



## **MINUTES**

## **HUNTINGTON'S SA & NT INC., ANNUAL GENERAL MEETING 2020**

| DATE  | 7 December 2020                                       |
|-------|---|
| VENUE | FitzJames Building, 16 Malwa Street, Glandore & Zoom. |

## Meeting opened at 7.00pm by the Chairperson Liz Thompson.

| 1. | WELCOME          | Liz Thompson, Chairperson, welcomed all present.   |  |  |
|----|------------------|--|--|--|
|    | PRESENT          | 14 in attendance (list attached) – 8 in person and 6 via zoom.  Minutes taken by Michele Giles-Clark               |  |  |
| 2. | APOLOGIES        | Carmen & Chris Warnes, Graeme Andrewartha, Anne McMahon, Mark Corby & Jan Faust.                                   |  |  |
| 3. |                  |  |  |  |
|    | MEETING          | and correct record subject to date change as recorded below. Passed by Chris Glasson seconded by Janet Andrewartha |  |  |
| 4. | Business Arising |  |  |  |

| AG | SENDA ITEM            | DISCUSSION  |  | ACTION   |  |
|----|-----------------------|---|--|----------|--|
|    |                       |   |  |          |  |
| 5. | Chairperson' s Report | 1   |  |          |  |
| J. | Champerson's Report   | being a challenging year due to the                           | ed those zooming in. Liz mentioned 2020  | <b>'</b> |  |
|    |                       | boiling a challering ing your due to the                      | To pulldome.   |          |  |
|    |                       |   | tify and address the needs of people in SA   | <b>\</b> |  |
|    |                       | & NT who have or are impac                                    | cted by Huntington's disease.  |          |  |
|    |                       | Strategic plan: Liz outl                                      | ined the Associations strategic plan.  |          |  |
|    |                       |   | upports & Services; Awareness, Training &  |          |  |
|    |                       | Education; Advocacy; Northern Territory; and National Agenda. |  |          |  |
|    |                       | 1 Sustainable   | Organisation: To build a canable   |          |  |
|    |                       |   | Sustainable Organisation: To build a capable,     financially sustainable and well governed Not For     Profit organisation. |          |  |
|    |                       | _   |  |          |  |
|    |                       |   | In terms of governance, we have  |          |  |
|    |                       |   | continued to add to our suite of <b>policies</b>   |          |  |
|    |                       |   | and procedures led by Chris Glasson  |          |  |
|    |                       |   | and compilation of Association's risk  |          |  |
|    |                       |   | assessment continues.  |          |  |
|    |                       | b.  | Our main aim is <b>FINANCIAL</b>   |          |  |
|    |                       |   | SUSTAIN ABILITY, to be able to fund  |          |  |
|    |                       |   | Association's operating costs on an  |          |  |
|    |                       |   | ongoing basis. Liz touched on the lack   |          |  |
|    |                       |   | of SA government funding for the   |          |  |
|    |                       |   | Association as compared to the other   |          |  |
|    |                       |   | State Associations who still receive   |          |  |
|    |                       |   | funding from their State governments for   |          |  |
|    |                       |   | core activities.   |          |  |
|    |                       | C.  | Grants: several Grants were applied for,   |          |  |
|    |                       |   | with one successful.   | 1        |  |

- d. Fundraising has been a casualty of the pandemic with all fundraising activities cancelled. Liz mentioned Bunnings BBQ's have recently resumed. The upside of this being that expenses have been less, minimising impact to the bottom line.
- e. <u>Volunteers:</u> Liz thanked our very dedicated group of volunteers and asked for people to put their hand up if they are able to do some volunteering.
- f. NDIS: An application has been submitted for the Association to potentially become a National Disability Insurance Scheme provider.
- 2. Supports and Services: To provide a quality range of supports and services to the Huntington's community that meets their needs.
  - a. Recreation Program aka Coffee and Co: held every WEDNESDAY was conducted by zoom during the pandemic (becoming Coffee and Co Zoom) and although now back to face to face, zoom is still being utilised to provide options and to include country folk.
  - b. The Rural Outreach Program: was placed on hold during the pandemic but has recently re started.
  - c. <u>Companion Program:</u> had to be placed on hold this year & is hopefully able to go ahead in 2021 if there are enough volunteers.
  - d. Metropolitan Outreach: has been ongoing.
- Awareness, training and education: To facilitate skill development in Huntington's disease care and greater understanding, awareness and education within the Huntington's and wider community.
  - **a.** Education sessions have been ongoing and have been conducted via zoom and face to face.
- Advocacy: To advocate to government and nongovernment agencies to improve the lives of those with Huntington's disease.

Advocacy has been ongoing.

 Northern Territory: To work with organisations and services in NT to better understand Huntington's disease demographics and support services to the community.

The pandemic has curtailed NT work.

- 6. National Agenda: an area of significant progress this year! Most State Associations have formed a national Consortium which is an agreement to cooperative and collaborate where possible for common purposes and for the benefit of all people with Huntington's and their families all over Australia. This may assist in our Association's long held aim of pursuing the possibility of an Incorporated national body, which, amongst other things, may better be able to lobby and apply for federal funding.
- Liz thanked all Board members, volunteers, the General Manager and the Association's Ambassador.

|                           | <ol> <li>Galpins Accountants, Auditors and Business consultants: Liz thanked both Galpins for their generous donation of this year's audit and Elise who does the Association's books.</li> <li>Donors: \$20,000 has been received in donations with bulk of this coming from two donors. Liz thanked them.</li> <li>Marion Council: Liz thanked the council for their generosity in opening up the office by removing more internal walls, giving the Association COVID friendly seminar &amp; work rooms.</li> <li>Conclusion: Even though this year has been a challenge Huntington's SA &amp; NT Inc. is still here and will be moving forward next year.</li> </ol>   |  |
|---------------------------|--|--|
| 6. Treasurer's Report     | The Treasurer's Report (see attached) and Auditor's Report was tabled by Chris Glasson Chris noted some areas of the report: Last year was not a bad result financially for us. After the difficult previous year, the Association made some adjustments, some sacrifices, pulled in our belts and made measured progress, notwithstanding some significant COVID impacts on revenue in the last half of the financial year. For the year we had an income of \$79,278 and Expenses of \$68,101, leaving us with a before tax profit (our first in a few years) of \$11,177. This was an improvement on the previous year's loss of nearly \$60k - a larger than \$70k turnaround.   |  |
| 6.1 Auditors              | It was accepted that the 2020-2021 Financial Auditors will be Galpins.   |  |
| 7. General Manager Report | <ul> <li>Michele Giles-Clark delivered her report as tabled (attached)</li> <li>Michele highlighted some areas:</li> <li>The positive changes which occurred through the chaos and challenges of COVID-19.</li> <li>The hard work and creativity that has emerged from our volunteers during this time with Coffee &amp; Co becoming Coffee &amp; Co Zoom and the creation of weekly care packs being delivered to members of the Coffee &amp; Co community.</li> <li>The coming together of both the City and Country HD community has started via zoom.</li> <li>Michele thanked the Marion Council for the renovations which have occurred throughout the year. These have opened up the office giving the Association two covid friendly seminar areas and a work room which can become a third seminar room if required. These renovations have allowed Coffee &amp; Co to resume face to face in a COVID safe way.</li> <li>Michele reiterated that fundraising events put on hold would be planned for 2021 and she acknowledged the ongoing support from Bunnings and that BBQ's had recommenced</li> <li>Michele thanked SAHDS for their ongoing hard work with the HD community &amp; commented on the great team work which occurs with our Association.</li> <li>Michele thanked all the volunteers for their ongoing commitment to the Association.</li> <li>Michele mentioned that 2020 had been a time to reflect on how far the Association has come and that, despite the pandemic and many other challenges, the Association is still moving forward.</li> </ul> |  |
| 8. Board Nominations      | Michele Giles-Clark declared all Board positions open and stated that all Board members, are seeking re-election: Nominations: Liz Thompson, Chris Glasson, John Stronnar, Michele Giles-Clark New nominees: Tim Porter & Janet Andrewartha  Liz Thompson: proposed by Catherine Christian. Seconded by Rod Cameron. Passed unanimously by all present.  |  |
|                           |  |  |

|                              | Chris Glasson: proposed by James Draxler. Seconded by Janet                  |  |
|------------------------------|--|--|
|                              | Andrewartha.   |  |
|                              | Passed unanimously by all present.   |  |
|                              | · · · · · · · · · · · · · · · · · · ·  |  |
|                              | John Stronnar: proposed by Chris Glasson. Seconded by Garry Schilling.       |  |
|                              | Passed unanimously by all present.   |  |
|                              | Tim Porter: proposed by Chris Glasson. Seconded by Liz Thompson.             |  |
|                              | Passed unanimously by all present.   |  |
|                              | Janet Andrewartha: proposed by Michele Giles-Clark. Seconded by Rod          |  |
|                              | Cameron. Passed unanimously by all present.                                  |  |
|                              | Michele Giles-Clark: proposed Catherine Christian. Seconded Liz              |  |
|                              | Thompson   |  |
|                              | Unanimously passed by all present.   |  |
| 9. Introduction of new Board | Liz introduced the new Board. Liz Thompson, Chris Glasson, John              |  |
| 5. Introduction of new board | Stronnar, Tim Porter and Michele Giles-Clark. Michele explained that         |  |
|                              | positions within the Board would be decided on at the next Board meeting.    |  |
| 10. Guest Speakers           | Julie Stout via zoom from Monash University                                  |  |
| 10. Odest Opeakers           | B.S., M.A., PhD, FASSA   |  |
|                              | Fellow, Australian Academy of Social Sciences                                |  |
|                              | Professor, NHMRC Leadership Fellow   |  |
|                              | Research Program Lead: Ageing and Neurodegeneration                          |  |
|                              | Turner Institute for Brain and Mental Health                                 |  |
|                              | Julie spoke at length about her research project. Julie has received a grant |  |
|                              | for a 5year project for Huntington's disease research. Julie explained what  |  |
|                              | the project covered and how SA would fit into the project.                   |  |
|                              |  |  |
|                              | Michele Giles-Clark: 2020 Churchill Fellow.                                  |  |
|                              | Michele explained she had received a Churchill Fellowship to address the     |  |
|                              | gap in care for Australians living rurally and remotely with Huntington's    |  |
|                              | disease. Her fellowship takes her (when allowed due to Covid) to South       |  |
|                              | America which has the highest incidence of Huntington's disease in the       |  |
|                              | world. It will take her to Lake Maracaibo in Venezuela, Brazil, Peru and     |  |
|                              | Chile. In South America those with & impacted by HD often live rurally and   |  |
|                              | remotely. The care is very much family and community based. Michele will     |  |
|                              | be interacting with the HD community and those that support them in order    |  |
|                              | to learn new strategies (that can be bought back to Australia for            |  |
|                              | implementation) and in turn share her knowledge and expertise for the        |  |
|                              | benefit of those communities.  |  |

## 11. MEETING CLOSED

Meeting closed at 8.40 pm

Next AGM: TBA Time: 7.00pm Venue: 16 Malwa Street, Glandore SA 5037.