

ABOUT HHML SYNDROME, A PROS CONDITION

HemiHyperplasia-
Multiple
Lipomatosis

What is HHML?

- ▶ HHML is a PROS condition that is generally characterized by painless, fatty growths and asymmetry of the body
- ▶ Most people with HHML are born with the condition. It is not hereditary

Different Conditions, One Common Cause - PROS

- ▶ PROS, or PIK3CA-Related Overgrowth Spectrum, is a wide-ranging spectrum of disorders caused by a mutation in the PIK3CA gene
- ▶ PROS conditions are rare and diverse, and are typically characterized by atypical growths and anomalies in the blood vessels and lymphatic system
- ▶ PROS conditions can look different from each other in size, shape, and type of growth or malformation based on where in the body the mutation is found

What are features of HHML?

HHML is different for each person and ranges in severity. Most people living with HHML do not have every sign associated with the condition.

These features may include:

- Painless, benign masses on the body
- Abnormal overgrowth to one side or part of the body (hemihyperplasia) causing asymmetrical growth
- Asymmetry between one limb or half of the body
- Malformations in blood vessels (vascular malformations)
- Narrowing of the spaces within the spine, resulting in spinal stenosis

HHML Diagnosis



- ▶ Because HHML has observable features, it often can be diagnosed through a physical exam, imaging, and/or medical history
- ▶ Additionally, there are tissue tests to identify the presence of a PIK3CA mutation
- ▶ However, a negative test does not rule out having a PROS condition as mutations can be difficult to detect

HHML Management



- ▶ Managing HHML can be challenging and typically requires collaboration from a multidisciplinary team
- ▶ Like other PROS conditions, there are few management options for HHML
- ▶ Some options, such as surgery, address symptoms and manifestations rather than the root cause of the disease

Find resources and support for people with HHML and their families by visiting:

▶ [understandingpros.com](https://www.understandingpros.com)