



Interviewee: **Karen Palmer**

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Interviewers: **Athena Aardweg & Tony Buba**

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Karen Palmer

Interviewer: We'll just start out with you giving us your name and a little bit about your family, your history, if you were born here, whether your family started here or somewhere else.

Karen: My name is Karen Palmer and my husband's name is Chris and we are both from Pittsburgh. I grew up on the North Side of Pittsburgh. He grew up in South Fayette. We met through a dating service, which is kind of fun. We each have one child from a previous relationship. I have a 19-year-old girl and he has a 12-year-old girl from previous relationships. We were both single parents and it was important for me to meet somebody who had children, so I joined the dating service. He was my very first person I met and things took off from there. We got married two years later and within two years we had my daughter Carissa, who is now three. A few months later I was pregnant again, pregnant with twins, which is Shane and Shauna. So that's how everybody got to be where they're at.

When I was ten weeks into my pregnancy I had a test called a CVS done, because I was over thirty-five. They had asked me to have the test done when I was pregnant with Carissa, my three-year-old, and I decided not to, but since she was only going to be, I figured maybe 13, 14, 15 months when the twins were born, depending on when they were born, I decided I was going to have this test done, just to make sure everything was okay. I remember saying to my husband, "I'm sure everything's fine, but you know, if there's a problem we should know beforehand, so that we can be prepared."

So I had it done – I think I was ten weeks along when I had it done, and that's when I found out that Shauna had a chromosome disorder, so that was a tough time for us. I had what was called a fish result. And for the CVS they take a sample of the placenta and they do a quick test on it. They test, I think mainly for three chromosome disorders, trisomy 18, trisomy 13, and trisomy 21, which is Down's Syndrome. The next day they called me back and they told me that there was a problem with one of the twins and that I should give them a call immediately. So my husband and I gave them a call and there was good news and bad news, and the good news was that both twins weren't affected. It was only one. They told us the sex of the babies, a boy and a girl, so we were thrilled to know that we were finally having a boy, so you know, we had already had three girls at that point, and they told us that Shauna had what we believe was trisomy 18, which was incompatible with life.

If I can go back though, a little bit, because I do have a faith in God and I do think that angels are sent to you for reasons, and up to the point of getting that news was a very unique situation for me. I have a very good friend of mine who has a child who has a very rare chromosome disorder, as well. Her name is Reilly, and my friend did not know that her daughter had this until she was around eight months old, she was missing some of her milestones. When she found the news out she was devastated, and very scared. She had told me, "If I would have had genetic testing done when I was pregnant, I probably would have terminated my pregnancy." Well, Reilly has turned out to be just a

remarkable girl. She's just – My friend, Tanya, is extremely proud of her. She just continues to amaze us every day, and I don't get to see her very often. When I had the CVS done, I was talking to my friend, Tanya, and I said that I would have to be on bedrest for the next day because, you know, they don't want you to have to pick up anything heavy or anything, so I asked her, "Could you come over my house to help me with my three-year-old – well, she was a year old, not even a year old, a couple of months old at that time. And so Tanya came over and she brought her daughter, Reilly, with her. Now Reilly is... I think Reilly was about four at this time. All day long Reilly just, you know, she continued to show me how much she has advanced, and I remember telling Tanya how proud I was of her and how proud I was of Tanya for doing such great work with her and we were just reminiscing about how it would have been so different if she had found that test out and what she would have missed out on and what joy Reilly brings into this world. So the call came from the doctor's office and Tanya was here with me, and she was actually in my kitchen making me something to eat, which was really nice, and I got the call and it was a beautiful summer day, so I went outside on my porch and I sat down. And for some reason, I don't know what it was, Reilly came running outside and sat down next to me, just as – I was sitting on the swing and Reilly was sitting down next to me, and just as the nurse was telling me on the phone, "We think there's a problem with one or your twins," Reilly put her hand on my leg and looked up at me with this beautiful smile, and I'm looking at her with this beautiful smile on her face, and I'm hearing in my ears, "We think there is something wrong," and my heart is just dropping, because those are really hard words to hear when you don't expect to hear them.

I just remember looking at Reilly and it was such a contrast of the worlds. Like I was seeing everything that, "Okay, here's a child that has something wrong with her," so to say, and she's brought so much joy and I'm so proud of her, and everybody loves her so much, and I'm hearing the news in my other ear that I was going to have some difficult news given to me, as well. Looking back at that, I really, really think that that was God's way of letting me know that, "This is going to be hard for you, but it's going to be okay."

So, you know, when she told me that, I said, "Well, my husband's not home. Could I get him home and we'll give you a call back," and she said, "Yes."

So my husband came home and we called the nurse back, and she said that, you know, I had a boy and a girl. The boy was fine, but the fish results for my daughter showed that she had what they believe was trisomy 18, which is considered incompatible with life. She said that, I believe that the statistics she told me was about 70% of babies die in utero, and about 90% die within the first year of their life. And so that was really rough to hear.

She said that we should come in for an appointment and we should talk about what we needed to do. So Chris and I did, and to make a long story short, I guess in some sense, we were told, and I know that it's because you have to be told these things, but we were told the worst case scenarios of everything. Were, basically, also given the option to terminate, and I think I would say that I was actually encouraged in some ways to

terminate... to reduce my pregnancy. I was told that carrying a baby that might not survive in utero could cause me to go into labor early and lose both of my children. They said for me to think about what we wanted to do. So we did and I actually did make an appointment to reduce my pregnancy. But I was devastated by doing this. To me, aborting my baby is just not something that I'm capable of, I just could not see myself doing something along those lines. It was really bothering me a lot.

I went down and I talked to my pastor at my church about it. I talked to many people about it. I felt helpless. I didn't know what to do. I didn't feel good about carrying on my pregnancy because I was afraid of losing both babies, and I didn't feel good about reducing my pregnancy, either. So I did some research. I guess for me the only way that feel like I could help was to learn as much as I could about it. So I joined a support group called Trisomy18Support.org, which was just an amazing group of people, comprised of people who had babies affected with trisomy 18, who had lost their children, or who were pregnant, or who were living with their children who were still surviving, although there weren't too many of them.

Some of the parents in that group decided to end their pregnancies, which they termed as "saying goodbye early." And some of them, the majority of them decided to go through with their pregnancy, and whatever chance, whatever time they had with their children is the time that they had with their children. So they helped me a lot in thinking about what I wanted to do, as well, which choice was right for me.

In the meantime, the results from my CVS were still going through more testing, more thorough testing. The fish test is just sort of an initial test to see if there are any extra chromosomes, and then they go through more testing to see is it in every cell and how bad is it, and things along those lines. So that took almost three weeks to get the results of that.

So I was leaning in the sense of not terminating my pregnancy, but I still had the fear of, "What if I don't and I lose both babies?"

I talked to several doctors. Most of the doctors I talked to, seemed to insinuate that I should reduce, uh – I remember one doctor in particular sort of made me feel guilty about if I did decide to keep my pregnancy going, I remember him saying, "Well, if you decide to go on with this pregnancy, the only thing I can guarantee is that your baby will be anything but normal." I remember thinking in my mind is that, "The only thing I can guarantee is that you won't be my doctor." I didn't want to work with somebody like that. But it bothered me that, uh, I almost felt pressured to reduce my pregnancy, so after talking to my pastor some more, I ended up finding a wonderful doctor and I remember saying to him, "What would you do if this were you?"

And he said, "I can't tell you that, but I will give you something to think about." He said, "Look at the worst case scenario. If you terminate your pregnancy, if you reduce your pregnancy..." Now there was a risk of me losing both babies if I reduced my pregnancy as well, although it was a much lesser risk than carrying on with my pregnancy. And he

said “If you reduce your pregnancy and you lose both babies, or if you continue in your pregnancy and you lose both babies, what could you live with more?”

I thought about it, and thought if I make that choice and lose both babies, that’s my doing, you know, I made that decision. And it goes against everything I ever, all my beliefs anyway. My closest friends knew that if I didn’t continue on with this pregnancy, it would haunt me the rest of my life. I would always wonder, “Did I do the right thing?” I would always wonder, “What would my little girl have been like? You know, would she have lived, what would she be like, what would she sound like, would she look like, and I knew myself that to do that would stay with me the rest of my life. And then the other option was, “What if I continued with this pregnancy and lost both of them?” Then I had to lean with saying, “That’s not my doing then. That’s God’s decision. It’s in his hands. I did the best I could, and if I lost both of them, it was out of my hands.”

And so my husband and I talked about it some more and we felt that that was the right decision to make. And so we decided to save the pregnancy.

Not long after that we got the official results back of the testing for Shauna, and the doctor’s told me that she didn’t have exactly trisomy 18, and I said, “Well, what does that mean?”

He said that she has a condition called tetrasomy 18p, which means that she has four extra chromosomes instead of, or she has two extra chromosomes instead of one extra chromosome, so she four chromosome 18s. But they’re not the entire pieces. And he said, “This is very rare, we don’t really know a whole lot about it. We can’t say that she won’t have the same effects of a baby with trisomy 18, she might even be worse off because she has extras. We don’t know.”

Once again my way of finding out about that was to get on the Internet, research the condition, find other parents and thankfully, with technology being what it is, I was able to do that, connected with other parents whose children had the very same diagnosis as Shauna, and I remember the very first thing I had asked was, “Do your children have, you know, shortened lifespans?”

Immediately I got back response that said, “Although the oldest person on that list was maybe in their twenties, they had no reason to believe that these children would not have as much of a lifespan as any other person.” That thrilled me, but then it was like, “Okay, so what are your children like?” It was like, I was terrified, I didn’t know, you know, what she would be like?

I quickly found out that there’s a pretty big range of how this affects children. A lot of people are familiar with Down’s syndrome, and realize that some people with Down’s syndrome might be affected more severely than other people with Down’s syndrome, and it’s sort of the same way with this. Each children, each child who has this condition can turn out a little bit different. Some are more severe, some are less severe, they all have common characteristics, but I remember looking at pictures of the children, and the first

thing I could think of was that all of these children were happy, and to me that was the most important thing, that they were happy.

So I've been in a listserv with this group for a long time, since my pregnancy and we continue to exchange information with each other. And we learn from each other, because quite frankly, doctors really don't know a whole lot about their condition. Actually, often we are the ones telling the doctors what is common with our children. But it's been a life-saving thing for me to have that. **TRACK 3** I look back at how closely I could have made a very wrong decision in my life, had I chosen to listen to the worst-case scenario of what my child could have been. I would have missed out on the best blessing of my life. She's a joy. I mean, she has her things about her, but she's a total joy to me, and I thank God every day that I didn't reduce my pregnancy. I don't want to cry.

But it's sad, because I know that genetic testing is a double-edged sword. It can be, you know, in my case it was wonderful, in the sense that, during my pregnancy, because I found out early on, it gave me the time that I needed to grieve, that okay, my child is going to have something – I don't want to say “wrong,” because I don't think there is anything wrong with her, but there will be challenges in our life with her. She may not drive. She may not graduate. She may not talk. I mean there's a lot of things she may not do, and so I had to grieve that perfect child that everybody envisions having. And then it also did give me the chance while I was pregnant to research and to learn what is this condition, what kind of services can I get, what can I expect? So that by the time I was ready to give birth to her, I was ready for her. I knew what I had to do. I knew what I could expect and, instead of being devastated by finding out that I had a child with something, you know, abnormal, I was ready to celebrate her life. To me that was a blessing. But on the other end, I know that with genetic testing, it can go the other way, where people can be so scared by the facts of all these things that doctors have to tell you that it scares them away and they make a decision that could really be a, you know, it's sad that many pregnancies end because of the results of the genetic testing.

Background Voice: On the other hand, do you think that genetic testing, maybe the people who decided to terminate the pregnancies would not have been as good parents to even handle...

Karen: No, I don't think that, because I look at my friend, Tanya. Now Tanya told me, “If I would have known that Reilly had this, I know myself, I would have ended my pregnancy,” and I know she would have. She's a wonderful mom to Reilly. When I found this out, believe me I questioned myself, and I said to myself, “Why me? I'm not the one for this,” and, “God, are you sure you got the right person? Because I don't know if I can do this, I don't know, I don't know.” You know, you're so scared by what you think you can't handle, but once it's given to you, you can handle it, you do find a way of doing it. You love your child, you'll do anything for your child, and so I don't think that, I think that people don't give themselves the chance to find out if they can be that type of parent. I mean, I'm no different than anybody else, but I think I'm a good parent to my daughter, and I love her with all my heart. I think people think that having a child with a

disability is going to be a burden. She's not a burden, she's a blessing. She is an amazing blessing that many people don't get to share that experience that I have.

I actually feel fortunate to have her, because she has pushed my level of love in a capacity that I didn't even know I had. And if I didn't have her, I wouldn't know the side of me that is able to handle this, and I wouldn't know how strong I can be, and I wouldn't know a lot of things about myself. She makes me a better person, she makes my husband a better person, she makes my children better siblings. We wouldn't have thought this before we found out, but she's brought things to the surface that we never realized we had. You know, qualities that we didn't realize we had.

Interviewer: So tthe rest of the pregnancy was... kind of... ?

Karen: The rest of the pregnancy, you know, the pregnancy was very, you know, it was a very trying time for me because I knew my decision. Early in the pregnancy I didn't feel supported by my doctors about my decision, until I found the right doctors. I made it very clear that "I know the risk, I know what I'm doing, this is my decision, please stand by me," and then my doctors did, but I was nervous every appointment, because I was afraid of something being wrong. Because I kept being told, "There could be something, there could be something," and you know. And the other thing was that she tetrasomy 18p, not trisomy 18. Trisomy most doctors know about; tetrasomy, they don't.

The other flip side of having the genetic testing done was that I felt that she was now labeled, even in utero, she was labeled, and I wanted it to be known that her care and her looking after meant as much as her twin brother did. She's to be treated no differently, just because she may not live, according to all we knew. And even when I was going to deliver her, I had to talk to doctors about what would happen after she was born, you know. "If she wasn't in a state that she could live, what measures did I want to take? How did I want her treated?" And I needed to be very clear to them that she was not a baby who should be considered to be just kept comfortable, if anything should be wrong with her, I wanted every measure taken with her that would be taken for any baby that didn't have a chromosome disorder, and I guess you could say that I learned early on in pregnancy that I had to stand up for her rights and let people know that it is important that she be treated just like any other person. She is a person as worthy of life as any other baby or any other being. So I learned early through pregnancy and probably will be doing that through my last breath, but it's important.

Interviewer: And then when she was born the doctors and everyone were all on the same page, that she gets the same treatment....

Karen: Yes.

Interviewer: Did you see the same treatment?

Karen: I think that I had some very good doctors. Yes, I did. I was very verbal about letting it be known that her care was to be handled a certain way, and I think that, I don't

know if it was just the particular staff or the doctors that I had, but I think that everyone was very professional, and once they evaluated her, they could see that thankfully all her organs were fine, and they could see that there was no reason to expect that she wouldn't live.

What the quality of her life was, they really couldn't say. I mean she was premature, too, so she had some things about her. But the doctors that I encountered in the NIC unit were wonderful, very supportive of me.

Interviewer: So, what about the rest of your family at this point? Did you talk about it or did you just decide to wait until...

Karen: Of course, I shared the news of her condition when I found out. My family was a big support to me and standing by me, no matter what decision I had made. I think that they sort of were along the same lines as I was. They were nervous and they were scared, not sure what to expect. But they were very anxious to meet her and ready to embrace her with love. Pretty much, she's been loved since the minute she's been born. Yep, pretty much! So, um, my family really had open arms for her, and will always tell me that they're very proud of me for making a decision that they thought was very brave.

Interviewer: And what about the kids? You know, in talking to them about not knowing what the quality of life would be, did you discuss that or how was their anticipation?

Karen: Well, my daughter, my oldest daughter was seventeen, I think, at the time, so the conversation I had with her was pretty much the same as I would with an adult, and she knew that whatever I decided, she put the decision in my hands and was okay with that.

My other one was nine or ten, so we sort of limited what we had said to her when I was pregnant. I told her that Shauna would have things about her that would be more challenging – she has many cousins, as well, and they're all younger – so we did explain to her that Shauna is going to have special challenges, Shauna can do everything that any other child can do. It's just going to take her longer to do things. She's going to have to work harder at things, and she's going to have some challenges about her. She may stand out a little bit more from her other typical peers, but that she was just as important in life. And that she was very special and – really, they didn't ask me too many questions after that.

It's really amazing. I think kids have a very accepting personality to differences, and I think that if you don't play it up that much, they don't really play it up that much. So we put it out there very lightly, you know, that this may be the case with her, and no one's really questioned things after that. They love Shauna. They know there are things about her; Shauna being a twin, it's obvious. Her twin brother is doing a lot more things than Shauna is doing, but no one ever says anything about it because we know that that's just Shauna and she'll do it in her own time and she has so many good qualities about her that they just outshine her challenges.

Interviewer: And so how old are the twins now?

Karen: They're 2-1/2.

Interviewer: And you said you take them to daycare?

Karen: Yes

Interviewer: So they go to a regular daycare?

Karen: Well, Shauna goes between two day cares and that's because of the location where I work. She does go to a daycare on Shadyside, called "Child's Way," which we're very, very fortunate to have in this area. They have children with all ranges of disabilities there, many medically fragile children who are there. Nurses are on staff and it's a wonderful place. She gets therapy there and a lot of very good care there; and then she just recently, I started having her go two days at a daycare with typical children. I think it's a really good environment for her. It gives her role models and she seems to fit in just fine. She does great. She doesn't have as long of a day there, she has shortened days there because of my work schedule, but I really don't see the children thinking of her any differently. They're very young. I think that's one of the very great things about inclusion, and I think that the blessing in our world today is that when you introduce a child with a disability to a typical setting, a two-year-old doesn't look at a child as being handicapped in any way, or being disabled in any way. They just look at that child as anybody else. They get to know and love her just like a friend, and I think that that's great. I think that it makes for a much more accepting society.

Interviewer: Do you have any other therapists or anything aside from the day care?

Karen: Oh, yes. I work with therapists. Shauna gets therapy both in daycare and at home. She gets the full range, you know, physical, occupational, twice a week, speech, twice a week, developmental, and she works with a nutritionist. And it's nice because they work at her daycare and then they work with me, as well. Either I meet them at the daycare or they come here at the house. So either way, it gives me an opportunity to work with them. It's wonderful because I have to work. You know, I don't have the option of not working, and so it's good that I can have a way of letting Shauna's therapy be consistent, but I can still be a part of it, too. They really work with my schedule.

Background Voice: Is that an agency, or...?

Karen: Well she gets... It comes through the Alliance. I guess the therapists are from different agencies, but the Alliance for Infants and Children coordinates all of the therapies for me. The Alliance has been wonderful. They're really a great agency.

Interviewer: I find it interesting, because a lot of parents, even of really young kids say that "I'm taking it upon myself to go get the knowledge, and I'm teaching the

doctors,” but you’re the first person that’s really talked about the internet and online groups, and I’m kind of surprised that just because when I think of getting knowledge, that’s kind of the first step... let’s kind of talk about that role and just how much easier it makes it now. I have a couple of other families that have extremely rare conditions that where do you get, when you think about going to an encyclopedia...let’s kind of talk about how you found answers on the internet when you couldn’t find answers elsewhere, and ...

Karen: Well, I am so very fortunate that I had the ability to have internet. If I didn’t have the internet, the only thing that I could go by was what the doctor’s knew, which was a small medical paragraph, that there could be severe mental retardation, da, da, da, da, da. All these worst-case scenarios, which would frighten the world out of anybody. Very technical terms. Having the internet gave me the ability to connect with other parents whose children have this. There aren’t many, there might be on the list about sixty throughout the world, that are on the listserv, if there’s more I don’t know but that’s who is on the listserv. And it gave me the opportunity to find out how many children have this and see pictures of the children. I could never have gotten that through a doctor. Talk to the parents, actually talk to the parents on the phone. Okay, these are people just like me. We were able to compare notes about, “How old was your child when they were doing this? What worked for you? What didn’t work for you? What kind of therapy do you have your child in? Do you have these issues with their swallowing?”

You know, there’s just no other way of finding that connection. I don’t think that there’s any big study being done that connects all that information that would be available readily, so it was just a lifesaver. It was amazing to me to have that. It was actually was one of things that gave my heart, that assured my heart that I was doing the right thing. It gave me the peace of mind of knowing that these parents are happy that they have their children. Their children are great people. We share in joys with. We’ve become friends. We’ve actually met in Massachusetts last year. A group of about 15 of us went to meet. Which was great. I was given the opportunity to meet other children. I could never have had that without the internet.

Interviewer: I think another benefit of the internet is that when you call your doctor, they don’t get back to you. When you ask somebody on the internet, I just think it’s really interesting.

Karen: It is, it give me a great feeling, knowing what I might expect. Like, as an example: Many of the children with Shauna's condition develop seizures. Shauna has not yet, but I know that that’s a possibility. And so if she ever has something, I might know in my mind, “Okay, she could be having a seizure.” It really helps me to know what to expect with her. It’s been really amazing. We support each other, and we don’t feel so alone. It’s hard when doctors don’t really know a lot about your child’s condition, although I have wonderful doctors. I love them dearly; it’s just that there’s only so much medical information out there. It’s hard to feel that you’re not treading in an ocean of water all by yourself. And it’s really nice to know that there are people out there who can say, “I know exactly what you’re going through.” You know, our baby had that same

issue, or you might want to try this. My best recommendations have come from the parents in the group. And there are new parents who are coming in, and now I'm able to support them and say, "I know you're scared. It's going to be okay," and you know, this is what we've done and we're all there to help each other out, which is great.

Interviewer: So, what has been the most challenging part so far?

Karen: Well it's early on with me in this journey with her.

Interviewer: Or maybe, if nothing comes to mind what do you foresee as being a bigger challenge based upon what you have known and what other parents have provided?

Karen: I think for me right now, the biggest challenge is the... it's hard for me to say because I don't look at Shauna as a challenge, so I think the biggest challenge for me right now is the... the uncertainty to a certain point as to what will be. I do have the internet and I do have the other parents to lean on, which is wonderful. But again, there is that range of what the children are like. And where Shauna's going to fall in there. And I think to me that's maybe the biggest challenge because it's hard for me to know how to plan. I'm a planner. I like to know what I'm doing, when I'm doing it. I like to plan way far ahead of time, and I really can't. I sort of have to take it on a day-by-day basis with her and see how things develop. I think, for me, I would say that's pretty much I would say the biggest challenge, to do that.

Ahead of time, I don't know, I would hope that, I think for me that getting people to accept her and love her and understand her worthiness is really important to me. Shauna's just, she's just such a wonderful girl. Anyone who knows her loves her, and it really makes me sad to think that as she gets older, people may be, may judge her more without knowing her, and judge her in a negative light without knowing her. It hurts me that she may have those things ahead of her, but we just have to surround her with a lot of love and, hopefully, as more and more children are included in a school setting or in social settings, that that will be less of an issue as it has been in like past years. You know what I'm saying. For me growing up, a child with a disability always seemed to be more segregated, and I'm hoping that that's not going to be the case with Shauna, and I'm hoping that she will never really see herself as being any different than any other child.

Interviewer: I think it's kind of interesting to look at now. Inclusion starts at the time of birth, in essence. Which hopefully, will start to change that. Kids are so impressionable. ...by their parents, their peers, and if you can start them in understanding that no one is any different, one can only hope that through inclusion...

Karen: Even if they are different, I mean, different isn't bad. We're all different in our own ways.

Interviewer: And realizing that different doesn't mean just any type of a physical or, you know, we're so quick to judge on anything...

Karen: I don't know where judgmental comes in here, because like I said when Shauna's at her day care, the kids aren't judgmental, They don't have a judgmental bone in their body. I don't know when it develops, at some point later in life.

Background Voice: Twelve.

Karen: You think twelve?

Background Voice: I remember growing up and playing with African-American kids and when we hit 12, all of a sudden white kids went into white groups and African-American kids went into African-American groups.

Interviewer: When you start trying to be your own...

Background Voice: When you hit puberty, that's when you really start developing...

Karen: Hopefully, if the children are a part of them when growing up, they'll see that there is no reason to judge them.

Background Voice: And there's the whole peer pressure and all that.

Interviewer: I think like we were saying that inclusion, the earlier the better so now we've got it where it's inclusion early maybe that can start to have an impact.

Background Voice: The other thing I think everybody is so upset with property taxes. So then they have to pay more school tax to have accessibility. To me, they have to figure a way to fund school systems so it's top order to serve everybody. So we have to go to a state tax, an income tax, something to keep public school systems funded. And I think everybody has to fight for that because as more and more people go to private schools, there's less funding for public schools and it's going to be harder for inclusion.

Karen: Well, I definitely think that there is much more an awareness going on now, which is, which is wonderful. The more aware people become, the better. So that's good you're doing this type of thing. Because it is. It's worthy of being noted of, um, these disabilities and how much they need to be a part of, I mean it's a part of our society.

Interviewer: I still think we all have that "It won't happen to me" mentality, which still creates that divide. Even you said you kind of had to grieve and that's still a very common... Almost every family and every individual we talk about the grieving process that it's not the perfect... or what you expected.

Karen: I still grieve now. I love Shauna with all my heart, but I still go through periods where I get sad because I wish she didn't have to work so hard at certain things and I wish it could be easier for her, but it is what it is, and then you move on. I mean we all wish that there were things about us. You know, I wish that I looked like Cindy Crawford, but I don't. Okay, so we move on, you know. I know that's sort of a weird example to give. But it's true, I do go through periods where I wish it wasn't so hard for her, but it's sort of a quick thing and then I move on, and I look at her and she melts my heart, and I'm okay again. Whatever it is will be with her, will be with her.

Interviewer: And you go through that with other family members. When they're in their teenage years and you go through a difficult time with them, you wish it wasn't so hard. It's not a different feeling by any means but people think it's different still and they tend to look at you differently for being in that position.

Karen: I actually sometimes feel guilty for feeling that way, and I don't know why I feel guilty for feeling that way. I think it's a normal thing to do, but in some ways I don't want it to seem like "Why do you feel guilty about it, because you know you love her with all your heart?" and I do. And maybe this little part of me feels like I shouldn't be feeling that way because I love her so much. And, I don't know, I think you just feel whatever you feel, and that's okay. I know, on the other hand, all the happiness and joy and the wonderful things that she brings to my life are so worth everything, so worth any challenges that we have, you know, I just, you know. I wouldn't change her at all. I mean, I would make things easier for her if I could, but if I couldn't, I wouldn't change things at all. I'd just leave them as they are because she just brings me that much joy.

Interviewer: Let's go to the other side and think about what has been the most inspiring or favorite moment that you can fall back on. I don't know if you pick one.

Karen: I've had so many good moments with Shauna. I've had so many favorite moments with her. Probably many parents will tell you that, in particular, when you know that if you have a child with a disability, their first in doing anything is ten times more meaningful to you, and I will say that that is the truth. Her first time eating or her first time sitting or crawling, or her first time walking, to me, just was so magnified, because I didn't know when or if she'd be doing that. But I will say one thing that stood out to me a lot when I was pregnant. It was right after I had made the decision that I was going through this pregnancy, that I felt in my heart that I was doing the right thing, I had an ultrasound done, and they were trying to take a certain scan of the shot of her, and I could see the ultrasound on the screen. And it was really ironic because no matter which way they would put the scope, Shauna would just keep looking up. Like her face would just keep looking up and she would put her hand up, and I just kept feeling like that was her way of telling me, "Thank you, Mom. I'm here. Thank you." The technician even said, "I don't know why, but I can't get the back of this baby, she just keeps turning her face everywhere that the scope is going."

I do have a strong faith and I truly believe that that was God's way of letting me know that, you know, God's way of letting the baby sort of thank me and say, "I'm here Mom, and say 'thank you'. You did the right thing." I just always hold that in my heart. At that very moment I really felt like a good peace, like okay this was the right thing and she knows that I'll keep fighting for her. And she knows that we're going to be together. We're in this together.

Shauna's had just so many things about her that stand out. I don't think I could pick out any one thing that really stood out above the others. They're all just, you know, they're all just magnificent in their own way. All her moments are good, pretty much. She has her bad moments like any other baby, but when she smiles she just lights up my whole world.

Interviewer: Where do you feel that you've gotten a lot...? We've talked about religion, but what about family members or friends is there someone who gave you that support? Because the pregnancy was a lot of thinking and...

Karen: It was a lot of thinking. I'd have to say that all of my family and all my friends pretty much equally supported me. I was very lucky to have people around me that respected whatever decision I made, but, you know, just really trusted that I made the right decision and never really questioned it. And constantly even when I started to have my own fears throughout the pregnancy, like "I don't know if I can do this," you know, they just always said, "You'll be fine." I can just remember my mother-in-law saying me, "If there's anyone who can do it, it's gonna be you, Karen. You're such a strong person." And my mother just would tell me over and over again how proud she was of me and, you know, how she felt that I would be a great mom to Shauna, and I just think that hearing those voices over and over again, whenever I started to have doubts about any ability that I would have, really helped push me through a lot. I got a thing from a woman I had met briefly who had twins, one with a disability. And I remember her telling her, this is when I was pregnant, "I'm just so nervous, I'm not sure I'm going to be able to care for Shauna and yet care for her twin brother and care for her sister, who's only going to be a year old, too, I'm not sure how I'm going to do this."

She said, "I had my own fears," and she said "I keep this saying up on my refrigerator and I look at it often." And since then I also have the saying up in my kitchen and I look at it quite often, and it was "God doesn't call the qualified, he qualifies the called."

I thought about that and she said, "You know, you don't feel qualified right now, but don't worry about it. As time goes on and the days go on, you'll find that you can do this, and you'll be okay." And she was right. I mean, it's not something that you can really prepare yourself for. I mean you do research and you look into things, but you can only prepare yourself to a certain extent, and then you have to take things day by day as they come up. And that's pretty much the way it's been, like, okay, we work on this issue and – for instance, Shauna had trouble eating – she has sensory issues with textures, so we worked on those issues and that's passed, but maybe something else has come up

now and we have to get her to learn to do something else. And you learn along the way, you do. And the next thing you know, you're qualified.

Interviewer: How did you hear about this? What made you become interested, what made you come in to--

I heard about this through someone you had already interviewed. His name was Kurt Kondrich and Kurt goes to my church. Kurt's actually... Kurt's family has been a big help to us. They prayed for, throughout my pregnancy, that everything would be okay with Shauna. And after Shauna was born, Kurt and Margy introduced me to a therapist that they had used that is now Shauna's therapist, and they've sort of been someone who helps me. They're a little ahead of me in this journey, and so they sort of are the people I look up to, and I say, "What did you come up with? How did you handle this?" and they're the people that I can always come to that I trust. So Kurt sends me e-mails and things along the way, and he shared his interview with you and Kurt and I have talked about he knows the whole journey about Shauna and how I could have made a different decision with her. And Kurt feels very strongly about advocating for life, and so I think that when I told him that I meant to talk to you, I think he was very pleased with that. Because any time we can get a message out that you give these children a chance, any kind of encouragement we can have to any parent, particularly prenatally, who are facing this diagnosis, not make a decision that is made in haste or made out of fear because you don't know what will be. Of course, I would highly encourage anybody to continue with their pregnancy.

Background Voice: I think you might be the third person to mention Kurt.

Interviewer: I know. His character and personality is very memorable and very dynamic. He really is so willing...

Karen: Well, his whole life changed because of his daughter, his career, everything has changed because of her. He's really embraced his new world. And he's actually a great example to many people, about how having a child with a disability isn't a burden, it's a blessing, and it's opened up an entire new world for him and his family. So I think that's why a lot of people see Kurt. He's so involved now in everything, I mean that's his career now.

Interviewer: Is there anything else that we didn't touch base on or that you wanted to make sure was recorded? Anything about maybe what you hoped this project might do?

Karen: Well, I said it before, in a sense that I hope that this brings an awareness to people that having a child with a disability is not a, it can be frightening, and it's something that is definitely... a lot to absorb at first, but it definitely is not a bad thing. In many ways, it's a blessing that most people would never realize. It just opens up an entire new world. So I just guess I would hope there's an awareness to people that there is many good

things that these children offer, and that the world is more accepting and willing to embrace our kids, you know?

Interviewer: Well, thank you.

Karen: I know that I'm probably not as articulate as Kurt is, but I definitely really have a big desire to let our kids get as much help as they can get, and somebody has to be a voice for them, and so I hope that a lot of parents participate in this and bring that awareness to other people.