

Gavin Finkelstein is President, Haemophilia Foundation Australia



FROM THE PRESIDENT

Gavin Finkelstein

OUR FINANCIAL RESOURCES AND FUNDRAISING

When anyone asks us about how HFA funds are used, we are pleased to explain because it is important that our members, supporters and stakeholders understand the work we do and how it is paid for. We aim to be very open and transparent about all our income and expenditure in line with good business practice, to comply with reporting requirements to government bodies and regulatory agencies, and because we want to be accountable to our community.

HFA prepares and submits a range of reports to government agencies, including to the Australian Taxation Office. Most external reporting is done at the end of the financial year, after external auditors have come in to our office to inspect our books and we have prepared annual reports for members at our Annual General Meeting. Annual reports are published on the HFA website. You will find our most recent publication for the 2017-2018 financial year at <https://www.haemophilia.org.au/publications/annual-report>, and we expect our 2019 annual report to be available in October 2019. We also provide our reports to the Victorian Department of Business Affairs as well as the Australian Charities and Not-For-Profits Commission.

HFA relies on government grants and donations and some sponsorship income to cover the cost of the work we do. Even though government grants may be for two or three years, we report each year according to our agreed proposal and plan about how we intend to use the funds received each year. As there is little opportunity for variation, we take care to align our work plans with the strategy and outcomes identified by HFA Council before we establish agreements about the funds. As the funds are provided incrementally and usually after we have completed the work, we can't afford to deviate from our plan.

The government grants include funding to cover a part of the cost of things you would expect such as rent, printing and stationery, business insurances and

other office expenses. It also includes funding for the salaries of our staff who run our office, to make sure we are doing our job as the national peak body for the bleeding disorders community, and for the education and project work we undertake. Staff salaries are included as a part of our administration expenses in our financial reports and we make no apology for this because we do so much of our work 'in-house'.

HFA has not only developed a body of expertise within our staff group, which works with sound planning and goals, but we also have a team of volunteer community members and health professionals who share their expertise and enable us to be more effective than we would be if we outsourced our work. We believe that working with community is the best way of understanding needs, getting feedback and to develop our responses to meet the needs of our community. Our model for employing staff with appropriate expertise to work with the community stands us in good stead to achieve our objectives. A good example of this is our education resources - by working with the community about the information they need about their bleeding disorder we can in turn establish the collaborations needed to produce education resources that our materials relevant, timely and cost effective.

We are only too well aware of the dangers of 'having all our eggs in the one basket!'. A key strategic objective for HFA is to have a specific focus for fundraising, so that we are financially independent and capable of responding to the needs of our community when issues arise. Although we would like to be sustainable without reliance on government grants, this is not yet realistic. We are grateful for Australian Government Department of Health grants which give us the capacity to do some of our work, such as to operate the secretariat. It is a win-win situation. We receive funds from them to run our office and support our State/Territory Foundations, and produce high quality, evidence-based education resources on bleeding disorders for the general community as well as for our own members.



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As a relatively small organisation with a very specific focus on rare bleeding disorders, it is easy for our fundraising program to be swamped by other larger charities. I am proud of the way we juggle our income and expenditure to have sufficient funds to achieve the outcomes our community wants.

HFA also raises funds through traditional fundraising activities such as direct mail campaigns, events and sponsorship. Each of these need expertise, and I am proud of the work our staff and volunteers do to raise much-needed funds for our community. We have a group of caring and responsive donors who respond to our calls for support for activities run by HFA or at state/territory level such as camps and peer support workshops and so we can ensure members of local foundations have access to reliable education resources, and the benefits the national office representation and advocacy work. In the last two years we have taken action to increase our number of donors, and to nurture and encourage their support to the Foundation.

There are many challenges and it is important that we only source funds from partners who share our interests and are in line with our ethical approach. It is important that HFA decides how it will spend its money, and that we always act in the interests of our community. Sometimes people ask me how HFA handles income opportunities from pharmaceutical companies which manufacture treatment products and therefore have a strong interest in the sale of their products. HFA addresses this ethically and transparently. Our collaborations can help us raise awareness of bleeding disorders, and their sponsorship for activities such as our national conferences or other education programs are appropriate and beneficial to the community. HFA reaches out to these companies, and to governments who pay for our treatments as part of our advocacy to improve access to best practice treatments and care.

Our Annual Reports always make clear where our income has come from and the partnerships and collaborations we have fostered during each year and I am always happy to discuss this further.

TREATMENT ADVOCACY

The HFA Council has been assured by the National Blood Authority (NBA) that a new tender for treatment products funded by governments will be called in upcoming months. We believe a range of treatment products should be available to meet the needs of the community, including regular and long acting clotting factor products, and we will work with the NBA to ensure they are aware of the needs and preferences of our community. Some of these products were first registered in Australia in 2014 but, other than for an 'expanded access program', which has provided limited access to some extended half-life products, there has been no opportunity for them to be considered for public funding.

As discussed in previous *National Haemophilia* publications, we are entering an era of new treatments for haemophilia, and research and clinical trial experience suggests we are getting closer to a cure!

I believe it is important that Australians with bleeding disorders have funded access to the most effective treatment products. This includes having access to innovative treatments. We have reports from people who have shared their experience in clinical trials and are well aware of the challenges for governments when assessing their value to the Australian bleeding disorders community, but we are seeing and hearing remarkable outcomes.

Currently HFA is advocating to the Medical Services Advisory Committee (MSAC) in support of government funding for emicizumab (Hemlibra®). This is a new non-clotting factor product registered for prophylaxis treatment for people with moderate to severe factor VIII deficiency (haemophilia A) with or without inhibitors. Earlier MSAC consideration of an application from the manufacturer, Roche, for government funding for this treatment to be available for people with inhibitors found it to be cost-effective. Further consideration is now underway for the application in respect of this drug being publicly funded for people with haemophilia A without inhibitors. HFA has been invited to provide further stakeholder input and will do so using feedback provided by our members. Patients and their doctors have reported excellent outcomes with this treatment, including little or no bleeding over several years in people with severe haemophilia. ■