

# kids with food allergies support net<sup>®</sup>

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news, views and supportive information for families raising children with food allergies

Fall 2007

## a boy with incredible spirit



### Despite challenges Ian still keeps upbeat attitude

By Tanya Bumgardner

We all know how difficult managing food allergies can be, but imagine surviving cancer as well. Five-year-old Ian Black has done just that, but it doesn't stop this incredible boy from enjoying life to the fullest.



Ian  
Age 5

Ian was diagnosed with a Wilms' Tumor, a rare childhood cancer, in July 2005 when he was just three and a half years old.

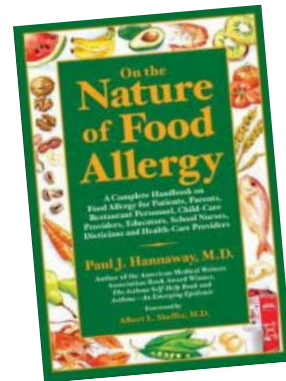
He underwent surgery to have the tumor and his left kidney removed. After months of treatment and clear CT scans, Ian's situation improved. He has now been treatment-free for 18 months.

In spite of Ian's challenges, he's still upbeat, says his mom, Carrie. Ian is "happy, silly, fun to be around. He is a very loving child," she says. He loves kindergarten, trains, cars, and climbing anything that can be climbed. But he especially loves making music.

See Ian: P. 4

## MANAGING FOOD ALLERGIES @ SCHOOL

*As food allergies become more and more common – now affecting three million U.S. children – parents, caregivers and school personnel are among those impacted most. Transferring from the safe confines of one's home to a daycare or school setting can be a difficult and bewildering experience for the food-allergic student and his or her family.*



*As part of our ongoing efforts to provide members with helpful information for preparing for back-to-school, Kids With Food Allergies is pleased to share an excerpt from the just-released food-allergy handbook, "On the Nature of Food Allergy," courtesy of author and allergy specialist Paul J. Hannaway, M.D. For tips on choosing the right daycare or preschool, also see the article on page 5.*



### Food Reactions at School

In 2000, a joint study from the Jaffe Food Allergy Institute in New York City and the Food Allergy and Anaphylaxis Network (FAAN) described the clinical features of allergic reactions to peanuts and tree nuts in school and day-care settings. Of the 124 reactions reported in the study, ninety percent required treatment. Antihistamines were given in 84% of the incidents and epinephrine was administered in 28%. A school nurse was available for only 23% of the

reactions. Cooked or baked products served at birthday or holiday celebrations triggered many reactions. Other sources of accidental exposure included arts, crafts, and science projects and poorly supervised field trips and bus rides.

Most schools in this survey were not prepared to deal with the reactions. Only one in every three students had a food allergy action plan or treatment plan in place. Treatment delays were a result of delayed recognition of a reaction, attempting to call parents

See School: P. 3

# inside:



*Finding the right daycare or preschool for your food allergic child. P. 5*

## >>> OUR MISSION

The mission of Kids With Food Allergies is to foster optimal health, nutrition and well-being of children with food allergies by providing education and a caring support community for their families and caregivers.

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## President's Message



**Lynda Mitchell**

*President*

**Kids With  
Food Allergies**



When I say I understand a parent's anxiety about sending a child with food allergies off to school, I really mean it! I was very anxious when I was preparing to send my milk-allergic son to half-day kindergarten. Just two months prior, he had suffered a severe anaphylactic reaction while hospitalized following stomach surgery. He had been accidentally served a beverage fortified with whey, a milk protein; he took one sip thinking it was orange juice. One sip! After receiving epinephrine and some other treatments he recovered by the end of the day.

With that frightening experience fresh in my mind, I knew what a minefield a kindergarten classroom could be. I contacted the school prior to September and worked very closely with the school nurse to get the school prepared to manage his food allergies. Thankfully, kindergarten went without incident.

I continued to work with the school nurse on refining his plan for first grade; everything was in place on the first day of school that following year. During the second week of school, he went into anaphylaxis on the school playground following lunch. The school nurse followed his emergency plan and gave him his EpiPen and called 911. It saved his life.

While each child's food allergy situation is different, one thing remains the same — careful planning can help ensure a safe, enjoyable school year, and possibly even save a life.



*Lynda Mitchell*

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Donations help us expand our online support programs and educational materials for families and caregivers, and strengthen our mission of food allergy advocacy and outreach. Kids With Food Allergies is a tax-exempt charity, so your gift is fully tax deductible to the extent of the law.

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# MANAGING FOOD ALLERGIES

## KEEPING KIDS SAFE AT SCHOOL

### **SCHOOL:** *Continued from front*

first, not following emergency plans, and in one case, an inability to administer auto-injectable epinephrine. The study concluded that peanut and tree nut reactions were common in school and day-care settings and that school personnel needed more education on how to recognize and treat allergic reactions.

### **Managing Life Threatening Food Allergies in Schools**

At this time, there are no federal food allergy management guidelines for schools. The amount of awareness in schools and school districts about keeping food allergic children safe at school varies greatly. Some schools may offer resistance to putting protocols and policies in place to keep the allergic child safe. In these situations, sometimes the allergist can intervene to meet or speak with the school to address the need for putting programs in place to ensure the safety of food allergic children in school.

Some states and school districts have taken matters into their own hands and have published proactive guidelines for managing life-threatening reactions at school which can be used as models for developing similar guidelines in other school districts or schools. These guidelines outline the roles and responsibilities of specific individuals – from the school administrator to the school custodian and bus drivers – in a detailed checklist format. Also included are templates for composing letters to classmates, families and parents, detailing how to respond to a student with life-threatening food allergies, and much more.

*Examples are:*

**Managing Life Threatening Food Allergies in Schools** by the Massachusetts Department of Education.

**Guidelines and Practices: Managing Food Allergies in Elementary School Children** by the Ann Arbor, Michigan Public Schools.

### **The Role of Parents or Guardians**

Prevention starts at home. The parent's first job is to develop an Individualized Health Care Plan (IHCP) that should include reports from primary health-care providers or allergy specialists that details the student's allergy and medication program. The best plan is the **Food Allergy Action Plan (FAAP)** developed by FAAN that describes the signs, symptoms and appropriate treatments for allergic reactions. The FAAP provides informed consent and contact numbers for parents, guardians and health care providers. Responsible parents should review the IHCP and FAAP with the

school nurse and classroom teacher each year prior to the opening of school.

Parents must provide schools with a minimum of two up-to-date EpiPens® or Twinject® devices and be sure that these devices are stored in an unlocked cabinet and accessible to all school personnel during and after school hours. Parents should provide safe snacks for classroom parties and whenever possible, accompany food-allergic children on field trips.

### **PARENTS MUST TEACH CHILDREN:**

- How to recognize the symptoms of an allergic reaction
- How to communicate clearly as soon as possible when a reaction begins
- How to read labels
- To avoid food-sharing at lunch time
- To stress the importance of handwashing before and after eating
- To report teasing, bullying and threats to an adult authority
- To not share their auto-injector devices with other student
- How to say “no thank you” when offered food not from home

### **How to Handle an Acute Allergic Reaction**

Once an emergency situation arises in a school, the first responding staff member must assess the situation. The signs and symptoms of an allergic reaction can range from mild to a severe life-threatening emergency. A delay in initiating treatment is the major reason for a near fatal or fatal reaction. In many cases, the early signs are deceiving, as warning signs like hives are not apparent. The first sign or symptom may be a “funny feeling in the mouth” or abdominal discomfort.

The biggest decision for the first responder will be whether or not to administer injectable epinephrine. In my opinion, all too often there is hesitancy and a delay in administering epinephrine. When in doubt about whether to give epinephrine, better to give it immediately and then seek additional medical attention as most fatal reactions occur when epinephrine is delayed. Remember, there are no medical contraindications to giving epinephrine in a life-threatening emergency. In my opinion, anyone who requires epinephrine in the school setting should be transported to an emergency room for additional evaluation and treatment. Remember a significant number

**See School: P. 4**

# Ian's family turns food allergies into positive experiences

**IAN:** *Continued from front*

According to Carrie, he can turn nearly anything into an instrument. "He is quite the musician. If it can be played, he will play it! Kindermusik is great for this." He gets a lot of his influence from his bass-playing dad. However, Ian's biggest love is the drums.

When it comes to his allergies to dairy and peanuts, Ian takes it all in stride. And dealing with allergies has been a learning experience for the Black family. Carrie found that learning to cook safe meals for Ian that the whole family could enjoy has been the most difficult part of living with food allergies. But on the positive side, she states, "I am more apt to experiment with my cooking now." Ian also gets involved by helping his mom make safe chocolate chip cookies.

Aside from providing her with cooking advice, Kids With Food Allergies has also helped Carrie



Ian with siblings Tessa and William.

explain Ian's allergies to others. She feels that people usually don't take allergies seriously. She says they are treated as if "it's something you can just take an antihistamine for and be fine. I am now armed with research that I can use to get others to understand how serious a food allergy can be."

While the Black family has had much to cope with managing both cancer and food allergies,

Ian's attitude has been contagious. The family's motto is, "You can do this. It will take some time for you to learn how, but with patience, you will succeed!"

*Tanya Bumgardner is a freelance writer from Cleveland, Tenn. She joined KFA in 2002 to help her manage her son's allergies to eggs and peanuts. She is a member of KFA's Publications Team and is also anaphylactic to kiwi.*

“He is quite the musician. If it can be played, he will play it! Kindermusik is great for this.”

— **Carrie Black**  
Ian's mom

## **SCHOOL:** *Continued from P. 3*

of patients who experience an anaphylactic reaction may develop a delayed, biphasic reaction.

### **Final Words**

The key to the safety and well-being of food allergic children in schools is developing a collaborative partnership among the school, families, and medical personnel to provide a safe and healthy learning environment that enables parents and their children with food allergies to make the transition from the safety of their homes into the expanding world of schools. The parents play a vital role in initiating the process and in making the child's needs known; in providing the school with a IHCP or FAAP, and a supply of epinephrine autoinjectors and/or other needed medication; and in teaching their food allergic children responsible behavior in school. The school plays a vital role in training personnel and setting up systems to keep

food allergic children safe at school, and to promptly respond when a reaction occurs.

### **Reference:**

Sicherer SH, Furlong TJ, DeSimone J, Sampson HA. "The U.S. Peanut and Tree Nut Registry: Characteristics of Reactions in Schools and Day Care," *J Pediatrics* 4(2001): 560 - 565.

*Paul J. Hannaway, M.D., FAAAAI, is a practicing allergist and Associate Clinical Professor at Tufts University School of Medicine. He is an author of the newly released *On the Nature of Food Allergy*, Lighthouse Press: 2007, a complete handbook about food allergy, from which this article is excerpted. Visit Dr. Hannaway's Web site at [www.onthenatureoffoodallergy.com](http://www.onthenatureoffoodallergy.com) for more information.*

For most parents, finding an affordable, reputable center is the main concern when sending a child to preschool or daycare. But safety comes first for parents of children with food allergies, who have to do a lot of planning to make sure the center can safeguard against exposure.

Because food allergies have become more common, some preschools and daycares already have experience working with food allergic children. However, if you find a center that has never dealt with food allergies before, make sure they are willing to work with you and learn what needs to be done to keep your child safe. Following are tips to keep in mind when evaluating potential caregivers for your child.

would they be willing to learn? Are they aware that each child's sensitivity may vary and that what works for one child may not work for yours? Are they willing to consider working with other parents to make sure only safe foods are brought in or possibly becoming, for example, peanut-free for the safety of your child? Think of ways you can make the situation easier, such as sharing training materials on food allergies with school staff, offering to provide safe snacks for your child's class, or signing up as a classroom volunteer to ensure a smooth transition.

As explained in Dr. Hannaway's article, one of the most important things you can do to protect your child is to create a written

plan, the following are examples of important issues to address:

- Making sure there is no food sharing.
- Making sure all children wash hands and faces when they arrive and also after eating.
- Making sure your food allergic child does not sit near children eating allergenic foods.
- Making sure your child is easily observable by a teacher during snack and meal times.
- Making sure arts and craft projects do not include allergenic foods or ingredients.



# Finding the Right Daycare or Preschool for Your Food Allergic Child

Visit the daycare or preschool to evaluate its appropriateness for your child. As you talk to the staff, try to get a sense of their compassion and competence for your child's situation. If they appear reluctant to learn about or manage your child's food allergies, then you'll want to keep looking. Sometimes you may have to pass up the "best" center in terms of academics or convenience if you have doubts that it might not be the safest for your child. Safety is the priority.

During your visit, be sure to ask a lot of questions. Examples include have they had any formal training on food allergies? Are they familiar with injectable epinephrine, like EpiPen® or Twinject®, and if not,

action plan before the child starts attending the school or daycare. The action plan should contain two parts: 1) an emergency plan outlined by your child's physician that details signs of an allergic reaction, and medication, dosages, and treatment that should be used in the event of a reaction; and 2) a plan describing how the staff will manage the environment on a daily basis. Discuss this with your child's teacher, the school director, and other key staff. Also, make sure the center is willing to have all staff trained on recognizing a reaction and administering epinephrine.

When you work with the preschool or daycare to develop an allergy management

Other things to consider include rules about your child using the water fountains (bottled water may be a safer alternative) or accepting classroom treats. For special events that occur, a safe treat box, provided by you, will give your child safe food to enjoy while the other children are having treats. If possible, volunteering or chaperoning for special events, parties or field trips can help ensure your child's safety.

To ensure buy-in and commitment to the child's plan, try to work in partnership with the school to develop a plan that's realistic while ensuring your child's safety. Also,

*See Daycare: P. 6*

## DAYCARE: Continued from P. 5

consider getting your child a Medic Alert® bracelet for easy identification and as a constant reminder to staff about your child's allergies. Finally, you can teach your child to ask the teacher "Is the food safe for me?" and if in doubt to say, "No thank you."

If a daycare or preschool is unwilling to take on the responsibility for your child's medical needs at school, know that the Americans with Disabilities Act (ADA) specifies that children with severe, life-threatening allergies cannot be denied admission to a daycare program because of their allergy, and that a child care center is required by **Title II or Title III of the ADA** to administer medication for an allergic reaction. There is, however, an exception for religious preschools or daycares.

Other helpful information for you and your child's daycare or preschool can be found at **KFA's resources** or the **FAAN Web site**.

If you'd like to compare notes with other parents as you prepare your own child to attend preschool or daycare, be sure to check out the **support forum**.

SOMETIMES  
YOU MAY HAVE  
TO PASS UP THE  
"BEST" CENTER  
IN TERMS OF  
ACADEMICS OR  
CONVENIENCE  
IF YOU HAVE  
DOUBTS THAT  
IT MIGHT  
NOT BE THE  
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## Annika's Fall Colors Pumpkin Bread

### Ingredients

- 1/4 cup cornstarch
- 1/4 cup tapioca starch
- 1/4 cup rice flour
- 1/4 cup oat flour
- 1/2 tsp baking soda
- 1/2 tsp baking powder
- dash of salt
- 1 tsp xanthan gum
- 1/4 cup + 2 Tbsp canola oil
- 1 15 ounce can pumpkin
- 2 tsp vanilla
- 1 Tbsp cinnamon
- 2/3 cup sugar
- 1/2 cup of dried cranberries
- 1 tsp rice flour

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## safe eats

### Instructions

Toss cranberries with rice flour to dust them. Set aside. Mix all remaining ingredients together in a large bowl. Beat for about 1 minute, until mostly smooth. Stir in cranberries. Spray an 8.5"x4.5" loaf pan with non-stick spray. Spoon batter into pan, and smooth top. Bake in preheated 350F oven for 1 hour and 15 minutes. Cool in pan for about 30 minutes before putting on wire rack; cool completely before slicing.

### Substitutions

This recipe will work gluten-free. Simply omit the 1/4 cup oat flour, and use 1/3 cup rice flour, 1/3 cup cornstarch, and 1/3 cup tapioca starch to replace the 1 cup total flour volume.

To make with wheat: Toss cranberries with all-purpose flour. Substitute one cup all-purpose flour for the first four ingredients and omit xanthan gum. Do not beat; instead mix together until there are no lumps.

Use dairy, soy, egg, wheat and/or gluten free ingredients as needed.