

Huntington's SA & NT AGM 20th November 2023

Chairperson's report

1. Welcome

Welcome to everyone who is here in person and also those joining by zoom.
Thank you for coming or tuning in.

2. Acknowledgement of country

We acknowledge that we meet on the land of the Kaurna people and recognise their people and leaders, past present and emerging.

3. Last AGM

This is a day of mixed emotions. It is sad that it is the final AGM of Huntington's SA & NT, but we are happy to have formed our national Association, Huntington's Australia.

4. Highlights of Huntington's SA & NT

2014: Michele Giles-Clark convened a meeting of people impacted by HD with a plan to form an Association.

2015: Huntington's SA & NT began, Board appointed.

2016: First AGM held in Highgate Park once the Association had full registration.

2017:

- Vision, mission and strategic plan developed
- Moved in to FitzJames Building, Marion, in March
- Official launch 5th March opened by the Shadow Health Minister, Stephen Wade and attended by many including Anne Wills, one of our Patrons
- Michele Giles-Clark appointed as General Manager
- Coffee and Co started on alternate Wednesdays
- Michele started training and education sessions which she has continued to this day
- Fundraising activities included a 'Good Willow Huntington's Football Game' at the Norwood Oval, honouring Ben Wilson, one of our Ambassadors
- Rhue Bequest received

2018:

- New shorter mission statement: 'Our Mission is to identify and address the needs of people in SA and NT who have or are impacted by Huntington's disease.'
- City to Bay Fun Run raised over \$20,000
- Coffee and Co alternating weekly with Recreation, Respite and Resilience Program (funded by a grant)
- By now we had a small but dedicated group of volunteers
- Loan of a car from a generous family for use by the Association
- Renovations of FitzJames Building by Marion Council

2019

- 5 grants obtained (applications written by Chris Glasson and Michele)
- Started formal Outreach Program with grant funding
- Bunnings BBQs started and continue to this day
- C & C now weekly after the Rec program grant finished
- The Association bought the car for a generously reasonable amount from the kind family who had loaned it to the Association
- Fundraising Calendar developed
- Marion Council: grant to renovate the kitchen. The kitchen cabinetry was donated and built by a generous family in memory of their mother; MC also funded installation of toilet for the disabled

2020

- The year of Covid
- Michele and volunteers provided C & C by Zoom
- Chris Glasson now not only Secretary but also Treasurer
- Board adding to list of Policies and Procedures (thanks to Chris G)
- National Consortium of Huntington's Associations (CAHA) formed in early 2020 (CEOs/general managers and chairpersons of state Associations, except Victoria) initially to collaborate and cooperate and soon to discuss a merger to form a national Association
- More renovations by Marion Council
- Michele won Churchill Fellowship

2021

- CAHA continued to meet monthly by zoom with the agenda of considering whether merging to form a national Huntington's Association was feasible
- Large ILC grant thanks to Chris and Michele, to extend our Social and Recreation program regionally in SA, WA, Queensland, NSW/ACT and Tasmania.

2022

- At the AGM, we voted to alter our Constitution to merge with all states (except Victoria) and become a national organisation
- Huntington's Australia commenced, new Board met regularly
- Chris Glasson became the Chair of Huntington's Australia (HA), Liz Thompson a Board member

2023

- Coffee & Co, Bunnings BBQs continue
- Board of H SA&NT continued until last meeting on 11 September
- HA officially commenced operations on 1 October 2023
- We meet today to vote on whether to deregister H SA & NT
- Michele has a new role in HA as an HD Specialist

5. Thanks to:

- a. **The Board:** I would like to thank all Board members.

- i. Our Secretary and Treasurer, **Mr Chris Glasson**, has since 2016 devoted an enormous amount of time and effort to our state Association and now to Huntington's Australia.
- ii. **Mrs Janet Andrewartha**, our advisory Board member and previous Board Treasurer. Janet is not only a wise adviser but also an inspiring volunteer at Coffee and Co each week and at Bunnings BBQs.
- iii. **Dr Tim Porter**, an anaesthetist by training with a business qualification (MBA) and business experience, has been a valuable member of our state Board.
- iv. **Ms Elise Jaeschke** has again contributed much not only on the board but also on Facebook, with fundraising ideas and at the BBQs and continued, as an employee of Galpins, to do all our financial bookwork.

b. Our General Manager, Michele Giles-Clark: Michele continues her passionate desire to improve the lives of people impacted by Huntington's. She still hasn't made it to South America for her Churchill Fellowship but we hope this will come to pass soon. Michele is now an HD Specialist with HA. This role will free her up to do what she does best – looking after people with HD and the HD community. In the New Year, there will be 2 new staff members who Michele will be involved in selecting, to assist her and HA with admin, finance and general support and also to look after the new area of NDIS Support Coordination.

c. Our volunteers: We have a dedicated team of volunteers who undertake such important work for the Association and, we hope, will continue to do so:

- Coffee & Co: Coordinators Rod and James; also Michele, Carmen, Janet, James, Rod, Rose, Anna, Robbie
- Reception and Newsletter: Anna
- Cleaning until earlier in 2023 and maintenance: James
- Transport & support: Garry
- Bunnings BBQs: James, Michele, Janet, Chris G, Carmen, Chris W, Elise, Rod, Pete, June, Garry, Philip, Holland, Julie, Louise, Talia, Jen, Jada, Catherine, Robbie and Liz
- Bunnings flowers: James, Elise, Carmen, Julie, Shirley and Philip Nash, Robbie, Michele and Liz
- Board members and General Manager (see above)

and anyone else who has contributed.

Thank you all for giving your time and energy for people with Huntington's and their families. We hope that you will continue to help

us. In December, the Board will host a dinner to thank volunteers for giving generously of their time and effort this year.

- d. **Yang Sun of SunAccounting:** Yang has come on board as our auditor and audited our books for a generous price.
 - e. **Donors:** We received many donations totalling just over \$7000 for the financial year for which we are extremely thankful.
 - f. **Bequests:** In the last financial year, we received a wonderful bequest from the estate of Shane Lemon. In September this year, we have also received an extremely generous bequest from the estate of Mikkel Blignault. We have been in close contact with his family who stipulate that the funds are to be used in SA and the NT for support and recreation and for bringing people together. We will ensure that this occurs.
 - g. **The Marion Council:** We have been grateful to the Marion Council from whom we have rented our premises at a very generous rate for the last 6 years. Our lease is up for renewal and they have asked us to put in an EOI which we have done and are hopeful we will be successful in securing another 5 year lease. We will know the outcome by mid-December.
6. **Lastly:** Our main duty this evening is to vote on whether to deregister (close) Huntington's SA & NT. As we have already merged and transferred most of our assets (you gave the Board approval to do that at last year's AGM), we have been winding down the Association and now there is only the final task of deregistering Huntington's SA & NT. But in order to do that, we need the members to vote in favour of doing so. If we vote in favour, then Huntington's SA & NT will by the end of the year, cease to be. All assets and liabilities will have transferred to Huntington's Australia to continue the work of supporting everyone impacted by Huntington's disease knowing that we will have more resources, greater sustainability and more ability to raise awareness and provide advocacy for people with Huntington's.

It has been a great pleasure to be chair of this Board and I look forward to being able to offer the Huntington's community in SA and NT, as well as the wider Australia, excellent services under the banner of Huntington's Australia.



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