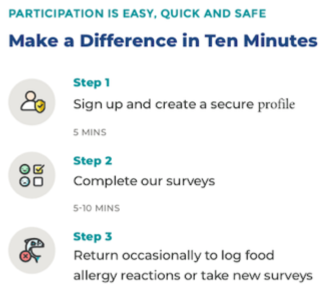
FARE
Patient Registry

FARE Patient Registry Talking Points – FARE Clinical Network

What is the FARE Patient Registry?	The FARE (Food Allergy Research & Education) Patient Registry invites food-allergic individuals and their caregivers to quickly, conveniently and privately share their food allergy experiences through simple online surveys in order to help advance food allergy research.
Why is the Registry important? How is information used?	Information shared with the FARE Patient Registry helps researchers **better understand food allergies and their impact and reveals opportunities to improve the care** food allergic individuals receive, including speeding the search for new and better ways to diagnose, treat, and, ultimately, cure food allergies. By providing real world insight into the incidence and quality of life impact of food allergy, the Registry supports the development of knowledge, tools and resources needed to quickly advance clinical research and build a pipeline of new therapies. Insights from the FARE Patient Registry are also used to **support food allergy education and advocacy initiatives**, serving the more than 32 million Americans with potentially life-threatening food allergies. **When you share your food allergy experiences, you help contribute to food allergy solutions.**
Is there a simple video to help explain the key points about the FARE Patient Registry?	**Yes!** An animated video explaining the FARE Patient Registry can be found on YouTube**.** The direct link is: https://youtu.be/3k-aWsej0zU Please share this with patients directly, or through your communication channels, including your website, social media platforms, patient-facing email outreach, and more. The video covers all of the basic information about the Registry including: • What is the Registry and how does it help advance research? • How does individual participation make a difference? • How is participant data kept private and secure? • How does one join and participate, and how much time is needed?
What does participation involve?	**Participation = filling out short, online surveys about food allergies.** • Where? FAREregistry.org • Registration, including informed consent, takes about 5 minutes. • Participants complete a series of 5-10minute-long surveys, at their convenience. • There are currently three surveys. They are: Food Allergy History, Food Allergy Reactions and Mental Health Concerns. • Food Allergy Reactions is designed to retake. Participants are encouraged to record each allergic reaction they experience as the data from different reactions provides useful information to researchers.  PARTICIPATION IS EASY, QUICK AND SAFE **Make a Difference in Ten Minutes** **Step 1** Sign up and create a secure profile 5 MINS **Step 2** Complete our surveys 5-10 MINS **Step 3** Return occasionally to log food allergy reactions or take new surveys

Rev. 10/13/2020

Learn more and register at FAREregistry.org

Who can join?	Anyone with a physician-diagnosed food allergy. Parents can join on behalf of their food allergic children. **About 12,000 have joined to date**, of all ages and from different backgrounds and communities.
Not ready to join? Need more information?	To receive information about the FARE Patient Registry, please encourage patients/caregivers to scan the QR code (on any of the materials or here) and follow instructions to enter contact information.
How is my personal information protected and kept private?	**The FARE Patient Registry is firmly committed to protecting participant privacy.** • Participant data is stored and maintained in a secure, password-protected database, assuring the privacy, security and confidentiality of all personal information as described in our Privacy Policy. **No one outside of the Registry team will be given access to any personally identifiable information** (things like name, email address, etc). **Participation is 100% voluntary. You control what you share, how much you share.**
How can one person really make a difference?	1. **Each person's experience with food allergies is unique** and holds important clues that will help better understand this disease, an essential first step toward improving care and making food allergy management both safer and easier. 2. No one understands food allergies better than those living with them every day. **3. Unless researchers hear from ALL VOICES -- the full range of people who are living with food allergies** – all different ages, genders, races, ethnicities, geographic locations, socioeconomic situations – **the solutions and programs that emerge to improve care and support will not meet ALL needs.**
More Questions?	• Visit FAREregistry.org and click on FAQ at the bottom of the home page. • Email farepatientregistry@foodallergy.org

The bottom line is that 32 million American live with potentially life-threatening food allergies and as many as 85 million Americans – or approximately 1 in 4 – are actually impacted, according to a recent study of household grocery purchasing behavior that included Registry participants. **Registry participants are vital partners in the quest for food allergy solutions.**

Dr. Tom Casale, FARE Patient Registry Principal Investigator, said this:

> *"The pace of food allergy research is accelerating every day and there's much hope on the horizon in the form of new therapies and a deeper understanding of the disease.* ***The FARE Patient Registry is a powerful tool that will help us get there faster*** *by promoting* ***collaboration*** *between two groups of* ***experts - the individuals and families living with food allergy*** *and the research community committed to solving this epidemic."*