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AAFA Announces \$250,000 Funding Award to Amplify the Patient Voice in Clinical Trials

WASHINGTON, D.C. (May 10, 2018) – The Asthma and Allergy Foundation of America (AAFA) recently received a Eugene Washington Engagement Award from the Patient-Centered Outcomes Research Institute (PCORI) to support AAFA's Building A Scalable Infrastructure to Connect Patients and Researchers (BASIC) project.

Building on AAFA's capability to advance research, the BASIC project will give patients and family members an opportunity to get directly involved in the advancement of asthma research. Led by Lynda Mitchell, AAFA's chief operating officer, this project will leverage what AAFA has learned through their prior patient-centered outcome research projects, including the <u>Promoting Asthma Patient Engagement in Research (PAPER) project</u> and the <u>Asthma in Families Facing Out-of-Pocket Requirements with Deductibles (AFFORD) study</u>.

"I'm excited about this project, especially since it is the first of its kind for both asthma and allergy communities and reflects what we have heard from patients in our online community," says Kenneth Mendez, AAFA's president and chief executive officer. "There is a widespread need for more effective patient, family member and research collaborations. We are honored to receive this award from PCORI that will allow us to continue our innovations in patient engagement."

The BASIC project includes the creation of online resources for patients and family members to learn how to provide meaningful input into research. The project will also design processes to connect researchers with trained and engaged patients and family members who can provide meaningful input into their research studies. The long-term goal for BASIC is to scale a system for increasing the number of patient-centered outcomes and clinical effectiveness research studies for asthma and allergic diseases by fostering productive collaborations between patients, family members and researchers.

"We want researchers to think of AAFA if they are doing patient-centered outcomes research on asthma or allergic diseases," says Mitchell. "The BASIC project is an important new opportunity for AAFA to advance research by building an infrastructure that hasn't previously been possible. By training patients and family members to effectively engage with researchers, we will provide more researchers with opportunities to conduct their work and more people the chance to participate in studies."

"This project was selected for Engagement Award funding not only for its commitment to engaging patients and other stakeholders, but also for its potential to increase the usefulness and trustworthiness of the information we produce and facilitate its dissemination and uptake," Jean Slutsky, PCORI's chief engagement and dissemination officer, says. "We look forward to following the project's progress and working with AAFA to share the results."

AAFA's project and the other projects approved for funding by the PCORI Engagement Award Program were selected through a highly competitive review process in which applications were assessed for their ability to meet PCORI's engagement goals and objectives, as well as program criteria.

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Asthma and Allergy Foundation of America





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ABOUT AAFA

Founded in 1953 and celebrating 65 years of service, AAFA is the oldest and largest non-profit patient organization dedicated to improving the quality of life for people with asthma, allergies and related conditions through research, education, advocacy and support. AAFA provides practical information and community-based services through its digital communities and national network of local chapters and educational support groups. Through its <u>Kids With Food Allergies division</u>, AAFA offers the most extensive online support community for families raising children with food allergies. AAFA also helps consumers identify products suitable for those with asthma and allergies through the <u>asthma & allergy friendly® Certification Program</u>. For more information, visit <u>aafa.org</u>.

ABOUT PCORI

PCORI is an independent, non-profit organization authorized by Congress in 2010 to fund comparative effectiveness research that will provide patients, their caregivers, and clinicians with the evidence needed to make better-informed health and healthcare decisions. PCORI is committed to seeking input from a broad range of stakeholders to guide its work.

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