

## Proposed Merger – Explanatory Statement

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### Background

This year, in addition to the usual business of the AGM of Huntington's NSW & ACT Incorporated (**Association**), there will be the matter of decision making in regard to the proposed merger of the Association with Huntington's WA Inc, Australian Huntington's Disease Association (Qld) Inc, Huntington's Tasmania Inc, and Huntington's SA & NT Inc (together, the **State Associations**) into one new national entity to be known as Huntington's Australia (**Proposed Merger**).

We have written to you previously to provide information and have conducted online forums for stakeholders of the five State Associations outlining why we are proposing to merge and what the benefits are. We believe that greater combined knowledge, capacity, reach and advocacy as a single voice will enhance outcomes for people impacted by Huntington's disease. The goal of the Proposed Merger is to provide sustainable and improved services and support to the Huntington's community. We know that goal is not easily attainable, but together we can put in place the business and financial models that will allow us to grow and enhance services in all states.

The new national entity, Huntington's Australia Ltd, is being registered as a company limited by guarantee (**National Entity**). Its initial board of directors will comprise six Directors with representation from each of the existing State Association Boards (**Board**). We are still in the process of identifying a suitable candidate from Huntington's Tasmania Inc to join the Board and are currently recruiting an additional two directors independent of the State Associations.

The initial Directors of the National Entity are:

- Elizabeth Thompson (SA&NT);
- Kaila Stevens (WA);
- Christopher Glasson (SA&NT);
- Jason de Bakker (Qld);
- Stephen Garrard (NSW/ACT);
- Martyn Jenkins (WA)

A constitution for the National Entity is being drafted and will be made available. The National entity will be a members-based organisation with the following Object (or purpose):

The company's object is to enable those impacted by Huntington's disease to live their best lives (purpose) by means which include, but are not limited to:

- a.* promoting the prevention and treatment of Huntington's disease;
- b.* seeking to relieve the impact, distress or misfortune of all people with Huntington's disease and those impacted by Huntington's disease;
- c.* providing support, respite, recreation, interaction and education for all people with Huntington's disease and those impacted by Huntington's disease, with consideration to age and culture;
- d.* promoting greater awareness and understanding by providing education about Huntington's disease and facilitating skills development in Huntington's care, especially within:
  - i.* government and non-government agencies dealing with people that have, and are impacted by, Huntington's disease;
  - ii.* aged care and nursing facilities/homes and hospitals;
  - iii.* the wider medical profession;
  - iv.* the housing accommodation sector;
- e.* improving the community's awareness of Huntington's disease and its effect on individuals, their dependents and the community; and to enhance the community's awareness of the need and moral obligation to provide adequate help for people with Huntington's disease and their dependents;
- f.* facilitating the provision of suitable services, professional help and advice for:
  - i.* those at risk of having Huntington's disease;
  - ii.* non-professional people having the responsibility of caring and making decisions for people with Huntington's disease; and
- g.* giving families of people with Huntington's disease a strong single voice when making representations to government and other bodies.

## The Proposed Merger

The Boards of all five State Associations are supportive of the Proposed Merger and have voted to proceed to a membership vote. What eligible members of each State Association will be deciding is whether or not to approve amendments to the existing rules or constitution (as applicable) of that State Association as set out in this explanatory statement to enable the Proposed Merger to proceed. If the Proposed Merger proceeds, it is envisaged that the merger will be effected by each State Association:

- transferring all of its assets and liabilities to the National Entity (currently intended to occur by 1 July 2023); and
- being wound up (currently intended to occur at an appropriate time after 1 July 2023 once all residual matters have been resolved).

These timings are indicative only and may be subject to change. A further special resolution to wind up will be put to members once we are ready to finalise this process.

## Summary of proposed changes to the rules of State Associations

The changes required to the existing State Associations' rules to facilitate the Proposed Merger pertain to the Object (or purpose) of the State Association and to the Powers of the Association (or its Board). In some States, changes are also required to the Winding Up and Distribution of Surplus Funds clauses in the rules, as well as revocation of the State Association's Deductible Gift Recipient status. The changes can only be effected via a Special Resolution passed by members at the AGM and require a 75% majority to pass.

The proposed Object changes are designed to ensure that the Object (or purpose) of the State Associations are consistent with each other and with the Object of the National Entity. This will support the transfer of State Association assets to the National Entity as most State Association constitutions stipulate that assets can only transfer to another charity with a similar Object (or purpose).

The proposed Power changes are designed to confirm that each State Association has the power to enter into all transactions necessary to give effect to the Proposed Merger, including to transfer all of the assets and liabilities of each State Association to the National Entity.

Please note that the proposed amendments to the rules of the Association set out in this explanatory statement are not subject to members of the other State Associations resolving to adopt corresponding changes to their rules or constitution.

## Proposed amendments to the rules of Huntington's NSW & ACT Inc

Members of Huntington's NSW & ACT Inc eligible to vote on the Special Resolution at the AGM are being asked to consider and if satisfied, approve the rules of the Association being amended as follows:

### Proposed amendments to constitution of Huntington's NSW & ACT

#### 2 Objects

The Association's objects is to enable those impacted by Huntington's disease to live their best lives by means which include, but are not limited to:~~for which the Association is established are~~

(a) promoting the prevention and control of Huntington's disease;

(ba) providing benevolent relief of suffering, distress or misfortune of ~~for~~ persons having,

~~or~~ suspected of having, or at hereditary risk of having, Huntington's ~~d~~Disease (~~Disease~~), their families and their dependants:

(i) ~~facilitating~~ facilitating access to health services that will give analysis, care, relief and treatment for sufferers;

(ii) facilitating access to other care services including in-home services, residential and nursing facilities for sufferers;

- (iii) facilitating the provision of suitable professional help and advice for:
  - (aA) those at risk with the dDisease; and
  - (bB) non-professional people having the responsibility for caring for and making decisions affecting sufferers from the dDisease;
- (iv) providing supplementary activities for sufferers, their carers and family

members, where appropriate, to improve social engagement; and  
 (vcb) raising and expending funds in pursuit of the objects of the Association;  
~~(b) — to act as trustee and to perform and discharge the duties and functions incidental thereto where this is incidental or conducive to the attainment of these objects; and~~

~~(de) to do such things as are incidental or ancillary to the attainment of these objects, including by:~~

~~(i) — improving the community's awareness of the dDisease, and its effect on sufferers, their dependants and the community, and its awareness of the need and moral obligation to provide more adequate help to relieve the suffering and distress of sufferers and their dependants;~~

~~(ii)(df) promoting a better understanding by the medical profession of the signs and symptoms, occurrence and control of the dDisease; and~~

~~(iii)(eg) providing families of sufferers a strong, single voice when making representations to governmental and other bodies.~~

### 3 Powers

The Association has the legal capacity and powers of an individual and also has all the powers of a body corporate under the Act, including (where in furtherance of the Association's objects) to transfer all or any part of the property, assets, liabilities and engagements of the Association to another entity with the object of promoting the prevention and control of Huntington's Disease.

## Resolution

The Special Resolution being put members of Huntington's NSW & ACT Incorporated eligible to vote at the AGM is as follows:

### Amendment of the Rules

To consider, and if thought fit, pass the following resolution as a Special Resolution:

'That the rules of the Association be amended as set out above in this explanatory statement'.

If eligible members vote yes to this Special Resolution, they will be voting to amend the rules of the Association as described above to facilitate the Proposed Merger.