

# Empowering others to contribute to rare neuroendocrine tumor research

Lacey Koelling was first diagnosed in 2018 with bilateral carotid body tumors called paragangliomas. These are a type of neuroendocrine tumor that forms near certain blood vessels and nerves outside of the adrenal glands, which are important for making hormones that control several functions in the body. The nerve cells involved in paragangliomas are part of the peripheral nervous system (outside of the brain and spinal cord).

After her initial diagnosis, Lacey received annual screenings to monitor for any other growth. At her scan in 2023, her doctors found that her paragangliomas had metastasized. Multiple physicians in different states all agreed that due to the size and locations of the tumors, and her lack of symptoms, she should “watch and wait”. But Lacey was determined to do more for herself.



*Lacey Koelling joined an NIH trial in 2024 for her paragangliomas. She still lives a normal life outside of her NIH visits and enjoys hiking.*

Lacey reached out to support groups within the Pheo Para Alliance, an organization that helps to advance research and provide advocacy and support for patients with pheochromocytoma or paraganglioma. Someone within this organization suggested she get in touch with [Jaydira Del Rivero, M.D.](#), Associate Research Physician in the [Developmental Therapeutics Branch](#). From there, she was able to enroll in an NIH trial.

In the video below, Lacey describes her experience being a patient on an NIH trial. She encourages others to consider NIH clinical trials if they can.

“For me, knowing I am contributing not only to my own health but the future of pheo and para research, is very empowering,” she said.

"My life motto since my diagnosis is to 'Live like I'm living.' This trial is my way to live my life to the fullest."

## Lacey Koelling — CCR Patients Perspective



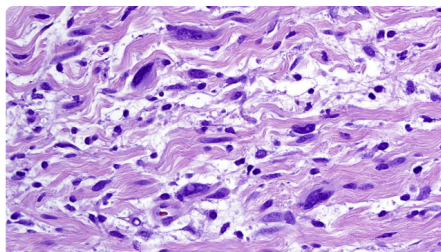
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