

INTEGRATION



INTEGRATION:



Hopes for an
Interabled Future

written and illustrated by

Elizabeth Spehar

INTRODUCTION

"Stories of Wisdom from Bodies in Separation"

When I was invited to be a part of the team for this project, I enthusiastically said YES because of the focus on the body through an artistic lens. The chance to investigate a health and body related subject against the backdrop of a global pandemic was very appealing to me. I have always wanted to explore my own complicated relationship with my health and here was a chance to do so! While considering the subject for my personal creative project, I thought about cycling and the role it has played in my health journey along with the way it has become increasingly popular during the pandemic. A couple of weeks into this project, I ended up breaking my foot and was forced to (temporarily but rather bitterly) give up an activity that was so vital to me maintaining mental and physical health through quarantine. This brought up a whole array of new quarantine challenges and my "Brokenfoot Sidequest" turned into a unique opportunity for me to learn, grow, and transform.

Exploring my health and body experiences through a creative process has been cathartic and empowering. The process has been mentally and physically tiring at times. I'm a little nervous to share but I think that sharing our stories is powerful and important. I hope that my story might help someone else who is going through a challenging period in their bodymind feel a little less alone. And I hope that it might encourage others to consider their health story and maybe even share it in some way.

I am grateful for the chance to share.

BIKER

MYTHS AND MYTH-MAKERS.



I



I LOVED riding my bike as a kid but gave it up for about a decade, during which I experienced nearly countless injuries. Within the last year or two, I feel I have emerged from that span of darkness and lost health. In the spring of 2019, my partner and I took a long-ish ride on the Munger Trail and it was truly an awakening of mind and body. A remembrance in my bones and muscles of how good it felt to pedal and a new awareness in my mind that I could do it. Until that spring day, I had been in the depressing process of accepting that somewhat stable health was the most I could hope for and that health disaster and body betrayal were what I should probably expect. I remember standing on the bridge in Thomson, looking down at the St Louis River and feeling nothing short of triumphant that my body had carried me all that way to see that view.

**Looking south
during a snack
break above the
Saint Louis
River.
Photo taken
15 July 2020.**

Thomson, MN

**This spot is
my favorite
destination on
two wheels.**



I have a rare genetic disorder called OI, which stands for *osteogenesis imperfecta*, or "imperfect bone formation." It is a bone disease that also affects muscles, joint tissues, and organs. Its severity, presentation, and effects vary from person to person. For my body, OI has meant a lot of fractures--about 4 dozen in my 34 years. In April 2020, I celebrated my longest stretch of no fractures with a chilly bike ride.



Celebrating
THREE years
with ZERO
Fractures
on a gravel
ride with
my partner
Cait!
25 Apr 20

After that revelatory spring day in 2019, I began going for longer solo rides on the Munger Trail and developing a bike routine for myself. On those rides, I continued to build confidence in myself and revelled in my newfound sense of body security and safety. The opportunity to simply *participate*, after it had felt so far out of reach for so long, was life-shifting for me. Through participation, I began to notice a growing sense of connection to people and place that counteracted the deep feeling of isolation I had experienced as the result of many years of injury.

The following spring, the benefits I had begun to realize and enjoy took on a new significance when Minnesota imposed a stay at home order due to the Coronavirus pandemic. It was a mild spring and as soon as the temps rose above freezing, Cait and I started going out for bike rides on a gravel road about 20 minutes from our house. Saturdays on that 14 mile stretch of gravel were like a bike parade, with smiling riders on various styles of bikes, from skinny-wheeled gravel bikes, to hardtails, to monster truck-like fat bikes. Because of the highly contagious nature of COVID and with the resulting closure of so many meeting spaces, the list of choices for physical and social activities had been drastically reduced. Happily, biking remained a safe outlet that combined both.

Health related purchases during the pandemic:

Realizing that biking was one of the few healthy and social activities we would be able to do during the pandemic and wanting to equip me with the right tools for safety and fun, Cait researched hardtail frames. We decided on this one from a Minnesota based company. More rugged than my skinny tire gravel bike, a hardtail can get me riding earlier in the spring and longer into the fall. From conversations with local bike shop employees we learned that we weren't the only ones thinking this way. With the supply chain interrupted by the pandemic and increased interest, bikes and parts were selling out everywhere from spring to summer of 2020.



Accidental meet-up on the
Munger! Cait was on a
distanced MTB group ride and I
was on my solo paved ride.
The separate trails we were on
meet in just one spot.
Perfect timing.

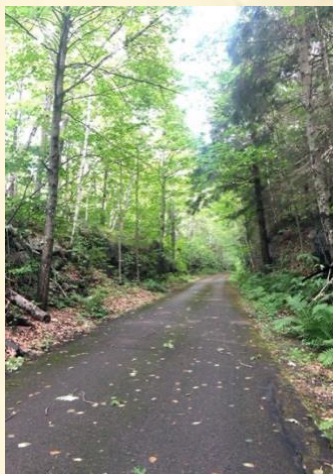
Photo taken on
15 July 20





Friday, May 29th

A long solo ride to think and take a break from constantly checking the news. Protests in response to the police murder of George Floyd had erupted in Minneapolis and all over the country. The next evening, the city of Duluth announced a 10 pm curfew to avoid further violence.



Lovely shaded stretch with ferns galore.

Pandemic plant friends: Mullein

Mullein is indicated for dry, harsh, hacking coughs, and weak **lungs**. It is also **helpful** to the kidney and nervous system. The flowers of this plant are soothing and coat the **lungs**, while the leaves are more astringent and expectorant, helping to the **lungs** to expel unwanted particles that have been inhaled.

Willard Munger State Trail is a paved, 70 mile trail that runs between Duluth and Hickley, MN. Of Minnesota's 23 state-maintained trails, three have been highlighted as accessible and the Munger is one of these three. Developing a familiarity with the Munger has been an important part of my ongoing healing process in a couple of ways.



Safety through familiarity: While new places and spaces present the thrill of adventure, the unknown also presents potential risk to many bodyminds, mine included. Constant vigilance is a drain on energy that might otherwise be used for more pleasurable pursuits; eliminating as many risky variables from a situation as possible can help preserve our precious mental and physical energy.

Relationship to place: Freed-up energy in my bodymind gives me a chance to reorient to my senses. With delight, I observe unfurling leaves, nesting birds, and singing frogs in spring. Thimbleberries, luxurious warmth, and wild blooms in summer. Crunchy leaves, crisp air, and the smell of decomposing plants in fall.

Willard Munger State Trail

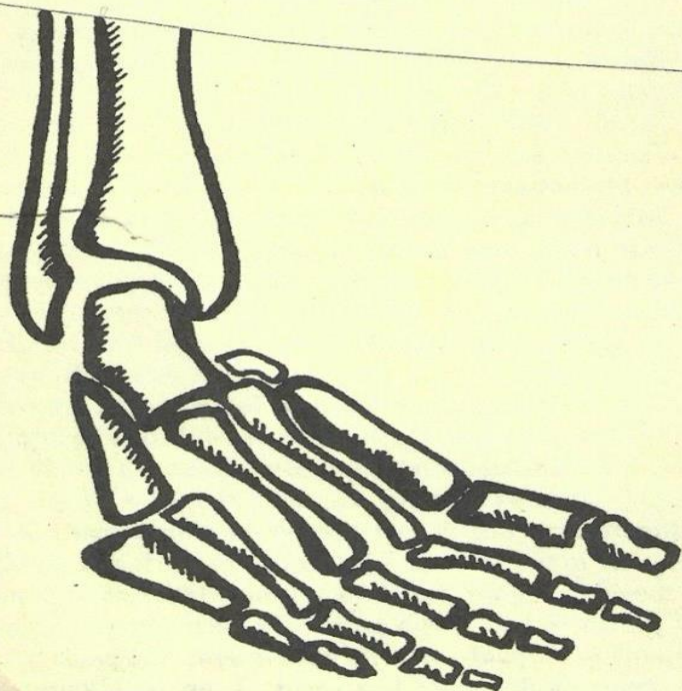
Pine, Carlton & St. Louis Counties



The 14-mile segment from Carlton to West Duluth runs through a spectacular mixed hardwood-pine forest. Sections along the beautiful bedrock cliffs overlook Lake Superior. The trail crosses the St. Louis River gorge and parallels Jay Cooke State Park. There are three moderate grades in a one-mile stretch between Carlton and Duluth, where the trail ends. The first is a pair of 9% to 10% down, then up, grades through an old washout area, followed by a second dip of approximately 8% grades. The third grade is 4% to 6%. The remainder of the trail descends to Duluth at a 1% slope. A parking lot alongside the trail at Carlton is gravel. Duluth has an asphalt parking lot.

II.

BROKENFOOT



Saturday, July 25th It was only 8 in the morning, but you could tell it was going to be a hot and humid day. I was grateful to have gotten such a marvelous ride in the evening before and prepared for a low-key day of house chores and relaxing. Carrying an armful of boxes down the steep basement stairs, I missed the last one and fell to the concrete floor with a harsh smack.

Over the years, I have practiced and gotten very good at the instant injury scan—a very specific and situational form of body awareness.

Assessment Mode: Activate.
Commence injury location sequence
Determine severity of injury

A sharpness in my dominant hand demanded assessment first. Patched with hardware and donor bone tissue, my right wrist has been through a lot and I am exceedingly protective of it. Gently rotating it, I determined the wrist was probably only sprained. With great relief, I allowed my awareness to settle on any other injuries. Left foot. There it is. The unmistakable sensation of a fracture—intense pressure, heat, and a deep throb. Broken. Everything else seemed ok. Body assessment complete, I laid back and began to cry.

Lying there on the basement floor, I cried for minutes on end. My partner Cait had heard my fall right away and rushed downstairs. Cait tried to talk to me, encouraging me to sit up, but I couldn't move. Even in the moment, I had some sense that I was taking a long time to get myself together but the emotional overwhelm demanded release and kept me in a crumpled heap. I cried for the dream-shattering fall back to brokenness and the end of my three-year fracture-free streak. It felt like I was being mocked for having the audacity to reimagine myself as a strong, confident, independent person. Mixed in with my tears for myself, were tears for the people suffering in this pandemic and the collective grief we have all been carrying. And finally, I cried in anticipation of what I knew was coming: a masked-up, anxiety-infused trip to the emergency room.

With Cait cradling my foot and my sprained wrist of little use, we made our way up the stairs as quickly as possible. The adrenaline was wearing off and I was entirely wrung out by the time we emerged from the basement. Cait saw how fast I was fading, weighed the two sets of stairs yet between us and the car, and made an executive decision to call the paramedics for a lift assist. I waited on the floor in my mask and Cait put additional masks and hand sanitizer in a bag. The crew who showed up a few minutes later were the first and will probably be the only people to come into our house during the pandemic. Their presence in our home was a little disorienting but they acted quickly and soon enough, I was being carried out the front door. In light of COVID considerations, the first responders brought me to our car instead of the ambulance and wished us good luck.

Emergency Room

Multiple temperature checks. Questions about symptoms and travel. An especially tense atmosphere. The waiting room at the ER feels small outside the context of a pandemic and I remember my anxiety spiking as Cait wheeled me to it. I remember trying to measure the distance between me and the several other care-seekers and asked Cait to reposition the wheelchair several times. Sheets of plastic had been hung around here and there and various air-circulation devices had been placed around. Doing my best to interpret the invisible lines of air flow and estimating how best to orient my body in relation kept me distracted from the pain in my foot.



A masked-up selfie for my family to let them know I had broken my foot and that we were staying safe.

X-Rays confirmed what I hoped and suspected: My wrist was sprained but not broken. (Hurray!) Foot was definitely broken and needed to be pinned. They put me in a splint and sent me home to wait for a call from orthopedic surgery.



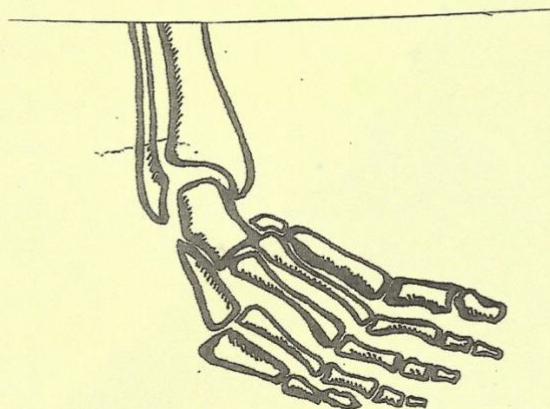
Another selfie to let family know my "rapid test" had come back negative. Moments later, I was on my way to surgery.

Wednesday, July 29th

A few days after our trip to the ER, Cait and I were back at the hospital in an outpatient surgery unit. I was gowned up and ready to go. As part of surgery prep, the nurse had administered a COVID rapid test and we were waiting for the result. About an hour and a half later, the nurse reappeared and told me I had been cleared for surgery. The test was negative. At this point all I had to do was remember my name and birthday when asked and let the professionals do their work. It's a familiar feeling to me by now: safely vulnerable and in the charge of others, getting sleepy and comfy with a warmed-up blanket draped just so, IV started and taped. (Please can I keep my glasses on right 'til I go to sleep? THANK YOU) A change this round: two masks and a surgical hairnet pulled down to their tops with glasses fogging up. I said goodbye to Cait, the nurse took the brakes off my bed, and off to the OR we went.

The thin feeling of safety my private room and Cait's presence had created became thinner still as we made our way to surgery. I remember the sensation of my body winding up tighter and tighter. Growing tenser and tenser. It's like my body was trying to pull itself into an imaginary shell or to conjure up some invisible bubble, as the internal-facing elevator grew fuller and fuller with doctors, nurses, and staff. I realized I was subconsciously holding my breath. I was thrilled to be getting my foot fixed and deeply grateful to the hard-working care providers and support staff but that unfamiliar feeling of wariness towards others crept in. Noticing it and then recognizing I couldn't do anything about it was somewhat helpful. At some point, I was going to have to take a breath. I did my best to relax and the procedure went very well. For the roughly 10-14 days after our visits to the ER and OR, Cait and I tightened up our already strict isolation practices just in case we had contracted COVID at the hospital. To our relief, no symptoms appeared.

On to healing.



INTEGRATION

III.

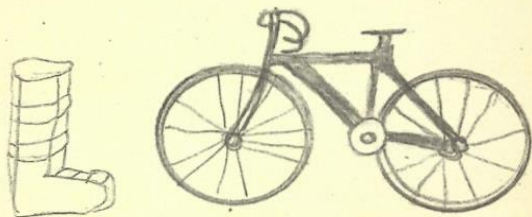


From the chilly spring days of Minnesota's stay at home order, into summer's tumult and social uprising, riding my bike had helped me maintain a semblance of calm within myself and a connection to other people. In a time of quarantine, where we have been isolating from one another to preserve health, dealing with the aftermath of my fracture pushed me further into my own miserable interior with little hope of distraction or escape.



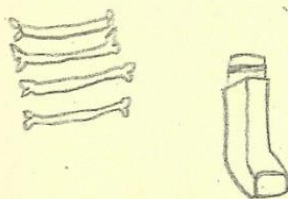
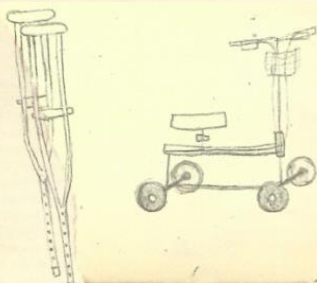
Trying to remain buoyant a month into recovery and reminding myself that healing is ongoing and non-linear.

I struggled. Stuck at home and stuck in my body, I watched my mental health deteriorate. I could see it crumbling but had no idea how to fix it.



I withdrew from relationships that were already difficult to maintain and grew resentful of bodies who got to actively enjoy the beautiful days of August in Duluth. The pandemic had multiplied the negative effects of this personal struggle and the personal struggle multiplied the negative effects of the pandemic.

The pandemic has created distance in some relationships and put strain on others. Simply put, my personal state of resentment and misery, compounded by the effects of the pandemic, strained my relationship with Cait to the point of breaking. Wanting the very best for me as an individual and for us as a team, Cait encouraged me to seek out tools and resources for myself. I started to consider this challenging set of circumstances as an opportunity for transformation. Around me, there was ongoing public debate about health and safety. I had extra time and space due to unemployment. I was dealing with my first fracture in years. And I had the support and encouragement of Cait.





I joined some Zoom calls about disability justice. I read books and articles. My foot had healed well and I got my cast off.

TRIUMPH!

**My foot is healed and
the cast is coming off!**

21 Sep 20

I painted and drew myself as a cyborg. I took carefully calculated risks and began taking my walking boot off for short bike rides.

ULTIMATE TRIUMPH!

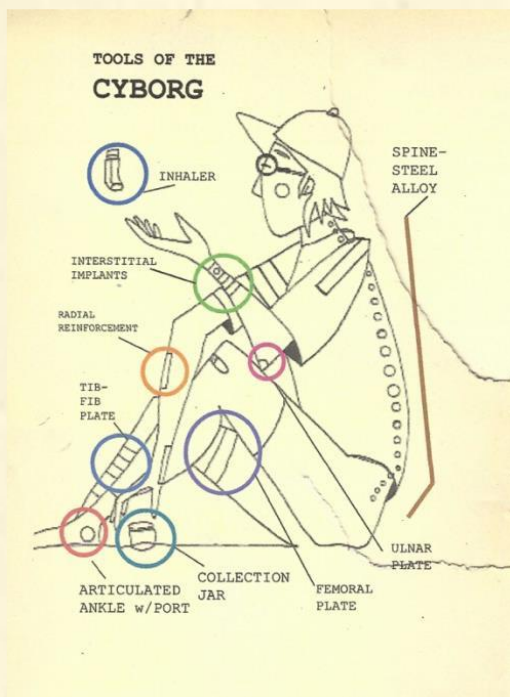
**Three days after the
cast came off, I went
on my first bike ride
since July.**

24 Sep 20



"the dignity of risk"

Thinking of myself as a cyborg was helpful--it allowed me to be playful in how I imagined my body and its various states of being. I reimagined myself as an integrated, whole, adaptive being. When new information is presented in the form of an experience (for example, a fracture) and a new tool is required for best functioning (for example, crutches) the adaptable being incorporates them. In my mind, I placed my walking boot in the same category as my bike: Mobility Enhancement. It might be a little silly but it reshaped how I relate to my injured body and what it's capable of. For example, there isn't one set of tools for "broken" me and another set of tools for "not broken" me. They are all tools of the cyborg.



My entire life, I have struggled to understand and describe my body experience of going back and forth between the physical and mental states that a swift and painful change in health can produce. In a recent interview with Trevor Noah of the Daily Show, disability rights advocate Judith Heumann corrected Noah's description of himself as "able-bodied," saying "I'd describe you as temporarily non-disabled," because, she added, "the likelihood of you [or any other person] acquiring a disability, either temporarily or permanently, is statistically very high." Noah asked her if she was threatening him, to which Heumann of course responded "No." Why is the thought of becoming temporarily or permanently disabled threatening to people who call themselves able-bodied? Obviously, a major shift in health can be really scary and painful.

But there is this pervasive idea (one I began to recognize in myself) that to be disabled means to live a less meaningful or rich life. Without the consideration of and input from people of all abilities, this becomes self-fulfilling. Heumann wasn't threatening Noah. I see her language shift as an invitation to relate to our bodies differently and to question the disabled/abled binary.



**Happy cyborg,
harvesting mullein**



Integration

Hopes for an Interabled Future

In the face of the COVID-19 pandemic, people who have maybe never done so before have had to ponder the temporal quality of health. How might that motivate more of us to dream and build a world that is more accessible and caring in its design? The pandemic has had a disproportionately devastating effect on people with disabilities. It has increased isolation for an already-isolated community, resulted in higher mortality rates, and given rise to the horrifying injustice of treatment rationing.

As we slowly come out of this pandemic, how do we welcome each other back into life together? How can we create literal, relational, and psychological space for the unique bodyminds of all? This pandemic has forced us to get more creative in our practices across all areas of life and we have adopted new routines and ways of doing--distance learning, curbside pickup, telemeetings, masks and hand sanitizers are just some of the ways we have adapted.

Embracing new practices has become critical to our health and the health of our communities. Is it possible for us to carry this health-responsiveness to post-pandemic life and apply it to the broad and unique health needs of all?

Even with vaccines coming, we have a long road of healing ahead of us. I think about the people who have recovered from COVID but who will have lifelong side effects from the disease. I think about healthcare providers who will carry psychological wounds out of this time. I think about people who have been under other forms of duress during this time because of economic strain and those whose health and well-being were under threat long before the pandemic due to racial and climate injustice. I believe that the more we consider and share our health and body stories, the more we come to realize that:

every body is unique in its abilities

every body is unique in its needs

every body is sacred.

**"There is no neutral body from
which our bodies deviate."**

-Aurora Levins Morales, in *Kindling*

**Enjoying a muddy, snowy
excursion on a "fat tire"
bike, November 2020.**

**Cait and I plan to
continue riding through
the winter and I am
training for a race
in May 2021.**

**Thank you for allowing me
to tell you my story.**

-Elizabeth

