

## DREAM BABIES

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ON 25 NOVEMBER 2018, two days before the start of the Second International Summit on Human Genome Editing in Hong Kong, a clip appeared on YouTube entitled ‘About Lulu and Nana: Twin girls born healthy after gene surgery as single-cell embryos’.<sup>1</sup> In the clip, He Jiankui 贺建奎, an American-trained Chinese associate professor of biophysics at Shenzhen University of Science and Technology, stands in his private laboratory (he oversaw a state university lab and founded his own private biotech company lab), speaking in English (with English and Mandarin subtitles). He claimed he had just brought into the world the first genetically edited babies — that is, the first babies to have had deliberately induced changes to their

germline, which is a series of cell lines descended from previous cells that are passed down through generations of humans. This germline would be inherited by any future children they may produce.

At the summit, organisers quickly rearranged the program so He Jiankui could appear solo to explain himself. To a shocked audience, he revealed that he had represented the experiment to his participants as a study into an HIV/AIDS vaccine, and that they may not have fully understood what they were consenting to.<sup>2</sup> Later investigations revealed that the ethics committee he cited as overseeing the ‘trial’ claimed to have no knowledge of it and the paperwork produced as evidence of institutional ethical approval contained an extremely



**Controversial dreams:  
designer babies**  
Source: Pixabay

unusual reference to the advancement of the People's Republic of China's (PRC) global reputation for scientific innovation as an ethical justification for the procedures.<sup>3</sup>

A flurry of controversy engulfed the conference, and both Chinese and international attendees were swift in their condemnation.<sup>4</sup> He Jiankui had broken many of the rules, but also the norms, of the genomics community. He contravened protocols of how scientific advances are communicated by announcing it via YouTube<sup>5</sup> and, as George Estreich of Oregon State University pointed out in *The Conversation*, it was a bizarre announcement, riddled with misleading, emotive, and deceptive language.<sup>6</sup> Was He Jiankui genuinely interested in scientific advancements or was he just courting publicity? There were a number of glaring holes

and inconsistencies in the evidence he provided and the scientific process he described.

Scientists the world over have been investigating the multiple possible applications of a gene-editing procedure, known as CRISPR Cas-9, since the technique was pioneered by American molecular biologist Jennifer Doudna in 2012.<sup>7</sup> The technique holds much promise for therapeutic genetic editing, which is commonly represented as a 'cut and paste' technique to add or remove genetic markers for conditions that adversely impact one's health, thus curing genetically inherited diseases. It could possibly also be used to create 'designer babies', by altering genetic traits for aesthetic purposes as a matter of preference. Many laboratories are experimenting with its application in human embryos

*in vitro* up to fourteen days from creation, which has been agreed by the international genomics community as the ethically acceptable limit. The scientific consensus to date holds that it would be unconscionable to allow any edited embryo to progress through the process of invitro fertilisation (IVF) in a woman, ultimately resulting in a live birth. The scientific, ethical, moral, legal, and social objections for doing so are vast. The arrival of Lulu and Nana brought fresh urgency to the issue of ethical standards in research, which is hotly debated in the international genomics community.

He Jiankui expected to be hailed a national hero in the name of advancing China's dreams of international biomedical leadership. Instead, he was swiftly condemned both locally and internationally, removed from his university appointment, and soon after disappeared from public life.<sup>8</sup> The end of 2019 saw him sentenced to three years in prison, along with two colleagues, for practising medicine without a licence and 'seeking fame and wealth'.<sup>9</sup>

Prior to this, China had already attracted uncomfortable international scrutiny over the

growth of commercial industries selling highly experimental, even unproven, treatments — notably, stem cell treatments.<sup>10</sup> Despite China's recent attempts to rein in the market for unproven stem cell treatments, He Jiankui's story revealed that the structures of Chinese scientific institutions and enterprises still allow scientists and biotech entrepreneurs to operate away from the regulatory eye. In July, a Spanish scientist employed by the Salk Institute in the United States announced that he had created the first human-monkey chimera (cells from both species combined in one organism) in a lab in December. This research — purportedly the first step in using animals for human organ transplants — is not permitted in the United States.<sup>11</sup> The first pigs containing cynomolgus monkey cells were born full-term in December 2019, although they survived for only a week.<sup>12</sup>

Since China's Reform and Opening Up in 1978, increasing numbers of scientists, doctors, biotech entrepreneurs, and patients in search of treatments not permitted in their home countries have travelled there to take advantage of so-called

regulatory grey areas.<sup>13</sup> But beyond this, how did China become a favoured home for scientists wanting to push the limits of ethically acceptable scientific innovation?

As the anthropologist Aihwa Ong has argued in her work on biotechnology in Asia:

[B]iotech mechanisms are presented as ethical operations that link the immediate needs of the individual consumer or patient to the political generation of civic virtue, that is, appropriate conduct and social obligations to contribute to national prosperity and security.<sup>14</sup>

If his motives were indeed sincere, He Jiankui might have believed that he was employing a highly technical pathway to enhancing the health and prosperity of his country's population. This would explain why he thought his work would be received positively in China.

As for Lulu and Nana's story, we know very little about the lives of the twins or their parents; however, the father's HIV status is a crucial element in the story. In his commentary on the YouTube announcement, He Jiankui cites the high level of anxiety

experienced by the girls' parents about the possibility of passing HIV on to any child they might conceive naturally.<sup>15</sup> Couples of whom either one or both of the parents are HIV positive are not allowed to access fertility treatment even if they can afford it. This dynamic was a key part of their willingness to participate in the experiment, which offered them a chance to have a baby who would not inherit the father's virus. He Jiankui offered a procedure that would 'wash' the sperm to prevent transmission from parent to child, while introducing a genetic edit that purportedly would 'switch off' the embryo's ability to acquire HIV.<sup>16</sup> As he explained in the YouTube video, 'discrimination in many developing countries makes the virus worse'. He rightly pointed out that people living with HIV face discrimination in employment as well as from medical professionals; some women even face forced sterilisation. Precisely because of the plight of people living with HIV in China, some critics considered the way the 'study' was presented to the couple to be a coercive recruitment strategy.<sup>17</sup>

He Jiankui imagines a future in which genetic editing in babies will be considered as uncontroversial as the

IVF procedure he used to implant the embryos into the mother. He cites the case of Louise Brown, the first baby born through IVF, and argues that ‘for forty years, regulations and moral [sic] have developed together with IVF’. But meanwhile, He’s ‘dream babies’ turned into a personal nightmare for him. He lost his lucrative university position, his professional standing, and ultimately his freedom, and his name is now synonymous with the 2019 global reckoning with the ethics of innovation in genomics. The impact of the procedure on Lulu and Nana in the long term remains to be seen. Yet, as He Jiankui hints in the video, it may be just a matter of time before

he is vindicated. In May 2019, new regulations were introduced in China stating that anyone who manipulates genes in humans is legally liable for anything that happens to the health of that person.<sup>18</sup> Yet in June 2019, undeterred by He Jiankui’s fate, and beyond China’s regulatory borders, a Russian scientist announced his plans to proceed with a genetic-editing procedure that he is now stridently defending from criticism,<sup>19</sup> and vowing to pursue.<sup>20</sup> For those dreaming of a future of therapeutic genetic editing and designer babies, that future may be closer than anyone thought.

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