

### Southern Support Group

Jacqui lives in Dunedin and was introduced in the July newsletter as our Southern Support contact.

She has access to video conferencing through Parent 2 Parent who have offices now in 9 centres including Nelson, Christchurch, Dunedin and Invercargill. So it makes for a perfect chance to get together and meet the other Turner members in the South Island. The Video Conferencing is free for families to contact one another or individuals. It is a wonderful facility if you want to make contact. So if you live in the South Island or know of another Turner girl or women please let Jacqui know.

Jacqui.

e: [jak\\_fras@xtra.co.nz](mailto:jak_fras@xtra.co.nz)  
p: 03 487 9585

*"...a wonderful facility if you want to make use of it"*



### 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.

### KORU Care 25th Anniversary

Koru Care have taken a group of 50 kids to Disneyland to celebrate 25 years of taking children with health issues on the trip of a lifetime.

We farewell Karisha, Bryony, Hannah and Claudia on 26 October for 2 weeks of fun. Visiting LA's hot spots including Disneyland, Universal Studios, Knottsberry Farm & SeaWorld.

We look forward to hearing the stories and seeing the photos, watch this space. Thank you Koru Care for making these girls dreams come true.



### Calling all Turner Girls and Women

**You can make a difference!**

Dr Rinki Murphy, Diabetes Specialist, Auckland Diabetes Centre is researching into relation between Genetics in Growth and Diabetes. This is a study Rinki has been working on for a couple of years and still requires more data to complete her research.

She requires a simple blood test. This research will assist in the research of Growth & Diabetes which is an issue for all Turner females.

We have put the latest forms up on our website under LINKS; for more information:

[www.turnersyndrome.co.nz](http://www.turnersyndrome.co.nz)

Or contact Rinki Murphy on: Fax: (09) 630 0709  
Ph. (09) 307 4949 Ext: 26839 Email: [rinkis@adhb.govt.nz](mailto:rinkis@adhb.govt.nz)  
Mob: 021 1428470

### 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](mailto:turnersyndrome@forening.dk)

### Turner Conference in Adelaide

Mum and I got up and were on the road at 3am to make our 8am flight. We made it to the airport and were off to Adelaide, Australia. We landed in to 27 degree sunshine; it was hot. At the airport we met my brothers girlfriend's parents. We went to their house, dropped off our things, and were off again for a walk along the beach.

We got up early in the morning and we were off. We arrived at the Hotel where the conference was being held. We got our name tags and we went upstairs. The kids were in one room, that was me and the parents, and conference was in the other room across the hall. The kids were doing arts and crafts e.g. badge making and screen printing bags. The adults had many speakers who spoke for approx 45min each, we found them interesting and we learnt heaps and there were lots of things that we learnt that we never thought were involved with having Turners. The conference finished at 5:30pm for the day and then the fun started. We all had dinner, the kids as they watched DVD's. The DJ started and we had almost everyone up dancing until 11pm. The DJ had to finish because the music was too loud, much to all our disapproval because we were all having fun.

Conference started as usual the next day and we arrived at the hotel and we had discussion groups. The adults were talking about what they had learnt over the weekend and gained different experiences. The teenagers were talking about helpful things that could go into the TSST (Turner Support Sharing Together) newsletter, and we talked about what it is like being a teenager with TS.

The conference ended with a big lunch, and a talk from family members and girls/ladies about their experiences with TS in their lives. We then said our goodbyes, and the conference finished at 1pm. I had a great time and made a friend in Perth so I will be saving my money and am looking forward to the next conference in Perth in 2010.

After the conference Mum and I had the chance to go to:

- Granite Island in Victor harbour where we saw a horse pulling a tram and a little penguin and some amazing views.
- The Barossa Valley where we visited 7 wineries.
- The Murray River where we saw some amazing house boats, and also Dundee's wild life park where we fed birds, kangaroos and emu's.
- The top of Mt Lofty where we were almost blown off because the wind was so strong. Then we went to the Mt Lofty Wildlife Park where we fed kangaroos and saw our first real live snake outside of a glass box.

It was a wonderful holiday and we learnt heaps and I am looking forward to 2010 – Denise and Julie Van Dam



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](mailto:info@turnersyndrome.co.nz)

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



### Calendar of Events

#### 2008

**26 October** Koru Care Disneyland Trip

**8 November** Camp Raffles drawn

**15 November** Turner Meeting  
Turner End of Year picnic  
Hamilton

**4 December** Koru Care Cruise  
Auckland

#### 2009

**13 – 16 January** Camp for Girls  
MERC – Auckland

**14 February** Auckland AGM Meeting

**August** International Conference  
Copenhagen

Got a pen or a mouse pad?



18 yr old request for penpal. Lives West Coast North Island. Diagnosed at birth. Would like to correspond with someone of similar age.

To contact email: [info@turnersyndrome.co.nz](mailto: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.

The camp will be fantastic. We have had a wonderful response – 18 girls are coming from all over New Zealand, the farthest coming from Dunedin. This is double the number of girls who went to OPC camp 2 years ago.

There are cool activities & new friends to meet.

**Websites to check out:**

[www.merc.org.nz](http://www.merc.org.nz) and [www.vaughanpark.org.nz](http://www.vaughanpark.org.nz) (Accommodation next door).

For full info see our website: [www.turnersyndrome.co.nz](http://www.turnersyndrome.co.nz) & contact us if you have any questions and register on: [info@turnersyndrome.co.nz](mailto:info@turnersyndrome.co.nz).



### The 'Chair' in the Corner Chairpersons Report – October 2008

Welcome to the October "Turner Connections".

We have been very busy working on a fresh new look for our brochures and newsletter, and the website will also reflect this at a later stage. Hope you love the new look. Thanks to the girls who had input into the new colours – well done.

I was talking to a mother the other day & discussing some of the subtle things our daughters may do, often we push things aside and often it is hard to define for ourselves or our daughters what is Turners and what isn't. We discussed having a mothers conference but for now how about a Mothers Corner / column? This will enable other mum's to write in and give their views or experiences – like Jacqui did last newsletter with the behaviour & concentration being markedly improved by the taking of Omega 3. She gave us her problem and solution which I am sure will help others in a similar situation. All I know is, the more we talk about things, the better it is; as we know we are not alone and nor are our daughters.

This also goes hand in hand with Sally wanting to set up a column for Questions and Answers, on relevant topics concerning teenagers through to adults. This would be a valuable resource for everyone but we need your input! This newsletter is yours – the more contributions the better it becomes.

Our AGM is coming up on 14 February in Auckland – put it in your diary now, we would love to see you there. If anyone has fundraising skills or experience I would love to hear from you. We can do so much more with funding.

There are a lot of students at school and at Tech or Uni studying for exams – study hard and good luck for the exams.

The End of Year Party is in Hamilton – if anyone from Auckland would like to go, please contact me and we can carpool; Tauranga carpool is already arranged. Should be a great time, we have ordered a great day for the weather! – see details within. Look forward to seeing you there.

By Karen Pratt

### The People

#### Chairperson

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#### Australian Group

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[info@turnersyndrome.org.au](mailto:info@turnersyndrome.org.au)



### Next TSSG (NZ) Meeting Saturday 15 November 2008

Narrows Park, Tamahere Park  
Hamilton.  
Meeting begins 1.30pm

Followed by...

End of Year Party  
Sat 15th Nov - 3.00pm till 7pm

Barbecue Narrows Park, Tamahere, Hamilton

There is a swimming pool and Archery so bring your togs, towel, sun tan lotion, kite / ball etc...

Barbecue will be 5pm onwards with a Sausage Sizzle. Please bring your own picnic plates, cutlery, cups, drink etc. Salad and nibbles to share. Please contact Marina on 07 855 6290 or via [mgrantham@nettel.net.nz](mailto:mgrantham@nettel.net.nz) if you are able to come or require further information.

## Marina's Story

**Hi everyone. I'm Marina. I have Turner Syndrome and was diagnosed last year with Coeliac Disease. Since I have been taking Eltroxin for low thyroid function, I have been asked to write about both these issues.**

Firstly, Coeliac Disease IS/CAN BE connected with Turner Syndrome and as such should be one of the many things to be on the lookout for. People should have a coeliac markers blood test done to make sure. I managed to slip through the system! I was diagnosed because I took Fosamax for low bone density which gave me moderate gastritis; because I had such an upset tummy we had to check out all avenues and find out what was going on. I had taken Fosamax previously and stopped because of oesophageal irritation but this time my tummy was sore and painful as well as irregular bowel motions. I stopped taking it and went to my doctor and we decided on a follow-up which was coeliac markers, colonoscopy and gastroscopy. No after effects, and I remember nothing about the procedures except waking up and having some lovely soup and a date scene afterwards, which tasted wonderful following 24 hrs of no real food! I went back to the specialist, my coeliac markers were positive and the biopsy they took with the gastroscopy was positive – so, no escape – no gluten from now on. Gluten is commonly found in wheat, rye, oats and barley, but hides in a lot of products, everything has to be purchased with care.

I have joined the Coeliac Society and it is a wonderful source of information especially when you first find out. There is a great web site and copy in book form sent out each year: [www.mfd.co.nz](http://www.mfd.co.nz), which lists gluten free food. This is food that has been tested and proven to have no gluten. I am going overseas and you can also get cards, requests for chefs etc in different languages which makes things a lot easier at restaurants etc.

When you are first diagnosed you do not know where to start, and I have never spent so long in the supermarkets as I did in the first couple of months! But you get the hang of it. There are lots of things available from nearly an infinite range of flours and mixes to bread, biscuits and ready made treats and even in the year I have been diagnosed it has increased. So while it is frustrating when there is nothing on the table you can eat at supper, and pot luck meals can be limiting, you learn to adjust – to not being on a 'see food' diet! The gluten free food actually tastes better to me, no doughy reaction in my mouth and you gradually start to get more energy etc.

## An Eltroxin Story

I started taking the new form of Eltroxin in Feb/March. I had just started feeling pretty good after the gastritis and sorting out the gluten free diet, but then by April/May I started not being so well in a number of ways. It was then I heard about the Eltroxin reactions people were having, so I monitored myself for a couple of months, by which time I was starting to get dizzy and lose sense of balance. I went to my doctor with my list of reactions and he added my reaction report to the many others that have been received. My reactions were dizziness/loss of balance, headaches, fuzzy thinking, nausea, tingling hands and feet, lack of peripheral circulation, general aches and pains, and lack of energy.

As I write, I have only been on another form (which has only just become available and you have to pay for at the moment) for a couple of days, but I no longer have cold hands and the dizziness etc is disappearing. Hooray! I'm beginning to feel normal again. If you are on Eltroxin for your thyroid function and are having funny things happening, it could be the cause, so get to your doctor and discuss the situation with them. By the time you read this, the new medication could well be funded. These side effects creep up on you and you do not really realise how much effect one little tablet is having!

## The latest on Thyroxine

Low thyroid function is a common TS symptom, and many of us rely on thyroxine to increase our thyroid levels. There was a story on Close Up about some negative side effects of a new brand used by PHARMAC. If you missed the report re: thyroxine, you can see it at [www.tvnz.co.nz](http://www.tvnz.co.nz), under Close Up.

There has been much interest in the thyroxine supplied by PHARMAC (who are the government agency that subsidises medications). From what I understand PHARMAC has changed supplier of thyroxine (basically from one brand to another) and it appears that for some reason some people have experienced side effects when the brand changed. Unless you have experienced side effects from the current thyroxine there is likely no need for concern. Any drug side effects should be discussed with your doctor / pharmacist.

PHARMAC reports on their website, [www.pharmac.govt.nz](http://www.pharmac.govt.nz), that: "If your medication has changed, it usually means that another supplier has successfully bid for the supply contract or the previous supplier has withdrawn from the New Zealand market." If you find yourself in this situation, there are a number of options open to you:

- If your former brand of medication is still available you could buy it at your own cost.
- If your former medication is no longer for sale in New Zealand, your doctor or pharmacist may be able to import the drug under Section 29 of the Medicines Act, again without subsidy.
- You could apply to have your former medication subsidised by the Exceptional Circumstances Panel. Certain criteria must be met to qualify for Exceptional Circumstances approval. See the 'Exceptional Circumstances' section of the PHARMAC website for more details. <http://www.pharmac.govt.nz/EC>

The latest I have found is straight from the horses' mouth – via a media release 30 September 2008. This is edited from the PHARMAC website:

### PHARMAC begins consultation on alternative thyroid treatment

PHARMAC has begun consultation on a proposal to subsidise a further brand of the thyroid treatment levothyroxine. Consultation is a further step towards introducing an alternative to the Eltroxin brand that is currently funded. PHARMAC medical director Dr Peter Moodie says the proposal affects pharmaceutical companies, doctors, pharmacists and patients so it is important there is an opportunity for people to give their views of the proposal. Levothyroxine (also known as thyroxine) is widely used in New Zealand with approximately 70,000 patients prescribed it. The proposal involves the listing of the Goldshield brand of levothyroxine, which would be supplied in New Zealand. The Goldshield brand is widely used in the United Kingdom, from where stocks will originate. Dr Moodie says that usually there would be a 4 to 5 month lead-in time for a new pharmaceutical to be available, because of manufacturing, shipping and other issues. However, PHARMAC has made a particular effort to ensure an advance shipment of Goldshield is available sooner, from early November.

For the full media release see:

[http://www.pharmac.govt.nz/2008/09/30/Goldshield provisional agreement release.pdf](http://www.pharmac.govt.nz/2008/09/30/Goldshield%20provisional%20agreement%20release.pdf)

For those of us on thyroxine, and in fact any medications, we need to be aware of what the potential side effects are, and of course see your doctor or pharmacist if you are concerned. My advice is to continue taking your prescription medication, as prescribed, until you have got medical advice.

– Sally

## Starting a New School

As we are approaching the end of this year and into a new year there will be girls changing schools from the security of primary school or familiarity of Intermediate into Secondary school. I have had a couple of people ask me how our transition from primary went – I have to say it was not an experience I would choose to repeat and nor would Victoria, but could with the experience we have gained along the way. We are very proud of Victoria who has battled to keep up but still goes back for more!

We went from the comfort of primary school where expectations were, "She is doing OK" to a totally different standard and environment. Here are a few pointers that we found helpful to us as a family and child with learning difficulties, compounded with hearing loss.

1. Visit the school and speak to the Dean and Principal and inform them of your daughter's needs e.g. she has Turner Syndrome, needs a friend in the class, need for simple instruction and a patient/understanding teacher etc...
2. Meet the class teacher / year Dean with in a week or so of starting the school year to build a report with her – most teachers are happy to have parents on board – (keep in touch with teachers as the year goes on, particularly the first year when so many new expectations need to be met). Often the girls can be so keen to learn that the teacher may not realise that added pressures and work load compound and create stress and overwhelming.
3. There is a lot to cope with in a new situation and from my experience disappointment can creep in & situations can be magnified:
  - a) Put in place simple tasks to be completed before school – just the basics of remembering teeth, lunch, etc... as this is where the day can get off to a good or bad start.
  - b) Colour code subjects so all the text and exercise books for say maths are green and science is purple (the \$2 shop have clear files that have different coloured zips – perfect for the job!).
  - c) Encourage your child to use a diary to record her homework or tasks that have to be completed or reminders.
  - d) If she is shy encourage her to get a class members phone no. so she can confirm the homework.
  - e) Don't assume she knows things like how to use a locker – what it is for.
  - f) Encourage peer support (or buddy system so they are familiar with the new schools rules and layout).
  - g) Report any bullying immediately to the school.



4. If you suspect your child has learning difficulties (they are often subtle) get an assessment of her learning style and needs. This may cost if you are not able to get it through the public system but well worth it as then her needs are documented. The school also requested an RTLB (Resource Teacher Learning Behaviour) who was amazing and called all teachers involved, Michael & I and the Hearing Special Ed person and explained to us all, Victoria's requirements. We quickly found out that Victoria had processing problems and when in classroom situations she was not able to grasp a lot of instructions at once. She was not a fast writer so when she was asked to write something from the board it was often incomplete, this coupled with the teacher talking became an impossibility to write and absorb the teachers instructions. Strategies put in place by RTLB for the teacher were:
  - a) Simple clear tasks were given.
  - b) Hand outs from the teacher as apposed to copying from the board.
  - c) Minimizing tasks to be completed – complete 6 out of 10 questions.
  - d) Organisational sheets were given to Victoria to assist with composing stories, organizing projects etc...
  - e) To sit at the front of the class where it was easier to see & hear the teacher and minimise distractions.
  - f) A special hearing device (edulink) with the teacher wearing a microphone and Victoria wore a special ear piece – this aided concentration as the teachers voice was clear.
  - g) Private tutor for maths who went right back to basics but in doing this her confidence grew and she was able to complete her school maths.
5. These processes together with teachers understanding that Victoria could complete work required made a huge difference to Victoria's self esteem and she tried so hard to get the best out of her classes. She was so diligent, and would often spend all night on her homework, I would often have to tell her not to do any more homework as she battled often to complete it all.
6. As these processes have been in place, and yes at the beginning of each year we make sure that the teachers (and there are many!) know to look on Victoria's file. She would often come and say she had been told off for not completing something and we would have to assess if the teacher had just cause or just needed reminding of her ability.

Victoria is with the support of the school, her teachers, classmates and family doing achievement standards NCEA this year (internal exams are sat at the end of each strand – this takes the huge pressures off big external exams) and has had a very good year and has surprised a couple of teachers. The school has also recognized Victoria not once but twice in her 5 years at this school with special awards for her perseverance and consistency across the curriculum.

This is our story – you don't get a second chance to do the right things and being a parent at the best of times is challenging, but hopefully by telling our story, it may just get you thinking or be able to pick up on something you can use to help your daughter.

**Remember – You are your child's best advocate!**

Karen, Michael & Victoria Pratt

## Supporting Social Skill Development

Dr. David Worling, R, Psych. Westcoast Child Development Group, Vancouver, BC. [dworling@childdevelopmentgroup.com](mailto:dworling@childdevelopmentgroup.com). (Excerpt adapted from Dr Worling's slide presentation with permission).

**"The single best childhood predictor of adult adaptation is not IQ, not school grades, and not classroom behaviour, but rather the adequacy with which the child gets along with other children"** (Hartup, 1992).

Getting along with others is termed social competence and involves the ongoing and appropriate use of empathy, humour, eye contact, language (volume and loudness, amount of talking), gestures, closeness (proximity) as well as the ability read social and novel situations and facial expressions for intent and a variety of perspectives.

For girls and families dealing with Turner Syndrome many of the ingredients of social competence need to be taught and reinforced over time. Dr. Worling's general recommendations for social skill development in building social competence for girls with Turner Syndrome include:

- 1) **Continued gentle 'forcing' of social contact with known peers.** This involves the need to push past the high degree of anxiety often associated with novel social situations for many girls with TS and requires the continued parental/school 'brokering' of social situations.
- 2) **Attaching meaning to emotion.** This involves having adults verbally express their intent or reaction to a given or occurring situation. Dr. Worling suggests that using a 1-10 system to more clearly articulate mood/feelings with facial and verbal cues. For example "when you did/said \*\*\*\* (describe the behaviour) when I was doing/saying \*\*\*\* I was at an 8 for anger/relief/happiness etc.

3) **Role-plays.** Provides your daughter the opportunity to practice in a safe environment judgement free. In role plays you can exaggerate poor choices and help her to process constructive feedback on addressing how she responded and could have responded to a given scenario.

4) **The use of Social Stories** to assist children to articulate and answer the who, what, where and why questions, thoughts or circumstances of their lives. Look to the [www.thegraycentre.org](http://www.thegraycentre.org) for more information.

5) **Supervised dyads and triads.** Allows for direct feedback/instruction on turn-taking, sharing, etc. Start with a successful dyad (your daughter plus one peer) then work up to a triad (your daughter plus two peers).

6) **Practice, practice, practice.** TS girls learn best by rote.

7) **Walk through social experiences before they take place.** Problem solve throughout your walk through. Provide alternative choices and teach your daughter how to anticipate and predict scenarios and responses.

8) **Use video interpretation.** While watching videos help your child to understand by (occasionally) pausing the tape/DVD to question or anticipate what is happening or going to happen. Pause/question/play, pause/anticipate/play.

9) **Use drama programs.** They are an excellent way to enhance emotional expressions and they provide a script for acting and reacting where the meaning is often overt and scripted. A fun activity for all!

This article has been printed with the permission of Dr. David Worling, R, Psych via Turner Syndrome Society of Canada. We thank them for their support.

# RAFFLE!

## Fundraiser for Girls Camp 2009

**This has been a great success!**

Raffle tickets have been distributed and all \$ raised go towards the camp costs for the families who have sold them.

Thank you to all those wonderful people and grandmas who sold tickets to assist those going to camp.

**Please ensure all tickets and money (as a cheque) are sent to:**

Vicki Maaka, 5 George Deane Place, Greenhithe, Auckland, By 1st November 2008.

p: 09 413 6246 e: [info@turnersyndrome.co.nz](mailto:info@turnersyndrome.co.nz)

If you would prefer to deposit the money please credit:

TSSG(NZ) Inc account at National Bank – 060287-0519802-00 ensuring you state your name & raffle \$; also advise Vicki to ensure the funds are applied to your name on:

e: [Vicki.maaka@nbnz.co.nz](mailto:Vicki.maaka@nbnz.co.nz)

Drawn on 8 November 2008 – all winners will be contacted by phone and posted on the website.

## Mother and Daughter Evening

We had our first Mother and Daughter evening in August in Auckland. Thanks to the Malcolms who opened their home to us. We had a great night – lots of talking and getting to know one another, and reacquainting ourselves with out of Aucklanders! Vicky from Matamata made her grand entrance by driving on the grass in the pouring rain!! The rivets are there today! The Olympics were on - it was the night of the Ever-Swindle twins winning Gold (we thought it was silver but found out in the morning they had got the gold!) Also Valerie Vili took gold, so that added to the evening, watching from the sleeping bags on the floor!!! Some of us slept over! Here is the proof!

Lynette with Karisha and Vicky with Molly in their jarmies.

