



FARE
Food Allergy Research & Education

ANNUAL REPORT 2018



**“I AM NOT MY FOOD ALLERGY. I’M
NOT SCARED ANYMORE. I WANT
TO HELP OTHER KIDS GOING
THROUGH THE SAME THING.”**

—Rachel (Not pictured)

MISSION:

FARE is the world's leading food allergy advocacy organization and the largest private funder of food allergy research. Our mission to improve the quality of life and the health of individuals with food allergies, and to provide them hope through the promise of new treatments.

VISION:

FARE is transforming the future of food allergy through innovative initiatives that will lead to increased awareness, new and improved treatments and prevention strategies, effective policies and legislation, and novel approaches to managing the disease.



Lisa Gable
Chief Executive Officer

Dear Friend,

It is an exciting time as new innovations are on the horizon and I'm honored to be leading the charge. As a team, we are building out a transformative and unifying strategy to better meet the needs of kids and families in our community. We can't do this critical work without you. [This year, your collaboration proved vital for collective impact.](#) We thank Dr. James Baker for his vision and work in laying the foundational pieces for a bold collaborative, the FARE Clinical Network, that is changing the face of food allergy research. We saw the Teal Pumpkin Project achieve unprecedented reach as we encouraged the community to embrace and own the movement. We created a Board of Governors to help steer FARE toward a sustainable future by providing guidance, research oversight, and investment stewardship. We developed a Board of National Ambassadors to assist us in the development of strategic relationships, elevate our thought leadership, and raise the funds and awareness necessary to enable us to meet mission-driven goals of safety and inclusion.

[Our national fundraising and awareness campaign](#) will raise a historic amount of funding for research, therapies and treatments, and have exciting community engagement opportunities across the country, with potential for tremendous reach nationwide.

[We know our kids are not problems to be fixed; they are assets to be gained.](#)

The entire FARE team joins me in expressing our appreciation for your support. It will take all of us working together to deepen our collective impact and rapidly drive much needed change for our children. [Thank you for your friendship and your commitment.](#)

Warmest regards,

A handwritten signature in black ink that reads "Lisa Gable".

Lisa Gable, CEO, FARE

A group of seven children and one adult are lying on their backs on a lush green lawn. They are arranged in a circle, with their heads pointing towards the center. The children are of various ethnicities and ages, all smiling and laughing joyfully. The adult, a man with a beard, is also smiling broadly. The scene is bright and cheerful, capturing a moment of pure happiness and connection in nature.

FARE IS THE **LARGEST**
PRIVATE FUNDER OF
FOOD ALLERGY RESEARCH IN
THE WORLD.

OUR FOCUS IS COMPREHENSIVE:

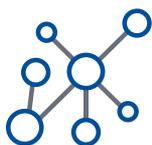
Through support for academic and industry research, FARE promotes the development of new therapies and offers hope for effective treatments. We provide educational tools and advocacy resources to raise awareness and deepen understanding of food allergy issues among broad audiences.

RESEARCH

FARE is the leading national voice in accelerating life-changing and life saving work for the food allergy community. We are a catalyst for driving research collaboration, and an accelerator for new treatments and cures through the following initiatives:



RESEARCH INVESTMENT: FARE's research infrastructure has funded some of the most groundbreaking developments in the food allergy space including the LEAP studies, the first to show early allergen introduction as a way to prevent development of a peanut allergy. FARE also funded widely cited prevalence studies and immunotherapy studies. Additionally, FARE made a significant seed investment in Aimmune Therapeutics, which is moving toward the first FDA-approved food allergy therapy. In 2018, the Bunning family made an incredible commitment of \$5 million to accelerate research toward life-changing therapies and innovations to improve the quality of life for the food allergy community.



FARE CLINICAL NETWORK: The FARE Clinical Network is a collaborative of food allergy centers of excellence offering high-quality clinical care and phase III clinical trial patient enrollment. The network, which currently encompasses **31 centers of excellence in 17 states plus the District of Columbia**, links leading clinicians and investigators across the country to collectively ensure that food allergy patients have access to state-of-the-art diagnosis, care, research and clinical trials. Since the network's establishment in 2015, its

centers have served nearly 95,000 patients, resulting in a 400 percent increase in the number of patients enrolled in clinical trials for food allergy. To simplify a patient's search for food allergy research studies listed on the National Institutes of Health's www.clinicaltrials.gov site, FARE created an online Clinical Trial Finder, www.trials.foodallergy.org, in 2018.



FARE INVESTIGATOR IN FOOD ALLERGY AWARDS: In 2014, FARE launched the Investigator in Food Allergy Awards, which provide salary and research support to attract exceptional young scientists to the field of food allergy and encourage established researchers to pursue innovative food allergy studies. This support led to key discoveries in 2017 and 2018. After identifying a type of immune cell found only in those with food allergies, Dr. Erik Wambre received a \$5 million grant from the National Institutes of Health to speed the search for peanut allergy treatments. Dr. Michiko Oyoshi showed in mice that a nursing mother exposed to a food can transfer antibodies through her breast milk that protect the newborn against allergy to that food. Dr. Simon Hogan identified immune pathways active in severe reactions that may offer new targets for drugs. And Dr. Jessica O'Konek took the first steps in developing a nasal spray vaccine to suppress peanut allergy. We look forward to further advances from a new cohort of FARE Investigators who were awarded grants in 2017.



PATIENT REGISTRY: In May 2017, FARE launched what is now [the world's largest registry of food allergy patients](#). The FARE Patient Registry empowers patients or their legal representatives to help drive food allergy research forward by sharing their de-identified (anonymous) medical histories with the research community. More than 5,200 food allergy patients have enrolled in the registry, providing vital data on food allergy demographics, reactions, treatments and outcomes, with additional surveys planned to assess psychosocial impacts of food allergy. We will soon begin collecting de-identified medical records – and, eventually, biological specimens – from the 31 clinical care and research institutions of the

FARE Clinical Network. This large, robust data set will be an essential resource in the search for effective therapies.



RESEARCH RETREAT: In 2011, FARE launched the annual Research Retreat, where academic scientists, clinical care providers, pharmaceutical industry representatives, government officials and patient advocates come together. They discuss progress in food allergy research and identify opportunities to design clinical trials that test the effectiveness of new treatments. They reflect and respond to the psychological and social needs of food allergy patients and their families. This year, FARE's Outcomes Research Advisory Board addressed psychological and social issues that affect quality of life for patients and their families with 130 retreat attendees. Researchers from pharmaceutical companies also reported on advances in drug development.

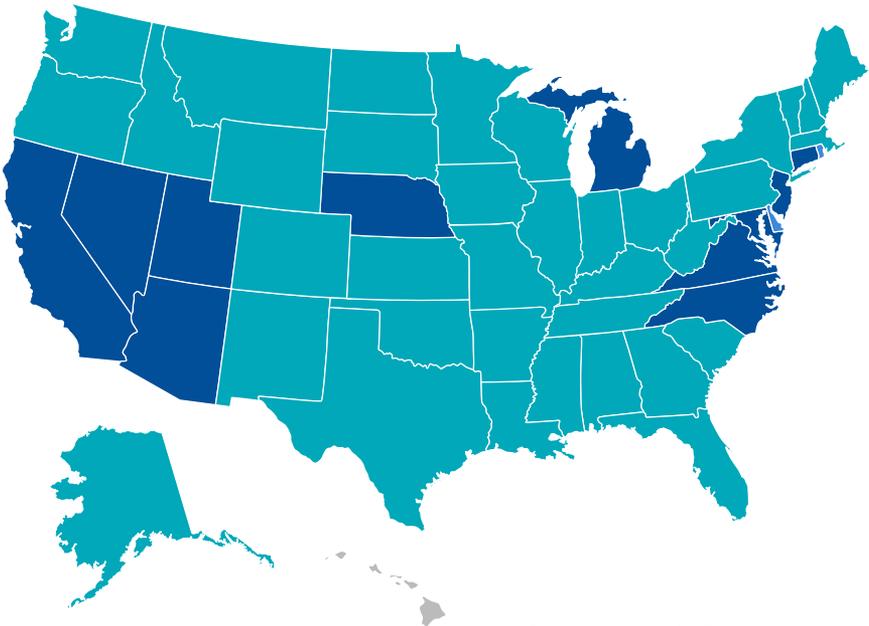


INTERNATIONAL FOOD ALLERGY & ANAPHYLAXIS ALLIANCE (IFAAA): Formed in 1999, IFAAA is a coalition of patient advocacy groups working to advance the interests of the food allergy community worldwide. The IFAAA's first Partners in Action Day in 2017 brought together patient representatives from 19 countries to share their insights with regulators, drug and food manufacturers, scientists, clinicians and others. This year in Copenhagen, [Partners in Action Day drew 89 participants from 20 countries on five continents](#), bringing diverse patient perspectives to inform the direction of food allergy research and public policy.

ADVOCACY

To date, FARE has influenced more than 100 pieces of legislation resulting in [more than 1 million epinephrine auto-injectors in circulation in K-12 schools](#). These advocacy efforts in recent years have included:

- Working on laws that have resulted in [49 states permitting or requiring schools to stock epinephrine auto injectors](#). There have been more than 2,000 uses of stock epinephrine to treat anaphylaxis in schools
- A campaign to allow public entities to stock epinephrine autoinjectors that has led to [laws in 32 states](#)
- Laws that specifically provide [access to epinephrine on college campuses](#) in Indiana, New Hampshire, New Jersey, Texas and Virginia



- State has law/guideline allowing schools to stock epinephrine
- State has law/guideline requiring schools to stock epinephrine
- State has pending legislation.

- Laws in New York, Pennsylvania and West Virginia that [allow school bus drivers to administer epinephrine](#)
- Laws that [require restaurants to be trained in food allergy preparedness](#) in Illinois, Massachusetts, Maryland, Rhode Island, and Virginia
- A [change in policy by American Airlines](#) to allow passengers with allergies to preboard, thanks to a complaint filed by FARE with the U.S. Department of Transportation
- Working with a coalition of allergy organizations to encourage FDA to look at [adding sesame to the list of allergens](#) regulated by allergen labeling laws

FARE works with the Food & Drug Administration (FDA) on both food and pharmaceutical issues. On the latter, we called for affordable solutions for families facing a shortage of epinephrine, including increased competition and innovation. The FDA has since taken steps proposed by FARE including: declaring a national shortage; granting approval to applications for generic autoinjectors; and extending the expiration date on certain lots of autoinjectors. FARE also sits on the Conference for Food Protection, the entity that recommends updates to the FDA Food Code, and has encouraged the formation of a food allergy task force to look at issues related to food allergen handling in food service. FARE has invited FDA officials to participate in next year's annual Research Retreat and hear directly from patients and leading researchers on the urgent need for new treatment options.

FARE secured language in the 2019 Labor-Health and Human Services Appropriations Act that encourages the National Institute of Health (NIH) to expand its clinical research network to new centers of excellence that have proven expertise in food allergy research.



EDUCATION:

FARE offers many tools to help educate the community about food allergies. Our teaching resources are utilized to drive understanding and awareness at individual, classroom and institutional levels:

- Our free online course, *Save a Life: Recognizing and Responding to Anaphylaxis*, was created to address the need for simple, evidence-based educational training on anaphylaxis. It has been [downloaded almost 10,000 times](#) since its launch in March 2018.
- Our *Food Allergies: Keeping Students Safe and Included* presentation, an online training course providing clear, actionable information to

schools to help them support students with food allergies, has been [downloaded over 3,000 times](#) this year

- FARE conducted a live training for 600 directors, teachers, aides, program specialists and other staff from childcare and preschool centers in New York. FARE was subsequently invited to create an online [training for an additional 2,000 preschool and childcare staff](#) to attend virtually.
- Our *Your Food Allergy Field Guide* for newly diagnosed individuals and families, has been [downloaded over 8,000 times](#) since January 2017
- Our *Food Allergy & Anaphylaxis Emergency Care Plan*, which outlines recommended treatment in case of an allergic reaction, has been [downloaded almost 129,000 times](#) since January 2017

FARE COLLEGE FOOD ALLERGY PROGRAM: The FARE College Food Allergy Program provides colleges and universities with a comprehensive program to improve the safety and quality of life for college students with food allergies. To-date, our College Program has [served one million graduates and will reach 100 schools](#) by the end of 2018:

- 700+ colleges and universities utilized FARE-approved food service training
- 600+ colleges and universities accessed other FARE resources
- 3,000+ disability services reps received FARE resources through partnership with Association on Higher Education & Disability
- 600+ colleges and universities representing over 7 million students have received access to resources through FARE's training webinar and presence at the National Association of College & University Food Service (NACUFS) conferences
- 40 colleges participated in FARE's pilot program

Plans are underway to leverage and link the FARE Clinical Network centers of excellence with college campuses in their regions.

OUR IMPACT IS FAR REACHING:



1,000,000

Undergraduate students have been reached by the FARE College Food Allergy program since 2016



4,200,000

in research grants awarded since 2015 through the FARE Investigator Award program



1,000,000+

Autoinjectors stocked in more than 54% of the nation's schools



47 MILLION

Increase in National Institute of Health (NIH) spending



CO-FUNDED

Clinical trials in immunotherapy LEAP study encouraging early exposure, changing years of recommendations



31

31 Centers of Excellence across the country with more coming on board



INFLUENCED 100+

Policies for food labeling, epinephrine access, school safety, and restaurant training



**“FARE is an invaluable resource
for anyone impacted by food
allergies. Their resources
have helped drive life
saving decisions for me.”**

**- Jennifer, food allergy mom
(not pictured)**

COMMUNITY ENGAGEMENT

It takes a village, and we are so thankful for ours.

FARECON FEATURING TEEN SUMMIT:

In November 2018, FARE hosted what is believed to be the [largest in-person educational event for the food allergy community](#): FARECon featuring Teen Summit, just outside Washington, DC. With double the attendance of past annual conferences and 200 more attendees than the previous record-holding Teen Summit, FARECon featuring Teen Summit attracted 700 teens, parents and adults managing food allergies, plus [registered dietitians from 34 states and five countries](#) for a weekend of learning and bonding.

"I appreciate the emphasis on empowering our teens with their voice. You were trying to teach kids how to use their voice and how to teach parents to trust and empower our kids. You modeled how our kids must learn to live in a world surrounded by food: be diligent, teach, take precautions, and trust."

- Mike, food allergy dad



TEAL PUMPKIN PROJECT:



Photo: Instagram.com/jessicagrnt14

The Teal Pumpkin Project is well on its way to becoming as commonplace as an orange jack-o-lantern on Halloween. Since FARE launched this national awareness initiative in 2014 with a single post on social media, the Teal Pumpkin Project has grown exponentially.

Teal pumpkins are now found in national retail stores, have been spotted at the White House, and the initiative has received widespread coverage in national media outlets such as TODAY, ABCNews.com, Better Homes & Gardens and Cooking Light.

Our 2018 Teal Pumpkin Project social media launch achieved a combined total of almost **150,000 unique views**. Teal Pumpkin Project-related social posts over the course of Halloween saw **over 800,000 reach on Facebook**, **over 120,000 impressions on Twitter**, and **over 100,000 impressions on Instagram** – demonstrating the movement’s unparalleled reach among digital communities across the country.

For the first time in 2018, the Teal Pumpkin Project was supported jointly by 10 national food allergy organizations, providing this important awareness initiative even more momentum and creating collective impact.



COMMUNITY WALKS:

FARE’s Food Allergy Heroes Walks have made an impact from coast to



coast, providing a supportive environment and opportunity for members of the community to put the walk’s tagline “Connect. Unite. Inspire” into action. These walks celebrate the everyday heroes in our community – families, educators, health professionals, emergency responders and others – whose dedication helps keep their food allergic neighbors safe.

Over the past two years, **more than 20,000 walkers have raised \$2.3million** in communities across the country.

THE CAMPAIGN

Imagine a world where every kid feels liberated, courageous and empowered.

CONTAINS: COURAGE™ is a transformative five-year fundraising and awareness campaign supporting families living with food allergies, and educating ALL communities about the disease. We will host activities in 10 cities each year and scale up over the next five years by partnering with donors, sponsors, pediatricians, school districts, universities and non-profits. FARE will amplify the powerful voices of kids as storytellers. With your support, we will [drive awareness locally and nationally, and raise a historic amount of funding](#) for research, therapies and treatments.

We are engaging food allergy families and meeting them where they live, work and play:

- Building on your vital work and providing the tools needed to continue supporting the food allergy community in your city and state, with the goal of expanding our footprint nationally
- Partnering with after-school, religious institutions, and athletic programs to ensure supporting food allergy kids becomes integral to every child's life
- Reaching 330 million Americans and raising an understanding of the disease's complexity, and the role each American has in ensuring that kids with food allergies are safe and included

[Join forces with us to advance our critical work for families across America.](#)



FARE

Food Allergy Research & Education

www.foodallergy.org

#ContainsCourage

INGREDIENTS: Intelligence, passion, singer, great friend, loyalty, piano and ukulele player, cross country runner, math whiz, future President, allergic to peanuts and tree nuts

CONTAINS: COURAGE™

Every dollar raised brings us closer to improving the quality of **LIFE**, and the **HEALTH** of individuals with food allergies, and providing them **HOPE** through the promise of new treatments.



OUR DONORS (2017)

When you support FARE, you're investing in programs and resources that change and save lives. We strive to be good stewards of our funds and to faithfully represent the voice of our community. We are grateful for the relentless commitment and support of our donors. Together, we will continue to actively seek transformative solutions in managing and reversing the rise of food allergies.

\$1M+

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\$500,000-\$999,999

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MOCHA (Mothers of Children Having Allergies)	RotoGrid LLC	Texan Allergy and Sinus Center
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Dawn Moore	Andrea Rubinfeld	The Hartman Family Foundation
Cara Moore	Mike Rutz	The J. Douglas and Marian R. Pardee Foundation
Kelly Morgan	Kevin Sainiak	The Safe + Fair Food Company
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Gretchen Munaretto	SC Johnson	Thrivent Financial
Nancy and Harold Oelbaum Fund	Linda Schaps	Wendi Trilling
Sarah Kugelman and Dan Nanes	Marc Schlachter	UBS Matching Gift Program
Scott Nardi	Gary Schless	UnitedHealth Group
National Jewish Health	Mindy Schneider	University of Chicago Medicine
Newmark Family Properties	Mackenzie Schultz	Nick Valenti
Northwestern Medicine Lake Forest Hospital	Schwab Charitable Fund	Meredith Verona
Carol Novak	Erica Schwartz	Marc Vesecky
Jane Novick	Schwartz Family Foundation	Village Lutheran Church and the Chapel School
Christopher Nuss	SCS Direct Inc.	Jill Vollmer
Charley Ogata	Searchlight LLC	Geralyn Walsh
Elisabeth Olivo	Cynthia Seeman	Washington State Employee Combined Fund Drive
Omni Allergy	Michelle Seifman	Sharon Weintraub
Oracle Corporation Matching Gifts Program	Sequitur Energy Resources LLC	Chrissie Wetherbee
Michael and Alonna Ostad	Marsha Seslowe	Allison Wexler
Anita Padilla-Fitzgerald	Lisa Shabsels	Whole Foods Market
Wendy Pake	Bria Shepherd	Fred Wiesehan
Palo Alto Medical Foundation	Michelle Silberstein	Dave Williamson
Pamela Pantzer	Rockville Silent Auction	Rita Wilson
Danielle Pavlonnis	Kansas City Silent Auction	Stephen Witthuhn
PayPal Giving Fund	Adrienne Silver	Michele Wolkoff
Pearl River Pastry and Chocolates, LLC	Skelmir, LLC	Adele Wolpers
PepsiCo Employee Engagement Fund	Gwen Smith	Gilber Wootton
Gail Perl	Brandy Solinsky	Wynne Health Group, LLC
Harold Philipps	Paul Sonderman	Tim Yerdon
PM Pediatrics	Stephanie Sorkin	Lisa Zagorin
Melissa Pontikes	Soros Fund Charitable Foundation	Elizabeth Clark Zoia
Portroyal Trading Service LLC	Tova Soto	Paul Zugnoni
	South Texas Allergy and	Lori Zych
		Zygmunt and Audrey Wilf Foundation

BOARD OF DIRECTORS (2018)

David G. Bunning, Chair	Christine Olsen, MD
John J. Hannan	Elise Purcell
Helen Jaffe	Robert L. Rich
Rebecca Lainovic	Mary Weiser
Adam Miller	Elliot S. Jaffe, Chairman Emeritus

BOARD OF GOVERNORS (2018)

Kim and Alan Hartman, Co-Chairs	Leigh Feuerstein
Janet Atwater	Louise Matthews, MD
Denise A. Bunning	Robert Nichols
Hillary and Ben Carter	Joelle Resnick
David A. Crown, PhD	Ira and Diana Riklis
Talia and Andrew Day	

BOARD OF NATIONAL AMBASSADORS (2018)

Kim Yates, Chair	Michael Lade
Maria Acebal	Lori Stokes
Andrew Gilman	Julie Wilcox

Please note that Board of Directors, Board of Governors and Board of National Ambassadors are correct at the time of printing and subject to change.

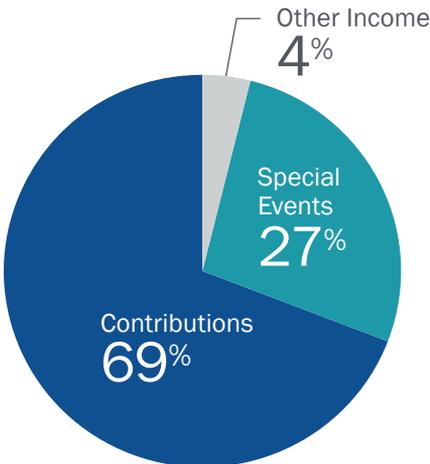
FINANCIAL OVERVIEW

During 2018, FARE began a restructuring program to shift to a greater emphasis on research and to bring total expenses more in line with current and anticipated revenues. Revenues increased 21% in 2018 from the equivalent period in 2017, and the organization reported a profit of \$2.4M compared to a loss for 2017.

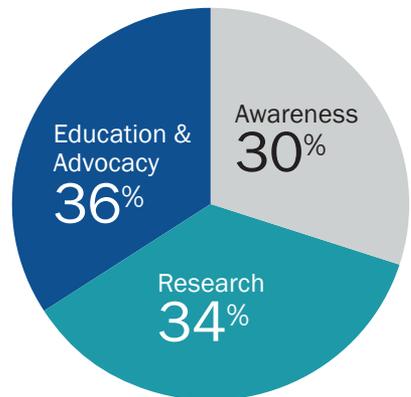
Revenue from contributions were the largest revenue source in 2018 (69%), followed by special event revenue (27%). Expenses were split between Education and Advocacy (36%), Research (34%) and Awareness (30%). FARE expects to continue a transformative shift in spending in absolute and relative terms to research, while continuing to support education, awareness, and advocacy in 2019.

A key strategic asset going forward is the \$37.5M of Investment assets in the FARE Endowment which will be used as an investment tool for innovative research over the next several years to address new therapies and diagnostics for the food allergy community.

REVENUE AND SUPPORT



PROGRAM SERVICES



FINANCIAL OVERVIEW (CONT.)

2018 Audited Financial Statements

ASSETS

Cash and Cash Equivalents	\$10,406,269
Investments	37,497,777
Accounts Receivable	112,788
Pledges Receivable	7,005,259
Prepaid Expense	204,402
Property and Equipment	385,256
Deposits and Other Assets	72,537

TOTAL ASSETS **55,684,188**

LIABILITIES AND NET ASSETS

Accounts Payable and Accrued Expenses	\$537,406
Grants Payable	2,749,355
Deferred Rent and Lease Incentive	457,237

TOTAL LIABILITIES **3,743,998**

Net Assets (without donor restrictions)	40,799,051
Net Assets (with donor restrictions)	11,141,139

TOTAL NET ASSETS **51,940,190**

TOTAL LIABILITIES AND NET ASSETS **55,684,188**

REVENUE AND SUPPORT

Contributions	\$10,764,108
Special Events	4,225,782
Other Income	388,260
Federal Grants	98,837
Interest Income	39,080
Product Sales	34,966
Educational Conferences	10,000
Advertising Income	9,350

TOTAL REVENUE AND SUPPORT **15,570,383**

EXPENSE

Program Services	\$8,204,441
Supporting Services	4,999,180

TOTAL REVENUE AND SUPPORT **15,570,383**

NET INVESTMENT LOSS **471,760**

CHANGE IN NET ASSETS **1,895,002**

JOIN US AND REALIZE A
FUTURE WHERE WE **REVERSE**
THE RISE OF THIS DISEASE, AND
ULTIMATELY FIND A CURE



We want to continue to impact communities across the country and believe our Contains: Courage™ Campaign will help shift the narrative to a more inclusive, proactive story – one that unites families living with food allergies with their neighbors who are not. Your partnership and support of FARE provides a platform for our kids to share their stories in a courageous, liberated and empowered way.

www.foodallergy.org



FARE

Food Allergy Research & Education