

# PLASMINOGEN DEFICIENCY



FOUNDATION

## Why You Need a Medical Home

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Plasminogen Deficiency Foundation

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## Definitions

### Medical Home:

A Medical Home is a central hub for your healthcare needs. Often a patient's medical home is their primary care provider, but when you have a rare chronic disorder like type 1 plasminogen deficiency, you need a specialized type of medical home that knows all the manifestations of your disorder and will treat and coordinate all your care needs. A medical home is more than just a place for medical care; it's a comprehensive, patient-centered approach to managing your health.

### Hematologist:

A hematologist is a doctor who specializes in managing disorders of the blood. There are adult and pediatric (who treat children) hematologists. Hematologists treat many different types of blood disorders and some kinds of cancers of the blood; just because you see a hematologist does not mean that you have cancer. Hematologists work as part of a team in Hemophilia Treatment Centers (HTCs); HTCs are specialized centers dedicated to treat blood clotting disorders.

### Hemophilia Treatment Center (HTC):

A Hemophilia Treatment Center (HTC) is a clinic where teams of doctors, nurses, pharmacists, social workers, and other healthcare providers work together to treat many different kinds of blood disorders. You can receive treatment at a Hemophilia Treatment Center even though you do not have hemophilia. HTCs are important medical homes for patients with blood clotting disorders, because they bring together all the specialists and staff that are needed to coordinate the many aspects of your care.

You and your doctor have just confirmed a diagnosis of type 1 plasminogen deficiency (PLGD-1). You may have symptoms of PLGD-1 in one area at this time, like your eye(s). Although an Ophthalmologist (specialized eye doctor) is important in the care of your eye lesions, they may not be aware of symptoms that are present or developing in other areas of your body.

That's why the most important step after confirming a diagnosis of type 1 plasminogen deficiency (PLGD-1) is to establish a "medical home" where all your care can be viewed from a multi-system standpoint and can be coordinated.

Ideally **your medical home is a Hemophilia Treatment Center, or HTC**, where your care will be led by a hematologist. Your HTC hematologist will have a team of nurses, pharmacists, social workers, insurance specialists, and other staff who work together to address your needs and coordinate your care. Hematologists at HTCs are very familiar with the use of products that replace missing or deficient clotting factors. PLGD-1 is caused by a decrease in the functional activity of plasminogen, a clotting factor. Therefore, HTCs are a place that is well suited to understand your needs, manage your care and replacement product. Also, hematologists working in an HTC setting have the ability to train you to do home infusions, monitor your use of replacement therapy, and other specialized access to research and trainings that other specialists do not have access to.

If an HTC is not accessible to you, find an adult or pediatric hematologist who is comfortable managing your care and can work collaboratively with an HTC to be your medical home.

Here's why having a medical home, particularly one focused on the specific needs of PLGD-1, is essential:

**Coordinated Care:** A medical home provides a central point for all your healthcare needs. This means:

1. **Integrated Services:** All aspects of your care are coordinated, from routine check-ups to specialized treatments.
  - a. **You may need referrals to other specialists**, such as Ophthalmology, Dentists, ENT, Pulmonology, GI, Renal, Ob-Gyn, or Neurology; these visits will be coordinated by your hematologist and the team.
  - b. **You may need to obtain scans** such as chest X-ray, chest CT, or abdominal ultrasound or CT. Your team can help get these scheduled and use the results to guide your care.
2. **Streamlined Communication:** Your healthcare team communicates effectively with each other, reducing the risk of fragmented care and ensuring that all aspects of your health are considered.

**Personalized Care:** With a medical home, your care is tailored specifically to your needs:

1. **Individualized Treatment Plans:** Your care is customized based on your unique health conditions and personal preferences.
2. **Holistic Approach:** Comprehensive care that addresses not just your physical health but also mental, emotional, and social well-being.

**Preventive and Proactive Management:** A medical home focuses on preventing issues before they become serious:

1. **Regular Monitoring:** Consistent check-ups and screenings to catch potential problems early.
2. **Preventive Measures:** Strategies and recommendations to prevent complications and manage your condition proactively.
  - a. **You may be planning a pregnancy.** Your hematologist can work together with your obstetrician to guide your treatment during pregnancy so you and your baby are as safe as possible throughout your term.

**Enhanced Access to Care:** Your medical home ensures you have the support and resources you need:

1. **24/7 Support:** Access to care and advice when you need it, including after-hours.
2. **Emergency Preparedness:** Personalized plans for handling emergencies related to your specific condition.

## WHY SHOULD I GO TO A HEMOPHILIA TREATMENT CENTER FOR MY CARE?

A Hemophilia Treatment Center, or HTC, is a clinic where a team of doctors, nurses, pharmacists, and many other staff members work together to provide the best care for rare and complex blood clotting disorders including type 1 plasminogen deficiency. Your team will be led by a hematologist, a doctor who specializes in treating problems with blood clotting disorders, including PLGD-1.

### How an HTC can help you:

There will likely be many areas of your life that are affected by PLGD-1, and an HTC is equipped to help you in all of these areas.

Your **hematologist** is trained to examine the whole body and will monitor your symptoms and coordinate care with different specialists. The HTC staff understand not only how to administer clotting factor replacement therapy, but also how to monitor levels, and adjust dosing over time to achieve the best outcomes. They are skilled at managing chronic diseases over a patient's lifetime and adjusting your care as your needs change. They are the first to learn about new and emerging treatments that may benefit you.

The **pharmacy staff and nurses** will help you learn to infuse this medication at home. They can train young children and parents to do infusions, and help families to access all the supplies needed to go along with the medication.

The **social workers** and **child life specialists** on your team will be there to support your mental health, and any needs that might arise at work or at school as a result of PLGD-1.

**Improved Quality of Life:** A medical home is designed to enhance your overall well-being.

1. **Better Management of Chronic Conditions:** Ongoing, coordinated care helps manage your chronic conditions more effectively, reducing the impact of symptoms on your daily life, and leading to better health outcomes for you.
2. **Increased Confidence:** Knowing that your care team is thoroughly managing your health can give you peace of mind and improve your quality of life. You can feel empowered to manage your condition with the help of your team.

**Support and Education:** You'll receive education and support tailored to your needs.

1. **Patient Education:** Information and training on managing your condition, using treatments, and making informed health decisions.
  - a. You will be trained on how to perform infusions of your medication at home.
2. **Support Services:** Access to social workers, counselors, and support groups that can assist with various aspects of living with a chronic condition.

**Continuity of Care:** Consistency in your care is crucial for effective management:

1. **Long-Term Relationship:** Building a lasting relationship with your healthcare team ensures continuity and understanding of your health history and needs.
2. **Consistent Care:** Avoids the disruption that can come from seeing different providers for different needs.

A medical home provides a coordinated, comprehensive approach to healthcare that can significantly improve the management of type 1 Plasminogen Deficiency and improve your overall quality of life. A specialized center like an HTC, or a hematologist who can work closely with an HTC, offers the expertise and resources needed to effectively manage your condition and maintain your well-being.

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The **pharmacy staff and nurses** will help you learn to infuse this medication at home. They can train young children and parents to do infusions, and help families to access all the supplies needed to go along with the medication.

An HTC puts together this team for you, so you can access all the care you need in one place.

Getting started with an HTC:  
Finding the right Hemophilia Treatment Center can make a significant difference in managing your PLGD-1.

HTCs are located around the country. You can find a list of HTCs here: <https://dbdgateway.cdc.gov/HTCDirSearch.aspx>

**NEED A REFERRAL?** We can help.

Email [contact@plgd.org](mailto:contact@plgd.org) with your name, age, and city and state and we will reach out to you directly with recommendations for care.

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