NATIONAL CENTER ON DEAF-BLINDNESS

LESSONS LEARNED – A PARENT PANEL

February 19, 2020

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>> ROBBIN BULL: For those of you just joining welcome. We will get started in about five minutes. This is a chance for you to run and get a cup of water or soda or whatever you want to drink this evening during the webinar.

>> ROBBIN BULL: It looks like we are at the top of the hour. This is Robbin Bull with the National Center on Deaf-Blindness. I think we will go ahead and get started as people are settling into the room. I want to begin by welcome everybody. This is going to be a great webinar tonight. I am very excited I get to preview the presentation before everybody I was looking over the presentation and I am very excited for tonight. I wanted to let you know that all of the phone lines have been muted to reduce background noise. If during the question answer session at the end of people want to come off of you to speak use*6 to come off of mute and*6 to mute your phone line but we will wait until the end of the session to do the question and answers session.

I am going to start the recording. This will be recorded so I will remind you that this will be posted on the website and say just want to make sure you don't share anything that is personal that you don't want to live on forever on the web. With the recording and transcript. All right? So I am going to start the recording and then I am going to hand it over to Megan Cote who is going to introduce today's speakers. Tonight, excuse me. I am Pacific Coast time so I am earlier than a lot of people.
>> MEGAN COTE: Hi everyone welcome to the CHARGE Syndrome Foundation webinar entitled a parent panel lessons learned. I am a board member with the CHARGE Syndrome Foundation and we are thrilled to have you join us tonight. It is an honor for me to be able to introduce our presenters for tonight who each

happen to serve as the CHARGE syndrome family liaison in their respective states. Thorton Gallimore from Illinois, Penni Echols and Samantha Teed from Iowa. They each raise a child with the CHARGE syndrome and we are thrilled they are willing to present to us tonight. As you know the CHARGE Syndrome Foundation is a not-for-profit organization that provides support to individuals with CHARGE syndrome and their family. Our vision is a better world for people with CHARGE syndrome. If you like what you see tonight and you believe in the work be foundation does on behalf of individuals with CHARGE syndrome and their families is important please consider becoming a member of the foundation or making a donation through our website. Thornton, Penni and Samantha will provide their presentation and then as Robbin mentioned there will be time for questions and answers at the end. If you have questions however while they are presenting please feel free to write them in the chat pot on the right-hand side of your screen and we will make sure to cover as many as time will permit after they have shared. Thanks for joining this evening' that I will hand off to Thornton. Enjoy everyone.

>> THORNTON GALLIMORE: Thanks everyone for joining us for tonight's parent panel. This is an exciting opportunity to connect the community on a lot of the things we have in common with families that have kiddos with CHARGE. You might see this interesting little gadget I am wearing right now. This is really a testament to this is a tiara and a testament to what this organization is all about bringing in families from a very unique perspective. There is no judgment, there is no perception differences that would prevent you from wanting to engage with such a wonderful community and if you take one thing from this parent panel it is the simple fact that doing what you're doing right now, reaching out and connecting with other families and with the foundation is absolutely pivotal in the well-being of yourself and your family. And you will not find a better organization out there to connect with that brings people together and just does such, in such a loving, caring, compassionate manner. So thank you so much for being a part of that and I encourage each and every one of you to continue to connect with family as you are right now.

It little bit about me and my family. Again my name is Thorton Gallimore and I am an active-duty Air Force servicemember and I have been in the military approaching 20 years now. I have got a phenomenal lovely beautiful wife Ana. We have been married since 2015. We have one child Max with CHARGE syndrome and he has completely transformed our worldview and we are in a very blessed and amazing way. We represent Illinois for the foundation and for the National Center on Deaf-Blindness so being a liaison helped unite the families in the foundation and all the resources there pivotal in giving these kids what they need. And caregivers as well. We also set up a first military liaison for the foundation as well and that offers military members a specialized capability to navigate many of the things that are different about being in the military and having a severe special-needs child to the effect of we could be moved anywhere in the world at a moments notice and sometimes that makes our living situation and medical situation more difficult. Or just a little more unique.

I bring a variety of experiences not just from the military but from a new perspective. We have only been in this community in the CHARGE community for a couple years now swear learn a lot from the families that have been involved in this for many years and as soon as we learn of a new diagnosis or a family reaches out. I also bring experience from my education in posttraumatic stress disorder, traumatic brain injury, closely associate with combat trauma can associate well with medical trauma even if it is psychological medical trauma. And a lot of the families who have experienced charge have endured is a special circumstance that I have been surprised to learn can mimic a lot of the symptoms and excite a lot of the same symptoms that you get from the battlefield. So I am excited to share more of those with anyone who is interested in that concept. Please feel free to call me, email me or reach out and we can discuss more.
Another special thing that we have tonight is and again the one thing that I really want to stress is connecting with families. As we were a military family and moved to a new area as a result of our CHARGE diagnosis we were able to connect with a family that reached out to us, the Vyn family, Mike and Amy, their son Gabe is almost 5 with CHARGE syndrome and a 2-year-old who is a typical Kiddo. Mike joined us tonight. He was going to be with here but Gabe was not feeling well and he is home taking care of Gabe but Mike and his family have been a tremendous resource. They visited us in the hospital when we were transferred which I will share more of the story about how that transfer went but those connections are extremely powerful. We need them, we need to network and connect with families all across the US as frequently as we can because those relationships are incredibly important and I encourage all of you to continue to build your networks and your resiliency scope should take advantage of those situations and care and love for each other because Mike and Amy absently done that for the Gallimore

family and have certainly built an incredible relationship and resource for us to be able to understand a little bit more but not only what these kids are up against but how family dynamic can impact that as well. So I would like to give Mike a few minutes to vocalize some things that he feels are of concerns. Mike?

>> MIKE VYN: Good evening, thanks Thornton again my apologies for not having a snazzy presentation and not be able to be there in person. Thornton mentioned that Gabe, our foreign 1/2-year-old charger is a little under the weather. I am not sounding 100% so I don't want to bring germs into your house but anyways I am the special guest. Thornton and I were in the Air Force together so that was our connection. He will talk more at length about their journey but a look about us. My wife Amy and I attended our first CHARGE conference last year we are expecting our third here momentarily. We are on baby watch and if I go running there may be another one arriving so hopefully not but we will see. And again we went to our first CHARGE conference last year and I cannot stress enough how thankful I am for the foundation and everything they do for our kids and our families. And that is what I am going to focus on here today is the family side of thing and the support.

I am going to fall on Thornton's theme here and pass a lesson that was pretty tough for me. As someone who is still on active duty and still struggles with this occasionally, I have to remind myself that it is okay for things to be difficult, a difficult diagnosis both setback or whatever our kiddos go through but I recognize some of the names that are here and some of you helped our family along the way in meeting with you and conferences and all that stuff. But this is a lesson I think that we are all here again and I am going to spend it a different way.

For all the caregivers them up my discussions on posttraumatic stress and I will talk about one thing that made me realize that this is a pretty significant journey and it is really important that you understand, that what you have weathered that it is okay to realize that you struggled with it. So as I mentioned before I am still on active duty in the Air Force. We obviously for those of us who have done deployment have done more than a few and we talked but having posttraumatic stress and challenges on deployment and all of that stuff. I used to fly C-130 now I do an awesome desk job which is pretty safe but in the Air Force they talk about exposure to posttraumatic stress and what some of the symptoms are and how to realize that you are dealing with things or that you had some traumatic event and what you can do to take care of yourself.

I realized that my traumatic event was my son Gabe arrival. We were not expecting anything. All the prenatal screens looked good. We had one abnormal marker and when he was born we were immediately rushed to the NICU. Had a relatively short NICU state by CHARGE standard just short of a month we were back in with code and stuff like that. Talking with the CHARGE families that is the norm for us and a lot of us to understand that. But I realize that I personally had an issue when Amy and I took Gabe back to the hospital for a routine appointment if I remember correctly it was a kidney ultrasound. Gabe is not going to be hurt by this and it was just diagnostic we were checking other things but I, sorry the 2 1/2-year-old is not happy. Close to bedtime. The same hospital I went into wash my hands and it was the same brand of soap in the same smell that I washed my hands with during all the NICU and PICU visits and because of the way our bodies work all of that same fear and uncertainty and all those feelings I had when I was in those situations with my son came rushing back. And I was not ready for it at all. It took literally every ounce of my being to hold it together in front of all the medical staff and it was over wash my hands. We did not get any news that day but it was the sum of all the other events and all those memories that had come rushing back and really challenged me during a routine appointment.

After some introspection I realized that I needed to take care of myself too and work through some of those challenges. I also learned that hey, that soap, that hospital, we have been back more than a few times actually the hospital where my wife works. So we have been back there a lot but I know when I have that smell that trigger is coming and it is all coming back so I have worked to realize hey this is coming, these emotions are normal, this is okay, this is a normal experience to a significant emotional event and that is okay.

But I learned that in order for me to function, move forward and be there for my family not only my wife and son but my daughter as well, we needed to take care I needed to take care of myself. And as caregivers we often like to say we are the worriers that I have seen all the T-shirts. My wife is amazing at what she does, taking care of our family and I think one of the shirts is you know, are you strong enough for the storm and the CHARGE mom says I am the storm. True point but you cannot be on all the time. You need to do something for yourself and I am not going to get here and say okay here's a self-help thing all of that stuff. I am going to tell you that based on my background take care of yourselves, do what you need to do and it is not an act of cowardice or not being strong enough or anything. It is truly the strong that ask for help and go hey I am overwhelmed. That takes a lot of courage and is not easy. But no part of this journey is and that is okay. So I will close with find what you need to do with, as an individual to grow and change, build your family with CHARGE families. Thornton talked about what we did for them. I view it as merely paying it forward. There are other families here in the Metro St. Louis area. I spoke with, the family where I grew up within Northeast Ohio that helped me understand and kind of process some of the waypoints we would see on our journey and I understand every kid I was different and I definitely learned that but build your network. This CHARGE family I often joke with my wife it is the best group you never wanted to be a part of but we all understand each other's journey so talk with another CHARGE family. They are going to get it more than your extended family does everyone's family I know they all love us but they don't quite get it the way a CHARGE family did and that was all right. And I would say talk to a professional. Do what you need to do to take care of yourself and I will close with a cheesy aviation analogy. I know we have all flown the back of an airliner and the safety tips that everyone ignores is put your mask on first before you put on other people. Yeah it comes off as little selfish but really if you are not there to support your charger because you are not ready you cannot handle it you are no good to them, you're no good to the rest of your family and everyone, everyone has the opportunity to take a knee or say I need help or backup. This is a long journey and there are people in this room that of been on this journey a lot longer than I have but the perspective I can offer is take care of yourselves. Because we are all in this together and we can help out. That was the lesson I learned that the day that wash my hands was going to be a wave of emotion was one I was not ready for. So that was my way long-winded speech but thanks.

>> THORNTON GALLIMORE: Thank you Mike. We love you all. Thank you so much for building those connections and being such an important part to our family and you all really are a special crew. Thanks for joining us tonight. We will move on through our agenda I'm going to channel my inner princess again here.

We are going to talk about our journey really quick and the three things. What you talk about specifically is the life care if you find yourself having hospitalization away from home for an extended period of time. Also the implications of insurance. Will talk about the two categories of insurance: private and state. And finally adding the most out of therapies. We have interesting experiences on different philosophies on therapy and how that translates to success.

Here is oh my gosh look at that lady. That is my super hot smoking wife Ana and our awesome incredible brilliant smart charger Max and our very weird dog, keeper if you want to classify him as a dog. He is a strange little animal but that is our family and here is a little bit about our journey. Ana and I got married in 2015 we were both single all through our 20s and both of us never really thought we would get married or have children and God presented a different path for us and luckily we met and several years later got married and she was from Arkansas and I swooped her up and got an assignment to Alaska which are being a girl from the South she likes the warmer weather. Her first new home away from home was going to be all the way up in Alaska. We bought our first house together and settled in to our new base up in Elmendorf which is in Anchorage, Alaska. Settled in and it was absolutely amazing we decided we wanted to expand our family and we were blessed with our with news of our first kid and as we learned that we did not really know any different going through the ultrasound and the progression of the pregnancy but approaching between 16 and 20 weeks there was a pretty clear indication that in Alaska they didn't really know what specifically the issue or the concerns. But they knew it was something but they were a little reluctant to really share much about what it might be.

So there is not really a lot of specialties up there and they decided to go ahead and at 20 weeks have Ana move down to Seattle to deliver somewhere that had more capabilities. And Seattle was the closest Children's Hospital that would have the capability of some of the things that they suspected might be wrong.

So we got coordinated everything the military and actually the military was very incredible in supporting our family and they sent me on TTY orders down there to Seattle with Ana as a nonmedical attendant and we just had someone take care of our home and our dogs. We set up a plan for our unit to make sure the bills were paid and someone was able to step in and help out with that which was challenging but we got through it. So we went down at 20 weeks and we waited for her to deliver she delivered at 35 weeks and we were left with Max in October 2017 and from the day he was born until about one week into it we didn't know that it was CHARGE specifically but there was a lot of turmoil as you can imagine in the hospital as postdelivery just keeping him alive and establishing an airway and maintaining his vitals. So looking back on it it was honestly more, kind of a blur but it was also it was our only experience. Didn't have anything to compare it to so it was a wild ride also what we thought the norm would be.

After about one week we learned of the CHARGE diagnosis and we established some light care plans on what we might be looking forward to and as many of you might imagine that changes almost daily when you are in the NICU or PICU.

As they struggled to manage his airway was the biggest concern, Trach placement was a pretty contested item. We did know what that was. Just being on a ventilator, being fed through a tube all of that was new to us as I am sure it was to a lot of you. So the reason I mention this is because when you have these types of experiences right out of the gate with nothing to compare it to is pretty scary but it is also pre-powerful to know that if you have the right team around you is certainly something that you are capable of enduring. Not only with success but with confidence, with pride, with passion and I really feel like we had a great team supporting us through all these decisions because it was scary as you all have experienced. But it was also, we felt we had the right folks in our corner.

As we were in Seattle for several months inpatient in the NICU eventually the military said Sergeant Gallimore you are going to have to either come back to work or move somewhere that has the capability of taking care of your family. So Ana was not able to go back to our first home that we established together. She stated with Max in the hospital. OVERTURE that with the military that we would not be able to bring our son home and that is okay we could find a viable solution that works for everybody and the military has a pretty good program for figuring out where the medical care can be served as well as where the skills that I have can be extracted and utilized. So engaged with that program and I went up to Alaska, packed all of our belongings up, put our house on the market and out processed my base and waited on Uncle Sam to tell us where we were going to be cared for medically and where my base was going to be. After a few weeks we got to fill out some preferences on what part of the US we might be able to leverage some family support and also had my job and the most prominent availability as far as medical care and the closest to Ana family in Arkansas was in St. Louis. There is an Air Force Base about 30 miles east of St. Louis and they sent me to that base and they medevac Ana and Max via fixed wing aircraft from the NICU in Seattle to the NICU in St. Louis where we stayed for several more weeks until he could get fully trained, get nursing staff in the home and at this point Max had a Trach tube ventilator and needed full-time nursing in the home.

We were transported over to St. Louis. I went to Alaska and drove all my stuff down, everything I could fit in the trailer and the military shipped everything else. We found a home and stayed in the hospital till we were discharged and finally in March 2018 we brought Max home for the first time and we have been here now a little over two years and we are still getting settled in but we had a good experience making sure that Max gets every thing that he needs. So a few milestones I like to share is certainly ASL American sign language. Max has profound hearing loss in both ears. He has a BaHa bone-anchored hearing aid which gives him some sound with conductive hearing however his vision is viable enough to where he could extrapolate hand signs adequately and this kid has absolutely taken off the sign language and adjust works for him and he is at about 150 probably approaching 200 signs now. He is two years old and we are really proud of his ability to communicate because once we figured out that was something he was interested in doing of course the family and the nurses and the therapists we were all engaged in expounding on that and it really grew into a very amazing capability in sign language so we are still all learning but it has really been fun and a great way to see him express himself and communicate.

The bone anchored hearing aid we did not have a lot of confidence in that at first but we learned he does indeed respond well to it and sometimes you have to be patient with the BaHa or whatever type of hearing aid you may have and we have pretty marked success on the access to sound.

We have had some concerns and delays with primarily airway. Some of the major issues we have had in the home are centered around airway and also some episodes of traumatic bleeding through both incidents and passive. So we have all had situations in the home I am sure that our kiddo has experienced that could be life-threatening and that is a terrifying moment for any parent or caregiver to be in and I encourage you all to just have a plan, go through it come execute that plan verbally or write it down and go through it with your fellow caregivers and it makes it so much easier to respond when you need to. There been a few occasions when Max lost his airway and was not able to breathe and was quickly losing consciousness and desaturated and luckily Ana is so thorough about where things are knowing where the nurse and the caregiver knows exec we were to go to access the emergency equipment or to respond to the correct way. We do that by talking through things I really encourage everyone to have those plans, go through them regularly and make sure your team is confident in having a plan and executing that plan. It is an easy thing to forget about doing we really try to keep it in the forefront and it has served us numerous times whether loading everything up to get him to the emergency room or calling the emergency services to at least get the response initiated or knowing where the equipment is, is it serviceable, the right size, the right location? Is it the right technique applied to him? And continuing to develop that education and access to materials and techniques.

We have had successes and failures but they need us these kids need us to stay engaged and educated for their well-being. So one of the key elements of what we would like to talk about is if you are from a rural area especially if you have a lot of families from rural areas you may find yourself having to travel for appointments. You may also find yourself traveling for extended care whether for surgery, emergency or accident and these hospitalizations when you have no resources at your disposal seems like no resources it can be really difficult. So we found ourselves living out of a hospital room for months at a time and I want to share a few things we learned in doing such. One key item is reaching out and vocalizing that you are displaced from home, that you do have things going on back at your normal home. Other kids or a job that needs you back to work or you have to figure out the financial implications. Those are all really challenging things so vocalizing that and working with your family, your friends, your team back home, your employer, you have to vocalize that these things are happening so you can formulate and execute a plan responsibly.

Family is a big part of that but your network, your community in that area can really be pivotal and there is a lot more people out there who want to connect with you in those situations than you would think. Hence our connection with Mike and Amy Vyn. We had three other CHARGE families come and visit us in Seattle shortly after diagnosis and these connections were really powerful helping is not only understand but having those relationships where we feel we may otherwise be isolated.

Other concepts I would like to focus on our be very engaged, be very educated on what you are learning about your situation and displaced care take notes, recorded in your phone, ask questions. Be as engaged as you can be. Be that parent who wants all the information. I would discourage you from being standoffish and asking those questions because there is no bad question in a medical environment. We are not experts on the stuff we are not experts scientifically but we are experts from a love and compassion standpoint that is much more powerful so be engaged with the medical team. Use their services and skills to your advantage and be inquisitive and write things down and find a way that captures those concepts for each and every one of you see can capitalize on what your child needs.

I say child and some folks are adults. The concept stays the same. Be engaged and stay is heavily involved as you can you can build on that knowledge base all the way through childhood and adulthood to get these folks the best opportunities. So engaging with friends and family and caregivers. People want to genuinely help. Keeping up with the finances or anything going on with the work situation at home or the pets. Simple things like mowing the grass or dropping things in the mail they could become afterthoughts. People really want to step in and help with those things you simply have to ask.

Scout out the resources through the social workers like Ronald McDonald house. What a phenomenal charity they are. They are such a great resource if you are traveling to get services at another Children's Hospital or you find yourself with an emergency hospitalized some place you did not expect to be. Definitely reach out to them you could have an affordable, safe, close option for lodging and food. That charity really does a great job taking care of families whether inpatient or passing through. Working out a plan with your team whether it be your spouse or your family. Be open, be honest. If things are not feeling like they are collaborating with a should be is not something one parent or person can do. It takes a team, it takes complete cooperation with everybody because they were so much on the line with these folks who need our help. So engage with your partner, your spouse, your family, your siblings. Keep that dialogue rolling and robust.

Financially I would certainly encourage everyone to have an emergency fund set aside. Things get expensive really quickly and especially if you find yourself without employment or with out-of-pocket medical expenses, saving for that now can certainly be crucial when emergencies occur or when you find yourself with unplanned medical expenses. Food, lodging, travel costs, those things really add up quickly and I would encourage you to build those six months roughly of living expenses to have those for these types of situations.

And just like Mike mentioned pay it forward. There is a lot of folks who could use your help and reach out to those families at any opportunity you see. It feels so good to connect with families and help out even if you don't know what you can do, just saying that you are there can open a door to engaging with families and building partnerships that you would otherwise never get the experience and pleasure of engaging with. So pay it forward just like Mike said and reach out to those families, make those connections.

For insurance this could be a really pivotal item. Some families may have an employer who provides full private insurance. Others may be state equipped with insurance through Medicaid. So identifying with those are in your particular region is really important so I would encourage you to connect with your foundation, state liaison or Medicaid provider. You can go to the children's health insurance program website to find out what Medicaid is called in your state because it is not Medicaid across the US. There's different categories of what they classify state insurance as. So find out what your state that you reside in offers for services for Medicaid and register for them and use them as either primary or secondary insurance means. There is a lot of things they don't cover but there are a lot of things they do and they are really critical in setting up early access to therapies and services especially birth-three.

Early intervention there is also a connection you can establish through the state typically or with your state liaison's. Connect with those early intervention resources to access therapies and services that you may otherwise not know about. Connecting with NCDB is very powerful. There is tons of resources that we can access through NCDB again through your state liaisons and through the foundation. There are grants, there are local initiatives, there is a ton of information. Webinars like these. A lot of great information comes out of those. There is a specific categories, initiatives in each state that may be either supplement by insurance or they are similar to grants where they can be completely a self sustained capability such as here in Illinois they have project reach for the actually funded the travel of our whole family to go down to the conference in Dallas. So look for those opportunities and apply for those grants and use those insurance capabilities to your advantage. There is a lot of organizations that are eager to step in and help with your kid again just like asking for help, you have to initiate that conversation and sometimes there is paperwork involved or some referrals or some medical information but be diligent providing that so you can get some assistance from folks who really want to help you and your family out.

Leveraging the insurance, your primary pediatrician can go a long way recommending what year charger needs. I know a lot of you have engaged in those in the past they can be really pivotal in getting access to those things but sometimes it does not work in their other means of advocating for this equipment or supplies or therapies or services and in our experience the more aggressive you can stay in those avenues to capitalize on getting access to equipment or services or supplies, going through that channel of has your primary care manager or pediatrician or doctor for engaged at the level that you need him to? Have they advocated for your child? If not you can ask for a second opinion or a different doctor or go visit another provider. Be a very aggressive advocate for anything that your charger might need. We have had to do that on a daily basis with insurance because they don't want to provide anything most of the time, will nothing that we wanted them to and we really have to fight hard and it is worth every breath of the fight to get what a kid needs but it is a daily churn of staying engaged with any medical equipment or supplies or treatments or specialists. So we just take it for what it is and we stay engaged and we keep fighting for what he needs.

Therapies have been another key element of our experience. We had therapies about three times per week for each, occupational therapy, physical therapy, hearing therapy, vision therapy. We noticed a tremendous difference once we figured out that there was not much response to these therapies when we doubled them. We had minimal input, minimal response from the therapies. Surely after we asked to intensify based on a recommendation of the therapist, intensify therapies and double it down. We do six therapies per week usually about one hour, and hour and a half each time. It is a lot. Our house is a revolving door of either therapies or nurses folks coming in to try to teach Max something. Once we did that it was a tremendous difference in his response and he really took off and started exuding some of the abilities that we were trying to teach him. He is really responding well. One thing that Ana likes to emphasize to families and this is been interesting to observe is don't ever put a boundary or an expectation limit on what you think these folks are capable of doing. There are no boundaries and they will present what they are capable of, what they are willing to do and not willing to do and whatever level that is is the right level. And be patient, be persistent and don't ever, please don't ever let anyone else define what your child or your charger is capable of and don't let anyone place a boundary or a border around what he or she might be able to do. Because there are none.

So thanks for giving me a moment to speak about our experience. Let me bring Ana over here real quick. You guys are awesome. Thanks for tuning in. Awesome job for the CHARGE Syndrome Foundation. You will not find a more collaborative team that is willing to bring everyone in in such a great manner. Illinois has a specialized care for children and project reach all of these resources go out and find what these resources are in your state, connect with your state liaison, engage with other families and make sure that you build those networks, build those teams that establish robust communities and don't ever put a boundary on your kiddo. Thanks everybody and Samantha I believe you are up.

>> SAMANTHA TEED: Thanks Thornton for your presentation and Mike for your input as well. Everything that you guys shared I just remember being there agreeing with everything. It was phenomenal. Your slides were awesome as well.

My name is Samantha Teed, we have Hannah who is 10 years old. She is our kiddo with CHARGE and Ricky is my husband. You see him in the picture right there. We have been married 14 years. We've been married for about four years when we started our journey with Hannah and here we are.

I am a little nervous and Ricky sent me a message telling me to look more interested so I apologize if I did not. I told him that is just my face. [LAUGHING]. I was very interested and I loved it.

So like I said I am going to talk about, I'm going to get real and some of this stuff is think that we don't always talk about or are afraid to talk about as far as having more kids. I have five kiddos so I am going to see if this works for me. Yes. So I have five kiddos and some people might call me crazy, some think I am crazy for having five kiddos and most just know I am crazy. And we added a dog, a puppy into the mix. The things we do for our kids. I have Zoey she is eight and she loves animals and we knew this was something she needed test as we do things for Hannah we really try to pay attention to the needs of our other children and we knew in our hearts that if we did not get Zoey a dog before Hannah required a service dog that it might be something she would carry into her adulthood and may be needing therapy. We took the plunge and dogs are like having more kids just a little bit different.

I have found that each of the conferences we have attended that I have at least a couple of mothers or women come up to me and asked me about having more children and how did we do it and why and how scary it is and how do you take that step and that leap? So Caleb is our oldest we had Caleb before we had Hannah so that is unique for us. I know that some people when they have their kiddo with CHARGE they are their first so that definitely is a different dynamic. Keep in mind these are just personal experiences hopefully it will help you in any way whether it is just feeling peace in your life or just being able to relate. Because this is a personal decision, a personal choice. Again I am just sharing our personal story about our family and what it has been like to add more children to the mix.

So when Caleb was 2 I had Hannah. We are from Iowa originally and we moved to Topeka, Kansas for Ricky's first job out of college and we did not know anything was wrong of course. So we get there and I was 25 weeks pregnant when we moved there and everything was going just great that we seemed to be and we went into have Hannah and of course things were not going good in the labor process and my doctor was very kind and gracious and knew I did not want a C-section and agreed to let me labor force long as it was safe for the baby, for Hannah. And he did and I think we all just have that feeling and I just here is something I knew something was not right and she had been taken via emergency C-section but being young and naïve I had this vision of what it would be like having a second child and having a daughter and I was so excited to go to the zoo and put bows in her hair and just the future of what it would be like to have a girl and have two kiddos and my idea that was in my head. I realize now that that is naïve even with a regular kiddo it is not always go the way we think is going to go in our minds. Life is life and it happens. And you have to learn to move forward with it.

And so she was born it was really scary. Likely we were just in the right place and had a great medical team for her and we learned along the way. I got a lot of support from people and friends from our support groups however one of them I received was I don't know how many of you have heard about the problem welcome to Holland. About coming to Holland and you are on this train ride and you are on your way to Paris but all of a sudden you find yourself in Holland and all of the tulips and you have to accept it. I got a lot of those poems sent to me about Holland and for a long time I did not like it because I was so frustrated. I did not understand why I could not have Paris not the way the glitz and glamour but the way that the poem explained that I was just stuck in Holland amongst the tulips and be okay with it and I really was not okay with it and that is okay. We grow and we learn and I have learned to actually like the poem in my own understanding and the poem is really about slowing down and taking a look at the beauty of what life is not what you imagined it to be but also I could still have Paris. We could still have some things we envisioned and that looks a little different but we can have it both. We can slow down and enjoy what is been given to us but also still go for what we wanted in life.

A little bit we will talk about just what it was like deciding to have more kids. The pros, the cons, the what if's come of course adding children into a more complicated and fragile situation. Obviously when we went into have Hannah we did not know what would happen. I remember after having her crying in the shower and thinking I don't ever want to do this again. How could you ever have a child and do this again? This is so scary. It was so terrifying. Of course I was also just newly had this child and did not know which we expect and emotions played a big role in that and feeling that way. But as we move forward we had Caleb, a great big brother. He was 2 and also had to endure a lot just being the older brother and still really little. But moving forward it was really scary deciding to have another kid and we were not sure, we knew we wanted more kids but how do you take how do you make that next step? That next leap of faith? How do you do it? Right? Obviously we all know how babies are made so when I say that Zoey was surprised I don't mean that obviously but we were not actively trying to have another child at that time. They were preventatives in place that did not work so surprise. We found out Zoey was going to join our family on Hannah's first birthday and I remember taking the Pregnancy Test on Hannah's first birthday and dipping positive late at night after her first birthday party and just crying and I told Ricky and he looked at me and said how about we just go to bed and take another one in the morning like it would change that but there that is. And it did not change in the morning. And my girls are 20 months apart.

What I can tell you about that is that it was scary. Because I had finally felt like I was getting used to being able to be the mother I mean I think we all have those fears of how are going to be the parents we need to be for this child with his medical condition and give them what they need but also I had Caleb and making sure he was feeling loved and then adding a third child and how my going to give all three of these children this love and I was finally at a place in my life where I felt like I was connecting with Hannah and I apologize I am a crier. I try not to but talking about some of this is emotional and I cry. I will do my best.

But these emotions are real and they are raw but I just remember laying in bed one day and thinking oh I don't know how I am going to do it. I don't know how I am going to take care of this child and take care of a third child. I just got used to the idea being the best mom for this kiddo that I am what she needs. And that is okay to feel those things. But I also learned along the way that your heart grows, your abilities grow and you figure it out. I also learned from another mom who has a kiddo with a fragile medical condition that went on to have five children, she said you know, it never really goes away, the fear of having more kiddos. You worry through each of your pregnancies. Just do it just natural just like we did with our healthy kiddos. You have those fears and so you don't really feel 100% okay until you count all of those little toes and fingers and see your baby for the first time and it is true. I feel I had in the bit more peace with so it just something I needed. But I have those fears with Jacob and Claire as well and that is okay but they have all you know don't let those fears prevent you from moving forward with life. So while Zoey was a surprise I can say she has been one of the best things for Hannah as far as therapies go and just helping her progress in life. Because while she had Caleb as an example she had Zoey to want to keep up with.

I am going to talk about how each of the kids has played a significant role in the life of Hannah. This picture is in the crib that is Caleb he is 2 and Hannah is four weeks old. We went in for a heart cast and we were supposed to go home and she went into heart failure that weekend and there is Caleb giving his beloved

George monkey to her he just was with her and then I love this picture we were at a park. Hannah was about 1-year-old at this time and she is just looking at him like he is her whole world and I love it. I love that they have each other and he is, Caleb is so helpful. We go to the hospital and it is amazing what kids are like. He would hold the door open for me with the stroller when other adults would not even notice to do that. He is tender, he was able to be a model in the infant development center in Kansas for other kiddos with special needs and now he goes to public school in our home town and there is a friend of mine whose kid is wheelchair-bound and cannot communicate but Caleb says hello to him every single day and talks to him just like a normal kid and includes him in the mom comes up to me and says it is the best part of her day that people include her kiddo like that and that is something he is going to carry with him. He will not be the kid staring in the park he will always be the kid who goes up and says hello. How are you and he will make a friend with them. That comes from teaching them and showing them the world. So that is shaping him as a person.

I get back to Zoey so here is Hannah laying on top of Zoey as a baby. She loved her from the get go. She would not talk with me for two weeks after I came back from the hospital I think she was worried but she loved so it and laid on top of her and then here are the girls just this year at a dance scene. They danced together. They have played with their babies together. They do everything together. They really are best friends. Kind of like having twins and sometimes they fight and that is okay. Hannah teases Zoey. It shows me she is there and loving life and with it. And the kids tease her and treat her like a typical sibling. She just is, she is part of the family and everybody loves her and she loves them and so Zoey we started feeding therapy with Hannah went so it was two weeks old and I remember trying to start feeding therapy before we could get into a program and Hannah left the table in tears and I left the table in tears and I had no idea what I was going to do that would say that Zoey was an important part of that because once Zoey started eating Hannah saw that and just really wanted to eat like her sister. Obviously that is personal and every kiddo is different but that seemed to be a trigger for Hannah and really help her and helped her continue to walk and all of those things in life and do the things to keep up with Zoey and so it from the time she was born was a runner.

And we have Jacob and Claire so it has been really great as far as Jacob goes he was a healing process for me. Obviously with Hannah I was not really able to hold her at all in the beginning she was sick like most of our kids and then Zoey she had really bad jaundice and I really could not hold her a lot because she was on the -- but I would like to say was all glorious and glamorous. I don't want to scare anybody away but I want to be real and it was really hard. Hannah had just started pulling herself up. I had this new baby. 20 months apart again like having twins it was just developmentally Hannah was just learning to pull herself up and of course our kids don't have balance so it was a lot and then it was if one of them were crying who do I choose? Well Hannah I am going to go to Hannah because she could aspirate and so it would be okay so I did not get that time to just snuggle and enjoy that babyhood and it is okay Zoey is turned out fine and Hannah is fine. It is just a part of life that we learn that it is okay. We work with what we have but Jacob oh my goodness I got to snuggle that boy. He was born and Hannah was excited about that. Hannah loves babies. That is her thing and babies are her thing she really loves kids and babies. She just wanted to be involved. The girls would have their baby dolls and nurse their babies together. Their babies together have had CHARGE syndrome and been deaf blind and Caleb had animals, a G-tube, I remember going up to her feeding machine taking the G-tube and Ricky and I were looking at them going what is going on and he said I am feeding my polar bear and put the G-tube in the polar bear’s tummy. It is just a part of their life and they think nothing other of it and that is wonderful. But Jacob was a healing aspect for me because I just got to really enjoy being a mom to a baby and looking at him. I had to have my gallbladder out after having him that I had extra downtime. I had nursing help and support. It was all in place. Going back to what Thornton said about advocating and asking for help sometimes you have to be aggressive I remember postop coming out of having Zoey for my C-section and I still did not have respite care for Hannah and I was on the phone and postop calling the nursing agency asking where my respite nurse was I needed the respite approval and I had to let go further up the line and guess what by the time an hour later they had my respite care figured out and you just figure it out.

And so Jake is a playmate he is our silly boy he is our class clown just super fun and Hannah loves playing with him and being silly with him. And you can see Claire is in the back of the bike. Hannah just got a bike for grandparents this September and it was so freeing and wonderful having this piece of equipment provided to her and watching her play. Put a plug-in for the [indiscernible] the adaptive equipment or therapies or whatever your kiddo needs fill out that application if you have not thought about it because again having the sort of things really just help our kiddos be included in activities that we do as a family. Hannah can ride a bike without feeling she is falling off and having that confidence and then she can take her sister for a ride in the basket. It is amazing. They all play together. They have all been an amazing role for Hannah and sometimes it is crazy but it is great. It is it has enriched our life.

So again having more kiddos is a personal choice like I said though it has enriched our family greatly. We fully believe that having siblings has helped make Hannah stronger. Is helped us as parents. Hannah and Zoey danced together, they play with their animals and dolls together. I also want to just put, I had stuff written out but obviously we don't always talk about the things we write out. Other things come to our mind so I am sorry if I seem scattered. I am trying to keep it all together in one place and I hope this makes sense. But Caleb is funny that Thornton mentioned the support system really while we have our families it is really our other families that kiddos with CHARGE or other friends with special needs -- we were at a family get-together for Thanksgiving and we love our families sometimes they just don't get it. We don't live it you don't get it. And we were sitting around and Hannah had to patch her right eye to strengthen her left eye and here she has the cute little patches on and one of the cousins asked his mom why she wearing that patch? What is that on her eye and the mom said oh she is being a pirate and I just went. And here's my three-year-old, four-year-old and I said no she is not. She is wearing a patch because it strengthens her eye. She needs it to help her vision. Here's this four-year-old teaching was adult and it makes you go aha. For Zoey one day driving in the car and Hannah being deaf, Hannah is deaf in her left ear and has a moderate hearing loss inter-right ear and I don't know how we got on the topic of her being deaf but it was like why am I deaf she asked? Why can't I hear and as a parent you are trying to figure out how to answer that and here's this child that says because that is the way heavenly father made you Hannah and we love you. And I just, you know, kids keep it simple. Kids are easy. Kids make it real. As adults we sometimes make it harder than it has to be they bring a real to it all that helps us keep focus and explain things. They just love. Kids just love.

So like I said having the kids has really helped. Hannah loves taking care of Claire. She recently asked when she can start putting her to bed by herself. I am not sure I'm ready to really wish that but just last night I went Rick was busy doing other stuff he went to a movie with Caleb because it is important to give each of our other kiddos personal time, that is important and you can do it. You can split it up. It is possible. I want you to know that. Is very possible to give each kiddo what they need when they need it. And, but I went into put Claire in bed and there is Hannah in her bed reading her a book it was wonderful to walk in on that. There is never a dull moment. Is honestly terrifying at times. It is not all theories and fairy dust and on top of all that we have Hannah who has a complicated medical condition and complicated just it is hard sometimes.

Some of the complications we found recently as we have navigated this life is we have transitioned from them being little and getting older and then just some of Hannah's care changes because as we all know it does not ever stay the same, it changes so we four years ago moved back from Kansas to Iowa and I found myself having to find a different pediatrician and will I thought we had it all figured out that I was still close enough that I could drive back to her pediatrician for all the follow-up but a nurse practitioner moved to Dallas if any of your in the Dallas area there is an amazing Dr. Cotter at the Children's Hospital in Dallas. He is amazing, look him up you cannot go wrong. There's my plug for Dr. Cotter. So sad to see them go but it pushed us to find another doctor here in Iowa and I cannot say I was thrilled. I lecture but in terms of a medically complex child I was honest with her and she was honest with me and said I never took care of a kiddo with complex needs and we are willing to learn together and help each other and Welsh did a great job she was still newer and just recently we took our first trip via ambulance to Iowa city and found out that none of Hannah's records from Kansas were in the U of I medical system because they had never been requested like they were supposed to or her notes that were supposed to were getting put in. She was great for the basic stuff with Hannah it is just a learning process. Sometimes it is not a great fit so here I found myself again finding another pediatrician for Hannah and we now drive almost one hour and a to a pediatrician who does care for kids with complex needs so find the doctor that is good for you but my point is life changes and we have to make those transitions and my other kiddos that I have had that have been the more easy part of it when you go to fill the medical paper and sometimes it is a relief when you fill out all the medical stuff for that CHARGE and you fill out the medical work for the kiddo that does not have it and that was simple. Kind of nice just a great support for Hannah and to have them here and keep her busy. But anyways we -- we have found that we are going to be transferring some of her care to the U of I after four years. I was making the trip to Kansas and we also put a couple of switches over into Cincinnati and I cannot do it all and we cannot do it all and I remember driving to Kansas for a routine trip thinking I cannot do this I am getting tired. My kids are getting older it is not fair we have to figure out something better that works for everyone but I was not willing to let go of those doctors who had been with us since she was a baby and letting go of my friends there because we built a life there. It is hard moving on but with the trip that Hannah just took to U of I it was a little bit PTSD like Mike said and like Thornton shared with things that just throw you back and you have to deal with you have to figure out how to deal with it because if you don't you're not going to know how to move on and to help yourself and to help your kiddos and so while we had a few of those experiences I recently had a scary email like not scary but not ideal interactions with some of the doctors, the residents teaching them about CHARGE syndrome that they don't know anything. Teaching them about your child. But 10 years of medical records and it is scary and it was really scary to try to I told her doctor in Kansas that I didn't want to do it that was the scary part I did not want to take that journey. I just did not want to do it and she basically told me you have to do it. It is time to let go. Time to move on and you have to do it and she is right for my other kiddos, for Hanno and for myself so we have made the transition we are starting to and I have to say I met with a neurologist today and I absolutely loved him. He was phenomenal. He understood Hannah. He understood us. He listened to me as a parent and the only question I had for him was to make sure he was not a fellow and leaving in three years and he is not. He accepted her as a patient and it is great to get your foot in the door to start making that transition and can be done and it is great. It is scary but could be done. We can do hard things and sometimes as scary as it is adding more kiddos to the mix it is more rewarding because of all the good things that come from it. I hope I am making sense.

I want to talk about counseling a little bit with adding kids to the mix and having a family of five when we attended the conference this summer I attended one of the sessions that talked about counseling for families and for your kids and it was kind of an aha moment for me that Caleb is a worrier and always worrying about how I am feeling and I tell not to worry about me that I will be okay and he said it is okay to not be okay. And I went you are right he doesn't have to be okay and neither do I but we can talk about it and figure out how to move forward. And so instead of telling him that it is okay and you will be okay I just need you to be okay we are learning together and it has been really good. And then counseling because sometimes some really scary stuff happens. I will share a few of those. Just things that we were not prepared for. In May Hannah was eating food we all know that our kiddos can sometimes choke on food. Outside of carrots and stuff we have never had it issue of Hannah choking on textures or foods with like that and we were here it was Memorial weekend and all of a sudden Hannah was choking on a hamburger. It was kind of moist and sticky and first you path them on the back and it was not coming out and then I did the Heimlich and Rick is doing the Heimlich and is nothing like when you're doing it on a dummy is not the same thing. It was really scary and she was turning blue and I don't even know what was going on around me other than I literally thought after everything was done medically I am going to lose my daughter over a hamburger. And it was so scary and luckily it finally thoughtful, it came out and she started breathing again because she was turning blue and getting ready to pass out and as things start to come together again you see the baby with her hands on her chest and everybody else will it was like it is okay she calmed down and started eating her food and everyone was fine but Zoey is still very affected by that incident so and them with just what happened two weeks ago where we had to have the ambulance come to our house because Hannah we don't really know what happened other than Hannah collapsed and passed out and turned blue and seized and we took a trip to the hospital but the ambulance came to our house. It was scary for us as parents, scary for the kids who saw it and then just being in the hospital again and being admitted. With Mike I smell that hospital hand sanitizer and you have to figure out how to deal with it. Counseling is one way. Figure out how you can deal with it because these are real experiences for us and for our kiddos. And so we Ricky and I are looking into ways that we can get counseling for our kiddos and we also sit down and we sat down and talked with our kiddos about what happened and what scares them. I also love the sibling shops that the CHARGE Foundation does for the kiddos. And we got to talking about what happens and in the shop they were able to talk about but it is to have a sibling with CHARGE. What scares you, what you love, what annoys you frustrates you and we were able to talk about that and that is an amazing tool for them to be able to just opportunity for them to be a part of so the sib shop I think are phenomenal and would love to see them continue.

Siblings are also the future of the foundation. Recently we were able to, we were we realized that we did not want to take a step back from the foundation. We had thought about it for just going to conferences for a while and then I was asked to be a state liaison and we were like okay yeah we can do this we will give it a try and see if we can continue to make this work but we of course went to this conference again this one and realized that it is a part of our life, a part of our kids life, they look forward to it, something they still talk about, the camp, we are the future as the parents we are the future of the foundation. Our kiddos are the future of the foundation. Is important to be involved and so we of course want to continue to be involved at all that and however we can support them.

So just a few things. I am with Thornton, something one of the best advice we were ever given was don't let her syndrome define her. Use her condition for when you need it to get her the equipment and resources that she needs but don't ever let it define her so Hannah was never treated like she had CHARGE syndrome or a condition. We don't this is just personal we don't even refer to her as our charger. She is just Hannah. That is our own personal choice for us and she is Hannah and she did not even know that she had CHARGE syndrome. And it is not because we did not tell her it is just something we do not -- she was like what is CHARGE syndrome? Is a medical condition you have. It is a medical condition it is not who they are and we had a mobility specialist come to our house and try to see what she does amazing and that is because we did not ever put any boundaries up with Hannah and with Thornton don't put any boundaries on your kiddos -- let them be who they are and let the siblings be who they are ethically grow up in a society telling us to be something that we are we try to always be who we think other people think we should be, we try to be that and we can learn a lot from kids just be like a child. Grow and love and love life and be you and let them be them.

Do what is best for your family. It is a different journey for each of us. Just don't let fear hold you back. If Zoey had not been a surprise I honestly cannot say where we would be with the children but once we had Zoey we took the leap and had Jacob and Claire and we are done. We have a dog, we are done. We love all five of them it is wonderful. You can see in the photo that is shredded paper everywhere. [LAUGHING]. One of them got into it and they started throwing up and it was one of those moments where I was like sure, just go for it. Play, have fun. I will tell you is one of the hardest things to ever clean up so if you do it do it under advisement but it is hard to clean up but they had a blast and sometimes that is all that matters.

I want to put a plug in about self-care. It is really important. It is essential. It hit home for me this summer we talked but in our training for the liaison meeting. Mike is right if you don't put the mask on yourself first you're not going to get the oxygen you need to help others. I am a control freak. I like to have the control. Ricky can attest to that. I have a really hard time letting go. I just like to know exactly what is going on and doing it and being involved in an active part however being real here this past summer I was diagnosed with rheumatoid arthritis and autoimmune disorder and can make you very tired and your bones hurt sometimes and it is sometimes I just have to let Ricky take over and learning how to take care of myself. I've had to go to doctors appointment's for myself so it is a lesson we have to take care of ourselves whether it is five or 10 minutes had need to check out for five or 10 minutes and listen to music, take a deep breath. You have a very capable partner trust them. Find a friend somebody you can get the support from will give you those 5-10 minutes whatever it is that helps you get through the day in a positive way do it. Even if it is taking a nap. Do it. Self-care is really important. I have learned that not just with having Hannah but with having five kiddos. It is a must. They need us to be around and we have to take care of ourselves. And we are mentally more clear to be there because when I am tired I snap a bit more and my kids sometimes it is not even snapping sometimes you are quiet and your kids can sense it so take care of you whatever that is and it is not selfish is good. I also want to put a plug-in for I know some of the moms have been open and shared that they had to take some medicine and that is okay it is like after having a baby and postpartum care it is okay to get help for whatever you need is okay to get help because it will make you a better parent, better spouse, better partner, better friend whatever it is you need do it for you because it is a good thing.

And like I said it can be overwhelming at times but having these kiddos have been so wonderful and beneficial to Hannah and just I hope that it has helped you just to give you a little viewpoint into our life with five kiddos and the creationist but they are beautiful and we love them and we would not trade it for anything. And now Ms. Penni.

>> MEGAN COTE: Because we are so tight on time and there's only six minutes left Penni and I have been talking behind the scenes while Sam and Thornton have been sharing and she has agreed to do her portion of the presentation on another evening so I promise you guys this webinar is being recorded so you have proof that I said it that Penni said she would do another time and I will make sure that happens so that with the remaining like five minutes that we have got with

you all and many says in many is listening to with the remaining time that we have got if there are any questions that folks have for Thornton and Sam please by all means either hit star 6 to unmute your phone lines or you could put your questions in the chat pod and we will take two or three of them before we have to close out at half past the hour. Do we have any questions for Sam and Thornton about things they shared? Everybody's being so quiet. They are mesmerized and full of good information. Here comes one from Rachel. Thank you for sharing your story. And Susan said you did a fabulous job, Sam. Thank you so much. All sorts of praise coming in for you guys.

So if there are not any questions that I am seeing come in, Robbin Bull just put the survey link for the webinar tonight in the chat pod. It would really really help the foundation if you would take two minutes to fill it out because we really do use the survey results to inform our thinking about the remaining upcoming webinars for this year as well as future webinars so we would love to get your input. Also the foundation will be sending you the link tomorrow so if you don't have time to fill it out tonight when you get it if you would take time to fill it out we would really appreciate it. On behalf of the CHARGE Syndrome Foundation I would like to thank Thornton and Sam and also Penni for being here tonight and sharing your knowledge with us and we will get Penni here to share it with us down the road. Also want to thank Robbin Bull from the National Center on Deaf-Blindness to make sure the technology worked well tonight as well as the captioner and we hope that you will join us for our next webinar just scheduled for Wednesday, March 25 at it is entitled the role of the family in the IEP process and it will be held at the same time from eight-9:30 PM Eastern standard Time. The initiative leave 0-0- four assessment planning instruction will be speaking about the parent role and sharing resources and then we have a few parents coming on to share their stories about their perspective in the IEP process so we hope it will be a really interactive and engaging webinar and hope you can join us. So with that I want to say --

>> This is Susan I wanted to say while you were closing it out we have two minutes left. Maria did pose a question in the chat box maybe Sam or Thornton or Penni can answer real quick like. She says what is your advice if you cannot have more children and you don't have a partner?

>> SAMANTHA TEED: I don't know your situation Maria this is just my personal

point of view, people might call me crazy but I also I realize I cannot have more children. We are not in a place to do that but I have a friend who was a social worker in Kansas and she has been posting kiddos who need homes. It is something that Rick did not even bat an eyelash he said that would be wonderful to could do that when the kids are older. So there are opportunities there are different ways to share your love with other kiddos that need it as far as not having a partner, do you have a friend? Do you have family members who are great support? There are so many parents who are single parents who are rocking it. Whatever is best for your situation that is personal, that is my two cents. May be Thornton or Penni have something they can add.

>> PENNI ECHOLS: I would just say I have felt really close to other parents and families in our state deaf blind group. They have different diagnoses but the journey is really similar and those women are like a rock for me, can call any time of day or night so I would encourage you to get involved with your state deaf blind project and find friends there who understand.

>> THORNTON GALLIMORE: Maria, good question. I come from a family of nine brothers and one sister and of that large family only two of those are biological siblings. So certainly I am absolutely passionate about adoption through, it can start from a variety of means. There is international adoptions, there is respite care that you can offer temporary care for children and work towards an adoption process. There is a lot of different initiatives for blended families and certainly I have a special connection to those because I am from one. Sam and Penni highlighted some really great ideas on just connecting with different resources and different communities. There is so many amazing networks of folks out there that can help. Ana and I are going through the discussion of adoption versus fertility assistance and there is communities out there online through email or Facebook that you can connect with and really maximize your access to resources and experience from so many different avenues and like we talked about on many occasions in this venue people want to be involved in those conversations and want to help guide you through. Meeting the desires of your family. And growing your family. There is a lot of cool resources out there to do that and just building that support structure around yourself through your friends, through your local community, through your family and then looking for resources that are already existing to be capable and willing is certainly something I would recommend. Keeping an eye out for.

>> MEGAN COTE: Thank you for your awesome answers. Maria the other thing I would say to Penni point to be afraid to connect with your state deaf blind projects I'm sure they could connect with other families. On behalf of the foundation I know she is on the call tonight as well she would be a really helpful resource for you to think about how to connect to other families as well. So with that I really want to provide one more quick huge thank you to everybody who gave their evening to us. To Thornton, Sam, and we will hit Penni up very soon to do a follow-up webinar to share her story and if you are on the call tonight you have a child with CHARGE and something is heavy on your heart that you would like to share about your experiences and your lessons learned feel free to reach out to us because we can assemble an additional parent panel and leave more time as well for some open dialogue and Q&A where real parents can provide real answers in a healthy unfiltered way. With that thanks again to everybody. Thanks to Robbi, thanks to the captioner thanks to you all for coming and allowing these guys to share their story with you tonight and have a great evening.

[End of webinar]