



## Committee & Staff Report for 2020 HFV AGM

– summary of annual programs and services for period 1.07.2019 to 30.06.2020

**Vision** *Connect, support and empower our community with bleeding disorders*

**Mission** *provide support, advocacy, information, programs, and activities that lead to positive healthy outcomes for those affected by genetic bleeding disorders*

**Values** *Respect Diversity Leadership Responsiveness Integrity*

**Strategic Goals**

1. Health Promotion
2. Community Wellbeing, Connectedness & Engagement
3. Partnerships and Collaboration
4. Governance and Stability

### HFV Program Achievements or Challenges

Before the arrival of Covid-19 in March 2020, HFV successfully provided programs, services and events for members and the wider bleeding disorder community. These included:

- Quarterly HFV magazine, *The Missing Factor*, 4 editions
- Outer metropolitan “outreach” program, 2 events with 20 and 14 attendees respectively
- Red Classic – Albert Park Walk - 117 registrations
- Family camp & incorporating youth leadership project - 84 registrations
- RCH/HFV Haemophilia teacher seminar - 60 registrations
- Ladies lunch & massage session - 14 registrations
- Christmas picnic – 45 registrations
- Stakeholder dinner- 30 invited attendees
- Membership Engagement survey – emailed to members and results quite beneficial for future planning
- Live Well Program: 9 applications approved approx. \$2,500

The camp continues to be a very significant event for our community and, we are extremely grateful to HFA for the significant funding support provided to us each year that enables HFV to run a comprehensive and successful camp program in comfortable surrounds. The youth leadership component continues to grow with more youth leaders coming on board. This program has particularly helped to maintain engagement with mid - late teens, a group that had previously been quite challenging to engage.

Covid-19 impacted HFV’s ability to deliver face to face programs from March onwards. It was very disappointing to cancel regional outreach sessions and the men’s weekend retreat; both

significant and important HFV programs. Similarly, the 2<sup>nd</sup> Red Charity Ball fundraiser scheduled for October 2020 was postponed and now aiming for October 2021.

Since March HFV has been quick to adapt with staff setting up to work from home, committee meetings held via phone or video conference and regular (weekly) catch up phone conference calls between president and staff to help keep things ticking along.

Committee meetings (all online) are kept shorter and include a personal check in so we have a better understanding of each other's individual Covid circumstances and challenges and can support if/as required. The Men's Group, while not meeting formally together, do maintain contact and support each other behind the scenes.

On a positive note, Covid has prompted HFV to develop a greater online presence. Firstly, we re-visited our engagement with social media platforms relaunching the dormant HFV Facebook page and opening a new Instagram account. Both are now active, quite well established with small but growing member bases. Secondly, we ventured into online peer support. Three events have been held to date, a kids trivia with Tim from Purple Soup (9 families), and a Women's event (15 ladies) and a Family Games night (33 participants) both facilitated by a professional organisation. The Games night also involved our youth leaders who had a separate Zoom planning session in the weeks prior which of itself was extremely valuable. Feedback from each of the online events has been positive, so we are now looking to explore further opportunities for online peer support in our community, regional on-line visits for example.

Thirdly HFV has launched a series of short online videos. Raw video footage was provided to HFV from staff at the Alfred (adult) HTC team: social workers, nurses and the physio have all contributed. HFV staff then streamlined the video footage, editing and adding captions and then uploading to our website. The videos offer advice to patients and carers to help them manage during Covid-19 and, also more general tips for the younger cohort on creating resumes and writing job applications. We aim to add further videos at regular intervals in the future including some from members representing particular cohorts.

Our two HTC's report successful transition to telehealth for most patients during Covid but both have expressed some concerns that patients were not presenting to HTC's for treatments when they should be (due to covid issues/fears) which is an ongoing concern during the extended Melbourne second wave and lock down period.

DHHS funding has continued, enabling HFV to run the small office and part-time staff for which we are extremely grateful. The funding continues to be linked to BBV's and is guaranteed until the end of the 2021FY, beyond that we are unsure at this time. We look forward to once again offering face to face activities in 2021 as the new 'Covid Normal' world permits.

**HFV Committee & Staff**