

The Heart of FAAN

We posed the question, “What Is the Heart of FAAN?” to our members to gain insight into how we can better serve them. We were overwhelmed by the quick and varied responses that shared the challenges that come with managing food allergies and the ways FAAN has been able to support our members’ efforts. The responses also emphasized our community and that we’re all in this together! Read the excerpts below, which are from e-mails and notes we received.

We believe the heart of FAAN is people helping people – educating the public about food allergies that pose a threat to us or our children. Most people wouldn’t intentionally hurt a child. But someone at school might accidentally offer your child a peanut butter and jelly sandwich that could be his or her last. FAAN saves the lives of an unknown number of children each year. How do they do that? By educating our educators. The newsletter is a great tool to help families keep up with what is going on in the world of food allergies, and it also helps them be better prepared when dealing with the public when it comes to dining out or having your child stay over at a friend’s house.

Where would we be without FAAN? I hate to even think about that. Thank you, FAAN, for being our support group – a friend we can always call on. And we would like to say a special thank you and “Job well done!” for your work on ingredient labels.

Sam & Danna

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“What is the heart of FAAN?” In my opinion, as the mother of children with food allergies, the heart of FAAN is information and education. Together, they comprise the most effective tool with which to navigate the many risks posed by a world that contains foods dangerous to individuals with food allergies. It is a tool that remains sharp because FAAN’s efforts to inform and educate are constant. FAAN provides CFAE (Continuing Food Allergy Education) for parents of children with food allergies and the individuals with food allergies themselves. Thank you.

Meg

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FAAN is a wonderful gift to families with food allergies. It has been like a huge extended family to us. Knowing they are there to support, advocate, inform, and nurture us is a wonderful feeling.

On the two occasions we actually were able to meet with FAAN members, we were overwhelmed with emotions. The first was at a Food Allergy Conference. It was an amazing feeling, to be surrounded by people who really understood and could relate to what we go through every day. The second experience was at a FAAN Walk for Food

Allergy in Buffalo, N.Y. That was one of the most meaningful and powerful days of our lives. We were overcome with a joy deep inside knowing that all the hundreds of people were there to show support and understanding. It was truly a day of celebration!

My three-year-old daughter cannot yet understand how wonderful FAAN is, but she sure has reaped the benefits of it! We have met so many wonderful families, and now we know we are not alone. Being a part of FAAN is like having a huge, extended family that will offer unconditional support and kindness. Thank you for all of your dedication and hard work. You are making an enormous contribution to our lives!

Paula and Jay

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For some background, I am the mother of an 11-year-old boy, Aaron, who is allergic to peanut and egg. We lead an active lifestyle and eat out often.

I strongly believe that we are able to be active in our community and sports and at the same time keep Aaron safe solely because of the support and education we received from FAAN, starting when Aaron was a toddler. FAAN filled the huge knowledge void we felt when our son was first diagnosed at 9 months of age in 1996. We were sponges for the basics – what food allergy is, its risks, and how it can be managed.

Then we learned from FAAN about teaching Aaron, even when he was only a toddler, to be responsible for himself and to stop and think before eating anything. We believe that starting at such a young age is the primary reason he is responsible today and why we have been successful at avoiding accidents. We continue to learn from FAAN about lobbying efforts, law changes, medical studies, new medicines, new risks, all the while refreshing ourselves on the basics – read labels, carry the EpiPen®, inform those around Aaron.

From my experience over the years, I continue to see FAAN's most important core value, FAAN's mission, to be education. I see this as including four main audiences:

1. families living with food allergies
2. schools, camps, and other similar organizations
3. the food industry, including restaurants and manufacturing
4. government agencies and lawmakers

In addition to education, I have come to respect and depend on FAAN for their efforts to

- support research for a cure for food allergies
- lead lobbying efforts to improve food labeling and manufacturing disclosures
- gather data for studies on the growing numbers of people living with (and dying from) food allergies

In all these areas, I see FAAN leading the way.

We eat out; buy food at concession stands; go to sporting events, concerts, picnics, theme parks; and more. We carry the action plan and EpiPen® everywhere we go. We have family and friends that help. But through it all, we thank FAAN.

We hope you continue to lead the way!

Sharol

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“What FAAN means to me” changes as my child grows older, but the core values remain constant: reliable education for the novice and old hand; resources for home and school use; and support during the myriad challenges of having a child with life-threatening food allergies.

Almost 12 years ago, when we learned our son was allergic to peanuts, milk, soy, eggs, and some fruits, it was overwhelming. FAAN offered immediate education, recipes, resources to use with the school, and very practical items to address things I hadn’t encountered yet.

For example, we bought stickers to go on containers in the pantry, so visitors or babysitters would know what was safe to feed our child. Wallet-size ingredient listings for milk and egg were helpful in the grocery store.

Food Allergy News has been a much-appreciated source of ideas for food substitutions, dealing with allergies while traveling, how to educate peers and family, and countless other topics. The website saves me a lot of time and hunting around the Internet; it's a central place where I can get information.

Now that our child is entering the teen years, I appreciate the balance FAAN has in their information on all ages, from tips for toddlers to teaching teens to assume more responsibility for their own safety.

Keep up the good work, and thanks for seeking opinions.

Mary

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My 11-year-old daughter Jessica has an allergy to peanut and tree nuts, and we've been members of this organization since she was diagnosed seven years ago. Since then, we've received more of our education and support from FAAN than from any other source. FAAN has been helpful in numerous ways, including helping me advocate when I had

problems with an airline and making us feel like part of a community when we participated in the Fun Run in Pennsylvania this past year. My daughter feels better knowing that there are others like her when she reads the newsletter for kids.

I'm especially grateful to FAAN for their efforts to improve food labeling. I've witnessed over the years how the information on labels has improved, and this has personally helped us to buy safe foods for our daughter. Finally, FAAN's effort to ensure that EMTs can carry epinephrine is important to us, since we've had to use an ambulance to get our daughter to the hospital following a reaction.

Pamela

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One of our daughters is highly allergic to peanuts and all its derivatives. So, when asked what FAAN means to us, we would say that the answer is multifaceted.

FAAN is our network of information; it is our voice in numbers, it is our home in keeping our daughter aware of what is going on. It is our hope that FAAN gets its message out across the country about the severity of food allergies. It is also our hope that we can keep everyone educated so that we can help lessen reactions and accidents. We need all people and businesses to know that this is a serious matter! We need legislation! We are all in this together. If we can be of assistance to FAAN, please let us know.

Thank you, and thank you to Anne and all of her associates at FAAN who speak for us.

Keep up the fantastic work. We continue to count on you.

Andrea

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What is the heart of FAAN?

- I can always call or e-mail, and someone will find the answer or resource to help – as a dietitian for a school system with 43,000 students, this is an *enormous* help.
- Food Allergy Conferences introduce, reintroduce, and reinforce the basics and dispel myths.
- Resources are available to help parents and adults teach children to learn effective self-care.

Anonymous

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I know you asked for an answer to one simple-sounding question, but as a mom of children with potentially fatal food allergies, I do not have a simple answer for you. First and foremost, for me FAAN means that, as a parent, I am not alone in caring for children

with food allergies and that my two boys (ages 2 1/2 and 8 months) are not alone in a life of restrictions without dairy, any type of nuts, and egg. It also means that I have a source of information to turn to for issues impacting us now – such as feeding my children on a day-to-day basis, reading food labels, and learning new recipes – and issues impacting us in the future, such as the recent article on bullying. I also enjoy reading in the Legislation and Advocacy Updates about new laws being passed and worked on that impact people with food allergies.

I truly love being a member of FAAN. It gives me a constant resource, and I am very much looking forward to attending my first Food Allergy Conference this spring to learn as much as I can to help my boys.

Keep up the great work of researching for a cure, advancing necessary legislation, and supporting families also in our situation with knowledge and compassion.

Rebecca

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You have asked what FAAN means to me. One thing, really: The hope for a cure or therapy that will be available for my daughter by the time she's in her teens. She's six now and doesn't trust food from anyone but her family, but I know that will change during her teen years.

We now have a better understanding of why teens make poor choices through a deeper understanding of brain development. What this means to me is that no matter how responsible I try to make my daughter, the likelihood of a poor decision on her part is going to go way up during those years. I want to know that there are people with the necessary knowledge and commitment who are advocating for her and others like her.

Cassi

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As a grandmother of 9-year-old twins with food allergies, I can't begin to tell you how much your newsletter means to our family. Until the twins were diagnosed with their allergies to milk and eggs, we had no idea what a problem food allergies could be when raising a child in today's world.

We live in a small town, so we are the only family that has children with food allergies in our school system. Before the twins started school, we could stay right on top of everything that they ate, but now that they have started school and have a social life away from our family, it's getting more difficult with each passing year.

We look forward to your newsletter and read it through several times over, because it is so important to us, knowing there is someone else who understand our concerns about our grandsons' food allergies.

Thank you from the bottom of my heart.

Kathy

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I appreciate your efforts, and also the opportunity to let you know what FAAN means to me.

I learned of my son's food allergies over 11 years ago on the weekend of his first birthday. It was a time of sadness, confusion, fear, and frustration. These feelings grew into a feeling of loneliness when we realized that virtually nobody knew anything about what we were going through. We had very little information at our fingertips, and no one really understood what we were going through emotionally.

We struggled with how to cope with this diagnosis, from the practical concern of what to feed this child to how to prevent, recognize, and treat an emergency.

A year later, I learned of FAAN. What a relief to know that there are people out there who truly understand and can actually offer help!

FAAN's most valuable contributions to my experience with food allergies as a mom have been (in varying order at different phases of our experience):

1. emotional support
2. practical solutions, such as recipes, products for carrying self-injectable epinephrine, forms for emergency school plans, educational literature, and programs for schools, relatives, friends, baseball coaches, and so forth
3. advocacy that FAAN provides through many avenues
4. a personal approach

Please continue all efforts to enact legislation that mandates emergency plans for kids at school, allows students to carry their EpiPens® at school, empowers first responders in every state to administer epinephrine, and ensures accurate food labeling. Please also continue fundraising for research to find a cure and interim treatments.

It is greatly underestimated how difficult food allergies are to manage on a daily basis. What adds to the difficulty of managing food allergies is that most of the time, people with food allergies have no other outward disabilities; they look like they can do, and they often do, most normal things other people do. That actually adds to the lack of understanding by other people.

That makes FAAN *so* valuable, *so* unique, *so* loved. Please continue to do all the positive things that FAAN has been doing to help families cope with food allergies and to make the future brighter for them, as well. Thank you, thank you, thank you!

Tracy

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When my now 12-year-old son was diagnosed with life-threatening food allergies at the age of 8, you were our first resource. The allergist just told us not to feed him nuts. He told us about ingredients and cross-contamination, prescribed epinephrine, and sent us home. We were confused and frightened. It was through FAAN that we learned that he could have a normal life and eat tasty food. It was through FAAN that we learned that he was by no means alone. When we joined FAAN, we joined a community of people in similar situations who helped each other. We found strength, and we found hope. That is the heart of FAAN.

The educational materials that FAAN produces have helped us to understand food allergies and to educate the adults who interact with my son. Ultimately, they have helped him to understand and control his exposure to food allergens. Currently we are preparing to send him to a week-long school camp. We hope it goes well.

In the future, I would like to see FAAN continue to support families with food allergies through both education and research. I have a dream that some day there will be a cure for food allergies. In the meantime, let us continue to do what we can to make the world safer for those with food allergies. Until there's a cure ... there's FAAN.

Michelle

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FAAN has been a source of valuable information and reinforcement about the impact food allergies have on the lives of those who live with allergy, as well as their families and their friends.

The heart of FAAN is made up of support and education. One cannot be separated from the other. Thanks for the newsletter; it reinforces what I know every time I read it.

Elizabeth

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My son is 6, and he is allergic to nuts, peanuts, and eggs. The severe reaction he had that brought this to our attention happened five years ago, when a babysitter gave him a bite

of her peanut butter sandwich. His face swelled to twice its normal size, and his hand where he touched the sandwich also swelled up.

We deal with the allergy pretty well; we hardly ever eat out, and when we do, we eat only at places I am fully confident about. I have some good friends who I can trust to feed him; for everyone else, I pack foods for him to eat on play dates. This year he has an understanding school; there is epinephrine in his classroom and in the office, and we carry it everywhere.

But though I don't worry about him on a daily basis, when I read your question about what FAAN does for me, I started to tear up.

Even though all I actively do with FAAN is read the newsletters, I know from them that I am not alone and that many other people are struggling with food allergy. The newsletters give me the latest results in research, providing me with hope and reminding me of my need to be vigilant.

I am incredibly impressed with FAAN's work and am truly grateful.

Jane

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What does FAAN mean to me, and what are the core values FAAN needs to nurture? I really appreciate being asked those questions.

My son was 16 months old when he was sent to an allergist for food allergy testing. Prior to the testing, we had made several 911 calls and lived through some very scary moments with him. When the tests came back positive for dairy, egg, peanut, and tree nut allergies, I was totally overwhelmed. I was a first-time mother, and my confidence was still in the shaky stages. Feeding your child was supposed to be one of the simpler tasks in parenting. But now I had to ask myself, how would I prepare meals for him? What if I made a mistake? The consequences could cost him his life! And he had not only food allergies but asthma as well, which meant that a food reaction for him was more likely to be fatal.

Our son's allergist handed me a pamphlet about FAAN and recommended them as a good resource in dealing with all of this. Thank God I followed through. I was desperate for help, and I found it in FAAN! They were a gold mine of information. I bought small cards from them to carry in my wallet that helped me read food labels at the grocery store. I had no idea what a complex task that could be! I bought a cookbook that gave me not only recipes but also ideas for substituting the ingredients my son was allergic to.

Then there's the newsletter. FAAN published an article that told me what to do when it was time for my son to go to school. I learned about filing an action plan with the school. They also provided a video to my son's school that explained food allergies. I made sure

his teachers each year had an opportunity to view it. I also learned through the newsletter that some fast food restaurants provide an ingredient listing for their foods on their website. That was huge for my son. We could now go out to eat once in a while, just like his friends did. I could go on, but I think you're getting the idea.

What FAAN has meant to me – Wow! They have given me the tools to empower me for living with food allergies. I had no idea how much food is entangled with socializing in our society until my son was diagnosed. FAAN helps us teach our child how to live in this world where food is a part of almost every activity. One of the things I hope will always continue at FAAN is the great newsletter with articles on research, laws, consumer alerts, recipes, and all the other wonderful bits of information they regularly pass on. I read it cover to cover when it arrives. I even appreciate the reports of deaths, which cause me great distress for days. I feel so deeply for the family and friends. But it's also a potent reminder to me that I can't let down my vigilance in caring for my son in every circumstance he takes part in. I also hope great products continue to be available to help in educating others our child is in contact with and make our lives easier and safer.

To me, the heart of FAAN is a lifeline to families regarding how not to just survive with food allergies, but to thrive in spite of them!

Joan