

IMPURE HOPES

CRISPR and an HIV Cure

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A media spectacle emerged as news about the world's first gene-edited babies broke in 2018 from the Genome Editing Summit in Hong Kong. I participated in the Summit as a speaker on the ethics panel and an observer of science in action. Later, I traveled from Hong Kong across the bay to Shenzhen—a city in mainland China known for “economic, technological, and social dynamism” and the “constant pursuit of ‘the future’ itself” (Yang 2017: 195). In Shenzhen I charted a path as an ethnographer into the laboratory of Dr. Jiankui He (see Kirksey 2020). I talked with laboratory personnel as well as experimental volunteers—HIV-positive men living with complex epistemologies of the closet (cf. Sedgwick 2008).

Impure hopes—mixtures of heterosexual desires for reproductive futurity, biotech speculation about an HIV cure, and national dreams of glory—drove the experiment forward (cf. Edelman 2004). The men who signed up their families for the study were living in a cultural milieu where queers, Marxists, and capitalists had created “intellectually hybrid, impure, and even promiscuous” alliances (Liu 2015: 20; cf. Rofel 2007: 168). Volunteers were caught between dreamworlds, harboring hopes that were not entirely their own. The story of these men and their genetically modified children is linked to CRISPR, a fast and cheap tool for manipulating DNA that has animated speculation in the biotechnology innovation economy. Building on earlier work about “impure science” (Epstein 1996), this article makes an argument for the importance of contaminated hopes in ethically compromised times (Shotwell 2016).

Hope is shot through with ambivalence in queer and critical theory. Optimism can be cruel, according to Lauren Berlant (2011: 24), when you discover that the dreams you are attached to are either “impossible, sheer fantasy, or *too* possible, and toxic.” In studying hopes connected to an HIV cure, it is important to acknowledge the work of disabled scholars, like Eli Clare (2017: 12), who dis-

avow the “pursuit of hope through cure.” Instead of being fixated on medical or scientific cures, Clare finds more modest hopes through social justice initiatives in community with people who have differently abled bodies and minds. Even still, Alison Kafer (2013: 27) insists that “a desire for a cure is not necessarily an . . . anti-disability rights and justice position.” She embraces the “critical promise” of fantasy “to imagine ourselves and others otherwise” (Judith Butler, quoted in Kafer: 45).

Against the backdrop of open-ended promises in fantasy worlds, the specificity of hope for an HIV cure has been shaped by decades of activism and utopian longings (see, e.g., Adam 1995; Chambré 2006; Muñoz 2009). In the United States, the political movement that emerged from the AIDS crisis produced collective hopes focused on innovative and risky research, alongside anger, indignation, rage, and disillusionment with the conventional medical establishment (Gould 2009: 3). Neoliberal capitalism has since reconfigured the horizons of queer dreams and aspirations in the United States as well as China. New cosmopolitan aspirations, novel identities, forms of public culture, and political projects have emerged within countervailing fields of power (Rofel 2007; Liu 2015: 3). The impure hopes that congealed around an HIV cure in the field of gene editing arose as patients and activists entered into uneasy alliances with scientists and investors. Different groups of people shared hopes—or articulated them together—in a field of imagination shaped by speculation in the innovation economy (cf. Hall 1986).

CRISPR is a biotechnology tool that has animated much hope and hype in the marketplace and mainstream media. A cover story in *Wired* magazine reported that CRISPR could mean “no hunger, no pollution, no disease. . . . And the end of life as we know it.”¹ When I began this research project in 2015, CRISPR was what Sarah Franklin (1997: 224n20) calls a “hope technology”—something that contains “the tantalizing promise of technology” and lacks clear medical uses or commercial applications (see also Ahmed 2010: 181). To understand the dream-worlds surrounding CRISPR, I deployed the methods of multisited ethnography, to “follow the controversy” and also follow the molecule (Marcus 1995: 110) from media reports to scientific laboratories and into the bodies of living people (see also Kirksey 2020).

Boosters of the biological sciences have celebrated “technology as the locus of agency and the driver of history” (Hurlbut 2016: 213). CRISPR itself has no power. This molecule can only change human DNA when it is deployed by people. As scientists, biotechnology executives, and investors pushed CRISPR into the clinic, they were in a position to determine which hopes about gene editing would

remain in the realm of sheer fantasy and which dreams would enter the domain of historical possibility. At the same time, patients, queer activists, and government officials subtly guided commercial and scientific agendas—insisting that “pure” science and enterprises focused on pure profit needed to address other values, priorities, and norms. Abstract hopes for a cure in HIV-positive communities of the United States and China became increasingly concrete, as *articulation work* took place—as contingent, non-necessary connections were maintained among patients, entrepreneurial scientists, and government representatives (cf. Hall 1986: 53; Muñoz 2009: 91).

China Dreams

Jiankui He was born to rice farmers in the impoverished countryside of the Hunan province. After excelling at school, he attended a top university in mainland China before pursuing graduate work in the United States (Kirksey 2020). During his postdoc at Stanford University, he was mentored by Stephen Quake, a molecular biologist and Silicon Valley entrepreneur with investments in ten separate companies worth more than \$1.5 billion at their peak valuation. Dr. He was recruited back to mainland China through the Peacock Plan, a special incentive program aimed at attracting overseas Chinese innovators, scientists, and entrepreneurs. This program was part of a broader plan by the municipal government of Shenzhen that aimed to turn the city into the Silicon Valley of China.

A local Communist Party official, Bingwen Xie, mentored He and helped him become established in the local biotechnology start-up scene (Cohen 2019). After importing intellectual property from the Quake laboratory at Stanford, He established a series of companies—including Direct Genomics, which was valued at over 2 billion yuan (\$314 million) (Yuan 2018). Dr. He began living the China dream. He was a self-made man who participated in a broader national project that aimed to displace the status quo of Western modernity with an Asian future (Yang 2017). President Xi Jinping had just announced his signature “Chinese Dream” policy with massive investments in “cutting-edge frontier technologies . . . modern engineering technologies and disruptive technologies.”²

When Dr. He began planning his CRISPR experiment, he thought that this would fit the president’s vision of a disruptive technological innovation. Chinese scientists have seen technological progress as a largely secular enterprise ever since Chairman Mao tried to sweep away religious beliefs with the Cultural Revolution. Jiankui He was not a religious man and did not share the moral objections raised by Christian bioethicists to genetically modifying human embryos.

Like other international biotechnology entrepreneurs, he equated ethical values with market values (Sunder Rajan 2006). In the new era of the “Chinese Dream,” the time seemed ripe to take the lead and achieve a world first with CRISPR.

Initially He conducted preclinical experiments on PCSK9, a gene associated with high cholesterol (Musunuru 2019). As he began laying the groundwork for the world’s first use of CRISPR in reproductive medicine, his local mentor in the Communist Party shaped his research trajectory. Bingwen Xie took the enterprising scientist on a journey to China’s hinterlands (Kirksey 2020), where his research agenda shifted away from cholesterol and toward a disease deemed more important by many patients, policy makers, and scientists. Dr. He became interpolated into dreams that were not his own. He became inspired to pursue a cure for HIV.

The politician and the scientist traveled together to Wenlou Village, nearly a thousand miles north of Shenzhen. Wenlou is one of the epicenters of HIV in China’s rural Henan province. Here the story of the virus is linked to a money-making scheme from the early 1990s, when visiting entrepreneurs started buying up human blood (Jing 2006). At the time, few regulations governed blood donation in China. Local villagers who did not have formal training in sterilization procedures established makeshift blood banks. Farmers stopped tending their crops and instead began to sell their blood as a new moneymaking strategy. By the time these operations were shut down in March 1995, hundreds of people were infected with HIV in the village (Ning 2016).

The Chinese government tried to address HIV with a bold national program in 2003 that guaranteed free HIV tests for all citizens, a lifetime supply of antiretroviral drugs, and counseling services for anyone with the virus. In China, as in the United States, the virus is no longer a death sentence but a manageable chronic condition. But people who live with HIV continue to experience extreme social stigma (Guo and Kleinman 2011). Jiankui He was impressed by a profound need for an HIV cure when he talked with long-term patients in Wenlou Village. They told him about intense experiences of prejudice and discrimination. Villagers who were HIV-free were extremely anxious about the virus and actively shunned others who were known to harbor infections.

Upon returning to his university laboratory in Shenzhen, He had a fresh sense of purpose. As an entrepreneur, with the support of local government officials, he brought a naive sense of optimism to an old and difficult medical problem (cf. Irani 2019). He knew that Jennifer Doudna, the biochemist at Berkeley who had first developed CRISPR as a molecular biology tool, had successfully used it to “delete” a gene called *CCR5* in a petri dish. Doudna showed that it was possible

to manufacture synthetic T cells that were resistant to HIV. If this experiment were repeated in human embryos, it seemed plausible that the babies resulting from the experiment would be protected from HIV.

By creating the world's first CRISPR babies and developing an HIV cure at the same time, He thought he would bring glory to the nation. Beyond the birth of the babies, he also saw the promise of a profitable future (cf. Ahmed 2010: 181). His impure hopes, as a Chinese court later charged, involved dreams of “fame and fortune” (Kennedy 2019). He put a profit-driven venture ahead of the health and well-being of future human children. Plans were afoot to establish an international medical research center—with a full-time R&D team of three hundred people, including one hundred doctors—where He would train people to create genetically modified children (Cohen 2019; Kirksey 2020). Speculative ventures in the innovation economy were propelling CRISPR into the clinic before the science was ready and before clear ethical and legal frameworks were in place.

The First “Edited” Humans

While Jiankui He laid the groundwork for his experiment in reproductive medicine, a controversy was playing out in the United States over HIV research and the future of human genome editing. Nearly a decade earlier, some veteran members of the ACT UP movement had signed up to become the world's first “edited” people. Matt Sharp was an activist who had routinely put his own body on the line—at ACT UP protests and in experimental ventures—in hopes of advancing science toward an HIV cure. He was asked to join the gene-editing experiment by a researcher one day in 2010 over lunch in San Francisco. The physician conducting the study had a reputation in the community of HIV-positive people for conducting groundbreaking and risky research. “They gave me this opportunity,” Sharp told me. “Do you want to be the first person in this safety trial? I said nooooo. But, I said that I'd be number two. This is a true story. I knew my number, 102.”³

Along with legions of other HIV-positive activists, Sharp was a veteran of battles with government officials, corporations, and scientific researchers who did not always have the interests of the patient community in mind. Sharp was arrested more than eight times at protests aimed at disrupting the status quo of AIDS treatment and research.

In May 1990, he joined ACT UP members from around the country who stormed the National Institutes of Health (NIH) campus with rainbow-colored smoke bombs and signs: “Drugs into Bodies,” “Red Tape Kills Us,” and “One AIDS Death Every 12 Minutes” (*Fight Back, Fight AIDS* 2002). Around the

country, thousands of people afflicted with AIDS were demanding new clinical trials, choosing to risk exposure to unvalidated drugs instead of dying in silence (Treichler 1999: 285).

A principal organizer of the “Storm the NIH” protest, Brian Zabcik, told me that there was a conflict in the movement between people who advocated for cutting-edge research and others who cared more about social justice (also see Maskovsky 2018).⁴ While some made demands of experimental science—shouting “Get us a cure!” and “Clinical trials now!”—others were focused on broader questions: “Who is getting AIDS, how, and why? Who gets access to treatment?” Many desired medical interventions that addressed discrimination on the basis of race, sexual orientation, and national origin (see Kirksey 2020). An earlier manifesto, “What We Want, What We Believe,” outlined sweeping goals for the community. This 1971 declaration called for the liberation of humanity with “free food, free shelter, free clothing, free transportation, free health care, free utilities, free education, free art for all” (quoted in Muñoz 2009: 19).

Many HIV-positive people left the movement in the mid-1990s, despairing since no end to the crisis was in sight, “feeling both helpless and hopeless” (Gould 2009: 433). As others turned away from activism, Matt Sharp renewed his commitments to advocacy and started shaping national policy. This new era of activism came with impurities. Sharp joined other ACT UP veterans in making uneasy alliances with policy makers, scientists, and even drug companies. Like other long-term HIV survivors, Sharp and his friends became “fundamentally dependent on their adversaries” in the words of Steven Epstein (1996: 351).

Sharp came to see participation in clinical trials as his primary route to survival. Over the years he signed up for more than a dozen experiments. With each trial he hoped to live just a little bit longer. One doctor cut Sharp open and inserted tissue from a fetus into his chest, trying to transplant the thymus, the immune organ where T cells mature. Sharp remembers “a lot of blood and a lot of tissue.” Scientists thought that a thymus transplant might boost his immune system. But it didn’t seem to work. As legions of HIV-positive men like Sharp signed up to become guinea pigs, their vulnerable bodies helped produce a suite of new medications.

Impure science—shaped by a mixture of patient perspectives, political agendas, and even big pharma investments—turned out to be good science (Epstein 1996: 256). Hopes that once seemed cruelly unrealistic became concrete (Berlant 2011). Instead of “a future continuously deferred,” with hopeful subjects focused “on the promise of the coming” (Edelman 2004: 114), dreams of AIDS activists came into contact with reality. As a new generation of effective medicine

was approved for widespread use, HIV was no longer a death sentence. The virus became a manageable and even generative part of queer cultures (Dean 2009).

A new era of healthy living with the virus became possible. But Sharp did not enjoy the same medical benefits as many of his peers. He was out of sync with the dominant affects in the poz community (cf. Gould 2009: 338; Ahmed 2010: 41). The new pills did not fix his immune system. While he was able to control his viral load with the new drugs, his T cell count stayed below five hundred—dangerously close to an AIDS diagnosis. He continued to live with a sense of precarity, not knowing when his health might suddenly take a turn for the worse. About 20 percent of people who live with HIV are like Sharp—they are called “immunological nonresponders” in the primary scientific literature. This simply means that they have abnormally low T cell counts even while taking daily antiviral medication.

Compared with the early HIV experiments, the gene-editing study that Sharp joined in 2010 seemed relatively safe and full of promise. The research was taking place on the heels of news about a medical breakthrough: Timothy Ray Brown, the “Berlin Patient,” had just experienced the world’s first HIV cure. Brown was receiving a medical treatment for leukemia when the doctor offered him an experimental bone-marrow transplant from a donor with a rare genetic condition: a mutation to the *CCR5* gene. Scientists discovered *CCR5* by studying people who were exposed to HIV but who did not get infected with the virus (Jackson 2015). *CCR5* contains instructions to build a receptor—a tiny docking bay—on the surface of white blood cells. Without this receptor, human cells are resistant to HIV because the virus does not have a way to get inside.

The company conducting the gene-editing experiment, Sangamo Therapeutics, wanted to replicate the Berlin Patient effect. Even though it was a small business, it was aiming for a blockbuster medical breakthrough: an HIV cure. When I visited Sangamo’s headquarters in May 2017, the company’s stock was trading at around \$3 a share. Sangamo’s headquarters and laboratory were in a mixed-use office park—right next to a West Marine boat parts store and a train yard in Richmond, California. This neighborhood, on the margins of the San Francisco Bay, is also home to a Chevron oil refinery, a yacht club, and Rosie the Riveter National Park. Sangamo had been entrusted by an ethics committee at the National Institutes of Health to conduct the experiment.

It is unclear who first started talking about “gene editing,” but this metaphor suggests that new tools for tinkering with DNA are more accurate and safer than genetic engineering technologies of yesteryear (O’Keefe et al. 2015). Sangamo claimed in a press release that they had conducted the “first in man” gene-editing

experiment with a molecular tool called zinc fingers (see Levin 2014). Gene therapy experiments began in 1990, when a synthetic virus was designed to target a rare immunological disease. The therapy did not reliably work, but the viral vector seemed to be safe (Addison 2017). More than four thousand people had their DNA modified in gene therapy experiments over the next decade. But the experiments did not always go as planned. When scientists at Penn Medicine killed a young man named Jesse Gelsinger with a gene therapy experiment gone awry on September 17, 1999, the incident produced a chilling effect in the field (Stolberg 1999).

During my tour of Sangamo's facilities, the scientists were working to convince me that zinc fingers were more reliable than CRISPR—the newer, faster, and cheaper alternative tool for manipulating DNA. Later, their CEO told reporters: “We look at CRISPR like the boy band and we are the Rolling Stones” (Edmiston 2018). On the tour, they showed me the clean room where patient 102's cells were “edited,” where scientists tried to “delete” one of Sharp's genes (see Kirksey 2018).

Sharp waited several months while his white blood cells underwent gene surgery in Sangamo's laboratory (described in Kirksey 2020). He felt hopeful, not at all concerned. “I wasn't nervous,” he explained, “but excited and impatient as I waited.” When the laboratory finally called, saying that his genetically modified cells were ready for infusion, Sharp booked an appointment right away—during a lunch break from work. The edited cells were waiting in a shipping container that looked like R2-D2 from *Star Wars* with liquid nitrogen inside. A tiny IV bag held the frozen cells inside the pod. After thawing the bag in a hot-water bath, bringing the cells back to life, his nurse plugged it into Sharp's IV line.

As the nurse slipped an IV needle into his arm, ready to infuse the cells with edited DNA into his body, Sharp was calm. “I was just excited to see the gene therapy and watch it drip into my veins,” he told me. Cloudy yellow fluid slowly flowed into his arm. Within thirty minutes, he was headed back to work with billions of genetically modified cells reproducing in his arteries and veins.

Having experienced the cruelty of optimism before, the jarring slap that comes with disappointing medical results, Sharp was very cautious in harboring hopes in the early days of the experiment (cf. Gould 2009: 415; Berlant 2011: 48). Maintaining optimism can involve difficult emotional and imaginative labor. In the coming months, Sharp's cell counts stayed normal, but he did not know if this was an idiosyncratic fluke or temporary blip. The scientists were tight-lipped about the results from other patients—saying that they needed to keep the findings under wraps until they unveiled the data at a leading HIV conference in Boston. Sharp wanted to be in the audience for the big reveal, so he flew across the country in February 2011.

When a slide flashed the key results on the screen—showing a significant and lasting increase in T cell numbers for the patients in the study—the audience gasped. “It was the first time, in my mind, that I realized that I was going to make it,” Sharp told me. “I realized that the virus would not kill me.”

Rather than the wishful thinking of Ernst Bloch’s “abstract utopia,” where the wish is not accompanied by action aimed at achieving change, Sharp was reaching toward a real possible future with willful thinking and participatory action (cf. Muñoz 2009, 91). The experiment had not produced the hoped-for “cure” to HIV, but it had fixed his immune system. The abnormally low T cell counts of the “non-responders” in the experiment rebounded to normal, healthy levels. Sharp’s health improved, and his cautious optimism started to settle into stable hopes for the future. But then the machinations of capitalism quickly crushed his dreams (cf. Halberstam 2011: 1).

Shortly after Sangamo announced its results in Boston, the value of its stock shot up to more than \$22, with the company peaking at over \$1 billion in market capitalization. But then its shares plummeted to penny stock territory as an insider-trading scandal threw the company into disarray (Kirksey 2018).

Despite the health benefits enjoyed by Sharp and others in the experiment, Sangamo started to back away from its HIV research. The company began channeling resources toward other diseases that seemed like more profitable investments. When I interviewed Sandy Macrae, the CEO, he said that HIV research was not the company’s most valuable investment. “I had to make a decision about where our portfolio was best applied,” he said. “My company has only so many things we can do.”⁵

Sharp was outraged. He felt trapped in a time warp, still dealing with the same core problems that ACT UP had been fighting since the early years of the epidemic. Banding together with other participants in the Sangamo experiment and ACT UP veterans from around the country, he began to fight the corporation that had edited his DNA. The activists signed an open letter to Sangamo urging the company in the “strongest possible terms” to continue their HIV research. Sharp wanted to get new HIV experiments started so that other immunological nonresponders could access this potentially lifesaving treatment. He also wanted access to a second dose of the gene therapy himself if his cell counts dropped again.

The activists wanted to meet with the company’s leadership team, but a Sangamo representative refused to let them visit the headquarters. After Sharp spent many months “kicking and screaming,” Sangamo eventually agreed to sit down with him and other members of the HIV-positive community at a Berkeley hotel. The activists reiterated their demand: follow up the initial experiment with

further studies. “They simply refused,” Sharp said. “They said that they did not have the resources. And they probably didn’t.” Mark Harrington, executive director of the Treatment Action Group (TAG) in New York City, had sharper words: “The company put it back on the shelf because they couldn’t figure out how they were going to make enough money.”

By early 2020, HIV was no longer included on Sangamo’s online list of Therapeutic Programs Under Development. Instead, the company was pursuing a diverse array of other medical applications for gene editing: cancer, sickle cell disease, organ transplantation, plus half a dozen other genetic conditions. HIV was no longer a priority for the company.

Sharp deserves credit for helping push HIV gene-editing work forward. After failing to get funds from Sangamo, he began lobbying US government officials and university researchers to start a fresh round of experiments. One professor was inspired to pick up where Sangamo had left off, thanks in part to this advocacy effort. The National Institutes of Health awarded an \$11 million grant to support new work by Rafick-Pierre Sékaly at Case Western University (Kirksey 2018). Sharp “has always been extremely passionate,” according to Sékaly. “He has always been very forceful, pushing us to do more.”⁶ The grant opened slots for a new cohort of thirty HIV patients in early 2019. Even though his cell counts were falling again, Sharp himself was ineligible because he had participated in the earlier trial.

Amid the enthusiasm for new research, a number of patients in the Sangamo trial developed prostate cancer. Sangamo’s CEO warned me not to draw hasty conclusions, saying that many older men get prostate cancer. The company was gearing up for a new study of the long-term consequences of “off-target” genetic damage. Among other things, its researchers planned to study malignant cells to see if they were an unintended result of the experiment. But the jury was still out on key safety questions.

Tongzhi Desires

Jiankui He knew about the partially successful Sangamo study. He was confident that he could cure HIV—not because CRISPR was a more powerful tool than zinc fingers but because he would approach the experiment from a completely different angle. In meetings with his laboratory staff, he chalked up Sangamo’s failed cure to the “mosaic effect.” After participants like Sharp had their genes edited, they ended up with a heterogeneous genetic makeup. The participants in the Sangamo study walked away from the experiment with different genotypes in different cells,

like tiles in a mosaic floor, with different colors. Some cells had fully functional *CCR5* receptors and were therefore susceptible to HIV, while other cells had the genetic code scrambled at this site. Conducting the experiment shortly after fertilizing human eggs with sperm, He aspired to design genetically homogenous children who would lack functional *CCR5* receptors from birth (Kirksey 2020).

As He began recruiting volunteers for his experiment, he knew that he was operating at the edge of the law. While he secured backing from some Communist Party officials in Shenzhen and Beijing, the laboratory was working in conditions of secrecy—skirting around national guidelines for clinical trials and reproductive medicine. As the laboratory began to actively recruit volunteers, they found vulnerable people who were already living with closely guarded secrets, who had fragile hopes and conflicted desires.

When I reached out to talk with some of the experimental volunteers, I nearly lost the interview when I intimated that I had been talking with veterans of ACT UP in the United States. Any association with loud and proud international queer activists—however tenuous—could put the volunteers under unwanted scrutiny from Communist Party operatives. The volunteers spoke with me under conditions of absolute anonymity. In China I encountered people who valued opacity and inscrutability. They identified not as *queers* but as “comrades” (*tongzhi*) who experienced unity and solidarity—if not clandestine complicity—through a shared sexual identity (Leung 2009: 3; cf. Liu 2015; Tong 2016).

Many of the men who signed up their families for He’s experiment had profoundly complex social and sexual lives. Gay marriage is prohibited in China. As a result, more than 14 million men in China have opted for a “fake” marriage, according to one study (Zhu 2018). Without a marriage certificate, gay couples are barred from adopting a baby, undergoing fertility treatments, or even registering a child that has been born out of wedlock. As a result, many men have entered into open agreements with lesbians, living in fictitious social situations to appease their parents (see, i.e., He 2010). Some men, those who are deep in the closet, keep their sexual desires a secret—even from their wives.

Online support groups for Chinese women who realize that they are married to gay men have provided a forum for venting anger about “marriage fraud.” Jingshu Zhu, an anthropologist who has lingered in these chat rooms, reports that many women share similar experiences as they go from a “sweet honeymoon period” to “sensing something suspicious,” then to “finding out the shocking secret of their husband’s ‘gayness,’” and finally “feeling used and fooled” (Zhu 2018: 1077).

Outrage about bisexuality is a relatively new phenomenon in China. In the late Qing Dynasty, men enjoyed the freedom to have erotic liaisons with each other,

even while maintaining heterosexual family lives (Kang 2009). In contemporary China, discretion and even outright dishonesty can be important for gay and bisexual men. “The zealous pursuit for honesty,” writes Zhu (2018: 1085), faults people for “not disclosing enough rather than disclosing too much about their sexuality.” Chinese society continues to put gay men in a double bind where it is both mandatory to tell the truth about their sexual affairs and forbidden to reveal the salacious details of their homosexual desires (Sedgwick 2008: 70).

The *tongzhi* men who signed up for He’s experiment harbored impure hopes that were not entirely their own: they shared the dreams of their parents and wives for a child, hopes for a definitive cure for HIV, and excitement about CRISPR as a cutting-edge technology. Lee Edelman (2004: 12) has argued against social norms that drive us to reproduce—suggesting that the figure of “the Child” should not be celebrated as humanity’s future. Queers should resist heteronormative mandates, according to Edelman, and oppose “the child as the prop of the secular theology on which our social reality rests.” If a certain reified purity is present in Edelman’s opposition to reproductive futurity, the *tongzhi* hopes linked to He’s clinical trial were remarkable for their impurity—with a crowded multiplicity of objects, subjects, and figures of desire. Above all, they wanted to have healthy children who would be protected from the HIV virus.

A man I call Paul learned about the experiment through Baihualin, China’s largest mutual aid organization for HIV-positive people.⁷ The organization was run by a man in Beijing who goes by the pseudonym Baihua (white birch). Every month, Baihua staged a small salon-style discussion, webcast live from his living room. Like thousands of other HIV-positive people around the country, Paul watched his WeChat feed for news of these monthly events. No recordings were made, so unless he watched in real time, he missed out. Sometimes Baihua’s salons featured presentations about a new HIV medicine or research findings. Other times, the guests just had informal conversations where people shared personal stories about living with discrimination, as well as acquired knowledge and skills.

The online community of Baihualin became a utopian place for Paul (cf. Muñoz 2009), an isolated oasis where gay and bisexual men could virtually hang out with people who shared common needs and interests. Remote viewers could write in with questions or topics that they would like to see discussed—like how to navigate the Chinese government’s health system, how to deal with the side effects of a particular HIV medicine, or where to go for international reproductive tourism.

While Chinese intellectuals were developing elaborate critiques of neoliberal homonormativity (reviewed in Liu 2015), these men were busy living with norms about reproductive futurity that are pervasive in Chinese society. The con-

roversial one-child policy had come to be experienced by people of reproductive age as a “must have one child” policy, with stories celebrating “miraculous” test-tube babies and an intensified stigmatization of childlessness for men and women alike (Handwerker 2002; Wahlberg 2016).

While many members of the Baihualin community wanted a baby, their HIV-positive status put them in a double bind. Many wanted access to a fertility treatment called “sperm washing,” a procedure that can greatly reduce the chance of viral transmission to the mother. But Chinese fertility clinics turn HIV patients away as a matter of national policy. The law states that “men and women who suffer from severe mental illness, acute infection of the genitourinary system, and sexually transmitted diseases” are ineligible for treatment with assisted reproductive technology (Chinese Society of Reproductive Medicine 2016). HIV-positive people are also prohibited from adopting a baby in China. International reproductive tourism is an option for some couples, but others cannot afford the expense or are prohibited from travel by Communist Party officials.

Paul was diagnosed with HIV in December 2016, just months before the call for volunteers in the genetic engineering experiment came through Baihualin’s social media feed. Understandably, he gets uncomfortable when asked about the source of his infection. It was either from a needle stick at work or from having sex, he says. People with HIV routinely lose their jobs in China, so he was trying to keep his viral status a secret. Paul was not overly concerned about his own health, but he was worried that his career and his family life would fall into shambles if his infection became public knowledge.

Even before the diagnosis, Paul’s marriage was fragile. He traveled for work and was often away from his wife, Mary (also a pseudonym), for months at a time. Mary sobbed for hours when she learned that her husband was HIV-positive. She was worried about his health but also about her own future, because he was the breadwinner. After the diagnosis, the couple almost divorced. Then an idea emerged that they thought might save the relationship. They decided to have a baby. The couple hoped for a boy.

At the time of Paul’s HIV diagnosis, the idea that “undetectable = untransmittable” was not yet accepted by the medical establishment in China. Now it is well established that HIV-positive men can safely make babies the old-fashioned way, as long as they are able to control their viral loads with pharmaceutical medicine. “People who are undetectable do not transmit HIV to other people through sex,” according to the San Francisco AIDS Foundation (2019). But at the time of his diagnosis in 2017, “sperm washing” seemed like the only way to protect Mary from an infection. Paul knew about the national laws. A conventional doctor

would not help them use this technique to have another child. In Paul's mind, He's experiment was his only hope.

Jiankui He was not entirely honest with the men and women who signed up for his experiment. Half-truths surrounded the project. The participants believed that He had the full support of the government when they signed a confidentiality agreement pledging to "strictly observe the secrets of the project team." The agreement explained this requirement as the laboratory's wanting to protect intellectual property with commercial value. There was a conspiratorial atmosphere; He indicated that he was willing to help the men fake an HIV test so that he could conduct the research in China.

When Paul traveled to Shenzhen with Mary in June 2017, the young scientist at the center of the experiment made a good first impression: Dr. He came across as an intelligent gentleman. It was a hot summer day. A small group of scientists and patients gathered in an air-conditioned conference room in the Biology Department on the main campus of the Southern University of Science and Technology, where He was an associate professor. Paul and his wife sat next to another couple, known to the laboratory as P2, at the end of a long wooden table. Frosted glass windows to the hallway were partially covered with blinds. Students and researchers walked past in the hallway even though it was a Saturday.

In the United States, bioethical principles focus on "the individual, seen as an autonomous, self-determining entity rather than in relationship to significant others," in the words of Renée C. Fox and Judith P. Swazey (1984: 339). By contrast, a system of medical morality has emerged in China that is perhaps more aptly described in a Lacanian account of the subject: one who is not a self-transparent, rational, and pure presence but an irremediably decentered agent (Evans 2006: 195). Doctors, nurses, and scientists in China are expected to care for patients who are "enmeshed in the network of human relationships" (Fox and Swazey 1984: 339).

Hybrid norms of US bioethics and Chinese medical morality came together in He's experiment. Participant consent forms presented to each family, modeled after the standards established by the NIH in Washington, detailed possible medical risks faced by the women and any future children who would result from this experiment. These forms were set up as "self-conscious, rational, specific agreements by persons involved in interaction with one another, that explicitly delineate[d] the scope, content, and conditions of their joint activities" (Fox and Swazey 1984: 352).

Participants knew that He would be bending the law by offering them

access to “sperm washing” technology. He did not disclose that his personnel would be violating another part of Chinese legal code governing reproductive medicine: “It is forbidden to carry out genetic manipulation on gametes, zygotes and embryos” for actual human pregnancies.⁸ In the conspiratorial space that opened up with this experiment, with *tongzhi* men entangled in complicated heterosexual fictions and with researchers bending and breaking the law, values of veracity and truth-telling were overrun by other ideals and norms.

Dr. He welcomed everyone with some preliminary remarks. They would be discussing the technical material that members of his lab had already discussed with participants ahead of time and then securing their written consent. A GoPro camera started up and panned around a room full of men. Jun Yu, an observer from the Chinese National Academy of Sciences, was there. Michael Deem, He’s former mentor from Rice University in Houston, was also there. Dr. He explained in Mandarin to everyone in the room that Deem “can speak a tiny little bit of Chinese,” gesturing with his hands, with a finger and thumb close together.

As He and his male colleagues described invasive procedures, the two women volunteers leaned forward, perched on the edges of their chairs. Mary bent over the participant consent form, studying the written text, occasionally brushing back her hair. The other woman, whom I’ll call Anne, listened intently, leaning on the table, resting her chin on her hand, making eye contact with He throughout. The male volunteers did not really face any risks to their own health, they were told. All they needed to do was stay on their HIV medication and ejaculate into a cup. Still, the men were being asked to help make a consequential decision: did they want to expose their wives and children to known and unknown hazards?

Replaying the video of this consequential moment, it is easy to see that the risks and benefits were shared unequally by different people at the table. The two women clearly had a lot on the line, since they could contract HIV from their husbands or experience complications from the fertility treatments. The white scientist lurking in the corner of the room was not at risk of bodily harm. Like the other researchers who were present, Deem stood to gain notoriety if the experiment was successful. The future children, a haunting presence in the conference room, were on everyone’s mind as these adults made consequential decisions. But in the moment, perhaps one key player did not seem to be seriously considering the risks he was taking himself. Dr. He looked calm and collected—leaning back in his chair, graciously smiling—as he walked the volunteers through the complexities of the experiment.

The Future Will Not Hold a Place for Us

A few weeks later Paul and Mary traveled to Guangzhou, another city in southern China. They checked into a hotel, courtesy of the He laboratory. The procedure took place at a modern hospital with an in vitro fertilization (IVF) clinic. One doctor at the hospital helped with the experiment, keeping it hidden from his colleagues. The hospital's gynecologist was partially in on the secret but chose to treat it as a "don't ask, don't tell" situation. He knew that an experiment was taking place but was not privy to all of the details (Kirksey 2020).

Mary went through standard IVF procedures at the hospital. IVF is the classic "hope technology" in feminist science studies, and it has become an increasingly banal set of procedures that bind human desires to technology, producing situations where hopes for a child are kept alive even in situations in which the technology is expected to fail (Franklin 1997: 310; also see Inhorn 2015). Before Mary arrived at the hospital, she had already been taking drugs to stimulate egg release. As her eggs emerged from her ovaries, the gynecologist collected them with a long needle and then passed the eggs along to the embryologist for gene editing.

Someone else came with the couple to masquerade as a hopeful father and offer up a blood sample for the HIV test, to help them skirt the law. Hospital staff helped Paul and his friend, telling the pretender how to trick the nurse who would take his blood. Then Paul gave a sperm sample in a separate room. His sperm counts were normal. He hoped that the washing procedure would enhance the "quality" of the sample (cf. Wahlberg 2018).

Working under a microscope, the embryologist—a man named Renli Zhang, who was later charged with illegal medical practice—fertilized a number of Mary's eggs with Paul's sperm. Moments after conception, he injected the eggs with a CRISPR-Cas9 construct that had been designed to target the *CCR5* gene. One viable embryo emerged from this initial procedure. The embryologist put it into a warm incubator to grow. Five days later some cells were taken as a sample and sent off to a laboratory for DNA testing. The embryo was stored in liquid nitrogen while everyone waited for the results. Within a few weeks the team and the couple would know if the genetic surgery had been successful. They had moved one step closer to creating the world's first genetically modified baby.

Everyone was disappointed when the results of the DNA tests came back, showing that the genetic surgery did not work. The embryo was healthy—perfectly fine to transfer into Mary's womb. Rather than have a normal baby, with financial assistance offered from the laboratory, Paul and Mary wanted to keep trying for a

baby who lacked a *CCR5* receptor. “China has contributed a lot to humanity,” Paul later said. “Gunpowder was invented by Chinese people; now it is being used all over the world. The first rocket went up and then fell down. People kept trying until they sent people up into the space.”

In trying to make a baby with help from CRISPR, Paul was engaged in a project of selective biological self-destruction (cf. Edelman 2004: 30). His personal hopes for the future of his marriage, and his political dreams about the future technological power of China, were pinned on the figure of a child who would never share part of his social and biological identity. Paul wanted to bring a child into the world who would never have to experience the stigma associated with HIV.

Paul and Mary were seen as the ideal experimental subjects by He’s laboratory staff—they were full of hope and enthusiasm for the research. Ultimately, Paul and Mary were unable to have a child with the experiment, so the scientists decided to move forward with other couples who produced more viable embryos. All told, seven couples participated in the experiment. Dr. He was moving fast, throwing caution to the wind. Multiple embryo transfers took place in a short period of time—some at the hospital in Guangzhou, others at an overseas facility in Bangkok. But the first round of pregnancies failed to take—the genetically modified embryos did not implant in their mothers’ wombs. IVF is known to have low success rates, with less than 29 percent of transferred embryos resulting in a live birth for women of prime reproductive age.⁹

When one of the couples became pregnant, news leaked to some of the other volunteers. Other participants started to become frustrated—their desire for a child was stronger than ever; they did not want to have their hopes endlessly deferred (cf. Franklin 1997: 310). The experiment started to go off the rails when couples began approaching the hospital directly, demanding their embryos (Kirksey 2020). A second couple became pregnant, as they conspired with the doctor in Guangzhou and forged ahead—refusing to remain in the anticipatory space of imagination (cf. Edelman 2004: 24).

A Cure for HIV?

As the news broke from the Genome Editing Summit in Hong Kong, Jiankui He posted some videos on YouTube playing up vague hopes and hype attached to CRISPR: “Two beautiful little Chinese girls, named Lulu and Nana, came crying into the world as healthy as any other babies.” Even though He said that the twins were at home with their parents, Mark and Grace (both pseudonyms), they were actually in a hospital neonatal intensive care unit when the video was recorded

(details in Kirksey 2020). “The gene surgery worked safely,” He claimed. “No gene was changed except the one to prevent HIV infection.”

Later, I poured over the raw genetic data with leading researchers in the field and found that this announcement glossed over the complexities of the actual DNA sequences. One of the babies, Lulu, appeared to have a mosaic genetic condition, with a damaged copy of the *CCR5* receptor in some cells and two functioning copies of the gene in other cells. The other newborn, Nana, appeared to have targeted damage to *CCR5* on both of her chromosomes (Kirksey 2020).

Tests were planned to confirm that the babies were resistant to HIV. At the moment of birth, the laboratory collected blood from their umbilical cords and stored it in a freezer for later research. This blood could have been subjected to a relatively simple experiment, like the earlier *CCR5* experiment conducted by Jennifer Doudna in a petri dish, to see if the children’s T cells were susceptible to the HIV virus. But amid the controversy, the assays were never run. In the absence of further research on the twins, it is hard to know whether this experiment was simply a dream born of Shenzhen’s innovation economy—full of abstract promise, hope, and hype (Yang 2017: 203–4)—or if they did make babies who are now resistant to HIV. No matter the scientific result, this risky venture certainly did fundamentally alter the basic facts of human life (cf. Helmreich 2008: 472).

Shortly after He was detained on January 21, 2019, he was taken to a black site—unable to contact his lawyers or even his family. Amid a national and international controversy, the institutions that had previously supported his research disowned him. The Southern University of Science and Technology fired him and shut down his laboratory. His mentors in the Communist Party and investors in his ventures sought to distance themselves.

As the Chinese authorities investigated He’s laboratory, the families who participated in the experiment became swept up in the inquiry. On social media some Chinese influencers blamed the volunteers, saying that they should be shot or even burned to death. One couple who participated in the experiment made a bold rebuttal in a letter addressed to the investigators: “Is the negative impact of these comments even greater than the research itself?” The couple applauded He for making bold strides in the field of HIV research. At the same time, the letter pointed to hypocrisy in Chinese society, taking aim at the most powerful person in the nation:

President Xi often claims that he cares for the people and their living conditions. Mother Peng [his wife] is the most beautiful representative of the HIV red ribbon. Is this all just a beautiful lie? Today there are people who

are not scared of risk, who can put themselves in other people's shoes, and do something for people infected with HIV. Yet, they are being brutally crushed, pushed onto the cold sand beach by the tidal wave of comments, leaving them to die alone. What kind of dream should the China Dream be? Have the promises of harmony, love, and unity burst like bubbles vanishing into air? (anonymous, quoted in Kirksey 2020: 233–34)

The impure hopes of the experimental participants—desires for a child, dreams of being fully embraced by Chinese society, hopes for an HIV cure—remained strong. CRISPR still contained tantalizing promise (cf. Franklin 1997). Even though He had not yet demonstrated any clear medical benefits of his experiment, some participants held onto hopes for a genetically modified child. Their edited embryos were still being stored in liquid nitrogen as the professional ambition, business dealings, and scientific vision of He came under critical scrutiny. The embryos became quasi-living figures of fragile hope—frozen in time—ready to be reanimated if political, economic, and biological forces would someday realign (cf. Radin and Kowal 2017).

Conclusion

The impure hopes of experimental volunteers who signed up for the risky gene-editing experiments were tangled up with the scientists' dreams of national glory, alluring technological visions, and get-rich-quick schemes of the innovation economy. Modest hopes—of being accepted by society, of saving troubled marriages, of having a child—were mixed together in an experimental space where an HIV cure seemed like a near-term possibility. During the experiments, participants rode an “emotional roller coaster, [with] swings from pessimism to hope and back again,” much like early AIDS activists who were just trying to stay alive (Gould 2009: 422). Even though they had experienced the cruelty of optimism (cf. Berlant 2011), some volunteers held onto hope even after they were betrayed by companies and scientists who were pursuing profit over patient well-being.

Impure hopes can be understood with the articulation theory of Stuart Hall (1986: 53): “A theory of articulation is both a way of understanding how ideological elements come, under certain conditions, to cohere together within a discourse,” writes Hall, “and a way of asking how they do or do not become articulated, at specific conjunctures, to certain political subjects.” Articulation theory has been used to understand discourses, political platforms, social movements, and cultural forms as contingent assemblages (see, e.g., Hall 1996; Clifford 2001). Pushing

ideas about articulation into the domain of hope offers an opportunity to theorize contingent discursive formations and affective intensities that arise at the intersections of political movements and historical situations (cf. Gould 2009: 2–3).

Hopes, like political ideologies, are not eternal—they need to be constantly renewed. At times when hopes fail, some subjects embrace despair and turn away from political projects (Gould 2009: 433). Other hopeful subjects renew their articulation work in moments of failure, examining weak links between potentiality and actuality and distinguishing between elusive promises and future probabilities. Moments when hopes are actualized can also be profoundly disappointing. Optimism can be cruel, according to Berlant, as quoted above, when you discover that the dreams you are attached to are either “*impossible*, sheer fantasy, or *too possible*, and toxic.” Renewing hope, in moments when possibility becomes actuality, can involve both imaginative and practical labor.

When Matt Sharp’s immune system was repaired by gene editing, when Lulu and Nana were ushered into the world as babies who were likely resistant to HIV, techno-scientific hopes moved from the realm of impossible fantasy to actuality. For the volunteers who signed up for these experiments, these moments of technological success nonetheless proved to be disappointing. The parents of Lulu and Nana found that their children may have been protected from the social stigma of HIV, but at the cost of being deemed “monstrous” (Julian Savulescu, quoted in Keach 2018). While Sharp enjoyed some medical benefits himself, he found that hope was stolen away from his community by fickle market forces. Only after Sharp did more articulation work, renewing his alliances with university researchers and linking Sangamo to government funds, was he able to sustain modest hopes for other immunological nonresponders.

There are no guarantees that gene editing will ever deliver a cure for HIV. In fact, other developments in the field of HIV cure research—involving conventional pharmaceuticals, small molecules, and antibodies—may be more promising than genetic surgery with CRISPR or zinc fingers (Jay Lalezari, pers. comm., October 19, 2018). If a gene therapy is approved by regulators and brought to market, it might introduce new pathologies of power (cf. Farmer 2003). Disparities in health and well-being could be radically exacerbated by new approaches to genetic medicine. A spokesperson for Sangamo Therapeutics has intimated that its HIV treatment would be “premier-priced”—costing upward of \$100,000 per dose—if the experimental therapy is ever approved. Engineering HIV resistance in children with CRISPR would also be expensive if it were approved for use in fertility clinics. Standard IVF already costs upward of \$20,000 in the United States and

can be much more expensive if more than one cycle is needed for a successful pregnancy.

Horizons of hope for many people who live with HIV worldwide—especially those far away from centers of innovation in China and the United States—are increasingly oriented away from visions of a scientific breakthrough and toward current possibilities of life (see, e.g., Farmer 2003; Dean 2009; Ngure et al. 2016). While promises of bright techno-futures continue to be alluring in developing countries, many people are starting to hold onto hopes for an unchanging present rather than a radical new future to come (Zee 2017).

Impure hopes were perhaps once found predominantly on the margins of hegemonic dreamworlds. Queer communities in the United States, and the opaque and inscrutable *tongzhi* spaces of China, have long been sites for critical and creative articulations as hopes were forged in hostile circumstances. In contemporary times any semblance of ethical, political, and material purity is becoming increasingly difficult for anyone to maintain. Hope now demands ongoing articulation work amid “contingent and unsettled decisions about how to be in relation to the world” (Shotwell 2016: 10).

When theorizing hope, it is critical to ask: hope for whom? “Some futures (and some bodies) are more protected than others,” as Alison Kafer (2013: 33) observes in *Feminist, Queer, Crip*. As powerful political and economic forces threaten to steal queer hopes or simply capitalize on them, it is important to make our own ethical, political, and discursive cuts—to selectively renew some articulations while breaking other connections. As Christian bioethicists express alarm at ongoing efforts to genetically modify human embryos, it is important to further develop impure ethical frameworks to guide emergent reproductive and genetic technologies toward an affirmative politics of the future.

Notes

1. *Wired*, cover blurb, August 2015.
2. Full Text of Xi Jinping’s Report at Nineteenth CPC National Congress, www.xinhuanet.com/english/special/2017-11/03/c_136725942.htm.
3. Matt Sharp, interview with the author, New York City, June 3, 2018. All subsequent quotes from Sharp are from this interview.
4. Brian Zabcik, telephone interview with the author, June 3, 2018.
5. Sandy Macrae, interview with the author, Richmond, CA, November 8, 2018. All subsequent quotes from Macrae are from this interview.
6. Rafick-Pierre Sékaly, telephone interview with the author, November 7, 2018.

7. “Paul,” interview with the author, Shenzhen, China, June 11, 2019.
8. Ministry of Science and Technology, “Guidelines for Ethical Principles in Human Embryonic Stem Cell Research,” no. 460, December 24, 2003, www.most.gov.cn/fggw/zfwj/zfwj2003/200512/t20051214_54948.htm (Chinese language).
9. “Overview: IVF,” UK National Health Service, www.nhs.uk/conditions/ivf/ (accessed June 11, 2021).

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