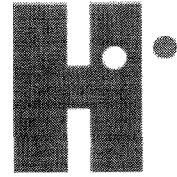


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President: Gavin Finkelstein  
Executive Director: Sharon Caris



HAEMOPHILIA FOUNDATION AUSTRALIA

22 October 2009

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23 OCT 2009

BY: *AS*

Clerk Assistant (Committees)  
House of Representatives  
PO Box 6021  
Parliament House  
CANBERRA ACT 2600

Submission No 10

Dear Sir/Madam

Please find enclosed the Haemophilia Foundation Australia submission to the Joint Standing Committee on Migration in relation to the *Inquiry into the migration treatment of disability*.

Thank you for the opportunity to make comment.

Yours sincerely

Sharon Caris  
Executive Director

MEMBER ORGANISATIONS - HAEMOPHILIA FOUNDATIONS: • AUSTRALIAN CAPITAL TERRITORY • NEW SOUTH WALES • QUEENSLAND • SOUTH AUSTRALIA • TASMANIA • VICTORIA • WESTERN AUSTRALIA  
• NATIONAL MEMBER ORGANISATION OF THE WORLD FEDERATION OF HEMOPHILIA

1624 HIGH STREET GLEN IRIS VICTORIA AUSTRALIA 3146 TELEPHONE: (03) 9885 7800 FACSIMILE: (03) 9885 1800  
EMAIL: [hfaust@haemophilia.org.au](mailto:hfaust@haemophilia.org.au) WEBSITE: [www.haemophilia.org.au](http://www.haemophilia.org.au)

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HAEMOPHILIA FOUNDATION AUSTRALIA

## HAEMOPHILIA FOUNDATION AUSTRALIA SUBMISSION TO JOINT STANDING COMMITTEE ON MIGRATION INQUIRY INTO IMMIGRATION TREATMENT OF DISABILITY

### Summary of response:

- Haemophilia Foundation Australia's view is that people with bleeding disorders should have access to the treatments they require and that everyone should be valued for their contribution regardless of health needs or their level of disability; that to exclude individuals from migrating to or visiting Australia on the basis of their bleeding disorder alone is neither ethical nor just.
- Haemophilia Foundation Australia calls on the Committee to review the Schedule 4 Public Interest Criteria of the *Migration Regulations 1994*, in particular the clauses relating to the person having a disease or condition which may result in provision of health care or community services for their condition.

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### Haemophilia Foundation Australia

Haemophilia Foundation Australia (HFA) is a not for profit organisation which represents people with haemophilia, von Willebrand disorder and other rare inherited bleeding disorders in Australia. It is the national peak organization for bleeding disorders and provides advocacy, education and support to and works to promote Australian based research. As a member organization of World Federation of Hemophilia (WFH), HFA participates in a range of activities to improve care and treatment for people with bleeding disorders around the world. HFA provides active support to the WFH vision of *Treatment for All* through the Twinning Program and is currently a twinning partner with Thailand.

### Bleeding disorders

There are approximately 3600 people with inherited bleeding disorders in Australia, of whom 2000 are males with haemophilia. Haemophilia occurs when blood clotting factors VIII (eight) or IX (nine) are missing in a person's blood or don't work properly. It is incurable and can be life threatening if not treated properly. Bleeding is internal, into muscles, joints and organs. Long term bleeding can cause permanent damage resulting in pain, disability and reduced quality of life. However, with appropriate treatment bleeding can usually be stopped. Today in Australia, children and young people who have been treated all their lives with the required replacement clotting factor are less likely to have the problems of older adults. However, many adults live with significant joint damage caused by inadequate clotting factor therapy in

the past. Some of this group may also live with blood borne viruses, including HIV and hepatitis C due to treatment with unsafe blood clotting products before safe blood screening tests were introduced.

### **Treatment for bleeding disorders in Australia**

In Australia most people with bleeding disorders now use imported recombinant treatment products for their treatment for safety reasons; however, some still use plasma derived clotting factor as a matter of choice or for clinical reasons. The financial cost of all clotting factor products is shared by Australian governments under the National Blood Agreement. Treatment and care for people with bleeding disorders is best managed through a model of comprehensive care which is provided by specialist haemophilia centres. These are currently located in major public hospitals around Australia. Haemophilia is an inherited condition and occurs in families. In one third of cases it also appears in families with no previous history of the disorders. Haemophilia is found in all races and socio-economic groups.

Von Willebrand disorder (vWD) is another inherited bleeding disorder caused when there is not enough of the von Willebrand clotting factor in a person's blood, or it doesn't work properly. It is thought that many Australians with vWD are undiagnosed as it is more common in a mild form, and most people do not need treatment unless they have surgery or an injury. However, some people have severe vWD with frequent bleeding episodes and joint and muscle bleeds. Some people with vWD can only be treated with clotting factor VIII concentrates made from human plasma, while others can be treated with synthetic hormones.

Each of these bleeding disorders is categorized according to levels of severity, eg mild, moderate and severe, and treatment requirements are specific to the individual. Some people require treatment rarely in their lives while others may need treatment two to three times weekly.

### **Comment on immigration treatment of people with bleeding disorders**

HFA's view is that people with bleeding disorders should have access to the treatments they require and that everyone should be valued for their contribution regardless of health needs or their level of disability.

Any questions the committee may have about the costs of care and treatment of people with bleeding disorders should be addressed to the National Blood Authority which manages the purchase and supply of treatment products on behalf of all governments and to relevant State/Territory governments which provide care and treatment services. This submission does not seek to address the cost to governments of care and treatment to Australians with bleeding disorders; however, it does wish to make the point that whilst haemophilia is an incurable and potentially life-threatening inherited blood clotting disorder, these days, it can be well treated with infusions of replacement clotting factor and people living with this and related bleeding disorders can live full and productive lives. They can be expected to participate fully in the community, and will be able to engage with few limitations in education and work.

However, there is a widely held perception that the cost of treatment is expensive in dollar terms to governments, and that it is reasonable to apply restrictive policies. For example, although having a bleeding disorder is not a stated reason for refusal of visa by the Australian government, HFA is aware of many applications which have been refused apparently on the basis of the perception of cost, quite possibly without an accurate understanding of the variables that need to be taken into account when assessing cost for specific applicants. It is recommended that the Committee takes into account that there are varying levels of severity and some people require little or no treatment throughout their life, while those who are severely affected may well need treatment on a regular and lifelong basis.

It is recommended, however, that any consideration of cost also includes a discussion of community benefit: people with bleeding disorders contribute in all walks of life, as do their families, and a "blanket" exclusion to migrate will exclude people who might otherwise participate at a valuable level in the Australian community in a range of areas. It is neither ethical nor right that having a bleeding disorder in itself should be such a barrier to migration and policies which result in barriers, even if unstated initially, are inappropriate and discriminatory.

HFA receives inquiries from people from around the world about the potential to migrate to Australia. It appears there are categories of visas which may be considered less favourably by Australian authorities where the applicant is a person with a bleeding disorder or has a dependent child with a disability and injustices occur.

For people who enter Australia on a range of visas we hear personal stories of frustration and sadness, where outcomes appear to lack compassion and sense, especially when they are based upon a view that people with chronic health conditions will place a predictable and unsustainable financial burden on the government and community.

Ultimately, the Australian government has to consider why it is inviting specific individuals to migrate to or visit Australia. If it values the individual's potential contribution to the Australian community through their skills, building of family relationships or other reasons, or has assessed that the person is experiencing persecution in their country of nationality and warrants refugee status, then as a basic human right, it owes the person the standard of health care available to all Australians.

Unlike many developing countries, Australia can currently offer its citizens sufficient treatment for their bleeding disorder for most to live functional and fulfilling lives. HFA appreciates the benefits of this for members of the bleeding disorders community. HFA also considers Australia is well placed to consider a contribution to the world efforts to provide treatment for all people with bleeding disorders and extend that generosity to the very small number of individuals with bleeding disorders it has otherwise assessed as appropriate to migrate to or visit Australia.

Accordingly, it is recommended that the Committee consider reviewing the Schedule 4 Public Interest Criteria of the *Migration Regulations 1994*, in particular the clauses relating to the person having a disease or condition which may result in provision of health care or community services for their condition.

*October 2009*