



## How to write a World Hemophilia Day letter to a government official

This World Hemophilia Day, the WFH encourages all members of our community to be proactive. We call on WFH national member organizations (NMOs), hemophilia treatment centres (HTCs), other bleeding disorders advocacy organizations and individual members of our community to advocate for improved access to treatment and care with an emphasis on home treatment and prophylaxis to effectively manage and prevent bleeding episodes for people with bleeding disorders (PWBDs). One way of doing this is to contact government officials and policymakers with a letter. Below, we have provided some tips on how you can write such a letter, along with an example.

### How can you start your letter?

#### Open the letter with official address

- Include the date for reference and accountability
- Include the name, title, and address of the government official or policymaker you are writing to
- Include the subject line of your letter
- Begin with a salutation

#### Explain the purpose of your letter

- Be very specific: include a focused sentence to ensure that the recipient knows immediately that you are referencing hemophilia and other inherited bleeding disorders
- In one sentence, state who you are and who you represent, or who the organization you are writing on behalf of represents

#### Explain your concern related to inherited bleeding disorders

- Explain the current situation in your country with regards to access to treatment and care for people living with bleeding disorders
- Clearly define the issues and/or disparities that this situation is causing for people living with bleeding disorders and their families (as relevant)
- Explain the impact of bleeding disorders on members of the community, such as missed school or work
- Tell the official which group of people are affected by the availability of care and treatment and define, based on accurate statistics, how many people are affected



- Use statistical data to strengthen your argument. You can find relevant data from your national patient registry (if available); local HTCs; the WFH Annual Global Survey; the WFH World Bleeding Disorders Registry (WBDR) if HTCs in your country are part of it; publications in official medical journals, and other resources available on wfh.org
- Present comparative data using data-driven determinants of health, such as comparing Annualized Bleed Rate (ABR) and/or Annualized Joint Bleed Rate (AJBR) for patients receiving prophylaxis versus those who are treated on demand to help strengthen your arguments
- Use WFH interactive and informative visualizations to summarize Annual Global Survey data. This system allows you to select your own country on a world map and gather country specific bleeding disorders statistics: <https://bit.ly/3GRUQhS>
- Make it relevant to a policy maker. Mention any relevant existing national laws or health policies and strategic plans to improve care in the country to support your request. Also mention any commitments to international resolutions or other healthcare policy instruments (for example: the United Nations Declaration on Universal Health Coverage, the United Nations Resolution on Addressing the Challenges of Persons Living with a Rare Disease and their Families, etc.)

### Use personal or relevant stories and examples

- Describe the positive effects of the requested action will have on you personally or those you represent (for example, a certain family, member of the community, etc.)

### Acknowledge any past support

- Mention appropriate actions or decisions the government has made in the past to support inherited bleeding disorders, and express thanks for them
- Demonstrate the positive change/outcomes that are the result of previous support received from government institutions

### Describe what action you hope the official will take

- State specifically what action you (and those you represent) hope the official will take

### Propose how you or your organization can help

- In addition to stating the issues and problems your community faces, make sure you offer a solution
- Explain how you, your organization, or your partner organizations can help
- Detail any technical support, expertise, community support, or other contribution you can make to help address the concerned issue
- Make yourself available for a follow up meeting for further discussions

### Close and sign your letter

- Thank the official and sign your full name, and the names or logos of any affiliated organizations sending the letter
- If you are writing on behalf of an organization, include a brief paragraph with more info about the organization
- Make sure your address and phone number are included so that you can receive replies



# Example of a Letter

April 5<sup>th</sup>, 2023  
Mr. John Smith, M.P.  
House of Commons  
City, State  
Postal Code

**Subject:** Increasing access to treatment for better bleed control and prevention for people with bleeding disorders in (Country)

Dear (name),

I am writing to you concerning the persons living with inherited bleeding disorders here in (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 hemophilia (PWH) can experience uncontrolled internal or external bleeding that can result from a seemingly minor injury or 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 17<sup>th</sup>, our community celebrates World Hemophilia Day. In honour of this important day, we would like to ask you for support.

The majority of those living with bleeding disorders remain **undiagnosed**. Using the established prevalence (lorio et al., 2019), it can be estimated that there are over 800,000 people worldwide living with hemophilia. However, according to the World Federation of Hemophilia Annual Global Survey 2021, there have been only 256,840 patients identified and reported globally. In our own country, (country), the percentage of identified patients compared to the expected people with hemophilia is x%. The identification rate for VWD (which is the most common bleeding disorder) is even lower, with only XX people with VWD reported in our country. The majority of those of who are diagnosed with hemophilia don't have access to adequate care and still experience frequent bleeding episodes and related health complications. The Annualized Bleeding Rate (ABR) for people with hemophilia in (country) is x%, indicating that it is necessary to provide a more equitable access to adequate treatment and care to those affected.

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

With immediate treatment including an adequate quantity of treatment products and specialized care, people with hemophilia can live perfectly healthy lives. Without treatment, most children with severe hemophilia will die young and risk having permanent disabilities. Patients will experience not only health complications, but they will also have impacted employment and educational experiences. In (country) only X% of adults and X% of children with severe hemophilia receive prophylactic treatment—and for patients with severe hemophilia A or B, especially children, the WFH 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)

\*\*\* *Information on each countries percentage of patients receiving prophylactic treatment can be found from your local registry or in Annual Global Survey Report. You can also add any statistical data on people with VWD or other bleeding disorders if available.*



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 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.

\*\*\* Depending on your country, if home treatment and prophylaxis are already available, you may ask more specifically for support for introducing access to certain therapies that may not be available in your country for people with bleeding disorders. 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.

We are very grateful for all the support you have provided to us including (xxx). 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 (xxx) is ready to support your efforts. We can offer you (xxx).

Thank you for taking the time to consider our concerns. We look forward to hearing back from you and we remain at your disposal to discuss collaborative opportunities and be part of the solution to improve access and treatment for people affected by bleeding disorders.

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

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 2021  
<https://elearning.wfh.org/resource/report-on-the-annual-global-survey-2021/>

The World Bleeding Disorders Registry (WBDR) 2021 Data Report  
<https://elearning.wfh.org/resource/wbdr-2021-data-report/>

