

Time to End Tragedies

Little Amarria was the wakeup call. We have the tool, the auto-injector, to stop the senseless allergy deaths like hers. Now we have to use it.

by SARAH SCOTT

On the first day of school after Christmas, 7-year-old Amarria Johnson and her Grade 1 classmates in Richmond, Virginia bounced outside of Hopkins Road Elementary after lunch to play. You could usually hear Amarria before you saw her: she loved to sing, in church, for the video camera, in the car, at school. She would sing for anyone, and she had big plans to be a star on the Disney Channel. For this first day back to school, Amarria's mother had carefully rolled her daughter's long hair in a bun. The girl was excited to be going back. "She loved everything," her mother Laura Pendleton told *Allergic Living*. "The world was an awesome, innocent place."

Then a child in the playground gave her a peanut. Amarria had always avoided the peanut butter and jam sandwiches that the school offered for lunch every day because she had an allergy to peanuts. But this time, for reasons no one knows, she popped the peanut into her mouth. Amarria knew right away she was in trouble. She asked the teacher outside to help. That was exactly what she was supposed to do. But then the system failed her.

The teacher walked Amarria to the school's health clinic, where an aide searched for an epinephrine auto-injector with Amarria's name on it. An auto-injector shoots epinephrine, also known as adrenaline, into the body. The drug can stop a severe allergic reac-



Laura Pendleton with her daughter Amarria as the girl began school.



school,” acknowledged Shawn Smith, the board’s spokesman. “It’s illegal to give a prescription drug to someone else,” he said. The staff at the county’s public schools are instructed that they are only allowed to use an epinephrine auto-injector if it is specifically prescribed by a doctor for the child in question and if the school has the child’s written action plan for allergy emergencies. “Absent those two,” Smith said, “we’re unable to carry out the doctor’s [verbal] orders.”

It seems unthinkable not to give a child life-saving medicine, and it shouldn’t happen again. Amarria should be the last child to die in North America of anaphylaxis at school. This isn’t some far-out dream that requires a medical breakthrough in the distant future. It can happen right now, with existing technology. People with life-threatening allergies, parents and the staff at school all need to know that these deaths can be prevented. Amarria likely would be alive today if someone had used an epinephrine auto-injector to save her life.

It’s an easy procedure: all you have to do is pull off the safety cap, ram the device’s tip against the outside of the patient’s upper thigh, and hold it there for 10 seconds. The EpiPen and other brands are even designed to go through clothes. Although epinephrine is a drug, it is highly safe to use, according to numerous scientific studies. What is not safe is withholding the epinephrine, or putting off giving the shot. That can be deadly, as it was for Amarria.

With anaphylaxis, we know that the prompt use of epinephrine in the first minutes of an attack is literally a shot of life. So what’s standing in the way? Three things: First, you need to have an auto-injector available. Second, you need to know when to use it. And third, you need to take a breath and just use it when that moment arrives.

It wasn’t only Amarria who didn’t have her own auto-injector at school that day. Canadian researchers surveyed adults with food allergies and parents of allergic children to discover that only about half of them carried an epinephrine auto-injector. Since this condition can rapidly incapacitate a child or an adult, the patient, parents, friends, teachers or colleagues, and even the broader community need to know both what anaphylaxis looks like [see “Signs of a Serious Reaction,” page 39] and what to do. They need to know that the auto-injector is the first line of defence – not an antihistamine, not waiting to see what happens.

Yet people hesitate before using the auto-injector. “One of the big factors is fear, fear of the needle,” said Laurie Harada, executive director of Anaphylaxis Canada. An estimated 10 per cent of the

tion outright or buy enough time for paramedics to arrive. Amarria desperately needed that shot of life; in the minutes after she arrived at the clinic, she was struggling to breathe. But the clinic did not have an auto-injector prescribed for Amarria.

Over the next few minutes, the little girl ran out of breath, right there in the clinic. Just before 2:30 p.m., the school called 911, but by the time firefighters and police arrived, Amarria’s heart was failing. The rescuers tried CPR. They tried to restart her heart with a defibrillator. They rushed her to Chippenham Hospital, but it was too late. Amarria was pronounced dead just after she arrived. The cause of death: anaphylaxis and cardiac arrest.

It is such a senseless, heartbreaking loss of a little girl so full of life. But beyond the tragedy, this disturbing issue has emerged: there were likely auto-injectors prescribed to other students in the Hopkins Road Elementary clinic. (*Allergic Living* has learned this was likely the case, though the school board declines to comment on specifics.) If an auto-injector was there, however, the aide was not allowed to use it. Why?

“Many of our students [in Chesterfield County] have EpiPens at

population admits to a fear of needles. "They're also not sure when to use it," says Harada. "It's a sad thing when you've end up with deaths."

To gain insight into the resistance to using the auto-injector, University of Manitoba professor and anaphylaxis expert Dr. Estelle Simons and Harvard epidemiologist Dr. Carlos Carmago conducted a survey in 2009 of 1,885 people who had suffered anaphylaxis. The symptoms must have been scary, yet only 27 per cent of the people who experienced anaphylaxis used an auto-injector; 73 percent, or almost 1,400 of the patients, did not. Why? Among the reasons given, 38 percent opted for an antihistamine; 28 per cent said they didn't have a doctor's prescription; while 13 percent perceived their episode to be "mild" anaphylaxis. Clearly, many still do not know the facts about this life-saving tool.

People are also wary of taking a drug, and especially giving one to someone else's child. Is this concern well-founded? The leading allergists say the real danger lies in waiting to give the drug, *not* in giving it. "Failure to administer epinephrine early in the course of treatment has been repeatedly implicated in anaphylaxis fatalities," say the new allergy practice guidelines issued by the U.S. National Institute of Allergy and Infectious Diseases. Sure, the report says epinephrine may cause anxiety, fear, restlessness, headache, dizziness, palpitations, pallor or tremor. Rarely, it can lead to heart trouble, but that's not likely unless you overdose, which won't happen if you use an auto-injector.

Now compare those side effects with the risk of waiting: One study looked at 13 fatal and near-fatal cases of anaphylaxis. Of the seven who survived in this group, six had taken epinephrine within 30 minutes of eating the food allergen. The upshot: epinephrine is not foolproof, but it's your best chance of surviving if you are succumbing to anaphylactic shock. "It's a safe medication," says Dr. Scott Sicherer, chief of allergy and immunology in the pediatrics department of New York's Mount Sinai School of Medicine. "Even if you accidentally use it, that's OK."

To prevent more tragedies, people need to get past the fear of needles and drugs and learn how to use the auto-injector. But having an auto-injector at the ready is still a problem in too many places. When Sabrina Shannon began to wheeze after eating some French fries at her school in 2003, her auto-injector was in her locker on the other side of the building. A teacher raced to get it, but Sabrina lost consciousness and went into cardiac arrest before the needle arrived. Her death was ruled anaphylaxis, likely triggered by dairy protein on the tongs that served her food.

Following Sabrina's death, Ontario passed a law named after her. Sabrina's Law, which took effect January 1, 2006, requires schools to make extensive plans to protect students at risk of anaphylaxis. Under the law, everyone who will supervise children (from teachers to coaches and bus drivers) needs to be trained to recognize symptoms and to use the auto-injector. The law has had a deep impact across the country. Manitoba has passed a Sabrina-style law, while several of the provinces have adopted extensive food allergy guidelines.

Under Sabrina's Law, school staff are authorized to use the auto-injector if they have reason to believe the pupil is suffering anaphylaxis. In an Anaphylaxis Canada survey of Ontario principals in 2011, 29 per cent said they are now stocking auto-injectors

Kids and Food Allergies

1 in 13

children under the age of 18 has a food allergy¹.

Food allergies

are the most common trigger for anaphylaxis in this age group².

Up to 18%

of children with food allergies have reactions at school². (Most aren't anaphylaxis.)

25%

of kids who have serious allergic reactions were not previously diagnosed².

9,500 children were admitted to U.S. hospitals for food-allergic reactions between 2004 and 2006, over three times the number admitted between 1998 and 2000³.

Sources

1. *Pediatrics*, "The Prevalence, Severity, and Distribution of Childhood Food Allergy in the United States," June 2011.
2. *Pediatrics*, "Clinical Report: Management of Food Allergy in the School Setting," Dec, 2010.
3. CDC/NCHS, "National Health Interview Survey," Oct, 2008.

in schools. This could save many lives since studies show one-quarter of students experience their first severe allergic reaction at school. This level of readiness needs to spread – across the continent. Having an auto-injector available for any student having a reaction could have saved Amarria's life; she didn't have an auto-injector at school.

Her case shows the importance of crystal clear communication between the school and a parent on serious allergies. Amarria's mother says that when her daughter began Grade 1 at Hopkins Road Elementary, she took an auto-injector, along with Amarria's action plan for asthma and allergies to the school clinic. Laura says she remembers that the woman in the clinic said: "We have everything we need for Amarria. You can take it (the EpiPen) home just in case you need it." So Laura trusted the school employee; she sent her daughter to school without her auto-injector. (The spokesman for the school declined to comment on Laura's account.)

Laura was at her job as a practical nurse at a senior citizens' home when the call came at just before 2:30 p.m. on January 2. "Amarria had a peanut and her tongue is swelling," someone in the school clinic said to her. The next thing Laura says she heard was this: "Can someone come and get her?" "I said call 911!" Laura raced to the hospital, but her daughter was dead by the time she got there. The rest is a blur. A few days later, a group of supporters gathered in front of Amarria's home to hold an evening vigil. "It's a hurting thing," Amarria's grandfather, Leroy Green, told reporters. "We need to educate our schools. We need to educate our parents. This could happen again."

We need to teach the teachers. Look at what happened in Quebec, the biggest province in Canada without a province-wide law or policy to protect children from severe allergic reactions. One evening in September 2010, 6-year-old Megann Ayotte Lefort started crying at a school daycare shortly after having eaten a store-bought sandwich. Her parents were down the hall at a meet-the-teacher session. Megann's asthma and food allergies were



Megann Ayotte Lefort, with her father, Sylvain Lefort.

known, but the teachers in charge waited 20 minutes before giving her two puffs from her reliever inhaler for her breathing symptoms. When the girl was still having trouble after 40 minutes of symptoms, one of the teachers ran to tell her parents. By the time 911 was called and the ambulance arrived, it was too late. Megann died of asthma and anaphylaxis.

A group of advocates called the Coalition for Megann's Law and supporters across Canada are urging the Quebec government to pass legislation [see pages 41 and 25] that would instruct the teachers and staff precisely what to do in an emergency with a child like Megann. "We need people who are knowledgeable on when and how to use the auto-injector," says Maria Acebal, CEO of the Food Allergy & Anaphylaxis Network (FAAN), which is leading the lobby for a U.S. bill that encourages all states to require their schools to stock non-prescribed auto-injectors. (States that comply would get preferred access to a federal grant fund.)

Teachers, like many others, still struggle with the fear of needles and drugs – even though medical authorities say the auto-inject-

Signs of a Serious Reaction

New guidelines from the National Institute of Allergy and Infectious Diseases (NIAID) state that anaphylaxis includes a range of symptoms "that can occur in many combinations. Some symptoms are not life-threatening, but the most severe restrict breathing and blood circulation." The guidelines note the areas of the body that can be involved:

Skin – itching, hives, redness, swelling

Nose – sneezing, stuffy nose, runny nose

Mouth – itching, swelling of lips or tongue

Throat – itching, tightness, difficulty swallowing, hoarseness

Chest – shortness of breath, cough, wheeze, chest pain, tightness

Heart – weak pulse, passing out, shock

Gastrointestinal tract – vomiting, diarrhea, cramps

Nervous system – dizziness or fainting

ed epinephrine is safe. "Unless the school gives them the information they need," says Acebal, "it's a very scary situation for them." Sicherer thinks it shouldn't be hard to instruct the teachers on how to recognize severe allergic reaction and treat it with a simple injection: "If a parent can learn it, any adult can learn it, and adults in charge of our children should learn it."

We also have to teach and re-teach the families. One U.S. study in 2000 of 101 families with kids with food allergies showed that only about half of them owned non-expired auto-injectors. It also revealed that only 32 per cent of the parents knew how to handle the device properly. "If people are properly educated, and vigilant, they'll avoid these tragedies in most cases," says Marilyn Allen, an Ontario food allergy consultant who lost her daughter Robyn to anaphylaxis in 1990. A big challenge is to convince adults to carry their own auto-injectors. Harada calls it a key safety issue, just like wearing a bike helmet. Parents put the helmet on their kids, and then they climb on the bike without their own helmets. "That's when accidents happen," she says.

The campaign to make epinephrine more widely available and to stop the tragedies has naturally begun in the schools. But why stop there? We can prevent even more needless deaths and traumatic hospital stays if we start viewing the epinephrine auto-injector like any other rescue device. The automated external defibrillator, or AED, delivers a jolt that can save a person from sudden cardiac arrest. AEDs are all over the place – in government and corporate offices, shopping centres, airports, casinos, sports stadiums and movie theatres.

Given that food allergies today affect about two million Canadians and 12 million Americans, why not put epinephrine auto-injectors right beside them? You can already find backup auto-injectors at many private camps in Ontario, and the airline WestJet has decided to stock them in case of emergency at 35,000 feet.

So will we see auto-injectors alongside the AEDs? Some practical issues need to be resolved first: Where would they be kept? How will an organization make sure they're replaced every year to be certain the medicine is up to date and effective? Who will be authorized to use them, and how will those individuals be trained to spot the symptoms and use the auto-injector effectively? These are hurdles, to be sure. "But I think it will happen," says Chris Weiss, FAAN's vice president of governmental relations. It might just take a while.

In the meantime, Virginia's Bill 1107 just awaits the governor's signature to become law. This bill would oblige all the state's schools to stock two auto-injectors, and it would allow trained school employees to give epinephrine without fear of being sued. Perhaps it's coincidence but the number of the bill matches Amarria's birthday, November 7, the day she opened the gift of an MP3 player and sang all day. "She was robbed of her life," says Laura, who cries every morning and wonders when she'll be able to pull herself together enough to go back to work. Laura doesn't sleep much these days, but she does see one ray of hope. Maybe the new legislation could be called Amarria's Law. "The least they can do is name it after her," she says, choking back tears. "It would give me a little comfort to know that her death was not in vain."

Join the campaign for Megann's Law at www.Allergicliving.com/Meganns. To comment, write: editor@allergicliving.com