



Interviewee: **Hunter & Patti McGowan**

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

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Voices of Our Region

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Hunter McGowan

Judy: Let's start by telling us your name, where you live, and a little bit about your family.

Patti: My name is Patti McGowan, my husband Mike and I live in North Huntingdon, PA. And we have three children. My oldest is my only daughter, just graduated from high school Friday. I have another son Conner who is just about 15 going into high school next year. And then Hunter is my youngest of 3, and he is 12.

Judy: And, um, we're here at DePaul School—is that what you call it—it used to be institute right?

Patti: Yeah, DePaul School for Hearing and Speech.

Judy: Hunter has, um, some hearing loss, or are you totally deaf?

Patti: Hunter is sensorineural hearing impaired, moderate to severe, profound in the high frequencies. He is a habitual hearing aid user. Too much residual hearing at this point for a cochlear implant, so we're very hearing aid dependent. And he does really well. I think that brings him down to about, uh, more of a moderate hearing loss. He also has visual impairment of retinitis pigmentosa. He actually has a genetic syndrome, Usher's syndrome type II. Diagnosed kind of in a two part nightmare for us, but very early, which was kind of statistically and as a mom, it was a blessing to us, but he was probably about 3 when the diagnosis started. He started with the night blindness, and there were some things with it being my third child that just weren't right, and um so you know it started pretty much with the vision end, and in the course of trying to figure out what was going on visually, I started noticing he wasn't talking as well as he had earlier. I would notice certain things where it was obvious that he wasn't hearing, kinda had to work through a couple pediatricians to make them believe me, and just kinda persevere through it all. And um, luckily Children's here in Pittsburgh had sent me to Children's in Boston, and the diagnosis of the RP was then, and by that time we knew about the hearing impairment so he was already aided. And um, so we missed all that early intervention because he was after 3, um again I'm from Westmoreland County, so he had started a preschool, a hearing impaired preschool through our IU, and um then I... when we were getting ready to transition into school age, I just started doing my homework. And um luckily found DePaul, and um DePaul has just tremendously given Hunter a great foundation. Of course at this point they've, um you, know it is an oral education for the school for the deaf, but they have been wonderful as far as bringing in the supports that we've needed for the visual impairment. And, um, we've been a good team...so Hunter's done really well, we we have 2 more years here at DePaul and we're gonna get the most out of it.

Yeah. How what grade does this go up to?

Hunter: Uhh...to 8<sup>th</sup> grade. And I am in 6<sup>th</sup> grade.

Judy: Okay. And then where will you go to high school?

Hunter: Norwin. We think.

Judy: Oh, Norwin?

Hunter: Yeah. That's where we think we're going.

Patti: That's our goal.

Hunter: Yeah.

Judy: Mmmhmm.

Hunter: Yes.

Judy: The um, is the, now I've heard about your syndrome, and of course we've heard more about it, I don't know if you are a horseracing fan...

Patti: Yes.

Judy: Kent Desormeaux, the jockey's son, has Usher's. So we've heard about it on TV even. Um, but is the hearing loss progressive?

Patti: It can be.

Judy: Ok.

Patti: Now, knock on wood, we have his hearing has been pretty stable. And we have it checked 6 months and yearly. You know every 6 mos and every year. So far his hearing so we bank on that hearing umm because of the RP, and uh... You know after I initially got over my shock, um, I uh I knew that there was no cure for the RP. And so my job was to prepare him the best that I could. And, um, he's done really well. We've, he has a teacher of the visually impaired, he's learning Braille, he's what Braille 1 and 2 and contractions. Um he does have the night blindness so he does the orientation mobility and works with a cane, uses a cane at night...

Judy: Now is that thru the IU too, the orientation mobility specialist?

Patti: Yes, that comes, yes. So his TVI, or teacher of the visual impaired, is really more of a resource teacher here at DePaul, opposed to just an itinerate. You know it's funny because I think as we came into DePaul he was a deaf child with a visual impairment, and we're slowly watching that kinda full circle, um, so.

Judy: Tell me a little bit more about um the doctor's wouldn't believe you.

Patti: (Laughs) Well, um, it was strange because as Hunter being my third child and everything, all his milestones were very typical. And um this one day, he was bringing me his crayons. And um I noticed it was the nystagmas, but I wasn't sure what that was. I thought "Oh he has a tic." Well it never went away. And so of course I think the doctors at first thought perhaps it was a brain tumor, so we did an MRI...

Judy: Oh how scary.

Patti: Well yeah you know. And I think they worked from the worst scenario down. And they thought perhaps neuroblastoma. And we did the CAT scan, and finally um lots of tests and lotsa doctors, they said to me "Oh its idiopathic. It's benign phenomenon, learn to live with it." And I kept thinking "But something, ya know..." And then the hearing part set in, ya know I thought, "He really was talking better." And I would notice it if we would go into the garage with the car and I'd go to put him in a car seat and walk like over he would not hear. And so the first pediatrician um basically told me I needed to get a life. (Hunter sighs/laughs) You know go back to work and so what had happened was I was doing an aerobics class, and um both Hunter and my other son Conner were young enough that they would go into like a playroom while we did aerobics. And there was this little lady that used to help watch the kids. And this one day she came up to me and she said "Honey I don't want to upset you, but have you ever had your son's hearing tested?" And I thought "See I'm not crazy." Like, and from there, I just went. Ya know, I told the doctor, ya know, referral or no referral I was taking him for the ABR and the hearing test and I did. And it just kinda snowballed. But it took awhile because it was always twofold, I was dealing with the vision and the hearing on two separate ends, and it wasn't till we got to Boston and um ya know some different things and back here to Pittsburgh for genetics and some things where ya know with hearing, and uh, er with the Usher's syndrome, ya know..

Judy: So how old was he when the diagnosis finally?

Patti: I'd say a little after 3. And it threw the doctor's too because from what I understand statistically children that are hearing impaired and/or deaf don't necessarily know about the Usher's syndrome. Because the RP usually doesn't set in until about this age, adolescence, when they start noticing the night blindness, ya know and that type of thing. So it is unusual for that night blindness to have set in so early. But that I noticed when he was younger because if we would be in a well lit room, and then go outside to get in the car say in the evening or something he would stop and like kinda tap tap tap step and I thought because of the hearing impairment his equilibrium was off. I had no idea that there was any visual impairment there. The only other clue there was when he was little he's very photophobic. And so you know what toddlers or 3 year olds wanna wear sunglasses usually you know they throw them off and hats and so you could just tell. And so when I took him to the eye doctor and started saying "Some things just don't seem right" I think he knew and they could tell. And then that's when I went up to

Boston, so. But like I said, it's been a blessing to know about it early, because I feel that we've gotten the supports and, um, you know the younger he learns Braille and cane and all that and the assistive technology that's out there. If he never has to use it that's great but uh, it's certainly there. Okay your turn to talk. (laughs)

Judy: So Hunter do the glasses help you?

Hunter: Uhh yeah, they do a little bit, they just magnify, uh yeah the just magnify whatever I'm lookin' at.

Judy: Ohhh.

Hunter: Yeah.

Judy: So can you see print on a page?

Hunter: Like this type of print? Probably not. I'd have to use like a TV or something to magnify to read. Cause that's small print.

Judy: If it was large print?

Junter: Yeah if it was 28 or like 36, I could read it.

Judy: Okay. Okay. How many kids..you know what's amazing to me, how many kids know what that means...26 or 38? Ya know?

Tony: I was thinkin the same thing...how many kids know the size of print font?  
(laughs)

Judy: Yeah. Right. That's great! And you're um...so what do you think about coming to school here?

Hunter: Oh I kinda like it.

Judy: It is school though, ya know.

Hunter: Oh it's school. Sometimes its hard, and sometimes its kinda hard but... Sometimes its hard because in my room I have a laptop with turbo 3000, it comes with a screen and it has a scanner. And then the school gave me it, the laptop, so I use that, and this program, I can scan like homework on it. I can take it home and use it and type on it, and then there's a button and I can press it and it can read to me.

Jusy: On the laptop?

Hunter: Yeah the laptop. It has a program like it can read to you, sentences, paragraphs, stuff like that. And then you can answer the question.

Judy: That's cool!

Hunter: Yeah.

Judy: Do you have a computer...well you have the computer the school gave you...you take it home and bring it back.

Hunter: Yeah they give it to me but I can only keep it for like 2 more years and at Norwin they have to provide me with it, so yeah.

Judy: Right, right.

Hunter: It's pretty heavy though.

Judy: Is it?

Hunter: Yeah heavy with all the stuff and the case and I have to carry my book bag up the steps. They don't give me an elevator key, and I can't go back downstairs!

Judy: (everyone laughs) Oh man, how mean can they be huh? Wow...yeah because I always yell at my son that he's going to put his back out of joint because his backpacks too heavy...now you've got the backpack AND the computer.

Hunter: Yeah it's pretty heavy when you have to carry all that stuff.

Judy: Yeah.

Hunter: Even in the winter with the heavy jacket on.

Hunter: Oh yeah...I guess you'd better start lifting weights. Well, um, how big is your class...do you have a lot of kids in your class?

Hunter: Oh no...it's kinda odd because I have 3 girls and a teacher that's a girl too, so I'm kinda overpowered by girls.

Judy: Let's see you have a brother and a sister at home?

Hunter: Yeah, I have a brother and a sister at my house, and then I have 3 girls in my classroom including my teacher that is a girl and then I'm the only boy...

Judy: Go ahead.

Judy: I was gonna say you know what that means when you get older and you get married you're going to be very sensitive to your wife because you'll have been surrounded by girls so you'll know how to treat them.

Hunter: Yeah.

Judy: Yeah (laughs)

Hunter: Sometimes they can be a pain, give you a headache and stuff.

Judy: Oh man.

Tony: That never changes.

Judy: That's gonna happen.

Athena: It's alright, I think the same thing about boys.

Hunter: The classes are usually small about 4, 5, 6 people in a room. The classes are very small in this school.

Judy: That's good.

Hunter: Yeah it's kinda good.

Patti: Yeah. It's wonderful.

Hunter: Because then... plus, uh, when you go in school they have kinda like an implant thing, where you put it on. And it... they just got this new thing where it like has a monitor or something. Has like a microphone, and they talk and it goes to that thing, goes to that speaker and goes through your hearing aid. And then you can hear it much better.

Judy: Do you use that?

Hunter: Oh uhhh, yeah they use it they wear them...I've heard they can work on home hearing aids and school hearing aids so kinda both. It kinda depends.

Judy: The technology is amazing.

Hunter: Yep it is.

Judy: I think you're a pretty bright kid, aren't ya?

Hunter: Yeah I am. (laughter)

Judy: Do you get good grades? (laughter)

Tony: You're a humble kid, too!

Hunter: I try to get good grades, I do. Yeah the only trouble I have is just in math. Math, you know, like math I'm doing algebra. Not like the 7<sup>th</sup> grade algebra, we're just starting it. We just started it a couple weeks ago. We're just starting algebra. Sometimes it's hard to understand and sometimes I get it, and then I forget, ya know.

Judy: Yeah. Is that with all the x and y's?

Hunter: Yeahhh.

Judy: Yeahhh.

Hunter: My brain's confusing with all the n's y's and everything.

Athena: Why don't they just use numbers right?

Hunter: Yeah.

Judy: I never understood why we needed algebra to tell ya the truth.

Hunter: I was thinking the same thing when I was in my classroom. Some algebra's easy, but I got to one where it was 3 problems in one. I was thinking "Oh man." My teacher had to help me out. So sometimes it can be a pain. But that's the only trouble... in math. But other than that it's pretty good.

Judy: Yeah. Good, Good.

Patti: I was gonna say, he um, he has some struggles with reading and writing. And last year through the assistive technology Kurzweil 3000 that he was speaking it's a software program, and that does allow him to get up to grade level because of the reading, and then ya know he can keyboard, so, um, because of the impairments. So that's been really good.

Hunter: And the other thing you can't really do on Kurzweil is math. You can't really, so when I do math homework I have to write it on paper. I wish it was on the computer so that everything was on there, and then I wouldn't have any papers to take home. (laughs)

Judy: That's right.

Athena: You just love that big laptop!

Hunter: Yep.

Judy: So when you go to high school, the district will provide you with, um, all the equipment that you need...

Hunter: Yeah just the laptop, because the scanner and the screen, there's like a screen, you can plug it into the laptop behind it, so when you turn the laptop on, uh the laptop is blank but on the other screen it's there. And those two, the scanner and the big screen, will go with me to Norwin. So, all I need is just the laptop. Just the..yeah.

Judy: It will go with you from this school or from home?

Hunter: It will go with me from this school to Norwin, and then all I'll need is the laptop.

Patti: We had an um, AT eval... I'm trying to think. I guess it was early last fall. And so the district agreed to buy some, um DePaul agreed, that type of thing. I'm sure financially that'll happen. I've also with my team just kind of informally begun to meet. Um, because over the next two years, um because this is kind of a transition before the real big transition. Just really in hopes to have a very positive transition into, back into the mainstream. And not to pull any punches with anyone that I've asked, um the one AT guy to kind of facilitate our team, and to do a SETT document. S-E-T-T, the documentation so that we're kinda knowing past present future needs. Because I really think he is gonna be a kid that's gonna need the assistive technology. And I realize that's an expense, um which ya know will probably be an obstacle of some sorts. But hopefully if we have all that documentation, because he really does do well, but he does need that type of support.

Hunter: Yeah.

Judy: How is the school district? I mean have they traditionally been willing to work with parents, or are they resistant?

Patti: Um, ya know so far we've had a pretty good team. I don't, I'm thinking positive, and I think if we have the proper documentation, that um... It's not just something that we want because it's the newest thing, but if it definitely helps him and keeps him on grade level, and cause he certainly is a bright child, its just he definitely learns very differently than you and I. Ya know I've done my best, and he can tell you all about what he does in our community, and he's very inclusive in that way. And ya know I believe in inclusion and all that. But for us personally and our choices, DePaul has been the least restrictive environment for him. And you couldn't ask for the more one on one, um because that educational. Socially we do lots of stuff. Tell them what you do. Swim team, and...

Hunter: I just want to say one more thing about the school: they have a good lunch here. Their lunches are good.

Judy: Ahh, that's important. So you don't have to bring your lunch, they serve you lunch?

Hunter: No we don't they make it for us. It's kind of a good lunch, today I think we're having chicken fingers, I love those.

Tony: I've never seen a chicken with fingers though, I've seen chickens with toes.

Hunter: Chicken strips, I think.

Judy: I have a 16 year old who lunch is absolutely the most important part of the day.

Hunter: Yeah same with me. (laughs)

Judy: So I want to hear what you do out in your community. Are there any extra curricular activities here at school? Any clubs or any sports?

Hunter: Umm no, but I do, do, I do swimming with Norwin club, I go every night, practice on Tuesday and Thursday at night. But now they're starting in the morning, because my brother doesn't have any school, his school's done. And I do Boy Scouts, I'm Second Class right? Second class, I work pretty hard... I do service hours like work at the food bank, and that type... I go to camp, I already went to Conestoga Camp last year, but I can't go this year because my cousin in North Carolina is getting married on the same week. So I can't go because I have to go to NC and I'm not happy about that.

Judy: Aww that might be fun!

Hunter: Yeah but I want to be at camp and get some merit badges, and make stuff.

Judy: Yeah. Where's the Camp Conestoga? Where is it?

Patti: Up toward Somerset, Somerset PA.

Judy: Oh, it's pretty up there.

Hunter: Yeah it's a nice camp. They have like a, where we camp, you can choose your spot, like our group, we're 252. And we have a spot down at the lake. They have a little lake, and we're down there kinda, with tents and everything. And everybody goes fishing, except me I don't like fishing.

Judy: Why?

Hunter: I don't think it's fun, you just have to sit there. And plus the little thing that you have to see to move, it's too small. So, if I knew it was coming it would have to pull it down, but I can't see that little ball pulling down. So whenever we have free time from the merit badges classes, I have a collection of pocket knives, and then I take a couple up there, and I just open it and I just whittle sticks, you know?

Judy: Oh do you?

Hunter: Yeah, that's what most of us do up there, around the fire sometimes, you know. Just to do something.

Judy: I agree with you, I never, I thought that fishing is boring.

Hunter: Yeah, My... Yeah.

Judy: Deep sea fishing I think might be more exciting.

Hunter: You mean sea, ocean fishing?

Judy: Yeah, yeah.

Hunter: Ocean fishing would be cool because all the waves, and everything.

Judy: So what do you do at the food bank?

Hunter: Um I just, my church has one, but I can't work there yet...is it because I can't work there, because is it an age thing?

Patti: Probably in the fall you'll be ready. But what else do you do at church?

Hunter: Uh I uh sing in the choir.

Judy: Do you?

Hunter: Yeah I'm moving up to the teen.

Judy: I was gonna say, is it a children's choir?

Hunter: Yeah, yeah so I'm moving up to the teen this year, that's exciting. And then uh, I go to Sunday school. Uh, I play soccer, but not for Norwin. I don't like to play the competition soccer. I play with Penn Trafford. It's kind of like a recreation soccer game, where just a bunch of kids come out, and they separate us and we just play for like an hour or more ya know.

Judy: Do you like soccer?

Hunter: Yeah I do, I like playing defense the most.

Judy: I don't even know what that means in soccer, but I'll believe you. All I know is that there's a goalie.

Hunter: And then there's the goalie and two defense. Two are on the team to keep the ball away from the goalie. And the offense just runs around with the ball and tries to hit it into the other goal.

Judy: Okay yeah. Yeah.

Athena: So are you a fullback?

Hunter: What?

Athena: Are you a fullback?

Athena: Do you use words like that? Or halfback?

Judy: No that's football!

Hunter: I don't know what that means!

Athena: No that's soccer, I played soccer for years. But I haven't played it in years. But I didn't like defense, I liked offense.

Hunter: Defense is fun!

Athena: Oh no, you get beat up!

Hunter: (laughs) Yeah!

(Judy-- laughs) That's what's fun!

Athena: People charge ya!

Hunter: I like defense because offense you have to run around, it makes my legs tired. And sometimes when I run, the ball's here and it goes over here. And then I have to run over here and catch up with it, ya know so I like defense.

Patti: We had a laugh because um Hunter had done an adaptive baseball team for about 5 years out in Greensburg. Southwest Greensburg had a league, and he enjoyed it, but we did 5 years and that was really neat...

Hunter: I was getting tired and plus...we had a ball, like a yellow ball just for me to see. But it was still a little hard to see it, so I kinda quit. And I kinda stopped playing the game.

Patti: So Penn Trafford was the only place that offered a top soccer, which again is an adaptive soccer. Well there were a lot of children that had more physical disabilities. So they were either in wheelchairs or walkers, so this one was like such a hot dog, it was like (laughs)... So the director kinda came and said, we need to sort of figure out...like you know, and Norwin (wait a minute) is so competitive, and of course Penn Trafford had a big competitive league, but they also have this recreational team, rec soccer, and like Hunter was saying they just get together. There's no practice during the week, and they split them and have the game, so it's been fun.

Hunter: Mama, I think when I go to Norwin I can play soccer with them.

Patti: Sure, you can do anything.

Hunter: Yeah.

Patti: Except maybe hockey. (laughs)

Hunter: (laughs) No, no, no. My brother does that.

Judy: Ice hockey or deck hockey?

Hunter: Ice hockey. He does ice hockey. Sometimes I go to his games but they're kinda boring.

Judy: Oh they're boring too?

Hunter: Yeah. So yep.

Judy: I always thought it was more fun to watch ice hockey on TV because they follow the puck for you, I don't think I could follow the puck.

Hunter: Plus I'm kinda sad because the Pens lost...

Judy: I know. Yeah but look how far they went!

Hunter: Yeah they played pretty well this year...

Judy: Yeah...

Hunter: And the exciting thing is, our school, in October I think, way way back then, you know like Sidney Crosby's box? We didn't know about it, all the kids left on Friday, it was like a normal Friday. And my principal, Sister Mary Jo, called us but we didn't answer but she was on the message machine. But she said, you can come with us to Sidney Crosby's box, with us on Saturday...yeah.

Judy: His boss, or box?

Patti: Box.

Hunter: Yeah, go there and call me back. I had a tough time I didn't really want to go, my sister kinda made me...it was kinda nice... and about I think 6 groups went. I think I was the first, not the first caller. But I was the fifth caller...I was the fifth caller, and it was fun going there, we saw the game, they had cookies and everything...

Judy: Uh huh. Food's important, yeah.

Hunter: Yeah. Food's important.

Tony: How old's your sister?

Hunter: My sister's 18, right? Seventeen... 18 today.

Patti: Tomorrow. She'll be 18 tomorrow.

Tony: No wonder she wanted to go see Sidney Crosby! (laughs)

Hunter: She likes hockey, a lot, she knows more than we do... so she made me kinda go, and I had fun. And I think about, I was the first group to go there. And I think a couple other groups went there, because they called us up again a couple times for us to go, but now the kids knew about it so they all wanted to go...

Judy: I was gonna say, call me next time! (laughs)

Patti: The Pens have been great, they have donated a couple times, the boxes for kids at DePaul, so DePaul has been very fair about giving everyone a chance, so it was neat.

Hunter: So it was fun.

Judy: Yeah they do have good food there too.

Hunter: Yeah they had chips, but I ate all the cookies. Chocolate chip cookies, that's my favorite cookie ever.

Judy: Is it?

Hunter: Yeah.

Judy: Um, Hunter, I don't know why I keep blanking on your name because I work with a woman whose son's name is Hunter, and we hear about him all day long...(laughs)  
Um, Hunter when you started to lose some of you vision, do you remember that?

Hunter: You mean going everywhere? Oh no, I meant like going to...where did we go? Boston? I never remembered that...

Judy: No but do you remember that maybe you could see at one time better than you can see now?

Hunter: Um I don't know what you're trying to say...can you explain it a little more?

Judy: I'll try!

Hunter: Yeah, if you can.

Judy: Um, can you see...when you were in, um, 4<sup>th</sup> grade, could you see better than you can see now?

Hunter: I think I can see... I think no...it's the same. I have the same vision, so yeah. It's...yeah.

Judy: Okay, okay. What's the toughest thing for you?

Hunter: The toughest thing in school, or anywhere?

Judy: No, the toughest thing about having a hearing loss, as well as some vision loss?

Hunter: The hearing loss isn't really bad, because I can hear pretty well...from my classmates, because yeah. I can hear pretty well, more than my classmates can, but my vision, my classmates probably would have better vision than I would, because if the teacher was writing something on the board, I couldn't see it... I have a chair like this, a black chair, on the computer like this that rolls around. So what I do is, when she writes on the board, I wheel to the board right in front of it. Not trying to get in anybody's way, I'm cautious of that. And then I just I'm up there like this close to the board, and I can see what she's writing. Then my desk is pretty far away from her, I can't really see it. So I have to be up there close to see what she's writing.

Judy: Is it a big room?

Hunter: Umm...Probably the size of this.

Judy: Okay, so there's room to move around.

Hunter: Yeah, probably the size of this I would say, about, maybe a little longer, I'm not so sure...but yeah.

Judy: You look like you have a question Tony ...go ahead.

Tony: I was just going to change tape first....I was going to ask you...you have a very large vocabulary for someone your age...

Hunter: Oh yes thank you. It's from all the educational shows, like the history, and I watch the History and the Discovery, and all that type of stuff...I watch a little bit of cartoons, but mostly history, I like that...

Patti: He soaks it up.

Tony: Okay let me change tape...

Hunter: But I ride my bike, ya know?

Judy: Ohhh, you do?

Hunter: I have a ...I ride my bike, there's a nice little place where I can ride, my neighbor has a road that goes down that curves and then there's like a gravel road up back there straight, and there's someone that lives down there. And what I'll do is I'll ride my bike down there, go back there, come back, and I'll do laps, laps. Ride my bike back and forth...and then I have a neighbor named Paul, that was in WWII. And I always liked him, he's a good friend of mine. And I'll stop over there a couple times and eat some cookies (laughs) and we talk, yeah, we talk. And sometimes on Saturdays I'll eat zucchini bread with him, yeah that's good. We're pretty good friends....

Patti: He tells you all the war stories.

Hunter: Yeah.

Patti: Hunter loves history, wars.

Hunter: We talk about the knives and everything...and he hunts. I think he's 81, right?

Patti: 88.

Hunter: What?

Patti: 88.

Hunter: Oh 88? Oh that must be a grandfather...but yeah. He's still good. He still goes hunting, and he has a garden, so he's active too. And he'll he loves his garden, he grows stuff. He'll give them to me and I'll take them up to my mom's house, we'll eat them, she'll cook them...it's kinda nice...

Judy: Isn't that nice...

Hunter: Yeah.

Tony: What's his name?

Hunter: Paul. And I have a...

Judy: Should we invite him to the big party when we have it in November? Since you're talking about him?

Hunter: Alright, alright I guess. Maybe.

Patti: That'd be nice huh.

Hunter: Yeah that'd be nice.

Patti: We'll bring him down.

Hunter: And I have another neighbor that I'm pretty close with, her name is Joyce Lynn. She's nice, and we always go to Halloween to her house, and she always liked to scare us. She'd always like sit in her chair, a long time ago, and she'd...you know like the grim reaper? Kind of like that and she'll sit, and then she'll sit...and that time down at my neighbor's house, when I was walking from school on Halloween night, and I thought Paul had a, he always sits under a tree. He has a chair down there, it's shaded. It's kinda nice. I saw like this thing...this Grim Reaper, and ....this um...

Patti: Hoodie? Like a hoodie?

Hunter: It was wearing a pumpkin head remember? And then she would... We'd all go to Paul's house first, and she would... We went there and we talked and then we went out and there were two brown bags down there, sitting right next to each other, near the scarecrow. We asked Paul is that the scarecrow? I went down to get it, and bam, there she was, she was dressed in the suit, and she moved, and she startled Conner and me...so we always laugh about that. And she has a dog, um named Chloe I think. But she used to have her son, right? Her son used to live there, and the son bought a little pit-bull a long long time ago, it's grown up now. It's probably like 4 or 5, yeah 4 or 5. It's named Maddie, and it's a black and white pit-bull, but it really is a nice dog. It's not mean. It likes people, likes to jump, likes to play... And her son was moving, but he was going to get married. So they took Maddie to where they were living, an apartment I think. And one time because Maddie wasn't over at her house anymore. So then Maddie was there and one time Maddie was in a fight. I mean she was just playing with this other dog, I think a pit-bull, but it bit her accidentally. So now they leave her with...every day they drop her off at Joycelynn's house, early in the morning so she doesn't get hurt. And Chloe and her, they're okay, ya know. They're friends. Sometimes they get in play fights, ya know, stuff like that.

Judy: So she's the dog sitter?

Hunter: Yeah, and we have a dog. A white Labrador. Her name is Sancha. She's about 8 years old or 7. 8 years old right? In dog years she's 56. And then... She's pretty clever ya know. When we have food out, she's up to no good...she wants that food!

Athena: Kind of like you right?

Hunter: Yeah. (laughs) If we leave cookies out...cookies or bread. She loves bread, especially bread. If you leave bread and you leave she's napping, she'll wake up and just quietly walk over there and jump on the table and get it!

Judy: Is it a full bred lab?

Hunter: Yes. Right? Yeah. She's actually pretty.

Judy: Is she um, is she big?

Hunter: Yeah she's big. She's chubby a little bit. I mean, you know, she's a good dog, I love her so much.

Judy: We were at a lady's house who has a seeing eye dog.

Hunter: Oh yeah, I want one of those one day.

Judy: And it was a black lab, and of course we were in the house, so the dog wasn't working.

Hunter: Yeah so you can pet it and stuff.

Judy: Oh she was so beautiful. But he, it was a he I think. He was as big as...he came up to Tony's hip...that's how big he was! And she said that he is kind of a bigger... She's had different dogs throughout her life, and that this dog was big enough that they sometimes have trouble like fitting under the seat of the plane, or places they go because that's what they do they go underneath...

Hunter: That'd kinda be hard I guess. Pretty hard.

Judy: Yeah really. So what are you gonna do this summer? School's gonna be over this week.

Hunter: What am I gonna do this summer? There's a lot of stuff...

Judy: Well besides going to North Carolina.

Hunter: What I'm gonna do this summer, first of all watch TV, watch TV a lot. And don't worry about school, and um I have a go-kart and my brother has a dirt bike. So he rides with his friend that has a dirt bike, so they ride together. And when they ride in front of me I'll ride in the back with the go-kart. It's a two-seater, because I didn't want a one-seater, because my Dad, because sometimes when I'm riding in the forest alone, there's a tree in my way, but I won't know that. So it's like camouflaged, so if I hit it that would be bad. So sometimes my dad would go with me, or Conner would go with me, or Brian would go with me, that's Conner's friend. And then sometimes my sister Paige would go. Yeah so.

Judy: So the go-kart is big enough for your Dad to fit into?

Hunter: Yeah. Yeah.

Judy: Oh I didn't know that.

Hunter: I mean it's a pretty good go-kart, pretty fast, pretty powerful to go up those hills... We live on hills a lot, and we asked this neighbor that we can ride on his property because he has a lot of property. So he said yes. We just have to stay on the trail and respect the land. And he said treat the land like you would, you know.

Judy: Can I take you home with me? Maybe you can teach my boys something. (laughs)

Patti: He has a gift.

Hunter: I watch the History Channel and the Discovery; I'll watch Man Vs. Wild, Dirty Jobs, stuff like that. And then I'll watch TLC. My mom watches that, we're renovating our house.

Judy: Oh are you?

Hunter: I mean we're in the process of being done. We're almost done with the bathroom; we're working on it... right mom?

Patti: Yes! (laughter) It's been a couple years.

Judy: Do you have any good friends at home?

Hunter: I do at school, I mean at school here, but they live so far away...like this one...Lauren, where did Lauren live?

Patti: Vandergrift.

Hunter: Vandergrift. So she lived in Vandergrift. We live in North Huntington, so it's kinda far away from each other. But we do go out like to movies and stuff like that with our parents. But ya know from my district Norwin, I don't really have any friends. Only the friends that Paige has, I know them. So I'll say hi I'll stay around and just listen to their conversations. And Conner has some good friends that I know that are nice to me and I talk to them...

Judy: Are people ever mean to you?

Hunter: Oh, no but at my swim practice more kids know me than I know them. They say "Hi" I say "Hi" and I'm like "I don't know that person" or something ya know.

Judy: Yeah

Hunter: And my mom always says “Learn those names” because I’ll be going to Norwin, but it’s kinda tough because when we’re stretching our legs and stuff I have to have my hearing aids out, so that’s kinda,

Judy: Ohh that’s right...

Hunter: I need the hearing aids to talk and hear, so...

Judy: Right, right. So swimming, you’re in a world all alone?

Hunter: Yeah.

Judy: Cause you don’t hear anything else around you?

Hunter: I can hear some stuff, like the splashing of the water, the yelling of the coaches. Sometimes I can hear the kids laughing, or I can hear them loud or something...and what I do, the coaches know that I’m deaf and I can’t see. So I have this thing where I was in the pool and I was in lane 6. And the coach, she knows that I’m deaf so she’ll come kinda close so I can hear. And I’ll get out from the pool and I’ll stand right next to her to hear. And I’ll just stand there and listen to her while she’s saying it, and I ask her to repeat it or I don’t get it, she’ll try and explain it more, so yeah...

Judy: What’s your best stroke?

Hunter: Backstroke. And butterfly.

Judy: Butterfly really?

Hunter: Butterfly yeah I like butterfly. And freestyle’s alright but it makes my head dizzy in the water.

Judy: Makes your head dizzy?

Hunter: You know moving my arms and you have to do the flip turn, when you do this and this, and you have to do the flip turn, and if you don’t get it right it goes up your nose and makes you sneeze and all that type of stuff.

(\Laughs)

Judy: Mom I want to ask you a question...what’s been the hardest thing for you through this journey?

Patti: Um, the hardest thing...probably educating myself and keeping my emotions intact, and understanding, because there’s so much information out there, and I’m just a mom. I’m just a mom. So it can be overwhelming. Luckily I think my grief early on took me in that direction where I felt “Alright, I have to educate myself.” And so I have gotten very

involved. I've gotten a lot of great supports. I take advantage of trainings and network and ya know anything I can. That's probably the most difficult, but to really try to keep those emotions intact. He has a true gift, and um you know it's funny because I know the worst is yet to come. And that's probably the hardest thing. I really think he's gonna be fine. It's my heart that breaks. I think, you know...

Hunter: Mom, mother, are they going to feed me lunch?

Patti: Yes they are. (laughs) Yes I had Dave call down to Linda at the lunch.

Hunter: Okay. Did you tell them what I wanted?

Patti: Yes.

Hunter: Okay, okay, that's good.

Patti: Yeah that's pretty much.

Judy: Yeah, what are you most proud of?

Patti: Wait a minute, they're talking to me this time. I think I am most proud of his self-advocacy, that he has pretty much... and I pray that he continues with that. Because I know as he gets older it'll be a little tough. And we've been very spoiled here at DePaul's sometimes I feel like I'm getting ready to throw him to the wolves. But he truly has been a gift, and that whole word of special really puts on a new meaning. And sometimes I feel guilty because I think I wouldn't change him for the world. And uh, but he's made me proud. He's a nice person. He's a good person.

Hunter: Yeah.

Patti: A little sassy now.

Hunter: What?

Patti: You're a little sassy.

Hunter: When it comes to talking I am.

Judy: How old is, um, Conner?

Patti: Both my older children have birthdays in June, so he's just about to be 15.

Hunter: 15..so he's 14 gonna be 15.

Judy: And when's your birthday?

Hunter: December 15<sup>th</sup>, so I'm 12 years old going, on my 13<sup>th</sup>. All my other friends are already all 13, their birthday is like in March, April that type of stuff.

Judy: And has anybody had an influence on you that you can think of? You know like if I said to you, who taught you the most about this, who gave you the courage to be an advocate, or to learn?

Hunter: Well the person...

Patti: Hunter. I think they're asking me this one. My turn.

Judy: Sorry! I'll ask you next.

Patti: Probably, um, well definitely to that question um, am I allowed to say names?

Judy: Sure.

Patti: I have a dear friend Pam DeGeorge, who is a mom of twin girls with Down syndrome. And actually, my daughter had befriended the girls when they were in elementary school. And she was probably the first to mainstream MR in our district, and there was some not so nice things going on... I had Hunter, but he had not been diagnosed, and I remember thinking "Wow, this poor lady," and I gave her a lot of credit. And I had taught children with Downs—I am a former ballet dancer, and I still teach ballet, that was my chosen career, and this is my given career. And so it was really funny. We're friends, and so when all this happened with Hunter, she was very helpful. I also have turned to the Deaf Blind Project, under Pennsylvania, under PaTTAN comes the Deaf Blind Project through the state. And I now work for them as a family liaison part-time, and they have been extremely supportive, because again it was very hard to find the dual sensory impairment. I could find lots of information and correspondence courses and anything I could find on deafness, and the same thing on blindness, but it's the dual sensory. That's probably my hardest struggle even now, is just finding my Annie Sullivan, the one that really knows about the dual impairment.

Judy: You know she was blind.

Patti: Yes, yes.

Hunter: Who?

Judy: Annie Sullivan.

Patti: Helen Keller's teacher, Annie Sullivan.

Hunter: Oh she was?

Patti: And but like I said, with DePaul the teachers have been great, and Tracy, the teacher of the visually impaired has been working with Hunter, how long's Tracy been with you?

Hunter: Oh she's been with me 3<sup>rd</sup> grade to 6<sup>th</sup> grade (counting), I don't know a couple years.

Patti: She's great.

Hunter: She started with me at 3<sup>rd</sup> grade, because I had another vision teacher too that we liked too, remember?

Patti: Right.

Hunter: We had a couple, we had actually like 3. All of them were good.

Judy: Did anybody ever say to you...umm...because I know the School for Blind Children also had children who are deaf...did you have a choice?

Patti: Yes, and when we were looking into Hunter's placement, I certainly looked into Western Pennsylvania School for the Deaf, and the School for Blind Children. Um, I always laugh. Hunter's a little low incident of low incident. Um the children at School for the Blind have so many medical issues, and severe, you know, that sometimes I think the deaf/blindness is probably sometimes the least of their troubles. And we're very compassionate, I work with lots of families...we have families that do have children there. It just wasn't the right placement for Hunter. And it was funny, when we came to DePaul, I had to laugh, because I'm really originally from the South, so I'm like a good Southern Protestant...I'm thinking Catholic school...I had these images of Catholic school and nuns...and I was afraid. But I thought I really need to see what's out there as I went in for that kindergarten transition thing. And I just fell in love. I remember there in Brookline crying all the way home saying "I wasn't supposed to like this school!" And at that time he did do a little signing a little gestures, and I thought are they gonna like hit him? Or ya know, and they've been great... I mean, nothing's perfect in this world, but this placement's been pretty perfect. When we came here we really thought we would go all the way through, and it was probably just 2 and a half, 3 years ago that the board made the decision. And I understand, I mean the children now are being implanted so much earlier. And they're getting this really great foundation, so it's easier to go out earlier. And I'm sure economically most of the kids are mainstreaming... And I support any parent in there because I really believe each family has to have that individual um... Like I said we've done our best as a family to get him out in the community. And you know its funny, when he talks about friends, where we live, we're not in like a neighborhood anyway. So none of my other 2 children really had any real neighborhood friends. I mean, they do. So that is hard, and we keep him on the swim team and Scouts and at least he's got some contacts. And these kids are good with Hunter, and Hunter's pretty good with them. I'm sure it'll be a little bit of a struggle.

Hunter: It probably won't.

Judy: So if his hearing loss increases, the loss increases, then he's eligible for an implant?

Patti: Yes if he...I think he's moderate to severe, so just those high frequencies in the profound, so if his loss would become more progressive, and he would kind of bump up from severe to profound, and become a candidate, I wouldn't hesitate. We'd do the implants tomorrow.

Judy: The fact that he has hearing is tremendous.

Patti: And like I said, I bank on that hearing. And it was funny, a couple weeks ago... Who was that? Sister Mary John? One of the teacher's here who's just wonderful had questioned something. And we weren't sure, was he just not listening—Sister Jeremy—but it was great. You know, DePaul, I called the audiologist here Debbie. Right away and we got a test in. And he was okay, you know I never know...I think that's the worst part with this Ushers. Those were so many questions I had for doctor's, like okay, since he was showing these signs earlier, does that mean he'll lose his sight earlier? Nobody knows. He could lose it at 20, 30, 40, maybe 80. So my job's to prepare him. We're real honest. We make a lot of bad jokes about it. We laugh about it. It was funny because he's legally blind. We know he'll never drive a car but my husband and I probably partly out of guilt once again said "Well, a go-kart we could do!" And he does pretty well, you know somebody's always with him, and you know. But those experiences in life, and hey...

Tony: Who knows by the time you get that age, they might be able to just talk to the car and tell it where to go!

Hunter: Yeah that's what I want!

Tony: By that time who knows what the technology will bring!

Patti: Yeah so it is great, so we're hopeful, you know and if we can certainly pioneer the wave for anyone else that's great, and I keep kinda looking at gene therapy that's coming up, and hey...anything would be great.

Judy: So Usher's is genetic?

Patti: Yes, basically my husband and I both carried this recessive mutated gene, and it was like who knew? And because of the jockey I heard that over 20,000 in the US are diagnosed. They're working right now with certain genetic, you know, which genes, you know and all that. And there's not quite all the testing up on that for the Usher II, where with Usher I the child is born profoundly deaf, and then has the RP. So the common thing is the retinitis pigmentosa. It's just the different degrees of the hearing. And then

there is an Usher III actually that I think begins in the 2<sup>nd</sup> or 3<sup>rd</sup> decade. Usually the 20's they start with the progressive hearing and vision loss.

Judy: Would this be something that your children will be tested for then, right?

Patti: Yeah.

Judy: So Hunter, you're learning Braille. This'll be my last question because I know you're hungry. You're learning Braille. I think people who know Braille are geniuses, because I could close my eyes and I couldn't tell you one dot from the next. Is it easy or hard for you?

Hunter: It's easy. But like on Christmas break, you've been off from Braille for a couple days, and when you try it again, get back on track, you don't know. You're not completely sure what the dot means, like the contraction. Sometimes you just forget a little bit, and you just have to get back in the mode to read it. But it's pretty easy.

Judy: And I just found out that there's new technology for that too, for writing Braille. It's amazing.

Hunter: On the computer, you can type it, and all that you know.

Judy: Is there anything you want to say that we didn't talk about?

Hunter: Umm no.

Tony: He wants to go eat! This man's hungry, he wants some chicken fingers!

Judy: But he could tell us a lot!

Hunter: You'd be here all night!

Judy: We don't want to be here all night. I really enjoyed meeting you Hunter, you are a delight.

Patti: Say thanks.

Judy: And we got the pictures right Tony?

Tony: A couple. But we need more. We need you on your go-kart!

Patti: Okay. Alright, we'll get lots.

**END**