

Spine Tingles

Newsletter of the Scoliosis Support Group of Qld Inc.

June 2008

Afternoon Tea
Saturday 21 June 2.30pm
37 Oleron Tce
PETRIE



We hope that a few members can come along to afternoon tea as advertised above. It is a while since we have had a get-together and it would be really great to catch up.

Re-flexion: magazine of the Scoliosis Association of Australia

The Scoliosis Association of Australia operates from Victoria. It produces an attractive and informative magazine *Re-flexion* which is edited by association president Susan Willis. Membership of the association is \$35 per annum. For more details go to:
www.scoliosis.org.au

Scoliosis - what it is and what to do

An episode of the U.S. children's health television series *Keeping Kids Healthy* looks at adolescent idiopathic scoliosis. Until it hits your own family, you can't imagine what scoliosis can do to your life. Katie's family found out when a routine checkup for their 10-year-old daughter made scoliosis a centerpiece of their lives. Their story is an emotional journey of discovery – from the moment of diagnosis, through years of treatment and ultimately surgery, to the outcome that can serve as a guiding light for other families confronted with scoliosis. Leading professionals explain what you need to know to understand and triumph over the challenge of scoliosis. View the episode at the following site:

<http://www.leechevideo.com/video/view1773810.html>

Thirty Second TV Commercial

Our major project for this financial year is the production and broadcasting of a 30 second television commercial. The commercial targets parents and demonstrates how to check for scoliosis in their children by getting them to perform the forward-bending test. The commercial will be shown on all WIN (Regional Channel 9) stations in Queensland. Regional members please note that the commercial is booked to be shown in the following timeslots:

Day	Date	Program	Program
Mon	30-6	Days of Our Lives	Million \$ W.O.F.
Tue	1-7	Days of Our Lives	4.30 News
Wed	2-7	Days of Our Lives	4.30 News
Thu	3-7	Alive and Cooking	Million \$ W.O.F.
Fri	4-7		Million \$ W.O.F.

Because the commercial is a community service announcement it will given some free airtime during July 2008, but these times are at the discretion of individual WIN stations and cannot be predicted.

Costs for the project are: production \$1800 and airtime \$2750. It is hoped that funds will be found to show the commercial on a Brisbane network in 2008-2009.

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.

Mindfulness-Based Stress Reduction – a Psycho-Educational Approach in the Management of Situational and Lifestyle Stress by Alison Keane MSSc, Dip IYTA

Mindfulness-Based Stress Reduction (MBSR), teaches people within a psycho-educational setting how to face serious illness, chronic pain and elevated stress with greater ease. To this end, it may be a useful adjunctive intervention for health care practitioners when treating people for stress and anxiety, and in the management of chronic and life-threatening illness.

The approach developed at the University of Massachusetts Medical Center in 1979, uses formal and informal mindfulness practice, gentle hatha yoga and somatic awareness, to encourage a willingness in participants to look deeply into emotional states and life circumstances that one might otherwise avoid, even highly aversive ones.

In particular it emphasises what people have in common - that everybody's mind goes through periods of agitation and calmness, and that everyone suffers at times from physical and emotional pain including anxiety and depression, and that there are profound and innate inner resources to learn how to deal with all this.

Participants may range from individuals simply seeking strategies to enhance their well-being and to better manage everyday stress to those experiencing chronic and/or debilitating medical and psychological conditions.

There are now more than one thousand research studies on MBSR worldwide in peer-reviewed journals showing that it can improve immune function and reduce chronic pain, anxiety, depression, excessive stress, serum cholesterol levels and blood pressure. Research also shows that mindfulness education such as MBSR can change the way emotions are regulated in the pre-frontal cortex, affecting the way that we think and feel.

Research has also found a consistent demonstration of enhanced psychological hardiness after MBSR for up to three years of follow-up including a heightened sense of self, and self in relationship, a greater ability to act effectively under high levels of stress and an appreciation in the value of engaging in own ingoing health and well-being through yoga, meditation and the systematic cultivation of awareness.

The author of this article is a Brisbane family therapist who trained under the direction of Drs Kabat-Zinn and Saki Santorelli at a 'Mindfulness-Based Stress Reduction in Mind Body Medicine: Residential Training/ Retreat' at Mount Madonna in northern California in 2007. An MBSR programme will be run in Brisbane during October/November 2008. An unedited version of this article may be read by visiting: www.alisonkeane.com.au
*** Mindfulness education including MBSR is not designed to replace current medical care. MBSR may be unsuitable for people experiencing severe depression or in early stages of substance abuse recovery.**

Coping with Bracing and Surgery

In mid February 2008 our soon-to-be 13 year old daughter Kaitlin had spinal fusion surgery at the Royal Children's Hospital Brisbane. We are pleased to say she has made a good recovery, though the road was a long and windy one. Kaitlin had a very rocky stay in hospital with an extreme reaction to the pain and surgery, but after 8 days she had turned the corner and we went home. Things are just wonderful with her and she has healed beautifully, walking tall at 174 cm, about 3 cm taller than pre-op!



Kaitlin was diagnosed with scoliosis in July 2006. We found out about her scoliosis by accident after she injured her tailbone and the physio picked it up. I remember when the physio mentioned surgery/rods/braces our initial reaction was disbelief and anger that she would start talking about that! A few weeks later we were at Dr. McPhee's office where I fully expected him to say that we would just monitor. So we were all gob-smacked to learn Kaitlin would need to wear a brace until such time the curve stopped progressing or she stopped growing! At that time her curve was 35°. It felt like we were all being swept along in some kind of a bad dream, trying to take in what the experts told us and what we read on the Internet.

The bracing itself went quite well, thinking back. Kaitlin was fairly compliant and whilst she did not want to wear the brace she went along with our wishes and wore it most of the time. The people who made her brace could not have been kinder or more helpful. The same I would say with the school, and school friends all seemed to understand. Even changing schools mid-brace was not a problem. Kaitlin was reasonably open about the brace and kids today seem pretty accepting - a few tried it on and even said it was "cool".



I was sure that the bracing would work, and as Kaitlin was already very tall we hoped she might not progress much more. Finding clothes that could be worn over the brace proved to be a time of clashing between us. Most of the time I think we just wished this was not happening to us and we did all we could to support Kaitlin and encourage her to just "live life" as normal, albeit with trying to wear the brace 20+ hours per day. A couple of melt downs from both child and parents ensued, but most of the time we just got used to it and hoped this was the end of the matter. At each 6 monthly appointment Kaitlin's curve proved to have become a bit worse and so on. We started to dread going to the x-ray place and then to Dr McPhee's rooms as there was never good news.

Fast forward to October 2007, where we learned that Kaitlin's upper curve was now over 43 degrees, the degree at which surgery is considered. We were very upset to learn of this and ended up seeking a second opinion from Dr Tuffley after meeting him at the Scoliosis clinic at the Royal Children's Hospital. We initially had surgery planned for 27 November which we subsequently cancelled as x-rays showed that Kaitlin had all but finished her growth and there was the possibility that her curve would not progress. During these months we also sought alternative treatment such as Pilates and Iyengar Yoga. The Yoga particularly helped with Kaitlin's posture and we hoped by her learning to hold herself so well that surgery may be averted for the time being.

We were scheduled to return on 24 January to see how things had gone. Our hearts dropped as we discovered her curve was now 50° and we quickly put plans in place for surgery. We were very lucky to be given a surgery date of 17 February and as we had already done all our grieving and stressing about it leading up to November we were all remarkably calm with this new date and plan. To be honest the lack of time leading up to this date helped as once again we were sort of just swept along!



We ended up having the surgery done by both Dr Tuffley and Dr McPhee at the Royal Children's Hospital in Brisbane and we have nothing but praise for the hospital, staff and everyone that was part of our stay there including Ronald McDonald House. Dr Tuffley advised us that Kaitlin could return to school a week or two post-surgery, slowly at first and build up from there. At the time I thought that was unbelievable and whilst in hospital I thought she would be home for months but the power of a 12 year old and her buddies is something to be reckoned with.

Seeing your child go through this whole process is not easy. Some children cope well, others scream and shout – the same can be said for the parents! I guess our experience was a combination of the two. I

would say the most important thing is to be patient and realise that any anger being directed at you by your child is an outlet for them during a very frustrating time.

Some advice I have for coping at this stressful time is to take time out for yourself while your child is in hospital. Go outside, have a coffee in one of the hospital cafes, read a book/magazine. I also bought a lovely journal and wrote of our shared experience every day which I found very therapeutic and it was good for Kaitlin and me to read back over it, as every day brings progress. If you have a partner, swap shifts at the hospital so that at least one of you can get a good night's sleep. Take some photos with a digital camera so that even while in hospital you can show your child how much progress they have made since the day before (which can be quite a lot!). In our case I was the "bad cop" and my husband the "good cop" so we worked out which areas of support caused the least amount of angst. If you feel it is too hard, talk to the nurses and they are more than happy to take over for you. You will find the nurses, physios and medical staff provide tremendous support during the stay in hospital so never be afraid to ask. Another great help is if you have contact with a family who has been through the same thing. Via the Internet we became friends with two families – one in Perth and one in Sydney. Their daughters both had the same surgery and were the same age as Kaitlin (one had surgery in November 2007, one the week before us). So it was a huge help to text message them whilst in hospital for support and advice. That way we didn't feel quite so alone.



We have had our ups and downs, we have shed many tears and worried terribly about the whole world of scoliosis - but we can look back now and honestly say it has made us stronger as a family, made Kaitlin stronger as a person, and given us incredible respect for medical professionals and others that have made our bumpy ride a bit smoother.

Kaitlin's mother Melinda contributed this article. Melinda, Greg and Kaitlin hope that it is helpful to others who may be heading down the same path. If you have any questions for Melinda, please direct them through the Support Group.

Farewell Jim

A long-time member of the Support Group and former Secretary, Jim McDonald, passed away on 21 January 2008 after an extended illness. Jim, Dawn and Lester joined the Support Group very close to its beginning in 1994 and attended the meetings that were held at Bray Park State High School. Jim's qualities of loyalty and compassion, and his fine intelligence were a great asset to the Group. We extend our sympathy to Dawn and Lester.

Spine surgery 'sewn up' before first cut

A computer modelling program that allows surgeons to simulate scoliosis surgery so they can design the best procedure before lifting the scalpel is being developed by QUT biomedical engineering researchers.

Queensland University of Technology spine research fellow Associate Professor Clayton Adam said the patient-specific computer models, developed by QUT-based Paediatric Spine Research Group, let surgeons try out different scenarios before they performed an operation to implant a rod in the spine to correct scoliosis.

"Spine surgery is one of the most complicated and painstaking operations because surgeons cannot afford to damage the delicate spinal cord," Professor Adam, a member of QUT's Institute of Health and Biomedical Innovation (IHBI), said.

"Our new computer modelling techniques let surgeons plan the most effective treatment for an individual patient by testing a number of crucial parameters before the surgery.

"By working out the best possible combination beforehand, surgeons can position the implant with confidence and therefore the patient is likely to have fewer complications and a reduced healing time."

Professor Adam said patient-specific computer modelling supported the new keyhole and single-rod surgical procedures that had been developed for straightening the spine.

"This surgery is much less invasive because doctors can now insert a single implant through keyhole incisions in the side of the patient," he said.

"For certain cases, it replaces the traditional 'open' surgery in which two rods were implanted through an incision along the length of the patient's back and left big scars."

He said scoliosis was the most common spinal deformity, affecting 2 to 4 per cent of the population, nine out of 10 of whom are girls in their early teens.

"Scoliosis can cause reduced lung capacity as the spine twists into the right side of the chest cavity, leaving less space for the internal organs.

"However, one of the biggest effects of spinal deformities is on the self image of the patient and their quality of life."

Professor Adam said 130 keyhole, single-rod operations had been performed in Australia.

"To ensure that our computer models are valid, we are carefully comparing the simulation results with clinical data from these scoliosis patients," he said.

The Paediatric Spine Research Group was also studying the spine as a whole and exploring bone at the microscopic level to understand how bone responded to surgical implants.

