

## Connecting the Type 1 Community - A Social History of the Type 1 Diabetes Network

The Type 1 Diabetes Network (T1DN) began as a group of young adults with diabetes, who wanted to help make a difference to the services and supports that were available to people like them. In 1998, at the prompting of endocrinologist Alison Nankervis and diabetes educator Trish Streitberger, Kate Gilbert organised a dinner for young adults with diabetes, asking people to come along and meet others like them, who were dealing with the lifestyle changes that young adulthood demands, along with the added stresses of managing a complicated and dangerous disease like Type 1 Diabetes. This group called themselves Reality Check.

Reality Check was a place where people could share stories and experiences, and connect with others who were in a similar situation to them. Diabetes support services at that time were limited, and most were focussed either on young children, or on older adults (often adults with Type 2 diabetes). Reality Check was something new: an energetic, fun group of 18-35 year olds who wanted to make life easier, or at least less isolated, for their peers. Colleen Clarke, a long term volunteer with the T1DN, was diagnosed with Type 1 as an adult. She had tried out some of the support services out there, and found that she couldn't relate to a "room with all these 50 year olds." She remembers going along to the events that Reality Check would run: "I really liked meeting a group of people who were quite proactive about their diabetes and how it fitted into their life... I still get the biggest kick out of it, and it was the same then, just being with people who "get it" and understand what it's like." For Monique Hanley, was told about Reality Check a year after she was diagnosed with Type 1, going along to a pub night was a revelation. "It was a pretty awesome feeling knowing that there are other people out there, and it was a very exciting discovery and amazing to come along to my first night...and meet other people."

Reality Check stuck with a relaxed and informal style, which appealed to a lot of people who had been looking for a support network that was more relevant for them. Kate continued to organise the group, with lots of help from Virginia Scarff, another young adult with diabetes, who was involved from the first dinner. Kate and Virginia, with a small team of enthusiastic volunteers, started producing a newsletter, *yada yada*, which was full of stories sent in about embarrassing hypos, diagnosis experiences, product reviews of the latest meters, pens or pumps, and news on upcoming events. Virginia remembers *yada yada* as a way to not only communicate with members and potential members, but also to say, this is who we are: "We're not formal, you're not going to get into trouble if you tell us you've had an absolute binge on mars bars or something! And it's non-judgmental. Basically, everyone's welcome."

As well as the newsletter, and the social nights that Reality Check organised around Melbourne, the group organised seminars and events to get the latest information on diabetes research and management straight to the ears of the consumer, them. The biggest of these events was the Interactive Summit for Young Adults with Diabetes (ISYAD), which ran for the first time in November 1998. The idea was to take the model of a medical conference, and "turn it on its head." Kate remembers that Reality Check wanted to bring the biggest and best names directly to people with diabetes; "I felt that, the doctors get to go to all the conferences and hear the latest and the greatest in diabetes, why don't we?... We deserve to get this information as well from the best." ISYAD was a huge success, and was run again in 1999, 2000 and 2003. The success of the conferences made people in the diabetes world sit up and take notice of Reality Check, who were proving to be just what was needed to engage the young adult demographic in caring about their health, something that health professionals had been struggling with for a long time.

At the first ISYAD, Reality Check launched a website. Putting all its content on the internet allowed the group to get information out to its members quickly and cheaply. It also gave Reality Check the ability to grow outside the social setting of a Melbourne pub or café. The internet gave Reality Check an enormous reach to help young adults all over Australia, particularly in rural areas. The community bulletin board, an early form of the Reality Check forum, allowed people all over Australia to connect with people like them in a peer-moderated virtual community. This type of peer-to-peer networking is understood today to be a great benefit to people managing chronic disease. Given the rarity of a disease like Type 1, which affects less than 1% of the Australian population, it was particularly significant for connecting the diabetes population and combating the isolation that people living with Type 1 can experience. Having operated under the administrative umbrella of Diabetes Australia-Victoria for 3 years, Reality Check was approached by Diabetes Australia's national branch in 2001 about the prospect of becoming a national organization, supported by Diabetes Australia-National. The lengthy negotiations broke down over the issue of the forum, which Reality Check insisted could not become a medically moderated forum, but must remain under their control as a peer moderated community. Unable to be supported by Diabetes Australia-National, Reality Check formed a partnership with the Royal Melbourne Hospital for 3 years from 2001-2004, becoming incorporated during this time. The group operated independently after 2004, and gained charitable status in 2007.

Reality Check undertook some significant projects which improved their credibility in the diabetes world. Receiving two federal grants in 2003, it undertook a review of the transition clinics at the Royal Melbourne Hospital, recommending improvements to this service for young adults with diabetes, and also produced a publication for newly diagnosed adults, the Starter Kit, which has undergone two reprints and is widely distributed around Australia. In 2006, Reality Check changed its name to the Type 1 Diabetes Network (T1DN), a name that better reflected their purpose and broadened their demographic. The T1DN surveyed members to produce a consumer-led quality improvement research paper on people's usage of the healthcare system, which was accepted into the 2006 World Diabetes Congress in Cape Town, South Africa. The Network, led by President Kate Gilbert and with a lot of support from its treasurer Melinda Seed, continued to produce consumer-led research of this nature, and attended many conferences and seminars to represent the voice of the Type 1 community.

The T1DN has an active online community who use the forum as a platform for organising social events. It continues to run seminars and events to bring information on the latest research and technologies to its members. In 2007 the T1DN supported a new online forum for parents of children with Type 1, called Munted Pancreas. The website was redeveloped in 2009, thanks to a community grant, allowing the T1DN to easily maintain the site and its two peer-moderated forums. The T1DN now also has a small income thanks to some industry advertising in the e-newsletter, which has allowed it to invest in its administrative functions. In 2011, Kate Gilbert stepped down from her position as President, leaving the T1DN with a dedicated Management Committee and formal organisational structure.

The T1DN has empowered its members to be proactive in managing their diabetes, and living a healthy lifestyle. The organisation has connected the Type 1 community and given it a voice to improve the services and support available to them. What began as the vision of a group of young adults has produced a national organisation that has exceeded their expectations of what could be achieved; a group, 5,000 members strong, dedicated to the aims of connecting and empowering the Type 1 Diabetes community to live healthy and happy lives.