

Advent 2015

An Unwelcome Advent

A sermon by Rev Steven Epperson

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Beginning tomorrow and for the next two weeks, a crucial conference on Climate Change will be taking place in Paris. The hope of most nations attending will be to achieve a legally binding, universal agreement on climate from all the nations of the world. Our recent elections may mean that a very different Canada will be taking part. And I hope and pray, with all of you, for a significant, visionary and meaningful outcome.

This is a season of advent: we celebrate the imminent arrival of an important person or thing—winter solstice approaches, Hanukkah, Kwanzaa, Christmas, and Yule and a new calendar year; perhaps a new world-wide Climate Accord. We sing out the old and ring in the new. Many advents are cause for festivities and joy; others...more ominous, perhaps, maybe not be so welcome.

While all eyes may be on this conference in Paris, another one, hosted by the National Academies of Sciences and Medicine of the US, the Royal Society of the UK, and the Chinese Academy of Sciences will be taking place this week in Washington DC. The issues to be discussed by the more than two hundred scientists attending, the outcomes hopefully agreed upon there, are also momentous; they may have far reaching consequences for the well-being of our human species and perhaps for the very question of what it means to be human.

The conference in Washington is called the “International Summit on Human Gene Editing.” It has been organized in response to a flurry of events, scientific papers and articles that appeared just last Spring in the wake of astonishing recent advances in genetic technologies.

You know I’m just a clergy guy. I’m not a scientist, and my formal schooling in the sciences was subpar to put it mildly. But along with the rest of you, I do want to know, in a lay person sort of way at least, how our world works: how did our cosmos come into being? How

can we account for the rise and evolution of life on earth and beyond? What are the building blocks of matter? What's an atom? How do cells work? What's plate tectonics and photosynthesis, and what's it to me and you and the rest of all the blooming teeming, interconnected life around us, past, present and future?

We've explored many of these questions on First Sunday Advents for the past dozen years or so. And we've learned a lot together. I value these occasions. We stretch and deepen our understanding and our appreciation for Nature and our place within it. Sometimes, what we've learned entails certain kinds of consequences: *humility, awe, gratitude*—those are big ones for me. A sense of responsibility to try to be a better, more responsible steward of the earth and its resources is another. Now I'm talking moral responsibilities, ethical ones that impact principles of action and conduct as I walk this earth, and live out my one, unique life.

That one, unique life. Our one shot at trying to make the best of the time given us. We're also social beings, historical ones, too. Trying to make the best of our lives means sharing our knowledge, feelings, experience and gifts with others. We feel that it matters, don't we? We hope that in so doing, we'll add some value we possess to the cumulative sum of human goodness and knowledge, hoping that whatever good we've learned, experienced and shared will be handed on down along to future generations.

Up to now, being social and historical creatures has also meant the mostly haphazard, ad hoc passing along of genetic traits via our DNA. Tons of those traits show up as differences that don't have to do with a better diet or the reading of more books: some people are taller, or smarter, others have freckles and darker skin colour. Some species traits are a boon across the board to successive generations: I think most of us like having inherited an opposable thumb and being born to empathize with the feelings of others. Some heritable traits, however, are tragic and devastating: like cystic fibrosis, sickle-cell anemia, Huntingdon's Disease and host of other genetic diseases for which, until recently, there had been no real, curative therapies available in medicine's tool-kit. In sum, the genes that we humans carried in our bodies, for good or ill, were exclusively the result of chance—of how the genes in a sperm and egg, the father and mother

combined. Historically, the only way we could affect the process was by mate selection—and we know what a crap shoot even that is for influencing outcomes.

But that picture has changed, and is changing as I speak.

The women and men who work in the field of genetics study the differences that come from nature—all those different pairings of DNA that cue the work of different proteins and hence the differences that appear in plants, animals and people. Through their understanding of the way genes work and the technologies they've developed to manipulate genetic codes, geneticists have been able to modify plants to be more resistant to drought and certain diseases. (I know there's lots to say about GMOs in the plant kingdom; but that's another sermon.) From here on I'm focusing on us—on human beings and our future.

Geneticists have turned their attention to genetic diseases in the human family—to those errant instructions from the genes causing a flood or drought of some protein that ends up afflicting a person with a devastating disease. And that's been the principal, beneficial intent: genetic therapy to diminish or remove the symptoms of a disease of a living person.

There are two methods to change human genes; and this difference is really important. One is called *somatic gene therapy*. This method begins with a person with a genetic disease; let's say cystic fibrosis. Researchers try to deliver new, modified genes to some of the person's cells, usually by putting the genes aboard viruses injected into the patient. They hope that the virus will infect the cells and thereby transmit therapeutic genes. If the therapy works, the proteins causing the cystic fibrosis should diminish, and with them the horrible symptoms of mucus filling the lungs: no more hopeless cough, no more drowning in your own fluid.

It's important to note here, that *somatic gene therapy* is not designed to affect sperm and eggs; it is not designed to affect other cells in the body, just the specific types of cells that would be transplanted: for example, in the case of cystic fibrosis—the cells of the person's lung tissue. As well, the modified genes are not passed along. When the person dies, the modified genes die.

The first *somatic gene therapies* were introduced in the 1990s; real improvements and cures started to be reported a dozen years ago, and in just the past three years *somatic gene*

therapy has taken a quantum leap with the development of more accurate and effective gene editing technologies. I can't think of a reason not to wish this form of therapy well.

But there's another, more ominous way to change human genes. It's called *germline genetic engineering*. This is how Bill McKibben described and warned us about this form of therapy a dozen years ago; I've been brooding on it for some time:

Germline genetic engineering...is something novel indeed. "Germ" refers to...the egg and sperm cells...of the human being.....Scientists intent on genetic engineering would start with a fertilized embryo a week or so old. They would tease apart the cells of the embryo, and then selecting one, they would add to, or delete, or modify some of its genes. They could also insert artificial chromosomes containing predesigned genes. They would take the cell, place it inside the egg whose nucleus has been removed, and implant the resulting new embryo inside the woman. The embryo, if all goes according to plan, grows into a genetically engineered child. His genes would then be pushing out proteins to *meet the particular choices made by the parents, and by the companies and clinicians they bought the genes from*. Instead of coming [by chance] solely from the combinations of the parents, and so on back through time, these genes could come from any person, or any plant or animal" and would be passed on from one generation to the next with no clear, determined control of its outcome. (Bill McKibben, *Enough: Staying Human in an Engineered Age*, 10)

Germline genetic engineering, which take place routinely now for plants and animals,

sounded like science fiction when applied to humans only a short time ago. Here's a breathless, journalistic description from the *New York Times* fifteen years ago:

Lucy, a brown-black furred mouse, created by scientists at Chromos Molecular Systems in Vancouver, British Columbia, has an artificial chromosome that she has passed along to her offspring. Lucy's "descendants...represent another step in biotechnology's inexorable march toward the day when parents will be able to design their own babies: eliminating genes for undesirable traits, adding genes for desirable ones—and in the process altering the DNA of generations to come." (Sheryl Stolberg, "A Genetic Future both Tantalizing and Disturbing: A Small Leap to Designer Babies," *NYTimes*, January 1, 2000)

"There will be enhancements to life span, alterations to personality, like intelligence," says Dr Gregory Stock, at UCLA. "In the not-too-distant future, it will be looked at as kind of foolhardy to have a child by normal conception." Soon, says Dr Lee Silver, of Princeton University, a doctor will tell parents: "I've got your embryos under a microscope. How about if I add a couple of genes to provide cancer resistance, or genes for stronger muscles? Or musical talent?" "Going for perfection," is how James Watson, the DNA pioneer, put it crudely. "Who

wants an ugly baby?” or a normal one with an average IQ.... “It would be so easy. So bloody easy,” he said. (McKibben, 10, 18)

Gene editing technologies developed since 2012 have brought us to the cusp of a momentous choice—do we move from *somatic gene therapy* to **remediate**, that is to attempt to cure, heritable human disease in the living person to *germline genetic engineering* to **enhance**, that is to bulk up and change heritable human traits from one generation to another? What’s to stop scientists with the know-how, companies with an eye to potential markets and untold profits, and parents with the wealth—who want only the best for their offspring, who want to give them an enhanced edge—what’s to stop them from taking this step toward genetically engineering a desired advantage for their offspring?

(Good heavens, this happens all the time in the real world! Elite private schools, world travel, one-on-one tutoring, personal trainers.) But what if the enhanced edge was genetically programmed and within technological and financial reach of those who had the resources to pay: what if we could add height, muscles, beauty, smarts—you name it—advantages adults could order on demand and thus convey to their offspring a leg up in the competitive struggle for advantage in our obsessively image conscious, anxiety ridden, competitive society—what’s to stop them, all of them, from opting for *genetic engineering* their children and their children’s children? And don’t think that there aren’t people lined up, and ready and willing to do it.

Which brings me back to the “International Summit on Human Gene Editing” conference in Washington DC this week, and some thoughts about our Unitarian principles and ethos. Some of the very scientists who have developed the latest, most effective techniques for genome editing, like Jennifer Doudna, Emmanuelle Charpentier and Edward Lanphier, have called on scientists and clinicians world-wide for a pause, for a moratorium on any attempts to test germline engineering on human embryos. Together, they have helped to convoke this week’s conference. (The purpose of the conference is to survey the current state of the science and available technologies; the rationale(s), the potential benefits and risks inherent in conducting such research; to review existing regulatory principles, and the ethical concerns and legal and

regulatory considerations that will be needed to guide further research and potential applications of genetic technology.)

Here are the issues at stake: “Genome-editing technologies,” writes Edward Lanphier in the 26 March 2015 issue of *Nature*, “may offer a powerful approach to treat many diseases...but they are not designed to affect [human] sperm and eggs. In our view, genome editing in human embryos... could have unpredictable effects on future generations...Such research could be exploited for non-therapeutic modifications.... Permitting even unambiguously therapeutic interventions could start us down a path towards non-therapeutic enhancement.”

Unpredictable effects on future generations and non-therapeutic enhancement...

Let me put it this way: Why did we swing from euphoria to severe let down in late September 1988 when Canadian sprinter Ben Johnson broke the world record and won the gold medal in the 100 meter sprint at the Olympic Games in Seoul, South Korea? Or when cancer beating cycling superstar Lance Armstrong won seven consecutive Tour de France road races between 1999 and 2005? Do you know what I’m talking about? They took performance enhancing steroids and other drugs. What’s wrong with that? Turns out many of their co-competitors were doing the same thing. In fact, up to 80% of the athletes tested at the 1988 Olympic Games eventually showed evidence of long-term steroid use. If you look up lists of known doping cases in athletics for which athletes were punished—the numbers run into the thousands. The whole Russian track and field team was banned from international competitions just *two weeks ago* due to sweeping doping allegations against the country’s athletes, coaches, trainers, doctors and officials.

Why do we object to this? Aren’t we thrilled at the speed, the prowess, the records...the faster, higher, the further, the more and more....So what if athletes gain a competitive edge taking drugs doled out by doctors and coaches! No? What’s wrong with the picture?

Think about it! For the sake of prestige, wealth, prowess and power, *there are no limits*, no risks that individuals, bio-tech companies, teams and nations, doctors and parents will not take unless we say resolutely and collectively: Enough!

And not only in sports. What's more ominous still is the restless pressure and drive, enabled by genetic engineering technologies that are coming on-line, to apply germline genetic editing to human embryos: changes to a person's genetic make-up that she or he will then pass on down and out through their offspring with "unpredictable effects on future generations."

Listen carefully to following scenario: What will have happened to a newborn when we've installed into the nucleus of every one of her billions of cells a genetic code purchased by her parents from a bio-tech company that will pump out proteins designed to change her? Say she grows up and finds herself, at the age of sixteen, unaccountably happy all the time. Is it *her* being happy, she may wonder...or is it the corporate product inserted within her by design by her parents when she was a small nest of cells...Don't think she won't wonder why she's not feeling the highs and lows of being a regular teenager: at sixteen a sensitive soul questions everything. But perhaps her parents also "increased her intelligence" by genetic design—and perhaps that's why she's questioning so hard. But wait...she won't even be sure whether the questions and the emotions are really hers, *her very own*, or whether they were engineered for her so that she *will* have a relentlessly happy and high achieving life. (from M cKibben, 47)

This is a chilling scenario, "now that the capability for human germline engineering has emerged" (Lanphier) in just the past three years. What's dreadful about it even to contemplate is that having been genetically engineered from conception—that sixteen year young woman, and who knows countless others who will be engineered by design, what's dreadful is that she will have been robbed of her autonomy, her chance to truly understand her own life.

We Unitarians covenant to affirm and support "the free and responsible search for truth and meaning;" we see that as essential to "the dignity and worth of every person." In our long tradition, this *search for meaning* counts, I believe, even more than ability, or achievement or security or wealth or being right. Meaning and purpose emerges in that inefficient, difficult, all-too-human landscape of free will, in the tension of choice, where the true self is forged.

Though she contends that germline engineering human DNA lies far in the future, Jennifer Doudna, who may win the Nobel Prize for pioneering the latest, revolutionary gene editing techniques, has called for a moratorium and extreme caution on what seems like the inevitable: "it's going to happen," she said recently. And "I lie in bed almost every night and ask

myself whether this powerful new tool might do more harm than good.” (for this quote and accessible information about new gene technologies, see Michael Specter, “The Gene Hackers,” *New Yorker*, November 16, 2015)

The advent of something new—a child, a world Climate Change accord—is often to be welcomed and celebrated with thanks; some advents, however, are ominous, and may be a danger to the living and to future generations. *Germline genetic engineering* is one of those dangerous advents that call on us to say Enough! There are and should be limits to what human beings pursue and embrace.

I have shared all of this with you because it’s something we should know about, and I encourage you to find out more. In addition, I’ve shared this because this is one of those rare times when scientists themselves are calling for a moratorium on their work; and they are actually asking, in one published article after another, for public discussion that would include experts, academics, politicians, religious groups and human rights organizations.

To that end, I have written a letter to the National Academy of Sciences and Medicine, the International Society for Stem Cell Research and Dr. Jennifer Doudna at the University of California at Berkeley expressing support for the moratorium on human germline genetic editing in research and clinical practice. The letter will be available for you to add your signature in Hewett Hall directly after this service and after next week’s worship service.

I wish all of us a wonderful advent and holiday season. May the Paris Climate Change Conference achieve a truly universal, binding, visionary, and practicable accord; and may our nation’s government do the right thing and lead out on this. And may those attending the Summit on Human Gene Editing in Washington this week say: there is a line we should not cross. Enough! It’s OK to be cracked pots; human beings with limitations in all our ragged glory.