Food Allergy. A complex social dilemma!

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IFST Conference

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Food Is Everywhere

- Classroom Snack
- Play Dates
- Birthday Parties
- Holiday Parties
- Field Trips
- School Bus
- Restaurants
- School Science and Art Projects
- Special Events
- Cafeteria Lunch

The Challenge
January, 2008  Everyone's gone nuts: The exaggerated threat of food allergies in Harper’s Magazine

January, 2009  Nut allergies — a Yuppie invention in the Los Angeles Times

February, 2009  The Fear About Peanut Allergies is Nuts on www.salon.com

August, 2009  Nuts to That – The People Profiting From Food Allergies on www.slate.com
Nuts to That
The people profiting from food allergies.

By Meredith Broussard
Posted Monday, Aug. 31, 2009, at 1:44 PM ET

In a recent Wall Street Journal article titled "Save the Children (and Make Money)," fund manager James Altucher suggests investing in an "autoimmune index," a mix of stocks that have "good, lower multiples and that will supply the arms in our ongoing war against autoimmune diseases." I thought the article was a joke—until Altucher recommended buying stock in Novartis AG because its allergy drug Xolair was going into Phase II trials to see whether it could be useful in suppressing peanut allergies.

Altucher is on to something: Anybody who comes up with a new food allergy drug stands to make a boatload of money. The annual cost of allergies is estimated at $7 billion, according to the Asthma and Allergy Foundation of America, and the School Nutrition Association reports that about 35 percent of schools
The fear about peanut allergies is nuts

Parents and medical groups are doing more harm than good stirring up worries about food allergies.

By Rahul Parikh, M.D.

In 2005, a 15-year old Canadian teenager named Christina Desforges kissed her boyfriend and died. Her death, reported around the world, was initially blamed on peanuts. Desforges was allergic to peanuts and her boyfriend had eaten peanut-butter toast hours before her deadly smooth.

Sudden death due to an allergic reaction to food is known as anaphylaxis. When you eat peanuts (or some offending food), you break out in hives, your face swells and your larynx constricts until you can no longer breathe, all in a matter of minutes. Shocking. Tragic. Scary.

Desforges' story is the kind that has moved anxious parents, politicians and school board members to join a crusade against peanuts. Several states have passed laws mandating public schools be "peanut-free zones."
Allergens:
An Epiphany.....
Psycho-Social Aspects

Allergens:

Allergen Bullying

Social Stigma and Challenges
6 year old boy, milk allergic
Asked to drink milk by a classmate
The Child refused.
Classmate shot a straw filled with milk at the boy’s face. Anaphylaxis within 15 minutes

January, 2010 *Peanut Boy is Ruining Our School on*
When a school student smeared peanut butter on the forehead of a fellow student with a serious peanut allergy it was so shocking that the offender faced an assault charge and four days in jail.

“What were you thinking when you did this?” district court Judge Nancy Harmon asked the 19 year old student.

A new study of parents and kids living with allergies suggests that bullying of youngsters allergic to foods of all types is actually a widespread — and a potentially life-threatening worry.
In November 2010 a group of young people and parents gathered at the House of Commons in a meeting arranged by the National Allergy Strategy Group (NASG). The purpose was to discuss “allergy bullying” where someone with an allergy is threatened with the substance they are allergic to.
This anti-social practise is prevalent across the UK and was well illustrated by the young people present: Amie told how her classmates put dairy products on her desk despite knowing she has a Severe allergy.
Charlotte explained how she was afraid to tell anyone after her best friend waved a Chocolate Spread sandwich in her face even though she knows of her serious nut allergy.
James described how he has had to change schools after a group of boys held him down, punched him and threatened to force him to eat nuts. James managed to escape before they could carry out the threats but did report the incident to the police.
The key ask from the young people was that bullying someone by threatening them with an allergen should be an offence which carries an automatic suspension.

The Education Department will to try and ensure schools have the necessary knowledge and support to ensure this type of bullying is not allowed to continue.
Teenagers, questions they ask

What do you say to people at school who think it’s funny to throw peanuts at you?
Try not to panic, quietly get up and leave the room. If it is a good friend being silly, when they have calmed down you can talk to them and explain how serious your allergy is. Maybe show them your medical kit, explaining what everything is for and, with a trainer pen, give them a demonstration. If it is a renowned school bully, report the incident to a teacher. (Ref: Anaphylaxis Campaign)
Background to Research Project

There are reports of children and teens with food allergy being harassed because of their food allergy, yet no study to date has attempted to characterize these occurrences.

Objectives

To determine the presence and characteristics of bullying, teasing, or harassment of food-allergic patients owing to their food allergies.

Methods

Questionnaires were completed by food-allergic teens and adults and by parents of food-allergic children.
Research Results

353 surveys were completed. As most food-allergic individuals were children, most surveys were completed by parents of food-allergic individuals. The ages of the food-allergic individuals were:

- younger than 4 years, (25.9%),
- 4 to 11 years (55.0%),
- 12 to 18 years (12.5%),
- 19 to 25 years (2.6%), and
- older than 25 years (4.0%).

Including all age groups, 24% of respondents reported that the food-allergic individual had been bullied, teased, or harassed because of food allergy.

Of those who were bullied, teased, or harassed, 86% reported multiple episodes.
82% of episodes occurred at school, and 80% were perpetrated mainly by classmates.

21% of those who were bullied, teased, or harassed reported the perpetrators to be teachers or school staff. 79% of those bullied, teased, or harassed attributed this solely to food allergy. 57% described physical events, such as being touched by an allergen and having an allergen thrown or waved at them, several reported intentional contamination of their food with allergen.

Jay A. Lieberman MD, Christopher Weiss PhD, Terence J. Furlong MS, Mati Sicherer MA and Scott H. Sicherer MD

1 Food Allergy & Anaphylaxis Network, Fairfax, Virginia Elliot and Roslyn Jaffe Food Allergy Institute, Division of Allergy and Immunology, Department of Pediatrics, Mount Sinai School of Medicine, New York, New York. Received 6 July 2010;
Cyber Bullies:

Global Social Networking or ...........

....antisocial pain, suffering and hurt or a means for parents to share and learn?

STOP cyberbullying
“Eat this and die”
Nobody wants any harm to come to peanut boy but we wish Peanut Boy’s mom would stop insisting that she get her way, especially when there is a totally safe school in district that he could go to. Why can’t Peanut Boy’s Mom be a bit more reasonable?

“I’ll get a bucket of wheat and tip it over your head”

“I would have invited you to my birthday party but my mom says it’s too complicated with the food”
“I am 23 years old. I was bullied because of my peanut allergy. Often by people who were friends but didn't realise how seriously my allergy was. In school, I told another student I couldn't be near peanuts and he proceeded to put it in my face – I ended up swelling up and breaking out and going to the hospital. I wish parents would teach their kids more about being sensitive to others when they have an allergy.”

FAAN
Teasing, Bullying, and Harassment

One school student showed symptoms of anaphylaxis for 10 days, a teacher determined that the girl was being harassed by two students who were shoving peanuts in her face. School officials called the Police who informed students that such behaviour was considered assault, and would be processed through the juvenile courts. The harassment quickly stopped.

FAAN
“Bullies identify weaknesses in children and adults, food allergies are another angle of attack”

Respond, have fun & get to know friends better.
At a friend's house my daughter was getting drinks. Her friend's sister told my daughter: "Everything in there has peanuts in it. April Fool!"
My daughter took it in stride at the time and then told me about it later. http://nut-freemom.blogspot.com/
• I was teased at school for wearing my medic alert bracelet, because ‘only girls wear bracelets’.
• Called ‘Allergy Boy’ at secondary School, one boy put raw egg on his hands and slapped my face to see the reaction.
• I had peanut butter smeared on my phone.
• At University someone put peanuts all over the furniture so I could not go and watch TV.
• I’m a teacher and had pistachios nut shells put in my desk drawer.
Nut allergy boy, 7, suffers two heart attacks after 'teacher hands him chocolate HAZELNUT in class’

It is thought a substitute teacher at St Matthew's C of E Primary School in Bradford was handing out chocolates because it was a child's birthday and handed Rehan the 'Big Purple One' from a selection box.

1st February 2011
Mail Online

(2 cardiac arrests and one respiratory arrest)
Allergens:

Allergen Bullying

Social Stigma and Challenges
Parent Profile

• Generally a non-medical background
• Has severely allergic child
• Possibly also parent to non-allergy suffering child
• Wide socio-economic demographic
• Broad ethnicity
• Sometimes Member of the Anaphylaxis Campaign or other support Group
An allergic child – age 5

• Happy
• Healthy
• Naughty!
• Normal!!
• Allergic!!!

He is severely allergic to milk and egg. He passed peanut and hazelnut food challenges in early 2010.
The Parental Emotional Rollercoaster:

- **Shock** – personal lack of awareness of food allergy
- **Confusion** – what to buy, what to cook, substitutions
- **Fear** – of a medical emergency
- **Embarrassment** - social awkwardness
- **Sadness** – social exclusion and participation
- **Guilt and resentment** – impact on family/siblings
- **Stress** – travel needs to be very carefully planned
- **Aggravation** – shopping, last minute school events!
Personal relationships

Most difficult, yet least talked about, aspect of allergy:

- Anxious parents – see “threats” everywhere
- Trusting others - “letting go” (toddler groups, nursery)
- Other parents - nervous/uncomfortable initially
- Easy to feel quite “cross” with people for “not getting it”.

“At least he’s not allergic to nuts” (Grandmother to Mother)

“He can stand in the playground at snack time”
(owner/manager of a local nursery)
Why is it a rollercoaster ride?

- Lack of awareness in medical and educational communities
- Lack of accessible and reliable information
- Lack of awareness among some food manufacturers and many in the catering industry
- Lack of awareness among retailers (e.g. poorly communicated food labels when ‘online shopping’)

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Unexpected ingredients reduce packaged food choice

Not all Jammie Dodgers are equal!!
(“Minis” contain milk.)
Social Exclusion vs Inclusion

Exclusion
“home school to minimise the social stigma”

Inclusion
“the school has a care plan, supervision, training / awareness and a policy on self – management, close parental support and the support of all other parents and pupils”
“Within the food industry we need to accept that food allergies are more than a cost and exercise in minimising cross contamination, cleaning, testing and labelling declarations.”

“The underlying, ever-present fear is that one slip is potentially fatal. It truly is like walking a tightrope and [adrenaline auto-injectors] are my safety net.”

“My main concern is shopping and eating out. The “may contain traces of nuts” labels occur on so many foods that I am forced to play “Russian Roulette” or eat an extremely limited range of foods.”

Ref: NASG website
Conclusion:

Food allergens are a social stigma, can be fatal to a few and cause unimaginable grief to parents and sufferers alike. Compared to the parents, patients and sufferers, our job is easy!
What else would help?

- Increased awareness across society, generally. Allergens = CRS
- Improved online grocery website information
- Increased awareness and choice in catering industry (from school dinners to small local and tourist cafes to nice restaurants)
- Reduced use of allergenic food in processed food
- From Board to Production Line Awareness
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