

Outbreak

Why are so many young kids in Boston's well-to-do suburbs getting diabetes? Weston mom Ann Marie Kreft has been raising that question with anyone who will listen—and now she's enlisted some famous allies to find the answer.

By **Gretchen Voss**

The call comes at 3 a.m. Shannon Allen rolls over in her bed at the Four Seasons in Los Angeles and grabs her cell phone. "Ray," a sleepy Shannon says, "it's 3 in the morning." She knows the game tomorrow will be perhaps the biggest of his life. He's the most focused, disciplined man she's ever met: He should be sleeping.

"I'm praying," Ray Allen says, calling from the team's hotel, the Beverly Wilshire.

"Ray, you're ready. You've worked your whole life for this moment. You're prepared...."

"No," Ray cuts her off. "I'm praying for Walker. He just doesn't seem right."

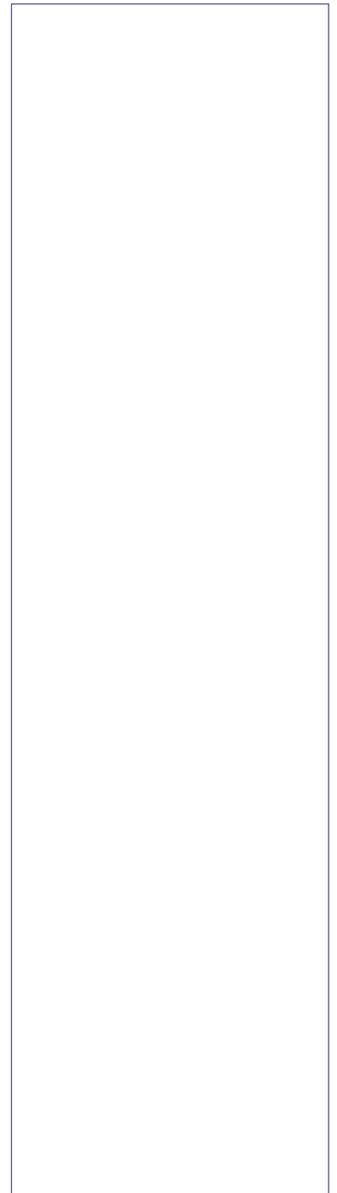
Walker, their 17-month-old son, hadn't been his usual wild-man self since they touched down in Los Angeles five days ago, on June 9. On June 10, Ray and the Celtics lost to the Los Angeles Lakers in Game 3 of the NBA Finals, giving L.A. their first win in the series. On the bus ride back to the hotel, Walker vomited all over Shannon's No. 20 jersey. He spent the next few days lolling about, listless and lethargic, wanting only to eat and sleep. *Juice, Momma*, he said over and over. He had never asked his momma for juice before; Shannon thought he must be dehydrated, maybe jet-lagged. But nearly a full week later, Walker wasn't feeling any better, and Ray, on his visit to the hotel earlier that evening, had been concerned. So concerned that he couldn't sleep. So concerned that he prayed. So concerned that he calls Shannon now and wakes her up. "Please keep a close eye on him," he says before hanging up. "I'm worried."

Walker sleeps through the conversation in the bed next to Shannon. Soon she herself drifts off. But at dawn, Shannon wakes to Walker throwing up all over the sheets. She phones the hotel's on-call pediatrician. Take him to Cedars-Sinai and have them run blood work, the doctor tells her. Just to be safe.

The hospital's pediatric physician does not think drawing blood is necessary. Walker probably has a little bug, she says. But Shannon insists. Twenty minutes after leaving the room with the vial, the doctor returns, tears in her eyes, her face wan. She tells Shannon that her son has type 1 diabetes. A normal blood sugar count is between 80 and 120; his is 639. Walker's pancreas is not functioning. His blood is full of ketones—the acid residue that develops when a body burns fat instead of sugar in a desperate bid for energy. If Walker doesn't get insulin soon, he will die.

Shannon calls Ray. He's in a cab on the way to the Staples Center for Game 5—the final game, if Boston wins. He wonders whether he should forget about basketball tonight. "Tell me what to do," he begs Shannon. She tells him to play the game. But that night Ray's mind is elsewhere. He scores 16 points on 4-of-13 shooting, and the Celtics lose. He leaves the arena immediately afterward.

Coach Doc Rivers issues a vague statement to the media about Allen attending to a sick child. When the team boards a Boston-bound plane Monday morning to prepare for Game 6 on Tuesday night, Allen stays behind. It doesn't take long for rumors to circulate through the blogosphere and the sports bars of Boston: Allen might miss the contest. He spends all of Monday at Cedars-Sinai with his wife and son.



Walker is by this point in stable condition. But the Allens listen to doctors and nurses and nutritionists explain how the boy's life—and theirs—will never be the same. Walker will need daily shots of insulin. Mealtimes will become an exercise in vigilance.

Ray and Shannon hire a private nurse, who flies with the Allens overnight on the Celtics' plane back to Boston. Further tests are scheduled at Children's Hospital. But first, Ray Allen must play Game 6. That night, as part of his pregame ritual, he palms the parquet floor before trotting onto the court. He points to his family sitting courtside: Shannon and Walker, now joined by oldest son Walter Ray Allen III and daughter Tierra.



Allen scores 26 points, and the Celtics bring home their 17th NBA title, their first in 22 years. Allen's family rushes the court. Confetti rains down and Ray reaches for Walker, hoisting the little boy in his arms.

Two days later, when Allen announces to the press that his son has diabetes but is doing well, newspapers and TV stations run a photo from that championship night—of Allen holding Walker and raising his thumb in triumph. It seems to tell the whole story.

But it doesn't. Ann Marie Kreft, a mother in Weston, sees the Walker Allen piece on the news. A few weeks later she finds out the Allens live just over the town line, in Wellesley. For Kreft, Walker Allen has just added to the mystery she is desperately trying to solve.



No one knows for sure what causes type 1 diabetes. It is partly genetic (sufferers have predispositions to autoimmune diseases in general), but the condition itself is also triggered by one or more environmental agents. After Ann Marie Kreft's son, Gus, age seven, was diagnosed a year and a half ago, she dedicated herself to finding out why, exactly, her son developed the disease—and why, exactly, so many other kids living nearby had it, too. The state does not keep a registry of diabetic children, so Kreft, with the help of other concerned parents, started compiling her own. What she found is that something unsettling is going on in the suburbs of Boston. And though it has taken a while, she is no longer the only one who sees trouble in the data she's collected.

In the medical community, there's a general sense that diabetes diagnoses are increasing everywhere, with the Centers for Disease Control estimating that one out of every 4,166 children under the age of 20 can now expect to develop the disease. What's happening in Massachusetts is alarming, but for a slightly different reason: Children are being diagnosed within weeks or months of one another, some of them living within a close geographic range. According to Kreft's figures, seven have been diagnosed within a two-mile radius encompassing Weston and Wellesley. There

have been five new diagnoses in just 10 months in Concord. Five children have been diagnosed on one 30-house street in Plymouth. A Boston University journalism professor, Elizabeth Mehren, recently e-mailed Kreft about her son, who was diagnosed within six months of another kid from the same Hingham street; a third child on the street had also been diagnosed around that same time, as had one on the street perpendicular. Suburban moms from Walpole to Marshfield, Westford to Belmont, tell Kreft that they are worried about their child, their neighborhood, their town.

Kreft, a 46-year-old housewife, has a lithe frame, straight blond hair, and an Erin Brockovich vigor about her. Her familiarity with diabetes extends beyond her son's diagnosis: Her father died of complications from the disease when she was 17 years old. His drawn-out death—from kidney failure, in the end—was devastating to watch. Though Kreft herself was spared the disease, she spent her teenage years worrying that her future children would develop it; she'd heard an old wives' tale that diabetes skips a generation. Once fully into adulthood, however, and certainly by the time she fell in love with Tim Ramsey, a chemist, who would later become her husband, that fear receded, and she fell into her life's routines. Then one day in September 2007, when Gus was seven, he needed to pee every 10 minutes. He also could not stop eating—devouring a third breakfast and asking for a fourth. She understood immediately that her son had her father's disease, and the next day, after a blood test, and out of sight of Gus, she bawled at the dining room table. When the doctors at Children's Hospital later tried to assuage her fears, she wanted to pummel them. She knew too well.

Kreft's need to understand why Gus had been handed this fate led her first to the Internet. She also started a charity, Treats for the Troops, in which kids donate the Halloween candy they cannot eat to be sent to soldiers in Iraq. Before the charity's inaugural event, she learned of a neighborhood family whose daughter had recently received a type 1 diagnosis. Two months later, Kreft heard of a boy down the road with the disease. The month after, another boy six houses down. "It just started to get more and more strange," she says. "And then every time we got a new diagnosis, I felt it all over again. That terrible punch in the stomach." She fixated on the unknown environmental trigger. *What the hell is out there that is making all these kids sick?*

When she heard about Walker Allen, Kreft felt she could use the high-profile case to make the public aware of the growing threat in her neighborhood. She wrote a pleading letter to the *Boston Globe*, which the paper published on July 17. "Something's not right here," she wrote. "These many diagnoses, in this tight proximity in this short period, are way out of the norm. We would be grateful if a researcher tried to figure out what's going on."

In type 1 diabetes, once called juvenile diabetes for its tendency to strike children, a person's immune system attacks the insulin-producing cells of the pancreas; when the pancreas stops producing insulin, which regulates blood glucose, the body stops converting the carbohydrates in food into energy. Theories about the disease's environmental trigger abound, some more credible than others. They include diet (type 1 is less common in children who were breastfed); hygiene (unnaturally clean suburban kids, Purell-ed by their nervous parents every five minutes, may have fewer early-life infections, and hence underdeveloped immune systems); viruses (some scientists think intestinal tract or Coxsackie viruses are possibly to blame); climate (type 1 develops more often in the winter and is more common in colder climates); psychosocial issues (stress may be a catalyst); or some unseen toxin sprinkled on manicured lawns. Immunizations, vitamin D insufficiency, heavy metals—all are under investigation. None has emerged as the definitive culprit.

For all the investigations of potential environmental components, type 1 diabetes is not viewed as an infectious disease, and accordingly the Centers for Disease Control doesn't keep a database of those diagnosed; instead, it classifies type 1 as an autoimmune disease. (Type 2 diabetes, associated with poor diet and irregular exercise, accounts for up to 95 percent of diabetes diagnoses. It is not autoimmune in nature, but rather is linked to genetic and environmental factors.)

The fact that no one is formally tracking the disease makes queries into the existence of type 1 diabetes clusters nearly impossible to answer. In fact, until recently the mere idea of a type 1 diabetes cluster was ridiculed in some circles. Dr. Giuseppina Imperatore, the head of the CDC's epidemiology team within the agency's diabetes division, barely suppresses a chuckle when asked about the purported cluster in Weston and Wellesley. While there have been a handful of investigations into "so-called clusters" over the years, none of them, she assures, turned up conclusive evidence of a pattern. Dr. Lori Laffel, an investigator in genetics and epidemiology at the Joslin Diabetes Center in Boston, inquired about clusters herself after Kreft told her about the data she had compiled. Laffel called the researchers at Search, a CDC-funded study of kids with type 1 and type 2 diabetes in six locations across the country. "The simple answer was that they have not been able to identify clusters in their data," she says.

Since the advent of lab-produced insulin in 1922 turned the disease from a fatal diagnosis into a chronic illness, diabetes funding has looked mostly to manage patients' condition. (Even with insulin, diabetes patients die younger and face the constant threat of devastating complications: kidney failure, blindness, nerve damage, amputation, heart attack.) Caring for type 1 diabetes patients is a \$17 billion industry, and researchers are therefore inclined to focus on those complications, rather than on the root causes of the disease. "It's safe research," says Dr. Denise Faustman, director of Mass General's immunobiology laboratory. "It's a revenue stream."

Faustman, a petite blonde with a big laugh who was once dubbed "the Madonna of modern medicine" by the magazine *Current Science*, is not interested in that kind of research. She's interested in curing diabetes outright. She feels it's obvious why previous attempts to do that failed, and that these failures illustrate a further point about the politics of diabetes research. They didn't (or didn't want to) address the autoimmunity aspect of the disease, in which the body's immune system inevitably kills the insulin-producing cells in the pancreas.

And yet in the early 1990s, Faustman conducted experiments on mice that used a generic drug to target the killer cells within the immune system. The drug reversed the cells' devastating effects, and the animals' pancreases healed. Just regenerated on their own. It was revolutionary. It also unleashed an ugly backlash within the scientific community: Here was a potential cure that could eliminate all sorts of research dollars. "If you change a paradigm, you're not going to get invited to cocktail parties," Faustman says. She received Food and Drug Administration approval to move forward to human trials in 2002, but none of the usual suspects would finance her efforts. The

Juvenile Diabetes Research Foundation alone rejected three funding applications from her. The reasons, it says, are confidential, but Faustman thinks she was done in by rival scientists who peer-reviewed her research results, and who knew they could be out of a job if her work went forward. The big pharmaceutical companies also weren't interested in her research, because her drug was a generic already on the market to treat other conditions. It wouldn't add to any of their bottom lines.

Faustman finally found a prominent backer in former Chrysler chairman Lee Iacocca. His wife had died of complications from diabetes, and he not only gave her millions from the Iacocca Foundation, but also convinced Chrysler to become an official sponsor of Faustman's human trials in 2005 and 2006. He's since been joined by other patrons: A legion of biking and baking and auctioning mothers much like Ann Marie Kreft have gathered millions of dollars for Faustman's research. "I call them the Mad Moms," Faustman says with a cackle. It's been a hard and weird slog, a molecular biologist raising her own funds. The results of her trials should be known in three to four years.

Yet notwithstanding her iconoclastic tendencies, Faustman, too, isn't much for cluster research. She thinks investigating clusters could mean, in the end, investigating nothing more than race and class. Seventy-seven percent of the children under age 10 diagnosed with type 1 diabetes are white. Ritzzy (and largely white) enclaves such as Weston and Concord, then, may not be ground zero for an emerging epidemic so much as they are areas disproportionately populated with hyperattentive parents who think the problems afflicting their children are as unique and special as the children themselves, and therefore warrant exhaustive study. "A family came in today and said six kids on the same street got diabetes six years ago in a three-month period," Faustman says. "Every parent comes in here and says the same thing."

Thwarted by the prevailing scientific attitudes, Kreft has found she needs a different course of action to get the public's attention. Here a local, and famous, precedent exists. The better analogy for Kreft, ultimately, may not be to Erin Brockovich but to a Woburn housewife named Anne Anderson.

Nearly 30 years ago, Anderson found similar patterns with cancer in her Pine Street neighborhood, as famously chronicled in the bestselling book and movie *A Civil Action*. After her three-year-old son, Jimmy, was diagnosed with childhood leukemia, she noticed there were an unusual number of children—12 in all—getting sick and dying in her part of town. Anne Anderson suspected the water in the nearby municipal wells was the culprit, and her persistence led her to a woman named Suzanne Condon, an environmental epidemiologist and now director of environmental health at the Massachusetts Department of Public Health. It was Condon who determined that leukemia rates were indeed abnormally high in east Woburn. She then linked the cluster to contaminant-laden water the mothers drank while pregnant.



As it happens, Ann Marie Kreft knows Suzanne Condon. They worked down the hall from each other at the Department of Public Health when Kreft was a health educator for cancer prevention. A year ago this month, on February 29, Kreft sent Condon a letter: "I am writing to ask for your help with a crisis that our neighborhood is encountering." She and Condon began corresponding by e-mail. In response to Kreft's July letter to the *Globe*, other parents from across the state deluged Kreft's in-box—a mom from Concord offering a tip about the five cases in her town, the worried professor sharing her report from Hingham, and so on. Kreft passed those messages on to Condon. Condon, wondering whether something might again be amiss in Massachusetts' towns, told Kreft she would look into the numbers.

One night this past fall, Ann Marie Kreft swings into a Weston driveway and pulls up in front of a sprawling Nantucket-style mansion. It's the home of Kevin Conley, chairman of the board of the Joslin Diabetes Center and owner of Conley & Company, an executive-recruiting firm that donates 25 percent of its profits to diabetes research. Inside, past the sweeping staircase curling off the grand entrance hall, Kreft accepts a glass of red wine from Conley and soon is chatting with his wife, Rikki. The Conleys have two daughters with type 1 diabetes. The girls are not part of Kreft's Weston cluster (they were diagnosed years earlier), but the Conleys and Krefts have become dear friends because of the disease—and the Omni brand of insulin pump—their children share.

Tonight, roughly 12 residents of "Omniville," as Kreft calls her neighborhood, have gathered to discuss their research into diabetes and clusters over a decadent spread of sushi and fruit, brownies, and cheese pastries. The mothers (and they are almost all mothers) have

come together twice before, but there is a notable undercurrent of nervous energy to this session.

Shannon Allen arrives 15 minutes late, her husband in tow. The rest of the guests are giddy as they shake hands and make small talk with the couple. Ray Allen, dressed casually in jeans and a white T-shirt, eventually folds himself onto a leather sofa and gracefully commandeers the conversation. He says he was shocked when he read Kreft's letter in the *Globe*. He ran into another father on the golf course, whose daughter is in the Weston cluster, and knew he had to come tonight.

Kreft perches on the edge of the couch, gently cupping her goblet of wine, as she explains to the Allens what she's learned about the neighborhood's diabetes cases. "One thing that's interesting to look at with us is that [on a map] five of us are in a straight line," she says. "And you can't help but notice we're hugging the [Charles] river, the golf course, the train tracks—everything right along the highway."

"I know what my gut tells me," Shannon says in a fast-paced, raspy voice. "After the diagnosis, all that I could think was that for the whole spring my kids were out in the backyard squirting each other with the hose and drinking out of the faucet. That was the first thing I thought: Oh my God. I am testing our water."

"But that's the thing," Ray says. "It will take us to figure out what's going on." He explains that while he was at the White House to meet President Bush after the championship in September, Illinois Congressman Tim Johnson introduced himself, relaying that his father has diabetes. Ray told Johnson about Kreft's letter, about the seeming cluster in his neighborhood.

Ray looks around, and the other parents lean in, rapt. He says the congressman mentioned he had contacts at the CDC, and said he would get the Allens some answers.

That same day, Dr. Thomas Sinks, deputy director of the Agency for Toxic Substances and Disease Registry at the CDC, called Shannon at home. His office—which is separate from the CDC's diabetes division—had never looked at the potential existence of type 1 clusters, but he wanted to be of service in any way he could. When Ray Allen later told Sinks about this evening's meeting, Sinks offered to speak to the group by phone (Allen graciously turned him down); he also said he would put in a call to the state health department. (When contacted for this article, Sinks wouldn't discuss the specifics of his conversations with the Allens, nor what he'll be examining based on those conversations, but did confirm that the calls took place.)

Kreft nearly falls off the couch upon hearing Ray's news. Despite the luck she's had with Suzanne Condon, she knows firsthand how difficult it can be to get access to the CDC and its resources. "I just think we have the most incredible, unique, wonderful opportunity," she says, her face flushed. "I mean, wow. I mean, how good is this? This is just amazing." Shannon agrees. "As horrible as this is, I told Ray, 'Things have to happen to people who have a voice that can be heard in order for it to matter to everyone else.'"

Suzanne Condon has a quote taped to the wall of her office on Washington Street in Boston: "Public health begins with surveillance. Without surveillance, it's difficult to learn anything at all." She lives by the words. It was surveillance—gathering the hard data—that allowed her to begin unravelling the mystery of the leukemia cluster in Woburn, to link its children's cancer to contaminated drinking water.

Before hearing from Kreft, Condon had noticed mentions of possible environmental triggers for autoimmune diseases in various scientific journals, including suggestions that the illnesses could be triggered by chemical solvents. Because type 1 diabetes is in part an autoimmune disease, Condon thought the chemicals could perhaps be its environmental trigger. Kreft's letter only further piqued her interest. These diagnoses in Weston and Wellesley did seem abnormally close in time and space. The only way to know for sure what was happening was to get some surveillance, some real numbers, to compare them with.

Condon oversees an annual statewide survey of asthma cases in students from kindergarten to eighth grade. In January 2008 she decided to include questions about diabetes on the form. It was the first diabetes survey of its kind in the country. Condon finished the preliminary analysis this summer, and she noticed something rather unusual. According to CDC estimates, about 183 in 100,000 children in that age group could be expected to develop type 1 diabetes, but in Massachusetts the number was significantly higher: 265. There are two possible explanations for the disparity: The CDC's estimates are off, or, for some nefarious reason, the disease is striking Massachusetts children at an alarmingly increased rate.

To try to determine which explanation is the right one, Condon's staff is now sorting through the data community by community and school

by school. It is a massive labor, made even more daunting by a federal law called the Family Educational Rights and Privacy Act, which was reinterpreted a few years ago to forbid school officials from sharing children's names or other identifying information with public health researchers. As it stands, Condon knows only the number of children in each Massachusetts public and private school who have been diagnosed with type 1 diabetes, as reported by the school nurse who filled out the extra questions on the asthma exam. She does not know whether any of them live in the same neighborhood or if they were diagnosed within a small window of time—in short, whether there is evidence of a potential disease cluster. Those vital details, Condon says, will have to come from Ann Marie Kreft's contacting the families in her database and asking them to share their personal information with her.

And marrying that information to Condon's numbers will only be a small step. To uncover what in the environment might be making these suburban children sick is the truly hard work, the stuff of, yes, blockbuster books and movies. "It may be a dietary thing," Condon ventures. "These are wealthier communities. Do they have a diet that's more likely to contain something that we may someday find out has something to do with type 1 diabetes? Some expensive cuts of meats and fish have higher levels of PCBs, for instance." It could be the river, much as it was Woburn's contaminated water. It could have something to do with the railroad tracks, which, Condon notes, may be sprayed with toxic pesticides otherwise banned from residential neighborhoods. It could all just be a bunch of horrible coincidences. The only way to find out is to keep digging.

In early November, the CDC's Sinks called Condon and asked her to open an official investigation into the type 1 cases in Weston and Wellesley. He was surprised to hear that Condon had already found more diagnoses than Kreft had originally turned up through her amateur epidemiology efforts. According to Condon's figures, there are now six children in Weston, and 17 in Wellesley, as well as 28 in Newton. There are many more towns still to tally.

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