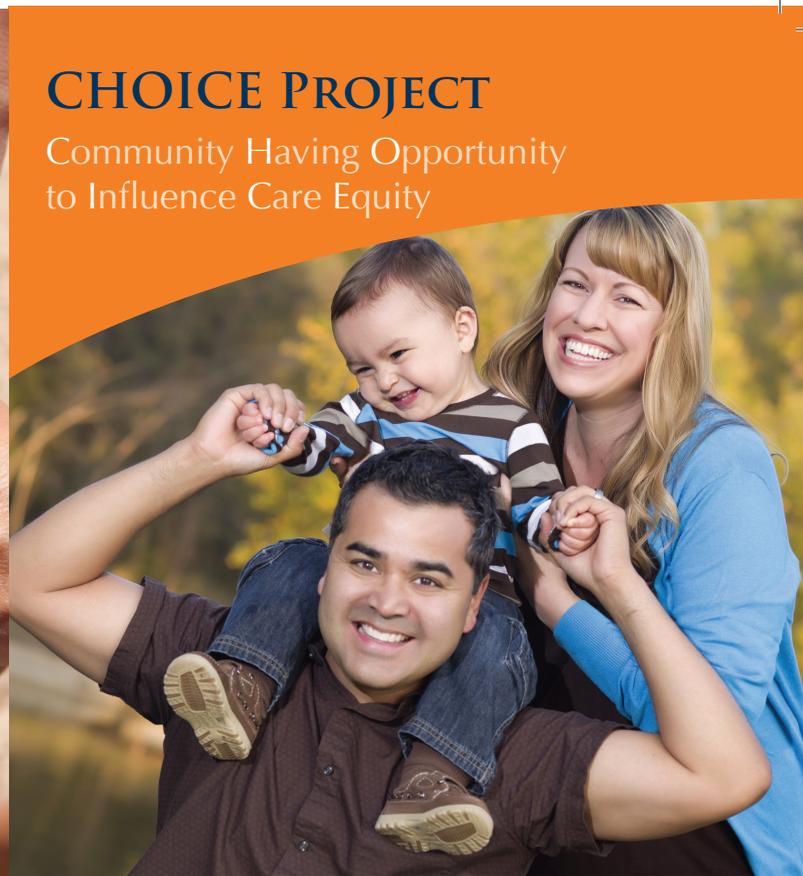
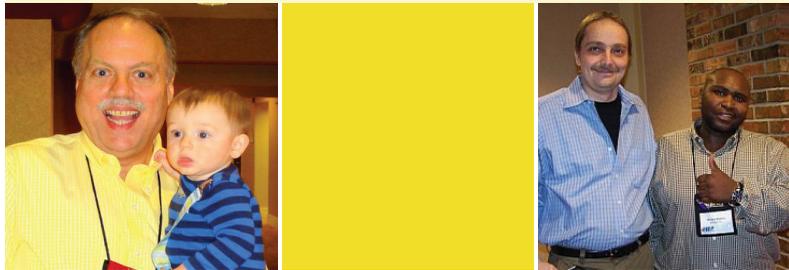




# CHOICE PROJECT



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Community Having Opportunity to Influence Care Equity

## About Hemophilia Federation of America

HFA is a national 501(c) (3) organization consisting of more than 30 member organizations and numerous individual members who offer assistance and grassroots advocacy education on behalf of the bleeding disorders community. Incorporated in 1994, HFA provides programs and services to improve the quality of life for persons with hemophilia, von Willebrand disease (VWD) and other rare bleeding disorders.



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[www.hemophiliafed.org](http://www.hemophiliafed.org) | 202-675-6984

## WHAT IS THE CHOICE PROJECT?

CHOICE is a new project driven by the Hemophilia Federation of America (HFA) and supported by the Centers for Disease Control and Prevention (CDC). CHOICE collects information through an online or paper-based survey. This survey collects information regarding health experiences of people who have a doctor-diagnosed bleeding disorder and do not get care at a federally funded hemophilia treatment center (HTC). De-identified information will be shared with the CDC to help understand the health status of people with bleeding disorders who do not get care at HTCs. Anyone with a bleeding disorder can take the survey.



Since 1998, CDC has collected information on the health status of people with bleeding disorders who get care at HTC. Much has been learned from this information. However, a study from the mid-1990's showed that a third of people got care outside of this HTC network.<sup>1</sup> In addition, the study showed that health experiences were different depending on where people got their care.<sup>2</sup> Little is known about the health experiences of people who do not get care at HTCs.

### How will the information be used?

The information will be used to understand the health of people with bleeding disorders who do not get care at HTCs. It will also be used to identify issues that need further understanding. These include things such as where care is being obtained, what complications are being experienced and what treatment is being used.

### Why should I take part in this project?

Because you matter.

The more participants enrolled in this project, the more information we can gather. With more information, we have a better chance of learning what we can do to improve the health of people with bleeding disorders.

Here are some other reasons to consider taking part in the project:

- It's easy, confidential and free to complete
- It may help improve the care of people with bleeding disorders
- It may help identify medical and social issues that require further study

### How is the information collected?

The information is collected in a survey that you fill out and send to HFA. You can complete the survey on paper or electronically. The survey should take roughly 40 minutes to complete.

### What information is collected for the project?

The survey asks questions about you, your health, your bleeding disorder and your quality of life. These include things like:

- Diagnosis
- Bleeding history
- Use of treatment products
- Insurance coverage
- Ability to attend school or work
- Overall activity level

### Will my information be kept private?

Yes. HFA will collect all survey information. Personal information will not leave HFA's secure, password protected database. Paper-based surveys will be compiled into this database and the paper documents shredded and recycled. Your name is not revealed to anyone outside of HFA. Data shared with the CDC will include a unique identifier code but will not contain personal identifiers such as your name or address. Information from this project may be published. However, no information will be published that could identify you or anyone else.

### How can I learn more about this project?

If you have a bleeding disorder, your voice should be heard – no matter where you get your care! To find out how to take part in this project, call **800-230-9797** or go to **[choice.hemophiliafed.org](http://choice.hemophiliafed.org)**.

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<sup>1</sup>Soucie JM, Evatt B, Jackson D, Hemophilia Surveillance Study Investigators. Occurrence of Hemophilia in the United States. American Journal of Hematology 59:288–294, 1998.

<sup>2</sup>Soucie JM, Symons J, Evatt B, Brettler D, Huszti H, Linden J, et al. Home-based factor infusion therapy and hospitalization for bleeding complications among males with hemophilia. Hemophilia 7:198–206, 2001.



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