



Pierre Huyghe, 'Human Mask' (2014)

Blue Gene Baby

Life will never be the same again.
Genetic engineering expert Fyodor Urnov
on 'designer babies,' 2018

IN 2018, AN EXPERT ON GENETIC engineering named Fyodor Urnov downloaded a data file sent to him by an investigative journalist at MIT's prestigious science journal, *Technology Review*.

Told that the data had been uploaded by a Chinese lab to a registry for clinical trials, Urnov recalled his trepidation, saying, "I did not want to open that file... Please, please, please no. Nobody's that crazy."

Shortly afterward, his worst suspicions were confirmed: The files indicated that someone in a Chinese lab had artificially edited a human fetus—if not the first, then certainly the first publicly-disclosed attempt to produce what has come to be known informally as 'designer babies.'

The ethical, social, environmental, and safety ramifications of genetic engineering—the artificial manipulation of a living organism's genetic material—are profound, and the proposed cloning of humans has long been its lightning rod, a proverbial step too far in the minds of most gene scientists.

In 2018, the man holding a metal rod at the center of this storm was He Jiankui, known to his colleagues simply as JK.

JK was a Chinese-born, U.S.-educated research scientist, working at a prestigious, state-funded university in Shenzhen for gifted, foreign-educated students.

JK's goal was ambitious: to eradicate a disease governed by a single gene. He chose AIDS, knowing he could recruit volunteers with HIV by offering them the chance for parenthood denied them by China's strict laws against transmitting HIV to offspring.

Using the revolutionary gene-editing tool known as CRISPR, JK planned to disrupt a receptor gene that allows HIV to enter human cells, thereby preventing AIDS.

JK worked in secret: Editing human embryos for reproduction in this manner is taboo in the world of genetic engineering, as the possibility exists that mutations that could effect endless future generations will unintentionally be introduced in the subjects.

After succeeding in his efforts, JK released a series of YouTube videos announcing the birth of twins named Lulu and Nana, edited as embryos with CRISPR, and subsequently repeated this audacious claim at a major gene-editing conference in Hong Kong.

The reaction within the world scientific community was swift, and almost uniformly negative. The Chinese government quickly reversed its stance on JK's research, locking him out of his lab and placing him under house arrest. The following year, he was tried and sentenced to three years in prison for what were termed "illegal medical practices," and fined US\$430,000.

Few technologies are as controversial within the scientific community as genetic engineering. Early concerns about genetically-modified crops (GMOs) have largely receded, but the prospect of altering human DNA is still highly contentious.

While genome editing shows enormous promise in one day treating intractable, genetically caused diseases like sickle cell anemia and muscular dystrophy, there are risks—both known and unknown—which must be urgently and seriously addressed.

Among these are risks to the health of the individuals involved, as well as their offspring and future generations, unforeseen dangers to the environment, and malicious use of genetic engineering by bioterrorists.

In addition are well-founded concerns about widening socioeconomic inequalities due to the cost of the technology, and its potential use in limiting diversity in the human genome community (eugenics).

Some religious people condemn the practice of genetic engineering altogether, believing it unethical to 'play God' by tinkering with the DNA of living things.

But even many secular observers view genetic engineering as a step toward an authoritarian dystopia, as depicted in Aldous Huxley's 1932 novel, *Brave New World*. (Ironically, Huxley's famous novel was set in the year 2540, nearly a half-millennium later than his vision started to become, in reality, technologically possible.)

And therein lies the conundrum: Similar to advances in Artificial Intelligence (AI), rapid progress in genetic engineering has overtaken attempts to create any sort of uniform, binding framework to regulate it.

Human gene editing is certainly—perhaps inevitably—in our future, so we must reckon with it while we still have the time, the will, and the opportunity to do so.

He Jiankui was released from prison in 2022, and (some would say recklessly) resumed his efforts at gene editing—this time focusing on diseases like muscular dystrophy, and more recently, Alzheimer's.

Regarding the international furor his earlier work had caused, 'JK' would admit no greater error than bad timing. Once again taking to YouTube, he predicted that in 20 or 30 years time, gene-edited babies would no longer be considered controversial.

We can only hope that in the interim, the world community can agree on how—if not to put the 'gene genie' back into the bottle—to at least make sure it grants humanity only its most positive and benign wishes. ■