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December 17, 2020

Biden-Harris Transition
1401 Constitution Ave NW
Washington, D.C., U.S.

Dear President-Elect Biden:

Thank you for your ongoing commitment to improving life expectancy and quality of life for Americans struggling with complex, life-threatening health conditions like pulmonary hypertension (PH). As you are sworn in and your administration begins work, the Pulmonary Hypertension Association (PHA) urges you to reduce barriers to life-sustaining therapy; place clinical judgement and the patient-clinician relationship at the forefront of healthcare decision making; and support health initiatives that protect and enhance the wellbeing of individuals with PH and similar conditions.

Pulmonary Hypertension and the Pulmonary Hypertension Association

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.

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.

Protect Individuals with PH During the COVID-19 Public Health Emergency

Due to the underlying vulnerability of their heart and lungs, individuals with PH are at risk for life-threatening complications if they contract the COVID-19 virus and should have high priority in accessing scientifically developed, tested and authorized vaccines.

Throughout the national vaccination process, individuals with PH may need to observe social distancing and other protective measures longer than those without underlying vulnerabilities. Robust access to, and appropriate reimbursement for, telehealth, regardless of insurance type allows those with PH to access the medical care they need in the manner that they and their clinician have deemed most appropriate. Similarly, financial supports, including but not limited to expanded medical leave, for those who cannot safely return to work are essential throughout the public health emergency and beyond.

Advance Prompt, Uninterrupted Access to Quality Healthcare

PHA urges you and your administration to support prompt, seamless access to quality, affordable healthcare, and innovative treatments for individuals with pulmonary hypertension. Key priorities include reducing out-of-pocket cost burden for individuals with pulmonary hypertension; advancing robust networks and formularies in all types of health insurance; and ensuring access to, and seamless transitions between, health insurance coverage options. Ensuring health insurance coverage must include ending the Medicare waiting period, continuing to expand Medicaid, and expanding opportunities and support for health insurance marketplace enrollment.

Support Robust Health Research Funding

PHA also urges your support of robust funding for public health agencies including the National Institutes of Health, Centers for Disease Control and Prevention and the Food and Drug Administration. NIH and PHA have a strong track record of working together to advance our scientific understanding of PH. The targeted, FDA approved treatments for some types of PH are evidence of the return-on-investment from these activities. However, much more needs to be done to improve the effectiveness of treatment and ultimately find cures for those who continue to struggle with this devastating disease.

PHA is happy to serve as a resource to you and your administration. We look forward to collaborating to shape policy that improves health outcomes and quality of life for individuals with PH and other complex, life threatening health conditions.

Thank you for your attention to this and please do not hesitate to contact me at 240-485-0749 or KatherineK@PHAssociation.org.

Sincerely,



Katherine Kroner
Sr. Director, Advocacy and Treatment Access