

## ABOUT CLAPO SYNDROME, A PROS CONDITION

- Capillary malformation of the lower lip,
- Lymphatic malformation of the face and neck,
- Asymmetry of the face and limbs, and
- Partial or generalized Overgrowth

### What is CLAPO syndrome?

- ▶ CLAPO syndrome is a PROS condition that is generally characterized by a malformation of the lower lip and, sometimes, the face or neck
- ▶ Most people with CLAPO syndrome 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 CLAPO syndrome?

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

*These features may include:*

- Capillary malformation of the lower lip
- Lymphatic malformations of the face, mouth, and/or neck
- Asymmetry of the face and/or limbs
- Generalized or partial body overgrowth

### CLAPO syndrome Diagnosis



- ▶ Because CLAPO syndrome 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

### CLAPO syndrome Management



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

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

- ▶ [understandingpros.com](http://understandingpros.com)