



## Hello Again!!!

Man it's cold! I don't know about you but I really struggle with wintery weather. I think I should actually be a bear. The idea of hibernating is very appealing to me at the moment!

As we start to get to the event planning stages of camp 2013 I feel lucky to have the summer to look forward to! The idea of sun and sand and fun is an awesome prospect!

I hope that you are all surviving ok and remember that we would love to hear from you. If you are doing anything exciting then please email me with details so we can share it with the group. We love to celebrate our awesome TS girls!!!

## Welcome to our new families XXX

I would like to extend a warm welcome to our most recent members and their families ...

- Shainia Ellingham lives in Tauranga and is 14 years old.
- Chantelle Drummond also lives in Tauranga and is 11 years old.
- Thalia Sunderland has rejoined us and lives in Dunedin. She is 12 years old.
- Brianna Thurgood lives in Kaiwaka and is 12 years old.

All girls will be joining us on camp next year and we are looking forward to meeting you all in person very soon!

## New Treasurer



Jacqui Ellingham (Mother of Shainia and a very new member!) has kindly volunteered to step into the crucial role of Treasurer in our committee. We are so grateful that she has agreed to take on this very important job. She is awesome!!!

If any of you would like to join our committee then please contact us at [youth@turnersyndrome.co.nz](mailto:youth@turnersyndrome.co.nz)

## 2012 Family Bake-Off

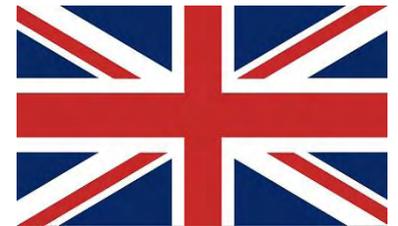
Unfortunately our Bake-Off did not go ahead this year. We had a small number of teams registered and then a last minute hospital admission made it impossible to proceed as planned. If any families in the upper North Island would like us to try and re-schedule another Bake-Off later in the year then please email me to tell me. It really is fun and it was such a shame that we missed the opportunity to meet some of our new members. It's also good to get your "game face" on now and again and get a bit competitive!!! No matter what, we will definitely try again next year!!!



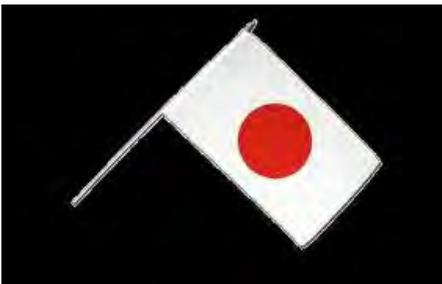
## International Turner Syndrome Conferences

### *UK, October 12-14, 2012*

The TSSS 13<sup>th</sup> Annual Conference will take place at Park Hall Hotel, Park Hall Road, Lancashire. The theme for this year's conference is Health and Wellbeing. A child programme will also be running alongside the conference programme. If you are interested or would like a copy of the draft programme it will be available in early September from [www.tsss.org.uk](http://www.tsss.org.uk). Feel free to get in touch!



### *Japan, November 23-25, 2012*



This November the 8<sup>th</sup> International Turner Syndrome Conference is happening in Osaka, Japan. This conference will have many lectures giving information about issues relating to TS. These conferences are also a great opportunity to meet other people with interest in Turner Syndrome from both a personal or professional perspective. If you are interested on learning more about the Conference follow this link to <http://www.turner-japan2012.org/>

## Thank you Pfizer!

Many of our girls are using growth hormone that has been produced by the drug company Pfizer and this year we are delighted to announce that they have generously sponsored us \$3000.

We will be using this money to purchase supplies associated with producing and distributing our newsletter and our 'new member packs' that need a face lift! We will also be using this



Proudly sponsored by 

money to reprint our brochures that include information about Turner Syndrome and our contact details. We would like to thank Yiannos Yiannakis at Pfizer for guiding us through the process and supporting our application. You are a star!!!

## Look Out America: Here We Come!

For many years we have had a wonderful relationship with Koru Care New Zealand. Many of our girls have been lucky enough to go on Xmas Cruises in Auckland, trips to the Gold Coast in Australia and trips to Disneyland in America!!!! This year's trip is to Disneyland and two of our girls will be going along to enjoy the fun! Here are some of their thoughts...



*"It all started with a letter in the mail. A letter that got my heart pumping. The letter that told me I was going to America. The letter that read "Congratulations, you have been selected by Koru Care New Zealand to go on the dream trip 'California Adventure'."*

*California Adventure is a group of 26 children and 15 caregivers that go on a 14 day trip to California. In California we visit Universal Studios, Knots Berry Farm, San Diego Zoo and the highlight of the trip... a 3 day pass to Disney land and Walt Disney's other theme park California Adventure.*

*The part of my trip I am looking forward to the most is meeting Minnie and Mickey Mouse. But we have to get there first. To contribute to my trip my Dad set up a fundraising page on [fundraiseonline.co.nz](http://fundraiseonline.co.nz) for me and we are selling fire wood. I can't wait to go ... as one of my friends was chosen as well so we will be going together!"*

By Shainia Ellingham, 14 yrs

*"Hi my name is Ella and I'm twelve years old and I have turner syndrome and I have applied to go to California in America with Koru Care in October.*

*We are staying in a hotel for two weeks and going to Disneyland and universal studios for most of the days and relaxing and get to met lots of other people and lots of new experiences.*

*in the way off fundraising my family and I are going to do some bake sales for a couple of weekends and do some jobs for family and friends.*

*I am really lucky to have this opportunity and really looking forward to it and can't wait until October."*



By Ella Lythe, 12 yrs

## New resources on our website

**A Teenager's Guide to Turner Syndrome** has been attached to the "Useful Books and Resources" section of the website. This was developed in the UK by the Turner Syndrome Support Society with input from their members (girls with Turner Syndrome and their families), and also with input from a pediatrician and community nurse. The TSSS (UK) have lots of resources available for free so check out their website: [www.tss.org.uk](http://www.tss.org.uk).

A **TSSSS Education Booklet** has also been attached. We hope that they will both be interesting and helpful.

The "Useful Books and Resources" page on our website has recently been updated to include links to some other resources you may find beneficial. Please take the time to have a look on our website or follow this link <http://www.turnersyndrome.co.nz/books-and-resources.aspx>

If you are aware of any other publications that you think might be good to add to this list then please get in touch.

## Camp 2013: January 14-18 Vaughan Park, Long Bay, Auckland



We are well underway in our planning for camp 2013. At our next meeting in August we will be confirming all aspects of the camp. Thank you to all the campers that have paid their \$50 deposits and we hope that your fundraising is going ok.



The remaining \$300 will need to be paid by October 31<sup>st</sup> 2012. As always we are optimistically hopeful that our funding applications will allow us to refund some or all of these costs but there are never guarantees so getting this money in on time is crucial for us. Please get in touch with us by email if you think this is going to be a problem.

For those of you that are flying into and out of Auckland there are a few things we need from you...

- 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!!
- Please email me at [youth@turnersyndrome.co.nz](mailto:youth@turnersyndrome.co.nz) as soon as possible with your flight details/ itineraries

Thanks for all your co-operation and support. Bring on January 2013!!!

## Disability Allowance



Are you aware that your daughter with Turner Syndrome could be entitled to a Child Disability Allowance through Work and Income New Zealand (WINZ)? This is not income tested and also entitles her to an individual Community Services Card that is not in any way linked to her parents income. Your pediatrician is the person to ask about this as they need to fill in paperwork to be submitted about her condition. You could also contact WINZ directly to find out what you need to do.

## Upcoming Events

- **Sunday August 12-** Committee meeting in Taupo-
- **October 12-14-** TSSS UK Conference
- **November 23-25** International Turner Syndrome Conference: Osaka -Japan

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](mailto: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 **daughters 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)

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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](mailto:info@turnersyndrome.co.nz) and our website is [www.turnersyndrome.co.nz](http://www.turnersyndrome.co.nz)



If you no longer wish to hear from us please email [youth@turnersyndrome.co.nz](mailto:youth@turnersyndrome.co.nz) to unsubsubscribe.