



It's Autumn already- how did that happen!??

Wow! It feels like only yesterday that I sent out the the last newsletter but it was 3 months ago! The camp committee has been working hard behind the scenes to arrange camp 2014 (with some exciting progress and major changes I might add!) There have also been discussions with the executive branch of TSSGNZ (formally referred to as the main or ladies branch) regarding the constitution of our group.

A few years ago the Turner Support Group decided to create a branch specifically responsible for liaising with and giving information to families of girls with TS and ultimately responsible for organising a youth camp. That is us! In previous newsletters we have been referring to the TS group as consisting of a main/ ladies branch and a youth/ camp branch. It is time to correct this as for those new to the group and even some of us that have been around for a while, it can be a bit confusing...



Heck, yes, I'm
SHORT.

God only lets things
grow until they're
PERFECT.

Some of us didn't take
as long as others.

TSSGNZ is made up of the executive committee and our youth/camp branch. Any information that the executive committee have to share is included in this newsletter throughout the year. The executive committee are organising the seminar day in Wellington in September and organise social events with other TS women.

Our youth/ camp committee is a branch of this executive committee but we have our own purpose and manage our own memberships and correspondence with those of you that have shared your details with us. We concentrate on organising camp 2014, keeping the website information updated with relevant information for families, connecting families, setting up a TS library, ensuring our brochures are in all paediatric hospitals etc etc.

The executive and the youth branch work together as a group to support one another for the greater good of girls and women with TS in New Zealand along with their families. We need your support and we hope you enjoy being a part of this journey with us!

P.S All contact for the youth branch is via youth@turnersyndrome.co.nz. Get n touch if you would like to join the committee.

Cheers Vicky X

Welcome to our new members...

We are delighted to welcome the following girls along with their families into our group...

Grace Stephenson, Auckland aged 3yrs
Georgia Jones, Taranaki aged 10yrs
And **Clare Fuller**, Wellington aged 12 yrs

It is also fantastic to have **Tori Neho**, Auckland, aged 15 yrs and her Mum Christine who have recently reconnected with the group

We hope you all get the chance to meet other girls and their families in the near future.



TSSGNZ Seminar day – September 2013

When: September 28, 2013

Where: Amora Hotel, Wellington
<http://www.wellington.amorahotels.com/>

Cost: \$50 per person (an extra \$10 per person may be required on the day if funding is not received). This includes morning and afternoon tea. Lunch can be purchased for \$34 at Amora hotel on the day or feel free to go out.



This day will be about getting together and finding out about/ discussing some of the medical and life issues around Turner Syndrome. It will also be about having a great time together. The seminar day is for Turner girls, women and family members

Contact Jessica Rogan info@turnersyndome.co.nz to register.

Please pay registration fees into the following account using the names of people attending as your references/ code/ particulars...

Please email Jess once you have deposited your fee so that she knows who has paid what.

Jenny's trip to Sydney - TS Australia Conference

Recently Jenny Merwyn attended the National Conference of the Turner Syndrome Association of Australia. She will be updating us in future newsletters but this is a little bit of what she has to say about what she learned... *" We need to stress to families the importance of knowing about the health differences of our girls and that they know how important it is in early adult hood to get the regular check ups. What I found most interesting was that Girls with TS even process sugar differently and the insulin levels spike differently. They are very prone to diabetes and should try to avoid too much sugar (as we all should). Dr whats his face was brilliant! It was nice to make Aussie connections and see how they operate. They are becoming a national group instead of different states"* It will be nice to hear more from her in the future!

Also...just a wee reminder to check out the resources and info available on our website, in particular our Useful books and resources page: <http://www.turnersyndrome.co.nz/books-and-resources.aspx> which includes a link to a really useful book: Turner Syndrome Know your body, which you can download for free. There is a lot of good information in this resource.

Upcoming Youth/ Camp Meetings

Please feel free to join us on the following meeting dates:

June 9- Taupo
September 8- Tauranga
November 17- Matamata

CAN YOU HELP US?

We still need someone to be in charge of fundraising. We have been incredibly lucky with our funding over the last few years but this will only continue if someone is prepared to help with the big applications. We try to apply to larger groups for larger amounts but we are open to any suggestions. Please email me at youth@turnersyndrome.co.nz if you can help us or if you would like to come to the meeting!

Have you seen our brochures?

Recently, our super star south island rep Catherine Coups sent TS brochures to all hospitals that have Paediatric services. Next time you go for a hospital visit could you please check they have put them somewhere accessible and visible. If there are none, can you ask them if they did receive any and let us know if they did not so we can send them some!

Let's celebrate one of our special members...

All our love to the Lythe family XXX

As a group we want to pass on all our love and best wishes to the Lythe family. Mardie (Ella's Mum) was involved in an accident earlier in the year and since then she has remained in hospital recovering. We have heard she is making good progress and we hope she continues to grow stronger and is able to be home with the family very soon. I hope Mardie is reading this and can feel all the warm fuzzies we are sending her way XXX



Proudly sponsored by 

New Venue for Camp 2014: El Rancho, Wellington



El Rancho is located in Waikanae New Zealand. This beautiful 70 acre camp facility is located along the Waikanae River, close to the beach and just 60 kms north of Wellington.

We are very excited to be having camp as at a new venue with new activities and new places to explore!!

Feel free to have a look at their website...

www.elrancho.co.nz

We will call for registrations of interest later in the year (Sept) and this will require a \$50 deposit to secure your daughters place on camp. Please keep that in mind and plan for this.

We will keep you informed so watch this space!!



Membership Fees – thank you!

Thank you to everyone that has paid your 2013 membership fees. If you have not managed to pay your membership fee yet or you have simply forgotten, please do so this as soon as possible by paying the \$20 into the following account...

06-0294-0178313-00

(using your **daughter's name** and **2012memb** as references)

This fee will continue to support the administrative tasks that go on behind the scenes and contributes to maintaining the website and making sure our meetings happen. We are also always looking to extend our library and the resources available to our members.

We are still looking for any donations that can help us to support our girls, please get in touch if you or someone you know might be able to help! Every cent is appreciated and welcomed!

Check out our [FaceBook page](#) to keep in touch with 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 youth@turnersyndrome.co.nz and our website is www.turnersyndrome.co.nz

If you no longer wish to hear from us please email youth@turnersyndrome.co.nz to unsubsubscribe.

Proudly sponsored by 

