UNDERSTANDINGPROS

PIK3CA-Related Overgrowth Spectrum



ABOUT FAVA, A PROS CONDITION

FibroAdipose Vascular Anomaly

What is **FAVA**?

- FAVA is a PROS condition that is generally characterized by a tumor-like mass usually found in one or more limbs, when the body's own tissue takes over a muscle
- Most people with FAVA 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 **FAVA**?

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

These features may include:

- Progressive, severe limb pain (arm, hand, leg, foot) that can occur in one specific area or radiate between areas. It can even be difficult to find the source. The most common location of the lesion is the calf, followed by wrist, thigh, foot, and trunk. The most common manifestation of FAVA is a severely disproportional, painful lump under the skin of the calf
- Contraction at the affected area causing stiffness and limited range of motion
- Skin irregularities, which can include visible veins or a bluish-colored tint

FAVA Diagnosis



- Because FAVA 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

FAVA Management



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

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

- www.projectfava.org*
- **▶** understandingpros.com

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