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February 25, 2021

Dear Member of the 117th Congress,

As the new Congress convenes, the Pulmonary Hypertension Association (PHA) urges you to support important medical research and patient access priorities affecting the thousands suffering from this fatal, incurable lung disease across the country.

Pulmonary Hypertension

Pulmonary hypertension (PH) is high blood pressure in the vessels of the lungs that develops when constriction of the vessels increases the pressure the heart must apply to pump blood. As with a tangled hose, pressure builds up and backs up forcing the heart to work harder while less oxygen reaches the body.

PH is a progressive, fatal condition that even with treatment can lead to heart failure and death. There is no cure. PH can occur without a known cause or develop in association with other conditions such as scleroderma, lupus or sickle cell disease. A common patient profile is a woman between the ages of 20 and 60, although PH can develop in anyone of any age, including children.

Common PH symptoms include fatigue, dizziness and shortness of breath, with the severity of the disease correlating with its progression. Without treatment, individuals with PH survive, on average, less than three years after diagnosis. Innovative treatment options have been developed and approved, but frequent misdiagnosis means that many people with the condition miss the full benefit of therapy. Average life expectancy after diagnosis remains less than ten years.

Pulmonary Hypertension and the COVID-19 Pandemic

Individuals with pulmonary hypertension (PH) are at a high risk for complications from COVID-19. As the pandemic continues to devastate the country, PHA supports ongoing access to multi-month medication refills, flexibility in REMS monitoring and broad telehealth access and reimbursement that allow individuals with PH to access the care they and their clinician have decided is best for their situation. People with PH should have high priority in accessing scientifically developed, tested and approved vaccines, due to their compromised heart and lung function and the high risk for COVID-19 complications.

PHA Legislative Priorities

As you work with your colleagues on legislative items and appropriations for this new session of Congress, we hope you will actively support the following community priorities:

Please reduce out-of-pocket cost burden to patients and protect access to financial assistance resources. Individuals with pulmonary hypertension and other complex, life-threatening health conditions sometimes rely on charitable grants or other sources of financial assistance to make ends meet. Currently, many health insurance plans refuse to accept this assistance or accept it but then choose not to apply it to a patient's deductible and out of pocket maximum, essentially double dipping. The 117th Congress should codify protections to charitable copay and premium assistance and require health plans to fully apply these payments to patients' out-of-pocket responsibilities.

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Please streamline access to life-saving medication by limiting the use of prior authorization and step-therapy requirements for individuals with complex health conditions. Pulmonary hypertension is a progressive and potentially fatal condition. Individuals respond differently to available therapies making medical management complex. Prior authorization and step therapy requirements lead to delay in optimum treatment that can result in irreversible decline and death.

- **Step therapy:** When insurance payers use fail-first requirements to shift a person with PH from one therapy to another without the agreement of a physician, these switches can create health setbacks from which the individual may never recover. The *Safe Step Act* places reasonable limitations on step-therapy requirements in the case of high-risk health conditions such as PH.

Please work with CMS to ensure that individuals with chronic lung disease have access to the full range of oxygen modalities prescribed by physicians. For individuals who require supplemental oxygen, the weight of the equipment is a barrier. For individuals who need a high oxygen flow rate per minute, a portable liquid system is likely the only equipment allowing them to engage in activities outside the home. Since the initiation of competitive bidding, reimbursement rates for liquid oxygen have fallen by as much as two-thirds and the number of suppliers has decreased dramatically. Even when physicians prescribe liquid oxygen, patients are often unable to access it and become unnecessarily homebound. Congress should work with CMS to ensure that oxygen suppliers are reimbursed appropriately for their services and held accountable for the provision of physician-specified oxygen equipment.

Please provide the National Institutes of Health (NIH) with at least \$46.1 Billion in FY 2022. NIH and PHA have a strong track record of working together to advance our scientific understanding of PH. The multiple FDA-approved treatments are evidence of the return-on-investment from these activities. Please provide NIH with meaningful increases to facilitate expansion of the PH research portfolio so we can continue to improve life expectancy and quality of life for people with PH.

Please provide the Centers for Disease Control and Prevention (CDC) with 10 billion in FY 2021.

- **Please provide \$5,000,000 for the Chronic Diseases Education and Awareness Program at the Centers for Disease Control and Prevention (CDC).** This program seeks to provide collaborative opportunities for chronic disease communities that lack dedicated funding from ongoing CDC activities. Such a mechanism allows public health experts at the CDC to review project proposals on an annual basis and direct resources to high impact efforts in a flexible fashion.

Pulmonary Hypertension Association

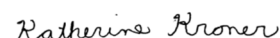
The Pulmonary Hypertension Association (PHA) is dedicated to extending and improving the life of those affected by PH. PHA was the first organization in the world dedicated to providing comprehensive PH patient and caregiver support; medical education; specialty care services that improve patients' quality of life; and research funding.

We encourage you to contact PHA with questions about pulmonary hypertension as well as the broader challenges faced by individuals with rare, chronic health conditions and the medical professionals who treat them. Katie Kroner can be reached at KatherineK@PHAssociation.org or 240-485-0749.

Sincerely,



Matt J. Granato, LL.M., MBA
President & CEO



Katie Kroner
Sr. Director, Advocacy & Treatment Access