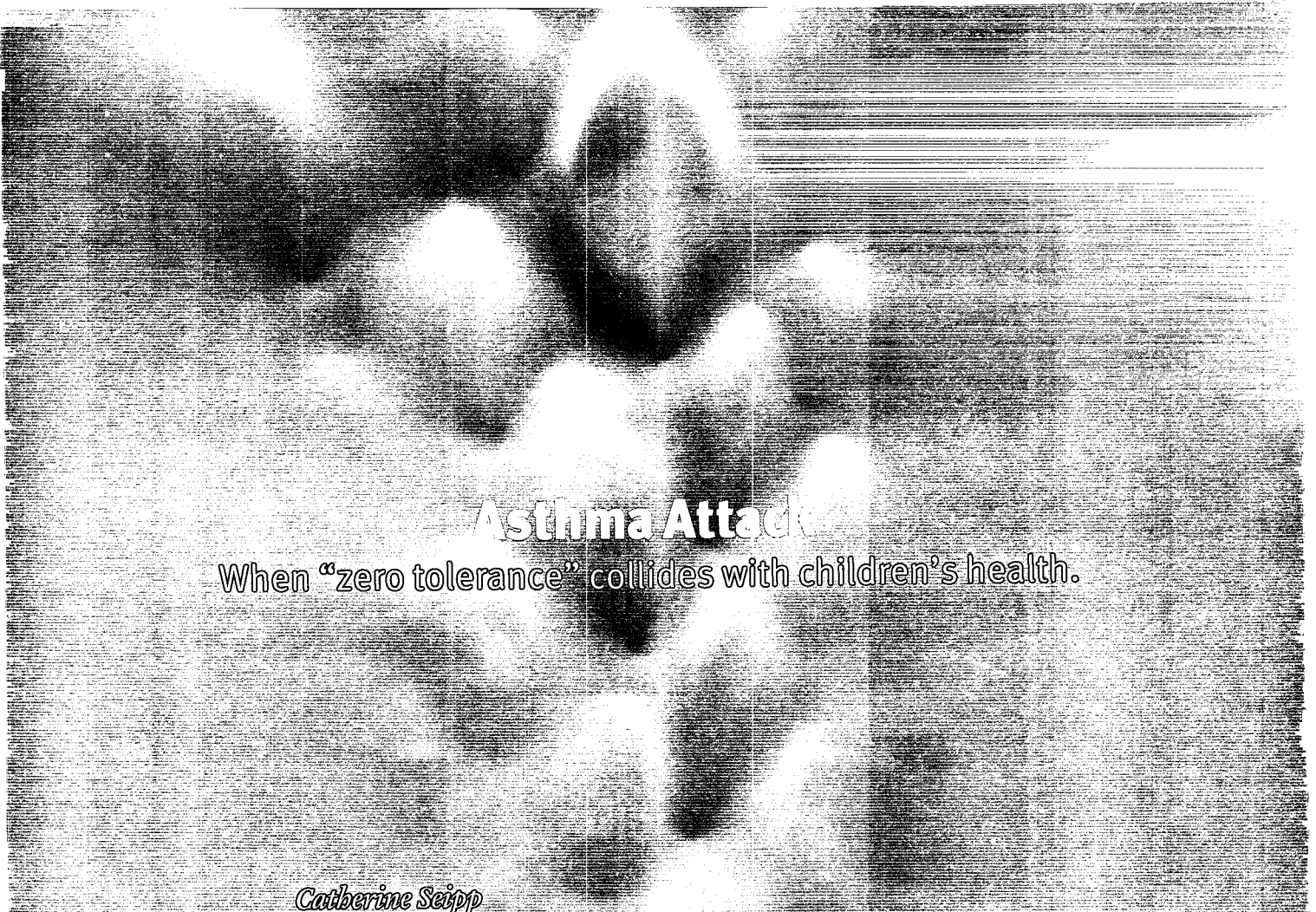


Asthma Attack

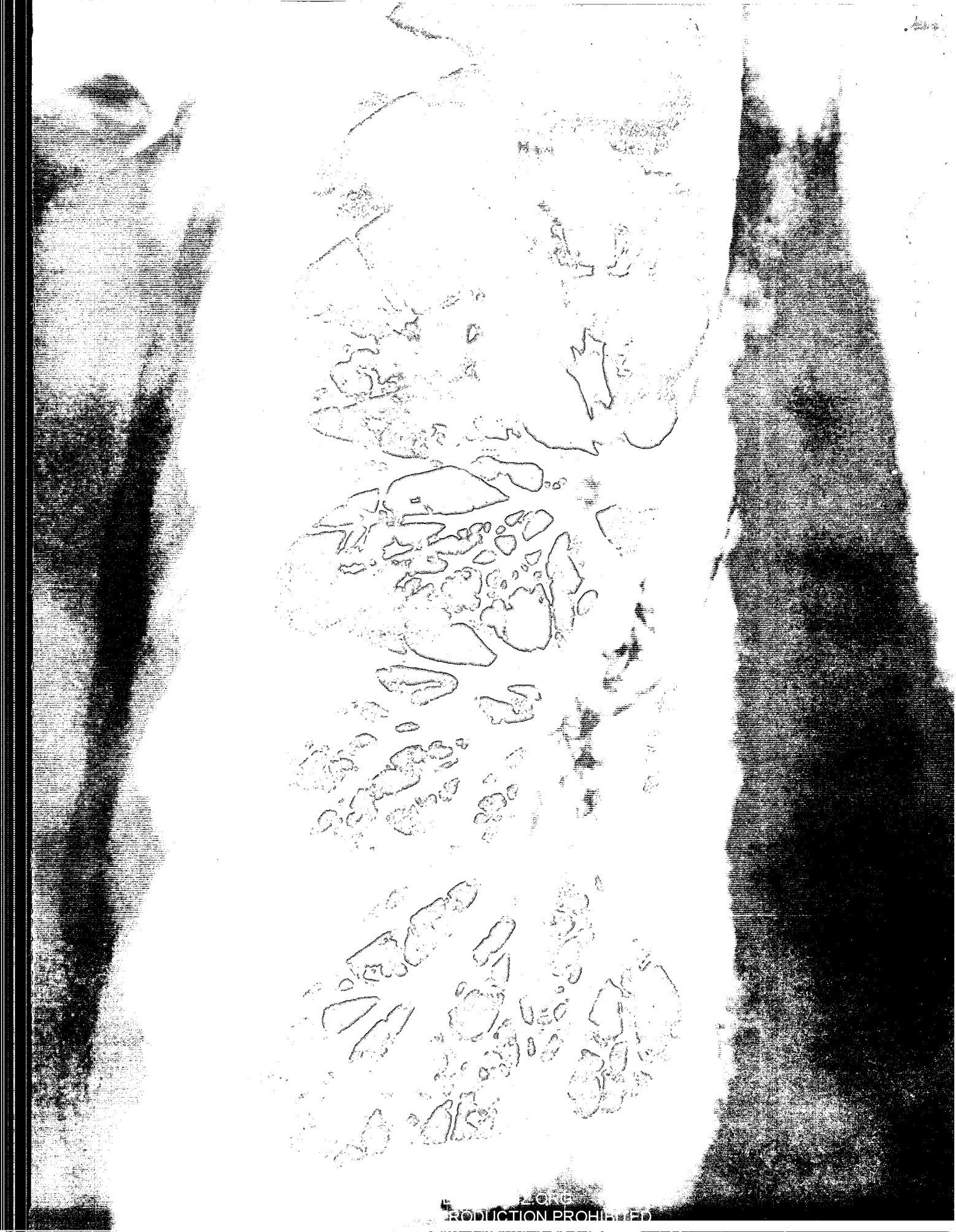
When "zero tolerance" collides with children's health.

Catherine Seipp

JUST BEFORE THE beginning of this school year, the Bristol Township School Board in Pennsylvania decided that students with asthma must keep their emergency inhalers in the school office, rather than on hand.

On September 7, the board received a letter from Nancy Sander, executive director of the Allergy and Asthma Network/ Mothers of Asthmatics (AANMA), a national asthma support and education group based in Fairfax, Virginia. Sander's letter neatly encapsulated the all-too-common frustration of parents when their doctor's advice about how to care for an asthmatic child encounters a school with an entrenched hall-monitor mentality. The letter read, in part:

"The decision to accommodate and facilitate a child's needs with asthma is far easier than pretending their needs do not exist or that restricting student access to medications is for the safety of all students. To do so places your students with asthma at greater risk of death or missed school days, their classmates at risk of witnessing their death, and your school board at risk of lawsuits....



"If a student placed a plastic bag over a teacher's head for a brief moment, the student would be charged with assault. But a school board voting to restrict a child's access to his life-saving asthma medication is no less guilty of a crime. Is Bristol Township School Board really ready to accept responsibility for violating a child's right to breathe? Are you prepared to breach the provisions of the Americans with Disabilities Act?"

Three days later, the school board held a hearing and reversed its original decision. Students in Bristol Township are now allowed to retain control of their asthma inhalers.

There are a couple of remarkable things about Nancy Sander's letter. The first is that it was necessary at all. Although school officials have often taken zero-tolerance laws against drugs in schools to mean that even asthma medicine must be kept locked in the office—which obviously defeats the purpose of rescue inhalers like quick-acting bronchodilators—in the past few years many states passed bills specifically exempting inhalers from such rigidly interpreted rules. Pennsylvania become one of them, to a fair amount of publicity, almost a full year before the Bristol Township School Board decided to deny asthmatic students easy access to their own medicine. On September 27, 2000, the state's House Education Committee voted unanimously to require its public school districts to let students carry asthma inhalers. This was partly in response to "The Flagpole Mom" (as the media dubbed her), a Pennsylvania mother who chained her lawn chair to her son's elementary school flagpole for 19 days to protest the school's asthma inhaler policy.

Similar laws are in place in Delaware, Florida, Illinois, Indiana, Massachusetts, Michigan, Minnesota, Missouri, New Jersey, New York, Ohio, Oregon, Rhode Island, Texas, Virginia, and Wisconsin. But ignorance and obstinacy among school officials often trump even their own local laws. In August, the Chicago Asthma Consortium succeeded in getting Illinois to pass a bill allowing students to keep asthma inhalers on hand; the group had previously persuaded Chicago's public schools to pass a local version of the law in 1997. And yet a survey of Chicago school nurses, sponsored by a local chapter of the American Lung Association in May of 2000, revealed that only 30 percent of asthmatic students carried their inhalers at school. "We have better control," one nurse told the *Chicago Sun-Times*.

The second remarkable thing about Nancy Sander's letter was its gloves-off tone. Heads of 10,000-member nonprofit groups who present their case to Capitol Hill every year are generally more circumspect in official communications. But Sander began her organization in 1985 as a simple support group called Mothers of Asthmatics (three of her four children have asthma), and I know from experience that when a mother of an asthmatic encounters school stupidity that threatens the health of her child, the result can be murderous rage.

My daughter, who is now in the seventh grade, attended one of the better Los Angeles public schools, Ivanhoe Elementary, through the middle of fifth grade. She has mild-to-moderate asthma and rarely needs to use her emergency inhaler. But when she did, the elementary school's involvement ranged from OK to inept. (Her current private school is better about the inhalers, but far from glitch-free.) In first grade, one of the after-school counselors helped my daughter, who'd been wheezing, take her inhalers. At the time, her doctor had prescribed two to three puffs of Proventil, a fast-acting bronchodilator, followed by three puffs of a slower-acting one called Atrovent, which takes about 20 minutes to work. It turned out the counselor had only given her the Atrovent; apparently he'd failed to read the written instructions and had just grabbed the first

When a mother of an asthmatic encounters school stupidity that threatens the health of her child, the result can be murderous rage.

inhaler handy. Luckily, her breathing improved anyway. Or at least it had by the time I picked her up, about 20 minutes later.

This is just the sort of situation that University of Iowa nursing professor Anne Marie McCarthy found two years ago, in a survey she conducted of 649 school nurses: Almost half reported medication errors in their school the previous year, and three-quarters said that medication was dispensed not by nurses but by other school employees, such as office clerks or playground aides. That's not surprising, considering that the national ratio of school nurse to student is 1 to 1,500 at best and 1 to 2,500 at worst, depending on who's estimating the figures.

Ellie Goldberg of Newton, Massachusetts, advises parents of children with various medical problems how to deal with schools. She gets calls about asthma inhalers every day. One of the most memorable: "A person from Louisiana called and told me about a teacher who pulled a drawer out, spilled all the medicine out of the cups, refilled them randomly and said, 'Gee, I hope this doesn't hurt anybody.'" When Goldberg's own asthmatic daughter was in the second grade, the school secretary mistakenly gave her Ritalin instead of her inhaler.

My daughter always keeps emergency inhalers with instructions in her backpack, a fact kept on file in the school's office. Despite that, no one in charge had been quite aware of this when she had that asthma attack in the first grade; apparently, she'd been wheezing too badly to speak. "Jasmine knew where the medicine was," a teacher later explained, referring to another first grader who was often in trouble for digging around in other student's backpacks. Considering how the adults at the school had handled the situation, I probably would have been just as well off leaving them out of the loop and going over the instructions with the enterprising Jasmine.

I was relieved when my daughter learned to read and proved she knew how to take her medicine by herself. Plus, unlike most adults, she was careful not to leave it locked in a hot car or sitting in the sun. One day when in the fifth grade, however, she was in tears when I picked her up from school. The teacher had yelled at her when she'd used the inhaler in class, claiming that she didn't really need it.

I spoke to Ivanhoe's then-principal, Kevin Baker. He said I'd been "breaking the law" for five years by keeping the inhaler in the backpack instead of in the office, and that he would "confiscate" it if he found it there in the future. If the school had allowed this before, he said, it was an oversight. "So now what we need to do," he explained, in a sing-songy, *Romper Room* voice, "is set up a series of intervention meetings to help *you* understand *our* concerns about *you* breaking the law." My arguments about doctor's orders went nowhere. "When your daughter is at school," Principal Baker said, "I am the ultimate authority concerning her health."

That Robert De Niro soundbite from *The Untouchables* that Howard Stern likes to play—"I want him *dead*! I want his family *dead*!"—kept echoing in my head as I left the school office. But I'd heard enough misinformed pronouncements over the years from that school—a jellyfish is a mollusk, "Indian" should be spelled with a small *i*—to consider the possibility that the principal didn't know what he was talking about. So I went home and called the Los Angeles Unified School District's director of nursing. Within an hour, I had a fax on Principal Baker's desk saying that district policy (Bulletin Z-19, Attachment F) does allow students to keep medicine on hand with a note from their doctor. I sent a copy to his supervisor, and he backed down quickly.

So it was with a sense of déjà vu that I read Nancy Sander's letter to the Bristol Township School Board. Just as my local school principal in Los Angeles should have known about his own district policies, so should those Pennsylvania school officials have known that state law allowed students access to their asthma inhalers. Why *don't* they know? Perhaps just because of how the school system tends to work.

"The nature of bureaucracy is you get these mailings with 57 pages that go out every two weeks and they go straight to the circular file," says Jura Scharf, executive director of the Chicago Asthma Consortium. "Anything that can carry risk, the short answer is going to be no. The paperwork gets to be cumbersome and so they fall behind."

"I think a large part of what happens," Scharf adds, "and this permeates all school situations, is the teacher and the school are petrified of being sued. They're almost afraid to admit they have children with asthma in the classroom, because then they have to do something about it."

It's when they don't do something about it, though, that schools end up on the losing side of lawsuits. In her letter to the Bristol Township School Board, Nancy Sander referred to the 1991 death of a New Orleans high school student, Catrina Lewis, who was delayed by security guards before being allowed to get her inhaler from the office. When it

didn't help, she asked school staff to call an ambulance; instead they spent a half-hour trying to call her mother first. Catrina's sister, another student, finally called 911 herself, but emergency help arrived too late. In 1996, a New Orleans judge ordered Lawless High School's acting principal, a school counselor, and the school board to pay $1 million in damages to Catrina's family.

For school officials to be so obtuse about asthma now requires a certain amount of effort. The American Lung Association estimates that 7 to 10 percent of children have the condition, but for unclear reasons the incidence has increased dramatically in recent years—almost doubling between 1982 and 1995, according to one study—and some urban school districts now report initial asthma screening rates as high as 30 percent.

Rescue inhalers work by opening the bronchial passages, ideally to 100 percent of what they should normally be. It can't dilate them any further, so a non-asthmatic student who grabs another student's inhaler would feel no change in his breathing. The only likely side-effect might be a mild jitteriness. Inhalers aren't dangerous; asthma, which kills around 5,000 people a year, is. What's really frightening is how it can surprise you. I know children with severe asthma who have never been hospitalized; my daughter, who rarely wheezes badly, caught a simple, non-feverish cold when she was five that put her in the hospital for four days. Parents who've experienced such situations, who've been forced to acquire a certain level of expertise, can be impatient when school officials—many of whom don't even know that asthma can be fatal—dismiss their concerns as paranoia.

This doesn't mean that schools are unaware of the problem. "Everything about asthma, in the last two or three years, has come up more in every context," says Bruce Hunter, director of government relations for the American Association of School Administrators (AASA) in Arlington, Virginia. "We spend a fair amount of time on it." They'll probably spend even more time on it now that the Centers for Disease Control has just issued a special grant addressing school management of asthma in adolescents.

The AASA is no fan of zero-tolerance policies. Hunter notes that "the inhalers are an issue where, if you don't have some flexibility, you end up causing problems. Our view is people need to have common sense. But that being said, I don't think it'll be too long before someone finds some illicit use for inhalers. I've watched kids trade Ritalin. Kids just amaze me." Indeed, school nurses have reported students trying to use the devices to increase athletic performance or open the airways before sniffing glue. But the medical viewpoint that schools should let asthmatic students keep their inhalers is quite clear, and made even clearer whenever specialists talk to schools. Doctors don't worry about misuse; they worry about lack of access.

"The asthmatic should always have the inhaler on hand," says Dr. Robert Nathan, a clinical professor of medicine at the University of Colorado and a spokesman for the American Academy of Allergy, Asthma and Immunology. "The issue with schools, obviously, is that it's a drug. But it's kind of hard to overdose on an inhaler. Periodically, we will meet with school administrators, teachers, P.E. teachers. There are some who say, 'You can't use this inhaler and you have to run around the track with everyone else.' It's ludicrous."

Common sense would suggest that children are naturally reluctant to call attention to themselves by asking for permission to go to the office and use their inhaler, and clinical observation backs this up. Elizabeth McQuaid, a Rhode Island Hospital pediatric psychologist and Brown professor who studies human behavior and asthma, has surveyed focus groups about just that issue. "Particularly

One high schooler asked school staff to call an ambulance; instead they spent a half-hour trying to call her mother. Her sister finally called 911 herself, but emergency help arrived too late.

with early teenagers, it's embarrassing for them to take medication with people looking at them," she says. "They're hesitant to disrupt sports or other activities to go take the medicine in the office."

Not all school administrators have opportunities to meet with asthma experts. But a simple Internet search quickly reveals that medical opinion is clearly in favor of asthmatic students having access to their inhalers. Even school nurses, who straddle the two worlds of school employees and medicine, generally agree, with some caveats. The Ohio Association of School Nurses (OASN) lobbied hard for amendments to the state's 1999 asthma inhaler law. "We saw gaping inadequacies," says Sandra Gadsden, a Worthington, Ohio, school nurse. "Originally the law was just going to allow inhalers." Still, the OASN supported the law after legislators added requirements such as a doctor's certificate that the child is capable of self-medication, as well as a written procedure attached to the permission if the inhaler doesn't help.

The National Association of School Nurses (NASN) has a position statement on its Web site stating that they "support the self-management of asthma, including the use of prescribed, inhaled medications on a case-by-case basis." Nancy Sander reports that "I rarely run into a school nurse anymore who feels she needs to be in charge of the inhaler at all times." At my request, the NASN, to which around 11,000 of the nation's 40,000 school nurses belong, sent out an e-mail survey to board members asking what they thought about students carrying their own asthma inhalers. Of the 25 responses, only three were negative. Most members were aware of new state laws exempting inhalers from zero-tolerance rules and reported few or no problems, although some asked students to keep a spare inhaler in the office and demonstrate proper inhaler technique.

Go further up the ladder of experts—to physicians specializing in asthma rather than school nurses—and medical opinion is much firmer. "Information for School Personnel Regarding Treatment of Asthma" is a peer-reviewed paper on the Children's Virtual Hospital Web site. It was written by Dr. Miles Weinberger, a University of Iowa pediatrics professor and the director of the Children's Hospital of Iowa's pediatric allergy and pulmonary divisions. Dr. Weinberger states flatly that "it is essential that all students with sufficient maturity have their bronchodilator inhaler in their possession at all times," adding, "The inhalers pose no abuse potential or other danger to classmates. It therefore constitutes unreasonable interference with the student's medical care for school personnel to unilaterally restrict possession."

In an interview, Weinberger notes that "virtually all kids eight years and up, of normal intelligence, and in some cases six years and up, are capable of handling the inhaler." He deals with school administrators by handing out a preprinted form authorizing the child to keep the inhaler on hand. "Most go along with it," he says. "Others have Tight Rectal Sphincter Syndrome. But there are very few principals who are really going to argue with a note from the doctor."

"Around Iowa, at least, I gather they're pretty reasonable," Weinberger adds. "I rarely have to call up and say, look, you jackass, the kid's an asthmatic and needs his inhaler. But then, Iowa is a state of small towns, and we're also largely a middle-class state. People go in and talk to the principal. They probably already know the principal personally. I can see the problem with bigger school districts, in bigger cities."

In Los Angeles, most public school students are the children of poor, Spanish-speaking immigrants, and I suspect that some of the problem with my daughter's elementary school principal—tactless as this may be to point out—came from his inability to switch out of patronizing Bwana mode upon encountering someone more, rather than less, educated than himself. (He soon became exasperated by the demanding parents in our middle-class neighborhood, and quit his principal's post for a district job deep in the bureaucracy.) But what about parents without the resources, or the will, to argue with school officials? Part of the reason I contacted Principal Baker's supervisor, cluster administrator Rowena Lagrosa, was to make him think twice about bullying other parents of asthmatic children. I also wanted the policy allowing students to carry asthma inhalers explained to other principals. "I can assure you the situation will be clarified," wrote back Lagrosa, who added that her own daughter has asthma.

Unfortunately, other mothers I tracked down who'd had similar run-ins with their children's schools had less satisfying results. Some threw in the towel and ended up homeschooling, like Connie Cruz of Phoenix. "We learned our lesson about working to change things, as that only got our children mistreated when they were in school," she comments. "[Our daughter's] teacher would not allow her to go to the nurse to use her inhaler unless she could hear her wheezing. At one point I recommended that the school nurse attend an informational lecture on the latest treat-

ments for asthmatic children. She had so little knowledge that she was a hazard."

At least Cruz made the transition to homeschooling without difficulty. The Home School Legal Defense Association reported in its July/August 2000 newsletter that an Olive Branch, Mississippi, mother named Patricia Vanderford decided to home school her daughter after a teacher refused to let her carry her asthma inhaler to class. Soon she got a call from a truant officer, who argued that the girl was only being kept home to avoid trouble about unexcused sick days—missed school that might not have been necessary had Vanderford's daughter been allowed access to her asthma inhaler in the first place.

Other families have addressed the problem by simply avoid- ing physical education classes—a shame, since along with its other benefits, regular exercise can help asthma. In Portland, Oregon, Kris Hasson-Jones' middle-school son had asthma attacks at least twice a week after P.E. "He missed an awful lot of school that term," she says. "Finally, his doc wrote him an excuse from P.E. and we didn't have the problem again."

In Salem, Oregon, Carolyn Berry's repeated argument that her daughter Kim needed her inhaler on-hand went nowhere. The school's response was essentially, "If they made an exceptions for asthma meds, where would it end?" Even a near-disaster when the P.E. teacher insisted she run around the track at the height of pollen season didn't change the situation.

"At the end of the half-mile, Kim was wheezing terribly," Berry recalls. "The track was a block from the middle school, so she had to walk (with assistance) back to the school office, at which point they had to track down the person with the key for the med drawer and wait for her inhaler to be found. I tried talking to the school administration again, and was told the same story I was always told. It seems to be the party line."

Much has been made of how school zero-tolerance policies can lead to absurdity. One of the most notorious cases was the 1998 incident in which Christine Rhodes, a quick-thinking sixth grader at Mount Airy Middle School in Maryland, lent her inhaler to another girl who was having an asthma attack on the bus ride home. For her trouble, the school labeled Christine a drug trafficker. At the time, the incident was bandied about Internet message boards as an example of anti-drug hysteria, but I suspect that some school officials' ingrained We Know Best attitude probably has as much to do with the situation. The Safe and Drug-Free Schools Act of 1994 put more pressure on schools by linking federal funds to their drug-free policies. But even in 1989, the *Journal of Allergy and Immunology* was complaining about longstanding school rules that restrict all medicine to school offices. I remember my daughter's second grade teacher, who had asthma herself and was near retirement age, telling me that in her day, "we used to keep the inhalers in our coat pockets, on the q.t."

The asthma inhaler legislation many states have passed recently has evolved in an independent, patchwork way: in Illinois, because of lobbying from the Chicago Asthma Consortium; in Ohio, because a Bowling Green doctor named Wayne Bell complained to Rep. Randall Gardner (R-Bowling Green). There is no similar federal law, although an argument can be made that access to asthma inhalers in school is a civil rights matter. "The thing I've been looking to see, that I haven't seen, is a 504 claim," says the AASA's Bruce Hunter. "But the federal data tends to lag." Under Section 504 of the Rehabilitation Act of 1974, any school receiving federal funds must accommodate children with medical problems—even problems not severe enough to merit special education services.

Schools will start to see 504 claims if Ellie Goldberg has her way. She worries that state laws simply allowing

In one incident, a quick-thinking sixth grader lent her inhaler to another girl who was having an asthma attack on the bus ride home. For her trouble, the school labeled her a drug trafficker.

students access to their inhalers can let schools off the hook. "A child's self-management of asthma does not relieve the school of responsibility for the safety of the child," she says. "Education is considered a property interest under the Constitution. What 504 does is require the system to respond." Goldberg recommends that parents frustrated with their school's asthma policy begin any 504 claim by documenting the situation, beginning with a "Gebser letter" to the school. In a 1998 Supreme Court decision, *Gebser v. Lago Vista Independent School District*, the court for the first time clarified just what parents need to put in writing when complaining to school officials about discrimination. (A good explanation, with examples, can be found at the reedmartin.com Web site.)

"You have to accommodate kids under 504," agrees Dr. Howard Taras, chairman of the American Academy of Pediatrics' committee on school health and professor of community relations at the University of California-San Diego medical school. But Taras, who spends about half his time as a school doctor, adds that not all parental requests are reasonable.

"We had one mother who wanted the child to receive free transportation to the school, which was four blocks away, because she said it was too cold for him to walk to school with his asthma," he recalls. "This is in San Diego. But only one-half of one-percent of all children with asthma have that kind of severity. She had a note from her child's doctor, but when I spoke to the doctor, he said, 'Yeah, she's quite a mom. Well, she wanted me to write that note.'"

Taras says that although he personally encounters school resistance to students carrying their own asthma inhalers only occasionally, he often hears other doctors complain that their own patients' schools don't allow it. "And I have to explain to them that the schools are misinformed. But as much as I would like every school to comply, I am hesitant to respond with legislation. Sometimes the treatment of the disease changes, and to get legislation off the books is a problem. It has a way of helping in the short run and harming in the long run." He would rather see the problem addressed in Department of Education guidelines. "That way it's not like a huge system interfering in a minute thing."

Nancy Sander, however, considers "right-to-carry laws," as the AANMA has labeled asthma inhaler legislation, an essential part of family rights. The "right-to-carry" phrase, with its echo of handgun rights, is perhaps an unfortunate term to use when dealing with schools. But Sander doesn't worry much these days about delicate sensibilities. "The older I get, the less tolerant I am of things that are easy to fix, where it concerns a child's life, and where suffering is unnecessary," she says. The Chicago Asthma Consortium's Jura Scharf notes that parents tell her such laws have made a world of difference in working with teachers and principals. "It allows them to begin some other conversations," she says. "About potentially irritating substances in the classroom, for instance, so maybe in that particular homeroom you don't have the gerbils. We're not asking the school to vacuum the ventilating system, but maybe you put a cheap filter over the vent."

Scharf, who has been a lobbyist for 25 years, adds that the best way to talk to schools about asthma inhalers may be in terms of how missed school days mean lost dollars for the school. About half the states in the country calculate funding by average daily attendance, rather than by average daily membership, so when students are out sick, that costs those schools money.

This argument tends to get officials' attention, even when the health of their charges does not. "You can talk about doing the right thing," says Scharf, "but in Illinois, if the child is not in school, the school loses funds for every day of his absence. If that absence could have been prevented by easy access to the inhaler, it's a powerful argument." ◻

Catherine Seipp (MissSeipp@aol.com) is a Los Angeles writer.