Huntington's Australia – a New National Association to Support the Huntington's Community.

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ABSTRACT

Huntington's disease (HD) is a rare, progressive, neuropsychiatric disorder that is inherited. Although there are treatment options for some of the symptoms, currently there is no cure, despite much research. In addition to medical, nursing and allied health care, a person with HD needs a great deal of support. Until now, this support, for individuals and their families, has been facilitated by Huntington's Disease Associations in each Australian state and territory. It has been a long-held dream to merge these Associations to form a national body, so as to provide better and more equitable support, increased resources, greater sustainability and create consistent educational material for everyone impacted by HD. The ultimate goal is to help people impacted by the condition live their best life. This dream is about to be realised as 5 states and 2 territories will merge to create Huntington's Australia, planning to begin operations later this year. The journey over the last 3 years towards this dream is described in this paper.

Key words: Huntington's disease, Huntington's Disease Associations, national merger

A SNAPSHOT OF HUNTINGTON'S DISEASE

In 1872, George Huntington, an American physician, described an inherited form of involuntary movements known as chorea, a word derived from Greek and Latin meaning 'dance' (Harper, 1991). He noted that this form of chorea involved a range of psychiatric symptoms, began in adult life and progressed with time. His was the first medical description of what came to be known as Huntington's disease.

Three main groups of symptoms are recognised: chorea; psychiatric and behavioural disorders; and cognitive decline. There are many other neurological aspects but it is not proposed to describe them here.

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The severity of symptoms, including their progression over time, varies between people with HD. A number of large studies are currently being undertaken world-wide documenting the natural history of HD, such as Enroll-HD (Sathe et al., 2021).

Symptoms of HD usually begin in adult life, between the mid-30s to mid-40s, however, HD can begin at any age, from a less common juvenile form affecting children and teenagers to a late-onset presentation in the 70s and 80s.

The prevalence of HD varies across world regions. One study estimated the prevalence in populations of European descent including Australia, Western Europe and North America as 9.71/100,000 (Rawlins et al., 2016). The prevalence in Asian and African populations is significantly less (Medina et al., 2022). In Australia, it is estimated that in 2020, there were about 2000 people with HD (Julie Stout, personal communication).

A cruel twist of HD is that it is inherited – each child of a person with HD has a 1 in 2 chance of inheriting it. It is equally likely to affect males and females. The gene that causes the condition, called huntingtin, was discovered in 1993 (Huntington's Disease Collaborative Research Group, 1993). The huntingtin gene contains an expansion of a CAG triplet repeat which in turn causes it to make an expanded protein. This leads to degeneration of neurons particularly in the basal ganglia and cerebral cortex which, in turn, cause the signs and symptoms of HD (McGolgan and Tabrizi, 2017). It is not proposed to describe the complexities of the CAG repeat in this paper.

Genetic testing (usually a blood test) is available for individuals who have a family history of HD confirmed on genetic testing, to see if they have inherited the condition or not, before they have developed any signs or symptoms (Quaid, 2017). Consequently, this type of test is called a predictive or pre-symptomatic test. In each capital city in Australia, there are genetics clinics which arrange such testing following international guidelines. A process of information gathering, discussion and counselling is undertaken for the individual seeking testing as it is clearly a serious step to take, to look into the 'crystal ball' and see whether the person can expect to develop HD in future or not. The result also has implications for the person's (future) children. Testing is generally offered only to people 18 years and over as they must be able to give informed adult consent to take the test. Whether or not to be tested is entirely the decision of the person themselves – no one else can decide for them, including relatives, friends, spouses, doctors or insurance companies.

Genetic testing is also done when symptoms suggest HD to confirm the diagnosis. This is referred to as a diagnostic test.

A woman and her partner, one of whom has a genetically confirmed relative with HD, can choose to test the Huntington's gene in pregnancy, if they wish. If the pregnancy is shown to carry the gene expansion and so would develop HD in adult life, the woman can choose to terminate the pregnancy. Testing is usually done at 11 weeks of pregnancy by a procedure called chorion villus sampling (CVS) in which a sample of the developing placenta is taken to be tested (Pina-Aguilar et al, 2019). It can also be performed at around 15 weeks gestation by amniocentesis.

Another option for a couple with a genetically confirmed relative with HD is to have in vitro-fertilisation at a reproductive medicine clinic in which the embryos are tested and an embryo predicted not to carry the expanded huntingtin gene is transferred to the woman's uterus (Pina- Aguiler et al., 2019).

Management of HD ideally involves a multidisciplinary team. Pharmacological treatment includes treatment for psychiatric symptoms, if required, and, in some people, treatment for the movement disorder. Currently, there is no drug that can alter the course of the disease but there is much research into it. Many health professionals such as nurses, physiotherapists, speech pathologists, dietitians and psychologists have an important role in managing HD. Other measures may include art therapy, music therapy and managing the environment because structured routines and calm surroundings are often beneficial for individuals with HD (Samperi et al., 2021).

There is much promising research into various aspects of HD (Tabrizi et al., 2022). Of particular interest are drugs that could lower the levels of the expanded huntingtin gene and therefore of the abnormal protein and so could potentially slow or halt the progression of the symptoms of HD. A website that summarises current research into HD in plain language is HDBuzz (https://en.hdbuzz.net)

Impact of HD

The symptoms of HD begin subtly so it is usually difficult to pinpoint the exact time when they begin. Gradual changes in person-

ality such as apathy, irritability, moodiness, irascibility, impulsiveness and depression are often present for several years before a diagnosis is made (Hayden, 1981). Difficulty thinking clearly and making decisions lead to impaired functioning at work or in the home. Jerkiness, clumsiness or mild incoordination are the forerunners of chorea.

Gradually, ability to carry out normal activities is progressively impaired until there is dependence on others for all aspects of care. Death occurs some 15-20 years after symptoms begin (Ghosh and Tabrizi, 2018).

As one family member described, a person with HD starts out having a normal life, may have a partner and children, a job, friends, interests and all the highlights and usual challenges of life. The appearance of HD introduces a relentless series of losses: loss of ability to think clearly, loss of judgement, loss of social skills, loss of control over physical functioning, loss of spouse or partner, loss of employment, loss of the ability to drive, loss of home, loss of friends, loss of independence and ultimately, loss of life. Marriages and partnerships are often early casualties as the person with HD is changing in so many ways. Especially difficult for the partner are the changes in personality.

For the family there is the added burden of knowing that relatives of a person with HD may also have inherited it. The decision to take a predictive test or not is complex and reproductive choices often pose another level of anxiety.

HUNTINGTON'S DISEASE ASSOCIATIONS IN AUSTRALIA

It is clear that Huntington's disease imposes a huge burden not only on the person with the disease but also their family. Friends and colleagues may become involved. Health practitioners need easy access to current information as this is a rare disease. The whole community is affected in the sense that appropriate support and accommodation must be found for people who are dependent on others for their everyday care.

In each Australian state and territory there is a not-for-profit Huntington's Disease Association offering a range of supports and services. They are Huntington's SA & NT, Huntington's Disease Tasmania, Huntington's WA, Huntington's Queensland, Huntington's NSW & ACT and Huntington's Victoria. Each Association is a separate entity with a governing Board and management structure. The Associations provide a wide range of vital community supports, services and programs including outreach, triage, education and awareness, connection to allied health and other services, support groups, opportunities for social engagement, counselling, advocacy, tailored individual supports and National Disability Insurance Scheme services. Each Association delivers these supports and services separately from the other states.

All the Australian Huntington's Associations have grown out of community concern and contribution, built from the ground up with passion, volunteer labour and fundraising, filling a void in government service provision. Some have progressed to going business concerns, with sound business models while others have struggled. Consequently, the range of service provision across the board is inequitable.

WHY HAVE A NATIONAL HUNTINGTON'S DISEASE ASSOCIATION?

Limitations of state-based Huntington's Associations

HD is one of many rare diseases but it has a devastating impact. Most people have never heard of it and even among health professionals and care institutions knowledge about it is often limited. Consequently, most state-based Huntington's Associations have a small membership and staff base, and lack sustainability. It is crucial to build a larger organisation that is sustainable in the long term to ensure ongoing support for the Huntington's community.

The Huntington's Associations are not alone – the changing regulatory and economic landscape of the Australian not-for-profit sector is placing unprecedented pressures on charitable institutions impacting how they manage their resources. Major national reforms, unprecedented crises and changes to government contractual practices have escalated the pressure on charities' operational and financial models. The competition for the charity dollar has never been higher. The Australian Charities and Not-for-profits Commission (ACNC) lists about 60,000 charities registered in Australia (https://www.acnc.gov.au).

BENEFITS OF A NATIONAL ASSOCIATION

It has long been recognised by the state Huntington's Associations that a national body would be stronger and more sustainable, providing enhanced and more equitable sup-

ports and services to the HD community. Key features would be:

- Amalgamation of the skills, resources and experience of the individual states while removing duplication of infrastructure, driving down costs, expanding services and building new skills.
- Greater ability to attract funding from governments, philanthropists and grant -giving bodies.
- Enhanced visibility for successful awareness-raising campaigns.
- More effective advocacy on behalf of those impacted by HD.
- Development of a consistent body of educational material for people with HD, their families and carers, and for health professionals.
- Greater opportunities for staff development which would attract high calibre staff to the organisation.

The ultimate goal is to provide more and enhanced services to people impacted by HD. There are risks associated with a larger national body such as:

- Loss of local autonomy and community outreach;
- Imbalance between the various states in terms of representation and resources;
- Loss of focus on the most important reason for the organisation – the people with HD and their families.

Over the years, several attempts at a merger of Australian associations have been made, unsuccessfully. The following describes the enormous progress that has been made in the most recent journey to create a national body.

CONSORTIUM OF AUSTRALIAN HUNTINGTON'S ASSOCIATIONS

In 2020, following a successful collaboration of the state-based Huntington's Association CEOs over the previous 18 months, it was proposed that the states form an alliance. A Memorandum of Understanding was signed by 5 state Huntington's Association board chairs in July 2020, supported by all their boards. The MOU articulated a willingness to cooperate and collaborate at a strategic level to maximise benefits to Huntington's communities, while sharing resources, skills and experience. The alliance was called the Consortium of Huntington's Associations of Australia (CAHA). All Australian Huntington's Associations were welcome to participate. Those that joined were in SA & NT, Tasmania, WA, Queensland and NSW/ACT.

CAHA soon found itself, on the back of the good will and cooperation garnered through collaborative state efforts, contemplating amalgamation of the state and territory Associations. A strong appetite developed for forming a national organisation and in November 2020, CAHA members wrote a Statement of Strategic Intent (SSI) that suggested a study be undertaken to assess the feasibility of a merger. State boards reviewed the SSI and agreed.

FEASIBILITY STUDY

After a competitive tender process, a company called Good Foundations was employed to guide the Feasibility Study. Good Foundations is a company that specialises in working with 'non-profit organisations to build effective operational, financial and strategic foundations for their business'.

(http://www.goodfoundations.com.au)

PHASE I OF THE FEASIBILITY STUDY

Good Foundations recommended that the Feasibility Study be divided into two phases. Phase I would consider the 'fundamentals' such as the willingness, readiness and alignment of the states, in order to assess if they were ready to merge and Phase II would concentrate more on the 'mechanics' of the merger, in terms of the practicalities and process to make it happen. Phase 1 took place in early 2021 in which CAHA members, state board members and other stakeholders completed a survey and were interviewed by staff of Good Foundations to gauge attitudes to the merger. CAHA members also attended an online workshop convened by Good Foundations. The outcome was a clear recommendation to proceed on the basis that the benefits of a merger greatly outweighed the risks and the states were willing, ready and aligned in their thinking. The new organisation would be a completely new single entity, that is, not built or based on one of the existing associations; Members of CAHA and the state boards agreed to proceed to Phase II, also facilitated by Good Foundations.

PHASE II OF THE FEASIBILITY STUDY

After months of planning and preparation, Phase II took place in the first half of 2022. Business and financial models were developed, organisational plans were drafted, legal and governance aspects considered and due diligence was conducted on all the merging Associations. The outcome of the Phase II study was that CAHA and the state boards agreed to continue the process and to merge the 5 participating state and territory Associations into one entity called Huntington's Australia (HA). It was clear that a single body would be able to better service the HD community and be more sustainable than if remaining as separate, relatively small entities. The original state Associations would remain operational until HA formally began operations ('Day 1') which is anticipated to be in the second half of 2023. Funding of the merger would be by the states and territories according to their ability to pay.

PHASE III – THE IMPLEMENTATION PLAN

CAHA's Feasibility Project Manager supported by Good Foundations then set about the arduous task of developing an all-encompassing Merger Implementation Plan, including scoping of the necessary resources and costs. This Plan was subsequently approved by CAHA and the state boards.

The Plan covered every aspect of the merger: funding & finance, IT, systems, people & culture, operations, legal and governance, marketing and branding, risk and compliance, NDIS registration and project governance.

Part of this planning process determined the merger to be a Transfer of Business under the Fair Work Act provisions which aims to provide a balance between employee and business needs in transferring work, resources and assets from one organisation to another. The Merger Implementation Plan also identified some initial tasks such as writing a constitution for HA, establishing and registering a new company (including gaining charity status), forming a new board and developing a stakeholder engagement plan, all of which have been completed. In addition, and before proceeding too far with broader Plan implementation, a legal pathway had to be forged towards seeking state board and then Associations' membership endorsement for the merger.

BOARD OF HUNTINGTON'S AUSTRALIA

The new board was assembled in August 2022. Its formation meant that the work of CAHA could now be handed over to it. The board held their first meeting by videoconference in September 2022. Their first face to face meeting was in Adelaide in February 2023. At that time, a workshop was also held, facilitated by the head of Good Foundations, at which board members got to know each other better, aligned their thinking on what sort of organisation they wanted HA to be, how they would work together, how the board should function going forward and also agreed on vision and purpose statements for HA as well as some initial thinking on the drafting of a Strategic Plan.

VOTING BY STATE BOARDS AND MEMBERS

A very important step was the vote by the 5 participating state and territory boards on whether or not to proceed to the merger. This voting took place in August 2022 and the result was unanimously in favour of a merger. Membership voting then took place throughout November 2022 with the states unanimously in favour of the constitutional changes that would enable the merger. A resounding vote of confidence – Huntington's Australia was truly going to happen! It may seem unusual that significant merger plan tasks were undertaken prior to the voting, but a number of these were necessary precedents to the membership voting. Members needed to understand what sort of new entity they were voting in favour of, what its constitution looked like and how it was going to be governed.

MERGER IMPLEMENTATION

In December 2022, the inaugural CEO was appointed to oversee the merger implementation process and then bed down and progress the aims of HA. The new entity's business model is strongly based on increased and national fundraising and introducing and enhancing NDIS service provision into all states and territories. This will be central to supporting and increasing the community services and programs arm of the business, the heart and soul of the offerings, and the critical interface with HD clients and community.

Now in 2023, the Merger Implementation Plan is largely on track and two senior staff members, in addition to the CEO, have been appointed to lead Finance & Corporate Services as well as Community Programs and Services. Key elements of the work include NDIS registration, staff transfer and recruitment arrangements, setting up of various systems (information and communications

technology, customer relationship management, banking, accounting), development of a suite of policies and procedures, and national branding, trademarking and marketing.

Throughout Phases I, II and III and continuing, there has been a small Project Management Team convened from CAHA and state boards, then by the HA board, led initially by a Project Manager (one of the state CEOs), then by the HA CEO to oversee the process and manage risks. The process, as predicted, has been an enormous amount of work undertaken by staff and volunteers, many of whom have worked countless extra hours. As also predicted, there have been numerous challenges both large and small along the way but the direction has always been forwards.

State boards, CAHA and now the HA Board are all indebted to Minter Ellison for a substantial amount of pro bono legal advice over the last 3 years to support the merger.

The board of HA looks forward to working with many partners and stakeholders in future, for example, the Huntington's Disease Network of Australia (HDNA), a research organisation aiming to prepare Australia for new treatments for HD. As 'Day 1' nears, everyone involved is excited about starting a new chapter in the history of support for people impacted by this insidious disease. It has been a tremendously exciting journey undertaken by many people passionately committed to supporting the Huntington's community. All involved in the gestation of Huntington's Australia look forward to her birth and anticipate the arrival of a thriving national body to walk side by side with the Huntington's community into the future.

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'In Loving Memory of Peter Glasson, 8 August 1963 - 21 February 2023'

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