



Editorial



New Beginnings

Editor: Dr. Linda Nichols

New beginnings for organisations such as Huntington's Australia are dedicated to bringing positive change for individuals and their carer networks.

The Nationalisation of the state based Huntington's networks has involved the process of transforming previously state based organisations and bringing them under the umbrella of a national organisation. Whilst the type the merger is in full swing, bringing with it benefits for individuals impacted by Huntington's and their carers

In 1974, the Whitlam Labour Government introduced Australia's first universal health care system. Whilst this ensured affordable health care for all, there was and continues to be gaps. These gaps have tended to be filled by not-for-profit organisations and disease specific organisations.

The state based Huntington's organisations have long provided support for families affected by Huntington's Disease. With support also extending to Huntington's disease clinicians and researchers. Given the rarity of Huntington's disease state based organisations have struggled. Memberships have been small and sustainability has been challenging.

The implementation of the merger and amalgamation to a National organisation will see current connections expand to provide the best care, support and clinical care. It is crucial to build a larger organisation that brings long term sustainability.

For myself, as a board member of Huntington's Tasmania this year has been busy and I am excited to have the opportunity to share news and be a part of the Huntington's community during the amalgamation

Huntington's Australia

Guest Editorial: **Alison Weir**

Following the recent announcement about State Association memberships agreeing to proceed with a national merger, Huntington's Australia (HA) has appointed a CEO to lead the new association.

Lenni Duffield, from Huntington's WA, has been unanimously endorsed by the HA Board as the inaugural CEO of Huntington's Australia. Lenni has held senior roles and provided business consulting services in health and community service sectors, has qualifications in business, management and leadership, community sector management and is currently in the process of completing her Master in Business Administration with the Australian Institute of Management, with whom she is an Associate Fellow.

"Lenni comes equipped with a range of skills, knowledge, qualifications, experience and personal attributes that make her a standout candidate. Her commitment to and passion for bettering the lives of people with and impacted by Huntington's disease is unquestioned." Says Chris Glasson, Chair HA.

"Fortunately for us, we have been able to see what Lenni can do in person over a good time-period, through her work as CEO in WA and thorough her Project Management work with the merger feasibility study and more latterly planning for the merger implementation. Her consistent, high-quality work and standards over an extended period give us great confidence that we have the right person to take the new organisation forward." Chris continues.

Amongst all the other things that are happening, perhaps the most important piece of work is continuing with the long process of obtaining the NDIS registration. This will allow Huntington's Australia to extend the NDIS support services currently offered in WA and NSW into all the other States. When planning was started for this mid last year, NDIS were working within their stated



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and nationalisation of Huntington services, support, clinical care and research.

The merger to Huntington's Australia brings with it a repository of information, skills and lived experiences. Previous gaps and opportunities for improving services are centre front of the merger.

I am excited to have Lenni Duffield leading the way as the inaugural CEO. Lenni brings to the position a varied and wide range of skills, experience, knowledge, qualifications and personal attributes. Lenni also brings to the position a high level of commitment, leadership and passion, that has been evident during this momentous occasion.

This year has already been very busy and it is exciting to have the opportunity to share and be a part of the implementation of the merger and amalgamation of what were state based services to a national organisation, Huntingtins Australia. I encourage you all to share the news and to watch this space and the benefits of sharing resources. The goal of the amalgamation of resources, skills and experience is to help individuals impacted by Huntington's disease live their best life.

Linda

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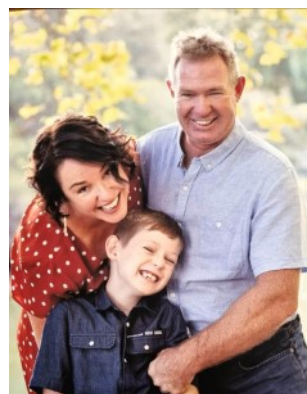


Huntington's Australia

Alison Weir

Comms & Fundraising Project Lead

policy of taking up to 3 months to approve registrations. Recently that timeframe has blown out and this may jeopardise the expected 1 July date for merging, as Huntington's Australia must be registered to continue to provide and grow the services. Whilst hopeful of meeting the 1 July merger date there has been discussions about Plan B, just in case, being a possible delay of up to 3 months. There were other options that might have enabled us to nonetheless merge on 1 July, but they were complicated and did not uphold our number one principle of putting our clients and community first. We will keep the community informed of the registration progress.



"This is my family, myself, my husband Adam and our gorgeous son Lawson. We are a busy little family juggling working life and living on a working property looking after a menagerie of farm animals, it's always hectic with something to do, but we love it! We have fruit trees, grow veggies and run our own sheep. I'm fiercely passionate about the for-purpose sector and championing the roles and vital contributions that organisations such as the HD state associations and Huntington's Australia contribute to communities and the government. When I'm not doing the work I love, I'm in the garden (a labour of love), or entertaining friends and family at home when not studying for my MBA or volunteering on local community projects. Also, when time permits, I love being creative!"

Alison

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