# **UNDERSTANDINGPROS**

PIK3CA-Related Overgrowth Spectrum



ABOUT PROS CONDITIONS WITH NEUROLOGICAL MANIFESTATIONS

**H**emi**M**egal**E**ncephaly (HME), **D**ysplastic **MEG**alencephaly (DMEG), Focal cortical dysplasia type II

## What are PROS neurological manifestations?

Some PROS conditions may have signs associated with the brain:

- **HME** is generally characterized by an enlargement of the brain, or abnormal development of the cerebrum, which affects only one side of the brain
- **DMEG** is generally characterized by both sides of the brain being impacted by overgrowth or abnormal development
- Focal cortical dysplasia type II is generally characterized by a problem with the development and organization of the brain layers
- Most people with these PROS conditions 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 PROS neurological manifestations?

PROS neurological manifestations are different for each person and range in severity. Most people living with PROS neurological manifestations do not have every sign associated.

These features may include:

Seizures

**Developmental delay** 

- Enlarged head or brain
- **Neurological impairment**
- Other neurodevelopmental syndromes

#### **Diagnosing PROS** neurological manifestations



- Because PROS neurological manifestations have observable features, they often can be diagnosed through a physical exam, imaging, and/or medical history
- EEG exams also can be done to diagnose seizures
- 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

EEG, electroencephalogram

## Managing PROS neurological manifestations



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

Find resources and support for people with PROS neurological manifestations and their families by visiting:

understandingpros.com



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