



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 hemophilia advocacy organizations and individual members of our community to advocate for inclusion of bleeding disorders into national policy. One way of doing this is to contact government officials and policymakers with a letter. Below, we have provided guidance on how you can write such a letter, along with an example.



How can you start your letter?

OPEN THE LETTER WITH AN OFFICIAL ADDRESS

- Include the date for reference and accountability
- Include the name, title, and directly 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 to the targeted government official 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 members of your community
- Explain the impact of bleeding disorders on members of the community such as missed school or work among others.
- 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), from local HTCs, the WFH Annual Global Survey, the WFH World



Bleeding Disorders Registry (if HTC's in your country are part of it), publications in official medical journals, and other resources available on wfh.org

- The WFH has developed 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 MOH 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 any support 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 where previous support has been 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 1st, 2022
Mr. John Smith, M.P.
House of Commons
City, State
Postal Code

Subject: including bleeding disorders in (Country)'s national health policies

Dear (name),

I am writing to you concerning the persons living with inherited bleeding disorders here in (country). Every year, on April 17th, we celebrate World Hemophilia Day. As you may know, inherited bleeding disorders include hemophilia, von Willebrand Disease (vWD), inherited platelet disorders, and other factor deficiencies. These are all lifelong bleeding disorders 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. Bleeding into joints and muscles causes severe pain and disability, while bleeding into major organs, such as the brain, can cause death.

Unfortunately, the majority of those living with bleeding disorders remain **undiagnosed**. Using the prevalence of 20.9 per 100,000 males (Iorio 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 2020, there have been only 241,535 patients identified and reported globally. In our own country, (country), the percentage of identified patients compared to the expected people with bleeding disorders is x%, indicating that improvements in diagnosis are necessary.

(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 persons with bleeding disorders risk permanent disability. Untreated hemophilia also affects the employment and education of people with bleeding disorders, forcing them to miss school and work, due to severe pain and or joint damage. 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. (Srivastava et al., 2020)

(Information on each countries percentage of patients receiving prophylactic treatment can be found from your local registry)

Lack of awareness also impedes identification and diagnosis. Without diagnosis, persons affected cannot begin their path to treatment. And, without medicine or access to medicine there can be no treatment. This vicious circle can be broken with the collaboration and commitment of all relevant partners: the government, doctors, and the patient community. The reality is that treatment centres can only rely on donations in the short term. For treatment to be sustainable, local access to a predictable flow of



medicine is needed. We would, therefore, like to call upon the government to step in so we may have treatment readily available for those who need it.

A comprehensive national strategy could significantly change the situation from an issue of concern to a positive reality. We are writing to ask for inclusion of, and integration of inherited bleeding disorders into the national health policy. One effective mechanism to initiate dialogue about the solutions that are best suited for our country is for a government-led National Hemophilia Committee be mandated to work on a comprehensive plan, alongside (name of organization).

(Depending on your country, if bleeding disorders are already included in national health policy, you may ask more specifically for support for improving or expanding national program coverage, for example: introducing or expanding prophylactic treatment, introducing treatment and care for other inherited bleeding disorders such as VWD, etcetera.)

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 hemophilia in our community.

Our organization (XXX) is ready to support your efforts. We are more than willing to discuss and explore the options and steps required to include inherited bleeding disorders into our national policy. We can offer (XXX).

Thank you for taking the time to consider to our concerns. We look forward to hearing back from you and we remain at your disposal to meet or talk further to discuss joint collaboration and be part of the solution to improve access and treatment for persons affected with bleeding disorders.

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>