

David

David Matheson has been a school counsellor for over 15 years. He works in 4 different schools in the beautiful Blue Mountains in NSW - 3 primary schools and one high school. He says that he 'meets all sorts of children with many different issues.' Twice in his career, David has counselled children living with TSC. Like most young children they were finding it hard to understand the condition, but he thinks they were both pretty shocked and pleasantly surprised to learn that their counsellor not only knew and understood the condition but lives with it himself!

Anyone who was at the TSA conference in 2011 or who has watched David's entertaining video on our website (<https://tsa.org.au/our-stories/david-getting-on-with-life/>) will know that David wasn't diagnosed with TSC until he was 26 years of age. Even then, being otherwise symptom free, he had only consulted a doctor to make sure the growths on his face that he'd lived with since childhood (angiofibromas) were not cancerous.

David remembers that receiving his diagnosis was difficult and confronting. He struggled to understand the condition and felt bombarded with all the things that could potentially happen to him as a result of having TSC. He says it was completely overwhelming: 'I seemed to spend the entire year following the diagnosis going to appointments with specialists I'd never visited before - neurologists, nephrologists, cardiologists and dermatologists - and undergoing what seemed like an endless round of tests.'



David's general practitioner suggested there might be a TSC support group. About a year after his diagnosis, David tracked down ATSS (now TSA) and phoned its founder, Lynn Wilson. Lynn was the first person living with TSC that David had spoken to. At her invitation, he went along to the ATSS picnic day in Hyde Park Sydney in 1995. Later he went to ATSS' Annual General Meeting and sat in on a committee meeting, both of which were chaired by then President Sue Pinkerton. It wasn't long before he found himself elected to the committee. He says he was keen to get involved because he wanted to learn more about TSC and felt that hearing other people's stories was the best way to do this.

Initially David felt he didn't have much to offer as a committee member but, over time, he took on a range of responsibilities and became really absorbed in the organisation. He says: 'I felt ATSS was doing really good work and I wanted to be a part of it.' Although he had no prior editorial or publishing experience, he boldly took on the role of Editor for *Reach Out* (this magazine) for 16 years, driving its evolution and seeing it through many changes. He also took up the committee posts of Secretary and Public Officer. He served on the committee for an amazing 20 years until November 2015 and believes it was a very worthwhile experience. TSA remains indebted to his dedication and commitment.

During his time as a volunteer committee member David met many people at conferences and seminar events. He thinks that many new parents found it refreshing to meet someone who was not so severely impacted by TSC, especially when they were only hearing and reading about people with the disease who had severe epilepsy, intellectual disability and autism. David notes that the thing he finds always surprises people about TSC is the range of possible symptoms and how it affects everyone in such very different ways.

David has not had any treatments despite the fact that he lives with TSC. He says he has lived with his facial angiofibromas for so long that he hasn't even felt the need to try topical Rapamycin. He finds his medical team are always stunned that he is on no medications at all. He has a renal ultrasound every couple of years and knows he has cysts, but says they are not causing him any problems and his nephrologist has no concerns about them.

Ten years on from his video at the TSA conference, David says that he is lucky and grateful that TSC still isn't having a huge impact on his life. After

diagnosis it took a couple of years before he could just get on with life again. Although there is always a thought in the back of his mind that things could change, he just takes life one day at a time and will deal with whatever arises if and when it happens.

When asked what advice he would give to other people affected by TSC, David suggests taking opportunities to connect with other people who understand TSC: 'It's important to be well informed and to gather as much information as possible. Talk to other people who have experience of TSC - getting involved and making connections through TSA is a good way to do this. I'd suggest reaching out to your regional contact or attending an event.'

Although he is no longer on the TSA committee, David stays connected and keeps up to date by reading *Reach Out* and through the TSC Facebook discussions group. He also participated in the recent TSC Virtual Conference and says it was good to get updates from the expert health professionals. And, whilst he's no longer a volunteer for TSA, David tells us that he is kept busy with his demanding job, married life and being a good uncle to his 12 nieces and nephews.

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