Hereditary Antithrombin Deficiency
How to know if you’re at risk for blood clots
What is a blood clot?

- A blood clot is a clump of blood cells and proteins.
- Blood clots form naturally to stop the bleeding when you have an injury (like a cut).

- Sometimes, blood clots form inside blood vessels even when there isn’t an injury.
- If large enough, these clots can stop blood flow and damage your organs.

What are the symptoms of a blood clot?

Abnormal blood clots may result in symptoms, such as:

- Leg pain (calf or thigh)
- Groin pain
- Vision impairment
- Lower leg swelling
- Difficulty breathing
- Weakness on one side of your body

If you experience symptoms associated with blood clots, be sure to speak with your doctor.

Who is at risk for abnormal blood clots?

People who get abnormal blood clots usually have one or more of the following risk factors:

- Cholesterol buildup in the blood vessels
- Sitting for a long time
- Smoking
- Pregnancy
- Surgery
- Genetics

Other risk factors include obesity, liver disease, kidney disease, cancer, and taking certain medicines, such as oral contraceptives, hormone therapy drugs, or some breast cancer medications.

People with these risk factors have a greater chance of experiencing repeated blood clots throughout their lives.
What you should know about blood clots

Blood clots interrupt the flow of blood in the body and cause a variety of symptoms, such as pain, swelling, or weakness.

There are many different causes of blood clots. It is important to know if you have a condition that may cause you to have more blood clots in the future.

Some causes of blood clots are genetic and can run in families. One of these is hereditary antithrombin deficiency.

If you know you have hereditary antithrombin deficiency, you and your doctor can take steps to lower your risk of a blood clot during certain high-risk times.

A blood test recommended by your doctor is the only way to know if you have hereditary antithrombin deficiency.

If you have hereditary antithrombin deficiency, other members of your family may have the same condition. Encourage them to get tested so they can take steps to protect their health.

Let your doctor know if you or your family have a history of blood clots.

What is hereditary AT deficiency?

• Hereditary antithrombin (AT) deficiency is a blood clotting disorder that occurs in people whose bodies aren’t producing enough antithrombin.

  − Antithrombin is necessary to prevent blood clots³

    Anti = against
    Thrombin = clotting

  − People whose bodies don’t produce enough antithrombin are much more likely to develop a blood clot³.

More than 8 out of 10 patients with hereditary AT deficiency have at least one clot by age 50⁴

About 6 in 10 patients with hereditary AT deficiency have recurrent blood clots⁴
How do I know if I have hereditary AT deficiency?

Only your doctor can determine whether you have hereditary AT deficiency, by testing your blood. That’s why it’s important for you to speak with your doctor.

Let your doctor know:
- Your complete medical history
- The medical history of your family, including any history of blood clots
- Whether a family member has ever been diagnosed with hereditary AT deficiency

If your doctor feels that you may be at risk for hereditary AT deficiency, he or she may recommend a blood test for hereditary clotting disorders.

You may be at risk for hereditary AT deficiency if:
- You’ve already had a blood clot, particularly if the clot didn’t have an obvious cause or if it was unusual in some way
- You have a family member with a history of blood clots

Remember: Your doctor is there to help you. The more they know about you, the more they’ll be able to help.

Why should I be tested for hereditary AT deficiency?

If hereditary AT deficiency runs in your family, or you feel you may be experiencing symptoms that are associated with hereditary AT deficiency, it’s important to be tested.

- Only by being tested can you be sure whether you have hereditary AT deficiency

If test results show that you do have hereditary AT deficiency, your doctor may ask you to take certain steps to manage this condition. These steps may include making lifestyle changes and/or taking certain medicines.

People with hereditary AT deficiency who have had at least one blood clot are at a higher risk for future clots.4
What else should I know about hereditary AT deficiency?

Should my family be tested for hereditary AT deficiency?

- If you have hereditary AT deficiency, other members of your family may have it, too.
- Encourage your family to talk with their doctors about getting tested for hereditary AT deficiency.
  - Knowing that you have hereditary AT deficiency will allow you to better manage the condition with medication and lifestyle changes. This can help reduce the serious risk of blood clots.

If I have hereditary AT deficiency, can blood clots be prevented?

Even with hereditary AT deficiency, blood clots can be prevented. Some of the best ways of preventing blood clots include:

- Knowing your risk for blood clots and recognizing signs and symptoms
- Telling your doctor if you have additional risk factors for blood clots
- Seeing your doctor as soon as possible if you experience symptoms of blood clots

How is hereditary AT deficiency treated?

- Some people with hereditary AT deficiency and a history of blood clots may need to take medicine every day to thin their blood and reduce the risk of blood clots.
- However, most people with hereditary AT deficiency will only need medicine in high-risk situations or when they have a clot. Medicine may include:
  - Blood thinners (often warfarin or heparin)
  - Extra antithrombin (to replace the antithrombin missing from the body)

When are people with hereditary AT deficiency at highest risk for blood clots?

People with hereditary AT deficiency are at especially high risk for blood clots in certain situations, such as:

- Surgery
- Pregnancy and childbirth
- When they already have a blood clot
Resources

Take charge of your own health. Visit these websites to learn more about clotting disorders. Write down any questions you have, and take the list to your next doctor’s visit.

National Blood Clot Alliance
www.stoptheclot.org

Centers for Disease Control and Prevention
http://www.cdc.gov/ncbddd/dvt/facts.html

ClotCare Online Resource
www.clotcare.com

Foundation for Women & Girls with Blood Disorders
www.fwgbd.org

North American Thrombosis Forum
www.preventdvt.org

This is Serious
www.thisisserious.org

Common risk factors for blood clots that you should be aware of

Below are situations that can put people with untreated hereditary AT deficiency at high risk for blood clots. Be sure to discuss these with your doctor.

- Family history of blood clots
- Had a blood clot after surgery
- Pregnant or on oral contraceptives
- Lifestyle of sitting/laying down for a long time
- Obesity
- Taking certain medications*

If you think you or a family member are at risk for hereditary AT deficiency, be sure to speak with your doctor.

*Medications may include oral contraceptives, hormone therapy drugs, and some cancer medications.
Are you or a family member at risk for blood clots?

Read this booklet to learn more about blood clots and hereditary AT deficiency.

For more information, visit www.HereditaryClottingDisorders.com

Don't let hereditary AT deficiency put you or your family at risk for serious blood clots. Learn about the risk factors and help prevent a clot today!