



**Remarks to the Institute of Medicine Consensus Study Committee
Food Allergies: Global Burden, Causes, Treatment, Prevention and Public Policy
August 30, 2015- September 1, 2015**

On behalf of the Asthma and Allergy Foundation of American (AAFA), I am pleased to have the opportunity to offer the following comments. AAFA is honored to bring the voice of the food allergy community (via AAFA's Kids with Food Allergies Division, KFA) to support and inform the Committee's work, and to help widely disseminate your findings.

AAFA, a not-for-profit organization founded in 1953, is the leading patient organization for people with asthma, allergies and related conditions. AAFA provides practical information, community-based services and support through a national network of chapters and support groups. AAFA provides health education, organizes state and national advocacy efforts and funds research to find better treatments and cures.

KFA is dedicated to keeping children with food allergies safe and healthy until a cure for food allergy is found. KFA is an essential part of the food allergy and anaphylaxis community offering free education programs for families and caregivers, webinars, an allergy buyers' guide, an electronic database of allergen-free recipes and more. Most notably, KFA's website hosts the largest and most active online food allergy and anaphylaxis community, a critical platform for parents and caregivers who want to network with others about raising kids with food allergies and related diseases. KFA has been educating and supporting families since 2005. KFA became a division of AAFA in 2013.

AAFA believes that while we seek a cure and more effective treatments there is significant opportunity to take the science that we already have and deploy it more consistently and reliably. Food allergy presents significant burdens for patients and their families. Food allergy is a significant public health issue that extends beyond the clinical care setting.

- Our community members, people with food allergies and their families and caregivers-tell us that in the absence of a cure, they seek ways to live safely-to be able to live each day without worry of dying from anaphylaxis. Being able to tolerate enough peanut to be able to send their children to school, confident that they will find accommodation and support; or being able to rely on clear, unambiguous and understandable food labels; and being able to understand if food ingredients in medications and vaccines are safe for them.
- The 10th anniversary of Hurricane Katrina reminded our community of the increased challenges people with dietary restrictions face during disasters. In the days following a disaster, emergency response groups like the Red Cross, HUD, and FEMA are not set up to address the needs of those with allergen-restricted diets. Emergency food supplies are often laden with common allergens. We urge the IOM to make recommendations that address food allergy needs during disasters.
- A related concern is the unavailability of allergy-friendly food at food banks for those who need them. Again, we urge the IOM to include meaningful recommendations to assure that the need for allergy-friendly foods is inherent in all federal food policies



including the country's programs that provide meals and nutritional support to children—such as school breakfasts and lunches, summer meals, and the Special Supplemental Nutrition Program for Women, Infants, and Children.

- We note that the Guidelines for the Diagnosis and Management of Food Allergy in the United States do not address the management food allergy outside of clinical care settings (for example, in schools, restaurants and airplanes) or the related public health policy issues (for example, laws about food processing or food handling). We have provided IOM staff with a copy of our 2015 State Honor Roll Report (www.StateHonorRoll.org). The report identifies states with the most comprehensive and effective public policies supporting people with asthma, food allergies, anaphylaxis and related allergic diseases in U.S. elementary, middle and high schools. We believe there is much to be learned from policy leadership in the states that can inform IOM recommendations at the national level.
- There are changes to the nation's approaches to health care delivery. We are mindful that people with food allergy may seek and receive care in community health centers, federally qualified health centers, retail clinics, and urgent care centers. Research is needed to assure effective and high quality food allergy diagnosis, treatment and management in such settings.
- There are populations who may face additional challenges to access and quality care. AAFA believes that attention to health literacy and cultural issues are important.
- We wish to emphasize the need to assure ongoing access to quality and affordable care and treatment. Issues related to benefits, coverage and reimbursement are critical. While many health insurance plans provide some level of coverage for food allergy patients, it is important to understand what is covered and under what circumstances and how this relates to the most current clinical evidence and FDA (drug and device) approvals. Availability, access to, and coverage for education, self-management, medications and treatment are critical.
- The economic burden of food allergy on families is high; there are not only out-of-pocket expenditures for medical services (epinephrine, physician visits) but also the costs of allergen-free foods and special childcare arrangements. These issues are especially challenging for low income populations. We recognize that these are complex issues, as the price people pay depends not only on the price pharmaceutical companies charge, but also on the structure of people's health insurance. We believe IOM discussion of these issues will shed important light on potential options to address them.
- We believe the issue of economic burden is one of special and great importance to families with food allergy. With the school year beginning, our community members are facing significant costs, assuring that their children will have the prescriptions, drugs, and devices that they need to assure them access while away from home. And they have expressed, very clearly and loudly, the concerns that they have about the cost associated with that. Families with multiple children with food allergies face extraordinary circumstances, as they have to acquire multiple sets of epinephrine auto-injectors to have in multiple locations—one set for home, one set for school—for each child. Current policies and programs to support these families—for example, the discount cards offered



by some manufacturers—are not meeting the need, as many families still face many hundreds of dollars in out of pocket expenses.

- People are telling us that they cannot afford to fill prescriptions for potentially life-saving epinephrine auto-injectors. Some are telling us that they will delay refilling their devices past their expiration dates. These issues are truly ones of life-and-death, and concern us greatly. We urge the IOM to consider them, and to offer recommendations.

Summary and Conclusion

We applaud the Committee’s efforts to undertake a comprehensive approach to better understand, prevent, treat and ultimately to cure food allergies. We believe the IOM Committee will contribute greatly, if it considers the policies and programs that will help assure that Americans with food allergy live in a world that is safe, and have access to the medications, educational programs, and food options that they need.

AAFA appreciates the opportunity to address the Committee today and stands ready to assist in any way that we can. Thank you for your time and attention!

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