

PATIENT REGISTRATION FORM

Clinician/Nurse to complete. Fields marked with an *asterisk are mandatory, optional fields are shaded grey.

New patient Change of name Change of address

Patient:

ABDR ID

(existing patients only)

Title

Australian Resident Status

Australian Citizen/Permanent Resident Overseas Visitor
 Temporary Visa

***First name**

Second name / initial

***Family name**

Known as / alias

***Gender**

Male Female

***Date of Birth**

 DD / MM / YYYY

Previous family name/s

***Address**

1

2

3

***State**

***Suburb**

***Postcode**

Home phone

Work phone

Mobile

Home email

Work email

*Tick preferred contact method; at least one contact must be supplied.

Patient contact (if necessary):

Mother Father Carer Grand Parent Emergency Other Please specify _____

Title

First name

Second name / initial

Family name

Address

1

2

3

State

Suburb

Postcode

Home phone Work phone Mobile Home email Work email Tick best contact method

Best contact number or email address

Diagnosis: see overleaf for # options

Date presented

 DD / MM / YYYY

***Bleeding disorder #**

***Severity**

Date diagnosed

 DD / MM / YYYY

Baseline Factor Level

 %

***Weight in kilograms**

Mild / Moderate / Severe / unknown / not applicable

(Where applicable)

Treatment: see overleaf for + ^ options

***Regimen +**

***Product name ^**

***Total Dose**

***Frequency**

Comments

Attending Physician and Clinic / Hospital Address: Missing data will be requested by an ABDR Data Manager.

***Title**

***First name**

***Family name**

***Name of Clinic / Hospital**

***Best contact number or email address**

***Address**

1

2

3

***State**

***Suburb**

***Postcode**

DECLARATION:

These details are true and correct at the time of completing this form. The patient is aware of the purpose for capturing their details in the ABDR and is aware of privacy and confidentiality protection arrangements as described overleaf. ABDR Pamphlet has been given to patient.

Name _____

Signature _____

Date DD/MM/YYYY _____

#bleeding disorder

Factor II deficiency (Prothrombin)
 Factor V deficiency
 Factor VII deficiency
 Factor VIII deficiency (Haemophilia A)
 Factor IX deficiency (Haemophilia B)
 Factor X deficiency
 Factor XI deficiency
 Factor XII deficiency
 Factor XIII deficiency
 Symptomatic Carrier Factor VIII deficiency (Haemophilia A)
 Symptomatic Carrier Factor IX deficiency (Haemophilia B)
 Asymptomatic Carrier Factor VIII deficiency (Haemophilia A)
 Asymptomatic Carrier Factor IX deficiency (Haemophilia B)
 von Willebrand Disease Type 1
 von Willebrand Disease Type 2 – Uncharacterised
 von Willebrand Disease Type 2A
 von Willebrand Disease Type 2B
 von Willebrand Disease Type 2M
 von Willebrand Disease Type 2N
 von Willebrand Disease Type 3
 von Willebrand Disease – Uncharacterised
 Fibrinogen – Afibrinogenemia
 Fibrinogen – Hypofibrinogenemia
 Fibrinogen – Dysfibrinogenemia
 Fibrinogen dysfunction – Uncharacterised
 Platelet – Glanzmann's thrombasthenia
 Platelet – Bernard-Soulier
 Platelet – May Hegglin
 Platelet – Macrothrombocytopenias
 Platelet – Storage pool (dense granule) deficiency
 Platelet – Primary secretion defect
 Platelet – Uncharacterised
 Acquired factor VIII inhibitor (Acquired Haemophilia A)
 Acquired von Willebrand's Disease
 Vascular disorders – Ehlers Danlos Syndrome
 Vascular disorders – Uncharacterised
 Other, please specify

#trigger for diagnosis

Trauma
 Surgery
 Family history
 Genetic testing
 Bruising/bleeding
 Menorrhagia
 Acquired disorder
 Other, please specify

*treatment regimen

On demand
 Prophylaxis
 Tolerisation
 Secondary Prophylaxis

^Product Name (type)

Advate® (rFVIII)
 Fresh Frozen Plasma (FFP)
 BeneFIX® (rFIX)
 Biostate® (pdFVIII)
 Ceprotin® (Protein C)
 Cryoprecipitate
 DDAVP (Synthetic hormone)
 Factor Eight Inhibitor Bypass Agent (FEIBA®) (Bypassing Agent)
 Factor VII Concentrate® (pdFVII)
 Factor XI bpl® (pdFXI)
 Factor XI LFB Hemoleven® (pdFXI)
 Fibrogammin P® (pdFXIII)
 Fresh Frozen Plasma (FFP)
 Haemocomplettan P 1g (pdFXIII)
 Intravenous Immunoglobulin (IVIg)
 MonoFIX® - VF (pdFIX)
 Novoseven® (rFVIIa)
 Platelets
 Prothrombinex™ - VF (pdPCC)
 Recombinate® (rFVIII)
 ReFacto® (rFVIII)

ABDR Patient Pamphlet

What is the ABDR? The Australian Bleeding Disorders Registry (ABDR) is a database that collects all clinical information related to the treatment of people with bleeding disorders, like an electronic medical file. This includes information about patient diagnosis, treatment details, hospital admissions and administrative information as well as details on ordering, supply and use of clotting factor products. Information is entered into the ABDR by staff at haemophilia treatment centres. The ABDR is managed by a service provider engaged by the National Blood Authority. The ABDR was first established in 1988 and has been upgraded many times with the latest significant upgrade in 2008.

Why do you need it? The ABDR provides your health care team and support staff with a record enabling them to monitor and manage your treatment over time to improve your quality of life. Depersonalised information available from the ABDR may be used by authorised organisations to understand and improve treatment for bleeding disorders. The ABDR also provides governments with information on total clotting factor product requirements to make sure there is enough available to meet the needs of all Australians with bleeding disorders.

What about privacy? Only the health care team and support staff involved in providing medical services to you have access to your personal information. Other authorised users only have access to limited, depersonalised and/or summary information where all identifying information is removed to protect your privacy.

Does information about me have to be included? A minimum amount of information about you is required to ensure the continuous supply of clotting factor product is available to meet your treatment needs.

Where can I get more information? Further information about the ABDR can be obtained from the Australian Haemophilia Centre Directors' Organisation (AHCDO) on (03) 9885 1777, email info@ahcdo.org.au or visit www.ahcdo.org.au

Endorsement from Haemophilia Foundation Australia

Haemophilia Foundation Australia supports the ABDR. It helps doctors and other treating health professionals to understand more about the care and treatment needs of people affected by bleeding disorders. The ABDR will assist and guide planning to ensure treatment product is available when it is needed. We are confident the steps in place will mean accurate, reliable and confidential data is available and that no patient details can be identified outside haemophilia centres.

www.haemophilia.org.au

Endorsement from Australian Haemophilia Centre Directors' Organisation

The ABDR is a valuable tool that provides an overview of those affected with haemophilia and other bleeding disorders in Australia. Data from the ABDR is the best information available for clinicians to advise governments making policy decisions regarding treatment needs and product availability.

National statistics available through the ABDR will give AHCDO an overview of practise and allow opportunities for improvement. This data can be pooled to compare Australian treatment standards with international benchmarks. The ABDR will continue to provide the ability to assess quality of life and other important clinical questions arising across Australia.

AHCDO's partnership on this initiative with the National Blood Authority, Haemophilia Foundation Australia and other specialist health professional groups is vital to the pursuit of excellence in clinical treatment practices.

www.ahcdo.org.au

Copies of this pamphlet can be obtained by contacting the ABDR Secretariat at abdr@nba.gov.au or 02 6211 8311.