



Dear Trans, Gender Expansive and Intersex (TGI) Community Members,

In early December 2020, researchers at UCLA Semel Institute for Neuroscience and Human Behavior reached out to TGI people across Southern California who are active in the community, work in advocacy, and work for organizations that provide care, resources, or safety for folks who are transgender. According to their outreach email, the purpose of this meeting was to request feedback on a brain imaging study including set up, appropriate and inclusive materials, and ways in which their study team can respectfully connect with community organizers and partners. During the meeting, we learned that this study was already underway with approval by the UCLA Internal Review Board (“IRB”) (#11-000459).

The research study was designed to purposefully cause mental health distress in order to trigger “dysphoria.” This included having participants wear tight leotards while taking photographs of their body. We were asked for input about why they had a low retention of trans participants and found the researchers unable to comprehend why this study is harmful. The researchers were falsely advertising this study without clarity about the expectations of participants and without consideration of being trauma informed and the need for direct access to mental health after care.

**It was in collaboration with you all, our community and family, that we were able to successfully halt this study and protect TGI folx.**

In response, the Principal Investigator (PI) of the study, Dr. Jamie Feusner, agreed to temporarily halt recruitment for the study and, according to the project website, that remains the status of the research program today. The Office of the Human Research Protection Program (OHRPP) initiated a review of the “Transgender Research Program,” which they concluded in August of 2021. Unfortunately, the OHRPP ultimately re-approved the study. In the meanwhile, however, Feusner left UCLA for the University of Toronto, leaving the project without a PI, although their website still lists him as PI. As of now, we understand that they have not assigned another PI to continue the project.

Although OHRPP closed their review in August of 2021, they did not respond to our community complaint letter until allied-faculty met with them in November 2021. After the faculty meeting, OHRPP sent their IRB Review and additional actions as outlined below (from UCLA to the lead organizers against the study):

“1) The PI convened a community advisory committee to “assist the research team with feedback about the current study, ongoing study procedures for the duration of the



study, and to establish ongoing engagement and dialogue between the research team and the members of the community for whom the research is relevant”.

a. Per the PI, the composition of this committee was “four people who are representative of the whole spectrum of the transgender community (including those theoretically eligible as potential participants), three representatives from local LGBTQ support and/or advocacy organizations, a clinician who treats transgender individuals, and an individual involved in transgender research who holds a non-neuroscience, non-medical academic role. This advisory committee will allow the research team to secure meaningful input from the transgender community and those for whom the study is relevant, regarding the evaluation, implementation, and communication of the research.”

2) This community advisory committee met twice to review and discuss the research. As a result of their consultation, the PI proposed revisions to the study plan that were submitted to the IRB for review.

3) The convened IRB reviewed the entire revised study plan. For their deliberation, they included a consultation review by a trans-identified scientist (clinical psychologist) who is a member of WPATH. The consultant was given the specific concerns you identified and reviewed the research with that in mind. They recommended that the revised study plan was scientifically valid and had addressed the concerns. The IRB agreed with the consultant’s assessment.

Additional Actions by the OHRPP office:

1) A training on social and medical vulnerabilities of trans individuals in research was provided to members of all five UCLA IRBs. This training included discussions of the history of medicalization of trans identity, medical gatekeeping to gender-affirming care, and a reminder to request external consultation whenever appropriate.

2) UCLA has signed on (with other UC campuses) to a letter from the University of California Office of the President to the Federal Office of Human Research Protections, requesting that the IRB registration system allow for specifying gender identity of IRB members beyond “male” and “female” to support diverse gender representation on all IRBs.

3) OHRPP is exploring hosting a series of lectures and/or trainings for the research community at UCLA (and beyond) on ethical research in gender minority communities. As part of this plan, we will work to obtain CME credits for the training, to encourage more physician researchers to attend.



4) OHRPP has met with various student and faculty stakeholders to discuss how UCLA can best support the transgender community becoming an active part in decision-making about research conducted at this institution.”

We asked the OHRPP if we could contact the WPATH consultant to learn what recommendations were made, and the thought process they had in order to agree for the study to continue forward. OHRPP stated the consultant wished to remain anonymous and was not available to meet with TGI community members and advocates. We also expressed concern around the PI only meeting twice with 4- Transgender folx who ‘represent the community as a whole’ and 3 ‘LGBTQ representatives from local support and/or advocacy organizations who may or may not have been TGI-identified.

**This process only reinforced for us the inadequacies and limitations of the IRB process, and the need for transparent and accountable processes for responding to community ethics complaints.**

Since Summer 2021, UCLA’s Center for the Study of Women (CSW) has hosted a working group on TGI communities and ethical research called [“Just Research? Trans Futures in Health and Scientific Knowledge.”](#) This initiative aims to cultivate a network of scholars and community leaders interested in strengthening the interdisciplinary field of transgender studies and in building capacities for community-driven and justice-centered research in alignment with the fight for liberation. Made up of trans and two-spirit community organizers, public university faculty, and students, the Just Research? team is reimagining TGI-relevant research that starts from the ground up: asking community-based organizers about research priorities, the values and ethics that are appropriate when conducting research with TGI communities, and how to center the perspectives of TGI communities at every level. This project is supported by CSW and UCLA’s Hub for HIV Intervention, Prevention, and Policy (HHIPP) as well as other campus units.

This research team created very intentional themes that uplifts the voice of TGI community members and advocates. These themes include:

**Grassroots knowledge practices or “embodied theories & calls to action”**

Intention is to learn more about:

- Practices, processes, and tools organizers use to produce knowledge and respond to community needs (e.g., observation, analysis, theorization, interventions, experiments, sharing info, etc.).
- The theories, knowledge traditions, and/or frameworks operating in these practices.
- The values or ethics operating in these contexts.



## **Academic-community organizational relationships**

Intention is to learn more about:

- Concerns about academic/institution research practices? (past, present, and future)
- How academic research is or could be useful to current and future needs of TGI community organizations (and what would need to change to make it more useful)
- How academic researchers and TGI people can address the current needs of the community and collaborate with community orgs.
- How aligned/out of alignment academic researchers are with institutional ethics? Grassroots ethics & values?

## **Institutional harm and preventing research exploitation of trans people**

Intention is to learn more about:

- Ideas about how to protect transgender people from research exploitation.
- Perceptions of accountability and ideas for creating meaningful accountability for academic institutions in response to past and future harms

## **Convening**

Intention is to explore potential next steps including:

- Goals and structure for a community-academic convening.
- Resources and supports needed in order to participate in a convening.
- Goals or visions for beyond a convening.
- Ways that academic institutions can support current and future calls to action.

Our goal is to increase access to public research university resources for transgender, two-spirit, gender-expansive, and intersex communities' (TGI) and to align these resources with the needs of these communities. We recognize an ongoing history of harm enacted against TGI people in pursuit of health and scientific knowledge in the academy. We also recognize that TGI people and community organizations have developed research and knowledge-making practices outside of universities. We dare to envision and enact a more ethical and justice-oriented role for public research universities in the pursuit of TGI-related scholarship.

We work for a future in which research about TGI people is relevant to and rooted in the knowledge, priorities, and practices of TGI people and communities and in which community researchers are valued, well resourced, and credited.

We are currently convening leaders within TGI organizations from across California to collectively create a vision for this initiative. A TGI-led convening will provide the stories, research needs and academic research demands in Summer 2022.



To be kept up-to-date on this advocacy effort, Just Research?, and the convening, please continue to check the CA LGBTQ Health and Human Services webpage "[Advocacy for TGI Research Participants](#)" as well as Gender Justice LA's website <https://qjla.nationbuilder.com>

Thank you for your continued support.

In Solidarity,

A handwritten signature in black ink that reads 'Dannie Cesena'.

**Dannie Cesena, MPH**  
Transgender Health Equity Manager  
CA LGBTQ HHS Network

A handwritten signature in black ink that reads 'Ezak Perez'.

**Ezak Perez**  
Executive Director  
Gender Justice LA