



Chairchat March 2012

The year is racing by, the morning's are darker and the evenings are drawing in. Sally resigned as treasurer at the AGM. A big thank you to Sally, for all her hard work during last year.

Victoria Sullivan, from Christchurch came to our AGM to speak about a Grant/Sponsorship she has set up in honour of her mother, who died recently. She and Jessica are working on the criteria for eligibility. So watch this space.

Jessica has kindly offered to be Treasurer for the short term, so a plea to anyone who has accounting experience and would be prepared to take on this position permanently, please contact Lynn or myself through the website.

Enjoy the Easter holiday, drive carefully,

Best wishes Rae

Hi Everyone,

Can I endorse Rae's request; please if you have the experience or even the willingness to learn, consider coming on board with the committee as our Treasurer. Jessica accepted as an interim measure, but she is very busy (yes I know; aren't we all?) and I'm sure there is someone out there who can help. I enjoy being part of making things happen for the group, and it is a great way to get to know one another. I'm hoping to put the girls or women in Christchurch in touch with one another through Victoria and Catherine; if any of you from other parts of NZ want to try to get together and are willing to have me contact others with your names please email me at secretary@turnersyndrome.co.nz and I'll forward your emails on.

I want to put an events slot at the bottom of the newsletter so if you are scheduling a coffee bar lunch or a get together let me know and I'll include it. Someone from out of town could be visiting and might enjoy meeting you. I was blown away when Victoria flew up from Christchurch just to be at our meeting, because she wanted to tell us about her idea for an annual award in memory of her mother. Wow!

I put together the article on dental care at the end of the newsletter because I have seen very little on this and I feel it is quite important. I hope it helps.

Just a reminder that membership is due. I look forward to hearing from you, and I endorse Rae's wish that you may all have a safe and happy Easter.

Lynn (Secretary)

Catherine Coups from Christchurch submitted the following article.

Support for girls with Turner Syndrome and their families in the UK

In July last we returned to the UK for a holiday; an opportunity to visit our families and to escape the winter weather and ongoing shakes down here in Christchurch for a while. Our daughter Scarlett, who has just turned four, was diagnosed with Turner Syndrome (TS) at a year old. As a parent, as well as a member of the Youth and Camp Branch committee I was keen to find out what support was available in the UK for families and girls with TS.

While I was in the UK I was able to speak to Arlene Smyth, Executive Officer of the Turner Syndrome Support Society (TSSS), which is a registered charity in the UK. Arlene is extremely passionate about her role and was very happy to share her knowledge and insights with me. The TSSS website is extremely informative: www.tss.org.uk you can also find a link to it on the TSSGNZ website.

The young women and girls involved in the TSSS have a strong and proactive role; they run a drama workshop each year and put on a "show" for all the members and their families at the TSSS annual conference dinner. The TSSS runs open days around the country and local groups organise smaller events.

The TSSS has developed some excellent resources including information leaflets and factsheets, many of which can be downloaded for free from the TSSS website. The factsheets cover a wide range of issues and subjects from those impacting younger children to those facing older girls and young women. Arlene particularly recommended "How to survive and succeed at school" and "Who is the woman I am less than anyway". She also recommended their book Turner Syndrome Lifelong Guidance and Support. One of the resources you can download for free from the TSSS website is the Paediatric and Adult Health Checklist (for the Management of Turner Syndrome). This was developed in the UK by the TSSS, Ipsen and a Paediatric and Adult Endocrinologist. The Paediatric checklist is very thorough and I have taken this along to Scarlett's endocrine appointments to help prompt me what to ask about. The Adult checklist is on the other side and includes list for transition.

We have joined the TSSS, and as this membership includes the extended family, it means my parents in the UK also receive copies of the TSSS newsletters. I am keen to further develop links between our two support groups, so if anyone is keen to get in contact with younger members of the TSSS, for example their teenage reps, do let me know. If anyone wants information on resources available from the TSSS, I have copies of many of the resources including their book Turner Syndrome Lifelong Guidance and Support, so feel free to contact me on mcatherinecoups@xtra.co.nz. You can also contact our Youth and Camp branch directly for resources, support and information about Camp on youth@turnersyndrome.co.nz. and check out the Turner Syndrome NZ facebook page.

We are keen to know if there are other families in NZ who have a daughter of preschool or primary school age with TS, as it would be great for Scarlett to have contact with other girls of a similar age with TS. If anyone knows of a family/families that would be happy to be put in contact with us then please let me know.

Catherine Coups
Research and Development; South Island Branch
Youth and Camp Committee

Dental Care and Turner Syndrome

There are some issues around dental care that Turner women and girls should note. Fosamax – if you take this you need to tell your dentist as it can make your jaw bone brittle.

Your dentist should be advised that you have Turners, and you should tell him/her that this can affect your heart and you may need antibiotics if there is a risk of infection.

If you have a known heart condition this is even more important. Bleeding through teeth or gums indicates an open track by which bacteria can invade, leading to cardiac infection, which can be serious, even fatal. Dentists know about this and can take precautions if you advise them of your being at risk. Please do this.

The Turner's syndrome Society of the US Healthcare site advises:

Teeth:

- It is recommended that all girls with TS see a paediatric dental specialist by the age of 2 years old
- It is recommended that all girls with TS visit an orthodontist no later than 7 years old
- Girls treated with growth hormone should receive periodic orthodontic follow-up.
- Specific recommendations are available in the Clinical Practice Guideline for TS.

Girls with TS may have the following issues with their teeth:

- Crowded teeth because of their small and receding lower jaw and narrow, high-arched palate
- Shallow root; placing them at risk for root resorption ("dissolving" roots)
- Early eruption of secondary teeth
- Thinner enamel
- Less dentine

Some of these issues obviously carry over into adulthood.

If your dental carer, dentist, nurse or hygienist isn't aware of this, be an educator.

They can't be expected to have come across it before, and they can't give appropriate treatment without full information.

Upcoming Events

Date	Event
1 April 2012	Youth/ Camp meeting in Tauranga. All welcome
10 June 2012	Family 'Bake Off' at Matamata College
12 August 2012	Youth/ Camp meeting in Taupo. All welcome
23-25 November 2012	8th International Turner Syndrome Conference Rihga Royal NBC, Nakanoshima Center Building, Osaka, Japan Further details on http://www.turnersyndrome.org/international_friends.htm
14-18 January 2013	Youth Camp - Long Bay, Auckland The planning for Camp 2013 is well underway and we hope you will be able to join us! Register your interest Youth Camp 2013

Check out our [FaceBook page](#) to keep in touch with long lost friends!

Don't forget to add our website to your favourites so you can check up what is happening and see if any new personal stories have been added – Or you might like to send in your story info@turnersyndrome.co.nz and our website is www.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
Turner Syndrome Support Group (NZ) Inc.
PO Box 4285, Hamilton East 3247
If you no longer wish to hear from us please email us to unsubscribe.