

Grant Gives New Breath to Patients Suffering from Severe Pulmonary Hypertension

Nearly \$8 million grant helps launch a nationwide patient registry to improve CTEPH practices

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Imagine trying to take a deep breath, but feeling like you're sucking air through a straw. That's how some patients with chronic thromboembolic pulmonary hypertension (CTEPH) describe living with the condition, which is estimated to affect several thousand Americans yearly but is commonly misdiagnosed. UC San Diego Health System is a world leader in CTEPH, and now with a \$7.6 million grant, has helped launch the first national CTEPH registry to improve best practices and patient care.

The United States CTEPH registry, funded by Bayer Healthcare Pharmaceuticals, is a centralized electronic database that will involve 30 sites across the nation. UC San Diego Health System will manage the registry with the goal of enrolling 750 newly diagnosed patients over the next six years. It will allow physicians to follow the short- and long-term outcomes of patients and learn more about CTEPH.

CTEPH is believed to be a complication of a common blood clot condition called pulmonary embolism. It has been reported that as much as 3.8 percent of individuals with first-time pulmonary embolism may develop CTEPH. This suggests there may be thousands of new cases of CTEPH in the United States annually.

"Currently, the number of patients in the United States with CTEPH is unknown. Because the symptom of shortness of breath is nonspecific, many CTEPH patients may be misdiagnosed as having more common diseases like asthma or COPD," said [Kim Kerr, MD](#), principal investigator and pulmonologist at UC San Diego Health System. "Using data collected from the registry, we will identify barriers to patients receiving the correct diagnosis and treatment of their CTEPH. This registry will also allow us to assess the effectiveness of established and evolving therapies of this disease."

UC San Diego Health System is the pioneer of pulmonary thromboendarterectomy (PTE) surgery, a life-saving procedure that removes the blood clots from the lungs' arteries that rob patients of their ability to breathe.

"The registry will serve as an educational tool for physicians and centers to learn more about the disease and its prognosis and outcomes, especially as it relates to surgical techniques used for PTE and the benefits to the patient," said [Michael Madani, MD](#), co-investigator and cardiac surgeon, chief of cardiothoracic surgery and director of UC San Diego Sulpizio Cardiovascular Center – Surgery. "People from around the US suffering from CTEPH are referred to UC San Diego Health System for PTE but usually after discharge we do not have the resources to follow up long-term. Another critical part of the registry is that it will give us a more thorough understanding of how PTE truly improves a patient's overall quality of life, even if they live 2,000 miles away."

[Nick Kim, MD](#), pulmonologist and director of pulmonary vascular medicine at UC San Diego Health System, adds that the registry will enrich physicians' understanding of all aspects of CTEPH in the U.S., including the subset of patients deemed not operable and treated with medical therapy instead.

"Centers across the nation working as a team will not only help health providers improve their approach to CTEPH, it will ultimately give patients more options, knowledge and empowerment in how their disease is managed," said Kim.

For more information on pulmonary vascular medicine at UC San Diego Health System, please visit <http://heartcenter.ucsd.edu> [↗](#)

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