Stop Requested:
A Collection of ALS Poetry

Brittany File

Preface

I first encountered Amyotrophic Lateral Sclerosis (ALS) at 100x magnification under a microscope during a summer research program at my undergraduate college, Emory University. I quickly became immersed in the disease; obsessed with the opportunity to make progress in pathophysiology and provide knowledge to push the research forward – and I spent countless hours at Emory analyzing it from the lab bench. However, the most important lessons I learned were not from successful experiments, but from patients.

When I entered medical school, I knew that my first two years would be intensely book-focused. While classrooms and labs provide the necessary scientific foundation for a medical career, it's our humanity that gives us the tools to connect, appreciate, and empathize with each other. Listening to patients to better understand their pains, struggles, successes, and failures is the foundation of building empathy and pushes students to think beyond standard treatments and remedies and treat patients holistically. I embraced the opportunity to work with ALS patients and sought a medium that could express their emotions and experiences in a thoughtful way. Writing *Stop Requested: A Collection of ALS Poetry* has been the most unexpected, thought-provoking, and insightful experience of my nascent medical studies, and I am so thankful for the opportunity to bring these thoughts and experiences to you.

ALS is a ruthless, unforgiving disease; it's a diagnosis no one ever expects to hear, a journey no one ever expects to travel. This collection of poetry aims to give you a variety of perspectives of patients on that journey; to put you on that same bus that these passengers are forced to ride. A bus that you can't get off. Each stop on this bus is personal to each passenger, each poem is inspired by one of their stories. Between stops, clinician perspectives serve as “interludes," guiding you along this journey with their expertise and knowledge about ALS and sharing their personal experiences. This collection serves as a narrative for a population of patients, students, and communities to better understand how ALS completely reorders someone's life.

The sadness that many patients experience is expressed throughout many of these poems. Sadness may be a theme, but it is not the whole story…

Acknowledgements

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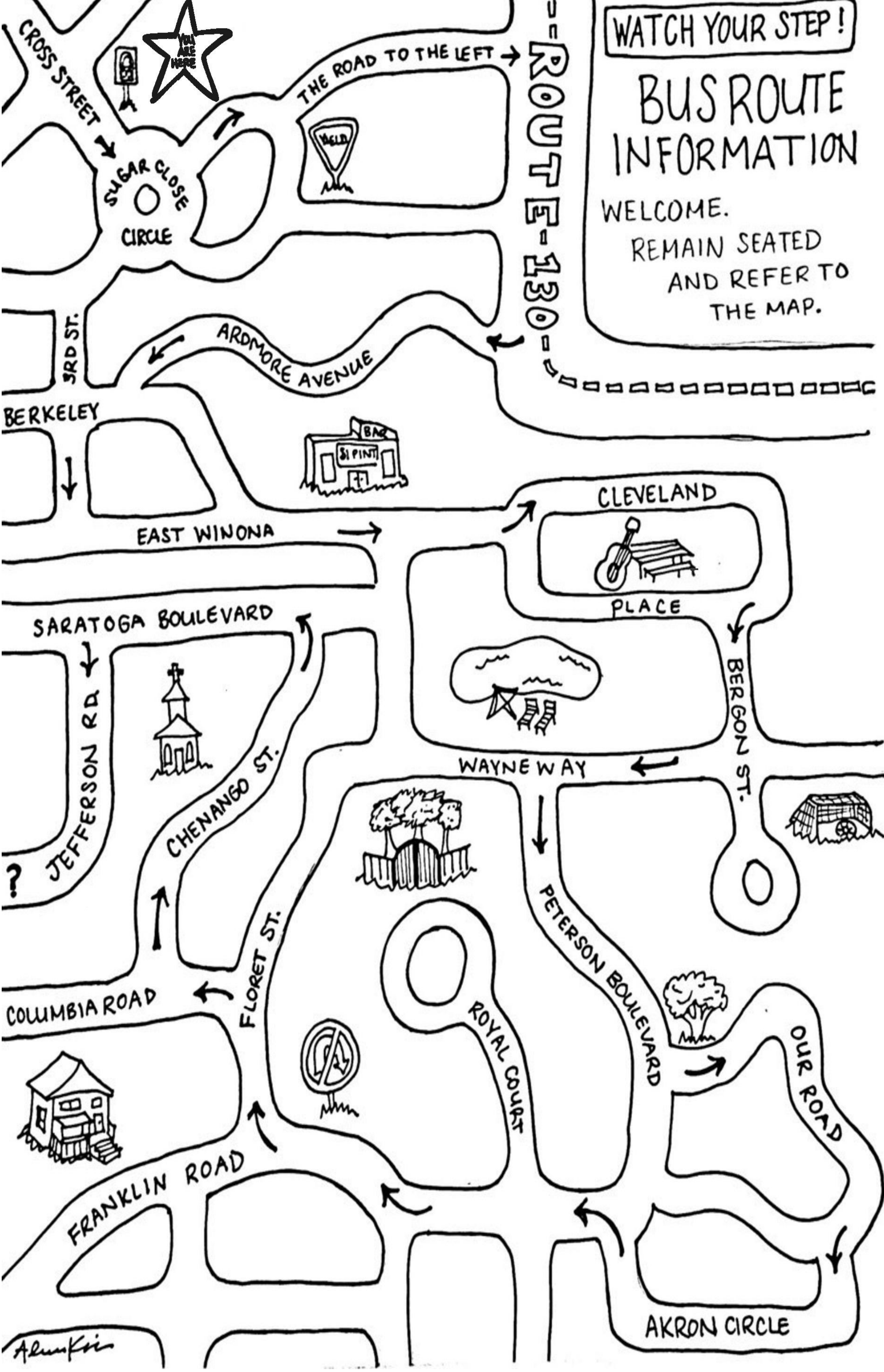

WATCH YOUR STEP!
BUS ROUTE INFORMATION
WELCOME.
REMAIN SEATED AND REFER TO THE MAP.
YOU ARE HERE
CROSS STREET
THE ROAD TO THE LEFT
YIELD
ROUTE-130
SUGAR CLOSE CIRCLE
3RD ST.
ARDMORE AVENUE
BERKELEY
BAR
$1 PINT
EAST WINONA
CLEVELAND
PLACE
SARATOGA BOULEVARD
BERGON ST.
WAYNE WAY
JEFFERSON RD.
CHENANGO ST.
?
PETERSON BOULEVARD
FLORET ST.
ROYAL COURT
OUR ROAD
COLUMBIA ROAD
FRANKLIN ROAD
AKRON CIRCLE

Schedule

Interlude One

“I always feel like there is a little bit of everyone that resides in me. I save small pieces of everyone’s stories. It might just be something little, like when I’m driving down a boulevard and I think ‘Oh! This woman lived down there with their dog, just down that street there.’

I feel like it is my goal to learn something new about our patients every day; whether it’s something dumb, funny, or sad. It’s my goal every time I come to clinic, to learn something about everyone that I interact with. Something that I can bring with me in life. There just has to be something uplifting. Sometimes we can become so surrounded by the sadness of patients, of the fact that they have this illness, and it can be difficult not to let that overwhelm you.
You have to find something good.”

- *ALS provider*

Section I:

"You see the bus turn the corner onto Cross Street. Fumbling for your card in your wallet, it slows to a stop and the doors squeak open. It's not crowded today, but it's warm with a nervous heat. You take a seat and the doors close behind you."

Cumulus Clouds

It was a clear day when
clouds appeared on the horizon:
small, innocent,
fragile
wisps
of white.
At worst a passing storm, and
anyway,
the rain never bothered me.

With a little patience,
the clouds would pass.

But the cumulus clouds accrued
and I began to question
their innocence.
I was never one to seek out the weatherman
but what kinds of clouds
linger for so long?

In August
they gave me an answer.
They told me the storm
in the distance
would
drown
me.

Stains from its rains
have already marked me.
For this storm
        I have no raincoat,
        no umbrella,
        not even a roof
And when the wrath
of this storm hits my shore
it will take me
        down
                with
                        it.

                Each week the storm edges forward;
                raindrops grow larger
                        and my wet clothes
                        weigh heavy
                        on my fragile body,
                gluing me down
                to this tired chair.

Defenseless,
I watch the sky;
        simply
        forced to wait

"The hardest part of this clinic is the implied anguish. It's implied that there is accelerated advancement of this disease, and there will be demise. It's implied. This disease is progressive, and you can never say 'come and see me in six months' because you can anticipate that the struggle will continue and grow every day for our patients. But what we can do is offer support and be there every step of the way."

- *ALS provider*

Forward On

I didn’t apply for the job.

My
disease
      hired
      me.

            It handed me an apron
            stained with the sweat
            of others,
                  and it
                  clocked me in
                  with no way
                        for
                        me
                        to clock myself out.
So I began work
because it was
the
only

      forward

option.

But this disease
does not
take mercy
on hard workers.

Instead,
it senses
adjustment
to the workload,

and elects to
thrust you into
a new position

you never wanted,
never asked for.

Harder work.
More adjustments.
Forward on.

"The hardest part about this disease is that it's always changing for our patients. It might be a two- to three-month process for a patient to come to terms with, and accept their new reality. And now that they've finally accepted it, maybe in those same months they've now changed further, and they look different than what they just spent so much precious time wrapping their head around.

It's like watching someone trying to drink out of a fire hose. You feel really bad about that. Someone might come back to clinic after a few months, and we recognize that it's time to introduce new equipment or expectations, and it can be really tough for a patient to have that conversation.

But as a physician, it's our job to be forward about this reality. It's our job to look to the future for our patients, to anticipate, and although it may be hard to hear it's our job to convey options. We help to prepare our patients for impending changes, whether it's by offering treatment options, assistive technology, or just by offering our hand."

- *ALS provider*

Your Easy Answer

You say
"I don't know"
They are three
simple words;
to you,
they seem innocent.

You say,
"I don't know"
You check your boxes,
You order more tests
You leave
to roam the halls in
your pressed and starched
white coat.
You leave
to treat those with
a definable disease
that you do know.

"I don't know"
It clangs in my head.
The callous fingertips
of uncertainty clench
tighter around my throat.
My stomach sinks
like a dense rock
into a dark pool, while

You say,
“I don’t know”
I go home
for the 10th straight month
to sit and wonder
why my tongue now
trips over my teeth

And now you say,
“ALS”
and I ask more questions
and your answer is still
we don’t know
and
I know
I can’t blame you for that.

Unreality

Speechless

Air
falls
out
of
my
lungs
until my abdomen tenses
and from my gut
I scream back at your words

It’s not ALS!
It can’t be ALS.

My muscles work fine

it’s just my tongue...

won’t cooperate…

with my thoughts…

And your diagnosis

creates an inferno in me
that only the frigidity
of the air outside this exam room
can extinguish…

    Until flames
    reignite

to make me
acknowledge
once again
that I
    may
        end
            up

                Speechless

"When you give someone the diagnosis of a terrible cancer, you think, 'Okay, we'll take it out. We'll offer surgery, chemotherapy, radiation. We'll offer them…something.' We have a plan of action. In this clinic, when you deliver this terrible diagnosis, my stomach clenches because we don't have a standard remedy. There is no standard plan that we know will work. We can try to compensate, but how do you make up for that?"

- *ALS provider*

What I Wish I Knew

She never lies down,
unless she’s very sick.

But
there she was
pale sheets hug her waist,

her dainty fingers
clutch the back of her neck
in what looks a desperate attempt
to stop some nameless pain,
I’m unaware.

She’s
Steady,
Sturdy
Stoic.

Visit after visit
every doctor declared normalcy
while she asserted aberrancy

and I made vows
though they wane in the face
of what looks Munchausen
pleas.

But now
they give it a name.

Exposing my distrust
and treachery

Explaining why she's
prone and cranky

and I've learned more of her struggle
in these doctor's few breaths
than I've ever heard
in the year by her side.

I reach out for my vows
and clutch them tightly.

"It's so important for a patient to have a supportive environment, whether it's family or friends. Because this is a terminal journey, it's impossible to do this alone. Patients have a lot of stressors: their own health, financial, home, family, kids. Having somebody to help you carry the load of some of those responsibilities isn't necessarily required, but it can be incredibly helpful for the patient."

- *ALS provider*

Section II:

“3rd and Berkeley is around the corner. You pull the cord on the window. Stop Requested. The bus speeds past the next stop. Did they not hear you? Something is wrong. Why does it feel like there is no air in this bus?”

The Bus Driver

Vinyl wheel feels warm
against my hands
and makes me smile
as it always has.

Under my control,
we’re safe.

Outside the safety
of these closed windows
life passes
too quickly by.

Rows of trees
and memories
leave only a blur
behind.

Let me stay
inside the safety
of these closed
windows

In this vehicle
that defines me
where normalcy remains
and my disease
does not
grip
the
wheel.

You
must
not
You
cannot
Take it
from me.

Because taking the wheel from me
would wreck me
worse than this diagnosis.

"The hardest part of this job is taking away somebody's independence or even talking about taking it away. For many people like yourself, or myself, your dignity is linked to your job, your car, your role in life, and now that is melting away, dissipating in front of you. So now you're forced, no matter how strong or feisty you are, to make a change. We're telling someone to redefine their life."

- *ALS provider*

Almost Normal

I hate that the bar is crowded tonight.

Full of loud and eager drinkers
who emphatically clink their
bottles to celebrate
this
          careless
                    moment.

Their reckless amber droplets
splash onto my white blouse
          “Ugh!”
          I shoot them all a death stare
          as I continue my indirect route
          through the crowd
          to the counter ahead.
                    I usually let Rob order
                    (these days)
          but he’s in the bathroom,
          and I’m thirsty.

I squeeze through to the front
and flash a smile to the bartender.
          She begins to make her way over
          and I repeat to myself
          “Vodka tonic with lime,
                    vodka tonic with lime,
                              vodka tonic with lime”.

The room is vibrating with 90’s music
and nostalgic adults scream the lyrics
so loud I can barely hear my own thoughts.

She doesn’t even bother to ask for my order,
just nods her head to show I have her attention

          “Vodka tonic with lime,” I say.

But that’s not what comes out of my mouth.

          “Voooka oonic wiii lamm.”

Instead slow, deliberate, slurred.
          It’s dysarthric.

I can see her contemplating
if I’m drunk,
          on drugs,
                    or mentally disabled.

I debate whether I should try repeating myself
She looks confused
and before I can make my own decision,
she dismisses me and nods her head
to the person on my left.

"The first time I saw a patient with ALS I didn't really know what I was doing. I didn't understand all of the details associated with it. His breathing numbers looked great, but when I told him he started crying. I was so confused, and he said, 'I don't want them to be good, I don't want to have to struggle, I don't want this to last long'. Obviously not everyone is like that, but I was so shocked. I think that beyond their own struggles, some people feel like a burden to their families. Maybe I'd feel the same way."

- *ALS provider*

My Guitar

I let my fatigued fingers
labor over chords
once picked
and plucked.

This disease has a long record
of attempted theft of passion.
No pick? No problem.
It’s no Aerosmith, but
blues will do;
it’s better than nothing.

But when this disease
picks on me
I lose myself in a time
when Rock n’ Roll
bounced off my guitar strings
and the sun was drunk on whiskey.

My head bobbed with rhythm
and there was
        nothing
        but music
        on my mind.

                I live lost
                in this trance
                where the sun
                tenderly embraces my skin
                and the guys jam with me
                until this disease makes
                that moment
                        a memory
                                again.

What Matters to the Second Hand

7, 8, 9, 10
The morning slips by so quickly.

My wife wakes early.
I hear her downstairs running the coffeemaker;
the aroma wafts up the stairwell;
makes a home around my nostrils.
I hang onto the vision of her
thick, brown curly hair
sprawled over the pillow next to mine.
I wait for her to return to our bed
where she can help dress me.

11, 12, 1, 2
Weekend afternoons are my favorite.

My son is home,
no school to take him from me
and no work to take me from him.
My eyes follow him running across the backyard lawn.
It’s unkempt now, and the soccer ball slows quickly
stuck among the weeds.
He kicks hard and rehearses his celebration.
To see him run, and love, and care as he does,
He’s my son.

3, 4, 5, 6
We have friends over for dinner.

My wife prepares lasagna
and I sit at the table
with old friends reminiscing
about shenanigans from high school.
Patient and compassionate,

they must wait a little longer for my memories
to reach their ears.
They understand this progression.
I eat slowly, until my arm is too tired to continue.

7, 8, 9, 10
Everyone has left, it's time for bed.

My son must be forced to brush his teeth
and my wife and I smile at each other.
He gets his stubbornness from her, I swear.
My bedtime routine is a struggle, too.
Though I no longer have the luxury of stubbornness
if I want to have my teeth brushed.
I'm helped to bed and
I close my eyes and focus
on the rise and fall of my chest.
I feel my wife beside me,
I think she waits for me to fall asleep.

11, 12, 1, 2
I should be asleep.

I hear my wife's heavy breath
in a deep slumber.
She's tired, I'm tired.

3, 4, 5, 6
I'm so cognizant of time now.

I feel every second pass
like heartbeats.
I no longer have time
to not care or stand idly by.
I only have time to surround myself with those
whom I care for deeply
and who care deeply for me.

"When you talk to patients often and see them through a difficult time, inevitably people get personal with you. You can end up knowing a lot about these patients' lives, their support systems, their struggles, their joys. Everybody is so different. People handle things so differently.
You try not to let too many people get through your walls, but sometimes they just do. These situations can be incredibly sad and sometimes you feel terrible. You have to let it out sometimes, you really do. I cry sometimes when I get a call that someone has passed away. You feel bad for what they and their families are going through. It takes an emotional toll; I never look away from my phone anymore."

- *ALS provider*

When Alanna was Five

When Alanna was five
I chased her on the beach
through the white foam
of low tide until our bellies
erupted into a fit of giggles
that forced our backs
to the sand and tears
from our eyes.
Together
we thrived in spontaneity.

Alanna grew older
more independent and bolder
and adjusted as I adjusted.
When she was eighteen
we learned together
what my heavy feet
and tripping meant.
Together we prepared for my future.
Tracked progress.
Outlined expectations.
Planned:
every curb cut
          every bathroom
          every detail
          of every excursion.
We created a new normal
where spontaneity no longer
had a home.

Lily was born
when Alanna was fifteen
into a home with no answers,
with only isolated evidence of
out of the ordinary tripping.
A home that arrived at a
conclusion when Lily was three;
when a toddler was too young
to understand why this family
might be different.
Her only concerns:
Mac N' Cheese for dinner
          weekend play dates
          SpongeBob before bed
          and pushing her limits.
She was born into my world
but could not adjust with me,
she adjusted as a result of me.

Lily is five now and Alanna
and I take her to the beach
so early in the morning that the
sleep is still crusted in the
corners of her eyes.
We rush to lease the only
wheelchair on this beach
that can carry me across the sand,
but this time, it’s already taken.
Lily looks at me with maddening eyes
and I know that she can’t understand.

The Cane vs. The Brace

The cane
you recommend for me
gleams in your hand
with new varnish,
            freshly polished.
It shrilly shouts
my weakness to those near,
but promises if I adhere
that it will
            support me.

                        OR

                                    hiding slyly behind,
                                    it’s the ankle brace!
                                                that shines bright
                                                like new plastic.
                                    It whispers to me:
                                    promises to hide neatly
                                    underneath my jeans,
                                                to wrap my weary feet
                                                like a fleece
                                                in a winter storm
                                                —futile—
                                    But it promises to try;
                                                discreetly.

I accept it cautiously,
but not because
            I need it.
It might just make things
            easier.

It's a hard choice

—to make—
—to admit—

that I need a brace
or that I need a cane,

but that
            I might
            just
            need
            help.

"Talking about introducing change into someone's life is not usually an easy conversation. Never easy actually. Normally I start by explaining how this is a neurodegenerative process, and that it is going to get worse. My whole mantra, what I tell everybody, is that I'm always going to work to maintain a high quality of life for them, and that's going to come number one. I only make suggestions to change when I believe it's absolutely necessary. I work with a lot of bad things, even besides ALS, and they're all really bad in different ways. While my job doesn't take away anything from me, it adds an appreciation for what I do have."

- *ALS provider*

Section III:

“You pull the cord again. This is a dream, right? The wheels don’t stop. The doors don’t open. Their road veers off past the oak tree, and you wonder how the bus became empty. You hurry to the driver’s seat, empty. No brake, no gas, nothing; only road.”

The Reunion

It’s wedding season
and I find myself standing
in a sea of familiar faces that
haven’t exchanged close words
in too long of a time.

                    But
                    I’m distracted
                    in the amusement
          snickering about who
          is drinking too much or greyed
          so early.

My eyes meet those of
an old friend who grins in recognition;
I see him glance down and raise
an eyebrow at the wooden
cane in my hand.

          He approaches me cautiously,
          and I know what’s coming.

Do I divulge my truth?
          Or do I lie

and laughingly explain how I swear
the last step of those stairs appeared
out of nowhere!

It’s just a twisted ankle.
I imagine the truth finding him later,
from someone other than me.

“How have you been?
Don’t tell me age has caught up with you already!
What’s up with the cane?”

They’re all the same.
They all have the same reaction
Shocked or embarrassed for inquiring.

And I feel bad
that they feel bad.

So I explain
“Well man, you're not guaranteed
anymore life than I am!”

But how is it that it has become
my responsibility
to comfort
the uncomfortable?

“It’s rewarding to help patients through their different journeys — journeys which they never thought they’d be on. It’s rewarding helping patients discover different ways of doings things that they normally did, helping them learn how to move through life and maintain normalcy, and how to manage relationships and have difficult conversations. Working with patients with ALS has changed my entire life, my view of life. It has made me appreciate life. I no longer worry about the small stuff.”

- *ALS provider*

Spinach Pie

She tells
stories of family holidays
        that mask the antiseptic air of this room
        with the smell of freshly baked
                spinach pie

        Her ease is magnetic.

Sitting, smiling
in that hard, clinic chair
        you would never guess
        the war that transpires
                in her spinal cord
                leaving motor neurons dead
                and her tongue limp.

And a stubborn world
does not care to know.

We cast judgment on the woman
who might stumble over words

Instead seeking out
the person beside her;

the one
we believe
might understand us better.

Yet it’s not her brain
that doesn’t understand
it’s our own.

Interlude Eleven

"I can see how somebody, a patient, might be judged by someone who thinks they're drunk or mentally disabled when they speak in public. They can be stigmatized negatively that way. I always try to make suggestions on what they may be able to do to be understood better. If they're still driving, I make sure they know to get a note saying they have ALS so they don't run into misunderstandings with others or the police. There are patients who stop speaking even before they can't speak anymore. They just stop. I think it's because they get to a point that people aren't understanding them as easily or they become embarrassed by it. For some people you can pass as "unaffected" in public if you just don't speak. I think this is one of the ways that patients choose to reclaim some of their normalcy."

- *ALS provider*

Caged

The bars that threaten
to trap me in this chair
            —quarantine me
            from Walnut Street
            and 2nd floors—   grow thicker.

                        They're built
                        quicker every day,
                        by those who close
                        their eyes
                                    to curbs
                                                and boundaries
                                                            and bias.
            My eyes are open
            stay
                        focused on
            stay
                        supported by
            my   faith,
            my   optimism,
            my   family.

            I'm thankful,
                        but not content.

I dream to tear
the iron down,
to
            scream
            my
            fury
                        so loud
                                    that these bars splinter
                                    into shards so small
                                    that I may
                                    melt them down
                                                into a prize
                                                worthy of my strife.

The shadow of this cage
does not frighten me,
            it invigorates me.

And when I arrive at your
office I pray for the tools
            to break these bars open
            to free myself
            to fight for access
            and autonomy
so that these bars
may be broken
for all that
deserve to be free.

For the Fix

Look, there's no story here
Okay?

My whole life I've been healthy.
And I'm still healthy
except for this...
thing.

I'm not here
for your sympathy,
I'm here for my strength

So I can wash my own body
without the hands of others

So I can descend down my own stairs
without the hands of others

So I can walk myself
to the porch

where the sun can dance
on my aging cheeks
and I can enjoy
this summer weather.

I’m not here
for your sympathy,
I’m here
for the fix.

"I think there might not be enough advocacy for or knowledge of this disease. What makes this disease so different is that the life expectancy of patients can be so short after their diagnosis. They have to jump through so many hurdles to get devices, medication, everything, and they simply don't have the time or the energy to go through the process of advocating more to society."

- *ALS provider*

Unshattered

I’m a self-proclaimed
egotist.

Ha!

When it comes to me
vs disease?
Disease who?
Don’t know him.

I’m not naïve,
I just know

exactly
who
I am.

And you
        should know

taking my muscles from me
doesn’t make me less
of a fighter,
        make me less me.

You think you’ve
pinned me?
        Backed me into some
        corner where you can
                wait,
                watch me shatter?

Well I hate
to break it to you, but
        this
        just
        ain’t
        it.

"The most challenging conversation to have with a patient is when we might convey an intervention, and they're not ready to accept it. Of course, if they're not ready, they can percolate on it, but eventually our goal is to provide an intervention that will prevent someone from falling, to prevent someone from going down a road that might lead to injury. We hope instead, to accompany a patient down the road where they will accept an intervention. Because we know what the future might look like without it."

- *ALS provider*

Section IV:

“The bus slows, but the doors don’t open. The wheel doesn’t bow to you on this phantom bus.
The road narrows, where are you going now?
The last stop on this bus isn’t listed.”

Foreigner

I am no longer welcome
in this place
where I’ve raised
my children;
Instead,
stairs
point
fingers
and
taunt
me
for the movement
I lack,
While
loved ones make
room
for understanding
and
endeavor
to find
light
in this
darkness.

So at least
when I blindly
drift
through the
hollow
halls of this clinic,
my conspicuous
instability
is picked up,
cradled,
sheltered
In the warmth
of a medical family that
welcomes me
to this unfamiliar

Home.

Interlude Fourteen

"I think that patients can feel how close we all are as a clinic, and they feel comfortable around us. They feel open and able to connect with us. I think everybody has somebody from the clinic that they really have a bond with. Everybody here remembers you."

- *ALS provider*

A Space for Suffering

Faith

is where I’ve found
my answer,
        in joy
        and in anguish.

        An anguish
        that has painted my shoulders
        with cherry red depressions
        and patches of petechiae.

        A superficial observation
        of the compression of vessels;
                evidence of the pressure
                from the cross that I carry.

I trudge forward,
and when I look up
I only see
        fog.

It coats what’s impending
in so many layers of uncertainty
that no matter how many
times I rub my eyes

    or pray for clarity

I’m still greeted with
the familiar fuzzy gray
and effervescences
of the inside of my eyelids.

But there is comfort
in the unknown.
    Because I know in my suffering
    that I walk the same path,
    bear the same weight,
    deepen my connection
    to Him.

The Brink

Do you see the brink there?
            We all see it.
The place where the cliff narrows
and arcane canyon cloaks
the thin air in false
peace.

I strain to pump the brakes
in a car that has none,
and so roll slowly.
            So slowly forward; sweat
slowly meets brow.
Fear
            slowly swallows
            panic into a state
            of quiet dread;
slowly stagnating.

But

this pace
permits time
to peer out
these car windows
at pictures of our road trips
passing by:

            your feet tap
            on the dashboard
            to Elvis serenading
            us through the speakers
            and our cacophony fills
            every corner of this
            old truck.

permits time to fasten new
memories to have
and to hold us together.

Do you see the brink there?
            We all see it.
We strain to pump the brakes
in a car that has none
and so roll slowly,
            so slowly forward.

The Voices that Echo

“Today I feel temporary
so much so
that if you shift your gaze
right
I’m afraid I won’t be here
when you shift your gaze
left.”

I set my pencil down
and meet his eyes;
        the brown
        of his irises
                muddy
        where tears
                puddle
        and spill
                onto his cheeks.

“They said   ALS   yesterday.”

The wound is fresh:
his pain, palpable:
                choking,
        his breath refuses
        to find lungs
and he can only
expel
        air
                out.

When he gasps inwards,
I hear his cords
quake, working
to find words.

"I'm trying to be strong.
I'm a man,
        I know I shouldn't cry"

I want to provide for him
more help than I am physically able:
        I know no medicine
        that can cure his fear.

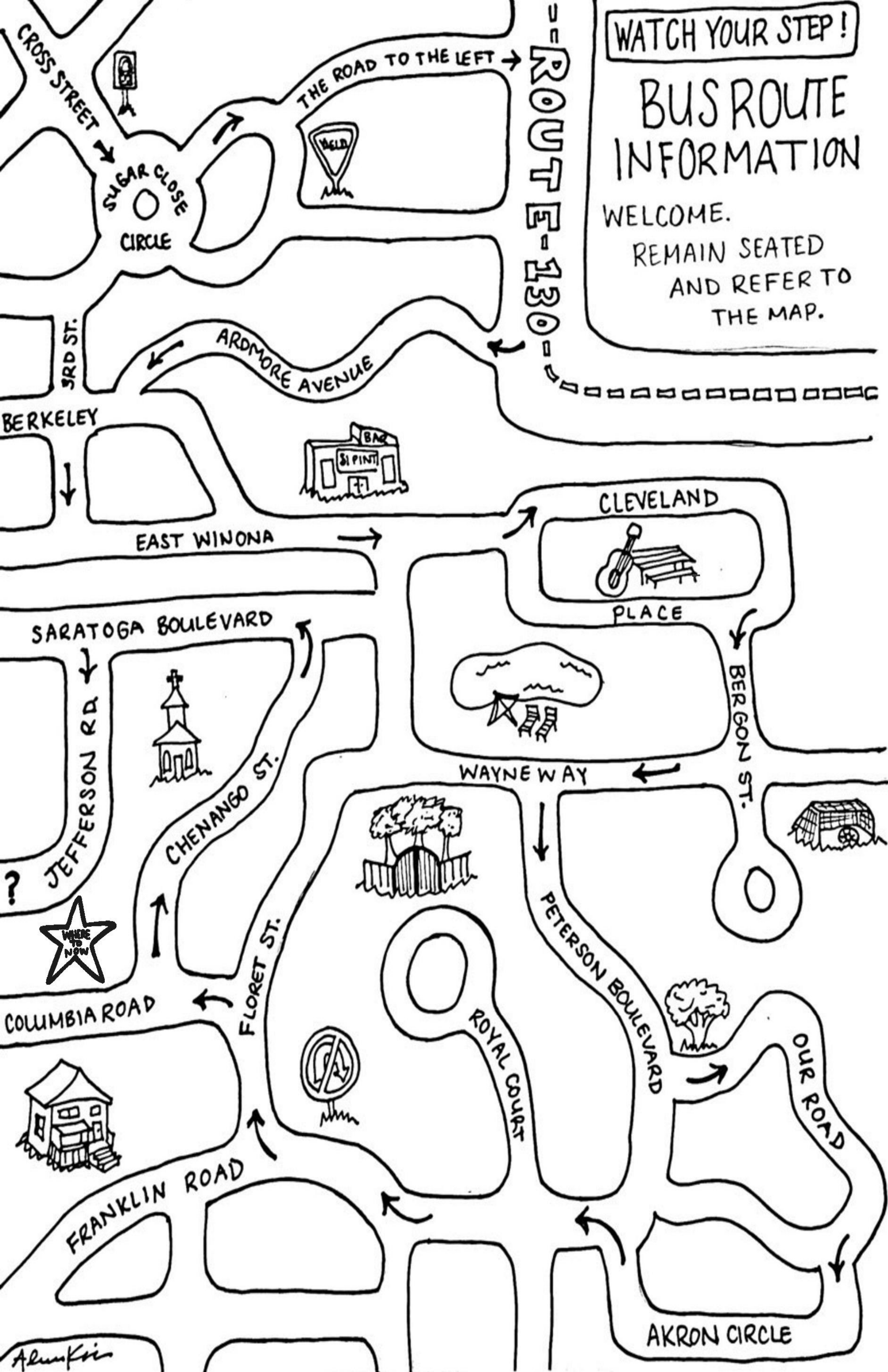
I pull tissues from the box
        and carefully place them in his
                trembling hands.

I hear my voice echo:
        I'm not a doctor, I'm only a student
but this is what I can tell him.
        I hear your frustration
        your pain
        your sorrow.
                I hear you.
You're allowed all of these emotions,
you're allowed to cry
        and
        I want
to be here to listen.

His sobs grow louder
and I don't know if I've helped,

"I haven't cried yet
but I'm so thankful you're here
because if I lose my speech
at least
you will have heard
and written my voice"

And I do remember their voices.


WATCH YOUR STEP!
BUS ROUTE INFORMATION
WELCOME.
REMAIN SEATED AND REFER TO THE MAP.
ROUTE E-130
CROSS STREET
SUGAR CLOSE CIRCLE
THE ROAD TO THE LEFT
YIELD
3RD ST.
ARDMORE AVENUE
BERKELEY
BAR
$1 PINT
EAST WINONA
CLEVELAND
PLACE
BERGON ST.
SARATOGA BOULEVARD
JEFFERSON RD.
?
WHERE TO NOW
CHENANGO ST.
WAYNE WAY
PETERSON BOULEVARD
FLORET ST.
ROYAL COURT
OUR ROAD
COLUMBIA ROAD
FRANKLIN ROAD
AKRON CIRCLE

Afterword

"*Stop Requested: A Collection of ALS Poetry*" takes readers inside the minds of ALS patients and helps us understand what it means to receive this diagnosis, to live with this disease, and to adjust to the day-to-day challenges. Through this collection of heart-wrenching poems, ALS patients invite us into their lives to hear their stories.

In the preface, Brittany writes, "*Sadness may be a theme, but it is not the whole story*." She is right. At the Weinberg ALS Center, we believe that the whole story is about taking action. ALS providers and researchers must respond to the needs of ALS patients and transform the patients' sadness into purpose by involving them in their care and in our research.

The Weinberg ALS Center was created with patients, and for patients. After 24 years researching ALS, I know how to describe ALS as a disease, but I don't know what it means to receive this devastating diagnosis or to get on a bus that won't stop. What I do know is that with my colleagues — researchers, physicians, nurses, therapists, social workers, technologists and patient liaisons — we will work to make the journey more manageable, however long it may be, while looking for ways to stop it through research.

Research teams at the Weinberg ALS Center work to identify the causes of the disease and to develop effective therapies and strive to educate patients and their families on the latest research and technology. With our personalized approach in the clinic and in the research labs, we want to give each of them the attention, help, and support they deserve.

We never promise the cure. We never give a timeline. What we promise our ALS patients is that we will put our passion and knowledge into action, working tirelessly through rigorous research and personalized clinical care, involving them in that process.

Our Center's motto is, "*Empower Life. Enable Research. Envision a Cure*". "*Stop Requested: A Collection of ALS Poetry*" reinforces the importance to live our motto with even more focus, dedication and empathy. Thanks to this poetry collection and our ALS patients, we are reminded to include the humanities in everything we do.

Sadness may be a theme, but it is not the whole story. Our story is action. With action, comes hope.

– Piera Pasinelli, Ph.D.
Frances & Joseph Weinberg Professor in Neuroscience
Director, Jefferson Weinberg ALS Center
Scientific Director, The Robert Packard Center for ALS Research