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Needed — More “Genetic Outlaws”

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Elizabeth R. Schiltz has been called a “genetic outlaw.” An associate professor of law at the University of St. Thomas, Professor Schiltz did the unthinkable — she received a diagnosis that the child she was carrying would be a Down syndrome baby, and she did not abort.



In her words:

From time to time, we are all confronted with the disconnect between how we see ourselves and how others see us. I've always seen myself as a responsible, law-abiding citizen. I recycle, I vote, I don't drive a Hummer. But I've come to realize that many in the scientific and medical community view me as grossly irresponsible. Indeed, in the words of Bob Edwards, the scientist who facilitated the birth of England's first test-tube baby, I am a "sinner." A recent book even branded me a "genetic outlaw." My transgression? I am one of the dwindling number of women who receive a prenatal diagnosis of Down syndrome and choose not to terminate our pregnancies. So when I hear about medical breakthroughs like preimplantation genetic haplotyping (PGH)—a new technique to screen embryos in the in vitro fertilization process for 6,000 inherited diseases—I can't help but see 6,000 new reasons that parents will be branded as sinners or made to feel socially irresponsible for bringing their children into this world.

Those are bracing words that reveal the moral revolution we have witnessed in recent years. An obligation to receive and protect human life has been transformed into an obligation to destroy and discard whatever life does not measure up to our expectations.

As Professor Schiltz reflects: *From my perspective . . . our increasingly sophisticated technological capacity to identify genetic defects in our children also presents some very real threats to the kind of world we will be passing on to them. A few years ago, author Christine Rosen wrote, "Those who oppose discarding unfit embryos or aborting unfit fetuses will soon become—perhaps already are—a dissident culture, tolerated at best, but more likely heavily regulated by a society that increasingly expects only healthy children to be born."*

Professor Schiltz has felt the scorn of those who tell her she is responsible for the birth of a child who will consume too many financial resources. She sees her son very differently.

Ponder this mother's testimony:

I would not want scientists to stop delving into the mysteries and wonders of the human genome. I am glad that I knew my son had Down syndrome before he was born. If one of these scientists found a "cure" for my son's Down syndrome, I almost certainly would give it to him. But I will admit that I would pause beforehand. I would think hard about this real-life conversation between a teenager with Down syndrome and her mother. The daughter asked her mother whether she would still have Down syndrome when the two were together in heaven someday. The mother, taken by surprise, responded that she thought probably not. To which her daughter responded, "But how will you know who I am, then?" And I would also think hard about whether the world would really be a better place without my son's soft, gentle, deep, almond-shaped eyes.

I know that the world would be a much poorer place without this kind of mother and her unconditional love for her child. What this world desperately needs is more “genetic outlaws” like Elizabeth R. Schiltz.

SEE: Elizabeth R. Schiltz, "Confessions of a 'Genetic Outlaw.'" *Business Week*, July 20, 2006.

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