

# ABOUT CLOVES SYNDROME, A PROS CONDITION

- Congenital
- Lipomatous
- Overgrowth
- Vascular malformations
- Epidermal nevi
- Scoliosis/skeletal and spinal

### What is CLOVES syndrome?

- ▶ CLOVES is a PROS condition that is generally characterized by overgrowths on the body and irregularities in blood vessels
- ▶ Most people with CLOVES are born with the condition or have features of CLOVES during prenatal scans. 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 CLOVES?

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

*These features may include:*

- Fatty tissue, known as a truncal mass, found on the back or abdomen that may extend into the chest or around the spinal cord
- Skin lesions, port-wine stains, birthmarks, or other discolorations known as epidermal nevi that can be flat, tan, or slightly raised
- Vascular anomalies in the formation of blood vessels and lymphatic systems
- Overgrowth of extremities, including arms, legs, hands, and feet
- Scoliosis or curving of the spine
- Differences in the size of the kidney, or a missing kidney
- Atypical knee caps and joints of the hip and knee

### CLOVES Diagnosis



- ▶ Because CLOVES 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

### CLOVES Management



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

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

- ▶ [www.clovessyndrome.org](http://www.clovessyndrome.org)\*
- ▶ [understandingpros.com](http://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.