

FAIRFIELD COUNTY

LOOK

Take Action with Hillary Carter

March 2022



Educating Families with Food Allergies

Hillary Carter is a powerhouse of knowledge and advocacy for the world of food allergies. Southern girl at heart, Hillary grew up in Atlanta, Georgia, and made her way to New York City, where she worked at MTV Networks, three prestigious public relations firms, and earned her master's degree in Strategic Communications from Columbia University. Hillary and her husband Ben moved to Riverside 10 years ago to raise their sons, Owen and Grayson, who are now 11 and 9 years old. Both boys were diagnosed early with multiple, life-threatening food allergies, a disease that affects 32 million Americans. Over the last nine years, Hillary has worked closely with Food Allergy Research & Education (FARE), utilizing her experience having worked at the top of the field in public relations and corporate communications to advocate for families with food allergies.

How has your role with FARE evolved?

FARE has been an integral part of our lives since both my boys were diagnosed with multiple, potentially life-threatening food allergies nine years ago. I jumped headfirst into food allergy advocacy to educate and empower my family, and then ultimately, to educate and empower others. It is my way of fighting back and showing my boys that adversity is what makes you stronger in life! I am so grateful for the work FARE does for the food allergy community and for the opportunities I've had to work with this special organization.

I started my relationship with FARE as a co-chair for their fundraising walks in Westchester and Connecticut, then moved on to co-chairing Luncheons here in Greenwich. Collectively, I have helped raise over \$1M for FARE as co-chair of six events over the last eight years. I loved working with Julie Karish, Jennifer Miller, Katie Rogers, Sophie Dowling, Jenny Andjelkovic, and Jocelyn Walls on these events. There is nothing women can't do when we join forces!

Based on my fundraising work and related media outreach efforts on behalf of the organization, FARE invited me to join the Board of Governors in 2018. I am honored to still be an active member of the Board today.

In 2019, FARE created a new digital platform, the *Living Teal Channel* on YouTube. They kicked off the channel with a series called *My Food Allergy Story* and asked me to share [our journey](#). As difficult as it was to re-live all the trauma we have been through with food allergies – fear, isolation, terrifying anaphylactic reactions, and so on – I felt it was important to let other families know they were not alone in this fight.

Tell us about *Take Action* and how you came up with the idea for it. Who are your guests? What are some of the topics you discuss with them?

Due to the success of *My Food Allergy Story*, Jonathan Cane, FARE's brilliant Creative Director, called and asked if I'd like to work together on additional content. My answer was an enthusiastic "YES!" and I immediately knew what I wanted to do.



I pitched an idea of highlighting other advocates in our community. I had shared my own story, and I wanted to shine the light on others who were working hard on shared goals of making the world a

safer place for those with food allergies. My undergraduate degree is in Broadcast Journalism, and I was excited to put my reporter hat back on.

Jonathan loved the idea and immediately thought of the show title, [Take Action! with Hillary Carter](#). Thanks to technology and an incredible team at FARE, we have produced three seasons (20 episodes!) of *Take Action!* over the last year and a half, despite the COVID pandemic. I'm deeply humbled that the show has gained over 73.5 thousand impressions, and I'm grateful to provide educational and inspirational content via this platform.

I have interviewed top executives, physicians, researchers, and advocates in the food allergy space. We discuss how food allergy impacts them directly and how managing this chronic disease caused them to pivot in their professional lives. We focus on the latest food allergy information – research updates, treatment options, or new safe food brands. AND we always provide tips for how those watching can "Take Action!" in their own special ways. I love to highlight that ALL experience in your life and be useful in your next chapter (as it was in mine!). No matter who you are, how old you are, or what you do professionally, you can make a difference in the world!

You mentioned Latitude Food Allergy Care. Please tell us about what they do and how you are involved with their team on the Board of Directors.

Latitude Food Allergy Care has literally [saved our lives](#). But first, let me back up...



In spite of how hard I work to keep my boys safe from their food allergies, the truth about living with food allergies is that accidents can and do happen. In early December 2020, my youngest son had a severe anaphylactic reaction to a food that should have been safe. You can find the long story on my [blog](#), but the bottom line is that we were able to find out through testing the package that my son

reacted to GLUTEN (he is allergic to wheat). In a certified Gluten FREE product. This was the absolute last straw for my family.

The world works in mysterious ways, and I had just been introduced to Debbie Taback, co-founder of [Latitude Food Allergy Care](#). We had spoken on the phone at length about our similar journeys, and I later interviewed her for [Take Action!](#). A few months after Grayson's reaction, we reconnected, and she offered to coordinate a call with Kim Yates, the CEO and co-founder of Latitude Food Allergy Care. Kim is a superstar in the food allergy world and is the co-chair of the FARE Board of National Ambassadors.

We scheduled a 30-minute call and spoke for almost two hours. That one phone call changed my life. Kim told me that Latitude could actually TREAT both of my boys' food allergies.

Latitude is located in the Bay Area in California, and our family was on a flight within a few weeks. During that first week of appointments in June 2021, the boys were able to pass several [oral food challenges](#) (where you eat the food to see if you are really allergic to it – the current “gold standard” for food allergy testing). We were incredibly grateful to cross off a few more allergens and then determine their “true” list of allergens. Based on this, we decided on a plan to treat the boys with Oral Immunotherapy (OIT).

Latitude Food Allergy Care is completely different from any other food allergy treatment center or allergist's office. It was created BY food allergy families FOR food allergy families. They focus solely on food allergy, with their evidence-based treatment protocols researched and developed at Stanford, UCSF, Baylor, and Duke. It is the only food allergy treatment center I know of that combines empathetic, transparent patient care with multi-allergen treatment expertise.

This January, due to the success my boys are already having with their program, my strong respect for the team, and my hope that this organization can grow to help more families like mine, I joined the Board of Directors at Latitude. I am excited to contribute my public relations and food allergy advocacy experience to help Latitude gain more awareness over the coming months as they plan to expand to New York City.

Please explain about the OIT your boys are receiving. It looks like an amazingly comprehensive program. Can your boys do the treatment remotely?

[Oral Immunotherapy](#) (OIT) refers to the medically supervised therapy of feeding an allergic individual an increasing amount of a food allergen with the goal of increasing the threshold that triggers a reaction. OIT can protect against accidental exposures to food allergens and improve quality of life. Research has proven OIT to not only be safe but also approximately 85% effective when performed under the care of a clinician who specializes in food allergy treatment.

In the six months since we started, Owen has already reached “maintenance” for peanut and cashew. This means that he eats enough of the protein (1 nut each a day) to protect him from a severe reaction should he accidentally consume these allergens. Grayson is consuming five allergens and is about halfway through his program. ALL of us feel less fear, less anxiety, more confidence, and more joy.

Latitude's protocol for OIT is to “updose” every two weeks – which means you increase the amount of allergen you consume. This is always completed in a supervised setting, similar to an oral food challenge. Since Latitude is located in northern California, flying across the country every two weeks would be nearly impossible.



We are profoundly grateful to our home allergist, [Dr. Gary Soffer](#) at [Yale University School of Medicine](#), who has partnered with us to make this program a reality. He has a clinic in Greenwich, and if you are in need of a pediatric allergist, I cannot recommend him highly enough. Not only does he communicate directly with my boys and make them feel comfortable and involved in everything that happens in his office, but he has also helped us cross over a dozen allergens off our list in [oral food challenges](#), which ultimately made it possible for us to even consider OIT. The entire Pediatric Allergy and Immunology Department at the Yale School of Medicine Greenwich clinic is truly remarkable, and we are thrilled to have this access in our own backyard.

Is there a light at the end of the tunnel for your boys? Or will they always have to be cautious about what they eat?

Now, with OIT, my boys are eating measured amounts of their allergens daily. In a nutshell (pun intended), OIT takes the fear of a life-threatening reaction off the table. My boys will still technically be allergic to their allergens, we will still carry epinephrine, and we will still inform those around us of our allergies. But we know that they will be able to tolerate small amounts should they accidentally ingest their allergens. Replacing that fear with the flexibility to do things like actually eat at a restaurant or go to playdates at other people's homes or go to camp is completely life changing.

We are at the safest, most stable, most all-around calm place we've ever been, and I'm so thankful for everyone who has helped us get here.

What can you recommend for families who encounter food allergies in their kids? Is there a quick checklist or steps they need to take? Who should they reach out to?

First and foremost, if you or your child are experiencing symptoms of a severe allergic reaction and have epinephrine prescribed, please use it immediately and call 911. "Epi First and Epi Fast" is the

rule. For more information on what constitutes an anaphylactic reaction, click [here](#).

If you think you or your child might have an allergy to a food, it is important to see and board-certified allergist for proper testing and diagnosis. If you need a local pediatric allergist, I again recommend [Dr. Gary Soffer](#). He is absolutely the best.

If you are interested in learning more about Latitude Food Allergy Care and OIT, please visit their [website](#) for more information and to sign up for their newsletter for updates about their NYC expansion.

My top recommendation for the latest, most factual food allergy information is [FARE's website](#). Check out all of FARE's digital content at the [Living Teal Channel](#).

I've never been more excited for the future for all families managing food allergies. OIT is an incredible treatment option and is completely changing our lives. I'm thrilled that more families like ours will have that option when Latitude Food Allergy Care opens in New York City. There is increasing attention and funding going into new treatment options, as well, and I believe we will have even more options within the coming years.

Community has been a savior to me as I've navigated this food allergy mom life. I'm happy to share that I'll be co-chairing a FARE event later this spring, with opportunities for connection with other local food allergy families, and to meet physicians from Latitude and Yale. If you'd like to hear more or be involved, please reach out to me. You can find me on my [website](#) or on Instagram @hillarytollecarter. I'd love to hear from you. We are all in this together!



Photography by ChiChi Ubina