DEEP IN THE ♥ OF CHARGE

14th International CHARGE Syndrome Conference
Dallas, Texas • August 2-5, 2019

Monday, August 5, 2019

Panel of Young Adults / Adults with CHARGE

Garland Goodwin, Brandon Marshall
Amita Srinivasan, Lacey Suter

Presenter Information - Lacey Suter, with Laurie Suter

Laurie is a single mom who adopted 4 children with special needs. Lacey was born in California and her birth family decided to give her up for adoption when she was 3 weeks old. Lacey was 21 on July 9th, Her siblings are Amanda, 31 (same birthday as Lacey), Jordan 29, and Noah 7. Lacey is non verbal and uses a wheelchair as she doesn’t walk independently. Her balance is very poor. She just graduated from Crotched Mountain school where she was a day student and we have been working on transition for over a year. We look forward to the next chapter in our lives! One of Lacey’s earliest plane rides was at 12 months to our first conference in Houston. We have been to every conference since then except one. Being Lacey’s Mom has been a blessing and has brought me so much joy and happiness despite the many challenges!

Presenter Information - Garland Goodwin

He goes by Garland. He is 17 years old with CHARGE Syndrome. He attends regular educational classes in his local high school. He enjoys school, volunteering at the Ronald McDonald house, is in the National Honor Society and loves collecting items. He has participated in Tae Kwon Do where he earned his red-black belt, also participated in Junior Cadet Corps in middle school where he earned rank of Corporal. He enjoys watching TV and YouTube, like any other teenager. He knows he has CHARGE Syndrome and he has learned how to deal with it through out his life on a day to day basis. He would like to educate people about the challenges he has faced and encourage them to always try. He knows life is not easy and he will always have to work harder than most to get through life. Garland understands that having a disability doesn't give him the right to get by with not doing something. He also believes in having integrity, telling the truth, being respectful, and working hard. He plans on going to collage after graduation in 2020. He enjoys traveling to different places in the United States and learning of the history of the areas.

Presenter Information - Amita Srinivasan

Amita Srinivasan is a sophomore at the University of Texas at Austin dual majoring in Psychology and Human Dimensions of Organization. She is the current President of DeafBlind Citizens in Action (DBCA), a disability rights organization founded by Deafblind whose mission is to empower through education, technology and legislation. DBCA runs a participatory leadership development program for young adults who are deafblind. It consists of an online module that helps prepare participants for the main component, a face-to-face weeklong seminar in Washington, D.C with Deafblind leaders and young adults. A graduate of the DBCA leadership program in 2017, Amita then became interim Secretary and also served as a mentor in the Leadership program meeting in Washington D.C. in 2018. Amita is also a co-director of the Inclusion and Disability Agency of the UT Student Government 2018-2019 and the Historian in Women of Excellence student organization at UT Austin. Amita has CHARGE syndrome and is passionately interested in inclusion, empowerment and accessibility for students with disabilities.

Presenter Information - Brandon Marshall

Brandon Marshall is 37 years old and has CHARGE, but that has not slowed him down. He is charming, funny and a gentle gentleman who lived in California most of his life but moved to Arizona in his early 20s. He's a writer, avid ballroom dancer, and from what I hear a pretty good cook. He's done it all while having CHARGE, not letting that stand in his way. He enjoys cooking, working, playing video games and dancing in his spare time. Brandon is attending his third CHARGE conference.

Lacey

Hi Everyone! Lacey will introduce herself using iPad, and then I will have her, using Touchchat, say what she likes to do, and what she doesn't like, where she has traveled to, and what she can do, how she communicates and about her family.

Lacey

About Me My name is Lacey I am 21 years old

Lacey

About Me I like...

I like to ski

I like to swim

I like to ride bikes

I like to go to the playground

I like to do puzzles

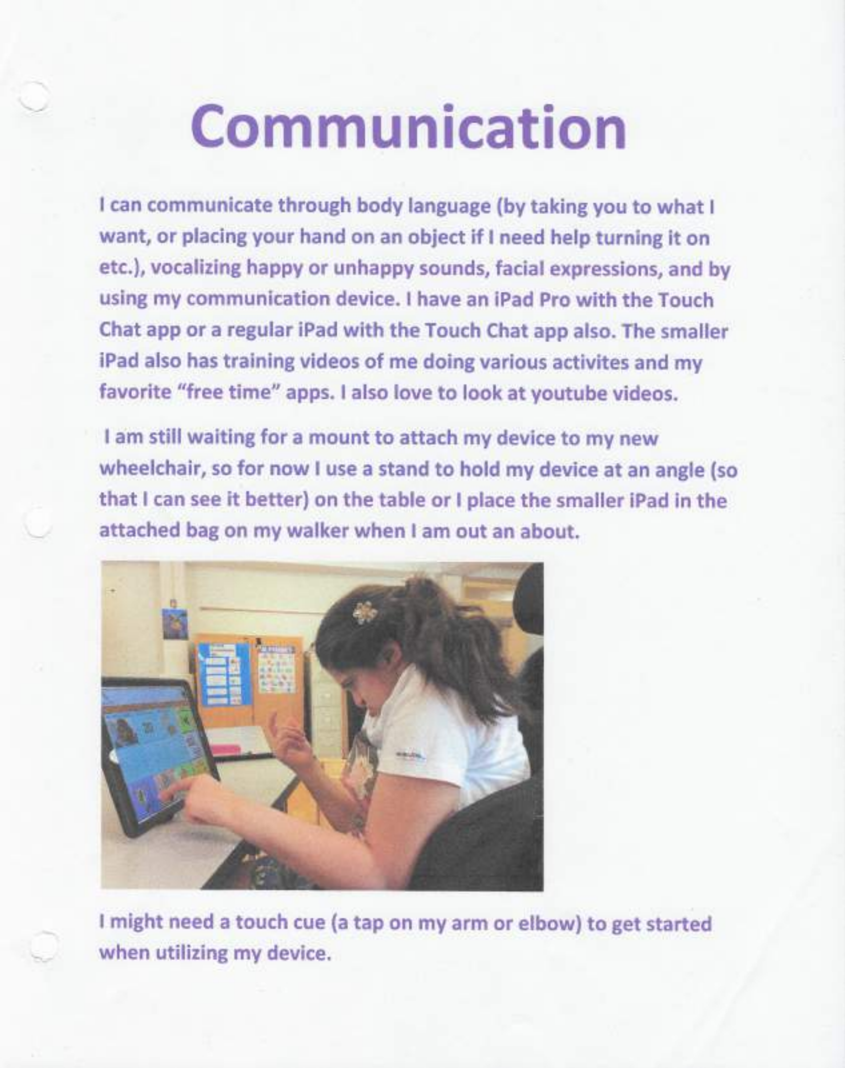
Activities I like to do

Lacey

My Family - I live with my mom and my sister Amanda who is 31, my brother Jordan who is 29 and my little brother Noah who is 7. My mom adopted us all. We have 3 dogs, Murphy, Dakota and Bella. Mom is going to share my story.

My Dislikes – It depends on how I'm feeling each day. Sometimes I don't like getting my coat on. I dislike too much assistance. I dislike too much downtime. I can get bored and will “tune out” by putting my head down and pretending to sleep.

Lacey



Communication

I can communicate through body language (by taking you to what I want, or placing your hand on an object if I need help turning it on etc.), vocalizing happy or unhappy sounds, facial expressions, and by using my communication device. I have an iPad Pro with the Touch Chat app or a regular iPad with the Touch Chat app also. The smaller iPad also has training videos of me doing various activites and my favorite "free time" apps. I also love to look at youtube videos.

I am still waiting for a mount to attach my device to my new wheelchair, so for now I use a stand to hold my device at an angle (so that I can see it better) on the table or I place the smaller iPad in the attached bag on my walker when I am out an about.

I might need a touch cue (a tap on my arm or elbow) to get started when utilizing my device.

Lacey

Mom - Here is Lacey's story. I received a phone call in July of 1998 from Penny, about a 3 week old baby girl who had CHARGE Syndrome. I found the CHARGE Syndrome Foundation in Exceptional Parent magazine and I called Marion Norbury who was one of the founders of the CHARGE Syndrome Foundation. She explained all about CHARGE and was very positive and encouraging.

Lacey

After talking to Marion I was very interested in adopting A few weeks later her birth father called me to tell me that they had received some very bad news. Lacey's heart was really bad and she most likely would only live until age 2 and there was nothing that could be done. Did I still want to adopt Lacey? I said “Yes” and that if I could only have Lacey for 2 years, I would give her the best life possible in those 2 years. Boy were they wrong!! Lacey just turned 21.

Lacey

Lacey was 10 weeks old, I went to California to bring her home to New Hampshire. I spent 4 days with her to get to know her and learn her care.

When I first met Lacey, she was in her crib in an adorable dress, listening to oldies music. (The only music that soothed her.)
She was so tiny, weighing 7 pounds at 10 weeks. She had a severe cleft lip and palate. I thought she was beautiful and I fell in love!!

Lacey

I was told by the nursing staff that she cried a lot but the whole time I was there, she didn't. They said she was at peace because she was with her mom. I brought Lacey home to New Hampshire, but I was very nervous on the plane. The first night home, Lacey threw up a large amount of brown blood. I was so worried. She vomited a lot! That week, Her G-Tube came out and I put it back in. Lacey was sick a lot. Lacey had severe Cyclic Vomiting Syndrome which started when she was an infant.

Lacey

She would become very pale, sleep all the time, drool and severely vomit. Any movement would cause her to vomit. Episodes lasted for about 6 days. She sometimes was in the hospital every month. From age 3 to 4, she was hospitalized every month and sometimes twice a month for Cyclic vomiting.

Lacey

She had 25 aspiration pneumonias by age 3. She has had over 30 surgeries. Lacey sat up at age 2 and a half, and I was so exited! And she took a few steps in a gait trainer at age 3 and this brought more excitement! Lacey started having seizures at around age 4 or 5. She also suffered from severe abdominal migraines which started at age 10. These episodes lasted 6 days, and happened every 10 days. These really affected her quality of life. She would scream in severe pain. Sometimes the screaming would last over 30 minutes or even longer. I felt helpless and it broke my heart.

Lacey

She was eventually started on Neurontin, Amitriptyline and

Cyproheptadine and these medications were life savers.

And they finally helped her. She hasn't had any episodes

in over 6 years and is now just on Amitriptyline for the migraines.

She does have regular migraines sometimes.

Lacey

Despite all of Lacey's medical challenges and disabilities, we don't let anything stop us!! As Lacey said, we love to travel! Lacey has been all over. Her first trip was to The CHARGE Conference in Houston in 1999 when she was 12 months. It was our first conference and Lacey got Pneumonia while at the conference and we were taken to the hospital. Despite this, this was such an enjoyable and wonderful conference. We loved meeting all the families and have been to every conference since except one.

Lacey

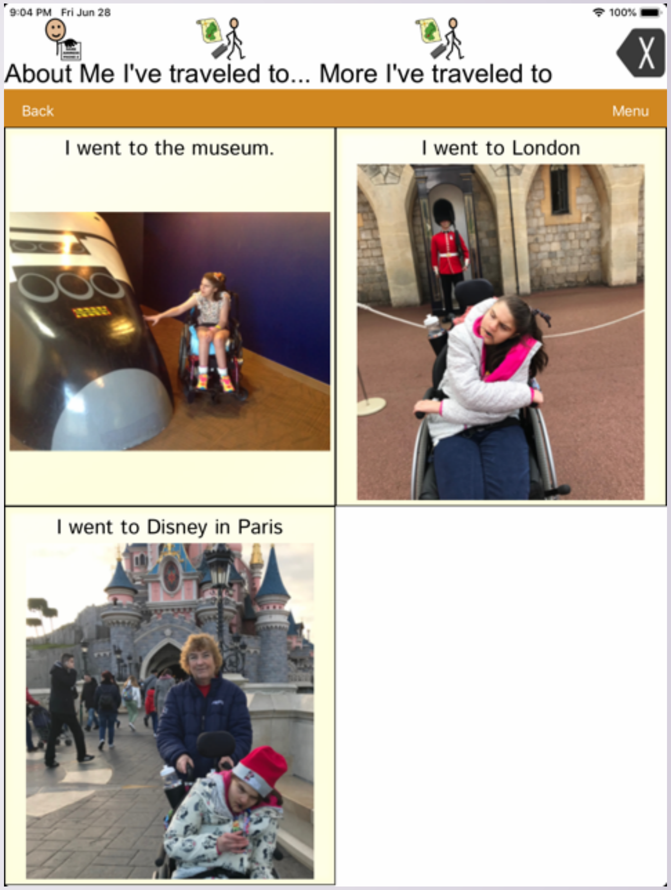
About Me I've traveled to...

I went to Disney

I went to Alaska

I went to Bermuda

more I've traveled to



About Me I've traveled to... More I've traveled to

I went to the museum.

I went to London

I went to Disney in Paris

Lacey

We have been to England and the first time for Lacey was when she was 16 months old and she went with my mom and I and this was a memorable trip. Lacey has been to Alaska on a cruise, a cruise to Europe, around the Mediterranean. She went up the acropolis in Athens Greece in her wheelchair and boy was that bumpy! We go to Disney World a lot and Lacey loves all the fast rides like roller coasters, and the tower of terror. When we travel I have to do a lot of planning. I have to bring many supplies and I have to catheterize Lacey 4 times a day but we still travel.

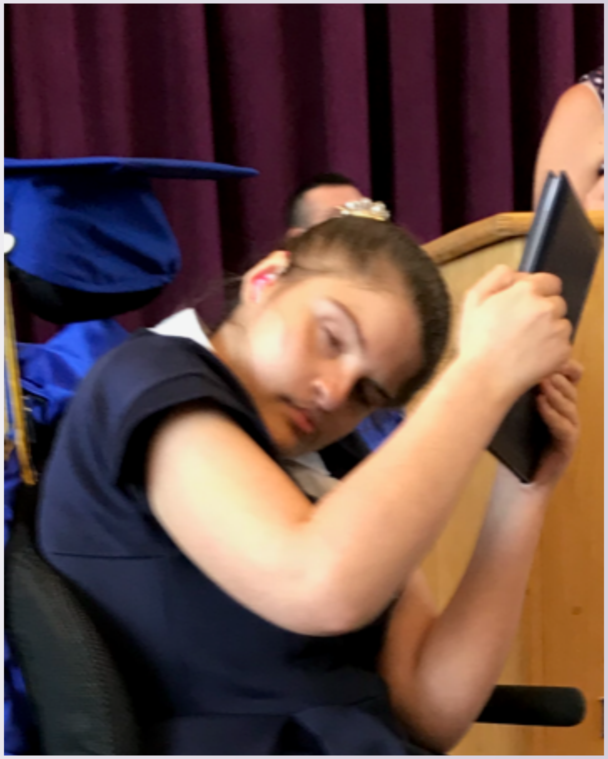
Lacey

I have had to fight for Lacey's education and she has proved others wrong!

When she was in public school, she made no progress in 6 years. I was told by Lacey's teacher at an IEP meeting that she was a robot! Lacey is far from being a robot. She has personality! Full of spunk, and has a great sense of humor, and she has the most infectious laugh and a beautiful smile.

Lacey

I was told by that same school that Lacey would never do an iPad. Boy were they wrong. Lacey does awesome on her iPad, and she is addicted to Youtube.

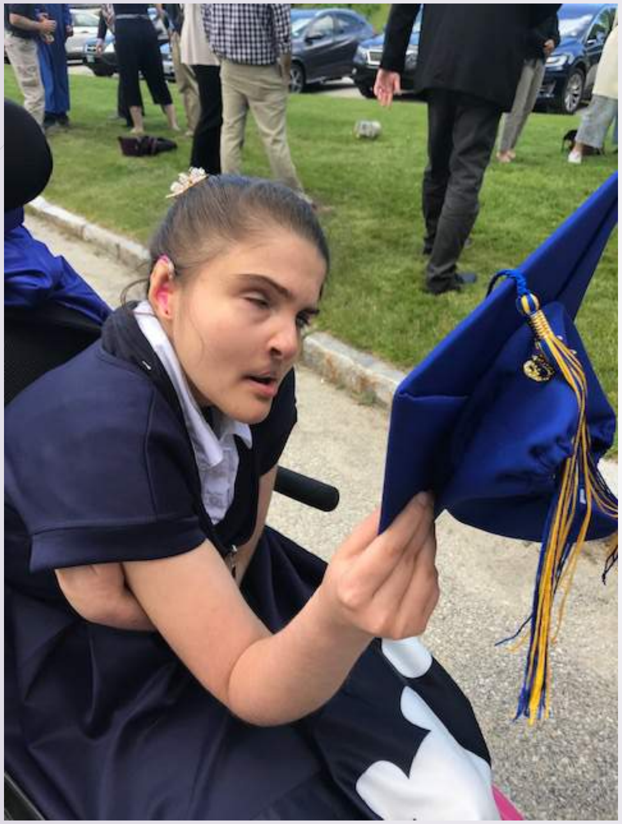


Lacey

I was able to get Lacey in an out of district placement. Crotched Mountain School when she was 14. She went as a day student. She thrived there and made so much progress. Lacey had an amazing teacher Judy and a wonderful aide Miranda. They believed in Lacey. Lacey did many thing there like adaptive skiing, adaptive kayaking, bike riding, riding horses, and being in school plays.

She was known as Miss Sassy Pants at Crotched Mountain. Everyone loved that about Lacey. She is so courageous and strong.

Lacey



Lacey recently graduated on June 14th and she won the Principal’s Award at her graduation I cried happy tears.

I am so proud of her!

Lacey

At age 21 Lacey is still making progress. Recently at school, Lacey took 12 steps unassisted all by herself. This is so amazing!!

She got new hearing aids and one day she was sitting on the couch and pointed and verbally said hi mom. I cried!

Lacey

Lacey

You may wonder what comes next for Lacey? I cant wait to see what her future holds. I am doing self directed adult services for Lacey. I have been able to plan her program. My sister Yvonne will work with Lacey 20 hours a week and she is going to take her to horse riding therapy one day, physical therapy the other day and work at some goals at home.

Lacey

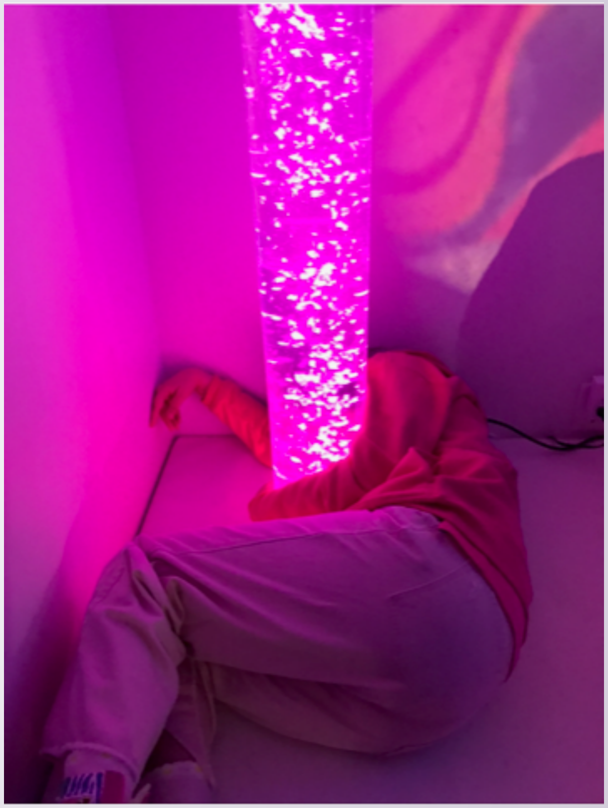
The other 3 days the plan was for Lacey to do a farm day program called Farmsteads of New England which is right in our town and they agreed and accepted Lacey and everything was submitted to the state, but at the end of May, they sent me an email and decided not to take Lacey even though they already said yes. I was very upset, but when a door closes, a new one opens.

Lacey

I found another day program, Opportunity Networks, and this is a much better fit for Lacey. They accommodate the interests and need of the individual, and focus on socialization, learning, daily living skills and working on creating a healthy life style. They accepted Lacey and she will go there 3 days. This is in Amherst NH. An hour away but so worth it. I will drop Lacey off and pick her up. She will get to participate in a variety of things:

Lacey

ASL social group, a speech pathology group, in which they work on their communication system. A photography club, cooking group, bowling, arts and crafts, health and wellness opportunities like swimming at the Y! Computer class, gardening club, various jobs and volunteer opportunities in the community, and they even have an amazing snoezelen room which Lacey loves.



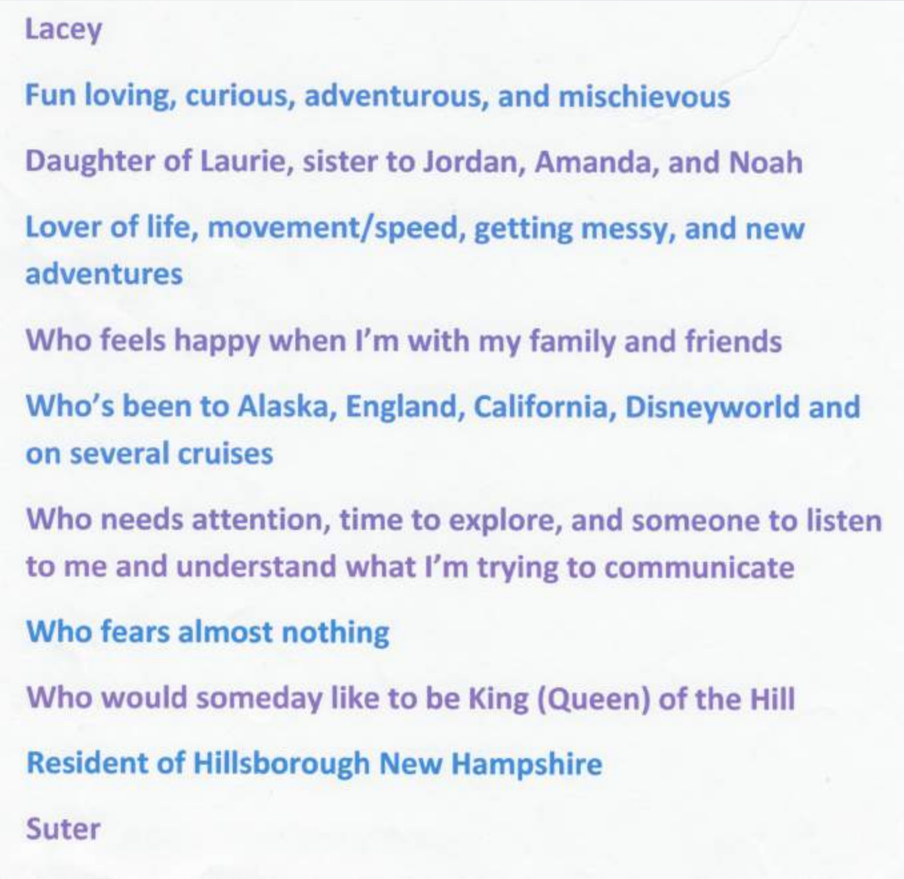
Lacey

But here comes the bad news. They day before Lacey turned 21, I found out that the governor of NH vetoed the state budget. So that means Lacey has no state funding and now no program because she is born in July. The state has 90 days and mostly likely it wont be until October that this may be resolved. So we are now in limbo. We will just CHARGE on as we always do.

Lacey

Lacey may not be able to talk, write, walk by herself or read, but she does read in her own way, on Youtube, on her iPad. But she has an amazing happy fulfilling life and I am so blessed to be her mom. Here is Lacey's bio poem that she did at school as part of her all about me transition book.

Lacey



Lacey

Fun loving, curious, adventurous, and mischievous

Daughter of Laurie, sister to Jordan, Amanda, and Noah

Lover of life, movement/speed, getting messy, and new adventures

Who feels happy when I'm with my family and friends

Who's been to Alaska, England, California, Disneyworld and on several cruises

Who needs attention, time to explore, and someone to listen to me and understand what I'm trying to communicate

Who fears almost nothing

Who would someday like to be King (Queen) of the Hill

Resident of Hillsborough New Hampshire

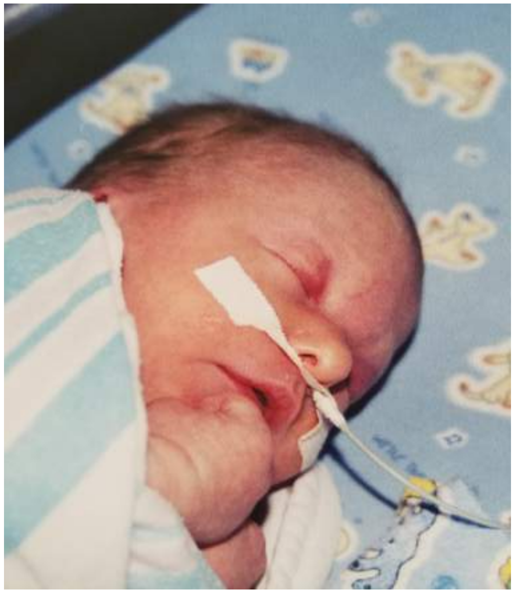
Suter

My Success Story

Presented by Garland Goodwin

Garland

Hello, my name is **Garland Goodwin**. I am **17 years old** and I am going to be a **senior** this upcoming school year. I am a young man in **public school** with CHARGE syndrome. I am from **Fort Worth, Texas** and I go to **Benbrook Middle-High School**.



Garland

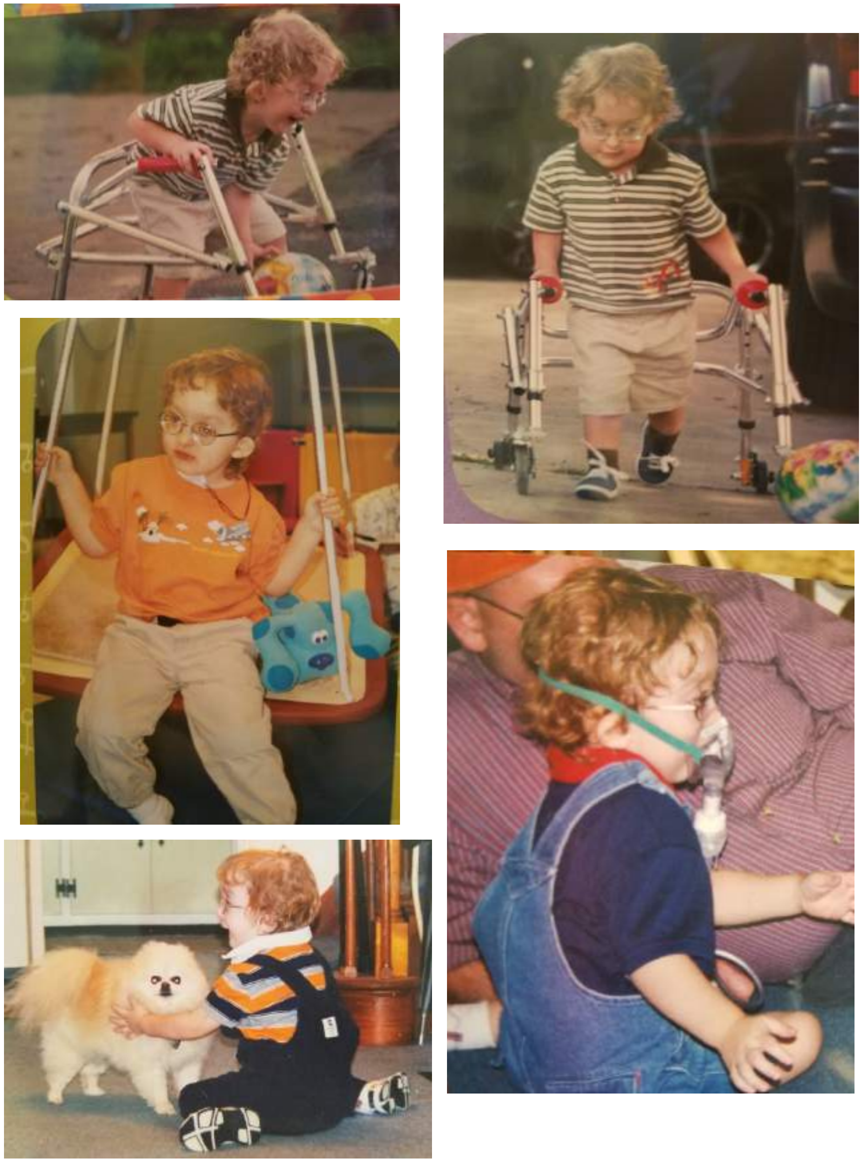
When I was little, I used to really like ***Thomas the Train*.** In elementary school, I started **Tae Kwon Do**. It helped me gain more balance and confidence. I have always loved **collecting *Transformers*, *Power Rangers*, and Build-a-Bears**. In high school, I do **Theatre** as my elective. I like helping put the sets together and finding different music scores for scenes. I even wrote a play that got performed by real actors at Stage West Theatre. I love **volunteering at the Ronald McDonald House** in Fort Worth, doing simple things like cleaning the playrooms for the kids.

Garland

I enjoy bike riding with my mom on my bike. I love traveling all over the country and camping with my family. One of my other favorite things to do is **drive my golf cart around my neighborhood, but it is even more fun to drive other around!**

Garland

I have a **Swallow Dysfunction** and had a **G-Tube** from birth to 5 years old. I also have **inner & outer deformation of both ears**, which is the reason I have super powerful hearing aids along with a speech impairment. I have **bilateral colobomas and high risk for retinal detachment,** and my low vision is the reason for the special glasses with thick lenses. I also have many other characteristics of CHARGE.



Garland

I am going to talk about how I've been successful in public school and how I work with accommodations provided by the school district. I **started public school in preschool** so I could start school early. The school I went to had interpreters and knew how to teach students who were Deaf. Most of the **other kids were profoundly deaf** in my class. I **switched schools to start kindergarten** because the teachers at the new school were more caring and willing to work with the IEP. At the end of first grade, I got an **evaluation from the Texas School for the Blind and Visually Impaired** at home and school that helped me get lots of accommodations in school. They ended up coming back in **4th grade to evaluate again** and help train teachers.

Garland

In 5th grade, I got **my first intervener** (who decided to focus on the other kids more than me), but I did do a little better in school. In that same year, **I got bullied in the bathroom**—they turned off the lights while I was in there—and then mom suggested the school let me use the teachers' bathrooms instead, which I still use the teachers' bathrooms now in high school (it is in my IEP).



Garland

My mom advocated for me and all my accommodations; we would hold **ARD meetings twice a year** until 7th grade to ensure that the accommodations were still being understood and make any changes that are needed. My mom **worked with other people higher in the district and TSBVI to advocate** for me. She knew the system from all the stuff she did for me, and **ended up being able to help other parents** with their kids with special needs.

Garland

In **sixth grade, I moved to Benbrook Middle-High School, I got a new intervener, and more accommodations**. Because the school has really bright skylights and of my vision problems, I get to **wear a hat inside**, even though it's against uniform code. Teachers provide me notes and my **intervener is my scribe** and writes down my answers for me. I **use the elevator** because the stairs are crowded and I might lose my footing and fall, quite possibly losing my vision.

Garland

I get to **leave five minutes before class is over** so I can walk when there are no crowded halls. **During testing, I go into another room by myself** with my intervener or someone to scribe for me during the test, and read the questions for me. My mom would always do her research on what to ask for, then make a suggestion for the accommodation. She would remind all in the meeting that **they were ALL here to make sure the committee did not set me up for failure**.

Garland

I was also able to do **Junior Cadet Corps in middle school**—I was able to be in a military-like program, even though I can't join the real military. **I loved middle school because I knew what to expect** from the schedule and the teachers were following the IEP put into place.

Garland

High school has been similar to middle school because I haven't had to change schools. I have the **same intervener** that I got in 7th grade and she's awesome! The teachers work with my intervener and make sure that I stay caught up and ensure that I have **large print paper** and material that we're using.

Garland

My school district provides every student in the district with a laptop. My **laptop has Dragon software that is voice to text**, so that I can easily speak and the words appear on the computer, so I can quickly get my ideas written down, which I can't do very well in writing (I have a "Written Expression Disability"). In high school, there have been lots of **technologies that help me be successful** in school. There are special magnifying devices, Dragon software, and other computer programs. I **tested out many programs** and devices that could help me until I found the one that worked best for me.

Garland

My overall experience with the public school system and having CHARGE was mostly positive. I had lots of people supporting me—my parents, teachers, administrators, therapist, and friends. I always worked really hard in school and my parents always supported me. My experience has been different in the fact that **I have helped my parents shape the future of my education and other kids' with disabilities and special needs.** If I had any other disability besides CHARGE syndrome in school, it would be completely different, but I still had a really awesome experience. **I got to help teach others about CHARGE syndrome, either just by being there or by having them help advocate for me in the educational system.**

Because CHARGE Syndrome is so complex, it makes it difficult to receive a public education. More parents with children who have CHARGE syndrome should be able to go into the public school system confidently, knowing someone has done it before and been successful.

Garland

I consider myself a success story because I have made it through a huge portion of my educational career. **I have had As and Bs** in school the entire time; I worked hard and earned them—**nothing was ever just handed to me**. I feel very smart in the fact that I have learned a lot in school—I can read, I can write (even it's not the best handwriting), I can do math—I even like math—, I like every subject in school, no matter how hard it is. **I like a challenge and I LOVE to learn!**

I **plan on going to college** after graduating high school in the top 25% of my class. I don't know what I want to do in college yet, but that's alright with me. **I want to try a little bit of everything** and just keep learning.

Garland

I hope that my actions inspire any person with a disability or special needs to do what I have done; I more than made it through public school—I am doing well and have goals for my future.

Garland

From my story, I want to inspire more special needs kids to attend public school. I want to inspire the parents to put their kids in public school. Public school will allow the students to teach others about their disabilities. I want to also assure parents that there are things that can help their students that are free when needed—my intervener has been the biggest influence in my education.

I want to let parents know that having a kid with special needs is just like having any kid, just with a disability. It's not a curse. It's not "why me." **You shouldn't have negative expectations of your child—they are special in their own way and they can be successful.** You only need to worry about if they know who they are and are working hard.

For a parent who is putting their child with special needs in school: **keep pushing for those accommodations**. The district may say no, but the parent knows their child best, and your kid may really need them. Don't give up. Always keep trying to get your child the correct accommodations.

Garland

Thank you for listening to me and attending the CHARGE conference!

Speech at CHARGE Conference

Powerpoint follows

Hello everyone,

My name is Amita Srinivasan and I am a huge fan of the show “The Office”. Naturally I am going to start off with a quote from everybody’s favorite regional manager at Dunder Mifflin, Michael Scott. “Sometimes I’ll start a sentence, and I don’t even know where it is going. I just hope I’ll find it along the way, like an improv conversation. An improversation”. I think this talk will be kind of the same. Let’s see where we can go with this.

(Next slide please)

So I want to talk mostly about the power of positive expectations and advocacy. And how they can lead to self-empowerment. But first let me briefly introduce myself.

I am a rising junior at the University of Texas at Austin. Hook’em Horns! I am dual majoring in Psychology and Human Dimensions of Organizations which studies how human psychology can impact business. We study behaviors, motivations and communicating across organizations. I am a mentor in Texas Women of Excellence which is a service organization at UT which hopes to increase the leadership of women on campus through the pillars of mentorship diversity and service. I am also active in the UT student government. Last year I was a director in the Disability and Inclusion Agency and this year I am one of the Academic Policy Directors. Also as many of you have seen at the conference, I am also the President of a national disability rights nonprofit called Deafblind Citizens in Action (I’ll refer to it as DBCA). In fact we have a lot DBCA members here, Chris Sence, Shannon Boelter and Nate Mathewson. But more about DBCA later.

(Next slide please)

I was born in Plano, which is a suburb of Dallas. I am 20 years old (ignore that typo). I was diagnosed with CHARGE syndrome at birth. In the NICU, I had swallowing difficulties which is when the doctors did intensive tests to figure out CHARGE. I have bilateral colobomas. I do not have any usable vision in my left eye. In my right eye, I do have central vision. I have some field defects in that eye and I use a cane to navigate my environment. I have bilateral sensorineural hearing loss. I do not have the auditory nerve in my left ear and therefore I am profoundly deaf in that ear. I have a severe hearing loss with my Behind the Ear hearing aid in my right ear. I depend on a combination of lip reading and hearing for comprehension. I also have heart defects. I had a G tube till I was 11 years old. Like many others I have had multiple major surgeries, about 12 of them including an open heart surgery that saved my life.

Enough about that: Let's go back to my formative years and find out what made me ME.

I was in early childhood intervention by 2 months. I got fitted with my hearing aids at 2 months and I got intensive physical, speech and oral therapy by three months. In order to help me communicate effectively and since my parents were unsure about my hearing and vision, my mom learnt SEE 2 or Singed Exact English which just happened to be a free class available through Plano ISD. My dad used speech and pictures. I went to Preschool at the age of 3 where I was put in a total communication class which just means that my teachers both signed and spoke to me.

(Next slide please)

My parents and teachers had an intensive journaling and communication approach. They wrote in a journal every day. My teacher wrote something about what I did in school and my mom wrote something that I worked on at home. It could be something as simple was taking a walk or playing but they reinforced each other. Here is an example of that with a page from my preschool journal from 2004

(Next slide please)

I had the best teachers in Plano ISD. I was mainstreamed but I got services through Plano Regional Day School program for the Deaf. My parents and teachers always had positive expectations and they advocated for me wherever possible. They never said no, you will not be able to do this, but instead always encouraged me gently and pushed me to try. In elementary and middle school my mom would email the teachers all my accommodations and work with them to make sure they were followed. I was allowed to run my ARD meeting from 9th grade. Social interactions are critical in school. My counselor in elementary school implemented a social thinking curriculum for me. In middle school and high school, I was in a program called Partners PE which paired me up with a buddy. In Senior High, I joined clubs like the ASL and Multicultural clubs and hung out at lunch with my theater buddies. Academically, I was in the National Honor Society and I graduated an AP scholar. I am an avid nature and macro photographer and have won awards for my photography. You can see some at my website.

(Next slide please)

Here is a pic of me in third grade from the Sports Extravaganza which is an awesome program of Texas Region 10 for visually impaired students.

(Next Slide please)

Let’s fast forward a bit into my college life. Many people here have asked about how to prep for it. So let me just segue into that. More of that improversation:

First of all, adulting is hard. You gotta be very organized. Make sure you get to the Disability services in your school and learn about the procedures to implement your accommodations.

While still in high school, my super awesome O and M teacher Mr. Kadlechek made sure I learnt how to use public transport and use financial resources. I learnt how to operate my checking account and use the post office etc. which comes in very handy in college.

One of the most important things I did in college was to join an organization. I applied to many organizations that caught my interest. Only one accepted me, so it is important to be persistent. and try. It is easy to make friends within an organization. If we are friends on social media, then you know I love my Texas Women of Excellence sisters at UT. I also applied for and joined the UT student government.

(Next slide please)

Here is a pic of me with my co director in UT student government.

(Next slide please)

And this brings me to DeafBlind Citizens in Action. DBCA is a disability rights organization that was founded in 2009 by a group of deafblind individuals who were interested in mentoring and leadership.

People with disabilities are used to facing discrimination when we are out and about in the world. We frequently have our abilities discounted and our disability is looked upon as a barrier to approach. We keep talking about disability, what we should really be talking about is accessibility. Debra Ruh said “the only disability is when people cannot see human potential.”

EVERYONE in this room has probably struggled to access their environment at some point in their life: if you have broken a limb, if you are older, or for that matter if you have your hands occupied with babies or you are pushing a stroller. How many of you have approached a door with a stroller and struggled to open it and enter through, all the time using only one hand? Ya, so my point is that our built up environment should be barrier free for everyone. In other words, it should be accessible to everyone.

As deafblind myself, I have faced problems accessing education, my community, transportation and in fact come to think of it IN EVERY WALK OF LIFE. I have to wait for paratransit, I have to wait for captioning of videos, images to be described and I have to wait if my courses have inaccessible material. People say time is money. Time is precious. Why not my time?

DBCA has a stated vision “To strive to create a better world where deafblind individuals are empowered through equal opportunities to live fully and productively, including full access to employment, education and technology”. We are working towards a barrier free society with equal access for all.

(Next slide please)

This slide gives some information about our board and our current exec team. I was elected the president this year. DBCA is well known for its summer program at the Capitol. We have a very unique online leadership course that I will discuss in more detail in a bit.

I basically joined DBCA in 2017. I was at the Texas School for the Blind for a stakeholder meeting and Ms. Bellah gave me the DBCA application form and wrote a letter of recommendation for me. I went to DC in summer of 2017. In 2018, I became the secretary and I ran the online outreach program for DBCA. In 2019, I ran for president and was elected in Jan.

(Next slide please)

Here is a photograph from the 2018 DBCA meet in DC. I was Nate Mathewson’s mentor and I helped him craft a message to the Department of Transportation about accessibility in pedestrian crosswalks. Also we have here our wonderful group of volunteers, interpreters and SSP’s who come to our summit meet and volunteer their precious time with us.

I forgot to tell y’all please go to dbcitizens.org or google deafblind citizens in action and read more about us and our work on our website. Give us a follow on Facebook.

(Next slide please)

As promised, here is a little teaser about our online course. If you are deafblind individual who is interested in service, giving back to the community and leadership, please reach out and apply to our program. We recruit deafblind students from all over the country who are interested in service and leadership. We have an online course related to leadership that is taught by deafblind leaders. Upon completion of the course, we meet up in person where the new cohort learns how to craft a message, how to present information to federal and technology leaders through one on one mentoring by a deafblind mentor. You will learn valuable advocacy and leadership skills and make friends while networking.

We are trying to diversify our program a little bit next year so we will be focusing on one topic – Accessibility in Transportation. The new cohort will meet in Portland, Oregon around the time of Mobility Matters conference which is in March during spring break. If you feel that you want to be in our program and I strongly encourage you to apply. For the parents and professionals here, DBCA is developing a course for professionals working with deafblind people, so do follow us and give us a like on Facebook etc. Keep in touch with us. We really appreciate your encouragement.

We are all different and unique and special. Each and every one of us. We communicate differently, use different languages and styles. Here is an illustration of that:

(Nest slide please: video should play here)

(Next slide please)

Since I am limited on time here I will quickly add a couple of things:

I am very passionate about inclusion and accessibility. At DBCA, I am pushing to focus on technology. Technology has made the world and our environment more accessible for us. We have made some wonderful progress. It has removed so many barriers to our environment. But there is still a long way to go. Think about accessibility in our community: driverless cars, airports, communicating in hospitals, emergency situation notifications on the smart phone, financial tech: venmo and bank payments, wayfinding etc. Tech should be designed ground up with accessibility in mind, unfortunately this is not true in most cases. Accessible features are usually added only at the end of the design process sometimes even after the product is launched. Our focus for 2020 DBCA meet will be transportation and mobility at Portland, Oregon. Email me for an application form.

(next slide please)

Another focus of mine is to lend DBCA's support to SSP or Service Support personnel legislation all over the country. I am here today because my parents and teachers acted as intervenors. The Cogswell Macy is ongoing at the federal level. Now 20 states have already have a SSP program. We are pushing to have a program in all states. We have a large CHARGE delegation here from Texas. Ending here by saying DBCA supports this legislation, and I am urging y'all to join up with us and let's get this done Texas.

HOOK'EM!!!!!!!!

My Texan Life

Amita Srinivasan

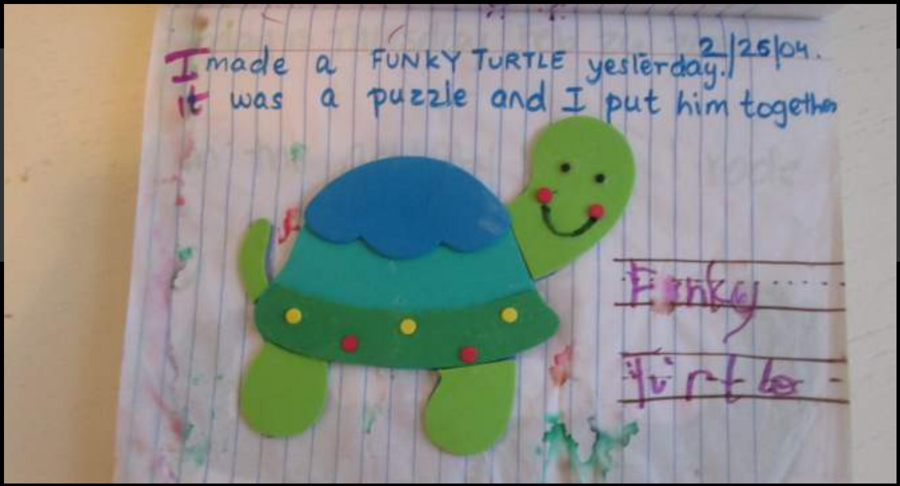
Introduction:

- The power of:
  - Positive expectations
  - Advocacy
  - Empowerment

- Introduction:
  - Rising junior at UT Austin
  - Majors: Psychology (B.S.), Human Dimensions of organization (B.A.)
  - President of DeafBlind Citizens in Action
  - Active in student government at UT Austin

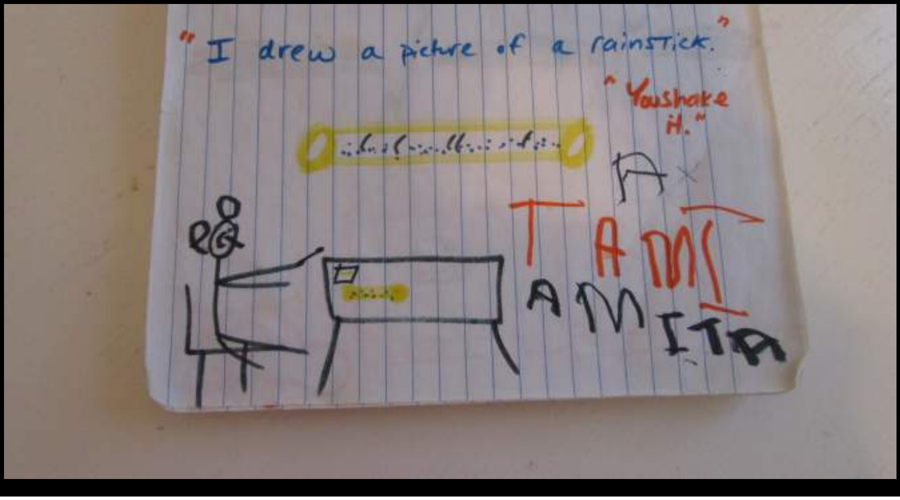
The Early Years:

- I am 19 years old.
- I have bilateral colobomas; bilateral sensorineural hearing loss: Severe-Profound; heart defects, Gtube (11 years), 12 surgeries.
- Early Childhood: BTE Hearing aids (2 mos.); Communication: SEE 2 and oral (total communication); intensive physical, speech, and oral therapies starting 3 mos.
- Early childhood school through Plano ISD starting 3 years
  - Total communication



I made a FUNKY TURTLE yesterday. 2/25/04.
It was a puzzle and I put him together

Funky
Turtle



"I drew a picture of a rainstick."

"You shake it."

TAMI
AMITA

Time for School:

- Accommodations and Advocacy- email teachers; remind them if they forgot; lead IEP (9th grade)
- Social interactions: Elementary, middle, and high school
  - Elementary: Counselor- social thinking curriculum
  - Middle: friends through Partners PE
  - High school: friends at lunch and shared classes
  - Senior high: after school clubs like: Multicultural and ASL clubs.
- Participation in Special Events: Deaf Ed or Region 10 events; homecoming; Imagination Celebration, Prom, and Spring Show.


8TH ANNUAL
SPORTS EXTRAVAGANZA
SHATTERING PERCEPTIONS
2007
BLIND AND V.I.
SPORTS EXTRAVAGANZA

College Life:

- Prepare for life beyond school: build a resume, learn skills, independence, handling finance.
- Be organized: Adulting is hard
- Accommodations: Tell your professors about them.
- Join an organization and make friends within that
- Use the career services your school provides.
    - Vocational Rehab
    - Workforce Solutions


#UTLeadandLearn
Post for a chance to win!

DeafBlind Citizens in Action

- Deafblind Citizens in Action (DBCA) is a national non profit that strives to promote leadership and advocacy among individuals who are deafblind.

- Our Mission: To empower people who are deafblind through education, technology, and legislation and to ensure that deafblind persons have a strong political voice so that they may lead productive lives with equal opportunities.
- Our Vision: To strive to create a better world where deafblind individuals are empowered through equal opportunities to live fully and productively, including full access to employment, education and technology.

DBCA: Our Team

- Our Board:
  - Dr. Amy Parker (Chair)
  - Distinguished members who specialize in disability studies and deafblindness
  - Maricar Marquez (Special advisor)
- Our current executive team:
  - Amita Srinivasan (President)
  - Divya Goel (Vice-President)
  - George Stern (Secretary)

- Unique Summer Program at the Capitol
- Leadership online MOOC
  - For Individual and parents
  - For professionals in the field
- My experience: Mentee to Secretary to President

DBCA Leadership Module

- Unique experience of being mentored and taught by DeafBlind individuals who have been through the process
- Learn about leadership and advocacy
- How to be an effective leader in your community
- Make friends and connections while learning advocacy and leadership skills

DBCA 2018 in DC at Verizon

Learning Targets of our Leadership Module

- Learn about the societal sources for expectations and how to spot them.
- Positive role models and peer mentors can help instill and maintain positive beliefs and expectations in adolescent and young deafblind students.
- Learn how to develop leadership and advocacy skills in young deafblind students.

Growing within DBCA

Hook'em

Thank you for your attention!!

If you would like to know more about DBCA or attend a seminar with us, please connect with me

Please visit our website dbcitizens.org and follow us on our Facebook page

Brandon Reid Marshall

—

CHARGing into The Unknown

Introduction

Hi guys, how are we doing? My name is Brandon Marshall, I'm a 37 year old adult with CHARGE. This is my third conference and I'm honored to be invited to speak on the CHARGE adult panel. I want to give thanks to the Charge Foundation for once again putting on an incredible conference. When Joanne asked me to speak, I thought to myself, “Ok, cool, bring it on!”.. I looked at a blank page for three days, then started writing what came into my head.

Birth

In 1982, on March 16, in a hospital in San Mateo, CA; I was born not breathing, so got rushed to the NICU and was returned to my mother several hours later, with tubes of all sizes connected to my body like a science experiment. This one was taken a month later, and I think the bunny was almost as big as me.

What is CHARGE?

CHARGE Syndrome wasn't really known in those days. I was born before the internet so my mom and the doctors couldn't look up info on all my medical issues and problems. They were basically clueless as to what was wrong or why. So you could say I was a clean slate. The doctors just dealt with issues present at birth which ranged from inability to swallow, bi-lateral cleft lip & palate, malformed outer ears, hearing loss and inability to completely close my eyes due to a cranial facial nerve palsy, and even affects my speech.

Admiting to NICU

I spent the first three months of my life at Stanford Children's Hospital in Palo Alto. I also spent the first few years in and out of the hospital, due to many procedures and surgeries. Because I could not swallow, I was fed with a NG tube into my stomach, until almost one year old. Working with therapists, they helped me learn to eat regular food by the time I turned two. I got my first hearing aid at three years old and got a real handle on walking on my own by the same time. My tentative diagnosis was at nine but even at 14, Stanford Genetics was still not convinced it was CHARGE.

Deaf school and horses!

I started attending main streamed school at age of three. I was placed into a Special Ed class with kids who were deaf and other kids with developmental delays. While I was attending the deaf program at Woodside school, I took horse riding classes, and I fell in love with horses. I rode one big white horse named Lollipop.

Brandon & Lollipop 12/89

Early childhood education

I stayed in special ed classes in the public school system, going to a different one until the end of fifth grade. My speech was much worse then, so people thought I'd say one thing, when I meant another, so I was always getting sent to the principal's office for behavior issues, and I mean.. what kid isn't getting in trouble in school, am I right? I encountered many bullies in that school, from the time I entered until the time I left.

Homeschooling

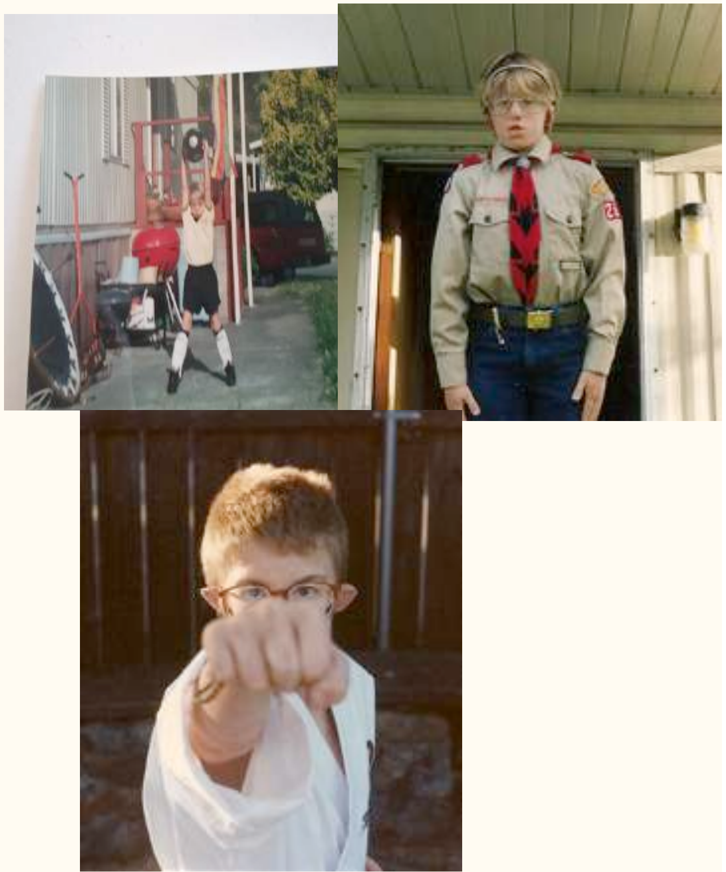
I was homeschooled for middle school and high school, because both of those schools in my town had a very bad rep. I hated being homeschooled, but now I sorta thankful that I didn't have to put up with bullies for those years. We moved to Santa Barbara when my Grandmother got sick. It was hard being away from my homeschool friends but I liked being near family and was always close to my Grandparents.

My Grandparents

Grandma gave me my passion for cooking, which I’m apparently quite good at! (at least nobody's died from it... yet.) My Grandpa gave me my first two cars. Then with my own money, I was able to buy a Kia Soul which I now love to drive!

Active Childhood

Good news! Grandma got better. We moved back to the Bay Area and hooked up with the same homeschool group, so it was fun reuniting. I did what every kid does: joined Tiger Cubs, Cub Scouts / Webelos and went up the ranks in Boy Scouts to Life Scout. Though I earned lots of merit badges, sadly, I never made Eagle. Camping, fishing, cooking and horsemanship were my favorite badges. I took karate classes, joined 4H, played soccer and was quite good at it, acted in a couple of stage plays with the homeschool group, and had fun park days. I also went to lots of summer camps. I was a very busy kid!



Job Experience and Intro to Dancing

Got my first job at sixteen from a guy who gave me a chance, and hired me as a courtesy clerk at his small grocery store. A community college up the street allowed high schoolers to take community college classes. In one class, I met a young lady named Irene who was a dancer, she talked me into taking ballroom dancing. My first thought, as any guy would have is

.. 'Eww, dancing is for girls! No guys wanna dance!”

Boy, was I wrong! East Coast swing was my first intro to the dancing world. It ended up being quite fun! I spent many summers since, taking dance classes, working, and taking other college classes.

Moving to AZ

By this time things were good and I was happy. Then one day my mother comes home from work and says we're moving to Arizona. We did not know anyone there. That's when I got depressed, because we were moving away from EVERYTHING!! We moved to Arizona during the summer, it was tough, it was HOT, it was lonely, no friends, no job, no school and no car yet. It wasn't long before I found a job in Arizona as a courtesy clerk.

GED and College

I yearned to move back to California so I could be closer to family, but we couldn't afford it.

In 2005, I went Rio Salado College, enrolling in their GED program. Being homeschooled, I did not have an actual high school diploma and I wanted one. I studied hard, passing four subjects in rapid succession, getting all high scores in each one. After struggling with math, my worst subject, I decided to take a break. In 2009, I met the most awesome, beautiful and smartest teacher, Ms Suzi Hobin.

Graduating from high school

With Ms Hobin's help, and a few friends, I FINALLY passed the math. Ms. Hobin made me realize that being good in math would help in everything that followed.

In 2010, I had two major achievements: I earned my GED and entry into the National Adult Education Honor Society.

My Dancing Career

A new dance studio opened up near my house called Fatcat Ballroom. I went in there soon after it opened for a Quickstep class. I took more lessons and learned many styles of dance. I competed, won some awards and trophies, and had a lot of fun doing it. Dancing has not been my only thing, but I do enjoy it. People tend to ask me alot, when they ask how I dance so well, after telling them I have no sense of balance, is I just tell them this.. I put one foot in front of the other and hope I stay upright!

Jobs are a pain in the back

In 2011, I had back surgery to repair discs after developing spondylolisthesis. This had caused me many physical problems including not being able to dance for a while. Finally, in late 2012 I was able to dance again.

I've had many jobs now since living in Arizona; from retail, delivery driver, even plumbing! My current job I've been freelancing for a temp agency all over my hometown to different stadiums, convention centers and everything else in between for just over a year now. Want to get into the games for free? Just go apply at a temp agency!

Discovering the CHARGE Community

One day during recovery, I was researching scoliosis, which I have, and stumbled on a page about CHARGE Syndrome.. Huh, interesting! Must've spent over two hours on that website, getting totally distracted.. others with CHARGE? Others that look like me? I noticed there was a CHARGE conference! 'Totally got to go to this' I said out loud, clicked on where conference was going to be, right here in my home state, less than 20 minutes from me!! How lucky can a guy get?! I saw there was going to be a talent show for people with CHARGE! Hmm, dancing was my first thought, that, and my dance partner Danielle.

July 2013, we walked into the CHARGE conference. I was awestruck by just how many others were like me! Both children and adults! Some walking, some not, some large, some small, but ALL looked like me!!!!!

I've now been to Chicago in 2015, Orlando in 2017 and now its 2019, and I am in Dallas!!!! While I may be new to having a CHARGE family, it didn't take long to feel like apart of each one of you in this room. Even my friends list on Facebook has doubled in size!

As I said in the beginning of this long-winded speech, I have CHARGE syndrome, but I don't let it define who I am, and neither should you. We rise to the challenge laid before us and prove the naysayers wrong. We've proven to everyone that we can do anything we want. Be it a lawyer, a nurse, and in my case as I mentioned before, a plumber!

I leave you with a quote I found recently, by Ayn Rand:

“The question isn't who is going to let me;
it's who is going to stop me.”

Full circle

As my talk time is running out, there is one more thing I'd like to do, to make this conference come full circle for me... it involves a song, a certain lady and a little willpower. Jody Wolfe will you make your way up here, please? At my 1st conference, I got to dance with the President's wife - not Michelle Obama - but the wife of this Foundation's president. I believe we still have a dance to finish.

Music Clip