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CHICAGO READER
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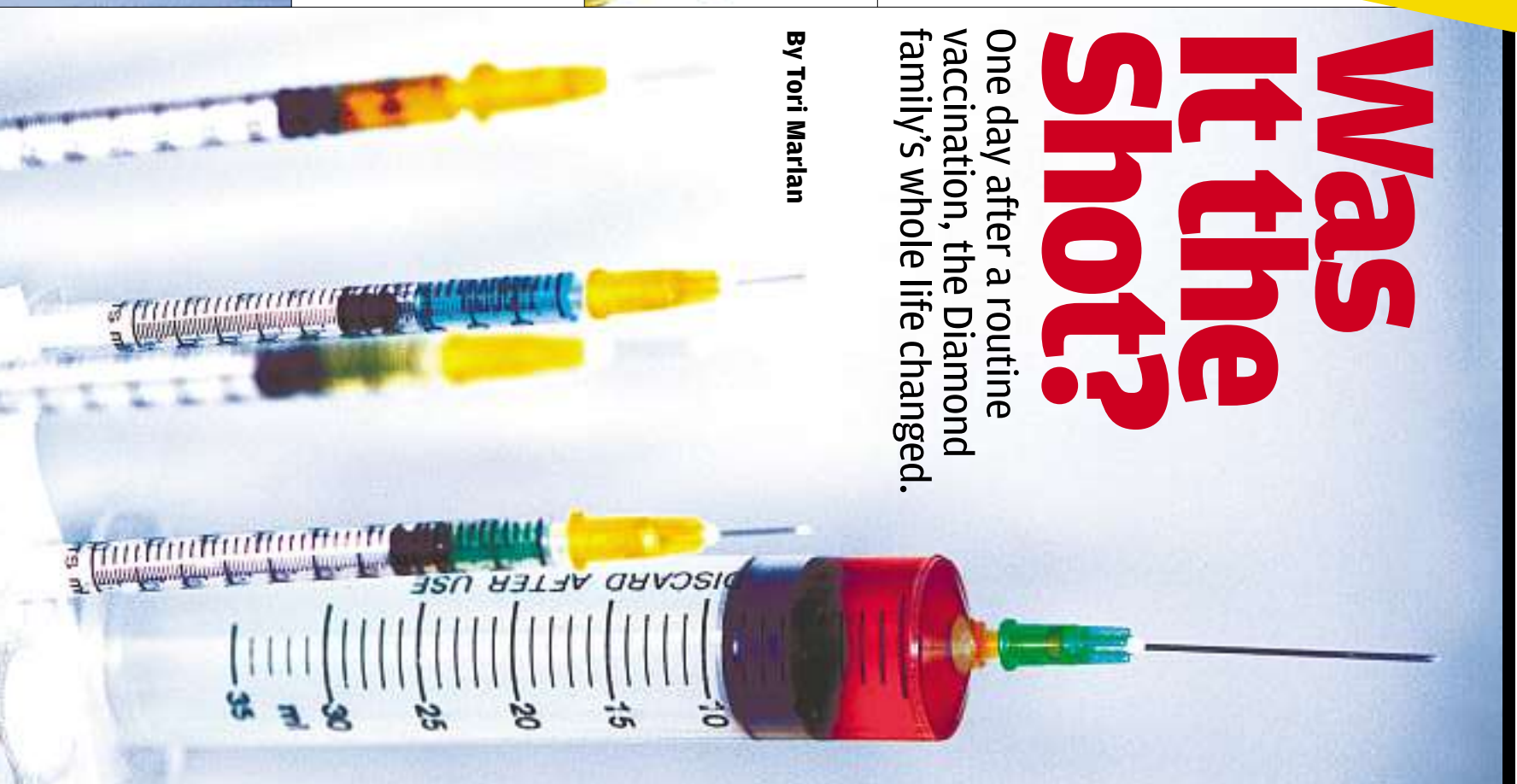
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Was It the Shot?

One day after a routine vaccination, the Diamond family's whole life changed.

By Tori Marlan



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Was It the Shot?

One day Jackson Diamond was a healthy, active toddler. The next he couldn't hold up his own head. What happened in between was a routine vaccination for whooping cough.

By **Tori Marlan** | Photographs by **Jim Newberry**

Before December 9, Jackson Presley Diamond was a healthy kid. He'd learned to crawl, sit, walk, and run right on schedule. At 18 months he was starting to talk and was rapidly accumulating vocabulary words. He liked to stack blocks and knock them down, and when he heard music—his father, Lee, plays drums in the local punk duo the Douglass Kings—he'd pull his parents up from their chairs to dance with him. After December 9 he could do none of those things.

It began as a typical day. Chaney Diamond woke her son up at 6:30, chased him around the room getting him dressed, then brought him downstairs, where she fed him some yogurt and let him watch *Sesame Street*. She left her north-side home around 7:15 and drove to Wells Community Academy High School in Wicker Park, where she taught special ed. A little while later Lee dropped Jackson off at day care, then headed to his downtown office, where he worked as a mortgage consultant.

When Chaney arrived at the day care center that afternoon to pick up Jackson, she saw emergency vehicles parked outside. She remembers assessing the situation and initially feeling relief—the building obviously hadn't burned down, she could see people inside. But her worst fears were soon realized: the emergency involved her son. Jackson had had a seizure, she was told, and he'd been taken away in an ambulance. The Diamonds later learned that no one at the day care center had been able to rouse Jackson from his nap, that his lips had turned blue, and that several people had performed CPR on him until paramedics arrived.



Chaney, Lee, and Jackson Diamond

A firefighter drove Chaney to Our Lady of Resurrection Hospital. In the emergency room Jackson lay on a table in his diaper, unconscious. He was intubated, and a nurse pumped air into his lungs through a bag, artificially breathing for him. He wore a neck brace—a precaution in case of a spinal injury—and a bracelet that said BABY DOE. Lee arrived a short while later, coming in on what he calls a "chaotic" scene. Doctors and nurses hovered over Jackson, conducting tests, taking notes, looking at readouts. "It was the scariest moment of my life," Lee says.

After receiving antibiotics for bacterial infections such as meningitis and pneumonia, Jackson was transferred to the intensive care unit at Children's Memorial Hospital, where doctors began furiously trying to diagnose his condition. **continued on page 22**



The Diamonds with Jackson at six months

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Vaccines

continued from page 1

Within a few days tests revealed that Jackson had encephalopathy—damage to the brain. But no one could say what had caused it.

The Diamonds told doctors that Jackson had been fighting a slight cold for the past couple of weeks, but that overall he was a healthy child. He'd never been hospitalized before, and he was up-to-date with his immunizations—he'd gotten the proper shots at birth, two months, four months, and six months. On December 8, the day before his brain stopped functioning normally, he'd had another round.

At the time the Diamonds hadn't thought twice about the vaccinations. "I just assumed because they're mandated and every child needs them there wouldn't be a problem," Chaney says. But as doctors struggled to make sense of the situation, the Diamonds couldn't help but wonder whether the vaccines were related to their son's sudden collapse. They asked the doctors if the immunization could have been responsible.

"There was a wholesale rejection of the notion that anything related to the vaccinations was even conceivable," Lee says. Even weeks afterward, "when they had conducted countless tests on our boy—and I'm talking about multiple spinal taps, multiple CAT scans, multiple MRIs, EEGs, video EEGs, blood tests, X-rays, a brain biopsy, even after all this, we kept saying, 'Are you sure it couldn't be related?'"

Within 24 hours of taking their son in for his shots, the Diamonds had lost the little boy they'd known. Jackson could no longer communicate with them or express his needs in any way. He could barely even move. The Diamonds took turns spending nights at the hospital by his side, waking every two hours to turn him over so he wouldn't get bedsores.

Doctors were stumped. They explored several possibilities—including his having been strangled—subsequently ruling out each and every one of them. "At one point they thought it was something related to his liver," Lee recalls. "At another point they thought it was genetic. Or viral. Or maybe he got suffocated. The one thing that they unilaterally told us that it couldn't possibly be was the vaccinations."

"It wasn't even like, I'll think about it, I'll look into it," Chaney says. "It was just like, No."

Yet encephalopathy is known to be a possible side effect of the DTaP shot, one of the four Jackson received on December 8. The DTaP protects against diphtheria, tetanus, and pertussis, or whooping cough, and the government acknowledges that there may be a causal relationship between the pertussis component of the shot and brain damage. On the Centers for Disease Control's vaccine information sheet for the DTaP, permanent brain damage, coma, and "lowered consciousness" are listed as possible side

effects—with the caveat that they're "so rare it is hard to tell if they are caused by the vaccine." John Iskander, a medical epidemiologist and pediatrician with the CDC's immunization safety office, says doctors may not recognize encephalopathy as a vaccine reaction because it's so rare—"on the order of one in a million."

Which leads Lee Diamond to wonder if adverse reactions are more common than we think. "If the medical profession that should be at the forefront of recognizing signs of a reaction not only doesn't recognize them but disavows them," he says, "how could we possibly have accurate reporting?"

The CDC maintains that vaccines are extraordinarily safe and effective. They undergo a battery of tests before they're licensed by the FDA and recommended for use by the CDC, which publishes a childhood immunization schedule. States then adopt it, making the vaccines mandatory. Proof of immunization is required to enroll children in school, though every state allows for medical and religious exemptions, and 18 states—Illinois is not among them—allow for so-called philosophical exemptions.

As a result of widespread immunization, deadly and debilitating diseases like polio and smallpox have been eradicated in the Western Hemisphere, and others like measles and chicken pox have been greatly reduced. But maintaining these public health benefits requires that each new generation be immunized. That's why there are mass immunization campaigns, government assistance for vaccination, and national vaccine awareness months.

The CDC recommends that children receive 21 shots by the time they're 18 months old to protect against 12 infectious diseases, including hepatitis B, chicken pox, measles, mumps, and rubella. The CDC also recommends giving children multiple shots at a time; some, like the DTaP, are combination doses, containing more than one vaccine. Health care providers will sometimes administer even more than what's on the schedule in an effort to bring kids who've missed appointments up to date. It's not unheard of for kids to get injected with a dozen vaccines in one trip to the doctor's office.

Yet for all the good vaccines do, they can sometimes do harm. The CDC acknowledges that no vaccine is 100 percent safe. They're biological agents, and since not everyone shares the same genetic makeup or biochemistry, people's reactions to them differ.

Doctors are required by federal law to provide patients with the CDC's vaccine information sheets. The Diamonds can't recall if they received any, but say that even if they had it wouldn't have educated them adequately. "Overall there's a lack of information and a very aggressive immunization policy," says Lee.



And as with any medical procedure, he adds, "you trust the doctor, and by default you're going to do what the doctor tells you. You get the shots they tell you to get, you sign the papers they put in front of you, you cross your fingers and hope for the best."

The Diamonds say that after Jackson's seizure the doctors told them he couldn't be having a vaccine reaction because vaccine reactions don't present themselves so quickly. (Children's Memorial Hospital wouldn't make Jackson's physicians available for comment.) It was only after Chaney followed an Internet link to the Department of Health and Human Services' vaccine injury table that the Diamonds learned otherwise. Studying the table, a document the government refers to when handling compensation claims, they found encephalopathy listed as a possible reaction to the pertussis vaccine if it occurs within 72 hours and doctors can't find any other likely cause.

Around this time the Diamonds came across the National Vaccine Information Center, a parent-run advocacy group that's been agitating for vaccine policy reforms for more than 20 years. The NVIC claims to receive between 20 and 30 calls a day, 5 to 10 of them describing symptoms that could indicate serious adverse reaction. The group says that, like the Diamonds, many parents have been told that their children's conditions are unrelated to vaccines. "Doctors deny there are problems with vaccines," says Kathi Williams, who cofounded the NVIC with Barbara Loe Fisher after their sons suffered neurological damage following shots of DPT, the precursor to the DTaP vaccine. "It's an ongoing problem"—and one, she says, that can cause further harm to children. According to Fisher, if a child has a negative reaction that's overlooked or misattributed, it's likely he'll be brought back for booster shots, putting him at increased risk for

a negative reaction, perhaps one worse than the first time around.

Until about 15 years ago there was no centralized system for tracking adverse reactions to vaccines. The CDC and the FDA each operated its own database, and reporting was purely voluntary. The National Childhood Vaccine Injury Act of 1986 changed that, making it mandatory for doctors and vaccine manufacturers to report adverse events occurring within 30 days of a vaccination. In 1990 the FDA and CDC began jointly operating a centralized database for monitoring them, the Vaccine Adverse Event Reporting System (VAERS).

According to John Iskander of the CDC, VAERS receives about 15,000 reports a year. Most involve minor side effects such as fevers, rashes, and swelling and redness at the injection site. But about 15 percent involve hospitalizations and life-threatening events and illnesses such as convulsions, seizures, and brain damage.

VAERS can help identify patterns—collecting the names, manufacturers, and lot numbers of vaccines as well as information regarding the amount of time between their administration and the suspected reactions. But the government doesn't study individual cases to determine whether a reported incident was anything more than a coincidence. According to Iskander, it's virtually impossible to know how many serious neurological disorders like Jackson's are caused by vaccines. During a recent three-and-a-half-year period, he says, seven reports of encephalopathy or encephalitis following a DTaP shot were made to VAERS out of 35 million administered doses. But even if those seven were followed up on, he says, it probably wouldn't tell the CDC much.

"It's scientifically extremely difficult for individual cases to come to a determination," he says—there's too much uncertainty with such small numbers and, with the

inactivated pertussis toxin used in the DTaP shot, there's no live virus to isolate. "It's hard," he says, "to imagine a situation where you could say yes, that was definitively the cause."

Fisher and the NVIC believe that, as a rule, the government understates the risks of vaccination. Her reluctance to take the feds—or for that matter the pharmaceutical industry or medical establishment—at its word goes back more than 20 years. In 1985 she coauthored a book with Harris Coulter, a medical historian, called *A Shot in the Dark: Why the P in the DPT Vaccination May Be Hazardous to Your Child's Health*. Though evidence linking the whole-cell pertussis vaccine, or DPT shot, to neurological disorders was mounting, the U.S. government appeared to the authors to be looking the other way despite the existence of an effective and safer alternative, the DTaP, which uses the acellular pertussis vaccine.

Other governments were more responsive. Sweden banned the DPT in 1979. Japan stopped using it in 1981 after worries about adverse effects led to a drop in vaccination in the 70s—and a resulting pertussis epidemic. Japan reported a significant drop in complications after adopting the alternative vaccine.

In 1985, according to a 2002 article in the *Journal of the History of Medicine and Allied Sciences*, the Institute of Medicine, an independent research organization charged with advising the government, found the whole-cell pertussis vaccine to cause serious neurological disorders once every 110,000 injections and result in more than 10,000 seizures, 164 cases of encephalitis, and two to four deaths per year.

Nevertheless, according to geneticist Mark Geier, the article's author, drug companies deemed it too costly to test and manufacture the less-reactive vaccine. The FDA finally licensed

the DTaP for boosters in 1991 and for routine use in 1996, and in 1997 the CDC recommended it as a full replacement for the DPT. Yet the DPT shot wasn't taken off the market until 2001—20 years after Japan had made the switch.

Even VAERS's greatest success story may give pause. In 1999 VAERS made it possible for the CDC to learn that 15 infants had developed intussusception—a rare but dangerous condition in which the bowel folds in on itself—within a couple weeks of being immunized for rotavirus, a disease that can cause severe diarrhea and that results in about 50,000 hospitalizations a year. By the time the vaccine, which was introduced in March of 1998, was yanked from the market in the fall of 1999, a total of 55 cases had been reported to VAERS.

While looking into how the vaccine wound up being licensed and approved for use, the House Committee on Government Reform gained some insight into vaccine policy that surprised and disturbed its chair, Indiana congressman Dan Burton: the CDC and FDA advisory panels that recommended adding the rotavirus vaccine to the childhood immunization schedule were manned with people who had conflicts of interest. Several panel members, the House committee learned, owned stock in pharmaceutical companies that manufactured vaccines. One person—a member of the CDC committee—even owned a patent for the rotavirus vaccine.

The NVIC does not consider itself antivaccine but pro-informed consent, which it believes is possible only with better research and education. The group questions the way we go about administering vaccines to children. What was the logic, Fisher wonders, of adding a hepatitis B vaccine to the childhood immunization schedule in 1991? Why do infants need to be immunized against a disease whose risk factors are dirty needles and sex, especially when that disease “is not highly contagious, is not deadly for most who contract it, and is not in epidemic form in the U.S.?” Iskander says that hepatitis B is a serious and even life-threatening disease—particularly when contracted early in life. In many cases there's a risk of mothers passing it on to their children.

The NVIC has also long been concerned about whether there's a connection between autism and thimerosal, a mercury-based preservative pharmaceutical companies started using in some vaccines in the 30s. A controversial article in *Salon* by Robert F. Kennedy Jr. recently linked skyrocketing autism rates to three new thimerosal-laced drugs added to the immunization schedule in 1991, which had the effect of tripling the amount of mercury injected into children's bodies. This week, however, an article in the journal *Pediatrics* argues that while there may be

an autism epidemic, the government figures cited in support of a huge increase are unreliable.

Although the CDC maintains on its Web site that the “vast majority of studies, which have involved hundreds of thousands of children in a number of countries, have failed to find any association between exposure to thimerosal in vaccines and autism,” the agency recommended in 1999 that drug companies begin manufacturing pediatric vaccines without

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thimerosal “as a precaution.” Without a recall order, however, drug companies continued to draw on their old supplies, and thimerosal still is in use as a preservative in flu vaccines. The NVIC also questions the one-size-fits-all approach to immunization, where virtually all children are given the same vaccinations on the same timetable. Mary Megson, a Virginia pediatrician who specializes in treating autistic children she believes were harmed by thimerosal, would like to see a more customized approach to immunization. “There's a subset of children that cannot get vaccines in the same way other children can and tolerate them,” she says. Megson says she's found a genetic marker for adverse reactions, claiming that children with G-alpha protein defects such as night blindness are more likely to experience problems after vaccination. Iskander says the CDC is sponsoring a study on siblings that may shed light on genetic risk factors in vaccination.

After the rotavirus vaccine debacle, the CDC eventually concluded that 112 cases of intussusception—one fatal—had developed during the time the vaccine was administered, more than twice the number reported to VAERS. While VAERS made it possible to get a dangerous product off the market relatively quickly, better reporting might have made it happen sooner.

Kathi Williams suspects that some doctors refrain from reporting adverse events out of the fear that they'd be opening themselves up to potential lawsuits.

They wouldn't be—at least not initially. As part of the 1986 vaccine act, Congress, to keep pharmaceutical companies in the business of making vaccines after an onslaught of DPT lawsuits, established a no-fault system that compensates injured parties while protecting from liability pharmaceutical manufacturers and the health care providers who administer vaccines. Under the act, parties claiming injury cannot file civil suits against

health care providers, clinics, or drug companies until they've gone through vaccine court, where claims are filed against the Department of Human Services, defended by the Department of Justice, and decided by special masters specifically appointed by the U.S. Court of Federal Claims to manage and arbitrate cases. If the parties lose or reject a judgment in their favor they can pursue civil litigation, but the process discourages it: if people lose in vaccine court they'll probably have trouble in civil court as well.

Lee Diamond finds the shield from liability troubling. “Where's the incentive for a company to make a safer product if that's how it's set up?” he says. “What's the acceptable rate of failure? I would say everything that happened to Jackson is ridiculously severe. What's the acceptable number of kids that can happen to?”

Sherry Drew, of the Chicago law firm McDowell & Drew, is one of a handful of attorneys in the country who specialize in vaccine injury claims. She says the government's compensation program was created to be a swift and fair alternative to civil litigation, but that in reality the cases often drag on for many years, and the Justice Department fights them tooth and nail. “The vaccine act was intended to be nonadversarial,” she says. “But the Department of Justice is very zealous with their cases. And they have a point of view, and I have a point of view, and it's like any plaintiff and defendant in any case—the points of view diverge.”

Drew says she probably files a new petition every other month but that lately half of them are claims she's simply adding to an omnibus proceeding that's pending on behalf of autistic children whose parents believe they were injured by vaccines.

The vaccine act permits people to file claims only after an injury has persisted for six months. “I'll have someone call me and say, ‘My child had a shot, just had this horrible seizure with fever and this and that and spent a week in the hospital. What should I do?’” Drew says. “And I'll tell that parent what you do is you keep a journal and keep records of your expenses, but if your child goes back to being what he was before that seizure and doesn't have any more seizures, then you don't have a vaccine case and you should be very, very happy in spite of the fact that you just incurred \$50,000 in medical bills.”

Before taking a case, Drew combs through a client's medical records to see if factors unrelated to the vaccine were ruled out as likely causes for the injury. Claims are harder to argue if there's no presumption of causation.

In Jackson Diamond's case there was, and Drew filed a claim on his behalf on June 3. If a special master rules, or the government concedes that he's entitled to compensation, the case will

enter the damages phase and each side will bring in “life planners” to decide how much he should receive for such things as medical care, special equipment, and loss of future wages, as well as pain and suffering.

After a month doctors at Children's had done all they could do for Jackson, and he was transferred to the Rehabilitation Institute of Chicago, where he stayed for two months. The Diamonds brought him home in mid-March, and Chaney took a leave of absence from her job to care for him.

Jackson turned two on May 31. He no longer tries out his new words, or for that matter speaks his old ones. When propped into a sitting position, his chin falls to his chest—he's unable to hold his head up by himself. His expression is often blank. His eyes sometimes cross. He has a feeding tube connected to his lower intestine, and a tube in his stomach that must be vented to release gas. Gastrointestinal problems cause him to experience discomfort when he's held in an upright position, so the once lively toddler now lies on his back much of the day.

Jackson's on several medications to prevent seizures, reduce stomach acid, and control secretions. He's gotten better at showing emotion—he'll smile or laugh sometimes now—and it seems as if he recognizes his parents' voices, but, Chaney says, “We have no idea how much he understands.”

The Diamonds say that sometimes people who mean well tell them their son will be better someday, that he'll be out on the swing set before they know it. “They want it to be true, and so do we, but it's just not likely,” says Lee. The couple says they have no illusions. While they occasionally notice improvements in Jackson's condition, they acknowledge that what they consider triumphs—his smiling and kicking when they say his name, his tolerating something in his mouth—“would probably be very depressing to people on the outside.”

“He's going to need care the rest of his life,” Chaney says. “He may never be able to live independently.”

Because Jackson can't get around on his own, the Diamonds know they'll have to start looking for a new house, one that's handicapped accessible. “He's two years old now and he's a big boy. What about when he's five?” Lee says. Chaney adds, “We have to carry him in, we have to carry him out, we have to carry him up to his room.”

Now getting by on just one salary, the Diamonds pay out of pocket for insurance. They worry about finances. Jackson requires specialists for physical, occupational, speech, developmental, and vision therapy. The co-pays add up, and only a certain number of rehabilitation hours are covered. Some equipment that the Diamonds think would be good

for Jackson—a car seat that would allow him to be strapped down in a horizontal position, for example—isn't covered at all because it's not deemed a medical necessity.

The support they've received so far astonishes them. Lee's bandmate and his girlfriend have spent hours learning to care for Jackson so the Diamonds can sometimes enjoy a reprieve. Just recently they went out to dinner to celebrate their 11th anniversary. Chaney's colleagues at Wells Community Academy threw a benefit for Jackson, raising over \$20,000. Another benefit—a show at Subterranean featuring Lee's band, the Douglass Kings, along with Shellac, Silkworm, and Telenovela—will be held on Sunday, July 10. The Diamonds plan to donate 10 percent of the door and all the Douglass Kings' merchandise sales to the NVIC.

John Iskander warns that if people lose faith in vaccines we could find ourselves in the midst of a public health crisis. August has been declared National Immunization Awareness Month—a time for “celebration and recognition” as well as for renewing the commitment to work for the continued success of vaccines, according to a letter the CDC's director, Julie Gerberding, sent to the executive director of the National Immunization Partnership, a group that promotes immunization. The NIP's pamphlets—headed “Are You Up-To-Date? Vaccinate!”—call vaccines among the “safest medicines available” and point out that the “potential risks associated with the diseases that these vaccines prevent are much greater than the potential risks associated with the vaccines themselves.”

But improving awareness about those potential risks, Lee says, “doesn't have to mean causing a panic.” Even now, with all that he and Chaney have learned about vaccine reactions, he says, “We're not of the mind-set that immunization does more harm than good. But we think there are quite a lot of things that could be done differently.”

One thing the CDC advises against is vaccinating sick children if they have a moderate or severe illness. Jackson's physician was following protocol when he gave him shots though he'd been fighting a mild cold in the weeks before his December 8 appointment. But some researchers recommend avoiding vaccinations altogether when a child is ill. “It's hard to tell what's a mild cold,” says Mark Geier, who's studied vaccines for 30 years. “It could be a serious viral infection that maybe they have a mild case of. It's better to wait until they're not sick.”

The Diamonds would like to have another child someday, and they say if and when they do they'll approach immunization differently. They'll ask questions this time, they'll demand answers. They'll talk to the folks at the NVIC. And without a doubt they'll seek a medical exemption for the pertussis vaccine. **D**