TALKING POINTS

About Pheo Para Alliance

Founded in 2007, the Pheo Para Alliance, a 501c3 organization, is the longest-standing internationally recognized leader in advocacy for, and awareness of, pheochromocytoma (pheo) and paraganglioma (para). Since its inception, the Pheo Para Alliance has dedicated more than $2 million towards research, diagnosis, education, advocacy, and finding a cure. The Pheo Para Alliance 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.

About Pheo Para

Pheochromocytoma (pheo) and paraganglioma (para) are rare slow-growing neuroendocrine tumors. They occur in both men and women equally, and they affect every race of people. 1 in 3,000 will develop a pheo or para sometime in their life. They can occur at any age, but the peak incidence occurs in the third to fifth decade in life. Pheos develop in cells in the center of the adrenal gland just above the kidneys. Paras develop outside the adrenal glands, most commonly, in the head, neck, chest, abdomen, or pelvis. Both can produce an excess amount of hormones called catecholamines. This leads to persistent or episodic high blood pressure, severe anxiety, heart palpitations, sweating, headaches, and even stroke and heart attack. If left untreated, pheo para can metastasize, and ultimately, lead to death. But, if detected early, pheo para can be successfully treated and managed in the vast majority of cases. If possible, the treatment of choice for the condition is surgery to remove the tumor(s), but there are other treatment options. Currently, there are approximately 20 genetic mutations identified that can be attributed to a greater risk of developing the illness, and can be passed down through children. Everyone diagnosed should talk to their doctor about genetic testing.