

Canary Knowledge: Chronic Fatigue, Chemical Sensitivities and the Limits of Medicine

**Oral Histories of Environmental Illness
(OHEI) Symposium**

UCLA Hershey Hall

**Friday, November 17, 2023 –
Saturday, November 18, 2023**



Canary Knowledge: Chronic Fatigue, Chemical Sensitivities and the Limits of Medicine

For accessibility copies of the presentations, please click [here](#).

Watch the captioned OHEI Symposium live-stream on the CSW|Streisand Center Youtube Channel:

[Friday, November 17](#)
[Saturday, November 18](#)

Conference Schedule

(All times in Pacific Standard Time)

Friday, November 17, 2023
UCLA, Hershey Hall (Room 158)

9:30 AM - 10:00 AM: Registration and Coffee

Location: Hershey Salon Foyer

10:00 AM - 10:15 AM: Welcome by Dean Alexandra Minna Stern (UCLA Humanities)

Location: Hershey Salon (Room 158)

10:15 AM - 10:30 AM: Opening Remarks by Rachel Lee (English, Gender Studies, and the Institute of Society & Genetics, UCLA; co-PI, Abolition Medicine and Disability Justice: Mapping Inequity and Renewing the Social) **and Helen Deutsch** (English and Disability Studies, UCLA; co-PI, Abolition Medicine and Disability Justice: Mapping Inequity and Renewing the Social)

Location: Hershey Salon (Room 158)

10:30 AM - 12:00 PM: Panel #1: Causes, Cascades, and Care

Location: Hershey Salon (Room 158)

Moderator: **Fuson Wang** (English and Medical and Health Humanities Minor, UC Riverside; co-PI, Abolition Medicine and Disability Justice: Mapping Inequity and Renewing the Social)

Panelists:

Julie Rehmeyer (freelance math and science journalist): “The Challenge of Keeping Us All Safe: Addressing Environmental Drivers of Chronic Illness”

Kelsey Kim (Anthropology, UCLA): “Oral Histories of Environmental Illnesses: Legitimizing Experiences and Alternative Ways of Knowing”

Emily Lim Rogers (Cultural Anthropology, Duke University): “Proximate Causes: Histories of ME and HIV/AIDS”

12:00 PM - 1:15 PM: Lunch Break

1:15 PM - 2:45 PM: Panel #2: Illness & Activism

Location: Hershey Salon (Room 158)

Moderator: **Nicholas Shapiro** (Institute of Society & Genetics, UCLA; PI of Carceral Ecologies Lab)

Panelists:

Liza Grandia (Native American Studies, UC Davis): “Thrice a Canary”

mads lê (Information Studies, UCLA): “Chronic Possibilities: Living in and with Toxicity”

Vanessa Barba (California Domestic Workers Coalition): CA Domestic Worker’s Ongoing Fight to End Racist Exclusion

2:45 PM - 3:00 PM: Break

3:00 PM - 3:45 PM: Art Interlude

Location: Hershey Salon (Room 158)

Screening of *Multiple Chemical Sensitivity and Environmental Illness: Awareness and Acknowledgement* (2020 film, dir. Marie LeBlanc)

In this film, Marie LeBlanc shares the struggles of four friends suffering from Environmental Illness, a.k.a. Environmental Sensitivities, including Multiple Chemical Sensitivity, Electromagnetic Hypersensitivity, and mold illness/mold hypersensitivity. They illustrate the pain of coming to terms with the disease and the loneliness and isolation it brings.

Screening of *The Stories of Maya and Aurora* (2022 film, dir. Ili Levine)

An abstract telling of two women impacted by MCS, focused on their intersecting identities.

3:45 PM - 4:00 PM: Break

4:00 PM - 5:30 PM: Keynote by Jennifer Brea (independent filmmaker): “Art and Disability Activism,” **introduced by Rachel Lee** (English, Gender Studies, and the Institute of Society & Genetics, UCLA; co-PI, Abolition Medicine and Disability Justice: Mapping Inequity and Renewing the Social)

Location: Hershey Salon (Room 158)

**Saturday, November 18, 2023
UCLA, Hershey Hall (Room 158)**

10:00 AM - 11:30 AM: Panel #3: Reflections on the Archive and Future Research

Location: Hershey Salon (Room 158)

Moderator: **Helen Deutsch** (English and Disability Studies, UCLA; co-PI, Abolition Medicine and Disability Justice: Mapping Inequity and Renewing the Social)

Panelists:

Nic Yiu (Gender Studies, UCLA): “Canary Survivorhood: The Calculus of Disclosure and Self-Advocacy”

Dana Salah (Social Welfare, UCLA): “Using the OHEI archive in research”

Abraham Encinas (English, UCLA): “Hemispheric Narratives of Environmental Illness”

Ili Levine (Gender Studies and Labor Studies, UCLA)

11:30 AM - 12:00 PM: Livestream of Mei-Mei Berssenbrugge reading “V is for Vulnerability”

Location: Hershey Salon (Room 158)



Biographies



Vanessa Barba (she/her) joined the domestic worker movement in 2014, just after the CA Domestic Workers Bill of Rights had been passed. She has organized workers from a variety of industries, including restaurant, garment and domestic workers, to develop leadership, organize workplace campaigns against wage theft and health and safety violations, and to strengthen relationships with labor law agencies. Vanessa's experience as an organizer includes drafting legislation, leading advocacy campaigns, and ensuring enforcement and implementation of grassroots policy successes. Vanessa joined the Coalition in 2020.



Mei-mei Berssenbrugge (she/her) was born in Beijing and is the author of fourteen books of poetry, including *Hello, the Roses*; *Empathy*; and *I Love Artists*. Her collection *A Treatise on Stars* was a finalist for the National Book Award and the Pulitzer Prize and received the Bollingen Prize for Poetry. She is a recipient of the Mary McCarthy Award in recognition of engagement in the public sphere. *Plant Thought*, a collaboration with artists Kiki Smith and Richard Tuttle was recently published by The Center for Book Arts in 2023. She lives in northern New Mexico and Maine.



Jennifer Brea (she/her) is an independent filmmaker based in Los Angeles. She has an AB from Princeton University and while studying for her PhD at Harvard she fell ill leaving her bedridden. In the aftermath, she rediscovered her first love, film. Her Sundance award-winning, Emmy-nominated feature documentary *Unrest* was shortlisted for an Oscar. *Unrest* has screened in over 30 countries, had its US national broadcast on PBS's *Independent Lens*, and was distributed worldwide on Netflix. She is also co-creator of *Unrest VR*, winner of the Sheffield Doc/Fest Alternate Realities Award. Brea is a TED fellow, co-directed *Call Me Cleo* for HBO Max and is writing her first narrative script as an independent project. Her forthcoming feature documentary, *4mm*, is in production.



Genoa Brown (she/they) (MA, member of AZA) is an interdisciplinary, multifaceted artist whose life blends music, education, entrepreneurship, and community engagement. A musician, teacher, business owner and resident in the well-known Tannery Artists' community in Santa Cruz, she played a pivotal role in community empowerment projects in Tannery programming in 2022. Genoa also holds a master's degree in counseling psychology. She embodies the fusion of family, music, and community advocacy, making a lasting impact on her community, nurturing emerging artists, and inspiring others to create a more harmonious future.



Helen Deutsch (she/her) is a Professor of English, founder of the Disability Studies Minor, and the former director of the Center for 17th- & 18th-Century Studies/William Andrews Clark Memorial Library at UCLA. She works at the crossroads of disability studies and eighteenth-century studies. She is the author of *Resemblance and Disgrace: Alexander Pope and the Deformation of Culture* (1996), and *Loving Dr. Johnson* (2005), as well as co-editor of *“Defects”: Engendering the Modern Body* (2000) and *Vital Matters: Eighteenth-Century Views of Conception, Life, and Death* (2012). She is currently finishing *The Last Amateur: Jonathan Swift, Edward Said, and the Profession of Literature*. Her current research asks how early modern understandings of human difference before “normal” existed might enable new ways of thinking disability justice and community today. She is grateful to be collaborating with Rachel Lee, whose inspiring work on the OHEI has changed the way she thinks about the archive and so much else. Deutsch is also a Co-PI on the MRPI-funded project, “Abolition Medicine and Disability Justice: Mapping Inequity and Renewing the Social.”



Abraham Encinas (he/him) is a PhD graduate student in English at UCLA. His dissertation examines the fraught relation between language and power by analyzing *novels of dictatorship* in US multi-ethnic literature and Latin American literature. He can speak, read, and write in academic Spanish fluently and has done work in oral and written translation. On the side, he has produced a podcast called *Extreme Vocabulary* which “looks at the culture behind words,” and he would someday like to write a graphic novel.



Dr. Liza Grandia (she/her) has collaborated as an activist-scholar with Indigenous, environmental, social, and agrarian justice movements in the Maya lowlands of northern Guatemala and Belize for the last three decades. Since 2005, she has coordinated a network of social-justice advocates in the Q’eqchi’ Scholars Network and collaborated with a Q’eqchi’ peasant organization called ACDIP. She joined Native American Studies at UC Davis as an associate professor and inherited leadership of the Indigenous Research Center of the Americas. In 2017–2019, she was awarded a national Mellon Foundation “New Directions” fellowship to pursue studies in toxicology and environmental epidemiology for her new work on pesticides and other environmental hazards. She has won several awards for her environmental advocacy for green schools, healthy campuses, climate action, and bilingual education. She is a survivor of cancer, long COVID, and chemical injury resulting in multiple chemical sensitivities. Grandia received her BA summa cum laude from Yale University in 1996 and PhD in Anthropology from the University of California, Berkeley, in 2006.



Pato Hebert (he/they) (Associate Professor, Art; Chair, Department of Art and Public Policy, New York University) is an artist, teacher, and organizer whose work explores the aesthetics, ethics and poetics of interconnectedness. He works across a range of media including photography, installation, sculpture, language, light, temporality, and graphic design. Progressive praxis, spatial dynamics, and the spirit of social topographies are of particular interest.



Kelsey Kim (she/her) is a PhD Candidate in Anthropology at UCLA. Her research examines gender, race, and labor in the Silicon Valley tech industry, specifically through the efforts of tech worker activists.



mads lê is a PhD student in Information Studies at UCLA studying how Vietnamese Americans articulate illness, disability, and caretaking practices across multiple generations to understand how militarism and migration shape how we live in and with toxicity. mads is also the Viet Rainbow of Orange County's (VROC) board chair, where mads supported the development of their oral history program and project.



Marie LeBlanc is a self-taught multidisciplinary artist. Through photography, multimedia projection, short film, performance, and wordsmithing she explores themes related to landscape, isolation, beauty, health, and nature. While living with environmental sensitivities herself, she focuses her art on the impacts of the environment on people, sometimes with an emphasis of the impact people have on the environment. Marie advocates for those living with an environmental illness through her art presentations, radio interviews and other public appearances. In the winter months, she travels to the US desert in a cargo van adapted for safe housing to ease the symptoms of Environmental Sensitivities (ES).

She holds a Bachelor of Arts in Human Geography and Sociology from the University of Manitoba. She has participated in the Making Our Mark II Printmaking Mentorship Program at Martha Street Studio, the Artist-in-Residency Program at Artbeat Studio, and the Art Salon Program at Arts AccessAbility Network Manitoba (AANM). Her story and artwork have been featured in interviews, articles, and newsletters throughout Western Canada, the US, and MCS Aware (UK). She was recently awarded Microgrants from Mentoring Artists for Women's Art and AANM for the completion of *Overdressed*. The short film *Multiple Chemical Sensitivity and Environmental Illness: Awareness and Acknowledgement* is her first major foray into film.



Cynthia Ling Lee (she/they) (Associate Professor, Dance, UC Santa Cruz) is a choreographer and scholar who instigates queer, feminist-of-color, and crip interventions in the field of experimental performance. Trained in US postmodern dance and North Indian classical kathak, she is committed to intimate collaborative relationships and foregrounding marginalized voices and aesthetics. Her current work researches the intersections between dance, disability, and chronic illness.



Rachel Lee (she/her) is a multidisciplinary humanities professor at UCLA. Lee is the author of *The Exquisite Corpse of Asian America: Biopolitics, Biosociality and Posthuman Ecologies* (2014), and editor of *The Routledge Companion to Asian and Pacific Islander Literature* (2014). Her current research focuses on frameworks that deepen relationality between individuals with “environmental illness” (including chronic Lyme, MCS, heavy-metal intoxication, and the like) and scholarship in an anti-racist and anti-colonial vein. She was team lead on the Oral Histories of Environmental Illness Archive and she is co-PI on the University of California’s multicampus research program initiative, Abolition Medicine and Disability Justice. To download recent and past articles, see <https://chavez-ucla.academia.edu/RachelLee>.



Ili Levine (she/they) is a 2023 graduate of the UCLA Department of Gender Studies and the Labor Studies program.



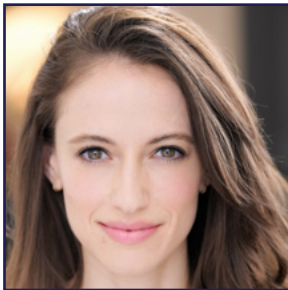
Megan Moodie (she/her) is a cultural anthropologist, writer, performer, and feminist theorist whose work spans genres from traditional scholarship to essays, fiction, drama, dance, and film criticism. As an Associate Professor of Anthropology with affiliations in Feminist Studies, Film & Digital Media, and Legal Studies at the University of California, Santa Cruz, she specializes in teaching experimental research methods that bring together social sciences and the arts.



Julie Rehmeier (she/her) is the author of *Through the Shadowlands: A Science Writer's Odyssey into an Illness Science Doesn't Understand*, an award-winning freelance math and science journalist, and a contributing editor at *Discover Magazine*. Her work has appeared in the *New York Times*, *the Washington Post*, *O Magazine*, *Discover*, *Science News*, *Aeon*, *Wired*, *High Country News* and many other publications.



Emily Lim Rogers (she/her) is an Assistant Professor of Cultural Anthropology at Duke University. She has articles in *Medical Anthropology Quarterly* and *Crip Authorship: Disability as Method* (NYU Press, 2023, eds. Mara Mills and Rebecca Sanchez), among others. She was also a researcher at the NYU Disability COVID Chronicles, an oral history project about disabled and chronically ill New Yorkers. Currently, she is working on her first book manuscript, *Clinical Proximities: ME/CFS and Biomedicine's Binds*, about the politics of ME/CFS in the US.



Dana Salah (she/her) is a graduate student in the social welfare program at The Luskin School of Public Affairs. She graduated in June with her Bachelor of Arts in Gender Studies from UCLA. For her undergraduate senior capstone project, Dana centered her research around three oral histories from the OHEI archive.



Nicholas Shapiro (he/him) is an assistant professor in the Institute for Society and Genetics and the director of Carceral Ecologies. He is a multidisciplinary environmental researcher that studies, and designs interventions into, issues of chemical contamination and climate change. He has worked tracking the quasi-legal resale of 120,000+ chemically contaminated housing units after Hurricane Katrina, developing air monitoring systems with communities impacted by unconventional natural gas extraction, and testing fossil fuel-free means of long distance air travel.



Alexandra Minna Stern (she/her) is the Humanities Dean and Professor of English and History, and at the Institute for Society and Genetics, at the University of California, Los Angeles. Dean Stern was previously the Associate Dean for Humanities at the University of Michigan's College of Literature, Science, and the Arts. Prior to that role, she held a series of other leadership positions at the Ann Arbor campus: Chair of the Department of American Culture (2017–2019), Director of the Latin American and Caribbean Studies Center/Brazil Initiative (2014–2017),

and Associate Director of the Center for the History of Medicine (2002–2012).

Dean Stern founded and co-directs the Sterilization and Social Justice Lab, an interdisciplinary, multi-institutional research team that is reconstructing and analyzing the history of eugenics and sterilization in five US states (Michigan, North Carolina, Iowa, Utah, and California). Her research has focused on the history of eugenics, genetics, society, and justice in the United States and Latin America. Through these topics, she has explored the dynamics of gender, sexuality, race, ethnicity, disability, social difference, and reproductive politics.



Fuson Wang (he/him) (BA, BS, Stanford University; MA, PhD, University of California, Los Angeles) specializes in British Romantic literature, disability studies, and the medical and health humanities. Having received undergraduate degrees in both mathematics and English literature, his work tends to approach literary studies with a consciously interdisciplinary orientation. He is the author of two books *A Brief Literary History of Disability* (Routledge 2022) is a monograph about how disability theory reshapes our notions of literary periodization and *The Smallpox Report: Vaccination and the Romantic Illness Narrative* (University of Toronto Press 2023) is a literary historical account of smallpox vaccination that contends that the disease's eventual eradication in 1980 was as much a triumph of the literary imagination as it was an achievement of medical Enlightenment science. His work has been supported by UCHRI, the Huntington Library in San Marino, and UCOP. His work has appeared in various peer-reviewed venues, including *European Romantic Review*, *Nineteenth-Century Contexts*, *Women's Writing*, and *Eighteenth-Century Fiction*.



Wei Nic Yiu 姚煒詩 (they/them) is a PhD candidate at the UCLA Department of Gender Studies. They previously received a Master of Arts in Gender Studies at the Women and Gender Studies Institute at the University of Toronto, Canada. Their current research project explores Chinese massage workers' experience in the United States. Their work is informed and inspired by their own experiences of migration as a queer Asian gender non-conforming person in Hong Kong, Beijing, Toronto, and now Los Angeles. They are a core member of the Black Feminist Initiative at the Center for the Study of Women|Barbra Streisand Center.