

One of the most powerful prayers of the Yamim Nora'im is known as unetane tokef, in which we make reference to the central metaphor of our days of awe, the "Book of Life." We read, "On Rosh Hashanah it is written, and on Yom Kippur it is sealed ... who shall live, who shall die, who shall be at peace, who shall be tormented, who shall become poor, who shall become rich.

A July 19 article in The Journal of the American Medical Association proclaimed that "Two rival teams of scientists announced last month they had assembled a rough draft of the "book of life"--the human genetic code. For this vital instruction manual, researchers have been working to catalog the identity and location of each of the estimated 3 billion chemical base pairs in human DNA."

The genome project is as fantastic and revolutionary a scientific discovery as sending man to the moon, mastering the structure of the atom, or discovering the earth is round. Aside from identifying the genes which give us physical traits or make us susceptible to certain illnesses, geneticists may discover which genes give us a tendency to be alcoholic or violent; generous or stingy; or which give us the skills to be logical thinkers or creative geniuses. A column by Charley Reese on the genome project asked: Utopia or Pandora's box?

On the positive side, understanding the human genome at a complex level could transform the practice of clinical medicine from that of "diagnosis and treatment" to that of "prediction and prevention," as so many medical problems, such as cancer, osteoporosis, Alzheimer's disease, schizophrenia, diabetes, and asthma have been confirmed to have substantial genetic influence. Such conditions may be treatable by gene therapy long before they appear.

On the other hand, the pitfalls of having the power to tamper with the makeup of human beings at such an elemental level are many.

Leon Kass, a doctor and ethicist at the University of Chicago, tells of a doctor he knows who went on rounds with his medical school students. They came to the bed of an intelligent, otherwise normal ten year old child with spina bifida, and this physician said to his students, "Were he to be conceived today, he would have been aborted." A doctor who casually makes such a statement in the presence of a patient scares me. Do we want to live in a world in which doctors and geneticists determine who shall live and who shall die on the basis of genetic merit?

Recently there was a case in New York, in which parents, following the advice of their doctor, insisted on the removal of the ovaries of their ten year old daughter because she carried the BRCA-1 gene, which is the gene that can sometimes lead to breast cancer. Parents in New York, not in Nazi Germany, but in New York City, under the advice of their doctor and geneticist, allowed an ovariectomy on their 10 year old daughter, which means that she will never be able to have children because she carries a defective gene.

A healthy boy who carried a gene predisposing him to a heart disorder was denied health coverage by his parents' insurance company, even though the boy took medication that eliminated his risk of heart disease.

Already in 1971, Dr. Bentley Glass, in his presidential address to the American Association for the Advancement of Science said: "no parents will in the future have the right to burden society with a malformed child." The consequences of such a view are frighteningly real. It happened recently that a pregnant woman whose fetus tested positive for cystic fibrosis was told by her HMO that it would be willing to cover the cost of an abortion but would not cover the infant under the family's medical policy if she elected to carry the pregnancy to term.

Asian countries and Arab Gulf states already have laws denying the disabled the right to be born.

Who decides what is normal and what is not normal, who has the right to be born, and who does not?

A genetic disease like “Huntington's chorea usually develops between the ages of 38 and 45,” says French geneticist and bioethicist Axel Kahn. “Yet think of all the great artists and musicians who died before reaching 40. We see here the difficulty in saying that a life isn't worth living if it ends or suddenly deteriorates at a certain age.”

Strong evidence points to links between environmental factors and cancer. If cancer is cast primarily as a genetic disease, then legislators may discard efforts to clean up environmental carcinogens in favor of a search for “cancer genes.” In effect, we encourage a “blame the victim” mindset, where we condemn people with “faulty” genes, and divert our resources into finding biomedical “solutions,” while societal measures get short-changed.

The genome project, despite a potential for very positive results, carries far more troubling negative ethical possibilities, only some of which I have mentioned.

The dangers of the genome project can be divided into two categories -- the potential to think we are God, and have the power and right to make whatever changes, enhancements, and alterations we want with the human genome to create more “perfect” human beings; and the potential to think we are not created in the image of God, but are merely a collection of strings of protein programmed to act in certain ways.

Scientific discovery cannot be suppressed. It would be foolish to argue, like some biotechnological Luddite, that the genome project should be stopped and put on the back of some dusty shelf forever.

But we need safeguards against the potential pitfalls of the genome project. My colleague Rabbi Jack Reimer suggests that the safeguards are right in front of us, in the mahzor for Yom Kippur. First, we need to believe in the words of the unetane tokef, that we do have the power to change ourselves. “Teshuvah, Tefillah, u'tzedakah, ma'avirin et roah hagezerah,” repentance, prayer, and good deeds can change our nature and our destiny. We may be programmed with a tendency towards addiction, violence, or selfishness, but these tendencies are part of our lower brains, our animal brains. As human beings, we have an upper brain, a soul, which can decide that we will no longer behave in destructive or selfish ways.

Second, we need to take seriously the words of the aleinu. It used to be that every single person in shul would bow and kneel and prostrate themselves for the aleinu on Yom Kippur, as they recite the words, “va'anahnu korim umishtahavim umodim lifney melech, malchey hamlachim, hakadosh baruch hu.” We bow and prostrate ourselves before the Sovereign One, above all earthly rulers, the Holy One, of blessing, as a sign of our collective humility before God.

Can you imagine Peter Singer, recently appointed as a full Professor of Bioethics at Princeton's University Center for Human Values, who who has written in favor of giving parents the right to kill severely disabled babies, including those with Down syndrome, within 28 days AFTER birth, because they might negatively affect the lives of the other children or their parents, coming to shul on Yom Kippur and bending his knees and bowing his head before God? Why should one who has written that newborn infants are not yet full persons and therefore have no inherent right

to life, wielding the godlike power to decide “mi yichyey umi yamut,” who shall live, and who shall die, why should he come to shul, and say Unitane tokef?

The safeguard against the misuse of genetic power has to come from the communities of faith. As I spoke about on Rosh Hashanah, we as a Jewish community have the obligation to work with other religious communities on issues where faith in God makes a difference. Our voice has to be the constant reminder that the ability to “play God” does not give a doctor or a geneticist the right to play God.

There is a book of life, in which our genetic characteristics are inscribed, that we are now beginning to decode. There is such a book of life, no doubt about it.

But there is another book of life as well, the one that WE write in, every day, by the way we live. This is what it says in Unitane Tokef -- that every day each and every human being writes in the book of life, and we sign what we write, with our own hand, so that we can't deny it afterwards.

We write in it by the way in which we live. We decide -- we, and not our genetic code -- whether we will be good or bad, vain or modest, disciplined or unruly, honest or dishonest.

The genetic code may determine our nature ... but only we determine our human nature ... only we decide whether we will give in to our nature, or whether we will transcend our nature.

The genome project tells us much about that part of our lives that is predetermined, that is decided before we are born, such as: how tall we will be, what color our eyes will be, what our metabolism will be, whether we will be prone to high blood pressure or to diabetes, or to putting on weight; but we, and only we, determine how moral we will be, how generous we will be, how kind and sensitive we will be.

The genetic code may determine, at least in part, how long we will live, but we, and only we, will determine how wisely we will live, how well we will live, with how much *mentschlichkeit* we will live.

Rabbi Reimer composed the following prayer: May God help us to use our new powers wisely and well, and with control. May we enter this new year that now begins, with courage in our hearts... and with new appreciation for the complexities and the wonders of God's world. In this new year that now begins, let us write in the book of life, let us write many good deeds, let us write them in a clear and a bold script, so that God may read what we have written, so that God may see what we have done with the life we have been given, and so that God may say to us: you have lived well in this past year ... you have written well, you have written many good deeds, and I am proud of you. Amen.