

Surprised to be Standing

by

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Tell Your Story

Every individual has a lifetime of stories and sharing these stories is one of the

Tell your story

Tell your story

It may bump from the page

like words of Braille

sizzling in tales of blazing glory;

it may glisten in the sunshine like the holy grail,

so tell me a tale, even if it's gory,

I'm yearning to hear *you*

Tell *your* story.

Have you heard

'bout the man

in the motorized chair?

Found no ramp at the

movie theater

did he despair?

No,

just let them dudes lift him in there.

Came back a few days later

after somethin' greater

brought with him a crew

people in chairs just grew and grew,

said they knew

they'd be part of the view;

no problem getting in,

just lift and push and

move those hunks of tin.

The chairs, they weighed a-plenty,

The ushers stressed and

strained and got somewhat benty.

Seeing the movie was not the goal

changin' the stage was the whole

they paid for gettin' in

but that theater knew it sinned.

People in chairs sealed their own personal stamp
on that theater's shimmering new wheelchair ramp.

Tell your story
Tell your story
It may enrapture the floating air
like ASL singing its flair
it might even glisten like the Holy Grail,
but no one will set their sail
toward your tale,
even if it's hunky-dory,
unless you tell your story
Tell *your* story.

Once I knew a lady
got caught in a picket line
changed her whole design:
came back to her hometown
mission bound.
Told a hospital it was ailing
cause it was failing to see
good health bound in the key of
phone lines hooked up with a TDD.
Said she'd seek cooperation or
she'd be mighty angry

might even round up folks and
stoke fires of insurgency,
gather signatures and seek publicity.
You know that hospital saw the light
put an end to the no TDD blight.

Last time I saw that lady
she was waving a sign
telling a TV station
she sure did mind
no news she could see
so why should she
listen to what they wanted her to be.
Now she knows how to stick it
with a picket and her
pockets have been lined with Advocacy.

Tell your story
Tell your tale
You will find you touch
with the sureness of a crutch
a framework for your dwelling,
a story needing telling,

steaming like a sunburnt trail
glistening like the Holy Grail.
Who will know what *you* entail
unless you risk the path to glory
tell your story
Tell *your* story.

Does he want another cup of coffee?
I heard the waitress ask about the man.
How did I know his plan?
Just cause he couldn't see
didn't mean his brain rested in incompetency.
The stories he has told
brisk and bold
I've shared with more than a few
over a cup of coffee or a tall, cold brew.

The lessons are in the telling
they provide a framework and a dwelling.
We all have so many stories to bear
Cry, laugh, sing, and despair;
how will our children learn and compare
if we're too timid to dare

to raise the flare
share that we care.

Tell your story
Sing your tale
Tell *our* story
Shout *our* glory!

Tell our story
Tell our story
It may not bring fame
It may have no glory, but
cut through someone's life like a ray of sunshine
break away barriers like a layer of turpentine,
tell your story
Tell your tale
We're not as elusive as that Holy Grail.

The story I share here comes from a book manuscript with the working title of

Liberation.

to

one with the shared bathroom. He slept in my remodeled basement room in Portage, Michigan, a semi-rural township next to the small southwestern city of Kalamazoo. My parents and sister occupied the two other bedrooms on this level of the house. I used much of anything.

I wanted to scream. No other outlets for my frustration existed. The pain consumed me, permeating every aspect of my being, drawing each second into hours. Nights dragged on into eternity. When the neighborhood quieted, all the lights turned off, I heard only crickets and other nocturnal nature sounds. I lay wide awake, immersed in my hurting body. I tried to read but put the book down. Screaming softly when I wanted to shout to the night skies as loudly as possible demanding why me, why do I suffer?

In my early teens, in the mid-1960s, resenting my body, my pain, my disease, my

simple most people complete it in seconds, lasted more than thirty minutes. Years later I described it in a poem:

I lie. I decide to get up. To go to the bathroom. To go to bed. To get something to eat. To see another room. To do something. I decide to get up.

Not I get up. This is conscious, deliberate. It will happen no other way.

I decide to get up.

I decide to get up.

I move.

I scream. I hurt. I will get up. I will get up.

I move.

My body begins to move with me. All of it. Except the knee.

Slowly, deliberately, painstakingly, I lift my knee.

I drag it to a sitting position.

I exhale.

Rest.

Sweat.

I hurt.

I curse.

I breathe.

I decide to stand.

I decide to stand.

I move.

I scream. I hurt. I will stand. I will stand.

I move.

My body begins to move with me. All of it. Except the knee.

Slowly, deliberately, tenderly, I lift my knee.

I drag it to a standing position.

I exhale.

I rest.

I sweat.

I hurt.

Curse.

Breathe.

Decide to move.

I decide to move.

I move.

I scream. I hurt. I will move. I will move.

I move.

My body begins to move with me. All of it. Except the knee.

Slowly, deliberately, tenderly, consciously, painstakingly, I lift my knee. I
drag it alongside me as I move.

I exhale.

I rest.

I sweat.

Exhausted, I arrive.

Hurting.

Cursing.

Breathing.

I await the next time I need to move.

I can wait for a long time, I think.

But, of course, I cannot.

Writing this poem, in my early forties, I could only imagine the rest of my life immersed in pain and immobility. Ten years later my life had changed. A frightening medical test in my late forties in which sophisticated medical machines could not detect my bone density compelled me to choose between ongoing pain and desperation or healing and liberation. After a fifty-

Mystery Limp

Imagine a five year-old boy playing on an autumn evening in 1957, on the freshly paved streets of a newly constructed neighborhood. My sixth birthday approaches in

recollection survive: my Mom telling me

I complained my right leg hurt; a memory of my Dad standing in front of our hall closet, probably getting out or putting away a jacket, not knowing what else to do; or my parents seeing their eldest son, who loved running around outside, limping. Doctors in

Kalamazoo, traveled for treatment of their own medical ailments.

Weeks shy of my sixth birthday I climbed steep airplane steps for the first time, squealing with delight to board with my Mom and grandmother, anticipating adventure. Mom dealt with the two of us and the onset of her third pregnancy. My father stayed home with Marty, born two and a half years after me, and whom I generally considered my bratty younger brother. I hoped, maybe more desperately than my parents, for a sister.

Tidbits from my time in the Clinic remain. A sprawling building with brown walls and light floors. Symbols, I believe, guided us to our destination. Beyond the shadows of the walls, little memory lingers--but scars remain. Lines, a quarter-inch wide, dissect my outer thighs. My right leg bears the longer mark, eight inches down, but the biopsy of my left leg revealed my fate:

GD is metabolic in origin, resulting in lowered production of an enzyme called glucocerebrosidase intended to discharge a fatty substance, or lipid, called glucocerebroside. GD blocks the elimination of glucocerebroside so it remains in the body, sometimes wreaking havoc, as detailed in following chapters.

Three general types of GD have been recognized. I was born with Type 1, commonly referred to as the adult type, meaning we are anticipated to have an average lifespan, unlike those with Types 2 and 3, who still die at an early age, during infancy or adolescence.

Type 1 GD can lead to a build-up of glucocerebroside in bones and in organs, such as the spleen and liver. These accumulations are generically labeled Gaucher cells.

Where the GD cells concentrate they tend to cause sometimes significant problems because of interference with typical production of, for example, platelets or bone regeneration. In some cases, as with me, GD symptoms can be extremely painful, leading to broken bones and the secondary condition of arthritis or excruciating bone crises, resulting from a lack of oxygen or blood supply to joints or bones.

Many of these details were unknown in my childhood, when GD first manifested. Even the name has changed. We used the plural form, G Today, the accepted form is Gaucher Disease. In both cases the abbreviation GD applies. In this story the plural or singular form is used to match the time described.

In 1957, doctors understood GD as a progressive, genetic disease frequently resulting in bone pain and liver and spleen distress. No one knew the cause the

disease. At the post-biopsy conference, my mother listened to the pieces of knowledge physicians then possessed.

Any child who inherits a combination of the recessive and dominant gene for GD, child with two dominant genes, like my brother, neither experiences symptoms nor passes the disease forward to his descendants. Inheriting the recessive GD genes from both parents, I had the disease.

Hayles wrote:

Dear Dr. Margolis. Thank you very much for your confidence in asking us to see your patient. I am sure you remember his history and

dic surgery. Bone biopsy as recommended. The boy was

Microscopic examination of the tissue removed from the right disclosed only evidence of necrosis and clusters of fatty acid crystals. The material from the left ntained

she has accepted these findings as well as one could expect.

It is our feeling that this disease

Home from Rochester eager to resume my first grade life, we played football in
end of our block. My
cropped hair, dark brown like the rest of my family

man, straight blond hair flowing to his shoulders, who resembled the Marvel comic book character, Thor. As people finished eating he walked toward us. Focusing on Lil, Herwig spoke:

Lil replied she channeled. A conversation began. Herwig had developed a kind of energy work called Reconnective Therapy. He stated we each possessed an energy body as well as our physical body. While these two bodies were distinct aspects of our physical body mirrors our energy body, a distinct entity, which some people see quite clearly, as others see auras, and still others see eye color.

Herwig believed dis-ease and dis-function existed because of a dis-connect between our energetic and physical bodies. He thought it possible to work on re-forming this dis-connect. In fact, he described himself as something like an electrician energy and physical bodies.

The kind of work he practiced dictated releasing our limited notions of time and space. Divested of temporal attachments, then through our essence, or higher self, we are connected to one another through the one constant of the universe, love. Accessing that realm and from there facilitate reconnecting information from our energy bodies into our physical bodies, leading to healing. He believed anyone could learn this skill.

