



## Hunger Strikes

### Rare food allergy stymies doctors and challenges families.

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By Mark C. Anderson

#### Young Francesca Sarubbi is hungry, but she can't eat.

She loves chocolate—and there is chocolate in her family's kitchen—but she's can't have any. Just a bite could trigger an assemblage of painful reactions—acid reflux, extreme nausea or debilitating shortness of breath.

Because of a rare allergic condition called eosinophilic gastroenteritis (EG), Sarubbi, a 15-year-old who lives in Pebble Beach, recently went three and a half months without eating. Prevented from swallowing even plain crackers, she sustained herself with juice-box-sized doses of amino acid formula. At times she had to drink up to nine of the less-than-appetizing formula boxes per day.

Doctors remain largely stumped on exactly how EG and other eosinophilic disorders (EGIDs) develop in an individual. Meanwhile, diagnoses multiply across the country.

Sarubbi and her family have been experimenting with very simple foods to see if her body will tolerate them. One by one, a week at a time, she has tried apples, pinto beans, grapes and potatoes. One by one, each set off searing reflux.

"Imagine waking up and having your five most favorite foods be allergic."

Nothing about Sarubbi's struggle is getting any easier—this weekend she was rushed to the ER with intense stomach pain—and even after two years of dealing with her disease, awe still seeps into her voice as she describes what has happened to her.

"I never thought I would miss school. I never thought I could not be physically fit," she says. "If I heard in 7th grade that a kid couldn't eat for three months, I wouldn't have believed it—and I never would've thought I would've done that."

Doctors understand little about EGIDs. They do know it involves eosinophils, a type of white blood cell.

Eosinophils are usually a good thing—they serve a vital role in helping the body fight off infection. But an overabundance of these cells in a place they don't normally belong, like the stomach or throat, creates a problem. Sarubbi's mother Vivian is a nurse who has come to know a lot about eosinophilic disorders in the last few years. "EGIDs are kind of like a hyperactive immune system," she says. "It's the body overreacting."

Almost all EGIDs are triggered by foods. Beth Mays, president of the American Partnership for Eosinophilic Disorders (APFED), quotes EGID guru Dr. Phil Putnam when she calls EGIDs "the mother of all food allergies."

"Imagine waking up tomorrow and having your five most favorite foods be allergic—or 20 or 100," she says.

"No two people are the same."

Dr. Seema Aceves is a pediatric allergist at Rady Children's Hospital San Diego, one of three established treatment centers for eosinophilic disorders in the country. "We really don't know



what causes them," she says. "When it comes to allergy in general, it's an interaction between genetics and the environment; with this, food and aeroallergens drive the disease."

Aceves says that the dearth of information on EGIDs makes her job difficult.

"The hardest part is watching kids that can't eat and are not growing well, and not having the answers for the families," she says. "We are learning more all the time, but right now we just don't know enough."

Cases of EGIDs—and all allergic conditions like asthma (which often accompanies EGIDs), allergic rhinitis, and eczema—are increasing. In San Diego, new cases of EE, an EGID of the esophagus, tripled from 12 to 35 per year from 1998 to 2002; in Philadelphia the new cases increased from 2 in 1994 to 72 in 2003.

"It's been really dramatic how much of an impact it's had," Mays says. "I used to get two or three calls every day. Now I can be on the phone for eight hours."

This month Francesca Sarubbi is experimenting with a diet of rice cereal in rice milk. She and her family had to make certain that the products contained absolutely no gluten, wheat, artificial sweeteners, barley, or soy. The Sarubbis have learned there are all sorts of additives in even the most basic foods—they got this cereal online because they couldn't find it anywhere else. For now, rice is a "safe" food.

So-called elimination diets, while terribly tedious, can be the most successful treatments for EGIDs. And they are far more palatable than the other options, like strict amino acid formula dieting and feeding by inserted tube. Topical steroids are also successful.

Francesca's life has been radically changed since she developed EG in October 2005.

"I miss school," she says. "Physically, I'm not ready to go back. I love being with my friends and go out but I can't. My body can't do it."

But Sarubbi has found a way to temper her isolation.

She and Adam Hansell, a 15-year-old with an EGID who lives in Ann Arbor, Michigan, met on a support group site and began exchanging e-mails and phone calls last year.

Eventually, they made plans to meet face to face; earlier this month, Hansell and his mother flew to California. The visit carried a mission greater than companionship: Hansell and Sarubbi wanted to craft a video together that would help generate more awareness of the disease, and inspire hope for those dealing with it.

"We just want to show younger kids with EGIDs that we grow up to be totally normal-looking, cool kids, with one little impairment," Hansell says. "It's hard, but it shouldn't take over your life."

Expanding awareness of the disease would also make it easier for kids like them to get treatment and would lead to more research into its causes. Currently, just getting an accurate diagnosis is sometimes difficult—it took the Sarubbis a year to discover what was causing Francesca so much distress and pain.

APFED's Mays, Dr. Aceves and Vivian Sarubbi say that is common.

"Everybody's story is misdiagnosis," Vivian says. "We visited 15 doctors. Everybody kept saying 'it might be this.' They see a teen who's a little anxious and even say, 'I think it's in your head.'"

"We want to get the word out there," Francesca says.

"If we had heard of this two years ago, it would've saved a lot of confusion and pain."



There are other complications. Paying for the elemental formula alone is a major expense that in many states, including California, isn't typically covered by insurance companies, leaving families to foot bills that can reach \$2,000 a month. As a result, APFED is currently gathering Congressional sponsors to make National Eosinophilic Awareness Week official.

The event, like APFED itself, will be entirely volunteer-driven by the growing legion of families affected by EGIDs. They share Francesca's desire to make things better for sufferers of the disorder.

"Someone always has it worse," she says. "In 7th grade, I wanted to be fashion designer, but now I think, 'How is that gonna help?' You want to do something that'll help people."