

## ***The Genome, Conception, and Human Destiny***

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### INTRODUCTION

Earlier this year, a slew of articles were published in various science and technology journals on the controversy surrounding human genome modification – “germline editing” – since the 2012 DNA editing technology known as CRISPR-cas9 was used by scientists from Sun Yat-Sen University to modify the genome of non-viable human embryos. Since their publication in *Protein & Cell* this past April,<sup>1</sup> the widespread use of CRISPR-cas9 in research has garnered much media attention in the biotech world. The rapid pace at which this technology took off is dizzying, and its potential uses even more so, as reportedly “it could at last allow genetics researchers to conjure everything anyone has ever worried they would—designer babies, invasive mutants, species-specific bioweapons, and a dozen other apocalyptic sci-fi tropes.”<sup>2</sup>

### ANALYSIS

More specifically, its potential for human gene therapy is enormous: the ability to edit single alleles that code for diseases such as sickle-cell anemia, Huntington’s, or cystic fibrosis, to prevent these genetic diseases from being inherited. However, the alluring possibilities of human biotechnology raise intensely difficult and existential questions that we do not often ask or think about. These questions concern our perceptions of the child and child-making, as well as the very origin and destiny of ‘what it is to be human.’ Our answers to these questions contain vast implications for the individual identity at hand and also for society as a whole. What are the effects of advancing a technology so fast without our ability to ask what it means, or what it will mean, for us and for the future?

To think deeply about the implications of germline engineering is to consider it in the act of generating a child through assisted reproductive technology (ART). Although the use of ARTs is no longer alien, their existential effect on the resulting child merits a deeper examination of this method of transmitting human life.

Consider the stories of donor-conceived children<sup>3</sup>, whose varying circumstances and feelings towards their coming-to-be all share one thing in common: they owe their existence to the explicit will of the people who ‘made’ them. Their ‘being’ would not be if it were not for the desire on behalf of the parent(s) that

chose them and the technology that made it possible, which can be a very beautiful thing. I recently came across the *UK Daily Mail's* story of 16-year old Gracie Crane, one of Britain's first adopted embryos who wishes she had never been born<sup>4</sup>. She was one of three un-selected embryos frozen from an IVF attempt by her genetic parents, and her fate was changed from incineration to adoption through one phone call. The contingency of her being is astounding - as is the fact of any person's existence - but hers in a unique way, as she was conceived on the condition of her genetic parents' will (their wanting a child) and was only made actual with the help of technology. The second moment of contingency (that her embryo happened to be the adopted one that implanted successfully) is only augmented by the first. The point is that this combination of deliberate will and the assistance of technology to bring about said will changes not only *how* someone has come to be, but also the very *meaning* of their having-come-to-be, by being existentially dependent on the will of other human beings.

This difference is especially relevant to the possibilities for the human germline created by CRISPR-cas9: enabling scientists and parents to choose not only the existence of their hypothetical child, but also their genetic fate. Granted, the intent behind this technological modification is the same as existing methods of genetic "disease prevention" that happens through prenatal genetic screening<sup>5</sup>, and is also the same idea behind GenePeeks Inc., which pairs intending parent(s) with an optimal donor to weed out life-threatening, life-changing childhood genetic diseases before any in vitro fertilization occurs. But these examples also illustrate the point that the fate of the future-child is in the hands of the people who want him or her in a way that places another's will at the very heart of that child's existence. Consider that when a husband and wife naturally conceive a child, he or she is given to them in a way that is beyond their choosing. Even their choice to engage in sexual procreation does not guarantee the generation of a child; conception is an event (a surprise) to be welcomed.

Although there are meaningful differences between the three methods of disease prevention (germline engineering, prenatal screening/embryo selection, and donor-pairing), the same *intentionality* is involved in the making of a genetic-disease-free child that is not present when a child is conceived as a 'surprise.' And so the question becomes: does it matter how we are conceived, and by whom? Is there a meaningful difference to the condition of human life when the 'chance' or 'surprise' nature of a child is removed from the fact of being born? And does a technologically conditioned origin affect the establishment of our personal identity?

## CONCLUSION

With germline editing, a technological intervention at the level of a person's very genetic make-up constitutes an entirely different footing: no longer one of natural endowment but of technological deliberation at the hands of another. The ethics of genetic interventions and assisted reproduction raise fascinating and difficult questions about the human being and human nature: existential questions that need to be thought about and worked through carefully, as it is not a metaphysically neutral and/or value-void matter for those conceived, nor for society.<sup>6</sup>

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<sup>1</sup> Liang, Puping et al. CRISPR/Cas9-mediated gene editing in human tripronuclear zygotes. *Protein & Cell*, April 18 2015. Vol 6 (5) 363-372. Accessed at: <http://download.springer.com/static/pdf/629/art%253A10.1007%252Fs13238-015-0153-5.pdf?originUrl=http%3A%2F%2Flink.springer.com%2Farticle%2F10.1007%2Fs13238-015-0153-5>

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<sup>2</sup> Maxara, Amy. Easy DNA Editing will Remake the World. Buckle Up. *Wired*. July 22, 2015. Accessed at: <http://www.wired.com/2015/07/crispr-dna-editing-2/>

<sup>3</sup> Further reading on donor conceived children:

- Donor Conception Network: <http://www.dcnetwork.org/about>
- The Anonymous Us Project: <http://anonymousus.org>
- The Institute for American Values Report *My Daddy's Name is Donor*: [http://americanvalues.org/catalog/pdfs/Donor\\_FINAL.pdf](http://americanvalues.org/catalog/pdfs/Donor_FINAL.pdf)
- The Center for Bioethics and Culture's documentaries on anonymous donor conception and surrogacy: <http://www.cbc-network.org/film/>

<sup>4</sup> Carrol, Helen. Donor IVF baby who says 'I wish I'd never been born.' *UK Daily Mail Online*. June 25, 2014. <http://www.dailymail.co.uk/femail/article-2669842/Donor-IVF-baby-says-I-wish-I-d-never-born-Its-great-IVF-taboo-child-feel-never-knowing-biological-parents-For-family-answer-shattering.html>

<sup>5</sup> Bosley, Katrine et al. CRISPR germline engineering – the community speaks. *Nature Biotechnology*. May 2015. 33, 478 – 486. Accessed at: <http://www.nature.com/proxycu.wrlc.org/nbt/journal/v33/n5/pdf/nbt.3227.pdf>

<sup>6</sup> For an illustration of combatting ethical views on the issue, compare scientist Stephen Pinker's recent comment on bioethics and CRISPR's potential with that of ethicist Margaret Somerville. See: Pinker, Steven. The moral imperative for bioethics. *The Boston Globe*. August 1, 2015. Accessed at: <http://www.bostonglobe.com/opinion/2015/07/31/the-moral-imperative-for-bioethics/JmEkoyzITAu9oQV76JrK9N/story.html> and Somerville, Margaret. "Immortalizing our Genetic Selves" in *The Ethical Canary: Science, Society, and the Human Spirit*. Penguin Books, Canada: 2000. 55-88.