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Heavy Hold: A Physical Score

A thesis submitted in partial fulfillment of the requirements for the degree of Master of Fine Arts at Virginia Commonwealth University

By Alx Velozo

Thesis Readers: Guadalupe Maravilla and Kendall Buster

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ABSTRACT

This document is a collection of essays, stories, and fictional interviews that are in conversation with my performance, teaching, and sculpture practice. My research and work considers chronic illness, disability, the historic cultural connection between swamplands and illness, the medical industrial complex, medical theater, the medical gaze, disabled performers, metatactile space, sensory learning, and access.

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INTRODUCTION

My studio currently has two beds (one on the floor and one atop cabinets), 2 rolling body dollies, 2 leaning canes, 1 wheeled walker, 3 chairs, 1 scooter, and 1 wide stool. Over two years I've accumulated these access devices, often out of desperation and other times out of excitement and acceptance to adapt to my new health. Before the world had begun to drag ill on COVID-19's global scale, and we physically entered one another's studios, the beds are the first thing people would comment on. Often in delight, visitors would affirmatively glance and coo things like "oooh, yes! Rest in art spaces!" For able visitors, it seemed that the beds easily collapsed into a symbol of resisting late capitalism's demands and extraction of artists' labors. For rest and horizontality to live in the conceptual and symbolic realm of my studio has not been my reality.

My recent body of work has developed as a response to navigating the medical-industrial complex as a chronically ill and trans person within a school institution. This navigation has led me to research landscapes steeped in illness- specifically histories of the swamp as theorized by Rod Giblett, the history of disabled performance as discussed by Petra Kupper, and other sensory modalities of navigating access, as envisioned by John Lee Clark. In this process, I also delve into the radical queer disability scholarship created by Leah Lakshmi, Johanna Hedva, and Carolyn Lazard. The connections I draw between swamplands, performing disability, and sensory spaces that center disabled access aim towards making my disabled agency explicit in my work.

MIASMA AND THE STATE OF THE SWAMP

In cultural and social imagination, the swamp holds sickness, disease, and the medicalized body in its landscape. The language of the swamp - dismal, unconquerable, and terrifying - persists in contemporary language defining and describing disability in the body (Giblett 106). For the culturally majority, the swamp was historically thought to be the originator of illness and was culturally positioned in opposition to conditions needed for healing. For some of the most marginalized people (including fugitive slaves), the nature of the swamp became a critical site of possibility, escape, and survival.

The association of the swamp with medical illness is over two thousand years old. Until the late 1800s, wetlands were thought to be the progenitor of malaria and other diseases (Giblett 103). The concept of *miasma* as "an unhealthy air rising from the ground," concretized into "the miasmatic theory" and "bad air theory" that persisted until the 1870's. This debunked notion held that "the swamps and marshes [exhaled] malaria, disease, and death" (Giblett 103). By the time the Anopheles mosquito was discovered as the vector of Malaria in 1890 (rather than the "bad air" of the swamp), the miasmatic theory of disease had already solidified the swamp's slimy, diseased reputation in the popular imagination. Germ theory, though eventually adopted and widely accepted, did not manage to sever the perceived connection between the swamp and putrescence, illness, and death (Giblett 103).

I did not have many human possibility models as a young person growing up on occupied Timucua Seminole lands, mapped by settlers as Gainesville, Florida. The town is in the middle of sunken land, otherwise edged with ocean and ocean breeze. It is hot; you organize your summer days (that are not purely organized by labor or discipline) around water. Otherwise, you are holding hot breath in a place of hot breath. I was quiet, queer, and gender-different (soon to be transgenering) inside of a southern town with conservative social norms and few trans or openly queer adults. Instead of searching out human kinship, I let myself be subsumed in the wet landscape. Toes suctioned and slurped, hands hovered over scat to feel for its previous body's warmth; I stomped vibrations into the soil for venom safety while palmettos clapped their blades against one another. I found resonance and an education in the sensations of this ever- in- between landscape.

Thinking Alongside Rod Giblett: A Fictional Interview

Rod Giblett is a scholar who traces historic understandings of swamplands alongside postmodern urban development. Alx is a trans*disciplinary artist and educator that grew up in Florida wetlands with a chronic illness and an interest in slime.

Giblett: *"The horror of the slimy for Sartre was ... associated with the relaxing of solids, [so] for Currie it was part of the horror of malaria. Both entail a slipping away from solidity and from a sense of property and propriety about one's own body, albeit a masculinised one, to something slippery, slimy, evanescent, insubstantial feminised"* (107).

Alx: The material of the swamplands ooze and change - transforming and transitioning the landscape itself. We know our bodies to ooze and change - between genders, between levels of healthfulness and disease. How can a swamp be wet and hot? How can a body be a man and a woman? Alive and ill?

Giblett: *"Not only does the turbidity of swamp waters mean that they mediate between solidity and liquidity (and so violate both these categories), but their stagnancy and hotness violates the qualities of fluidity and coolness generally assigned to waters... wetlands violate the normative qualities of the elements: air should be clear and dry; water, clear and flowing; earth dry and solid"* (108-9).

Alx: When does a body violate category? The culturally productive category is assigned white, cis-male, heterosexually reproductive, and without disease or physical impediment. This category supports the nationalist project of capital growth, population growth and borders. In 1881 the real estate developer Hamilton Disston made the first drainage attempt into the Florida everglades. Although unsuccessful, this paved the way for future endeavors towards expanding housing and cities into this swampland. We took on the modernist project to drain swamps in order to make edges of ownership and land to build houses for nuclear families. We define subjects and bodies by making a landscape that suited those bodies, and those bodies alone.

Giblett: “[the] drainage was to be carried out ‘to the great advantage and strengthening of the nation.’ The colonising and nationalistic aims of drainage were left in no doubt” (110).

Alx: Draining this eco-body into a dry state, a colonizable state, a stable, solid state parallels the modern project of defining a healthy citizen. The project of defining a healthy categorizable citizen is a project of colonialism and nationhood. To be a citizen of a Nation is to fulfill civic duty; to fulfill civic duty is to be well, be working, and be reproducing capital if not children.

Giblett: “I would go even further and suggest that wetlands’ drainage is the landscape change which quintessentially characterizes modernity and modernisation with all its cultural, corporeal and psychological conditions of possibility” (116).

Alx: Perhaps this notion rubs against the conceptual tenets of a place named “uninhabitable” and all its glorious possibility? Maroonage and autonomous communities are historically enmeshed in swampland ecosystems. For example, The Great Dismal Swamp (in the same swampland region from which I created molds of cypress knees) housed thousands of fugitives from enslavement in maroon communities in the 18th and 19th century (Grant 2016). In many southern swamps, including the Timucua land of Florida that I grew up in, indigenous tribes were repeatedly displaced towards the margins of their “habitable land” and many times relocated into swamplands on land that was deemed diseased and unprofitable by white colonizers.

Giblett: “The swamp is none too healthy at any time, and at night it is rank poison” (107).

Alx: Why is a swamp more rank at night? Is it the horror of removing one’s sense of sight? By further delving into the visually unknown, the night swamp puts us into a mythical, venomous, and intimate sensory experience. Without our eyes we must get close to touch and smell.

Gainesville, FL

I grew up digging my fingers through millenia. I was a little too odd and feral for indoor southern social moraes, but I knew the creeks of north Florida. Stomping in the sopped soil to scare the snakes out of my path I descended into creeks strewn with gasping plastic bags, chewing tobacco tins, and the occasional syringe. They were a part of the sewage overflow system in town and I felt at home at these margins of detritus. I parted curtains of Spanish moss and verdant green vines to wade thigh-deep in the trash-filled waters.

By the age eleven I could pick out shark teeth through the glimmer of the surface ripples without sifting. These fossils were a constant reminder that we had been underwater not so long ago. Megalodons had once roved the volume of air where I sheepishly stood and inhaled.

Even without these artifacts, the land constantly ached with water. Floodplains of duckweed caught light and shadow to project itself as solid ground, only to ripple with the deep growl of a nearby gator. The land held a betweenness of material and state that I still belong to.

I spent this year's solstice on the same swampland prairie that I fervently roamed as a kid and was overcome with a sense of belonging to this landscape. As a queer, gender-different person in the swamps of north Florida, most of my childhood was spent discreetly trespassing and quietly wandering. I don't know anyone in Gainesville any longer. My parents and sibling moved out of its reach towards South Carolina and the midwest. Whether it was adolescent discomfort or an ancient kind of mourning in me, returning to Gainesville in a gender-altered body and trying to know the people who had populated my growing-up felt like too vertical a climb from my horizontal spirit. Besides, I'm blessed with this type of belonging I've been given - that a landscape so fully taught me how to be in the body and personhood that I wanted to grow into when the people who surrounded me couldn't. It lessoned me on transness and illness in a way that feels unjust to dredge into language. This is an ode to that hot wet mouth of a landscape.



Prosthesis, process image. 2021

The swamp as a container for illness and sensation permeates my personal history, my installation *Heavy Hold: A Physical Score*, and, most directly, the work *Prosthesis*. *Prosthesis* directly positions the viewer in a swamp landscape. In this piece, 20 amber-colored urethane casts of Cypress knees litter the black linoleum gallery floor, collecting in small groupings to parallel the formations they were found in and molded from in a nearby Virginian Bald Cypress Swamp. The molds were taken from the portion of the knee that is revealed above the water surface. Thus, the dark floor stands in as the surface of the water these knees protrude from. Audience members are repositioned to be rolling, sitting or walking on tannin-dark waters of an imagined swampland. The rubber casts create a play between a swampland state of matter and the built floor, the

architecture both being a body and subsuming the viewers' bodies. Viewers are being supported and suspended in one of Giblett's "horrors of the swamp ecosystem." The solid floor penetrated by these knees mimics the ground of a wetland ecosystem that is in constant shift between liquid and solid. The casted cypress knees imply a depth to the water, while the linoleum supports the viewer's body on the surface of this mimicry.

Scientists have still not fully formulated what these knees biologically support in their cypress trees. It is hypothesized that they help stabilize the large trees in the flooded forests (another definition for a swamp) that they grow in while providing more oxygen and breath to the tree. The knees are a named prosthetic of the swamp, literally hearkening to the swamp as a body. Once placed in the gallery space, these forms become a prosthetic of the architecture. A play on anatomical "knees," they directly reference the swamp as a metaphor for the body while entangling the built architecture into this schema. The room becomes a many-kneed body that viewers are invited to navigate through.

Materializing my experience of breath and breathlessness presents itself in many iterations throughout the exhibition. While *Prosthesis* finds its form in hollow casted rubber, breathlessness is also overtly present in my performances involving disability and illness. Breathlessness has become a potent challenge to materialize. In doctors offices, there are few quantitative measures for the experience and in sculptural material breath is often invisible. In this current body of work I approach materializing breathlessness and supports around breath in arboreal reference (cypress knees) and performance.



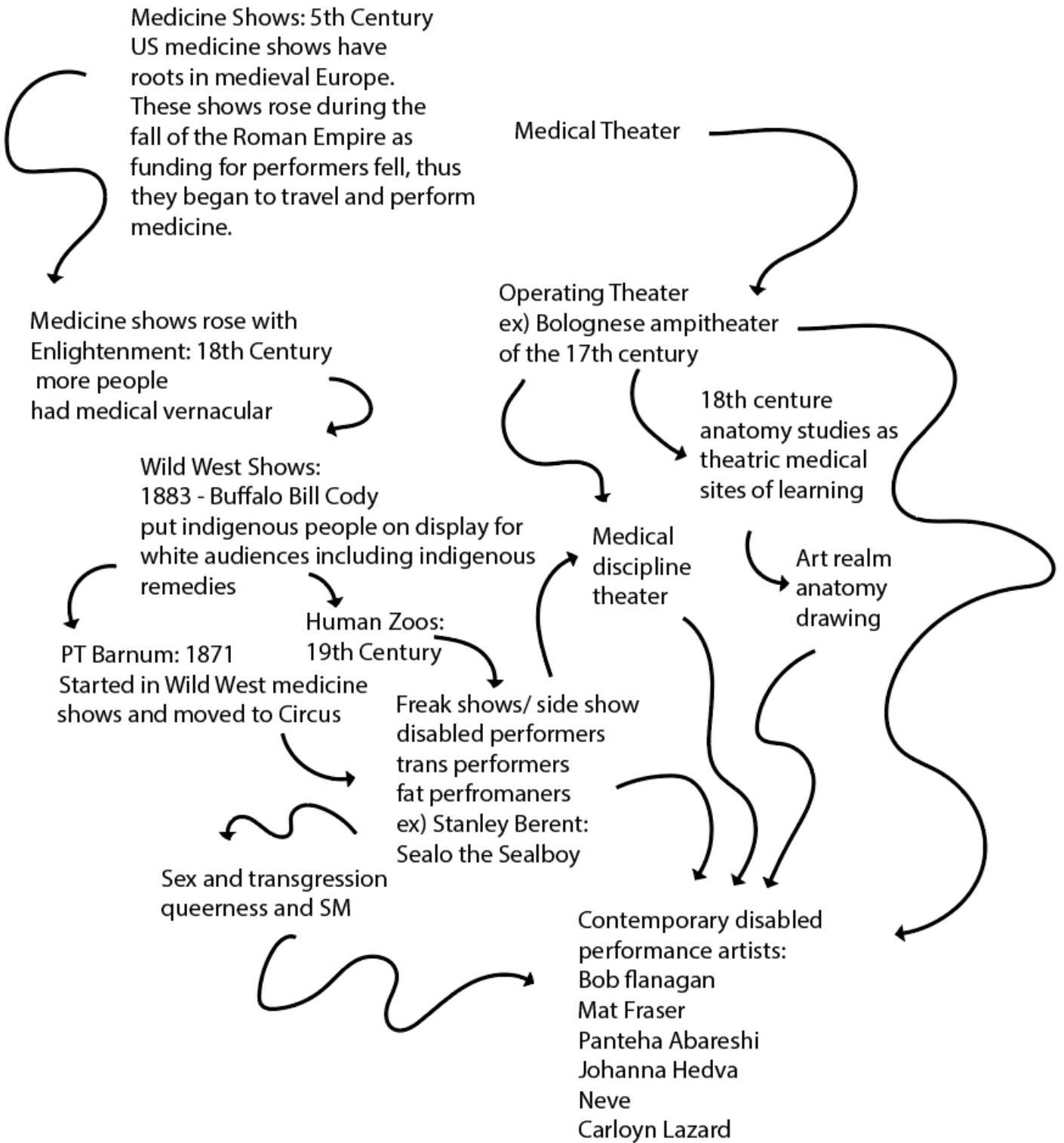
Prosthesis, Urethane Rubber, dimensions variable. 2021

THE MEDICAL GAZE AND DISABLED PERFORMANCE

*When people ask me with an upturned cadence, “Are you feeling better?!” it is not for me, it is for them. No, I am not. No, I may not ever. I find ways to be ok with that. I will not use my energy to make that ok for you. Am I feeling more agency in my choices around my body today? Sometimes, I am. And some days, that feels better.
I consider this as a form of [“Access Intimacy”](#) coined by Mia Mingus*

While the swamp is culturally represented as a sick body of land, performances of disability have historically narrativized illness from the perspective of an able and normative medical gaze. The earliest platforms for disabled performers were culturally created to support the development of the medical industrial complex. The diagram below traces that history.

Tributaries of Medical Performance



Thinking Alongside Petra Kupperts: A Fictional Interview

Petra Kupperts is a disability scholar focusing on the history of disability and performance, specifically focusing on how disabled bodies are made legible. Alx is a disabled performance artist and sculptress who loves to accessorize their outfits, access devices, and gender.

Kupperts: *“Disability theater exposes histories of ‘looking at the disabled.’” (Kupperts 47)*

Alx: This makes the direction of the gaze explicit. What happens when the disabled freak looks back, though?

Kupperts: *“The freak on the early stage becomes the other that serves to heighten self-identity, allowing the audience to disavow and suppress aspects of self, constructing themselves as happy, restrained, appropriate, normal.” (Kupperts; Garland Thomson, 1997; 63)*

Alx: How do we ever construct a “normal” without someone abnormal to compare against? It feels unfortunate that this long standing process encourages us to exile and disavow parts of us and our experience that would otherwise be connective and empathy-building.

Kupperts: *“The rise of the medical system is often linked to the shut-down of the sideshows, as bodily difference becomes a after of medical discipline, and displays become confined to the medical theater... The medical theater is a place of public performance: a body performs its materiality and meaning to a doctor, a specialist, who is empowered to read hidden histories and signs” (Kupperts 37-39; Foucault 1994)*

Alx: As a teen in north Florida, I encountered a specific up-down stare in public spaces. It began at my chest, grazed my hair, then trailed down to my shoes. This experience is familiar to most oth trans people I’m in community with. I think of it marking a stranger’s drive to find legibility on my ambiguous gender. As the effects of my chronic illness surpassed my shame at using assistive mobility devices, I have started getting a new kind of disarticulating stare. It begins where my palm meets the handle of my cane or walker. The public stare is always there, but this also makes me think about what you describe as the “medical stare” (36). When I’m in a doctor’s office, is the intimacy of my nudity and the closed door a hoax?



Follow My Tracks, 3 min excerpt of a 12 min performance, 3 day rest period. 2020



Take it, 12 minute performance, 2 day rest period. 2020

Images Swelled with Water

Hospital basements are full of water. It would seem to be a hygienic taboo for such a hermetically sealed place but it's how the insides come to be conjured into image. To read the tea leaves of this body I lie on a paper- padded table, slime spread across my chest, then abdomen, then genitals in preparation to dredge the images from my depths.

There is no need for windows here. To be distracted by an outside sun would directionally deter us. The fluorescent lights dim to a dusk and a plastic bulb (not far from the vibrating sex toy currently beneath my bed) is pressed and slid against my skin. I let my vision blur as the Ultrasound/ EKG/ Endoscopy/ Oncologist/ Cardio tech interjects the space with thin clicks of the keyboard, capturing my internal vectors for later analysis.

These dark rooms are the most calming in the hospital for me. I interact with no doctors, solely techs and nurses to whom I don't pose a threat of unknowability. We are here to lie quietly and look together. A doctor will later privately contend with their ego while gazing at my distorted innards.

Recently I lowered myself from cold 5 AM air into another dark basement for an MRI scan. From the chuckles of the techs and nurses, I gathered that I was the most excited patient they had seen in recent time. I assumed MRIs were for the rich or the actively dying and was elated to slide into this opportunity through neither of those doors. The MRI would reveal glittering caves of my innards I had yet to see. They were on the search for a third heart valve that was ostensibly lost to previous tests.

In the liminal space of the hospital basement my mind lightly grazed each material of the experience: the nurse's sheer blue hairnet, the marbled red and orange rubber caps suctioned to the vials of blood they drew, the magnetic, heavy breath of the Xray room. Without intention, I mentally reviewed the material of my medical history.

I had been busying myself and a younger sibling in hospital waiting rooms since I was five, when we started to care for my ailing parent. My father's first bone marrow transplant left my brother and I kettled into hallways and stark waiting rooms in order to protect him from our grubby child-germs and us from the sight of him drawing too close to the veil. My mom moved exhaustedly between paid and unpaid social work for the same hospital he lay in.

On the phone, I told my mom excitedly that I was preparing for an MRI and she cackled, "You're beating our Patient in Residence! He never even got one!" I laughed and said, "You got me, I'm medically abundant."

In my mid twenties, my sibling and I found ourselves traipsing back into hospitals for bone marrow testing, having been hesitantly asked by parents if we could be willing to give back our body matter to our father after the most recent set of treatments had failed. His next bone marrow transplant was incidentally but painfully scheduled for my birthday, July 24th.

August 13th I was scheduled for my own surgery after years of litigation, and testifying my transness in courtrooms. The case is recorded as "AV vs The State." My sibling and I both tested as bone marrow haploid matches for my father, but through streaming tears I gasped that I was "so sorry but I needed to be well enough for my own surgery."

My life is medicalized. Most people's lives are, to some degree. I often plug the bathtub while taking a shower and lie face down in the water. It's a soft drowning. In the water, I grope at the agency that I can decide when to be done with this ill body, this ill family, these systems relentlessly matting around these illnesses; or perhaps I am honoring my drive to cope using water, to vision through the current.

It is undoubtedly both.

In my early twenties it was also part of pausing. I kept finding myself welled up in anger and desperation on my subway commutes those years. A transiting time suspended just enough that I would be matriculating the hospital stays, the appointments, the care work... the everything that needed to be done five states below me. Anger at being put on this medical pause. Whether leaving my life in New York to shuttle south and care for my father, clawing through insurance hold lines, sitting in NY Medicaid pews while waiting to testify in front of insurance agency representatives who were telling me I am not applicable for care, or limping on three legs into my own medical appointments, I narrativized myself as being in waiting. This was not my life. I was waiting to feel better, to medically transition, for my family to get better soon.

Following the gauzy blue hair net, I was gently led into the MRI room. One large spaceship with a human-sized hole. The techs situated me with an IV that went in icy while I gazed up at a fluorescent tropic trompe l'oeil oculus. The techs drifted out of the room and behind a glass partition.

My body was slowly but loudly conveyored into the hole. Head phones inside my ears oscillated between the tech's voice checking up on me and a femme AI telling me when I was allowed to breathe. Medical breathplay in a sensory deprivation hole. The hole shuddered with sound around me. Surprisingly mechanical clanking raked an orbit around my flesh. I was kept inside for forty-five minutes but would have stayed the entire day.

The scans from the MRI are hallucinatory renderings of my chest, a heavily contested part of my gendered body. They are seductive and surprising as they shimmer into my own reaches of flesh.

My life is medicalized. It is made of horrific and beautiful medical experiences of illness, family, transness, care, advocacy, and hold lines. These are the waters that have trained how I love, how I care, how I know to cultivate and receive connection. They are not all what I would choose, but they are what has trained me.



Breath Play, video excerpt: 6 min excerpt, 3 hr performance, 4 day rest period. 2021

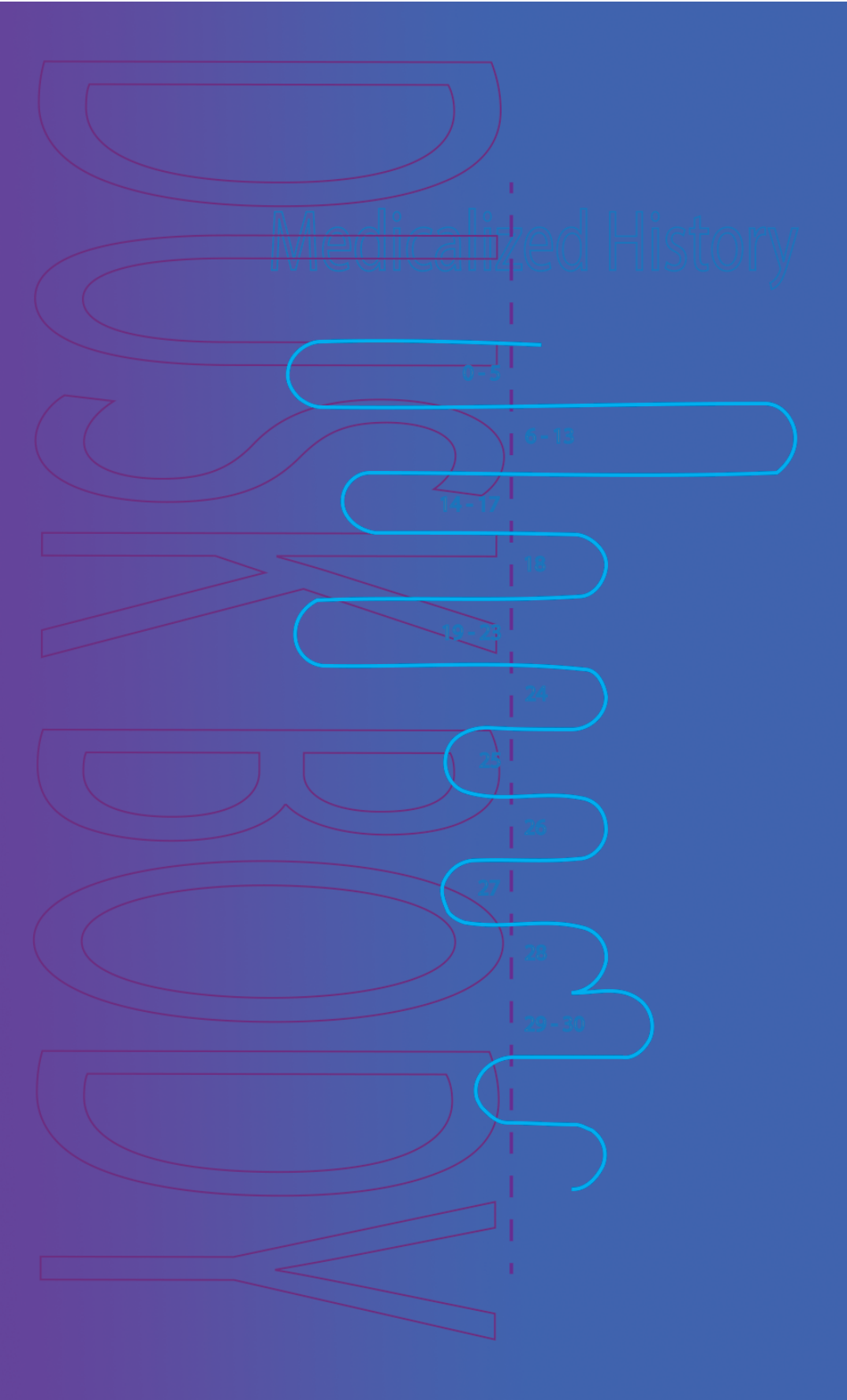
My performances explore the agency of my disabled body and material narratives. *Breath Play*, featured as the primary video in the exhibition *Heavy Hold: A Physical Score* moves through a series of distinct vantage points over a 3 hour performance. Rather than the live nature of *Follow My Tracks* and *Take It*, *Breath Play* was conceptualized and created during the COVID-19 pandemic, and thus performed safely for cameras rather than a live audience. In the video I move through the room in a latex costume that matches the clear off-white balloons, popping balloons and falling into them. The balloons fill the room and physicalize the breath. The video is littered with moments of my own breathlessness, falling, rest, and pain from the popping and the concrete floors on my joints. It sutures a painful sensuality with an exploration of movement and material. In this piece, I choose when to expend my energy, I choose the pain I engage with and the framing and sexualization of that pain.

Gaze and the manner in which the audience is implicated is in direct conversation with Kupper's history of disabled performance. The gaze and audience's complicity is made explicit in my earlier performances *Follow My Tracks* (January 2020) and *Take It* (February 2020). In my first medical performance *Follow My Tracks*, the audience is approached with 4 flashlights each tethered with a white coiled phone cord to the wall opposite to the performance. The audience members are asked if they would be willing to "light my performance" and if they agree are handed a flashlight in the dark room. The floor is covered in a thin layer of corn starch that becomes displaced leaving a record of my movements and cane support as I serpentine the space to a prerecorded audio track that combines hospital hold-line sounds, a pop song, and excerpts from Johanna Hedvah's lecture "Sick Woman Theory." The trace of movement left in the cornstarch functions as a material score for the performance. Both in the title and in the act of shining a flashlight on my and my movements, I ask for the audience to watch me traverse the medical waits, hold lines and physical exhaustion, while also implying that I am being tracked like an animal or something else less than human. Highlighting the audience's gaze in this performance heightens the boundaries between self and other. Inside of Kupper's paradigm I (as a performer) become "the freak on the early stage becom[ing] the other that serves to heighten self-identity" (Kuppers; Garland Thomson, 1997; 63)

In *Take It* we leave *Follow My Track's* dark queer dance club atmosphere to a medical theater stage. The performance opens with me sitting in my walker in a bulky paper patient gown giving my medical history to an implied omnipotent but silent medical worker. I lean my head to expose my ears, open my mouth for an implied tongue depressor and then grab my cane to stand and circle 4 blue surgical curtains hanging vertically on wheeled clothing racks in the center of the room. I turn down the lights and make slow concentric circles around the space I have transformed into a medical theatre. With every few steps I share another medical test aloud, asking the omnipotent doctor if they like to take another stool test from me, or blood test, endoscopy, etc. With each query I strip a medical gown off my body and drop it to the floor. The erotic tone in my voice escalates until I have circled the theater and stripped down to my last patient gown. I wheel the 4 surgical curtains into a shadow box with peep openings and take off my final gown leaving me in a white fishnet bodysuit. The song *Body* by Sinead Harnett rises in the room repeating the line "I'll give you my body / Just don't tell nobody / I'll give you my body / 'Cause being without you is impossible/ Rather be with you and be vulnerable." Audience members at the perimeter of the room can see into the strip tease as I dance with my cane to the song. As the song ends the fluorescent lights abruptly

come up and I exit the surgical curtained box semi nude and breathless. I lean on my walker and answer medical exit questions and schedule my next appointment aloud (in a disappointed tone and 6 months into the future) to the same silent omnipotent medical presence.

In this performance I draw on histories of medical theater and implicate the audience while eroticising my sick experience. This technique can also be found in performances by Dan Flanagan that combine his narrative of illness with SadoMasochistic practices (Musser 126). In *Take It* the audience is not meant to feel at ease with their gaze. I overtly eroticize my past medical tests and my disabled flesh without asking for consent from the audience. This parallels the complicated nature of consent between patients and the medical industrial complex. I will say yes to every test a doctor offers, no matter how intrusive, if it has any promise of diagnosis or medical access. This is a manipulated form of consent, biased along the power disparity between myself and my healthcare practitioners. I intend for viewers to feel complicit in this particular quality of medical consent inside of a chronically ill, yet undiagnosable experience. The manipulation of the audience's gaze shifts between these performances to explore the history and critique of disabled performance outlined in Kupper's work.





Dimness, nonlinear time, ICU Delirium

I have been incessantly bending birthday candles into chain links. I'm not certain the drive. Bending time, looping back on time. I'm experiencing the loop of yet another flare and grope to make meaning of it with my hands in the dim light of my bedridden room.

With that same pull, I recently diagrammed my flares, litigation with insurances, and roles as a mainline caretaker. I absentmindedly scribbled "DUSK BODY" across the page. The line loops horizontally back and forth across a contrived vertical meridian of "health." I looked at the page and thought of a horizon line and a sun that refuses to consistently set or rise. A refusal of diurnal time.

I map spreadsheets each time I am put in the position as caretaker-- whether it is of my own health or assisting a beloved. They map the treatment at hand, the next potential treatment when this one fails, the timeline for getting into an experimental treatment study, the contortions against insurance needed to get into that treatment, when the transplant is, who has the ability to cook and feed the household, what bathroom is cordoned off for chemo spill, when I might be able to walk 3 full blocks again. The spreadsheets quickly disintegrate into the reality of time and illness. I redraft them through frustrated tears and weeks later they are again inapplicable.

One of my beloveds, Emmanuela, has witnessed me repeating this process over the years. Through my frustrated tears she astutely softly coos to me, "I don't think it's about the spreadsheets working, sweetie... This can just be how you take in this time and information. Keep making the charts, but it's ok if they keep failing."

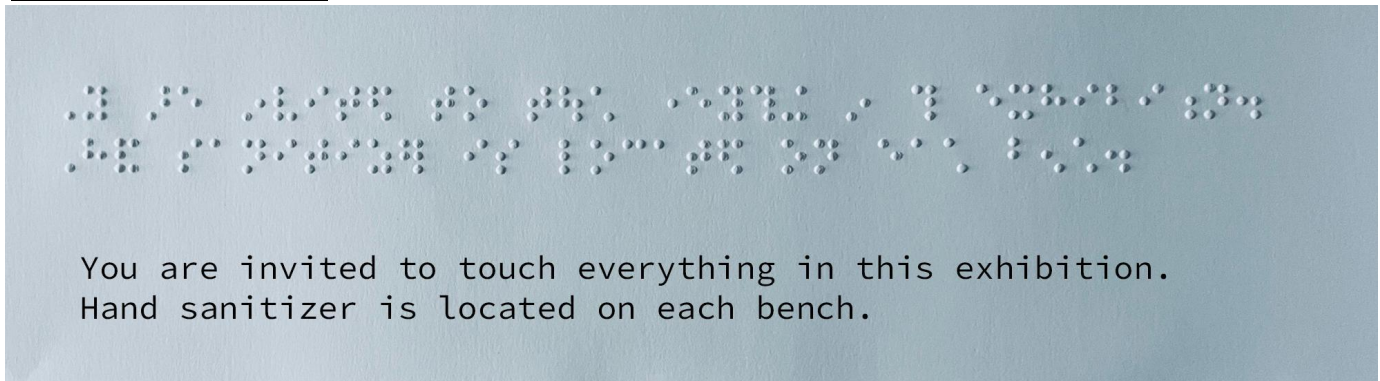
I scramble through these charts as my father is held for the third time in the ICU. There are no windows and the lights are never turned off in this ward. Patients often experience something called "ICU delirium," where they are unable to hold shifting time. The lights stay on to measure and surveil the failing bodies. To desperately contain them in the light of knowing. Contrast ink is lved in. Images are taken by shoving light through flesh. Light envelopes the body for maximum visibility. No shadows.

I love when my body drags as diurnal. Syncs with the rising and setting sun. Wakes with enough energy to stand and shuffle into the day. These periods come and then slowly bend into a ravenous fatigue. Breathless exhaustion that swallows days and weeks. Sitting upright becomes the drag performance of a health that I don't live in.

*So, I'll **revel** in my dusk - transitional light less meant for sight.*



METATACTILE SPACE



Signage throughout the exhibition *Heavy Hold: A Physical Score*

Thinking Alongside John Lee Clark: A Fictional Interview

John Lee Clark is a DeafBlind poet theorizing on sensation and disability, education, distantism, and Protactile space. Alx is a K-12 educator, chronically ill artist who deeply prefers kinesthetic teaching and learning.

Clark: *"Distantism refers to the privileging of the distant sense of hearing and vision"*

Alx: Thanks for introducing this term and defining it. Once your writing made me familiar with this term I find myself using it often in conversation. It is helpful to have a succinct and clear way to name such a culturally ingrained sensory prioritization.

Clark: *"We can see in the record how distantism set in, and how hearing and sighted people wanted things to look right. It didn't look good when we went around 'groping in the dark.' It didn't look good for us to cluster together and have too much fun. Education meant we had to sit behind a desk"*

Alx: I find that education spaces constantly reflect these inaccessible preferences. Teaching practices that allow for "groping in the dark" feel obviously nonnegotiable access points for DeafBlind learners, and also benefit the body minds of students with other abilities and disabilities. I also appreciate how you bring in a sense of critical play and how this is often removed from education spaces.

Clark: *"There are distantist modes of touch and there are protactile modes of touch. A distantist cannot truly teach or empower our children to live and lean as tactile people. Yet the field of education of DeafBlind children has never included us as teachers. Why is that?"*

Alx: This feels really important to acknowledge. I do not have a Deaf or Blind experience but your work resonates with me as a framework for thinking through the sensory-assumptive frameworks of physical and social environments. This becomes wildly explicit in teaching environments. I also

want to lift up and express appreciation for the incredibly rich knowledge discourse DeafBlind communities have created through in-community learning.

Clark: *"...metatactile knowledge. It involves feeling being felt... It involves many senses, senses that we all have but which are almost never mentioned---- the axial, locomotive, kinesthetic, vestibular... all 'tactile' to some extent but going beyond 'touch.'*



Grope Key, Video, Monitor, silicone rubber, metal hardware, dimensions variable. 2021



Grove, silicone rubber, metal hardware, dimensions variable. 2021

When speaking about disabled performance Petra Kuppers outlines the lineage of the word “grotesque” a term often used to describe the disabled performers of freakshows and medical sideshows. She states that “the word ‘grotesque’ stems from the latin for Rome’s ‘grottos’ hidden places, caves, places where the aesthetic eye can rest from order, symmetry, and can lose itself in the folds...” (45) This etymology de-prioritizes visual aesthetics to pull the reader into a realm of the closer senses; the touch, smell, and taste of the folds. In connecting disabled performance with the “grotesque,” Kuppers begins to bridge sensory learning with accessible pedagogy and disabled performance.

My installation *Grope* investigates the ways in which kinesthesia, material, and architecture are co-constitutive of cultural imaginations of subjecthood. In the gallery space, over 100 soft silicone-casted brightly marbled rockwall holds are installed at 40 inches or lower—a height that I can reach from sitting on the floor or scooting on my “body dollie” (which I use to produce work in my studio due to mobility limitations). A small monitor tilts upward from a corner of the installation as a “key” to the materialized performance score. It plays a recorded excerpt of me installing *Grope* with my dollie. I slowly scoot across the corners, touching the walls and using my body to determine the distance between holds. These soft holds score my disabled movement in the space by marking my touch and failing supports in the space. The silicone grabs were molded off of prefabricated holds along with forms custom to my own hands and desire. These soft casted rubber holds fail at holding weight towards a vertical climb and instead indicate lateral touch and movement across the floor and periphery of the gallery space.

This installation subverts the dominant privileging of vertical and able bodies oriented around visual knowledge production (a “distantist” sensation model, as coined by John Lee Clark). Instead, the work speculates on spatialization, objects, and performances that prioritize sick, disabled, horizontally-oriented bodies grounded in tactile and kinesthetic knowledge production. This critical horizontality extends beyond space orientation to become a speculative schema for lateral care networks (Lakshmi 10), political organizing webs, and crip time (Lazard 3).

CONCLUSION

My work started in the swamplands of north Florida and approaches my experience of illness, disability, and underlying need to find access in a fundamentally inaccessible institution. I approach this by transitioning the landscape of the gallery space into a horizontally oriented installation of wetlands and touch. While much of this work used my own body and chronically ill experience as the subject, with all hope this research will extend to support future collaborative educational projects. I hope to further explore sensory landscapes and disabled agency as I grow into this body of work.

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EMBEDDED EMBODIED METAPHOR APPENDIX: I'm asking you to pause before using sickness or disability as a metaphor. Here is a resource for that pause.

EMBEDDED EMBODIED METAPHORS

Arcing metaphor	Use / Definitions / Origins	Alternatives
Lame as value metaphor	Refers to people with physical or mobility disabilities	<i>Boring, uninteresting, monotonous, lacks excitement, uncool, out of fashion, frustrating, ignorant, not-my-thing</i>
Blind as Metaphor	Blind to _____ / turn a blind eye to _____ / blinded by ignorance/bigotry/etc. / double-blind review : Refers to Blind, low-vision, or sight-limited people	<i>willfully ignorant, deliberately ignoring, turning their back on, overcome by prejudice, doubly anonymous, had every reason to know, feigned ignorance</i>
Deaf as Metaphor	Deaf to _____ / turn a deaf ear to _____ / etc.	<i>willfully ignorant, deliberately ignoring, turning their back on, had every reason to know, feigned ignorance</i>
Addiction as Metaphor	I'm so Addicted to _____	<i>I love, I'm obsessed with, I'm enthralled in</i>
Mental or psychiatric disability or diagnosis as a metaphor	<i>Crazy/ Cuckoo/ Loony/ Bonkers/ Lunatic/ Mad/ Insane/ Maniac/ Nuts/ Psycho/ Whacko/ Insane/ Deranged/</i> Includes using diagnoses as metaphors: <i>OCD/ Schizo/ Bi-Polar/ Manic</i> : Refers to people with mental or psychiatric disabilities.	<i>wild, confusing, unpredictable, impulsive, reckless, fearless, lives on the edge, thrill-seeker, risk-taker, out of control, frantic, neat/ picky/ militant/ polished/ clean/ observant/ tedious</i> <i>Angry/ Enraged/ unbalanced/ peculiar/ up and down/ inconsistent</i>
Body Size as metaphor	<i>Morbidly Obese/ Obese</i> : Refers to fat people/people of size. Note that for many fat activists, it's often acceptable to use the word "fat" as a description, so long as it's not used as a pejorative in and of itself.	<i>fat person, person of size</i>
Intellectual disability as a metaphor	<i>Idiot(ic)/ Imbecile/ Moron/ Mouth-Breather/ Retard/ Short Bus/ Stupid/ Dumb (derived from "deaf & dumb")</i> : Refers to people with intellectual disabilities	<i>Uninformed, reckless, impulsive, ignorant, risk-taking, feckless, narrow-minded, dipshit</i>
Disabled movement as metaphor	<i>Spaz</i> : derived from cerebral palsy	<i>klutzy, clumsy, forgetful, impulsive, reckless</i>

Cripple as a Metaphor	Cripple/Crippled (by _____) : Refers to people with physical or mobility disabilities.	Frozen by, stopped by, completely stuck, totally halted all operations
Disability	Special needs/Differently abled/ Handicapped/	Disabled person
Mobility disability as a metaphor	Bound to a wheelchair, Confined to a wheelchair/ bed etc Bound/ Confined to the bed	uses a wheelchair, wheelchair-user, in a wheelchair, began using a wheelchair, needs or requires a wheelchair, is a full-time wheelchair-user In bed
Suffering in Illness as a metaphor	"Suffers" from [x illness/ x disability] : sick & disabled people get to self define full spectrums of experiences with their illness	Someone has or experiences [x illness/ x disability]
Standing and walking as a metaphor	Stand for a cause/ stand in solidarity/ Step up	I am in solidarity, move forward/ move back
Paralysis as a metaphor	I feel Paralyzed/ Paralyzed by fear	I feel stuck, I froze
		***many of these definitions and alternatives were adapted from Lydia X Z Brown's blog "Austichoya" and Nik Moreno's zine "This Not That" ***

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