



PHA ENGAGEMENT SERVICES

ENGAGE DIRECTLY WITH THE PH COMMUNITY:

- Hear from patients, caregivers and health care professionals.
- Advertise online and in print publications.
- Advance PH therapies and reduce recruitment costs.
- Receive feedback from PH experts.

PHA ENGAGEMENT SERVICES

Founded in 1991 by patients, the Pulmonary Hypertension Association (PHA) is the oldest and largest nonprofit patient association in the world dedicated to the pulmonary hypertension community. Pulmonary hypertension (PH) is a rare, chronic and life-threatening disease of the lungs for which no cure exists. PHA's mission is to extend and improve the lives of those affected by PH. To achieve this mission, PHA engages people with PH and their families, caregivers, health care providers and researchers worldwide who work together to advocate for the PH community, provide support to patients, caregivers and families, offer up-to-date education and information on PH, improve quality patient care, and fund and promote research.

Working with patients, caregivers and providers, PHA acts as a trusted liaison between the PH community and industry and academic partners who support PHA's mission by furthering the science and knowledge of the disease.

PHA's sponsored Engagement Services offer our partners distinct ways to engage and involve patients, caregivers and providers in every aspect of the patient experience. With this program, PHA aims to:



Provide leadership to partners to offer targeted, vetted opportunities for the PH community to participate in the treatment and cure of their disease.



Provide means for industry or academic researchers to gather information about patients' experience with PH, including the impact (physical and psychosocial) of PH or a related therapy or clinical investigation, and patient preferences with respect to treatment of PH, in line with FDA's June 2020 guidance on Patient Focused Drug Development.



Further PHA's mission to foster research and development of PH therapies to improve and extend the lives of those affected by PH, by matching partners with willing participants in this process.

PHA's community database contains thousands of patient, caregiver and provider records used weekly to share news and information with the PH community. The data is self-reported by PHA community members as they join PHA initiatives. In addition, thousands more visit PHA's website and social media channels to find resources on PH. In addition, the PHA Registry (PHAR) is the largest active patient registry containing over 2,000 PAH and CTEPH patients who receive care at more than 80 accredited centers in the United States. The PHA Registry contains diagnostic and therapeutic data updated at frequent intervals by a health care provider.

Purpose of Engagement

Community Input: PHA engagement services provide industry and academic researchers with the ability to collect market and community data from PH patients, caregivers and providers via focus groups, interview panels, quantitative studies, or advisory board participation.

Drug Research and Development: Partners may request clinical study design collaboration and participation with PHA’s accredited PH care center network as well as clinical trial subject recruitment

PHA offers three distinct ways to engage with the community



Advertising

Reach the PH community with your message by advertising on any of PHA’s media platforms (newsletters, magazine, journal, website). For more information and pricing for PHA Advertising, contact Kevin Heyen, PHA vice president of development, at KevinH@PHAssociation.org.



Targeted Communications

Provide PHA with your project’s inclusion criteria and let us find the targets in our CDb. PHA will assist you in drafting an email blast to the target list with your call to action and corresponding placement on PHA’s “Partner Opportunities” web page (promoted through our social media channels). May be used to engage patients, caregivers or providers, including center directors for clinical study collaboration. To request service information and pricing, contact Elizabeth Joseloff at elizabethj@phassociation.org.



Clinical Study Eligibility Service

For more precise and accurate targeting, PHA will query the PHA Registry (PHAR) containing over 2,000 PAH and CTEPH patients with diagnostic and therapeutic data cared for at one of PHA’s accredited centers. After locating the eligible subjects, PHA will facilitate communication with their corresponding centers for eligibility confirmation and study recruitment. To learn more information about PHAR Services and for pricing, contact Elizabeth Joseloff at elizabethj@phassociation.org.

	Advertising 	Targeted Communications 	Clinical Study Eligibility Services 
Reach ¹	Very high	Medium to high (depending on partner’s criteria)	Limited to PAH and CTEPH patients in PHAR
Specificity ²	Limited	Medium to high (depending on partner’s criteria)	Very high

Sponsorship and event exhibit and advertising opportunities are also available.

¹ Reach refers to the number of individuals receiving the message or being targeted.

² Specificity refers to the likelihood of the target being eligible to take part in the engagement. In any and all cases, PHA does not guarantee results of any type of engagement