

Essay

To Test or Not to Test?

Until recently, I was convinced that knowledge was an absolute good, something intrinsically worth having, whether acted upon or not. That conviction began to change, however, when my wife became pregnant a couple of years ago.

We were both overjoyed at the news. We'd been trying to conceive for nearly two years, and my wife was approaching 35, the age at which female fertility begins to decline. Because we're both of Eastern European Jewish heritage, we had already undergone genetic screening for a variety of hereditary illnesses that are especially prevalent among Ashkenazi Jews, like cystic fibrosis and Tay-Sachs disease.

We gave blood, held our breath for a few days until the results came in, and were relieved to learn that our potential offspring wouldn't be at risk of developing any of the genetic diseases for which we had been tested.

All clear, we thought.

We were wrong.

As anyone who has had a child within the past several decades knows—but as few others are aware—genetic screening prior to conception is just the tip of the testing iceberg. Pregnant women are now presented with a host of prenatal testing options, from simple blood tests and sonograms to potentially risky procedures like amniocentesis and chorionic villus sampling (CVS). All are meant to indicate the presence of potentially serious conditions like spina bifida and Down syndrome.

Prior to becoming pregnant, both my wife and I would have opted for the entire testing menu. Why leave anything to chance? If the tests indicated a problem, we could have prepared ourselves for the challenge of raising a disabled child. And if the problem were severe enough, and detected early enough in the pregnancy, we could even have chosen to terminate the pregnancy, as difficult as that might have been.

Once the pregnancy was no longer hypothetical, however, we began to change our minds.

For one thing, we were troubled by the inaccuracy of the non-invasive prenatal tests that are now routinely administered to pregnant women. One of the most common, known as maternal

serum triple analyte screening, or "triple screen," involves analyzing an expectant mother's blood to determine the risk she runs of giving birth to a baby with certain birth defects. Unfortunately, triple screen doesn't tell you whether your baby is healthy or not; it just tells you what your level of risk is compared to other women in your particular sample group. And like many medical tests, triple screen yields a certain number of false positives and false negatives. You can reduce the risk of a false result by visually scanning for fetal abnormalities with a sonogram, but even the combination of blood analysis and ultrasound won't guarantee 100% accuracy.

Bottom line: Every doctor we spoke with admitted that even the most sophisticated combination of non-invasive tests could miss problems when they did exist, and mistakenly register them when they didn't.

Only amniocentesis and CVS can reveal fetal abnormalities with absolute certainty. But those procedures carry a risk of miscarriage that is roughly equal to the risk that a 35-year-old woman like my wife runs of giving birth to a disabled child in the first place.

So if we proceeded with the triple screen, and it indicated a problem, we'd be faced with the following dilemma: Trust the potentially inaccurate test results and spend the rest of the pregnancy consumed by potentially groundless worry, or attempt to



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by Alexander Gelfand

verify them with an additional test that could itself precipitate a miscarriage. Neither one of us liked the idea of casting an unnecessary shadow over what ought to be a joyful experience—or, worse yet, of risking a pregnancy that had been so long in the making.

And then, of course, there was the issue of what we'd actually do if we knew for certain that something was wrong. Before getting pregnant, we were both willing to consider terminating a pregnancy if we knew that we'd have a severely disabled baby. But once we'd seen ultrasound images of our child and drawn up lists of boy's and girl's names, we both felt differently. As abstraction gave way to reality, we came to the conclusion that we were going to have this kid no matter what. And if that was the case, why even begin to walk down the potentially risky testing path? Why not do what generations of expectant parents did before prenatal testing was even possible, and simply deal with whatever happens—the good and the bad—as it happens?

I'm still not sure where I stand on all of this. Sometimes, I wonder if my unease about testing is simply irrational. Isn't it incumbent upon us all as parents, even parents-to-be, to do everything they can to insure the health and safety of our babies? Yet I've come to see even the most innocuous screening test as nothing more than an opener for a giant can of worms. And my wife and I both resented having to grapple with these issues when we would have preferred simply to have basked in the happy glow of pregnancy and the thought of our impending parenthood.

Long story short, we decided to go the minimal testing route, and we both felt a whole lot better for it, even before it became clear that he was indeed a he, and that he was just fine. We may not have known everything we could have about our baby before he popped out into the world, but we knew that we'd love him and care for him as best we could, no matter what. And in this particular case, that seems to have been enough.

Sometimes, ignorance really is bliss.

Alexander Gelfand is a stay-at-home dad and work-from-home writer whose work has appeared in The New York Times, The Village Voice, and Wired.com. He and his family live in New York City, where he finds himself daydreaming about the Salt Lick and Threadgill's.

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