

ABOUT WORLD HEMOPHILIA DAY 2022

April 17, 2022 is World Hemophilia Day. The theme of the event this year is "Access for All: Partnership. Policy. Progress. Engaging your government, integrating inherited bleeding disorders into national policy". By raising awareness and bringing hemophilia and other inherited bleeding disorders to the attention of policymakers, we can increase sustainable and equitable access to care and treatment.



#WHD2022 wfh.org/whd2022



"World Hemophilia Day is day for people who have been affected by a bleeding disorder—either because they have one, or because they care for someone who does. But we can't forget that governments play a critical role. It's important that they recognize bleeding disorders, and assist people who have a condition in their countries."

— Cesar Garrido, WFH President

HOW CAN YOU GET STARTED?

There are many ways you can bring attention to hemophilia and other inherited bleeding disorders in your local and global community to raise awareness of the need for inclusion in national policy. Whether you are a person with a bleeding disorder, a National Member Organization or a healthcare professional here are just a few things you can do to get started:

GET SOCIAL by posting about inherited bleeding disorders on Facebook, Twitter and LinkedIn using the #WorldHemophiliaDay, #WHD2022, and #LightItUpRed hashtag

ORGANIZE an event, host a community event, webinar, forum or Town hall and invite elected officials to learn more about your work first-hand and to meet with the community

PARTICIPATE in the World Hemophilia Day Light it Up Red campaign. Last year, thousands of people worldwide showed their support—while respecting local COVID-19 requirements—by lighting up 100+landmarks red in cities across the world

SUPPORT our global advocacy efforts by making a donation or organizing a fundraising event

CONTACT your local National Member Organization to find out how you can support them

SHARE your story on **wfh.org/whd** about how you or someone you know has been affected by inherited bleeding disorders, and read the stories of others

TAKE ACTION LOCALLY and use the WFH World Hemophilia Day materials to send a letter to your local policymakers, set up meetings with elected officials and health ministers and engage with the local media

media banners from **wfh.org/whd** to help build your World Hemophilia Day Campaign

SEND pictures, comments or questions to the WFH at marcom@wfh.org

CHECK our **wfh.org/whd** webpage regularly—new World Hemophilia Day campaign materials, tools and updates will be added monthly!

The WFH would like to thank our 2022 World Hemophilia Day sponsors for their continued support:

Bayer
BioMarin Pharmaceutical Inc.
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LFB S.A Novo Nordisk Octapharma Pfizer Sanofi Genzyme Sobi

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Takeda

RAISE AWARENESS ON SOCIAL MEDIA

- Use our hashtags #WHD2022, #worldhemophiliaday and #LightItUpRed
- Share photos and videos of your WHD plans and tag the WFH
- Share our WHD banners and images on social media
- Leverage our social media toolkit
- Follow us to stay up to date
- Update your profile photo with the WHD Facebook frame
- Update your social media cover photos for WHD
- Go live on World Hemophilia Day and share your story
- Share stories online of advocacy and thank government for their support





DOWNLOAD OUR MATERIALS

Download and disseminate posters, logos, and a range of digital assets that can be translated and adapted to fit your local campaign needs!

Download files here





FOLLOW US ON SOCIAL MEDIA







ORGANIZE AN ADVOCACY EVENT

- Check <u>wfh.org/whd</u> for examples of how you can apply our logos to shirts or masks for matching gear at your events
- Use our World Hemophilia Day Zoom background for any virtual events or meetings you host
- Host a fundraising event or competition, such as a walkathon or a team walkathon where you challenge your family, friends, and colleagues, or add a fundraising goal on your social media to support your ongoing advocacy efforts.
- Organize a forum/town hall or community event where you can invite local policymakers and persons living with inherited bleeding disorders and HTC representatives to discuss advancing care:
 - Public meetings with larger audiences mean more attention to the issues and more community involvement
 - This is an opportunity for community members to get informed and participate in public policy
 - This is a potential opportunity to bring elected officials to meet with the community to address the issue
 - It can also be an opportunity to invite the elected official to learn more about your work first-hand and meet board members, beneficiaries, and staff in an informal setting and highlights your organization and the work you do
 - Plan ahead, as it can take time to get speakers, and book elected officials, promote an event, secure a location and find a moderator
 - Develop a key theme for the event
 - How will the issues be presented and how will community members give their input on the issues and their effect? What can policymakers take away as an action item or next step?
 - Invite media to cover the event; contact local media as soon as the date, time, and location are finalized
 - Send out a media release the day before the event
 - Ensure that issues are clear and well- explained for the audience
 - Share handouts if they are helpful
 - Make sure there are opportunities for you, community partners, and audience members to outline the impacts of the issue on the community
 - Be solutions-oriented and have a clear ask. Give any elected officials who attend an opportunity to outline their position, answer questions, and talk about how they will respond to the issue.

LIGHT A MONUMENT UP RED

Every year, landmarks around the world are lit up in red as part of the World Hemophilia Day "Light It Up Red" campaign. Last year, 100+ landmarks around the world were lit up in a show of solidarity with the community.

The safest way for you to "Light It Up Red" is to bring the idea of "red" to your social media profiles. For example, you can download the WFH World Hemophilia Day Facebook banner or Facebook frame. You can also wear something red at home and share a selfie on social media. Another thing you can do is encourage your coworkers or schoolmates to post a picture of themselves wearing red for the day—or post a picture collage of everyone in your organization in red. If you're able to take a picture of a landmark while safely social distancing, you can also do that—just remember to always play it safe.

- A sample letter that can be used to request for a monument to light up red can be found in our advocacy toolkit at <u>wfh.org/whd</u>
- If you take pictures of the monument or building and post them on social media, use this hashtag: #LightItUpRed
- Email us at marcomm@wfh.org to tell us which monument or building you're helping to light up and to share photos of lit up monuments







TELL YOUR STORY

- Write your own story or submit a video story
- Read the stories of others
- Show your support by liking or commenting on stories

Share your story on wfh.org/whd about how you or someone you know has been affected by inherited bleeding disorders, and read the stories of others.

TAKE ACTION LOCALLY

There are multiple ways to reach out to local elected officials, raise awareness in the local news, and share your local impact:

- Send a letter to your local government, elected officials, or health ministers
 - The WFH is developing a template of this letter for your guidance coming soon check <u>wfh.org/whd</u> to download and modify it for your own local needs
- Set up individual meetings with elected officials, health ministers or local governments
 - Ask in person, call, email, or use a letter to each local elected official briefly outlining your organization's work, your key messages, and your asks. Request a meeting to discuss these items.
 - Follow up with a phone call or visit to the constituency office
 - Once the meeting is confirmed, put together a team to attend the meeting. Create a quick facts binder
 of key points about the organization and your impact to use at all meetings.
- Engage through traditional media:
 - Follow journalists who cover stories and issues related to your mission and contact them with ideas for articles
 - Write letters to the Editor or Op-Eds of local news publications. These types of articles help raise awareness of key issues your organization is working on, and can get the attention of parties and candidates. Make it relevant and tie it to what's happening in the community, in the general news cycle, or to what's been published recently in that media outlet. Use facts and figures and don't be afraid to use a compelling story to make your point. Even if your letter is not published, the more letters an editor receives on a given topic, the better the chances are that the news outlet will recognize public interest in that topic and cover it in some way. It can be helpful to have a group of supporters write their own letters and send them in. Turn it into a blog post or eblast to share with your networks and communities.
- Send a press release to media in your area:
 - You can find a sample press release from the WFH on wfh.org/whd to be released on April 1st
- Contact the press: reach out to local or regional newspapers, radio, and TV stations to get coverage of your
 event for World Hemophilia Day—use our key stats to share messages with the media
- Approach celebrities in your country/community to join the cause and show support for World Hemophilia
 Day by sharing a #WorldHemophiliaDay post on social media

