

// July 2010

Well we are mid way through this year.

At the AGM back in February we came to the conclusion that we are a small group and if we were to accommodate youth, young ladies and ladies that were best to set up sub committees to handle any event. At this stage due to the geographic logistics of our committee and this year we have a small committee, that the focus was the Youth camp, and maintaining the website to keep everyone in touch.

In March we held a Leadership Course in Hamilton, Facilitator was Linda Hutchings and 12 of our ladies attended the weekend seminar. Very worthwhile seminar by all accounts.

Congratulations to Emma (past Chairperson) and her husband Lee on the birth of their gorgeous daughter, Katelyn Rose Streeter born 11:38 pm 8th June 6lb11oz. All doing well. Katelyn was an IVF baby so is a wonderful miracle for Emma and Lee.

We had some sad news that one of our founding members died, Cheirre Barnhill from the Waikato, our condolences to her friends and family. Also our condolences to Lynn Carter whose mother passed away recently too.

Bryony Mills (12) had a major heart operation on 7 July they replaced a section of her Aorta and grafted an artery onto another. It was due to be a 5 hour op but went for 8 hours! (You will all know Bryony as the gorgeous face of TS on our brochure & website. She has been on all the Merc camps). She had the operation at Starship. Thank goodness for modern medicine! Bryony is back home now recovering for a couple of weeks. Get well soon Bryony.

We have had a postcard from Jess Rogan, (Secretary 2009) from Rome. She is having a wonderful time in Europe at the moment traveling around. You can follow Jess's adventures on her blog.

http://www.mytripjournal.com/JessicaRogan.

Our Secretary resigned within the first month so we have been back to very basic administrative tasks, of which accumulate, so if you have computer and email skills, I would love to hear from you.

Julie Karsten has been fantastic as our Funding person – she raised \$19,000 last year for the youth camp, leadership course, running expenses and other costs. It was an outstanding effort and has completed the accountability reports for each of the major funders.

Julie is resigning and will finish before the end of July, she is off the Australia to study next year and we wish her every success. We will miss her fantastic efforts and her ability to step up to secretary when she saw the need. Thank you Julie for all your time you gave to achieving the fundraising goals and more.

Here is a note from Julie:

I would like to thank everyone for the support I have received since joining the group nearly three years ago, now it's time to leave and move forward. It has been rewarding and often times very challenging, especially when I took on the fundraising officer's job last year. I have met some amazing parents, youth and ladies, whom I have bonded an made lasting friendships with. I omit I won't miss filling out application forms or meetings, will miss you. I wish you all well in the years to come.

Julie Karsten

So as you can see we are a very small committee now, with two major positions vacant.

Upcoming events are:

Turner Syndrome Support Group (NZ) Inc. – Meeting

Where: Birkenhead Library, Cnr Hinemoa and Rawene Sts, Birkenhead, Auckland

When: Saturday, 21 August 2010

Time: 11.00 Shared Lunch All Welcome.

For those who maybe can't travel but want to be at the meeting we could maybe able to set up a skype link – if you are interested in this contact me on info@turnersyndrome.co.nz or

09 480 66174

Turner Syndrome Support Australia – National Conference – Perth

When: Weekend of 2 & 3 October 2010

TSSA Australia National Conference, Perth at the Ibis Perth Hotel at 334 Murray Street, Perth,

Cost of the conference - still to be advised.

More information - see our website

If you are keen to come we have a raffle on the go to raise \$ - also good to know who else is keen to go – email Karen info@turnersyndrome.co.nz

Youth Camp - January 2011

When: 10-14 January 2011

Where: MERC - Sir Peter Blake's Marine Education & Recreation Centre Inc. Long Bay, Auckland

Ages: 10 years+

This has become an annual event due to all the positive feedback and demand. We have filled our numbers to 24 this year which is fantastic and the older ones are coming back as Leaders

For more details and funding ideas go to Events on the website.

The plans are going well for the Youth Camp it certainly helps to have it in the same place as we have systems in place and we have an awesome camp committee – we have our meetings via Skype, last meeting we had Vicki and I here in Auckland, Julie in Hamilton, Jenny in Taupo and Jess in Wales – the challenge really is getting everyone to agree on a date! So we can do this with modern technology.

We have new stock of Across the Lifespan - book - see our website for an order form

Check out our FaceBook page to keep in touch with long lost 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

Take care and hope to see some of you at the next meeting in August in Auckland.

Karen Pratt Chairperson

