



CHAIR CHAT

Whew – where has this year gone !!! It doesn't seem that long since we were at the AGM in Auckland, finally separating from the Youth and Camp Branch.

Now the Christmas decorations are up in the shops, Christmas music rings out and they are putting the finishing touches to the Christmas Tree in Garden Place (Hamilton).

The last event of the year is our Christmas get together at "Westwave Pool at Henderson, Auckland, on December 3rd at 11.30. I hope there is a good turn out from Auckland and further afield. Unfortunately I will not be able to attend, as I have my second dose of chemotherapy for Lymphoma on November 28.

A gap in the chemotherapy regime meant that I was able to get, with Marina as chauffeur, to the Turner Women's weekend at the Mount, for the Saturday. We arrived, meeting up with the others for lunch.

Those that attended were Diane, Nicole, Heather, Denise, Jessica, Lynn, Marina and me. Thanks to Heather for her hard work in organizing the venue, and coordinating the event.

Diane, Lynn, Marina and I went for a walk around the Mount. After returning to the apartment, to catch our breath, we had dinner at Hasan Baba, enjoyed a Turkish meal, lively political debate, and good company.

To the committee, I want to thank you all for the great job you have done this year, your support and friendship has meant a great deal to me. To everyone I wish you all a happy Christmas best wishes for the New Year

Rae (Chairperson)

From Heather (Committee member)

Thank you to those who came to our first annual ladies weekend. We stayed in a very nice and cosy apartment at Mount Maunganui. Early risers started off with a morning constitutional down to the beach and others of us started a little later with a walk around the village shops. After lunch it was a trek around the base of Mount Maunganui for the fit and keen or chatting beachside for the more tranquil among us.

The weather complied and fortunately the beach was looking lovely after its recent clean up. Then it was off for a yummy dinner at the local Turkish restaurant where we solved the world's problems (interrupted by an altercation between a certain lady and her wineglass) ending with me declaring a benign dictatorship. For the lucky ones the night ended with a lovely soak in the local hot pools. Nice.

The next day some of us went for lunch and a look around at Bayfair and for a visit to Lynns nearby. In all it was a happy relaxed weekend. Of course it was full of the typical chatting I warned about. Getting to know each other, extending the support network and sharing new information about Turners is the main focus of these gatherings. So we intend to build upon our success and are hoping for more ladies to join the fun next year. Keep your eyes open for next year's ladies weekend details on the Turner website and in the monthly newsletters.

You are all invited!

Hi Everyone,

We had a great time last weekend, getting together and just hanging out and doing stuff together. Unfortunately my prior commitment to sing in our choir's concert meant my weekend was mainly rehearsals and performance, but I did manage to connect up with the girls periodically. Diane, Heather and Nicole came down from Auckland, Marina and Rae came across from Hamilton, and Jessica and Denise (who stayed with Jess) all caught up with each other. I'd love to see us do things like this more often; it's a great way to make new friends and get to know each other. We will certainly get together again, but I'd love your feedback as to what would work best for you. If we meet where we have to book venues or accommodation we need to have a fairly firm indication of interest – we can't mess people around. Alternatively maybe we should just organise a weekend in Auckland, Hamilton or Wellington, where we find our own accommodation or billet each other. Let's get to know others outside our own neighbourhoods though if possible. Any suggestions welcome.

For now, our next get together is our Christmas break-up, 12.00 pm at the Westwave Aquatic Centre on Saturday, December 3rd. See the Website or contact Heather at Heamur@hotmail.com. I have another commitment, so may not make it, but it will be fun; do try to get there if you can. Have a wonderful Christmas and a happy New Year all of you, and take care.

Lynn (Secretary)

Osteoporosis in Turner Syndrome.

At our last committee meeting Julie van Dam asked me to spotlight Osteoporosis, and how it impacts us as Turner girls and women. What follows is my summary and interpretation of the article Gerard Conway submitted at the Copenhagen International Conference, which was printed in "Turner – Know Your Body", edited by Claus Gravolt ,

Q. What is Osteoporosis?

A. Bone is made up of calcium and minerals on a matrix (or mould) of mainly collagen based protein. Osteoporosis occurs where both calcium and collagen in the bone is reduced; causing an increase in the risk of fracture. This happens because the osteoblasts (bone building cells) are not laying down calcium as fast as the osteoclasts (bone dissolving or resorption cells) are breaking it down for recycling. Bones, instead of being relatively strong and solid may be 'honeycombed' inside, and therefore more fragile, though they may not look different from the outside.

This affects us because Osteoporosis is a major risk factor in breaking of bones. Fracture risk is doubled for Turner women (although this may be addressed by adequate estrogen replacement). Therefore we should have regular bone-densitometry scans to measure our bone density. Turner women tend to measure on the lower half of the population range, though this is disputed and some studies corrected for height report normal values for us. Nevertheless low bone density does correlate with high fracture risk.

So, what can we do?

There are three important things:

1. Estrogen
2. Vitamin D and
3. Exercise.

Estrogen.

In our case low bone density is often linked to lack of estrogen. Estrogen reduces the life of osteoclasts, which break down bone, and it may also increase osteoblast activity in building new bone. But it does close down bone ends, so must be used very cautiously in young women who have not achieved full height, until they have stopped growing. After that, taking estrogen (HRT or Hormone Replacement Therapy) until about age 50 will help stave off osteoporosis. Estrogen related risk of breast cancer is minimal till 50, and is cumulative so hormone replacement can continue even after 50 if there were long periods without estrogen in adult years.

Vitamin D

Vitamin D is important because:

- 1 It helps with calcium resorption.
- 2 It helps bones use calcium better.
- 3 It suppresses PTH (Para-Thyroid Hormone), which releases calcium from bones.

We get Vitamin D from exposure to sunlight on our skin (but watch for the excess UV exposure – it's a balancing act), and from fish, eggs and fortified milk. If your levels are low (get your doctor to test them) you may benefit from a supplement.

Exercise

Exercise is also important for bone health; it increases osteoblast (bone-builder) production, it increases muscle strength and decreases fall risk, and we Turner women often don't get enough (guilty as charged). We should aim to do 30 minutes of exercise two to three times a week,

If we have adequate calcium in our diet, exercise enough, keep up our Vitamin D, and take estrogen we are making a good start to maintaining bone health, and staving off osteoporosis.

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



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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