



## Press Release

# The Pheo Para Alliance Launches Inaugural Pheo Para Awareness Week, August 23 – 29, to Raise Awareness Internationally for Rare Disease Community who is #PheoParaPhearless.

Bethesda, MD, July 27, 2020

The Pheo Para Alliance has announced the inaugural campaign to raise awareness for pheochromocytoma (pheo) and paraganglioma (para), rare neuroendocrine tumors, will take place August 23 – 29. The objectives of this week-long campaign, presented by Progenics, are to inspire & empower pheo para constituents to tell their story, raise awareness of the illness among health care providers, educate pheo para patients, and build understanding of the struggles presented by pheo para.

“This campaign is an exciting opportunity to empower and inspire our pheo para community. Our theme is #PheoParaPhearless, which represents the courage of our patient’s collective voices as they navigate an often isolating and scary medical journey,” says Matthew Capogreco, Pheo Para Alliance Board of Directors President and patient.

A critical element to the success of the campaign will be participation by pheo para constituents, not only patients and caregivers, but clinicians, researchers, industry, and medical societies. Constituents are asked to submit video testimonials which will be used to create five 3-minute videos addressing a different pheo para topic. More information can be found at <https://pheopara.org/2020/06/pheo-para-awareness-week>.

### About Pheo Para Alliance

The Pheo Para Alliance is a registered 501(c)3 nonprofit organization, incorporated in the state of Virginia whose mission is to empower patients with pheochromocytoma or paraganglioma, their families and medical professionals through advocacy, education and a global community of support, while helping to advance research that accelerates treatments and cures. Founded in 2007, the Pheo Para Alliance is the longest-standing and leading organization internationally recognized in advocacy for, and awareness of, pheochromocytoma and paraganglioma.

### About Pheo Para

Pheo and para are rare neuroendocrine tumors that occur in both men and women of every race. They can occur at any age, but mostly occur in the third to fifth decade in life. Both produce an excess amount of the hormone called catecholamines which result in symptoms such as high-blood pressure, headache, profuse sweating, heart palpitations, severe anxiety, a sense of doom, and many more. Most tumors can be removed with surgery, but if left untreated patients can experience heart attack, stroke, kidney failure, and malignancy where tumors have spread to other parts of the body. Approximately 15% of tumor return after surgery, and approximately one in three cases are metastatic.

Pheo para is rare, approximately 1 in 3,500 people will be diagnosed in their lifetime. Because of its rarity, it is common for patients to not receive a diagnosis for years or even decades because symptoms mimic countless other illnesses. All patients are encouraged to have genetic testing because approximately 1/3 of patients will have a genetic mutation. Patients who have a genetic mutation have a 50/50 chance of passing it on to their children.

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Patient Ambassadors are available for interview.