



Friends, opportunities and counting our blessings!

Hi everyone,

WOW, can you believe that it is August already!!!

The seminar day in Wellington is racing toward us, we have a date booked for our end of year function at Hamilton Zoo and registrations for camp 2014 are now open! It's all go for the committee and we are all super excited about seeing old friends and meeting new ones at all these events. One of the aims of this newsletter is to communicate social events to support you and your girls to be able to meet each other. There is a lot of important information about upcoming events so please read it carefully and share news and events you have organised in your regions. Please forward us photos and details if you have managed it!!

Life has continued to be busy for our family in Matamata. Adjusting to a new job and the daily trip to and from Hamilton has had a few challenges but in general the family has coped well. Sometimes I think that being involved in this group is just too much, especially when life is so busy. In saying that, every now and again something happens to remind me why I am involved.

I am a member of a facebook page called Turner Syndrome (parents). I don't spend a lot of time on the page but I am able to see daily posts from parents all over the world sharing news, photos and stories about their gorgeous girls. Recently there have been posts from two pregnant Mum's who shared with the group that their unborn babies had been diagnosed with TS. They asked a lot of questions and were offered a great deal of support from parents all over the world. Sadly these two Mum's lost their beautiful babies. It was devastating and sad to hear this news. What it did do was remind me once again just how lucky we are to have our girls in our lives and just how special they all are. With that note of thanks I will end my little blurb and share my hope that you are all happy and healthy as winter comes to a close. Take care of yourselves and keep in touch!!!

Cheers Vicky X

Welcome to our new members...



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

Olivia McGavin (6 yrs) and her parents Mark and Saana from Lower Hutt

Courtney Wright from Palmerston North

Final reminder of TSSGNZ Seminar day

The Executive Committee have put in a lot of work to ensure the smooth running of this special day. If you haven't registered then please do so asap.

The youth committee will be travelling from Matamata, Tauranga, Taupo and Christchurch to attend and we are looking forward to meeting as many families as possible.

When: September 28, 2013

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

Cost: \$50 per person

This includes morning and afternoon tea. Lunch can be purchased for \$34 at Amora hotel on the day or feel free to go out. Some of the committee are choosing to stay at the hotel for lunch and we would love you to join us. Let the organisers (Jess) know if you want to book for lunch.

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 an opportunity to meet each others. 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.

Camp Funding Challenges: Are you or someone you know part of our solution?

Because of changes to the Lotteries application system we are unfortunately unable to apply for funding from Lotteries for camp 2014. Lotteries have given us many thousands of dollars over the years and this is a big loss. Jacqui is working hard on applications to other funding providers on a national level but we would appreciate you all looking out for opportunities with businesses, corporations or individuals in your area that might be interested in supporting our girls on camp. As we are a national organisation with girls travelling from a range of places then it would be great if we could secure funding from throughout the country. Let Jacqui know by emailing her on iws@orcon.net.nz



Proudly sponsored by 

**Registrations required for Camp 2014:
El Rancho, Wellington
9-13 July 2014**



Attached to this newsletter is a registration form for girls who want to join us at Camp 2014 in Wellington. The camp fee for 2014 is \$400 per girl. We appreciate that this is an increase from previous years but due to funding limitations (see above) and general cost increases we need to increase our fee this year. We strongly recommend that you start applying to your local organisations i.e Lions, Rotary, youth groups to secure funding for your child, especially if you have flights to pay for as well. Obviously, we are still hoping for funding to assist with travel and costs but as always we will have to wait and see.

To continue with our planning we need a commitment in the form of a non-refundable \$50 deposit to be made (via cheque or bank deposit) along with the return of this form via email or posted to 133 Firth Street, Matamata, 3400 by 30th September. A place on camp will not be secured until this has been paid and only those registered will receive camp newsletters. The reality is that we just don't have time to chase this up so we need your commitment.

To try and make it easier on families we have decided to implement a graduated payment system for this camp. We are asking for the following payments by the following dates. Hopefully this will reduce the pressure by dividing the payments over the next 10 months.

Initial non-refundable Deposit of \$50 by Sept 30 2013
Instalment 2 of \$100 to be paid by November 30
Instalment 3 of \$100 to be paid by 30 February
Instalment 4 of \$100 to be paid by 30 April
Last instalment of \$50 by 14 June

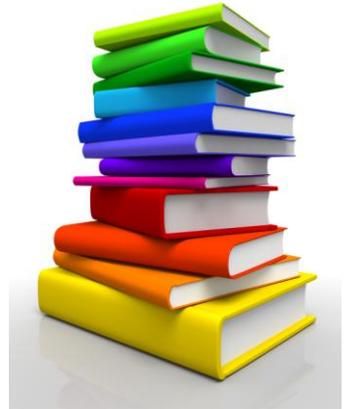
Of course you can pay larger amounts at anytime if that is what you want to do. If you want to set up a regular automatic payment then get in touch with Jacqui iws@orcon.net.nz If there are any problems with getting payments made then also let us know. We want this to be as easy as it can be for you all and we want ALL our girls to be able to attend our first ever Winter camp in Wellington!!

Feel free to have a look at the camp website... www.elrancho.co.nz

Do you know a Nurse that might be interested in coming to camp with us as our medical support person? Let Vicky know if you do.

TS Library

As a branch we recognise that whilst it is helpful for us all to have access to written information on Turner Syndrome it can be expensive to buy books or know which are good resources? We have put together a small library of resources that we have found useful, and which are free to loan for up to one month for those who are up to date with their membership payments. The following books and resources are available now, and we are in the process of ordering and sourcing new material to add to these. If you have any suggestions of items for us to purchase then please let us know.



If you would like to loan any of these please contact Catherine on catherinecoups@xtra.co.nz

Books available to loan are...

Coley's Story living with Turner Syndrome
Turner Syndrome Lifelong Guidance and Support
DVD: A New Journey: Turner Syndrome
Turners Know your Body
Heart Children

Parent to Parent Sibling Camps



Parent to Parent's SibSupport programme is holding two SibCamps before the end of the year – these are for siblings aged 8 – 18 that have a brother or sister with a disability or health impairment.

1 – 3 November @ Camp Columbia, Gore
http://www.parent2parent.org.nz/ai1ec_event/sibcamp-southland/

8 – 10 November @ Venue TBA, Bay of Plenty.

In early 2014 camps will be held in Auckland and Wellington.

There are no costs for these events. For more info visit www.parent2parent.org.nz email sibsupport@parent2parent.org.nz or phone 0508 236 236.

Child Disability Allowance

New members may not be aware that due to the ongoing issues of girls with Turner Syndrome, they qualify for a disability allowance. Discuss this with your health specialist as they will need to complete the paperwork required.

TS International Conference- Mexico July 2016

The Turner Syndrome International Group is proud to announce the next Turner Syndrome International Conference will be held in Mexico in July 2016. The date and venue are still to be confirmed. All information will be available on the new International Group website which will be live by the 1st of September 2013. Details will be e-mailed to all know International contacts. If you have any questions please contact Arlene Smyth @ turner.syndrome@tss.org.uk. If you are aware of other groups or individuals that might be interested please forward this e-mail to them.



Regional Get Togethers – are you keen?



I thought you might like to know how our group was spread around the country. I was hoping that it might inspire you to organise some regional events. I am happy to send information to families if you are keen to set up something in your area! Let me know at youth@turnersyndrome.co.nz

Wellington 5 families
BOP and Waikato- 9 families
Auckland and Northland -13 families
Nelson/ Tasman- 2 families
Manawatu- 3 families
Taranaki-3 families
Wairarapa, Hawkes Bay, Otago- on their own at this stage



Report: Sydney - TS Australia Conference
From Jenny Merwyn
(chairperson of youth branch)

I was excited to be able to attend the Australian Turner Syndrome Conference earlier this year. One of the things that it made me aware of was the need for parents to stay informed and connected with what other countries are doing. We are such a small country in comparison and I feel that we don't get as much information about TS upon diagnosis.

One thing that struck me was that Oestrogen is good for muscle development. Girls that have a normal hormonal pattern begin to develop this at about 8 or 9 years old. They also start to produce low levels of testosterone which would give them energy and drive. I have noticed from my own daughter and being on camp with many of the girls over the past few years that lethargy is a big issue. In Denmark they are doing research on the effect of giving women with TS testosterone to see if it helps with this issue. I was also interested to hear that recent studies in Denmark have shown that when a girl with TS is given a glucose tolerance test, their insulin spike remains higher longer than the average girl; which could add to the lethargy and problems with weight. Dr Claus Gravholt said "do you want to work hard now to stay healthy or do you want the hard work when you have diabetes" (something to that effect). As parents we need to be more aware of the very real risk of Diabetes for our girls which is then a life changing hassle of food changes and exercise changes.... so why not start now and help our girls make healthy choices!

I was also pleased to hear that for those of our girls who will not have normal fertility patterns, there is now the option to combine Oestrogen and Progesterone in a medicine called "Oestradiol Valerate". This means they will not have to have a period. This is what many of the Australian girls are choosing as the difference is that on the pill they have a whole week without Oestrogen and noone wants unnecessary hormonal imbalance!!!! Why have PMT if you don't have to! These are of course my own views on the matter and you need to discuss further with your endocrinologist.

If you have the opportunity to go to any of the conferences on TS make the time to go. The more of us that have information means the more we can pass on to families that are recently diagnosed. We have now known for 6 years and a lot of what I heard at the conference was new for me!

This is why camp is so important for our girls. When they see and know they are not alone in this journey they are more able to cope. Aleisha has made amazing friends over the years who understand where she is coming from. We have been unsuccessful in securing our major sponsor for our next camp so please start fundraising. You will be glad you did.



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

Hannah Gerrard- superstar!

Hi everyone!

My name is Hannah Gerrard, I'm 17 years old and am lucky enough to live in the beautiful town of Wanaka.

School for me has had its fair share of ups and downs. Year 8 and 9 were difficult times, as they are for a lot of people. I struggled with friends and low self confidence. However, by Year 10, I found a great group of friends. In terms of results, I have achieved both NCEA Levels 1 and 2 with Merit. I'm two-thirds of the way through my last year at school and feeling nervous and optimistic for and am hoping for the same at Level 3.



At the end of Year 9, I joined St John Youth and with that has come many amazing opportunities and many new friends from all around New Zealand. A particular highlight was being chosen as the District Cadet of the Year for Central Otago in 2012-2013.

Another opportunity I took up that is offered at many schools is the Duke of Edinburgh Award. I have completed my Bronze and Silver Awards and will achieve my Gold on a three week long expedition to Vietnam in December, which I'm very excited about!



Next year, I plan to study in Dunedin, working towards a Bachelor of Arts majoring in either Media Studies or Communication Studies and minoring in Teaching English to Speakers of Other Languages. Living away from home for the first time is a nerve wracking prospect, but I'm looking forward to meeting lots of new people and living in a city for the first time! If anyone ever wants to get in touch, I'm happy to talk to you and offer advice. 😊

Events coming up...

Sunday September 15 [Youth/Camp Branch Meeting](#)

11am 5 Harkin Close, Bethlehem, Tauranga

Saturday September 28- TS Seminar Day, Wellington

Sunday November 17 [Youth/Camp Branch Meeting](#) in Matamata

Saturday November 23 - end of year function at Hamilton Zoo

All members of TSSGNZ are welcome.

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 **2013memb** 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.