My Journey with Walker

By: Kathy Downs

My son is not like your son.

I try to understand why this has happened; why me?

But it is not about me, is it?

My son, Walker, has CFC.

They say he will live to middle age.

I am not sure if this is good luck or bad.

“What is the value of a life like this?”

Cardiofaciocutaneous Syndrome, or CFC:

A rare genetic mutation.

So rare that only 100 people in the world have been diagnosed.

He can’t speak, can’t digest solid food, he has a hard time to swallow.

He wears a diaper and eats through a tube.

He bashes at his head with his arms.

He appears to enjoy the sensation of beating his head like a drum.

He rarely makes eye contact.

He reminds me of a moon.

You know, when you think you see a man in the moon, but he is not actually there.

Our house, fairly big, is filled with toys for Walker.

Each floor of the house contains laundry baskets.

They are full of the latest gadget from our social worker.

This one will help with fine motor skills.

This one will help with perception.

This one will ‘fix’ his problem.

The cupboards are filled with formula, bottles and wipes.

The closets are filled with diapers, tubes and clothes that Walker will never wear.

My wife, Johanna and I take care of Walker and our daughter, Hayley.

He has a sitter in the daytime.

Her name is Olga and she is a saint.

We *have* to work to pay the enormous medical bills.

We are all sleep-deprived.

Johanna and I rotate night shifts with Walker.

We know that we cannot do this forever,

But we are not ready to give our son over to a home yet.

We both struggle with the fact that one day soon our son will go live at a home.

It is my night with Walker.

I will be up two to three times during the night.

Feeding through his tube, diaper change, restraining his hands so he doesn’t hurt himself.

I will feel resentful of my sleeping wife.

When it is Johanna’s night with Walker:

I will read all I can about CFC, visit a local bar, catch up on sleep.

I will feel guilt when I hear Johanna.

She is a zombie in a mother’s body, aimlessly walking the hallways trying to soothe our boy.

When it is my night with Walker,

I think about Johanna, our finances, our strained marriage.

I think about Hayley and all that she is missing out on.

I think about how sleep deprived we all are.

And when Walker finally falls asleep, spooned in my arms so I can restrain him,

I feel, for a moment, like a regular little boy’s father.

These moments are rare, and what I struggle with the most.

Walker is a difficult child to parent.

The rewarding moments are so few and far between.

He cannot communicate vocally when he is frustrated.

Some doctors think that when he hits himself it is because he is angry,

But I disagree,

I do not understand everything about my son.

I want to know him, to reach him.

To do that, I will take a journey to many places around the world.

I need to speak with other families who live with a child with CFC.

The summer that Walker turned eleven, I got in my car and drove.

I needed to find others like Walker.

The first CFC child I met was Emily.

Emily had dark, curly hair like most CFC kids.

She had slanted eyes, knobby fingers, thick skin, like most CFC kids.

Emily, however, was more focused than Walker.

I saw Emily as a CFC kid, without the emotional attachment that I had with Walker.

I met Daniel, a six year old with CFC.

He could talk.

He went to school and could read at grade level.

He was fairly independent.

His health, though, was worse than Walker’s.

He had ulcers, allergies and seizures.

Then I met Cliffie.

Cliffie was older. He could talk, helped cook supper and made a joke.

He drove a John Deere tractor on the family farm.

He didn’t have the harsh look of most CFC kids.

I return home from my journeys with the understanding that Walker is part of a community.

He is the same as the others, yet he is different.

In this way, he is the same as any other regular boy.

We all have our similarities and differences.

Walker is getting older, and bigger.

Johanna and I struggle to carry him, feed him and change his diaper.

He is strong like an ox.

It takes everything in me to restrain him now.

We both know that the time has come to place Walker in a care home.

After many months of visits to different places and waiting lists, we found a place.

Walker will stay at the care home for 10 days and at our home for 3.

It is a 45 minute drive to the care home.

Olga will still help take care of Walker.

We visit the care home several times before we have to drop him off.

We are devastated.

We don’t know how he feels.

We return to the house.

Filled with toys and tubes, diapers and dishes, wipes, but no Walker.

It is quiet and we don’t know what to do.

We have time to watch a movie, or to read a newspaper,

But it feels wrong.

So we just sit there on the couch in the silence.

I want Walker to have an MRI so I make an appointment.

We wait 2 months for the appointment.

Then we wait 3 hours to see the doctor at the hospital.

Walker is impatient. He yells and hits.

People stare.

We wait in the hallway.

I am sitting on the floor.

Walker is walking near me.

Suddenly he falls like a sack of potatoes.

He starts to tremble and shake.

I know what is happening.

He is having a seizure.

He has had two at the care home.

I can feel his heart beat through my pant leg.

He tried to look into my eyes.

He looked scared.

I held him in my arms and thought to myself,

‘this is what it will be like if he dies. It will be like this.’

There was nothing more to do.

I was already as close to him as I could be.

No space between us, no gap of air, no expectation or disappointment.

No failure or success.

Only what he was, my son.

I loved him and he knew it.