

## Huntington's SA & NT AGM 7 December 2020

### Chairperson's report

1. **Welcome:** thank you for joining us by zoom. We would much rather see you in person but this is better than not seeing you at all.
2. **2020: a challenging year.** This year has seen the world turned upside down by the tiny but cunning corona virus which has caused a COVID-19 pandemic. I know it has been difficult for our members in many ways. However, Michele Giles-Clark, our general manager, and her team of volunteers have worked hard to keep our members in touch. More of that later!
3. **Mission statement:** We aim to identify and address the needs of people in SA and NT who have or are impacted by Huntington's disease.
4. **Strategic plan:**

Our goals are divided into 6 sections: Sustainable Organisation; Supports & Services; Awareness, Training & Education; Advocacy; Northern Territory; and National Agenda. I will describe our activities since the last AGM in each section:

  - a. **Sustainable organisation: To build a capable, financially sustainable and well governed Not For Profit organisation.**
    - i. In terms of governance, we have continued to add to our list of policies and procedures, led by Chris Glasson (Board member, secretary and treasurer). Compilation of our risk assessment document continues,
    - ii. As always, our main concern is financial sustainability. We need money to fund the programmes that we run and want to run for people with HD and their community. In some states, the Huntington's Associations receive substantial amounts of money from their governments, but we do not here in South Australia.
    - iii. Grants: we have applied for several grants this year and Chris Glasson will describe them.
    - iv. Fundraising has been a casualty of the pandemic. The monthly Bunnings BBQs were cancelled and resumed only recently and the City to Bay Fun Run was cancelled. It is being run virtually but is very difficult to access. However, on the flip side of the coin, our expenses have been less which has maintained a reasonable balance of our overall financial situation, as Chris Glasson will tell you in his report.
    - v. Volunteers: we have a small but dedicated group of volunteers and I will say more about them further on. Of course, we need more volunteers, so if you know of anyone who would like to help, please let Michele know.
    - vi. NDIS: Chris Glasson has spent countless hours working on our application to become a National Disability Insurance Scheme provider. If and when this eventually goes through, it would greatly

help the Association to raise the funds we need to enable us to keep offering our programmes. He will discuss this in his report.

**b. Supports and Services: To provide a quality range of supports and services to the Huntington's community that meets their needs.**

Our main 'reason for being' is to offer programmes for the HD community.

- i. Coffee and Co every Wednesday started well but because of the pandemic, we were forced to come up with alternative solutions. Thank goodness for zoom! More recently, we were able to meet again in person but in the last few weeks, have had to revert to zoom. It is run by volunteers who I will mention further on.
- ii. The Rural Outreach Programme was also put on hold, but Michele has recently started visiting people again in country areas.
- iii. We want to have a Companion Programme where people with HD living independently are visited every few weeks by volunteers who offer friendship and companionship. The pandemic has meant it was impossible but we do also require volunteers.
- iv. Michele has still been busy visiting people in metropolitan areas.

**c. Awareness, training and education: To facilitate skill development in Huntington's disease care and greater understanding, awareness and education within the Huntington's and the wider community.**

Remarkably, Michele has continued her education sessions for staff working in care facilities. She has conducted 4 by zoom and more than 10 in person since our last AGM.

**d. Advocacy: To advocate to government and non-government agencies to improve the lives of those with Huntington's disease.**

As mentioned, if we become an NDIS provider, then this will be beneficial for our members.

If people are having difficulties navigating their way through government agencies, they are welcome to contact Michele in our office. She will be able to guide you in the right direction and tell you who to contact.

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

Because of the pandemic, our NT work has unfortunately been curtailed this year.

**f. National Agenda: this has been an area of significant progress this year!**

The CEOs/general managers and chairpersons of most state Associations formed a Consortium this year. A Consortium is an agreement to work cooperatively together. This paves the way for assessing whether a national Huntington's Association is feasible. A national Association would be better able to attract funding and we could use each other's resources to benefit all people with Huntington's and their families all over Australia. Professor Julie Stout, a neuropsychologist and researcher in Victoria, has won a large grant

to improve the lives of people with Huntington's and in fact she will talk to us this evening about her work.

**5. Thanks to:**

- a. The Board:** I would like to thank all Board members.
- i. Our Secretary and now Treasurer, **Mr Chris Glasson**, deserves special thanks. He continues to contribute an enormous amount of time and energy to the Board and the Association in general. He has played a leading role in the formation of the National Consortium and undertakes the arduous task of writing grants, along with Michele. He is also compiling a suite of Policies and Procedures which are needed when applying for grants.
  - ii. **Mrs Janet Andrewartha**, a long-serving Board member since the beginning of this new Association, and previous treasurer, left the Board last year but we persuaded her to come back in an advisory capacity. She continues her volunteer role at Coffee and Co each week, revealing hidden acting talents, and she is invaluable at Bunnings BBQs.
  - iii. **Ms Michele Giles-Clark**, our general manager, also joined the Board at the last AGM. More about her in a minute!
  - iv. **Mr John Stronnar** joined the Board at our last AGM and has given much needed IT support. His day job is as CEO of Loftus, an IT solutions company for businesses.
  - v. **Dr Tim Porter** joined our Board this year. He is an anaesthetist who also has a business qualification (MBA) and business experience. He has great ideas to help us in our fundraising efforts.
- b. Our General Manager, Michele Giles-Clark:** Michele has again worked tirelessly in a voluntary capacity. She is a very hardworking, optimistic and selfless person. Michele has had a dream to visit South America to see how their rural communities with high incidences of Huntington's disease are supported. This year, Michele won a Churchill Fellowship which means her dream will be realised, hopefully towards the end of next year (once she has had a corona virus vaccination!). This is not for personal gain but to bring back information to benefit our Huntington's communities and raise awareness of Huntington's disease. She will tell us more about it in a minute.
- c. Our Ambassador:** Ben Wilson's health issues have meant that it has been difficult for him to undertake this role. We understand and wish him well.
- d. Our volunteers:** The hard work and wonderful dedication of our team of volunteers makes everything possible including:
- Coffee & Co: Julie, Carmen, Janet, Sonia, Michele, James, Rod, Rose, Anna and sometimes Liz
  - Reception and Newsletter: Anna
  - Cleaning & maintenance: James
  - Transport & support: Garry

- Bunnings BBQs: Nathan, James, Michele, Janet, Chris G, Carmen, Chris W, Rod, Pete, June and Liz
- Board members and General Manager (see above)

and anyone else who has contributed.

Thank you all for giving your time and effort for people with Huntington's and their families. May you continue to help us and recruit many friends and relatives!

Last week, the Board held a dinner to thank volunteers who have worked so hard for us this year.

- e. **Galpins Accountants, Auditors and Business consultants:** Galpins are our (paid) auditors. In particular, we thank Elise who does the book-keeping for us. After this report was given, Galpins let us know they have provided the audit free of charge this year for which we are very grateful.
- f. **Donors:** We have received over \$20,000 in donations since the last AGM for which we are extremely thankful. The bulk of that sum came from two generous donors. Please note that donations can be made at any time on our website.
- g. **The Marion Council:** We are indebted to the Marion Council from whom we rent our premises at a very low rate. They have undertaken further renovations (at no cost to the Association), namely removing a wall so that there is a larger area in the main section which can be divided into two rooms.

- 6. **Conclusion:** This year, most people on earth have faced serious challenges thanks to the corona virus. However, Huntington's SA & NT is still here, and we will move forward next year in what we hope will become a more stable time. Be sure to have the vaccination when it is available and we look forward to gaining strength for the Association so that we can provide support, fun and assistance to you.



Elizabeth Thompson  
Chair, Board of Huntington's SA&NT