Genetics news deserves our best thinking

the moral life

By Patricia Schoelles, SSJ

We live in a fast-paced world, for sure. Scientific and technological advances seem to come at us almost daily. Some of the most significant developments for medicine surround the whole issue of human genetics. The press has introduced us to a sheep named Dolly, and we have all become aware of the successful "mapping the human genome."

I've become accustomed to new developments making a splash in the news. The customary pattern seems to be that a large university or company makes a scientific breakthrough that holds potentially hopeful consequences for human beings, but potentially questionable consequences as well. The news media then tries to pit those who are "for" the new development against those who are "against" it. This may be helpful in surfacing the issues that surround new developments, but it is also polarizing and frequently distorts the reasonable nature of the questioning that is needed.

Genetic screening and genetic therapy are two areas of concern in this regard. Genetic screening, or testing for genetic abnormalities, occurs already in some fairly common ways, and is beginning to be available in some more sophisticated ways as well. Almost everyone agrees that there are questions that we need to ask about the very idea of screening for genetic abnormalities. For example, while we can detect thousands of genetic anomalies, we understand the impact for our health of only a few of these. Why should we test for something if we don't know whether or how it affects our actual health? Furthermore, sometimes we can detect the genetic abnormality associated with a disease, but we don't know how to cure the disease.

In these instances we have to ask whether the information we derive from the testing will help or harm us. Some genetic diseases, for example, occur later in life. Huntington's chorea is an example; so is breast cancer. While we can sometimes treat symptoms of diseases like these, we have not yet developed a cure. We might imagine that the information derived from genetic testing in these instances would help patients and their families to prepare for the onset of these conditions. But there are difficulties associated with such information, too.

For example, people will have information but they will have few options for doing anything with it. They can avoid reproduction, perhaps. If screening for this sort of genetic information were routinely done prenatally, some people might abort. In the case of pregnancies carried to term, what would happen if insurance companies were given the information about an individual's "defective" genes? In the case of a society allotting only limited resources to health care, it is not difficult to imagine social pressure influencing decisions about what we would come to consider a "healthy child."

I'm not trying to construct an Orwellian fright scenario, but I think we serve ourselves well to the extent that we ask about the implications that might flow from recent breakthroughs in genetics. I don't think this means that we have to oversimplify things and come out either "for" or "against" them. I do think it means that we need to use our thoughtfulness and sensitivity as we consider them. Classic issues from medical ethics like privacy and confidentiality enter into this discussion, as do new considerations relating to the nature of the human "gene pool" and our potential control over it.

As we consider forms of therapy that may be made possible through gene alteration and transfer, most ethicists draw a distinction between two discrete processes. The first uses genetic alteration to correct an existing disease in a given fetus. The second, called germ line therapy, alters the genetic endowment that that individual will one day pass on to future generations. Many ethicists raise questions about this latter circumstance, even when it corrects a disease condition for a given individual. One, Maurice de Wachter, has claimed, "Germ line gene therapy techniques would violate the rights of subsequent generations to inherit a genetic endowment that has not been intentionally modified."

Several other ethicists argue that the human genome continues to be modified through natural evolution without human intervention anyway, and that preventing a disease from harming an individual's descendants as well as the person herself should be seen as a good thing. Others doubt whether there is such a thing as a right to inherit an unaltered genetic endowment. Debates about this matter continue, and they deserve our best thinking.

When the questions shifts from the cure or prevention of disease, however, to issues of enhancing human genetic structure to produce particular human characteristics in our offspring, there is consistent and emphatic rejection. Ethical considerations alone deliver a sustained negative judgment of attempts to "genetically improve" our offspring by enhancing traits we may judge to be valuable. Efforts like this would surely result in our coming to devalue human beings and the varieties among us even more than we do already. Good ethical thinking from both religious and secular ethicists and geneticists will be required for us to move ahead as a moral people.

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Sister Schoelles is president of St. Bernard's Institute.

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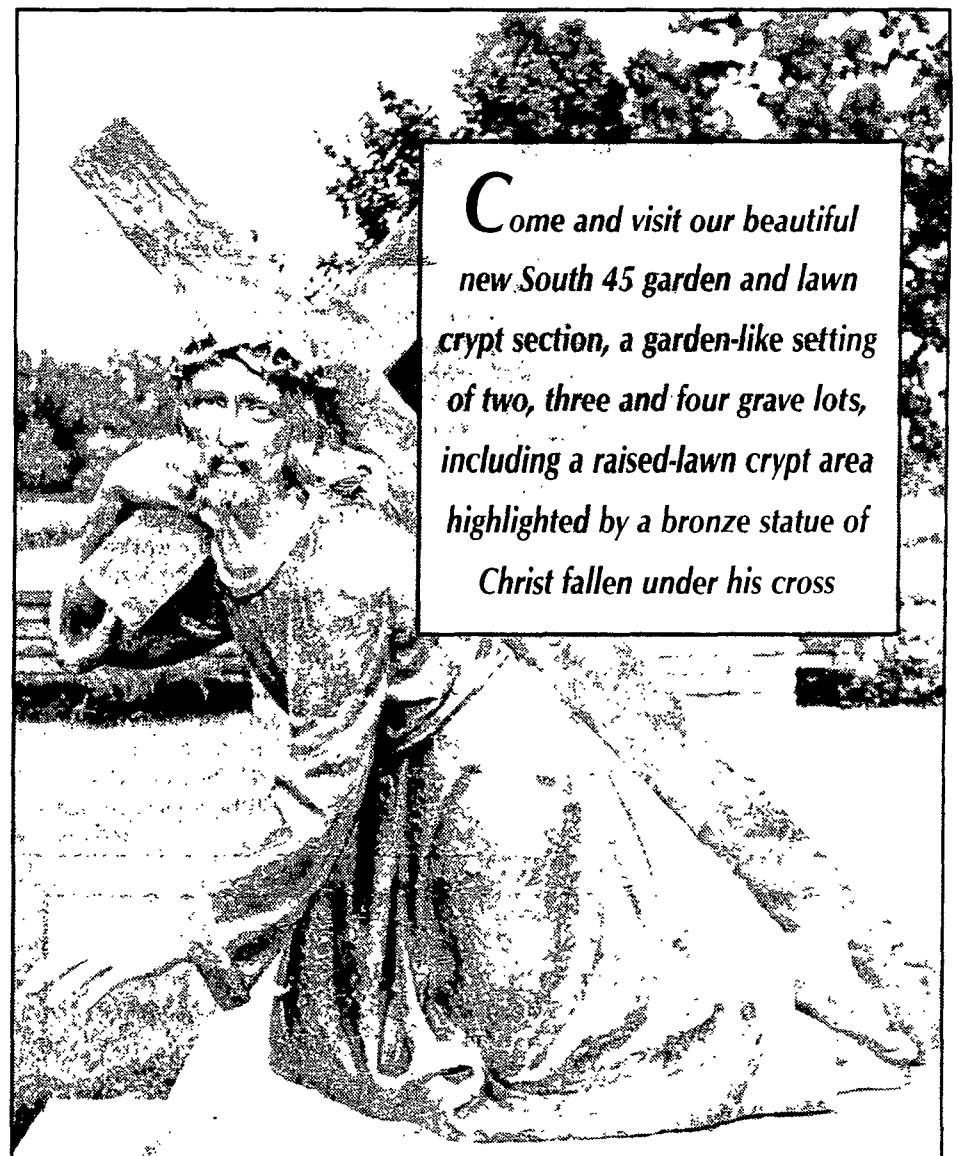

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