The Deaf Poets Society, Issue 3: January 2017

## POETRY SECTION

# Editors' Note

by Ava C. Cipri, Cyrée Jarelle Johnson, and Sarah Katz

There's such *love* in these poems.

Each poet—whether they're meditating on the violence of white supremacy or making intimate the phobia of driving—writes from a commitment to define disability as an illuminating and even divine aspect of the human landscape. A landscape of affection. Of inarguable beauty.

Kay Ulanday Barrett's "More than organs," for example, explores the disabled body as a state of sublime in-between-ness—in between life and death or pain and painlessness—which calls to my (Sarah's) mind a quote from *The Wisdom of Insecurity* by Alan Watts: "The notion of security is based on the feeling that there is something within us which is permanent, something which endures through all the days and changes of life." If there's anything that endures, it's the body-*not*-in-stasis—for each one of us is in a constant state of indeterminacy. Therefore, any sense of security in a body that doesn't change over time, that isn't responsive to environments, that isn't prone to decay, is necessarily false.

Barrett so effectively illustrates that changing body as triumphantly radiant in the final stanzas of his poem:

> If I told you that my life is basically cloud cover, between shade and safe haven, between starling and storm, you'd get why each cough is the split broken back of a palm tree, why my own palms
>
> hold out to the air and
> say *hello*,
> say *I missed you,*
> say *please stay with me here*

I sense that there's a unique power in defining this state of being as a disabled person, even though although we're all—disabled or abled—in an uncertain bodily state. Within the intimacy of that knowing is a crip wisdom—an intimacy that Barrett so deeply and lovingly conveys, too, in his second poem, "To be underwater":

> here's a promise:
> dare to press an ear against my chest
> and on this love,
>
> we'll grow scales for every current
> we'll part every sea like scripture.

So to be disabled is to be divine: capable of installing a new creation myth. That poetics comes through, too, in Andrea

Carter Brown’s “To an Unknown Goddess,” where two disabled characters—children and fellow goddesses—join in a sort of Edenic or pastoral landscape, “stranded here together on this Adirondack porch.”

Similarly, Leah Lakshmi Piepzna-Samarasinha’s “Adaptive device” offers to hold readers in the way that our adaptive devices can form the very seat of ourselves, act like a soft chair for sitting in. (My own hearing aids are, indeed, my comfort zone, although I often forget that they're there, tucked away as they are into my ears.) And Chelsea Grimmer's epistolary poems read as confessions, love letters to those who so often surround us when we're in the depths of chronic illness: doctors and our pets.

Isis Nelson’s “blackness in america (hurts),” a powerful epic written by a 15-year-old poet, is tough love, a demand for action, an elegy for black bodies and for all bodies that bear the brunt of white supremacy. They write the following:

> every human feels the pain of oppressed, enslaved, and suffering peoples /
> every invisible chain can be easily seen once viewed with empathy and compassion for others /

and, later,

> have you ever stared at the abyss and had it stare back
> at you?
> that’s what being black in america is like /

This poem puts another lens on the deep need to reclaim and redefine the Deaf and/or disabled body—to send every person back to themselves, into a space of compassion.

And finally, in Eileen Murphy’s “Down to Zero,” is a landscape I know very well: the phobia of driving. The poem unfolds in a way that is as perturbing as the anxiety itself feels, but it also acts a way *into* the psychic energy of the speaker, her vulnerability. To live there and feel the resolution unfold is to heal. I’ve been carved a space to sit down, to feel the valuable, exposed thoughts and feelings of a friend.

As I reflect on these poems of Issue 3, I feel we’ve traveled a long journey already since our founding in March 2016. The founding was in the midst of a new movement led by Deaf and disabled Americans—before the movement, the election focused on the usual (albeit important) topics: women’s reproductive rights, mass incarceration, immigration, LGBTQ rights—but without the nuance an intersectional lens would provide. The movement has started to turn that tide.

Now, we find ourselves on the other side of the election, our expectations understandably blunted, and our fears heightened for so many reasons. But you know what? We Deaf and disabled folks have been here before. We’ve always lived this, which means the fight isn't over. The movement continues.

Never forget that you matter. We matter. And we will not give up. In the meantime: here's the fuel for your fight.

**Ava C. Cipri** teaches writing at Duquesne University. She holds an MFA from Syracuse University, where she edited Salt Hill. Ava's poetry and nonfiction appears or is forthcoming in 2River View, Cimarron Review, decomP, Drunken Boat, Rust + Moth, WHR, Whiskey Island Review, and PROSODY: NPR-affliate WESA's weekly show featuring the work of national writers. Her award-winning tanka sequence "From the Barre" is featured in AHA Books' Twenty Years, Tanka Splendor. She is anthologized in Red Moon Press' Contemporary Haibun Anthology and SUNY's Unruly Catholic Women Writers II. Next reincarnation she wants to be drawn with wings. Ava resides at www.avaccipri.com.

**Cyrée Jarelle Johnson** is a black non-binary essayist and poet living and working in Philadelphia, 4 PA. Cyree's work explores femininity as resistance and rebellion, emerging femme thought, and community as a site of trauma. Their writing has appeared in digital and print outlets in the United States, Canada, and Europe including Feministing, Black Girl Dangerous, and most recently in the Spring 2016 issue of Bedfellows. Get in touch on their website cyreejarellejohnson.com.

**Sarah Katz** writes poetry, essays, and book reviews. Her work appears in Deaf Lit Extravaganza, MiPOesias, RHINO Poetry, and The Rumpus. She earned an M.F.A. in poetry from American University, where she received the Myra Sklarew Award for her thesis. She has also been awarded the 2015 District Lit Prize and a residency at Vermont Studio Center. Her poetry manuscript, Country of Glass, was named a finalist by Robert Pinsky for Tupelo Press's 2016 Dorset Prize. Sarah lives with her husband, Jonathan, in Fairfax, Virginia, where she works as the Publications Assistant at the Association of Writers & Writing Programs.

## Kay Ulanday Barrett

# More than organs

A person is more than organs, more than skin cell flecks
on bedsheets when your whole Monday is fading
away, out of breath.

The average person breathes seven hundred millions breaths
in a lifetime, but what happens when each one might taste of
blades, of pills. Between havoc and delirium, an inhale can
carve you out when you are all alone. I sometimes think I am
beyond statistics and that life is the trapdoor.

I think I collect knotted rust from bridges in my feet.
I bet warped twine is on a search party somewhere
just waiting to keep me together.

What do you say to limbs when they are good friends with
scalpels? When you feel your insides grate through chemicals
like a marathon with no winner? When the only metal comes
from you, hours of bleeding creatures you have no names for,
how do you answer those texts messages that
ask *Ho*
*w are you doing?*

It’s the salt, the stained smell of iron, the sea of your body is
a wave that makes it impossible to stand. The body is a letter

folded backwards, all strange angles and confessions
bleeding through the surface, making no sense. Like this, I
am something
that feels like it'll always be there but
manages to get lost somehow.

If I told you that my life is basically cloud cover, between
shade and safe haven,
between starling and storm, you'd get why each cough is the
split broken back
of a palm tree, why my own palms

hold out to the air and
say *hello,*
say *I missed you,*
say *please stay with me here*

## Kay Ulanday Barrett

## To be underwater & holy

every survivor is splendor.
every spoon is sacred.
every cough is an altar on the bend of ribcage.
every cane is a drum calling into the earth.

you will be told that you are not worthy of a party.
you will be told you are not a celebration.
why exist at all?

because breath is an exhausted ship lapping the wind.
because your muscles are the fatigue of a sunset.

when your bodies are carnal waves collapsing,
remember: together we can find the shore.
together we can rock and wave and rest and float, together.
we need to move together.
together we can rupture veins into storms and
together we can be the grit as promising as the sound of shells.
our lineage tells us
there will always be land and ocean
in our bones.

after every shift of tide,

no matter the catastrophe,
please hold on if you can.

here's a promise:
dare to press an ear against my chest
and on this love,

we’ll grow scales for every current
we'll part every sea like scripture.

## Kay Ulanday Barrett's Photograph & Biography

[Photo Description: a brown round queer person wears glasses and a fedora hat with purple bowtie. they look forward with a brick wall behind them.]

*Photo credit: Jess X. Chen.

A Campus Pride Hot List artist, Trans Justice Funding Project Panelist, and Trans 100 Honoree, KAY ULANDAY BARRETT is a poet, performer, and educator, navigating life as a disabled pin@y-amerikan transgender queer in the U.S. with struggle, resistance, and laughter. Kay has featured on colleges & stages globally; Princeton University, U Penn, UC Berkeley, Musee Pour Rire in Montreal, The Chicago Historical Society, Brooklyn Museum, and even an invitation to The White House.

Kay’s bold work continues to excite and challenge audiences. A seasoned speaker, Kay has facilitated workshops, presented keynotes, and contributed to panels with various social justice communities. Kay’s ideas have featured in PBS News Hour, Colorlines, Buzzfeed, Huffington Post, KPFA Radio, and WBAI Radio.

As a fellow of both The Home School and Drunken Boat Literary Retreat, honors include: 18 Million Rising Filipino American History Month Hero, Chicago’s LGBTQ 30 under 30 awards, Finalist for The Gwendolyn Brooks Open-Mic Award, Windy City Times Pride Literary Poetry Prize. Their contributions are found in Poor Magazine, Plentitude, The Margins, Kicked Out Anthology, Trans Bodies/Trans Selves, Windy City Queer: Dispatches from the Third Coast, Make/Shift, Filipino American Psychology, Asian Americans For Progress, The Advocate, Fusion.net,and Bitch Magazine. Kay turns art into action and is dedicated to remixing recipes.

Recent publications include contributions in the upcoming anthologies, “Outside the XY: Queer Black & Brown Masculinity” (Magnus Books) and “Writing the Walls Down: A Convergence of LGBTQ Voices” (Trans-genre Press). Their first book of poetry, When The Chant Comes, is due out from Topside Press in summer 2016. See their online wobble on twitter/tumblr/instagram as brownroundboi and on his website, kaybarrett.net

## Andrea Carter Brown

## To an Unknown Goddess

She of the missing digits, who cradles a handful
of sheaves which lost their tassels
so long ago the broken stems flower with mildew

and algae; she whose helmet of neat banana curls
is netted by spider webs, whose two
still perfect ears are stopped by fall’s drift and delicate

left nostril drips a dust strand with which the breeze
toys; she, whose voluminous dolomitic
folds, tender inside of bent elbow, and flexed toes

are dirty for eternity, or at least until they crumble
to grit, whose one bared breast is polished
by elements, her arched neck lovely, her open palms,

despite lacking fingers, relaxed; you, who cannot
see or hear, touch or feel, are more
beautiful for being broken. Once children like us,

imperfect, flawed, were left on a mountain to die.
Tell me, goddess, how we came to be
stranded here together on this Adirondack porch.

**Andrea Carter Brown**

## A Crash Course in Perspective

### i

Babies stare at you. Toddlers too.
In the wheelchair you are just
another big head on a little body.
Eyes, meeting, do not blink.

### ii

The elderly grin, approach, inquire
solicitously, listen, make comforting
sounds. Today they are walking, cause
enough, they know now, for rejoicing.
Tomorrow, well, you never know . . .

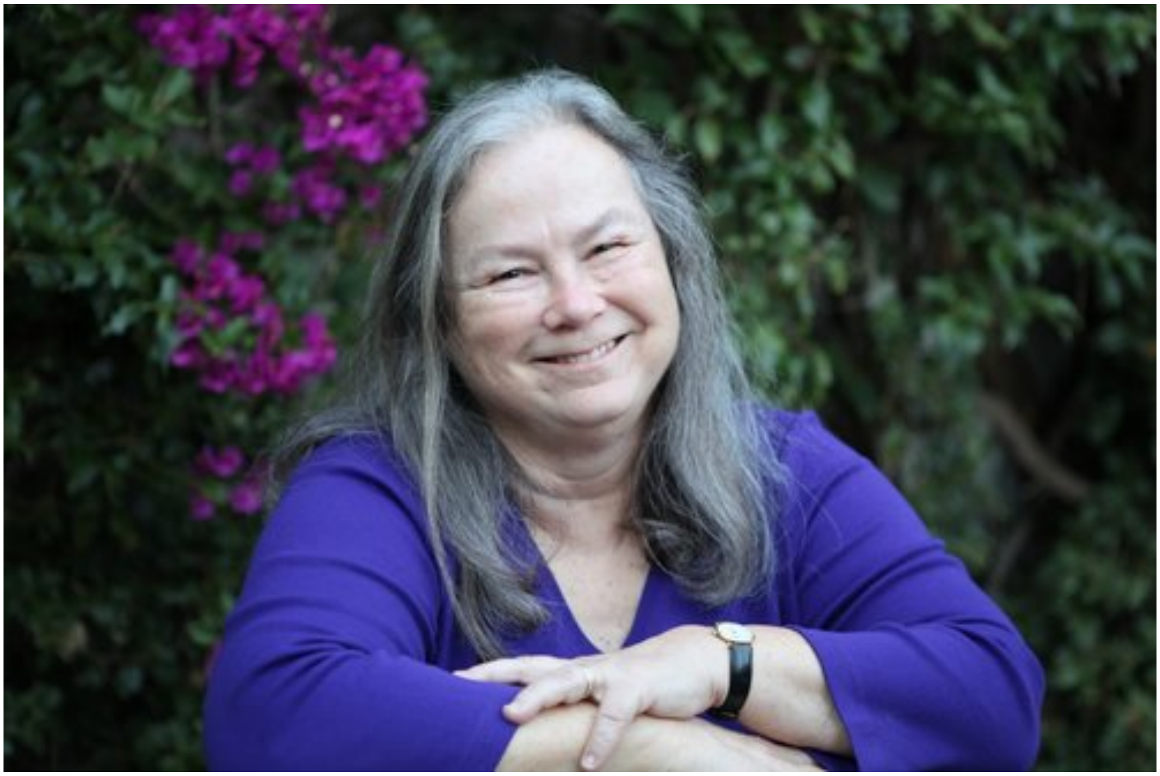
### iii

The truly, that is to say permanently,
sometimes terribly, disabled offer,
if anything, the ghost of a smile,
a flicker of recognition. The way
relatives identify a beloved's body
by the scar only they knew existed.

### iv

How about the rest of us? We rush
to open doors, crack sick jokes or make
unintentionally callous, cruel comments,
*If I were you I’d kill myself,* and soon
as decency allows, hurry on newly
grateful, independent ways, crossing
fingers, toes, thanking our lucky stars.

## Andrea Carter Brown's Photograph & Biography



[Image description: A smiling middle-aged white woman with shoulder-length wavy silver hair in a purple top sits, arms crossed, against magenta bougainvillea flowers in her garden.]

Photo credit: Lauren Del Santoro França

**Andrea Carter Brown** is the author of *The Disheveled Bed* and *Brook & Rainbow,* an award-winning chapbook. Her work about 9/11 won the James Dickey Prize from *Five Points*, the *River Styx* International Poetry Prize and is cited in the *Library of Congress Online Research Guide to the Poetry of 9/11*. Her poetry has appeared in *Southwest Review, The Gettysburg Review*, and *Ploughshares*. A founding editor of *Barrow Street*, she has been Managing Editor of *The Emily Dickinson Journal* and Visiting Poet at Pomona College. She lives in Hollywood, where she grows oranges, lemons, tangerines, and limes in her backyard.

Chelsea Grimmer

## My Dearest Dr. xxxx,

You smell like yellow
and sound like acupuncture
needles pressing into that spot
just below my knees.

With little found in your room to cool
the foot-fever each night
tell your fictions:

And I tell you:

I am healing. I am healing.

Then this waiting:
a yellow room
and few scents to satisfy

soft-salt cravings.

Holding the paper
    that will sand down
        bones: whiten them
a manageable size.

Wanting for an ache
        in the collarbone,
    waiting for a stretch
of the ribs.

I happen in a body: skin and hair
    and muscle and instruments
        compressing this diaphragm
and say again how:

THE PAST IS VAPOR AND YOU WILL DISSOLVE INTO THE
FUTURE IS A FABULOUS LINE OF BROKEN BOTTLES YOU
HAVE NOT YET BROKEN AND THEY SHIMMER IN MORNING
FOGS GO BREAK THEM

And I tell you:

            you are the magnificent healer of the body. you
assigned

a dog to the heart & flesh to smell the flesh. you
assigned
crispy chicken skin to the brain. you assigned
blue pills
to the lungs & say:

YOUR LEFT LUNG IS SMALLER TO
EASE THE HEART AND EASE THE LUNG BECAUSE YOU FIND
YOUR AIR AND HOLD FOR INFLATION THE LUNG AND THE
HEART WILL PUMP THE FASTER MUCH FASTER.

Thus, I am indebted
to the magnetic vibrations----

Yours of yellow
bruising and crackling cartilage,

----R

### Chelsea Grimmer

## My Dearest of Hairy Companions, Mon Chien Blanc,

about the smell of manic:
I hear the bee herds `tween our gazes

(pink tongues make teeth seem white)

you watch the shift the stir you smell
the changing brain blood & sniff it

how to make a scent-map for the body?
skin here bones there & then the flesh?
a taste & trace & map the course

when waiting to be here
the winter turned hot
& the earthquake woke & all
that was left were these

covenants turned to salt
with everything underwater I asked
but did not hear an answer

the bee herds plumbing my bones----

(i surfaced hairless but breathing & bones with bee-filled marrow)

oath to lead a lifetime
of chicken livers     red     pink     wet
& the sound of a brain clicking into

did the ticks do this?
can you smell my dead babies
swim this ransacked tubing?

----

I remember the first time I called
myself into a body & waited for you
to follow: prophetess I called & waited

in the buzzing until I heard
my brain crescendo into

& asked for you & surfaced hairless
but breathing & skimming the intos
sliding a sound called jouissance
& with it each scent I knew

now     my eyes are level with the water
& you smell it. now     I think

the world smells like fresh-cut

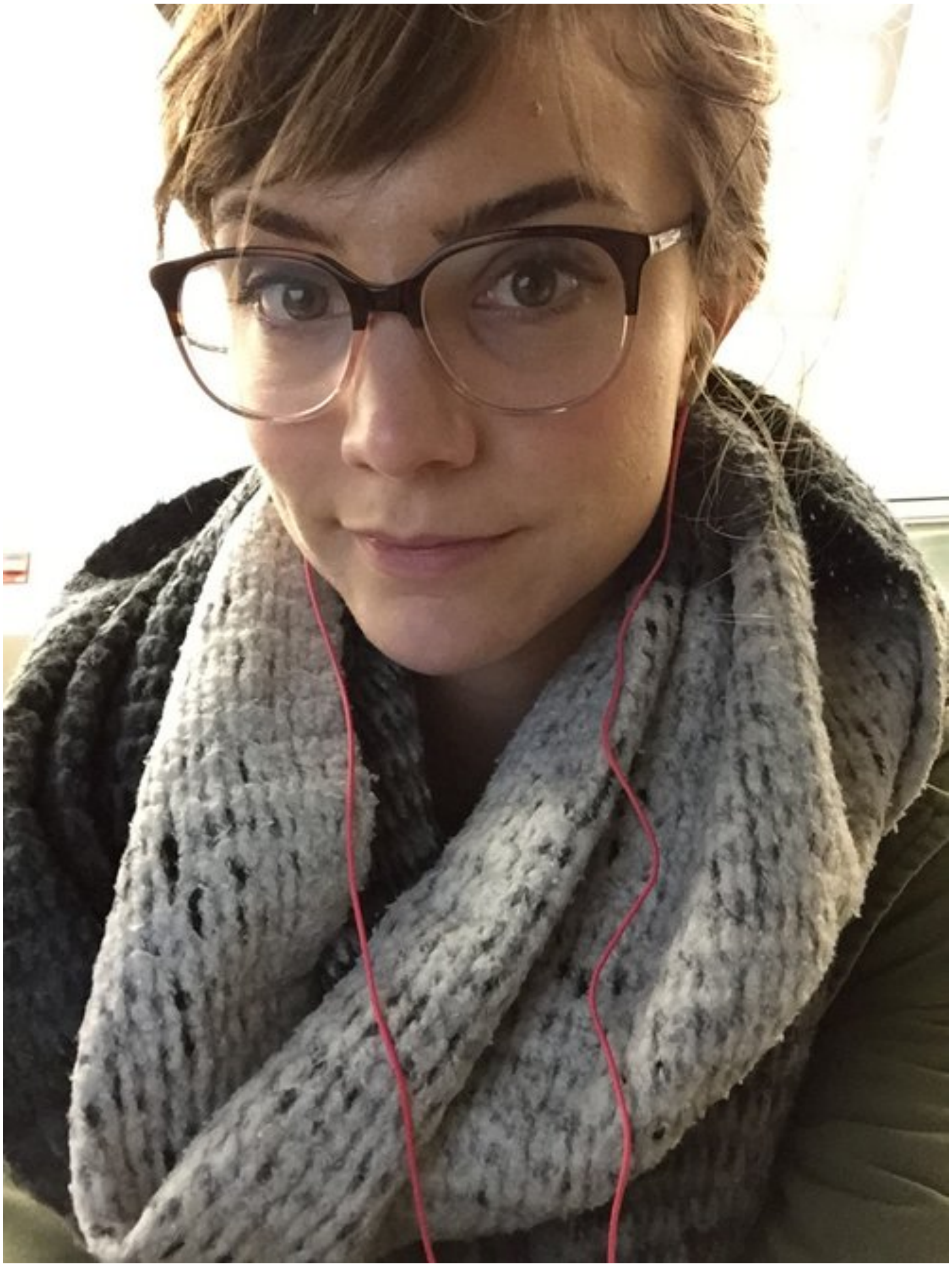
cow skin & I know you smell it     too:
it is the only way to know

you smell it     too     don’t you----

yours like the change
from open to scabbed,

----R

## Chelsea Grimmer’s Photograph & Biography



[Image description: The photo is a close-up of a mid-twenties femme-presenting person with pale skin, dark eyebrows, hazel eyes, and a close-lipped smile. Her hair is brown and pulled back with bangs that go to the side on her forehead. She is wearing large glasses with a pink rim on bottom and brown rim on top. She has hot pink earbud headphones in her ears and is a wearing a large, two-tone grey scarf that covers her shoulders and most of her neck.]

**Chelsea Grimmer** lives in Seattle, WA, where she is attempting a Ph.D. in English and Cultural Studies at the University of Washington. Previously, she lived in Portland, OR, where she did her MFA in Poetry and MA in English, but before that, she grew up and stayed for a while in the Metro-Detroit area of Michigan. Her poems have appeared in a variety of publications, such as *The Portland Review*, *Otis Nebula*, and *Drunken Boat.*

## Eileen Murphy

# Down to Zero

*After Joan Armatrading, Perf. "Down to Zero." (1976).*

Sunset—
in the air I see my breath.
Lost my car
in a parking garage,
ground floor booth
with (bi)pole(r) arm,
seven seas of cars,
seven floors of hell.
Once in a manic haze
I climbed to the open-air roof
& sang to the sky
where snow now covers the cars.

It’s a gray Toyota Camry
& with this depression
came the dread—
of driving.
Driving with the sun
in my eyes. Driving at
night. Driving
in a blizzard.
Driving in no traffic

on a fine day.

I don’t give in entirely
to my phobia.
I drove downtown
to the Chicago Loop
& parked my car here
though I don’t have
an electronic squeal
to guide me
into its arms.

Trembling now,
tired, thirsty, toes numb:
I check license plates
level after level.

It starts to get dark.
Trudging through the slush
in down coat & rubber boots,
Evil Me goes,
*You ought to kill yourself.*
I tell her again,
*Shut up.*
*I will find my car.*

## Eileen Murphy's Photograph & Biography

[Image description: A close-up of a smiling white woman with blonde hair, a black v-neck top, a grey blazer, and silver hoop earrings.]

A former Chicagolander, **Eileen Murphy** lives near Tampa, surrounded by the wild animals of Central Florida, most of them mosquitoes. She teaches literature/English at Polk State College and has recently published poetry in *Tinderbox* (forthcoming), *The American Journal of Poetry* (forthcoming), *Pittsburgh Poetry Houses*, *Thank You for Swallowing*, *Thirteen Myna Birds*, *Uppagus*, *quarterday*, *Right Hand Pointing*, *The Thought Erotic*, *Rogue Agent*, and a number of other journals.

## Isis Nelson

## blackness in america (hurts)

racism and white supremacy have existed since the beginning /
the suffering did not start with a whimper /
no, not a whimper, but a violent, deep and tremulous b a n g /

(it keeps on going, repetitive and loud; it shakes everyone, hurts everyone) /
(our eardrums have been pounded on for so long, some of us forget the noise ever existed) /

the stones in washington, all marble and pure, were laid by our ancestors /
(red stains, open wounds, infections, puss, dark skin cut open) /
once, we were slaves; now, we're barely human at all, it seems /

you're born with one foot in the g r a v e /
your legs stretch -- all you feel is sharp, unnerving pain /
you came into this world hated and condemned /
the system, the one every american is born and forced into, was not made for you /
(white men made this broken thing, they use and benefit from it) /

you can't shake the feeling of being shackled /

your chains are breakable /
(but you, and the people like you, do not have the tools to
shatter any binding) /

even most of our founding fathers, the men (and women) who
began this country “owned” slaves /
(we hold them so high, so reverently; they were never angels or
gods at all) /
they went on a quest in search of freedom /
but, they only found it for themselves /

every human feels the pain of oppressed, enslaved, and
suffering peoples /
every invisible chain can be easily seen once viewed with
empathy and compassion for others /
the ache of prejudice trembles in every heart, even in those who
don't experience it /
suffering poisons every well of humanity it touches /
sometimes i wonder if anyone else feels the piercing, all-
consuming agony we do /

imperialism has dirtied us all /
(the blood shed, domestic or not, is so large that it could turn
the ocean red) /

(we're no better than foreign terrorists when we kill the
innocent, helpless, and oppressed) /

i've watched as black bodies hit the pavement and asphalt, as
the warmth inside them flooded out /

as they're tackled by cops for crimes they didn't commit /

(no g o d saved them) /

i'm tired of war, i'm exhausted by fighting -- i just want
peace /
i've grown up with atrocities and they have slowly killed me /
my country is guilty of many things, the sins are listless at this
point /
(my innocence, if it existed at all, was stolen by a past that is
not wholly my own) /
i don't want this grief anymore, i’ve had enough of it /

african blood that once ran through enslaved veins paints my
house, my horror, my histories /

(that blood runs through me, yet i'm surrounded by it) /
somewhere inside myself, the remnants of tragedy covers
every wall /
(trauma doesn't let go, not even generations later) /

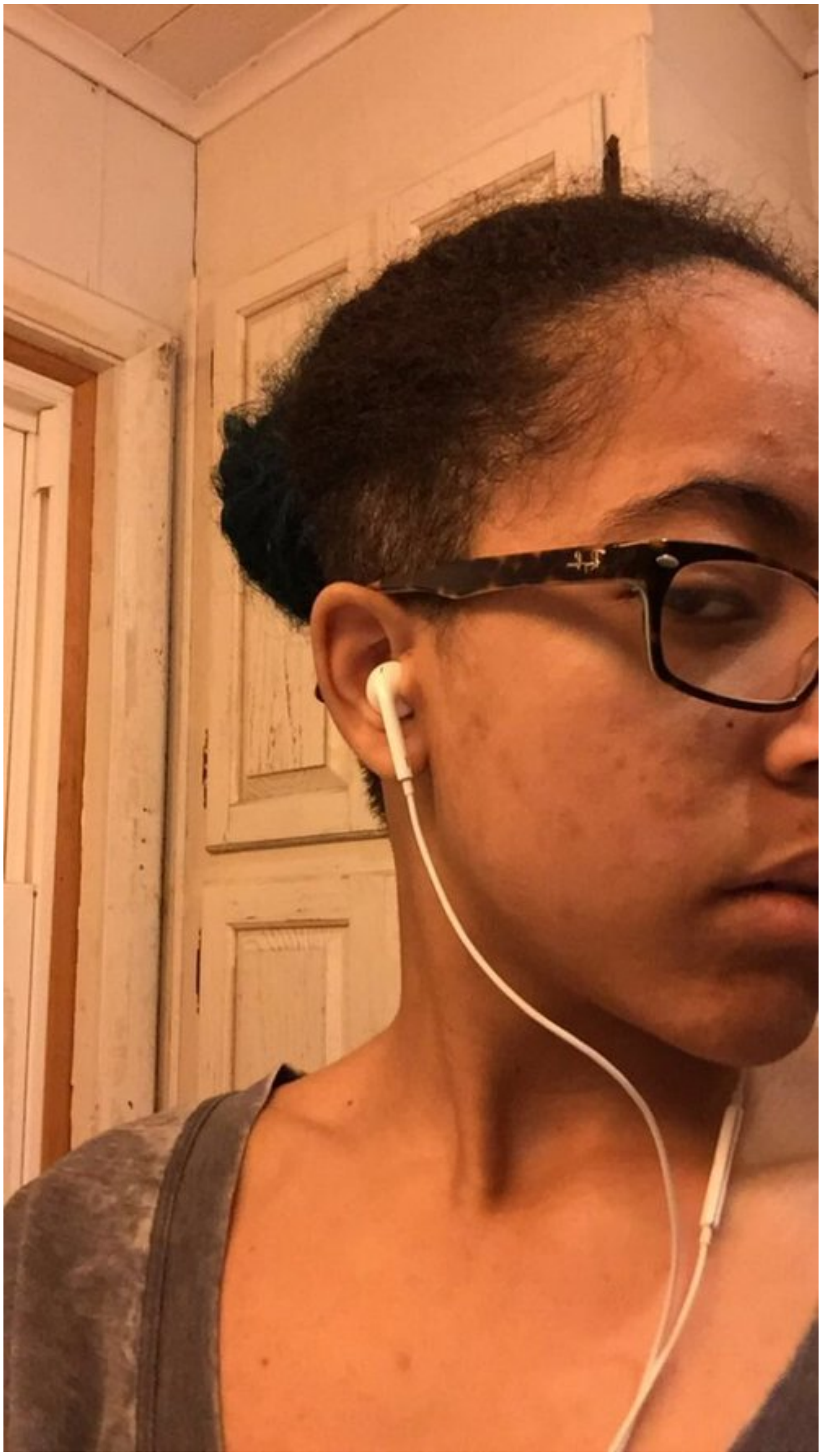
is this what freedom feels like? /
why does it hurt so much? /

every system is built against us, my chest hurts from the very weight of them /
i want real freedom, the type white people have had since the beginning /
the kind of freedom that it'll spill out of my mouth like i was punched in the face /
(tastes like copper and makes me feel a l i v e again) /
the freeness that lets me breathe like i don’t have asthma /

have you ever stared at the abyss and had it stare back at you? /
that's what being black in america is like /

we’ve been staring for a long time /
(we’ll stop one day, but not anytime soon) /

## Isis Nelson's Photograph & Biography



[Image description: A teenage non-binary girl looks at the viewer from the corner of her dark brown eye, through glasses with curved rectangular frames, only one side of her face visible. A gray shirt allows her collarbone and the area below her throat to be shown. Her curly hair, which is also dark brown, is in a bun with the ends being a shade of blue-green cobalt, and an undercut going from the middle of her head down. Multiple hairs stick up all over the place, seemingly unwilling to be held back by any elastic. The young girl is obviously not white, her skin an almost-golden tan with more yellow tones.]

**Isis Nelson** (she/they) is a 15-year-old student and part-time revolutionary in Pennsylvania. She is a disabled, queer, multiracial (black/white/?) girl. She's passionate about activism, human rights, intersectional feminism, and politics. Currently, she contributes to *Affinity Magazine* and *Moviejawn*, while editing for *Siblíní Literary and Art Magazine*. Isis has two blogs – one on Wordpress (isisnelson.wordpress.com), and the other on Tumblr (thelastfangirl.tumblr.com). She also blabs on Twitter @thelastfangirl (twitter.com/thelastfangirl) about nothing and everything.

Leah Lakshmi Piepzna-Samarasinha

## Adaptive device

I mean to give you a poem like an adaptive device
that will hold you just as good
as your favorite cane
bed sling, accessible toilet seat,
rescue ventilator.
Cigarette   crushed pocket Xanax      cortisone shot
Blanket weight  Mad map sign.
Give you the words that are what I know how to do
Give you the words that will take meaning, make language
make a word house to hold you, open doored and firm roofed
Shelter.  The steady tap tap thrum of your cane tip.
The steady roll of the charged battery
of your chair, your brain, humming.

What does it mean to call a poem
an adaptive device?   A piece of beautiful supportive tech
that puts in work to keep you alive?
Something your doctor will sneer at and never understand
*you mean, you just walk around with a cane all the time?*
Something the newly crip say
*I don't want to be, you know, pathetic, I just need a little help.*

This poem will never be found in a packet of home care instructions.
This poem will never be taught in medical school.
This poem is not behind the counter at the pharmacy or OTC.

If poetry is a means of telling the truth, June,
and poetry is as sturdy butterfly as the steady tap of my cane's dance,
then poetry is crip. Then truth is crip.
Then this poem be a crip hand to hold you.

This poem is short enough for even my memory to remember it!
This poem can be whispered or signed.
This poem unspools from a drooling lip
This poem can be sung from augmented communication!
This poem spoken from gesture and nuance
This poem is non verbal
This poem is crip kindness
This poem thinks you are desirable and love is coming,
Is here. This poem will help you get on and off the subway.
This poem is a reason to live.

## Leah Lakshmi Piepzna-Samarasinha’s Photograph & Biography

[Image description: A non-binary femme of Sri Lankan and Irish/ Roma heritage in her early 40s and a mixture of dark brown curly hair with fuchsia pink and gray streaks wears a leaf green dress, bright pink lipstick, and a silver nose ring in a Brooklyn park. She smiles in delight with her eyes closed as she reaches towards a cascade of light purple wisteria blossoms. Her upper arm bears a tattoo of three cosmos flowers and Tamil lettering, which translates to "in my blood a million stories."]

**Leah Lakshmi Piepzna-Samarasinha** is a queer, sick, and disabled nonbinary femme writer and cultural worker of Burger/ Tamil Sri Lankan and Irish/ Roma ascent. The author of *Dirty River: A Queer Femme of Color Dreaming Her Way Home* (Publisher's Triangle and Lambda Award 2016 finalist, American Library Association Stonewall Award winner 2016), *Bodymap, Love Cake* (Lambda Award 2012) and *Consensual Genocide.* She is also co-editor of *The Revolution Starts At Home: Confronting Intimate Violence in Activist Communities.* Her work has been widely anthologized, most recently in *Glitter and Grit* and *Octavia's Brood.* From 2006-2016, she co-founded and co-directed Mangos With Chili, North America's longest running QTPOC performance art tour. She is a lead artist with the disability justice performance collective Sins Invalid, and is a weirdo who writes about survivorhood, disability justice, queer femme of color bodies and lives in Sri Lankan diaspora sitting in her room. brownstargirl.org has more.

PROSE SECTION

## Editor’s Note

by T.K. Dalton

The first few days of this new year in New York have been warm and rainy, entirely unlike what I expect from January, and certainly unlike what I experienced during the January starting with the New Year’s Day on which my wife and I adopted our big, nervous dog. That winter five years ago may have lacked what has come to be known popularly as a polar vortex. That winter five years ago was our last as childless adults. That winter, during which I spent many mornings running my dog before heading off to days of teaching and evenings of interpreter school, was the first of many instances since in which the obligation to care for another being exposed something I’d been avoiding for years: a real reckoning with disability in my own life. Within the institutions of family and marriage, within the roles of first partner and then parent, I began to finally reconcile and adapt to my own body’s peculiarities regarding balance, weakness, neurodivergence, and proprioception. If that last term is a new one for you, I'll give you my favorite definition, from Nancer Ballard: “space without you.” At the moment, that seems an apt description of many institutions of civic life: marriages and families and hospitals and schools. This issue’s six selections of prose fiction and nonfiction each explore a variety of this tension between individual and institution.

If a thread connects the four pieces of fiction, it's the appealing poise of the slingshot-carrying ‘you’ resisting the inertia of a system, an institution, a social ‘space'--and in most of these pieces, that space isn't terribly interested in accommodating the 'you' -- it would just as soon do ‘without.’ Shannon O’Connor’s “The Roommate” explores the nexus of psychiatry, the legal system, and a lurid media. Raymond Luczak’s “Kidnapping” captures the inherent ableism and audism built into traditional family life. Grace Lapointe’s “Categories” captures the difficult initiation into a school system for a child with cerebral palsy. Carolyn Lazard’s “Colostomy Fannypack” addresses gender and beauty in the context of illness and resistance. Taken together, these pieces pay a cumulative witness of venues that often provide the backdrop of narratives rooted in disability experience.

This introduction is being written on the day that the Republican-controlled Senate voted 51-48 to repeal the Affordable Care Act. As a journal, we are beginning a project with the aim of bearing witness to the impact of the new administration on the outgoing administration's imperfect expansion of basic care. We are reading literature of witness for a special section, guest edited by Eileen Cronin, on access to healthcare. We are seeking fiction, nonfiction, poetry, and art; complete details are available here. Submissions close June 1, and the issue will publish in late summer.

The other way I've heard proprioception explained is a reverse of the initial definition, the mirror image of "space without you," and that definition goes something like "the body in space." The two essays in this issue both play with form as a way of grappling with the intersections of disability and perception, expression and memory. In "The Things That Resonate" M. E. Perkins writes, "If bodies were meant to fit a certain natural definition, my hearing loss would be unnatural. I would be unnatural." She describes an experience at camp, where a girl in her cabin showed her that "skin is just skin. It's a cover we can't judge without knowing the kinetic story beneath." As often as the self expands through interaction, it will also encounter its limitations. In "Ten Truths (and Ten Lies)" Cinthia Ritchie writes about her voice:

"There were times when my son was younger that I was unable to say his name. Why in the hell did I give him such a name, the hard constants in the beginning, those guttural sounds, my tongue flailing and struggling and nothing coming out but my own spit? It's a good name, noble and proud. It suits him. But holy crap, the years I stood grimacing and fighting my throat when someone asked, "What's your son's name?" And then the shame, the utter defeat of not being able to get it out."

I know this frustration -- of the body as seen from the outside trapping the language, precise and resonant, on the inside where it does no good -- and Ritchie's piece, along with the others in this rich issue, they reset perceptions about bodies in spaces, even just for a moment, resetting perceptions about the people in them.

I should come back to where I started, to the dog who in that first January knocked me down with her skittish power and my startled disequilibrium. She's older now, and has relaxed a little bit. But two children later, she gets shorter walks and less exercise than I'd prefer. At times, she pulls, and she was pulling on our way out of the apartment building one evening when I'd gotten home later than I'd hoped.

A woman looked in our direction and said the words, "Who's the boss of your body?" It was rude, sure, but more than that it was an attempt at being passive aggressive and clever that only ended up being vague and condescending. Was she talking to me, about my body, with the implication that the dog was and should not be the boss of my body? Was she talking to my dog, about her body, with the implication being that I was and she should stop trying to be the boss of her body? Or some other combination of these audiences or effects (whether desired or achieved).

It all comes back, as everything seems to these days, to witness of power and resistance to its abuses.

**T. K. Dalton's** essays have been nominated for a 43 Pushcart Prize and inclusion in Best of the Net. His fiction and nonfiction are forthcoming in The Common, Duende, and Front Porch Journal, and appear in The Millions, Tahoma Literary Review, Radical Teacher, Deaf Lit Extravaganza, Disability Studies Quarterly, and elsewhere. With poet John Maney, Jr., he edited What if Writing is Dreaming Together? He earned an M.F.A. from the University of Oregon and is currently writing a memoir. Tim lives with his family in New York City, where he works as an ASL-English interpreter.

## Grace Lapointe

# Categories

A long time ago, when I turned five last summer, a lady named Jackie came to my house once a week. She had short hair and red fingernails, and she was always friendly. Jackie worked in the hospital as something called an occupational therapist. Every visit with her was like a miniature Christmas because she brought bags full of the most amazing toys I'd ever seen. There was every kind of puzzle and game imaginable. I did them as fast I could because they were so easy. As soon as I'd finished one, she gave me more.

Later, around July, more people started coming to the house. They asked me lots of questions, like, "What color is my shirt?" or they showed me a bunch of pictures and asked, "Which one is different?" I remember that I liked putting the pictures in the right groups. Later, Mom said the groups were called categories. I'd put all the pictures of animals together, or everything that was the same shape. The strangers kept telling me that I was very smart and that I was doing a great job. Sometimes they'd go into the kitchen to talk with my parents. They didn't realize that I could hear every word they were saying anyway. "She's doing incredibly well," I heard from the other room. "It doesn't seem to have affected her intelligence at all. In most cases, I'd say no, but she definitely seems ready."

Mom would say, in an annoyed voice, "And why is that so surprising?"

That was usually when I stopped listening, because I couldn't understand what they were saying. They used the words "cerebral palsy" a lot. I know cerebral palsy makes the muscles in my legs tight, and that's why I had to go to Boston to see Dr. Schwartz. I liked Dr. Schwartz because he made me laugh and talked to me like I was an adult. He stretched my legs and then measured them with a giant ruler. Then he drew on my feet with a special purple marker that tickled. He molded plaster around my feet and used the plaster casts to make leg braces. The braces kept my legs straight so it was easier for me to walk.

When I started kindergarten in September, I wore my leg braces (Dad called them my "moon boots") and brought along my walker. It's made of shiny red metal and has a basket with Mickey Mouse on it. If I want to, I can make the wheels go really fast. "You can do anything they can do, but you just do some things a little differently," Mom reminded me. I can also do things other people can't do. I was already reading books with chapters back then, and now I can read like a sixth grader.

On the first day, my teacher, Mrs. Adams, came up to welcome me right away. She was kind of old and chubby, but she seemed nice, like somebody's grandmother. The classroom was cozy, with colorful posters on the walls. The desks were arranged in groups, with a nametag for each person. And there were books piled everywhere, picture books and chapter books.

At 10:00, we had recess outside for half an hour. The playground was a strange place, with lots of plastic, mulch, and concrete. I didn't know how to use most of the equipment, but I wanted to figure it out. All around me, everyone was running, jumping, or climbing. I felt like they all had a secret that they couldn't share with me. I saw benches, monkey bars, and plastic slides like the one I used at physical therapy. When Jackie, the occupational therapist, came to my house, we just played games and talked. But physical therapy is hard work because I have to do all kinds of exercises. I don't know how anyone can exercise for fun!

The schoolyard seemed to go on forever, so I just explored it for a while. At first I was a little afraid of falling on the gravel, but I felt safe with my walker. I liked watching its wheels make tracks in the mulch. I tried making different designs, like swirls and figure-eights. All the boys shouted, "Cool!" as soon as they saw my walker. They thought it was way better than their Hot Wheels. "Can I borrow your car?" one boy asked me. I said sure, as long as he brought it to my bench when he was done.

Once I had my walker back, a girl with dark brown pigtails and a big smile walked over to me. She pointed to my basket excitedly. "Hi, I'm Hannah! Mickey's my favorite! I met him when I went to Disney World!" she said, all in one breath. Soon, we learned that we both loved Disney movies and Dr. Suess books. We decided that we had about a million things in common.

Hannah seemed really nice, but a few minutes later, I went off exploring again. Suddenly, this other girl walked right up to me and said loudly, "What happened?"

"Huh?" I said.

"What happened to your legs?" She was standing in my personal space, exactly what Mrs. Adams had told us not to do.

"Nothing happened. I was born this way. It's my cerebral palsy," I explained. I like using words no one else can understand. I don't care if it makes them mad.

She just kept staring at me like I wasn't really a person, just a walker and a pair of leg braces. "Why?"

I wanted to yell at her, "Why are you so rude?!" but I didn't.

After recess, Mrs. Adams seemed angry. She talked to us for a long time about how everyone was unique. This confused us even more. Maybe everyone was unique, but not everyone had cerebral palsy.

That wasn't the last time we heard about being unique. Mrs. Adams had a giant box with millions of crayons, one for every color of human skin. We learned that even though skin came in different colors, our bodies were really the same underneath. We all had two eyes, two ears, and two legs. Eyes were for seeing, ears were for hearing, and legs were for walking. But I knew that already. I know there are all kinds of differences besides skin color. At physical therapy, I met people who have seeing-eye dogs, hearing aids, or wheelchairs. Some of them are my age and some are grown-up. But I don't really know any of them. Besides, no one else at my school has cerebral palsy or anything that makes them walk differently. So even though I know everyone's unique, I still feel different and alone sometimes.

I'm not saying my classmates in kindergarten were all the same, though. There was Julian, who was always nice to me. He always wore his short hair in beautiful designs called cornrows.

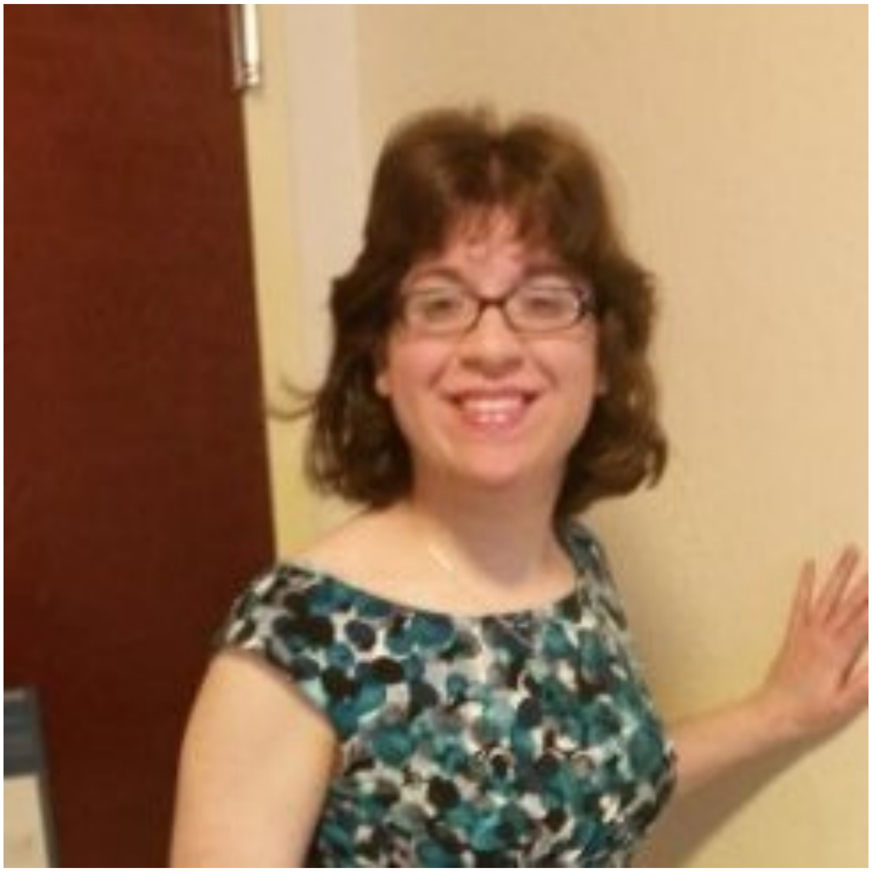
In December, when we were singing our holiday songs, Hannah told me that she celebrated Chanukah AND Christmas. "Daddy is Jewish and Mommy is Catholic," she explained.

"So are you both or half-and-half?" I asked. She didn't answer.

Since I already knew most of the things Mrs. Adams taught us, I spent a lot of time that year reading by myself. Once the letters were just been shapes, but I don't even really remember that. Now I can't look at letters without them magically turning into words. I picked up a book of puzzles from the bookcase. Almost every page had illustrations where something was terrible and wrong, like dogs that could fly or cats with two tails. At the bottom of each page, it said: "Find the one that does not belong." This is a stupid game, I decided. Besides, it was way too easy.

After that, I read a picture book about the Disney movie *The Little Mermaid*. Ariel is one of my favorite characters, but I don't like the end of the movie. I never understood why she'd want to live on land and have legs anyway, so I put the book away. I wished she had stayed in the sea and been happy with her tail.

## Grace Lapointe’s Photograph & Biography



[Image Description:  A young, white woman with hazel eyes, light brown hair, and glasses, smiling and wearing a dress with a blue, floral print.]

**Grace Lapointe's** fiction has recently been published in *Mobius: The Journal of Social Change* and is forthcoming in *Kaleidoscope*. She has cerebral palsy. She graduated from Stonehill College with a B. A. in English in 2011. In 2013, she interned at Beacon Press, where she wrote a readers' guide for *A Disability History of the United States* by Kim Nielsen. She works for a nonprofit organization in the Boston area.

## Carolyn Lazard

# Colostomy Fannypack

The girlfriends come. They bring gossip rags and nail polish to the hospital room. Morphine fogged, I am not sure if this is happening. They ask me if I want to paint my nails. Your nails look like shit. And they are right: my nails remain, probably for the first time in my life, long and unbitten. My wrists and jaw, inflamed, unable to withstand the stress of nail-biting resulted in the long Sally Hansen nails I had always dreamed of. They are brittle and yellow, as anemic as the rest of my body, but long! I am happy.

With the deft foresight of fashionable young women, they cut me very short, square nails, painted a matte grey. A post-recession austerity grey. The safe unimaginative square with the dull flatness of our foreboding futures. Now supplanted by Rihanna-style, almond-shaped nails in pastels,similar to hospital pastels, of historical erasure, amnesia, and out-of-placeness.

The life cycle of trends exists outside of the cycle of disease and decay. Looks are reassembled and repackaged, regurgitated and digested. The illness is never reassembled. The illness is both cyclical and progressive. It is more of the same with slight variations. Evolution determined by randomized studies. At its most horrifying, it feels oppressively teleological.

The doctor knocks and comes in. Smiling, unable to hide her irritation at the number of people in the room. It is important when you are hospitalized for extended periods of time to be surrounded by people. If you have visitors you must be worth visiting. When you are alone in the hospital you feel like you might slip away in the night, without a word. You need a witness.

The smiling, irritated doctor has my daily test results. As heroically as possibly, I say, “'whatever you need to say to me, you can say it to them.” She asks the girlfriends to leave anyway. Your hemoglobin is dangerously low. You are at a 5 and the normal range is 12-16. You are at serious risk of heart failure and you need a blood transfusion right now.

I know this is true.

I know this because I took two steps

to my mother’s car and then found

myself, back to the asphalt,

staring at a clear blue sky

and my mother,

screaming in my face,

slapping me to wake up.

This is why I am in the hospital for the third time in four months.

The day nurse is back with my fresh blood. She has seen much worse. She looks fabulous and is fashioned in such a way that I've never been able to pull off. Firstly, because my mother would disapprove, with the meticulous self-surveillance that immigrants employ to monitor and police their presentation. Secondly, because acrylics and weaves are expensive. Her acrylic nails are long and I watch them: lavender, French-manicured with rhinestones, as they squeeze my morphine bag, peel the EKG suction electrodes off my chest.

The librarians at my childhood public library had long acrylics. Sometimes pierced with rings, sometimes airbrushed with palm trees. They never needed to touch the books. Pages flipped with acrylics. Stamps held by acrylics. Books pushed toward you with acrylics. Acrylics: a buffer between you and the world.

Constructed for both utility and your humility the hospital gown reminds you that your body is not your own. Its empty back is the most humiliating of sartorial impositions. Whether tied in the front or tied in the back there is an assured oval space that leaves you exposed. It facilitates the easy unrestricted access of doctors, residents nurses, interns, and phlebotomists.

Weeks later, I am relearning movement. My occupational therapist teaches me how to: put on underwear put on a bra put on socks put on a shirt button a sweater put on pants zip up a jacket pull my hair into a ponytail loop a belt tie shoelaces. Contracting the muscles in my arthritic wrist to tie shoelaces is like slicing my finger off with a dull knife. I am praised for ordering chelsea boots without laces. I am relieved to have shoes that are both functional and fashionable.

To be chronically ill is to have jammed the cruise control. To see yourself in the course of a trajectory, determined by clinical studies trials, decades of paperwork. To live and die by statistics. To desire to be an outlier in this data set, allowing inclusion in the range of another.

At this rate, I would rather do the colostomy than increase the dose of the medication.

What the doctor actually says: It might be time to snip-snip. She is not looking at me. She is typing with one hand and snip-snipping with the other: moving her index and middle finger in a scissor-like gesture, cutting out the ulcerated part of my small intestine. I have been trying to avoid this surgery since my diagnosis. 80% of Crohn's patients require multiple surgical interventions. More than anything, I am dueling numbers. Sometimes it is reversible and sometimes it is not.

You get on the table, you go under, and you don’t know what you’ll end up with when you wake up. People go in for a colonoscopy and come out without colons. Surgeons must operate immediately based on what they see. They will not wake you up and ask you if you will miss it if they take it away from you.

Useless asshole. How will I wear high-waisted jeans? Will the colostomy bag come in different colors? patterns? Will it be “skin-tone” (white people)? Can I wear it over the waist of my jeans like a fanny pack? Will I have to wear peplum tops to hide it? EW! Who will fuck me now? My asshole was once precious and fragile. Out of its new obsolescence , can I now have anal?

Remember that pain is an illusion. It comes and it goes. If you do not remember that, you will feel like you are dying multiple times throughout the day. The multiplicity of those pangs merely points to their transience.

Went to the Crohn’s support group once, and once only. Everyone is in different stages of the same thing: time passed, spatiated in a single room. The oldest woman in the room no longer has a colon and part of her colon has been used to replace her good-for-nothing esophagus. Doctor’s have the flimsy ingenuity of broke girls repurposing sarongs as skirts.

At the nail salon, palace of ablution:

I hit reset for the week with a fresh set of nails.

I pick colors like “Need a Vacation,” look like Pepto Bismol.

I sit with a copy of OK! Magazine.

I used to be messy but I have become very, very neat. I have fastidiously prepared for anything. Everything must be in order. Always wear clean underwear, you never know when...

you might faint.

your colon might tear.

your knees might buckle.

Shitting, puking, pissing all the time, but my room is spotless. Sometimes I put on an entire outfit and stay in my room. The kind of outfit that I can wear comfortably for 10 minutes. Today I have the energy to put heels on and lie in my bed.

Stick thin arms and big belly, approximating the shape of a child. I used to be big tits, big hips, womanly. Now, I am supporting this orb of activity in my belly.

I am a vomit dispenser but I have gained a few hours of reprieve so I go to a bar just to stand and be seen. Outside, a girl from college I never see comes to me and says,

You look fabulous. Like really, you look fabulous!

I say, thank you with a paltry smile.

No really, what have you been doing?

Oh, nothing really.

But, you looks so different.

Another smile

I am wearing a suede cape with mink trim. It is glamorous and it helps hide the 10 lbs I've lost in a week because my body is rejecting everything, or so I think.

(Crohn's disease, dahhhling. I highhhly recommend it. It does wonders for the figure!)

Search #jpouch on instagram

there are all of these people

who are talking about being proud

and confident and living life to the

fullest and i don't want any of it.

On the DailyMail I read about a woman's life-saving ostomy surgery, She is quoted at the top of the article, “At least with my bag I don’t miss telly to use the loo!”

I am humming a song because the vibration makes me feel better, refocuses my attention away from the pain. I can feel sound from inside my body and it is drowning out the sound of all of the machines.

As if every joint were not alternately whispering and screaming at me to slow down,

to take off these dumbass shoes.

Traipsing across Brooklyn in platforms.

They make me taller, better.

I wear high-waisted jeans too. Pants push into the lower-right quadrant of my belly with every step, just pressing against the invisible turn in my intestines that,

as it's been explained to me by the people who have seen it,

is ulcerated and on the brink of snapping apart.

The dressed body is not a suffering body.

I am a fraud in the realm of the healthy!

Linen and silk-- my placebo, snake oil, and armor.

I am walking, eating, talking, being in the world-- passing,

DUPING everyone into thinking that I am one of them!

Quickly changing ensembles before Death catches up--

## Carolyn Lazard’s Photograph & Biography (Coming soon)

**Carolyn's website**: http://wearecanaries.com/tag/carolyn-lazard/

## Raymond Luczak

# Kidnapped

My smartphone vibrates. I pick it up. It's the latest model. I can video-call anyone, and I can lipread and talk at the same time. It's great. It makes me feel like I'm hearing.

I'm about to call my girlfriend Hannah and ask her if she wants to eat out with me at Pizza Luce. It's her favorite restaurant. It's also the same place where I took her out for our first date. Six months later I got down on my knee and flipped open the tiny velvet box. She signed yes yes YES. She wanted to be my wife more than anything. I never used my voice with her because she wanted to be with a deaf man who could sign.

We started having sex. We couldn't help ourselves. She wanted a baby right away. I said no, not yet. We made love some more. We were always careful.

The logistics for our wedding became a major headache. I didn't want a big-assed church wedding. I wanted to get it over with, but no, she had to think big big BIG. Hannah was lucky that her father had the money. He was bald and round-bellied with a double-chin. He taught genetics at the local university. He said I should call him Alec as if he was my best buddy, but I could tell he didn't like me.

I didn’t like him either.

But we both loved the same woman.

I knew I had the edge because I was deaf. He was hearing and didn’t sign very well. Every time I went to her house, I always signed without mouthing the words in front of him. He had to see that she and I had a language of our own. He was a true foreigner in our world.

Thinking it a call from her about another wedding detail, I click accept on my phone. The wedding is in two weeks. She hasn’t told me yet, but I know she’s pregnant. She has to be. Not sure how many weeks, though. I didn’t mean to find out. I was standing over the toilet when I spotted the home pregnancy test package in her wastebasket. I took it out. I saw the telltale color on her litmus paper strip. That’s how I knew.

I look at the phone’s screen. It’s not her. A thin man with slicked hair parted in the middle and a pince-nez perched on his nose peers at me. His skin is pale. He seems uncomfortable in his three-piece suit. He’s not of this century. He is all scratchy sepia.

I mouth the words as I sign, “Who are you?”

He looks gravely at me as if I’ve sinned.

"What do you want?"

"Me not understand." His signing is precise as a typewriter.

"You sign? Great. What you want?"

"Inform-you baby yours hearing will. Advise you-two move-away now."

"Who you?"

He looks as if sorrow has draped its shroud around him.

"True-business? How you know?"

He merely stares at me.

I notice that he's not holding his phone. His camera is floating smoothly like a Steadicam. There is no video stutter. "Call-me why?"

He brings a finger to his lips, as if to say, "Shhh."

"You odd! Bother-me finish." I hang up. I click on my list of received calls to see what his phone number is. There is none. How could that be?

I wait a day to see if he will call again.

I do not tell my future wife about the call. She would think I was loony.

Two weeks later the wedding goes smoothly.

My hearing parents are a mess when they over-enunciate to me how beautiful our signing was during our ceremony. If only my signing had been as beautiful back when I was young. Maybe they'd have learned my language, my world. Then they wouldn't feel so awkward around our own friends.

My new father-in-law uses an interpreter as he mingles among our deaf friends. I am surprised. Most hearing people talk among themselves on one side of the room. Deaf people stay put in well-lit areas. He's clearly a man with a plan, but I'm not too worried. He'll never master our language after a lifetime of listening.

Seven months later our baby is born. She turns out to be hearing. I don't tell my wife how disappointed I am. She is completely radiant. My father-in-law is already using his voice, cooing and whispering into our baby's ear. Our daughter Alice is already his. It doesn't matter how well she masters our language. The ability to hear will ultimately take her away from us. He gives me a smirk.

I spend the rest of my life like a tornado in need of a town to shred across the plains.

## Raymond Luczak's Photograph & Biography

[Image Description: The B&W photo of Raymond Luczak, who is a white, bearded middle-aged man, was taken by Andrew Bertke and shows the author wearing a dark-colored velour shirt and standing to the side against a white background; he gives a slight smile as he glances back at something out of the frame.]

**Raymond Luczak** is the author and editor of 18 books. Latest titles are *The Kiss of Walt Whitman Still on My Lips* and *QDA: A Queer Disability Anthology.* A playwright, he lives in Minneapolis, Minnesota, and online at raymondluczak.com.

## Shannon O’Connor

# The Roommate

When I was 16 going on 17, I went to Russia and went insane, but that is another story for a novel or two. What I want to write about now is the first time I was in the hospital. My roommate once I moved to the open unit appeared to be a sweet woman who held prayer meetings with her friends who came to visit her. Her name was Carol. She was convicted of murder a few years later.

After I was out of the locked unit, my head still buzzed with thoughts of God and why the world is so demented. Carol was about my mother’s age, and her husband and daughter came to visit her. The daughter’s name was Katrina, and she talked to me about music and things. She wanted to a singer.

I thought Katrina was interested in being my friend because she knew I was in touch with God. She looked older than fourteen; she appeared about eighteen. Her hair was long, and she had black roots with dyed red hair. She looked like she forgot to dye it, because she might have had other things on her mind for a couple of months.

“Wow, I heard you danced in *The Nutcracker*,” she said to me. Word had gotten out in the hospital that I had been in the Boston Ballet's production of *The Nutcracker* when I was a kid and everyone talked about it. I had danced in the show when

I was nine, but I hadn’t taken any dance classes in four years. They didn’t know that there were more interesting aspects of my life that I could talk about, like how I went to Russia and how I was destined to save the world.

There was a guy in the hospital, Matt, who was older than both Katrina and me who liked Katrina. She stopped coming to the hospital because I think her parents didn’t like a 20-year old man looking at their 14-year old daughter. Katrina never told me about her sister or why her mother was there. I didn’t know why anyone went to the plastic castle that passed for a hospital with the tank full of goldfish that spoke to me, telling me that everything would be okay.

Carol’s husband Paul was Italian, unlike Carol, and he discovered that I liked Pepperidge Farm Brussels Cookies, and he brought them to me sometimes. I thought he was being kind to me so he could be saved when I got out of the hospital. I would be magnanimous with everyone who was nice to me when I was released.

But Carol’s eyes would glaze over, and she would take a handful of pills, and she would sit and stare when Katrina and Paul weren’t there. She didn’t understand where she was or what she did. I thought she was like another mother to me when we slept in the same room. But she wasn’t. She was a stranger, and a murderer who had shot her own daughter to death.

*

Three years later, I still drifted in and out of the hospital. I wanted to believe I was in touch with God, I was a fish gasping for air coming up to the top of the tank; I took classes, I had a job at a coffee shop. I went shopping and I bought CDs, I bought clothes and shoes, and I tried to live like a regular person who had never been driven insane by a trip to Russia.

One ordinary day in February, I was watching TV with my parents and I saw Carol's face on *Current Edition*.

"What happened?" I said. "That's the woman from the hospital, Carol. She was my roommate."

"It turns out she did a terrible thing," my mother said.

It had been on the news that on February 14th of that year, Valentine's Day, the same day I left for Russia, Susan shot and murdered her sixteen-year old daughter Krystal, then tried to shoot and murder Katrina and kill herself as well. She told Katrina that she wanted them to all be together in heaven.

Carol and Katrina lied and told everyone that Krystal committed suicide. Krystal's friends were the ones investigating what happened because they said she would never have committed suicide. They said Krystal was a happy person, a normal teenage girl, who would never shoot herself in the head on a cold Valentine's Day morning when she was sixteen.

Shockwaves went through my body. I slept in a room with a murderer. She killed her own daughter, and was crazy enough to lie about it.

She could have killed me.

She could have thought I was her daughter, and might have strangled me in my sleep with a blanket or a pillowcase.

How close was I to death in that room in the hospital? How could I have been a victim in a version of psychotic filicide? I was sick enough, but the people in the hospital put me in a room with a woman who had shot to death a daughter who was the same age as me.

But the people in the hospital didn't know. They didn't know that Carol had murdered her daughter. She was completely insane, maybe more insane than me.

My parents were upset that she had been sleeping in the same room as me. I couldn't tell anyone because I didn't know how to explain the story.

Carol ended up going to jail for the murder of her daughter. The day of the trial, Katrina spoke in the courtroom, "My mother doesn't need jail time, she needs therapy. She needs help. She's sick."

Katrina kissed her mother on the lips in the courtroom. Her father, Paul, put his arms around Carol. I saw it all on the six o'clock news.

I pitied Katrina. I didn't know if she'd be okay. I knew that this is the kind of experience that could screw her up for the rest of her life. Her mother in jail for murdering her sister, both gone, her alone with her father. Would they torture each other? Would they love each other? There was no answer than I could find.  I tried to envision the best.

My hopes for them did not come to fruition.

I moved on with my life, I stopped going to the hospital, and I decided to go to school to study something completely different from me: marine biology. Studying the life of the ocean became my calling. I moved to San Francisco and left Boston behind with its crowded streets and rude people. I went to the opposite of Boston, where everyone was laid back and nobody knew that I used to be a crazy girl.

I did wild things when I was alone in San Francisco, I experimented with men and women, I got an aqua tattoo of an octopus on my back; I did cocaine, though it wasn't stylish anymore. I stayed away from heroin because I knew my fish friends needed me.

I went to strip clubs with friends from time to time. I didn't mind looking at women or men. I regretted watching women, though, when I saw her.

There she was, I would know her anywhere, Katrina, dancing on a stage, fully nude, her hair still long and two-toned, but blonde and black, on her ass a giant yellow butterfly tattoo. I didn't know what to think or do; I just stood there and gaped. I remembered everything, her mother, her father; the picture of her sister Krystal on TV. I didn't want to remember, but it all flew back at me.

I saw her grasping for her money like a fish flapping her fins, and I ran out of the club and to my car. I'd had too much to drink, and I didn't think I could drive, but I sat in my car stunned at the outcome of her drama.

I took some deep breaths. I tried to think of beautiful things, but the sight of Katrina's naked breasts still shone in my mind. How did she come to this? What brought her to the West Coast? I didn't have the nerve to talk to her. She might not even remember me.

After that, I decided to stay out of the strip clubs of San Francisco, and spend more time on the beach, looking at the ocean, trying to find peace in my mind that had been to a dozen different galaxies in the past, but had landed back on earth, where I didn't think I was God anymore, but that didn't matter because I knew myself and what I wanted, and that was to simply look at the color blue until it hypnotized me into sedation.

## Shannon O’Connor’s Biography

**Shannon O'Connor** holds an MFA in Writing and Literature from Bennington College. She has been published in *The Wilderness House Literary Review, Oddball Magazine, Wordgathering,* and others. She writes in the morning and at night works for the corporate grind. She lives in the Boston area, and enjoys reading while taking public transportation.

Cinthia Ritchie

# Ten truths (and ten lies)

## The first lie

Look at me. I look so normal, don't I? So fit, so healthy. I look like someone who runs marathons, lifts weights and swims sixty laps before breakfast. Someone more comfortable in the mountains than an office cubicle, who can build a campfire from scratch, who loves nothing more than running twenty miles on wooded trails littered with bear scat.

I look like a perfectly normal woman of a certain age moving through a perfectly normal life in a perfectly normal Alaska city.

Until I open my mouth. Then there's no way anyone would mistake me for normal.

## Truth #1

I have spasmodic dysphonia, a rare neurological condition that causes spasms in the vocal cords. My speech sounds strained and strangled, like a bad cell phone connection. No one knows how this happens or what exactly causes it, though it is thought to be a misfiring of signals due to a breakdown of the dopamine system in the basal ganglia area of the brain. Like other forms of dystonia, a movement disorder similar to Parkinson's Disease, scientists believe the DYT1 and THAP1 genes, along with environmental stresses and other interacting genes, to be probable factors.

There is nothing I can do to correct this, no way I can force my throat into making the smooth, even speech I desire. I've caught glimpses of my face as I've struggled to speak, seen the grimaces, the twists of my mouth, the way my jaw tightens and contracts with each spasm.

Is that really me, I've thought, looking down quickly and wiping my hands over the comforting firmness of my thighs. Is that really me, looking and sounding like that?

## A stinking lie

My voice is hideous. It follows me around like a dead piece of skin, like the smell of the port-o-potty up in the Glen Alps trailhead parking lot, the sides of the toilet smeared with old shit so that even as you sit down (making sure that your ass never touches that cold and clammy seat), you're aware of everyone else's smells, those hidden smells they try to hide.

My voice is a port-o-potty of stink. I try to keep it hidden but it rises up, reeking of shit.

Of course, I secretly love my shit, my stink. I think we all do this, secretly love the things we hate or fear, the parts of our bodies we struggle and fight against. If I were another woman, perhaps I would fear my breasts or cunt. But I'm not that woman, though sometimes I can feel her following me, clothed in lacy underpants and a cunning bra, all the hated parts of her body conveniently concealed in slippery silk.

I conceal my voice. I don't speak.

That's a lie. I speak as much as I allow myself.

Once, after I accidentally heard myself on a friend's answering machine, my voice wavering and sputtering through that digital darkness, I stood in her bathroom and stared at myself in the mirror. My hands reached out and found themselves around my throat, and it was as if they belonged to someone else, the way they enfolded my neck, almost like an embrace, my throat choking as I pressed harder, a type of apology. Please, oh please.

## Truth #2

I don't want to talk about my voice. Why in the fuck am I talking about my voice?

## A nighttime lie

Sometimes, late at night when I can't sleep and the darkness closes around and films everything in the purple-dead air of winter, I worry that there's no place in the world for me. There's no place where I belong. Where in the hell does a woman with a ruined voice and limited social skills belong?

For years I worked as a journalist and before that as a waitress, both voice-dependent occupations requiring a steely reserve, a hearty backbone to stand up to rude customers or interview senators about the budget proposal. My poor voice slipping and sliding and veering all the over the place. I learned to speak in half-sentences, to eliminate adverbs and adjectives. To get to the point and then shut the hell up. I spoke the way some men have sex, quick and fast and mindless of anyone's reaction.

Later, when I got home, I'd often unravel from the stress of it all, deep in the night after my son was asleep, just me and the dog and cats, the floor littered with books and pet hair. My layers peeling off, my armor evaporating, nothing left but me and my ruined voice sobbing in the night.

Once, in the middle of a particularly intense pity-party, I heard a knocking at the window. When I opened the blinds, a moose peered in at me, its nose pressed against the glass, its eyes focused on me as if it had a message, something it could relay only to me.

Well, imagine!

## Truth #3

These are the things that are impossible to do on bad speech days: Answer the phone, introduce myself at a party, read out loud, say “Good morning,” to my partner, ask for directions, order a sandwich at the deli, answer any type of question, partake in any type of conversations. Talk. Open my mouth. Say one stinking, fucking word.

## A shy lie

People think that I am hesitant, shy, uncertain. “She’s so nice,” they say, in that same tone they might say, “Her face is so pretty,” when they’re talking about a fat woman. They hear me speak and immediately assume I am insecure or fragile.

But I’m not. I’ve danced in topless bars, hitchhiked across the country, ridden a motorcycle through the desert at a hundred and twenty with no helmet, just my hair flying in the wind. I’m stubborn and willful and defiant, and more often than not, I find a way to get what I want.

Still, I often feel guilty that I am not the person people expect me to be, that I don’t live up to their expectations. As if I’m a fraud or presenting a false identity. As if it is somehow my fault that they so often get the wrong impression. It isn’t, of course. But then again, maybe it is.

## Truth #4

There were times when my son was younger that I was unable to say his name. Why in the hell did I give him such a name, the hard constants in the beginning, those guttural sounds, my tongue flailing and struggling and nothing coming out but my own spit? It’s a good name, noble and proud. It suits him. But holy crap, the years I stood grimacing and fighting my throat when someone asked, “What’s your son’s name?”

And then the shame, the utter defeat of not being able to get it out.

“I’d rather not,” I should have said. Why didn’t I say that? Instead I apologized, lied and said I had a cold. I still do this, sometimes, lie and blame my voice on a cold, a sore throat. It’s easier this way. I don’t have to deal with the looks of pity or, worse yet, the way people sometimes step back, as if I have cooties. As if I am contagious.

## An old but ugly lie

My life can be divided into two segments: The time before my voice broke and the time after. The split is jagged and unexpected. Even knowing what comes next, even knowing the inevitable, I still cringe when I remember those first weeks when my voice cracked, my lips stumbling and helpless.

"Do something," I want to yell. "Someone, please, do something."

But there's nothing anyone can do. No one knows why this happened to me, why I suddenly started talking this way when I was fourteen. Maybe I carry the mutated gene and, because of emotional stresses of that year, something in my head broke. Or maybe it was caused by the pesticides we scattered over the fields every spring, or an infection, or the time I was thrown off my horse and landed head-first on the hard, summer-bleached ground, my vision wavering for weeks afterward.

When my voice first faltered, it was blamed on a cold and then a sore throat. When those were eventually ruled out, it was blamed on me. I was too emotional, too nervous; I took too much to heart.

"High strung," the small-town doctor said, his stethoscope cold against my chest. He prescribed sedatives that caused me to slobber in my sleep. I walked around in a drugged fog, my mind cloudy and dead, but still my voice broke. At first this was tolerated and then ridiculed. Finally it was ignored. This was the worst of things, to be ignored, to know that something was wrong but have no one acknowledge it. It caused me to become quiet, to keep to myself for days before suddenly breaking out and turning wild, shouting and moving with a heated energy that frightened yet exhilarated me: That will show them, I thought, though I had no idea who I was referring to. That will show them!

As soon as my energy drizzled down, I became depressed again, lying in my room for hours and planning my own death.

I was so young. I hadn't been properly kissed yet but already I hated myself.

This self-hatred, this shame, would follow me, limp after me, for over two decades.

## An imaginary lie

Sometimes I imagine the person I would be if I didn't have a damaged voice, the person I was meant to be, perhaps born to be, walking beside me like a shadow. I imagine her wearing expensive clothes and sleek hair styles, high heels clipping along the sidewalk. I've never worn high heels in my life, never wanted to, yet this is how I imagine this other side of myself, this undamaged side: pretty and fresh and smelling of oranges and water lilies.

## Truth #5

Twice I was locked up in the looney bin. Crazy, they said. The first time was after a suicide attempt when I was sixteen. This wasn't because of my voice and yet it wasn't not because of my voice. It's hard to like yourself, and forget about loving yourself, when you can't say what you want to say. The second time I was in college. My vocal cords locked up and I couldn't speak, my throat choking as I strained and fought like hell to get out one small slippery word. I ended up on the psych ward, pumped full of medications. How those doctors loved to label me! I was depressed, neurotic, insecure, hysterical. I was afraid of my sexuality, afraid of food, afraid of my own words. I was borderline manic, I was lethargic, I was infantile, I was acting out, blah, blah, blah.

I spent four weeks in that first hospital, two weeks in the second.

Dudes, I want to yell now, my horrible voice cracking. Dudes, I wasn't crazy. I just couldn't talk the way you expected.

## That long, damned lie

For the longest time, for years and years, over twenty-five altogether, I didn't know I had spasmodic dysphonia. I was told that I had a speech impediment and so this is what I believed. Everyone implied that this was due to emotional causes, a weakness in my psyche, and this I also believed. I took on this burden, willingly, unquestioning, because lord knows my voice wouldn't work and lord knows no one knew why.

I felt damaged and helpless, as if there was something rusty and shameful inside of me, something that reeked of old metal. I spent thousands of dollars chasing a cure. I saw psychologists and counselors, attended support groups and 12-step programs. I tried acupuncture and reflexology, was rolfed and rebirthed and even, during one desperate and dark time, resorted to outlandish, possibly dangerous treatments: the "doctor" who put me on a diet of spinach greens and sweet potatoes to align my energy fields; the alternative healer who had me ball up strips of aluminum foil until my fingers bled; and the past life therapist who insisted I was strangling on unresolved karma from the sixteenth century.

Because I thought that there was something wrong inside of me, some deep, personal failing, I learned to keep myself hidden, to not open up too much; to keep everyone away. I became adept at slipping out back doors in the middle of the night, of packing my car and leaving when things got too tight. Twice I almost married but caught myself just in time, taking off with another man, to another city. I spent a good part of my life running away from things that never belonged to me in the first place.

## Truth #6

I talk more easily when lying down. Maybe that's why I've slept with so many men, not for the sex so much as for the talk afterward, my voice rising through the night like desert dust, flowers blooming, the smell of fresh-baked cookies. Wondrous and amazing, the things others take for granted, the things I can't do. And when I can, suddenly, each word becomes a small miracle, round and exquisite. Perfect.

## The lie of a cure

There is no cure for spasmodic dysphonia and some days this brings me down, makes me want to sink beneath a heavy quilt and never emerge. Other days, when I'm feeling more optimistic, I imagine a room filled with scientists, most of them pale and wearing crisp, white coats as they bend over test tubes, bending and reshaping the fraying genes that will miraculously repair my vocal cord nerves.

The recommended treatment course of treatment for SD is botulinum toxin (Botox) injections. By weakening the area where the muscle attaches to the nerve, it blocks the nerve signals prompting the vocal cards to spasm, allowing for smoother, more even speech. When it works. For like a temperamental god, Botox is fickle, granting some perfect voices while doing little or nothing for others. And the side-effects, while temporary, can be difficult: loss of the voice for one to three weeks, swallowing abnormalities, gasping and, in rare cases, breathing problems. After these subside and the voice smooths out, the injections can last anywhere from two to four months, although with larger doses, the voice might remain stable longer.

I tried Botox for over a year, and with little success. After the last course of injections, I walked the dog through the woods. The sweet, chemical taste lingered against my tongue and I held there, sucking it like a prayer. But when my voice returned two weeks later, it cracked and sputtered the same as before. I sat in the bathroom, a pink disposable razor in my hand, imaging how it would feel to slice my wrist, blood shouting over the walls.

Finally, I dropped the razor. I got out of the bathtub. I went to bed.

## Truth #7

Most people tell me that my speech is fine, they grant me this lie.

"You sound like everyone else," they say.

But I don't. Even when my speech flows toward fluency, my words are a lie. I'm never, ever able say what I want, in the way or with the words I want. Always, I edit inside my head, shuffling words, delineating hard and soft sounds so that once my vocal cords open, I can slip another word through before it closes again. This gives my speech a rushed and breathless cadence, as if I am forever running to catch a train.

Yet, I can sing. Most of us with SD are able to sing. It's a flux of the disorder, a wild-card brain-nerve connection that allows us to open our mouths and sing, with little to no voice breaks. So I sing. A lot. I sing at work and at home, while standing in line at the grocery store or driving down the highway. I sing whatever song falls off my tongue, sometimes oldies, sometimes rock 'n roll, sometimes blues and even rap. Because I sing so often, people see me as happy, cheerful.

Once, when I came back from a vacation at work, the reporter at the next desk said, "I missed your voice. It was lonely without your singing."

I almost laughed, what a joke: Imagine, someone missing my voice!

But he meant it. He was sincere. He had really missed my singing.

## A lie of vast proportions

Oh, the relief, the glory, the day I found a doctor familiar with spasmodic dysphonia, who didn't think I was crazy or overly sensitive or insecure. He stuck a scope down my throat, a small camera attached to the end and as I gagged, my eyes watering, my hands clenching that cold vinyl chair, he introduced me to my trembling vocal cords. On the computer screen, they were red and moist, moving in and out. They looked like a vagina, the damp lips, the secret folds and then that hole that you can never quite forget. I watched my vagina-looking vocal cords, transfixed. I had never seen them before.

The doctor explained spasmodic dysphonia and the brain nerve connection. He opened up a book and pointed out passages, told me that vocal cords normally vibrate to enable speech but to those with SD, spasms instead slam the cords shut, rendering speech difficult, if not impossible. I listened, and then I didn’t because I was so relieved, hallelujah! that I couldn’t move. I sat in that ugly green examining room chair and sobbed because, do you get it? It was as if I were suddenly set free, unleased from my bondage. This wasn’t emotional; I hadn’t brought my cracking voice upon myself. I had a disorder, complete with a bona fide medical name. Forget the fact that I was unable to struggle out the name of this disorder. It was still a victory, an affirmation, a confirmation or maybe a communion.

I felt, in a very strange way, blessed. I felt almost holy.

## Truth #8

Here are some other people who have SD: Robert Kennedy Jr., Scott Adams, creator of the “Dilbert” comic strip; radio host Diane Rehm; Chip Hanaver, race card driver; Darryl McDaniels, of rap group Run DMC. And hundreds of others from my online SD support group, people I’ve never met but whom I love, in that way we always love others when we recognize a part of ourselves inside of them.

One man from our group posted about the relief he felt after a successful Botox treatment allowed him to talk with his hairdresser for the first time. Usually, he kept silent. He sat in that chair and nodded his head, so ashamed of his inability to speak that he couldn’t look at himself in the mirror. But after the injection, he was able to talk, and in full sentences. He wept, he said, the plastic cape still draped over his shoulders. He felt such wonder. He felt normal.

## One wonderful lie

Years ago, when I still fought my voice, when I hadn’t yet learned to give in and accept it, to love it for what it was, a flaw and yet also a gift, I flew out to Philadelphia with my son for the selective laryngeal adductor denervation-reinnervation surgery on my vocal cords. This is the only successful surgery available for SD and involves cutting the nerves leading to the muscles on both sides of the larynx and reattaching them with nerves not associated with dystonia, thereby preventing the brain from sending the faulty signals that cause the spasms in the vocal cords. It’s a complicated procedure, with months of recovery time, and I was scared and yet exhilarated at the prospect of soon being able to open my mouth and talk, smoothly and fluently. I would be able to do anything; the world would be mine.

The night before my appointment, I sat in my sister’s apartment, in a spot of streetlight coming in through the window blinds. My son slept on the couch, wheezing from allergies, and I stared at his face, suddenly sure that I would die during the operation, that I would be punished for this desire of mine to speak. I got down on my hands and knees, bowed my head.

"Please," I prayed. "Oh please."

The next day during the pre-surgery exam, the surgeon determined that my type of spasmodic dysphonia didn't fit surgical recommendations. I had a mixed blend of adductor and abductor, the most difficult and rarest form, and there was no effective surgery at that time. His voice was kind as he told me this, as if he knew the cost of hearing such news. I sat in that room, all of my newly-found hopes for the future dissolving around my feet. I had no idea how I would get up from that chair, how I would force my legs to walk out the door. I couldn't understand the point of trying.

But finally I did. I got up and really, it was much easier than I had thought. I walked out to the waiting room and my sister looked up. A patch of sunlight streamed over my son's head, and he looked so perfect and calm that I couldn't swallow.

We walked out into the heat and noisy streets. We walked to the corner where street vendors squatted along the curbs with dusty, glaring umbrellas.

"Are you hungry?" My sister asked.

I stood there amidst all of those smells, my son’s hot hand folded in mine. I stood there and I didn’t think about food or the museums we would soon visit or my broken voice dragging me through the rest of my life. I thought (oh, wild, clever, glorious me!), I thought: Now I don’t have to talk. Now I can still be a writer.

## Truth #9

I used to believe in karma, that we all have lessons we need to learn and that sometimes we are so blind we need our illnesses to give us a nudge in the right directions. I’m not so sure I believe this anymore, all of that New Age dogma of creating our own reality. Maybe we do or maybe our reality chooses us and the best we can do is adapt.

This is what I do know: My voice led me places and I followed, out of desperation sometimes, curiosity others. But mostly I followed because I knew, in some instinctive way, that it would take me where I needed to go. How odd, how unexpected that it led me here to Alaska, a land of long summer twilights and black bears peeking their noses out from the brush when I run along the trails. Evenings spent in the mountains, the sun still high in the sky at ten o’clock. Smells of damp rock and spruce and alder trees. And always, the silver-blue-lavender shadows of the inlet, the tide falling in against my bare feet, cold and salty, the same flavor as my tongue.

I followed my voice to Alaska and built a life of small friendships and large landscapes. Later, I had a son. What a prize, my son. Shining like the tide. I read to him each night when he was small, my horrible voice wavering and cracking, but so what? To him, it was normal, a mother with a ruined voice. For years I was afraid I would ruin him, but I didn't. My voice touched and shaped him but it didn't drag him down. He's grown now, and off on his own, a beautiful, smart and kind man, and each time I hear him say, "Mom," my heart thumps as loud and round as the moon.

My voice is a house. It's where I live. I live in a ruined house with a ruined voice but still, so much beauty between the cracks, the breaks, the struggles of my own saliva. My voice fills my mouth like beach grass. Like wind-polished stone. Like the moose hairs I find along the trail and slip inside my mouth, my tongue and throat thirsty for this taste of wild.

## One final, glorious truth

Summers I run in the Chugach Mountains outside of Anchorage, the trails winding along the peaks and up through valleys so that wherever I look, I see nothing but mountains and green, so much green.

My eyes ache from green. My mouth tastes it. I swallow the color, which is sharp and wild and fills my throat like clover. My breath comes hard and fast, my feet fly over tree roots and rocks. I run for hours, no one around but the dog. I lose myself in the sky and the mountains until I am no longer a mother, a writer, a woman living in Alaska with her partner and dog. I am a breath, a sound, the flutter of wings as an eagle flies overhead.

When I run, I am whole and complete, my body moving in rhythm, my throat relaxed, my breath strong and even. I keep the same wicked pace for miles. I don’t give a damn about my voice. I don’t think of my voice at all.

As long as you’re moving, they used to say back home. As long as you’re moving, nothing can catch you.

I live in a wild place.

I live with a ruined voice.

I live with so, so much green.

## Cinthia Ritchie's Photograph & Biography

[Image description: A white woman crouches with her Labrador/husky mix dog on the far shores of Cook Inlet in Alaska. The Chugach Mountain range rises in the background.]

Cinthia Ritchie is an Alaska freelance writer, novelist and poet who struggles with a long-distance running addiction. She's a two time Pushcart Prize nominee and recipient of a *Best American Essay 2013* Notable Mention. Find her work at *Evening Street Review, New York Times Magazine, Under the Sun, Water-Stone Review, damfino Press, The Boiler Journal, Panoplyzine, Barking Sycamores, Postcard Poems and*

*Prose, Poetic Medicine, Clementine Unbound, Into the Void, Theories of HER anthology*, with upcoming work in *GNU* and Grayson Books Forgotten Women anthology. Her first novel, *Dolls Behaving Badly*, released from Hachette Book Group. She blogs about writing and Alaska life at www.cinthiaritchie.com.

M.E. Perkins

## The Things That Resonate

Setting: Restaurant
Setting: Music/TV
Setting: All-Around
Setting: Implication(s)

The summer before the Olympics (thank God)

WEST WYCOMBE PARK, UK — In the rainy part of England, there's a "grotto" you can stop inside for a moment, at the bottom of a small hill just below the garden's Temple of Venus. Walls spread like legs from the goddess's "parlor," heralding the hidden alcove where she receives and entertains the visitors—the ones frisking over the curving hills or swathing their bodies around the pillars. It's a whitewashed relic symbolic of the universal scar (i.e. she's an outie), and these people, they plaster their biggest You Wish You Were Me! smiles all over it, with a raunchy "CHEESE!" to boot.

This grotto, it's exactly what you think it is—grotesque. The man who built the estate, Sir Francis Dashwood, was a modern guy. Landscaping was the garden variety chichi of the eighteenth century, but Dashwood broke the ceiling, took it beyond, leaped with progress; he excavated the Hellfire Caves, where he and his cadre spent many a bacchanalian night.

"But how can someone be reborn?" Nicodemus asked Jesus (John 3:1-21). And yet here I stand, my fingers spread on the walls of this tiny cave, the muck of cockroaches and secrets slick against my palm. This grotto, it's not a part of the Hellfire Caves. It may have witnessed Dashwood and his hellbent party sprinting for the lake, dressed up in vines and whoops. But there's only room for two in here, a man and his mother, someone and his shadow, a self and a second self.

## Setting: Taboo

A week or so earlier

STANAGE EDGE, UK — I heard about the West Wycombe garden from my study abroad professor Dr. Lesser, #1 World Expert on Gardens, Queer Poetry, and Romantic British Literature. We were three weeks and an official theme song into our program when we took a trip to the moors to re-imagine Jane Eyre's plight. Over the two-hour trek, I kept to the back to chat with Dr. Lesser.

Maybe it was the grainy wilderness, in need of something bolder than just gravestone rocks and high-stepping grass; maybe it was the embodiment of Jane's flight from what she knew; maybe it was our unfiltered conversation and plain curiosity—for whatever reason, there was one question that popped out before I could stop it:

"So, when did you become aware you were a lesbian?"

Setting: A Reflection

Not more than 25 years ago, surely

ANONYMOUS FARM — When she was younger, she dated boys. While she might not have ever got caught up in the drama of asking a guy to a dance, she'd let a few hold her hand at the movies. But after spending a weekend on a farm with her best friend, that all changed.

One day it started to storm, she told me, and they'd been outside feeding the horses. The barn was the closest refuge, so she and her friend took cover while the storm kept up its barrage for several hours. It was during this deluge when she realized that she was in love with this girl, and that she'd probably been in love since the day they first became friends.

The rest she left up to my imagination, although she did say it was like the switch of a light, like she'd been trying to mirror someone else's actions, when the real mirror had always been at her back. She'd only needed to catch a glimpse of movement over her shoulder, of her moving, and with one pivot, she was in control of what she saw. She could do anything.

Sometimes I imagine they were hiding in a real barn, red like the sleepy poppies that populated the frontier. The barns pioneered an organic color then, with walls coated in linseed oil and rust—a mixture that protected the wood from fungal decay and increased insulation in the winter. To purposefully paint a barn red in those days would've been a vulgar extravagance.

When she mentioned the boys she'd dated in the past, it sounded like they were some sort of vulgar extravagance, like the love holiday we're obligated to perpetuate, implicitly and explicitly. But that weekend made it all plain. With rain coating barn walls in warm, familiar friendship, protected from the outside and any of its cold, rotten condemnation, my professor understood herself at a new volume. She'd never known the real width and length and depth of her heart, of all this space for someone like her friend to fill. It was renascent love, natural as a blush, found in a haystack world.

## Setting: The Unexpressed

n/a

NOWHERE — "Hey, let's talk about these things," said my mother, my father, someone, anyone.

Setting: (Un)Readable Bodies

Shortly after I got braces

THE SUMMER CAMP OFF MUDDY POND ROAD — Hair that just crowned her ears, clothes without discrimination of chest or curves, glasses that magnified an intelligence without puberty—this was C, a girl.

To me, she was a he. I did not question or struggle with this idea. The logic was infallible, even in an all-girls camp—until: "She. You meant, 'She went down to the lake,'" my counselor said.

I don't think I could've felt more uncomfortable if I'd tried to take a dump over a squatty potty full of bats. It was the gravest of social sins. Here was something I didn't even have to be taught, this ancient binary code of the world—how could I get it confused?

But still, I read her body as boy. I couldn't reconcile the gangly limbs with giggly laughter. All I saw was a "beware-of-cooties" bowl cut, even at shower time when she'd wrap up in her towel chest-high with the rest of us. And so, I decided I needed proof.

The showers were outside, placed on a wooden scaffold with the heads hanging above each tin partition. Trees fireworked for the sky, leaving shadow and stillness in their wake, interrupted occasionally by girlish chatter. It was a sun-sticky day, and C happened to be showering in the stall next to me. These were old stalls, riddled with stains and chinks by years of rapid-fire, crank-driven bullets of water.  They weren't very big openings, but still I pressed my cheek to the ridged metal, aligning eye to I with this tiny hole in my universe.

Setting: ". . . . . . . . . . . . . . "

n/a

NOWHERE — "You know you can tell me if anyone ever says or tries to do something that makes you uncomfortable, right? If an older kid from the neighborhood tells you to close your eyes while he unzips his pants—come to me. You can trust me. I wouldn't be mad. I would never be upset," said. . . . . .

Setting: (Non)Sense

A long, long time ago

ATHENS, ANCIENT GREECE — If you untether your mind from this reality and your experiences, you might be able to understand the man in the cave below — unaware of Pluto and Charon's orbital staring contest, or the Wikipedia game of following link after link until you inevitably end up at Philosophy, or the coyotes that devoured half of a local mechanic's 40 cat population, or the white coat scientists and black coat preachers, or the waiter that brought you rice with your burger when you said "fries" definitely "fries," or the house that was so tiny the family had to eat in shifts, or the uncle that wanted to get in every snapshot, or bald tires, or the butterflies that taste with their feet, or the box of 76 trombone paper clips — who's only ever known a wall and its shadows.

But when he emerges?

Setting: Regression

Unable to recover data (time/date)

THE WEIRD PART OF AUSTIN —

"Kaci's not coming? Just you and me?"

"Crap. It's almost midnight, and I just made this drink."

"That was disgusting. I hate chugging."

"I think you can see my underwear in this dress."

"Nah. Too far. Let's see, if I can just maybe—if I aim for the balcony—ha! Look, it just barely made it on to the porch. Imagine someone glancing up and seeing underwear just hanging there."

"Gah, where's are all the damn cabs? What if—hey, what if we asked that Big Bites delivery guy to take us—hey—hey!! Ha, just kidding."

"Chupacabra first? I'm down. But let's end up at Aquarium by the end. You'll be the one on the bar with me tonight—nope, nope, no backing out!"

"Yeah, look. He said he's at a strip club, and I told him I'd be more than happy to take all my clothes off for him. And look what he said back. Jerk, right? I'm basically serving myself up—no, yeah, please, you text him. I don't even know you, ha, but you'd still say something better. I always say stupid stuff."

"The random strangers you meet in bathrooms. It doesn't get better than that. Screw him, though. I need another shot."

"Shakespeare's? Never mind, the line is shorter at Cheers."

"Oops, sorry. These heels were a bad idea. Don't let me break an ankle."

"Blowjob shot! Let's do it! Do you want—no—okay, I'll sit on the bar, and you can take it. Yeah, you take it from between my legs. Have you not done these before? With me and Kaci?"

"He still hasn't texted back. Asshole."

"Tequila? Takin' this shit to the next level. Too bad we're wearing skank dresses. Otherwise… body shots!"

"I just wanna dance. Yeah, let's go to Blind Pig."

"Nope. Still nothing. Fuck him. I'm gonna find someone who appreciates this."

"Wait—my friend—did you see the other girl I was with? She said she was going to the bathroom. I can't find her. No, look, I've got all her cards, so I need to find her. ."

"Your face. It's not unattractive."

"Can we—would you mind waiting a moment? I need to find her. I don't know how she's going to get home without her stuff."

"I'm fine, I'm fine. Fuck these heels. Sorry. Can you—"

"My toe's bleeding. Fuck. It's bleeding a lot. No, I'm fine."

"Sorry, I'm drunk. Yeah, can I—I need to hold onto you."

"Sorry. I keep doing that. I'm drunk. I just need to make sure your face isn't unattractive. I'm drunk."

"This is your car? Nice. I like it. I don't know anything about cars."

"What? You don't have a condom?"

"Yeah, no, I'm good. I literally got tested literally two weeks ago. Clean."

"I'm really good at this."

"Do you want to come inside?"

"Wait. Stop. Stop. Fuck, where's my hearing aid? Stop. Shit. We've gotta find it. They're $3,000 apiece. What? Yeah. Maybe it fell down the side of your seat, when I—I—I'll check the floorboard. What?"

"Yeah, I've got all my stuff. Thanks for the ride. Goodnight."

"I'm not this girl.

I'm not this girl.

I’m not this girl.

I’m not this girl.

I’m not this girl.

I’m not this girl.

Oh god.”

Setting: The Prospect

A longer, long time ago

THE ADULLAM CAVE, JUDEA — The spider would’ve been an acrobat. Those guys in the circus with the rotten smiles and greased lives—they seem so free. Day after day, after the collective sitting and settling and searching the oily bag of peanuts, after the elephant's wobbled through a few tricks, the high-fliers come out. These guys, they could've worked at NASA for the way they've tamed gravity. They know the bend, the pull, the tuck, the unfurl, the catch—they understand that all of these must come out of the corner of gravity's eye. The spider would've been good at that. It would've had no qualms about climbing to the high, starting platform. It would've loved the bold sweep, like the women who draw their eyeliner along the bottom edge. It would've been good at catching its fellow partners, with fingers webbing around forearms.

But thank God spiders don't fly.

Thank God this spider made this old, old cave his home. And when he felt the gentle wind, a nudge, he began to spin his wild web, a silent symphony of strings winding through pizzicatos, sul tastos, and vibratos, spiraling into a sparkling crescendo, the grand 'ole Happily Ever After, complete with marriages and the punishment of evil, after men have come home from the war, lives lost for silk like this web, for the dress it becomes, the slutty red trap sliding smiles across the bar, so soft, so very soft. And then, the spider sighs. It is finished.

There are ten eyes in this dark cave, two that blink and eight that don't. There's also a sound coming from the bright gap. It's sharp, like swords outside their sheaths, and getting sharper, like a king's steely stare, before it's there, completely focused in the cave's open frame. Dust kicks up as boots impact the ground, and the king peers inside, hand shielding defiant eyebrows. He searches the shadows for the shepherd boy that slew a giant with nothing but a rock, the boy that became a young man with a destiny to replace him as king. But the king doesn't see ten eyes. He sees a perfect, unbroken web. And so, the weaponry moves on.

Maybe the spider watches all this. Maybe it pivots to study the young man, hiding in the dark and breathing again now. Maybe the spider wonders what's keeping the man here when he could bunk with clowns, break bread with the malformed, and, for the barest blink, fly with arms reaching, trapeze left behind.

With eight eyes to see it all—the searching king, the intricate web, the fall or the catch—maybe the spider leaned forward and whispered, what are you afraid of?

Setting: ". . . . . . . . . . . . . . "

". . . ."

". . . . . . . ." — "It's okay if you make a mistake—I'll always love you," said. . . . . .

Setting: (Auto) Assault

By this point, I should’ve known better

OUTSIDE THE HOTEL, VIRGINIA —

“Hey, hey! Sorry it took me so long. Traffic was awful.”

“Well how was last night? I can’t believe how much beer we drank.

“Did you have fun? I’m sore. I think it was the mechanical bull.”

“I liked him. He seemed like a pretty cool guy.”

“I hope you’re not one of those women who hate themselves afterwards.”

Setting: Emancipation

12:30pm Spring M/W

EDP 363 HUMAN SEXUALITY, UT AUSTIN — Overview of the course(s):

"Human sexuality and loving relationships will be taught from a psychological perspective with attention to the physiological, emotional, developmental, and relationship dimensions of sexuality."

19 The judgment you feel: Even as I clutched my stomach, I smiled up at my sister and said, Nice punch. That was a baby-killer. She walked away, unable to dignify me with words anymore, not after my announcement that I'd checked in the V-card. What I really wanted to say was You've never hit me before. Why now? Why this?

"Course goals are to present factual information and to promote scholarly examination of social, personal, and ethical factors in sexual expression."

20 The jokes you hear: The best one they came up with was Hey you must really enjoy that phone sex, huh? No wonder you've got hearing AIDS.

"We operate under the assumption that sex and relationships are appropriate and important topics of study, and that our understanding will be enhanced by reading about, thinking about, and discussing many aspects of human sexuality."

21 The things you learn: She took the newborn kitten from my arms. He was removed from his momma cat before he was weaned, my mother said. He thinks you're his momma

now, she'd told me. Kitty kisses, she'd called them. But there were other whispers too. Your first hickey came from a cat, freak.

"Virtually everyone will feel some self-consciousness and discomfort with some of the subject matter, but this usually improves fairly quickly."

22 The looks that make you uncomfortable: My mother towered over me and my bag, barely unpacked from spending New Year's at my boyfriend's house. That's what whores do, she said. I watched her hands, wondering if they'd strike.

"However, if you do not share our belief that it is appropriate and worthwhile to study and discuss sexual issues in the context of the university classroom, this course is probably not for you.

There used to be only one course in my life—the everyday education I received since I was little. But with this class, I have been emancipated. According to a class reading, "we don't touch our vulvas at the table" is what someone else tells their little girl. "We don't" is what I was told. All the childhood "shames"—the secret truths and dares that were whispered behind closed doors; the childhood games that always appointed me as the Prince; the curiosity about what our dog was always trying to do with the neighbor's little terrier—it was just normal behavior. The things I heard though, the trials I've been through since then—they've been righted in this rehearing, in all the class discussions from “demon rods” (evil penises) to “alphabet soup” (LGBTQQPA(H), BDSM). I’d been in a class that only teaches, but this was a curriculum of learning.

And that was just the ripple crowning the tsunami. This change from one course to another was as revolutionary as Bluetooth hearing aids. At last, I could tune through all the noise of the world to recognize what I should’ve learned then and what I needed to know now.

Now, I recognize how Dr. Lesser’s understanding of love opened my senses beyond the taboos and spectrums I’d been taught to see. In some ways, a conservative juvenescence can be more conducive than other upbringings for appreciating progressive opinions. For these kids, it’s not just a small jump to the Come on, it’s the twenty-first century type of free thinking. It’s a tooth-and-nail evolution from the assessment that “bodies are made for only one way of reproduction” to the idea If bodies were meant to fit a certain natural definition, my hearing loss would be unnatural. I would be unnatural. It’s as if I’d been mirroring other people’s ideas of love, and all it took was one pivot to see a Love I could be reconciled with, one that accounted for all shapes and sizes.

And now, I recognize that bodies shouldn’t be read in just one way. I was at that summer camp for over a month, most of which I spent hiding in a hammock with books from the

Animorphs series. One of the things I loved about this series was the flipbook in the bottom right-hand corner in each book. When you thumbed through the pages from front to back, you could see the narrator morph into the featured animal of that story.

It was a long month and I was too shy to make friends, but I did learn how to swim "the airplane" stroke and throw pottery and play badminton. And it turned out I needed a remedial reading lesson too. C was just another one of the girls in my cabin, but I'll still remember her for helping me learn that skin is just skin. It's a cover we can't judge without knowing the kinetic story beneath.

I also recognize now that there are other things—the unexpressed and omitted, the regression and auto-assault—that will always resonate, body and soul. A conversation that began with "I have something to tell you" and "Please don't tell me you're a lesbian"—and it's not unreasonable, with Broadway show tickets for friends' birthdays, jealousy over a neglected mani-pedi invitation, and preferences for the smart, funny, and pretty, I basically date my friends, and suffer many a lesbian joke for it, but so what? If it were true, would my name be on the over-my-dead-body list with tattoos, motorcycles, and signing petitions?— it echoes, faintly, but I'm the conductor. I'm in control of the song now.

The thing is, you have to contend with the cave before you can emerge. You have to grapple with the prospective nonsense—the prologues and origins and sources, the implied acronyms and discernable connotations, the trusty instincts, the theories trusted, the things you tell yourself (learned and unacknowledged), the jokes and judgment, the whispering blame and uncomfortable looks, the hoarded wishes and withheld confessions, the impressions and perceptions and explanations, and skeletons deep down with the awareness and knowledge and fear. It's a cage match, and you're up against your second self—the internal other generated by the people and the constructs they create. This world is not something you can change.

But you can change the setting you use. You can declare an independence, shouting from temple tops I recognize my body. I recognize this skin. I recognize me.

## Setting: Re:Birth

An even longer, long time ago

JERUSALEM, ISRAEL - "But how can someone be reborn? Surely they cannot reenter their mother's womb."

Perhaps the teacher ran his hands through his hair, long and mammalian, his fingers hauling up his mind from the deep sleep he'd been in moments ago. Then, maybe he turned to the question, to the man, this spiritual leader, crouched nearby.

And possibly, as the teacher's eyes lifted to the glittery heavens, the spiritual leader wondered at how dark and quiet it seemed, with only slow-burning coals to see by. The wind had pronounced the fire deceased long ago, but a breeze remained at the edges, plucking at the leaves and waiting to see if the bright, dead sparks would become enlightened again.

"Here's the crisis:"

The light's here. It's not going to be here in a week, it's not marching in on the Tuesday after next. It's landed, and it's not going to stop rolling in, whether you're on the beach wondering if the waves ever take a break from their ebb and flow, or at home watching your oatmeal in the microwave rise like the grudge. It won't ever stop crashing on and cracking in, even as eyes perspire from the earth, the homo sapiens leaning into ledges but not too far, keeping to their precious darkness, their hate carried in cartridges.

No solicitors allowed, the bullets scream. Get off our shores.

They don't want to see how worn their favorite teddy bear is; they don't want to know about the microscopic germs flying from a lid-up flush and now coating their toothbrush; they don't want to acknowledge that the #5 Chick-fil-a combo and a meaningless quickie are just fleeting moments, not memories.

But I'm here to bring the boys, the girls, all the people home.

Setting: Implicated

"...before..."

WEST WYCOMBE PARK, UK (continued) — Strike a pose, I hear. My friend stands a few paces out in the gap between the high, thigh walls surrounded by green green green. She holds up her camera and calls, Hurry up. It's a three-mile walk back to the bus, and the clouds were sagging like they were going to refresh this persistently fresh countryside once more.

I pivot in the tiny cave, slightly bending at the knees and bringing a finger to my lip in the universal shhh sign. I imagined the caption would be clever, like Keep it secret, keep it safe. This girl, she hasn't learned yet. Her world still caves in on her, but that's okay. The cave is her primordial home, the same one we all carry with us as we search for truth.

So when she leaves the little grotto, grabbing the camera from her friend to see, oh good, you can’t tell I don’t have any makeup on, it’s just a step—one of a thousand and a thousand more, stepping into the sun.

## M.E. Perkin's Photograph & Biography

[Image Description: At the edge of an ocean, a young woman with windswept hair looks out over the waves. She is silhouetted by a bright sunrise, rendering most her features indistinguishable—except for a coffee cup she has raised to her lips.]

**M. E. Perkins** is a Creative Nonfiction reader for *Gingerbread House*, an online literary journal. She currently teaches at Stephen F. Austin State University, where she received a Master's degree for English and Creative

Writing. Her poetry and nonfiction has previously appeared in *The Piney Dark Horror* collections (2015, 2016), *Hothouse* literary journal, and elsewhere. She was born with Usher's Syndrome—a genetic condition affecting hearing and eyesight—and, as such, has long been fascinated with studying disability in both her creative and critical work.

ART SECTION

## Editor’s Note

by MANDEM

In our last editor's note, we said that we "haven't and won't publish inspiration porn." As tends to happen when a chaotic creature like us states an absolute, the universe has forced us to eat our words. **The majority of the works we accepted this issue are directly engaged with probing around the outlines of "inspiration" and questioning its potential and integrity. Every piece we accepted challenged our ideas of what must emerge when disability poetics meets the demands of the modern socio-aesthetic trends.**

When planning this issue, we thought to discuss the appropriation of outsider art (as it relates to disability) by mainstream artists and the continued marginalization of outsiders themselves. But as the issue evolved, different subjects took on an immediate relevancy to our editorial practices themselves. In the end, a discussion of Judith Scott and *art brut* will have to wait for another time, because we have a story to tell you.

We aim to feature a student artist in each issue. In this issue we have a young (early teens) abstract painter, **Candy**

**Waters**, whose work would be a strong foray regardless of age.

When a preview of the upcoming issue of *Deaf Poets Society* went online, our editors started receiving emails (and Facebook messages on their personal accounts) warning us of the "controversy" surrounding our forthcoming student artist, Candy Waters. These messages encouraged us to "Google it" to avoid having Candy's inclusion "reflect poorly" on our journal. That's when we discovered an entire website dedicated to proving that Candy's work is a "SCAM!!!!" because (among other claims) sufficient evidence that Candy was doing her own paintings had not been released to the public. "Why did it take over a year and a half for video footage to be released of Candy painting?" the website asks. The amount of time and effort that has been put into denying that a child artist made her own paintings -- on this website, on Facebook, on copy-and-pasted Amazon reviews -- was shocking to us.

After an initial period of confusion, we took stock of the actual issues at work in a campaign such as this. Would strangers be so invested in proving that any adult, able-bodied artist's paintings weren't their own work? What was this assumption of incompetence that would require a young autistic artist to provide video proof of their working process, when adult neurotypicals are never asked to do the same? Quite to the contrary, there is an understanding in the fine art world that artists are permitted to create work by proxy. It is well known that Damien Hirst's paintings are completed entirely by highly skilled studio assistants, and that even many of the "old masters" had assistants who completed large segments of the work. So what would drive a person (...other than perhaps an art historian seeking tenure!) to stage a campaign calling any artist a "scam" for not carefully documenting their working process? It seems to us that the issue is a power differential. A (white, adult, cis, able-bodied, male) neurotypical artist is given assumed competence such that they can openly have others do their production, while an artist like Candy is assumed incompetent. As an art historian and studio art instructor who has experience with young neurodiverse painters, I see in this work familiar qualities -- it shares the exuberance of my own child's early paintings, a similar self-referential denial of the canvas as framework, and a strong instinctive use of color. As an editor, I'm willing to stand behind it and argue for the artist's right to refrain from defending their working practice.

And then there's the rest of the story.

We queried Candy's work in the context of a disability arts forum where it had been shared by her mother/caretaker. Candy is nonlinguistic (she neither speaks nor communicates with words); for this reason we had already made the decision not to publish a written artist statement. However, her work is frequently shared with text written by her caregivers, and much of this text is problematic. Candy's work is often labelled as "Candy Waters Autism Artist." Written descriptions speak of her abilities with clarifying phrases expressing the idea that her work is inspirational either because of her disability or "even though" she is disabled. Much of the promotion uses the language of exploitative "inspiration porn" that decenters individual achievement in favor of centering disability and the feelings of the abled viewer. This is in sharp contrast to the way "serious" artists are treated and not in keeping with the ideal of a disability aesthetics. No one speaks of how inspirational it is that Kandinsky was able to paint so beautifully *despite* his synesthesia. Nor is Monet's impressionism always labelled as "Claude Monet Short-Sighted Artist." There are questionable power dynamics at work here, too, when an artist is pigeon-holed by their disability or when a caregiver literally puts words to a work that was created by a non-linguistic individual. The art editors had a long discussion about the ethics of publishing and promoting work when we were not 100% certain that the artist would have given her blessing to the way in which it was being released. However, the work itself is clearly the result of an artist who finds joy in their materials and who creates as a way to communicate with the world -- and in that, it was something we wished to see shared.

Is this work inspiration porn? I feel certain that in an imaginary room apart, with just us "outsiders" as the creators and the audience, it is not. There is nothing in the aesthetics of these paintings that congratulates the viewer for their open-mindedness while de-centering the actual subject, nothing that dehumanizes, nothing that marginalizes. There is real beauty, and real talent, and a legitimate (if perhaps naive) contribution to contemporary aesthetic dialogue. But outside this imaginary room, in the context of its promotion and distribution -- and even its controversy? -- therein lies the rub. And yet, as a neurodiverse editor, I cannot allow the use to which society has put the work of my spectrum peers to be an excuse to silence that work. Art becomes meaningless without context, and yet a minority population cannot allow a majority population to define its meaning by defining its context.

This issue of content and context is also relevant the video work of our featured artist **Erin Clark**. She's a photographer, writer, and videographer whose online magazine *Sex Icon* positions itself as a crip's replacement for *Vogue* and focuses on documenting her traveling adventures and "babe life." Erin first came to our attention with a video whose description included the phrase "The #path into town is also accessible - if you have #wheelchair ninja #skills. Stairs, jutting rocks, gravel, steepths, all the #rugged #terrain. You #conquer all with your #sexicon #magnificence!" At first, a video like this seems related to the exploitative inspiration porn genre -- minimizing the need for accessibility while leaving the able-bodied viewer feeling good about their own lives. However, after spending some time with her work and looking more closely at both her magazine and her photography, a more complex conceptual and aesthetic element became clear to us... By re-appropriating the aesthetics and language of inspiration porn (and "sexy porn"), Erin works to infiltrate and destabilize the socio-aesthetic systems which are often otherwise oppressive for disabled individuals and for women. Under her intervention, memes which have been used to dehumanize disabled individuals are re-appropriated as a testimony to autonomy, and aesthetics which have been used to objectify women are re-imagined as a way to reclaim the physicality of her own body. Her photographs in this issue speak of the power of a woman asserting her autonomous disabled sexuality in a visual space that has long been dominated by normative bodies.

In the end, the video we accepted from Erin is somewhat unique in her *oevre* (a choice perhaps representing more of our editorial aesthetics than any inherent value). It deals less in either the coinage of popular travel videos or inspiration porn, and takes a cue from more intense, interior explorations of the body's relationship to its own limits and to the natural world. In this respect, it calls to mind Karrie Higgins' disability re-imagining of Parallel Stress.

We'd originally planned to discuss **Michaela Oteri**'s Neo-Art-Nouveau (how's that for a mouthful!) portraits in the context of how its power dynamics, class, and insider status have traditionally defined the lines between the art canon's embrace of "pop art" and its rejection of comic art, illustration, and self-taught artists. Michaela's work can be usefully thought of as contemporary outsider art because of its medium and form -- it is designed for individual consumption rather than public display, it is based in illustration and relatively self-taught methods, and it references a design-based tradition. Yet in a sense it can also be understood as participating in a form of social critique similar to that which manifests in fan fiction -- she is taking a specific pre-existing art practice (the pseudo-art-nouveau portraiture style has become common in online and youth culture aesthetic culture) and adapting it to be inclusive of people who are usually excluded by its makers. Art Nouveau, in its original form and its modern adaptations, is usually a movement which elides all flaws: it creates stylized and idealized figures. Michaela works in this tradition, but forces it to make room for bodies that are disabled, or queer, or people of color (or all of these!). She's working in a genre that could easily be used to erase the need for assistive devices (many portraits subtly remove any evidence of disability -- how many portraits of Roosevelt show a wheelchair?), and rather than erase those devices she faithfully includes them as part of the acceptable body. This also is a work of reclamation that attempts to integrate the disabled body into the aesthetics of established society. Her work is palatable rather than challenging, and in that it creates a space for bodies like these to exist.

Yet Michaela's integration stands in stark contrast to our final artist, **Hilary Krzywkowski**, whose work is a rejection of, rather than accommodation to, the demands of able society. In this respect, Hilary is ironically coming from a more traditional "outsider art" perspective. Her work includes elaborate intellectual positioning, protest of medical and social "treatment," and the engagement of pre-internet style text and visuals. (Engaged text has been a running theme among our recent artists.) Where other artists may seek inclusion within the established aesthetic dialogs, Hilary's response is raw and challenging... and yet it is also part of a continued "outsider art" aesthetic which has been actively co-opted for the last hundred years by the self-proclaimed avant-garde that has elevated insider-recreations over outsider-lived experiences. It participates now in a genre of "edgy" art that had its roots in 20th century asylums and the post-war mining of mental illness (and non-Western identity) for their artistic gold. But that's an essay for another day.

For today, we celebrate each of these responses. As neurodiverse or disabled or D/deaf or chronically ill or otherwise outsider artists ... How do we we create and thrive? What does it mean to be an artist whose work and value will inherently be questioned in a way that insider art will not? Do we let reception dictate our creation? Do we embrace the challenge and force our way into established aesthetics? Do we celebrate our victories even knowing that these celebrations may be co-opted by those who will use them against us? Do we try to forge our own way, risking failure in uncharted territory (and even if we could -- can any artist really escape the socio-aesthetic landscape in which they percolate?).

Good night, readers and listeners.

**MANDEM** is a media-fluid artist conglomerate that identifies as nonbinary, neurodiverse, and disabled. Their work on disability poetics, the visceral body, gender, and childhood is in critical dialogue with art history, religious iconography/mythology, and various -punk aesthetics. They can claim an MFA (studio art) and MA (interdisciplinary humanities) from Florida State University, where they were the recipient of the Florence Teaching Award Fellowship. They recently received an Ohio Arts Council (OAC) Individual Artist Grant for their work on the **Hypermobility series**. In addition to showing in many museum and gallery shows, MANDEM's art has appeared in numerous journals, including *Rogue Agent, Menacing Hedge*, and *Cahoodaloodaling*. MANDEM lives in a centenarian house in urban Cleveland, surrounded by the empty lots where Little Hungary used to be. They are currently artists-in-residence at Negative Space Gallery.

## Erin Clark

On the website is Erin Clark's Video "Hamnøy," published by The Deaf Poets Society.

VIDEO on website:
https://www.youtube.com/watch?v=Geg7UV7587E.

[Video description: We open on a bleak landscape of gray and moss-green boulders. A thin strip of gray ocean is visible beyond them, and in the distance imposing mist-bound mountains and storm clouds. In the far right of the image we see part of a wheelchair.

Title reads: Hamnøy.

The chair spins in place, disappears from view for a moment, and then re-emerges. From the back we watch a red-headed figure in a bright green jacket roll forward. They are the only spot of color in the gray world.

Title reads: Norway.

With great difficulty the figure begins to wheel out across the boulders. We see them struggle for what seems like hours (though time is compressed by a series of short cuts in the video). Repeatedly the chair gets stuck in the rocks, and the figure slides out, frees the wheels and climbs back in. At the end of the ocean, they climb from the chair, and their ankles and legs fold up under them as they climb out across the last rocks. At last, they sit on the rocks, looking out across the waves. The film goes to black, and credits read: Erin Clark, Published by the Deaf Poets Society.]

## Erin Clark's Artist Statement (for the video):

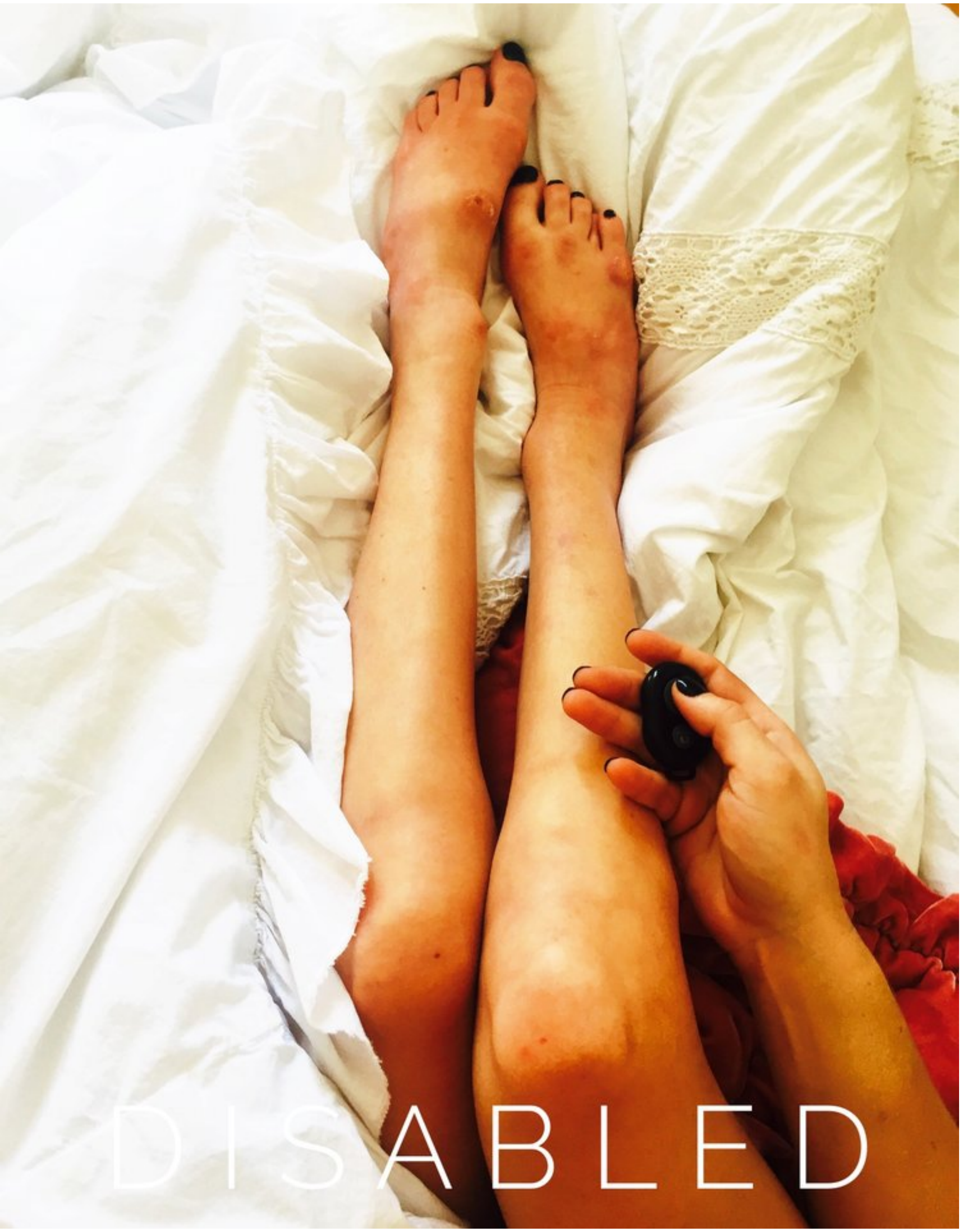
Moving a wheelchair through nature is awkward. But nature is my favorite place to be. While my efforts are incessantly praised as brave, inspiring and impressive - I experience the effort as a meditation. Physical effort, especially involving problem solving to reach a remote destination, is a pleasure that anyone who has been mountain climbing or wilderness trekking understands. Adding a wheelchair doesn't change the fundamental motivation or reward. The struggle is considered tragic in the case of disability and intrepid without it. My determination and skill in maneuvering my wheelchair is internal, personal and for my own benefit, not a moral or motivational statement.

In Hamnøy the focus is on the Fjord, the weather, the birds. I intend to simply be a part of the landscape. My love for nature, my profound love of Norway in particular, compel me to get closer to it. My body is made of the earth. Including the metal inside me and the metal of my wheelchair. This effort is not defiant, it is worshipful. A physical praise that I feel worthy of making.

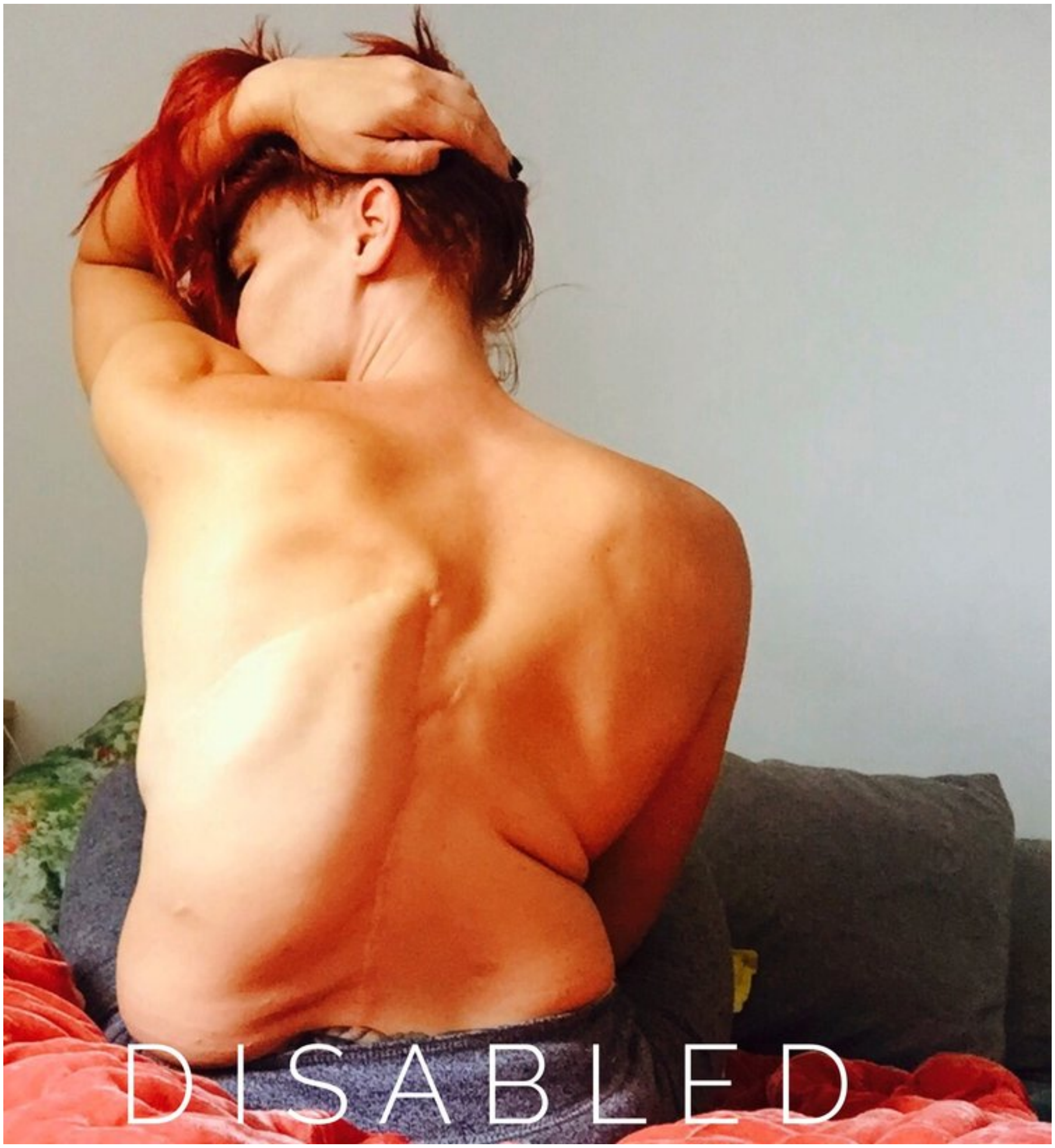
## Erin Clark

## "DISABLED (A series of self-portraits taken during Disability Awareness Month)."

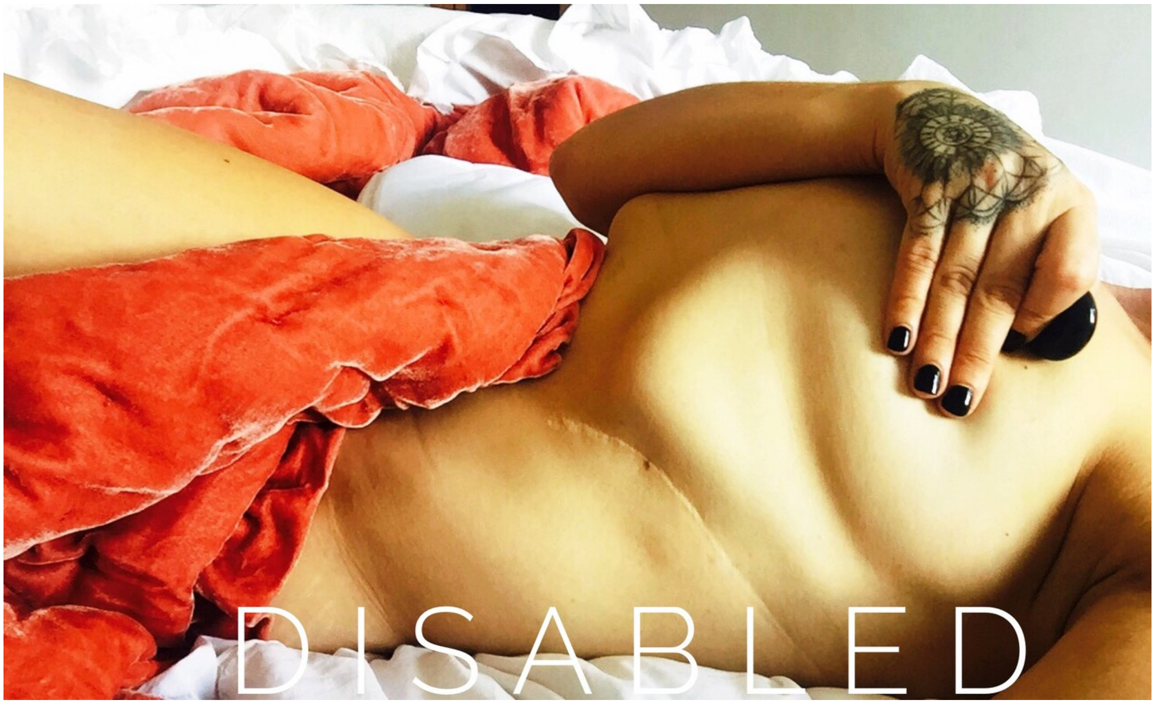
[Image Description: Erin lies on her back looking up at the camera. The image crops close, showing only the left half of her face and one shoulder. She has red hair and very dark eyes. Sans-serif font reads DISABLED.]



[Image Description: The photo shows Erin's legs and one hand (which holds a small black object), shot from an overhead angle with the knees foreshortened. Her long legs end in twisted ankles and subtly deformed feet decorated with black nail polish. The white rumpled bedsheets and lace beneath her gives the image a sensual feel, as does the visual impact of her flushed golden skin. Sans-serif font reads DISABLED.]



[Image Description: Erin sits on a plush red and gray surface with her back to the camera. With one hand she holds her red hair up onto her head, creating an s-curve with her shoulders and back. She glances back through the curve of her arm, almost making eye contact with the lens. A jagged scar is visible along the length of her back, but less prominent than the play of light across her muscles. Sans-serif font reads DISABLED.]



[Image Description: The photo shows a sensual landscape of flesh and fabric. Red and white fabric wraps around limbs and ribs that are at first difficult to make out, then slowly resolve into hips, thighs, an elbow and a protruding rib-cage. The artist's tattooed hand reaches across to obscure her breast, and her jet black fingernail polish reflects the same colors as the polished black object she cradled against her breast (a remote? a stone?). Sans-serif font reads DISABLED.]

## Erin Clark’s Artist Statement: "DISABLED (A series of self-portraits taken during Disability Awareness Month)."

I am not just an artist. I am also a Libra rising. I care a lot about aesthetics. Every element in my home is intentional. Placement, texture, layers, space, flow, colour, light. I am affected by it, so I compose a deliberate environment to keep me balanced. I do this for my state of mind, too. My psychic interior is curated as precisely as my apartment.

There are aesthetics I have no influence over. The lines of my body - out of proportion to each other - commonly referred to as deformities. Those I simply accept. I accept. I accept.

The only way I can connect is from inside my body, inhabited. So I'm invested in that - embodiment. Which doesn't require an opinion on form or function. I am responsible for the well-being of my body, not its appeal. Most of the time my body is a bewildering mystery, but the only true miracle is that after I have my aesthete way with the things I can influence - my environment, my mind, my expression - I sit quietly inside my body and listen.

These are my crippled legs. They taper, it doesn't appeal to me. They don't have to, they're legs. "Floppy feet" might be an actual medical term. I'm not sure. When I was a baby, I wore plaster casts up to my knees. I was too little for actual braces. I think the point was to prevent the deformity my feet have now. I hate wearing shoes. Finding ones I like, that stay on, that aren't too heavy when I do use my legs, that don't look 'off' - is emotionally draining. I mostly just wear kid-sized socks in fun patterns. Unless my shoes are specifically for the benefit of an outfit. Then my shoes fucking kill it.

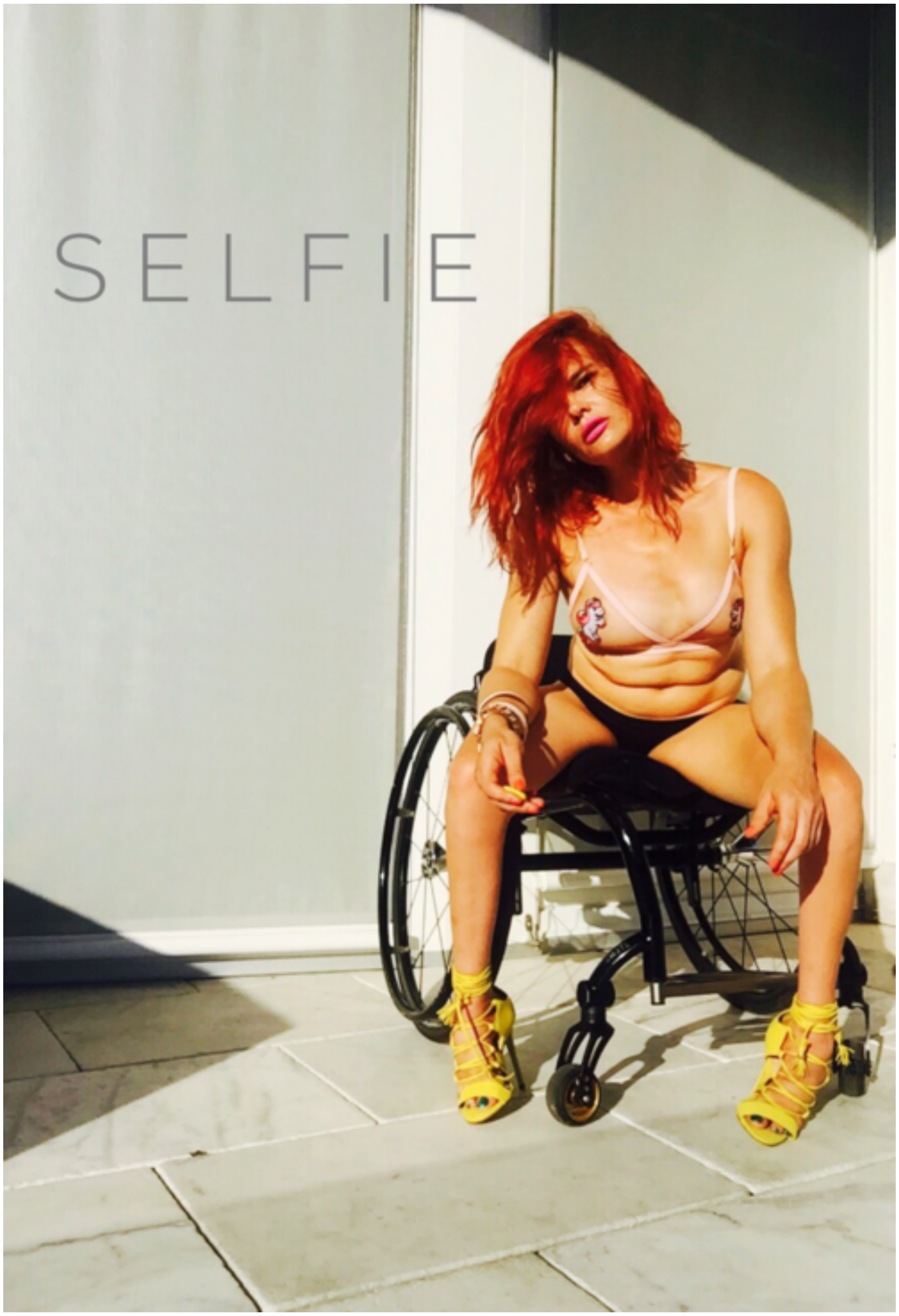
This is my resected rib cage. This one is hard for me. What are those angels even trying to do? Not be comfortable - to be in or look at - that's for sure. My sternum is an apex? If you trace, slowly, the scar - as you reach my freckle, I will feel the ghost of your finger trail across my belly button.

If I lie on my right side, eventually my rib bones bow under the pressure of gravity. Popping when I inhale. Grating against each other when I exhale. I switch to my left side until the crush of my own weight makes my bones ache and roll over again. Fragile as fuck.

You can feel my heart beat like it's sitting in the palm of your hand if you cup your hand under my breast and press. But I think that's the same with anyone so bony.

This is my curvature. My spine has three distorted directions - bent toward the right, twisted to the left, and hunched forward. A prominent ridge rises up one side of my back, making a valley of the other side. A steel rod was put in. It was too long and stuck out at the point between my shoulder blades - grinding audibly on soft tissue under my skin when I moved. So they opened me again and sawed off the top.

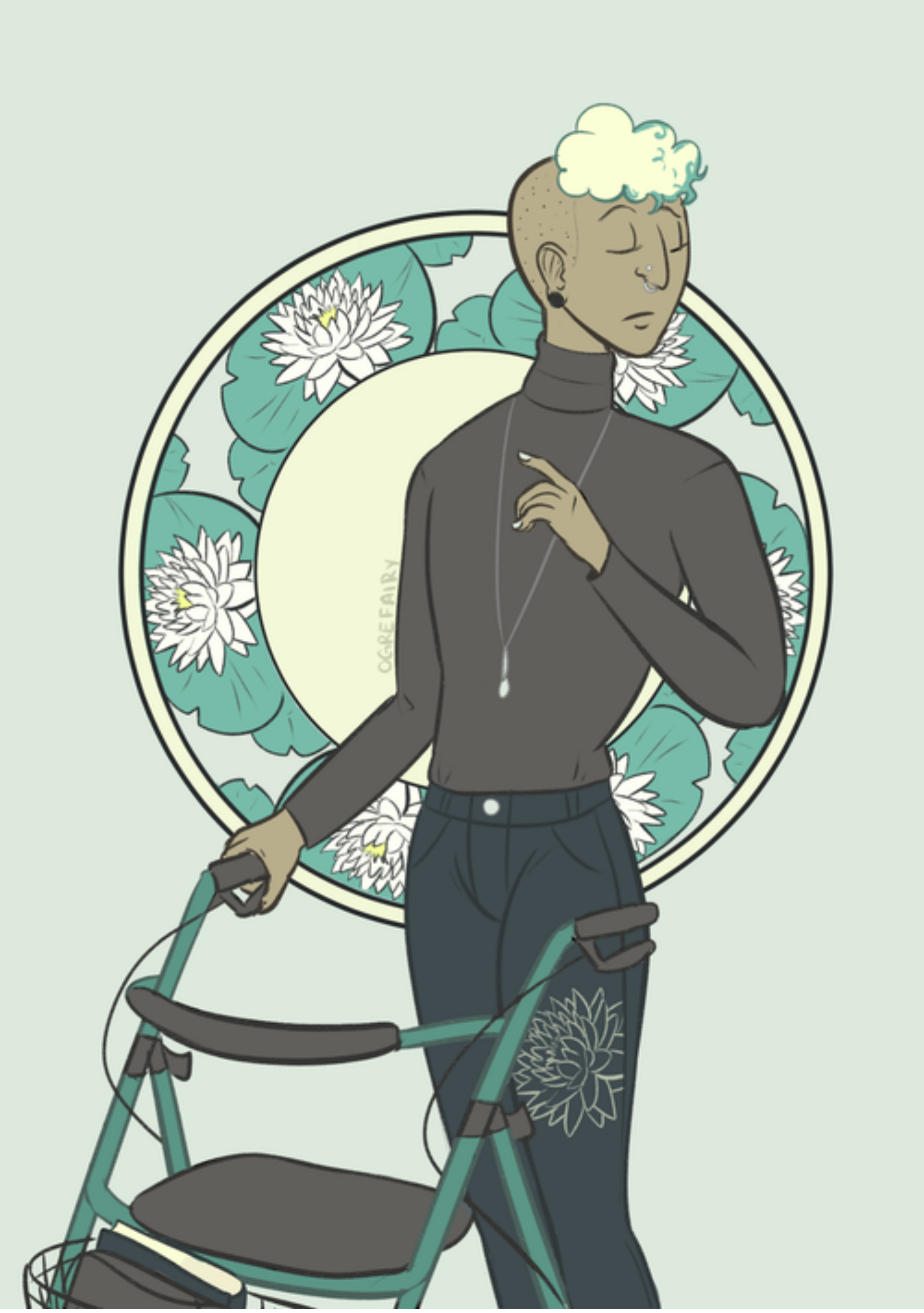
Erin Clark's Photograph & Biography



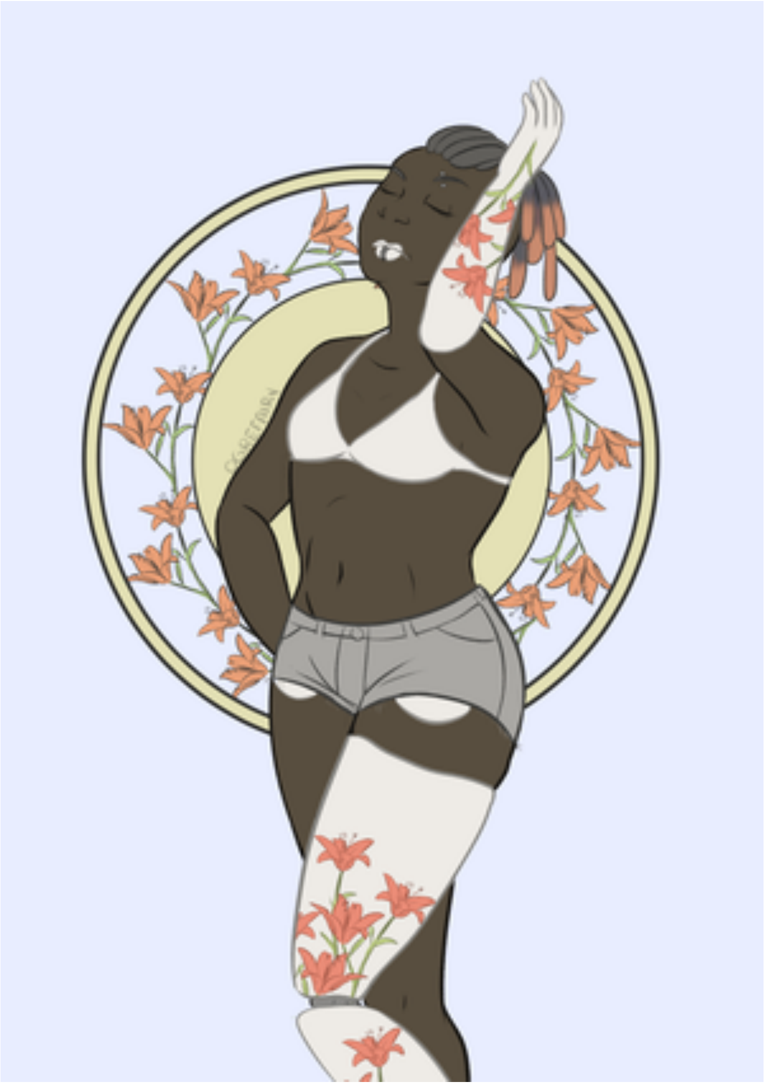
[Image description: Erin poses like a fashion icon in yellow high heels, a black thong, and a unicorn-decorated bra. Her hair is flaming red, and she sits on a minimalistic black wheelchair. High key lights and shadows create a dramatic horizontal V shape across the image, drawing the viewer's attention to Erin's figure and the sans-serif type reading "Selfie.]

**Erin Clark** is a Canadian living in Spain. Creator of *Sex Icon* magazine (www.howtobeasexicon.com) a lifestyle and travel magazine where she does all the photography, modeling, and writing. She recently began including short films to her list of forms of self-expression. Erin travels extensively, preferring adventures in wild nature. Most of her work is about her body, connection and progression of movement - between locations and states of being.

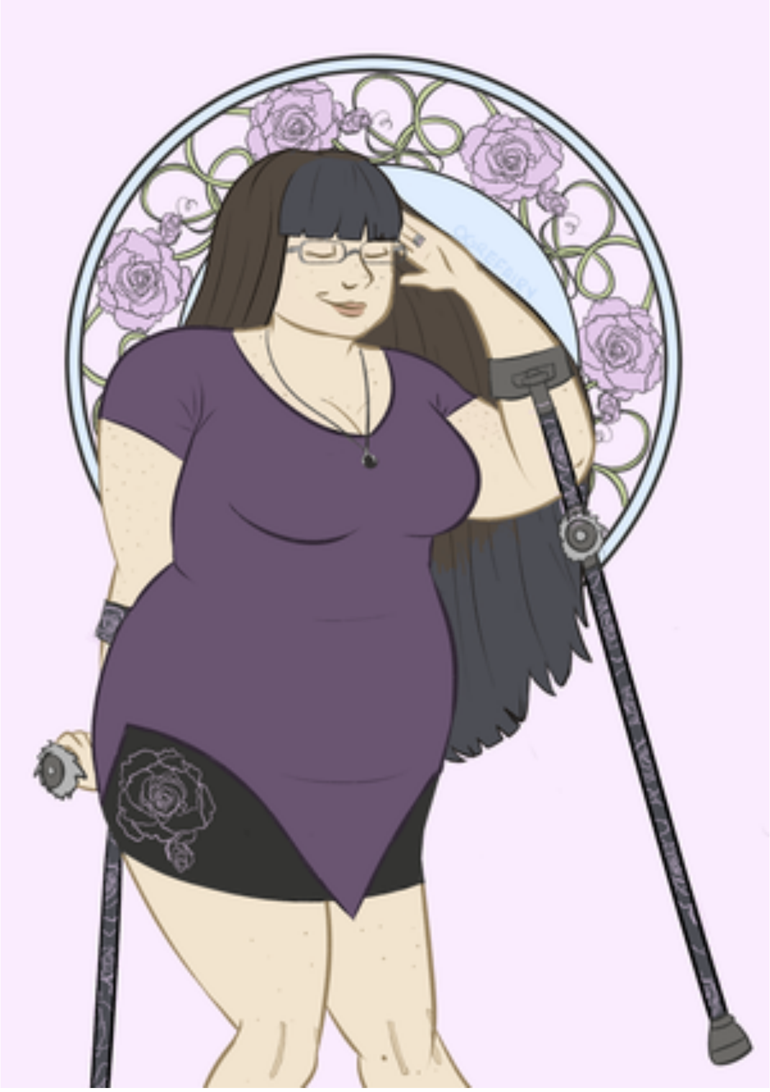
## Michaela Oteri



[Image description: A tall, brown skinned, non-binary person with a tuft of curly blond hair with teal-green dyed tips and the rest of the head shaved, standing with their eyes closed. They are wearing a black turtle neck and dark blue jeans. The jeans have a water lily, lined in white, printed on them and they are wearing a silver spoon necklace and black, large gauge plugs in their ears. They have a teal-green rollator with books in the front basket. This image is in an art nouveau style with a circle behind them, decorated with water lilies and lily pads with yellow accent and teal background.]



[Image description: A fit, black woman with dark skin and black dreaded hair that is dyed orange at the tips. Her eyes are closed and she has an eyebrow piercing and a ring lip piercing and is wearing white lipstick. She is wearing a small, white, bikini top and very short, gray, cut-off shorts. She has porcelain prosthetics on her left arm and leg. They are white and decorated with orange garden lilies. This image is in an art nouveau style with a circle behind her, decorated with orange garden lilies and accented with yellow. The background is blue.]



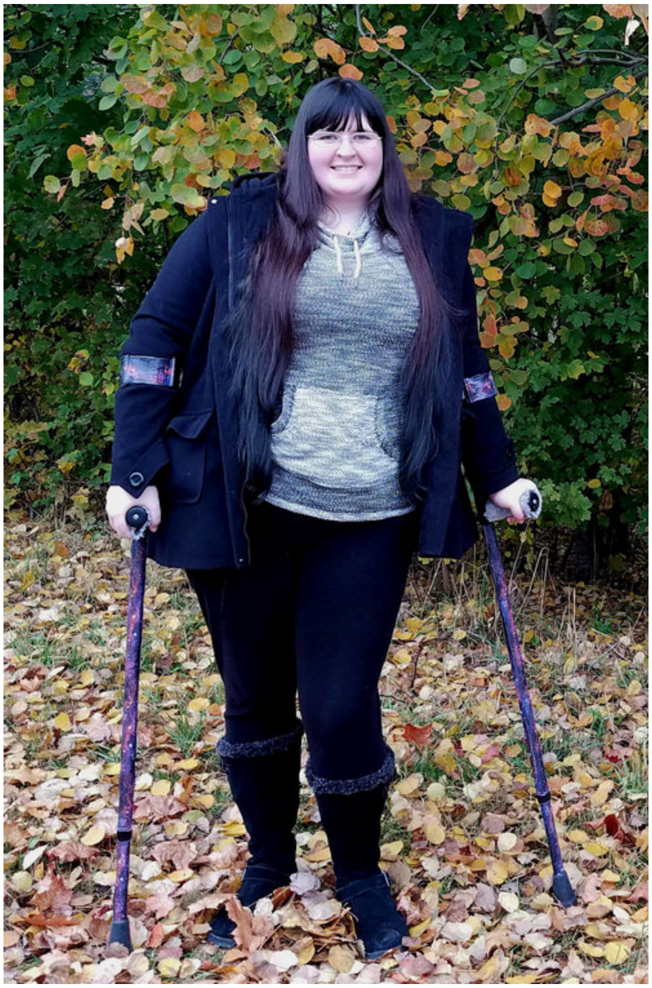
[Image description: A large, white woman with freckles with very, very long, dark brown hair with black tips and bangs and silver glasses, standing with a smile and her eyes closed. She is wearing a long, handkerchief-lined tunic shirt that is dark purple and has short sleeves and a black mini-skirt with a purple lined rose and bud. She has visible scars on her knees and is standing with a pair of crutches (one lifted as she has her left arm raised to brush back her hair) the crutches are black and decorated with purple lined roses. This image is in an art nouveau style with a circle behind her, decorated with purple roses and rose buds with blue accents and a pink background]

[Image description: A thin, white woman with short, light brown hair and silver glasses, looking out with a smile with gray eyes. She is wearing a navy shirt with baby Groot from Guardians of the Galaxy on the front and dark blue jeans. She is sitting in a black and red wheelchair with a red lined rose, printed on the backrest. This image is in an art nouveau style with a circle behind her, decorated with red roses and accented with white. The background is blue.]

## Michaela Oteri’s Artist Statement

When I first heard about the CripplePunk movement, I fell in love with the idea. Sometimes, when you're disabled, it can be hard to love your body, but this movement helps people see beauty in themselves despite, or maybe because, of their disabling characteristics. I love making these for people to help them feel beautiful and empowered.

## Michaela Oteri's Photograph & Biography

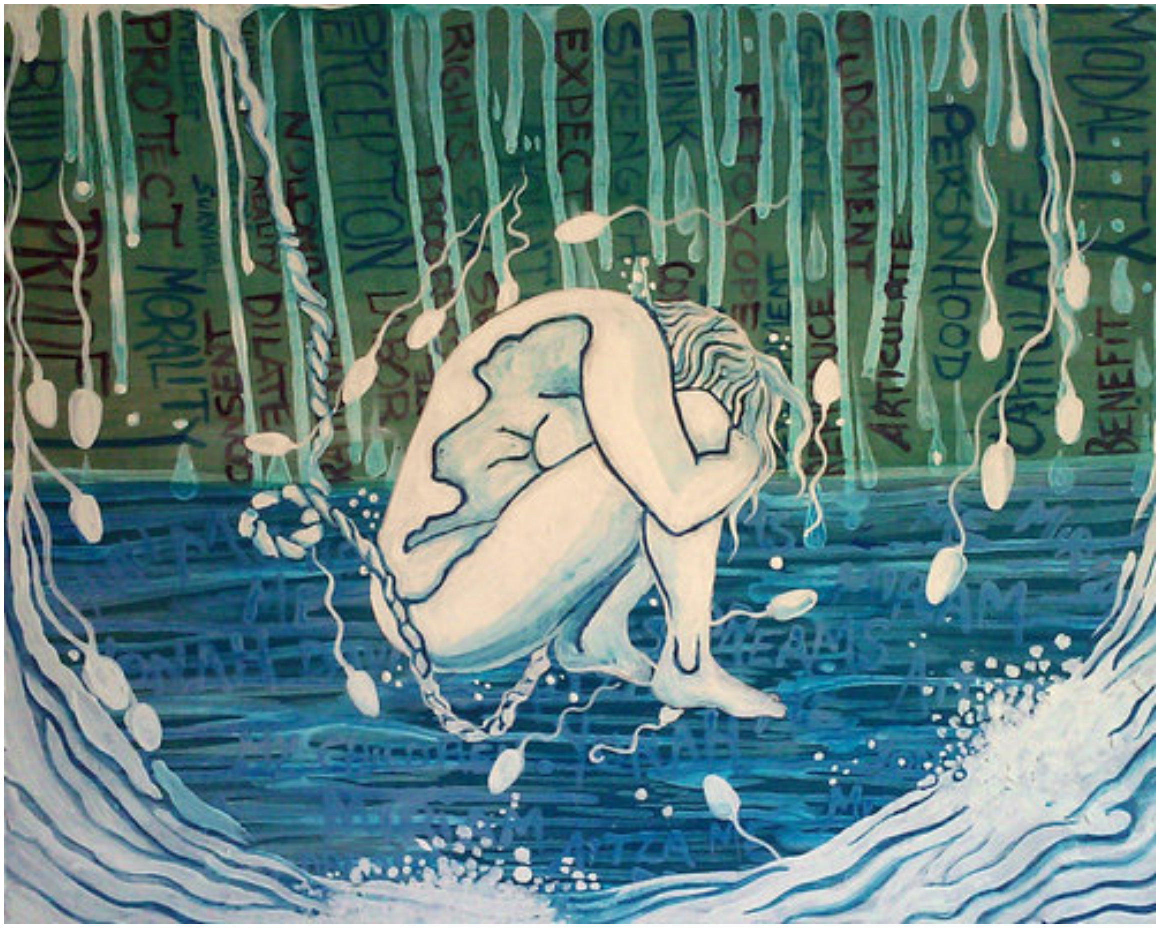


[Image description: A large, white woman with glasses and very, very long, very dark brown hair that fades into black and bangs that are also black. She is wearing a black coat over a black and white stitched sweater with a pocket on the front and black pants and boots. She is using a pair of forearm crutches that are decorated with purple outer-space patterned tape. She is standing outside in front of trees with green and orange leaves and the ground is covered in orange and brown leaves.]

Michaela Oteri is a Freelance Digital Artist and Comic Artist. She is a queer, chronically ill cripple who suffers from several disabilities and finds joy in using her artwork to give confidence to others with physical and/or mental disabilities. She and her autistic spouse are currently based out of West Florida but are in the process of moving to Stockholm, Sweden. You can see her work
@ https://ogrefairy.artstation.com

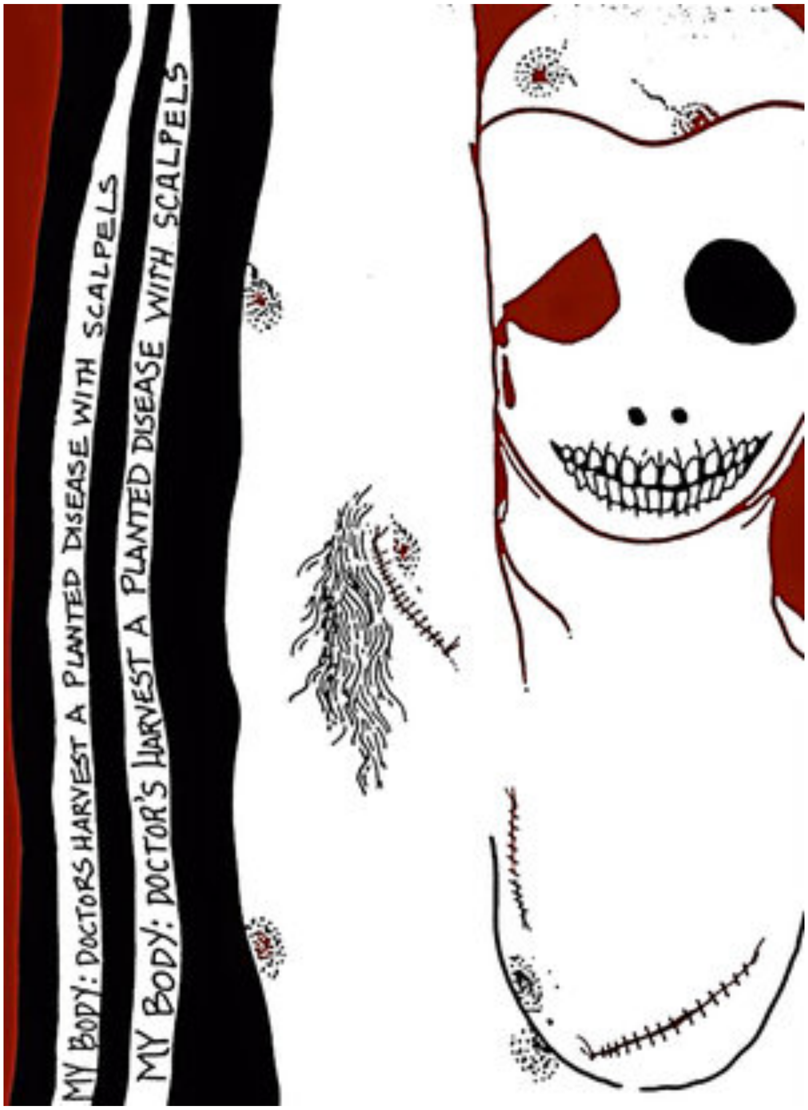
## Hilary Krzywkowski

### "Fetal Position"



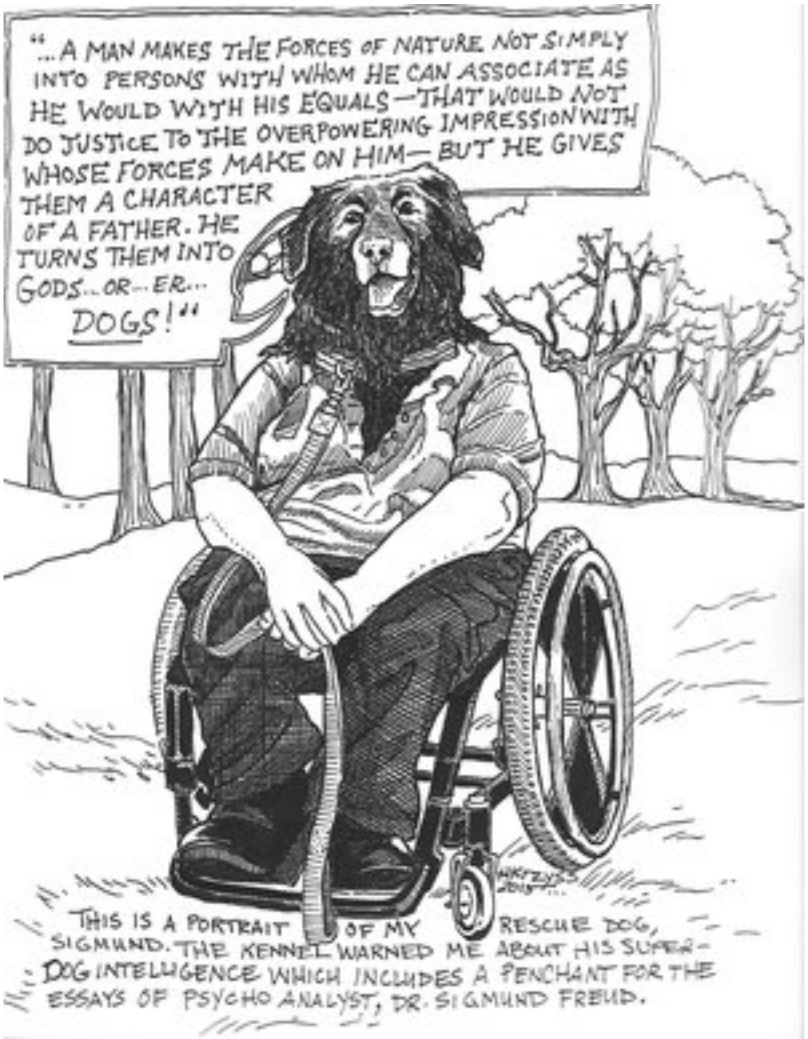
[Image Description: The acrylic and gesso on wood painting of a woman curled into the fetal position is not titled, but, the imagery has to do with the clinical world of psychology and "fertility/women's health", and the societal expectations that go along with that as affecting adults with Autism. It also, on a subliminal level, goes into the sexual and emotional abuse I survived as a pregnant person with Autism.]

### “Mask of Pain”



[Image Description: The graphic red, white, and black marker drawing of a masked person with a bare chest, skin lesions from hidradenitis suppurativa, and sutured wounds is titled "medical abuse: a self portrait". Again, depicting physical pain, disease, and powerlessness as an adult with Autism addressed as "woman"-- the lab animal.]

## “Freud’s Dog”



[Image Description: The pen drawing of the dog-person hybrid in the wheelchair is left untitled, and reflects my own experiences of outsider's views of myself while I was in my wheelchair. There is a hint at being my own master there, as the dog is holding its own leash. I may be a dog to many, but I OWN MYSELF. The dog is quoting Sigmund Freud (from Future Of An Illusion). At the bottom there is a caption describing this rescue dog’s obsession with Freud’s essays. The portrait of this scholarly dog gets into some of my obsessions--- dogs/animals, anti-religion, and the work of Sigmund Freud. This also hints at my Autism and the mentality of being my own rescuer. Did you know the term "little professors" was first coined by Viennese child psychologist, Hans Asperger to describe the children with Autism under his care? The intellectual-informative tone of this piece, reminds me of that.]

## Hilary Krzywkowski's Artist Statement

Much of my art and writing these days seeks to tell stories about trauma, sexuality, life with Autism, intersectionality, and the attempts at navigating (and sometimes rebelling against) a mainstream, neurotypical society. My work's been published by my father Tom Kryss (1960's Cleveland Beat and "outlaw" poet) with Black Rabbit Press, Alan Horvath with Kirpan Press, Bill Roberts with Bottle of Smoke Press, Richard Robert Hansen with Poems for All Series in Sacramento CA, Bree Bodnar with Green Panda Press, David Flexer with Sojourners Tent Press, Siegal Lifelong Learning Center at Case Western Reserve University, Bree Bodnar with Least Bittern Books, Squat Birth Journal, and the Journal of Pain & Palliative Care Pharmacotherapy. I've had work on exhibit at Standing Rock Cultural Arts, "In the Workplace"; Mandel JCC, "Slavery and Freedom"; Negative Space Gallery "Art Of The People" Political Art Showcase; Gallery 1299 "Somewhere Eye Belong"; and online at PainExhibit.org.

My present life calling is to not only be the storyteller, but an artist advocate, creating writing and art representative of the diversity of life experiences of those of us in the ID/DD community and those of us with chronic pain and health. I want to bring the hidden and the oppressed to light, and to create a safe space for dialogue in the visual and literary arts. Suffering, alternate realities, parenthood, unconditional love, and a desire for social change fuels my mojo.

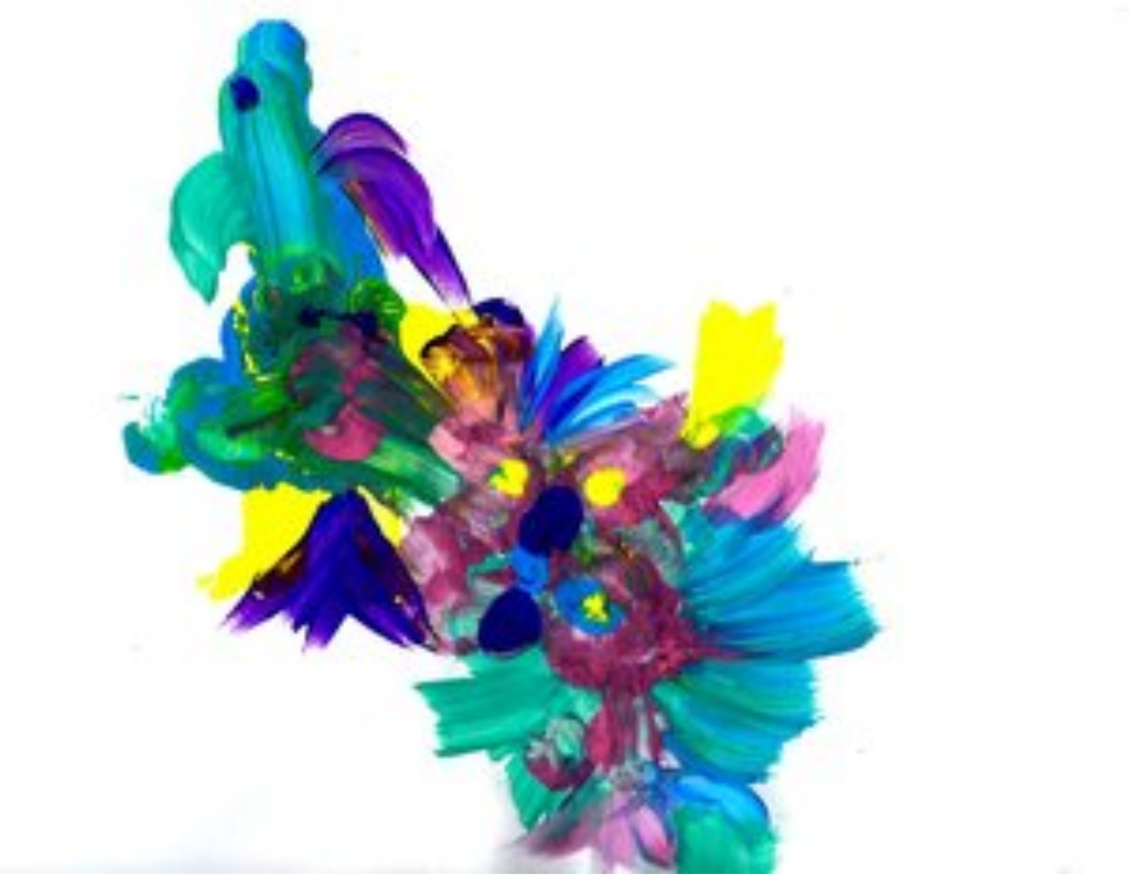
## Hilary Krzywkowski’s Photograph & Biography

[Image Description: This highly processed photo of Hilary shows a figure with swooping dark hair and paper-toned skin. Her features are obscured by the imaginings of the filter, lost in the play between noise and form, shadow and tone. Yet her dark eyes retain a sense of life through the machinations.] Much of my art and writing these days seeks to tell stories about trauma, sexuality, life with Autism, intersectionality, and the attempts at navigating (and sometimes rebelling against) a mainstream, neurotypical society. My work's been published by my father Tom Kryss (1960's Cleveland Beat and "outlaw" poet) with Black Rabbit Press, Alan Horvath with Kirpan Press, Bill Roberts with Bottle of Smoke Press, Richard Robert Hansen with Poems for All Series in Sacramento CA, Bree Bodnar with Green Panda Press, David Flexer with Sojourners Tent Press, Siegal Lifelong Learning Center at Case Western Reserve University, Bree Bodnar with Least Bittern Books, Squat Birth Journal, and the Journal of Pain & Palliative Care Pharmacotherapy. I've had work on exhibit at Standing Rock Cultural Arts, "In the Workplace"; Mandel JCC, "Slavery and Freedom"; Negative Space Gallery "Art Of The People" Political Art Showcase; Gallery 1299 "Somewhere Eye Belong"; and online at PainExhibit.org.

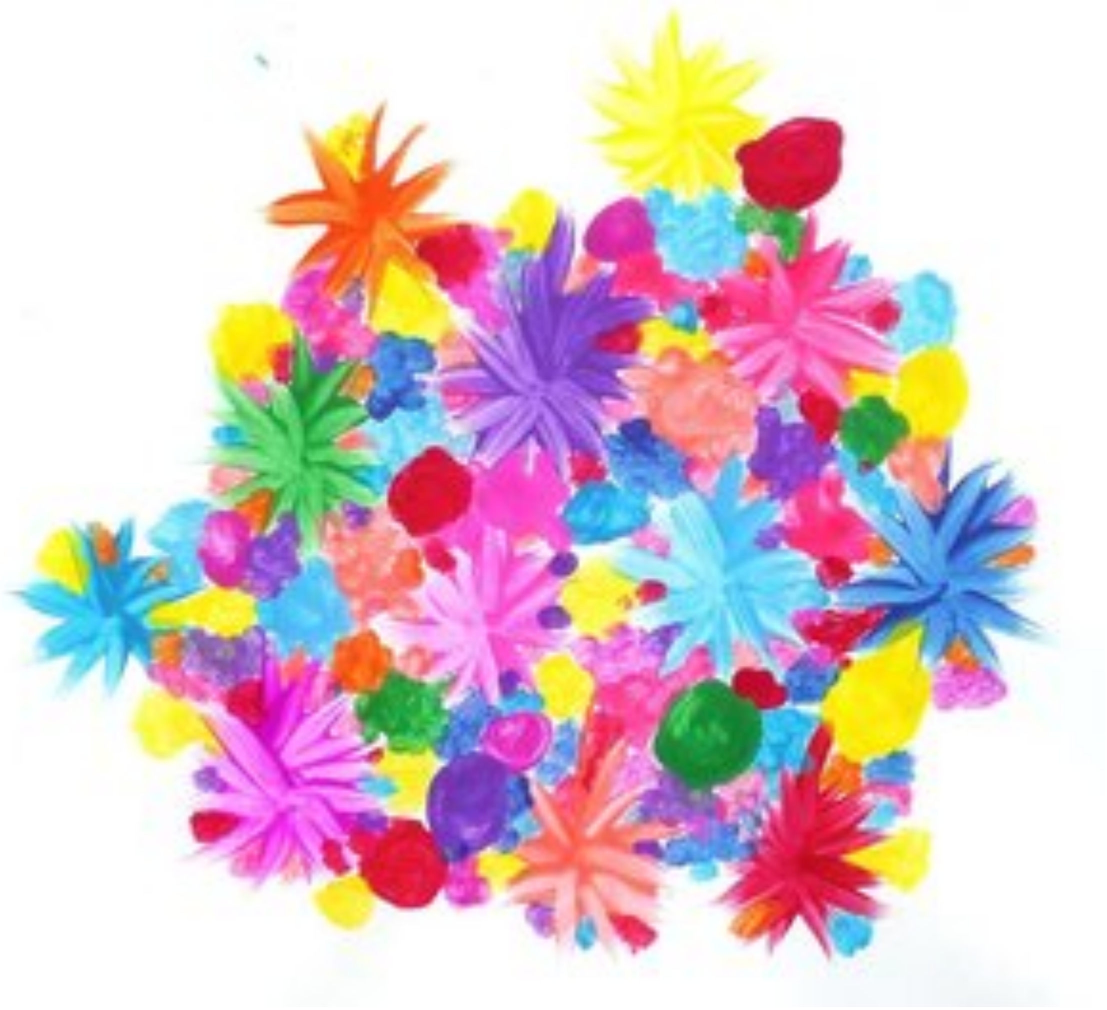
My present life calling is to not only be the storyteller, but an artist advocate, creating writing and art representative of the diversity of life experiences of those of us in the ID/DD community and those of us with chronic pain and health. I want to bring the hidden and the oppressed to light, and to create a safe space for dialogue in the visual and literary arts. Suffering, alternate realities, parenthood, unconditional love, and a desire for social change fuels my mojo.

Student Artist: Candy Waters

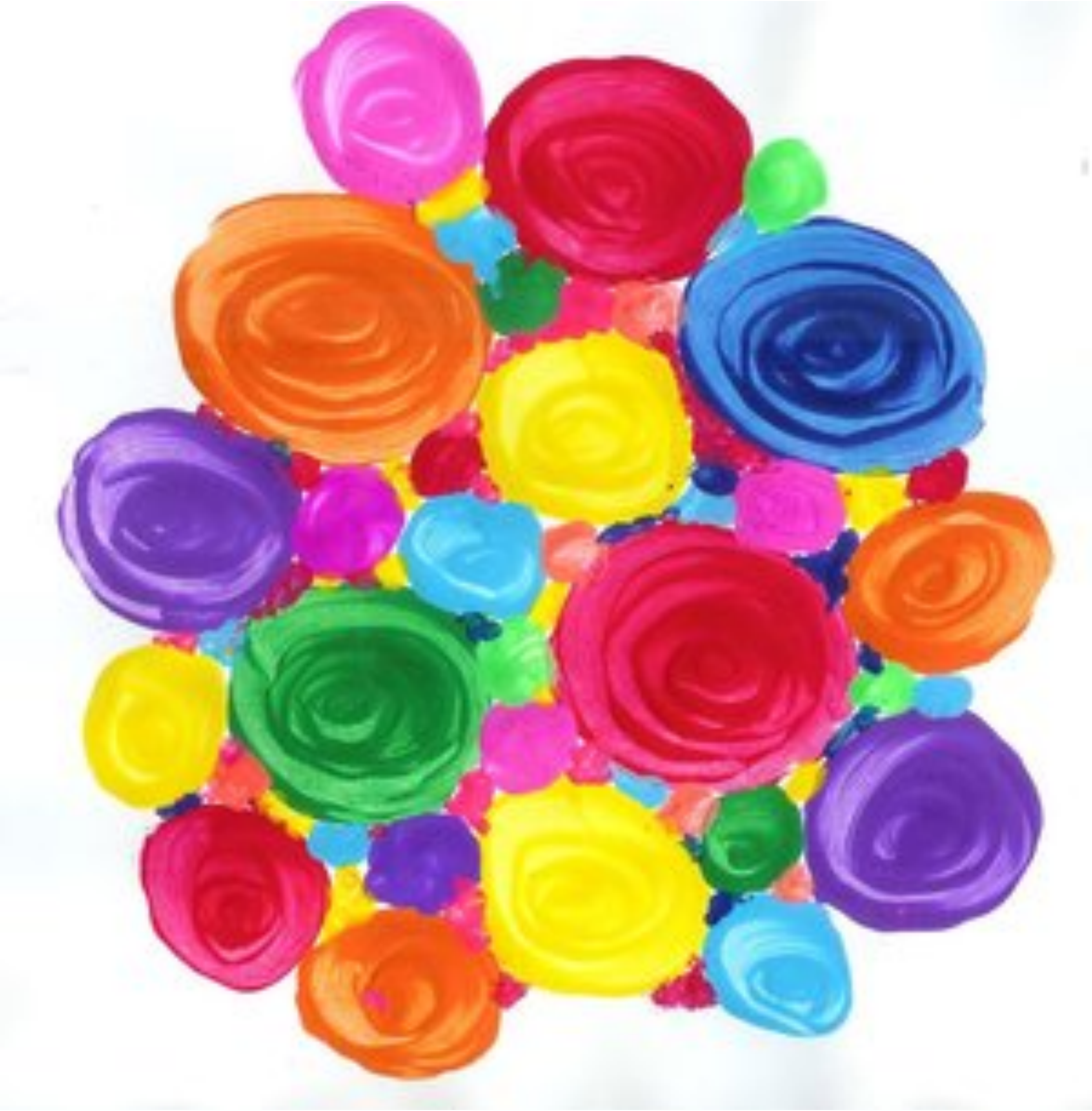
[Image description: A mass of brightly colored marks surge upward in a pyramid-like shape. Above the apex is a bright yellow circle.]



[Image Description: Brightly colored brushmarks push out from a curving center. The colors are mostly shades of blue, with a few purple and yellow highlights.]



[Image Description: A thick mass of colorful dots and dab-marks are interspersed with expressive single-colored starburst-designs that resemble flowers. The shapes squeeze tightly, expanding out into an irregular form.]



[Image Description: Dozens of bright swirled circles mass together into a single amorphous shape.]

(Note: Neither an Artist Statement nor artist photograph are included with this selection of artwork.)

## Candy Waters's Biography

Candy Waters is an autistic, nonverbal 16-year-old artist. Her first published art book, *Unspoken Gift,* has received praise from notable artists such as director David Lynch who described the book as an example of "remarkable talent and accomplishments." More information about Candy's work can be found on her artist page at http://facebook.com/candywatersautismartist.

IDEAS SECTION

## Editors' Note

by Travis Chi Wing Lau & T.K. Dalton

T. K. Dalton: So this is an experiment. We've got, at the moment, two editors of this section, and it seemed fitting to have a dialectical introduction to the work in this issue.

Travis Chi Wing Lau: Absolutely—it's a form that models a kind of dialogue.

TKD: Yeah. And it also models, or renders as transparent, a transition of power. Not that we're incredibly powerful as digital literary journal editors. But we do have a kind of power, and there's a change in that power, and transitions of power happen, I mean, in our own government, that's happening now. The pieces in our Ideas section this issue also address transition. Barbara Ruth's review of Sins Invalid, Avra Wing's review of Raymond Luczak, and your own review of Jay Besemer—in different ways, each of these works and each of our pieces about them I think underscore the way that transition is inseparable from the lived experience of disability. These three works, in very different ways, use our literature to reflect that instability.

TCWL: Especially if we are thinking of all bodies as being temporarily able. We are all in that strange liminality of ability, which can then be complicated by other vectors of identity as in Besemer's case of gender and chemical transition.

TKD: I definitely keep returning to this idea of transition as if it's a thing that has some end, like change will stop. I think what I like about Ruth's review of Sins Invalid is the way that their show represents change -- the aging of the disabled body, the stripteasing away of clothing to reveal the body of an amputee -- as active, not passive.

TCWL: Yes. How might we think of categories of identity like race, gender, or disability as verbs (active processes) rather than nouns (static states)?

TKD: Yes!

TCWL: Societal structures disable just as systemic inequality racializes bodies.

TKD: You should really get a Ph.D. But again, yes! And when I think about some of those systems -- say the federal government -- those structures feel a lot less stable and predictable than they did a month ago. Which makes them that much more potentially oppressive.

TCWL: Which is why campaigns like #cripthevote were so important in the recent election.

TKD: I think criticism (in both senses of the word) from our community is especially important after the election, too. These societal structures, they're old. They come out of antecedents as old as the country. I think of Wing's review of Luczak's *The Kiss of Walt Whitman Still on my Lips*, where she describes the eponymous kiss as "evoking Whitman's personae of comrade and lover, as well as acknowledging Whitman as a kind of father whose descendants—Luczak among them—are the poets who share his expansive view of life and expression." I love this calling back to history, especially in the context of the way placing oneself in a tradition can mark a kind of transition, can show a sort of change over time. Wing's review raises the question, How did this queer artist deal with the world he inhabited, and what is revealed through the perspective of another queer artist in the contemporary world. Know your history in other words. Know where you're transitioning from as well as where you hope to be transitioning to, or something. Is that overly hopeful? Romantic, even? (Whitman pun intended). Or maybe it's like what you said before, about the state of being being active, dynamic, not passive, assigned.

TCWL: I think that's perhaps one of the greatest challenges that face younger people in the disability and queer communities -- this lack of connection to and awareness of our histories just as new powers that be are seeking to erase them. Luczak's volume, I think, dares to find resonances across time, which I don't always feel like younger folks do enough.

TKD: Totally. And technology actually silos us (us? them? I'm 37...) even more.

TCWL: One of those sad ironies -- we're more "interconnected" than ever before and able to "access" more from the past than ever before yet seem more removed than ever from it. Transition seems appropriate -- technology advances in a way that culture has yet to catch up to. Millennials, especially, are caught in that in-betweenness. Luczak found a forebear and a mentor in Whitman. I think this is particularly poignant given how directionless a lot of disabled and queer folks feel right now. A turn to history seems timely and necessary.

TKD: For sure. It’s interesting to mention age and generation. Another thing I noticed was the way aging kept emerging in texts under review. Luczak describes a speaker “alone in my bed being unable to strip down to the boy I used to be. The Sins Invalid performance included a piece called “Midlife Crip Reflections” with these lines: “aging as a crip, / sometimes, feels like my body is aging faster / almost with a vengeance / as if claiming revenge / for all the years of forcing my arms / to also be legs and pushing my body / until it ran out of gas, /

and even then forced it to keep going.” There's an individual transition that's constant, even as the body in space becomes variously disabled, and as the body in time becomes variously oppressed. I maybe should use a word other than “constant,” since that sentence already sounds so intensely algebraic. Steady, maybe that’s it.

TCWL: Yes, yet disability problematizes this notion of linear development like queerness resists a kind of reproductive timeline. Disability can make you feel like you've aged beyond how old you really might be. It can also feel like it takes years away from you. Crip time in the midst of individual transition, perhaps?

TKD: Right. I wrote that and then thought -- yeah, but this cute little tautology was written by someone who can't sequence well enough to put together IKEA furniture in less than a full day. I love that idea of resistance. Being present or stating presence (in the case of folks with less visible disabilities) is a form of resistance, too, no?

TCWL: Yeah! Especially when disabled folks are so often infantalized or seen as not "fully developed." Those with less visible disabilities, especially in the academy, have been vital in resisting the "speed" of academic time and the "publish or perish" model of academic productivity. Being present, taking up space, and taking up time are all acts of resistance.

TKD: I am here, and by being here, here is now there.

TCWL:  And my being here challenges the assumption that there is only one "present" and one "future."

TKD: Or that line from Besemer, describing a moment “when making & unmaking have become the same action.”

TCWL: Yes! Again, processual rather than static.

TKD: And to quote you from earlier -- "[This] is why campaigns like #cripthevote were so important in the recent election" -- presence changes the content of the argument, even if it doesn't change the outcome. Maybe?

TCWL: Yes, we are challenging the narrative that the outcome is indeed inevitable and that the future administration cannot be changed and does not need to be accountable.

TKD: I think we'd gotten to this real enlightened point, then I dragged us back to politics. Um, so this is probably enough for an editor's intro. Though I feel like I could talk a lot more. ☺

TCWL: A lot of productive threads to follow! I smell a part 2.

TKD: Or at the very least a Deaf Poets Society, Issue 4. Before we finish, are there any thoughts you have about transition from, say, your own poetry, your research about disability through your Ph.D. or anything else you want to mention that you haven't yet?

TCWL: My involvement in DPS for me is part of a long process of transition, really -- to understanding the place of the personal in my academic work and the way my academic training and relationship with theory influences my poetic practice. Far too often, literary studies folks separate themselves from creative writing folks but at the heart of it, literary studies takes creative work as objects of study. I want to immerse myself more in the writings of disabled folks and be more attentive to how that writing is produced from the position of disability. My poetry, especially, is about trying to aspire to a certain accuracy about states of feeling, being, and experience. But if anything, if disability is indeed transitional in a verbal, processual sense, it's actually a futile pursuit to try to isolate disability experience. Instead, I guess, I'm learning to be okay with these snapshots of disability in motion, of fragments that capture mere instances of disability, if that makes sense. (Sorry, that was a little long.)

TKD: No, that was great!! Folks should get to know you. Any time a new mind comes on board, it alters the journal and the work we do undergoes a productive transition—maturation, we always hope. Presence changes content and direction.  So happy to have you, Travis, and speaking for the editors, we're excited to see your new Ideas.

**Travis Chi Wing Lau** is a doctoral candidate at the University of Pennsylvania Department of English. His research interests include eighteenth and nineteenth-century

British literature, the history of medicine, and disability studies. His academic writing has been published in the *Journal of Homosexuality*, *Romantic Circles,* and *English Language Notes* (forthcoming). His creative writing has appeared in *Atomic*, *Feminine Inquiry*, *Wordgathering*, *Assaracus*, *Rogue Agent*, and *QDA: A Queer Disability Anthology*.

**T. K. Dalton's** essays have been nominated for a 43 Pushcart Prize and inclusion in Best of the Net. His fiction and nonfiction are forthcoming in The Common, Duende, and Front Porch Journal, and appear in The Millions, Tahoma Literary Review, Radical Teacher, Deaf Lit Extravaganza, Disability Studies Quarterly, and elsewhere. With poet John Maney, Jr., he edited What if Writing is Dreaming Together? He earned an M.F.A. from the University of Oregon and is currently writing a memoir. Tim lives with his family in New York City, where he works as an ASL-English interpreter.

## T.K. Dalton and Eileen Cronin

# "Without grievance, how can we describe what we're going through?"

## An Interview with Eileen Cronin

*Eileen Cronin spoke with our Prose Editor, T. K. Dalton, by phone last December. Dalton was in New York, where he posed questions in a near-whisper in order to not wake up his toddlers. Cronin, in Los Angeles, spoke with fewer restrictions. "My husband is changing a lightbulb," she said as the conversation began, "So if you hear 'Oh shit!', just edit it out." While this exclamation was not among the cuts made in this piece, the interview has been condensed for space and edited for clarity.*

The Deaf Poets Society (DPS): You and I are going to be on a panel together at the upcoming AWP Conference. Part of the panel's description is a discussion of writing related to disability in "the current climate." I'm wondering what you think the role of writing fact-based narrative about disability is at the very beginning of what appears to be by any measure an ableist, anti-fact administration?

Eileen Cronin (EC): I don't see any likelihood of the next administration making disability its pet project. I am hopeful, though, about the possibilities in the broader landscape for the topic, especially for writers with disabilities. I'm hoping that people will get more serious about the press and its importance; it is the only thing that is left to counterbalance a very extreme government. Having a press that is more open-minded and broader might be more of a priority. I don't think the liberal press has been very welcoming of the topic of disability. It's great the New York *Times* has a Disability column. That's a great step forward. It'd be great if it weren't a separate section, though there are advantages to that, too.

I wish disability were included typically in mainstream articles or in television. I wrote a piece for *TruthDig* a few months ago, because I got really angry after seeing one more person shot by a police officer. This was the man in North Carolina who had a traumatic brain injury, Keith Lamont Scott. There's a clip of his wife saying, "He has a TBI, he has a TBI." Now, the press only talked about him as an African-American man. There is clearly a problem with police going after African-American men, but my article focused on how many people in these high profile cases are being shot by the police are people with disabilities. In fact, half the shootings are people with disabilities. We don't have disabled reporters; we don't have disabled guest experts. I was listening to an interview with Chuck Todd, in which someone referred to the [Democratic National Convention] hosting "a charming dwarf." And Chuck Todd just let that go. In the liberal press, hosts and guests are friends, and discussions are focused on identity politics, but with disability they are ill-informed and they don't call each other out, because they think they are expanding the idea of inclusion. But if they were doing that, we'd see more people with disabilities in the media. The charming dwarf was a Hillary friend, but Clinton had no outreach coordinator for disability issues.

DPS: I think that erasure is so systemic and difficult, and in the literary world, I think it’s especially for younger writers. You and I met through a mentorship program, which was a real watershed for me, to work with writer with a pre-ADA experience of disability. In the context of our cultural moment, and given the state of the media, do you have thoughts for writers with disabilities where there is so much ‘single-story’ stuff going on—for example well you couldn’t be Black and disabled. The complexity has to be boiled down to a discussion that can fit between commercials for laundry detergent.

EC: Pundits may feel that by pointing out disability they are distracting from a conversation about race. But in fact it’s hurting the people who are being shot. The suggestion is if you are Black and d/Deaf, Black and have a traumatic brain injury, Black and schizophrenic, you are a serious target. You can be targeted without any knowledge that you’ve become one, just because you can’t hear a siren or respond appropriately to a command. People with TBIs can be erratic; they can threaten violence with no intention of carrying the threat out. Police need much more extensive training than they have. Their training needs to be focused on race and disability. Both are equally important. You should have to work in an emergency service for a month of training on community mental health, interviewing psychologists and social workers, one person after another, and you will get a broad perspective on the problem, especially regarding mental illness and brain injury and developmental disabilities. I did trainings as a psychologist in Fairfax County, Virginia, one of the largest counties in the country, and they send their police force all around the world for responses to emergencies. At the time that I did the training, the force only included a half-day of training for police in terms of mental health. In reality, police are often called to handle situations that involve mental health. If they're not trained, they can quickly jump to assumptions by assigning to the individual a capacity that they may not have.

DPS: I don't know if you had a chance to read Jillian Weise's essay from the *Times*' Disability series, "Dawn of the Tryborg." The line is something like "Erasure is not news to us," and I think of that as we talk. And actually, she continues: "We have been deleted for centuries, and in the movies, you will often see us go on a long, fruitful journey, only to delete ourselves in the end." So staying with erasure for another minute, I'm going to shift from Washington to LA, where you're adapting your memoir *Mermaid* for the screen. What's that adaptation been like, given *Mermaid*'s focus on disability and sexuality, two topics that taken together are hardly present enough to get erased to begin with?

EC: Hollywood is trying, as much more than the literary marketplace. *Mermaid* is still very much in progress. The screenplay needs to get finished, and then I'll know more. But even though I think there is more disability represented in the publishing industry at large than in Hollywood, a lot of books don't represent disability in any nuanced fashion. In terms of television, *Speechless* is a great show about a boy with cerebral palsy, which is getting a lot of interest. The worst of the books about us puts people with disabilities in a weaker position because of the focus on inspirational stories. That makes it impossible if you're a person with a disability to ever make a request. Your job is to be inspirational, to make other people feel good. That's what the publishing industry does. Then, the literary folks look down on us because there's so much bad writing about disability. Did you see *The Writer's Chronicle* from a few months back about inclusion? I'd need to go look but I don't think there was anything about disability. And I was like, really, after all we did to get into AWP. Maybe they felt like, well there are a lot of disability panels. It's moving forward, but it's slow.

There is kind of a resistance to looking at disability. I can't figure it out. I just did a blurb for an anthology of fiction, *The Right Way to Be Crippled and Naked* (Sheila Black, Michael Northern, Annabelle Hayse, eds., Cinco Puntos Press, February 2017). Dagoberto Gilb has a story in there, which I really like. My husband and I wrote an essay for *Wordgathering* on grief and grievance and Robert Frost and reading Dagoberto Gilb through the lens of Robert Frost. So actually Frost wrote an introduction to A. E. Robinson's last collection of poems that didn't acknowledge the author at all. The publisher had to come back to him and say, could you at least mention the writer? It was the 50s and Robinson wrote about the Communist movement and Frost said, that's not poetry. His essay was about how grievance isn't the purpose of poetry, but it's the place for grief.

In the anthology, Dagoberto is writing in this cantankerous way about a character and a stroke he'd had, about how he thought the people in the hospital were racist but, he finds out from his daughter that he was just really out of it because of a stroke. He ends up mentoring a Latina woman who works overnight as a janitor, and she's having her own problems in life. To me, that story was this combination of grief and grievance. When you're an outsider you can't see anything else but grievance, because it's coming at you all the time. I think that is a much more interesting topic. I think we don't want to be preaching to the literary community about our grief but there are grievances to be expressed, and there will be, as long as there are people on the outside.

Without grievance, how can we describe what we're going through? Robert Frost said poetry is place for grief and politics is a place for grievances. It's very noble, he's a wonderful poet, but that view is extraordinarily dismissive and shows his perspective as a white male in New England in the 50s. He wasn't in contact with enough writers who had an intersection between grief and grievance. I don't think he understood in some ways that you can have an intersection, where the poet creates work that addresses problems, where there's a grievance underneath.

DPS: The grievance is rooted in grief, because grievances arise out of injustice and injustice causes, among other things, grief.

EC: Exactly. You can grieve about the loss of somebody, but if you don't care about social justice, you don't know why it's important. For Frost and other white male writers, grievance may not have a place in literature. But for us, if we don't write about grievance you wouldn't be able to write another word.

DPS: That brings us full circle, to the question of our work in the contemporary climate. You are going to be a guest editor of the nonfiction in our magazine this coming year. What sort of work do you want to see from writers with disabilities?

EC: I like to see work, not just nonfiction but poetry and fiction, where the disability is an integral part of the story. I like to see writers with disabilities working together to push more to get stories about disabilities in the press. I don't always want to be writing articles that are critical, say, of Hillary Clinton saying 'Hello, there are 56 million of us, why don't you pay attention?' Your interview for *The Common*, with Jillian [Weise]--we need to do more work like that, just trying to get heard. It's working on some level, like the Times features on disability.

DPS: The *Times* pieces I've read are very focused on personal narratives, and when I think of your work, the personal narrative you write can be very funny. Sometimes I wonder, I don’t get lots of funny stuff, why is that? Is there anything in particular with disability-related nonfiction that you don’t see enough of?

EC: I like seeing work that’s clever, that’s not only about disability but where the disability doesn’t need to be explained, where it’s played out in a dramatic way. Maybe it’s explained but the person’s disability is not the whole focus of the piece. That’s the thing about writing memoir; maybe that’s why I wanted to make it funny, because if it were just about disability I’d be like, “Snoozeville!” There need to be memoirs that tend to be more literary. We need more people on staff of MFA programs so that people are learning disability literature so that reviewers have a sense of what they’re reviewing. Right now they don’t know what they’re reading, they don’t have a schema in their head about that experience, approaching work without understanding it. Jillian’s piece, it’s brilliant, but I don’t know how many people know why. And maybe that’s fine, for them to say that this woman with an artificial leg is so wildly creative, I’ve never read anything like it. But we need more people familiar with the variety of storytelling tools about disability so it isn’t always, “I don’t understand.”

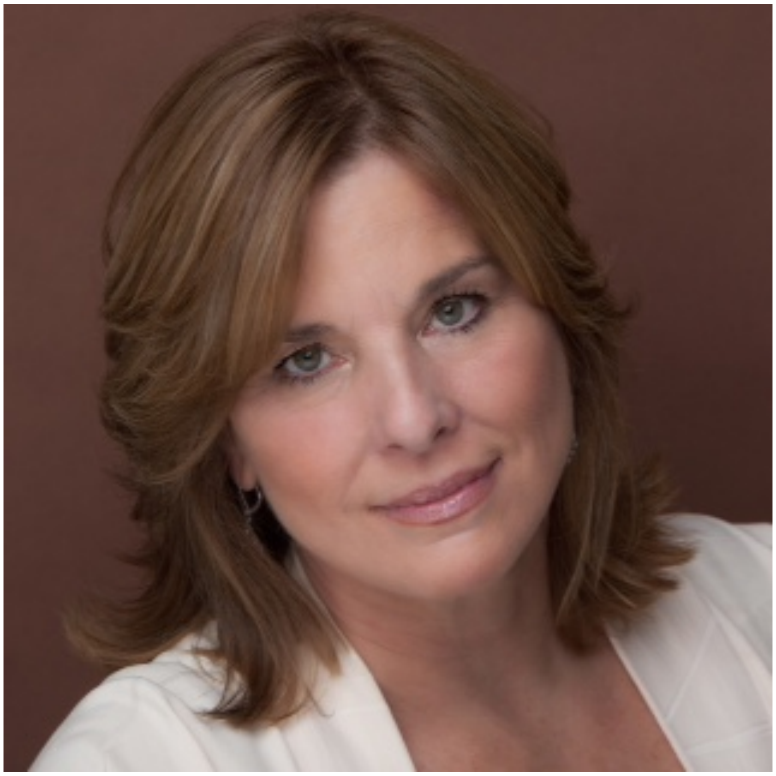
DPS: "You're not meant to fully understand, you're meant to go home and think about it. It's not my job to explain every single thing. There's a story to do that for you."

EC: There's judgment: the story should be inspiring. This person should inspire me. And if that doesn't happen, the reaction is often, Why doesn't this make sense to me?

DPS: It's like, welcome to my world. Welcome to the experience. Be polite.

EC: Nobody's giving you a tour, you're invited in, that's it. When I first read [Rita Mae Brown's] *Rubyfruit Jungle*, I didn't know half the shit she was talking about, but it was a view into that world. Why does our writing have to be an exposé about our life? Leave the explaining to newspapers. Let's access the mainstream media about as the place to explain our lives. Otherwise, let's be really creative.

## Eileen Cronin's Photograph & Biography



[Image Description:  A white woman with shoulder-length red hair and a white shirt looks directly at the viewer against the background of a solid maroon wall.]

**Eileen Cronin**'s memoir, *Mermaid*, which is on O Magazine's Best Memoirs of 2014, was translated into three languages. She is published in *Washington Post, Daily Beast*, and in literary reviews. She won the Washington Writing Prize in fiction. She teaches writing, psychology, and performs in The Moth.

## Travis Chi Wing Lau

# Review: *Chelate,* poems by Jay Besemer

Chelation, as a therapeutic process, operates by the injection of ethylenediaminetetraacetic acid (EDTA) into the bloodstream. This synthetic solution reacts with toxic metals and minerals by binding to them and rendering them innocuous to the body. Jay Besemer's *Chelate* (Brooklyn Arts Press, 2016) draws a provocative connection between this controversial medical intervention and the process of gender transition, which relies on similarly biochemical methods such as hormone therapy for the purposes of bodily transformation. Written in the midst of his transition, Besemer thinks through his body as a collection of barely-perceptible forces and microtransformations, ones that "chelate [him] into a new man" (74). *Chelate* is unapologetically about metamorphosis – matter and self in their vulnerable acts of becoming anew "when making & unmaking have become the same action" (18). Trans experience is all too often reduced to the "before" and "after," but *Chelate* generously gives us access to the interiority of trans experience, where "before" and "after" can only be understood through their interrelationship. Within this interstitial space, there are multiple bodies, selves, and worlds in motion.

Given Besemer's description of his work as a "book that lives in/is/is from the body," *Chelate*'s form merits particular attention. The only organizational structure is a set of section headings ("Xenophilia," "Making & Unmaking," "Adjustment Disorder," "My Inheritance," "Ordinary Wear & Tear) that break up what reads as a longer poem into parts that seem less distinct than blending into one another – a textual body that begs reading back and forth across its parts for their resonances. Besemer employs a paragraph-like structure on each page that is punctuated by colons. These colons both interrupt and aid the reading process, provocatively generating a simultaneously dissonant yet associative effect between phrases and words.

In an early passage from the first section, Besemer introduces two contrasting sets of images that pervade the work:

> the origami contrivances are burning : dead
>
> languages crisping & blackening between us, autumn
>
> leaves destroyed in a fish-gasp of protest : our cross-
>
> wired failure : what I need & intend are signals from
>
> beyond the rim of your galaxy : the tune you want
>
> me to play is impossible for one of my species : so be
>
> it : no more false deaths : down payment for the big

one : this departure is also the arrival :: (19)

The passage unfolds with the vegetal images of the burning "origami" paper and languages likened to dead "autumn leaves," yet then transitions abruptly to the scale of "galaxy" and "species." This tension between the earthly and cosmic produces a disorienting effect as these images are made to coexist with another on the same passage and page through a series of enjambments. Such a structure begs different readings depending on whether one reads by the colon breaks or by the line. Without conventional punctuation, phrases and fragments emerge as the primary units of meaning, rather than complete thoughts confined to the level of sentence. Reminiscent of analogies formatted for standardized tests, Besemer's colons challenge the reader to inhabit the immediacy of language, to work through (or perhaps against) the linkages of words put in proximity to one another. As Besemer describes of his own embodied poetic practice, meaning is consistently made, unmade, and remade. Besemer hints at how his work should be read: "open the words out into small instants of occurrence: short, declarative : hardworking ::" (84). Chelate rewards a diligent reader who can zoom in and out between the individualized "instants of occurrence" and larger sections that may complement or even contradict one another.

Yet most poignant in Besemer's volume is its narrative of illness. As opposed to a simplistic, triumphalist trans narrative of a healthy body coming into its own, Besemer defines transness as "changeable beast : a work / of time," which necessarily involves struggle within and without (112). What Besemer powerfully risks in this volume is the "deliberate exposure of the turbid self" to the possibilities of not only change but to the non-linear temporality of disease and disability that cohabitates with his trans experience (117). Chelate reads breathlessly in the present tense, but in one of the volume's characteristic enjambments, Besemer embraces a vision of time, where a "day also stretches into one 365-part day" or "ceases to mean" anything at all (40, 96). As opposed to a daily account of his transformation, Besemer offers what seems to fall out of our conventional sense of time in favor of how "tendons tell stories : mystery tales of limbs that fit suddenly into larger interests" (96). Selfhood seems to exist in these localized "instants" rather than in linear progressions.

Besemer is frank about the grueling "work of maintaining coherence" when we are "bodies forced into matter" as "coerced by externals"; we, as subjects, are always subject to enforced ways of being – be it able-bodiedness, heterosexuality, or gender normativity (40, 45, 65). It is possible, as the enigmatic yet confessional "I" admits, to "fail" – to be matter out of place, to be askew, to be queer. Yet rather than framing such failure to be normal as negative and unproductive, this transition into both gender deviance and toxic illness marks the creative capacity of chelation – a precarious, uncertain in-betweenness, where cultural and bodily toxicities can become entirely another.

**Travis Chi Wing Lau** is a doctoral candidate at the University of Pennsylvania Department of English. His research interests include eighteenth and nineteenth-century British literature, the history of medicine, and disability studies. His academic writing has been published in the *Journal of Homosexuality*, *Romantic Circles,* and *English Language Notes* (forthcoming). His creative writing has appeared in *Atomic*, *Feminine Inquiry*, *Wordgathering*, *Assaracus*, *Rogue Agent*, and *QDA: A Queer Disability Anthology*.

Barbara Ruth

# A Ceremony of Cripdom:

## A Review of *Birthing Dying Becoming Crip Wisdom* by Sins Invalid

(October 15, ODC Theater, San Francisco)

Sins Invalid is something rare: A performance project that centers queer disabled people of color, holds a commitment to social justice, and expresses a spectrum of crip sexuality. The name, according to co-founder Patty Berne, "references 'invalid,' which is what we're often referred to. That's just inane, it doesn't apply to any human. The name also plays on the idea of 'sin'—meaning 'without'—so, without the concept of the invalid. It's also a play on words in terms of our bodies, or the act of embodiment somehow being original sin, or a problem to overcome." *Birthing Dying Becoming Crip Wisdom*, the most recent offering from Sins Invalid, presents a dreamspace, a ceremonial embodiment of the life cycle. It reflects the deaths of parents and beloved friends of the ensemble, and their own aging disabled bodies which insist on being seen and heard and felt, as they resist, confirm, and ultimately transform concepts of old age and disability.

The performance begins with a drummed invocation to the Orisha Legba, who in Voudoun and other Yoruba-based cosmologies brings about communication with ancestors and the other Orishas. Traditionally Legba uses a cane, but there was no expression of his cripdom. This omission is a missed opportunity.

Drummed prayers to the Orisha Obatala, creator of human beings, flow into the piece "Obatala Blessing/Obatala Opens" danced by Lateef McLeod and Sean Shelly with voiceover by Baba Afolabi. In other pieces Lateef uses a rolling walker as mobility aid. In this piece Sean walks behind him, tenderly supporting him as they dance about and on the floor.

"Obatala's Blessing" proclaims that crips, with our divergent bodyminds, are fashioned in perfection. We are not mistakes. Like two-spirit/non-binary individuals in cultures which recognize them as necessary to the wholeness of the community, we, too, are essential.

"Bringing It Black" (written by Neve Be(ast) and Malcolm Shanks, voiced by Malcolm, danced by Neve and Antoine Hunter) reminds us of the stark reality that "we cannot take for granted the birthing of Black and Brown bodies." But it affirms in the face of oppression:

*I was searching for beauty and named myself so….*
*I am meant to love a world more precisely than it had ever been loved……*
*I exist as a refrain.*

The ableist world intrudes with callous questions. "Were you born like that?" Countless disabled people have been wounded by this question. But Sins asks with loving curiosity, with awe,

*Do you find yourself inside your edges?*
*How did you first understand your name?*
*Who are your people? Were they there at your birth?*

This is the bending dreamworld Sins has created, in which the peculiar, the divergent, the queer are revered.

Todd Herman's silent video "When I Stop Looking" slowly pans across faces changed by burns, variant in pigmentation. Faces with atypical variations on two eyes, one nose with two nostrils, one mouth. Faces touched, kissed, explored, desired, known. Watching, we inhabit the dream of loving curiosity.

The first half concludes with "Rooted," by Deaf choreographer Antoine Hunter and Deaf dancers Zahne Simon and Leah Mendelsohn who perform before a backdrop image of a redwood. The lights go blue to a recording of Miles Davis' "All Blues." The metaphor of rootedness shows the power of connection to both ancestors and the present through Deaf community.

Sins Invalid's access accommodations are far beyond what most events provide, including events in disabled communities. There are provisions for scent sensitive, wheelchair using, neurodivergent (a low-stim room to chill in), and Deaf audience members. The description of access in the pre-performance publicity was helpful and accurate. No one is turned away for lack of funds.

Members of the ensemble participate in different ways, through videos, soundscapes, some without being physically present. Because Leah Lakshmi Piepzna-Samarasinha has "cognitive differences that make memorizing a 7 page piece difficult" (Disability Remix Blog) unlike the other actors she uses a script.

Ironically, the inadequate access is to information about the performance. *Birthing Dying Becoming Crip Wisdom* uses a framework of Yoruba-based beliefs but this isn't made clear in the program, which never acknowledges or names the drummers, essential to summoning the Orishas. Nor does the program let the audience know who created and performed which piece. One of the reasons for Sins' existence is to "incubate and celebrate artists with disabilities," according to the mission statement on their website. A program which lists the pieces, the authors, and all the performers would greatly advance that mission.

The second half begins with Neve's piece "Welcome Back to Life" combining dance, projected images, and spoken word voiced, offstage. This piece is a precious gift to the disabled audience, a love poem whose "vibrational hinged tongue" celebrates:

*the wild place that is our bodies……*
*We are complex, iridescent, splendid people.*
*And yeah, we want you here.*

That wildness develops in the song "Primordial" performed by the many-worldly vocalist Nomy Lamm. Magnificent lighting enhances Nomy's crimson garment, provided by Hamilton Guillen and Cubacub/Rebirth Garments. Evoking the Red Sea, it flows out toward the wheelchair-reserved front section of the audience while India Harville and Neve crawl under Nomy's skirts. Throughout the evening, dancers often move from their wheelchairs to the floor, overturning the phrase: "confined to a wheelchair."

Leah Lakshmi Piepzna-Samarasinha takes the stage with "Crip Magic Spells," another profound welcome, this time to "beautiful baby crip."

*We're waiting for you….*
*We've already survived the worst things in the world…..*
*Asking for help is the thing everything else rests on……*
*There is no such thing as too disabled to live.*

While these words are healing and aspirational they are not of course the whole story. Maria R. Polacios reports in "Midlife Crip Reflections:"

*aging as a crip,*
*sometimes, feels like my body is aging faster*

*almost with a vengeance*
*as if claiming revenge*
*for all the years of forcing my arms*
*to also be legs and pushing my body*
*until it ran out of gas,*
*and even then forced it to keep going.*

In "Crip Magic Spells #2" Leah tells the new member of the crip community what to expect from the abled world:

*They will forget (about your disability) and they will think*
*they're doing you a favor*
*They'll think you're in a wheelchair AT them.*

Leah's "All the Femmes Come Back" is a raging grief at the suicides of many disabled femmes of color in her world, and the suicidality of many more, including herself. Trying to witch them back, she proclaims:

*I don't need any more ancestors. I've got plenty……*
*I choose life as spiteful revenge.*

I could feel the audience weeping throughout this piece, which I hope will soon be in print.

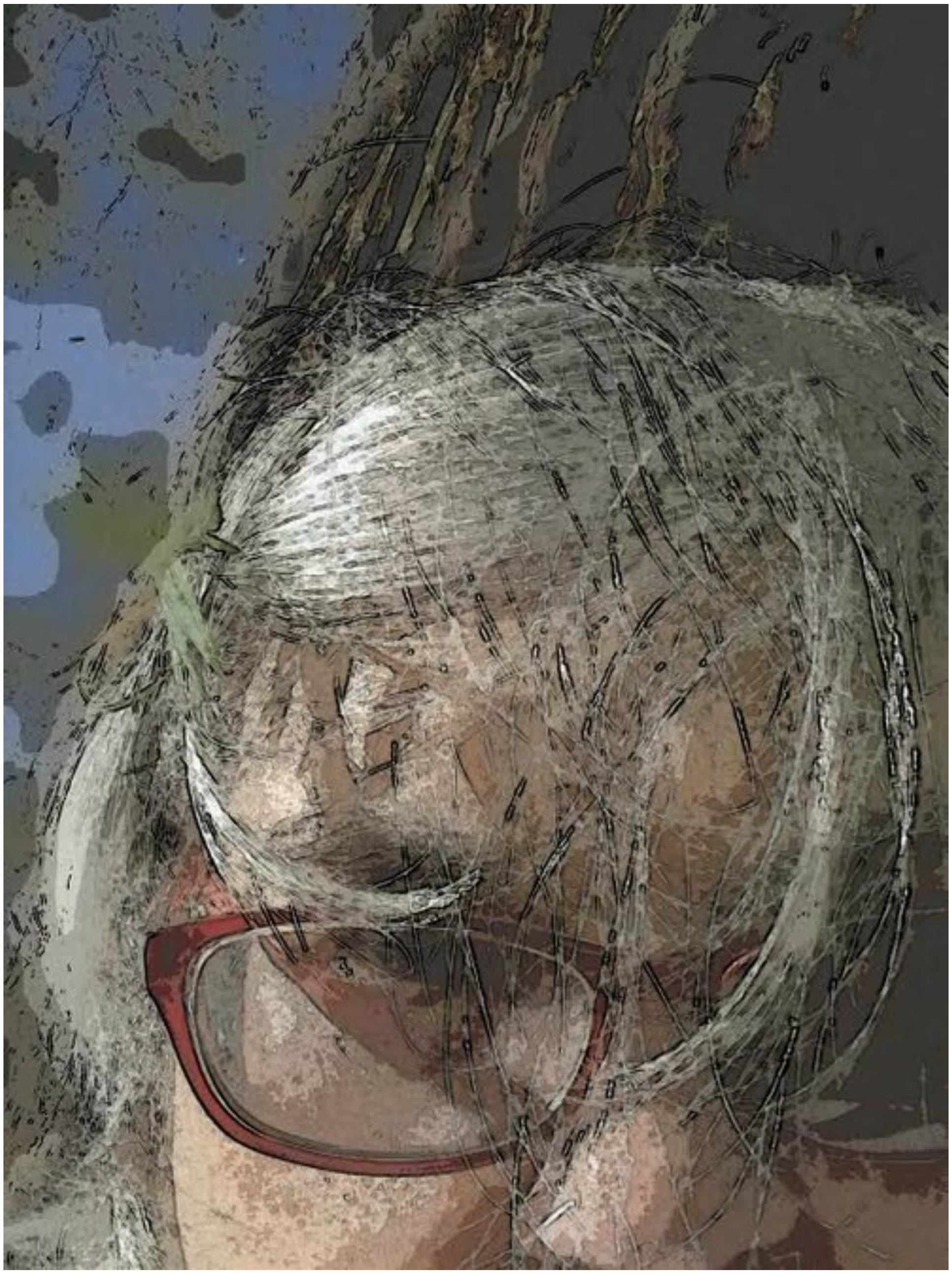
Nomy sings/prays "Stay Open" which includes the Hebrew phrase Lulei Hemanti ('If only I could hope/Only because I hope') from Psalm 27. As the song progresses she reveals more of her lusciously fat crip body and at the end drops her covering cloth to reveal herself naked and amputated, with a quick fade to black. I believe she is challenging the audience to question our discomfort with the combination of striptease and prayer. That said, this piece would have worked better for me if she had used the cloth to steadily adorn and reveal herself, having the body parts and absences which convention censors openly and lingeringly displayed.

Neve, in "If and When We Die," speaks of a time "when you marry that creature named death." They tell of "Disabled people who tried everything. Or nothing at all." And Neve wishes us this:

*I hope you will have loved other people…*
*A beautiful way to die.*
*A wonderful way to have lived.*

The night ends with more prayers to Legba, with the entire cast on stage. We, the audience, showered them with love.

## Barbara Ruth's Photograph & Biography



[Image description: Approximately two thirds of Barbara Ruth's face appears. She has grey hair, which is in her face, over her red glasses. Her eyes are brown and a tree trunk appears behind her. Her mouth and left eye are not visible.] Photo Credit: Barbara Ruth.

**Barbara Ruth** is a 70 year old physically disabled and neurodivergent lesbian who is Ashkenazi Jewish, Potowatomee, and Welsh. She performed with Mothertongue Readers Theater in San Francisco and with Wry Crips Disabled Women's Theater Project in Berkeley from its inception in 1985 until 2001. Her poetry, photography, reviews, memoirs, and fiction have appeared in disability, feminist, literary, and queer journals and anthologies from Australia, Canada, India, UK and US. She is a daughter of Yemaya, Orisha of the ocean.

## Avra Wing

# Review: *The Kiss of Walt Whitman Still on My Lips*, by Raymond Luczak

Raymond Luczak's new book, *The Kiss of Walt Whitman Still on My Lips* (Squares and Rebels, 2016) is a passionate, personal tribute to the great poet. The title comes from a quote by Oscar Wilde, who met with Whitman in 1882. According to Wilde, Whitman kissed him in parting. As Luczak says to Whitman, whom he addresses directly throughout this volume, "You left him enough of a kiss to brag."

Luczak yearns to be in Wilde's place, to receive a kiss from the poet. He interprets that kiss in several ways: As friendly, as erotic, and as paternal. In this he is evoking Whitman's personae of comrade and lover, as well as acknowledging Whitman as a kind of father whose descendants—Luczak among them—are the poets who share his expansive view of life and expression: "You claimed once to have sired five children./ Only five? You've fathered generations after generations!"

Near the beginning of the book, Luczak refers obliquely to the idea of the kiss when he mentions lips in the context of lip reading. He notes that he was forbidden when he was young from using "the language of hands," and that, "Until I learned Sign, I had to make do with watching/ the mystery and misery of lips masticating words." He was barred from the physicality of signing, and therefore limited in his understanding of the world and himself. He did not fully have the language of the mind or body. As a "child" of Whitman, he understands that these must be one and the same. He says to Whitman, in a particularly perceptive line, "You knew how to celebrate America through your body."

As Whitman did in *Leaves of Grass* and even more pointedly in "Calamus" and "Children of Adam," in *The Kiss,* Luczak is also celebrating the sexual love between men. His own love for Whitman is expressed in an erotic way, as if the famous poet is a lover with whom he wishes to become one. He imagines himself with Whitman, blending physically with him: "Walt, I dreamed of you and I together sleeping,/ beards commingling and bodies clinging,/ hands entwined and legs enmeshed,/twin plants woven together from the same pod." In fact, there are photographs in the book, including close-ups of Whitman's and Luczak's beards, that "conflate" the two men.

*Kiss* is a kind of biography of Whitman, and, in part, an autobiography of Luczak himself, who is looking back on his life and that of the gay community. He refers to a failed love affair with a "gardener" that makes him feel that "I've been without water all season." There is a longing expressed for his youth, for a vitality he attributes to Whitman even in his old age. For his part, however, Luczak laments, "Alone in my bed

I am unable to strip down to the boy I used to be," and, more directly, "How the hell can I compete with the body I have?" He is in need of revitalization, such as the "mouth-to-mouth resuscitation" he says that Whitman performed on nineteenth-century America.

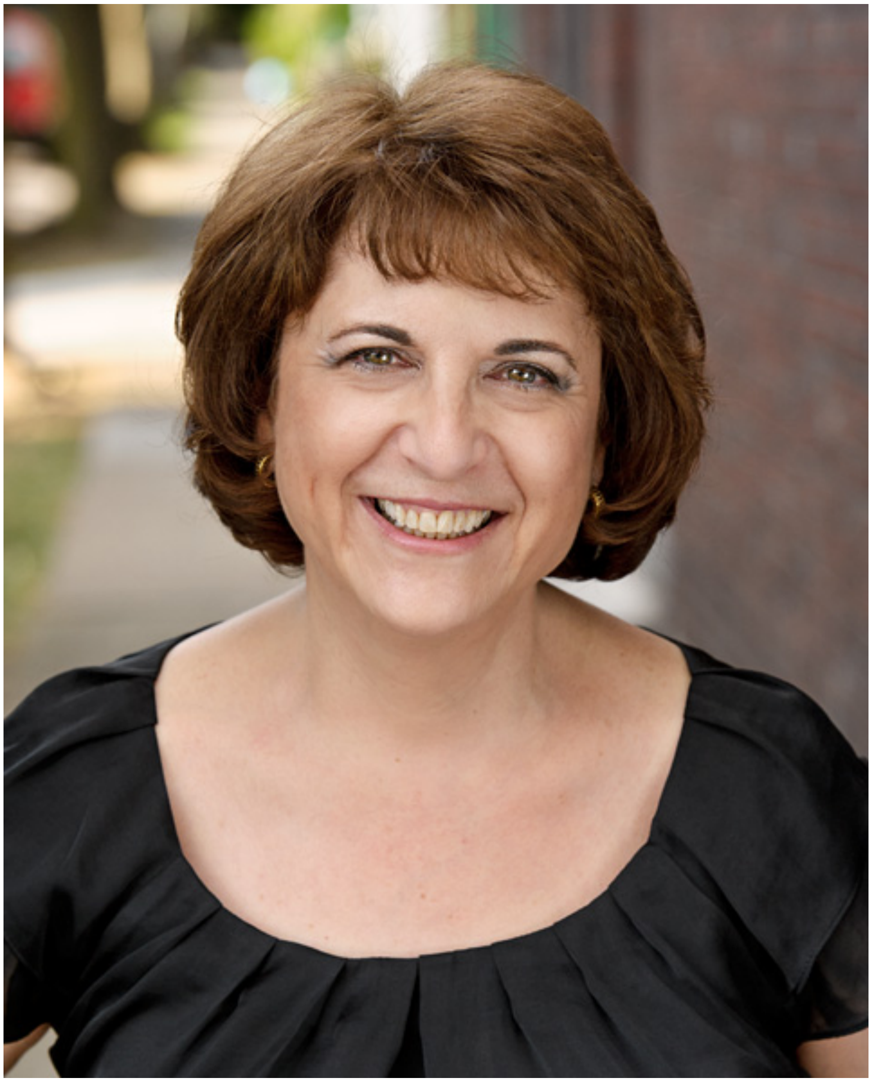
Devastated by the losses from HIV/AIDS, the gay community, Luczak feels, has lost a certain spirit: "there's no genteel bohemia left in Mannahatta./ Your specimen days of comradeship are gone." His view of Whitman and his time is entirely romantic—in the lower case "r" sense that it is idealized and sentimental—and this lack of a balanced perspective can be seen as a weakness in the book. While Luczak is aware that Whitman had to hide his homosexuality to an extent ("You cloaked your unspeakable love in a language /that only others of your kind could translate.") and the prejudice, legal penalties—and violence—gay men were (and are) subject to, he portrays Whitman's era in a purely positive light. He contrasts it with contemporary life, which he finds lacking, despite a more open sexuality and the increasing acceptance of homosexuality by the "normative" culture. He begs Whitman, "Please rescue me from the sterility of America." He notes that while Whitman would be surprised by today's society, he would also embrace aspects of it. He imagines the poet, who loved to be photographed, taking a selfie!

Luczak echoes some of Whitman's themes and even at times his language. As it was for Whitman, the capital "R" Romantic, nature is a consistent and unifying subject throughout. Luczak states he realized when young that "nature sang songs I could hear perfectly/without my hearing aids." His poems veer from Whitman's in form, however: they are more structured than Whitman's. Whitman, often cited as one of the preeminent practitioners of free verse, wrote characteristically, although not consistently, at considerable length in long lines. As Luczak says, "You spoke in clangorous lines as long as trains." Luczak does not follow this model, but reaches further back, writing each poem as an unrhymed version of nine-line Spencerian stanzas. This series of short poems reads somewhat like diary entries in which Luczak is commenting on, and relating to, each aspect of Whitman's life.

At times Luczak gets tripped up by figurative language: "My lungs were robust like Vikings at sea/... when my first love left me, I needed an iron lung." Occasionally, too, he falls back on clichés such as "killing with kindness" and "gossamer threads." He is best when he speaks in a more contemporary way, rather than when he attempts Whitman's ecstatic tone. For example, he talks of love as "mooning sweet ass." And in a plea to the poet to infuse him with new life he says, "I'm so tired of all this crap, Walt. Hum me a lullaby./ Allow me to sleep beside you, your sure hand /stroking my back…"

Luczak concludes the book more hopefully, however, imagining, "One night a dream handsome and lonesome will slip/ beside me underneath the shivery sheets, /stitch his arms around me as you have." With this renewed energy, he says, bestowed like a "kiss lingering on my lips," he knows he will go on, in the spirit of Whitman, to "sample /here and there in the dark and the daylight /the mouths and bodies and hearts of men…" In this unique and valuable book, Luczak proves he has truly incorporated the spirit of the poet.

## Avra Wing's Photograph & Biography



[Image Description: Close-up photograph of smiling woman with brown hair and eye crinkles on a small-town street in summer.]

**Avra Wing** is the author of the young adult novel *After Isaac*, praised in Publishers Weekly as a "complex story of life, love, grief, and recovery." Her first novel, Angie, I Says, was made into film Angie starring Geena Davis and James

Gandolfini. Avra's poetry has been published in numerous journals, including *Hanging Loose and Michigan Quarterly Review*, and her collection, *Recurring Dream*, won the 2011 Pecan Grove Press Chapbook Competition. For many years, she has lead a creative writing workshop through the NY Writers Coalition at the Center for the Independence of the Disabled, New York. Find her at www.avrawing.com.