



PR Contact:

Adam Bailine, Vice President, Marketing & Communications
(202) 466-7643, ext. 254
abailine@aafa.org

AAFA Launches Food Allergy Patient & Family Registry to Propel Patient-Centered Research

*The First and Only Patient-Centered Food Allergy Registry Focused on Real-World
Experiences to Help Drive the Future of Food Allergy Research*

February 28, 2017, LANDOVER, MD – The Asthma and Allergy Foundation of America (AAFA) is proud to announce the official launch of the [Food Allergy Patient & Family Registry](#) (Registry). Designed to collect data that will help amplify the voice of people and families with food allergies, our goal is that this Registry will support research that will improve quality of life and ultimately help to end food allergy.

As noted in the recent release of the [food allergy report](#) from the National Academies of Sciences, Engineering, and Medicine – a report that AAFA co-sponsored – more precise data are required to unravel all of the scientific and quality-of-life issues surrounding food allergies. By engaging and involving people with food allergies in research, AAFA's Registry will collect and analyze data to help answer those questions.

“Collecting data from patients with food allergies about their health and lifestyle is a potentially transformational moment for food allergy research,” said Cary Sennett, MD, PhD, FACP, AAFA's President and CEO. “The Registry will provide “real world evidence” that speak to the patient and family's experience; a critical complement to strictly medical data. Ultimately, bringing these disparate data together will help us better understand how to prevent, diagnose, and treat those with food allergies—and also how to improve the lives of those for whom it is a constant reality.”

The Registry is a secure, private, Web-based program. Participants will be able to share information about their experiences and opinions about living with food allergies and their quality of life. Participants can also provide feedback and suggestions for future research that would be most meaningful to them.

“This is a natural extension of the support we provide to the families who are part of our [Kids With Food Allergies](#) (KFA) community,” said Melanie Carver, AAFA's Vice President for Digital Strategy and Community Services. “Collecting data on quality-of-life issues can also advise AAFA on where best to focus our education and advocacy efforts with policymakers and others.”

Patient participation in medical research is critical. Patient involvement helps researchers understand the issues involved with living with the disease – giving researchers unique insight that doctors and other health care providers may not be able to give.



"Patients play a bigger and more critical role in research today," adds Lynda Mitchell, Founder of KFA and AAFA's Chief Operating Officer. "The Food Allergy Patient & Family Registry is the only registry of its kind, and an exciting way for AAFA to engage adults with food allergies and families raising children with food allergies in the research process."

AAFA's Food Allergy Patient & Family Registry was made possible by a technology grant from the Genetic Alliance and the Robert Wood Johnson Foundation. The Registry is built using the Platform for Engaging Everyone Responsibly (PEER).

About Genetic Alliance

Genetic Alliance engages individuals, families and communities to transform health. Founded in 1986, it is the world's largest nonprofit health advocacy organization network. Genetic Alliance's network includes more than 1,200 disease-specific advocacy organizations, as well as thousands of universities, private companies, government agencies and public policy organizations. For more information about Genetic Alliance, visit www.geneticalliance.org.

About AAFA

Founded in 1953 and celebrating over 60 years of service, the Asthma and Allergy Foundation of America (AAFA) is the oldest and largest nonprofit patient organization dedicated to improving the quality of life for people with asthma, allergies and related conditions through education, advocacy and research. AAFA provides practical information, community-based services, support and referrals through a national network of chapters and educational support groups. Through its Kids With Food Allergies division, AAFA offers the oldest, most extensive online support community for families raising children with food allergies. In addition, AAFA sponsors and advocates for research to advance the basic science relevant to treatment and cure. It also champions translational research so that the science that we have is applied more consistently and reliably. For more information, visit www.aafa.org, and www.kidswithfoodallergies.org.

END