



TAKING CHARGE IN ORLANDO 2017: ADULT PANEL

13th International CHARGE Syndrome Conference
July 30, 2017



NATE

Hello everyone! I am your friendly future neighborhood librarian Nathan Mathewson, second of his name. I am 23 years old and reside in the suburbs of Pittsburgh. I have Charge Syndrome and for once, I don't have to tell an audience what it entails.

I have had many obstacles to overcome, but somehow I rode a plane by myself on Thursday with minimal assistance needed. I have the Orientation and Mobility training to take a shuttle from the airport to the hotel, and later a bus from the hotel to Publix and back to the hotel.

My mother is the biggest reason I've been able to have success and failure. Along the way I've been cared for by doctors, nurses, occupational and physical therapists, and teachers who have had faith in me.

NATE

[In the Beginning]



Here is a picture of me when I was 29 days old before my very first surgery
#ThrowbackSunday! I was an average sized baby, however I of course had a feeding tube. Being totally honest, I think I looked pretty cute.

So, I was born March 2, 1994 in Boston, Massachusetts. I lived there with my parents and one older sister until we moved to Pittsburgh in 1997. My mom has told me that the first year or two was my most tough as I tried to deal with a hole in my heart and GI issues.

After getting the hole repaired, the GI tube inserted and my fundus kept intact to alleviate reflux. I was able to have a more “normal” life as a goofy legally deafblind toddler who walked like he’d consumed a vodka factory aka very clumsy.

My most noticeable feature that wasn't the CHARGE ear was my hair. It looked like an almost white mass of curly hair was trying to take over my head! I've included a picture. This is my mom and I sitting on the steps at Perkins School for the Blind during the 1997 Charge Conference. I have a bored expression because I was 3 and didn't know any better. My mother looks at the camera and smiles.

NATE



So I started school in 1999 at Dible Elementary School. I was in a regular classroom from K through 12 and I appreciate that. While I know its not for everyone, I think I did well in the mainstream classroom with periods during the day with a vision instructor or hearing instructor. Sadly, I never got the hang of ASL or Braille while in grade school.

NATE

During elementary school I started to eat solid foods and watch TV. This of course meant I gained 20 pounds and became a lover of nature. Steve Irwin was the first tv celebrity I was really interested in. So of course, by 4th grade when Make a Wish offered a trip to me I wished to meet him and visit Australia Zoo. Sadly, I didn't get to go to Australia (although maybe Ms. Belinda can give me the grand tour?)

My family instead got to go to the San Diego Zoo and Wildlife Park along with Legoland and Seaworld. We went behind the scenes and got to feed the giraffes and hippos. Here is a picture of the smallest and tallest mammals in one photo.

NATE



We went in January 2004 and I learned that California can still be chilly in winter. By the end of elementary school I was doing well and was starting to get Orientation and Mobility lessons in 2006 or 6th grade.

I realize I am skipping over a bunch, but somewhere in the 40 or 50 plus procedures I have had over the years, my memory has blank spots. If I do remember it, it will be two weeks from now at the most insignificant moment of my day.

I got my first computer in 2003, and started to have fun with games like Zoo Tycoon and The Sims. By middle school I became a Harry Potter fan and my introversion began to truly grow. I have really enjoyed reading and playing video games as they have allowed me to escape the stress and sensory overload of life.

Super duper fast forward to the end of 11th Grade in which I had a surgery to once again repair a GI issue. They inserted this implant called a Saphra Barrier and no surgery required GI issues since!

After this surgery I aimed to advance through my senior year of high school to get myself properly oriented to the world. My case worker had not prepared me well and I had to advocate for myself to get vocational assistance and assistance with college.

I went on a nice dinner with a childhood friend for senior prom, as we both agreed we would not be comfortable on a cruise ship with too much sensory overload.

I got dressed up with a teal bow tie and vest, along with a black suit jacket and dress pants. I graduated June 2012.

July 2012 I went to the Summer Academy run by the Office of Vocational Rehabilitation of Pittsburgh. Me and several other high school age students learned vital O and M skills along with cooking and cleaning skills adapted to our vision loss. We learned how to use a cane, travel a route using a map or using expensive GPS devices for the blind.

This program was very helpful to me and the other students. Several of them I am still in contact with online. August 2012 I entered my first semester of community college! Oh boy, the workload was certainly different but so was the transportation! I had to use paratransit services and the local bus route as paratransit was very unreliable.

NATE

I spend August 2012 to May
2015 in community college
when I was accepted into
Clarion University



NATE



At Clarion I majored in Library Science and joined some extra curriculums such as the College Democrats and Alpha Phi Omega which is a national co-ed service fraternity.

NATE



NATE

I was accepted by Guiding Eyes for the Blind for a special needs dog. June 8, 2016 was when my life changed forever as I now have a furry companion who helps me get everywhere safely and independently.



I will be graduating with my bachelor's degree of Library Science from Clarion University May 2018! I'm currently a volunteer at the Carnegie Library of Pittsburgh and hoping to earn my masters in Library Science by 2020.

CAITLIN

She is 29 years old and the oldest of 4 children from Kevin and Jillana Reuter. She has 2 brothers (Michael and Kenneth), and 1 sister (Taylor), with a nephew who is 4 years old named Chase. She also has many other brothers and sisters who live in Colorado along with another mom. **Sign** Who is Mom? Who is Dad?





CAITLIN

Since Caitlin is non-verbal and isn't a strong ASL user, her story is more from her family's perspective with Caitlin's likes, dislikes, and attitude infused into all that we talk about, but we will speak as if this is from her.



CAITLIN

I live with my mom and 2 brothers at home in San Marcos, TX. This is about 30 miles south of Austin. COME SEE ME! We can plan a trip to Morgan's Wonderland and their new fully accessible water park.



CAITLIN

That would be a ton of fun because I LOVE TO SWIM!!! I also like to ride horses, go out to eat, and care for animals. I do indoor sky diving from time to time and I wish I could jump out of a plane and go real sky diving like my brothers because I enjoy it very much.

CAITLIN

Mom says I can't go "jump out of a perfectly good plane" because my back has a bunch of hardware in it. Whatever.... I don't let it hold me back. I fly around in the wind tunnel at iFly with the best of them.



CAITLIN

I am currently learning to kayak with my friend, Evelyn, and she is super experienced and patient with me. We use touch and some sign to communicate and we have a nice time on the river together. Maybe you saw it on Facebook??





CAITLIN

I really enjoyed sitting in the kayak leaning back on Evelyn and looking at things and helping her paddle. It was my first time and I hope not my last. My mom and dad said Evelyn is the best person for me to go out on the river with and that I could trust her, so I did. We used to swim together A LOT when she used to come over almost every day.



CAITLIN

I don't work right now because I need extra supports to have a job and some people think I am not capable of having a job because I don't communicate well and can have a hard time understanding what is expected of me.



CAITLIN

What I do know is that I like to give and do things with people, every day. I like to go to Sam's club to eat pizza and to shop. Shopping is my favorite!!! Daddy likes to give me these green paper things all the time and the people take it and I get to walk out of the store with things I like! It's amazing!!!



CAITLIN

I have friends with wheels and they come over
EVERYDAY to spend time with me. One is named
Ginger and she has been my friend with wheels for a
long time. I have had 3 birthdays with her! Ginger
takes me to camp twice a year and we have a
blast!!!!

CAITLIN



CAITLIN

Marina is another friend with wheels and she has been with me for 2 birthdays. She helped me get Archer (my cat) and I have to care for him every day. I kiss him and tell him I love him every night.



I remember seeing Ginger and Marina at camp. Next thing I knew, Mom started talking about them being caregivers and they get paid and yada yada yada.... I don't know what all of that means, I just love having friends with wheels to take me to the movies, yoga, PetsMart, hiking, and anywhere I want to go in my community, including a search for a great margarita because I really don't like beer.

CAITLIN

Ginger and Marina take me dancing to the best music but I don't stay up late enough to go see some of my favorite people: DRAG QUEENS!!! They wear the coolest stuff!!!!!! Makeup, Dresses and sparkly SHOES!!! Oh MY STARS I love to see them and 3 of them ARE MY FB FRIENDS!! I get to see them at local Pride events.



CAITLIN



One of my friends that come over every day is my brother Mikey (Michael if I am upset with him). Some days he is a big fat pain in my.... well, you get it. Siblings.... UGH!! He doesn't ever let me get off easy. He pushes me to be independent and tries to help me have fun while I am doing it. Other than that, he lets me do whatever I want!!! He helps me live *my* life. I love him so much but I hear mom and dad talk about him moving out. I hope he doesn't move far away.

Well, my mom said y'all want to know more about my life growing up with CHARGE and other stuff (BORING!!!) and I don't know about all of that so I'll let her talk now. She's pretty good at it and likes to help people too. Dad is newer to it but he'll be okay. He's just a bit shy. Thanks for letting me share!!!

She was born when I was 19 years old and by a fantastic group of midwives in Florida that I still think about even today. She was 3 weeks late and has been late or made us late ever since. She has her own time zone. It's a small time zone but it's there nevertheless. She didn't have any real complications at birth but there were a few physical findings. She was given a clean bill of health and we went home.

Due to some prenatal findings on ultrasound, I had chosen a pediatrician that had more experience with disabilities. When she was 4 weeks old, I noticed that she didn't startle when the door slammed shut while she was nursing. It took 2 weeks to get in to the pediatrician and he said she was fine. I didn't believe him and started my search for an ENT. This led us to a path of 27 surgeries and we had no idea what laid ahead.

Her first genetic test was in 1989 and even though the report stated they suspected may have CHARGE Association or Aicardi's Syndrome, no one ever stayed up with this as she grew and continued to miss important milestones. I never missed giving them this genetic report though. In 1991, she was looked at through a new genetic probe and clinical test for CHARGE Association. We were told that she didn't have enough major or minor criteria to have it. Life, went on.

I was satisfied with a multiple disability diagnosis and when she was 7, she was diagnosed as deafblind multi. It stuck with us for over a decade. I was pretty engrossed in the deafblind community by this time and was working hard to get her language. I went to everything I could go to but things weren't the same back then.

She was born before the Americans with Disabilities Act and even before it was called IDEA. Those laws didn't happen until 1990 (IDEA from Education of Handicapped Children Act of 1975) and also in a time that Conferences and symposiums weren't geared or accepting of parents much at all and so I would lie and say I was a professional just to get in. So, you see... she is old school, just like her momma.

It took me to the beginnings of my advocacy and I used to attend these conferences done by the National Technical Assistance Consortium that is now National Center on Deaf-Blindness. There, I was paired with someone that changed our lives... She was my roommate and one of the things we had to bring to this event was a picture of our child or student we were working with.

I had forgotten mine and so I had one faxed (thermal curly paper too) over to me from Colorado, which we lived in for 17 years and as soon as she saw her picture on that curled up thermal fax paper, she said, "Oh, she has CHARGE Syndrome." I gave her the rehearsed spiel I had learned to say because so many people would tell us that. Ellen then said 2 words that changed our lives forever. "Criteria changed."

I went home and looked up the CHARGE Syndrome Foundations website and instantly thought of Sheri Stanger and her family because I have known about CHARGE for almost 2 decades by this time and had met their family, including the lovely Megan. Ellen Steinbrick is Caitlin's fairy god-mother and watches over her still today. I will be indebted to her for the rest of my life for uttering those 2. Small. Words.

CAITLIN

Six months later, Caitlin was clinically diagnosed with CHARGE Syndrome at the age of 18. There were no other families that we knew of with a child or any adults we knew with CHARGE so we don't feel like we live a CHARGE Life. We just live life. Eight months after she was diagnosed, we moved to Texas with the help of Texas Deafblind project's Outreach department. Three weeks after having moved to Texas, we attended our first event where we saw families that had kids that looked like ours, for the very first time.

CAITLIN

After 18 years of being the only one.... Well, there are no words to adequately describe that. The first parent we ever met with a child with CHARGE since Caitlin's diagnosis was Derrell Roberts. His alternative look, welcoming words, and heart to bless us is still something that we love about him today. He is truly one of my dearest and best friends and Molly is someone we think of as having the patience of a saint because not only does she have 9 kids, she is Derrell's wife.

Would you like to know who the first presenter about CHARGE ever was for us????? Go on... GUESS!!!! The infamous, and colorful genius, David Brown. Now, due to the magic of Facebook, we have all of YOU as friends. Some of you are sisters, brothers, aunties, and uncles, and some of you we've yet to meet, but we are all connected through CHARGE.

CAITLIN

Would you like to know who the first presenter about CHARGE ever was for us????? Go on... GUESS!!!! The infamous, and colorful genius, David Brown. Now, due to the magic of Facebook, we have all of YOU as friends. Some of you are sisters, brothers, aunties, and uncles, and some of you we've yet to meet, but we are all connected through CHARGE.



CAITLIN

We aren't doing anything special with Caitlin. We simply allow room for her to live her life without judgment from what she is or isn't capable of. Sure, she needs a guardian legally, but we make a dedicated space for her to learn, grow, and live her life, without us. Someday, we may not be here. Someday, she may not be here. When either of those days happen, there are plenty of people in our lives to help her navigate through it all and help continue to protect her quality of life.

CAITLIN

As a family, we are ready to take on the unknowns of CHARGE life. Not as CHARGE parents, not her as a CHARGER, or as the siblings in a CHARGE family, but as humans in need of kindness, love, compassion, and support because we are affected by CHARGE Syndrome but it doesn't define all of who we are.





MICHAEL

Hi my name is Michael Archuleta and I am very excited to be here talking with you today! I am new to this public speaking thing so bear with me while I gather my thoughts. While I do that, allow me some time to mess with the interpreter.



MICHAEL

Hi my name is Michael Archuleta and I am very excited to be here talking with you today! I am new to this public speaking thing so bear with me while I gather my thoughts. While I do that, allow me some time to mess with the interpreter.

MICHAEL

This guy is the best speaker I have ever heard in fact he is probably the nicest guy I have ever met, he is super handsome and funny too....





MICHAEL

Okay , Okay back to talking with all you amazing people! I was not diagnosed with CHARGE syndrome until I was almost 33 years old in early 2013 and that was after all 3 of my kids had been diagnosed. It was odd for us to all be diagnosed, as CHARGE syndrome was typically thought to be a new mutation only and not familial.

MICHAEL

In fact, the chance for a child to have CHARGE syndrome when a parent has it is only 50 % and all 3 of my kids were born with the syndrome. My family is one that likes to break the rules, especially my kids, but with joking aside we have now discovered that 2 of my nephews also carry the same CHD7 gene mutation that myself as well as all 3 of my kids have.



MICHAEL

My brother just found out at 38 that he has Coloboma in both eyes but it does not severely impact his vision. My mom passed away at 41 of a pulmonary embolism and was never tested. She was adopted, so we did not have a lot of family history until we got in touch with my mom's birth family in Canada.



MICHAEL

My wife Cindy put together a family chart of sorts and took it to the geneticist and the testing began. First our middle child Lauren tested positive for the mutation, then our other two children and finally myself. My early life was fairly typical aside from lots of ear infections which is where we originally thought my hearing loss started.



MICHAEL

I was implanted with the first BAHA attract in the state of Idaho in July of 2015 after Cindy and I found an ENT that was willing to consider what was causing my hearing loss and do something about it. We discovered that like most CHARGE syndrome patients my inner ear anatomy is malformed and my vestibular system definitely took a hit.

MICHAEL

It is an interesting feeling when you are first able to hear correctly again after so many years of not being able to and when my BAHA is off it feels like someone has cut off my ear. I have been told that I have lost more hearing in my right ear now and have the option to do a hearing aide or another BAHA, but that is on the back burner for now.



MICHAEL

I will say there is positive and negative things about being able to hear so clearly again, for instance with the BAHA it makes all the background noise louder. I tend to avoid highly populated areas (like this) for that reason!



MICHAEL

The positive is I can finally hear things clearer like my wife yelling at me, the kids fighting and good things too like my favorite TV programs or having conversations without having to guess what people are saying or having to say what 50 times.

MICHAEL





MICHAEL

When I was around 11 I began having an explosive temper and mood swings that only got worse with age. I went to counseling and was seen by a psychiatrist who wanted to put me on medication, but my mom decided against it. I was 17 when my mom passed and I had nowhere to live and that was a big breaking point in my life that changed my view of the world.



MICHAEL

I struggled with depression and anxiety. I was an excellent worker but the anxiety, OCD and behavior issues always came into play in my jobs and I would have to quit and take a break. After Cindy pushed me to get help, I was finally diagnosed in 2007 with Bipolar disorder, generalized anxiety disorder, OCD, PTSD, and borderline personality disorder and started my journey with medication management.



MICHAEL

My moods and depression have fluctuated up and down for so many years, I finally had to stop working. I still struggle with everything but I am happy to say that this year I have been stable enough to go back to work after 10 years.

MICHAEL

Me →



My
Mom ←

MICHAEL

I did have issues when it came to learning certain things but excelled at others. It is hard for me to know what aspects are CHARGE related since I discovered later in life and which aspects are due to a typical learning/ mental illness and I hope to seek those answers out from some CHARGE syndrome professionals, but with the support of those close to me I have been able to overcome a lot.



MICHAEL

I have been able to work independently throughout my adult life. I worked in hotels for around 7 years until I decided to give Corrections work a try and fell in love with it. I had been working in corrections for 2 years when Lauren had to have an open-heart surgery, when we found out about this surgery we decided to move closer to Cindy's family in Colorado for additional support.

MICHAEL

I went back to work in the corrections field in Colorado but with the stress, severe anxiety, depression, agitation and OCD of people doing things in a way I did not feel was correct took a toll on me and I soon found working and contact with others to be too much for myself. As I mentioned before I just went back to work recently after taking 10 years off to take care of my health

MICHAEL

I just completed Academy in Georgia and I am officially a Georgia correctional peace Officer. It has been stressful but I am doing it.



MICHAEL

I just completed Academy in Georgia and I am officially a Georgia correctional peace Officer. It has been stressful but I am doing it.

I know a lot of Doctors that will tell you or your children what you cannot or will not do but with hard work and the support of loved ones and the ability to stand up for yourself and find doctors and a support team that works with you it is possible.



MICHAEL

In closing lets head back to that interpreter I am the best interpreter ever, I should do this for all the conferences for years to come, I am simply amazing! Enough about me back to all you, if there are any questions feel free to ask and in the words of Henry Ford- coming together is a beginning, keeping together is progress, working together is success! I hope you all have safe travels home.

Coming together is a beginning;
keeping together is progress;
working together is success.

- Henry Ford

SYMONE

For the next 11 minutes and 59 seconds I will be talking about myself; which after sleeping, eating and shopping, is one of my top five favorite things to do. My name is Symone Griffin. I am 24 years old and I am from Peekskill, NY.





SYMONE

I am more than honored to be a part of the Adult Panel at the 2017 International Charge Syndrome Conference. This is what Advanced Speech Communications class in college prepared me for. Let's begin, shall we?

SYMONE

Let's start with the most important date in world history, My birthdate. I was born on April 4th 1993. I entered the world quite dramatically. I was born via C-section and it was quickly noticed something was a bit off with me. I did not have a right eyelid and my eye was severely underdeveloped. There was just a small socket, tissue and eyelashes.



SYMONE

Also when they tried to clear my nasal passages the medical team could not get the smallest of suction catheters down my airways. If my mother wasn't numb from the chest down she would've flipped out, rightfully.





SYMONE

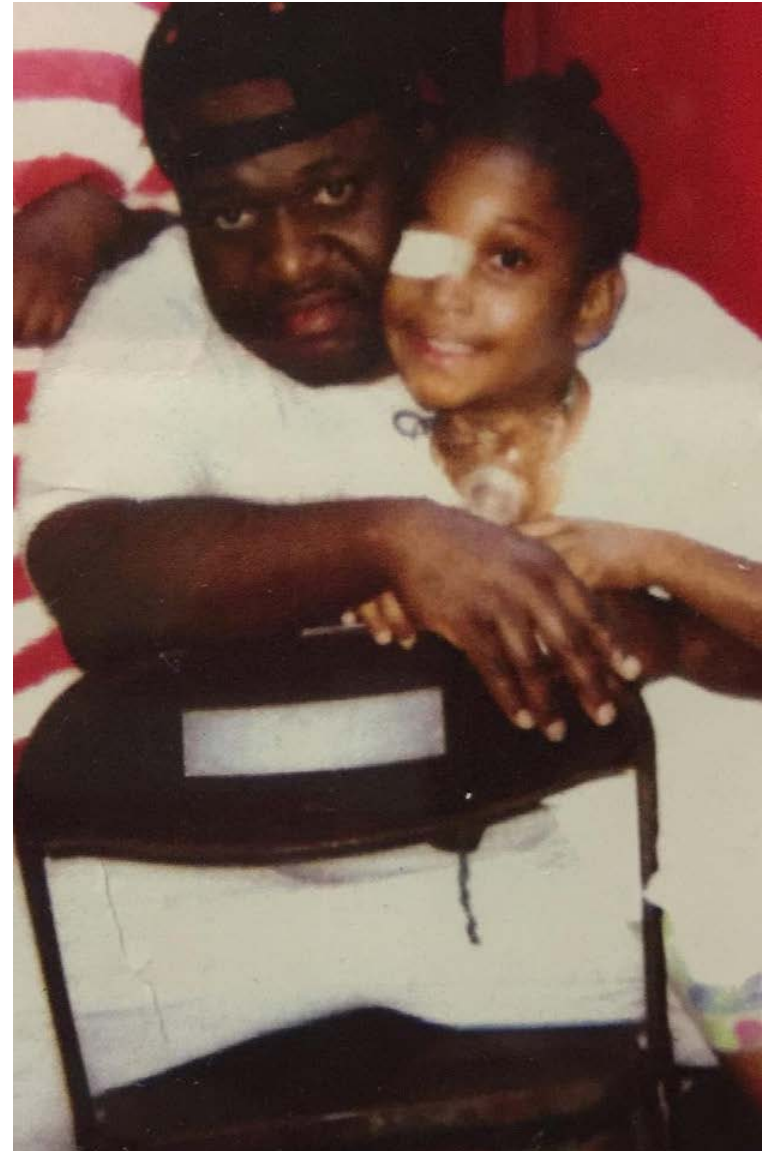
Over the next few weeks I had genetic testing, and it was confirmed that my birth defects were from Charge Syndrome. None of the doctors had ever heard of this and as there was no invention of Google, I became a medical wonder. My mother cried on my father's shoulder for 3 whole minutes, wiped her tears and then discussed what would be the next steps for me.

SYMONE

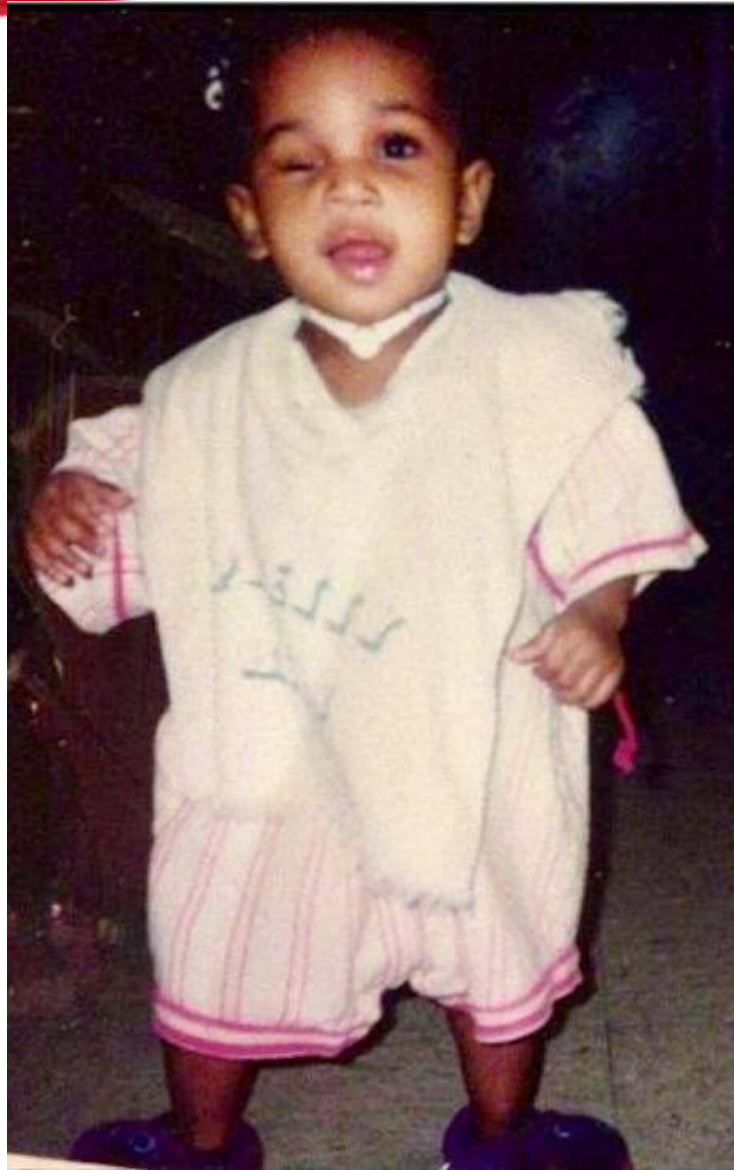
I stayed in the hospital for a long 10 months. During these 10 months, I had multiple invasive surgeries to construct an eye for me and to correct my bilateral choanal atresia. I was fortunate enough to not have more of the CHARGE characteristics although I did have kidney reflux for a time. While the surgeries for my coloboma were very successful, the ones for my choanal atresia weren't and one day at 8 months old, I decided to stop breathing, which resulted in an emergency tracheostomy. And thus, I gained a new body part for the next 11 years.

SYMONE

After I came home, I became a 'normal' child... with a special body part. My parents never treated me any different than my two older sisters. Mommy and Daddy both praised and scolded me the same way as they did Rayisha and Lytisha. They held the same expectations for me.



SYMONE



Obviously at times I needed a bit more attention especially those days where I was recovering from a surgery, or gravely ill from the common cold. But as soon as I recovered, it was back to basics.

SYMONE

I attended Early Intervention at Blythedale Children's Hospital, because I didn't walk or talk at the appropriate age. I had no oral feeding issues but it was more of a sensory issue that I didn't like having food touch my mouth. Until this day, I clearly remember having my swallow barium test and the "pink milkshake" they gave me. After I met the goals set out for me. I attended my home district from Pre-K until 12th grade.



SYMONE

I was fully mainstreamed into regular education classes, with an hour of 1:1 with a special education teacher to help me catch up on lessons from when I would take “hospital vacations” I had an IEP and was classified as Other Health Impaired due to obvious reasons.

SYMONE

I received occupational therapy once a week until 6th grade and much to my dismay speech therapy where I would sit for approximately 30 minutes and suffocate because my therapist wanted to use a Passy-Muir speaking valve when I couldn't even pass air through my mouth. Luckily I was decannulated in 5th grade before I loss any brain cells from the lack of oxygen.



SYMONE

I never had any major issues with my IEP except that when I first registered for pre-school, my district wouldn't allow my private duty nurses to stay with me in my classroom. Everything worked out and I could attend school with my wonderful army of nurses and occasionally, my Mommy and Daddy filled in. They were such a good team in my care.

SYMONE

Academically, I was such a good student. Due to my "hospital vacations" and in the time before iPads and Tablets I spent a lot of time reading books that were above my reading level. I also I read my nurses notes and my dad's Jet magazines which I probably had no business reading. I was always a part of my class discussions even with my speech impairment and even if a laryngeal reconstruction surgery left me with no voice for a few months.

SYMONE



Mathematically, I struggled so much because I was so embarrassed to ask for help and everyone (school staff) just seemed so frustrated to help me catch up and understand. Thank GOD I graduated elementary school before this common core nonsense came about because I'd be probably be repeating 4th grade for the 30th time by now.



SYMONE

I wanted to become a nurse since a little girl. I used to make all my dolls and stuffed animals have medically complex issues so that they needed me to take care of them. Then proceed to use the medical equipment that my mother would be placed on hold for hours with the insurance company to get for me, on my “very sick” toys.

SYMONE

When it was my senior year in high school I was highly discouraged from attending nursing school because I thought I wasn't smart enough. I said to myself: "I can barely do long division, and I'm supposed to save someone's life?" and I quickly dismissed my career goals. My mother also passed away during my senior year of high school, so although I had a lot much emotional, and academic support, I wasn't very logical about my college decisions.



SYMONE



For example: I ended up going to Monroe College in New Rochelle NY only because my best friend boasted about all the boys and how many party flyers she saw on her college tour. I only used these college tours to get out of class, so I didn't care. My dad never went to college so he was just happy to see me go. I didn't have a lot of preparations other than the movie, American Pie.



SYMONE

I blinked and I was in college with my pink and purple dorm room theme. I had a rough adjustment academically (I failed two classes). I soon got on track and studied, and partied and worked my way through college.

SYMONE



I even studied abroad in Jamaica for a semester on a missionary trip giving medical care to individuals who otherwise wouldn't have it. I received my bachelor's degree in Public Health in 2014. This fall I am planning to continue my education so that I can one day be a Pediatric Respiratory Nurse, and suction the tracheostomies of my little patients.



SYMONE

Currently, I am a Nurse's Assistant and I work in a pediatric facility with children who have medically complex disorders. Many of my kids have Charge Syndrome, and when it was discovered by my coworkers that I too have royal blue blood flowing in my body their reactions were priceless.

SYMONE

On days that I am not at work making my kids comfortable, I become a world-famous couch potato who still lives at home with her father, her two sisters, her two cousins, her niece, and her over-the-top spoiled dog, Cupcake.





SYMONE

If I had to give advice to any parent whose child has a medically complex disorder such as Charge, One I'd tell them that everything would be okay because you are here today. When your child was born, it was probably a very dark tunnel and you didn't think you'd see the light of day.

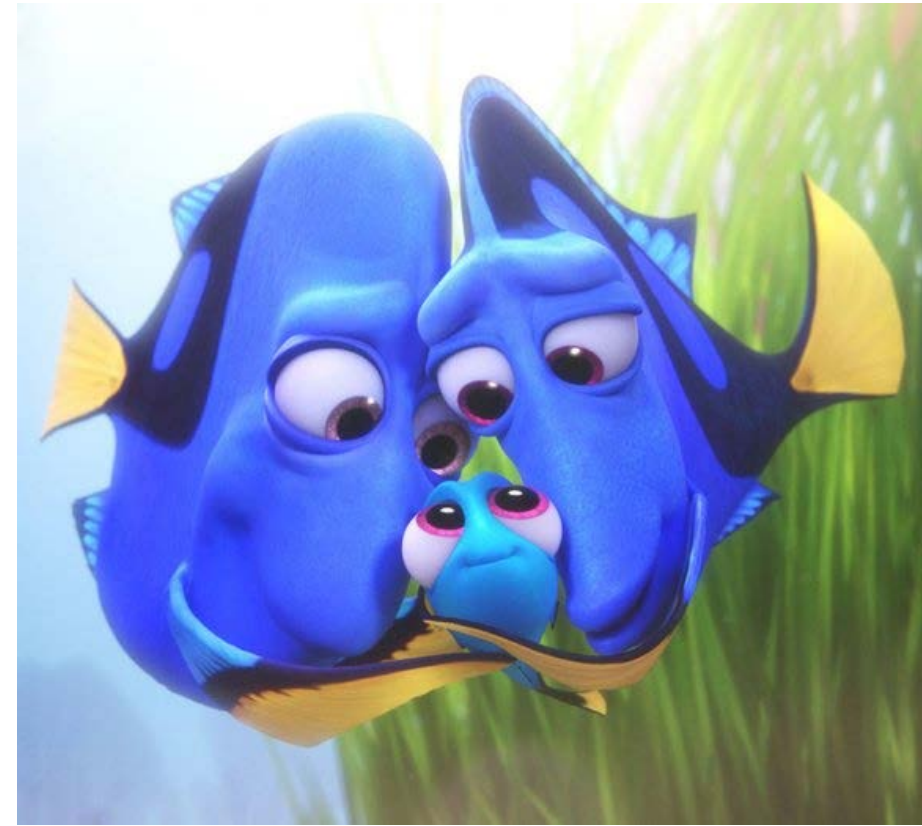


SYMONE

And that's okay because everyone gets scared sometimes. But look at you now and look at your child now. You made it through some rough patches, and you came out alive and without a scratch. Secondly, I'd refer them to the sequel of my favorite Disney Pixar movie; Finding Dory.

SYMONE

In the beginning of the movie you see Dory's parents teaching Dory who isn't like the other little fishies how to survive in a world that wasn't made for her. They come up with songs and helpful reminders that Dory can use if she ever needed them. I love this and I think it is a wonderful example for parents to follow by.





SYMONE

Never allow yourself, your child or anyone else to treat the “disability” as an end all be all situation. Take it for what it is and run with it. Let your child be great. Play the cards the God dealt you. Your child will thank you in the end.