

ABOUT ILM, A PROS CONDITION

Isolated
Lymphatic
Malformation

What is ILM?

- ▶ ILM is a PROS condition that is generally characterized by clusters of atypical lymphatic vessels, most commonly found in the head and neck
- ▶ ILM is synonymous with other lymphatic disorders, such as lymphangioma, lymphangiomatosis, and more
- ▶ Most people with ILM 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 ILM?

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

These features may include:

- Masses filled with liquid, also known as lesions
- ILM most commonly occurs in the head or neck, but it can be found anywhere in the body
- Overgrowth and swelling of the affected area, including the lips, tongue, jaws, cheeks, arms, legs, fingers, or toes
- Recurrent inflammation or bleeding into the malformation

ILM Diagnosis



- ▶ Because ILM 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 result does not rule out having a PROS condition as mutations can be difficult to detect

ILM Management



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

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

▶ www.lgdalliance.org*

▶ understandingpros.com

* This link takes you to an external website that is independently operated and not managed by Novartis Pharmaceuticals Corporation. Novartis assumes no responsibility for the site.