


IN

V I  B L E



A collaborative effort
by
Matt & Katherine Wong

Special thank you to my sister Natt for giving me permission to tell her story.

In exchange for an interview...

... I discreetly bought McDonalds as payment.

Was the whole effort of doordashing and going through the garage way and whatnot really worth this?



We later crashed for hours due to the ungodly calories.



But anyways, I just wanted to let you know that not everything written here is exactly her words.

Some stuff is modified or shifted around to make things flow and more clear.

Nevertheless, most is 'exactly' straight from the interview.



Also, while 'Natt' is one of numerous individuals with spina bifida, Natt and

I hope that by telling this specific story,

we can highlight

"invisible" disabilities, which can even be invisible to a disabled person. Hence, these invisible disabilities

require actually knowing the person/self, to look inward beyond the physical. That's why I chose "In Visible" to emphasize these two things.



Date: ∞/∞/∞

Please Excuse: Natt Hong

From:

School

Work

Other _____

Due to:

Injury

Illness

Other _____

ABSENCE SLIP

Name: Natt Hong

Age: 16



I was born with spina bifida, specifically

lypomeni-

lypomenigo-

lypomyle-

...

how pronounce?

lypome...

lypo...

lypo?



Other spina bifida

Honestly, I'm not sure about all the details.

As far as I'm aware, it's something about the spine drifting because of fat on the bottom part of the spine?

So, you have to get rid of it or it'll cause serious problems.

Wikipedia

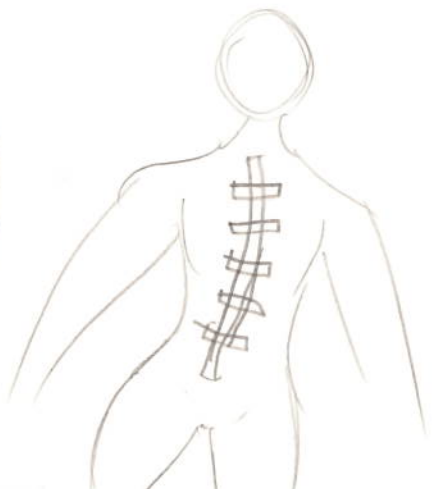
A lipomyelomeningocele is a type of closed neural tube defect that affects around 3 to 6 babies out of 100,000 births. It is an example of a spinal lipoma, which is a collection of adipose tissue, or fat, that is located at or around the spinal cord.

Essentially, it is a tumor of fat located on the spinal cord.



lypo-my-elo-men-in-go-seal

I guess the most noticeable thing is that I have a long scar down my back.



But definitely the more annoying thing is that I often am late to stuff or miss events because I'm stuck in the bathroom.



Health Issues

- Incontinence (can't control when to use restroom)
- Limited feeling in some parts of body
- Weakness in legs





I can understand people's frustrations with me. It is annoying when someone flakes last minute or cancels plans. But sometimes they have to realize that there is only so much I can do.



I do wish sometimes that people would have a better understanding of my condition so I'm not forced to explain every time I'm late or miss something.



But some stuff is private so don't pry either.

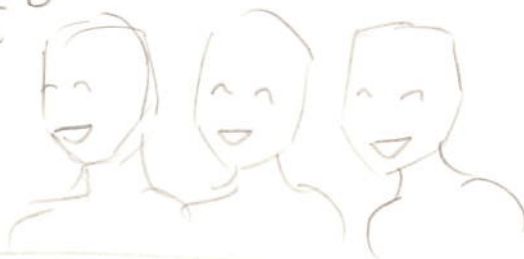


But other than all of these issues, I pretty much appear normal.

Long as I avoid physical contact with my back (no football for example), I can pretty do much anything.

- Video games.
- Typical messing around with friends.
- P.E.
- etc.

But even when hanging out with friends, I can feel a bit isolated.



Not particularly because of them but because I know I'm different.



I'm not depressed per say, about my condition but I do want to feel normal, so treating me like a normal person is the best thing you can do for me (though please have considerations for the problems that arise with my condition).



Me joking about it does help me cope a bit.

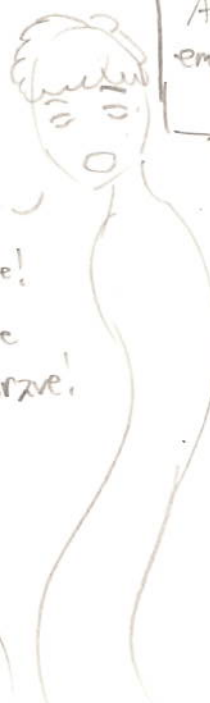
And please don't treat me like I'm a "special person". It's really frustrating...



Oh, you poor soul!



A miracle!
You're so brave!



All you're doing is emphasizing that there is something wrong with me.



literally just existing.

An inspiration to us all!

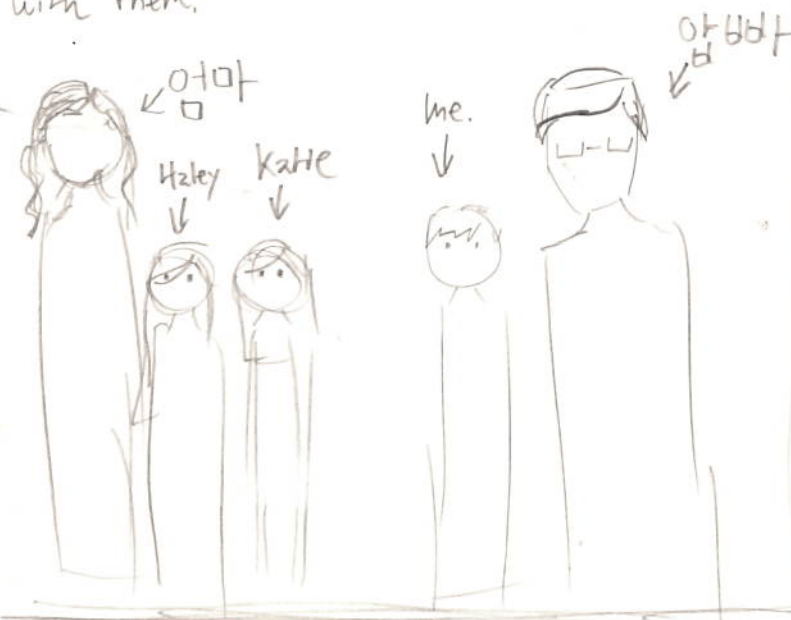


My condition does mean that I have to travel every year to visit a specialist.



Our family actually built a special event based on this. Out of everyone, $\alpha\beta\gamma\delta$ (Dad) understands my condition the best.

And someone needed to take care of Katie and Haley, so $\alpha\beta\gamma$ (mom) would stay with them.



Though I do get to hang out with $\alpha\beta\gamma\delta$ and we do some activities and eat out.



Originally, I had to go to Alabama, where I got surgery. When I was born. Thanks to the surgeon, I got pretty lucky. But, he's retired now so he referred me to someone in D.C.

So while they get to eat out and have fun...



I get to enjoy rigorous testing.

어머 is
admittedly
not as
familiar with
my condition
compared to
아빠.
H



There's this kinda funny
story when we got into
a disagreement.



She got annoyed when I
couldn't name what
her nerve condition
was.

After telling me,
she said this :



Knowing the name of my
condition shows that
you care about me!



So, of course, I then asked...

Okay, then
what's the name*
of my condition?



She looked at me...




* Specific one, not just spina bifida.

... And then walked away.



Surprisingly,
 it was relatively
 easy to get
 accommodations at
 Upper Dublin *



High school.

For me, it took
 one talk with a
 guidance counselor.

ok cool, you're
 good to go lol.

Uh, I have
 this -



Of course, not every teacher
 is receptive to accommodations.

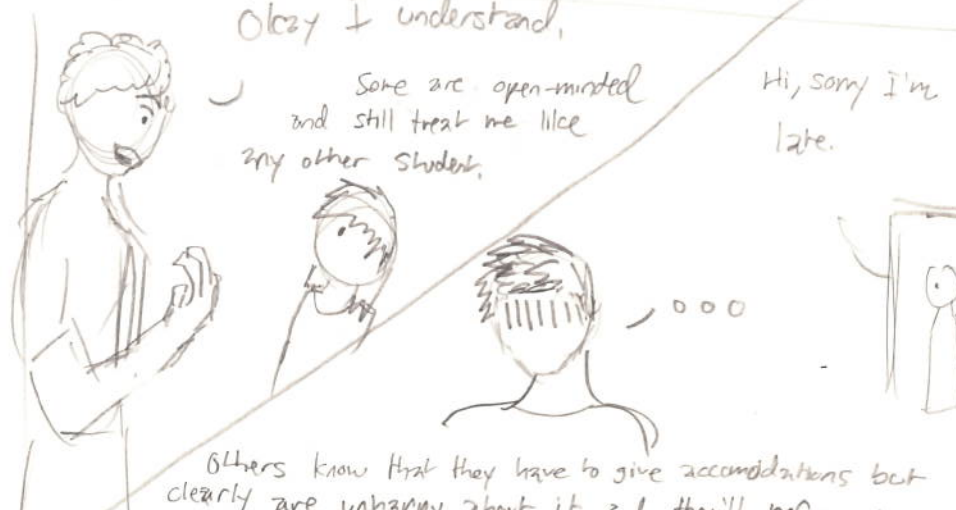
sigh.



Okay I understand,
 some are open-minded
 and still treat me like
 any other student.

Hi, sorry I'm
 late.

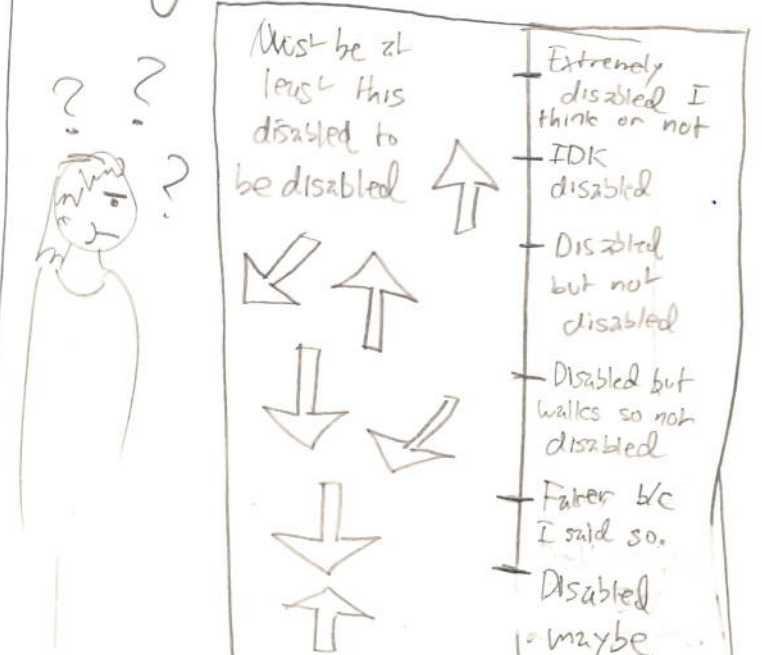
Others know that they have to give accommodations but
 clearly are unhappy about it, and they'll refuse to
 acknowledge me when I arrive late.



Disability, visibility, and accommodations can
 often feel like an amusement park
 ride.



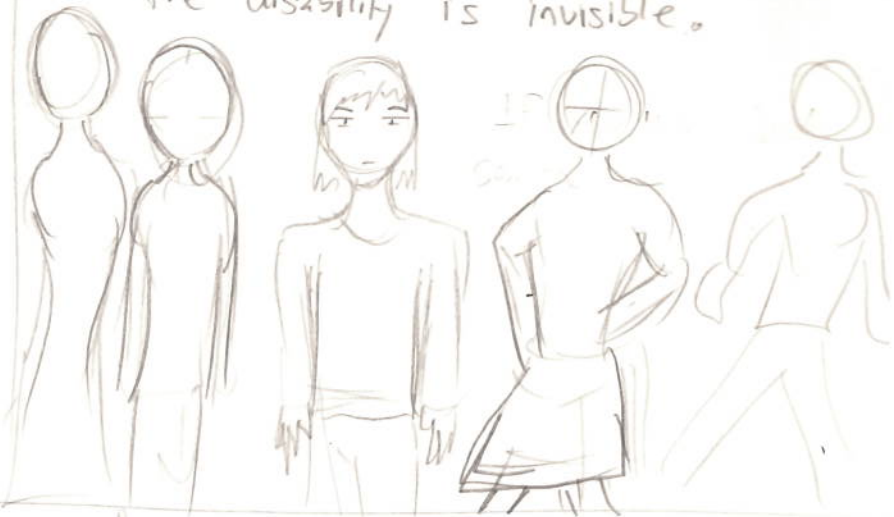
But instead of height, the sign says "must be at
 least this disabled to be disabled" and the
 indicators on the ruler are arbitrary and
 confusing.



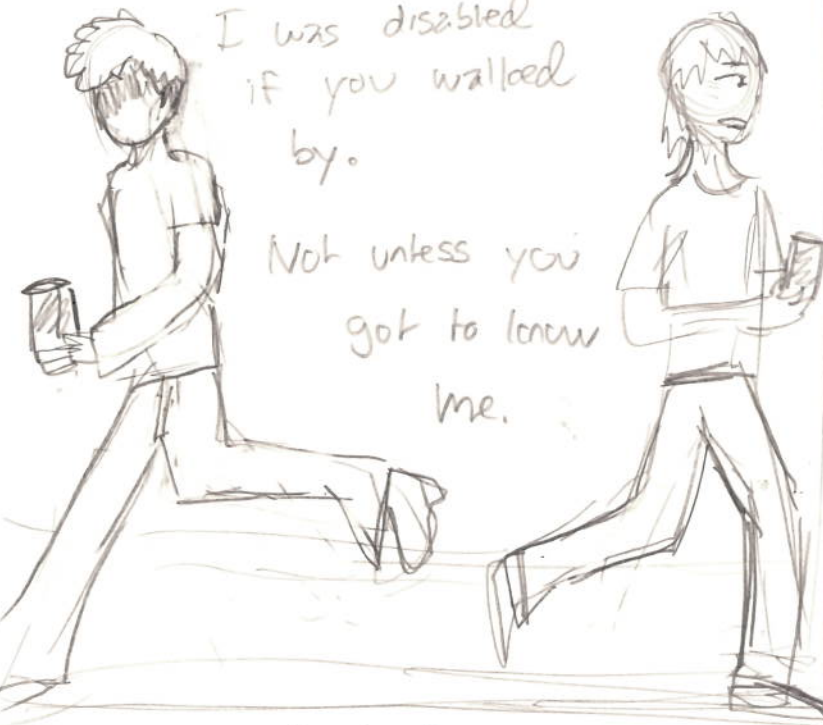


I guess, in short,
I wanted to show
that there is
no clear image of
a disabled person.

In lots of cases, like me for instance,
the disability is invisible.



You wouldn't guess that
I was disabled
if you walked
by.



Not unless you
got to know
me.

Disability isn't fun, but it's not
necessarily a bad
thing.



It's just how I
was born.

But it's not
the only thing
that defines
me.

To truly understand a
disabled person requires going
beyond this surface-level
perception of disability that's
focused on physical
appearance.

Name
Interests
Academics
Family



Hi! My name is...
Nath Hong
Spina Bifida
Family
Things I play!
Riot of Ran 20
TF2
Valorant



Instead, really get to
know the person
inside...
and be patient!