

May 15, 2015

National Heart, Lung, and Blood Institute Attn. Strategic Visioning Team Building 31, Room 5A48 31 Center Drive MSC 2486 Bethesda, MD 20892

<u>Re:</u> Request for Information (RFI): NHLBI Strategic Visioning - Developing the Research Priorities for the Next Decade--Notice Number: NOT-HL-15-252 (http://grants.nih.gov/grants/guide/notice-files/NOT-HL-15-252.html)

Dear NHLBI Strategic Visioning Team,

On behalf of the Asthma and Allergy Foundation of America (AAFA), I am pleased to submit these comments in response to the above-referenced request for information (RFI). AAFA is dedicated to improving the quality of life for people with asthma and allergic diseases, and their families and caregivers. AAFA develops and disseminates information and educational resources and provides support to the broader population of people with asthma and allergic diseases. AAFA's work includes educational programs that support patients with these conditions and the clinicians and allied health professionals who care for them. AAFA's programs are also directed at increasing public awareness, through campaigns and social research projects which highlight the growing problem of asthma and unprecedented rise in allergies. Our websites—www.kidswithfoodallergies.org and www.aafa.org—house hundreds of pages of evidence-based resources for disease prevention, management and treatment. AAFA's vision is to help these people live a life without limitsTM.

AAFA thanks the National Heart, Lung, and Blood Institute (NHLBI) for seeking input to help guide the NHLBI in setting scientific priorities, making decisions, and allocating resources over the next decade. In the discussion below, AAFA offers a few general comments and then identifies a number of knowledge gaps and related opportunities for NHLBI's consideration.

General Comments

Currently, more people than ever are struggling to live normal and healthy lives in the face of the daily limits that asthma and allergic diseases create. More than 25 million Americans have asthma, 15 million have food allergies, and 50 million have other allergic conditions. AAFA urges the National Institutes of Health (NIH) to continue to focus and accelerate research on asthma and allergies, which are life threatening chronic conditions for which there are no cures.

While asthma affects all populations, the burden of asthma falls disproportionately on the black and Hispanic/Latino—largely Puerto Rican—populations, and especially on minority



children. Asthma is the third leading cause of hospitalization among children under the age of 15 and is a leading cause of school absences from chronic disease – accounting for over 10.5 million lost school days in 2008. Asthma costs our healthcare system over \$50.1 billion annually and indirect costs from lost productivity add another \$5.9 billion. Asthma claimed the lives of more than 3,400 Americans in 2010. According to the American College of Allergy, Asthma & Immunology, allergic diseases, which include asthma, are the fifth most prevalent chronic diseases in all ages, and the third most common in children.

It is essential that people with asthma and allergies have access to affordable, quality healthcare for the treatment and management of asthma and allergies, and that research is funded to address prevention, screening, and lifestyle interventions to reduce the incidence and adverse effects of asthma and allergies. These conditions impose significant costs on the overall health care system and on patients and their families.

Developing Research to Address the Critical Problem of Nonadherence to Effective Treatments

A large gap in healthcare is nonadherence to proven effective treatments. One important area for reducing morbidity, mortality and cost for patients with chronic diseases that require frequent home, non-healthcare assisted, administration of treatment is the promotion of adherence to treatment recommendations. It is recognized as a gap in care but not a priority of the National Heart Lung and Blood Advisory Council (NHLBAC) Asthma Expert Working Group's assessment of the need for a potential update to the 2007 National Asthma Education and Prevention Program's (NAEPP) Expert Panel Report. The report provides a description of the needs assessment methods used by the Working Group, their recommendations for selected study topics, and their views on the potential respective roles of NHLBI and NAEPP in the process of updating the 2007 guidelines. Adherence was not considered as a priority since there was not significant publications/research to add to the update.

The lack of research highlights the need for more research in not only asthma but all chronic diseases. One entrant in the NHLBI online forum is entitled: "Improve patient compliance through community health workers." That is just one of a multitude of ideas that might be considered by an Expert NHLBI Panel in the Adherence Research field. The Institute is gathering ideas for the most compelling scientific priorities to address over the next decade and addressing adherence research to enable the maximal effect of proven medical therapies to reduce unnecessary morbidity and improve the quality of life deserves critical attention.

Other Knowledge Gaps and Opportunities for Additional Research

- Need to advance translational research
- Innovations and discoveries for treatments of allergy and asthma
- Develop and integrate biomarkers of asthma into phenotype/endotype driven asthma management algorithms
- Develop disease modifying treatments for asthma and asthma disease prevention



- Approach, diagnostics and management of asthma-COPD overlap syndrome
- Enhance compliance with asthma controller agents
- Increased representation of the elderly in research
- More evidenced based-scientifically proven interventions to ensure that scientific information is translated into clinical and public health practices and programs to reduce the burden of asthma and allergies on individuals, families and society
- More effective strategies for community-based participatory dissemination and implementation of research initiatives in rural settings
- Incorporation of patient-centeredness in all research
- Research to adapt evidence-or practice-based interventions for urban, rural and minority populations
- Integrate real time data acquired from/through mobile health care applications (apps) and devices into asthma and allergy management

Concluding Comments

AAFA appreciates the opportunity to submit these comments. Again, we thank NHLBI for issuing this request for information and for inviting public input. Please feel free to contact me (csennett@aafa.org) or Meryl Bloomrosen (mbloomrosen@aafa.org), AAFA's Sr. Vice President for Public Policy, Advocacy and Research at any time for further discussion of these comments.

Sincerely,

Cary Sennett, MD, PhD

Cary Sorrett

President and CEO