

The following is a memoir of my sister Cecilia Rose Bien who passed away on the 14th of December 2014, shortly after her 16th birthday, because of a severe mental disability. My sister suffered from a mental disability called Mucopolysaccharidosis (MPS) type III, or Sanfilippo disease, which is “a rare disease in which the body is missing or does not have enough of certain enzymes needed to break down long chains of sugar molecules. These chains of molecules are called glycosaminoglycans (formerly called mucopolysaccharides). As a result, the molecules build up in different parts of the body and cause various health problems.”¹ People who are affected by MPS are born with it and start experiencing its effects at a very early age. The disease causes a shortened life expectancy and slowly depletes the brain's ability to function because of the decreased high levels of long sugar chains. My sister was diagnosed with this disease at the age of 4, which made my parents realize just how precious this little girl was. Knowing the shortened life expectancy that she was bound to have, my parents made her a very important person in my life. Most of the following stories, I have never told from my perspective. These stories have been told by my family through their viewpoints, but I have never shared my side. In these stories, I will share my memories of my big sister.

¹“Mucopolysaccharidosis Type III: MedlinePlus Medical Encyclopedia.” *MedlinePlus*, U.S. National Library of Medicine, medlineplus.gov/ency/article/001210.htm.

Day She Died

I never knew the importance of life until she
was gone
The endless laughter and joy
The space she filled in my heart
The hearts of everyone she touched
The space in my heart
That will never be filled again
No matter who tries
The space that was emptied that one horrible
day
The day I will always remember
The day I lost her
The day my family lost her
I will never forget
Sitting on the couch with my cousins
I got a call from my dad
Telling me I needed to come home
immediately
I will never forget
Running up to my front door
Standing there
I will never forget
Running to her room and seeing her
Motionless, pale, cold
The men who entered the room to take her
away
The final goodbye
Before she was driven away
Watching the car drive down the road
And my sister
To never be seen aging
I will never forget this day

Two Weeks

Those last two weeks
The two weeks of sadness and despair
The two longest weeks of my life
The two weeks that led up to the rest of my
life
The two weeks that led up to the end of hers
The two weeks where I would wake up
Every morning
And run down to her room
To make sure she was still alive
To see my mom sitting in the chair next to
her
To see her stomach move
Breath by breath
This picture will never leave my head
The picture that gets replayed in my head
daily
Who knew that this would end
To not see her stomach move with every
breath
She had left
But my mom
Still there, still next to her bed

Mesh Net

The hospital visits
They seemed endless
But this one
The one where I laid next to her
We watched the 49ers game
With the screen right above the bed
The screen that was hard to see
Because of the web shaped net
The net around her bed that kept her from falling out
One of my favorite memories
The one where she laid there next to me
The one where time was endless and ten minutes turned into six hours
Because with my sister time was endless
The joy she brought to me in that moment
It made me completely forget that we were in that hospital bed
It made the mesh over our heads disappear

The Train

Oh how my sister loved the train
The train at the San Francisco Zoo
Sometimes the only reason we would go there
Was so my sister could ride the train
There is that one time
I will never forget
The time where the leaves were bright orange
And the air was cold
Where the brown trees flew by
But most importantly
When I look to my right and I was by my two best friends
My sister and my brother
Taking in every moment with shared passion
My sister sitting there in her orange wheelchair
And my brother just looking off into the trees
These moments are precious to me
Because there are so few of them
There are few moments like that train ride
Where all of the arguments came to an end and it was just pure joy
Shared equally between three people
Me and my two best friends

Sweet Sixteen

Bittersweet

The cold morning that turned into the best day of her life

The whole family

Circled around her and made her feel special

Special

How she felt everyday

Because my family is the best

Because my aunts, uncles, mom, dad, and brother knew

We knew it could be the last

We knew we should live everyday like this

We knew because of what she taught us

To be good to people

To be so good to someone

Like it could be the last time

The last time to be so good to someone that they notice

Cece taught me to be good

My Companion

7:30 am

Out of the house and in the car

Get Cece in her wheelchair

Roll her into the back of the car

7:45 am

Leave the house

Going to school

Sitting right next to her

8:00 am

Get to Cece's school

New Brighton Middle School

Get Cece out of the car

Wheel her to class

Her aid waiting at the door

8:05

Say hi to all of Cece's friends

Hang out for a little bit in her padded area

Say hi to all of her teachers

The kind teachers

That have been taking care of her

For as long as you can remember

These teachers make sure she is happy

8:15

Leave to my first day of fifth grade

Every first day of every year

Cece was with me

Cece's Area

Another hospital visit
This one came with a surprise:
Make a Wish Foundation
But with this one
No famous people or trips around the world
But a new area added to the house
The area that will forever go down in history as Cece's Area
This place padded with blue pads
From the floors to the walls
This became the new hangout
Where Cece would always crawl around
This area stayed with us from Noe Valley
To Diamond Heights
And back to Santa Cruz
And even when she's gone
The name has still stuck
In every conversation and corner of that room
Cece's Area

Cece's Orange

Sixteen
Sixteen years
Too young
Who would she be today
If she sat next to me
What would she say
Orange
Her favorite color
Our favorite color
Our Moms favorite color
The color of her wheelchair
The color of her everyday outfits
The color that laid over her as she took her
last breath of cold air
The color I can't unsee
The color of the autumn leaves
As we rode the train
At the San Francisco Zoo
The best memories
The memories
That pictures can't capture
The feeling of her next to me

Like no other
The color I see
When I close my eyes
And think about her
The lessons she taught me
To accept all no matter their differences
To take every moment
Like you can lose them tomorrow
Because it does happen
The shock
That I still find myself in
Waiting for it to hit
The fact that I dont have her
The fact that she loved orange
The only color that could describe her
Strong.
Inspirational.
Awesome.
My sister Cece.
Loved Orange.
More than.
Anyone.
1998-2014

The saying teach someone a lesson has stuck with me for the last few years. The saying that has personally explained to me how I act and treat others. In the week of my sister's death I have tried to come around to figure out who I really am. In this journey I have learned many valuable things that I can directly relate back to the life of my wonderful sister Cecilia Bien. The lessons she taught me throughout the wonderful years I got to spend with her will forever empower me through the difficult decisions I face now and later in life. The lesson I came across nearly weeks after her death was people who I know today may not be here tomorrow. I personally feel that my sister showed me you can never love someone too much. One of my biggest fears is losing someone while in a fight with them. Because of this I have learned through my sister to treat all with respect. No matter how someone acts or how they are different than you, they are still a human. A human that will walk this earth one foot, knee, or wheelchair wheel in front of the other. As I grew up I realized how special my sister was. The ability of people like my sister have to change people's lives. The brightness that my sister would give me on a day to day basis, or even just the joy she would give my whole family even on the worst days. The days where at school you hear kids making fun of people like your sister, but you can't stand up for them because then you are considered weird or different. Because you care about people no matter their differences. Or even just the days where you got no sleep because of your parents yelling at each other, because of the immense amount of stress that your sister puts on them. But your parents still get up every morning to make you breakfast and go to work. All of this stress and work put into this one human. All of this work put into one human just to be discriminated and made fun of at school. We have no idea what someone could be dealing with at home. Where school is their escape from their home, but to them they cant tell if school or home is better because they are never treated the same no matter where they go. So why can't we just all take a lesson from my sister and learn, learn to take that extra step to care for everyone because you never know who needs it the most.