



Hi Everyone,

I went down to the lower North Island last week and caught up with five lovely Turner women from Wellington. Anna, Ruth, Christine, Penny and Hayley all came out to meet me and have dinner in town with me.

I really enjoyed meeting up with them and I hope they enjoyed the evening too. The weather wasn't great, but the company was good and we can't have everything can we? If some of you are feeling isolated and would like to meet up with other Turner women when you or they are travelling I would like to start a contact list.

This would not be the same list that the committee keep; only those of you who are interested in having others contact you would be on it, and everyone on it would get a copy, but I think it might be a really good way of building friendships among those who are interested.

If you would like your name on it please email me at secretary@turnersyndrome.co.nz, or through the website. Please also contact me to update your details on our committee list, or if you no longer wish to be on it or receive the newsletter.

I want to encourage you again to catch up with us at the Ladies Weekend on November 18-20. Don't leave it too late or you could miss out. Any questions and registrations to Heather at heamur@hotmail.com registration money (\$50 deposit pp) to Sally at treasurer@turnersyndrome.co.nz. It is here in the Mount (my hometown), though it was Heather and Nicole who planned it.

There will be loads for you to do; both pay and non-pay options. Pay options include: helicopter flights, parajumping, horse riding, white-water rafting, Marshalls Animal Park, swimming with dolphins, and our hot salt water pools. Non pay attractions include: walking around Mauao (Mt Maunganui), Kaiate Falls, McLarens Falls, our harbour and ocean beaches locally, and so much more within an hour of here. If you can manage it, do come.

I hope you find the following article informative. Let me know if you have any topics of special interest to you – others might be interested too, and I want to cover relevant medical issues.

Cheers Lynn.

Turner Syndrome and Coeliac Disease

Girls and women with Turner Syndrome have a higher risk than the general population of developing Coeliac disease. Coeliac occurs when the body develops a toxic reaction to gluten. Gluten is found in all wheat and related grains including rye, barley and possibly oats, and their products. Eating these causes the immune systems of Coeliac sufferers to attack and damage the lining of the small intestine, where most of the bodies nutrients are absorbed.

Sufferers are affected differently, some in childhood and others as adults, and may experience any of these symptoms:

- recurring abdominal bloating and pain
- chronic diarrhoea or constipation
- unexplained weight loss
- pale, foul smelling faeces
- anaemia (low red blood cell count)
- chronic gas
- poor growth

Diagnosis is not straightforward. Your doctor may test your blood for gluten antibody levels. They may then do a biopsy of the small intestine to confirm damage.

Once Coeliac disease is confirmed all gluten needs to be eliminated from the diet. This usually stops symptoms, allows the intestine to heal, and prevents further damage. This process starts within days of switching to a gluten free diet, and complete healing takes 3 - 6 months.

The above information was found on the Internet. I asked Marina Gratham-Campbell, who has Coeliac disease, to give me some idea how it had impacted her life. Marina, who believes that the trigger which activated her Coeliac problem was taking Fosamax for osteoporosis, wrote:

Hi I am Marina and was diagnosed with Coeliac disease about 3 years ago.

Although it makes life interesting, it does not stop you doing anything you did before. One can spend a long time in the supermarket, especially at the beginning, finding food you like!!!

There is a wide range of gluten free products available now in all supermarkets, some are better than others and you soon figure out where to buy things.

I would encourage anyone to see a dietician and join the Coeliac society and network with others, just as in the Turner support group. Do not let it stop you enjoying time with friends. I go out for lunch, which used to be the hardest but there are more and more cafes offering gluten free. I go out for dinner, (my husband disappears for 15mins while I cross examine the chef), it is really annoying or worse when people pretend to know what gluten free is!!

I have travelled, taking gluten free food with me; while it is frustrating to not be able to try the local food as much as one would like, it is better to be very careful!

Marina

If you have any items for inclusion on the Website please contact Turner Support:
info@turnersyndrome.co.nz or email either Emma - moogleshome@gmail.com or Karen – sprattz@xtra.co.nz.

Please check out the website.
www.turnersyndrome.co.nz



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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