

# Diagnosis and Beyond: Treatment Options and Resources for People with Inhibitors

There are many options for treating inhibitors, and in some cases inhibitors can be eliminated. If you have been diagnosed with an inhibitor, it's important to discuss treatment options with your doctor and follow your treatment plan carefully.

People who have hemophilia use treatment products called clotting factor concentrates, which are infused or injected into a vein to replace the missing proteins in their blood. Clotting factor concentrates improve blood clotting, and are used to stop or prevent bleeding episodes in people with hemophilia. When a person develops an inhibitor, their body responds to the clotting factor treatment in the same way it would against a foreign substance; their body stops accepting the clotting factor treatment as a normal part of their blood and tries to destroy it with an inhibitor. The inhibitor stops the clotting factor treatment from working, making it more difficult to stop or prevent bleeding episodes.



As many as **1 in 5** people with severe hemophilia A will develop an inhibitor at some point in their lifetime.

## How are inhibitors diagnosed?

Inhibitors are diagnosed with a blood test. This blood test determines if a person has an inhibitor; if so, it can also measure the amount of inhibitor present (called an inhibitor titer) in the blood. If you test positive for an inhibitor, your doctor will advise you on how to treat bleeding episodes, as well as how to get rid of the inhibitor. If you ever have concerns that a bleeding episode is not responding to treatment, contact your doctor right away for advice.

## How are inhibitors treated?

### Getting rid of an inhibitor:

- **Immune Tolerance Induction (ITI):** With the goal of getting rid of an inhibitor, a new treatment plan is prescribed, in which factor is given (infused into the bloodstream through a vein) regularly over a period of time until the body is trained to accept the factor without trying to destroy it. ITI is effective in many, but not in all patients.

### Treating and preventing bleeding events:

- **High-dosage Clotting Factor Concentrates:** If factor treatment still works, but maybe not as well, the amount of factor or frequency of infusing the factor can be increased to overcome the inhibitor. For example, the factor amount given remains the same but the number of infusions is increased, or the factor amount given is increased, but the number of infusions remains the same.
- **Use of Bypassing Agents:** These medications help the blood form normal clots in people with inhibitors. Bypassing agents do not replace the missing clotting factor; instead, they correct the clotting process by going around (or bypassing) the factor that does not work because of the inhibitor. Bypassing agents can also be given on a routine schedule to prevent bleeding episodes.
- **Products that Mimic Factor VIII:** This type of product works by replacing the function of factor VIII (8) without being affected by inhibitors, and can be used to treat and prevent bleeding episodes in people with hemophilia A. This treatment product can be given by injection under the skin.



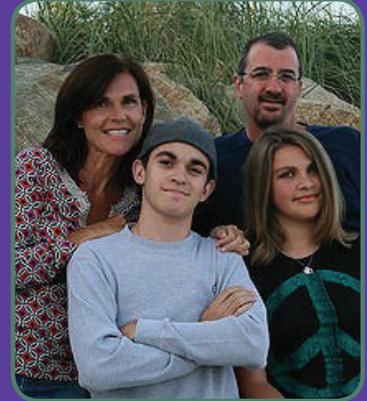
Centers for Disease  
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and Developmental Disabilities

## What can I do to help make treatment successful?

- ✓ You can carefully follow the treatment plan given to you by your doctor.
- ✓ You can keep in touch with your doctor and let him or her know of any concerns you have about your treatment.
- ✓ You can keep track of your infusions so you know if there are changes in your treatment pattern.

## Where can I seek support?

- **The National Hemophilia Foundation (NHF) Inhibitor Education Summits.** These summits are intended for patients, caregivers, and staff members from hemophilia treatment centers and NHF chapter organizations. The Summits allow attendees to learn from each other's experiences, as well as from experts. Past topics have addressed new drugs in development, tips for parents, sports and exercise, immune tolerance therapy, and the needs of older adults with hemophilia and an inhibitor. For more information, visit <https://www.hemophilia.org/Events-Educational-Programs/Inhibitor-Education/Inhibitor-Education-Summits>.
- **The NHF's Viviendo con Inhibidores.** Living with Inhibitors is a full day of educational sessions in Spanish, presented by experts in hematology, health, and other related areas, aimed at people with hemophilia A or B with inhibitors and people within their support network participating in their daily care. For more information, visit <https://www.hemophilia.org/Events-Educational-Programs/Inhibitor-Education/Viviendo-con-Inhibidores>.
- **The Hemophilia Federation of America's (HFA) Helping Hands Program.** This program offers financial assistance to those in need to pay for their attendance at eligible national and state bleeding disorder educational meetings; travel for necessary medical procedures, surgeries and second opinions; and tutoring or educational-related expenses. To learn more, visit <http://www.hemophiliamed.org/programs/helping-hands/helping-hands-inhibitor-support/>.
- **CDC's Flickr Album.** This album features stories of people with hemophilia who have also experienced life with the added challenge of an inhibitor. To read their stories, visit <https://www.flickr.com/photos/cdcsocialmedia/sets/72157654059374830>.



*"Having a son with hemophilia and then, the added challenge of an inhibitor, is not always easy. As a parent, I would love to fix things and make everything better. The inhibitor has taken away a lot of the control that parents have in effectively managing hemophilia."*

— Jane Cavanaugh Smith

## Where can I find additional information on inhibitors?

- **CDC's Webpage** at <http://www.cdc.gov/ncbddd/hemophilia/inhibitors.html>
- **NHF's Webpage** at <https://www.hemophilia.org/Bleeding-Disorders/Inhibitors-Other-Complications/Inhibitors-for-Consumers>
- **HFA's Webpage** at <http://www.hemophiliamed.org/bleeding-disorders/inhibitors/>
- **World Federation of Hemophilia Inhibitor Primer** at <http://www1.wfh.org/publication/files/pdf-1122.pdf>
- **World Federation of Hemophilia Treatment Website** at <http://www.wfh.org/en/page.aspx?pid=652>
- **Canadian Hemophilia Society Inhibitor Guide** at <http://www.hemophilia.ca/files/All%20About%20Inhibitors.pdf>