

genetic frustration

by Gerry Strauss

I don't want my child to suffer. As a hopeful father-to-be, I have visions of healthy, happy children dancing in my head. I want to feed them right, raise them right, and protect them from anything that could harm or threaten them. With so many illnesses in this world, I plan to do everything in my power to keep them disease-free.

But what if they're doomed from the start?

Some of our most devastating medical conditions are inherited. Many cancers and other ailments (or the chances of developing them) commonly pass through the generations of a given family. For these children, there's no chance for prevention. Their fates may be written in their genes before they're born.

As a human being, I am blessed with the ultimate power to help create life if I so choose. That said, I also can decide against it. If I knew my children would likely develop medical conditions that would destroy their ability to enjoy their years on earth, would I willingly allow it?

Please understand that there's no right or wrong answer here. These decisions are affected by a million variables, and inevitably can only come from the hearts and minds of the individual. The important thing is that we have the freedom to decide in an informed manner if we so choose. Or do we?

Last year, my wife and I excitedly began to plan a family. After more than 30 years of life and several years of marriage, we were ready. Neither of us is a hypochondriac, but we agreed to take every reasonable precaution to ensure the good health of our baby. Our first step? Genetic testing.

Since neither of us was acutely aware of our families' medical histories, genetic testing seemed logical. We hoped we'd discover nothing frightening enough to dissuade us from our plan. However, if something foul was afoot, we wanted to know about it ahead of time. Unfortunately, the world didn't agree.

My wife first broached the subject with her gynecologist. He didn't share her urgency regarding the matter, but nevertheless agreed to hook us up with a genetic counselor in Trenton. We scheduled our appointment, secure in the knowledge that a specialist would teach us everything we needed to know about the implications of our families' medical history.

Wrong.

While our counselor was pleasant enough, she immediately said medical insurance doesn't cover most proactive genetic testing.

Worse, she repeatedly suggested we thoroughly reconsider what we would do with the information from these tests. Her thinly veiled message was loud and clear: Ignorance is bliss.

We expected to walk out of our counseling session full of pride and insight. Instead, we left feeling empty and confused.

We believed we were acting responsibly for the sake of our family. So why wouldn't anyone help us? Why didn't anyone agree with us? Even stranger, why wouldn't my medical insurance company pay for this?

A subsequent conversation with my insurance company was even more befuddling. They do cover genetic testing, you see, but only after impregnation. What good is that? So we can find out our child may be destined to have a terrible disease, but we're powerless to prevent it?

Our society is overpopulated. Our nation is struggling financially. Millions of children live with sickness each day. Millions more are orphans, or are unwanted. Now, more than ever, we need to act responsibly.

Every day, people make major family decisions based on any number of factors. Some might decide to have two children because two is their lucky number. Some might stop at one because they own a smaller home. Some may decide not to become parents altogether because they prefer a life of leisure. Yet we can't even obtain and act on medical data that would likely affect our children's well-being without costly testing we practically must beg for.

If you learned tomorrow your future child would likely live a painful, unfulfilled existence due to a genetic condition, you might reconsider bringing him into this world. As much as it might hurt, you might ultimately believe you'd done the right thing for him or her—and for you.

Instead, you might think about all the wonderful children out there who need families, and decide to open your heart and home to them. Or you might not, and that's ok, too.

The point is: shouldn't the choice be yours, and shouldn't we be encouraged to get the information we need to make that choice? **f**

Gerry Strauss, from Hamilton, is a national magazine columnist, freelance feature writer, and self-appointed champion of genetic justice.

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