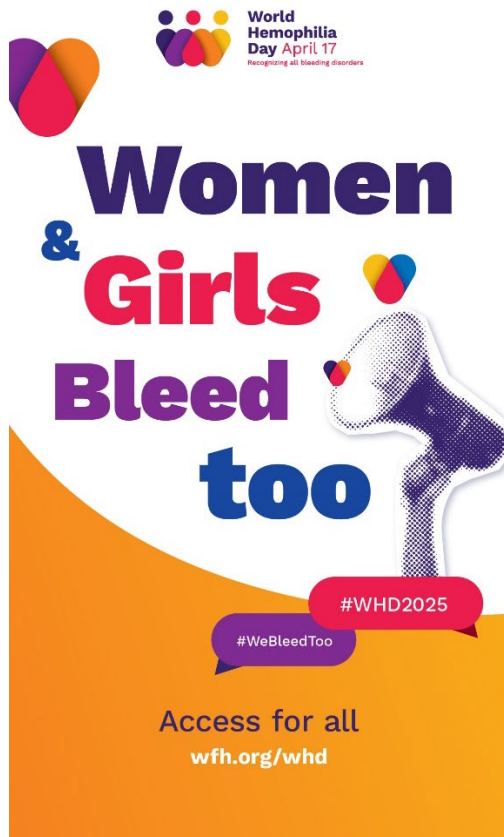


How to advocate for better recognition, diagnosis and care by writing a letter to your local government



This World Hemophilia Day on April 17, the WFH encourages you to help support women and girls with bleeding disorders (WGBDs) in your local community. WGBDs face significant barriers to recognition, diagnosis, and access to care. By advocating for change, you can help strengthen the bleeding disorders community and improve quality of life for WGBDs. One concrete way you can make a difference is to contact your local government and urge them to act to support the community. This document offers step-by-step instructions for writing a letter to government officials and policymakers, outlining a specific call to action with a special emphasis on WGBDs.

This document is designed to support you in your advocacy to improve recognition and access to care in your country. You can use it to ask your government to support initiatives that promote the recognition and diagnosis of WGBDs and ensure equitable access to treatment and care for all people with bleeding disorders (PWBDs).

Below we provide some **tips for crafting an effective advocacy letter**, along with a customizable **letter template**. We encourage you to tailor the letter to your situation to maximize its impact.

Step-by-step guide

Here is a step-by-step guide for writing your own letter from scratch. Or, if you prefer, you can use the example letter in this document and adjust it to your local context.

1. Open the letter with an official address

- Include the date, as well as the name, title, and address of the official you are writing to
- Include a subject line in your letter

2. Introduce yourself and the purpose of your letter

- State who you are, or who the organization you are writing on behalf of is
- Indicate in the first paragraph that your letter concerns PWBDs with an emphasis on WGBD

3. Explain your concerns related to inherited bleeding disorders

- Explain the current situation in your country regarding access to treatment and care for PWBDs, including disparities in cases for WGBD
- Clearly define the issues and/or disparities this situation is creating for WGBD and their families
- Explain the impact of bleeding disorders and late diagnosis on WGBD, such as life-threatening postpartum hemorrhages, heavy and debilitating menstrual bleeding and its impact on school and work attendance

4. Use statistical data to strengthen your argument

- Leverage reputable data sources like your national patient registry; local [hemophilia treatment centres](#) (HTCs); the [WFH Annual Global Survey](#); the [WFH World Bleeding Disorders Registry](#) (WBDR); publications in [Haemophilia](#) or other medical journals; resources available on [elearning.wfh.org](#); and resources from other reputable organizations
- Present comparative data (for example, data on number of identified people with hemophilia or other bleeding disorders, number of WGBD identified, data on gaps in identification by gender or geographic areas, etc.)
- Use [WFH interactive visualizations](#) to summarize Annual Global Survey data and gather country-specific statistics

5. Include personal stories and examples

- Personalize the letter by highlighting experiences from women and girls with bleeding disorders in your community

6. Make it relevant to policymakers

- Mention any existing laws, policies, or strategic plans to improve access to treatment and care for PWBDs in your country and highlight whether they include relevant provisions for WGBD

- Also mention any commitments to international resolutions or other policy instruments such as the United Nations Declaration on Universal Health Coverage ([read the declaration here](#)), or the [Political Declaration](#) of the Third High-level Meeting of the General Assembly on the Prevention and Control of Non-communicable diseases, etc.

7. Acknowledge any past support

- Mention any appropriate actions your government has taken to support PWBDs including positive outcomes of past support, and express thanks for these actions

8. Describe what action(s) you hope the official will take

- Explain how further supporting specific initiatives for WGBDs would be impactful
- Clearly state the action(s) you hope the official will take
- Describe the positive effects the requested actions may have on individuals or the community

9. Offer support

- Explain how you, your organization, or your partner organizations can help the government official
- Detail any technical support, expertise, or other contributions you could offer to support your government in addressing the issues facing your community
- Make yourself available for further discussion or a follow up meeting

10. Close and sign your letter

- Thank the official and sign the letter using your full name
- Include the names or logos of affiliated organizations
- Provide your address and phone number so that you can receive replies

Example letter

You can customize the following letter based on your information and your local context.

April 17th, 2025
Mr. John Smith, M.P.
House of Commons
City, State
Postal Code

Subject: Improving diagnosis and access to care for all people with bleeding disorders, including women and girls in [Name of Country]

Dear Mr./Mrs./Ms. [Name of Recipient],

My name is [Your Name] and I am writing on behalf of [your organization's Name] concerning people living with inherited bleeding disorders and more specifically concerning the health inequities that women and girls with bleeding disorders here in [Name of Country] are facing.

Inherited bleeding disorders, including hemophilia, von Willebrand Disease (VWD), inherited platelet disorders, and other factor deficiencies are lifelong conditions that prevent blood from clotting properly. People with bleeding disorders (PWBDs) can experience uncontrolled internal or external bleeding that can result from a seemingly minor injury or can occur spontaneously. These bleeding episodes can cause severe pain, musculoskeletal complications, and disability, and can even result in death if left untreated.

Each year, on April 17th, our community commemorates World Hemophilia Day, a global disease day established to recognize and raise awareness about all bleeding disorders. This year, we are focusing on the underdiagnosis and lack of specialized care services for women and girls with bleeding disorders and are seeking your support to address these inequities.

In our own country, [Name of Country], based on the established scientific prevalence (Iorio et al., 2019), it is estimated that there are over [#] people with hemophilia and [#] with VWD (which is the most common bleeding disorder). However, according to the latest records only [#] and [#] have been diagnosed, respectively.

Tip: Information on each country's percent of identified patients can be found on the [Annual Global Survey Interactive maps](#), or your local registry.

The disparity is more pronounced by gender. Based on a ratio of female somatic carriers to males with hemophilia, approximately 30% of individuals with hemophilia are expected to be women and girls (Weyand AC, James PD., 2021) but

only 4% of people worldwide reported with hemophilia were women and girls (WFH AGS 2023). This illustrates that underdiagnosis and under-reporting of hemophilia remains a challenge in women.

Women and girls with bleeding disorders (WGBD) face significant under-diagnosis, with a median diagnostic delay of 8 to 16 years (Weyand AC, James PD, 2021 and van Galen K, Lavin M, Skouw-Rasmussen N, 2021). This is a major concern, as WGBD are at increased risk for conditions including anemia, iron deficiency, and bleeding during pregnancy, as well as negative impacts on physical health and quality of life (Weyand AC, James PD, 2021). Furthermore, women and girls face greater barriers to accessing healthcare than men due to menstruation stigma and marginalization, gender bias, and sexism (van Galen K, Lavin M, Skouw-Rasmussen N, 2021).

We are writing to request your support for improved access to diagnosis, treatment and specialized care for women and girls with bleeding disorders in [Name of Country]. Early diagnosis and treatment of WGBD will ensure they are able to complete their studies, remain employed and fully contribute to society. With the right diagnosis, complex, invasive and expensive procedures like hysterectomies could be avoided, thus creating a positive impact on the physical and mental health of WGBD, and allowing public funds to be used more effectively.

We are very grateful for all the support you have provided to our community with [...]. Today, we hope we can count on you to make the needs of women and girls with bleeding disorders a priority in [Name of Country]. We very much hope that we can continue to build on our existing collaborations to ensure women and girls with bleeding disorders are diagnosed, treated and cared for as they need.

Our organization, [Name of Organization], is ready to work with your invaluable support in raising awareness and [...].

Thank you for taking the time to consider our concerns. We look forward to your reply and remain available to discuss collaborative opportunities and be part of the solution to improve access to diagnosis, treatment and care for WGBD.

Suggestion: If your organization has planned an advocacy or awareness event in relation to WHD, you can also take the opportunity to invite the government official you are writing to this event.

Sincerely,

Name
Signature
Organization
Address
Phone number
Email address

Sources:

Iorio A, Stonebraker JS, Chambost H, et al. Establishing the prevalence and prevalence at birth of hemophilia in males: a meta-analytic approach using national registries. *Ann Intern Med.* 2019; **171**: 540- 546.

Srivastava, A, Santagostino, E, Dougall, A, et al. WFH Guidelines for the Management of Hemophilia, 3rd edition. *Haemophilia.* 2020; 26(Suppl 6): 1- 158. <https://doi.org/10.1111/hae.14046>

World Federation of Hemophilia Report on Annual Global Survey 2023
<https://elearning.wfh.org/resource/report-on-the-annual-global-survey-2023/>

The World Bleeding Disorders Registry (WBDR) 2023 Data Report
<https://elearning.wfh.org/resource/wbdr-2023-data-report/>

Weyand AC, James PD. Sexism in the management of bleeding disorders. *Res Pract Thromb Haemost.* 2021;5(1):51-54.

van Galen K, Lavin M, Skouw-Rasmussen N, et al. European principles of care for women and girls with inherited bleeding disorders. *Haemophilia.* 2021;27(5):837-847.