

*Opinions expressed here are solely those of the authors and do not necessarily reflect those of the Empire State Stem Cell Board, the New York State Department of Health, or the State of New York.*

### Learning Activity 3: Eggs & Blood: Gifts & Commodities Case Study Symposium Eggs & Blood: Gifts & Commodities Module

*by Katayoun Chamany & Alexa Riggs*



This case addresses controversial issues in cell biological research, and specifically, human subjects and gamete payment in the context of informed consent, privacy, ownership, patriarchy, autonomy, risk-benefit analysis, commodity, and compensation. The case draws on the history of assisted reproductive technology and the ways in which biology intersects with race, class, gender, sexuality, and ability in the development of stem cell research. In this case study, students achieve depth of understanding by adopting the role of a particular stakeholder and acquire breadth through engagement with other stakeholders in a simulation that models a symposium at the International Network on Feminist Approaches to Bioethics. There are three parts to the case study: **Part I** adopting a role and presenting a position based on that person’s values, expertise, and experience; **Part II** engaging in dialogue with other stakeholders; and **Part III** which you shed your character role and use evidence from the historical and contemporary examples presented in this case study to craft an evidence-based argumentative essay that promotes particular policy changes regarding compensation for egg provision for embryonic stem cell research (ESCR) informed by the case activities, resources, your personal values, and societal values. You are encouraged to move beyond the “gut reaction” or binary superficial responses, to relativistic reasoning, and ultimately an informed and committed position evidenced by an analysis of the risks, benefits, and tradeoffs of this position compared to others.

#### **Part I: Symposium In Character Preparation Online**

Amari studied the list of possible attendees one more time. Having the responsibility of organizing an international conference symposium was definitely exciting, but it was also challenging. The [International Network of Feminist Approaches to Bioethics](#) had held a session on “Ethical Challenges in the Uses of Human Reproductive Tissue in Scientific Research: Procurement and Protection?” in 2012. Now Amari was being asked to organize a session specifically to discuss compensation for egg provision to serve embryonic stem cell research supported by the public sector. The number of stakeholders had grown exponentially since 2012 and Amari had ensured that the diversity of participants would reflect the balance between conservative and liberal views. Additionally, advances in adult stem cell I research and associated compensation schemes could bring a new dimension to the symposium.

As the newly appointed [Wittig Postdoctoral Fellow in Feminist Biology](#) at the University of Wisconsin, Amari had access to leaders in a range of fields and used those connections in assembling the attendee list. The undergraduate major in Interdisciplinary Science combined with a minor in Gender Studies had led to an interesting graduate thesis at UC Berkeley in embryonic stem cell research. The social justice mission of [Eugene Lang College](#) proved useful in graduate school, especially when it came to using reproductive tissue acquired through clinical settings. Amari had recalled learning about the [Nuremberg Trials](#) that eventually led to the current practices and policies regarding human research subjects. But the issue of “dual use,” when tissues are secured for clinical diagnosis that informs therapy and *also* used in research studies, continued to be a topic of hot debate, raising questions about autonomy, therapeutic misconception, coercion, privacy, and ownership.

Amari remembered discussing dual use with Professor Charis Thompson at a public event hosted by the [Chau Hoi Schuen Gender & Science](#) program at UC Berkeley. Dr. Thompson remarked that “egg sharing” schemes created connections between the reproductive sector developed to treat infertility and the stem cell sector seeking to devise new therapies and expand basic scientific knowledge. She mentioned studies on egg sharing conducted in the United Kingdom, South Korea, and Israel, where compensation took the form of reduced costs for IVF treatment. In some cases, egg sharers provided 50% of their eggs to the stem cell sector to receive the discount. But Amari also remembered stem cell researchers from the California Institute for Regenerative Medicine ([CIRM](#)) working closely with the fertility center to obtain human eggs for ESCR. No doubt this was something that was happening more often now that Governor Jerry Brown had vetoed the “Bonilla Bill.” The state bill would have allowed surplus embryos from the IVF sector to be used for research, which was not unlike the federal [bill put forth by Congresswomen Diane DeGette](#), which had died once again on the House floor.

Currently, the only state that separated the issue of dual use for eggs or embryos was New York (NY) through its [NYSTEM](#) initiative. In 2009, the state decided to [dedicate public funding for compensation](#) of up to \$10,000 for egg provision specifically to support embryonic stem cell research. In this scenario, eggs are collected and embryos created intentionally for stem cell research *only*. Amari was pleased that those who had worked on this NY model would be in attendance, alongside those that were more familiar with egg sharing schemes, and those who opposed any form of compensation in exchange for human eggs. Incentivizing biospecimen contribution was something that Amari had learned about in her coursework focused on diversifying the cord blood contributions in public banks as proposed by Seema Mohapatra in the last section of [her law review paper](#). Amari was impressed by the way these proposals were able to recognize diversity as an important component in biomedical research given the international focus on addressing health inequities.

With only a few weeks left before the symposium commenced, Amari shot off an email to the attendee list in hopes of sparking some initial discussion online via the conference portal. Since the symposium session would be relatively short, Amari wanted some of the discussion to take place in advance of the symposium, allowing for more robust dialogue during the session. To ensure that everyone was on the same page, Amari decided to include a trajectory of policies and practices to frame the discussion.

Dear Colleagues

We are very pleased that you will be joining us for The International Network of Feminist Approaches to Bioethics symposium “Compensation for Oocyte Provision Using Public Monies?” As you know, the International Association for Bioethics Conference is an interdisciplinary forum for the exchange of moral views, practices, and insights in methodologies, where established and young bio-ethicists meet. Because the question at hand could be informed by scholars holding expertise

in a range of disciplines and professional practices we expanded our attendee list to include stem cell researchers, American Studies, Disability Studies, and Social Justice scholars. Because of this diversity, we ask that *in advance* of the symposium, each attendee provide a brief statement (500 words) regarding their expertise, position, and/or proposals, and a counterargument (300 words) to those who might oppose your position or proposals. Because the symposium is designed to showcase diverse views, you can expect that some attendees will hold opinions that oppose your own, but may not be familiar with your area of expertise or experience, so please provide a bibliography for your counterargument. We also ask that you pose one question to each of two attendees to get the conversation started. Because our time is limited for the face-to-face dialogue we anticipate that doing some groundwork prior to the symposium will lead to more robust and meaningful conversation. We have taken the liberty to provide you with some resources to ground our work and these include the **Trajectory of Shifting Policies and Practices**, a **Stakeholders Possible Connections Chart and List of Annotated Biographies and References**. We apologize in advance for any misrepresentation of anyone's views or position; our intent was to stimulate conversation. As a reminder, we are planning on publishing the conference proceedings in a special issue of the [International Journal of Feminist Approaches to Bioethics](#) and the format for these paper submissions might be useful during your preparation for the symposium and a number of **Questions to Consider** have been provided for your review. We look forward to seeing you soon.

Sincerely,

Amari Vega

Wittig Postdoctoral Fellow for Feminist Biology

Co-Chair of the Symposium on "Compensation for Oocyte Provision for Embryonic Stem Cell Research Using Public Monies?"

*You will be assigned to play the role of a particular character/stakeholder for the duration of the simulated conference symposium. You will be expected to defend this stakeholder's position, even if it differs from your own. The roles include figures that span scientists, egg providers, policymakers, theologians, bioethicists, sociologists, activists, feminist scholars, and physicians. After reviewing the **Trajectory of Shifting Policies and Practices**, the **Stakeholders Possible Connections List and List of Annotated Biographies and References**, and **Questions to Consider** you will write a statement. Be sure to know basic biographical information about your character and the character's specific interest in oocytes or using human tissue for research or biomedicine. The references below each biography provide you with some background. Review the list of other stakeholders who will be present and consider who might ask which questions and who will answer these questions during the conference session. A quick Google search can provide you with more information about your character role or any others you find interesting.*

*For PART I you will write and post a statement that addresses the following:*

- **Who Are You?** *The 500-word character statement will state who you are, what expertise or experience you draw upon, and the unique perspective you bring to the discussion. **This statement should clarify your position regarding public funding for compensation to oocyte providers to serve human embryonic stem cell research.** Consider which stakeholders at the symposium serve as allies and which will oppose your stance or perspective and be sure to highlight these. You may want to review the list of questions associated with the position paper (Part III). Remember that not everyone in attendance has necessarily vocalized a position on compensation for oocytes for stem cell research, but they do hold views on the use of bodily tissues in research, or the role of*

*payment or compensation, or access to goods created with public funds. Cite your sources and include a bibliography.*

- **What** are two questions you hope to have answered? As you construct your profile, questions may arise. Pose one question to each of two stakeholders that you hope to have addressed during the symposium. Remember that not everyone in attendance has necessarily vocalized a position on compensation for oocytes for stem cell research, but they do hold views on the use of bodily tissues in research, or the role of payment or compensation, or access to goods created with public funds.
- **How** will you answer to those that disagree with your position or rationale? The symposium is designed to showcase diverse views on the same subject and, thus, you can expect that some stakeholders will hold opinions that oppose your own. Prepare a ~300 word statement that outlines the opposition and the evidence you would provide to counter your opposition's evidence and argument. Cite your sources and include a bibliography.

## **Part II Symposium Session In Person Role-Play**

Based on the online postings last week, Amari knew it would take some expert facilitation to ensure that all views would be heard during the symposium. With past experience in intergroup dialogue, Amari was confident that the symposium would run smoothly. Once everyone was seated, Amari set the stage:

“Thank you everyone for attending our symposium and participating in the online conference portal. We asked that you consider a number of questions regarding the use of public funding for oocyte provision for embryonic stem cell research, and many of you provided responses online. As one attendee wrote, ‘Should human tissues and cells be treated as sacred gifts, commodities that result from performed labor, or products whose retrieval places the provider at significant risk requiring compensation? ‘We all agree that as stem cell and fertility research advances there is a need for democratic deliberation concerning the status of tissues and cells and the cost of “labor” surrounding their retrieval and manipulation. In the United States the history of assisted reproductive technology (ART) suggests that without government regulation a range of practices persists including compensation, payment, and gifting. But even in countries where public funds are used in the context of reproductive technology and stem cell research (SCR) we continue to see a dynamic range of possibilities. These practices and policies are a result of human egg scarcity and increasing demand in both the ART and SCR sectors. With the identification of ovarian stem cells by [John Tilly's research team](#) in 2012, stem cell researchers may be able to create a large number of human eggs *in vitro* thus, shifting the supply-demand ratio. [Similar advances](#) have been made with induced pluripotent stem cells (iPSCs) that can be coaxed to become oocytes. Will these advances in science and technology eliminate or exacerbate human egg markets? If fewer egg providers are needed for SCR, will this shift the risk-benefit ratio for human research subjects that are providing the ovarian stem cells, and will this affect compensation? Can stem cell amplification from the peripheral blood supply, menstrual blood, and fat lead to other types of compensation schemes in an effort to diversify the supply in public and private stem cell banks? Given economic disparities, will those of lower economic status find themselves being targeted to create this initial supply of stem cells, or will these compensation schemes provide equitable participation in research and access to stem cell products?

As invited scholars and activists spanning a wide range of disciplines, practices, and identities, we ask you to bring your expertise with health, science, and social justice in the international, national, and local sector to determine the best way forward for oocyte procurement and provision. As questions were distributed in advance of the symposium, we ask that you jump right in and begin to engage in robust consideration of some of the proposals that have been laid out including moratoriums, bans, payment, reimbursement guidelines, compensation models, recruitment guidelines, data gathering on health risks, and access to publicly funded research and technological innovation. Be mindful that we are striving for dialogue not debate.

As Co- Chair

1. I ask that when you respond to the chair or a peer for the first time that you 1) state your name, your relationship to, or interest in, policies surrounding oocytes or other tissues for stem cell research, 2) what unique perspective you bring to the conversation, 3) which positions around the table with which you identify, 4) which positions around the table with which you take issue, and 5) direct questions to participants, which will then lead to an answer by the next person who will introduce themselves prior to answering the question. Remember you must *try* to have at least one of your two questions answered, so pose one from the start.
2. I ask that each participant monitor time and keep the conversation moving among participants. If you have not heard from someone and would like to, consider asking that individual to weigh in on a particular discussion point or question.

*In character, you should arrive at the symposium prepared to address any questions that may have been posed in the online environment, provide a clear statement on where your character stands, and use language that is inclusive to promote dialogue not debate. As you engage in the symposium and listen to your peers explain their position to those around the table, you may recognize that the same evidence can be used to support or refute a solution. The role-play provides a wide range of views very quickly and allows you to engage with the material broadly through peer learning. You are expected to engage with other stakeholders in this discussion. It is important that you extemporaneously join the discussion, and provide succinct and relevant points of view. As the discussion moves quickly it is best to refrain from reading any prepared statements and instead to have a set of bullets, questions, and abbreviated notes on hand.*

### **PART III: Post-symposium Student Position Papers**

It had been a busy week, but the symposium was a success in its ability to create a space for dialogue and exploration of places of compromise. The diversity of the group was vital and allowed each attendee to share, learn, and challenge various solutions to address the needs of bioresources for stem cell research. Amari noticed that some attendees had developed a tolerance for views that opposed their own and were able to find common ground despite the differing value systems of the participants. Though each attendee would be drafting a paper to be included in a [special issues journal](#), some universities and colleges had sent students to attend the symposium and had asked them to submit a position paper based on their experience. Amari thought it would be interesting to read these position papers. Since the students had no prior knowledge of the controversy, their opinion would be shaped by the discourse at the symposium and the brief biographies list and references provided to them. Amari wondered if the students would arrive at similar or divergent positions, given that each one would shape their response based on different life experiences and personal values. How would the students fare at merging their personal views with that of

such a wide range of activists and scholars? Amari opened the email containing the zip file of student papers to find out. Amari was eager to mentor these students to a successful publication in the [Penn Bioethics Journal](#) dedicated to undergraduate interdisciplinary work or to present their policy proposal to the [Debating for Democracy National Conference](#) dedicated to civic engagement.

*To prepare for this assignment, you will shed your character role, and write a policy position paper in which you defend **your** (not your character's) **position on the recruitment and compensation of oocyte providers for human embryonic stem cell research** (~2000 words). You must defend **your** (not your character's) position and decide whether this use of public money is warranted, or whether other models prove to be more ethically and scientifically relevant. The range of stakeholders involved with the symposium allows you to extrapolate from the singular historical case of Calla Papademos, who provided eggs in the reproductive context, to the contemporary practices used to collect and use of eggs in the research context. You are not constrained by the views of your character, and instead are expected to grapple with multiple points of view. Consider who were your allies, what evidence was brought to bear to support your position. Carefully explain and examine the biological, social, ethical, and legal dimensions of issues involved and any implications for policy. You should ground your recommendations in evidence, paying close attention to social values, risks, benefits, and tradeoffs of any one position and the implications of such a decision for procedural and distributive justice. The strongest proposals will be those that use precedent or existing structures to promote social change, but a revolutionary proposal can also be presented if the evidence base can support it. The most convincing proposals are those that can preempt opposition and identify places of agreement. Think of how to build coalitions. This is not a response paper to the experience of the role-play symposium but, rather, an academic position paper. Some questions to consider are below and a **Grading Rubric** is provided to help you direct your efforts.*