhile reading for parents of children who face similar problems.

This book is available to be borrowed by members. The loan period is one month. Postage out will be paid by the support group, and return postage will be paid by the member.

Financial Planning for 2006-2007

Our annual grant of \$5574 will be spent according to the following breakdown:

	\$
Resources (probably bookmarks)	1,500
Postage	1,500
Telephone (line rental & 1800 no.)	1,000
Advertising	800
Library	472
Audit	165
Stationery	100
Incorporation	37



A Few Words from a Mum

July 2006

Hi, my name is Loretta, my husband is Greg and we have 3 beautiful children: Lachlan 9, Callum 6 and Grace 4. Grace is the member of our family who has scoliosis and it was Greg who first noticed the scoliosis. He didn't tell me at first because he was hoping that he was wrong, but after a few months he knew he had to tell me as the curve was becoming more noticeable.

It was a week I will never forget. It was early July 2003 and on the Friday night we had a call from Greg's parents who told us that his Dad had been diagnosed with prostate cancer. On Sunday Greg was bathing Grace and he noticed the curve had grown and knew he had to say something. On the Tuesday we had an appointment with a Speech Therapist for Callum thinking he could use a little help but were told he had mild dyspraxia, which means the messages from his brain were getting a little scrambled and that he should also see an Occupational Therapist. On the Wednesday we had an appointment with the optometrist for Lachlan as he had been complaining of headaches and were told we needed to see a specialist as his sight was quite poor.

Talk about "rock my world", needless to say we spent a lot of time visiting doctors and specialists. That was when we joined the Scoliosis Support Group, we went along to a meeting and were very glad to chat with the members and hear their stories. *(continued overleaf)*

Best quotes ...

... from the Edinburgh Fringe Festival

I realised I was dyslexic when I went to a toga party dressed as a goat.

Marcus Brigstocke at the Assembly Rooms.

The right to bear arms is slightly less ludicrous than the right to arm bears.

Chris Addison at the Pleasance.

My dad is Irish and my mum is Iranian, which meant that we spent most of our family holidays in Customs.

Patrick Monahan at the Gilded Balloon.

I saw that show '50 Things To Do Before You Die'. I would have thought the obvious one was shout for help!!

Mark Watson, Rhod Gilbert at the Tron.

Employee of the month is a good example of how somebody can be both a winner and a loser at the same time.

Demetri Martin at the Assembly Rooms.

I enjoy using the comedy technique of self-deprecation - but I'm not very good at it.

Arnold Brown at The Stand.

If you're being chased by a police dog, try not to go through a tunnel, then on to a little seesaw, then jump through a hoop of fire. They're trained for that.

Milton Jones at the Underbelly.

Scoliosis Support Group of Queensland Inc

Proxy Form

I, _____ of _____, being a member of the abovementioned association, hereby appoint _____ of _____, or failing the member, _____ of _____¹ as my proxy vote for me on my behalf at the annual general meeting of the association, to be held on the 26th day of August, 2006, and at any adjournment thereof. Signed this _____ day of August, 2006.

Signature: _____

Unless otherwise instructed the proxy may vote as the proxy thinks fit.

¹ If you do not have a particular person to act as your proxy, you may indicate an office bearer, such as "The Chairperson"

Our first appointment for Grace was with Dr. Robert Labrom who advised that her curve was 31 deg. with minor spina bifida. He sent us for further tests as sometimes with juvenile scoliosis there can be associated problems. Dr. LaBrom also referred us to the R.C.H. and there we saw Professor Bruce McPhee and Dr. James McGill (a paediatrician who specialises in metabolic disorders). There she had an Ultrasound and an M.R.I.

In June 2004 we returned to see Prof. McPhee who told us that usually scoliosis progresses between 5 and 10 deg. a year but Grace's curve had increased from 31 to 45 deg. and that we needed to operate. In September we saw Dr. McGill who wanted to do some final x-rays before giving us the all clear with Grace and that was when he found she had lesions in her limbs and that he wanted to send a report of her x-rays to a Professor in Sydney before he could make a diagnosis. The diagnosis was a condition called Dysspondyloenchondromatosis, I thought wow, that has more letters than the alphabet.

In November 2004 Grace had her first operation, they had to go in through both front and back where they had to collapse the lung, remove the 10th rib, do a fusion and attach an internal fixation. She came out with a lung drain and was in I.C.U. for a couple of days and then back down to the ward. In March 2005 we returned to see Prof. McPhee and found that the curve had gone back out to 58 deg. The growth plate at T12 had decided to grow at an angle, so they sent her for a C.T. to see exactly what was going on. It was decided that they would need to remove the cortical plates of T12, remove the internal fixation and attach a cannulated growth rod from T4 to L3. This meant more time in I.C.U. and back down to the ward. A week and a half later when her bandages were being changed Grace, knowing what was coming, struggled and pulled the rod off at the top. She was sent for another C.T. to see what damage had been done, luckily not too much. Prof. McPhee had just left on a flight overseas so Dr. Labrom went back and reattached the rod a little higher with metal bridging.

So far things have been going smoothly now with Grace going back every 6 months for a lengthening, she has had two so far and will be due for another at the end of the year. Grace has the most amazing spirit and I think Grace has been the one to help us get through this; ironic isn't it? We have no idea what lies ahead or how Grace's Scolio is going to behave but one thing we do know is that we are lucky enough to have some of the best surgeons in the world at the R.C.H. and Greg and I have utmost faith in them. So, a big thank-you to Professor McPhee, Dr. Labrom and Dr. Tuffley along with all the staff there who help make this journey a little easier.

