

# **12<sup>th</sup> International CHARGE Syndrome Conference Adult Panel 2015**

- **Shannon Boelter • Dylan Lauger •**
  - **Meri Dwyer • Belinda Arnell •**

# Shannon

Hi everyone!

My name is Shannon Boelter. I am from Minnesota and I am happy to be here on the Adult Panel. It is nice to meet some new faces and reconnect with old faces. You all are awesome people!



# Shannon

First some about my history.

My parents found out that I have CHARGE when I was 11 months old. I had my first heart surgery at 5 weeks of age, then a second one at 11 months. When they found out I am Deaf, when I was 5 months old, my mom quickly found a Deaf woman who started a part-time daycare for me and a few other Deaf children that I am still friends with today! I am thankful for that, because I learned a lot of signs and said my first word at nine months, "More."

# Shannon



# Shannon

I had a teacher of the Deaf come to my house once a week and my mom and I went to a parent/infant program for Deaf children at about 1 ½ years old. At age of three, I went on a bus by myself to Cedar Preschool with other Deaf children. Two years later I went to Metro Deaf School, a Charter school that my mom started, and graduated from there in 2009.

# Shannon

I went to St. Paul College, a Community College, for two years, and then transferred to Gallaudet University. I graduated with honors from Gallaudet in 2014 with a degree in Family Child Studies/Development.

I am currently am working full-time at a Montessori school in Minnesota since January. I have taught the toddlers some sign language. Fun ages, huh? Myself love work with children. When I am here at the conference or any other places, when I see little kids, it always makes me smile. They are so innocent and smart in their own ways.

# Shannon

I also wanted to be an author. I wrote a book before and published it. Now, I realize that I don't like that book anymore and I have different interests now. It is still available in Amazon.com. In life we learn our mistakes and we make them when we are young. Now I want to write about something new and original. Some people told me to write about my school or CHARGE Syndrome. However, I feel like writing a biography. If you want to know more about my old book or my new idea, feel free to come up and talk about it! I am interested in your opinion.

# Shannon

Now, more on me as a CHARGEer. When I was around a Pre-teenager, I start to understand what CHARGE is. My friends can tell I am different and some understand and some don't. I have some friends who help me with my balance and support me. When I was younger I didn't really open up about CHARGE and was very secretive about it. For example, if somebody said I am Deaf-Blind, I would say, "I am not blind!". I didn't fully understand Coloboma at that time.



# Shannon

However, things change through the years. I have gone to church for my whole life and I believe in God myself. I enjoy hearing Bible stories, and I learned that God made me for His purpose. Then I became more accepting of who I am.

One day I discovered a verse, 1 Samuel 16:7: "But the Lord said to Samuel, "Do not look on his appearance or on the height of his stature, because I have rejected him. For the Lord sees not as man sees: man looks on the outward appearance, but the Lord looks on the heart."

# Shannon

This means we shouldn't really judge people on how they look, but how good that person is in their heart. For example, one time I met a four-year-old child. I played with him and chatted with him. He seemed to be a smart and funny boy. Then one person told me that he had CHARGE syndrome like me. I was shocked and said, "Really? I don't notice that." The more I knew him and watched him, I could tell he had CHARGE. It still didn't change my behavior toward the boy.

# Shannon

People give me a shocked look when I tell them I have CHARGE syndrome. They say, "You look normal and don't look like a CHARGEr." I always answer, "What is normal?" All of us are different and God made each of us different and special. We are not a mistake in His eyes and we are prefect! Look at the children and CHARGErs around you, and they are so prefect! Just look!

# Shannon

I have a story to share; I went to Italy last October. I had a good time! I even went to the Leaning Tower in Pisa. Before that I was not sure if I would be able to because of my balance issues. I checked out the Internet and saw others' experiences. And all I found was, "If you have a balance issues, don't go!" or "Balance issues? You can't go up because you would fall."



# Shannon

I did feel stupid asking the tour leader if it is possible. The tour leader laughed and said, "What? It is possible! It is not that hard!" He had faith in me. I even walked at Pompeii; I am telling you it is hard NOT to fall. However, I have people around me to help me to walk. I realized something that there were friends here. They would help me go up in Leaning Tower.

# Shannon

When I went to the Leaning Tower and I looked up. It is pretty tall and leaning. I entered the tower and found those steps were not that bad. I just needed to have my hands on the wall to keep myself from fall. They said I could always go back if I didn't feel comfortable. Around 200 steps and I made it to the top!



# Shannon

I looked down in disbelief. I made it that far and was successful. Even a couple of other people in my group had a knee problem and back problem and they are making it fine.

Right now, I love myself as CHARGEr and known God have a plan for me.

Thank you for watching! If you want to meet me or any questions then feel free to ask me!



**Hi. My name is  
Dylan.**



I am 19 years  
old and live  
with my mom  
and dad.



Roy, Kim, and Dylan



**We live in Tucson, Arizona.**

My brother and his wife live in Alaska.



Tyler and Chanelle



**My sister lives  
in Colorado.**



**Kayla**



**We all flew to New York.**

- The doctors say I have no hearing, limited vision, underdeveloped inner ears, one kidney and am non-verbal, CVI-like, autistic-like, and tube fed.

- My parents say I am
  - Pure
  - Happy
  - Cognizant
  - Competent
  - Heaven - on - Earth

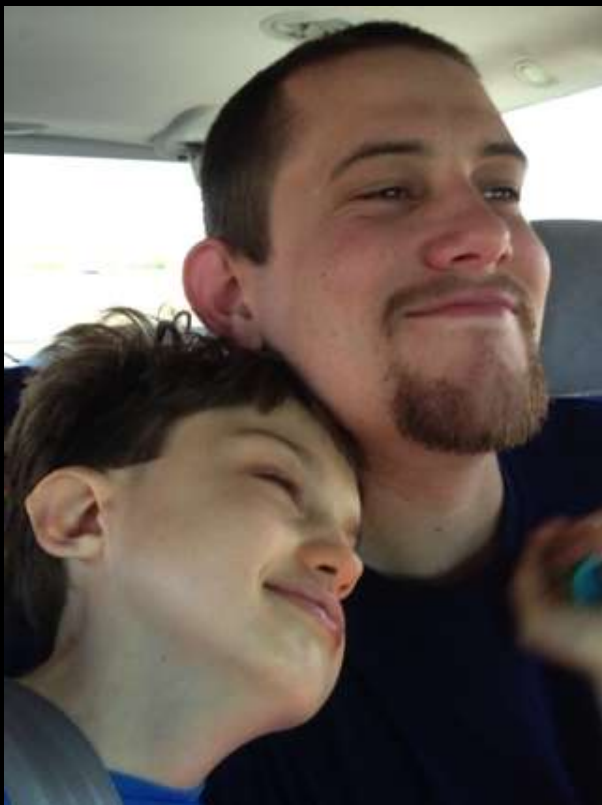


I like  
ice cream,





tickles, kisses, hugs,





and my friend, Quinn.



I go to  
School-Home.







The Solar System

**Mom is my teacher. Deb and Doe are my Interveners. Ed teaches O&M. Megan teaches communication. Kristina teaches literacy.**



September 2014

**I like when Quinn comes to School-Home.**





**At School-Home my team follows my lead and teaches through my interests.**

# I like water bottles,



and power tools,





and duct tape.





# I like riding horses,





riding my bicycle,



driving my scooter,



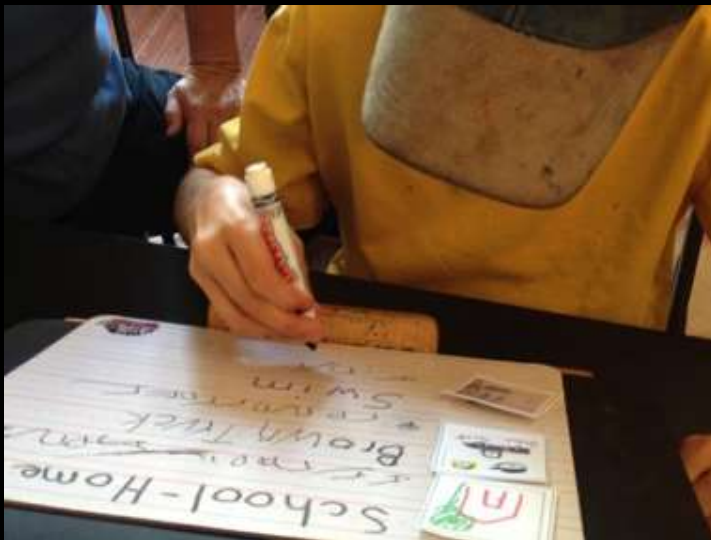
# swimming and swinging.





I like science,





reading, writing, and knowing.



**I like the solar system.  
The sun, moon, stars, and planets.**

I like rockets,



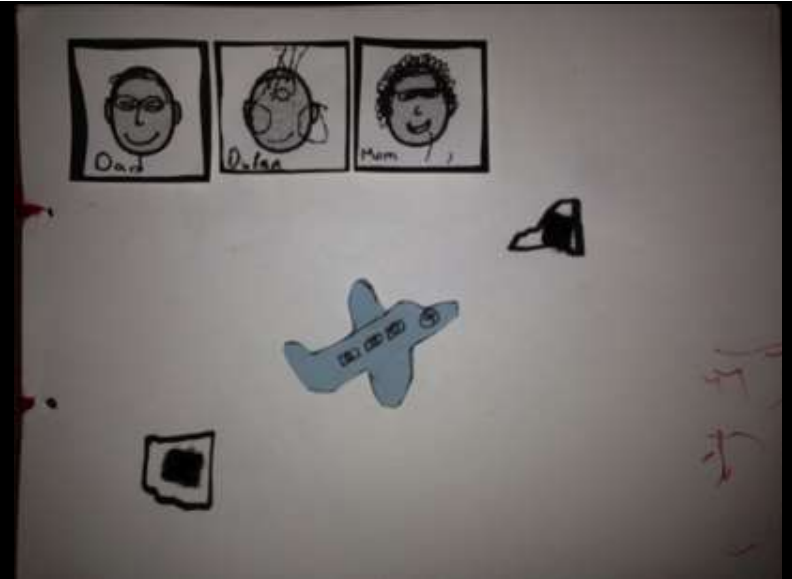


# space shuttles,



and the planetarium.





I like knowing where my family lives and when I will see them.



I like knowing what is going to happen.





**I like School-Home.**

**I understand, communicate, and do more.**

# Meri

Hello everyone! My name is Meredith Dwyer, but everyone calls me Meri! I'm twenty-two years old and I am here to discuss my life with CHARGE Syndrome. I'm the middle child of three. My sister, Megan, is two years older and my brother, Billy, is a year younger. I have so much to tell you about myself as an individual with CHARGE.



# Meri

First let me begin with the basics. CHARGE is an acronym for six different anomalies. As an individual with CHARGE, I was born with the C, H, A, R, G and E.

When I was diagnosed, generally people who had four of the six letters were identified as having CHARGE Syndrome.

# Meri

For C (Colobomas), I have large colobomas in both of my eyes. I have peripheral vision in my right eye and light and dark perception in my left. I have been going through tough times with my vision over the last few months, though. I had two retinal detachments and repairs and one laser for the scar tissue when I was thirteen. Recently, my colobomas have been giving me difficulty, so I visit the retinal specialist every six weeks. Because of the vision problems, I'm trying to get all my books on CD, Audible, Overdrive or BARD on my iPad. I even use JAWS when working on my stories when necessary. This allows me to rest my eyes.



# Meri

For H (Heart Defects), I have three ASDs (which are holes in my heart) and Pulmonary Stenosis, but my heart is mostly healthy.

For A (Atresia), I was born with choanal atresia. That is I had a blockage of my left nostril. It took three surgeries to finally open my nose.

For R (growth and development delays), I was tiny and developed slower than other kids my age.

# Meri

With G, I had an enlarged bladder and frequently got bladder infections. Lucky for me, I outgrew this.

Last but not least is E (ear malformations and hearing problems). I have a moderate hearing loss in my right ear, but I can't hear anything in my left. I have hearing aids, which I made sure came in fun colors! Here's something funny: I'll sometimes hear when someone's whispering when I'm listening to music or a book, but I don't always hear when my parents want me to do something.

# Meri

Other CHARGE related issues are low muscle tone and poor balance. And also, I don't have a sense of smell. However, I feel as though I can taste smells. If I'm near flowers, I can taste their scent.

As you can guess by the mention of audiobooks on my iPad and on CD, I'm an avid reader. I enjoy science fiction/fantasy like aliens or people with special powers, plain fantasy like *Harry Potter*, Dystopian like *Divergent* and *Hunger Games* and sometimes even mysteries, if the plot is right.

# Meri

I am also a writer. Well, not exactly but I'm working on it. I enjoy writing stories about videogames, anime and other points of interest. I am currently writing stories/books that I would like to publish. The major one being my novel—that, may I add, is taking awhile—*Anything's Possible*. It follows four different people with disabilities and how they have to save the world from an alien species known as the Intimidators. I also enjoy watching anime, reading manga, playing videogames, listening to music and going for walks when it's nice out.

# Meri

For a year and a half, I attended HKNC—Helen Keller National Center. HKNC is a vocational and independent living training program for teens and adults who are deaf/blind, this includes hard of hearing and visually impaired not just completely deaf/blind. HKNC also teaches mobility and communication skills. It's a very good program and I loved it. I made a lot of friends there, too! I have learned some ASL and Braille. I got to practice my creative and teamwork skills. I made a cane holder out of macramé, a tactual cherry blossom aka my favorite plant, key chains and I even got to create my characters for my novel!



# Meri

I learned how to travel independently via taxi and bus (SCAT for my home area and Able Rides for HKNC).

I got to create a play with two of my closest HKNC friends, too! It was called "If You Don't TRY, You'll Never Know." It was about three pixies, T, R and Y, and a sassy elf who went on an adventure to find clues with the letters T R and Y. It had the theme of there being no magic to communication; you have to try it yourself. My friends and I had a blast!

# Meri

Lucky for me I live in the Suffolk County area of New York and the location of HKNC Headquarters is only an hour and a half away, so I was able to come and go over the weekends. I was wheeling my pink backpack—loaded with books, my computer, video games and some other goodies—back to the residence and there was a weird noise like something was stuck to my backpack. I was talking to some staff and someone said, “Meri, something’s stuck to the wheel of your bag!” I looked and saw a twig in the shape of a Y! I was laughing hysterically and said, “Oh my gosh! I found the third clue!” Within seconds every single person at the Center knew!

# Meri

I even had my own apartment. I learned to cook and clean and do laundry. I also learned how to use voiceover on an iphone! I received a CCTV for work. I took part in a Public Speaking class and gave a speech on my dream of becoming a writer. This speech was a huge success. I worked on advocacy! I had many interesting advocacy experiences at HKNC. Once, I was going to Kohl's and the taxi driver didn't know where he was going. I kept saying, "Kohl's is on Jericho Turnpike," since he seemed to have no clue where to take me. That same day, my taxi was an hour late and my phone battery was dead. I had to ask the people at Kohl's to call Deluxe Taxi Cabs. A kind lady let me borrow her phone and I called HKNC and no one was there, but the store was able to contact the taxi company and they arrived. I remained calm the whole time.

# Meri

Now that I am home, I am using the independence skills I have learned while I was away. I am currently on a job search. I had an internship at Barnes and Noble for about a year. I was able to do everything booksellers did. I shelved books and other material, scanned books to be pulled with what's known as a PDT and I even ran two book discussions! Now, I am searching for a job as a file clerk, since retail positions are hard to come by. As for education, I currently attend Suffolk County Community College part-time. My major—though I want to be a writer, I need something to, as my mom says, “pay the bills”—is liberal arts.

# Meri

I have what's known as a Self Direction Plan. I have staff that comes out with me into the community. The workers are like friends or assistants. I continue my skills with laundry and cooking. I also go out to the mall, coffee or food places and you guessed it the library! Sometimes I run errands with the staff. I also go for walks down Port Jefferson or the nearby park. I took a swimming class for a while at Stony Brook University. I take therapeutic lessons with horses at a place called Palomine Equestrian. There, I play with the horses and other animals. I've even started a program known as JSTEP. It's a vocational program that teaches job skills.



# Meri

Sometimes being disabled is frustrating—Not being as independent as I would like, finding a job is proving challenging (as it is for numerous people in general) and worrying about continued changes in my vision—all of these things can be hard.

Even with these challenges, I am a force to be reckoned with. I have many supports in place and I continually work on increasing my independence. I schedule my days doing things I like and even though I love being home I look forward to the day when I can have a job, travel and have an apartment of my own.

# Meri

Despite my disabilities, I'm a very positive person. I believe—as the theme of my novel states—  
*Anything's Possible*, as long as you put your heart and mind into it!

# Belinda



Good morning everyone. Ten years ago I stood up here in front of many of you and said you all look beautiful, but I'm blind. Well today, I still think you all look beautiful, but I'm still blind!

The theme of this year's conference has been The Sky's The Limit. Well I'd like to say that as artist Paul Brandt said "Don't tell me the sky is the limit when there are footprints on the moon" For those like me who flew to this conference.....we have already reached the sky so even that is not a limit!

# Belinda

I think one of the worst things we can do is place limits on ourselves. I am sure that many here today who have children with charge or who care for children with charge have seen them exceed many expectations and go way beyond limits that people had set for them. Things such as life expectancy, if they would walk, talk, eat, see or hear. Simple things such as enrolling in kindergarden and more challenging things such as graduating from university. 10 years ago I travelled to the U.S. independently to attend my first international conference. I know here today there are at least 3 adults with CHARGE Syndrome who have travelled here independently from overseas and I'm sure there are more.



# Belinda

So let me tell you about myself and how I have been very determined to have no limits in my life.

I am 32 years old and live in Melbourne Australia. I still live with my parents though I am beginning to think about moving out as I am becoming more confident that I can live independently.

My particular CHARGE eye conditions are bilateral coloboma and high myopia, which results in severe vision loss even with my glasses which I have had since 13 months old, and contact lenses that I have worn since I was nine. My vision is what affects me the most. I am actually eligible for a guide dog or to use a cane, but I have learned to use the vision I do have very well.

# Belinda

I have bilateral Choanal Atresia for which I have had many repairs. Because I used to have drainage tubes sticking out my nose, people would come up to my Mum in the supermarket and say things like "Excuse me, is your baby alright, there are straws or something stuck up its nose

I have moderate severe deafness for which I wear two hearing aids which I started wearing at 17 months. I started talking around 2 years of age and have never stopped. I also wore a radio frequency unit at school which allowed me to hear the teacher better. The teacher would often forget to take their part off which has caused me to hear a few toilets flushing over the years.

# Belinda

I have no heart defects and have not required a feeding tube. However I had very uncoordinated swallowing and it took a few years to be able to eat solid food and it took many years to be able to eat and swallow many foods. These days I can eat anything, when it suits me. Wine and coffee go down extremely well.

I had delayed growth and puberty for which I have been on hormone treatment since I was 13. I also have no sense of smell which has often come in quite handy. Though, only a few weeks ago I was at work getting lots done and we were evacuated due to paint fumes. I was a little irritated since I was getting so much done and couldn't smell anything. We were sent home early so that was ok I suppose.

# Belinda

I have other central nervous defects including balance problems. However this does not stop me from being an active member of my gym by running on a treadmill, strength training and attempting to follow fitness classes even though I can barely see the instructor and have had a few crashes into the ground. I have a great personal trainer who is excellent at accommodating different needs. For example I have extremely short shoulder blades which limit rotation and range of movement. I have participated in, and even won a number of health and fitness challenges.

When I was younger lots of crawling, walking and jumping on my trampoline helped my balance improve although its still challenging at times.

# Belinda

I was often very sick when I was young and have had many surgeries. I saw many medical doctors and therapists for various conditions. I always had a lot of trouble sleeping and would often get up at 3 A.M. and not understand why my sister wouldn't get up and play with me. I've had a few surgeries as an adult for my eyes, palate repairs and jaw realignments.

I attended both regular and special playgroup to widen my experiences. I was always breaking my glasses when I fell over or knocked into things due to very bad balance and vision, and also losing or hiding my hearing aids various interesting places.



# Belinda

At primary school, I had an integration aid for about eight hours per week and the Vision Australia sent out a visiting teacher once a week to help me maximize my learning.

I also had a teacher for the hearing impaired come out weekly. I started doing lots of extra activities outside school including swimming, drama, and dancing.

# Belinda

High school was a challenge. I had extra help with an integration aid for about eight hours per week and I continued to have visiting teachers. I also did lots of drama and singing as extra activities. I was involved in many plays and musicals both in and outside of school. I enjoyed doing this a lot although once I did walk right off the edge of the stage into the audience. I obtained some sought after acting roles and received singing awards.

When I was born the doctors told my mum I was totally blind and would never see anything. Well I'm not totally blind and I can see plenty (Especially your beautiful faces..ha ha)

# Belinda

My mother was told to send me to a special school as it would be more 'suited' to me. Well I graduated from a mainstream primary school and a mainstream high school. I went to university and attained a Degree majoring in psychology and legal studies. I have also done studies in computer technology and have a Diploma of justice studies. I must point out that the university degree should have taken me 4 years but instead it took me 12...but I still finished it because I was so determined. I did do a lot of it part time whilst working full time.

# Belinda

I had a few casual jobs during high school and now work full time for the police force doing data entry and computer administration. I have worked there for 7 years and feel fortunate to have a stable job in which I am able to perform duties like anyone else with the help of a text enlargement program on the computer.

Driving a car...I have been told there is no way I can drive a car because of my poor vision. I like to rephrase that to there is no way I can drive a car legally. When my sister went into a shop to buy us lunch one day. I waited in her car and decided to give driving a go. I only managed to go backwards and only made about 50 meters across the carpark before hitting a garbage bin but I count that as driving!

# Belinda

Travel...I know people thought I couldn't travel safely on my own. Well I started my independent travel at an early age when I decided to take myself on my first solo vacation when I was about 3 years old by telling my mum I was going on a holiday and riding my bike out an open gate and down a few blocks. I was found at the police station a few hours later after a frantic search.



# Belinda

Travelling has become a huge passion in my life because it has allowed me to become more independent than I ever thought I could be. I took my first solo international trip here in 2005 and since then have travelled independently and with friends to about 25 countries. Last year was my biggest trip which saw me going around Europe for 8 weeks. I am always very organized and book most things myself and have learned a lot along the way.

Of course things have not always gone smoothly. Multiple times I've been at the airport and heard "Belinda Arnell if you are in the terminal please proceed to the gate immediately". I've missed a few flights, boarded the wrong train and slept through my destination station a few times.

# Belinda

I've had some wonderful friends looking out for me. For example I almost stepped off the platform onto a train track. Not sure if it was my vision or the wine that contributed to that. Also, when I couldn't figure out how to unlock a bathroom door in a pub. Once I was at a concert where people rushed the stage at the encore, and my friend had warned me about the speakers sticking out from the stage. Of course when the time came to run, I ran smack bang into the speaker. I also took a while to convince a very concerned customs officer I had done this travelling thing before and could manage just fine.

# Belinda

My latest challenge is cooking. I can't say I've mastered this skill yet but I will! My mum is teaching me a lot and I'm improving and haven't burnt the house down yet!

These days I enjoy going to the gym, helping coach young children dancing, spending time with my three, almost 4 nieces, and being with good friends who always look out for me.

Despite my personal achievements life is still a struggle for me at times. As well as having negative life experiences that many of us have I often find it hard to fit it and people are still discriminating towards me at times. I see a psychologist to help cope with these things.

# Belinda

By far and away the biggest limit I had to prove wrong was simply to live. At birth the doctors told my mother I would not make it and sadly some even attempted to accelerate my death as they saw no life for me. Well here I am 32 years later...alive, kicking and living life to the fullest.

If I had have simply accepted all the limits that were placed on me throughout my life I would not be half the person I am today. I challenge limits and I will continue to challenge limits.

# Belinda

My experiences and achievements are not unique. There are multiple individuals with CHARGE Syndrome who have travelled independently, are married and have children, have college degrees and full time jobs and can drive a car (legally). I was picked up from the airport by a lady with CHARGE Syndrome and I'm here to tell the story. All these people like myself have various medical complications, have had countless surgeries, negative experiences we all have in life and many other struggles.



# Belinda

So I leave you with this. Don't put limits on yourselves or on your kids. You never know what they will one day achieve.

I end with this quote from athlete Jerry Dunn. "Don't limit your challenges, challenge your limits".

Thank you.