



turner connections

TSSGNZ Inc.

// JANUARY 2009

The 'Chair' in the Corner Chairpersons Report – January 2009

Happy New Year!!

We have started this year running! 17 gorgeous enthusiastic girls went on camp from the 12 – 16 January at Sir Peter Blakes' Marine Education Recreation Centre, Long Bay, Auckland. We all met at SkyCity for a bird's eye look at the city, then pizza at Mission Bay. All out of towners were billeted with Auckland families for the night then off to camp on Tuesday morning. Activities included kayaking, sailing, abseiling, archery etc... The weather was second to none and being on one of Auckland's top beaches, the girls were spoilt with the best of summer. A huge thank you to Jenny Merwyn and Michelle Williams for being the real camp mums and organizing fun activities for the girls in the evenings, Jess Rogan as team leader helping the girls to achieve the activities, and Lucy Vickers for coming to help in the evenings and getting to know the girls. Also to Vicki Maaka, Julie Van Dam and the Malcolms for their input and support in organising the camp. Your time and support was fabulous and very much appreciated.

Guess what? The girls have asked for another camp next year so we will have to see if we can make this an annual event?! Will keep you posted! The photos say it all! Check them out inside.

There has been no time for sitting in the corner, summer is here! We have picked strawberries and yes we just had enough left to make jam!! The beach and pool have been favourite places to chill out on.

The new brochures are being printed, the newsletter is reaching you all and plans for the planning meeting and AGM on 14 February are in full flight. We welcome new members and of course your input. If we want to be an active support group we need active members, together we can achieve great things. Look forward to seeing you there.

On reflection 2008 was a big year for the Turner group. We have achieved: • *rebranding of the brochures and newsletter* • *sourcing articles of interest for the newsletters* • *setting up Southern Support contact – Jacqui Sutherland* • *girls camp* • *maintaining Big Days out – the next one is 1 March – officially Children's Day so what better time to get together. (See back page for details).*

Our Turner group is a nonprofit group and we rely on our annual membership (Jan–Dec) of \$20 to assist with the basic communication and organizing events, it also assists in keeping in touch with others. We want to offer you more and your membership can assist us as a group. There is a membership form enclosed, we are offering a free DVD to those who pay their membership by 31 March - A New Journey: Turner Syndrome – a collection of stories reflecting true life experiences of living with TS, produced in Victoria, Australia by girls, women and their families with their own accounts of living with TS.

I have again included Calling all Turner Girls and Women – Rinki has been carrying out this research for a couple of years and only has 17 participants she would have liked 40 or so to be of benefit – she is ready to close it off but I said I would ask you all again to consider contacting Rinki for a simple blood test form – by taking part in her study you would be assisting Rinki in her research of Growth and Diabetes which are both issues Turner females face.

The People

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Next TSSG (NZ) Meeting

Saturday 14 February 2009

**Parent and Family Centre,
Spring St, Onehunga**

10.00am – 12.30pm Planning Meeting

12.30pm – 1.30pm Shared Lunch

1.30pm AGM Meeting

**All Welcome – we would like your
input, do you have any skills to offer?**

I have found a lot of new and interesting things just surfing the net and encourage you to go online to the other website addresses under links on the back page, and have a look around. Please let us know if you have any stories of interest or your own journey would be great.

Wishing you all the best for the year ahead – new school, friends, challenges, jobs etc... **By Karen Pratt**

Girls Camp 2009

What did the girls like best about camp?

Denise: I liked meeting new girls with Turner Syndrome and doing the different activities.

Fleur: Kayaking and making new friends.

Ella: I liked being part of a team and doing the activities and meeting everyone.

Victoria: Abseiling, meeting new girls, and talking to someone going through the same sort of thing.

Karisha: I liked the group stuff, talking to the others and the night where we sat around and "talked" about Turner Syndrome things.

Aleisha: I liked meeting other girls the same as me, the night we had our chat about TS and abseiling.

Ashleigh: Meeting other girls and abseiling.

Brenwyn: I liked making new friends, it's good to know there are others out there who are the same. It really helped to have the talk night.

Bryony: Everything, I liked talking to other Turner girls.

Simone: Just hanging out with the girls and being a real part of the team instead of feeling left out.

Liz: Activities.

Paula: Finding out about other girls with Turner Syndrome and the encouragement that I got from the other girls, I felt a part of it.

Claudia: The food, the lollies, having a swim tonight.

Alana: Abseiling, being with other girls with TS and having "jab parties".

Casey: Meeting other girls with TS.

Monique: Kayaking, abseiling and being with other TS girls.

Caitlin: I loved the kayaking and everything else about camp.



Disney 2008

Hello, my name is Karisha Malcolm and I was one of the lucky kids to have had the opportunity to go on Koru Cares Californian Adventure in October last year. Because it was Koru Cares 25th anniversary for taking children away on adventures, they took 50 kids instead of only 25. 25 caregivers also came along to look after us and made sure we were kept safe.

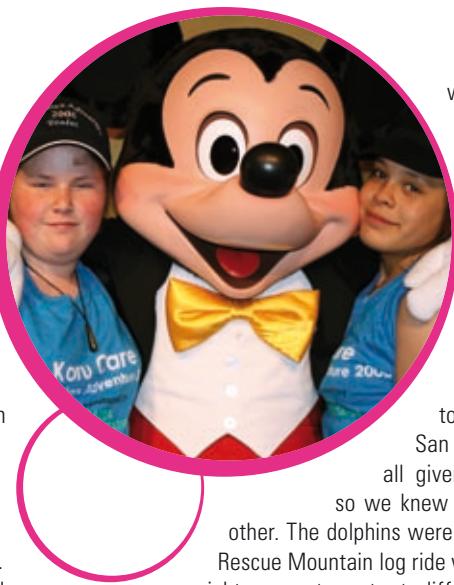
We all met at Auckland International Airport on Sunday 26th October where we had the first chance to meet each other. Everybody was excited and rearing to go. Ivana, my caregiver was there to meet me, along with Violet who Ivana was also looking after. My Mum and Dad were just as excited and they wished they were going along as well. Before we boarded the plane, we had heaps and heaps of yummy pizzas and drinks. We all said goodbye to our parents and boarded the plane for two weeks of fun and adventure. At 7:00 pm the 12 hour plane trip left Auckland for Los Angeles. The plane was cool, each seat had a TV screen on the back of the head rest that showed movies, music, TV shows and games. We were given dinner and then treats like chocolate bars, chips and cookies and then in the morning had bacon & eggs and hash browns for breakfast. Most of the people went to sleep on the plane but I managed to stay awake the whole time.

At LA the fun began. Two buses met us at the airport to take us to Radisson Hotel Resort at Beach Boulevard. After settling into our rooms most of us had a sleep for a few hours and then it was down to the pools. The hotel was five stories high with about 500 rooms. It was really flash and had a doorman to open and close the door every time we went in or out of the hotel. The pool was shaped like a jellybean and had two spas around it. There were hundreds of patio sunbathing chairs lined up all in a row around the pool. We played, swam, splashed and sunbathed until it was time

to go shopping. Oh it's so hard being a girl. The malls were huge and all on one floor. You had to walk for miles to get around all the shops. Its funny but I didn't see any food courts. The next day we were taken to the Highway Patrol in LA. The police took us out in their patrol cars and motor bikes. They showed us their guns and tasers. That night for dinner we ate out at Medieval Times, a restaurant set in an arena with knights dressed up in medieval gear on horses. It was really great entertainment while eating our dinner. The next day it was off to Universal Studios in Hollywood. It was also great and packed with rides and tours around the TV studios. We drove down the Desperate Housewives set as well as Fast and Furious, CSI Miami, House and heaps of others.

The Hollywood Walk of Fame was interesting because we saw all the stars handprints. We had dinner that night at Hard Rock Café; the children size meals were huge. They were as large as an adult size meal at home. The drink cups they gave us held a litre of fizzy and as soon as it was empty, they would refill it, even though you didn't want them to. It was like being in food heaven.

Disneyland was really big so we had three days to get around all the rides. The California Screamer, a roller coaster ride was cool, so was the Hollywood Tower of Terror. Some of the rides made me sick but I just kept going back. Ivana came on all the rides with me and together



we had a great time. All the characters like Mickey Mouse and Minnie Mouse and o t h e r s from Walt Disney were everywhere.

When we went

to Sea World in San Diego we were

all given yellow T-Shirts

so we knew how to find each other.

The dolphins were fantastic and the

Rescue Mountain log ride was so cool. Most

nights we ate out at different restaurants

and when we got sick of doing that we ordered Subway which was right beside our hotel. After the first week I started missing my family so I sent a postcard to each of my brothers and one to my mum and another to my dad who was away working. On the 31st October the Americans celebrated Halloween so we all decided to participate and dressed up in weird outfits. We all played tricks on our caregivers and had heaps of lollies. On the free days, I swam in the hotel pool or took a spa and went shopping. At San Diego Zoo they let us pat a lion, a panda and a zebra. This was the first time I had been so close to these animals so I was a little scared. On another free day some of us went to the Boulevard beach that has a really long pier with Ruby's restaurant at the end of it. For dinner that night we had a BBQ. The LA Coast Guards took us for rides in their boats and we sped around the bay. That was also a bit scary. That night we ate at a restaurant that had a pirates theme with pirates fighting around us. I lost count of the number of rides I went on at the theme parks and different restaurants we ate at. So many great things to see and do there wasn't enough time in the day. At night I was so tired.

Unfortunately our adventure was coming to an end, although I wanted to see my family again after two weeks of being away. I was sad to leave but also excited to be getting home.

The best part of going to LA was going on the mean rides at the different theme parks and I really, really loved the Dare To Ride It ride at Knott's Berry Farm. I also loved meeting all the different people and made so many new friends. Ivana, my caregiver was great and heaps of fun and took care of us well. I also noticed that the portions of food we received were huge and I couldn't eat it all. This made me think how much food must

get wasted in America. This trip made me aware of how lucky I was to go; all my friends at school were so envious. I had a great time and would one day like to do it again with my family.

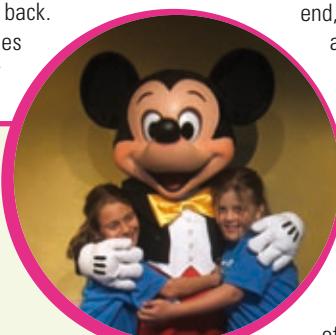


"My trip to Disneyland was amazing. It was a once in a lifetime experience. I enjoyed everything we did and had the time of my life. Thank you to all the helpers and the people who organised it. It was amazing."

- Bryony

"My trip in October to California was an amazing opportunity for me and Disneyland was awesome. My favourite place though was at California Adventure where I went on a ride called California Screaming this was the ride with a big loop, at first I was too scared to go on it and had to be convinced and then I loved it. I would like to thank Koru Care for taking me on this trip. I truly felt so lucky."

- Claudia



My Koru Care Californian Adventure Holiday

On Sunday 26th October 50 children aged 7-15 and 25 caregivers involved in the Koru Care Californian Adventure holiday farewelled their families and friends as they embarked on the journey of a lifetime. This year Koru Care doubled the number of children on the trip because this year is their 25th Anniversary.

After a 12 hour flight to Los Angeles, we were all very tired and jetlagged when we arrived on Sunday 26th October. On Monday 27th October we headed first to the California Highway Patrol Office in San Diego. We got to look around the office and sit on the motorbikes they use, we also got to have a look inside the cars and we met one of the patrol dogs. Then we went to Carlsbad Shopping Centre for some serious shopping. For dinner that night, we went to Medieval Times. When you enter the main building you are given a crown, the colour on your crown represents the knight you will be cheering for. You then enter an arena type area and you watch your knight battle it out against other knights while eating dinner with your hands!

The next day, Tuesday 28th October, our first stop was the Hollywood Walk of Fame. There were lots of souvenir stores to buy gifts from as you walked past all the stars on the pavement. Another interesting sight was the Kodak Theatre where the Oscars are held each year. Our next stop was Universal Studios. On a studio tour you got to see things like Wisteria Lane where Desperate Housewives is filmed and you also got to see the cars from The Fast and the Furious practising their special effects.

On Wednesday 29th October we enjoyed our first of three days at Disneyland. Today was all about experiencing as many rides as possible. My favourite rides were Space Mountain, Matterhorn and Big Thunder Mountain.

The next day Thursday 30th October we travelled south to San Diego again but this time to experience Sea World. Here, I was lucky enough to be in the Shamu show and touch a killer whale. I had my picture taken a few minutes before the show and the picture that was taken was displayed on a big screen in front of a large audience. This was definitely the highlight of my trip.

On Halloween, October 31st, we went to Knott's Berry Farm which has some scary roller coasters including an original wooden one

that has been around since the park first opened. But there were also some less scary rides. For dinner that night we had a barbecue with the whole group and most dressed for the occasion.

The next day Saturday 1st November was a free day and Melissa (my caregiver) Poppy and I caught the shuttle to Fullerton shopping centre where we found a few bargains and a good Mexican restaurant for lunch.

On Sunday 2nd November we went to the San Diego Zoo where we saw lots of different animals such as a jaguar and 2 panda bears.

The following day, Monday 3rd November, was Poppy's birthday and it was also a free day. We headed up the road to Buena Park mall to do more shopping. We had another group barbecue that night.

The next day Tuesday 4th November we went to the U.S Coast Guard Air Base where we had a look inside the helicopters they use to rescue people from the water. Then after that we went to the set of the original Baywatch series. We separated into groups and Melissa, Poppy and I were in Shelly's (David Hasselhoff's stunt double) group. For dinner that night we went to Pirates,

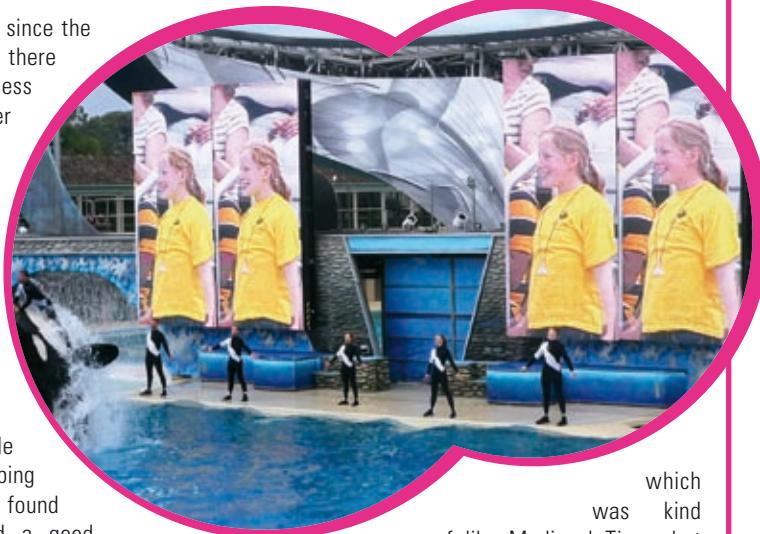
which was kind of like Medieval Times but instead of cheering for knights you are cheering for pirates and you got a knife and fork this time!

On Wednesday 5th November, we headed once again for Disneyland. We experienced California Adventure Park which is a separate park from Disneyland but they are almost connected. My favourite rides here were California Screaming, Tower of Terror and the Maliboomer.

The next day Thursday 6th November was our third and final day at Disneyland. We did all the rides that we wanted to do again and some rides we hadn't done yet.

On Friday 7th November we spent most of the morning packing our bags and in the afternoon we relaxed beside the hotel pool. Then at 5 o'clock we headed for Los Angeles Airport. After a 12 hour plane journey, we said our goodbyes before going our separate ways. The two weeks that I spent with all the other children and caregivers in California was truly the best two weeks of my life. Being on the trip really changed my life for the better and I would like to thank everyone who helped make my dreams come true.

By Hannah Gerrard



African Adventures

My friend and I had a wonderful month in East Africa (Uganda, Kenya, Tanzania and Zanzibar) in September 2008. There were 18 of us altogether, all Kiwis, travelling on the back of a truck with old coach seats and lockers underneath. We camped in tents most nights, except for 9 out of the 28, when we had proper beds and a roof over our heads. Our guides were a native Kenyan and his Kiwi wife, their almost two year old son providing most of our entertainment! We certainly had plenty of experiences, when the truck got stuck in the mud, when it broke down for 9 hours, seeing all the wild animals and hot-air ballooning over them, rafting down the River Nile, seeing the Ngorogoro Crater and Mt. Kilimanjaro (just the top of!), going to visit a school and our guides mother, brother and sister at their home for lunch etc., etc. We only had 2 days of rain and it wasn't too hot as we were

fairly high up most of the time, till we came down to the coast and over on Zanzibar, where it was very hot, but we could at least have swims in the Indian Ocean. There were also some depressing parts, seeing how the African people have to live, in their mud huts, with little power or water, and hearing about the slave trade.

I think we were all glad we'd done the trip, but were glad to be home, and think how lucky we are here in good old New Zealand.

Your Secretary,
Kate



Wellington Group

There is a small group who meet informally and socially in Wellington. If you are in the area and want to get involved / find out more then contact Julie on 04 970 1802. Please leave a message if there is no answer.

Hamilton Group

Hamilton Group get together for dinner regularly – if you would like to be part of it please txt Emma and she will add your number to her list, and advise you of the next one. Ph 021 505 122

"ICE" (In Case of Emergency)

The concept of "ICE" is catching on quickly. It is a method of contact during emergency situations. As cell phones are carried by the majority of the population, all you need to do is store the number of a contact person or persons who should be contacted during emergency under the name "ICE" (In Case Of Emergency). For more than one contact name simply enter ICE1, ICE2 and ICE3 etc.

The idea was thought up by a paramedic who found that when he went to the scenes of accidents, there were always mobile phones with patients, but they didn't know which number to call. He

therefore thought that it would be a good idea if there was a nationally recognized name for this purpose. In an emergency situation, Emergency Service personnel and Hospital staff would be able to quickly contact the right person by simply dialing the number you have stored as "ICE". Sourced & Printed with the approval of Parent and Family Networker magazine – July 2008



Southern Support

This year I hope to coordinate a local support group. I plan to advertise in the local hospital clinics and hopefully get contact from there. If anyone is down this way and would like to make contact my phone numbers are 03 487 9585 or 027 412 7242 or e-mail jak_fras@xtra.co.nz



End of Year Do!

We had our last meeting in November 2008 in the beautiful surroundings of Tamahere Park in Hamilton, followed by a Barbeque with Marina and Annie.

The chef's – great job! There was a pool for those needing to cool off and lots to catch up on. It was great to see so many come along and travel to be together.





Calling all Turner Girls and Women

You can make a difference!

Dr Rinki Murphy, Diabetes Specialist, Auckland Diabetes Centre is researching into the relation between Genetics in Growth and Diabetes. This is a study Rinki has been working on for a couple of years and still requires more data to complete her research.

She requires a simple blood test. This research will assist in the research of Growth & Diabetes which is an issue for all Turner females.

We have put the latest forms up on our website under LINKS; for more information:

www.turnersyndrome.co.nz

Or contact Rinki Murphy on: Fax: (09) 630 0709
Ph. (09) 307 4949 Ext: 26839 Email: rinkis@adhb.govt.nz
Mob: 021 1428470

International Turner Syndrome Conference

- Copenhagen August 2009

The Danish Turner Syndrome Group is organising the next International Turner Syndrome Conference.

When: 27-28 August 2009

Where: University of Copenhagen

For more information contact the Danish Turner Syndrome Group:

turnersyndrome@forening.dk

Got a pen or a mouse pad?

If you would like a Penpal, contact us at info@turnersyndrome.co.nz



Publications:

Canada's New Information Book Turner Syndrome Across the Lifespan

A new information book "Turner Syndrome Across the Lifespan" was launched at Canada's annual conference May 23rd, 2008. This 240-page book, edited by Jill Hamilton, MD, FRCPC, and Irena Hozjan, RN, BScN, MN, is a comprehensive and up to date overview of

Turner Syndrome. It is written for girls and women with TS and their families and covers issues related to medical and psychosocial health. Topics discussed include genetics, growth, puberty, infertility, and advanced reproductive technology. The medical topics are interspersed with comments and stories written by girls and women with TS.

Please email info@turnersyndrome.co.nz if you would like a copy – we will be getting some stock and we can advise you of the cost.

Links:

www.turnersyndrome.org.au
www.turnersyndrome.org.ca
www.tss.org.uk



We would love input from you on what you would like to read about or if you have a story (maybe your own story) we would love to hear from you. info@turnersyndrome.co.nz

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