

## Huntington's SA & NT AGM 31 July 2017

### Chairperson's report

#### 1. Welcome

2. **Vision statement:** Our Vision is to provide a full and confidential range of support and services to the Huntington's disease community that will include counselling, advocacy, accommodation, education and research while promoting awareness to the wider community.

**Mission statement:** Our Mission is to identify and address the needs of those people in SA & NT affected by Huntington's disease with our practises guided by confidentiality, integrity and mastery.

#### 3. Strategic plan:

- a. **Effective organisation: To operate an effective financially viable not for profit organisation with a strong commitment to continuous improvement of the organisation, for the Huntington's community.** The Board meets monthly (sometimes more often) if necessary. One of our prime goals is to build up and properly manage the funds of the Association. In the last year, we have had some major developments such as the appointment of Michele Giles-Clark as our general manager. Michele has worked tirelessly for very small remuneration (and before the beginning of this year, NO remuneration). One of her big achievements this year has been to find this wonderful building for the Association to call home from which we held our official launch in March (March 5<sup>th</sup>)
- b. **Huntington's Community Services and Support: To provide a range of support/services to the Huntington's community.** Having premises with so many rooms (15 in total) has meant we have been able to start some community services eg the Coffee and Co every Wednesday. People from the Huntington's community are all welcome and many have been coming and enjoying each other's company and have completed a huge jigsaw in remarkable time. Michele will fill you in more about what other services and activities are coming up.
- c. **Awareness, training and education: To facilitate skill development in Huntington's disease care and greater understanding, awareness and education about HD in the Huntington's community and the wider community.** Many of you know that HD can be something that people with the condition, their family and friends do not talk openly about. We want to encourage openness in families, raise awareness about HD in the wider community and train many groups of people about it, eg, school students, the police. As you know we have a website and Facebook page which are the

modern way of making our presence felt. Michele will tell you more about her training and education activities.

- d. **National agenda: To work collaboratively with all other states Huntington disease Associations towards the formation of a national Association and the implementation of a national strategic plan.** There is more power in numbers when lobbying government and other organisations for support. One of our board members, Mick Heasman, has been involved. There is some resistance from some states, so it is proving to be a slow and at times frustrating process. There has been one teleconference meeting this year.
  - e. **Advocacy/Government: To advocate to government and non-government agencies to improve the lives of those with Huntington's disease.**
    - i. The NDIS for adults is starting to be rolled out in areas of SA. This will enable funding of services for people with HD.
    - ii. Grants. Our grants team Michele, Chris & Michael have submitted a total of 8 government grants with no success so far. The grant process is extremely competitive with applications far outweighing the available funding. It is a circular process – because we are new and originally had very little in the way of funds (and because of the sad history of the previous HD Association in SA), we were not looked upon favourably. However, we are assured that as we grow, we will be successful. Michele & Chris also applied for 2 philanthropic grants and 2 from the Marion Council, again unsuccessfully. But do not despair! One of Michele's most outstanding qualities is sheer determination and hard work. We will get grants in future.
    - iii. Transforming Health Select Committee: The HD social workers at Flinders Medical Centre have had their activities curtailed by the government. They are no longer funded to visit clients in the country. Michele put in a submission to the Transforming Health Select Committee which led to Michele and Chris appearing before the committee. This has opened political doors which were previously closed to us & is still very much a work in progress through these doors.
    - iv. Advocacy: if people are having difficulties negotiating 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.
4. **Northern Territory: To research Huntington's disease demographics and conduct a community needs analysis in NT in order to set strategy to meet those needs.** We know of 5 families in the NT with a relative with HD. Michele is collecting information from Carers NT, & other agencies so the Association has a starting point re numbers & geographical location. To be able to put a plan in place statistics are needed for applications to the NT government for funding in this area.
  5. **Fundraising:** Michele will talk more about this and you will see that we have made great progress in raising funds this year. This is in a large part due to the efforts of people in the community. The 'Inaugural Good Willow Huntington's Game' at the Norwood was a great success, honouring Ben Wilson, one of our Ambassadors. Another was a lunch event put on by Tom Gray from Macquarie Bank. Staff members

of Macquarie are encouraged to fundraise for causes that are of interest to them with the Macquarie Foundation matching funds raised to the amount of \$10,000. Tom wanted to raise funds for the Association but also for a person he knows with HD. He advertised his event as such and people donated generously knowing that half would come to the HD Association and half would go to a specific person. If any of you know of a similar entrepreneur, then ask them to chat to Michele to see how it is arranged. The total funds come to the Association, then are distributed to the Association and the person who raised the money to pass on to their nominated recipient, using our DGR status, ie our licence that allows donations to be tax deductible.

6. **Thanks to the Board:** I would like to thank all Board members and ask that they now make themselves known. We have one Board member leaving, Carla Ratcliffe, and I thank her for her wonderful dedication and service. We will have two new Board members after tonight. I would also like to thank Kathy Grieve who takes the minutes for our Board meetings.
7. **Thanks to our Ambassadors:** Ben Wilson and Mardi Espinosa. Ben has sent in his report which I will read shortly.
8. **Thanks to our volunteers** without whom many of our projects would not take place.
9. **Thanks to our GM:** Without Michele, nothing would have happened! She is a powerhouse of activity, determination and kindness. I don't know anyone else quite like her. Thank you Michele, we are truly blessed to have you working for the HD community.
10. **Conclusion:** Well that is enough from me and we will now move to our next agenda item.

Elizabeth Thompson

Chairperson, Board of Huntington's SA&NT