TRANSCRIPT:

Faith's World

a BYkids film
THEIR WORLD THEIR FILMS

Faith: Hi, my name is Faith and I'm 16 years old and I have cerebral palsy. I don't have much hand control if I were to use the camera so Joyce and Kat are helping me with the camera and I'm just, kind of, directing.

Joyce: No big deal, I'm just the director, no big deal.

Kat: [laughing]

Faith: One of my favorite things to do for fun is go to I Fly, especially since my parents Carrie and Jesse love it as much as I do!

Father: Alright I'm not gonna close your lid now.

Faith: Please don't.

Father: Please don't? Gonna do the brother? Chin up. I've got you. Okay!

Skydiving Instructor: Alright, you feel okay? Looks good! Awesome!

Faith: When I'm high up in the air, I feel like I'm floating. It's scary at first, but it's neat to see everyone through the glass.

I was born with cerebral palsy because I was a couple weeks early and premature, and it cut off the oxygen to my brain, which also caused part of the vision issue. When I was born, my brain damaged my optic nerve. I can see certain colors, and I can't see far away, but I can see close up.

Father: We found out the main difficulties Faith would have in life when she was born. Before that we knew she was gonna be premature and we understood that. We had a son that was premature before that and he worked through his issues. She was dark purple, not breathing, they rushed her over to a table, resuscitated her, basically, at that point. Color flushed in–we were very concerned once the doctors got a chance to examine her. They told us 'she's never gonna do this, she's never gonna walk'. Just, like, very, very bad situation for her.

Faith: I just started attending the Maryland School for the Blind a couple weeks ago and I love it already.

Okay, so I know there are 6 reds, and 1, 2, 3, 4, 5 yellows. So 5 plus 6 is… 7, 8, 9, 10, 11, 12, 13.

Teacher 1: Okay, now, let's start on the left. What color do you get to first?

Faith: The teachers here understand what it's like to have cortical vision impairment. CVI is a neurological blindness; it's a problem with the brain, not the eye. I see what you see, I just have a hard time interpreting it. So for me, it helps to touch the objects when counting because it reinforces my learning.

2, 3, 4, 5.

Teacher 1: Can I have your hand? Can we do it together? Okay, so we're gonna count the way we read, from top to…?

Faith: Bottom.

Teacher 1: And from left to…?

Faith: Right!

Teacher 1: Okay, so count with me.

Faith: 1, 2, 3, 4, 5.

Teacher 1: So how many yellows?

Faith: 5 yellows.

Teacher 1: Good. Now what?

Faith: And 6 reds.

Teacher 1: Uh huh, yes.

Faith: So, 7, 8, 9, 10, 11, 12?

Teacher 1: Count them all together and check.

Faith: 1, 2, 3, 4.

Teacher 1: Mmm, mmm, mmm, mm, mmm, mm!

Faith: Wait, 1, 2, 3, 4, 5, 6, 7, 8, 9, 10, 11!

Teacher 1: So what's the problem?

Faith: Eleven.

Teacher 1: Can you guess?

Faith: 1, 2, 3, 4, 5. So 6 plus 5 is eleven.

Teacher 1: Good. Now, which works better–when you count from bottom to top or from top to bottom?

Faith: Well, counting that, counting either way is not really something they taught me in my other school, so it's really teaching my brain something.

Teacher 1: Yeah! That's hard!

Faith: I just know I need to learn eventually.

Teacher 1: Right! You have plenty of time.

Teacher 2: We are opening notes, and we are writing a birthday message to Mr. Hare.

Teacher 3: There you go. And right in… there.

Faith: Happy Birthday Mr. Hare!

Teacher 3: But what should we have different about the word Hare?

Faith: Oh, capital?

Teacher 3: Yes, so, so shift… right…

Faith: Oh I just deleted the whole thing!

Teacher 3: You ready? You've got a little trick to get it back.

Faith: He–I was gonna say he recovered it.

Teacher 3: It is back! Another way… if it's hard to hold down shift, you can hit the caps lock button. Press it once and it'll make all of the letters capital. And now hit H. There you go, and now hit caps lock again to turn off the capital letters.

Faith: I was so excited to start the therapeutic horseback riding, and even more excited when I found out Sally was going to be my horse. I met her last summer when I here with camp.

Horseback Riding Instructor 1: You got her in the back? Yup, okay, alright, get yourself a hold again, and then we're gonna bring those legs down. We're gonna scoot back in that saddle too. Can you scoot back for me? Alright, you hold on, and then I'm gonna wiggle your legs now.

Hands up towards the ceiling! Alright, sit up nice and tall, put both hands up towards the sky! Be as tall as you can! As tall as you can get yourself, all the way up! Both hands as close to the ears as you can get them, so bend at the waist, lean forward!

Horseback Riding Instructor 2: Therapeutic riding is beneficial to our clients in a myriad of ways. One of the most evident ways is the physical activity that the rider experiences, because a lot of people think that they're riding and not getting any exercise, but when you're sitting on top of a horse you have to use your core to balance yourself because the horses walk just like a human does–so there's the forward, backward, side to side, and up and down movement. So in order to stay upright on your horse, you're going to have to engage your core. So when your core is strong, then you are able to move your diaphragm to push air from your lungs past your vocal cords, which also helps with our clients' speech.

And then, there's what I call the fun side. When you're riding horses, it helps your self esteem, your self confidence, because if you look at our riders, some of them arrived in wheelchairs, so they're looking at their world from a belt-buckle level. But when they're on their horse, they're above everybody else.

[Indistinctive chatter]

Faith: There you go!

Roll sound, roll camera, action. So, Mom, tell me why you made all of those videos of me while I was growing up.

Mother: Well, I think that's just a mom thing that you're supposed to do. I did it with your brother. But I think what was different with you was that I had social media, so we were all sharing our photos and videos, and I had a lot of people asking questions…

Faith: Kind of like having gravity towards you?

Mother: Yeah, they gravitated–not towards me, towards you. They gravitated towards you, and how you overcome all of the struggles that you are, and how fearless you are, and everything that you have to do every day. And then also for awareness too. So when we do the videos, then it shows other people–because a lot of people take a lot of things for granted, and they don't realize everything that you have to do, or that we have to do as a family.

Faith: I don't have a lot of friendships, and some days I felt like I was invisible, but that's why I like having people who are friends with me with disabilities because they can actually understand me. So like, because sometimes people actually don't understand me and don't see my point and where I'm coming from. They're like "why is she in a walker, that's weird".

Do you ever get sad because you have cerebral palsy?

Friend 1: No, not usually, because it's just normal to have CP to me, so I don't get sad about it.

Friend 2: Me neither. I mean, when I was younger, I used to always ask "why me? Why do I have to live the life I live? I don't like my life, I want a cure." But now, I have changed my mind on it, because I heard this song, and there's this one lyric that really resonated with me. And it's "I didn't choose to live the life I live, but I can choose to make the most of it" was the lyric. And that really hit home with me, because at the end of the day, I didn't choose to have CP, I didn't choose to have hearing loss, but I choose not to feel sorry for myself, I choose to live a good life.

Faith: So, I used to think when I was younger, people would say "hi" because I was in a walker and they would feel bad for me, but whatever it is, I don't feel bad for myself, even if they feel bad for me.

Friend 1: People tell me that I'm an inspiration, and I don't feel great that they're telling me that I'm an inspiration, because I just feel normal. I'm not an inspiration. So it kind of just is wrong that they say that.

Friend 2: Whenever people make these stories about people with disabilities, it's always seen as either pity or inspiring. And that kind of bothers me, because I don't want people to feel bad for me. I appreciate sympathy, but not pity, because it just seems like my life is bad, and that's not the case. My life is great, and you get to see the world through a different lens, not just how everyone else sees it, but your own unique perspective. And you get to be part of the disabled community, which is so cool! To me, friends with CP and forming these good friendships that are friends with other disabilities…

Faith: You bond with people!

Friend 2: Yeal! It's cool!

Faith: So, one day, I was like, I am sick of going to the doctor's appointments. And I didn't like taking off of school because I love school! But, uh, one day, I just decided to deal with it and keep going. You do have your moments and you get sad, but you find ways to be happy and uplift yourself.

Garett: I guess that's the person doing homework?

Family: Those are chili peppers, chili peppers.

[laughing]

Faith: He probably didn't see. It's okay, I do that a lot. is

Garett: Show what this is!

Mom: Those are 2 dogs going at it, fighting! Fighting.

[laughing]

Family member: They're angry!

Faith: That kid that was over here the other night playing games with me, his name is Garett, and I met him at rehab with my friends. Apparently, he was all normal, and acted like, 4 years ago, and then he got sick, and now he's in a wheelchair, but he's just a cool kid about it and has a great personality.

Mother: Scream it!

Faith: Action!

Mother: Alright! It's like getting on the horse.

Father: Mmhmm. Is that where you want them?

Faith: Yeah. But I feel like I need to move it because the brakes are literally right here.

Father: You've got it!

Mother: That way when the doggy poops, Daddy can pick it up!

[laughing]

Father: My biggest fear in life is when I'm gone, who's gonna look after her? How's she gonna do things now without [chokes on words]? Things we take for granted, if you need to go to the corner to get milk. You can get in a car and go down there or you can walk, but what is she going to do in those time frames? And the technology that is coming out now that's helping people… Autonomous cars are going to be a huge thing for people that aren't mobile themselves. The possibilities out there as we are growing is just amazing, and I look forward to hopefully be here to see these things come to fruition.

Faith: Sound, rolling, camera, action! How did it feel having a sister with a disability growing up?

Brother: Growing up, it didn't seem different to me because I was so used to it, and honestly, I wouldn't have had it any other way with the life experiences we've had and the way it's made me grow up and the way it's made her grow up.

Mother: Now you're gonna make me cry.

Faith: No, don't start crying!

Brother: It's changed my life a lot. It makes me view things a lot differently than other people. Especially being on TCU, since it is such a good campus–like, there is kids here with disabilities. And I see them get out of things, and people talking bad behind their backs, and I've told a lot of people to be quiet, honestly, the past 2 years, and to not view people so different because they're just humans and they want the same things we want.

Faith: Is there anything special you would like to do when you come home for Thanksgiving? I'm asking because I know what it is.

Mother: I have no idea

Brother: What?

Mother: I have no idea why she's laughing. Is there anything special you would like to do while you're home for Thanksgiving next week?

Brother: Umm, mostly just get to hang out with my family and friends, maybe get to do a little…

Faith: And your girlfriend.

[laughter]

Brother: Just relax and be home.

Mother: She said "and your girlfriend".

Brother: Yes, that is true.

Ms. Jessica: Okay, tuck your chin. Good. Good?

Faith: I've been having physical therapy with Ms. Jessica for the past 3 years. It's important, especially if you have cerebral palsy like me.

Ms. Jessica: Get that foot up in the air. It helps so you don't drag your feet. There you go, good job. So I want you to work with it, right? So while it's on…

Faith: Feels goofy!

Ms. Jessica: So who's in your class?

Faith: There's Erin, Lily, Dylan and me, and a boy doesn't actually come until Christmas.

Ms. Jessica: 'Til Christmas, you get a boy? In your classroom?

Faith: He doesn't actually arrive 'til Christmas, it's kinda funny.

Ms. Jessica: That is funny! So you have all girls right now. And then at Christmas time you get a boy, is that what you're telling me? Yes?

Faith: Yes.

Ms. Jessica: Awesome! Sit nice and tall, this one, okay look at what you're reaching for! Good job. Okay look on this side, actually, instead. Faith, keep it on this side. Good. Nice work. Now get as high as you can! Go, go, go, go, go! Higher! Go! Good job. Awesome! Oh, try not to slide it, try to lift. That was better, good job! Okay one last one.

Faith: On each side?

Ms. Jessica: Nope, just on this side. Okay, lift. Good. Nice. Okay, step with the right. All the way into the center. Good! And then go ahead and step out. Oh. No, you're doing good! You're doing an awesome job!

Faith: Take 5, these are velcro pants that open and then you can put them back together, and they're really easy for putting them back together because you can just snap it, and there's actually a fake snap right here. Hear that click? It's great that they have adaptive clothing for people who can't really dress themselves and need a lot of help but they also want button pants. These are really easy because they have magnets and you can just open them right up!

It was so cool when I was asked to model adaptive clothing again at the runway of dreams fashion show in New York. The highlight of most is being able to connect and meet other people with disabilities.

Mother: Oh I love it!

Stylist 1: And you've got lots of fun accessories. Yeah, I think a little bit more. Do you like it that short?

Stylist 2: Yeah, yeah I do.

Faith: The woman I look up to, Mindy Scheier, is the one who started it all.

Mindy: I'm a fashion designer by trade, and a mom of 3 kids. My middle child, Oliver, was born with a rare form of muscular dystrophy that affects his muscles and certainly makes buttoning and zippering pants and putting on shoes very difficult, so he wore sweatpants every day. And when he was 8 years old, he came home and said he wanted to wear jeans to school. And this was the first time that we had to think about, well, how was he going to go to the bathroom? How was he going to be able to be independent weathering jeans, and I went home and decided that I needed to rip apart a pair of jeans and figure out ways that could make it more manageable for him. And what that did was open my eyes to the fact that there is an entire world of people with disabilities out there that are not able to wear what they want to wear because of clothing challenges. And that is really the reason why I started Runway of Dreams.

Faith: That's so cool!

[Music]

[Chatter]

Mindy: The future of fashion is now. The fact that we have 3 major brands on our runway–Tommy Hilfiger, Zappos, and Kohls–sharing the runway to show their adaptive clothing options, is a revolution. And you're all here to be a part of it. We have 40 models with all different types of disabilities about to go down this runway, which is exactly where they should be, kicking off New York Fashion Week!

Faith: I've had a couple of job ideas, but I don't know exactly what my future would look like, so I'm just kind of living on. At school, they have us fill out job applications, and I have several ideas of what I want to do and where I want to live, I just don't know yet. Because in the future, you can alway change your mind, and then it's like, a way of gravity.

It's a wrap!

[Credits roll]