# Membership

Membership of Haemophilia Foundation ACT is open to all persons with haemophilia and related bleeding disorders, their families, and also professionals involved in the care of persons with haemophilia. Annual membership of HFACT is \$20 (incl GST), or \$55 (incl GST) for three years.

To join, please complete a membership form, available online at www.hfact.org.au/join or by contacting HFACT using the contact details in this brochure including by contacting our counsellor. A form can be posted or emailed to you.

Membership subscriptions may be paid by bank deposit, credit card or cheque. Payment methods are on the membership form.

#### Member benefits include:

- Informal support through friendship networks.
- Formal support from our counsellor.
- Peer support groups.
- Family camps and kids' functions.
- Social functions.
- Local newsletter several times a year.
- Membership of the peak national body, HFA.
- Subscription to HFA's National Haemophilia Journal
- Fact sheets and booklets on haemophilia, von Willebrand disorder and other bleeding disorders.
- Representation and advocacy at the local and national level.
- Subsidies for medical bands or bracelets.
- Support to attend HFA conferences.
- Entitlement to vote at the HFACT AGM.

# **Brief history**

Haemophilia Foundation ACT started as a small support group in late 1983. At that time, about six families got together to share their experiences and thought it would be a good idea to continue to meet on a regular basis and to support each other.

After a few years it was decided to set up a more formal structure for the group, so a constitution was drawn up and steps were taken to become incorporated.

Registration as the *Haemophilia Support Group of the ACT Incorporated,* was granted on 31 October 1986. Recognition as a tax-deductible charitable organisation followed soon thereafter.

The group continued to operate at a low-key level for a number of years, providing some social and educational gatherings each year.

Following the discovery of viral contamination of blood products the group sought, and received, funding from the Federal and ACT Governments to enable it to support its members through these difficult times.

In June of 1993, we changed our (registered) name to *Haemophilia Foundation Australian Capital Territory Incorporated* (abbreviated: HFACT) and took up formal membership of Haemophilia Foundation Australia.

Since that time, HFACT has continued, not only to provide support to its members but also to lobby governments and hospitals for continuing improvement in products, services and haemophilia care.

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#### Patron

The patron of Haemophilia Foundation Australian Capital Territory Incorporated is Dr Richard Pembrey AM MBBS MD FRACP FRCPA



# HAEMOPHILIA FOUNDATION A.C.T.

# Information Brochure

# **Our Mission**

"To improve the well-being of the haemophilia and related bleeding disorders community in the Canberra region through mutual support, networking, advocacy and striving for optimal health care."

Incorporated in the ACT as
HAEMOPHILIA FOUNDATION AUSTRALIAN CAPITAL TERRITORY
INCORPORATED, Registered number A1280
ABN: 39 089 502 414
Member of Haemophilia Foundation Australia

HFACT is registered as a charity with the Australian Charities and Notfor-profits Commission (ACNC), Charity ABN 39089502414.



Donations of \$2 or more are Tax Deductible Donate using a credit card via PayPal our web site.

Web site: www.hfact.org.au

## What we do

Haemophilia Foundation ACT Incorporated (HFACT) is a non-profit organisation representing people, and their families, affected by an inherited or acquired bleeding disorder including haemophilia, von Willebrand's disease and other rare bleeding disorders. HFACT operates in the ACT and the surrounding region of southern New South Wales.



The five main areas in which HFACT operates are:

### **Advocacy**

Bringing haemophilia issues to the attention of governments, health-care professionals and the broader community, through education, advocacy and constructive representation.

#### **Services**

Striving for ready access to optimal health care for all persons with haemophilia, and related bleeding disorders, and paying due attention to any issues that may arise.

## Networking

Ongoing interaction with government, hospitals and other agencies.

## Membership

Maintenance of an enthusiastic membership through provision of educational and social activities and other opportunities to share experiences.

#### Governance

Activities of the group are managed in an open and effective manner.



HFACT provides a range of opportunities for members to get together to share their experiences and learn about the latest developments in treatment and care.

HFACT also provides the services of a counsellor who is available to attend to any problems or issues that may arise. This service is provided through funding from ACT Health under the Public Health Outcomes Funding Agreement, and is available to anyone affected by a bleeding disorder. You do not have to be a member of HFACT to use the counselling service.

# **Haemophilia Care in the ACT**

Haemophilia Care is provided in the ACT through the Canberra Hospital Haemophilia Treatment Centre located at:

Level 4, Room 401 Capital Region Cancer Centre, Building 19 The Canberra Hospital Yamba Drive, Garran ACT.

Patients may attend the Centre or order treatment product and supplies during business hours on weekdays.

Weekend or after-hours treatment can be obtained from the Canberra Hospital Emergency Department (ED).

Special arrangements are in place for children through the Canberra Hospital Paediatric Department (contact the Haemophilia Nurse for details).



Contact details for the Haemophilia Centre are:

**0481 013 323** 8:30am to 4:30pm Mon-Fri

No appointment necessary, but a call prior to arrival to check that staff are available would

be appreciated.

Haemophilia Nurse / Bleeding disorders Co-ordinator: Ms Jayne Treagust, APN (primary contact)
Phone: **0481 013 323** 

Email: haemophilia@act.gov.au

Haematologists: Dr Michael Pidcock

Dr Nalini Patti

If you cannot contact the Haemophilia Nurse on the above number, please use the following contacts:

Medical Oncology Reception

(02) 5124 8444 8:30am to 4:30pm Mon-Friday

Contact numbers for other hospital departments are:

Emergency Dept. (02) 5124 2611 (24 Hours)

Physiotherapy (02) 5124 2154 Switchboard (02) 5124 0000

## **Contact information**

**Postal** PO Box 331

Mawson ACT 2607

**E-mail** secretary@hfact.org.au

**Web site** www.hfact.org.au

**President** Mr Claude Damiani

Telephone: 0412 839 135 E-mail: president@hfact.org.au

**Counsellor** Ms Kathryn Body

Telephone: 0409 830 472

E-mail: counsellor@hfact.org.au



Disclaimer: Haemophilia treatment contact information in this brochure is provided to you as a service by the HFACT and reflects our understanding of the arrangements which apply at time of printing. These may be changed by the hospital without notice.

# Acknowledgment

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