Quantities and Qualities:
Embodied Encounters with Genetic Disorder

by

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Abstract

This research investigates the possibility of communicating human experience from, through and to the body. While investigating the experience of my own genetic disorder I will examine the dominant discourse on the subject and how it might be subverted, shifted or avoided as required in order to grasp this ineffable phenomenon as a patient. Methods of movement observation and embodied filmmaking will be used to explore the clinical environment during the course of my own treatment. If we put aside discussions of probability and risk, cause and effect, how can we characterize genetic disorder? What is the nature of the experience and how does it relate to the body? How can art, and specifically physical practices of film and movement, establish a fruitful interdisciplinary exchange with medicine on the subject of patient experiences?

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Dedication

To the memory of my father,
Dr. J. D. MacLean

Table of Contents

List of Figures

An eternal dream
Takes form for a moment,
Then goes back to the fields,
Back to the mountains.
– Lee Ufan[1]

Chapter 1: Introduction

> Art, technology, and even science seem to me three veils for the same face, three metaphors that cover, then dissolve, into a single reality. (Davis 187)

This project explores my experience of being diagnosed with a pre-symptomatic genetic disorder, and subsequent testing and treatment in various hospitals. CHROMO attempts to interpret and circumvent intangible information about states of risk, wholeness and fracture, as represented in contemporary genetic era clinical protocols and discourse. CHROMO is a practice-based research project located at the intersection of film, installation and movement study. Two works precede CHROMO: the first, CHROMO 1, is a performative re-embodiment of my own medical scans on film and shown as a dual-screen expanded cinema performance. The second installation, CHROMO 2, features a circular video projection on the floor, and seating in the round. The video contains cymatic resonance experiments with the percussive sounds of an MRI machine via particles vibrating on a cymbal. In CHROMO, the final work, the spatial and tonal qualities of the hospital environment itself are explored. Dancers perform routine postures, and the camera itself expands, contracts and creates the space, offering

[1] (Qtd. in Yi and Anderson 211).

opportunities for kinesthetic empathy within the audience encounter. The body is singular and multiple, it enters and exits, waits and watches, is hidden and revealed. The work is contextualized theoretically within movement studies and phenomenology and offers ties to new clinical practices such as narrative and personalized medicine.

On a personal level, the goal of this exploration is to foster a sense of agency and bodily presence during diagnostic procedures and treatment. Can the dominant genetic narrative that speaks of numeric odds and risk levels be complemented by an artistic and personal consideration of possibility and agency? How can we perform, express or communicate the experience of genetic disorder and health risk?

What follows is an account of the background, theoretical framework and methodology that I developed for this project, and a description of the work itself. I will address various aspects and challenges of my experience of diagnostic tests and medical imaging, clinical examination, hospitalization and the qualities and affects of the hospital environment itself: its textures and shades, pace, sensory affects, affordances and community. As I worked through the sections of this series, these explorations mirrored my lived experience, which changed month to month as my health status evolved. In retrospect I am able to identify that the phenomenon of waiting, of uncertainty and repetition without apparent progress created the arc of this series.

Through the making of CHROMO 1 & 2 my asymptomatic genetic disorder prompted a consideration of abstract risk factors. These two works were an attempt to grasp the implications of this diagnosis, and provide some sort of tangible grounding for this experience. My thesis work, entitled simply CHROMO was to be a third part of the

series. I had initially intended to depict metaphoric visualizations of the interconnection and intersubjectivity of bodies, health populations, families and people circulating within medical spheres.

By the time I reached CHROMO 3 however, I was surprised to be confronted with the diagnosis of a tumour, signaling a tangible, physiologically identifiable disease. This "medical outcome" (to use the telling common parlance), initially brought with it what seemed to be an anchor narrative resolution. This development seemed, at first, to promise an experiential shift from my genetic disorder's immaterial, looping abstraction to a different space created by the physical aspects of treatment of disease. My body required surgical and pharmacological interventions, but surprisingly I came to feel that my experience of disease – its familiar testing and waiting cycle, the language of the clinic – was in fact very similar to my previous experience of having a genetic disorder without symptoms.

The series' methods and creative approaches held fast throughout this change, and served this new phase well. They have helped to mitigate the powerful pull of a narrative that suggests that this illness is an appropriate outcome of my cycle of waiting. The concrete diagnosis quickly ceded, however, to a new cycle of waiting and uncertainty, a continuation of the experience rather than a separation. As a third act, from a narrative standpoint, illness and treatment seem strangely appropriate. Instead, I am invoking themes of interconnectivity, of shared bodily presence using embodied experience as my material rather than metaphoric visualization. It is satisfying to conclude that the results of this choice are successful in CHROMO as well as appropriate and authentic to my

embodied experience.

Medical Film

While attending the Medical Film Symposium in Philadelphia in 2010, I had the opportunity to hear filmmaker Barbara Hammer speak to the assembled group of artists, archivists and scientists. She presented her film "Sanctus" featuring the filmed, motion X-ray films of James Sibley Watson (remarkable at once for their beauty and the implicit horror of the inadvertent irradiation of the filmed participants), and her autobiographical cancer survival film "A Horse is Not a Metaphor". In the latter, Hammer uses her art practice in the clinic itself, shooting video during her own treatment. This act of sharing images of her body and illness struck me as very brave and transgressive. What I have discovered while shooting film in hospitals during my own treatment is that it can lend a powerful sense of meaning and active presence to the experience itself. Hammer spoke about her experience, and her distress at the limited presence of human touch in her clinical treatment ("Medical Film Symposium").

What was particularly remarkable about this experience, beyond the engaging and thoughtful reflections of the artist herself, was the context. The Medical Film Symposium was a unique combination of academic presentations by a mix of medical historians, filmmakers, artists, doctors, film archivists, scientists, film collectors, radiologists… all bound by an interest in "medical film". This interdisciplinary experience was unique and seemed to open up a world of possibility. The film genre itself is a mix of medical-themed fiction and non-fiction films, documentaries, training and educational films, clinical vignettes, art, and even medical imaging. To consider medical moving image

culture with a diverse mix of people, texts and materials, not separated by discipline or function, was a revelation. It enriches the study of medical communication as well as modeling a fruitful interdisciplinary collaboration. The experience of this conference and exposure to Barbara Hammer's methods and work helped me shape my own approach to the use of my medical images and the sharing of experience.

Pheochromocytoma

The decision to disclose the name and nature of my illness was not a foregone conclusion. Throughout this project I have wondered if the act of naming and describing this condition could inadvertently suggest that I intend my experience to stand in for that of a larger group of people, which is decidedly not the case. It also troubles me that this research could be coloured by preconceived notions about cancer, which unlike genetic rhetoric, I do not plan to deconstruct in this paper[2]. Finally, this condition is very difficult to define. Ultimately I am opting to share the details because I think this rare and unusual disease provides a rather unique model of medical uncertainty and inconclusiveness. As such it lends itself well to my wider philosophical questions about genetic determinism, embodied agency and possibility. The medical condition I am exploring is a high-risk, rare genetic disorder that requires vigilant life-long monitoring. This watchful-waiting phenomenon cannot be reconciled with a narrative expectation of conclusion or resolution.

[2] Susan Sontag's *Illness as Metaphor* was influential to my research and a useful complement to my inquiry into genetic rhetoric, but I do not take up the problematic thematization of cancer in this paper.

Five years ago I was diagnosed with a genetic disorder that predisposes me to a type of neuroendocrine tumours called pheochromocytomas[3].My testing was not prompted by symptoms of disease. A cousin had the illness and eventually within her treatment a genetic disorder was suspected and confirmed. The gene was traced through the family tree and I tested positive. The tumours themselves are often called "the great mimic" as their telltale symptoms are hypertension, headaches, anxiety, sweating, and heart palpitations – all easily misdiagnosed. In the general population they are rarely malignant, but my particular genetic disorder makes them significantly more frequent and dangerous. The tumours themselves do not have recognizable pathological markers of malignancy so the only way to find out that they are malignant is in retrospect, if they have spread. Treatment options are somewhat limited, they resist certain cancer therapies, and surgery is ideal when possible. They trigger the release of stress hormones (which cause the symptoms listed above) and can cause catastrophic hypertensive crisis. Those who have these tumours can experience these symptoms very regularly and be in and out of emergency rooms. A simple colloquial description of these events could be to characterize them as an extreme and at times unrelenting episode of the "fight or flight" response. I have not had those symptoms regardless of my tumour.

As the disease is so rare, many report difficulty in finding appropriate care and may be treated for other suspected conditions or referred to therapists if this is mistaken for other diseases, anxiety disorders for instance.

[3] There are actually two types of tumours involved: *pheochromocytomas* occur on the adrenal glands, while *paragangliomas* arise elsewhere in the body. For simplicity's sake I use *pheochromocytoma* here as an umbrella term for both, a shorthand that occurs in the medical research as well.

Since I was diagnosed with the genetic disorder that predisposes me to these tumours I have undergone regular testing and monitoring. My thesis was intended to address that experience alone. Near the end of 2012, however, my annual scans revealed that I had a tumour, and its location and size suggested it should be surgically removed immediately. I had successful surgery three months later and now I am back to a testing and waiting pattern, with enhanced monitoring for recurrence of my tumour, but otherwise familiar routines.

The key things I wish to underscore are the following. Most importantly, the account of my experience in this research is *not* intended to reflect the experience of other patients with my disorder or disease. I am a member of several online patient support groups that feature daily stories of unimaginable suffering, struggle and bravery. I am exceedingly aware that I have been very fortunate thus far. Secondly, I have access to the best available treatment at no financial cost. If I did not have access to these resources my experience would be entirely different.

The CHROMO project has significant practical, personal implications and goals in regards to finding a resonant and effective mode of engaging with my ongoing medical experience. I therefore set out to formalize my approach to filmmaking, material exploration and movement observation in this project. I will proceed to problematize the use of risk calculations, and investigate the status of the body in genetic discourse and clinical practices. I must continue to use and accept many of the operational concepts that I critique to guide my own treatment however. This requires an attempt to separate the discursive failures from the intentions and actions of the considerate, empathetic medical

professionals who provide my care. At issue in this study is the position and qualities of my embodied presence in this experience. I will attempt to discover the characteristics of my engagement with the environment, and address some of the dilemmas involved in navigating this realm as a patient.

Chapter 2: Background

My previous experimental films have often involved explorations of brief human gestures in found or filmed footage. In one such work, my 16mm film *Chute* (2009), I filmed an older male runner at the end of a marathon, as he walked ahead of me wearing an otherworldly post-run silver space blanket for warmth, with his arm on his daughter's shoulder. I looped the moment when he removed his hand, isolating and emphasizing the point of disconnection and release, as it struck me as very poignant[4]. This mode of documentary-style film shooting, selection of evocative fragments, and looping in the final edit to underscore a human physical or vocal gesture, is characteristic of my work.

Trouble Leaving

The body of art that directly led to CHROMO explored the clinical experience of both patients and caregivers through movement and embodiment. I had recently spent many hours and days at the hospital bedsides of two family members, and was struck by the physicality of those experiences. After the fact, certain ways of sitting and particular gestures could immediately place me back in that timeless, suspended world. When visiting the hospital we join a community that can be at times characterized by deep and

[4] My father had passed away just a few months prior.

immediate understanding amongst strangers. Yet once we leave that realm we may find ourselves at a loss for how to express the experience. The traces I carried were physical: task-oriented gestures such as the acts of straightening bed linens and adjusting pillows, tactile sensations of various surfaces, the endless entering and exiting of rooms, and the specific lingering muscle strains from maintaining specific seated postures of attendance and stillness.

The first piece that explored this experience was a slide show entitled *Trouble Leaving*. The title alludes to the difficulty of leaving the time, space and presence of patients, both at the end of each day and on the final day. It also refers to the troubled departures of those who are dying.

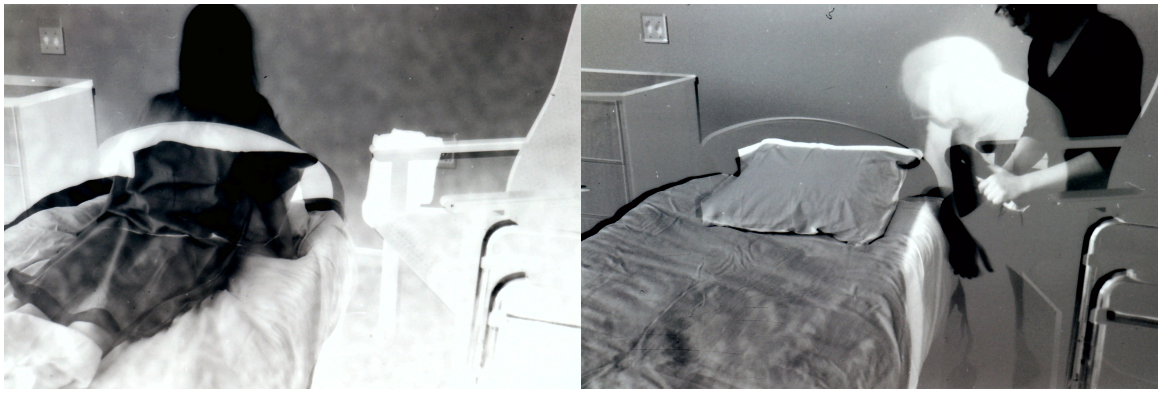

Figure 1. *Trouble Leaving* – Two 35mm slides

Staging a photo shoot in a long-term care facility allowed me to re-inhabit physical postures and gestures in that setting, which I photographed on black and white 35mm film. I embody the roles of both patient and caregiver/visitor, who subsequently never appear together on the screen. The negatives were printed as a roll of film at Niagara

Custom Lab[5], rather than typical photographic negative strips, and a positive film print was then struck. I cut out frames and layered multiples in each slide mount, creating stills that contained shadow traces of movements and a blend of these negative and positive images – stills containing multiple points in time. The figures alternately appear (as enacted by me in the photos), become light or dark, multiply or are absent from the frame. In performance, dual slide projectors are used to animate the material very slowly. Referring back to my earlier practice of working with isolated, slowed and looped time, *Trouble Leaving* possessed the qualities of a film projected at one frame per second.

While originally envisioned as an installation that would be automated to run infinitely by itself, technical issues arose with the slide projectors and I had to advance the slides manually when I first showed the work in class. This performance provoked a key shift in my practice. I discovered that being present and showing this material by hand added jointly to the sense of risk and immediacy for the audience, creating an active and demanding experience. *Trouble Leaving* represents the first iteration of the movement exploration work and performance style that came to characterize my wider approach to these themes.

Noteworthy as well is the specific movement style I employed in the advancing of slides. As a culmination of the physical and emotional difficulty of executing this project[6], I found myself pressing the slide projector buttons forcefully. Coupled with the noisy mechanics of the machines themselves, this created an intensity of energy that

[5] A Toronto motion picture film lab for artists that has supported my work and explorations for many years.
[6] One of the hospital experiences that inspired the piece had ended just a few months prior, and the residual physical sensations were still very present.

interrupted the contemplative nature of the photography. This embodied physicality of traumatic experience and mode of energetic movement recurs in particular sections of camera work in CHROMO, unbeknownst to me at the time it also reflects a recurring style in my personal movement preferences. *Trouble Leaving* also represented my first foray into the concept of Kinesthetic Empathy, which I will expand upon further in relation to the creation of CHROMO.

In order to contextualize my position and my process for CHROMO, it is necessary to provide an account of the practice-based research that preceded the final work. Before deciding to intentionally bracket genetic rhetoric and clinical politics in order to conceive of new possibilities, I delved into that literature while creating two preliminary works. Initially conceived as a three part series, I will refer here to CHROMO 1 and CHROMO 2. When the final work branched off in form and content, in part because my health status changed, it became an independent piece. I stopped calling it CHROMO 3 and it is now simply CHROMO, shifting the status of the first two works to that of a sort of prequel. They remain an informative complement to this thesis work and now function as a two-part performance work[7]. What follows is an account of the development of CHROMO 1 & 2 and the literature review that led to the theoretical framework of my thesis research. Through the making of CHROMO 1 & 2 my asymptomatic genetic disorder prompted a consideration of abstract risk factors. These two works were an attempt to materially grasp, feel and absorb the experience of occupying this uncertain realm.

[7] They were first shown as a pair of projector performances in London, Ontario on August 29, 2012 – presented by Sweet Magic London & McIntosh Gallery.

CHROMO 1: Rhetoric & Resonance

> When looking for perspective—of one sort or another…(h)ow does the haze of possibility manifest—in which way, in which direction, and with what selected attention? Or does the direction itself determine the way… wait(ing) for the wandering idols of already congealed meaning to tell it which way to go…? Is looking not itself Icarian— a fall from the sanctity of understanding into the cascade of perspectival variation: patterns coming and going, uncertainties and stories and possibilities and truths and falsities and manifestations both realized and denied? Interference... invisible perspectives, hidden perspectives, suddenly manifest despite their own impossibilities. (Hiebert 103)

My thesis began with the aim of expressing my specific experience of genetic disorder in the absence of disease. Well into the project, my status changed when what was formerly an abstract disorder manifested itself as a tangible disease and re-shaped my trajectory. So while I have contemplated this genetic disorder for five years, I am new to the realm of the illness itself. Nevertheless the genetic disorder continues to shape the course of my treatment and the calculation of my individual risk. It requires life-long medical monitoring that guarantees my continued presence in this clinical cycle. The unusual nature and rarity of the disease itself presents difficulties of categorization and comprehension. This lends it an indefinable quality and seems to prevent a certain type of concrete meaning making. Both the genetic disorder and the disease seem to be highly resistant to easy explanation. As a result there is surprising continuity in terms of the questions raised and the qualities of the experience itself. The differences serve to highlight the similarities and vice versa. The boundary between the two experiences is slippery, despite the rather drastic change from a clinical point of view.

I would not suggest that genetic disorder and disease are the same type of phenomenon. Due in part to the particular ethical issues surrounding genetics, they

occupy a unique place in our cultural imagination. Genetic psychologists Macleod, Craufurd and Booth would seem to corroborate that clinical practitioners make this distinction as well:

> It has been argued that the dilemmas raised by genetic disease are *qualitatively* different from those raised by non-genetic diseases… genetic tests can also predict future events in the life of a person who may not yet be experiencing any form of ill health or symptoms…this raises questions about individuals' perceptions of their own bodies, or indeed future bodies. (126)

When genetic testing and diagnosis are performed, invariably a genetic counselor is involved to explain the unique implications of the test and its result. This protocol is not enacted in the case of diseases diagnosed in the clinic, even in cases with strong indications of hereditary factors. Genetic diagnosis is seen to require an active intervention and interpretation to help patients navigate the complexities they face.

The discoveries I made during the early phase of practice-based research and art making, while considering my genetic disorder, determined the direction of my final thesis work. The theoretical approach also remained fitting despite the seemingly abrupt transition in my health status. The contemplation of the state of illness was enriched by its beginnings in explorations of genetic determinism and clinical power dynamics.

Ultimately the choice to set those discourses aside was informed by their explanatory failures when held up alongside my experience as a patient with a genetic disorder. I have found that the physical manifestation of illness with a specific location in my body has not radically shifted the clinic's explanatory language. The conversation can seem like a bounded discourse of risk and probability, cause and effect. Instead of provoking the radical discursive re-alignment that one might expect, at times it simply

appeared to shuffle my case forward in a linear fashion along a seemingly narrowing field of probabilities (one assumes towards a final negative outcome). The well-intentioned resident who informed me that I had a tumour responded to my initial confusion (I believe I asked "what does this mean?") with the reply, "this is good, we knew this would happen and now it has happened." Her statement was clearly meant to be reassuring and not an existential riddle for me to attempt to solve for weeks (…we knew?). The manner in which this seamlessly positioned cancer as a plot point within a natural narrative arc of my genetic disorder highlights some of the shortcomings of our explanatory language. This sort of linear, causal narrative may be diametrically opposed to a patient's lived experience and limit their sense of agency and potential.

Our Western approach to understanding our health often would seem to boil down to positivist concepts of probability and risk. We may attempt to locate our numeric "percent chances of" or try to grapple with the likelihood of being the unlucky "one out of" a specific size of population who will develop a given illness. In our eagerness to avoid an unlucky outcome ourselves we may seek to characterize illness as some sort of individual, even moral, failing. Susan Sontag's *Illness as Metaphor* elucidates the ways that illness can become thematized as an "inner failing (that) puts onus of the disease on the patient" (47). It is difficult to disrupt this discourse and replace the desire for quantifiable, "real" determinations about our health with an equally compelling alternative. All medical opinions rely on a host of slippery factors and defy complete finality, but how do we integrate this uncertainty and contingency into our lives?

My genetic mutation is materialized in every one of my cells, abstract though that remains to me. This vague and invisible reality has become a tangible experience however. I have spent a vast amount of time going to hospitals so that my body can be tested, sampled, scanned, examined, and surveilled. This experience has caused a shift in my sense of bodily wholeness, composition and solidity.

Our genetic discoveries seem to have resulted in a certain enchantment with the notion that all is knowable, and perhaps can be controlled. In the words of Nobel-winning geneticist James Watson "We used to think our fate was in the stars. Now we know, in large measure, our fate is in our genes" (Jaroff 1989). This sort of re-assignment of control over our fates spawned an explosion of metaphors, positioning the gene as the secret or code of life itself, a computer, the book of everything – an entity that determines our health and even perhaps our behaviour. Nicholas and Hilary Rose wrote, in *Genes, Cells and Brains: The Promethian Promises of the New Biology*, of the "gene sequencers' failure to recognize the sheer complexity of humans as biosocial creatures shaped by evolutionary and social history" (2). Typical of other members of the radical science movement[8], the Roses undertake an interdisciplinary analysis (he is a neuroscientist and she is a feminist social scientist) to reveal and dissect the technoscientific utopianism that underlies genetic rhetoric. This scientific progress has not developed in isolation from commercial and political interests, and they highlight that context and the ideological

[8] Founded by scientists who were outraged by the misuse of science for the development of biological weapons during the Vietnam War, this international movement called for a science for the people and for peace. They shared a concern about the possibility of dangerous future applications of genetic discoveries. The movement included paleontologist Steven Jay Gould, geneticist Richard Lewontin amongst others, and helped lead to legitimization of the "social production of scientific knowledge" within academia. (Rose & Rose, 5-9)

underpinnings of the discourse. Rather than analyze the sociopolitical origins of genetic rhetoric, my work attempts to find resonant alternatives located within my own experience.

In his book *On Beyond Living: Rhetorical Transformations of the Life Sciences*, Richard Doyle asks what it is we now mean when we refer to and study "life". He characterizes the formulation of the body that has emerged from the "complex relations between the practices of rhetoric and the technoscientific triumphs they accompanied" and claims that this "'postvital' biology … increasingly elides and questions the boundary between organisms and machines" (68). This reference to unstable boundaries between body and machine speaks to my own fluctuating sensations of solidity and (im)permanence while submitting to inner examination by enormous medical imaging equipment. Huge machines passed invisible waves though my ordinarily non-transparent body, therein to resonate off of my various inner densities and properties. I was injected with contrast dye and swallowed barium and iodine pills. When radiologists were kind and compassionate towards me I was tempted at times to assure them "it's okay, I'm not sick." That instinct made me wonder whether I understood the relative seriousness of my situation that seemed to be suggested by the heft and significance of the machines and environment.

At a conference organized by Subtle Technologies called "The Art and Science of the Brain" held at the Centre for Brain and Mind at Western University in October 2011, I had the opportunity to make a sound recording of an MRI machine while Adam McLean, one of the Centre's researchers, put it through its paces. The MRI is the most sensorially

impactful of the range of scans I have had. Patients are inserted into a small space within a huge magnet that emits various patterns of forceful and very loud radio frequency magnetic fields. These intense vibratory tones are felt viscerally and spatially in the body, which itself is prevented from moving. Being in an MRI for as long as 90 minutes per session gave me time to contemplate the effect of the test on my very atoms[9].

The boundaries of my body seem porous in that small, dark enclosure with forces passing through my body. I no longer experienced my body as a solid, fixed entity. While straps and foam blocks prevented me from moving and instructions such as "don't move, don't swallow" came through speakers in the machine, I realized I was not actually still. My breath expanded my chest to the sides and front, as my back pressed against the table. I felt the hard contact points at my heels and elbows. In stillness I was intensely present and aware of micro movements throughout my body. The world of bodies and objects beyond the machine struck me as similarly porous and interrelated at the most minute level. CHROMO 1 is the resolution of these observations and processes.

This project began as a problematization of an atomized, genetically determined view of life, and an intention to somehow subvert that discourse. In turning my focus to

[9] Magnetic resonance imaging (MRI) is "a diagnostic procedure that uses a large, high-strength magnet, radio-frequency signals, and a computer to produce images. During an examination, a patient is placed in an MRI scanner where the body is surrounded by a magnetic field up to 30,000 times stronger than that of the Earth. The nuclei within the atoms that make up the body's tissues are like tiny magnets, each with a north and south pole. The nuclei usually spin in many different directions and at many different angles, but in the presence of the strong external magnetic field generated by the scanner, the north and south poles of the nuclei align themselves with the external magnet. The magnet causes them to vibrate at a specific frequency, so that they act like radios, receiving and transmitting radio-frequency signals. When the signal stops, the magnetic poles of the nuclei realign themselves in the direction of the magnet and, at the same time, release their own faint radio signals. The scanner receives the radio signals and, with the aid of a computer, characterizes the different body tissues by the strength and duration of these signals. The computer then reconstructs the information into a two-dimensional anatomic image." (Lopiano, Del Fava).

my physical experience, however, this shifted and became instead an exploration of micro-movement, resonance and vibration. Using a vibrating cymbal, I filmed the movements of various powders and particles from above in black & white video. I also created and filmed deep, crumbling wells within a blender as it ground a mix of dark and light powders[10], while lit by a strobe light. The vibration was generated by the sound recording of the MRI machine, accompanied by additional manipulations of the cymbal with a drumstick.

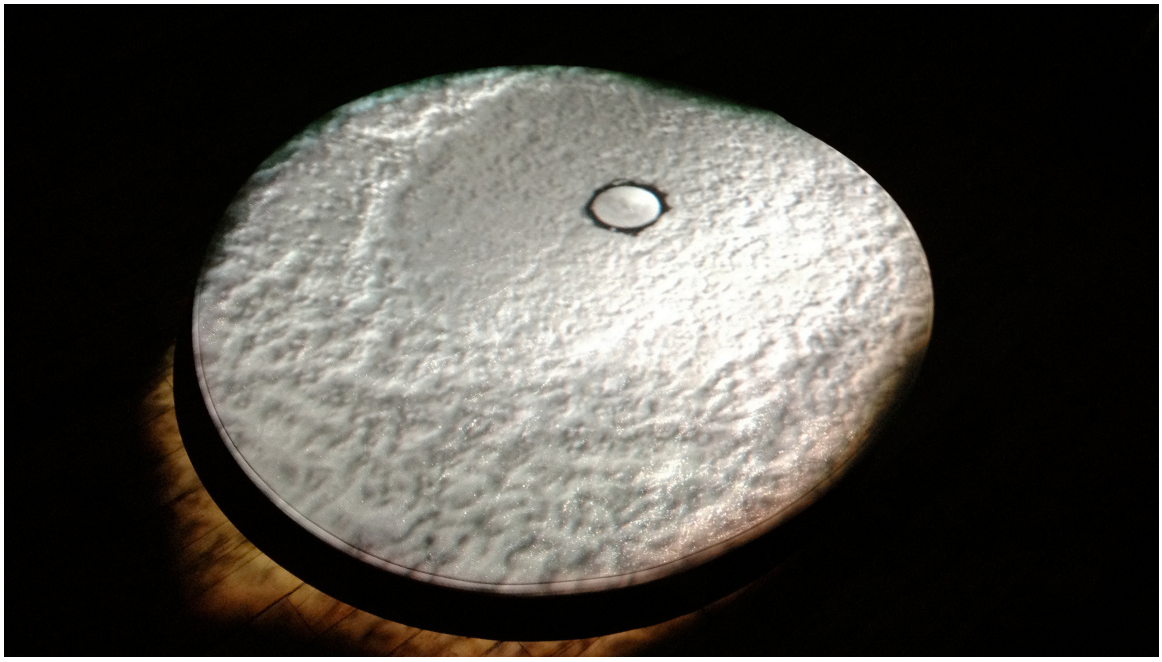

Figure 2. CHROMO 1 – Performance documentation

In performance his footage was projected from the ceiling onto a round floor disc, with the audience seated around it, like a campfire. The sound recording played on speakers set behind them in the room. This approach transmitted the intensity and deep

[10] Blender ingredients include: flour, poppy seeds, flax, and salt. Fig. 2 shows baking soda forming patterns on a cymbal, which is vibrating to the sounds of the MRI (this audio plays during the screening).

vibrations of the MRI experience. We feel sound physically, in our ears and our bodies in contact with the ground. By sharing this collective resonance, the erasure of the body's boundary extended not only to objects and the environment, but to each other as well. In this work I found a manner of engaging with my genetic disorder, and I was struck by the fact that the concept of "disorder" largely fell away. I had been trying to come to terms with the forceful intrusion of a set of processes and discourses into my life. The discoveries I made at this stage emerged from the material and physical experience.

Geneticist Richard Lewontin describes the two poles of the dualism that can emerge when resisting the dominant discourse. On the one hand he describes:

> (An) atomized society matched by reductionist view of nature: whole is to be understood only by taking it to pieces – bits/atoms, molecules, cells & genes are the causes of the properties of the whole and must be studied to understand complex nature (12)

This model's failures, he claims, are the isolation and alienation of the individual (or molecule) from the outside world (13). On the other hand, he describes the opposite view as essentialist, characterized by an "obscurantist holism" wherein all of nature is an "indissoluble whole" (15). His conclusion is that both of these views prevent us from apprehending the "full richness" of the world.

These distinctions help me crystalize my own framework. I can appreciate the allure of the second view as it seems to offer a form of wider meaning that would be useful when other explanations seem unsatisfying. This is not the view I espouse, however. My dissatisfaction with the reliance on probability to contextualize genetic disorder does not inspire me to seek other, opposing cause and effect narratives. This is not a quest for truth or the secret of life itself but an enterprise with practical objectives regarding this

experience. To clarify, my references to vibratory resonance are not intended to invoke "universal forces" and likewise my observations about porous boundaries do not lead me to posit an essential interconnectedness.

Richard Doyle sets out a similar binary to that of Lewontin, only then to illustrate the similarity of the two positions:

> (B)ehind or beyond the practices, symptoms, and deaths of organisms lay a unity, a primitive, invisible force on the basis of which living beings *were*. For the postvital body, the overlooking or disappearance of the body displaces this "beyond" onto and ever denser and ever more complex genetic apparatus. (17)

Lewontin had concluded that both ideologies prevent us from seeing the "full richness" of life (15). Doyle suggests, however, that this is in fact a false dichotomy, as we are using the same explanatory structure in both models. The result in both cases would then seem to be an externalization of life and agency. Cultural theorist Judith Roof suggests that oppositions to genetic metaphors that seek to replace scientific myths with "an Enlightenment notion of truth… where cause and effect can be traced" are doomed to fail, because "(s)uch a truth, even if it exists, can never escape the twistings and shadings of its representation" (8).

CHROMO 1 was an exploration of genetic discourse, as well as some of the critical responses to its rhetorical shortcomings. This work provided a useful warning against attempting to combat genetic rhetoric with another form of universal essentialist meaning or metaphor construction. The task at hand is not to combat the minuscule with the infinite. What I carried forward from this work was the physical experience of fluid boundaries, fluctuating inner composition and bodily interrelatedness, as they are tangibly

manifested in my experience of the MRI. As artist Lee Ufan, who has written at length about making art with the body and the relationship between the body and the world, simply suggests that "the world does not remain external but penetrates the body and permeates its interior" (qtd. in Schwabsky).

CHROMO 2: Our Bodies, Our Genes

Figure 3. CHROMO 2 – Performance documentation
Double 16mm film projection, Sweet Magic London, August 29, 2012

The social and political structures that shape the institution of the clinic have naturally had a significant effect on our estimation of our own agency. CHROMO 2 began as a study of the ways we look at the medicalized body. A pile of DVDs containing digital medical images of my body accumulated on my shelf. In CHROMO 1 I considered the direct embodied experience of medical testing itself. While I recognized physiological resemblances of these images to my own body, I was at a loss for how to interpret them further. What tangible knowledge could these images offer, I wondered, when I lacked

the expertise required to interpret them? What if anything could this data tell me about my body and health? Was there anything I could do with them to interrupt their intended use and explore my own experience?

In his essay "Still/Moving: Digital Imaging and Medical Hermeneutics" Scott Curtis reveals (surprisingly, if we had presumed that the advent of digital technology had revolutionized our methods of studying medical imaging) that the ways we manipulate and interpret the images themselves have not changed much at all. There is a clear continuum between the techniques of image manipulation devised with film cameras, and those used to view digital images. Curtis identifies these techniques as the use of looping, the freeze frames and tracing. More generally he claims:

> If medicine concerns itself with the confrontation between life and death, and if the humanities similarly focus on the human condition, ultimately both attempt to understand their objects…with a common hermeneutic strategy. This strategy…involves conceptual movements between part and whole, depth and surface, past and present, and stillness and movement. (Curtis 219)

The techniques Curtis describes are very similar to my own methods of film manipulation. It therefore strikes me as appropriate to apply those techniques in this project – I may not be able to distinguish healthy tissue from disease, but I do know how to loop a film.

CHROMO 2 was initially conceived as an act of reclamation through the hands-on manipulation of my own digital medical images. I endeavoured to restore tactility, light, and intimacy to the images themselves with fitting creative methods. In light of the discoveries of CHROMO 1, however, I attempted to avoid creating a binary in which I seek to find some universal truth in, or beyond, these images.

In his discussion about the history of anatomical illustration, medical historian Michael Sappol explains, "Digitization is based on the idea that the continuous physical world of our experience can be divided into tiny pieces, and that these pieces can be measured and represented by a set of numbers." The correlation to previous descriptions of genetic rhetoric is clear, and echoes Richard Lewontin's statement that by focusing on the atom and the individual, modern biology "prescribes a way of studying the world, which is to cut it up into the individual bits that cause it, and to study the properties of these isolated bits. It breaks the world down into independent autonomous domains, the internal and the external" (13).

Using medical software I digitally animated select sequences from my medical imagery. I applied movements such as a looping rotation of my shoulder bones and skull, as well as virtual passes through layered cross sections of my upper torso. I then observed the movement qualities of these animations and attempted to re-embody them through filmed gestural improvisation. This movement work and the animations themselves were then re-photographed onto black and white 16mm film. At times I combined and layered the two elements while re-photographing the material. Various effects emerged through this combination of images. In one passage my gestural interpretation trailed behind a rotating image of my skull, for instance. In another sequence my scanned upper ribcage appeared alongside a similarly framed shot of my live body. My fingertips pressed on my collarbone, demonstrating a common gesture of self-examination. The two 16mm film rolls were then projected as a ten-minute, dual screen, expanded cinema performance. The two types of footage were not restricted to a single screen but intermingle, creating

movement between the two frames. At times the edge code of the medical images counts off coordinates alongside my name and date of birth, while my fingers themselves begin to resemble my rib cage.

A productive discovery occurred when part of my gestural video footage unexpectedly degraded on screen while being re-filmed. My moving shoulder froze and broke down into a grid of square blocks, which revealed the compression artifacts of a particular video codec. This moment drew attention to the materiality of the digital materials themselves. Once both types of footage had been printed on 16mm film, it began degrading again (very slowly of course) as it came in contact with the environment. The organic degradation inherent in film itself is not simply a material reality of the format but was made visible in the work. Roughly half of the 16mm film had been hand processed, leaving a contrast between clean, newer looking film sequences and those that were scratched, stained by uneven chemistry and at times solarized. The intended blurring between the external surface and internal depths of my body was now accompanied by a constant fluctuation of intermingled digital and organic materiality.

Like our bodies and material objects, digital media also degrades over time. The pace and blending of these various materials reflects their conceptual and physical inextricability. This may suggest a manner of apprehending the manifold relationship between our bodies and our genes as well.

Choreographer and writer Susan Kozel describes a similar formulation in relation to performance "(the) performers phenomenological experience: part-split, part-organic relationship between corporeal and virtual self" (672). Her distinction between a split and

organic *relationship* adds an interesting layer. It suggests that not only are performers negotiating their corporeal and virtual selves, but that the mode of relation between the two oscillates between integration and separation. Kozel is specifically referring to performance here. In the exhibition of CHROMO 2 I am present and operate the projectors, which is relevant to the specific context she describes. My interest in her statement has more to do with establishing a model of how we might navigate genetic disorder in relation to our bodies. In CHROMO 2 this shifting interplay at times registered to me as a fluid transition and other times it seemed abrupt and jarring. This relationship was expressed in multiple gradations, degrees and tempos. The movements I perform on camera were intended as embodiments of these states.

Summary

My initial identification of the problem of understanding the nature of my genetic disorder was to characterize it as a threat to my body's "wholeness." The genetic and clinical rhetoric seemed to threaten my agency and intentionality, as well as limit my future possibilities. This was physically manifested in what I perceived as enforced stillness and passivity in the clinic. The question of how the part/whole dichotomy is interpreted and used is still at issue and likewise the blurring and expansion of the surface/depth boundary remains an ongoing project. As this work progressed however I gained an appreciation for the adoption of a degree of abandonment of wholeness and boundaries. Rather than focusing on the genetic and the digital as units of measurement and data for various calculations, I now seek to access their materiality. Although these units may be too small to be visible to the eye, perhaps that does not prevent them from

being integrated into my perception of my physical being or comprehensible as a moving play of levels and modes of being with physical correlates. Could the MRI be an access point to our smallest selves? Not through its use as a tool for ever closer medical looking, but by way of our physical sensation of the powerful resonance being enacted as the massive magnet noisily aligns our very atoms?

My body contains the kinesthetic residue of time spent lying in scanners, the sense of the shape of the enclosure, the pressure of restraints on my limbs, the unusual effects of contrast dye entering my blood stream through an IV. For days after my last MRI I was revisited by claustrophobia triggered when the air became still in small spaces. This acute awareness of my body surface, depths, and relationship with the environment does not suggest to me a state of stillness or passivity. Likewise the digital medical images no longer strike me as frozen in time, foreign or separate.

Richard Doyle suggests that the body itself "ha(s) been overlooked and recast as an effect of a molecule, an extension or supplement to the real, timeless, deathless bit of immanence known as DNA" (8-9). In CHROMO 2 I created a revitalized body and uncovered the images' own capacity for movement and materiality. I discovered that instead of simulating a corpse, my still body was decidedly alive, aware and undisciplined.

Michel Foucault's theory of the clinical gaze underpins the pervasive characterization of the body in the clinic as an inert object and compliant agent of social discipline and signification. This has corollaries in the radical science movement's deconstruction of the ideological underpinnings of the way genetics are wielded. There is

an apparent consistency between this disciplining gaze and what we might call the bio*tech* power of the new genetic rhetoric.

Dance scholar Mark Franko notes that, in a radio talk show in 1966 for France Culture, while Foucault reasserts his well-known views of the body as defined and created by a disciplining gaze, he also speaks of embodiment as a phenomenon. Franko recounts that:

> Foucault described some dynamic aspects of corporeality in phenomenological terms… the only text in which Foucault comments (if only once) directly on dance [and] explores alternative scenarios of the personal experience of bodyliness. The entire talk is, in fact, a meditation on the body as a medium of movement in relation to desire as a transcendence of place (*lieu*) to which our bodies condemn us. (103)

This window of agency and Foucault's specific reference to movement and desire, while clearly a rare remark, strikes me as very well aligned with my discovery in the MRI. The immobilizing surface trappings of bodily restriction (including actual restraints and disembodied commands for stillness) did initially suggest a physical state of inert discipline and biopower. This gave way however to a bodily awareness and sense of interrelatedness with others and the environment. The situation had not changed, but when I released the dominant perception and simply experienced my body in the space, I found movement in the stillness, and both agency and engagement with my environment through movement. Once again this does not refute the power dynamics at play, but would seem to lend my wider experience a new degree of openness and possibility.

During this exploration I made an additional discovery that further shaped my direction. Out of sync with a depiction of a clinic that sets up a binary of power between doctor and patient, the majority of my direct interpersonal contact is with administrators,

nurses and radiologists. I have a vivid memory from early in this process of a kind radiologist touching my arm and assuring me that a scan wouldn't take long. That particular type of scan requires that patients take iodine tablets and the label had referred to their use after nuclear disasters, so I was actively trying to cognitively unravel my situation at the time. The radiologist's contact returned me to my body, and rather than an experience of powerlessness I retained the physical sensation of empathetic contact.

My experience in general has been shaped by the embodied presence and actions of hospital workers. To depict a version of my experience that focuses solely on the power dynamic between patient and doctor, positing the entire institution as an extension of the clinical gaze would require that I set aside my actual experience. In addition, I would need to discount the subtleties of my relatively rare interactions with the doctors themselves. There have certainly been times where the disjuncture between my experience and the risk narratives and language of medical experts has been alienating. My difficulty in expressing my needs and questions has resulted in deep frustration. Generally speaking however my doctors have been excellent communicators and compassionate caregivers. The troubled ideological underpinnings and rhetoric remains problematic. I have found an approach to being in the world of the hospital and having a genetic disorder, however, which seems to help circumvent the disempowering model contained in gaze theory.

It is instructive to consider Foucault's concept of the clinical gaze alongside the rhetorical underpinnings of genetic medicine. Similar to Scott Curtis' revelation that the uses of digital medical imaging are not a radical departure from earlier manipulation of

medical images, the model of power and the body that emerges from genetic determinism sounds markedly similar to the dynamics of the clinical gaze. This particular passage from *The Birth of the Clinic* contains two interesting turns:

> The Gaze that envelops, caresses, details, atomizes the most individual flesh and enumerates its secret bites is that fixed, attentive, rather dilated gaze which, from the height of death, has already condemned life. (Foucault 171)

The action verbs used by Foucault are somewhat unexpected. While the gaze in general was not intended to be simply a visual relation of looking and being seen, the words "envelops" and "caresses" strike me as unusual in their suggestion of tactile contact and intimacy. This is but another minor counterpoint, on par with his singular reference to movement and transcendence noted earlier. Foucault's pronouncement, which is not dissimilar to my critique of the use of genetic probability explanations in the clinic (whose risk narrative narrows towards death): "(t)o know life is given only to that derisory, reductive, and already infernal knowledge that only wishes it dead" (171). The similarities between the critical literature about genetic determinism and the construct of the postvital body would seem to exist as an extension of this school of thought.

The research and creation of CHROMO 1 & 2 located a space for exploration of my own medical experience amidst the dominant discourses, and yet a wider theme remains to be addressed. As noted, risk calculations are a prevalent manner of addressing the uncertainty of health issues in general. We accumulate notions from popular science and a stew of valid and fictional statistics that offer numeric assurances or nightmares. I am conscious of my own ongoing use of this type of information to navigate my medical

situation. I will not attempt to analyze the reasons this discourse emerged and gained such prevalence as it is beyond the scope of this research. Ian Hacking and others have provided compelling accounts of the historical emergence of the concepts of probability and statistical inference. Instead, my starting point is what I experience as a limitation of agency when medical odds-making is invoked in the course of treatment. Artist and philosopher Manuel De Landa summarizes Henri Bergson's assessment of the foreclosure of possibility that occurs:

> Henri Bergson… criticized the inability of the science of his time to think the new, the truly novel. The first obstacle was… a mechanical and linear view of causality and the rigid determinism that it implied. Clearly, if all the future is already given in the past, if the future is merely that modality of time where previously determined possibilities become realized, then true innovation is impossible. To avoid this mistake, he thought, we must struggle to model the future as truly open ended. ("The Machinic Phylum")

What then are we actually talking about when we invoke probability in a clinical context? To what end this endless calculation and re-calculation of risk? We rarely if ever speak of the "chances of remission" or the "chances of cure", we measure our disease against death. Martin Heidegger claimed that death is the "possibility of impossibility", the limit of our "potentiality-for-being" (255). In the specific case of my disorder, lifetime monitoring is required. There will be no stage at which I am released back into the risk category of the general population. The only resolution of the cause and effect narrative is the discovery of disease (as exhibited in the young doctor's assurance that "we knew this would happen"). That discovery invokes a re-calculation of odds and accelerated monitoring before the pace can return to regular levels of vigilant watching and waiting. In this context and within this rhetorical model, how can I avoid seeing my situation as a

gradual, irrevocable narrowing of potential?

What other models of possibility exist and how might we enact them? Richard Doyle provides a useful warning about idealizing possibility as something we had but lost:

> If we think in terms of lost branches or pathways here, we inscribe a temporality of before and after, a logic of either/or… Indeed the model of a 'lost' choice or alternative to the present, by ghettoizing 'possibility' as lost in a nostalgic past, unwittingly grants a hegemony to the dominant discursive articulation even as it attempts to recuperate possibility from the past. (9)

I wish to highlight this reference to the manner in which one can inadvertently grant hegemony to the dominant discourse by idealizing the alternative. This statement provided a key manner to test my research throughout the project. Am I over emphasizing genetic determinism by making it the focus of my critique, and missing other possible avenues of inquiry?

CHROMO was originally conceived as a tool of resistance to concepts and structures that seemed to detract from my ability to understand my experience. Yet I need the science, respect the practitioners, and recognize our shared goals. Some of the existing models of critical resistance I explored provided excellent context for disentangling some of the ideological foundations and operational principles of the clinic itself, and were thus valuable in devising my own practical framework. I moved forward by placing these interpretive models and accounts in the background. My source of knowledge production instead will be my own embodied experience. I have devised a set of methods and tools that respond to and resonate with this lived experience, in the hope of generating new ideas and uncovering pathways that may have been obscured.

In her analysis of the phenomena of waiting and surprise, philosopher Françoise Dastur helps outline the new problem I wish to face. She asks what happens in the case of extraordinary events that suddenly impact or reverse our sense of the future as open and undetermined, what occurs when:

> the event fractures the horizon of possibilities in such a manner that the mere encounter with the event becomes impossible? How can we account for these moments of crisis, of living death, of trauma, when the whole range of possibilities of a human being becomes unable to integrate the discordance of the event and collapses completely? (185)

The following work explores the space where my new conception of an open field of possibility meets the murky implications of my genetic disorder and disease's incomprehensible threat. Is this crisis based on a reasonable appraisal of likely outcomes of my disorder (which can therefore be used to guide my choices), or simply a side effect of the rhetoric of genetic determinism and probability?

Chapter 3: Theoretical Framework

CHROMO is first and foremost a work of art, the creation of which was intentionally characterized by an open and embodied awareness and response to the experience itself. Useful literature exists concerning the phenomenological status of ill bodies, but I found relatively little writing about the experience of genetic disorder itself. That which I did find frequently pertained to the bioethical challenges of genetic counseling and patient decision-making (regarding testing, disclosure and treatment). There is of course a fair amount of personal patient testimony on the Internet and popular media, which often focuses on healing, community building and empowerment. The

visibility this creates seems valuable, as well as the contribution to genetic discourse from the perspective of direct experience. Public discourse and popular science is powerfully contributing to our interpretation and framing of this phenomenon as well. This multiplicity of voices and strategies cannot be distilled or generalized.

In contextualizing this project as a case of physical knowledge production, embodied phenomenology provides a theoretical underpinning. It supports my development of a method of film and movement practice located in embodied experience and a mode of sharing the results in an audience encounter that invites an embodied reception.

As established in the previous chapter, a key objective is to engage with the environment and experience without the mediation of preconceived meanings and rhetoric. Most of this project was filmed in hospitals as my experience unfolded, and reflects the tone, temperature and dynamics of the moments depicted. This is also a case however of my own specific embodied manner of being in the world in a specific place and time.

Illness & Medical Phenomenology

I have found a complementary discourse rooted in phenomenological, embodied inquiry regarding the body and illness, as well as clinical practices. I have borrowed certain parameters from the former, but on the whole have put them aside after recognizing key differences in their mode of analysis, conclusions and perspective.

One prevalent manner of characterizing ill bodies is to suggest that we consciously experience them as separate or absent from other bodies and/or the world. At times this is explained as an apart-ness or alienation from one's self or the world, "being ill is before all alienation from the world" (Buytendijk qtd. in Leder 79). Drew Leder, in his book *The Absent Body*, suggests that "the normal and healthy body largely disappears so direct experience of the body is skewed toward times of dysfunction" (Leder, 86). I would suggest that in my experience the healthy and "normal" body (if such a thing exists) in fact does not necessarily disappear from our awareness during everyday activities. This is a useful point of departure for my later considerations of body awareness in the context of movement and experience.

My own sense is that states of intentionality, and the direct and indirect focus on my own body, are always in constant fluctuation. Awareness of the body and its boundaries would seem to include an infinite range of scale and style – from a microscopic, vibratory form of awareness that I will explore further, to a sense of expanding into (and creating) immense space. The sense I may have of my body during a handshake, a mosquito bite, the posture of lying still in an MRI machine or on a sunny beach, do not in my view fall into binary categories of awareness/disappearance, presence/absence, good or bad[11]. Relying on a universal thematization of specific bodily states seems to be a problematic activity for patients, clinicians and caregivers alike. To be fair, Leder is not suggesting a prescriptive model for clinical interactions or being in the world. My own objective is to

[11] Leder differentiates two ways in which the body can dis-appear from one's attention, distinguishing between bodily dis-appearance and what he calls "dys-appearance" which occurs when the body appears to me as ''ill'' or ''bad'' (84). He claims that in the latter "I experience to my body, not simply from it… the body appears as a thematic focus, but precisely as in a dys state (dys = bad, hard, ill)." (80-1)

evaluate theories of the ill body in terms of their resonance with my own embodied experience and potential consequences for absorbing them into my art practice. While I may not agree with the notion of disappearance, or the existence of an objectively healthy or normal body in the first place, this analysis helps me crystalize my sense of the fluidity and coexistence of direct and indirect focus, and various forms of body awareness, which arise again in my discussion of movement observation.

As for the notion of bodily absence when ill, I am conversely struck by our co-presence in those states and spaces (such as the hospital). In one of my inpatient experiences a thin curtain between my bed and another separated me from the woman in the next bed, and this floating boundary was constantly re-arranged. Our IV pumps were slightly faulty, if either of us moved an arm even slightly they commenced beeping at the same interval. Since the sound of this alarm was commonplace the response was slow. A great deal of the time there was a persistent aural reminder that fluids were moving from the room into each of our veins, accompanied by the varying occlusion and restoration of a tangible flow. Nurses addressed us both in their visits, taking each of our vital signs and repeating a ritual of caregiving that encompassed us both. In a straightforward sense I was apart and away from my usual routine and home, but in my sense of intercorporeality and shared experience is in fact often heightened in these states and spaces.

Words like alienation and apartness are not apt descriptors of the visceral, tactile and sensory intercorporeality I experience with other patients, nurses, radiologists, caregivers and so on. I have also witnessed close bonds forming amongst the patient community online in forums and social media. In those groups there are often expressions

of a powerful sense of closeness, and colloquialisms such as "we are right there with you" when suffering is expressed. Is it possible to envision these forms of distant closeness to be an extension of our embodied experience as well? The experience of other patients and the ways online patient communities function are beyond the scope of this analysis. Their existence does however, contribute to my resistance to categorizing this experience as a form of alienation and separation from our bodies, from others or the world.

The specificity of my temporal experience will play a large role in CHROMO. John Brough claims that "illness provides a unique window on to the many levels of time that inform our lives" (qtd. in Toombs 45), while Drew Leder refers to an "episodic temporality of rally and relapse" (81). These complementary depictions provide a useful model. The cyclical nature of my experience feels closer however to the description Susan Leigh Foster developed while reflecting on her own choreographic work[12] and her creation of a "co-presence of different moments" which she characterizes as "a kind of meditation on different ways that one can think about dancing and also on a different experience of time in which past and present coexist and reverberate with one another" (12).

Among depictions of the ill body as absent or invisible are more specific discussions of this absence as a change in the body's experience of space and time. Leder refers to pain and disease as effecting a ''spatio-temporal constriction'' for the subject while pleasure is described as "expansive" (73). In her influential study, Elaine Scarry

[12] I would like to underscore the added significance to my research when accounts such as these are found to have emerged from the embodied movement practice of another artist.

describes pain as "experienced spatially as either the contraction of the universe down to the immediate vicinity of the body or as the body swelling to fill the entire universe" (35). Once again my experience suggests that these changes in body awareness are not mutually exclusive, nor universal.

I have experienced and observed the ill body enacting an expansion and extension in space. The spatial terms themselves help me contemplate the experience of the space and time of illness and treatment. Scarry's description of the "universe" contracting and the body swelling also underscores a reversible relation between our bodies and space (for she also refers to the body itself expanding instead). I am reminded again of my discovery in the MRI in which the boundaries of my body were felt as porous and my presence expanded to intermingle infinitely with the atoms of the world. Within the tiny, constricted space of the MRI enclosure, while bound to a table, with powerful forces directed at my body (which itself was in a state of illness), I expanded into the world. In another moment I was overwhelmed by claustrophobia and indeed could say that the world "contracted" around me. This fluctuation underscores my sense of the fluidity of states of embodied presence. The intensity of that shift may be a result of the extraordinary nature of that space, but I would suggest that my body does not disappear in more mundane environments either. This consideration is useful in the classifications of states of time and space later in this study.

A focus on body awareness in space and time is central to the methods of movement study I practice in CHROMO. Maurice Merleau-Ponty's notion of intertwining is reflected in my approach to space, as an acknowledgement that our body

and space are inextricably interrelated and co-created: "I am not in space and time, nor do I conceive space and time; I belong to them, my body combines with them and includes them"[13] (*Phenomenology of Perception* 140). I have set out to determine the form of the intertwined shapes and qualities of my body in hospital spaces.

There is a growing field of literature generated from within medical discourse itself about the phenomena of illness and clinical encounters. This is not where I have focused my theoretical inquiry, for the following reasons. First, these texts frequently aim to enhance medical professionals' understanding of patient experience and thus often situate the goals of study within clinical practice. This is tremendously useful in uncovering the various biases, ideologies and operational necessities that underlie clinical practices themselves with regard to engagements with patients. There exists a methodology called "Interpretive Phenomenological Analysis" which is used to gather patient data about their experience of various clinical and health experiences. This has even been practiced to study patient adjustment to diagnosis and management of genetic disorder. When directed at the provision of effective genetic counseling, the focus tends to be on social, ethical and psychological issues. Clearly this is far afield from my own current study. The experiences recounted in this type of study are already necessarily second-hand and include the interpretation of the author according to the aims of his or her field.

In some cases however the study involves the direct observation of patients' experience and understanding of illness and their bodies, and is generated through the

[13] In Merleau-Ponty's original text this passage ends "mon corps s'applique à eux et les embrasse" (*Phénoménologie de la perception* 174). I prefer my own amateur translation, "…my body embraces them" to capture the connotations of movement, warmth and intentionality found in the French word "embrasse".

researcher's direct and meaningful patient encounters. One notable example of this practice is the work of bioethicist Richard Zaner, who has employed phenomenological observation to document his decades of daily "clinical encounters" with patients, their families and health care workers, with the goal of grasping each patient's "life world" based on their concrete experiences negotiating states of illness in the clinic (Zaner, *Conversations on the Edge*, *On Evoking Clinical Meaning*). The focus of his study is described as the "often-overlooked features of disruption and crisis, the changed self, the patient's dependence and the physician's power, the violation of personal boundaries and their necessary reconfiguring, and the art of listening" (Wiggins, and Schwartz 73). His approach is of particular interest to me not only for its patient-centred approach and the vantage point provided by his daily immersion in the hospital environment, but I appreciate his inclusion of both caregivers and health care workers. Considering the experience of the ill and hospitalized in isolation has struck me as a very partial view and it seems logical that conclusions would then focus on alienation and apartness. This has largely not been my experience, which instead has been shaped by intercoporeal and empathetic relationships within the clinic. I have avoided delving into this material further in hopes of remaining focused on my own specific experience. Recognition of the existence of other patient-centred, phenomenology-based methodologies such as Zaner's has helped me further delineate my sphere of inquiry. It pleases me as well to note in general that a phenomenological method is being used to provide a richer conception of clinical dynamics and patient experience within medical discourse itself.

Movement

> It is clearly in action that the spatiality of our body is brought into being, and an analysis of one's own movement should enable us to arrive at a better understanding of it. By considering the body in movement, we can see better how it inhabits space (and, moreover, time) because movement is not limited to submitting passively to space and time, it actively assumes them…" (Merleau-Ponty, *Phenomenology of Perception* 117)

Our body's engagement with the world encompasses endless variations, dimensions, patterns and rhythms. In light of my own observations during medical experiences I have looked closely at the notion of stillness, as it arises in the general clinical phenomenon of "wait and watch". This common expression accounts for most of my experience of genetic disorder as well as illness and treatment. Initially I interpreted this as a form of temporal suspension and passivity. Part of the difficulty of apprehending my asymptomatic genetic disorder was that in absence of a physical corollary, the cause-and-effect risk narratives seemed to enact a constriction of possibility and a lack of embodied agency. When I shifted my focus away from attempts to cognitively grasp and counter the situation, and instead approached the phenomenon as an embodied experience, possibility emerged in the different scales and patterns of movement within the stillness.

Simon Critchley summarized Martin Heidegger's distinction between awaiting and expectation (which I associate here with genetic determinism and risk narratives) as opposed to anticipation in the following passage:

> *Being and Time* is a long hymn of praise to possibility and it finds its highest expression in being-towards-death. Heidegger makes a distinction between anticipation (*Vorlaufen*) and expectation or awaiting (*Erwarten*). His claim is that the awaiting of death still contains too much of the actual, where death would be the actualisation of possibility. On the contrary, for Heidegger,

> anticipation does not passively await death, but mobilises mortality as the condition for free action in the world. ("Being and Time, Part 6: Death")

While the word anticipation in English tends to be defined as a "looking forward to" which contains both visual and linear terms, Vorlaufen in fact translates literally as "running ahead".[14] This reconfiguration of waiting from the mental to physical realm would seem to offer a reversal of the passive, constricted and alienated depiction of the time and space of illness.

Locating an energized space of possibility within the body and its experience entails observations of movement and body awareness within perceived stillness. In addition to the specific MRI experience and general observations in waiting rooms (which figure prominently in the film), I also found myself recovering post-surgery in a state of restricted movement. All I could move freely were my head and right arm, various medical devices otherwise encumbered me. Once again I found myself aware of movements at a smaller scale.

The school of movement analysis developed by Rudolph Laban will figure largely in my creative methodology, described in the next chapter. His theory of stillness resonates with my sense that it constitutes a space of possibility. His definition of stillness

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[14] Johannes Friske provides additional temporal connotations in Heidegger's *antizipieren* or "running ahead" of death: "in German… it exclusively designates mental activities and never physical motions, whereas «*vorlaufen*» is used exclusively for physical motions and never for mental ones. Furthermore, if one anticipates (*antizipiert, vorhersieht*) some situation or event, one assumes that there is a temporal difference between the moment of anticipation and the occurrence of the anticipated situation. It is this time difference that allows one to prepare oneself in thought or action for this situation... However, with vorlaufen one does just the opposite. Someone *läuft vor* when he leaves a group, a place… he has been in so far and runs out, alone, into the open… Thus, *vorlaufen* is often the crossing of a line that…provides the individual inside with shelter from, and identity in opposition to, the dangerous, undefined outside… (As) soon as I *laufe vor*, I deprive myself of this safety zone as well as of the time difference and expose myself immediately to the dangers of the outside from which I had previously been protected.

is, “a gathering of strength for the moment… all stillness is gathered movements, and all movement is collected stillness (qtd. in Maletic 53).

I return again to my experience of body awareness and movement while in states of stillness, including the body shaping created by the breath, which varies in form, rhythm, scale and direction (and contact with other objects or forces). The scale of movement implied in examples such as the atomic realignment in the MRI machine, and by extension ineffable molecular activity and genetic states are far less tangible. The latter possesses a scale of movement that is at once a slow evolution over lifetimes at an almost geological pace, and also potentially much faster when genes mutate somatically or occur during cell development. In terms of direct experience of such miniscule entities, our bodies themselves may experience what José Gil calls “sonorous silence and vibratile stillness”. He wonders if those minute movements can be brought to our physical attention (and not just cognitively) via a “microscopy of perception” or “introspective proprioception” (qtd. in Lepecki 346). This form of micro-movement within stillness is also explored by André Lepecki, who refers to an infinite and unlocatable space of “vibrating stillness” which is restless and unfixed (344). Choreographer and dancer Susan Leigh Foster locates stillness spatially as a “sensorial threshold, a vibratile intensity provoked” (356).

Silence and stillness provide valuable areas within which to consider qualities of embodiment, as well as the spatial and temporal qualities of experience in the world. Furthermore we are offered a manner of approaching phenomena such as waiting or being ill, which have elsewhere been described as passive, absent or alienated bodily states, that

instead may now seem to offer endless possibilities. Numeric risk calculations now tend to cede their dominance in my estimation of my own genetic disorder and illness, and occupy a small position within an open and limitless field. This expanded field of embodied being in the world does not require us to discard an anticipatory awareness of death, nor the operational value of risk assessments in clinical treatment. In my case however it permits a physical re-adjustment of this experience that locates the latter in a small corner of a much wider view of my own possibilities and agency.

Embodied Film

In developing a theoretical and methodological approach to the use of film and movement, I explored various theories of embodied film and tactility. There is a great deal of literature employing phenomenology to frame the experience of both film (spectatorship and analysis) and movement study. The latter is somewhat more straightforward as we are accustomed to considering dance and movement to be physical activities. Dance provides a relatively natural platform from which to explore embodiment theory's various models of being in the world: from the blurring of the body's boundaries between performers, their interactions with space and objects, to dancer/audience intercorporeality. Film theory on the other hand must contend with the apparatus itself, the screen as possible mediator between the film and the spectator, the primacy of vision alongside models of unidirectional, cognitive or psychological perception, and so on. It is unusual to find examples of this discourse that are rooted in embodied film as a practice from the artist's perspective.

When we do think about bodies and film, our first point of access may be on-screen

bodies, or the camera as a stand in for filmmaker or audience point of view. Furthermore, the apparatus itself, as a mode of production and exhibition has a complex history. The study of medical imaging provides an interesting access point to the interrelated histories of film and medicine.[15] As a result the clinical gaze and the gaze in film theory overlap. Anne Rutherford explains that medical "conquest" of the body as an object of knowledge was transplanted into film theory's "physiological understanding of the body and of vision", resulting (in both cases) in a "foreclosure of the full resonance of embodied experience" ("Cinema and Embodied Affect").

Since I have already acknowledged the difficulty in avoiding ideological and political analysis of the clinic, and bracketed that discourse to the extent possible, so too will I attempt to set aside theories of the gaze and primacy of visual metaphors when considering the use and effect of film. In combining particular threads of embodiment theory as expressed in both film and movement, I have devised a theory and method I will call movement-film. The goal of this method is to use camera movement to access my own embodied experience of the hospital, and then to use film in an event-based audience encounter that is structured to create opportunities for intercorporeal resonance.

Vivian Sobchack has offers a nuanced and complex theory of embodied film, in which she positions the film itself as an embodied entity. The interplay between the viewer (or perhaps "feeler") and the film itself is characterized as reversible:

More than any other medium of human communication, the moving picture makes

[15] For a longer discussion of medical imaging and medical visual culture, I recommend Lisa Cartwright's *Screening the Body: Tracing Medicine's Visual Culture* and Kirsten Ostherr's *Medical Visions: Producing the Patient Through Film, Television, and Imaging Technologies.*

> itself sensuously and sensibly manifest as the expression of experience by experience. A film is an act of seeing that makes itself seen, an act of hearing that makes itself heard, an act of physical and reflective movement that makes itself reflexively felt and understood. (Sobchack, *The Address of the Eye* 3-4)

How can we understand the film itself as a body with agency? What Sobchack seems to describe is a relationship that is reversible because the viewer is watching the film, and watching the film as it watches something at the same time. The filmmaker has seen and felt an experience and now the audience views it, and as such the filmmaker, the film and the audience can "experience through common structures of embodied existence, through similar modes of being in the world, that provide the intersubjective basis of objective cinematic communication" (5). The concepts of reversibility and dynamic exchange in cinematic viewing provide a useful starting point. Sobchack's distinction between the filmmaker's body and the film's own body seems one step removed from my intentions however.

A significant difficulty in bridging phenomenological film theories and creative practice is that generally speaking they refer to finished films as viewed in the cinema. It becomes necessary to address the mode of embodiment and engagement in the production of CHROMO separately from the manner in which it will be experienced as a finished work. While I refer to the work as a film, it does not exist as a film entity that can be separated from the specificity of the exhibition context. I will revisit the audience encounter specifically later on. The common thread between my mode of engagement with my experience in the process of filmmaking and the style of engagement I hope to encourage in the exhibition, is the notion of kinesthetic empathy. This will be revisited in the discussion of movement theory after I turn my focus back to the film itself.

Touching Film

> Synapses and fingers are married (as are mind and body, and vision and touch more generally) in the experience of cinema. I also argue that to think, to speak, to feel, to love, to perceive the world and to express one's perception of that world are not solely cognitive or emotional acts taken up by viewers and films, but always already embodied ones that are enabled, inflected, and shaped by an intimate, tactile engagement with and orientation toward others—things, bodies, objects, subjects—in the world. (Barker, *Rorotoko*)

Jennifer Barker's expansion of embodied cinema discourse provides a key theoretical proposition about the all-encompassing nature of embodiment and tactility. Her description of bodily engagement extends it beyond other models of film/viewer intersubjectivity. Her analysis does not position visuality as the key locus of embodied spectatorship, subjectivity as a psychological construct. She describes film spectatorship "as full-bodied engagement with the materiality of the world" (Barker 2). I would extend that to filmmaking itself as well. She goes on to characterize touch as something beyond just direct contact, but more widely as "rather a profound manner of being, a mode through which the body–human or cinematic–presents and expresses itself to the world" (2). Barker then endows this form of touch with myriad textures and qualities that resonate within us to varying levels of bodily depth. She considers "movement, comportment, tension, internal rhythms" as well as "energy, inertia, languor, velocity, rhythm" to be "tactile" (2). Rather than characterizing movement as a form of tactility (not to suggest that Barker intends a hierarchy), I will generally use movement as our overarching site of intercorporeality. This focus reflects the particular intersection between film, dance and patient experience where my study and practice is positioned.

This more encompassing notion of touch is productive within the clinical setting as

well. While these theories refer to film and cinematic engagement, they draw from the same phenomenological theories that are found in the movement observation framework I am exploring.

Kinesthetic Empathy

Kinesthetic empathy refers to an engagement between bodies based on a reciprocal intercorporeal awareness or resonance. It has a dual role in the creation of CHROMO itself. The first application is within my own mode of engagement with those who appear in the film. This includes a reflexive self-awareness of my own response to movement. Secondly, it underpins the structure of the exhibition encounter, as an intended method of sharing experience.

This principle fits into the larger phenomenological approach and positioning of CHROMO. This concept emerged in my research at the stage when I discovered that the only resonant purchase I had on the experience of genetic disorder was my relationship with the physical environment I was occupying, and the people around me. The nature of the wordless, embodied connections (and disconnections) that materialized during my diagnosis, testing and treatment prompted a search for a resonant model of how we experience the world together.

Kinesthetic empathy frames a manner in which our bodies respond to other bodies – to posture, gesture, and specific qualities of expressiveness. As with movement observation, I am engaging with one particular formulation of this principle, which I will outline in further detail. When the concept of kinesthetic empathy is used in reference to film spectatorship, it is often described as a mimetic response to on-screen bodies.

We might find ourselves adopting the expression of a character, or ducking slightly to avoid an object in the film that is moving in our direction. On this end of the scale, the notion of kinesthetic empathy does not necessarily include the evocation of emotion.

Affect theory, a complementary field that also addresses emotional and embodied intersubjectivity, generally differs from kinesthetic empathy in its interpretation of how it functions. Concepts such as "affective resonance" do address the physical exchange that occurs when a person witnesses an emotive gestural quality for instance, and physically responds without apparent pre-cognition. The manner in which this response is subsequently explained by affect theory however, tends to involve a mediating step that resembles either conscious translation on the part of the receiver or a more ephemeral quality such as this depiction by Charles Altieri who describes feelings, as "elemental affective states characterized by an imaginative engagement in the immediate process of sensation." (12). The form of kinesthetic empathy that interests me however attempts to avoid a mediating step of cognitive interpretation during the course of experience itself. It bears acknowledging, obvious as it may be, that our basic operational explanation in day-to-day life is that there is indeed a separation between our bodies and the world. An empathetic state may typically be seen as a temporary bridge between individuals. This project instead positions intercorporeality and a lack of division between bodies and the environment as a general state of being in the world. This view runs against cultural assumptions of individuality (which also underpin the notions of illness as an individual problem and a case of cause and effect, and the clinic as a locus of top-down power).

Encounter

Projecting on multiple screens in an unconventional space and seating arrangement draws from the expanded cinema tradition[16] as well as choreographer William Forsythe's conception of "choreographic objects". These objects appear in his installation work and visitors can physically engage with them in order to develop their own physical sense of the work's meaning. In *The Fact of Matter* (2010) Forsythe hung plastic gymnastic rings at various heights in a gallery space, inviting viewers to climb on them and explore gravity and effort (Jennings). In this case the objects are the focus of the installation and the invitation to act is overt. My waiting room scenario is much more familiar and the body in a seated posture is an everyday activity. I intend to provide a very subtle and open choreographic environment. The effect of sitting across from another row of people presents additional triggers for embodied sensation and connection. Forsythe's intention with his objects is similar:

> A choreographic object, or score, is by nature open to a full palette of phenomenological instigations because it acknowledges the body as wholly designed to persistently read every signal from its environment ("Choreographic Objects").

Forsythe's theoretical work and his methodology[17], and most importantly his practice in choreography, dance film, and installation have been touchstones throughout my project.

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[16] Film scholar Jackie Hatfield explains that "expanded cinema as a term generally describes synaesthetic cinematic spectacle(s)… whereby the notions of conventional filmic language (for example, dramaturgy, narrative, structure, technology) are either extended or interrogated outside the *single-screen* space" (237).

[17] In Forsythe's DVD "Improvisation Technologies" he catalogs and demonstrates some of the complex environmental and geometric visualization practices that inform his methods.

Summary

This theoretical framework leads to the creative methodology of CHROMO. Using movement to generate possibility and film movement and tactility to explore and create the space of this experience feels like a fitting approach to the material. Anne Rutherford describes a way of approaching the world that seems appropriate to the creation and encounter with this space, one that is "more akin to a millipede than to a camera… a thousand tentacles feeling their way through a space rather than a single lens taking it in view" ("Cinema and Embodied Affect").

Chapter 4: Methodology

In order to devise a methodology that suitably enacts the openness of the wider aims of this project, I have integrated non-linear, experimental film and expanded cinema practice with an approach to movement observation and improvisation loosely based on Laban Movement Analysis and the improvisational scoring techniques of Anna Halprin. This resulted in a form of embodied camera movement and improvisational choreography that suits the themes and goals of this project.

Phenomenology underpins my theoretical framework but also offers a general methodology. Vivian Sobchack enumerates the following methodology in the context of film analysis and research:

> phenomenological inquiry is…a series of *critical commitments* made by the researcher to respond openly to phenomena… (it is) based on the *intuitive exploration* and *faithful description* of the phenomenon *within the context of the world of our lived experience (Lebenswelt)*, anxious to avoid reductionist oversimplifications and overcomplications by preconceived theoretical patterns. (Sobchack, *The Address of the Eye* 32-33)

This is aligned with my previous conclusion that this enterprise should not be intended to create specific types of meaning, universalize clinical experience, or contextualize and narrate my own experience to an audience. Both the film and the choreographed encounters themselves should form an undetermined and open site of shared experience and knowledge production. Therefore this phenomenological method persists throughout the research, creation and production of this work through to the exhibition and interpretation of it as well.

That being said, I am aware of the challenge of adhering to these rules. Observing and responding to my failures at maintaining this form of attentive openness becomes part of the method as well. In *Phenomenology of Perception*, Merleau-Ponty provides a quaint visual metaphor intended to convey the process with which the body itself navigates the environment: "A woman may, without any calculation, keep a safe distance between the feather in her hat and things which might break it off" (165). I appreciate this as a metaphor for my practical methodology. The feather represents not only my body's engagement with the world, but also my attempt to remain alert and open throughout the creation of CHROMO (which occurred during my own medical treatment and hospitalization). The safe distance in this case was between my ability to maintain a stance of possibility while surrounded by the forceful dominant views regarding this particular environment, always at close proximity to my trembling little antenna. As such, while I enacted this method I left a trail of broken feathers, which manifest themselves as various collisions and moments of distance in the film. My phenomenological method enables possibility and transcendence but also moments of collapse. This balance

ultimately characterizes the qualities of experience and exploration in CHROMO.

In devising a practical methodology for this project, I find myself positioned at the intersection of two disciplines. The first, experimental film (and expanded cinema), has been my area of creative practice for over a decade. My formal training in the second discipline, namely movement observation, has largely occurred only within the context of this project[18]. Increasingly I noticed connections between this newer field and my previous work and the spirit of experimental film practice. I recognize the challenges in this endeavour however, as Janet Kaylo indicates:

> It cannot be denied that the degree of imagination, intuition, and heightened kinesthetic sensitivity required… makes training in a discipline of movement observation a long and difficult one (9).

During the process of creating CHROMO I was therefore navigating a balance of learning and un-learning, both of which posed challenges to my attempt to avoid a search for cognitive meaning in this experience and in my selection of creative methods.

Movement Observation

In search for a fruitful engagement with physical movement and dance methods, I was fortunate to encounter and receive teaching in two complementary approaches during my research. The first is a particular strain of Laban Movement Analysis (LMA). Rudolph Laban's research and practice exploded into far-reaching and varied methodologies of movement analysis and dance notation.

In a standardized introductory course in LMA, I became acquainted with his system for breaking down human movement into component parts and observing the qualities

[18] As part of my previous theatre studies and practice however I do have training in movement for actors.

they reveal. There are a variety of approaches to this material. On one end of the spectrum, there is a rigorous system of notation devised by Laban to score movement. This system was not suited to my work, nor within my abilities to utilize. It involves a level of analysis that is beyond the scope of this project and not particularly well aligned with my commitment to a posture of openness.

Figure 4. Anna Halprin's dance deck in Marin, CA

It was my good fortune to have the opportunity to pursue a course in the York University graduate program in dance called *Methods of Movement Observation*. Professor Megan Andrews' pedagogical approach to the Laban material was to focus not on a rigorous application of scientifically dissecting human movement, but on a form of gentle observation of the movement of bodies. The observer/researcher position in this practice involves an awareness of your own body in relation to other bodies and the environment. As well it gently observes and re-routes cognitive meaning-making interruptions in the process of observations. Developing an awareness of my own movement preferences and the ways I tend to move in the world also helps clarify what we each are drawn to, notice and overlook in other bodies. Furthermore, acknowledging these unique preferences and my own specific range have helped me define and expand my camera work.

Improvisation

It was by chance that I came across the work of the legendary post-modern dancer Anna Halprin[19], while visiting the exhibition "West of Center: Art and the Counterculture Experiment in America, 1965-1977" at the Museum of Contemporary Art Denver. Her work was featured in a series of photos and videos along with a small wooden deck, representing the large version at her home in Marin County, California where she has held movement workshops and welcomed visiting artists for decades.[20] I was taken with Halprin's description of her methodology, based on improvisation, and her form of dance scoring. The latter often involved the provision of ordinary objects to her dancers along with instructions to perform everyday tasks.

As she explained to Yvonne Rainer, who often similarly based much of her dance practice on repetitions of everyday movements: "Doing a task created an attitude that would bring the movement quality into another kind of reality. It was devoid of a certain kind of introspection" (Halprin, A. and Kaplan 83). In one elaboration of this general attitude (in the score of her 1968 movement study "City maps") her instructions were to

> "adopt a 'general attitude' of openness and awareness to 'sounds, smells, textures, tactility, spaces, confining elements, heights … your own sense of movement around you, your encounters with people & the environment AND YOUR FEELINGS!'" (L. Halprin, and Burns 76)

[19] Halprin is often credited as the founder of post-modern dance, shaped by her creative process and methodology and of direct influence upon direct influence on younger choreographers such as Trisha Brown, Simone Forti, Robert Morris and Yvonne Rainer (A. Halprin and Kaplan 37-38).
[20] For *Always Moving Slowly Moving*, an installation work I completed the following summer, I was inspired to build a deck as a form of choreographic object for visitors, a "viewing platform" for a film loop featuring a dancer (myself) attempting to hold still poses in a windy mountain landscape.

When diagnosed with terminal rectal cancer in the early 1970s, Anna Halprin documented her development of a self-reflexive, healing movement practice. Upon her stunning recovery, she formalized and has shared this approach with others in workshops and her writings in the decades since.[21]

Another element of her practice that strikes me as particularly relevant to my methodology was developed in collaboration with her late husband, the renowned architect Lawrence Halprin. He claimed that:

> An environment is in fact simply a theatre for action and interaction to occur… their events and sequences are non-programmed but occur as a result of the constraints by the environment. (Friedberg 23)

Halprin's approach significantly influenced my exhibition design, manner of scoring the dancers, and helped frame my own approach to film-movement in my ordinary (or in this case, extraordinary) surroundings. Their interdisciplinary work attracted the attention of dance and architecture journals alike (Auther and Lerner 24).

Halprin is still teaching workshops at age 93, I had the incredible privilege of participating in one of her weekend workshops, entitled "Movement Ritual and Dance Explorations" on her famous forest deck in the fall of 2012. She led us in explorations of our own movement according to her scoring methods, and recounted her healing process and its grounding in anatomy. I used the workshop to explore my embodied sense of my genetic disorder while I was anticipating my upcoming annual appointment with my endocrinologist and test results (this workshop was six weeks before my diagnosis). I

[21] She makes no claims that her methods extend life or cure disease, but instead may "expand and transform the *quality* of life" (A. Halprin and Kaplan 207).

cannot overstate the value of this experience and the pleasure of collaborating with international participants from various fields under the guidance of this wise, witty and generous teacher.[22]

Chapter 5: CHROMO

> It has never been my ambition to treat artworks as illustrations of philosophical doctrines. Rather, I believe that the works explored bring forth their own set of concepts. Each and every one of these works of art… represents a productive environment – a heterogeneous apparatus which lets a subject emerge and unfold in accordance with a specific distribution of time and space. (Birnbaum 27)

In describing CHROMO itself, I am eager to remain faithful to the stance I took in the research and creation of the work. As such the following description will attempt to avoid overt linking of the artwork and audience encounter with added layers of interpretation and or theoretical contextualization of my creative choices. The experience itself is ongoing and without end, and likewise I wish for CHROMO to remain an unresolved space of possibility. This chapter will therefore enact the same challenging objective as the work itself.

I will address each section of the film's three-act structure, focusing on the material, tactile, spatial and temporal qualities of the work.

[22] I will share an insider tip: if you would like to still be dancing at age 93, keep your spine mobile – and to that end, stop jutting out your chin and crunching your poor neck, tilt your head to the side and rotate it diagonally when you look upwards. Practice movement and body awareness every day, and if I may editorialize, it probably would not hurt to live on a forested mountain by the Pacific Ocean either.

Enclosure 1

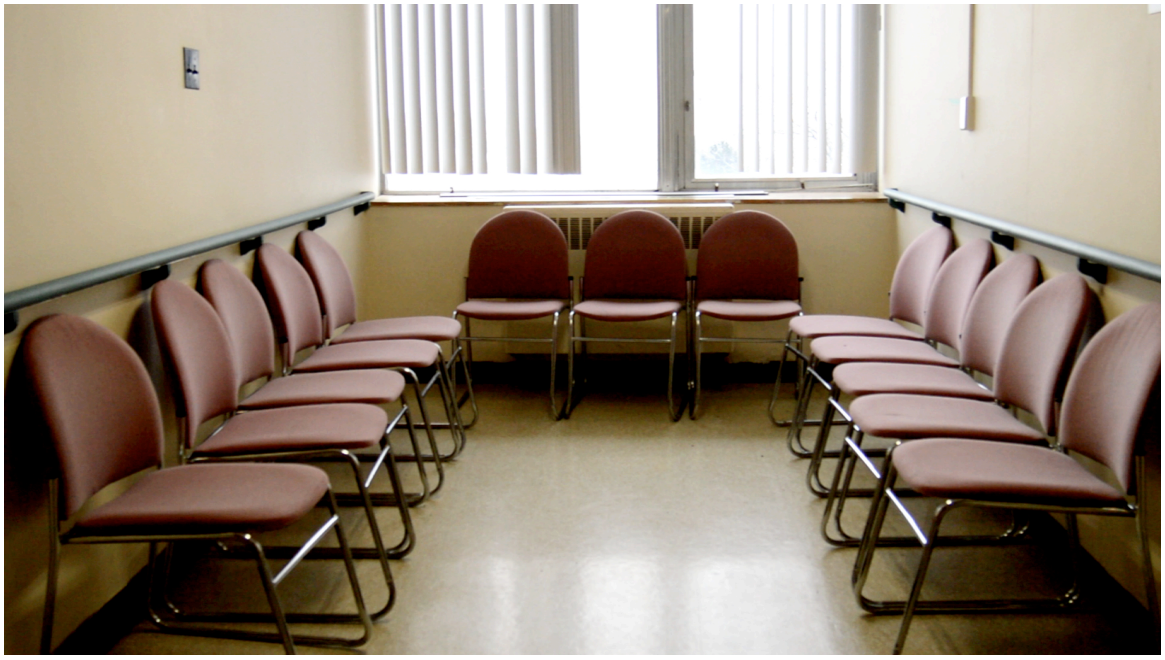

Figure 5. CHROMO – Enclosure 1

The first section was filmed in hospital waiting rooms. There is no body present when we enter the hospital building, the camera is the locus of film movement, a convention that persists throughout much of CHROMO. We quickly cycle through shots from a variety of hospitals. The dimensions of the rooms and arrangements of furniture vary, and the qualities of natural and artificial light suggest different times of day. The rhythm varies from relative stillness (the camera is hand held throughout and never quite stable) in empty waiting rooms, to more active compositions as the camera creates and outlines these spaces. The motion of the camera as it moves from room to room links the spaces together through the direction and qualities of motion, or by repeating a form of camera re-orientation (a re-focusing, or quick camera pans that are continuous but contain a cut between shots and so land in a new space after the motion blur).

The camera is hand-held throughout and as such the choreography reveals my own movement preferences, tendencies and style of engagement with those spaces. Spatially connecting the world of CHROMO, and shaping its overall temporal structure, is the use of hallways to move between various areas. The transitions from room to room use a movement that implies continuity but each new space is clearly from a different time and place. This gradually builds an interconnected hospital that is labyrinthine and endless.

The differences and commonalities of the textural and material qualities in this montage become more apparent with the addition of each new space. The chairs themselves vary in shape and position and their colours and fabrics change, as do the colour and texture of the paint on the walls as well as the style and sheen of the linoleum on the floor. The audio signals the change of space, each room has its own acoustics, spatial tone and atmosphere. The diegetic sound recording comes from rooms that are variously empty or occupied, large or small, carpeted or echoing. The rooms and hallways are new and old, shiny and well appointed or shabby and well used. The waiting room is not a single experience but a shifting, strange yet familiar space with a range of tensions, intensities and paces. As multivarious as this footage may be, it is also specific to my own body's forms of interaction with the space.

The quality of the act of waiting itself is similarly variable. One of the limitations I set for the film production was that all camera work in real hospitals would be performed during my own treatment cycles. My engagement would be entirely different and the stakes lower if I entered these clinical spaces to consider them as an outsider. If I filmed a waiting room, I was there waiting for my name to be called.

Figure 6. CHROMO – Enclosure 1

This improvisational material filmed during my own hospital experience is suddenly disrupted as we turn down yet another hallway that unexpectedly leads to an empty hospital (used as a set). Changes in the sound design further signal a change in intent. This new material was filmed in a rented set on a decommissioned floor of an active hospital. Despite being a movie set, this location remained an evocative space during the filming, situated as it was in an otherwise fully functional and populated hospital. I filmed alone and was immersed in this potent environment. It did not create a dislocation from my wider experience but instead allowed me to explore and enact a larger movement response to the experience. This section of movement work contrasts with the more subtle and everyday movement in the live hospital footage, and allowed for more active and direct exploration of the space of the hospital. The more restrained feel of the previous sections on the surface strikes me as only partially attributable to the

conventional limitations on movement in public. In characterizing the patterns, styles and rhythms of the waiting room passages, I can sense the tensions and connections that are writ large in the more dynamic and dramatic movements of the second section.

A shift in tone, movement and intensity occurs in this second environment, as additional movement possibilities were possible. The previous section involved movements that tended towards indirect tracing shapes, low diagonals along the edges of floors of hallways in passing, with a medium-high camera angled downwards, glancing off of feet, walls and chair legs.

In this new location the choreography shifts noticeably: the flow is freer, movements are stronger and more direct. This is coupled with wider and higher camera angles, an eye-level perspective and central position that commands the space without having to pay heed to the presence of other bodies. In some cases the pace is accelerated, as I run in circles around a bank of brown waiting room chairs, for example. The hallway movements are now smoother gliding motions. I used a wheelchair as a camera dolly in these instances, but my own movements remain palpable, as I am sitting in the chair and propelling it forward by paddling my feet along the floor. The floating quality provided by the wheelchair is in tension with the jarring starts and stops of my feet on the ground. This results in a halting glide, a simultaneous forward and backward motion with tiny reversals throughout – at once both a push and a pull. The editing in these sequences is also more abrupt.

As discovered through improvisational work with Anna Halprin, the embodied movement qualities that characterize my medical experience are marked by an interplay

between gravity and levity, of active and passive weight. The film movement floats and glides or crashes and drags – often in the same sequence. My spatial focus oscillates between direct and indirect, in Laban terminology.

Enclosure 2

Figure 7. CHROMO – Enclosure 2, John Ottman and Valerie Calam

This section begins, like the first, with a revolving door and entrance into the hospital from outside. Once again there is a reference to the world outside of the hospital and this section in particular goes on to blur the boundary between the hospital interior and the outside world. The flash of a pair of feet and the hem of a lab coat usher us through a doorway into this new enclosure, an examination room. We are located in exam rooms throughout the rest of this second act. Once again, rather than fulfilling any narrative expectations that arise in relation to this new space, as if we were on a forward-moving, reliable trajectory – we wait.

The shape of the space, its colours, forms, surfaces and contours, are felt by the camera. In this section there are no longer any hallways or movement through other parts of the hospital. Various exam rooms are blended together, again with continuous camera directions or qualities of movement, and doors feature prominently but are never used. If waiting rooms are a space created by patients waiting, exam rooms are the end of that temporal sphere. In my experience the anticipation of an event is simply prolonged upon entry into the exam room. More often than not another wait of significant duration may occur, this time in isolation, before someone enters.

As in the first enclosure, the hospital footage is interrupted by a contrasting passage that was shot on a set. In this section, the principles of choreography and improvisation, that I have embodied thus far as film movement, are externalized. I worked with two dancers, John Ottman and Valerie Calam, using sparse scoring as an opportunity for experimentation. The room (a dance studio) is large and sparse, with two simple chairs and a white table in front of a large window. The furniture is similar to that of the live hospital's exam room, a box of Kleenex sits on the simple table. The camera remains active and moving, and two figures appear on screen to embody the experience of receiving medical results.

Using dancers rather than actors was very deliberate. This was not an attempt to re-enact a scenario or improvise a narrative. The dancers were classmates of mine from my "Methods of Movement Observation" course at York University. In addition to being wonderful and experienced dancers, they both possess highly developed body awareness, and natural, well-tuned capacities for kinesthetic empathy. They have the ability to work

with everyday movement with an understanding of the fine variations and effort qualities involved. Their bodies are shown in silhouette, emphasizing movement over expression, as well as the play between figure and ground.

Instructions were simple and scoring happened in the moment. I asked Valerie to enter, sit, wait and exit repeatedly. The space is occupied and traversed, but nothing accumulates. The resonant experience is the waiting itself, the qualities of movement within the space. On the other side of the window blind, figures occasionally pass by, their shadows moving with Valerie's entries and exits, or tracing the opposite direction. The white window blind is thin and forms only the faintest of boundary between the interior and exterior. As she waits, Valerie's posture and gestures echo some of those we saw in the first enclosure, interesting parallels since her improvisation was filmed before those live waiting rooms. Valerie's seated foot-swings, for instance, begin with both feet together and then begin to alternate. The same foot sequence was echoed at a later date by a woman in pink sneakers as she waited in a real hospital setting.

Before the sequence where John finally enters the room, we return to the live exam rooms where I explore the tactile qualities of the space. A variety of paper covers on exam tables are observed at close range. The paper's wrinkles, folds, textures and torn edges offer themselves to our sense of touch. Their practical purpose is to separate us from the last and next patient, and their edges suggest the hands and gestures of the nurse or doctor who unfolded, or rolled off and tore each length of paper. One sheet is white and of similar translucency to the blind in the dance studio. Two flimsy white boundaries:

the first between the inside and outside of the hospital and the other barely separating patient bodies and the objects that co-inhabit and inform our interactions in this space.

When we return to the dance set John is present with Valerie, and a beige envelope sits on the desk between them. His outstretched arm hovers above the desk and he performs a demonstrative gesture, sliding his fingertips back and forth between two points on the surface of the desk. The trembling camera stays with his hand as it comes to rest palm down on the desk and then is retracted and his hands folded together. He rises and leaves the room, and the second act ends. This movement section forms the only offer of vague narrative in the film. The meaning is not apparent and the focus is on gesture.

Enclosure 3

Figure 8. CHROMO – Enclosure 3

The final section locates us within hospital inpatient wards. Unlike the previous sections that entered the space of the hospital through revolving doors, this time we see a

hospital complex in the distance through an institutional window as night falls, one of several time-lapse segments in this section. Once again we are in a room, and in a reversal of the first section the camera now typically angles upwards towards the ceiling and traces the boundaries of a shared hospital room and a bed in daylight and nighttime. The time-lapse sections of window views accelerate time while underscoring the slower underlying duration of the experience. The camera movement is languid as we linger on the ceiling tiles, or bed sheets. Smaller spaces, smaller movements and stillness characterize this section. As the locations vary, the larger temporal dimension presents itself. Like the waiting rooms and exam rooms, the time of this experience is multiple. We are uncovering the space of experience of the piece as a whole, as an interconnected and varied superstructure. The movement qualities display certain consistencies and specificity while the locations themselves clearly continue to change.

As the hospital bed itself becomes the latest enclosure, the environment shrinks again (or perhaps we expand to fill it) and the boundaries between the interior and exterior are blurred and slippery. In one scene, we exit the room and there is a shuffling walk out of the inpatient ward to a glassed-in walkway. We linger over a long sunset as viewed through a window overlooking a courtyard (Fig. 8). The hospital walls frame the exterior space on all sides, while the sunset and the outlines of trees are in fact reflections on the glass windows on the opposite end of the courtyard. This is the first section where my own presence is noticeable, briefly here as a shadow in the center of the frame, backing away from the window.

As in the other two sections, there is a contrasting section featuring larger scale movement work. In this case the location is a large empty patient ward. Shot in a nursing school, the camera moves up and down an aisle with multiple beds on both sides. Dragged roughly past the beds, the camera tripod's feet stick and grab at the floor. Unlike the sections where the camera feels (and is) hand-held and evokes relatively restrained movement in public spaces, there is an added force and tension in this scene. This section is an amplified echo of the push/pull motion of the bumpy wheelchair dolly hallway shots in enclosure 1. Here the movements oscillate between a floating drift past rows of beds, contrasted with rougher and more forceful manipulations of a resisting camera, a resisting body.

The diegetic sound emphasizes these movements, as the tripod noisily rattles and bumps along. The wild movement in these scenes is potentially unsettling. Despite being interspersed with moments of stillness the tension does not abate. An active and restless body is present and able to resume the empathetic and noisy style of choreography at any moment, in any direction. The stillness is not still but a moment of unrestricted possibility.

Throughout this section are various textures: flannel sheets, ridged bedcovers, made beds, unmade beds, soft pillows, hard metal bedframes, molded plastic (Fig. 9). My body is again on screen briefly (as legs under blankets) and the angles of the beds and curtains are clearly only possible from a position within the bed itself. Before the film ends the camera moves beyond the confines of the bed itself into the space around it, slowly and shakily surveilling the environment from a standing posture and slightly larger space.

Figure 9. CHROMO – Enclosure 3

A white dividing curtain is hung in this final room, and we examine it at length. The luminosity of this fabric comes from a window beyond it. There is a second occupant in the room. I am being discharged from hospitals in these last scenes, and the space behind the curtain seems still. A nurse can be heard in conversation with my neighbor, inquiring about the qualities of her pain. The final moments in this room are directed towards a section of window beyond the curtains (Fig. 10). Stacks of clean folded hospital gowns line the windowsill, a soft material measure of the days ahead for this patient. Beyond the window is another hospital wing, another wall of windows. As we linger in this space steam rises from a vent and floats past the window. In this tiny measure of space, surrounded by curtains and blankets and a pile of folded gowns, the light of the sun varies as clouds pass. The steam rises on the other side of a pane of glass, floating into the great expanse beyond. After a long duration the camera is lowered and tucked into my

palm, a fast blur of pink. CHROMO ends with a wait at a revolving door as someone enters from outside. Finally a slow shuffling walk traces a path across a grey carpet, past rectangles of bright sun and into the revolving door, exiting the building. The shot ends before the door opens upon the world.

Encounter and the Choreographed Environment

> I want to create a situation where people can become more aware of their own experience rather than more aware of some version of my experience.
> – Robert Morris, 1971 (Bird 97)

CHROMO is not a film intended for cinematic exhibition or gallery installation but is to be presented as an event. The audience is seated in a pattern that suggests a hospital waiting room environment. Two projections exist on opposite walls and the rows of seating are arranged between them. Each aisle contains two rows of chairs, back to back, which means every row must face another row of people and look beyond them to see the screen. The intention is not to create one-to-one pairings across the aisle, the rows will be offset by half a chair's width, but will allow for a mutual observation of multiple bodies in the room. The space of a chair width will be empty after every fourth or fifth chair, resulting in smaller groupings, a further reference to the seating arrangements of waiting rooms, as well as the practice of visiting the hospital and sitting with a friend or family member in smaller groups. I am always struck by this practice in waiting rooms, noticing those who have come alone and with others, and where we choose to sit in order to either be close to others or more alone:

> Where bodily experiences multiply and overlap…certainties are questioned but retain their enunciatory force. Knowledge becomes performance, a recitation, an ordering, an action. (Kuppers 8)

I anticipate that this arrangement will create parallels between the audience's connection to the environment and bodies in the waiting room scenes on screen, as well as the other people in the room. The sections depicting the feet and hands of patients while they wait contain reflections of the physical tensions and dynamics often exhibited. This audience encounter may generate embodied displays of the tension and risk of seated waiting. The emphasis here is not on mimetic response, but the aforementioned resonance and exchange of kinesthetic empathy.

This seating arrangement will be accompanied by a lighting design that further binds the audience to the bodies in the hospital environment (and by extension the spatio-temporal experience embodied by the film). At two points during the event, stage lighting will illuminate individuals within the group, from above. This will not be an abrupt, hard spotlight, but a gentle fade up and down of a light only bright enough to reveal pre-selected chairs and their occupant. Light will spill beyond the individual to include a dimmer view of the neighbouring seats. These sequences will illuminate 4-5 people each time and take place during the intertitles between the second and third sections[23].

One could argue that this method of suggesting of risk, by way of singling out individuals from the group to evoke the calling of names in the waiting room, undermines the stated aim of avoiding symbolism and pre-determined meaning in this project. Importantly, the light effects take place during intertitles, which themselves provide the only appearance of language and narrative structure. On screen these will announce each

[23] By way of post-script I should add that in the first exhibition of CHROMO on August 7, 2013, which occurred after this paper was written, this lighting plan was not used as the room itself was already quite bright. It became a technically unwieldy part of the process to plan and execute. Instead I used green chairs for 3 of the clusters of 6 seats, instead of blue like the rest, hinting at the risk of being singled out.

act, named Enclosure 1, 2 and 3. These short moments of opposition to the otherwise non-narrative, open-ended qualities of the film allude to the phenomenological observation of general patterns, the larger shape of the piece and the cyclical, affective qualities of the experience. These are offered as an anchor of overt meaning, and the contrast should serve to enhance the disorder of the piece in general. Additionally, the lighting effects occurring at this same moment may undermine any offer of narrative-based cognitive recognition and comfort offered by the intertitles by increasing the sense of embodied risk in the audience.

This lighting design will not be effective if an optimal balance of these elements is not found, and an adverse effect occurs for spectators. Both the intertitles and the lighting effects could conceivably activate an ongoing interpretive, cognitive search for meaning that undermines the effort to provide an open, embodied choreographic environment. Instead my hope is that it will counteract the potential for getting lost in the abstraction. As time passes, comfort with the seating arrangement could increase, so I am using these interludes to re-activate bodily and intercorporeal awareness.

A practical benefit of this performance design is that the technical requirements are relatively simple. CHROMO is not intended to end after this single event, I would like to re-install it in different spaces. This is not an attempt to gather audience response data as social science. In addition to opportunities for discussion of the work, remounting the piece offers further chances to observe movement, sense empathetic interplay and enhance my own body awareness. This feeds back into my practice of improvisation, choreography, camera work and editing.

Figure 10. CHROMO – Enclosure 3

CHAPTER 6: Conclusion

CHROMO is an attempt to activate a space of shared corporeal experience. The potentially destructive and alienating nature of current genetic discourse has been acknowledged and then bracketed in order to open up a space of possibility. There is significant evidence that the physical knowledge and experience of patients and an empathetic method of reception is gaining foothold in clinical discourse and practice. Regarding the fruitful potential for the integration of Interpreted Phenomenological Analysis (IPA) methods to understand the "new genetics"[24], Chapman and Smith suggest they are not alone in recognizing that "(w)hat is lacking… is the voice of those directly

[24] Chapman and Smith use this phrase to describe the "scientific and clinical advances of the human genome project" (126).

affected by genetic conditions, and their perspective on quality of life and medical technology" (129).

I am a patient who is able to communicate my experience in my first language, in a medical setting that is familiar and relatively comfortable, in a country with universal access to health care. The treatment I receive in the United States is likewise without personal financial cost as I am enrolled in a research protocol studying my rare disorder. It is easy to imagine financial and social barriers that would exacerbate difficulties in understanding one's genetic disorder and pursuing appropriate treatment. If I did not have access to affordable care and the ability and time to advocate for myself, it seems unlikely that I would have established a relationship of trust in my health team, which in turn relieves a great deal of the burden of self-monitoring and uncertainty.

Contrasting the theory of the clinical gaze (and its depiction of still, passive patient bodies) with the actual qualities of embodied, empathetic hospital relationships that characterized my specific experience was revelatory. Experiments with resistance to atomization, genetic and digital reductivism led to my discovery that alienation and disempowerment are not implicit results of these conditions' ineffability or immateriality. Instead this seems to be a function of our discursive assignation of causal power to genetics (the secret of life!) that otherwise has been located in other external forces. These dominant modes of theorizing the clinic and genetics both may produce a discursive erasure of the body and our agency. What shaped my lived experience however was my embodied encounter with and construction of the space, time and community of hospitals, my physical engagement with the machines and processes of testing. My years

with an asymptomatic genetic disorder could be experienced as an open, active and productive locus of possibility rather than a passive conversation about risk narratives, narrowing odds and probabilities measured against negative outcomes.

The tools and methods used to arrive at these results were found in my art practice. The theoretical readings helped clarify the discursive problems that I initially had set out to combat (and instead was possibly re-enforcing) with new metaphors and alternate truths. It was the practice-based creative research undertaken in the actual time and space of my medical experience however that led to direct, tangible engagement with my genetic disorder. This methodology and my personal results appear to have wider implications regarding the potential for art practice to activate agency both in sudden moments of medical crisis and longer experiences of unresolvable conditions. What we may have interpreted as an alienation of the body, loss of agency and limitation of possibilities may in fact offer an opportunity to establish a new, embodied sense of constantly fluctuating borders and connections, varying dimensions and durations.

Cognitively interpreting and assessing my health status based on the most recent or most dramatic thing I have heard or read about my condition (in the clinical encounter or in journals, popular science articles and online patient accounts) will continue to occur. I am writing this at the end of a week of post surgical follow-up appointments that I entered without anticipation of any sort of conclusive information. Despite my new posture of openness and grounding in my body and experience, I noted that the style of communication taking place in the clinic retained its impact upon me. During one of my appointments we discussed the apparent success of my surgery and determined that I

could wait 8-12 months for further testing. I read this as good news and spent the afternoon contemplating whether I might be in the clear (despite knowing that I still have the genetic disorder and that this first occurrence of disease carries with it an elevated probability that it will return). The following day that schedule was changed and I will instead undergo tests two months from now. While the reason for this does not necessarily suggest cause for increased concern, and nothing had changed in my body overnight, I felt myself reverting to a posture of high alert.

Before this project I would have assumed that these changes signaled actual risk. My response to new information or treatment plans would be to scour the Internet and medical literature for data that could help me interpret what I had been told, my symptoms and likely outcomes. I will sheepishly admit that I did that this week as well, and not in some sort of magical art research modality that restored my agency and ownership of the data. It was a classic case of the panic-inducing practice sometimes referred to as consulting with "Dr. Google". Apparently it will still be necessary to travel down that rabbit hole to face the worst outcome on occasion, be it real or imagined.

What struck me suddenly during this web surfing horror quest was that the impetus for my shift in focus this week was not the discovery of a tumour, symptom or a clinical conversation about risk. The date of my return to the hospital had simply been moved up six months. Rather than being released until my MRI in one year, I require a more invasive test in two months as well, which will require a very brief inpatient hospitalization. What had actually changed was a compression of the temporal trajectory of my experience (which will entail a quicker cycle back through the clinic). I will also be

entering and engaging with a different space (different dimensions and tactile qualities) and embodying a different set of postures. This recognition of the experiential shifts that will occur disarms my initial reaction and reversion to risk assessment and prediction of outcomes. Meaning making thus can again be located in the body and its relation to and engagement with space, time, the environment, and others.

I remain acutely aware of shortfalls in our culturally determined modes of communication about disorder and disease. This is not a case of patient and clinic envisioned as opposing forces. We are all of the flesh and the body, our genetic and medical discourse implicates all of us and can be developed to suit our experience. I was struck throughout this project by the frequent denial of specificity and difference in our embodied experience.

It turns out my main objective was very practical. The difficulty in framing this question reflects the rhetorical baggage and uncertainty surrounding genetic disorders. Might I ask: how do I *absorb* the fact of my genetic disorder? That language suggests this has come to me from the outside, that it was not always present or exists somewhere outside of my body. For five years this disorder existed without significant physical or biochemical symptoms. There was no appreciable materiality or physicality, it was something presented to me to be apprehended consciously, and the tools offered with which to do so were both abstract and mathematical.

My aim has therefore been to create an open experience of multiple possibilities in the exhibition as well. I am aware that I will physically carry the shared, embodied awareness of the exhibition experience of CHROMO back into the hospital waiting room

spaces that I must continue to occupy indefinitely in my medical experience. Much in the manner that the earlier bedside postures of caregiving stayed in my body after the fact (as explored in *Trouble Leaving*), so too will these encounters. While it contradicts my efforts to avoid predicting audience response to the work, I must confess to hoping that this experience may offer that general use to audience members as well. Perhaps in some measure they too could carry a productive aspect or embodied memory of this encounter forward when they occupy difficult medical settings if only to briefly sense their connection to something outside and the presence of other bodies, to their community.

I was pleased to come across a familiar story in a new context during the course of my research. Eighteenth Century author James Boswell's account of an exchange he had with Samuel Johnson was interpreted by theatre scholar Baz Kershaw in a novel fashion. Here is Boswell's story, followed by Kershaw's re-application of it to a performance context, which bears inclusion in full:

> "We stood talking for some time together of Bishop Berkeley's ingenious sophistry to prove the non-existence of matter, and that everything in the universe is merely ideal. I observed that, although we were satisfied his doctrine is not true, it is impossible to refute it. I never shall forget the alacrity with which Johnson answered, striking his foot with mighty force against a large stone, till he rebounded from it, 'I refute it thus!'"
>
> That instant of low drama as the foot makes contact with the stone is the moment of performance as research. Let us call it, just half-seriously, a dictionary-maker's creative practical experiment in energy exchange between his foot and a stone. One kind of knowledge – theory, philosophy, books, libraries, archives – is challenged profoundly by another. As such, twenty-first-century artist-scholars might consider this a quintessential practice-as-research experiment. But where were its results located? Were they in the stone, in Johnson's body, in the story told by Boswell, in this reflection on its significance, or in some relationship between all four and more? (Kershaw 22)

I find Johnson's dramatic physical intervention tremendously compelling as it contains

such a dynamic, expressive finality followed by a lingering complexity. The act resonates with my own style of forceful physical gestures that recur in my own work, the exaggerated slide projector button presses of *Trouble Leaving* and the heavy push/pull of the camera in CHROMO, for instance. It speaks to a physical form of vigorous rebuke that manifests itself in my work as a physical response to a range of challenges to my embodied experience. These challenges are posed by the genetic disorder itself and all of its manifestations and implications, by my adjustment to the clinical environment and protocols, and by a frustration with the discourse and rhetoric that can create such difficulty in sharing and processing this experience.

Kershaw's use of this story as a metaphor for performance as research extends its relevance even further. My own artwork on the subject of clinical experience and genetic disorder is similarly intended as a firm kick to a hard rock. In applying Kershaw's questions about the location of the knowledge created by Johnson's gesture, I would suggest that CHROMO's contribution to meaning and knowledge cannot be extracted from the rock, the foot, the kick or the story itself. Instead it sparks forth from the point of contact between them all. Furthermore CHROMO does not intend to simply show or tell a story of my own experience for further consideration, the rock kicking is intended to take place within the audience encounter. As such it will be as variable as the participants themselves.

The specificity and rarity of my disorder has resulted in a spectacularly difficult problem of comprehension. It defies categorization at every turn, mimics other diseases and evades notice and effective treatment. In a very real sense it creates a dilemma that

reflects and enacts our human condition. This forces me to actively challenge and overcome the urge to establish finality or control, without abandoning my role in monitoring for symptoms and participating in treatment. Monitoring my health to this degree tends to feed back into an expectation of answers, and conversely even create a form of self-reproach upon reporting symptoms deemed irrelevant in the clinic. The challenge is to strike a balance between appropriate vigilance, hypochondria and abandonment of the whole enterprise. This is certainly not the only disease that evades categorization and resolution. Understanding and enacting a productive role in our treatment, and establishing effective ways to communicate and share our experience in the clinic has widespread implications. There is a great need for more satisfying discursive strategies with which patients, clinicians and the public alike might address the medically unknowable or never-ending. Discomfort with a lack of linear narratives hinders our ability to empathize, care for, treat and experience these conditions without being overtaken by existential anxiety and loneliness. CHROMO offers a shared, embodied experience of these states of disorder and illness within the clinical environment. How can we “be” there, how do we visit, arrive, return and leave?

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Appendices

Appendix A: Event Poster

Figure 11. Event poster

Appendix B: Event Program

The printed program is available (see "Accompanying Material"), and the inside cover's double page spread is reproduced on the following page. This introduction appears in the program:

> CHROMO was filmed over the course of one year, while I underwent medical tests, diagnosis and treatment for a rare genetic disorder and disease. Using movement studies and embodied camera work, I explore and shape the space and time of my experience as it evolves. This act reveals unlimited possibility in my lived experience – counteracting genetic rhetoric and clinical discourse of risk, and often narrowing calculations of probability. CHROMO is an open and repeating cycle, existing only now in this encounter, with you, here in this waiting room. (Sara MacLean)

CHROMO

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Array Music, LIFT, Niagara Custom Lab

Figure 12. Event program credits

Appendix C: Photo Documentation

Event photographs by Allan Kosmajac. OCAD U Great Hall, August 7, 2013.

Figure 13. Event documentation

Figure 14. Event documentation

Figure 15. Event documentation

Appendix D: Accompanying Materials

The following accompanying materials are available upon request from the OCAD University Library: the event program containing credits and performer biographies. Anyone requesting the material may view it in the OCAD Library or pay to have it copied for personal use.