THE HAEMOPHILIA SOCIETY

Takeda

WE BLEED DIFFERENTLY

RARE BLEEDING DISORDER PATIENT CHARTER

This project is initiated and funded by Takeda in partnership with The Haemophilia Society

Document number: C-ANPROM/GB/HG/0047
Date of preparation: November 2021

WE BLEED DIFFERENTLY

THE HAEMOPHILIA SOCIETY

Takeda

The development of the Rare Bleeding Disorder Patient Charter was initiated and funded by Takeda.

This document was developed using insights from The Haemophilia Society, people with rare bleeding disorders and health care professionals.

Participants received an honorarium from Takeda for their valuable input and advisory contribution into the development of this Patient Charter.

Developed with the support of

THE HAEMOPHILIA SOCIETY

Sarah Mangles
Consultant Haematologist

Debra Pollard
Advanced Nurse Practitioner

Kate Khair
Consultant Nurse

Paul McLaughlin
Consultant Physiotherapist

Together with a working group of individuals and carers supporting individuals living with rare bleeding disorders

CONTENTS

WE BLEED DIFFERENTLY

ABOUT THIS CHARTER

Rare bleeding disorders are predominantly hereditary conditions which affect the ability of the blood to form clots. If supported by their healthcare teams with effective therapy and care plans, people with rare bleeding disorders (such as haemophilia A and B, Von Willebrand's Disease, rare factor deficiencies and acquired haemophilia A) can live the lives they want to.

The challenge of living with a rare bleeding disorder is particularly pronounced in the UK. An international study examining outcomes for haemophilia patients has found that those living with a rare bleeding disorder in the UK have the lowest health related quality of life in the EU5 (UK, France, Germany, Italy, Spain). In addition, in 2019 the APPG for Haemophilia and Contaminated Blood released a report following an inquiry which found people with bleeding disorders did not have access to the best therapy or care in a timely way and were subject to variations in standards of care.

This Patient Charter was developed to articulate where improvements in care for PWRBD are most needed.

OUR AMBITIONS FOR CARE FOR PEOPLE WITH RARE BLEEDING DISORDERS

We believe that every person with a rare bleeding disorder should have equal access to excellent care.

By working together, we will achieve our key aims of:

1. Improving quality and access to care and treatment for people with rare bleeding disorders, and
2. Empowering people affected by rare bleeding disorders to advocate for improvements in care

APPG – All-Party Parliamentary Group

PWRBD – People With Rare Bleeding Disorders

The development of this Patient Charter was informed by a series of joint projects between Takeda and the Haemophilia Society, including an Advisory Board held on 12 November 2020 attended by people impacted by haemophilia and HCPs working with people with rare bleeding disorders (PWRBD), and through the national bleeding disorder patient experience survey conducted between December 2020 and February 2021. 96 people with rare bleeding disorders completed this survey, of which 60% had haemophilia A, 24% had von Willebrand disease, 13% had haemophilia B and 3% had acquired haemophilia A.

WE BLEED DIFFERENTLY

THE HAEMOPHILIA SOCIETY

Takeda

EXPECTATIONS FROM CARE

Ambitions		Recommendations
1. Treatment outcome measurements should be more than just a number		1. Measurement of treatment outcomes should include wider measurements of outcomes that impact a person's quality of life, such as bleed frequencies, intensity, pain and mental health indicators
2. PWRBD should always receive personalised care that recognises the unique aspirations and lifestyle of that individual		2. HCPs should be adequately supported, trained and resourced to a consistent standard across the UK to ensure that conversations around care are able to meet the unique and individual needs of PWRBD
3. PWRBD should have a seat at the table when decisions are made around data collection and use to further the use of shared decision making in rare bleeding disorders		3. PWRBD and HCPs should be able to influence how data collection happens, which data are collected and the tools used to gather data, to ensure it is fit for purpose and for the correct audience

WE BLEED DIFFERENTLY

THE HAEMOPHILIA SOCIETY

Takeda

EXPECTATIONS FROM WIDER NHS SUPPORT

Ambitions	Recommendations
4. PWRBD living in all parts of the UK should have timely access to comprehensive care via a full MDT including a doctor, nurse, physiotherapist and psychologist, as a minimum standard	4. Comprehensive Care Centres (CCCs) across the UK should be appropriately resourced and funded by commissioners in accordance with the NHS standard contract to ensure PWRBD in all locations have access to specialist and comprehensive care. This would ensure: a. Every PWRBD has access to a full MDT b. HCPs have access to appropriate technology to improve communication between emergency services, specialist care and wider care services such as dentistry, and allow the use of virtual consultations, to ensure equitable outcomes c. PWRBD should have a care plan developed with their MDT that can be presented in emergencies or in circumstances when they are not able to be treated by their usual HCPs d. Smaller Haemophilia Treatment Centres (HTCs) should arrange access to a full MDT and out of hours care via arrangements with a larger centre
5. PWRBD who use factor regularly should have access to a reliable and timely medication delivery service, with minimal administrative burden	5. Medication delivery services should be in place, and medication should be delivered correctly and on time, with minimal administrative burden on the recipient and HCP. This process should include: a. A named team member responsible for managing medication delivery b. A clear complaints and investigation procedure for errors
6. PWRBD should have a timely and accurate diagnosis	6. Recommendations to improve diagnosis: a. GPs and HCPs working in A&E in the UK should be appropriately trained to recognise symptoms of bleeding disorders b. Rates of early diagnosis must be improved for all PWRBD, including girls and women c. Examples of best practice of care should continue to be shared across haemophilia treatment centres, comprehensive care centres and other care settings in the UK, with appropriate platforms set up to enable this d. Data should be collected by NHS Digital to provide an accurate understanding around the rates and speed of diagnosis and the care offered to PWRBD

PWRBD – People with rare bleeding disorders

MDT – Multi-disciplinary team

EXPECTATIONS FROM WIDER SOCIAL SUPPORT

Ambitions		Recommendations
7. PWRBD should be able to benefit from consistent and appropriate social support services across the UK		7. Local Authorities should be appropriately resourced and connected to relevant healthcare providers to ensure PWRBD receive consistent advice on what they are entitled to and consistent support from their HCPs and patient organisations to help them complete the relevant applications
8. Education providers including schools and universities, as well as employers should be able to access information to support PWRBD to access social support and other services		8. To ensure that PWRBD are supported throughout applications for wider support services, local authorities should work with PWRBD and patient organisations to develop appropriate guidance for education providers and employers

EXPECTATIONS AROUND COMMUNICATIONS

Ambitions		Recommendations
9. The language used around rare bleeding disorders should be patient centric, inclusive and non-stigmatising		9. Everyone involved in the care and support of PWRBD and any tools and resources developed for PWRBD, should use appropriate language that is based on the lived experience of PWRBD

WE BLEED DIFFERENTLY

GETTING THE RIGHT INFORMATION

The following groups provide ongoing information and campaigning activities to support improved outcomes in rare bleeding disorders. Please visit their pages for further information.

The Haemophilia Society

haemophilia.org.uk

The Haemophilia Society is a UK-wide charity supporting those affected by rare bleeding disorders to live fulfilling lives, make informed choices and support others. The society organises external campaigns to raise awareness of rare bleeding disorders and membership services such as advice forums and publications.

All Party Parliamentary Group (APPG) on Haemophilia and Contaminated Blood

publications.parliament.uk/pa/cm/cmallparty/210714/haemophilia-and-contaminated-blood.htm

The APPG on Haemophilia and Contaminated Blood exists to promote awareness of, and campaign for, people with haemophilia and other bleeding disorders and people infected with blood-borne viruses due to contaminated blood and blood products used in their healthcare treatment.