

A man wearing a yellow polo shirt and a blue and white helmet is riding a bicycle. He is looking forward with a neutral expression. The background is a blurred outdoor setting with green foliage and a bright sky. A red circular graphic is overlaid in the top left corner, containing the website address.

WBDR.WFH.ORG

THE WFH THANKS THE FOLLOWING
PARTNERS FOR **THEIR VALUABLE SUPPORT
OF THE WBDR:**

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WBDR

WFH WORLD BLEEDING
DISORDERS REGISTRY

JOIN

THE WFH WORLD
BLEEDING DISORDERS
REGISTRY (WBDR)
TODAY!

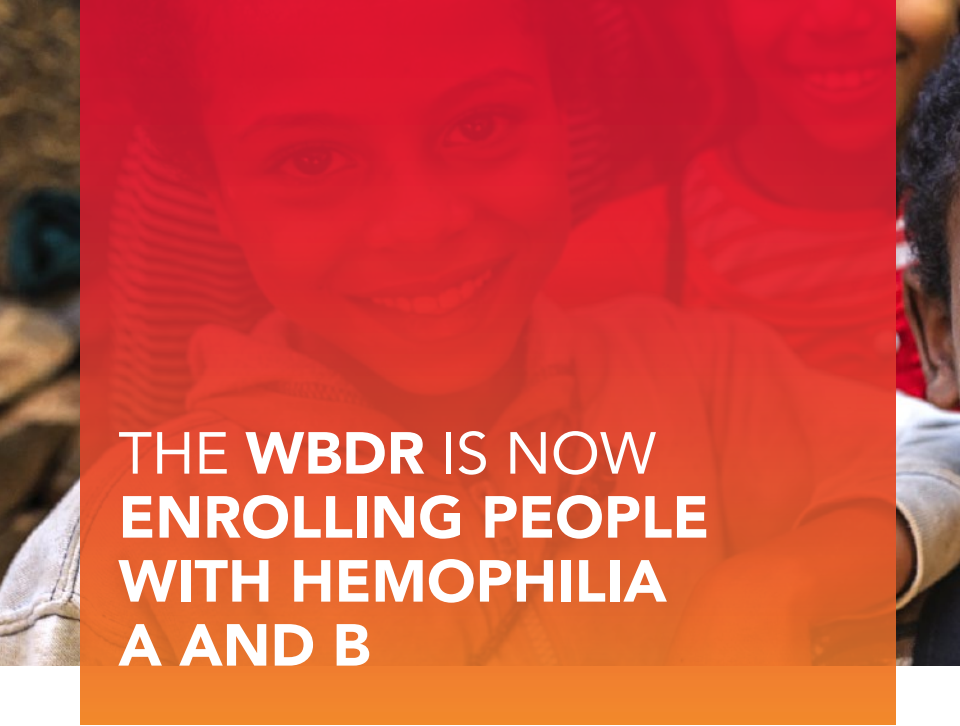
**BY
PARTICIPATING,**

you can help shape
the future care of people
with hemophilia around
the world!



WFH

WORLD FEDERATION OF HEMOPHILIA
FÉDÉRATION MONDIALE DE L'HÉMOFILIE
FEDERACIÓN MUNDIAL DE HEMOFILIA



THE WBDR IS NOW ENROLLING PEOPLE WITH HEMOPHILIA A AND B

What is a patient registry?

A patient registry is a collection of information (data) on a group of people with a particular health condition, usually kept on a computer. Patient registries such as the WBDR aim to collect data from a large number of patients.

What is the WBDR?

WBDR stands for the World Bleeding Disorders Registry. The WBDR is a secure online, web-based data entry system that provides a platform for a network of hemophilia treatment centres (HTC) around the world to collect uniform and standardized patient data.

Who can participate, and how?

People diagnosed with hemophilia who are registered at one of the participating HTCs are eligible for participation in the WBDR. Ask your doctor about it.

What information will be collected and how will it be used?

The WBDR stores data about the person's disease, such as hemophilia type and severity, symptoms, and treatment. This data will be stored with the aim of sharing the confidential data with the scientific community, helping them to address important questions around patient care and advocacy/health policy issues.



Why is the WBDR important?

By participating in the WBDR, people around the world living with hemophilia can play an active role in collaborating to build this important resource and improve the future of global hemophilia care.

Your information is secure and confidential

All of the information that is entered in the WBDR is secure and confidential. Patient names or other identifying information will not be stored in the database. All data in the WBDR is secure and compliant with the highest standards of data privacy of the European Commission. Only the WBDR project team will be able to view the confidential data.

Do I have to be in this registry?

You do not have to participate in this registry. If you do not want to be included in the WBDR, it will not affect the treatment and care you receive at your HTC. If you do participate, and decide at a later date that you don't want to be in the database anymore, you can ask your doctor to be removed.

For more information, contact your HTC or the **WBDR** at **WBDR.WFH.ORG**

Questions?

Please send them to

WBDR@WFH.ORG