



Interviewee: **Kegg & Stebler Family**

Interviewee Number: **36**

Interviewers: **Athena Aardweg, Judy Barricella
& Tony Buba**

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Stebbler & Kegg
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(TRACK 1 started at 1.04)

Okay this is Chris again and I think we were talking about having a disability and having to work overtime. And this professor just said that you could never I would never be a teacher. She would never let that happen. I think I was a sophomore at the time. So what I decided was to go into social work but then I realized that nothing was going to stop me and I would get as many degrees as I possibly could. And I did. I got two masters degrees and now it's sort of irrelevant. It does get in the way sometimes but I can't get a job where I have to travel around a lot because I don't want to take the bus to 50 different places. So that's sort of been my ticket.

Where did you go to school for your degrees?

Slippery Rock was my undergrad. Duquesne University for a Masters in Counseling and Pitt for a Masters in Social Work Administration.

You went to Slippery Rock Corinne?

No, I went to Robert Morris. Just a two year degree in Medical Transcription and I did not go into it because at the time there were not computers and word processing and things like that. But I did end up getting a job at Chatham College and it was because I was a Robert Morris graduate that I got the job because my supervisor had pretty much the same degree that I had from Robert Morris so I ended up at Chatham for 17 years and then when it was Maura going in to public school and we had to get her on and off the bus I had to leave my job. So I did. I wanted to make another little point about Maura and when she was born and a couple of things when we were in NICU. There was a team of doctors and when you have a team of anybody, be they educators or medical staff, you get a lot of different opinions depending on who you are talking to. And I remember one doctor who was a pessimist telling us that things were very grave and we came home from that visit donating organs. And then we talked to another man and he said, "No, no, no. She's going to be in the upper two thirds of recovery people. It's going to be an issue but not as much as you think." And luckily he was more right than the other person. And the other thing is that we did not get a diagnosis of cerebral palsy. How old was she Bill? Eight months?

Yeah, around Christmas time.

Which is pretty typical but the waiting is terrible. But you start to figure it out when she's five months old and not rolling over. When she's not sitting up independently. You know like you start to figure it out but no one will tell you "Yes, this is it."

This is Bill. The turning point I think for me was, let's see Maura was born in May of 1990. At Christmastime of 1990 we finally got ourselves a VCR. We didn't have one before. And we had these old tapes that they had shot of Billy, Maura's brother, during the summer of 1987. So I wanted to see those; I had never seen those tapes. So I popped them in one night and I watched him and I thought "Maura isn't doing any of those things." And, you know you lose your perspective. You know we wouldn't trade you for anybody, but that was when we realized that.... Corinne realized it in her way and I realized it in mine that we had to address those, those issues. And when you address them the fear kind of goes away because you have to confront them and you have to meet them head on.

Then you have knowledge on your side. That's Corinne speaking.

And I think too that the two of you working so hard together you know, is good. Sometimes there are single parents who have to face that on their own and you know you have one another.

The stress level of any family with two working parents and two children is pretty high but when you add several disabilities to that picture, it's magnified. It seems like there are, I seem to sort of know about several families where there's single parenting and maybe the disability that was brought into the situation through a child brought so much stress that maybe the marriage ended. I don't know that for sure but it seems like that would create enough stress to cause that.

What are you most proud of in your life?

I am, I think I'm the proudest of all of my mother because she is a stick of dynamite. Like Chris has already said, we were never allowed to think that we were different than anybody else. The expectations that she had for the sighted children she had for us. We all had chores. We all went to the same places. Movie theaters. We went swimming. We just weren't any different. And whatever the school said, went. There were no IEP teams then. What the school said was what happened. The parents didn't have the input. What the school said was sort of the Bible. So that's what parents were expected to do. Now some of them did it and some of them didn't and my parents did. Now my dad, who's passed, he was a softie and I would say to him, "Would you take me for a walk?" And he'd say yeah and he'd carry me. Okay. My mother would come out and say, "Wait, wait, wait, wait. She was supposed to make her bed." So I wouldn't go on the walk and I would have to go in and make the bed. And I don't think he ever got the idea of "What did your mother say?" you know when I would go to him for something. I was pretty slick that way but I don't think he ever got the idea to say, "Did you ask your mother? What did she say?"

That's how grew I up too. Well that's okay. You can have one softie and one tougher.

You know I think you're right because I'm softie with Billy and Bill's more of a disciplinarian with him and I'm more of the disciplinarian with Maura and Bill's the softie with Maura. So they're blessed that they have one of each in the household.

Yes, I'm blessed. And I have two things. When I was six years old I got my first wheelchair.

That's what you're proud of?

Yeah. It was almost like me doing the terrible two's. And like my Aunt Chrissy said when she was here getting better from the surgery I offered my bed to her and I had to sleep in my mom and my dad's room and I had to hear my dad snore and he kept me up all night.

Uh oh, we're telling the tale now.

But I wanted to elaborate a little bit about my mom and that is I'm very proud of a lot of other accomplishments in my life, i.e., my marriage first and foremost and my children and my job history and my education. But if it wasn't for my mother pushing, none of that would have happened. And so if anybody can ever be sort of that encouraging, pushing force to anybody with a disability it's really a worthwhile thing.

And this is Maura (**TRACK 2**) speaking and I also want to thank my grandma because she pushes me and pushes me also. Thank you, Gram.

It's like the time when grandma made you walk with your walker and I said if you walked by Christmas you would get money. And you tried and you tried and then you fell and you hurt your tooth so that was the end of that for a little while. But then you did try to walk.

This is Maura again. I was walking and she did, when I was walking she would give me money. And like she said I fell. I was like, was I walking Gram or was I running when that happened?

She didn't get it all because she didn't walk. But she tried.

She tried. Trying counts. Do you walk today, Maura?

I walk more at school now because I have a one-on-one aide named Miss Tose.

She walks therapeutically.

This is Bill. Maura is really fortunate because she can bear weight. She can transfer. She's not going to walk down the block to the store. She doesn't need to. But she can get up out of bed. Get into the bathroom. Go back to bed. She can come downstairs on her own. Get into her wheelchair on her own. That's a lot more than a lot of kids with CP can do.

Maura's very social. She comes over and we watch the Steelers and the neighbors can hear us yelling.

They think she's getting killed sometimes.

Come by when there's a game on.

This is Maura again. And I remember, I don't know what age I was, I remember I got a splinter in my finger. And I was in the bathroom and my mom and my brother had to hold me down when my dad was getting it out.

You know she doesn't seem despite all this.

You know, we have managed to, we see the humor in some things, you know. Like one time, this is just one story. I was at the Giant Eagle. When I shop at the Giant Eagle by myself it's like trying to crack the nuclear code to find things because they switch things around. And then I'm like forever, I spend a week in there on one afternoon looking for stuff. But I remember one time I was pushing my cart and at the same time as I was pushing my cart I thought I ran something over and a baby cried and I'd thought I ran over a baby. But when I looked it was a loaf of bread. So you can get the humor out of a lot of stories that happen to you. You sort of like shake your head and go "This is so weird."

Well when Chris was in college. What year was that we did the wheelchair? Well she had an assignment. We decided to take Chris in the wheelchair in town and try to get her around town. Well that was pretty good. Her and I. I was pushing her and she said, "Should I get out of this chair?" I said, "No, you're supposed to get up and down on the streets." So finally, I think it was two years later, they put the ramps on the curb for the wheelchair. Because you sent or the school sent all this to the Mayor.

No, that was Slippery Rock that did that.

And they made the wheelchair accessories on the pavements. Then my son said to me, "Oh that was a good idea mom but us blind people are walking into the street." So what do you do? You're helping the wheelchairs but you're also not helping your son.

But you know Corinne and my Keith who is blind, we'll be walking downtown. Maura I think was with us one day. And people stop us and they give Maura money. They gave Maura \$3.00 and Billy was totally honked because he didn't get money.

And one time Corinne and Keith and I were walking with our canes like three blind mice you know and this guy came up and gave us all an orange. We went into the Tick Tock Shop and we were having lunch. Corinne and my brother Keith and we were sitting there having lunch and this lady kept bringing us these big plates of potato chips, just because we had a disability I'm sure. Not because they were free or anything.

We get all kinds of free things. Because of being blind you know. What are some of the things we've gotten? We never got a free steak over at Costco's or anything like that yet. Or anything at the state store. Nothing like that.

This is Bill. Remember we had gone to see Dr. Valko. That was Maura's physiatrist years ago when she was little. And Maura always had to do some walking in there so she could see how she was doing and all that. So we had her walker and we're outside the building out in Monroeville and our son was with us. Maura was about six and Billy was about eight. And Maura said I'm going to walk so we got her in the walker. And Billy loved that wheelchair at that time. He'd jump in that chair and be doing wheelies and everything. So we're walking along and here's Maura with her walker, Billy is in her wheelchair spinning around, Corinne's walking with me. We get up to the door and there's a lady coming out and she sees the four of us coming up and she holds the door and she looks at me and she says, "Oh you poor man." I mean she figured his daughter can't walk, his son is in a wheelchair, and his other daughter is blind. If you don't laugh. You know I mean you have to.

Sometimes I think sometime when we pull up in the van with the lift I think sometimes people think we're like a group home unloading. We went to a firemen's benefit one time. Somebody gave us free tickets or something and it was Billy and four of his friends and Maura and myself and Bill. And when we got into the auditorium.

I don't remember that.

Yeah, it was the magic show and he invited you up. But anyway when we first got there and got seated somebody came up and asked, "What facility are these children from?"

Our house!

What did he do? Saw you in half Maura?

No, I just helped him with the magic show.

I forget. It was some sort of a card trick.

This is Maura speaking and I remember we went on... we were at a... We were, what was that thing I going to say? We were go... We were camping. It was me, my mom, my grandma, and my Aunt Linda and my Uncle Keith. And we were snickering and in the bed we could hear Uncle Keith eating chips and rattling the bag.

In the dark, huh?

In the dark. And the next morning we were getting ready for breakfast and I wanted cereal but I ate the wrong cereal and I ate the wrong milk too. Billy had soy milk and I ate the wrong cereal and it had soy milk on it. And I remember, well my grandma keeps on telling me this story, is when she was young and her sister. **(TRACK 3)** Why doesn't she tell you the story?

Which story's that?

The one with the alligator.

That's not relevant. We'll tell it later.

What are your greatest accomplishments? Who's your hero?

You know I think just being able to compete in a sighted world but also I would not have been able to accomplish that without my family and my friends. And that's as simple as it is. I think we're all here for a purpose and hopefully I'm living out that purpose in a good way.

Do you have anybody that you admire?

My mom. And my sister Corinne tremendously. And I'm truly blessed to have them. All of my siblings but in particular...

What about me?

Especially you Maura. Really.

Real fast now, who's your favorite child?! No, I'm just kidding.

Who's my favorite child? All seven of them. Eleven grandchildren and 12 great.

Twelve great-grandchildren?

It's going to be 12.

Wow. Oh yeah, these two are the youngest.

I have 11 grandchildren and 11 great. I don't know why I said 12. I think one's getting married, so I just added her in.

Excuse me this is Maura and I'm the youngest grand. And I'm 18. I'm getting there so.

It was very interesting when our father was alive. His perspective on disability was very different than my mom's. And he would always feel sorry for anyone with a disability. And in particular Maura. He'd say, "I feel so sorry for her." And he would give her money or whatever.

He would give me, when he passed away and he was in his casket we each put a quarter in the casket and when they moved him the quarters would move and make a noise of the quarters.

And we had to work with that too. She would take care of him during the week when she worked and then we would take care of him here on the weekends or he would go to one of my sisters' houses. And that was very difficult to watch him. There becomes a lot of issues with someone say with Alzheimer's because if he wanders off am I going to be able to see him? Am I going to see where he's going? That was always a concern that we had. But we managed to get through that. And when we couldn't then we had to place him in a nursing home.

This is Maura again and when he was still here he would come over and he would sleep on my bed and I would be in my mom and dad's room. And my mom would be in my room with him and he wouldn't sleep. So he would play with that little, the night light thing. You would hit the lamp and it would turn on.

For years we had a daycare because I had to work during the day and I had to change my work from 6:00 in the morning until 1:00 or 2:00 to 4:00 in the afternoon because he would come home at 5:00 and then my son that lived with me would take him off the bus and I would put him on in the morning at 8:00. And then I would go to work. But he liked it. He liked the daycare sometimes but he always gave me a hard time. "I'm not going." I put his feet on the floor and I'd say "You're going. Are you going to go in your night clothes or are you going to get dressed?"

Which one did he go to?

He went to Life Pittsburgh. These people there made him comfortable. And then he had this lady and she'd say hi to him all of the time and she was in a wheelchair. And the bus driver would say, "Oh, where's your girlfriend today?" And he'd say, "I'm married." I said to him one day, "I'm so glad you have a friend there. It could be your girl friend she doesn't have to be your girlfriend. Just your girl friend." And I'm glad she was there

because it made him go to the Center more. But it was nice. And my family helped out on weekends. If they couldn't take him then my other daughter did. Because I had to work. It was compelled I had to work weekends.

I was glad when he came because he would watch the Waltons in the big chair with Ramona our dog, one of our dogs and he would end up sleeping.

Yep, that's what grandpas do.

This is Corinne. I just want to make two more comments and that is one of the things I noticed about having a disability is that with the public in general or new people that you meet. You get two attitudes from them. One is either is pity or pedestal. We can't seem to get that middle ground. Once you know people after a while, like I just recently joined Curves the gym and these people were so uptight when I walked in there. And they're settling down; I've only been there three times so we're still in the settling down stage. And the other thing is I've realized too over the years that in life there's really only one road and you can take it miserably or happily and I always tell Maura if we take it more optimistically and happily and more with a sense of humor we'll probably have more people with us.

Yes, I agree mom.

Do you?

Yes.

Any other comments or anything you want to say?

I'm so glad my family has gotten this far the way they are. I mean, yes we have a lot of afflictions but when they were little they had a lot of little. And we treated them like they were the sighted world. We did not treat them like a blind person and that was so grateful because I don't know why I did that, it just came automatically. You're not going to be blind you're just, I guess because I had others I couldn't play partiality so I just made them fit in with the rest of the kids. And which I see today was a good blessing to help them.

Absolutely. Do you have anymore to say Chris? I'm going to let Tony shut that off because he's got to go.

(TRACK 4)

Watching the Penguins game and we switched it to the Pirates and I said it's one to one in the 7th inning and I said what, I said what and then it was actually 13-1 Pirates.

You know I didn't believe her. I put my nose on the screen like "What? No, it's not possible."

And then it was 14 – 4 that night.

Yeah, they creamed them. So let me try and lay the groundwork here.

This is the first time we've done a group per say.

A Group. Yeah so.

What you're going to have to do before a person talks is say your name.

Each time?

Yeah, so the transcriber knows who's speaking.

And I'll spell mine the first time around.

Okay okay

And then this way I can cut it out in the editing process.

Should we have your mom sort of give the lay the groundwork for the family? Repeat what you just said about you had seven children, blah blah blah, and then. Oh yeah. I'll be asking the questions but if you just start off by giving us your name, where you live, and then tell us about your family.

My name is Jacqueline Stebler and I live on the North Side, Perrysville Avenue and I'm here to talk about my family who has afflictions.

And you have how many kids?

I have seven children. The two older boys have sight problems and then I had three who didn't have it and then the last two were twins and they had the sight problem.

Is there a diagnosis of what? Do they all have the same diagnosis with their vision?

Yes, and they called it, after so many studies that we did. We let them do a study at Falk Clinic and it took us like almost a year. They took bone marrow. They took anybody that had had broken bones and they didn't come up with anything. So they called it cataglobus.

Cataglobus?

It's "keratoglobus."

Keratoglobus? And what's that supposed to mean?

I never could understand.

Well it's basically, this is Chris Stebler speaking, and it's basically a thin cornea is what it means. And where you or anyone who didn't have the condition has a cornea that if something would bump your eye it would not affect it. But with us our cornea is so very, very thin that a minor injury caused injury to our eyes and they're not sure how it happened. It was sort of in the amino acid, you know in the development of the fetus that caused it.

So where are you living right now you had all your children?

I lived in, first I lived in Spring Garden Avenue which was only a four room house and I moved and I moved to Perrysville Avenue. That's a 10 room house and the so children had a lot more stuff. And when Keith lost his first eye, we were shopping and when came downstairs he let out a scream and when I checked him the water was running down his cheek. I threw a towel on him and I took him to Allegheny General Hospital. And right then and there his eye had bursted or got hurt somehow and they couldn't do anything with it but take it out.

How old was he?

Four years old. So we had to get through that and that was kind of hard because I had to go in and tell him, no that wasn't the time I told him that. He lost that eye. Well they operated on one of his eyes thinking it was glaucoma and one day he was coming downstairs and I saw his eye was all red. I couldn't understand that so I called the doctor and I ran him down there and he lost that one also. Then I had to tell him that he wouldn't be able to see anymore. And that was the hardest thing for me to do. I went in and gave him a book and I said, "You see this book?" "I can't see the book." I said this time he was seven. I said, "Well that's what you're going to have to look at from now on. You're not going to see anything and we're going to have to tell you different things. We'll have to work together." Well I thought that was pretty easy going and I went to walk out of the room and he left out a scream and was screaming "I can't see. I can't see." That was hard. So then we brought him home and the day before he came home I told everybody around the table "We're not going to cry. We're going to try to help him as much as we can. I know we don't know how but we will try." So whenever he would eat his supper we would put 12:00 which is meat, quarter after was the potatoes, his vegetable would be quarter to and he understood that because he did know what a clock was before he lost his sight. And it went on from there. A blind man came from blind

school and he said, "What do you want for your child these days?" And I said, "I'm at a loss, I don't know what to do." And he says, "Do you want your child to be on a street with a tin cup or would you like an education?" I said, "Oh I want an education but I don't know how to do this." So then he told me about the blind school. And the very next two weeks I took him out and put him in the blind school. And from then on he learned. But he was never, ever left there. He came home on weekends. And our children, he was raised in a sighted world. I didn't change anything. I didn't set anything up so they wouldn't fall. If they ran into a chair I would say "One would think you're blind or something." Because the outside world is not going to be that easy with them. So I learned as I went along to different things. And then my older son, he had these issues and him and his brother were fist fighting one day and somehow or other he hit his head on the table and hurt his eye. I rushed him to the hospital but it just was too far gone. And I kept saying not again. We he still had one eye intact and I thought "We'll have to be careful with that." So he's had his share of being we call it disorientated because he always thought he was going to lose the other one. So he had depression and he had all that. Still today since I babied him too much he got very depressed and he became mama's baby. Today he's 60 some years old and he still relies on his mother.

This is Corinne. My other brother Keith who mom talked about first is a jazz musician in Pittsburgh. Five Guys Named Moe.

Jimmy Saviani. I know him.

Keith is the keyboard (**TRACK 5**) and plays all over Pittsburgh.

Keith?

What's the last name?

Stebbler.

I was suggesting that we need music cuts between and I knew the keyboardist in Five Guys Named Moe had a disability.

That's my son.

Maybe he could do some music.

What my mom misses when she tells this is that she's been a very strong force in all of our lives and we were not allowed to sit at home and you know whine about our disability. We got our 10 minute pity parties but she was our driving force to get us up and get us moving and looking for resources and getting us to where we needed to be.

It was never if we could do something, it was how we would do it. And she, by just putting us at the School for the Blind Children was up against a lot of criticism within the family, the extended family. Because it was perceived as an institution in those days. Now we're talking about the early, the 50's and the 60's. The thought processes of people, extended relatives, back then were a little different than they are today. And so it was... She single handedly saw to it that we were enrolled there and went there.

Because it was residential you stayed during the week and came home on the weekend?

Nights. And our father brought us home on Friday afternoons and some children, not us because we were local, but some children stayed there from September till the first holiday or even maybe till Christmas. But yeah, we stayed there.

Little ones stay there for months at a time right?

We went there at five years of age.

This is Christine. My mom would pack their suitcases every week. Iron and wash their suitcases and send them back. And my father would take them back and bring them back. And in the meantime the whole time my parents were working and raising seven children. So it was quite a busy household.

So how many went to the School for Blind Children?

Corinne and Keith Stebber went. And I went to public school. And Ken went to public school but he dropped out earlier because it was not an era, he was growing up in the 50's and 60's and it was not an era where when you wore thick glasses you could survive. Especially if you were male. I went to public school and I'm partially sighted. What I try to explain to people is when you have, when you're partially sighted you're in an in between world. You don't have normal vision and you're not totally blind and so there's this in between world that you live in and you're running from to and fro much of the time. And that sometimes is a little difficult.

Christine lost her sight when she was in high school. We signed papers that she couldn't do gym because we were afraid she was going to get hit with balls or fall or something. I was a little careful and she said, "Mom, I want to play tennis. Please let me play." She begged and begged and begged and I said, "Well you know what we're in for if I sign this paper?" And she said, "Yeah we all know. But it's not going to happen." Well it did. The ball hit the wall and it hit her in the eye and she lost her eye.

At the time I only had one eye and when I was playing tennis the ball came and hit me in the glasses and the glasses went up into my eye. And I'd say for about, I'm going to say for about six months, I was blinded totally. And I went to the Guild for the Blind in Bridgeville and learned how to cross streets and how to cook and how to clean. Although

some people would say I really don't know how to clean. But now. And then gradually in that eye my sight started to come back. I got a little bit of sight back. And there was a wonderful surgeon who operated on the eye. And there was a discussion about taking that eye out and he said, "No, we're going to save it and see what happens." So some of that did come back and so I went for years with that sight being repaired. And it was probably like 20/60 or 70 and then over those years a cataract formed and that became very difficult. They couldn't get the cataract off because of the thin cornea. You have to go through the eye and take out the cataract. So we found this wonderful man named Dr. Biglan who referred us to somebody and Allegheny General who took the cataract out. But before the cataract was removed I was way down past like 20/200. I could barely see and when they took the cataract off I could see again. It was a miracle. I could see colors and prints and it was just unbelievable. And then in the year 2000 I started to lose sight again and we couldn't figure out why. The eye doctors were on top of it at Eye and Ear and we couldn't figure out what was going on. Then I fell down a pair of steps and I thought "Eh, I didn't trip." So I went to my PCP and he said I'm going to send you to an Ear, Nose and Throat specialist and I said, "No, I need a CAT Scan." And he said "No you just need to go to ears, nose and throat." And I was not leaving that office without a prescription for a CAT Scan. And when I had the CAT Scan two days later he called and said I had a brain tumor and it was sitting right on the optic nerve.

Oh, of all places.

So then I met a surgeon at UPMC who was incredible, who went up through my nose and took, Dr. Amin Kassam, and took the brain tumor out. And that was an experience in itself but my family was behind me and with me the whole time. I think throughout all of this the thing that I think is most important is what I call the Ebb System and that is you know you have to have your family. If you don't have... Not only just family but friends or your or your minister. Someone has to be with you or behind you. Because if you don't have that and you're in this kind of situation, you don't make it. And you also have to have faculty. By that I mean this wonderful surgeon. Your experts that can tell you "This is what's going on and here's what I want you to do." And then you just need to have fortitude. You learn to be tough in the situations. And then you have to have fun. We do. We have fun too.

So he was able to take out the whole tumor?

Well they got most of it but it was really wrapped around the carotid artery. So they got most of it out and it was pretty intense for awhile. Without my family there watching over and what was going on and saying do this and try that, because they were giving me medicines that I was allergic to. So they got it out and there was just a wee little bit left and they did something with the gamma knife later on and now it's sort of sitting well.

Did you have to have any chemotherapy or radiation?

No, it was benign.

Oh, it was benign. Good.

It was a meningioma.

Oh okay. This doctor that operated on you, was he pretty young at the time?

Yes.

Dark hair?

Amin Kassam, yeah.

He operated on my mother. What did you say?

You see him on those UPMC Moments.

Exactly. No it was pretty dire. It was a burst in her brain. It was pretty dire when she went into the emergency room. He told us that but they had to operate. Everybody told us he's the guy you want to do it.

Oh by all means. The thing of it is when you look at anything like that. If you have a disability, it's hard on the people in the family who don't. But also when you do have one, like I always tell people it's like carrying around this extra plate and sometimes it gets very heavy. Because you have doctor's appointments and you have to call off of work. You have to go do that. You have medicine that you have to take. There's additional expenses. There may be barriers to wherever you're going, like with Maura and her chair. Transportation is a big issue. I take the bus. If someone gives me a ride from here to work it's 15 minutes. If I take a bus it's an hour and 15 minutes one way. So there's all that extra stuff. **(TRACK 6)**

Two buses to Oakland?

No, above Oakland.

Yeah, but still.

So there's all this extra weight when you have a disability. But the other side of the coin is that you learn to appreciate what you have, what you get, and all the nice things about, that there are about life. You're a little bit slower, I think, you don't take things for granted is what I mean. So I should let Corinne talk.

Okay Corinne.

Well I'm Corinne Kegg and I was born fully sighted and lost vision in my right eye when I was two in much the same way as everyone else in the family. The thin cornea ruptured and then I lost the remainder of my vision in my left eye when I was four and a half. I think I want to make a big point to say that while I only had vision until I was four and a half, I'm very blessed because I remember colors and people. Now admittedly I remember my parents with dark hair, black hair. But I remember, I can visualize is the point I'm making whereas somebody who was born blind can't do that. I attended the School for Blind Children. Kindergarten through 12th grade and it was a wonderful experience. I wouldn't have traded that for the world. Mainstreaming was just coming into play when I got into junior high and early high school and my mother was adamant that she did not want me going to a public school. Because we really valued the education that the school was giving and an education at an approved private school such as the School for Blind Children lends itself not only to reading and math and all those extra curricular activities like swimming and bowling, but it's role models in the teachers who were blind that taught us. It's being able to be a role model to the younger students who were there coming up. It's the expectations that are set for everyone there and you are no exception. It was truly, it really gave us a lot of confidence. And while we were separate from the world in a sense because we were all there and we were all blind we gained a lot of confidence because we had peer pressure. You tied your shoe when you were seven years old there because everybody else was doing it and if you didn't you got picked on. I see a lot of differences between the education that I got and the education that Maura has received in the public schools. And I don't think, I wouldn't criticize Pittsburgh Public Schools for the education that Maura got but if I had a choice she would have been at an approved private school. Anyway so I got through school. Went to Robert Morris for awhile. And then in my 20's lost the hearing in my left ear. Which the contrast that I want to make there is that it's so much harder to have an adult onset of a disability. It's so much harder to accept and know "yeah I'm going to get through this". My blindness, I've known that all my life, that was really not a, yeah I'm sure when I was tiny and it was happening I was scared and confused. But those memories die pretty quickly when you're that age. I had much more difficulty accepting the loss of hearing. But I guess you could say that added on to the blindness it made things a lot more difficult. If I had sight and I lost a little hearing in my left ear that might not have been as significant at 25 as it was.

And it's just your one ear?

I have a profound loss in my left ear and a moderate loss in my right ear but I have hearing aids.

This is Chris. It's really true that you go through like those stages of loss. You know like maybe some denial, some anger, but finally you resolve it. In terms of disability it's not just deaf but also when you lose a part of you also go through that.

So go ahead Corinne.

I married Bill.

Where did you meet Bill?

I met Bill at the school. At the School for Blind Children. He was an employee there. We did not date until I graduated. But then we dated for awhile and then married. And I took a job at Chatham College as a switchboard operator and then nine years into our marriage we had Billy our son.

How old is your son now?

Billy is 21.

Oh what an age!

And then we had Maura in 1990 and she's 18 now. And it was a real interesting experience in that, first of all when I first had Billy the all-thumbsness of the nurses and their reactions to me in the maternity ward were interesting. I mean everybody who's disabled goes through that. If you're in a new situation where somebody hasn't met somebody with a disability, it's... You know it's coming. You just simply know they're going to be all worked up and all worried. You know the first bath that Billy ever had everybody was so worked up over it and it went okay. It was not a big deal. And then Maura was born.

Did they make you to see a social worker?

No I would have probably refused. And even myself not knowing and everybody was doubting me so and I called all my friends and said, "Now don't call the hospital for two hours because we're going to be giving this baby his first bath." And it was like 35 minutes max. It was not a big deal. And my family members, I remember my sisters thinking, "Why would they be making this big deal? We don't get it." But they didn't grow up with me. They just don't know.

This is Bill here. And the nurse that supervised that first bath with Billy actually came to his high school graduation party here.

How cool.

And she was pretty much a turning point because she was a little older and she really believed in Corinne from the beginning and when she said Corinne gave the best bath of any of her new moms she meant it. And if you have one person like that, that's who you remember from that whole hospital stay.

Was that at Magee?

No, that was at West Penn because I was high risk. I had gotten phlebitis during the pregnancy. But truth be told too at the School for Blind Children we had had a childcare class or two. So it wasn't something and they actually designed it so that people were bringing in babies and we were getting to bathe them. Not that we were doing that once a week but we had done it at least once.

They didn't do it with dolls, they did it with live children. Mostly staff members' babies.

Nobody drowned?

Nobody drowned. But I remember Bill and I being out with Billy and older folks that we knew would say, "Who's taking care of the baby?" And Bill would say, "Well she is." "Well haven't you hired a nurse?"

Oh gosh.

Oh yeah.

And then Maura?

And then Maura was born and it was quite unexpected. One hundred miles away in Meadville. The umbilical cord ruptured and we went to the hospital. And she was born and not expected to make it. She was given a 2% chance.

Was she premature?

Five and a half weeks. And she had a lot of anoxia which is lack of oxygen to the brain. She has cerebral palsy. I'll let Maura talk but I wanted to make one comment and that was I remember when we were in the Neonatal Intensive Care Unit. Sometimes we got a lot of attitudes. And they were...

Was this in Meadville?

No, we had come down to Pittsburgh. They transported us down here. But we experienced so many different people's ideas of you know "God wouldn't give you anything you couldn't handle" to "Well you'll be pros because Bill's been in the disability community forever and Corinne's disabled so this will be easy." It was kind of interesting.

So Maura do you want to say something?

Hello. I'm Maura Kegg. I have an older brother Billy and it is (**TRACK 7**) a pleasure to have him. Sometimes we fight but I really love him. It's just fun.

Where do you go to school?

I go to Allderdice High School and I'm a junior.

How do you like it there?

I like it good and we're going to probably do finals this week.

Tell them you're in Life Skills.

And I'm in Life Skills. And I have good friends.

For school, do you go on the bus?

Yes. It's only five minutes away and I do not, well, I sort of have a nice driver.

What happened to you when you were nine years old?

When I was nine years old we don't know if I was, when it was Christmas Day, we don't know.

No, what happened to you on the bus?

I know. I was on the bus going to school and I was just talking to my friends and one minute later, or a couple minutes later, I was out conscious with a seizure.

Oh. Was that the first time you ever had a seizure?

Yes but we don't know if I had one during a Christmas morning. Cause I... On a Christmas morning I fell down the steps and broke my foot.

Right before that, huh?

Yes.

Is there an aide on the bus?

No.

Up to that point we didn't think she needed one.

And the bus driver went... the bus driver said, "Maura, Maura" trying to get me to... And I was like just drooling and he pulled over and he called my mom and he said, "Do you think I should call 911?"

What did I say?

And my mom said, "By all means. You have to."

This is Bill. That bus driver was the nicest man you could imagine but he never was in that situation before and he just panicked. It just so happened that the seizure was a block from the Baldwin paramedics so everything got...

And the bus driver quit shortly thereafter. Just couldn't deal with that stress. And you can understand that. It's a pretty scary thing.

And then we went I had a EEG. What year was that mom?

Right after that.

Right after that I had an EEG and I had the next seizure on the table. And the people there said, you know, tell my mom "Don't worry, we'll take care of it and we'll know what is going to happen."

It's a blessing, huh, to do that on the table. Because then they know what's going on.

Yes and they had my head, they put things on my head. Wires on the head and I was shaking all over. And I have an aura that gives me a signal when it's going to happen.

Tell them the good news. About how many you've had.

I've only had two in two years.

Do you take medicine for that?

Yes. I take Depakote and Myzalone three times a day. The Depakote... I mean the... Four and one in the morning. Three and one in the afternoon and four and two at night.

This Bill. I have one little thing to add. When we went to Children's for that first EEG, certainly we were always glad that she had seizure on the table because they just look for something like that. But I was amazed at when the technician came in there was absolutely no time to even introduce herself to us or get... Her first words were "Okay, get her up on the table." Not "Hi Maura. My name is Mary." And there was no explaining anything. As a result of that I spoke to people at Children's and served as a parent representative on one of their committees for awhile. Fortunately that kind of stuff

has changed an awful lot. We haven't had, uh, experiences quite like that since then but that's a big point that I think is important. Even though they are working at Children's, every family is different and they just weren't recognizing the fear level that she had.

Well I think that's a good point. This is Chris speaking. As having a disability, you're sorta like... I'm an individual. All people that are blind don't have the same needs or resources or family. When you have a disability, when you compare yourself to others who don't, you have to work. Like, like... Without a disability you can operate at like 75% and get away with it. With a disability you constantly have to work at 150% and you get tired. You get sick and tired of it. That's sort of the downside but the other side of it is that I think you become a stronger person. When I was in college there was a professor in my undergraduate at Slippery Rock and this was in the 70's and I was going into Education. And she said "You will never graduate from here with a degree in Education because you are visually impaired and you will hurt someone in the classroom."

Let me just tell you this. I cannot tell you how many times we have heard that people with disabilities were discouraged from going into Education. It's just amazing to me. Just amazing. Go ahead, I'm sorry.

Well what I realized from that was that what I had to do was get an education and get a lot of education, i.e., I have two master's degrees. Because then that would take my disability and put it back here and people would see the degrees and the capability first. Corinne and I talk about it all the time because what we want people to see is us as people first and not our disabilities. And it's always invariably it's the opposite way. You take a walk through Oakland where there's all this disability in Oakland. . .