



Global Action Network for Sickle Cell
and Other Inherited Blood Disorders

How to Engage Your Government on Inherited Blood Disorders

A Step-by-Step Guide to Writing Advocacy Letters



www.iblooddisorders.world



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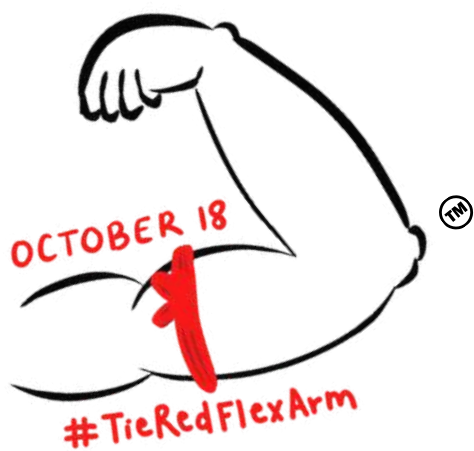
World Inherited Blood Disorders Day, observed annually on **October 18**, is a global opportunity to raise awareness of inherited blood disorders, including sickle cell disease, thalassemia, bleeding, aplastic, PKD, and others. This day recognizes both the challenges and the resilience of individuals and families affected, while highlighting the urgent need for better recognition, timely diagnosis, and equitable access to care and treatment.

One powerful way you can make an impact is by writing to your government officials and policymakers. Your voice can help bring attention to the needs of people with inherited blood disorders (PWIBDs), reduce stigma, and strengthen support systems.

This document provides step-by-step guidance and a customizable letter template to help you advocate effectively in your country.

Use it to ask your government to advance initiatives that promote the recognition of National Inherited Blood Disorders Day, advance the diagnosis of inherited blood disorders, and ensure equitable access to care and treatment for all people living with these conditions.

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.





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Step-by-Step Guide to Writing Your Letter

You can either draft your own using these steps or adapt the sample letter provided.

1. Official address and subject line

- Include the date. Follow it with the name, title, and address of the official you are writing to.
- Add a subject line (e.g., Recognizing October 18 as National Inherited Blood Disorders Day in [Country]).

2. Introduction and purpose

- Clearly state if you are a constituent (as this often carries more weight with elected officials). Also, indicate if you are (an advocate, a caregiver, or a clinician), and your organization.
- Clearly articulate your purpose for writing in the opening paragraph and reiterate it in the closing paragraph.

3. Explain the impact

- Describe the current situation around your “ask” in your country (e.g., lack of awareness and the resulting limited access to care, leading to stigma, discrimination, and preventable complications).
- Highlight how these challenges affect you, other patients, and families in your community/country.

4. Strengthen your case with facts

- Use reliable sources such as GANSID resources and stick to the facts

5. Be concise and clear

- Keep your letter to 1-2 pages. Proofread your letter to ensure there are no errors and content is easy to understand.

6. Include personal stories

- Share your own experiences and the experiences of patients and families to humanize the issue.

7. Make it relevant to policymakers

- Reference national health policies or commitments to international resolutions on universal health coverage and equity.
- Show how addressing inherited blood disorders aligns with these commitments.

8. Acknowledge past support

- Mention any positive steps your government has already taken and outline the actions you want (e.g., enacting October 18 as National Inherited Blood Disorders Day, including inherited blood disorders in health policies, ensuring equitable access to care and essential medicines).

9. Offer collaboration/solutions

- Suggest solutions to the problem
- Provide suggestions on technical expertise that you or your organization may be able to provide

10. Request for a meeting and response

- You may want to complete the letter by requesting a follow-up meeting and response to your letter. Also, ensure that you thank the official, sign your name, and provide your contact details.





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Sample Letter

(This is a template. Please adapt it to your country and context.)

October 18, 2025

[Recipient's Name]

[Title]

[Government Office / Ministry of Health]

[Address]

Subject: Recognizing October 18 as National Inherited Blood Disorders Day in [Country]

Dear [Recipient],

My name is [Your Name], and I am the Chief Executive Officer of [Your Organization] and an advocate supporting people affected by [X disease]. I also live and work in your constituency.

I am writing to bring to your attention the poor health outcomes experienced by people living with inherited blood disorders (IBDs), including [X disease] in your constituency. The majority of babies born with IBDs go undiagnosed, and many of them die in childhood. Those who survive childhood are underserved, receiving limited or no access to specialized care, and face a life marked by stigma, discrimination, preventable complications, and premature death.

There is a lack of awareness around IBDs, including [X disease] in [Country], and as such, there is an urgent need for changes to happen, starting with the recognition of the day to raise awareness on inherited blood disorders.

Globally, millions of people are living with IBDs, and an estimated X people live with various IBDs in [Country]. In [organization's name], we serve X people living with [X disease], one of the more [common or rarer] IBDs, and we continue to witness patients and their families suffer due to their diagnosis.

Each year, on October 18, the global community marks World Inherited Blood Disorders Day—a day to amplify the voices of people living with these conditions, raise awareness around their challenges, and look for opportunities to ensure they have improved access to care and treatment.

We respectfully urge you and your office to support more awareness of inherited blood disorders by helping to enact October 18 as National IBDs Day. We believe that with such a law passed in [state] or [Country], there will be improved:

- Screening and early diagnosis of more inherited blood disorders.
- Equitable access to comprehensive care and treatment.
- Access to clinical trials and research opportunities.
- Funding trajectory for inherited blood disorders
- Inclusion in national health policies and programs
- Reduced stigma, discrimination, and social and economic burden on the families and the government

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Sample Letter

(This is a template. Please adapt it to your country and context.)

We are committed to working with you to support these efforts and can provide technical support, data, and community perspectives to ensure that policies are effective and inclusive. We are also grateful for your past support of the inherited blood disorders community and look forward to continuing to work with you and the government in advancing IBDs.

I would appreciate the opportunity to meet with you in your office at your earliest convenience, and I hope to receive a response to this letter, including your availability for a meeting, hopefully within the next two weeks.

Thank you for your leadership and consideration.

Sincerely,

[Name]

[Title / Organization]

[Contact Information]

