



A New Start



I have a new job. Yip, I am now working basically 40 hours a week and oh how my life has changed! I know many of you have done this forever but I have always worked part time. First as a swim teacher and then as a relief school teacher . It has been a long time since I have had something regular. 2013 seems to be a year of fresh starts. Our youth committee chairperson Jenny Merwyn has just launched her business 'Pampered' in Taupo at new premises and our education and South Island liason person Catherine Coups has also started a new job this year.

Because our group is small this is a good time to mention that we need help. The committee were forced to begin a new era last year in response to the resignation of our longstanding leader Karyn Pratt. We have learned a lot in the last year and we work well together as a small but motivated group. Later in this newsletter we will be talking about our next meeting and branch AGM. We would like to invite you to join us in planning our first ever winter camp at the new time of July 2014. Apologies for the late notice but I had intentions to get this newsletter out a week or so earlier!



We also need help in other areas. Fundraising applications, website maintenance, hospital links, newsletter editor, camp nurse, goodie bag collection, camp transport co-ordination etc etc are just some areas that need to be maintained if we want the group to continue to grow and prosper. There is much to discuss and much to plan so if you are keen to join us please let me know asap! . We can skype anyone that is joining us from other areas of NZRemember that we are all Parents just doing the best we can on top of everything else so every little bit helps!

Cheers Vicky X

Camp 2013- Another fantastic experience!

This is the first year that I had the privilege to attend camp for the whole week. WOW! What an amazing time it was too. Although I had always known the amount of work that goes into camp for the girls, being there showed me exactly how full on it really is AND how seriously cool our girls are. What a fun, happy, positive groups of girls we have raised.

This year only 3 out of 21 girls came from Auckland. The other girls came from... Wellington, Central Hawkes Bay, Northland- Kaiwaka, Taupo, Tauranga, Woodville, Wanaka, New Plymouth, Oamaru, Matamata, Nelson, Dunedin and 3 from Australia!!!!

The flights in and out were at times challenging but we were so thrilled to see so many girls coming from all over New Zealand! It was very cool to introduce the girls to yet another awesome Auckland attraction in Waiwera Hot Pools on our big day out.

MERC and the activities of sailing, abseiling and snorkelling as well as the favourite 'stack'em' were well received again and we had a neat speaker who came to talk to us about our personality types and how we work. Jenny ran another beauty night and the girls danced into the night looking and feeling gorgeous. This year the girls had a bit more time to relax and spend time together without as many planned activities which seemed to go down well. Camp 2013 was neat!

If you are interested in seeing more photos then please go to our face book page via the front page of our website www.turnersyndrome.co.nz

Jess's last camp



For 6 years our lovely Jessica Rogan has been a driving force behind fundraising, planning and developing our camp into what it has become . She has also been a motivator and role model to our girls. This year Jess sadly told us that this would be the last time she would be involved in planning and attending camp. We understand that this amazing woman has many responsibilities in other areas of her life and we totally respect her decision but she will be missed.

As a woman with Turner Syndrome she has been in the same shoes as many of our daughters. Her experience and success as a physiotherapist , athlete and all round successful person has shown our girls what they are capable of. Her kindness and ability to listen and relate has been so important and we hope she will still be able to join us as a guest speaker on future camps.

Jess has also been the person that submits our invaluable and successful funding applications to people like The Everyone Foundation and The Lotteries Commission. Without this funding our costs would be huge so we thank her very much for everything she has done. Jess will continue as part of TSSG but will be taking on a greater role as part of the main branch. She is a driving force behind the seminar day that is mentioned later in this newsletter.

Thanks again to our sponsors



Once again we wanted to thank our fantastic sponsors for their invaluable support for camp 2013...

- Pfizer- pink '10' bags and trucker caps
- Lotteries Commission- \$10,000 towards accommodation and catering, nationwide travel costs, volunteer costs, administration costs,
- The 'For Everyone Foundation'- \$ 1304.10 for MERC activities
- Countdown- \$120 voucher for extras
- New World Brookfield- drink bottles, yummy snacks, lip glosses,
- The Morris Family- mini shampoos and conditioners for everyone
- Karen and Belinda Duxfield- hand knitted slippers and hats
- The Lavendar Farm- mini lavender soaps and hand creams
- Johnson and Johnson- moisturisers
- Sanitarium- cereals and 'Up and Go's'
- QVS- nail files, nail clippers, makeup brushes

The girls had so much fun opening their goodie bags and we cannot thank everyone enough for their support. Feel free to keep an eye out for opportunities for camp 2014!

Reimbursement and camp finances



For the last few years we have been lucky enough to be able to offer those going to camp a reimbursement of all or part of their camp fee and transport costs. This has been amazing and the result of significant funding from lotteries, particularly over the last two years. This funding comes with restrictions and must be used for specified areas of our camp. Jacqui our treasurer has done a wonderful job balancing the books and we are incredibly lucky that in this current climate we have still been gifted such large amounts of money. The reality is that without this funding our costs of camp for each girl would have been more like \$600+ per person so the \$350 we asked for this year is VERY reasonable. As a committee we have decided that if we do get funding our priority will always be getting our girls to camp from all over the country. Camp fees can only be reimbursed once travel and all other immediate expenses have been accounted for. We will try and keep our costs down but I think that we all need to be realistic that future camps are probably going to start costing more. If you have opportunities for fundraising please take them throughout the year. Get others involved and share what you are doing with the rest of the group.

Planning for Camp 2014

At this stage we have locked in July 10-14 2014 as the dates for our first ever very exciting winter camp. We have taken into account school holiday dates and university breaks and we hope that this will allow the maximum number of girls to be able to attend. We also hope that by making pick up day a Sunday, it might make it easier for parents to juggle around work commitments.

When we ask the girls what the aim of camp is, it always comes back to **friendship, spending relaxed time together** and doing things together that are **challenging, fun and safe**.

Over the years as a result of camp evaluations and daily summaries we have evolved our camp and learned that there are some things that are very important to a successful camp for our girls. They are...

- That familiarity is important i.e the girls are more relaxed and comfortable when they know the routines and layout of where we are staying. It is important to have limited travelling between buildings and activities. This is important to avoid anxiety ESPECIALLY for our new girls.
- We need to be in a place where we can easily manage the diversity of the medical challenges that our girls have i.e we need to be within a reasonable distance from a medical centre and hospital. It also needs to be warm (especially because it will be winter)
- Communal sleeping arrangements are crucial to the interaction of the girls especially because of the age range and the different personalities of the girls that attend camp.
- Catered meals make the whole experience MUCH easier for everyone. We want to be spending our time with and for your girls, not worrying about domestic arrangements
- That costs are kept as low as possible!
- That we need to be near a main airport

If you are interested in helping on camp we would love it! We would also need you to join the committee to be part of the planning process. This way you get to learn why and how we do things. Please also remember that as a helper on camp you are a mother to ALL our girls for the week. We find that we actually see very little of our own daughters as we are so busy.

At this stage for the reasons above and because this will be our first winter camp, the adults that were on camp this year are leaning towards staying at Vaughn Park for at least one more camp. Vaughn Park offers an incredibly good accommodation rate that includes incredible food so the helpers can focus on all the other stuff. It is warm, well set up for everything we want, close to Auckland attractions and the staff really look after us. In saying that, we have had some suggestions of venues elsewhere in New Zealand which we are happy to consider.

Because the committee is made up of busy mums, if you would like to suggest another camp venue/location for July 2014 then please help us out by emailing me with the following information before March 8 (our meeting to make decisions is on March 10) to youth@turnersyndrome.co.nz. We need any proposed venue to take into consideration the things we discussed above about our groups unique needs. Please also forward me all costs including catering options, accommodation, websites, associated winter activities that would suit our girls and their related costs ie travel times and costs to get to them, cost of flights from the 3 main centres and possibly Rotorua, Nelson, New Plymouth etc. We will need all this information and anything else you want to add if we are to consider a new venue. Any suggestions will be welcomed and discussed at our next meeting.

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

Scarlett Kentell- My Heart Operation

My name is Scarlett, I am 5 years old, I live in Christchurch and I have just started school. I have Turner Syndrome; I was diagnosed just after my 1st birthday. I was tested for Turner Syndrome because I wasn't growing very well and I was short compared to all my friends the same age. I had lots of tests after I was diagnosed and one of the things they found was that I had a hole in my heart. The medical term for the type of hole I had is an Atrial Septal Defect. The hole didn't make me sick at all but it did give me a heart murmur which the doctors and nurses could hear when they listen to my heart with a stethoscope. The Cardiologists (Heart Doctors) kept an eye on me and last year they decided I would need to have an operation to close the hole before I started school.

I had my operation just before Christmas; on Wednesday 12th of December 2012 (the 12th of the 12th 12....my Mum and Dad thought this was a very lucky day to have my operation!). We had to fly up to Auckland as my operation had to be done at Starship Hospital. This was very exciting as I got to go on a plane and I love flying. It was also good because I used to live in Auckland and I while I was there a lot of my friends were able to come and see me once I was feeling up to it.



Recovering at Starship: 4 days after surgery

My Mum and Dad came with me and we stayed at the Ronald McDonald House near the hospital. Everyone at Ronald McDonald house was really friendly, and it was very nice, a bit like a hotel but with a kitchen area where we could make our breakfast, lunch and dinner. There was also a TV area, lots of toys and kids to play with (some of them were in hospital too), and an outdoor playground.

I went to Ward 23b on the day before my operation and had a blood test, an X-ray and an ECG. I don't like having ECG's but the Play Specialist helped me to understand what was happening and to be very brave. I made a doll in the playroom, and I snuggled up to her while I had the ECG, I named her Zoe. Zoe stayed with me while I was in hospital and I was able to bring her home afterwards.

On Wednesday the day of the operation I went to theatre in a bed on wheels, my Dad sat on the bed with me while we went down the lift. I was able to take my favourite toy from home (Baby Sarah) into theatre with me and my Mum stayed while I went to sleep. When I woke up I was in the Paediatric Intensive Care Unit. I was very sleepy but I wasn't sore after my operation s the nurses gave me lots of medicine to make sure it wasn't painful. My Mum stayed all night, and early in the morning my Dad came back to see me. The next morning, I was able to eat and drink and I was doing so well I was able to go back to the Ward. I went into the Intensive Observation Room so the nurses could keep a close eye on me, and I was very tired but I was able to sit up and eat and talk to my Mum and Dad, and I even had a few visitors.

On Friday I got up and sat in chair next to my bed and when the Physio came to me I also went for a little walk. Once I had been up for one walk I quickly got bored of being stuck in bed all day, so soon I was able to get up and go to the toilet and go for short walks around the ward with my Mum or Dad. That afternoon I moved to a room all of my own with a bed in it for my Mum or Dad to sleep in so they could stay with me at night. I stayed there for two more nights. I had lots of visitors on Saturday and my friend Harriet and her Mum and Dad came at dinner time and we had fish and chips and party hats and balloons to celebrate how quickly I was getting better. My doctor saw me exploring the ward with Harriet and he said I was doing so well that I could go home the next day!!!!

That was Sunday, my Mum's friend came and helped us carry all our stuff (I had been given lots of presents by all my friends that had visited) and my Dad borrowed a pushchair and we went back to Ronald McDonald House. The next day I went shopping with my Dad in Newmarket and he brought me a beautiful Princess Dress for being so brave while I was in hospital.



Flying home after surgery

We flew home on Tuesday, less than a week after my operation. I still have a scar on my chest but I don't mind it at all and my Mum puts Rosehip Oil on it every day so now it's gradually fading. I have to be careful and put lots of sunblock on it. It was quite boring after my operation as I wasn't allowed to climb, ride my bike or go on the tramp for six weeks, but after two weeks I was allowed to go swimming. So on Christmas Day I went for a swim in my friend Monty's pool, it was so exciting, and no one could believe it was only two weeks since I had had heart surgery!!

I am back to my normal old self now, and really enjoying being at school. My Mum Catherine is on the committee so if you or your family wanted to talk to her about what it's like having to go for heart surgery she's be really happy to talk to you. Vicky can put you in contact with her.

Love from Scarlett
Feb 201



Recovering at home!

TSSG Seminar Day

Please find attached to this email, a registration form and information regarding the TSSG seminar day to be held later in the year

When: September 28, 2013

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

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

Events coming up...

Sunday March 10 Youth/Camp Branch Meeting

Matamata College, Firth Street, Matamata

10.30-12.00 – Summary and discussion of camp 2013. Finalisation of accounts

12-1- Pot luck lunch (*new members welcome to join us at this stage*)

1.00-3.00- AGM. Important group discussions around policy/ branch organization. Start to plan camp 2014. *We will attempt to include anyone new by using skype from 1pm if you are elsewhere in the country.*

TS Australia Conference April 2013: Sydney, Australia



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

When: April 6-7 2013

Where: The Menzies Hotel, Sydney

Please look at their website for information and registration forms
www.turnersyndrome.org.au

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

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 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.