

Asthma Nation

There is a crisis in asthma across North America. In Canada, an astonishing 16 percent of our kids have the disease and for a majority, it's out of control. *Allergic Living* goes inside this crisis of life and breath to ask: What can be done?

by SARAH SCOTT

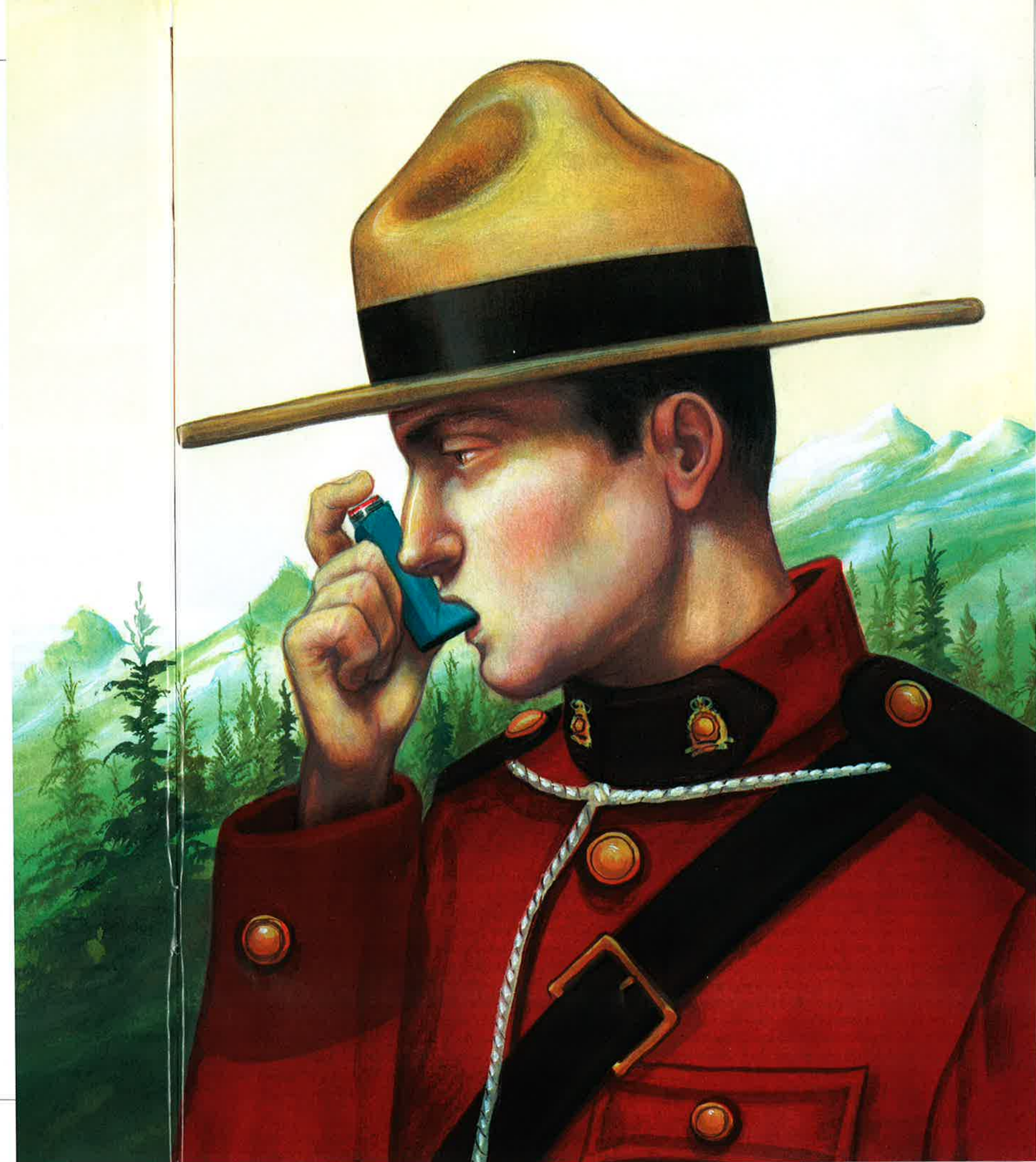
The phone rang just after 1 a.m. on a damp September night in Maria Thulion's house on the outskirts of Savanna, Illinois. It had to be her 22-year-old daughter Erin, she thought. The blonde college senior used to call her mother six times a day to chat, and sometimes she'd call late into the night like this, often while off dancing with friends at a bar a couple of hours up the highway in Cedar Falls. There, she was attending the University of Northern Iowa, studying to be an elementary school teacher. "We called it drunk dialling," recalls Maria. Erin was rarely drunk, though; she just liked to stay in touch with her mother.

Maria pulled herself out of bed and pressed the button on the phone to return the call. A man answered. "Chief of police," he said. "Oh my gosh," Maria thought. Erin, the policeman said, had just collapsed at Joker's, a popular dance club on Main Street. She'd been rushed off in an ambulance. "You need to call the hospital as soon as possible," he said. By the time Maria reached the nurse at the hospital, she was screaming into the phone: "She has asthma! She has asthma!"

"How far are you from here?" the nurse asked. "You'd better hurry. I don't think she's going to make it." She didn't.

That terrible night four years ago is not what we expect; most people underestimate the seriousness of asthma, thinking of it as disease that causes some coughing, maybe wheez-

Illustration by Anita Kunz





Some parents are steroid-phobic, afraid to give their children the medication they desperately need.

ing, but all resolvable with a quick puff or two from an inhaler. Even within the vast community of those *with* asthma, most consider the disease a minor inconvenience on the pathway of life. After all, modern medicine has asthma under control, right? The widely prescribed duo of controller medication, usually an inhaled corticosteroid, and fast-acting rescue medication are supposed to give us the freedom to breathe, to run and play without gasping for breath. But that sunny picture is easily fractured by stories like Erin's and by new findings this year from the Centers for Disease Control and Prevention (CDC) that show 3,447 Americans died of asthma in 2007. In Canada, one-tenth the size, 223 asthmatics died. Fewer people actually die from a serious asthma attack than in previous years. But the fact is: any death from a highly controllable disease is an unconscionable loss of someone's husband, mother, brother, son – and daughter.

Fatalities aren't the whole story, of course. Far too many Canadians end up in a hospital emergency room seeking urgent help for an asthma attack – over 55,000 in Ontario alone in 2009, according to the Canadian Institute for Health Information. Tens of thousands of them are children: asthma is one of the top reasons to rush a child to hospital in this country. Consider how scary that it is: a child struggling for every breath.

Put simply: there is an asthma crisis across North America. Almost three million Canadians have the chronic respiratory disease. In the United States, the CDC reported in May that a phenomenal 25 million Americans now have it, an increase of 4.3

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million asthma patients since 2001. In Canada, we have one of the highest rates of asthma in the world at 8.4 percent, and an astounding 15.6 percent of our kids today have asthma. But it's the prevalence among Canadian boys ages 4 to 11 that truly astonishes: almost 19 percent have had an asthma diagnosis. Another group being hit hard is women. The number of Canadian women between the ages of 35 and 44 who have asthma has grown by over 60 percent since the mid-90s, and the rate climbs to 80 percent in older women.

Why this disease has become so prevalent remains a mystery. The leading scientific theories on the cause of asthma include the hypothesis that our society is too clean to properly "switch on" young immune systems; genetics; pollution and allergen expo-

Asthma by the Numbers

2.7 million Canadians have asthma
up from 2.4 million in 2005

WE'RE NO. 5

Canada has the 5th highest rate of asthma in the world
Better news: 5th lowest rate in adults for hospital admissions

8.4% of Canadians over the age of 12 have asthma

15.6% of children ages 4 to 11 have been diagnosed
19% of boys ages 4 to 11 have been diagnosed

WOMEN & ASTHMA

Age 35-44: rate up
60% over 10 years (as of 2005)

Ages 45-64: rate up
80% over 10 years (as of 2005)

STATE OF CONTROL

56% had an asthma attack in past year

57% do not have controlled asthma

18% visited an ER in the past year

30,000 kids visited an ER in 2004 in Ontario alone

ECONOMIC BURDEN

\$1.8 billion Total cost of asthma in Ontario alone in 2011

\$96.7 billion Projected total cost of asthma in Ontario by 2041

Sources: "Life and Breath: Respiratory Disease in Canada" report, Public Health Agency of Canada, 2007; "Economic Burden of Asthma: a Systematic Review," K. Bahadori, *BMC Pulmonary Medicine*, 2009; AllerGen NCE; "Your Lungs, Your Life: Insight and Solutions to Lung Health in Ontario" report, Ontario Lung Association, 2011; Hospital for Sick Children, Dr. Teresa To; GINA (Global Initiative for Asthma).

sure in the womb and early life; sensitization at work and several of these factors combined.

However, one thing is clear: Far too many people are allowing this highly treatable disease to control their lives or their children's lives – and not the other way around. Kids crowd our emergency rooms – a data analysis from a senior scientist at the Hospital for Sick Children showed that nearly 30,000 children in Ontario alone visited an ER for asthma in 2004. Meanwhile, more than half of the adult asthmatics in Canada report significant daily symptoms; a sign of uncontrolled asthma.

Too many people with asthma are resigned to a life that is less than it could be. In the United States, a 2008 survey showed that 55 percent of those with asthma accept the unacceptable, an annu-

al asthma attack. The settling, the resignation, the fear, the attacks, the hospitalizations, the mortality statistics – they add up to a monster of a problem. Half of asthma in North America is out of control, and those with the disease don't even realize it.

Even one death from asthma is too many in the 21st century. But as Dr. C. Everett Koop, the former U.S. surgeon-general, once said, "Drugs don't work in patients who don't take them." Unfortunately, many asthmatics do not. According to several studies, over half of asthmatics fail to take their controller medications as prescribed. "The problems are almost all avoidable," says Dr. Louis-Philippe Boulet, who heads up the respiratory unit at Laval Hospital in Quebec City and is part of the AllerGen research network. Yet "asthma is still often poorly managed and insufficiently controlled."

This problem of patient compliance or adherence is the biggest challenge in asthma management today. Solving the adherence puzzle could have a massive impact, according to a 2003 study by the World Health Organization; it could halve the asthma attacks that kill people or send them to hospital, says Boulet, one of the study's key contributors. It could do more to improve health than the discovery of any new drug.

When Erin was a little girl, she never liked to run. Erin grew up in Sabula, Iowa, a town surrounded by the Mississippi River and its backwaters. At night, when the windows were open, she'd often wheeze. In Grade 5, the family found out why. Erin had a mild case of asthma, the doctor said, and the triggers included mold spores that flourish in humid air, as well as dog dander, white oak and elm trees. The prescription: inhale corticosteroids twice a day, and use emergency albuterol when necessary, plus go for allergy shots.

By the time Erin reached her final year in university, life was in full swing. She was studying to be a teacher, helping out at a child-care centre, and clocking in a few hours at a Payless shoe store on weekends to afford the sandals she'd buy in every colour to match her outfits. In her senior year at university, Erin was living with some girlfriends, who opened the windows at night to let in the cool air. "I'm having trouble breathing," Erin told her mother. "Are you taking your meds?" Maria asked. She knew she didn't have to ask; her daughter used her controller inhaler faithfully. "Yes, mother," Erin said in that voice every mother knows. Erin said she was using her rescue medication too, puffing three to five times a night.

What neither she nor her mother knew was that Erin's asthma was out of control. In fact, using a puffer three or four times a night is a sign of "impending doom," a red alert that should send you directly to the hospital, says Boulet. Erin, like so many others, was on the wrong side of an information gap. A 2008 Ipsos Public Affairs survey, published by the Asthma and Allergy Foundation of America, offers insights: while most asthmatics claimed to appreciate the danger of uncontrolled asthma, seven out of 10 stopped or reduced their corticosteroids because they stopped having symptoms. Then they had exacerbations: two in 10 required Prednisone pills to handle an asthma episode, 17 percent rushed off to an emergency doctors' visit, and 12 percent went directly to the ER.

Why aren't people protecting themselves? For starters, many people don't understand the disease or the drugs. Asthma is a chronic disease that inflames and swells the airways to and from the lungs. This makes it hard for the lungs to move air in and out, causing symptoms like coughing, wheezing and a tight chest, or worse. The inhaled corticosteroid (controller) medications reduce and prevent the swelling of the airways. But to work, they need to be taken as prescribed, in most cases twice a day, every day, and their effects are not immediate. Only one-quarter of the 600 patients Boulet surveyed in Quebec City, as part of the WHO report, understood this. As a result, nearly half were reluctant to administer a controller inhaler on a regular basis. "The main problem is nobody took the time to explain why," said Boulet. Patients will often wait for symptoms, then rely on a reliever inhaler for help. But it's only a rescue tool, not a controller drug. It can open up airways during flare-ups, but it can't prevent or



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treat the disease, the inflammation of the airways.

Many people confuse the disease with its symptoms. They think asthma is coughing, wheezing, shortness of breath and chest tightness, and that if they don't feel the symptoms, they don't have the disease. "It's like saying cancer is losing your hair," says Mike Tringale, AAFA's vice president of external affairs. What they don't understand is that the inflammation of the airway can get worse without causing noticeable symptoms. And then one day they appear, with a vengeance.

Consider the case of the great running back, Pittsburgh Steeler Jerome Bettis. "The Bus," as Bettis was nicknamed, was diagnosed

with asthma at 15. His parents encouraged him to keep playing as long as he followed the doctor's prescription to control his asthma. But after high school, Bettis stumbled. "I took my health for granted," Bettis told *USA Today*. "I only took an inhaler when I felt I needed to." In 1997, during a nationally televised game, asthma attacked. "I was fighting for my breath and I almost died," Bettis said. "It was the most frightening experience I've ever had, but it also served as a turning point in my life."

Not so long ago, health authorities blamed the patient alone for this information gap. No longer. "It's not enough for a person to be told he has asthma and be given a prescription," said Dr. Paul Garbe, chief of the CDC's Air Pollution and Respiratory Health Branch and director of the National Asthma Control Program. People need asthma education to understand how to assess and monitor their symptoms, avoid environmental triggers, how their medications work and how to use the inhaler properly. Yet only half of Americans with asthma get the education they need. One reason is money, says Garbe. U.S. insurance policies rarely cover

Money may be one barrier to asthma control. Another may be "steroid phobia." Unfortunately, some people mistake inhaled corticosteroids with the anabolic steroids some bodybuilders use to pump up their muscles. More education would help fill the knowledge gap.

asthma education, and many can't afford to pay for it.

The situation is not much different in Canada. In 2008, Wendy Ungar, a senior scientist at the Hospital for Sick Children, found that only 30 percent of Toronto-area children with asthma have good control. To find out what happened to the other 70 percent, she collected more data on 500 of the children. Although they were all covered by private or public drug plans, some of their parents had to pay a co-payment of 30 percent or more for asthma medications. That money was a barrier: for every 1 percent more of the household's income required to pay for the asthma drugs, there was a 14 percent increase in visits to the ER. "Parents may be trying to make the inhaler last as long as possible," Ungar suggests. "They're sparing." The problem is that the most important medication, the inhaled corticosteroid, is far more expensive, giving parents the incentive to rely on the cheaper rescue medication.

Then there is the widespread resistance to taking the controller drugs. Many people are "steroid phobic," says Dr. Monica Kraft, incoming president of the American Thoracic Society. Perhaps they mistake inhaled steroids for asthma with the anabolic steroids some bodybuilders take to pump up their muscles. Or maybe they fear side effects, which are minimal. Some people do get minor effects, like thrush, a yeast infection in the mouth, from inhaled corticosteroids. But they don't weigh minor discomfort against the

far greater risk of an asthmatic attack without proper disease control, and the side effects they will get from intense doses of steroids an emergency physician may have to give them.

Sometimes doctors are part of the communications problem. When AAFA polled primary-care physicians, more than one-third believed that patients with moderate to severe asthma can reduce inhaled steroids or even stop them if symptoms subside.

We'll never know exactly what Erin's doctor said, for example, but the only message Maria got was: *Erin has a mild case of asthma controlled by medicine*. That's what she kept thinking on that awful September night as she and her husband Ron picked up Erin's father Ken and raced up the highway to the hospital in Cedar Falls, where Erin was fighting for her life. "She was so swollen," said Maria. "I took her hand, and said I was there and that I loved her. She just needed to breathe."

Four years later, Maria still leaves the light on in Erin's bedroom. "It could have been prevented," she says, choking back tears. "I know that for a fact." Basic information would have helped. A few months after Erin's death, Maria went to an asthma educator for the first time. Asthma educators are trained to teach asthmatics how to manage their disease and avoid attacks. Yet many families don't go, and educators can be hard to find. "We need to get more health-care professionals trained and certified as asthma educators," says Cheryl Connors, executive director of the Canadian Network for Respiratory Care. "It also makes sense economically." Unfortunately, provincial governments don't see it that way.

The educators help patients learn to use their asthma action plan, too. That's an individualized chart that a doctor creates with a patient to assess her condition (the safety zone is green, caution yellow and red means risk) and then manage the situation accordingly. An asthma action plan would have saved Erin's life, of that Maria's certain. Yet Boulet says only one in six asthmatics has one.

Significant improvement in asthma awareness and education is clearly vital to taming the asthma crisis. Several studies show that patients are more likely to manage their disease successfully when they assume a much more active role in the doctor-patient relationship. Self-management can go one step further: those with asthma or with children with asthma can use the reach of the Internet to spread the word about what constitutes control and support each other on discussion forums at the National Asthma Patient Alliance's website (see www.Asthma.ca/napa) or PatientsLikeMe (www.Patientslikeme.com). We can all help to fill the potentially deadly information gap.

Empowering patients is just the start. It may take the whole health system to declare war on a disease that's this enormous and this widely misunderstood. Finland, for instance, declared a zero-tolerance policy for asthma deaths in 1994 and aimed to slice the burden of asthma on individuals and society. The small Nordic country educated patients and followed up to make sure patients were using their inhalers as prescribed. The result: total hospital days for the disease were cut in half. In 2007, only 13 people died of asthma, and seven of them were over the age of 65. That's a fraction of the fatality rate in North America. "I'd love to see zero tolerance," Kraft says of the United States. "But until we have access to health care and access to medicine, until we can fix that, we can't have zero tolerance."

Garbe believes that to successfully attack asthma, you need a

comprehensive asthma management and control system. In Canada, a long-term strategic action plan called the Lung Health Framework, which covers all respiratory diseases, began in 2009. With \$10 million in federal funding, the initiative is led by the Lung Association of Canada and involves other patient groups, the medical community, government officials and pharmaceutical industry representatives. The framework's goals include earlier diagnosis of lung diseases, greater awareness and access to information, improving the quality of life of those with asthma and other lung diseases, and a heavy emphasis on reducing respiratory diseases among First Nations communities. It's a laudable effort and a big undertaking but what's yet to be seen is whether there will be measurable results, particularly among the huge community of asthmatics.

In the U.S., meantime, the CDC has been running programs in 36 states and territories to monitor asthma, support disease control programs by local organizations, and fund asthma education in schools, residences and local clinics. Garbe unfortunately is facing a 50 percent budget reduction for 2012, so the number of states involved in the program will be ratcheted down to 15, but the CDC program's early results do show what *could* be done. In Connecticut, for example, asthma educators were sent into the

WEB RESOURCES FOR ASTHMA INFO

www.AAAAI.org

www.Asthma.ca

www.AAFA.org

www.Lung.ca

www.ucalgary.ca/icancontrolasthma

www.CNRHome.net

homes of low-income people who were showing up in emergency rooms with breathing troubles. The results: fewer than one ER visit per patient in the six months following. That's an impressive return on investment, considering the disease cost the U.S. economy a total of \$56 billion in 2007.

At a time when health care is taking a backseat to the economy, the CDC's new findings at least shine a bright light on the enormity of the asthma crisis. Big media outlets across the globe were shaken out of

their indifference to asthma news to communicate the sheer magnitude of the disease and the risk: 25 million Americans – half of whom live lesser lives, oblivious to the fact that their weekly coughing or wheezing may one day cause that big and unexpected attack. It's testament to front-line hospital workers that more asthmatics don't end up on the fatality side of the ledger. Change has to come, and communication is the key. That's why a grieving mother speaks out today in the media and in the burgeoning community of those with asthma. "All I can do," Maria says, "is go forward and prevent something happening to someone else, so one more mother doesn't have to go through what I went through."

We want to hear your views on the asthma crisis. Write to: editor@allergicliving.com

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