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A Wrongful Birth?

By ELIZABETH WEIL

Like most American women who give birth to a severely handicapped child, Donna Branca became pregnant with A.J. well before the age of 35. Had she been older, her doctors would almost certainly have recommended amniocentesis to screen for genetic disorders. But she was 31, so they did not, despite the fact that she had an unusual pregnancy. Branca bled during her first trimester, a possible indication of birth defects, and at her midterm sonogram, when she was 20 weeks pregnant, her fetus looked smaller than it should have based on when her doctors originally presumed she conceived. Branca had not gained much weight, either, but her doctors — whom she is barred from identifying, by a legal settlement — saw no cause for alarm. "Looking back now, of course, it's easy to say I should have asked more questions or maybe been a little more concerned," she told me last fall, sitting in her grassy backyard in Orangeburg, 20 miles north of Manhattan. Branca is a pretty woman, dark and compact, with a winning suburban New York accent. She glanced at A. J., a 6-year-old with a head of dark curls and the mental capacity of a 6-month-old. Her 3-year-old twins from a subsequent pregnancy ran around collecting acorns.

On April 22, 1999, when Branca was 28 weeks pregnant — four weeks past the legal window for terminating a pregnancy in New York — she saw her regular doctor (for what would be the last time) and was reassured that her baby was fine. But three weeks later, while on vacation on the Jersey Shore, Branca began to bleed again. Her husband, Anthony, drove her to the emergency room at Southern Ocean County Hospital in Manahawkin, N.J. Anthony Branca, like his wife, is compact and mild-mannered. When the obstetrician arrived, the doctor got out a tape and measured Donna's belly, a standard procedure to gauge a fetus's size. Although such measurements are a routine part of prenatal medicine and require only a few seconds, Donna had never had her belly measured. The obstetrician on duty that day asked Donna if she had had any prenatal care at all. Then he told her, based on his calculations, her fetus appeared to be only 24 weeks old, not 31.

An emergency sonogram confirmed that the fetus was indeed abnormally small, and an amniocentesis later performed at Westchester Medical Center in Valhalla, N.Y., revealed much worse news: Donna Branca's fetus had both a gene duplication and a gene deletion on his fourth chromosome. (It was not until after birth that it would become clear that her baby had Wolf-Hirschhorn syndrome, which commonly includes mental retardation, physical disfigurement, inability to speak, seizures and respiratory and digestive problems.) After two weeks of bed rest, during which doctors tried to delay labor, Donna delivered A.J. Branca on June 11, 1999, about six weeks before her due date. He was 15 inches long and weighed two and a half pounds, and he didn't cry when he came out. "One of the first things the attending doctor said to me," Donna told me, "was, 'It's not hereditary, so you should just have another child right away.'"

What happened next — the years in which the Brancas came to love A.J. deeply and also to file a multimillion-dollar lawsuit claiming that Donna Branca's obstetrician's poor care deprived her of the right to abort him — sheds an uncomfortable light on contemporary expectations about childbearing and

on how much control we believe we should have over the babies we give birth to. The technology of prenatal care has been shifting rapidly: sonograms became standard in the 80's; many new genetic tests became standard in the 90's. Our ethical responses to the information provided has been shifting as well. As in many other realms, from marriage and its definition to end-of-life issues, those ethics and standards are being hashed out in the courts, in one lawsuit after another. And what those cases are exposing is the relatively new belief that we should have a right to choose which babies come into the world. This belief is built upon two assumptions, both of which have emerged in the past 40 years. The first is the assumption that if we choose to take advantage of contemporary technology, major flaws in our fetus's health will be detected before birth. The second assumption, more controversial, is that we will be able to do something — namely, end the pregnancy — if those flaws suggest a parenting project we would rather not undertake.

The practice of terminating specific pregnancies, as opposed to aborting pregnancies so as not to have a child at all, is seldom discussed in its baldest terms. It is also poised to rise. Just this past November, scientists at Columbia University published a major paper in *The New England Journal of Medicine* on the effectiveness of new, noninvasive techniques for screening for Down syndrome in the first trimester, when the decision to terminate will most likely be more common and, some argue, more humane. In in vitro settings, a new technology called P.G.D. — preimplantation genetic diagnosis — allows doctors to test for genetic defects days after fertilizing an egg in a petri dish. Perhaps most important, the number of prenatal genetic tests is increasing exponentially — it jumped from 100 to 1,000 between 1993 and 2003 — and no regulations yet guide parents and doctors about fair reasons for terminating or going forward with particular births. Should it be O.K. to terminate a deaf child? What about a blind one? How mentally retarded is too mentally retarded? What if the child will develop a serious disease, like Huntington's, later in life? According to one reproductive legal scholar, Susan Crockin in Newton, Mass., "As reproductive genetics opens up new possibilities, we should expect to see more of these cases, and we should expect to see more novel issues."

At present, courts in about half the states recognize wrongful birth as a subset of medical negligence or allow lawsuits under the more general malpractice umbrella if a doctor's poor care leads to the delivery of a child the parents claim they would have chosen to terminate in utero had they known in time of its impaired health. In some of these states, like New York, where the Brancas' case was tried, emotional damages — compensation for the distress incurred by having an impaired child — cannot be recovered. No matter the legal context, terminating a wanted pregnancy is no one's first choice, but for the time being at least, when faced with a fetus that will become a severely handicapped child, all the choices are bad. At this moment, we are fairly adept at finding chromosomal flaws and horribly inept at fixing them. There is no chemical or surgical remedy if you find out your child-to-be has cystic fibrosis, fragile X, Down syndrome, Tay-Sachs, anencephaly — the list goes on and on. As Leon Kass, former chairman of the President's Council on Bioethics, has noted, in prenatal cases, often the only way to cure the illness is to prevent the patient.

The first significant wrongful-birth lawsuit involving a disabled child, *Gleitman v. Cosgrove*, reached the New Jersey Supreme Court in 1966. One plaintiff was the child's mother, who had contracted rubella early in her pregnancy in 1959. Worried, she consulted her doctor and was assured that her unborn baby would be fine, despite the common understanding that rubella early in pregnancy can lead to birth defects. The baby in question was born with "substantial defects. . . in sight, hearing and speech." Interestingly, the court recognized the physicians' failure as well as the parents' anguish and attendant financial burdens although it still decided in favor of the defendants, in part, it seems, because it did not want to enter the ethical thicket inherent in finding for the parents. "A court cannot say what defects should prevent an embryo from being allowed life. . ." the opinion reads. "Examples of famous persons who have had great achievement despite physical defects come readily to mind, and many of us can think of examples close to home. . . The sanctity of the single human life is the decisive factor in this

suit in tort. Eugenic considerations are not controlling. We are not talking here about the breeding of prize cattle."

By 1978, however, when the next significant wrongful-birth case was decided by a higher court, the 1973 *Roe v. Wade* decision had established a woman's right to choose — that is, to terminate a pregnancy. The new case, *Becker v. Schwartz*, involved a geriatric mother (a medical term for a pregnant woman over 35) who was not advised by her doctor that her advanced age put her unborn child at greater risk for birth defects. Her child was born with Down syndrome, and shortly thereafter the mother sued. This time, the New York State Court of Appeals found in favor of the family, declaring it had the right to seek financial damages for the added cost of raising a child with a disability. The court, however, refused to allow the claim of emotional damages. It did recognize the family's suffering, but reasoned it "may experience a love [for their child] that even an abnormality cannot fully dampen."

This paradigm — awarding financial but not emotional damages — has become the standard in contemporary wrongful-birth lawsuits. Only a few states — including Georgia, Kentucky, Minnesota, Michigan and Utah — have barred wrongful-birth cases through legislation or case law. (Conversely, wrongful-life lawsuits in which disabled children sue doctors for the suffering they are incurring by being alive have generally been rejected. These arguments come down to "better off dead," and courts have claimed it is impossible to weigh suffering versus nonexistence.) Yet the ethical thicket that the first court feared is as thorny as ever. We may not want to give birth to disabled children, but at the same time we do not want to see ourselves as reproducing in a way that calls to mind prize cattle.

The moral quandary we find ourselves in pits the ideal of unconditional love of a child against the reality that most of us would prefer not to have that unconditional-love relationship with a certain subset of kids. "I think the reason that this topic is as loaded and painful as it is," says Adrienne Asch, a professor of bioethics at Yeshiva University in New York, "is that prospective parents want to think that they are open to loving whomever comes into their families, and they don't want to think that they aren't." Asch is one of this country's most outspoken advocates for disability rights and against the "automatic assumption" that prenatal testing that reveals disability should lead to abortion. It is her observation, shared by many on both the left and right, that prenatal testing "is not a medical procedure to promote the health of the fetus. It is a procedure to give prospective parents information to decide whether or not to eliminate a possible future life."

The reasons to oppose termination are both obvious and subtle and not necessarily tied to abortion views in general. (The question of abortion rests on a single issue: is it O.K. to destroy a potential life? Termination involves an infinite number of heartbreaking queries that boil down to this: what about this life in particular?) Some argue that our desire not to raise impaired children is based on prejudice. Others claim that a choosy attitude toward fetuses brings a consumerist attitude toward childbearing and undermines the moral stature of the family. Still others maintain that the act of terminating impaired children drags us into a moral abyss — or its opposite, that raising children with impairments increases our humanity.

I had to face these very questions in my own pregnancy two years ago. I was 23 weeks pregnant with our second child when my husband and I were told that our unborn son had contracted cytomegalovirus, or CMV, a virus that if contracted by the mother for the first time while she is pregnant and is passed along to her fetus can lead to serious birth defects. Most likely our child would be deaf, blind and have serious mental retardation — a doctor friend told me that this prognosis could make a child with Down look like a walk in the park — but no one could tell us for sure what our unborn son's health would be like. What is more, no good studies existed because most of the women in the samples terminated before birth. The uncertainty was awful: weren't we supposed to be given solid information on which to base a decision? In lieu of that, we were offered a sonogram riddled with

anomalies, a 20-something genetics counselor and terrible odds. We tried to take solace in the fact that our older daughter had never picked up on the fact that there was a baby in her mother's belly. We did what seemed right at the time: we aborted.

David Wasserman, a bioethicist at the University of Maryland, wrote a paper with Asch titled "Where Is the Sin in Synecdoche?" in which the two argue that prenatal testing is morally suspect because the system leads people to reduce fetuses to a single trait, their impairment. "Since time immemorial people have felt fear and aversion toward people with impairments, but these tests legitimize those fears," Wasserman says. Parenthood, according to Wasserman, is and should remain a gamble.

Opposing this, of course, is the plain fact that a healthy newborn is the best outcome — what every parent wants. No reasonable person would choose sickness over health, and we seem to have the ability to choose. So how to proceed? Much hand wringing goes on about a sci-fi "Gattaca"-like future in which terminating kids with Down syndrome leads to selecting for only highly intelligent, physically powerful blue-eyed children. Yet in truth we are not at risk of creating a society of such supposedly perfect human beings any time soon. "There's enough evil and caprice to always assure there will be disabilities," says Laurie Zoloth, director of the Center for Bioethics, Science and Society at Northwestern University. "But could there be fewer? When people worry about curing too many things, I'm always glad that bioethics wasn't around when people were thinking about infectious diseases or polio or yellow fever."

The Brancas have little way of making sense of how Donna's primary doctors failed to apprehend that her pregnancy was not going well except to assume that they saw too many patients, believed her baby would be fine because she was relatively young or jumped to conclusions about the Brancas' ideas about abortion based on the gold cross that Anthony wore around his neck. Whatever the case, A.J.'s first days and weeks were a horrendous roller coaster. One of the earliest, hardest moments was when a doctor approached the Brancas with a D.N.R., or Do Not Resuscitate, order. They struggled with the choice, but decided to sign.

During A.J.'s first few months, he was hooked up to oxygen tubes to help him breath and to feeding tubes to help him eat, and he lived in an incubator to regulate his temperature. He remained hospitalized for 17 weeks. Donna spent every day by his bedside, usually returning home to eat a takeout dinner with Anthony and then driving back to the hospital again with her husband. During this time, the Brancas had to decide whether to institutionalize A.J. or raise him at home. Wolf-Hirschhorn syndrome is so rare that virtually every doctor who counseled the Brancas could tell them no more than what the Brancas gleaned from a single study they found on the Internet. The Brancas were also cautioned that severely disabled children are often easiest on parents both emotionally and physically when they are infants, as all infants are wholly dependent on their parents.

When A.J. was discharged in October 1999, four months after his birth, he was still "medically fragile," he needed round-the-clock care and he spent nearly as many calories trying to eat and regurgitating his food as he managed to keep down in his stomach. The Brancas feared that if they took A.J. home, he might not make it through his first year. With the encouragement of their families and A.J.'s doctors, the Brancas placed him at St. Margaret's Center for Children in Albany.

"It was just awful," Donna told me, tears streaming down her otherwise composed face as she recently described the experience of dropping him off years ago. "Anthony and I just sat in the car and cried for hours. I was a mother, and yet I didn't feel like a mother. It didn't seem natural. As a mother, you have this feeling: no matter what, you're supposed to care for your child."

Back home in Orangeburg, Anthony and Donna tried but failed to find solace in the Catholic Church. (Neither had been churchgoers before, though both were raised in religious families; both identify with Catholicism culturally but say that families at times need more leeway than the church allows on family-planning issues.) They also started hanging around their single friends because they couldn't bear hearing about children. When A.J. was 5 months, Donna returned to work in marketing for I.B.M. part time because, she says, "I just needed to think about something else, or I was going to have a nervous breakdown." Around this time, too, the Brancas started considering legal action. Anthony's mother, a court stenographer, encouraged Donna to requisition her medical records, and when Donna showed them to Dennis Donnelly, a medical malpractice lawyer in New Jersey, he immediately took the case.

Donnelly cautioned the Brancas that her doctors probably wouldn't settle — about 75 percent of medical malpractice cases are found in favor of the defendant — though he also told the Brancas that if they won, they should expect a settlement in the millions. For the trial, he prepared a video called "A Day in the Life of A.J.," since Donna and Anthony did not want A.J. to take the stand. The trial started in June 2004 and lasted three weeks. By then, Anthony and Donna had 2-year-old twins. In court, Donnelly asked the Brancas' doctors why they had never measured Donna's fundal height, particularly in light of her low weight gain, why they had been unconcerned with her first-trimester bleeding (a possible indication of chromosomal damage) and why they had not done any follow-up testing after her 20-week sonogram suggested the fetus was small. He also showed the video in which the jurors could see A.J. hooked up to a feeding tube and taking endless meds.

The defense, for its part, tried to insinuate that Donna herself had declined to seek follow-up testing and that even if she had sought such testing, the results might not have arrived in time for her to abort. Furthermore, they argued that the Brancas would not have terminated. (Donnelly used the signed Do Not Resuscitate order to argue that the Brancas would, in fact, have terminated.) The doctors conceded that the falloff in Donna's due dates should have raised a "red flag" and that a follow-up sonogram after her 20-week sonogram would have showed a further deterioration in fetal size and weight. Donna's doctors also had little recollection of Donna as a patient, so they could speak only about their practice in general and of her case based on her records.

Separately, both Donna and Anthony told me that they believed they might not have sued had Donna's doctors just called to apologize. "They never felt any remorse," Donna said, "never called me after my son was born to say, 'I'm sorry this happened.'"

The jury deliberated for two hours and found the doctors guilty of medical negligence. Ultimately, all parties agreed to a multimillion-dollar settlement — its exact amount is confidential — which remains in a trust for A.J.'s care.

Some people argue against the idea that we should have a right to terminate unwanted genetically flawed children on scientific, not moral, grounds. Bill Hurlbut, a Stanford professor and a member of the President's Council on Bioethics, asserts that a lot of genetic testing is hyped. "Genes are not like Legos," he says, mocking the idea that the results of an amniocentesis, often delivered to parents as a neat picture of 23 chromosome pairs, can tell you who a child will be. "Our genes mix with whole societies of molecular interactions, including our environment. It's not just nature-nurture; it's cycles of momentum that get going. A lot of very sophisticated people believe there is a straight line from a gene to an expressed trait, and that is just wrong. We're going to regret we had this phrase, 'It's in our genetics.'"

Serious questions have been raised by preimplantation genetic diagnosis. P.G.D. is available to families undergoing in vitro fertilization, and it works like this: an egg is fertilized and starts dividing. When the

embryo reaches the eight-cell stage, a single cell is removed and tested for genetic abnormalities. If the cell's DNA looks normal, the embryo is implanted in the mother. If the DNA does not, the embryo is frozen or tossed out. But it is not so simple. In 2005, a team from Reprogenetics in West Orange, N.J., continued growing 55 embryos that previously tested as abnormal and found that a surprising number of the cells, when tested later, were genetically normal. After a few more days, an average of 48 percent of the cells were normal. After 12 days, one embryo contained 76 percent normal cells. This raises some interesting questions: do embryos containing some genetically flawed cells tend to heal themselves? How do you know if the cells selected for P.G.D. are representative? Is basing termination decisions on genetic information as solid a footing as we have thought? If not, how can we conscience the decision to abort?

Susan Crockin, the legal scholar, says she believes that P.G.D., as well as other types of pre-pregnancy testing, like screening donor eggs and sperm for genetic disorders, will very likely be the causes of all sorts of new lawsuits. For instance, a sperm bank in California has already found itself facing a wrongful-conception lawsuit, brought by parents who argue that their genetically impaired child would not have been conceived at all had the donated sperm been vetted properly. Egg-donor programs may soon be in the same position.

An unintended and particularly disconcerting consequence of all these new reproductive lawsuits is that they may bias the medical establishment toward termination, and some argue that such a bias already exists. This is alarming for many reasons, not least of which is the fact that several studies have shown that the raising of children with impairments is on the whole a lot less difficult and a lot less different from raising so-called normal kids than we imagine it will be. "Families with severely impaired children do not differ significantly in stresses and burdens from families with normal children," Wasserman, the bioethicist, maintains, citing articles like "The Experience of Disability in Families: A Synthesis of Research and Parent Narratives." The idea that a handicapped child will destroy a marriage is exaggerated, he told me: "A child prodigy can have just as large an impact on a family as a child with cystic fibrosis or Down."

The ways in which genetic counseling is biased toward termination are both systemic and subtle. Research suggests that counselors may steer patients toward, as one counselor said to me, "starting again with a clean slate." As another expert, Barbara Biesecker, director of the genetic-counseling training program at Johns Hopkins University, explains, "There's kind of a trend out there to call people at home and then just refer them back to the hospital" — meaning that the family who has learned that a fetus has a genetic disease is quickly referred to someone who will help get rid of it. This, according to Biesecker, is "a cop-out." Delivering the news on the phone, often without a spouse present, is, she says, "filled with assumptions about what's right for people — it assumes that they'll act," meaning terminate. "When I ask counselors why they're doing so much work on the phone, they say, 'That's what people want.' But people are in crisis; they need to slow down. I believe we're capable of making good decisions for ourselves in hard circumstances, but I think we should be putting up roadblocks to quick answers. I don't think it should be easy."

Compounding the problem, most of the news that genetic counselors provide to prospective parents about disabilities is negative and clinical. Face-to-face meetings, which often occur before amniocentesis, tend to be filled with mini-science lectures about how chromosomes replicate or how trisomies occur, not the swirling emotions that surround the news that the baby in your belly may not be the baby you dreamed of having. In an attempt to rectify the situation, Senators Sam Brownback, Republican of Kansas, and Edward Kennedy, Democrat of Massachusetts, last March sponsored the Prenatally Diagnosed Conditions Awareness Act, a bill designed to mandate that more positive information be given to parents about the life of a disabled child. At a news conference to announce the bill was Brian Skotko, a Harvard Medical School student. Skotko published a paper in *The American*

Journal of Obstetrics and Gynecology last spring based on his study, the largest and most comprehensive on prenatally diagnosed Down syndrome. It showed that obstetricians and genetic counselors failed to give expectant mothers who received a prenatal diagnosis of Down encouraging data about raising a Down child. One mother in Skotko's study reported that her genetic counselor "showed a really pitiful video first of people with Down syndrome who were very low tone and lethargic-looking and then proceeded to tell us that our child would never be able to read, write or count change."

Few would be against parents getting a complete and accurate picture of raising an impaired child, but how, exactly, does that picture look? Different families' experiences with similar impairments are wildly disparate, and Skotko's study has been criticized for having sample bias, because he collected his surveys through Down-syndrome family associations, groups presumably filled with people having relatively good experiences with the disease. (Skotko has a sister with Down.) Not included in his sample, for instance, was a 66-year-old woman named Wendolyn Markcrow of Buckinghamshire, England, who last year on Easter Monday gave her 36-year-old son, Patrick, 14 sleeping pills and suffocated him with a plastic bag and then attempted suicide. Patrick had Down syndrome, rarely slept at night and hit himself in the face so regularly and forcefully that he detached his retina. When arrested, Markcrow told the police that she had "snapped."

“Why does A.J. have to get on the bus?” Julia Branca, one of Donna and Anthony's 3-year-old twins, paused to ask her mother, referring to the shuttle that was taking A.J. back to St. Margaret's on a Sunday afternoon. (A.J. has since moved to the Center for Discovery, in Harris, N.Y., closer to the Brancas' home.) The sun dappled the lawn through the tall oak trees. A.J., three years older than his siblings, but about the same size, played with a LeapFrog infant piano in his wheelchair in the shade.

Julia is extremely engaged with the world of disability. At "A.J.'s house," what she used to call St. Margaret's and now calls the Center for Discovery, she says hello to all the kids, whether they respond or not, while her brother Johnny hugs Donna's leg. Julia ran off for a few minutes and returned with a cup full of acorns and set them on A.J.'s wheelchair tray. A.J. raised his head, as if to acknowledge Julia's gift, then sank back into the looping riffs of his musical toy. Nobody knows how much A.J. comprehends. He turns his head toward his family, sometimes reaches out an arm. "One time," says Anthony, "up in Albany, he started to cry when we left. He started to moan."

In A.J.'s infancy, when his son visited home, Anthony slept in the same room with A.J., often in the same bed, dispensing food and meds at one- and two-hour intervals and making sure A.J., who weighed only nine pounds at 1 year, didn't vomit and choke. When he found out Donna was pregnant with twins, he felt guilty because he "knew it was really going to take away from A.J. When the twins were born, it was like having triplets." Now, thanks to the settlement, when A.J. is home, a nurse comes at night. In some ways, being A.J.'s parents has grown harder as he has grown older. Yet despite the direst predictions from some of his doctors, A.J. is progressing, if slowly. No one expects that A.J. will ever talk, but last summer he learned to belly crawl, and his father was intensely proud. "Everyone talks about when their child says his first word," Anthony says. "With A.J., we don't have that. But I think Donna and I have more satisfaction." Anthony sounds calm but surprised, like a man long accustomed to unexpected and unsettling news. "A.J. was voted Most Improved Mobility last year at school," he told me. "I was more proud of that. Every kid who has what he's got doesn't learn to belly crawl. I felt like he'd hit a home run in the Little League World Series."

The Brancas love the son they wish they hadn't had. My family continues to mourn the child we don't regret terminating. "Anything you might say about the wrongfulness or the rightness of a birth," Laurie Zoloth, the bioethicist, says, "the particularity of that choice is only, and always, experienced by a

particular set of parents in a particular family with certain grandparents, certain aunts and uncles, in a certain religion on a certain block in a certain neighborhood. These are circumstances that as professionals, and certainly as bioethicists, it's nearly impossible to fully understand. And then, of course, we have the luxury of walking away."

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