

Introducing *How We Make It: Disability Justice, Autoimmunity, Community*, a Multimedia Project

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How to Read this Entry

How We Make It: Disability Justice, Autoimmunity, Community is a born-digital multimedia piece that lives on the Scalar platform and that was submitted and eventually accepted into the Special Section on Autoimmunities in the Wake of COVID-19. The text below is a close reproduction of the Navigation page within the Scalar piece. While reading this text, one cracks open the door to glimpse the ten-person collective behind this project. However, we invite the reader to go directly to the website (link provided below) to fully partake of the variety of

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paths—including embedded sound and video files, image annotations, and links to other sites—that perform a listening to and reflecting upon crip knowledge and joy as it was catalyzed and recorded by this ten-person collaborative ruminating on chronic illness, long COVID, anti-Asian violence, incarceration, care burdens, mental distress, electromagnetic fields, and deep listening. After going to the Scalar website, please make sure to turn your speaker volume up. Linger over key images (while in Scalar) will also reveal pop-up annotations.

Keywords

crip joy, chronic illness, anti-Asian violence, incarceration, long COVID, disability, AIDS activism, electromagnetic fields, care burdens, mental distress, art of deep listening

[Link to *How We Make It: Disability Justice, Autoimmunity, Community*](#)



Figure 1. Pato Hebert, *Spoonies*, from the *Counter Measures* series, salvaged eucalyptus, 2021, dimensions variable

Alt text: Softly arcing assemblage of thirteen wooden spoons, in a top row of four, middle row of five, and bottom row of four. Darker whorls in the eucalyptus from which they were carved are visible. A spoon directly at the center point is missing a chunk at the tip of the bowl.

Navigation

How We Make It Collective: Disability Justice in the Wake of COVID's Long Haul (hereafter HWMIC) is a ten-person collective of sick and disabled artists, academics, and their allies in various stages of career and capacity: we are newly minted PhDs and distinguished professors; we are exhausted with chronic fatigue, disabled from mold, capitalism, mast cell activation, viral reservoirs, and also not-yet-disabled or passing for well.



Figure 2. HWMIC members: *top, left to right*: Megan Moodie, Cynthia Ling Lee, Pato Hebert, Marina Peterson, Nikita Simpson; *bottom, left to right*: Rachel C. Lee, Tammy Ho, Alexandra Juhasz, Charles L. Briggs, Sharon Daniel

Alt text: Ten headshots (both color and black and white) set in two rows of five above text, which reads "How We Make It, Disability Justice for the Long Haul, UCHRI, Spring 2022."

Each of us brought individual projects to a hybrid (in-person and online) convening of our research collective, initially as a one-quarter residency in spring 2022 at the Humanities Research Institute located at the University of California-Irvine. Our project leader, (h)Ehler-Danlos spokesperson and activist Megan Moodie (UC-Santa Cruz), has continued in 2023 to make online space for our group to reflect on the embodied mentorships and life transformations enabled by this residency.

This Scalar assemblage acts as a partial archive of our collective's choreographies, conversations, documentary images, and DIY manuals, as we waxed and waned in varying degrees of muscular shaking and tic-ing (dystonia), of invisible but felt chronic inflammation and brain fog—a hallmark of [post-acute sequelae of COVID-19](#)—and other both progressive and intermittent symptoms of chronic illnesses. While some of us remain in proximity to autoimmune disorders such as Graves disease, we are less interested in demonstrating the congruency of our conditions

to autoimmune disorders as established by US medicine, as we are in conceiving embodiment as never “auto” nor “immune” but a co-inhabitant ecology—indebted to the variegated biological and social communities in which we dwell and that dwell within us.

If more of us had been excellent digital artists with more [spoons](#) on hand, our table of contents would be a circle of several matryoshka dolls, each nesting twin and triplet creative acts from our siblings in this collective. At the center of this circle would be the mother matryoshka—a textual reflection by Moodie on autoimmunities in relation to How We Make It.

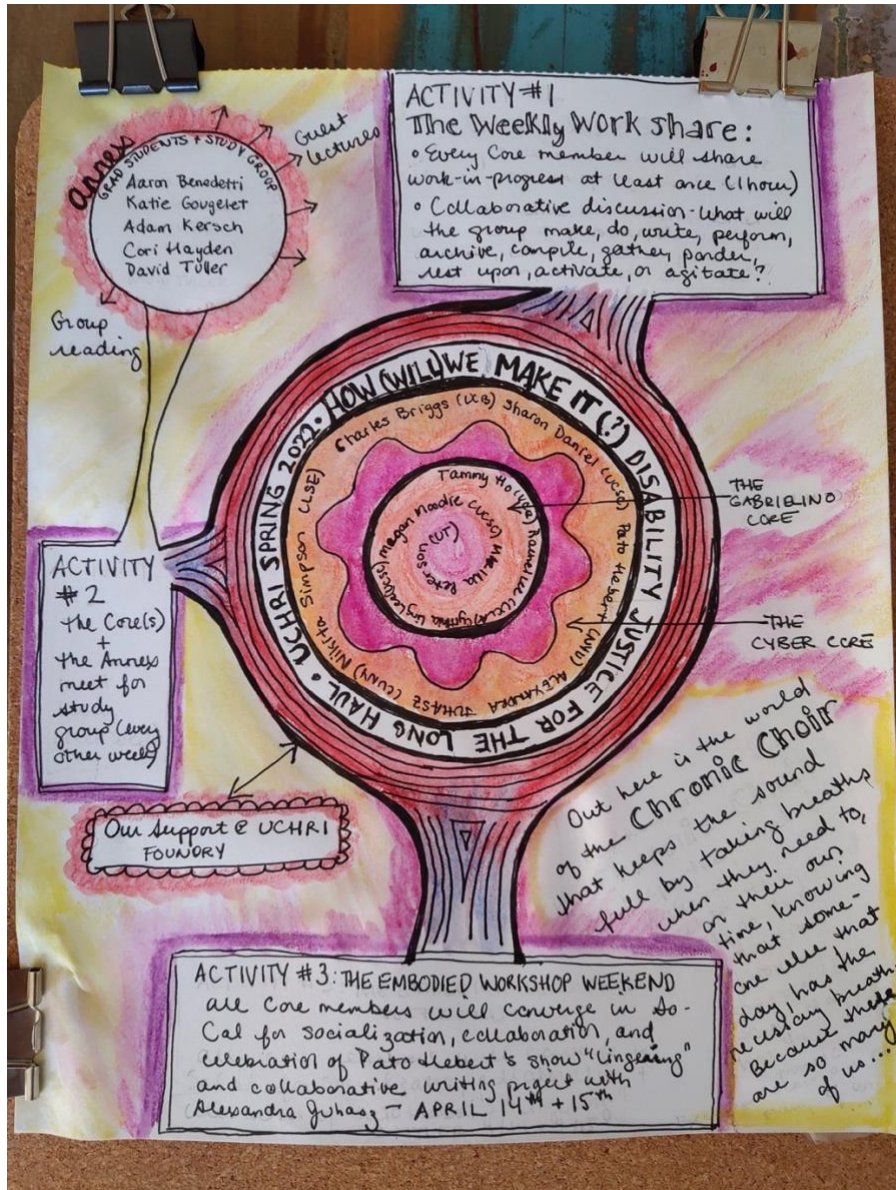


Figure 3. M. Moodie’s watercolor drawing and visualization of the HWMIC, its relation to institutional supports (at University of California Humanities Research Institute), and upcoming gatherings

Alt text: Pink and orange flower or amoeba cell sits in the center of a circular design bounded by a white circular border in which is written, "How (Will) We Make it (?) Disability Justice for the Long Haul * UCHRI Spring 2022.*" Names of five HWMIC members are written in a spiral design in the center of the flower bud. An arrow pointing to this center disc labels it "The Gabrielino Core"—those members residing at the UC-Irvine Gabrielino apartments in spring 2022. In the orange, circular dish in which the flower sits are written names of five HWMIC who attended the University of California Humanities Research Institute (UCHRI) seminar both virtually and with scattered in person visits. An arrow pointing to this disc labels it "The Cyber Core." Three roads of connective tissue lead to boxes with handwritten "Activities: (1) The Weekly Work Share (*top right*); (2) the Core(s) and the Annex meet for Study Group every other week (*left middle*); and (3) The Embodied Workshop Weekend (*bottom center*)." A yellow wash of color lends a warm tone to the poster.

A circular or spiral organization feels apt to how our group functioned. However, we realize that some readers may want a clearer pathway through the images, videos, sound files, and reflective writing that our ten members have composed as recipes for and queries into "how (will) we make it" after long hauling with chronic illnesses, disabilities, autoimmunities, and grave losses, some related and others not to COVID-19. In the toolbar in the upper left, adjacent to the compass icon, is a table of contents with three headings: Linger, Aligning, and Crafting.

LINGERING refers to Pato Hebert's solo exhibit at Pitzer College, the occasion for all but three members of the HWMIC to linger with each other on a beautiful April evening and to contemplate how art practices and relations of care have to be rethought as COVID lingers for long-haulers. To linger is to listen with gratitude for another's pauses, stutters, slower pacing, newer rhythms, and to archive how structures of inattention and abandonment have been visited on those who cannot or do not return to the land of the well.

ALIGNING takes inspiration from dance and sound studies, the allowing of fractious energies to vibrate through one's embedded body rather than attempting to overcome or go against and thereby amplifying the velocity of clash and crash. The emphases in this cluster are on noticing "magical collaborations" between electric weather patterns and neuroscience; and learning across linguistic and cultural differences about the tensions negotiated by those caretaking and needing care.

CRAFTING taps into the amateurism, creative joy, and rejuvenating play we allowed ourselves as we adjusted to the ways our art and scholarship could not keep up with the rate of losses we were documenting and experiencing in each other's company. Though compromised in the capacity to analyze, stay on point(e), or carry on as if COVID were over, we could and did give ourselves permission to yarn, color, collaborate, and fold (over) with laughter and camaraderie.

The form that we have given to this assemblage is designed both to honor the heterogenous mediums and languages of each contribution and simultaneously

map the synergies that emerged and the spirit of care and deep listening that helped sustain our bodyminds ([Schalk](#)) and cravings for nurturance in isolating times.

Collective Bios

[Charles L. Briggs](#) is a cultural/medical/linguistic anthropologist who has documented cholera and rabies epidemics in Venezuelan Indigenous communities: *Stories in the Time of Cholera* and *Tell Me Why My Children Died*, both with Clara Mantini-Briggs.

[Sharon Daniel](#) is a digital media artist who creates interactive and participatory documentary artworks addressing issues of social, racial, and environmental injustice, with a particular focus on mass incarceration and the criminal justice system.

[Dr. Alexandra Juhasz](#), Brooklyn College, CUNY, works as a media artist, curator, and writer engaged with linked social justice commitments, including COVID-19, AIDS, Black lesbian media, feminist and queer/trans film, and activist archives and collectives.

[Pato Hebert](#) serves as Chair of the Department of Art & Public Policy at Tisch School of the Arts, New York University, where his students have thrice nominated him for the David Payne-Carter Award for Teaching Excellence.

[Tammy C. Ho](#) is an Associate Professor of Gender and Sexuality Studies at UC Riverside. She wrote *Romancing Human Rights* (2015), co-produced the [Transformative Hope video series](#) (2022), and is on the managing board of [Asian Pacific American Religions Research Initiative](#).

[Cynthia Ling Lee](#) instigates crip, queer, and feminist-of-color interventions through embodied art and scholarship. Her choreography has been presented across North America, Asia, and Europe. Recent publications include writing in the *Michigan Quarterly Review* and *The Routledge Companion to Dance Studies*. Cynthia is Associate Professor of Performance, Play & Design at University of California, Santa Cruz.

[Rachel C. Lee](#) is the author of *The Exquisite Corpse of Asian America* and a professor at UCLA. Currently, her research focuses on frameworks that deepen relationality between individuals with “environmental illness” (e.g., chronic Lyme, multiple chemical sensitivity, heavy-metal intoxication) and scholarship in an anti-racist and anti-colonial vein.

[Megan Moodie](#), a cultural anthropologist, writer, and feminist theorist, is an Associate Professor of Anthropology at the University of California, Santa Cruz. Her recent work on disability, motherhood, and artistic practice has appeared in the *Los Angeles Review of Books*, *Hip Mama*, *MUTHA Magazine*, and *Sapiens*.

[Marina Peterson](#), Professor of Anthropology at University of Texas at Austin, is the author of *Atmospheric Noise* (2021), which traces entanglements of air and body through noise. Her current project “Weathering Uncertainty” composes a nervous system that stitches together the meteorological and the neurological, and in doing so taking up conceptual concerns that are central to COVID in general and long COVID specifically.

[Nikita Simpson](#) is a Lecturer in Anthropology at School of Oriental and African Studies, University of London. Nikita’s research on mental health, care, and inequality has appeared in the *BMJ Global Health*, the *Journal of the Royal Anthropological Institute*, and *Medical Anthropology Quarterly*, amongst other venues. She is preparing a manuscript titled “Tension: Mental Distress and Modern Time.”