

“10 years in the making”

I write this report as my last for MND Tasmania President and as a Board member. I'd like to use this opportunity to reflect on the previous 10 years of the association to distil what I think are some of the major pivotal moments in our history. From when I joined the MND Tasmania Board in 2006 and over the proceeding 12 months, we raised our eyes as a Board to start looking at what other state MND associations were doing well to support people living with MND. Our history and relationship with other state associations appeared strained at and we worked hard to repair relationships and start learning what we can do better in Tasmania.

One of the first pivotal moments in our quest to improve was the establishment of the information and support line through MND Victoria on 1st April 2007. Up until this point we had relied on Board members and volunteers to staff a local phone number. Through this contracted service, MND Tasmania members now had access to a service open Monday to Friday 9:00am to 5:00pm with nationally consistent information packs for both those diagnosed and Tasmanian health professionals. At the same time a new peak body in Tasmania emerged called the Neuro Muscular Alliance of Tasmania (or NMAT) and along with other neuro-degenerative disease associations, sought to raise common issues with Government and service providers.

We started 2008 with much sadness at the passing of a life member, Bill Braithwaite. Bill had contributed much to the cause of MND Tasmania over many years and was a strong advocate for people in Tasmania. 2008 was also a time for us to hear what MND Tasmania members needed most to help cope with MND. This is what they said:

- *Access to quality information*
- *Assistance to access services*
- *Disability equipment*
- *Counselling and support*
- *Information on research*
- *Information and training for health professionals*

These member survey results were clear and the current Memorandum Of Understanding (MOU) for support services with MND Victoria was up for review. I remember this time as the second pivotal moment. We were happy with the results of the previous MOU (to improve *access to quality information*) yet we knew so much more was required to provide members *assistance to access services*. It was with some trepidation yet courage that the Board sought to expand the MOU with MND Victoria for a further 3-year period, deepen the ties and extend services. Our aim was to seek funding for a Regional Advisor service like most other MND associations nationally and internationally.

We were ecstatic to learn at the end of 2008 that a philanthropic trust in Victoria had seen the work MND Tasmania and MND Victoria had been doing to establish a service and build long-term partnerships. They consequently provided 3 years of funding for our inaugural adviser, Jennene Arnel. From early 2009, Jennene began the ground work for creating knowledge amongst health professionals, understanding the Tasmanian health, disability, community, palliative and aged care services available. Importantly, she provided face-to-face visits to MND Tasmania members and linked them into services they needed. By the end of 2009, MND Victoria and MND Tasmania hosted the first health professionals forum at the Tramsheds in Launceston. I consider this the third pivotal moment. Right in front of us was a group of passionate health professionals with a thirst for MND knowledge and networks that had eluded Tasmanian health professionals.

In 2010, we consolidated the Regional Advisor service across the state, welcomed Anna McPherson into the role of volunteer fundraising coordinator and continued lobbying Government for funding our important services.

During 2011 MND Australia and MND NSW hosted the MND / ALS International Conference in Sydney, with 2 MND Tasmania Board members able to attend thanks to grant funding. One of the Board members, Joyce Schuringa, reflected on her learnings and conversations and shared something inspiring with us. Upon returning Joyce commented that “...we have it good here compared to many other places, but there is still much to do for those living with MND...”.

We got a new face and brand for MND Tasmania in 2011 in the form of a young and brave member, Jackie Chugg. Jackie never stopped putting herself in front of the cause and the camera to raise the profile, awareness and donations for the MND cause. We also celebrated one of our own Tasmanian advocates, Guy Barnett MP. Guy was appointed MND Australia ambassador and has continually advocated for and supported the MND cause in Tasmania and Australia. We also got a new volunteer fundraising coordinator in Mary Erickson who took over the great work that Anna has commenced the year prior.

In 2012, we were fortunate enough to receive a grant from the Winifred D Booth Charitable Trust for \$20,000 over 2 years to support people living with MND in Tasmania and we also watched the emergence of the National Disability Insurance Scheme (NDIS) closely. As the no-fault disability insurance scheme gained momentum we were increasingly hopeful that the benefits for our members were greater access, choice and funding for services they need. Of concern was the discrimination of people aged over 65 years of age who are unable to access the NDIS. To this day this age barrier is still in place for the scheme and MND associations across the country must continue to advocate that this is removed. Over 50% of people diagnosed with MND will not be eligible for the NDIS.

As 2013 rolled on we turned our attention to governance. Behind the scenes, we worked hard on our Board policies and procedures including revising our constitution for the following Annual General Meeting (AGM). We also welcomed a new Regional Advisor Leanne Conway to the role to fill the enormous shoes of Jennene Arnel who had established and built the role over the previous 5 years.

We were very sad to farewell our Treasurer Dora Hugo in 2014, who took great care and diligence to maintain our accounts and audits for the 7 years prior. She left us with a clear, accountable and organised chart of accounts for us to budget and forecast confidently into the future. I was also honoured to be voted in as Vice President of MND Australia and be part of the encouraging national team that was forming. Excitingly for the association the Lions Club of Tasmania undertook a state-wide drive to raise money and awareness for MND in Tasmania and in May 2014 we received a cheque of over \$10,000 from Lions District Governor George Bugeja. In August 2014, we had arguably our third and greatest pivotal moment – the ‘ice bucket challenge’. This grass roots viral campaign starting in America was a catalyst for enormous exposure and awareness for MND across the community and led to significant donations in Tasmania, Australia and around the world. This birthed a great idea from Jackie Chugg to create a Facebook page for MND Tasmania for people to post their ice bucket challenges. Jackie created and managed this Facebook page right up until she passed away in 2016.

As we entered 2015 we said goodbye to Inez van Polanen from MND Victoria who had supported us for nearly 9 years in coordinating information, newsletters, administration and health professional forums. Our pivotal moment number five was an exciting maturity of the MND Adviser being appointed and based on ‘the island’. For the first time since the inception of the service through MND Victoria, we welcomed Hayley Tristram who is based in Launceston. In September 2015, the MND Tasmania community were very saddened to hear of the passing of Lady Sally Ferrall. Lady Ferrall had been a founding member of the association and our patron. Like her son, Guy Barnett, she had always advocated for the MND cause in Tasmania.

In 2016, we said goodbye to Mary Erickson in her role as Northern Support Group coordinator and fundraising coordinator. Mary was a stalwart of the association and has contributed a huge amount of time and energy for more than 15 years of volunteer service. Hats off to you Mary.

MND Australia also commissioned Deloitte Access Economics to report on the cost of MND in Australia. Shockingly to the economists yet no surprise to many in the MND community was the cost of someone being diagnosed with MND. Figures from 2015 come in at over \$1.1 million per person diagnosed. Nationally this equates to \$2.37 billion per annum. Access to quantitative information such as this is a powerful driver for arguing the case for investment in both research and care for people living with MND.

The MND community was again saddened by the passing of Jackie Chugg in October 2016. Jackie spoke for all people living with MND in Tasmania in the powerful and moving advertisements shown on Southern Cross television with Shane Chugg, Anna McPherson and herself. She has become the face of MND Tasmania. We also had a very important birthday celebration for MND Tasmania, our 30-year anniversary. We celebrated in Launceston with a great turnout including life members and stalwarts of the association Anne Steer, John Hughes AM and Rosemary Stobart. Longstanding member Kerry Upchurch was also there with his wife Sharon and their sons.

For me personally, 2016 was the toughest year I’ve faced. My father, Tony Hynes finally succumbed to his battle with MND after more than a decade. It has been hard to keep my flame burning as brightly inside as it once did.

As I draw us into the here and now I reflect on the growth and maturity we have achieved in MND Tasmania. We’ve grown up to provide the services we know we need to be delivering across this state to help people living with MND. To this end I would like to say very special thanks to Rod Harris (CEO, MND Victoria) for your partnership, vision and belief in me and the association.

Lastly, I’d like to say a very heartfelt thanks to my fellow Board members for the incredible support, energy and passion you have given to this cause in Tasmania. I wish you all the best and look forward to staying in touch!

I still believe strongly that we are not far from beating this disease and until we do always remember to “Never Give Up”.

Tim Hynes, Retiring President