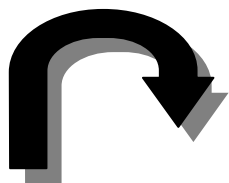




Victorian  
**Turner's**  
SYNDROME  
ASSOCIATION  
INC



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### Forthcoming Meetings:

#### All Welcome

7.30pm

9<sup>th</sup> Floor, 9 East Seminar Room

Royal Childrens Hospital, Parkville

#### Meeting Dates this Quarter:

Thursday July 6<sup>th</sup> 2006

Thursday August 10<sup>th</sup>, 2006

Thursday September 14<sup>th</sup>. 2006

Thursday October 12<sup>th</sup>, 2006

## Auxiliary Annual Report

It seems like an eon and yet only a day since last year. Our auxiliary history has seen many facets – bag sellers extraordinaire, fundraising and friend-raising activities by members and friends, stalls at RCH and public events including council, school and community functions, and much goodwill and merriment being part of the Auxiliaries umbrella.

The theme of the year has been the enjoyment of this goodwill at special auxiliary functions where Turner's Syndrome has succeeded in gaining awareness and recognition.

2006 has been deemed the year of TS awareness and so projects we have been busy with have had this focus. Like a snowball these have gathered momentum. A few examples are the fundraising Trivia Night this week in a community setting, the planned awareness event at Southgate next month, the planned Walk around Albert Park Lake in October, the support by a large contingent of members for the forthcoming National TS Conference in Brisbane and the much-debated research project on sexual self-esteem.

One of our members, Vassie Dandanis also won the opportunity to represent our group at the 'Communities in Control Conference – The Community Summit, Challenging the Power of One' next month with a complimentary registration. This is a major gathering of leaders in the field of community projects and will be a great opportunity. Our group is also a nominee in the 'Community Idol' competition, having put together a submission on what we do well.

So our first full year as an auxiliary has been about exploring all sorts of ventures, proceeding with the commitment to raise awareness of Turner's Syndrome, make meaningful connections between our members and the wider community, fundraise effectively and contribute to and participate in the wider life of RCH Auxiliaries.

We have had lots of fun as well and look forward to a long and prosperous future. We know what we've always believed – giving brings great rewards!

**Marie**

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# Newsletter

## **JOURNAL ABSTRACT**

### **RECENT PUBLICATIONS**

#### **Authors**

Pedreira CC. Hameed R. Kanumakala S. Zacharin M. Institution  
Department of Endocrinology and Diabetes, Royal Children's Hospital,  
Parkville, Victoria, Australia.

#### **Title**

**Health-care problems of Turner syndrome in the adult woman: a cross-sectional study of a Victorian cohort and a case for transition.**

#### **Source**

Internal Medicine Journal. 36(1):54-7, 2006 Jan.

#### **Abstract**

The aim of this study was to assess current care and to survey comorbidity in a cohort of 39 adult women with Turner syndrome in Victoria. Patients with Turner syndrome (TS) drift away from medical care as they achieve adulthood, despite the need for regular surveillance and management of associated conditions, which would reduce morbidity and prevent complications. Clinical assessment was undertaken for 39 women with TS, mean age 30.1 (+/-11.7) years and information was gathered through personal communication regarding past growth hormone use, oestrogen treatment, hearing loss and health problems. Twenty-four (63.2%) had regular follow-up, but only 17 (43.6%) had adequate recommended surveillance for co-morbidities. Forty-three percent had two or more cardiovascular risk factors. Thirty-four (87.2%) were identified with one or more associated disorders. Uterine size was of normal adult dimensions in patients who had received oestrogen before age of 15 years. Adult care for adults with TS is suboptimal and assessment of co-morbidities remains sporadic. Adequate transition guidelines and patient education are needed for long-term management of women with TS, to impact on quality of life and longevity.

**THIS WEEKEND A CONTINGENT OF MORE THAN A DOZEN VICTORIANS ARE ATTENDING THE NATIONAL TURNER'S SYNDROME CONFERENCE IN BRISBANE.** The program will include speakers on common ear problems, growing up with TS, heart problems, gynaecology and adult care, IVF, nutrition and healthy eating, learning difficulties, bone health and osteoporosis. Stay tuned for news!

‘Communities in Control’ Conference -  
Run by ‘Our Community’

**June 19 – 22, 2006**

I was lucky enough to find this opportunity for education and awareness and won a Leader Scholarship by Leader newspapers to attend the ‘Our Community Conference’ and represent VTSA. I was one of 1500 delegates held at Moonee Valley Racing Club. Through networking with other organizations and individuals there is a greater awareness of TS and the VTSA. The added bonus was that as a young person I attracted attention and was asked the role that I play as a young member. This resulted in **greater awareness and more discussion about Turners Syndrome.**

Pre-conference day

The day focused on funding and featured a series of workshops of which I attended the ‘grant writing workshop. This workshop taught the ‘step by step’ approach to success by showing what funding bodies are looking for. This included strategies of how to create a partnership between the funding body and the organization pursuing funds. Following the grant writing workshop I approached a lady who had set up a support group for a genetic condition and had been used for the case example for a group practice grant. This resulted in me telling her of the resources at the Royal Children's Hospital and GSNV (Genetic Support Network Victoria) and my involvement in VTSA and Hidden Treasure Auxilliary

This day however also included good news stories from country townships around Australia in surviving and thriving through times of economic hardship. The strategies that the towns used were playing on the name of the place or running or supporting events of public interest. These were **good ideas** to raise funds and awareness which VTSA is currently striving for.

Conference This proved to be a time of meeting with organizations and individuals of diverse backgrounds and experiences. I was at the conference representing VTSA but found there were many times where I also represented the ChIPS program.

The speakers that spoke often drew me in showed **how powerful telling stories about places and people can be.** The conference started by establishing what a community is and questioned if it exists,

in an online environment.

A debate was held to flesh out the issues of change in society and the increase in attention on the individual instead of the community. The result of the debate was that the team that argued that ‘the individual reigns supreme’ achieved this through using the term ‘community’ instead of ‘neighborhood’. **This meant that the community still matters to society.**

There was an emphasis on leadership and what makes good leaders. **Good leadership means to support others to act.** One problem of the current day is that leaders do not actively listen to the needs of their own community; this includes the politicians and CEO's as well as smaller community groups. Some common myths about leadership were destroyed to reveal the reality.

Two speakers that were memorable to me were the ‘Coach of Coaches’ Australian Football League's Kevin Sheedy who spoke of the importance of having a dream to work towards. **There was reference to looking at the clouds as a child and being free to dream, instead of dreaming of the new car or home renovation.**

Bryce Courtney spoke about his life and poverty and the impact of the support of one teacher's power of belief and support. He told of his life with great humor and in the form of a story. **I felt myself being pulled in like a little child wanting to know the next adventure (power of story telling and determination).** He would then also make the most of his past life and future opportunities by returning to live and work with homeless youth.

It was a stimulating experience which enabled me to meet many interesting people and hear many stories. I am confident that there was also a story of TS told.



## Trivia Night.....Jeannine le Vaillant (mother of Ruby & Nathan)

I am normally on the organising end of events, so was quite humbled to be on the receiving end of an organised event. My friend Barbara Stewart was reading a rare outpouring from me via the email about attending a TS conference, but it was in Brisbane.... Barb wrote me back a couple of days later to tell me she was going to hold a trivia night to raise funds for us to attend. I said I couldn't do that as Ruby is only 8 - there would be many more National Conferences in our lives.

But... never one to give up - Barb decided she wanted to raise awareness and funds towards the TS Awareness Walk and ACMI digital stories the VTSA are organising later in 2006. Within 7 weeks Barb, her husband Geoff, Penny, Neil, Mordialloc Theatre Company and members, many community friends that know Ruby, and members of VTSA attended the Trivia night on the 3<sup>rd</sup> June. Barb, Geoff, Penny pulled together people that know Ruby (and lots that don't) to support awareness of TS.

The night was simply terrific. 90 people gathered for Awareness and Sharing - Fun was had by all. Barb raised just over \$1300.00

Thanks heaps Barb and Geoff and the many others that did a little bit along the way.

Stay posted as Barb is already planning 2007's "TS" Trivia night!!

Many thanks!!

(And our committee greatly appreciates Barb's generosity and energy - all had loads of fun!!)

## NEWS FLASH

Research opportunity

Individuals with TS who are 18 years old or older are invited to participate in this study -  
Psychological well-being and sexual self - esteem in women with TS

This involves a series of 104 questions on demographics, psychological well-being and sexual self-esteem. Participation is voluntary and women can decline at any time. However participation means we can all learn more about these issues and can work on living life better.

Questionnaires are now available.

If you are interested contact Dr Jane McGillvray by phone 9244-6426 or e-mail [mcgill@deakin.edu.au](mailto:mcgill@deakin.edu.au)

Digital storytelling, TV productions, trivia night....These were some of the topics discussed at the May committee meeting.

The Trivia Night, held on 3 June was the inspiration of Barbara Stewart. Barbara is a friend of Jeannine Le Vaillant-Moffit, whose daughter Ruby shone at a production which was held at the Shirley Burke Theatre, late last year. Thank you Barbara for offering your services and organising this fun night.

Jeannine is working on an exciting digital story-telling project, which will be run in conjunction with ACMI. Storytelling is a powerful medium, especially when it is an individual relating their personal journey. ACMI run workshops during which trained facilitators show people how to present their story. The end result is a 3-4 minute video story which can be shared with family, friends and if you choose the wider community. Members of the committee agreed it would be fantastic to get stories from a cross-section of individuals: teenagers, TS adults, parents of children affected by TS.

We also discussed the research project to be undertaken by Deakin University student Rebecca Ward-Smith. We understand the project is awaiting final clearance from the Ethics Committee and questionnaires will be available soon.

And of course we are not forgetting the national Turner's Syndrome Conference to be held in Brisbane late this month. From what I have heard there will be a strong representation from Victoria

And a few more words from Marie

. The 'Vic team' will be sporting new blue polo shirts generously sponsored by Col Dyson, father of our President Margie Hill. Thank you so much for your generosity and thoughtfulness. We will wear them proud!

On swift return of the intrepid travellers to Brisbane, some of our committee will also be representing VTSA at Southbank on 4<sup>th</sup> July as part of a Genetic Support Network Victoria (GSNV) awareness initiative.

Meanwhile Vassie had applied for a competition in the local newspaper for a chance to win a sponsored place at the 'Communities in Control' Conference, in Melbourne on June 18-20, representing her association. Well, she was successful and now has a place (valued at \$485) in this annual conference of all community group leaders, local, state and federal government leaders, businesspeople and all people who value strong vibrant communities. Apparently there are about 1500 delegates, so it's sure to be a great experience with exposure to all manner of inspiring and stimulating opportunities. No doubt it will enhance her perspective and knowledge, as she continues to study for her Diploma of Community Welfare. It is also great that Turner's Syndrome will make its debut on a stage of such large proportions. Who knows where it will lead?

And being not shy of a challenge, in reading her material about the conference, I uncovered an opportunity to nominate VTSA in the 'Community Idol' Awards, where the process also includes interviews, participation in a debate and selection process according to innovation and energy. The submission has not been successful in reaching the final interviews and debate. No matter. I was proud to reflect the diversity and energy of our activities in the knowledge that not very long ago, these mainstream vibrant initiatives were on not on our radar. Now it seems our group represents a level of maturity that can be reckoned with, and has clearer vision on the horizon. Benefits to individuals also correspond to enrichment of our own resources, to be shared and generously exchanged. All in all quite a few exciting projects at hand.....

It's your VTSA  
Pool resources, and  
Make it work for you

# Something to think about

## TS Awareness 2006- Digital Storytelling Workshop.

VTSA has booked a workshop with the Australian Centre for Moving Image (ACMI) to produce a DVD combining a group of 3 minute individual stories from VTSA members:

*EXPRESSIONS OF INTEREST SOUGHT!!*

**What you will need to commit to is:**

1. a couple of hours in mid October to attend a briefing session with ACMI
2. Your time over 3 days (1-3 Nov)
3. Commitment to TS awareness
4. Sharing some of your journey.

**VTSA is looking for 10 willing  
(participants) members to do this  
workshop.**

- 3 teenagers/young woman
- 3 woman ages 26 - 45
- 2 women 45 onwards
- 1 mother and or father of TS child
- 1 professional specialising in TS care

The deal is:            You write your script  
                              You tell (speak) your story  
                              You choose the music  
                              You choose the photos / video footage  
                              You edit the story  
                              You own the journey to share.

The Combined Stories will be placed on the ACMI Memory Grid at Federation Square which is open to the public and could be offered to newly diagnosed TS teens / women /and parents of newly diagnosed babies and children to view.

**Are you interested?** Please call **Jeannine 95639107 or 0400124529** for more information or pop into the ACMI Memory Grid at Federation Square in Melbourne to view the many digital stories already being shared

"The highest reward for a person's toil is not what they get for it but what they become by it" - John Ruskin

Live Life to the fullest, you can never fail because you've always tried and those things or people that challenge you or hold you back only make you stronger" - unknown

"Courage is not the towering oak that sees storms come and go; it is the fragile blossoms that open in the snow"

- Alice McKenzie Swaim

"Too often we underestimate the power of a touch, a smile, a kind word, a listening ear, an honest compliment, or the smallest act

# Ruby's Pencil Race Way.

(Thanks Nathan and Ruby for your fun original contribution! How about a regular kids feature? – by kids for kids? Well done!)

For 2 or more players

2 races at once or go right around!

Place "NIB" of pencil on the start line.

Place one finger on top of pencil

Put gentle pressure down and forward to "flick" a line.

Have fun!.

