



turner connections

// MAY 2009

The 'Chair' in the Corner Chairpersons Report – May 2009

Well I can't believe it is already April and I am having to condense the last 3 months again!!

We have been so very lucky to have been funded by Pfizer for the newsletter for the last year and with the assistance of BGA we have been able to produce our wonderful newsletter to a very professional level.

We had our AGM in Auckland in February.

We welcome Jessica Rogan as Secretary and Vicki Maaka as Treasurer and all our other committee members. I would like to take this opportunity to thank Kate for all her support and assistance last year and Annie for her work as Treasurer.

Before our AGM we had a Planning Meeting where we planned for the next 2 years.

We have some exciting goals to work towards, & hope to offer more get togethers – we have organized another camp next year for the girls, and would like to organize a few things for the ladies. We are also working on updating the website to reflect the new look brochure and newsletter so keep a look out – also we will be posting notices of events and newsletters on the website to help keep in touch, so in the event you have not heard from us check out the website www.turnersyndrome.co.nz

I would like to take this opportunity to thank Marina for opening her home for the previous Hamilton meetings for as long as I can remember.

We had a great day out at Wood Hill Forest in March at the Tree Adventures, the girls were running over the ropes like monkeys and the dad's had fun too (I know the did!). It was the first time most of us had been and was a fabulous facility & highly recommend it if you get the chance. (At Right: Brianna with Dad Paul)

We are pleased to advise we have received the "Turner Syndrome Across the Lifespan" book, see details on the back page.

There is an international conference in August – in Copenhagen. If anyone is interested in going, please let me know – as it would be wonderful to get any new tools & your feedback and also maybe able to put you in touch with anyone else going. For information go to: turnersyndrome@forening.dk

We would love you to contribute to our Turner Group in the form of the annual membership fee \$20, we do rely on these to enable us to keep moving forward and help to keep in touch, & assist in planning activities for everyone. We will extend the offer of the free DVD (A New Journey – Turner Syndrome) till June15th for any new / renewed subscriptions.

Pay to: Turner Syndrome Support Group NZ Inc.

Account Number: National Bank 06-0287- 0519802-00



The People

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Committee (some of)
from left to right: *Annie Gu, Karen Pratt, Emma Streeter, Jessica Rogan, Vicki Maaka, Diane Jaram & Kate Wignall.*

Australian Group

www.turnersyndrome.org.au
info@turnersyndrome.org.au

Next TSSG (NZ) Meeting

Saturday 15 August 2009

All Welcome

**Would you like to receive
this newsletter via email?**

**Send us your email address
at info@turnersyndrome.co.nz**

Please ensure you include your name if paying by internet banking or include your phone no. if paying direct at a National Bank .

Remember to notify us if you change address or email address so we can stay in touch.

– **Karen Pratt**

Kasey's Otoplasty

Article from Australian TS Newsletter 2003

Kasey was 4yrs old and we were being asked to consider surgery again. Of course previous to this surgery decision there was never really any question or debate over the options. When Kasey was 12 days old it was very clear that she either have heart surgery or she would die. 12 days after her first heart surgery it was once again clear that she required further surgery to survive. There was never any doubt about whether or not to go ahead with the surgery, so the decision was relatively easy to make (waiting for her to come out of surgery was not so easy).

The decision for Kasey to undergo surgery at the age of 19 months was also a no-brainer. She couldn't hear due to glue ear and she needed grommets (tubes) in her ears. At that age Kasey couldn't even say no, shake her head for no or nod for yes. She wasn't even pointing at things. Later she would have more surgeries for grommets and another to take her painfully infected tonsils out. All these surgeries were for medical reasons and it would obviously improve Kasey's health and development.

This situation however was entirely different. We were being asked to allow Kasey to undergo another invasive surgery for purely cosmetic reasons. We were being offered a procedure to 'fix' the external part of Kasey's ears, a procedure called otoplasty. Kasey had no folds or cartilage in her ears and so they were smooth and poked out. It wasn't hugely noticeable, in my humble opinion, except that Kasey has very fine blond hair and her ears did poke through a bit.

Of course as a parent you always think your child is beautiful and perfect as they are, but TS throws in another element you aren't entirely prepared for as a parent. Your beautiful baby may be considered different by others and may experience life differently than your other children.

So how do you make the decision to place your child in pain and in an element of risk to undergo a cosmetic procedure? Will it be worth it? Will it improve their life? What would they do if they had the choice?

For me the dilemma was about choice. As parents we want our children to have choices and be able to make decisions for themselves. Is it fair to make a purely cosmetic decision for them when they are so young?

The argument is that they

can have the operation at 4yrs of age, before they start school and they will never be hassled for those 'pokey out' ears and in essence never know the difference. I figured the same philosophy is taken when considering growth hormone for young TS patients ie; start the growth hormone before the difference in height is too noticeable and therefore avoid the issues of feeling different.

The operation requires the patient to wear a turban-like bandage constantly for 2 weeks. You could imagine wearing that as a school aged child or adult. You would have to hide out for 2 weeks! And of course as an adult you would have to pay for the operation while we were being offered it at no cost.

You will never really know if you made the right decision or not. But then I feel that is pretty much what parenting is about. You make the best decision you can with the information to hand. Sometimes later down the track you might realise you got it wrong, but more often than not no one will ever tell you if you did or not.



But anyway I digress.

We decided to go ahead with Kasey's operation. Her ears were like little mouse ears and while I thought they were very cute, I'm sure that when her first boyfriend tries to whisper sweet nothings into one of those ears she might not consider them 'cute'.

So Kasey underwent the operation and I sat tensely waiting (with occasional tears), still wondering if we had made the right decision or not. Would she be okay? Would her ears look okay? Would she scar badly? The operation went well and we were presented with our beautiful little 4 yr old wearing a huge turban. The nurses had braided her hair at the top of her head so it poked out through a hole in the top of the 'turban'. She looked like some sort of genie gone wrong.

We bathed her in a bucket so that she couldn't possibly slip in the bath and get the bandage wet because it had to stay on her head for 2 weeks.

I wondered how she would sleep with that huge thing on her head but she managed okay. She didn't seem in pain but then she did

have about 4 inches of padding around her head.

We stayed home for the first few days but it became clear that Kasey was getting cabin fever and needed to get out. She wasn't phased by this bandage on her head at all, it was like nothing had happened to her. We ended up at the local shopping mall and the park. Kasey had a great time totally oblivious to the idea that she might look strange with a massive bandage wrapped around her head.

At the end of those 2 weeks it was just like a movie where you finally get to take the bandage off and see what the plastic surgeons have accomplished. We all stood around her while the nurses tried to get the bandage off. The plasters holding the bandage on stuck hard around her forehead and I had to hold her hand and calm her while it was painfully pulled off. And then her ears were unwrapped. There were perfect little folds and her ears sat beautifully and flatly against her head. No scarring. Frankly her ears are works of art!

The surgeon said we would need to touch and rub her ears because otherwise they could become very sensitive. She didn't like it and we probably didn't do it often enough. Soon after this Kasey had glue ear again and needed grommets. We had to wait for around 5 months for this operation so we got hearing aids as a temporary solution. This was fantastic for desensitising Kasey's ears as well as for her hearing and she was very good about wearing them and not losing them.

I am so glad we made the decision to go ahead with the operation, but of course that is because everything went well and in the end there has been no downside. I would never have believed that surgeons could produce such a perfect set of ears if I hadn't seen it myself. It still amazes me to look at them.

Kasey has a lot of the characteristics of TS and as a parent I really want to protect her from feeling isolated or 'different' in a negative sense. On the other hand she has the most beautiful TS eyes. Some doctors have encouraged us to have her eyes surgically corrected so that she doesn't have such a slack outer canthus. It's a simple procedure, they have told me as they write out a referral to her plastic surgeon. I agreed to the first consultation only because I was worried that the slack outer canthus might be contributing to eye infections. On consult, the plastic surgeon felt it wasn't a problem, I think he agrees with me that her eyes are far too beautiful and unique to want to change.

Kasey today

(Kasey's surgeon was Dr de Chalain)



Taupo Iron Kids!

Aleisha (10) and her brother Daniel (8) competed in the Taupo Iron Kids in February. It's the first time Aleisha has done the event. 100km swim, 4km cycle and 1km run. She did so well in that she started and finished with a smile on her face. The photo of her and Daniel shows them holding their medals and pride is written all over their faces – mine too as I watched them achieve a goal that at one point in time was not even something that Aleisha would have wanted to do. I think I was even more proud than them!! I think I would have struggled!

Jenny (proud mum)



Life with Turners and Celiac

Hi my name is Paula Harris, I am 17 years old. I was diagnosed with Turner Syndrome when I was 15 years old. Before this I had heard stories of me being sick as a baby, having ear problems and wondering why I was heaps shorter than my friends.

In year 9 I got a hearing aid in my right ear and have worn one ever since. I felt finding out about having Turners helped my family and I understand about all my health issues because at the same time I found out I had Celiac Disease (gluten intolerance). So that has meant a change to the food I eat. This has not always been easy because I come from a family with 5 kids, and having to suddenly alter my diet has caused difficulties with missing the foods I previously ate, in addition to getting used to the different textures of gluten free foods.

I am more at ease with myself now I know about having Turners because I can tell people why I am short and different to them. I know of only one girl who used to live in Wanganui where I live that has Turners. Going to the 2009 Camp for girls was a huge and fun new experience, for which I thank Karen Pratt & the other parents so much for arranging, and I can't wait till next years camp. It was great to meet other girls who have Turners. I am not very good friends with all of them yet but we are texting, writing and emailing all the time as teenage girls do.

I do have some advice for girls who have Turners and have only known for a short time as I have: don't let it become an excuse to not do anything with yourself. Remember you are a special and unique individual; dare to challenge yourself daily and don't let school become a drag; try your hardest and get the extra help you need. I am in year 13 (7th form) this year and have become a Prefect at my school. So if I can do it I believe each one of you can too, so get out there and just shoot for your dreams!

I leave you with this saying:

"Shoot for the sky because if you miss you will hit a star"

Paula Harris – age 17. Wanganui

Feel Isolated – Need support?

We have been discussing ways to keep in touch and offer support to parents & young girls, teenagers, young adults and adult Turner ladies. As we are a small support group and a lot of people around NZ feel isolated this may be a great way to bring everyone closer together.

One idea was to use Skype & have a night once a month were each group could be on line and anyone could hook into the conversation via conference call – this means we can have specific discussion groups – but first we would need to know if there is a need? Do you have questions about any issue but don't know who to talk to? – would you like to be able to talk to others in a similar situation and get their thoughts & advice?

What is Skype? Skype is a computer programme allowing users to talk and/or video chat with each other free via a microphone and/or webcam on their computers. To use this free software, visit www.skype.com and download the latest version.

We welcome your ideas and feedback as we know there is a need for this and we would like to provide you with the support you need.

Would you be interested in coming online once a month? Can you get Skype in your area? (ideally requires a broadband internet connection) What group would you be interested in coming on board? (could be more than one group).

Contact: Karen 09 4806617 or info@turnersyndrome.co.nz



Calling all Waikato Turners Ladies

All willing walkers are invited to a lake stroll every second Wednesday at 5 pm. When the nights get too dark and cold we will meet for a coffee instead. Meet at the entry off Ruakiwi Rd, by the new cafe/restaurant development. It's a great time to chat, exercise and unwind at the end of the day.

Please contact Jessica to get involved: jessicarogan@gmail.com
Phone: 07 839 7184
Mobile: 021 048 4913

Got a pen or a mouse pad?

If you would like a Penpal, contact us at info@turnersyndrome.co.nz



Youth Camp January 2010

We have organised another camp due to popular demand.

When: 11–15 January 2010
Where: MERC – Sir Peter Blakes Marine Education & Recreation Centre Inc. Long Bay, Auckland
Ages: 9 years+
Cost: approx \$330 per girl

This was indeed a fabulous way for all the girls to spend time together and meet others, especially those who do not have any support nearby. We took 17 girls this year and hope to get 24 next year. This is a first in first served basis. Please email or phone with an expression of interest ASAP to:

Karen: 09 480 6617 or info@turnersyndrome.co.nz



Parent Support

We are a small group here in NZ and sometimes it would be nice to be in touch with other parents around the world who may have something else to offer. There is a yahoo group that is restricted to parents/grandparents/caregivers only, it is understood that anything shared remains private within the group. Presently the group has 430 members from all over the world, but mostly from America, and has been running since 2001. This is an amazing resource through which to ask questions, to share and be supported. The group also shares articles and photos. It is a fantastic group.

If any parents are interested in joining an online newsgroup for TS Parents they can contact me at leanne@lrb.co.nz

Matarangi Weekend

Emma is organising a ladies weekend away at Matarangi (Coromandel) at her parents bach from 10-11 October 2009 Friday evening to Sunday. At this stage it is for 18+ age group, it will be a fun and relaxing weekend.

Please email Emma (moogleshome@gmail.com) with an expression of interest ASAP.

Publications:

We now have copies of "Turner Syndrome Across the Lifespan" book.

I highly recommend this book for everyone with Turners and also for parents and teenagers as it has very good practical advice. It covers all aspects of life with Turners in a very user friendly way.

A Canadian publication this 240-page book, edited by Jill Hamilton, MD, FRCPC, and Irena Hozjan, RN, BScN, MN, is a comprehensive and up to date overview of Turner Syndrome.

Cost is \$39.95 plus postage - \$41.95

To order one please contact:

Vicki Maaka – Vicki.maaka@nbnz.co.nz

Links:

www.turnersyndrome.org.au

www.turnersyndrome.org.ca

www.tss.org.uk



We would love input from you on what you would like to read about or if you have a story (maybe your own story) we would love to hear from you. info@turnersyndrome.co.nz

Turner Syndrome Support Group (NZ) Inc. PO Box 12611, Chartwell, Hamilton 3248.

