

My Journey

Personal Account by John Leatherland, Past VP given at the TSAV 20th AGM, 24 October 2010.

The 20th anniversary of Tourette Syndrome Association of Victoria (TSAV) is a wonderful celebration of a wonderful organisation. TSAV has been an incredibly important organisation, in fact a 'lifeline' for me and for my wife, Chris, for which I shall always feel a deep debt of gratitude.

I have been asked to talk about my life with TS, before TSAV. To do this I need to give you some glimpses of my life with TS before I was diagnosed. I point out that I have milder symptoms of TS than many. I don't in any way wish to suggest that my experience is comparable with many others who have a much harder road to travel. But it is my experience and I am happy to share it.

Let's wind the clock back 50 years:

A school speech night in the Sydney Town Hall. An important occasion. Best behaviour and presentation required. I was in the choir, aged 13.

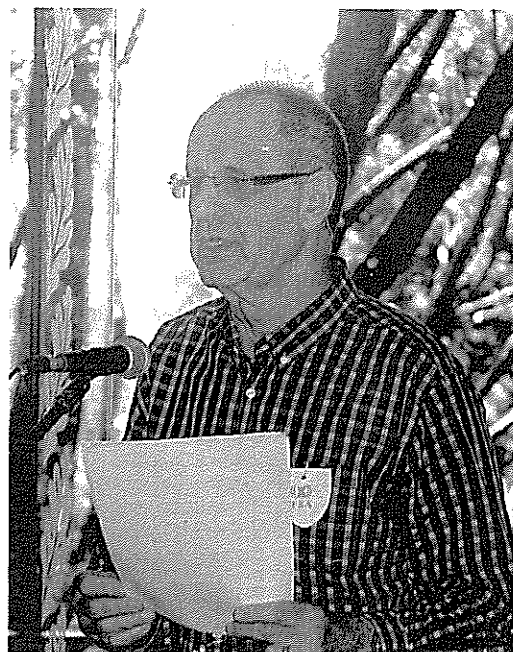
At the rehearsal I had an overwhelming urge which resulted in facial grimaces, eye blinking, squinting and large tics. A teacher told me that it was not the time to play the clown. At the speech night concert my parents were embarrassed and showed me that they disapproved. I did not know why I had the urge to do this. I felt I should have been able to prevent it and was weak willed.

The blinking, sniffing and snorting continued during my teenage years. I was mimicked a lot at school. On one occasion a teacher joined in. I had a small group of friends and we stuck together.

My tics and my growing outbursts of anger as a teenager were not talked about in our home. My sister still does not want to recognise that I have TS and just dismisses any attempt to discuss it. Not that I have ever wanted it to be a focal point of attention. I am sure some of you will have had similar experiences with family members who just don't want to know. I think that my parents thought it was their fault, a deficit in their parenting. I thought it was my fault. But the issue was buried and we all got on with our lives.

Fast forward to 44 years ago.

I was living at home and doing uni exams. The ticking, snorting and large shoulder movements got far worse, as they do under stress. Of more concern was that I had an irresistible urge to punch holes and the walls at home, to destroy precious glass objects, and to lash out at people who got in the way. Explosions of anger were going off in my mind which mirrored the tics which



had got to the stage of being physically painful. I felt that my mind and thoughts were fragmented and that I was hemmed in.

I was sooo angry. Angry at myself for letting my parents down who had high expectations of me, academically. Angry at my parents. There were other family dynamics that contributed to this but I am now sure, having read the literature and talked to other adults with TS, that TS was a major reason (not an excuse) for my behaviour.

A cycle of psychiatric 'care' began that led ended up being placed as an involuntary patient at Larundel (a major psychiatric hospital that thankfully has been pulled down). On one occasion, after an outburst, my father called the doctor who called the police. This was very distressing to my father who cared for me dearly but must have been at his wits end. Much to my father's protests I was handcuffed, but as the police were about to put me in the back of the wagon one said to the other, "let him sit beside us in the front without handcuffs. I don't think he is dangerous". They seemed concerned about me in a strange sort of way. They offered me two pieces of advice.

Firstly, "don't take too much notice of the shrinks but play along with them and you will get out soon". Secondly, "drink a bottle of red



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every couple of days and relax more". I was hardly in a position to argue with them.

At Larundel I had several courses of ECT, powerful sedative drugs morning, noon and night such as Largactyl, Nembutal, Mellaril and Amytal to name a few. When I was about to be discharged about three months later, the psychiatrist stated that he didn't think I was major mental illness like most others in there but he had to write a diagnosis on the discharge papers. After consulting me he wrote "explosive personality". Pity he didn't diagnose Tourette Syndrome, given it had been identified almost 100 years earlier. However we have to remember that TS and several other neurological disorders were not that widely known even among some medical professionals in the 1960s. I was given some medication, told not to 'explode' but sedate myself instead, and keep away from my parents for a while because they seemed to have caused some of my problems. A social worker found me a clerical job and a place in a boarding house. I proudly told my few friends that I was not mad, had never been mad but had 'an explosive personality'.

The police were half right. I did play along with what the doctors wanted and was careful what I told them because they kept trying to find family pathology and suggest what appeared to be endless treatment, and were of very limited help. I did get out as soon as I could. But the bottles of red made my tics worse, not better.

I got on with life. Got a job. Did part time study. Built a successful career. Got married fairly young and had three wonderful children. Tried to obliterate the past out of my mind. Absorbed myself and overachieved at work probably to compensate for feeling a bit of a failure interpersonally.

Let's fast forward again to just over 20 years ago:

Our children had grown up fast. Our marriage was in trouble, mostly



because of my tics, odd behaviour and a lot of angry feelings. I now know that my TS embarrassed my children with their friends on many occasions.

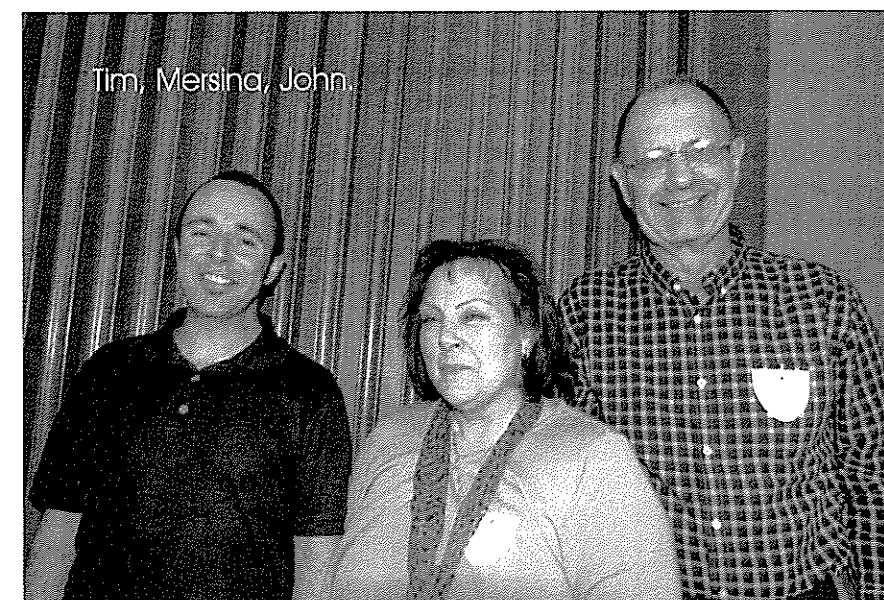
My wife, Chris, read an article in the Women's Weekly about Tourettes. It sounded to her like what I had. There was no internet in those days. Chris asked our eldest daughter who was a medical student to obtain some medical text books which she ploughed through. Being a nurse helped with the medical terminology. She was sure I had TS. I didn't want to know. Chris talked to our GP who had heard of TS and thought I may have it and had observed me ticking.

Then I saw the Sixty Minutes program. Stephen Franzini's courageous account of his experience and his skilled table tennis playing. Phillip Zillner's moving account of the impact of his experience with TS and, at the museum compulsively touching objects and sniffing books and magazines. These were the things I did! These were the things that convinced me that I had TS. The only game that I was moderately good at was table tennis. Was that a coincidence? Who knows. Thank you Stephen and Phillip.

I was officially diagnosed by a neurologist who had no doubts and placed me on Haloperidol which I took for a while and then found that the side effects were troublesome.

We were invited to the TSAV meeting at Oakleigh. I am sure some of you were anxious about going to your first TSAV meeting. What was this Agnes really like? She sounded really nice over the phone. Was it going to be what I imagine AA meetings to be like where people have to tell their stories?

I need not have worried. We were greeted so warmly. I was in wonderful company. It was the first meeting that I had ever been to when it didn't matter if I ticked! Then followed so much support: TopicS with great practical articles; family days; honorary medical advisers and presentations from experts; young people's activities; community and professional education; sharing experience, help to children in their school and so much more.



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TSAV was a major turning point for us.

I knew what I had. That helped me to manage my symptoms more effectively. It meant that I could disclose that I had TS on appropriate occasions. I no longer had to bury it and feel a sense of diffuse guilt about having it.

I shall give one example of the power of disclosure and finding strategies to manage symptoms.

I was working in the Child Protection/Family Services area. Sometime after I was diagnosed with TS I had to give evidence at a VCAT hearing. At least four hours of examination and cross examination lay ahead. Plenty of stress. My symptoms were acute. At the first adjournment my barrister said that the evidence that I was giving was good but that he was a bit worried that the tribunal member (similar role to a magistrate or a judge in a court) was getting anxious about my tics. Every time I ticked he seemed to twitch. The barrister said I was making him nervous and he might even think I was giving signals to the other side! I asked him to give me a question that would allow me to explain to the tribunal member that I had TS and in two sentences what it was. The barrister was reluctant and thought it might backfire but we did this and the tribunal member seemed to appreciate my disclosure and became more relaxed. At the adjournments I went to the toilet and ticked like mad in private which certainly reduced my need to tic for a while afterwards. We won the case, which was the main thing.

Then and now.

Let's face it: TS is a bugger of a thing to have.

TS is hard to cope with, hard for people to understand, hard for you to describe and there is no cure as yet. However it is not life threatening, and my experience is that it has become easier to live with/ manage as I have got older.

It is far better to have TS or to be a mum, a dad or a partner of a person with TS this century than it was in the last century:

You are likely to be diagnosed and given professional advice soon after the symptoms are apparent. Most doctors and many other professionals know about TS. Sometimes their knowledge is

incomplete. There are still challenges ahead in terms of professional education from the perspective of the person with TS or their carer and an important continuing role for TSAV in this.

You have access to gain and share accessible information....Google; emails, face-book etc It is no longer a case of 'hit or miss'...whether you have seen an article in a women's magazine or in a medical textbook.

Many people in the community now know about TS. I have recently been surprised about the people who know about it and sometimes by those who don't.

TS is no longer considered your family's 'fault' or your 'fault'. You know what you have and can let others know if you want to without appearing the 'victim'.

You who have TS are as good as the next person and probably better than most. Capitalise on your many strengths. Be proud of yourself, and people will see beyond your TS to the real you.

There are more resources for organisations, schools and elsewhere, but there is a long way to go. There will always be a strong advocacy role for TSAV.

You have TSAV. A fantastic source of mutual support, correct information that can be easily digested and practical care.

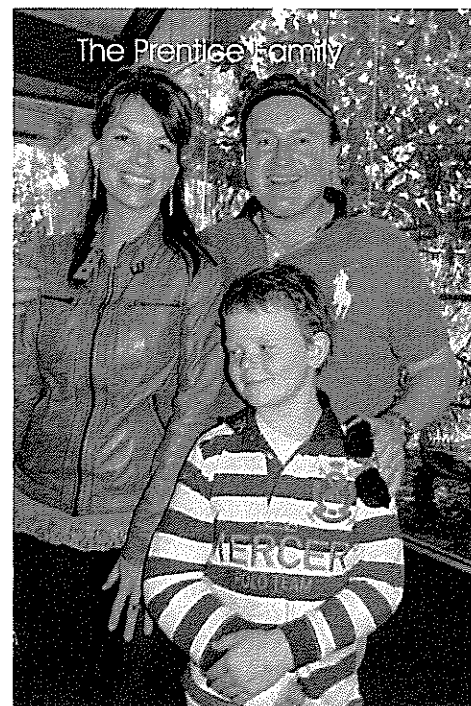
TSAV would not be here today if it were not for the dedication and commitment of many people. One person stands out has having been the key driving force: Agnes. Agnes is one of the most inspiring leaders, compassionate people and passionate advocates that I have had the pleasure of knowing. Thank you, most sincerely, Agnes for all that you have done and continue to do.

Best wishes to you all personally.

Best wishes to TSAV for the next 20 years!



Steve, Judi, Julie, Tim.



The Prentice family

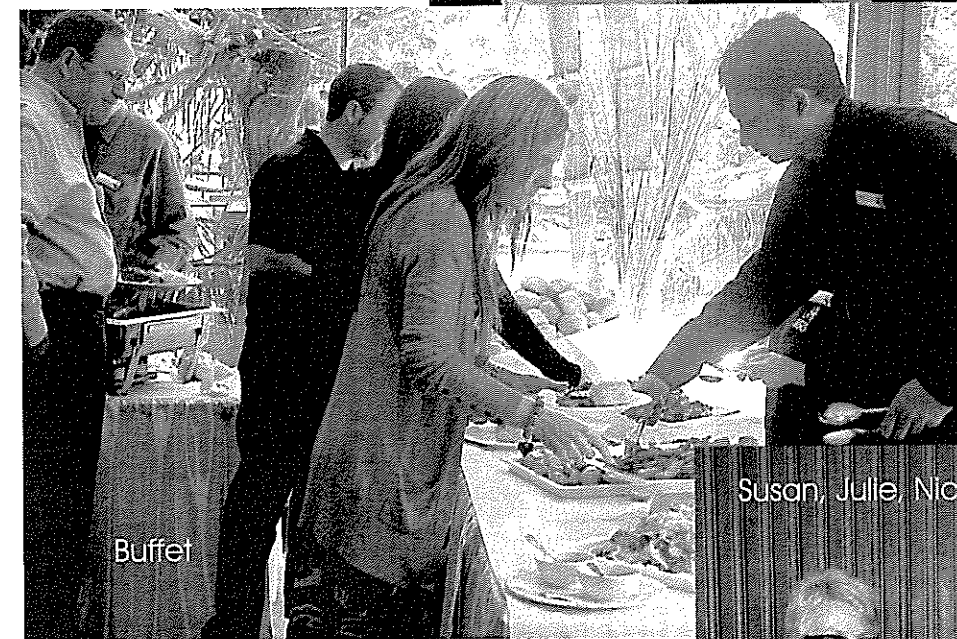
AGM and luncheon

Sunday 24 October 2010 was a significant day in the history of The Tourette Syndrome Association of Victoria. We celebrated our 20th Anniversary as a volunteer not for profit organization.

Since its humble beginnings in a family lounge room to our office space in the Nerve Centre Blackburn where we are today ... what a journey we have travelled. We had a glorious sunny spring day with 70 people attending the AGM and luncheon at the very elegant Rainforest Function Room at Melbourne Zoo.



Anniversary Wine



Buffet

At the close of the meeting we were all ready for a good feed and were not disappointed a delicious gourmet buffet BBQ was laid out for us to enjoy then finished off with tea and coffee. All members who attended the AGM received a commemorative 20 Anniversary TSA bottle of Australian Merlot.

Manuela Jovanovic



Susan, Julie, Nick.

Once the formalities were attended to Agnes Zillner and John Leatherland. Past President and Vice President respectively gave a personal account on the history, insights and reflections of what it was like dealing with TS in those early days to where we have arrived today.

To conclude the meeting we screened the 60 Minutes interview with Mike Munroe, it was very moving to watch this again. There were a few tears shed by those who first saw this back in 1991 and for those at the luncheon watching it for the first time. This screening just confirmed that we have come a long way since then to a better understanding of TS with a multitude of resources at our disposal today and medical practitioners and professionals that are now more aware of TS.