

Huntington's SA & NT AGM 29 October 2019

Chairperson's report

1. Welcome

2. **Mission statement:** To remind you, our Mission is to identify and address the needs of people in SA and NT who have or are impacted by Huntington's disease.

3. Strategic plan:

This is to make clear what we are trying to achieve and how we do it. We still have 6 Strategic Goals: Sustainable Organisation; Supports & Services; Awareness, Training & Education; Advocacy; Northern Territory; and National Agenda. We have simplified the actions arising from the plan to make them more attainable. I will describe the goals as follows:

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 and have started to formulate a risk assessment.
- ii. Our biggest issue is **FINANCIAL SUSTAINABILITY**. In other words, **we need money** to fund the programmes that we run (and hope to run in future) 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. We have done well with winning several grants since our last AGM:
 1. A federal grant for volunteers and equipment for \$5000
 2. A state grant for audio-visual equipment for \$4391
 3. A grant for salaries for the outreach services for \$25,000
 4. A BWLC grant for \$20,000 to get a business consultant to help us to transition Coffee and Co to become a financially viable business (financial year 19/20)
 5. An ILC (Information, Linkages and Capacity) 1:1 grant to provide us with a teacher who will show us how to write successful grants so as to be able to connect successfully with the NDIS (financial year 19/20)
 6. We were not successful in obtaining the Emergency Response Programme grant.
- iv. We have raised funds through donations, monthly Bunnings sausage sizzles, the City to Bay Fun Run and so on. However, recently it became apparent that we needed to restructure our finances to remain viable in the second half of this financial year. Our general manager, Michele Giles-Clark, who was originally a volunteer, and then, thanks to the bequest from the Rhue family, was able to be paid a salary, has now very kindly agreed to continue her role as a volunteer, for which we thank her most sincerely. However, this is not a viable proposition in the long term so we are developing new ways to raise more money

- v. We have developed a Fundraising Calendar, which outlines the activities and events we will be holding across 2019-2020 to raise funds.
- vi. And this brings me to our second biggest challenge which is recruiting people to help. In other words, what we desperately need is **MORE VOLUNTEERS**. Activities for volunteers include the Bunnings sausage sizzles which I must admit are great fun. The Companion Programme for visiting people with HD living independently is another. Many people have indicated they are interested but please get proactive and contact Michele to see how you can help, even if it is only for a few hours every now and again.
- vii. NDIS. If we could become a National Disability Insurance Scheme provider it would greatly help the Association to raise the funds we need to enable us to keep offering our programmes. **This is our main hope for future financial viability.**

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 continues to grow. About 30 people attend this popular event now. Lunch is provided and there is usually an activity either here or at another venue. This is run by volunteers, Julie Quinn, Carmen Warnes, Janet Andrewartha, Sonia and Michele.
- ii. The grant for the previously entitled Recreation, Respite and Resilience Programme was completed earlier this year. This programme alternated on a Wednesday with the Coffee and Co and was run by Julie and Carmen as paid staff. On completion of this grant, the Coffee and Co reverted to being weekly and Julie and Carmen very kindly became volunteers again.
- iii. Our Outreach Programme started in the metro area and then included country areas also. This involves arranged home visits to build an ongoing trust and rapport with the HD community, promote the Association and gain insights into the areas of need for individuals, families and carers and which will in turn support further planning and programming. As mentioned, we received a grant for salaries to help with the country arm of the programme. However, it did not include funds for costs, which are substantial, so we have had to rationalise this aspect of the programme. It will continue but at a slower rate.
- iv. We also want to have a Companion Programme where people with HD living independently are visited every few weeks by volunteers who offer friendship and companionship. We have only one volunteer for this so far, Janet. By law, there would need to be two people visiting each person, so we NEED ANOTHER (OR SEVERAL) volunteers.

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.

As mentioned before, 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. We have been fortunate to have forged links with SACARE, a disability services and support organisation. Milly from SACARE is updating our website and her colleague, Molly, is working on our Facebook page. With SACARE, we plan to develop educational talks and written material for key groups in the community who currently or in future, will care for people with Huntington's disease. Two representatives from SACARE are here tonight so you will hear more about it from them.

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

- i. The NDIS for adults has reached SA. We believe that the Association will benefit from becoming a provider. The complexities are a significant challenge but our will to succeed is strong!
- ii. 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.

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

Michele and Irene Scott (a retired social worker at Flinders Medical Centre) visited the NT in June 2018. There are plans for them to go again but we are waiting to hear from the NT about it. Our involvement with NT clients is still on a needs basis, but in future we hope to formalise our interaction with them.

f. National Agenda: progress has been made and there was a telephone meeting between the Chairpersons of the various state Boards. The Manager and CEOs have also met for a meeting in Melbourne. The ultimate goal is to have a National HD Association which will have more impact in obtaining funds from government, and will work together to enhance fundraising and provide continuity of information.

4. Thanks to:

- a. **The Board:** I would like to thank all Board members and ask that they now make themselves known.
 - i. **Ms Cheryl Shepherd, Deputy Chair of the Board**, who joined us at the last AGM has capably led the Board meetings if I was on leave. We have very much appreciated her calm and thoughtful contribution. I am sorry to say that she is leaving the Board due to family

- commitments. Thank you Cheryl for your time on the Board and your work as a volunteer and we hope you may continue to volunteer.
- ii. Our Secretary and now acting Treasurer, **Chris Glasson**, deserves special thanks. He contributes an enormous amount of time and energy to the Board and the Association in general. As before, Chris has led the review of our Strategic Plan this year. He has continued to develop our policies which is a huge task. He highlighted the need for us to re-think our finances in recent months. He, Cheryl and Michele have formed the Grants Committee which has had excellent successes this year.
 - iii. Our treasurer, **Melanie Armstrong**, has done a wonderful job and the Board has been so grateful for her hard work on our behalf. Sadly, Melanie will not be continuing on the Board due to competing work and personal commitments.
 - iv. **Mrs Janet Andrewartha**, a long-serving Board member since the beginning of this new Association, and previous treasurer, is also not re-nominating for her Board position. Janet has made a huge contribution and we have valued her wise comments during Board meetings. We will miss her very much. We are fortunate though that Janet will continue her volunteer role at Coffee and Co each week, Bunnings BBQs and the Companion Programme. We thank you very much, Janet, and are happy that we will still see you here.
 - v. We hope to recruit a new Board member this evening and you will hear more about that shortly.
- b. Kathy Grieve** who has taken minutes for our Board meetings from the beginning had to step down earlier this year for personal reasons but we would welcome her back with open arms at any time!
- c. Our Ambassador:** I am very sorry to report that our ambassador, Ben Wilson's health has deteriorated over the last year or so. He is fortunate to have Melanie Armstrong as his partner and great supporter. We are looking to find an additional Ambassador to work alongside Ben.
- d. Our volunteers:** The hard work and wonderful dedication of our team of volunteers makes everything possible including Coffee & Co: Julie, Carmen and Sonia (as mentioned), Reception: Anna; Website and social media: formerly Susan, now Millie and Molly; Book-keeping: previously Mel, now Elise; Cleaning & maintenance: James; Transport & support: Garry, Julie and Carmen; Fundraising & kitchen: Nicci and Damien; Rod and Nathan at BBQs and Nathan has provided maintenance help at the centre, other friends of existing volunteers who have helped at BBQs; Irene; Board members (see above), and anyone else who has contributed. Thank you all and may you continue to help us and recruit many friends and relatives!
- e. Galpin's are our (paid) auditors.** In particular, we thank Elise who has provided a lot of additional help with accounting, free of charge or for minimal



rates. Since Melanie, our treasurer, left the Board recently, we have asked Elise to do the books for us.

- f. **The Marion Council:** We are indebted to the Marion Council from whom we rent these premises at a very low rate. They previously did the renovations (at no cost to the Association). This year, we had a grant from them to renovate the kitchen which is completed and is a vast improvement on the one before. The instillation of a toilet for the disabled is now completed.
 - g. **The car:** A very generous couple who wishes to remain anonymous lent the Association a car which we have now purchased. Having a car is important for our General Manager and enables some of our clients to be collected by various volunteers for Coffee and Co.
 - h. **Our General Manager, Michele Giles-Clark:** Michele continues to be the wind beneath the wings of this organisation. She is enormously hardworking (often working 7 days of the week), energetic and compassionate and is a wonderfully direct and forthright person! Her dedication and determination are providing a brighter future for the Huntington disease community. Her recent decision to remain as General Manager but in a voluntary capacity, is truly commendable. Thank you Michele, we are extremely fortunate to have you working with us.
5. **Conclusion:** Overall, this last year has seen the Association face some challenges, especially financial ones, but we have addressed the issues and devised a plan to move forward. We are determined to continue this Association for the Huntington's community and we feel optimistic for the future! **But we need your help.** So please let Michele or any Board member know what you can do as a volunteer.

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