

Should human embryos be screened for genetic defects?

Stephanie Zinser well known for her book *The Good Gut Guide*

Investigates this morally thorny issue.

The issue of screening human embryos has dominated the media in recent months. Groups-both for and against-have represented their views, and the debate rages on. Families who are genetically susceptible to Familial Adenomatous Polyposis (FAP) have dominated the current debate, for it is these people who have just been allowed by the HFEA (Human Fertilisation and Embryology Authority) to screen embryos in an effort to prevent the tragedy and misery that this dreadful condition brings.

Previously it was only untreatable illnesses like cystic fibrosis and Huntington's disease that were granted permission for embryonic screening. Then recently, the HFEA gave the go-ahead for the technique to be used so that embryos could be selected purely because they are a tissue match for a sick sibling.

And now families with FAP have been given permission. Why? In FAP, the faulty gene (found on chromosome no. 5) exerts a huge influence in causing active disease to develop with it; there is an 80% chance of the aggressive cancer developing. Another disease with this high a level of risk is the genetic form of breast cancer, whose faulty genes BRCA1 and BRCA2 also give an 80% risk of cancer development in carriers. (This is still awaiting HFEA approval, however.) Although FAP generally occurs earlier than in the 'genetic' cases of breast cancer (FAP typically strikes during an affected person's 20's and 30's), treatment of both involves gruelling major surgery with no guarantee of eliminating the disease completely.

Pro-life groups such as Comment on Reproductive Ethics have been vocal in their disapproval of embryonic screening advances. Speaking to *The Times* recently, spokeswoman Josephine Quinteville. Says, "We are not thinking about curing the disease but about eliminating the carrier."

It's an interesting point. With a huge family history of breast cancer Jackie Hunter writes in a letter to the press that she also feels anger at the decision to allow embryo screening, because if this had happened 100 years ago, her entire family would now not exist. She points out that genes for disease aren't, perhaps, everything: "As well as our forefathers having cancer genes, they blessed us with entrepreneurial genes, artistic genes, literary genes, loving genes - indeed a veritable cornucopia of positive, wonderful genes." A persuasive argument.

History illustrates that many of our most famous names possessed a less-than-perfect complement of genes. Beethoven's mother, at the time she was pregnant with him, already had several children: three were deaf, two were blind, and one was mentally retarded. If she had had aborted the (also congenitally-deaf) Ludwig, the world would now be a musically poorer place. He's not the only famous person to have been born less than perfect. Aristotle suffered from epilepsy, as did Vincent Van Gogh. The poet and philosopher Homer was blind from birth. Toulouse-Lautrec suffered an incurable congenital bone disease. Stephen Hawking has motor neurone disease. One may

wonder whether their handicaps played a part in driving them to excel so magnificently in other areas.

Many of us (with FAP or without) might not be here if we had been genetically screened out by our parents for things that we suffer from today. How many of us would prefer to not have existed at all? We: may not be: famous, but I bet we're all happy to be here.

Life is all about risk. Whether we realise it or not, we spend most of our lives minimising risk. We choose: a salad over chips to reduce our risk of obesity and coronary heart disease. We put our seat belts on to reduce the risk of death and injury in a car crash. We teach our children to read and write to (ultimately) reduce their risk of poverty in later life. The more certain a risk is, the more likely we are to do something to minimise it.

And this is why the families with FAP have been sanctioned to screen genetically against the disease that they carry: there is a very high risk that any child carrying the FAP gene will develop the disease, and many of them wish to minimise that.

The Red Lion Group has a significant number of members with FAP, making the issue particularly relevant to us. So where do the answers lie? Is generic screening the ultimate solution, or can it bring its own and complex issues? Ultimately, is it right or is it wrong? Socially desirable or undesirable?

Genetic screening and embryo selection is, to the many who carry the genes for debilitating and fatal diseases, a godsend. It offers an escape route, a hope for freedom from a curse that you and your children don't deserve. People that are affected say it's easy for those who morally object to screening to pontificate, but unless you have actually experienced the vulnerability and torture of watching your children suffer or die from something you unwillingly gave them, it is unfair and inappropriate to comment on the rights and wrongs of those who do suffer.

No doubt there must be some people out there who know what it feels like, and who still maintain a staunch position against screening and genetic selection of embryos. That is their right. They may argue that we're not eliminating a disease, per se, but a whole person-and that medicine would be better off focussing on curing the disease rather than eliminating the people that carry them. When put in such terms, it almost carries the same unpleasant whiff that was used to justify ethnic cleansing. And put in those terms, they score a point.

But say you have decided in favour of embryo selection. Is this the end of all your troubles? Perhaps not. IVF has come a long way in terms of success rates, since its own conception 35 years ago, but it's not a procedure that is either pain-free or guaranteed. You don't always become pregnant during a course of IVF treatment the average couple needs three rounds of IVF before producing a baby-and it's expensive, around £3,000 per cycle. In the case of genetic screening for FAP, approximately half of a couple's embryos will be screened out, reducing the odds for success still further. There are risks associated with fertility drugs, such as ovarian hyperstimulation, and also the possibility of an increased risk of ovarian or breast cancer in later life. IVF

pregnancies are more likely to result in premature births, with an additional increased risk of congenital abnormalities like heart defects or cerebral palsy.

However, even the increased risks associated with IVF are in reality very small-and most would say irrelevant-in relation to those that already face a family with a known and serious problem like FAP.

In the end, the debate does not rage because of science, or the lack of it. The debate rages because of the visceral and deeply-seated views of humanity and life that lie at me core. The real nub of the problem is that the arguments both for and against are extremely emotive.

The sheer pain of watching your child being diagnosed with a crippling illness is emotive. Holding your child's hand as they lie helplessly in Intensive Care, wrapped in a cold forest of tubes and drips is emotive. Helping them try to thread their lives together after major surgery is emotive. Watching them undergo surgery after surgery with no guarantee of a cure is emotive. Burying a beloved child who has suffered years of needless and undeserved pain is emotive. Indeed, it is torture.

But then, take a look at one of your children today and imagine-for an instant-that they didn't exist because you had screened them out before they had a chance. You would never have seen the twinkle in their little eyes when they were excited, never have felt their warm, spontaneous cuddles, never felt their soft breath on your cheek, nor heard the soft chime of their voice in your ear. This too is emotive. Imagine that you'd never have seen them on their first day at school, nervous and out of place in their new, too-big school uniform.

Pretend that you'd never have sat in the audience, wiping away a tear as you watched them mumble their lines in their first school play. Imagine that you'd never given the loving face that smiles at you as you kiss them goodnight the chance to exist, that you had decided they shouldn't live.

Isn't this also emotive?

The fact that the HFEA has offered people a choice is no crime and shouldn't even be up for debate. Nobody is forcing anyone to screen their embryos for defects, nor forcing them to terminate a life. People who wish to let nature take its course are still entitled to do just that, and those that wish to prevent a terrible disease in their future children are now also being given a chance.

The decision to approve screening for FAP should be welcomed, and while all views are valid, it's time to accept that we all have a choice, and will all exercise it differently.