



# Turner Talk

THE TURNER'S SYNDROME CONTACT GROUP OF SOUTH AFRICA

MARCH 2005



## EDITOR'S LETTER



Hi there!

Greetings and best wishes for 2005. It is rather belated to be sending New Year greetings – We hope that the year has started well and will be an excellent one for you with plans working out and dreams coming true.

The committee too have dreams and plans – for the group. Meetings are taking place to set up a Turner Syndrome Day Clinic at the Donald Gordon Hospital – (previously the Kenridge). The clinic will function a couple of times a year. Turner children, teenagers and adults will be able to make appointments to see various specialists (Endocrinologists, Audiologists, Gynaecologists and others) all on the same day so that you do not continually have to take time off school or work to keep medical appointments. This should prove to be of great benefit to all with Turner Syndrome.

In this Turner Talk you will find the notice of the Annual General Meeting. Please note that we are specially focusing on Teens – and the teen image:- Dress, make-up etc. It will be really fantastic to see you there.

We have approached the producers of '3 Talk' on S.A.B.C. 3 T.V. about airing a programme on Turner Syndrome. We don't know when and if this will happen but do believe it would be an interesting topic of discussion if it actually does take place.

It would be wonderful to have some news from you. Sharing any good, positive and interesting events that may be happening in your life or challenges and difficulties that you may be facing and how you are handling them and hopefully have overcome them.

Wishing you a healthy and prosperous year.

Your Editors  
Liz and Samara



Please send us your e-mail address for our records

## Annual General Meeting

TEA  
TIME



Date

Sunday 15<sup>th</sup> May 2005

Time

15:00p.m.

Venue

Pearl Greenbergs' House  
6 Roselyn Street, Percelia Estate  
Johannesburg

R.S.V.P.

Tel/Fax (011) 447-9593

COFFEE  
TIME

-X-

**NOTE: OUR NEW  
E-MAIL & POSTAL  
ADDRESS**

E-mail address:

[turnersa@tiscali.co.za](mailto:turnersa@tiscali.co.za)

Turner club bulletin board address:

<http://clubs.yahoo.com/clubs/turnerssyndromesouthafrica>

Postal address:

T.S.C.G.

3 Denbigh Road, Parkwood, 2193

Tel./Fax No's:

(011) 447-9593

Banking Details:

T.S.C.G.

Permbank, Eastgate

Account Number: 2737013690

Branch Code: 173743





By Liz Zylstra

### GO WELL HAZEL

Those of you who had met or knew Hazel Stein (Ucko) – the wonderful lady who had the vision to initiate and became the founding member of the T.S. Group in South Africa in September 1989, will be sad to hear that she has recently relocated to Sydney Australia. Hazel really has been the driving force behind our committed group for many years.

She showed great concern and empathy for parents facing the diagnosis that their daughters had Turner Syndrome.

Hazel encouraged several T.S. teenagers along their career paths, with assistance from the group, helped them to reach their potential and their goals.

Her characteristic chutzpah ensured that several of the committee members had the privilege of attending a number of international T.S. conferences.

Hazel, we will miss you terribly. Our loss is definitely Australias' gain. We wish you well in your new life 'down under' and hope that we will receive news from you and keep in contact with you in the future.

Thank you for all your unconditional time, care and concern for T.S. females and their families in South Africa.

Best of luck and we wish you all the happiness and success you so richly deserve.

We will all miss your presence and support.

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### T.S. SYMPTOMS

Women with Turner's syndrome will usually have at least some of the following symptoms, although they are unlikely to have all of them:

- Shorter than average height for their age
- A web of skin that runs from either side of the neck to the shoulder
- Unusually shaped ears
- Low hairline
- The outward angle of the arms at the elbows is increased
- Female sexual characteristics often do not develop properly. This leads to underdevelopment of the womb, vagina and breasts, lack of pubic and armpit hair and absence of menstrual periods.
- The largest artery of the body (the aorta) is often narrowed (known as coarctation of the aorta)
- The eyes and the bones do not develop normally
- Slight swelling of hands and feet
- Broad chest and widely spaced nipples
- Learning difficulties

By Jessica

Extracted from a Newsletter from the  
U.K. Support Society - December 2003 Edition

### A TEENAGER'S STORY



I found out I had Turners Syndrome when I was 15 years old, which is quite late in life. It was all a big shock at first. I remember coming out of the appointment in which the doctor told me simply stunned, not really able to feel any emotion, but feeling more like I'd just been slapped in the face.

I was devastated as learning that I probably wouldn't have children and I was very overwhelmed by the amount of problems that were associated with this syndrome, and the amount of medical tests I had to have. However, I soon realised that most girls with Turners will only ever have a very small fraction of these problems in their lifetime.

Fortunately, the only medical problem I have so far is a horseshoe kidney, and problems with my ears (which are getting better as I get older). The worst part of finding out I had Turners syndrome came when I went for my second hospital visit. I was told that I had a form of Turner syndrome mosaicism with fragments of Y chromosome.

I was told that this meant my ovaries ran a strong risk of being, or becoming, cancerous. My doctor recommended that I had them removed as soon as possible. This really threw me back. I just started to get used to having T.S. when I was told my life could be at risk from it. I felt like I'd taken a step forward and was now taking 3 steps back. However, a few weeks later I had the operation and it was all a success. There was no sign of cancer and after a few days I had nothing to show from it apart from a couple of small scars. Because of this drama, I hadn't given my height a second thought.

However, a few months after I found out I had Turners syndrome, I decided to go on growth hormone. I didn't hold much hope for it doing much at first, as I was quite old to be starting. However, after just under 2 years I have already grown from 141cm (4ft 7 and 1/2) to 154cm (almost 5 ft 1) and still have some more growing to do. It goes without saying that I am delighted at the difference it has made.

For the past 3 years, I have attended the TSS conferences in Blackpool once a year. To all you people who have considered going to these and then decided not to, please do. They are brilliant. On writing this, I have returned from the 2003 conference a few days ago and, yet again, had a great time!

My biggest advice to you all as somebody who has Turner Syndrome would be to go to any meetings and conferences and get in touch with others in the same boat. There really is no better way to learn what Turner Syndrome is all about, and I myself have formed some really close friendships.

Also, PLEASE don't feel like a girl with Turner Syndrome cannot achieve anything they want to. I got 6 A\*'s and 4 A's in my GCSE's, and hope to become a doctor, so you truly can do whatever you want to just as well as anybody else.