Understanding Plasminogen Deficiency

Plasminogen deficiency (PLGD) is a rare disorder that can be hard to diagnose. It is important to understand PLGD and get the treatment and support that you need.

What Is PLGD?

PLGD is an inherited condition in which your body does not produce enough of a clotting factor called plasminogen. **There are two types of PLGD:**

Type 1

Plasminogen activity and protein (antigen) levels are both below the normal range. An accumulation of fibrin material can occur in the eyes, ears, nose, mouth, airways, gastrointestinal tract, female genital tract, urinary tract, central nervous system, and other areas of the body, leading to symptoms. Excessive blood clotting (thrombosis) is not a symptom of PLGD-1.

Type 2

The plasminogen activity level is decreased but the total protein (antigen) level is normal. Patients do not have symptoms of fibrin buildup.

➔What Are PLGD Symptoms?

Symptoms include:

Abnormal fibrin accumulation that looks like a membrane can develop on mucosal surfaces, such as the eyelids, gums, and many other areas. Growths may appear on their own or develop after an infection like pink eye or an ear infection. Growths often reappear soon after removal.

These growths, if not controlled or treated with plasminogen-specific therapy, may result in long-term issues related to the area where they develop, such as loss of vision or hearing, difficulty breathing, painful menstruation, infertility, or kidney problems.

Some people have more symptoms than others; some people may not have symptoms. Symptoms can be mild to severe. They can come and go over time.

➔Hereditary Risk

PLGD is diagnosed by blood tests. Because it is inherited, all siblings of anyone diagnosed with PLGD should also be tested even if they don't have symptoms.

Sharing news about an inherited condition can be hard to explain and uncomfortable no matter how close or distant family relationships are. A genetic counselor can help you.

Your health care team will also offer emotional support as you deal with issues related to PLGD, such as self-image and managing school or work.

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➔PLGD-1 Treatments

There is no cure for PLGD. There is a plasminogen replacement therapy that can treat or control symptoms. Concentrated plasminogen (Ryplazim) is the only drug approved by the FDA for PLGD. Other therapies, such as fresh frozen plasma (FFP) have been utilized but are less effective.

Managing Treatment at Home

You or a person close to you may be able to administer infusion treatments at home with instructions from your care team on:

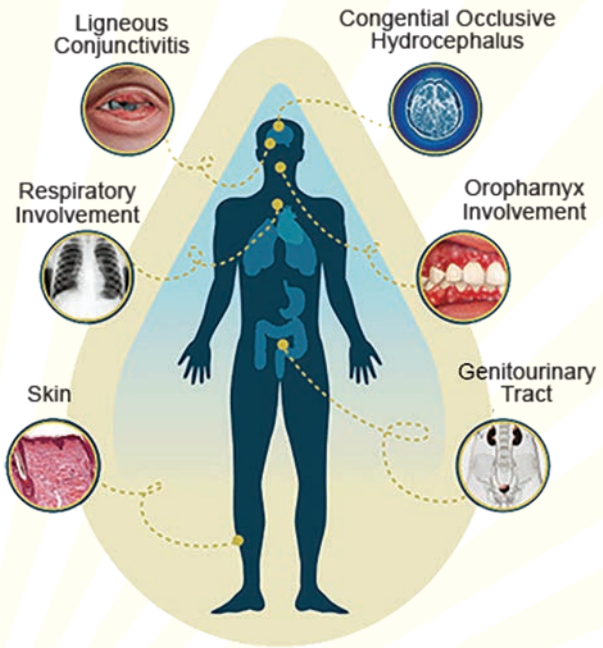
Preparation – Understand dosing and scheduling and be sure all needed supplies are available. Know who to call if there's a problem, including delayed or missed infusions.

Administration – Learning to give a medicine at home directly into the bloodstream (vein) can be taught to you by your care providers. They may also be able to provide assistance at home if needed.

Storage – Follow directions to make sure the medicine stays active.

Waste disposal – Use a sharps container to throw away needles and blood-soiled items. Putting these items in the trash might injure family members or others.

Reporting – Track your usage and report back to your care team to help with monitoring your therapy, including response and supply.



➔Coordinating Care

Managing PLGD-1 is complex, which is why it's important to get care at a hemophilia treatment center (HTC). The HTC will be your "medical home," where a hematologist who specializes in blood disorders will coordinate care with all HTC staff (such as nurses, pharmacists, social workers, insurance counselors, etc.) and your primary care provider and other medical care partners as needed.

For additional resources on PLGD, visit the Plasminogen Deficiency Foundation at **www.plasminogendeficiency.org**.