

YOU
AT YOUR
BEST

SELF

They said the baby was fine.

Wrongful life?
Hardly. But
how do you
decide if a
child is worth
the risk of
being born?

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He wasn't.

Cutting-edge prenatal gene tests now give parents a chance to detect birth defects in time to end a troubled pregnancy. But what can families do when a child's clean bill of health turns out to be tragically wrong? SELF reports on the heartbreaking and hugely controversial step one mother decided to take. By Sabrina Rubin Erdely

for the first six months of his life, Shari Ungerleider's son, Evan, seemed completely normal: He babbled and cooed just like the other babies in their Wayne, New Jersey, play group and was all chubby-cheeked smiles for his doting mom. But by the time Evan turned 8 months old, Ungerleider began to notice that her blond, dark-eyed boy was falling behind. He slouched, unable to sit up for long. His alert smile turned vague and distant. While other babies his age scabbled on the floor like turtles, Evan seemed content to lie on his back—and was growing more and more listless.

Shari and her husband, Jeff, rushed their only child from specialist to specialist for three frantic months, watching helplessly as Evan endured blood work, biopsies, exams, EEGs. Ungerleider nearly broke down at the sight of Evan's diapered and sedated body lying on a conveyor belt, sliding backward into an MRI tube. *Please*, she prayed, invoking the worst diagnosis she could imagine, *don't let it be a brain tumor*.

Evan's true diagnosis proved even more dire. He had Tay-Sachs, an incurable genetic disease that kills by age 5. As she struggled to digest the news, Ungerleider's mind reeled with grief, but also confusion: She'd been screened for Tay-Sachs during her largely uneventful pregnancy and had tested negative. Ungerleider called her obstetrician and begged him to review her records. Later, he called her back.

"Oh, my God," she remembers him telling her. "I misread your test. You are a Tay-Sachs carrier."

The memory of that moment in 1995—of the magnitude of what went wrong—still makes Ungerleider cry. "It was a *mistake*," she says bitterly, grimacing at the inadequacy of the

word. Seated at her kitchen table before a mug of steaming coffee, Ungerleider, 36, dabs at her eyes with a manicured fingertip. "A *mistake* is telling someone they have a cold when they really have the flu. This *mistake* was going to kill my child." The Ungerleiders wanted to fight back however they could. They decided to file a controversial medical malpractice complaint known as a wrongful-birth lawsuit. In it, they contended that had they been properly informed of Evan's genetic defect, she would have had an abortion.

"I loved every second I had with Evan," Ungerleider says, her dark eyes filling. "But as a parent, would I have spared him a life of suffering? Absolutely."

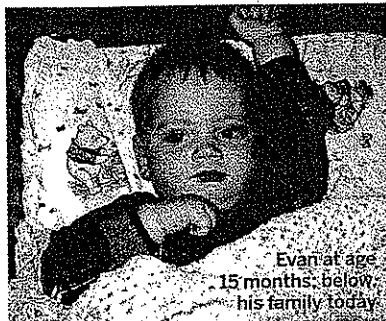
It's a harsh—and heartbreaking—statement for any parent to make, to wish that your child had never been born. But in wrongful-birth lawsuits, it's invoked not only by parents of terminally ill children, but also by people whose doctors failed to diagnose a range of defects in a fetus during pregnancy, including Down syndrome, spina bifida and fragile X syndrome, a chromosomal defect that is one of the leading causes of mental retardation. A sampling of some current lawsuits sounds like a rundown of any pregnant woman's worst fears. One California couple is suing a doctor for allegedly neglecting to mention a state-mandated test that could have detected spina bifida, a condition that left their daughter partially paralyzed. A Minnesota woman whose baby was born with fragile X claims that a miscommunication by her doctor led her to believe that a screening had turned out negative when it hadn't been performed at all. An Indiana couple sued a lab, claiming that an ultrasound revealed that their daughter had hydrocephalus,

or fluid on the brain, but, due to a clerical error, their doctor was never informed. Whatever the details, there's one necessary ingredient in a wrongful-birth complaint, explains Ungerleider's attorney, Bruce H. Nagel, of Roseland, New Jersey, one of the few lawyers who specializes in wrongful-birth cases. "In all cases, the mother must testify that had she had the medical knowledge, she would have terminated the pregnancy. Without that, there's no cause of action."

Therein lies the controversy. Advocates for the disabled decry the cases as endorsing a form of eugenics. And antichoice activists are up in arms because the cases rest on the notion that the mother has the right to terminate a pregnancy (a right that is, of course, guaranteed under current law). "I think of Hitler's Germany," says Mary Spaulding Balch of the National Right to Life Committee in Washington, D.C. "You're choosing who gets to live and who dies, based on an arbitrary standard, and that's a dangerous situation." Ethicists, meanwhile, are torn over wrongful-birth claims, as well as similar wrongful-life suits, in which disabled children themselves (or people acting on their behalf) argue they shouldn't exist. After all, some disabilities are so devastating that the child would probably be better off never having been born, says Arthur Caplan, Ph.D., director of the University of Pennsylvania Center for Bioethics in Philadelphia. "But where do you draw that line?" he asks. "It's one thing if we're talking about a genetic disease where a child is in constant, terrible pain, like Lesch-Nyhan syndrome," a rare defect that makes a child compulsively mutilate himself before dying an early death. "But Down syndrome? That's a call a lot of people don't want to go on record making."

In fact, many courts haven't been willing to enter such Solomonian territory. While wrongful-birth cases have surfaced in malpractice-friendly states such as California, Florida, Illinois and New Jersey—and in countries like Australia and the Netherlands—they've been rejected or limited in more than two dozen other states, including nine whose legislatures have passed laws barring the suits altogether. "Simply stated, the life of a child cannot constitute an injury," wrote a Kentucky Supreme Court justice in a 2003 ruling. Idaho's top court concurred this past spring; at the same time, the issue was being debated in two cases before Ohio's Supreme Court, whose decisions are due any day now.

Despite some courts' reluctance to handle them, wrongful-birth claims are on the rise, says attorney Dennis Donnelly, whose office in Chatham, New Jersey, has handled dozens of the suits. The increase has been spurred in part by the growing sophistication of the nearly 2.8 million prenatal screening tests given each year in the United States; the more doctors are able to predict bad outcomes, the more they're being held responsible for accurately passing along that knowledge to patients. The rising cost of health care also plays a role, Caplan



Evan at age 15 months: below his family today



notes. Some parents simply can't afford their children's medical bills, making a lawsuit a financial necessity, especially when they have other children to support. And there's a third reason.

"These parents are pissed," Caplan says. "Some of the angriest people I've ever seen are people who have children with birth defects and could have avoided it. As odd as it is to say, 'My child shouldn't exist,' they're so intent on punishing the health care provider that they don't care."

Shari Ungerleider, for one, doesn't think it's an odd claim at all. "As a parent, you always want to protect your children," she explains. "And it starts from when you're pregnant." Even if, she asserts, that means protecting your child from being born in the first place.

Shari and Jeff Ungerleider couldn't wait to have a baby. They'd married when Shari was 24 and working as a human resources administrator, only 11 months after meeting on a blind date. "You just know when it's right," she says with a smile, fiddling with her sparkly wedding band. Ungerleider got pregnant almost immediately. She was thrilled—and petrified. "I was the first of all my friends to have kids, so I was in it by myself," she recalls. Her mother had died of cancer months earlier, which compounded Ungerleider's isolation. But being pregnant also helped her focus on something other than her grief. As her August 1994 due date approached, she pictured her afternoons spent nuzzling with her baby at Gymboree classes and pushing him on playground swings.

Instead, their days were a blur of doctor's offices, beeping monitors and panicked phone calls. Tay-Sachs children lack an enzyme that breaks down fatty acids; as a result, the nerve cells of their brains and organs accumulate too much fat, which gradually shuts down just about every body system. At the age when other kids were taking their first steps, Evan was no longer able to hold himself up for more than a few seconds. He had a feeding tube implanted into his stomach, as he would soon lose his ability to swallow. He never uttered a word. "He'd smile sometimes, but a lot of those were seizures," Ungerleider says. "We didn't realize it at first—or didn't want to realize it—because we were happy he was smiling, whatever form it was." The Ungerleiders asked their parents and siblings to each wear a signature cologne, so that by the time Evan went blind, he'd be able to recognize them by their scent.

Ungerleider tried her best not to think about where all their efforts would inevitably lead. "But I couldn't help myself; I thought about it every day," she says. "It tore me up inside."

From looking through her ob/gyn file, Ungerleider had quickly figured out what went wrong with her prenatal screening. Tay-Sachs is a disease that typically afflicts Ashkenazi Jews—Jews of northern and central European descent, like Shari and Jeff—and, therefore, Ungerleider's doctor had

ordered a genetic blood test to make sure she wasn't a carrier. As Ungerleider recalls it, her blood was sent to her insurance-approved lab, which in turn farmed it out to a second lab. That lab's conclusion, which it submitted to the original laboratory, was reportedly unambiguous: She was a carrier. But the first lab rewrote the results into a busy, poorly organized report; as Ungerleider looked through the sheaf of papers that eventually made it back to her doctor, she realized that, if one read it at a glance, the eye was drawn to the word *normal*. Which is evidently how her doctor had read it.

"I adored him. I trusted him. I thought he knew what he was doing. And I was wrong, obviously," she adds. The Ungerleiders met with lawyers about a malpractice claim against the doctor and the original lab. They'd never heard of a wrongful-birth suit before, but it fit their situation perfectly, and painfully. "Does it hurt to say, 'Had I known, I wouldn't have had Evan?'" Yeah. It does," Ungerleider says. "But I don't think anyone can truly understand what it's like to have a child and to know that child is going to do nothing but suffer for five years. To me, that's wrong, to knowingly put a child through that."

Awash in anger and sorrow, the Ungerleiders were certain of another thing: "We wanted to have more children," says Shari, and when Evan was 18 months old, she became pregnant again. The couple knew that because they were both carriers, their odds of a Tay-Sachs pregnancy were one in four. It was 10 weeks before Ungerleider could have the genetic test to determine if the fetus had the disease. The wait seemed interminable. "I was afraid to get attached to the pregnancy," she admits. Luck was on their side: The baby was healthy.

The Ungerleiders tried to give their new son, Justin, a normal life. It wasn't easy, when even the simplest family outing meant leaving the house loaded down with Evan's special handicapped stroller, medical kit and portable oxygen tank. The family pulled out all the stops for Evan—including round-the-clock home nursing—bearing substantial out-of-pocket costs. They still managed to make ends meet, thanks

to Jeff's well-paying job for a financial-services company and all the grandparents chipping in.

As is typical with parents of disabled children, Ungerleider's own needs fell by the wayside. Going to graduate school was out of the question. Lunching with a girlfriend or unwinding in front of the TV was unthinkable. Bedtime reading consisted of self-help books. And the house was always filled with people; the couple didn't even have privacy enough to argue. Little by little, their relationship cooled. "We had to get to know each other again," Ungerleider says. They began seeing a psychologist, which proved so helpful that they made it part of a standing Thursday-night date: dinner and a shrink.

By age 3, Evan was as floppy as a rag doll, except during his seizures, of which he'd have some two dozen "on a good day," Ungerleider says. His resistance was so low that any venture out of the house meant risking pneumonia. He'd already outlived the life expectancy of many Tay-Sachs sufferers.

It was then that Ungerleider discovered she was pregnant for a third time. A gene test revealed that her fetus had Tay-Sachs. "Devastating," she remembers, shaking her head. The decision was clear. She had an abortion.

Most wrongful-birth cases are settled out of court. With tales this emotional, however, it's little wonder that when a suit does go to trial, jurors find themselves brushing away tears—and meting out big money. New Jersey wrongful-birth juries have awarded \$1.85 million for a Down syndrome baby and \$1 million for brain damage; in a 1998 wrongful-life case, a Texas jury awarded a severely brain-damaged girl \$60 million (though the verdict was later reversed). As with any medical-malpractice suit, the standard for a jury to consider in a wrongful-birth suit is whether or not the doctor made a mistake. But with mothers sobbing as they testify about their suffering children, marital strain and astronomical medical bills—and even the lawyers getting choked up sometimes—it's difficult *(continued on page 198)*

SHOULD YOU BE SCREENED?

There's not much couples can do to prevent the misreading of a prenatal test. But even when the process goes smoothly, difficult questions can arise. Partners can prepare themselves by discussing these questions in advance, including the toughest of all. Get further guidance from the National Society of Genetic Counselors at NSGC.org.

How early can we get screened? Even before pregnancy, you and your partner can have blood tests to pinpoint gene mutations that are known to cause inherited diseases.

How high is our risk for a genetic defect? Tay-Sachs and Canavan disease, a fatal degenerative brain disorder, are most common among Ashkenazi Jews. African-American and Hispanic couples are more likely to pass on sickle-cell anemia. The American College of Obstetricians and Gynecologists in Washington, D.C., now recommends that all couples seeking prenatal care be screened for cystic fibrosis, which one in 29 Caucasians and Ashkenazi Jews carry.

What to ask each other before seeking a gene test

Is IVF an option? Couples who discover they are both carriers may decide to undergo in vitro fertilization so their doctor can prescreen their embryos for defects.

What about amniocentesis? This test allows doctors to look for defects by drawing amniotic fluid from the sac surrounding the fetus. But it carries a chance of miscarriage. Talk to your doctor about the rate in her practice.

How late would we wait? Doctors must hold out until the second trimester to detect some problems. Testing for spina bifida, for instance, is done between 15 and 18 weeks.

Would we end the pregnancy? "Of course, what you think you will do and what you will actually do sometimes differ," says Kathy Hudson, Ph.D., director of the Genetics and Public Policy Center at Johns Hopkins University in Washington, D.C. "But talking about it is an important exercise before you jump in." —EMILY DONNELL

Baby

(continued from page 195) for a jury not to feel sympathetic, says bioethicist Caplan. "Juries say, 'Boy, you deserve something.' But it doesn't mean that they've stood on the principle that a child shouldn't have been born."

That central premise, of course, presents the big ethical dilemma. A person might be able to justify preventing the birth of a baby with a terminal disease, in which a child like Evan Ungerleider lives his short life in misery. Or, perhaps, a case in which a child is born in a vegetative state, as in a wrongful-birth claim that the Kentucky Supreme Court dismissed in 2003; a woman claimed doctors had assured her that her ultrasound was normal, but the fetus actually had a giant cyst where most of its brain should have been. One might sympathize with the parents of a girl with cystic fibrosis, whose complaint the New York Supreme Court green-lighted in 2003: The mother became pregnant using a donor egg from a fertility clinic—but while the clinic doctors allegedly knew that the donor was a carrier of cystic fibrosis, they never offered to test the prospective father, who turned out to be a carrier as well. What, then, about the case of a New Jersey woman who sued after her doctor allegedly misread a sonogram, and her son was born without arms—a case that settled in 1996 for \$2.7 million?

Supporters of wrongful-birth lawsuits say that the type of birth defect is almost irrelevant. Rather, they frame the matter as a straightforward right-to-choose issue. "We wanted to be able to make an informed choice," explains former Salt Lake City resident Marie Borman, who says that her doctor failed to inform her that her child was at high risk for Down syndrome despite blood tests showing a 94 percent chance; Borman's daughter was born with the disorder. Because Utah's legislature forbids wrongful-birth lawsuits, Borman sued the state, claiming that its ban was unconstitutional—and that it shelters antichoice doctors who lie to patients in order to prevent abortions. The state Supreme Court agreed with the latter idea, writing that "the statute does create a safe harbor" for such doctors.

Nonetheless, it upheld the ban. "If we'd understood the baby would have Down syndrome, we could have prepared ourselves emotionally and gotten the information we needed. Or maybe had an abortion," Borman says. "Either way, it was our choice to make."

But advocates for the handicapped say that however commonplace it is to abort fetuses with birth defects, endorsing the practice in court devalues the lives of the disabled. "These lawsuits are repugnant," says Andrew Imparato, president of the American Association of People With Disabilities in Washington, D.C. "A jury that holds a medical professional liable for allowing a disabled child to be born is saying that disability is a fate worse than death." In reality, he continues, "disability is a natural part of the human experience. These lawsuits say otherwise, and that's arrogant and unrealistic." Overcoming life's challenges can be enriching and even lead to greatness, argues Nancy Starnes, vice president of the National Organization on Disability in Washington, D.C. Would Stevie Wonder have been drawn to music if he weren't blind? Would Stephen Hawking be as prolific if he weren't forced to race the effects of Lou Gehrig's disease? "There are 54 million Americans living with disabilities today, and I can't imagine anyone saying that those people don't have value," Starnes says.

Opponents worry, too, that if the courts endorse genetic selection to weed out people with birth defects, it will send us down what is inevitably described as a slippery slope. "Once you say that the life of a person with a particular disability is not worthy, then you've set an arbitrary standard based on your own prejudices," says National Right to Life's Balch. "Any one of us can be pulled into that circle." As prenatal testing becomes more and more sophisticated, it raises the question of what, precisely, qualifies as a defect. The extreme: a future in which parents sue for being denied the chance to abort for bipolar disorder, nearsightedness or the presence of two X chromosomes when the parents really, really wanted a boy. It might sound like science fiction. But consider that in

India and China, people already unlawfully use ultrasounds to weed out girls. And a woman in England recently set off a controversy when she had an abortion because her fetus had a cleft palate.

"It's what I call consumer eugenics," says Jonathan D. Moreno, Ph.D., director of the Center for Biomedical Ethics at the University of Virginia in Charlottesville—meaning that, rather than a Nazi-like directive from above, it's a bottom-up form of designing babies based on individual preferences. But while Moreno agrees that these are powerful ideas that bear consideration—and that the notion of sex selection, for one, is problematic—he feels that such hypothetical concerns have no real bearing on the morality of wrongful-birth lawsuits. "The problem with all slippery slope arguments is that they are predictions. They speak to the morality of what these acts might lead to, but they don't speak to the morality of this particular act," he says. And in the here and now, Moreno says, in keeping with *Roe v. Wade*, there's nothing wrong with a mother terminating a pregnancy. "We don't, in general, put obstacles in the way of people's reproductive decision making. We think *that's* a slippery slope," he adds wryly.

In April 1998, Shari and Jeff Ungerleider agreed to an out-of-court settlement for an undisclosed amount. Although Ungerleider would have liked to have seen her doctor on the stand, "I didn't want to relive it, and I didn't want to make a public display of Evan," she explains. She felt vindicated: Even though her obstetrician and the lab admitted no wrongdoing (and, under the settlement terms, cannot be revealed by name), at least they'd been forced to pay. But when the last of the paperwork was sorted out, Ungerleider was left with an empty feeling. It didn't change what was going to happen next.

One day that December, the family's home nurse checked the pulse oximeter that was taped to Evan's toe and discovered that the oxygen levels in his blood were dipping. Ungerleider frantically called their pediatrician, but the only measure left was to put Evan on

a ventilator, something Shari and Jeff had already agonized over and decided not to do. Ungerleider called each of her extended family members on the phone. "I have a feeling Evan's not going to make it through the night," she told them tearfully. They flocked to the house. Ungerleider spent that night cuddling her firstborn, caressing his face and hair, holding him close. At 5 A.M., as Evan's blood oxygen plummeted and his heart rate slowed, the night nurse looked at his parents. "You need to tell him it's OK to go," she said to them.

"That was the hardest thing we ever did," Ungerleider recalls now, sobbing.

With that, Evan slipped away.

"I miss him," she says, blotting her cheeks with a tissue. Justin, now 8, plays video games in a nearby playroom, and peals of giggles from daughters Leigh, 5, and Sydney, 2, issue from the Ungerleiders' furnished basement. "We would have let him stay with us forever if we could. But you have to take yourself out of the picture sometimes, and just do what's best for your child." ■