

Did you know?

- Diagnosing these rare disorders can be challenging due to their low prevalence and variable clinical presentations.
- Factor II One of the rarest inherited coagulation disorders, with a prevalence of about 1 in 2 million.
- Ultra Rare Bleeding Disorders can affect as many as 1 in 500,000 people or as few as 1 in 5 million people.
- Of all the ultra-rare factor deficiencies combined, there are less than 200,000 reported cases in the U.S



Additional Resources

National Bleeding Disorders Foundation
<https://www.bleeding.org>

Hemophilia Federation of America
<https://www.hemophiliafed.org>

Hemostasis and Thrombosis Center of South Carolina - Midlands

14 Richland Medical Park, Ste 410
Columbia, SC 29203
803-434-1028

Hemostasis and Thrombosis Center of South Carolina - Orangeburg

1724 Village Park Drive
Orangeburg, SC 29118
803-434-1028

Hemostasis and Thrombosis Center of South Carolina - Florence

101 William H Johnson Street, Suite 400
Florence, SC 29506
803-434-3533

Hemostasis and Thrombosis Center of South Carolina -- Upstate

900 W. Faris Road, 2nd Floor
Greenville, SC 29605
864-455-8898

Medical University of South Carolina

125 Doughty St., Suite 520, MSC 917
Charleston, SC 29425
843-792-2957

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Bleeding Disorders Association of South Carolina

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ultra rare
bleeding disorders

A Guide to Support Ultra Rare Bleeding Disorders

Created by the Bleeding Disorders Association of South Carolina

BDASC



Raising Awareness

BDASC is committed to providing support and raising awareness for those with Ultra Rare Bleeding Disorders! BDASC has created a support group for those with Ultra Rare Bleeding Disorders. Through this connection we are educating the public about Ultra Rare Bleeding Disorders and providing education and support to our Ultra Rare Bleeding Disorders community. Visit our website or social media for a list of upcoming events and to stay connected!

You too can help raise awareness for Ultra Rare Bleeding Disorders. By participating in community events and sharing your story, you can directly impact those around you.

Types of Ultra Rare Bleeding Disorders

- Factor I (1) Deficiency
- Factor II (2) Deficiency
- Factor V (5) Deficiency
- Factor VII (7) Deficiency
- Factor X (10) Deficiency
- Factor XI (11) Deficiency (Hemophilia C)
- Factor XII (12)
- Factor XIII (13) Deficiency

- Bernard-Soulier Syndrome (BSS)
People with Bernard-Soulier syndrome have platelets that are very large -- larger than red or white blood cells -- and are missing a protein (glycoprotein Ib) that helps them stick together to form a clot.

- Glanzmann's Thrombasthenia (GT)
People with Glanzmann's thrombasthenia have platelets that lack a protein (glycoprotein IIb/IIIa) that helps them stick together to form a clot.

- Platelet Storage Pool Disease (SPD)
There are a number of rare disorders that occur when a person's platelet granules -- part of the platelet that are involved in the clotting process -- don't work as they should. These disorders are known as platelet storage pool diseases.

BDASC supports all Ultra Rare Bleeding Disorders and Platelet Disorders, including ITP.

Common Symptoms

The most important thing you can do if you suspect you have a bleeding disorder is to be seen by a physician for testing, diagnosis, and treatment. This can lead to much better health outcomes and an improved quality of life. Here are some things you and your physician should be looking for*:

- Heavy periods, (changing pad or tampon every hour or more, or experience of sensation of "flooding")
- Prolonged periods, especially those lasting more than 7 days
- Easy bruising - including petechia
- Frequent or prolonged (more than 10 minutes) nosebleeds that are difficult to stop
- Low iron or treated for anemia
- Mouth and gum bleeding
- Joint pain
- Prolonged bleeding following injury, childbirth or dental work
- Family history of bleeding disorders

*note that rarely are all of these symptoms present and the severity of them can vary