



Spring is here and a few changes too!



It's hard to believe that October is already here and that before we know it Christmas and Summer will be upon us!

As a group, our goal is to share information about Turner Syndrome and to support families in any way we can. One way of doing this and something that has been our main focus in recent years has been to provide and support girls to join us at our annual camp. We are excited to bring you some planned future changes for camp in this newsletter and we want to encourage your input and support with these changes.

This year we are also trying to get more information out into the community. We have been lucky to have financial support from Pfizer to reprint our brochures and we are aiming to get them distributed around New Zealand to hospitals and support agencies. If you know of anywhere that would benefit from receiving brochures then please email us at youth@turnersyndrome.co.nz and we will do our best.

This newsletter is also designed to continue to bring you information on events and activities while also celebrating the success and special attributes of our girls. This is YOUR newsletter and we want it to reflect ourselves as a group and all the wonderful things that make our girls unique and fabulous!

As a committee we have been working hard at getting information about Turner Syndrome out into the community, trying to extend our membership throughout the country and trying to reach girls of all ages with TS. I know that this newsletter will reach some families that have only just made contact with us. To you we say a huge welcome and we hope to be able to meet you at some stage. As a National organization reaching all our members is a challenge but one that we hope you will help us to achieve by organizing events and 'catch ups' in your local areas and letting us know. By working together this group can continue to grow and flourish!

Cheers Vicky X





Some changes... TS Camp: 2014 and Beyond

One of the most important things we do as the youth committee is to organise camp. Like most things, our wonderful and worthwhile TS youth camp needs to change to suit the needs of the people who organise and attend it. Following our camp in January 2013, the committee have decided that our camp will then be held every 18 months. This will mean that our next camp will be held in the July school holidays, 2014.

At this stage Auckland will remain as our base for our summer camp as the venue and facilities there are hard to beat, it is an easy location to get to and it works very well for our girls.



The decision was made to change the timing of the camp for a number of different reasons. The committee found that by having the camp every January it was putting financial and time restraints on families at the same time every year and that by changing its frequency we would be able to offer greater variation while hoping to reduce that pressure. This is exciting for a number of reasons...

1. It opens us up to beginning our first winter TS camps. This will also mean that different locations in different parts of the country may also be considered to host our winter camp- how exciting!!
2. This will mean that we have an extra 6 months to apply for grants and sponsorship which will hopefully take the pressure off having to apply to the same places at the same time every year and the tight time schedule we always face.
3. This will mean that families will not have that tough decision to compromise their own family holidays in January every year if they want their daughter to attend every camp. We all know that this can be an expensive and precious time for families
4. There will be an opportunity for different parents to get involved in organising camp. Once camp 2013 is completed then we will be asking for anyone interested in helping to set up our first winter camp to join our committee. As in previous camps, only those people involved in the organisation and planning of camp will be available to attend. This will mean that they will need to attend meetings (we have used skype to do this in previous years) and be actively involved in the committee. We will welcome any new faces to our committee!

Please note that the places of adults on camp have been traditionally limited to just three each year because we have such wonderful 'young adult' leaders who do such a great job to assist. This is also a great way for our older girls to remain involved while extending their leadership skills. Obviously this will change according to the activities we do and the numbers attending each year.

Grandparents/ Extended family and whanau: Do they also want to be kept in the loop?

Your \$20 annual membership to our group is a family membership. If you have a Grandparent, Aunty, Uncle or anyone else in your family that is particularly interested in our group and who would like to receive our newsletter then please email us at youth@turnersyndrome.co.nz so that we can add them to our database.

Thank you: The For Everyone Charitable Foundation



We are delighted to share that we have heard back from the **For Everyone Charitable Foundation** (www.foreveryone.co.nz) who have agreed to award us \$1790.40 towards our 2013 youth camp. This will be used to fund our girls outdoor experiences at MERC (The Sir Peter Blake Marine Education and Recreation Centre) www.merc.org.nz

We are very lucky to have received such generous funding and we are very thankful for this support. We are hoping that our other applications will also be as successful.

Parent to Parent: Matua kit e Matua

Parent to Parent is a national organisation that provides support and individualised information to families with children with disabilities and health issues. Parent to Parent “*seeks to support, educate and empower families who have a child or family member with disabilities, health impairments or special needs*”.

Parent to Parent runs several development courses: *Personal Support, Support Parent Training and Navigating the System*. These courses are aimed at providing “*an environment where parents can discover an awareness of their personal journey, develop their communication skills, and review the resources available*” within the health and disability sector. All courses are free of charge to any parent who has a child with a disability, health impairment or special need and who is interested in learning more for themselves, to support others and to refresh their skills.

Parent to Parent have regional offices around the country, if you contact your local office they can add you to their circulation list so you can receive regular updates and e newsletters of events and courses happening in your area. Check out the Parent to Parent website: www.parent2parent.co.nz

Kasey Griffin: Tumbling through Turner's!

Hi, I'm Kasey, I live in Central Hawkes Bay. I am 15yrs old and I have classic TS. I have had two heart operations and a range of other medical stuff. I have just stopped taking growth hormone (after 7yrs). I am pretty stoked to be 5'3".

I love gymnastics and have been doing it since we moved down to Hawkes Bay when I was 6.

However I only restarted this year after quitting for couple of years. I rejoined after I came 1st in the local primary school gym competition. That kind of convinced me to join gym again. It works for me because my gym training is at the same school I now go to. Twice a week I help the younger kids after school till 5pm and then I do 2hrs gym practice myself.

I also did dancing for 5yrs and swimming when I was younger.

I have just moved up to level 4 in gym and came 1st in vault in my most recent competition. Earlier in the year I had the opportunity to go to the National Secondary schools Gym competition in Auckland, along with the rest of the team from Central Gym Club. We didn't win anything, but it was an amazing experience. At the Hawkes Bay Secondary School gym competition as a team we came 3rd.

Recently I had some tests on my heart. I had an MRI and then had to run on the treadmill. I did manage to do better than average on the treadmill, however I fainted afterwards (an embarrassing moment!). Now I just have to wait to see what the tests show, hopefully I will still be able to do gymnastics!



I
a



Best apparatus: Vault



Fav apparatus: Bar

Some exciting events coming up...

TSSGNZ Christmas/ End of Year Outing- Tauranga, 10 November

The ladies from the main branch of the TSSG have extended an invitation to our youth members to join them for a combined Christmas/ End of Year function.

When: from 2.00 pm 10 November 2012

Where: at the beach opposite the corner of Tay St and Marine Parade for a picnic. If it is wet, the plan will be to change venues to the Baywave Aquatic Centre, Girven Rd, Mount Maunganui.

Contact Jessica Rogan jessicarogan@gmail.com 021 048 4913 if you have any queries

TSSGNZ Seminar Day September 2013: Wellington, NZ

Plans are underway by the main/ ladies branch of the TSSG to plan for a seminar Day

When: Meeting Date: September 28, 2013

Where: Meeting venue: Wellington, to be announced.

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 their families if they are interested in more information.

TS Australia Conference April 2013: Sydney, Australia



Plans are underway for a conference to be held by the Turner Syndrome Association of Australia

When: early April, 2013

Where: The Menzies Hotel, Sydney

Please look at their website for information as it comes to hand

www.turnersyndrome.org.au

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Camp 2013: Important updates and reminders

We are delighted to announce that our leaders for camp 2013 are...



Hannah Gerrard

Hello all, my name is Hannah Gerrard, I'm 16 years old and from Wanaka. I have been on 4 camps in the past and have loved making new friends that will be friends for life. I am so excited to be coming as a leader in 2013 and hope to make many more new friends and lifelong memories.



Alyssa Jacobsen

Hi! I'm Alyssa and I've been on all the turners camps! I was about 12 or 13 on the first one? I'm now nearly 20 and I have been a leader for the last 3 camps. I enjoy it SO much and every year I get to meet wonderful girls who make my summer so much fun and it is always the highlight of my year. I cannot wait to return as a leader again and I'm so looking forward to seeing new faces and also spending time with the wonderful ladies I already know! The friendships made on this camp last a lifetime and heck bring on camp 2013!!! :D



Belinda Duxfield

Hi my name is Belinda and I have been coming to turners camp for 3 years now and I love it. I love seeing the girls and meeting new girls that come every year. my best memories of turners camps was reaching the top of the rock climbing wall for the first time and going to Auckland zoo but there are so many more great memories and it would take up to much room lol.

(Can't wait to see you all next year :)

Brenwyn McDougall will also be a leader (I haven't got a pic yet)



Paula Harris (will be joining us an extra adult support)

Hi my name is Paula Harris. I will be 21 at Turners Camp 2013. I have been going to camp annually since 2009, being one of the older or the oldest there. This has meant that I have had the opportunity to plan these amazing camps which takes a lot of planning time and energy. I want to welcome all the new girls who will be joining us for the first time in 2013, as well as welcoming back our returning girls. Get ready for an amazing week of fun, laughter and making new friends you will keep for the rest of your life.



Please note that the \$350 for each of the girls going to camp will need to be paid in full by October 31.

Remember to forward me your flight details...

Because we have to pick up a number of girls from the airport can you please endeavor to book flights that arrive between 12 and 2pm on the Monday and leave between 4 and 6pm on Friday from Auckland Airport. This will hopefully allow us to minimize time lurking around the airport!!

Medical Forms and gear lists...

will be posted following our next camp meeting on November 11. These will need to be returned asap. We cannot take your daughter to camp without full payment and receipt of ALL the paperwork.

Upcoming Events

- **Saturday 10 November 2012-** Family Christmas/ End of year Event, 2pm
- **Sunday 11 November 2012-** Camp Committee meeting in Tauranga 10.30 am
- **November 23-25 2012** International Turner Syndrome Conference: Osaka – Japan
- **April 2013-** TS Australia Conference: Sydney, Australia
- **September 28 2013-** TSSGNZ Seminar Day, Wellington

For more information on any of these events or if you are holding an event/ catch-up in your part of New Zealand please contact us at youth@turnersyndrome.co.nz.

We love receiving information, personal stories and photos from all our members and we would love to advertise upcoming events on the website and in the newsletter.

Membership Fees – thank you!

Thank you to everyone that has paid your 2012 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!

Many Thanks
Vicky Burgess-Munro
(Mum of Molly, 10yrs)

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 info@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.