

Rare Disease Day Takes the Lead for Team Phenomenal Hope

Physician Athletes Race to Educate on Pulmonary Hypertension

FEBRUARY 29, 2016 – Having just returned from a seven-day trek along the Southern Alps, Team Phenomenal Hope now eyes its next lap in the journey to beat Pulmonary Hypertension (PH). The nonprofit, which consists of members from the healthcare and athletic communities, uses ultra-endurance sporting events as a platform to spread PH awareness.

Earlier this month, Team Phenomenal Hope sent several members to New Zealand to compete in The Pioneer bicycle race. They raised more than \$15,000 for the cause, and see Rare Disease Day 2016 as an appropriate homecoming welcome.

“We want to use this day to tell the story of our patients... they’re the champions in this fight,” said Dr. Patricia George, a pulmonary hypertension specialist at UPMC (University of Pittsburgh Medical Center) and leading founder of Team PH. “Whether we’re cycling, running or competing in triathlons, our main mission is to raise money for research and honor the people we service day-in, day-out. We’re their biggest fans.”

PH is a disease that has flown under the radar for some time, yet effects millions internationally. When it progresses, it leads to heart failure, and some patients require lung transplants to survive. George said Rare Disease Day 2016 is just one more opportunity to educate policy makers and the public about an illness that often goes unrecognized or misdiagnosed.

“The average life expectancy is three years after diagnosis,” George said. “We’re at a critical point when it comes to pulmonary hypertension research, and now’s the time to apply a full press.”

According to the Website RareDiseaseDay.org, “Since Rare Disease Day was first launched by EURORDIS and its Council of National Alliances in 2008, thousands of events have taken place throughout the world reaching hundreds of thousands of people and resulting in a great deal of media coverage.”

ABOUT TEAM PHENOMENAL HOPE

Team PHeNomenal Hope is a nonprofit made up of professionals in the medical and athletic communities. The group uses sporting events as a platform to spread awareness about the disease Pulmonary Hypertension. Specifically, Team PHeNomenal Hope members compete in cycling, running and triathlon outings around the world to raise donations for research, while at the same time educating the public on the greater cause. Since its launch some four years ago, the nonprofit has garnered national attention and support from major sponsors and the pulmonary hypertension community. For more information, including a schedule of events, visit <http://www.teamphenomenalhope.org/>

ABOUT PULMONARY HYPERTENSION

People living with PAH often don't look sick, but become tired and short of breath with exertion. This makes basic activities like climbing stairs or playing with grandchildren a challenge. Fortunately, there are medications that help many patients, but not all patients respond to therapy. When the disease progresses, it leads to heart failure, and some patients require lung transplants to survive. We are racing with the pulmonary hypertension community to make a difference, and we hope you will join us in supporting research for a cure.