

# 40 YEARS HAEMOPHILIA FOUNDATION AUSTRALIA

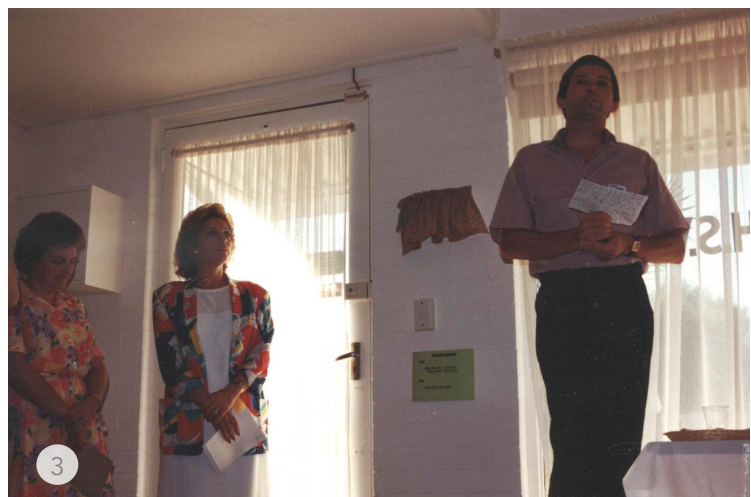
This year is the 40th year of Haemophilia Foundation Australia (HFA). Over the years we have represented and supported the bleeding disorders community in Australia and internationally. As a community we have worked together on the struggles and the achievements of those years and we invite you to join us in reflecting on them.

This article is a short summary of some of the key milestones, and we look forward to sharing more stories and reflections in the next 12 months.

By 1979, state/territory societies had been representing people with haemophilia locally in Australia for 20 years, and we still hear many stories of lasting friendship and peer support since that time.

From humble beginnings in former HFA Executive Director Jenny Ross's dining room, HFA has made an impact in many areas, affecting the lives of people living with a bleeding disorder and their families. Only recently, Jenny recalled the extraordinary time at the start of the AIDS epidemic in 1984 when HFA was suddenly transformed from a small national organisation to an active and respected member of national and international teams struggling to understand and deal with the issues – this was a time of great upheaval and sadness.

1. The HFA AIDS Press Conference in 1989
2. The first HFA meeting in 1979 at Jenny Ross's home (left to right Ted Troedson, Neville Acklom, Alison Bellamy, Bevelee Cassell, Jenny Ross AO, Alan Ewart inset)
3. Ita Buttrose opening the first HFA office in Hawthorn 1986





4. Our volunteers welcomed the world to Melbourne.

People are living longer than ever before and the future looks very different for many in our community.

Since then there have been advocacy campaigns for improved treatment and care, and many collaborations, some lead by our community to new address issues as they have occurred. While treatment for HIV and hepatitis C improved, the legacy of blood borne viruses has been profound.

Our older community members gave their blessing for children to have first access to treatment prophylaxis sooner to prevent or reduce bleeds. As a result, health outcomes and quality of life have been better for some people in younger generations, in comparison to those who lived through earlier times and experienced treatment product rationing due to supply shortages. Many people in our community still live with the complications of joint damage, poor mobility and pain. Since 2004 supply has been steady, and after a long campaign, we entered a new era of recombinant clotting factor for all, including prophylaxis for adults where this was appropriate.

A significant milestone for HFA was to win its bid to host the World Federation of Hemophilia World Congress in Australia and we had great pleasure introducing the global bleeding disorders community to Melbourne and Australia at the 2014 World Congress.



We are entering a new decade. For people with bleeding disorders in Australia these are exciting times, with groundbreaking new treatments becoming accessible and gene therapy and other promising treatments in advanced clinical trials. People are living longer than ever before and the future looks very different for many in our community.

*To all those who have contributed to HFA over the years and have made it the organisation it is now – thank you!*

**HFA will recognize the challenges and celebrate the successes of the past 40 years when it releases a series of short videos to mark the different chapters in our growth and development during the next year.** H

