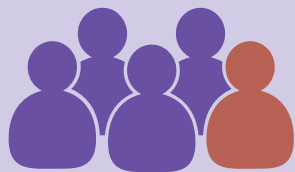


Beyond Diagnosis: Treatment Options and Resources for People with Inhibitors



As many as one in five people with severe hemophilia A will develop an inhibitor at some point in their lifetime.



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 with hemophilia use treatment products called clotting factor concentrates. These treatment products improve blood clotting and are used to stop or prevent a bleeding episode. When a person's immune system develops an inhibitor, their body stops accepting the factor treatment as a normal part of blood. The body thinks the factor treatment is a foreign substance and tries to destroy it with an inhibitor. The inhibitor stops the treatment from working, which makes it more difficult to stop or prevent a bleeding episode.

How are inhibitors diagnosed?

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

How are inhibitors treated?

Getting rid of the inhibitor:

- **Immune tolerance induction:** With the goal of getting rid of the inhibitor, a new treatment plan is prescribed, where factor is given (infused into the bloodstream through a vein) regularly over a period of time until the body's immune system is trained to accept the factor without trying to destroy it. It is effective in many, but not all patients.

Treating and preventing bleeding events:

- **High-dosage clotting factor concentrates:** If factor still works, but maybe not as well, the dose or frequency of infusing the factor can be increased to overcome the inhibitor. For example, the factor dosage remains the same but the number of infusions is increased, or the factor dosage 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, without increasing the amount of inhibitor in the blood. 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.

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 and from experts. Past topics have addressed new drugs in development, tips for parents, sports and exercise, immune tolerance therapy, and 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 Inhibitor Education Summits Webinar Series.** This webinar series is designed to enhance and expand upon the education provided at NHF's annual Inhibitor Education Summits. For more information, visit <https://www.hemophilia.org/Events-Educational-Programs/Inhibitor-Education/Inhibitor-Education-Webinars>
- **The NHF's Inhibitor Parent Mentoring Program.** This peer mentoring program matches parents whose children have or had inhibitors with parents of children with hemophilia with active inhibitors who might be feeling socially isolated and seeking guidance and coaching. For more information, visit <https://www.hemophilia.org/Events-Educational-Programs/Inhibitor-Education/Inhibitor-Parent-Mentor-Program>
- **The NHF's Regional Inhibitor Conferences.** These conferences provide a weekend of education for anyone with hemophilia A or B who currently has active inhibitors, as well as their caregivers who reside in the same household. For more information, visit <https://www.hemophilia.org/Events-Educational-Programs/Inhibitor-Education/Regional-Inhibitor-Education-Conferences>
- **The Hemophilia Federation of America's Helping Hands Program.** This program offers financial assistance to those in need to pay for attendance at eligible national and state bleeding disorder educational meetings; travel for necessary medical procedures, surgeries and second opinions; and tutoring or education 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>
- National Hemophilia Foundation's Webpage at <https://www.hemophilia.org/Bleeding-Disorders/Inhibitors-Other-Complications/Inhibitors-for-Consumers>
- Hemophilia Federation of America's Webpage at <http://www.hemophiliamed.org/bleeding-disorders/inhibitors/>
- World Federation of Hemophilia Webpage at <http://www.wfh.org/en/page.aspx?pid=652>
- World Federation of Hemophilia Inhibitor Primer at <http://www1.wfh.org/publication/files/pdf-1122.pdf>
- Canadian Hemophilia Society Inhibitor Guide at <http://www.hemophilia.ca/files/All%20About%20Inhibitors.pdf>
- Managing Your Child's Inhibitor: A Practical Guide for Parents, by Laureen A. Kelley at <http://kelleycom.com/books.html>