

Social Science Perspectives on Childbirth and Reproduction

Series editor: Robbie Davis-Floyd (Rice University)

This series focuses on issues relating to childbirth and reproduction from social science perspectives. It includes single-authored, co-authored, or edited books concerned both with people's reproductive experiences and with birth practitioners such as midwives (both professional and traditional), obstetricians, nurses, doulas, and others. It seeks to provide new viewpoints on functional and sustainable birth models and the challenges to their creation and maintenance, as well as on obstetric violence, disrespect, and abuse and their root causes. Single-case or comparative ethnographies on birth and other reproductive issues are featured, from high-tech conceptions to normal pregnancy and birth, including reproductive politics and human-rights issues in reproduction worldwide.

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Human-Technology Co-Evolution and the Future of Reproduction

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BIRTHING TECHNO-SAPIENS

Human-Technology Co-Evolution and the Future of Reproduction

Edited by Robbie Davis-Floyd

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EGG FREEZING ACTIVISTS:

Extending Reproductive Futures to Cancer Patients, Single and Minority Women, and Transgender Men

Marcia C. Inhorn

Introduction: The Global Rise of Egg Freezing

In 1978, Louise Brown, the world's first "test-tube baby," was born in England, allowing her working-class parents, Lesley and John Brown, to overcome 9 years of heart-breaking involuntary childlessness. Forty years later, more than 8 million in vitro fertilization (IVF) babies have been born (ESHRE 2018), comprising a whole generation of IVF-conceived "techno-sapiens."

But IVF has also led to other births, including a multitude of IVF-related assisted reproductive technologies (ARTs) designed to overcome intractable reproductive barriers. As Sarah Franklin (2013) has argued, IVF has been a "platform" technology for other innovations, including preimplantation genetic diagnosis (PGD) (Franklin and Roberts 2006), human embryonic stem cell (hESC) research on unused IVF embryos (Franklin 2013), and even the future possibility of human reproductive cloning (Franklin 2007).

The most recently conceived repro-technology is "oocyte cryopreservation," or egg freezing. First tried in the early 1980s—with the first reported frozen egg baby born in 1986—egg freezing remained technologically challenging because of lethal ice crystal formation and concerns about chromosomal damage to the human egg (Lockwood 2011). While cryopreservation of human sperm and embryos had been mastered by the 1980s, the successful freezing of human eggs remained elusive. Not until the early 2000s was a new method of flash-freezing called "vitrification" introduced (Mertes and Pennings 2012). Vitrification is a process by which oocytes are treated with cryoprotective substances and then submerged into liquid nitrogen. The cells cool so rapidly to –320 degrees Fahrenheit that they become "vitrified," or glass-like in structure. Unlike older slow freezing methods, vitrification takes minutes rather than hours. Most importantly, with vitrification, the egg survival rate post-rewarming increases

from 70% to 90%, with good evidence that fertilization and pregnancy rates are similar between fresh and frozen (and then thawed) eggs (Cobo et al. 2016). Furthermore, in terms of reproductive outcomes, no increases in chromosomal abnormalities, birth defects, or developmental deficits have been found in children born from frozen eggs (IFFS 2019). Thus, vitrification has proved to be a “game changer” in the world of oocyte cryopreservation, simplifying the procedure and increasing its efficiency (Inhorn et al. 2021).

A clear-cut need for egg freezing through vitrification was first seen in the world of clinical oncology. Women at risk of losing their reproductive ability via chemotherapy could now freeze their eggs, potentially preserving their ability to conceive genetically related offspring (Inhorn et al. 2018a, 2018b). Given the success of vitrification in clinical trials with cancer patients, healthy women concerned about their own age-related fertility decline began to volunteer for these studies. By 2012, both the American Society for Reproductive Medicine (ASRM) and the European Society for Human Reproduction and Embryology (EHSRE) lifted the “experimental” label, allowing the clinical use of both *medical egg freezing* (MEF) for cancer patients (as well as for women with other fertility-threatening conditions) (Inhorn et al. 2017, 2018a, 2018b), and *elective egg freezing* (EEF)¹ for healthy women hoping to preserve their remaining reproductive potential (Inhorn et al. 2018c, 2018d, 2019).

Calling egg freezing “one of the most significant recent advancements in assisted reproduction technology,” the International Federation for Fertility Societies issued a 2019 global report depicting the global spread of egg freezing. Of 82 countries surveyed, 68 (83%) reported that MEF was being performed in their countries, while 56 (68%) also reported the performance of EEF. Eighteen of 42 (43%) countries reported that both MEF and EEF were being frequently performed in their IVF clinics (IFFS 2019).

Yet the 2019 IFFS survey did not report on the extent of *transgender egg freezing* (TEF)²—potentially one of the most revolutionary aspects of this new cryopreservation technology. With the growing social acceptance of gender assignment technologies, individuals assigned female at birth can now preserve their eggs before initiating testosterone therapy in their gender transitions (Birenbaum-Carmeli et al. 2020). An international survey of fertility preservation providers in 9 countries (Tishelman et al. 2019) showed that TEF is on the rise around the world, thereby extending reproduction to transgender men and preserving their potential for future fatherhood.

In the United States, all forms of egg freezing have increased in usage since the ASRM lifted the experimental label. Today, most American IVF clinics

1 Although the terminology to describe egg freezing is quite variable in the literature, I have forwarded these terms and acronyms, “medical egg freezing” (MEF) and “elective egg freezing” (EEF), to most accurately represent women’s own preferences.

2 “TEF” is my own term and acronym, intended to align with medical egg freezing (MEF) and elective egg freezing (EEF).

now offer MEF and EEF routinely (the extent of TEF remains unknown), and multiple EEF commercial clinics and egg banks have opened in major urban areas across the US (see Chapter 3). The response to egg freezing on the part of US women has been quite significant. Within the first year of clinical acceptance (2013), approximately 5,000 egg MEF and EEF cycles were undertaken in the US. Five years later (2018), that number had more than doubled, to 11,000 cycles, according to the Society for Assisted Reproductive Technology (SART). Over the past decade, it is estimated that 36,000 US women have frozen their eggs.

Despite the rise of MEF and EEF—and to a lesser extent TEF—in the US, there are still many barriers for those who would access this technology. Most importantly, egg freezing is an expensive technology (see Chapter 3), not covered by most health insurance plans (Inhorn et al. 2018a, 2018b). Cost concerns are especially daunting for young cancer patients, who rarely have the financial resources to undertake a cycle of MEF, especially under extreme time pressure prior to chemotherapy. Young women and their families must raise sufficient funds on a rapid timescale, usually within days of a cancer diagnosis.

Given these problems of access, egg freezing has been the site of much “behind-the-scenes” activism, primarily on the part of “early adopters,” who saw the need for this technology in their own lives, and then worked to make egg freezing more known, available, and affordable to others. Indeed, egg freezing technology has co-evolved with human interaction, specifically through the work of *egg freezing activists*, as I call them here. These individuals were not necessarily part of reproductive activist circles, and thus initiated egg freezing activism mostly on their own. Their major focus was on changing policies among employers, insurers, and professional organizations to make egg freezing more visible, affordable, and beneficial to others. Some of these activists described their approach to change as “vocal” and insistent, while others adopted quieter, yet “proactive” measures.

In this chapter, we will meet 4 of these egg freezing activists: Corinne, a cancer survivor who formed a successful MEF non-profit; Julie, a single professional in Silicon Valley who fought hard for EEF to be funded by a major tech firm; Kamila, an employee of a global reproductive rights organization, who advocated for EEF coverage, as well as access for women of color; and Andrew, a young transgender man, who worked with his university employer to initiate TEF services and insurance coverage. (All names of individuals and organizations in this chapter are pseudonyms.) As we will see, all of these egg freezing activists succeeded as change agents—creating reproductive futures for *cancer patients, single and minority women, and transgender men*.

The Ethnographic Study

These stories were collected as part of an ethnographic study of oocyte cryopreservation in the United States. Between June 2014 and August 2016, I undertook

in-depth ethnographic interviews with 150 individuals who had undertaken at least one cycle of egg freezing. These included 33 MEF patients, the majority with cancer diagnoses; 114 EEF users, most of them single women who underwent EEF in their late 30s (or early 40s) because they lacked a reproductive partner; 2 women who underwent EEF because their husbands were infertile; and 1 transgender man who undertook TEF in his mid-20s. These individuals were recruited through four IVF clinics (2 academic, 2 private), 3 of which were located in major cities along the East Coast and one in the San Francisco Bay/Silicon Valley region. Participants often led our discussions, narrating their egg freezing stories and their decision-making processes in detail.

The participants in this study were diverse. About two-thirds were white, and about one-third were non-white, including 30% of the MEF patients and 31% of the EEF recipients. Black, Latinx, Asian American, mixed race, and women of Middle Eastern heritage were represented in this study. Especially among the MEF patients from working-class backgrounds, affording MEF was a significant struggle. In fact, across the MEF and EEF groups, the major recommendation of study participants was to make egg freezing more accessible by bringing the cost down and/or increasing its insurance coverage. This also provided a major focus for egg freezing activism, as we shall see.

In the 4 stories that follow, Corinne, Julie, Kamila, and Andrew explain how they came to adopt activist stances and what they hoped to achieve by them. Such activism is part of the untold history of egg freezing and its birth in American society.

Egg Freezing Activists

Corinne—MEF for Young Cancer Patients

At the turn of the new millennium, when egg freezing was still considered experimental and vitrification not yet perfected, Corinne discovered, at the tender age of 22, that she had a rare form of tongue cancer. She was told by her physician that chemotherapy would put her at high risk for permanent sterility, the thought of which made her panic. But, in an unlikely turn of events, Corinne found her way to egg freezing:

To kind of paint the picture at this point, I had just recovered from surgery, where they had removed one third of my tongue. So I was, like, lying in bed, on pain meds, it was hard to talk. And, literally, I was watching the movie "You've Got Mail." Well, in the movie, one of the women drops the kids off with a babysitter and says, "I'm going to have my eggs harvested." And I really ran downstairs to my mom, like, "Mom! Egg freezing is possible! I want to freeze my eggs! Then I can do chemo!" And it was really silly, obviously, that it was in this movie. But I thought, if it's in the movie, it exists.

Recovering from her tongue surgery, Corinne began calling different research centers around the country to ask about egg freezing:

Essentially, it was so unusual—so experimental—that everyone told me it wasn't possible. You can bank sperm or freeze embryos, everyone said. You know, you can have donor sperm, freeze embryos, etc. But that's not what I wanted. The donor sperm kind of scared me at that age...I kept calling the same centers over and over, because they had different receptionists who would say different things. And so on my fifth or sixth call to [a California university] someone answered the phone, honestly, by mistake. It was either a nurse or a doctor, [who] said, "Oh my gosh! We have a new egg freezing clinical trial for cancer patients! We would love to see you. Come in tomorrow!" And 11 days later, my eggs were frozen. And then I started chemo on time and everything was fine. But yeah, it was definitely, there was no information out there. I was basing it on a Hollywood movie, and what different receptionists were telling me at different times during the day.

Corinne's elation made going through her second round of chemotherapy much easier:

I was so excited about my egg freezing experience! You know, I was in this whole journey, where I sort of resigned my eggs and my body over to medicine. Those were my favorite appointments, those were my favorite injections, where all this stuff was happening to me. And I think part of why this was my favorite was because I was actually planning for the future. It was some tangible hope. So, in the chemo room...you're kind of in there with a bunch of people, including with some people who were my age, my peers. [Fertility preservation was] what I really wanted to talk about. So, the first day I was talking about it, and would ask people what they had done. You know, "Have you banked your sperm?" No one else knew that infertility was a risk, let alone that there were these options, often in the same hospital. And so I'm essentially telling them they might be becoming sterile right now, with the needle in their arm, and they didn't know that before. And so that hit me really hard, and...I felt two things. One, I felt the obligation of truth. Like, I need to do something to give back. And a little bit of survivor's guilt. And I felt like I had this secret, because I knew that everyone was being sterilized, and I knew that there were these amazing options out there, and it was sort of beyond me why no one was linking the two. And so that led me to do some research and see, "Is anyone talking about this? Is this just a bad experience in my hospital, with my physician, or is this a problem in the treatment of young cancer patients?" And I determined it was just like a void in the treatment of young cancer patients.

After recovering from her second round of cancer treatments, Corinne decided to start a small non-profit organization to fill in this void:

Essentially it had two goals. One was to make sure that every cancer patient is informed of their risk. Research at the time suggested less than 10% of cancer patients were being informed of the fertility risk. And so my goal was that at the end of the day, you shouldn't be sterilized without your knowledge and information. Everyone should know this. And so (1) we wanted to change that, and then (2) we wanted to increase access—access being defined by knowing where the resources are in your area, and actual financial access. And so essentially, we were able to achieve Number 1. It's now an ASCO [American Society of Clinical Oncology] guideline, which is the main body of oncologists, that every patient must be informed. So it's now malpractice if the doctor doesn't inform...Of course, in operation it's not perfect. But we were able to change a standard of care, and then with regards to insurance and access, we got a lot of financial assistance from them, and then worked with a lot of insurance companies to get them to change their benefits...I pushed the "insurance for fertility" agenda, and now egg freezing—fertility preservation—is covered by a number of insurers, for cancer patients only, because of my work. We didn't get every [insurance] company out there...But for the most part our goals are achieved.

Corinne added, "It's exciting. I didn't know back then that I was at Ground Zero of something huge."

Julie—EEF Activism for Single Women in Tech

Julie, also a California native, found herself still single at the age of 35, with no partner in sight, even though she worked as an IT director in the heavily male-dominated Silicon Valley tech industry. This was in the era before all of the Silicon Valley tech giants—Apple, Facebook, Google, and Intel—were offering egg freezing as part of their "fertility benefits" for company employees. Julie worked for one of those companies when she decided to freeze her eggs:

I know there's a lot of information out there now about how [the company] covers egg freezing. They did not three years ago when I did it. I would actually like to think that my very vocal feedback to our internal benefits group around it maybe played some sort of a role in them eventually moving to this...I was incredibly vocal going through that entire time...I felt like the insurance company really didn't know how to deal with a situation like mine. I mean, even the questions they were asking about infertility and having a partner...You could tell it was just something that was completely foreign to them and they didn't know how to respond.

Like most Fortune 500 companies, Julie's tech firm only offered fertility benefits—namely, full insurance coverage for infertility diagnosis and treatment, including IVF—to married couples. Single women like Julie facing age-related fertility concerns were not eligible for fertility coverage. In the many conversations Julie had with the company's HR department and insurers, she began to feel a sense of discrimination as a single woman hoping to preserve her remaining reproductive potential. She also thought about how LGBTQAI+ employees might be treated in this situation:

I really felt like they didn't even know how to ask the questions. I mean, everything was about "your partner"...Even three years ago, going through this, it was all about your male partner. Now I do have a male partner, but I was even thinking on the flip side, you know, if I had a female partner at that point in time, how would they have approached that? And it was funny: Not only on the insurance side, but even when I was going through the classes to learn how to inject myself and all of that. I was the only single person in there. And I even remember one of the women saying to me, "Well, you know, don't worry; my husband didn't come with me to the first class, either." And I said: "Well, I'm actually not married. I don't have a partner. I'm actually going through this because I'm going to be freezing my eggs." It's already an emotional time and an emotional issue. And, like I said, for a lot of people it can feel like, "What's wrong with me?" You kind of feel like...you should be able to reproduce. And just all of their questions! "How often are you having sex?" Really? Is this really necessary? "How many doctors have you seen?" Just the way that they ask the questions and phrase the questions to go through this. It's incredibly invasive at a time when you are already feeling emotional, overwhelmed. It's a very sensitive topic, and there's just no sensitivity in how this is handled.

Still, Julie persisted in her vocal advocacy of egg freezing, eventually convincing her tech firm to subsidize egg freezing for single women employees. In retrospect, she was both bewildered and bemused by the negative media attention this decision garnered in American society:

It's funny to me, even now. Obviously, there's been a lot more coverage of it recently, and especially with both Apple and Facebook announcing that they cover it as a benefit for their own employees...It's funny for me to see how things get blown out of proportion. All these stories came out that said that Apple and Facebook are paying female employees to freeze their eggs. And that then, in turn, "Well, they're paying you because they don't want you to have kids, because they don't want you to walk away from the workforce." And it just made me laugh so hard, because I said, "They're not paying to freeze your eggs! They're saying that they're going to cover it if you decide to do that." They're not offering any financial incentive.

In terms of her own finances, Julie was required to pay \$16,000 out of her own pocket for her single cycle of egg freezing. But once the company benefits were in place, Julie's \$750 annual egg storage fees were covered. For Julie, however, the best "company benefit" was meeting another employee who would soon become her husband. Following two unsuccessful IVF cycles together, they turned to Julie's frozen eggs—rewarming 36 of them, fertilizing 24 of them, transferring 2 to Julie's womb, and freezing 22 embryos. In the middle of my interview with Julie, she received a phone call from the clinic. Recent blood test results showed that Julie was pregnant—probably with frozen-egg-conceived twins.

Kamila—EEF as a Reproductive Choice, Including for Black Women

Kamila was a New York-based communications specialist, who had spent most of her mid-30s working for an international reproductive rights organization. Kamila was in a relationship, but not sure that she wanted to have children with this man, or even become a mother. Still, she decided to pursue egg freezing at the age of 38:

I just know that I want the choice. Right? Like, I want the option to decide that if I'm in a relationship and I decide that we want to start a family, have children, that I have that ability. But, also, if I decide that I don't, that's okay, too.

Kamila checked with her medical insurance, only to discover that egg freezing was one of the only reproductive technologies *not* covered by the reproductive rights organization for whom she worked:

You know, we had great healthcare coverage! But what it didn't cover was the egg freezing process...And my health insurance would have covered the process if I was doing IVF and if I could have shown a pattern of having a fertility issue—showing that I tried to get pregnant for six months and was unsuccessful. I was like, "No. That's not exactly what I'm doing here"...I think Google and some of the other...very progressive organizations were offering that as a lifestyle bonus to their employees. And so my thing was, "Come on! This is [a reproductive rights organization]! So if everything else is covered, then you guys definitely need to get behind this as well."

I was the one who was like, "Listen, if I'm on the road all the time, this is the part of my lifestyle, then my insurance should cover it to the same extent that [they cover IVF]." One of the great things about [the organization] is they cover unlimited IVF for their employees...And so my response to our HR department was, "If you guys are covering all of these great procedures and we are [a reproductive rights organization], then you

should support my decision." So now [they] will cover egg freezing! They had to do some negotiating with the insurance companies and were able to get it covered. So I'm pretty proud of that. To have unlimited coverage for egg freezing is just above and beyond—pretty amazing!

In addition to the changes Kamila was able to enact in her reproductive rights organization, she was also keen on making egg freezing more visible in the Black community. So she began documenting her process on Instagram and Facebook—recording videos of herself and "talking about how I was feeling and all of those things." As the co-founder of a Black women's mentoring organization, it was very important to Kamila that she share her egg freezing story, because, as she said, "the voice of the African-American woman is missing":

I think that there's just an increased shaming of women that is above and beyond anything that you can imagine. And I really don't think that it's anything to be ashamed of...So many women would say, "I did it, but I just didn't share my story." I think that the sense of keeping it to ourselves is because there is an inherent shame attached to it, especially in the African-American community. I think the shame for women is that you're expected to be married, to have a family, and to have kids by a certain age, and with no problems attached to it. I think that in the African-American community, religion, especially Christianity, plays a huge role there. And so the idea that you are trying to control something that is outside of God's plan, I think, is a big thing... The shame is overwhelming. And I think the shame is related to just women making decisions on their own and for their own health...And if you take that and put it in communities of color, and then you put it in the South (laughing)! I mean, you just, you know. You're pushing a brick wall there.

Kamila continued, sharing her thoughts on the importance of reproductive choice and bodily autonomy for African-American women:

I think reproductive healthcare in and of itself is an issue among all women, but has a very sensitive vibe in the African-American community, from the historical ability to control our own bodies and our own reproductive healthcare. So, for me, it was very important to do the procedure, but to also share it with someone who may...need that voice to know that it's okay, and that it's our choice. Like, it's really our choice and our decision to make, and what it means to have, you know, bodily autonomy. I control what I do. So I wanted to share that message.

Interestingly enough, after Kamila completed her egg freezing cycle, the young women in her office "went crazy! You know, wanting to know more information on how they could do it." So, I actually got the policy reversed," Kamila

explained, "and I want to be proud of myself for standing up and saying, 'This is something I wanted to do, so I did it.'"

Andrew—TEF "Proactivism" for Transgender Men

Kamila, Julie, and Corinne were educated professional women confident in their abilities to push for change and reproductive choice. Andrew was a young, relatively uneducated, working-class transgender man, only 25 at the time of our interview. A recent graduate from a culinary technical school, he was working as an assistant chef in a university dining hall. Always a tomboy, Andrew became motivated to transition from female to male after following Caitlyn Jenner's well-publicized gender affirmation. At that point, Andrew started to mobilize, reading everything he could get his hands on and describing himself as "proactive."

Andrew's entrée into the physical process of gender transition began with a visit to a new primary care physician, who referred him to others who could help him on his way. After making numerous telephone calls and inquiries, Andrew soon discovered that he was the first person at the university where he worked to request TEF, which was definitely not covered by his university's health insurance plan. From that point on, Andrew spent many hours with university benefits personnel to justify insurance coverage. Without it, Andrew explained, TEF was entirely out of reach.

Nervously, Andrew waited for a decision, which had to be approved by a board of medical experts. Fortunately, the decision handed down was a positive one, based on the rationale that the use of testosterone in the gender transition is equivalent to the use of chemotherapy in young cancer patients. Both have sterilizing effects.

Andrew, who was told by his therapist that he was "the first transgender case to get accepted," was elated by the decision:

I'm very, very grateful...All of the doctors I've seen just showed me so much that I can trust them. I feel like I have great support [from] them. So this is very new to them and new to me as well... so we're kind of going through this together for the first time. I am so lucky [that] it's just been a smooth ride.

At the time of his interview, Andrew had just undergone his first TEF cycle. Without the insurance coverage, it would have cost him a total of \$8,100. Yet his only expenses were a \$90 co-pay and a \$600 annual storage fee. At this point, Andrew was also hoping that 3 additional egg freezing cycles would be approved—comparable to the 4 IVF cycles approved for married couples under the state's insurance mandate:

I will do all four if I can. I just feel like this is kind of, you know, my one shot right now to have children, and I feel really strongly about this. And

it is something that is very important to me, before I start pursuing, you know, the transition...And I'm also thinking about donating or selling a couple cycles of my eggs...if I'm allowed four cycles. It's something I want to consider. Because I feel like I'm very grateful for the position I'm in and having all the help I have and financial aid, just, you know, has been a blessing. I want to give back as well.

As a practicing Catholic who had been confirmed, accepted all of the sacraments, attended church each Sunday, and believed in God, Andrew had a strong sense of moral responsibility. He hoped to use his own transition and egg freezing experiences to improve the situation for other transgender men living in the US:

Like I said, this was a very important thing for me, being able to have my own children, and I didn't want to harm that in any way...I may not be carrying them, but I'm saving and preserving my eggs...for the future... There's so many unique things about me that I just question all the time, and I told [the doctor that] I'm definitely willing to do any kind of research. Yeah, I just feel like very powerful. I feel like my eggs will be powerful. I feel like I will have numerous amounts of them...I feel like I definitely was made who I am for a reason.

Conclusion

In closing this chapter on egg freezing activism, it seems important to hark back to the title of this volume—*Birthing Techno-Sapiens: Human-Technology Co-Evolution and the Future of Reproduction*. I argue that egg freezing constitutes an apt example. As seen in this chapter, egg freezing through oocyte vitrification: (1) was birthed from IVF; (2) was its most recent birth, considered the newest in the world of assisted reproduction; (3) was made possible by early adopters, some of whom served as human subjects under experimental conditions; (4) was forwarded through human-technology co-evolution, beginning with cancer patients, then single women facing age-related fertility decline, then transgender men; (5) was the site of significant egg freezing activism among individuals who benefited from this technology; and (6) was a way for all of these humans to potentially extend their reproductive futures.

As this chapter has also shown, egg freezing activists in America have worked hard to achieve significant reproductive gains, including: (1) creating an egg freezing non-profit for cancer patients; (2) extending egg freezing insurance coverage to women in the tech industry; (3) advocating for egg freezing as a single woman's reproductive right; (4) making egg freezing more transparent, imaginable, and accessible for minority women; and (5) mandating egg freezing insurance coverage for transgender men. Only through in-depth ethnography with egg freezing activists and others like them can we begin to tell the story of egg freezing—a true exemplar of human-technological co-evolution in the 21st-century United States.

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