



// JULY 2008

Chairpersons Report – July 2008

Its Newsletter time again, which means another quarter has rushed by. We started off in May with our meeting in Hamilton. We had a great turn out with a few of the girls coming with their mums to use the opportunity to get together. We also welcomed Rachael from Te Puke and Julie from Hamilton.

Helen Wemyss was our guest speaker from Fertility Associates in Hamilton – she gave a very interesting talk on the options in IVF treatment and discussed the option of donor eggs and how surrogate mothers could play a relevant part in a Turner woman becoming a mother particularly if they maybe have a heart condition that could make carrying a baby difficult. It was great to know that there are wonderful specialists specialising in fertility who are the best people to contact should anyone require information re starting a family.

We are underway for the girl's camp in January 2009; one of our fundraising ideas is to have a raffle that would be nationwide. See back page.

We are on the look out for articles of interest so please let us know if you have anything to share or would like to see. We are presently seeking approval to publish some articles. So hope to have them by next newsletter.

Some of you may have had a call from one of our committee members; we have been proactive in keeping in touch with past members to ensure we have the correct contact details. Thanks to those who have given feedback.

Thanks to those who have paid their membership fee. Please note that the membership though \$20 is a calendar year so if you haven't paid this year and received a membership card we have enclosed another membership form for your convenience. This assists us in keeping the website going and ongoing costs of keeping the group together.

We are also looking at support in the South Island – Jacqui in Dunedin has an article within. I am delighted as I feel the South Island families all need local support. Good on you Jacqui.

The next meeting is in Auckland, Parent & Family Centre, this is a good opportunity for Auckland members to come along.

The next Big Day Out will be after the Auckland Meeting on 16 August, mum and daughter evening and sleepover for those keen to stay. We need confirmation of approximate numbers by 10 August - venue yet to be confirmed - will be in Auckland. Contact me for further details.

By Karen Pratt

The People

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Next TSSG (NZ) Meeting

**Saturday 16 August 2008
Parent & Family Centre
92a Princes St, Onehunga
Auckland**

**11.30pm - Meeting
Followed by a pot luck lunch**

ALL WELCOME

Diarise these Dates: Future Meeting Dates for 2008

- | | |
|------------------|---------------------|
| 16 August 2008 | - Auckland |
| 15 November 2008 | - Xmas function TBA |
| 14 February 2009 | - Hamilton |

ALL WELCOME

Your Thoughts...

I am setting up a column in the newsletter for questions and answers. If you have a question about TS that you would like answered, or are wondering what others thought then I would love to hear from you.

I was talking with a friend the other day about when in the relationship to tell a potential life partner about TS and what it means. I thought this would be a great topic to debate and please let me know of your experiences, concerns or thoughts. I had always chosen to tell potential partners about TS when I thought it was getting serious and trust had been built up. There are many younger people in the group and I was wondering if you had thought about this for the future? Luckily for me it went down well, but I think that it can go either way. This affects all of us when getting into relationships so please let us know your thoughts. Your name and address will be withheld unless you let us know otherwise.

Sally – Editor

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Health check available for the management of Turner Syndrome...

On the UK website there is a useful tool that has been developed for both health professionals, and women and girls with Turner Syndrome. The Checklist is designed to slot into the patient record and act as a 'prompt' to ensure that each girl or woman is treated according to her individual needs.

"The Checklist will be a useful audit tool for health professionals involved in the care of people with Turner Syndrome and we're delighted that Ipsen was able to sponsor this project. We hope that the Checklist will benefit those who have Turner Syndrome and provide continuity of care." said Arlene Smyth, Executive Officer of the Turner Syndrome Support Society.

For further information and an electronic copy check out the UK website www.tss.org.uk

Wellington Group

There is a small group who meet informally and socially in Wellington.

If you are in the area and want to get involved / find out more then contact Julie on 04 970 1802.

Please leave a message if there is no answer.

Alyssa's Sleepover

Potluck dinner, Singstar and loads of fun!

Well what a fun sleepover we had a few weekends ago with Rachael and family, Fleur and family, Julie, and Denise.

We had an awesome time playing Singstar and having a potluck dinner then Fleur and her mum Michelle and family stayed the night.

"Mum, me and Alla have the same hands!"

We all had similarities for example Rachael and Fleur were both missing a knuckle in their fingers and an upturned toe. Fleur and I also compared hand sizes with each other and she said "Mum, me and Alla have the same hands!" It was so sweet.

Fleur and I get along very well since she has been newly diagnosed she has found it hard but she is a very strong able girl. It was also lovely to meet Rachael a few weeks ago at the meeting in Hamilton. We both found that we both have the same learning difficulties in the same areas whether its university or school. It is so cool to have everyone living very close especially Rachael only living in Te Puke and Fleur who lives in Papamoa we all had a fun filled night of laughs and making connections.

AllA_RoX

A New Journey: Turner Syndrome

A collection of stories reflecting true life experiences of living with Turner's syndrome. There are many resources available including websites and books written about Turner Syndrome.

There is a DVD that has been produced in Victoria, Australia by girls, women and families with their real life accounts of living with Turners.

The digital resource was instigated to aid in the emotional healing for families, teens and women after diagnosis and during initial treatment of TS.

This DVD was launched in December 2007 and I am getting copies of the DVD sent to us. The DVD covers the full spectrum from child, teen, to adult and relationships.

Contact me if you would like a copy – price will be nominal, but yet to be confirmed.

e: info@turnersyndrome.co.nz

Or go to www.turnersyndrome.org.au for more information on the DVD, they also have a book 'Hidden Treasures' which is also an account of life with Turners. This is a great read as there are stories we can all identify with being a girl or adult or a parent.



Southern Support Group

Hello, my name is Jacqui and I have Thalia (8 years old) with Turners. Thalia was diagnosed at 1 week of age due to her being born prematurely.

Like the rest of you our family has been on a roller coaster dealing with this condition. Thalia has three heart conditions, but so far has required no surgery. She is awaiting her 5th set of grommets and we are hopeful these ones last more than 3 months!

Thalia is behind her peers at school, but has a great attitude to learning. Recently Thalia has been diagnosed with ADHD. This was no great surprise to us as Thalia is a very busy girl. The psychologist recommended Ritalin; we have refused this so far.

We were advised by a naturopath to try her on Omega 3 fish oil. So we stumbled across the best medication ever! Thalia now has 5mls of Metagenics Kids Omega Care twice a day. What a difference there has been. She has gone from

"...we stumbled across the best medication ever "



a very stroppy girl to a fairly compliant one. She has gone from a level three reader to level 12 in just two terms! It does cost \$31.50 a month, but it is well worth it. Added to that we have put her onto 2mg of Melatonin at night. She now asks to go to bed at 8.30pm instead of being forced in at 10.30pm. This again costs \$30 a month, but it is worth every penny!

I have recently trained as a support parent with Parent to Parent, in the hopes to help other parents going through the same issues. As a result of this I have decided that it is time to get a support branch up and running down this way.

Over the next few months I hope to make contact with families down the South Island in the hope to set up a meeting together.

I live in Dunedin, but have access to video conferencing facilities. If you live in the South Island or know of a family that does then please let me know.

Jacqui.

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National Conference

The 2008 National Conference of the Turner Syndrome Association of Australia will be held on the 26th - 28th September.

The program will include Speakers, Workshops, Banquet Dinner and a separate program for TS girls and teens.

The latest information about TS will be presented, as well as opportunities to socialise and get to know each other. We welcome women, teens and girls with TS, families and medical professionals interested in TS.

A few of us are planning to go across for the Conference – for more information please go onto the website:

www.turnersyndrome.org.au

International Turner Syndrome Conference

– Copenhagen August 2009

The Danish Turner Syndrome Group is organising the next International Turner Syndrome Conference.

When: 27-28 August 2009

Where: University of Copenhagen

For more information contact the Danish Turner Syndrome Group:

turnersyndrome@forening.dk



Weetbix Tryathlon

We were all having fun at the Milford Big Day when someone suggested we put a team together for the Weetbix Tryathlon. Denise said she would do the cycle event, Victoria said she was good at swimming (because she no longer has ear infections) and would be the swimmer, and Karisha loves to run so she was the runner!!!

We had to be at Narrow Neck beach at 7am! So much fun! Denise & her mum came from Putaruru and stayed with us the night before – we had a very early start. We strapped Denise's bike to the tow bar, & off we went to the beach fingers crossed for better weather (rain clouds loomed).

We managed to meet up with Karisha. Donned with T-shirts and race numbers we went to the start. I was first one up; I joined my age group and wore a purple skull cap. It was freezing, the waves were huge and I was numb swimming the 200m down the beach then run up to tag Denise so she could get on her bike and race! She went twice around the circuit up hills and around not an easy ride but she did fantastically.

Off she got and tagged Karisha who was waiting patiently rearing to go! Karisha was off she loves to run! She blitzed the field and as she came up the last straight Denise and I joined her and ran through the finish line together. We got medals from Nick Evans, Hamish Carter and Kevin Mealamu all fantastic medals. I felt so proud & happy with myself that I had accomplished the Tryathlon with the help of my friends. It was so much fun!!!

By Victoria Pratt



From Left: Karisha, Victoria and Denise

Turner Times

RAFFLE!

Fundraiser for Girls Camp 2009

We have been offered some great prizes so we will be having two raffles:

RAFFLE 1: A collection of some cool girlie prizes:

- A quilt
- A nest of hot pink luggage
- An iPod Shuffle.

RAFFLE 2: Accommodation prizes:

- Two nights accommodation for 2 at a fabulous bed and breakfast in Herne Bay, Auckland.
- Plus two weekend stays at a house in Kinloch, Taupo.

Please email me if you would like tickets to support the girls going to camp – \$2.00 each. All families involved with the camp will be sent books.

Contact Vicki Maaka for more information.

p: 09 413 6246

e: info@turnersyndrome.co.nz

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

Turner Camp for Girls 2009

Sir Peter Blakes Marine Education & Recreational Centre Inc. Long Bay, Auckland on 13-16th January 2009.

This is a fabulous opportunity for girls 8-18yrs and also a couple of leaders will be required. We are hoping to be able to take 20 girls on this camp. The aim is to get as many girls from around New Zealand here. We have set up two raffles to assist with raising the much needed funds for the camp. We feel this is a great way to get the

families and particularly the girls involved, as we have a girls raffle for them to sell to their friends and cousins etc. Many thanks to those who kindly donated prizes. By now all interested in the camp should have paid their membership and deposit.

Websites to check out:

www.merc.org.nz and www.vaughanpark.org.nz (Accommodation next door). For full info see our website: www.turnersyndrome.co.nz & contact us if you have any questions and register on: info@turnersyndrome.co.nz.

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

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