Welcome to the ATHNdataset

Improving care— for you and the blood disorders community

athn™
american thrombosis
& hemostasis network

What is the ATHNdataset?

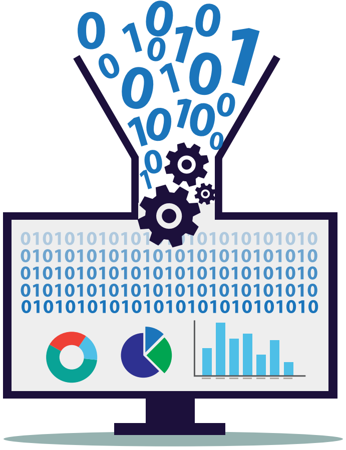
The ATHNdataset is a large set of de-identified data contributed by persons with blood disorders in the United States. Tens of thousands of people across the country have already signed up to be part of this vital community resource. The health information that makes up the ATHNdataset is helping us gain a better understanding of blood disorders so that together, we can transform care and improve lives.

A vital resource for the blood disorders community

Persons with blood disorders in the United States make up a large and diverse community, making the need for a comprehensive, centralized resource a high priority. The ATHNdataset's large pool of data from persons with blood disorders is helping researchers answer scientific, public health, and policy questions:

- **What is the safest, and most effective way to care for people with blood disorders?**
- **How can we reduce the social and economic costs for persons with blood disorders and their families?**
- **How can we prevent complications and improve health outcomes?**

The more people contribute their information, the richer the ATHNdataset will become—and the more certain we can be that decisions made represent the whole blood disorders community.



ATHNdataset

> "Participation defines a data set's success: the more the community supports it, the more it can give back."
>
> – HTC Physician

COUNT ME IN!

Talk to your HTC about being part of the ATHNdataset today.

Your HTC and ATHN

Your hemophilia treatment center (HTC) it is part of a special group of HTCs called ATHN Affiliates. The American Hemostasis and Thrombosis Network (ATHN) and our affiliated HTCs across the country are working together to build up the ATHNdataset as part of our shared commitment to supporting blood disorders research and improving care.

You're invited to be part of the ATHNdataset

ATHN and your HTC are pleased to invite you to be part of the ATHNdataset—and join the 45,000+ people across the country who have already signed up. Talk to your HTC care team to sign up or learn more.

Health information that's included

When you agree to let your health information be part of the ATHNdataset, it includes things like:

- Your type of blood disorder
- The date you were diagnosed
- Your family history of the disorder
- Laboratory test results used to diagnose and manage your condition
- Your treatments and how they are used to stop bleeding problems from occurring or getting worse
- How your body responds to drugs used to treat blood disorders
- Routine care and trauma
- Allergies
- Types of bleeds you have and how well the bleeding is controlled
- Genetic information

In addition, your health information will be updated regularly to reflect any changes to your current health status.

How health information is identified

The ATHNdataset is a de-identified data set defined by the HIPAA Privacy Rule. Your HTC assigns you and your child(ren) with a unique, computer-generated code. That unique code is then used instead of your name to label your health information. This code system ensures confidentiality by allowing researchers to use your health data without knowing who you are.

Benefits of participating in the ATHNdataset

One of the greatest benefits of the ATHNdataset is its power to help researchers better understand blood disorders and address important questions, such as those related to inhibitors and long-term outcomes. When you share your health information through the ATHNdataset, it is combined with data from thousands of other people and helps:

- Increase knowledge of the genetics of blood disorders
- Study the results of treatments and learn how well they work and develop standards of care
- Better understand the clinical, social, and economic issues involved in these disorders
- Keep a closer watch on the safety of FDA-approved medicines for blood disorders

Remember!

By participating, you are helping to improve the care of all people with blood disorders

Frequently Asked Questions

Will I have to get any special blood tests or undergo other procedures?

No. There are no special blood tests, procedures, or treatments required.

Is there a cost for me to be part of the ATHNdataset?

No. Participation in the ATHNdataset is completely free.

Does being part of the ATHNdataset require me (or my family) to take part in clinical research studies?

No. You are not agreeing to be part of any clinical research studies. You may choose to join clinical research studies offered through your HTC if you wish, but enrollment is done separately. It is always your decision to participate or not.

What happens if I choose not to take part in the ATHNdataset?

If you decide not to participate, your HTC will not send any of your health information to the ATHNdataset. Your choice to participate or not will in no way affect the care you receive from your HTC care team.

If I take part in the ATHNdataset, will ATHN or others be able to contact me directly?

No. Your identifying information will not be part of the ATHNdataset.

What if I sign up to participate, but change my mind later on?

You may stop taking part in the ATHNdataset at any time for any reason. If you decide to stop participating, you must inform your HTC in writing. After that, your HTC will stop sending your health information to ATHN. Please note that any health information that has already been shared will remain part of the ATHNdataset, but no new information will be added. Be sure to speak with your HTC about any concerns.

How can I stay informed about the ATHNdataset?

Visit the ATHN website, www.athn.org, and watch for articles about ATHN in your chapter and HTC newsletters.

athn™
american thrombosis
& hemostasis network

www.athn.org

Securing Data. Advancing Knowledge. Transforming Care.

67 Red Rock Circle, Rochester, NY 14626

ATHN is a 501(c)(3) tax-exempt organization.