



RECOGNIZING
ALL BLEEDING
DISORDERS



How to advocate for improved access to treatment and care: writing a letter to your local government

This World Hemophilia Day, the WFH encourages you to take action to help support your local bleeding disorders community. One great way to do this is to contact your local government and urge them to change policies to better support people with bleeding disorders (PWBDs). This document offers step-by-step instructions for how to write a letter to government officials and policymakers, outlining two specific calls to action. Of course, you can do both, or just pick one.

1. **Call to Action: improve access to treatment and care in your country:** ask your government to improve treatment and care, with an emphasis on helping all people with an inherited bleeding disorder get access to care, regardless of their type of bleeding disorder, gender, age, or where they live.
2. **Call to Action: request WHO resolution on hemophilia and bleeding disorders:** ask your government to formally request that the World Health Organization (WHO) adopt a resolution on hemophilia and other bleeding disorders.

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

Step-by-step guide

Here is a step-by-step guide for writing your own letter from scratch. If you prefer, you can use our template and simply modify it for your situation.

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

Introduce yourself and the purpose of your letter

- State who you are and who you, or the organization you are writing on behalf of
- Indicate in the first paragraph that your letter concerns PWBDs

Explain your concerns related to inherited bleeding disorders

- Explain the current situation in your country regarding access to treatment and care
- Clearly define the issues and/or disparities this situation is creating for PWBDs or their families

- Explain the impact of bleeding disorders, such as missed school or work
- Highlight that having a WHO resolution would provide an unprecedented opportunity to create a much-needed global framework enabling coordinated actions by the WHO and its Member States aimed at addressing key barriers to increasing access to diagnosis, treatment and care for people living with hemophilia and other bleeding disorders.

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 journal](#) or other official medical journals, and other resources available on [wfh.org](#).
- Present comparative data (for example, data on number of identified people with hemophilia compared to the expected number, data on gaps in identification by gender or geographic areas, annualized bleed rate (ABR) and/or annualized joint bleed rate (AJBR) for patients receiving prophylaxis versus on-demand treatment, etc.)
- Use [WFH interactive visualizations](#) to summarize Annual Global Survey data and gather country specific statistics.

Include personal stories and examples

- Personalize the letter by highlighting your own experiences

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
- 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](#)), [Political Declaration](#) of the Third High-level Meeting of the General Assembly on the Prevention and Control of Non-communicable diseases, etc.

Acknowledge any past support

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

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

- 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

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

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

April 17th, 2024
Mr. John Smith, M.P.
House of Commons
City, State
Postal Code

Subject: Increasing access to treatment for people with bleeding disorders in [Name of Country]

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

My name is [Your Name] and I am writing to you concerning people living with inherited bleeding disorders here in [Name of Country].

As you may know, inherited bleeding disorders include hemophilia, von Willebrand Disease (VWD), inherited platelet disorders, and other factor deficiencies. These are all 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. Bleeding into joints and muscles causes severe pain, musculoskeletal complications, and disability, while bleeding into major organs, such as the brain, can cause death. I'm contacting you today because every year, on April 17th, our community celebrates World Hemophilia Day. In honour of this important day, we are asking for your support.

Most PWBDs are **undiagnosed**. Using the established scientific prevalence (Iorio et al., 2019), it can be estimated that there are over 830,000 PWH worldwide. However, according to the World Federation of Hemophilia (WFH Annual Global Survey 2022) there have been only 271,359 patients identified and reported globally. In our own country, [Name of Country], the percentage of identified patients compared to the expected PWH is [%]. The identification rate for VWD (which is the most common bleeding disorder) is even lower, with only [#] of people with VWD reported in our country. The majority of PWBDs who are diagnosed do not have access to adequate treatment or care. Significant gaps also persist among identification rates by gender, with only [#] of women with a bleeding disorder reported. The annualized bleeding rate (ABR) for people diagnosed with hemophilia in [Name of Country] is [X%], indicating ... [modify the data included, based on your needs and available data, add your conclusion].

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

With proper treatment, people with hemophilia can live perfectly healthy lives. Without treatment, most children will grow up with permanent disabilities—if they survive into adulthood. Patients will experience not only health complications, but also impacted employment and educational experiences. For patients with severe hemophilia A or B—especially for children—the World Federation of Hemophilia recommends regular long-term prophylaxis as the standard of care, and as the most effective means to control and prevent bleeding episodes (Srivastava et al., 2020). In [Country], only [X%] of adults and [X%] of children with severe hemophilia receive prophylactic treatment.

** Information on each country's percentage of patients receiving prophylactic treatment can be found from your local registry or in the [Annual Global Survey Report](#). You can also add any statistical data on people with VWD or other bleeding disorders, if available.*

[Call to Action 1]. We are writing to ask for improved access to treatment to ensure adequate care can be offered to people with bleeding disorders, with an emphasis on bleed control and

prevention. One effective solution is the introduction of home therapy and prophylactic treatment for concerned patients. Home therapy enables optimal early treatment, resulting in less complications, significantly reduced hospitalization rates and the prevention of long-term disability—especially for those on prophylaxis—when compared to episodic therapy.

** If home treatment and prophylaxis are already available in your country, you may ask for support for introducing access to certain therapies that may not yet be available in your country. For example: introducing or expanding prophylactic treatment through non-replacement therapies, introducing treatment and care for other inherited bleeding disorders such as VWD, increasing access to treatment and care for women and girls with bleeding disorders, etc.*

[Call to action 2]. Another way **[Government/official's Name]** can help to improve access to treatment and care for PWBDs is to propose and/or support a resolution from the World Health Organization on hemophilia and other bleeding disorders. This resolution would create a framework for guiding the activities of WHO and its Member States in addressing the health challenges of PWBDs. A WHO resolution could lead to increased awareness, better coordination of efforts, and international collaboration.

** Chose one call to action and delete the other, or use both.*

We are very grateful for all the support you have provided to us including [...]. We very much hope that we can continue to build on this past collaboration to ensure a better life for those affected by inherited bleeding disorders in our community.

Our organization, **[Name of Organization]**, is ready to support your efforts. We can offer you [...].

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 and treatment for all PWBDs.

**** 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

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 2022
<https://elearning.wfh.org/resource/report-on-the-annual-global-survey-2022/>

The World Bleeding Disorders Registry (WBDR) 2022 Data Report
<https://elearning.wfh.org/resource/wbdr-2022-data-report/>