

REFOCUS

Meet Lead Artist
Hollie Leggett



Hollie Leggett is a local photographer from Sioux Falls, South Dakota. She currently attends the Minneapolis College of Art and Design where she studies multimedia environments. Last spring, she was hired as lead photographer for the Refocus show, a collaboration between nonprofits [Untitled.io](#) and [Rare by Design](#). “I feel like it was important for me to be a part of this project and to be involved in this space so I could educate myself on different, diverse ideas,” Leggett says. She mentions that she hasn’t taken on a project like this before and was excited about the prospect of a new challenge. “It was kind of a learning curve on how to play upon these different parts of people and make it into something artistic, meaningful and exciting,” she states.

Why Did You Join This Photoshoot?

"I was in a creative rut," Leggett expressed. "I feel like a lot of times I'm taking pictures for monetary use, for the school, for weddings or modeling agencies – which are fun in their own ways – but I think I started to get really burnt out on working with people who are used to that sort of treatment." Leggett says she often works with people who know how a photoshoot is supposed to go and that that can suck a little of the excitement out of it. The Refocus show features individuals with little-to-no modeling experience. "It was my time to get out of that space and work with people who were excited about being in a photoshoot." She mentions she has wanted to be part of a project that makes people feel empowered by how they look. "Especially if the photos are able to speak to who you are as a person, that's even more important." Despite this photoshoot being a first for Leggett, she has some familiarity with the disability space. "I have a little brother who has cerebral palsy," she mentions. "Growing up, I got to watch him go through challenges and learned to understand some of them as well, from afar." That personal experience helped play a role in how she approached this shoot.



What Was This Experience Like for You?

"I think there was this breakthrough that happened in the middle of the shoot where I realized that everyone just wants to look hot and sexy," Leggett recalls. "I thought about that throughout the shoot, and I was like, 'Okay, this isn't really any different than like taking pictures of anybody else I've ever taken pictures of.'" Initially, Leggett says she was concerned with the photoshoot space not being accessible for the models. "Overall, the studio did do a really great job of accommodating all of us inside of one area." She states that she had everything planned down to a tee, as the days were going to have several moving parts. Her goal was to make the shoots both fun and efficient. "It just kind of ended up being like a party. Everybody who was there just had such high energy." But, through the hustle and bustle of the day, she kept her focus on each model that was right in front of her at the time. "It was an intimate experience in the midst of all the chaos." And she says she couldn't be happier with the end results. "The photos are amazing. They all look so cool and they're all so different. They all carry different energy."



What Do You Hope People Take Away from The Show?

"I want people to notice the person behind their disability," Leggett states. "Everybody is a person at the end of the day, and everybody just wants to show who they are, to look good and to feel good. I hope people are able to see a little bit about each person by just looking at a photo." She also wants the pictures to serve a purpose beyond the show. "People could use them for headshots, for their LinkedIn, dating profiles or whatever they want." Leggett mentions that there aren't many conversations about diversity in South Dakota. "Whether it's disabilities, race, gender and anything like that," she says. "We push a lot of things under the rug." Growing up, she remembers always feeling the urge to push against that mentality, with this show being a perfect outlet to do so. "Not a lot of people get this experience, including me, and I'm in the photography space a lot. So, I think this show is going to be a really special experience for everyone involved."

Keep up with Hollie's work by following her on social media:
Website: holliephotos.com
Instagram: [@hollielegget_](https://www.instagram.com/hollielegget_)

SPECIAL THANKS
TO THOSE WHO
MADE THIS EVENT
SO MAGICAL

CREATIVES

Lead Artist | Hollie Leggett

Writer | Max Hofer

Video | Theyself by Wake

Video | Kenzie Shubert

Designer | Tyson Schultz

Make Up | Megan Bertsch Beauty

Make Up | Kristi Adams Artistry

Hair | Modern Alchemy

Hair | Klipper Ky Barbershop

MODELS

Hailey Bork

Melinda Pallone

Scotty Briggs

Connor Roeman

Stephen Bruggeman

Kayley Shade

Kendra Gottsleben

Koni Sims

Laura Hayne

Vicki Stewart

Cameron Hoverson

Alma Stewart

Jeremy Neuheisel

Tana Zwart

Vicki Stewart

**“I am a very energetic
and active person.”**

Growing up in northwestern Iowa, Vicki Stewart had what can be best described as a fragile childhood. “One day my mom was giving me a bath and she heard something snap.” Worried, her mother rushed her to the doctor’s office. “They discovered that I had a broken arm,” Stewart recalls. Initially, police were called, falsely assuming she was a victim of child abuse. After further examination, the doctors discovered Stewart had Osteogenesis Imperfecta, also known as ‘Brittle Bones Disease.’ She was only three weeks old. “I’ve probably had around 45 broken bones throughout my lifetime.” When she was two years old, Stewart broke her legs when she tripped over the vacuum cleaner. “After that, I couldn’t walk,” she remembers. “When I started kindergarten, that’s when I started to use the wheelchair full time.” While at home, she would use braces and a walker to help her walk and she would use her wheelchair at school, due to the higher risk of injury.





That's not to say home didn't have its fair share of risks. "My sisters told me about how, if I had a dirty diaper, nobody wanted to change it because they were afraid that they would break me," she laughs. Growing up, her family was big into playing sports, a pastime she ultimately had to pass up for her own safety. "That was always kind of tough." In her lowest points, however, Stewart says her family was right there to pick her up. "I feel very fortunate that I came from a very supportive family," she mentions. Her siblings would often do their best to include her in the fun. "They always kind of pushed it a little bit," she laughs. "My older sister used to take me out on bike rides and I wasn't in a seat or anything. So, it probably wasn't the safest thing to be doing, but they always wanted me to have fun." When it came to her personal goals, she says her parents showed unconditional support. "They encouraged me to go out and do things, go to school, go to college and get involved in music."

Stewart mentions that her condition has gotten progressively better over the years. "I haven't had as many breaks since about age 13." She later moved to Sioux Falls, where she graduated from Augustana University (Augustana College at the time) and majored in Religion and Psychology. "I love Sioux Falls; I love being a part of it." She lives with her husband, Alma, in a home she built to be wheelchair accessible. "He also uses a wheelchair due to a spinal cord injury." In their spare time, they love to travel. "I've been to every state in the U.S., Israel and Ireland." Today, she's the Executive Director of Employment Disability Resources in Sioux Falls. It's here where she fulfills her greatest passion: helping others. "We promote employment and inclusion," she says. "I always think the more we can be out there and showcase that we [people with disabilities] do have jobs, we do have homes, we do have families...I think that's really important to show that we're not as different as some people may think."

What Are Some Stigmas About Disabilities in the Workforce?

"Unfortunately, people look at what we can't do instead of what we can do." She states that many of these misconceptions come from people having little-to-no experience around people with disabilities. "They might be afraid that they're going to say the wrong thing or do the wrong thing around them," she mentions. "That, and a lot of times businesses think, 'How will that work?' 'Are we accessible enough?' 'What kind of accommodations is this person going to need?' 'Will they have the skills to do the job?'" Stewart wants to assure people that the best way to combat this stigma is, simply, to ask. "A lot of times people with disabilities aren't asked," she says. "They're not asked to volunteer or to be on a board. To show how many people are involved in the Refocus exhibit might help people think to ask someone to volunteer at an organization or apply for a job."

What Are Some Common Misconceptions About Your Disability?

"People were afraid to ask." Stewart remembers a time in high school where she would hear rumors about her disability. "My best friend in junior high told me, 'I know you don't have that long to live.' I was confused, so I asked her what she meant," Stewart recalls. "She heard that I was going to die by the age of 21, and I told her, 'Oh, that's not true!' It was different because there were five other children in my family and no one else had this." When they get to know her, she says people are often shocked to find out how much she travels. "That can be challenging when you use a wheelchair," she mentions. "I grew up in a family where we always took a vacation every year. Traveling has been in my blood and—wheelchair or not—I just decided that was something that I wanted to keep doing, even as an adult."

Why Did You Join This Show?

"I want to be involved as much as I can just because I believe in the mission." Stewart has prior modeling experience as she participated in Rare by Design's The Style Show. In 1998, she competed and won the local Ms. Wheelchair South Dakota pageant. After winning, she moved onto the national competition. "I think we had 26 contestants," she mentions. "To see so many other women who used wheelchairs and hear their stories, it was very encouraging and it really kind of sparked my career." Stewart ended up making the top ten at the national pageant. "It opened new doors for me." She relates her experience with the pageant to her time in the Refocus exhibit. "I felt like I was really pampered," she states. "Having my makeup and hair done and getting to play dress up, I loved doing that as a kid and it felt like that." Her photoshoot was in the style of the Roaring Twenties. "I really wanted to do something fun and sexy."



What Do You Want People to Take Away from This Show?

"I just really think that it's a great way to show how people with disabilities are so different." She says people often tend to think individuals with disabilities are all the same. "We all have different interests, skills and abilities, and I just think this photoshoot is really going to showcase that." That reasoning plays a big part in why she took her photos with her husband, Alma. "I thought that was important that the community knows that people with disabilities can also find companionship, love and marriage," she states. No matter what people might assume, Stewart wants everyone to know that if they see someone in a wheelchair, it doesn't mean that they are confined. "We live active lives."

Today, you might find it hard to catch Stewart, as she still travels often. "I don't really stay home very much because I have so many interests." But she doesn't let that take away her focus from her mission in Sioux Falls. "I want to be involved in our community." Stewart says she wants people to know that she's not ashamed of her disability, nor is that all there is to her. "I'm so much more than my wheelchair." No matter what hurdles life throws her way, she pushes forward with a positive attitude and a spirit that is unbreakable.

ALMA STEWART

**“I’m just another
guy living life.”**

It’s not a leap to say that Alma Stewart has always lived his life on the wild side. In fact, it’s in his nature. “I prefer to be outdoors.” Growing up in Salt Lake Valley, Utah, he enjoyed fishing, hunting, and riding his motorcycle. But one night in 1985, he admits, things got a little too wild. “I was going too fast down a canyon on a motorcycle,” says Stewart. Nothing he and his friends hadn’t done many times before. “We always did it at two in the morning when nobody was out.” But it was the first time alcohol was involved. Stewart was twenty-one years old. “The funny thing is,” he recounts, “I just barely moved out of my parents’ house. I just paid all this money to be in a new home, spent one night there and then I ended up in the hospital.”



As a result of the accident, Stewart broke his back and was paralyzed from the chest down. It was an injury that might change a person's outlook on life, but, to Stewart, that's not in his nature. "I grew up in a family where you just do it," he mentions. "You don't dwell on it. I don't remember it being traumatic for me or anything, or really adapting. You just kept going. Everybody has challenges in life, some are just more visible." Instead of viewing life as a downward slope, he kept going the only way he knew how. "Don't let the little things slow you down or the big things will stop you," is what mom taught us. 'Adapt and conquer' is what the adaptive lifestyle has taught me." Stewart found new activities, such as basketball, tennis, handcycling, water skiing and snow skiing. Many of these sports he had never done before he broke his back.



While he found a love of skiing, he also found love in another place. "I love my wife. She's my best friend." Five years ago, he moved to Sioux Falls, South Dakota, to live with her. "It's pretty good. It's different," he says of Sioux Falls. "Utah was getting pretty full. It turned into a big city." While Stewart is semi-retired now, you'd be hard-pressed to find him taking it easy. "I still like my outdoor sports—fishing, hunting, cycling, tennis." And when he's not doing those, you can sometimes find him coaching future generations of adaptive sports players. "I do a little bit of volunteer coaching."



What Do You Love Most About Coaching?

"If I can do this, I can do anything" he states. A big reward is teaching people that just because they have a disability doesn't mean that they can't live life. Prior to moving to Sioux Falls, Stewart had been coaching students in adaptive athletics. "Watching kids get out and learn new sports is the greatest thrill of all. It gives them the confidence to live life," he says. After the move, he taught mono-ski lessons at Great Bear and still skis himself. Stewart also coaches wheelchair tennis throughout the year. He doesn't hit the slopes as often as he used to, but he doesn't mind staying close to the ground and sharing what he has learned with the next generation.

What Are Common Misconceptions About Your Disability?

"I don't really ask people what they think," Stewart admits. "They may think I can't do a lot." In fact, sometimes that way of thinking often sparks a fire within him to prove them wrong. "It's like, 'I can do it. I didn't want to do it. But now I have to do it because you said I can't,'" he laughs. Other times, he says he's faced misconceptions that are the opposite from what's expected. Friends will show him viral videos of people performing extreme adaptive sports. "So, everybody thinks that because they see one guy doing it, that every wheelchair user should be doing it."





Why Did You Join This Show?

"I'm not a fashionista," he states. "I like my clothes to be comfortable, on sale and work for what I need." Stewart strutted the runway in Rare by Design's first year of The Style Show and was invited back for the Refocus exhibit. "There are a few pictures we took of me in my sports gear or playing tennis." But his goal for his photo shoot was to show that he isn't playing solo. "My wife and I did it together," he mentions. "People don't think about other people in a wheelchair as being married and having a normal life." Just because his disability forces him to sit, doesn't mean that's all he's doing. "We're out in the world and we're living life and we're doing things. We're just people."



What do you Want People to Take Away from This Show?

"Everybody's got their own challenges, ours are just more visible." When he was young, Stewart recalls people looking up to adaptive sports players like they were heroes. And while they've overcome a lot and are doing amazing things, for him, the real heroes were the guys at home. "It's easy to go do sports and play," he states. "Life is the harder stuff. My heroes are these guys in wheelchairs going out working and raising a family." He says, if people can take anything away from his photos, it would be that he's just a regular guy, living his best life.

Today, when he's not working, you can still find him fishing, hunting, playing adaptive sports and coaching from time to time. While life may be moving a bit slower as the years go by, that doesn't make it any less exciting. Stewart says his favorite adventure is the life he gets to experience with his wife every day.



Kayley Shade

“I always tell people to focus on my abilities and not my disability.”

No matter how many times life has knocked her down, Kayley Shade always gets back up—which makes her love of football quite appropriate. “I’m a huge Cowboys fan and I’m a Longhorns fan. Football is kind of my true love.” She’s been a sports fan since she was a little kid, a passion that blossomed into a decade-long career. She started as a Digital Media Intern for the Sioux Falls Storm and is now the Media Director for the Indoor Football League (IFL). “I do all of their social media, their website, graphics and I make sure the teams get what they need from us.” On top of that, she’s developing her own freelance design business, which she describes as “a bit of a challenge,” but it’s nothing compared to what she’s faced through the years.



Shade was born with Spinal Muscular Atrophy (SMA). “It’s a disease that over time kind of wastes away your muscles,” she explains. “I’ve never walked. I’ve never crawled. I’ve been a wheelchair user my entire life.” From a young age, her parents quickly knew life would look a little different for their daughter, as she wasn’t hitting those, as Shade describes, “normal milestones.” “Every year you kind of notice something that gets a little weaker in your body.” She was diagnosed at sixteen months old and was given a life expectancy of two years. She turned thirty-one last August.

She undergoes routine treatments for SMA. “I was twenty-six when I started it,” she recalls. “That’s twenty-six years of my muscles wasting away, so as long as it stopped progression, it’s doing its job.” Despite the persistence of her condition, she’s able to find strength from the support of her team. “Before I got the job, I had doubts because I’m in a wheelchair,” she says. “The team told me to apply and that they will work with me and cater to what I can do.” On top of that, she also found strength within herself. “I got past my negative way of thinking, and it’s led me down a pretty awesome path.”



What Do You Enjoy About Your Job?

With a routine schedule of doctor appointments, taking medications and needing to rest, Shade says work provides a much-needed reprieve. Her SMA requires her to take breaks often on the job, and she'll occasionally rely on a ventilator when she gets sick. It's during those times when her team has her back. "They pick up my slack on that end of things, and they always tell me, 'Just get back when you can, and we'll pick up until then.' So, it's always been nice." However, even when she's out sick, you'd find it difficult keeping her benched. "Sometimes I come back to work sooner than they think I should," she laughs.

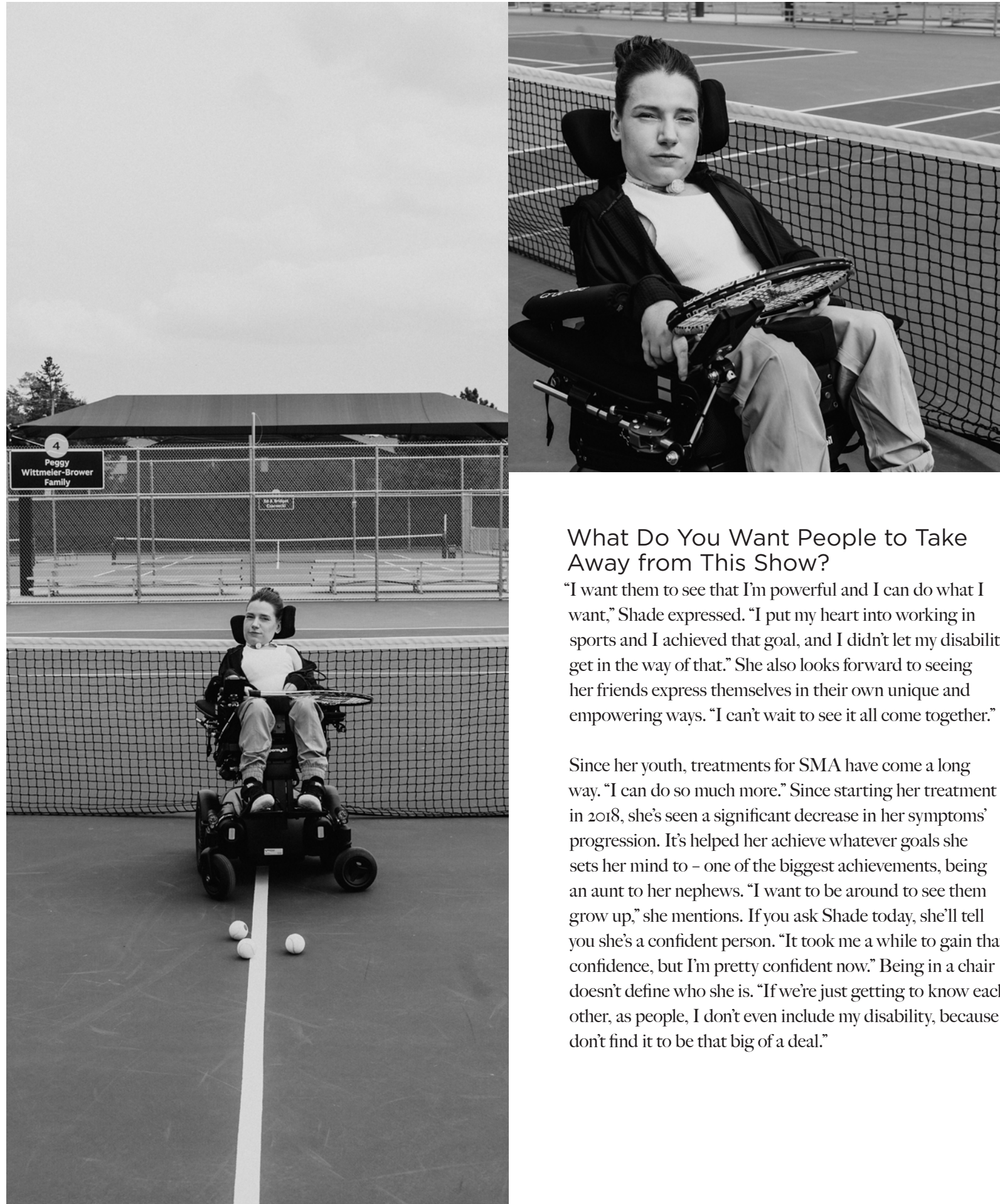
What Are Common Misconceptions About Your Disability?

"Because I'm in a wheelchair, people think I'm not mentally all there." Shade mentions there are times where people have talked to her like a child, or they speak loud as if she's unable to hear them. "I do have a nurse with me, sometimes, during the day, and if I go out, people will address my nurse instead of me – which is one of my biggest pet peeves." She says the same goes for family, friends or whomever is accompanying her that day.

Inconsideration also appears in more ways than one. "I've had situations where I've been out at a restaurant, it was raining outside and people walked right by me and didn't open the door for me or anything," she explains. "So, I had to sit out in the rain." But she refuses to let the rain wash out her spark.

Why Did You Join This Show?

"I love what Rare by Design is trying to do in this show and making it an inclusive experience." Shade has modeled in the past, but not on a scale quite like this. "We did more of a sports photoshoot," she says. "They put me in classic sports makeup—and they gave me a nice bun, which was very sporty. It was just a lot of fun." With this theme, Shade was asked to put on a more serious, game-face, but the more she tried, the more something else shined through. "I realized it isn't really me. I like to smile in my pictures."



What Do You Want People to Take Away from This Show?

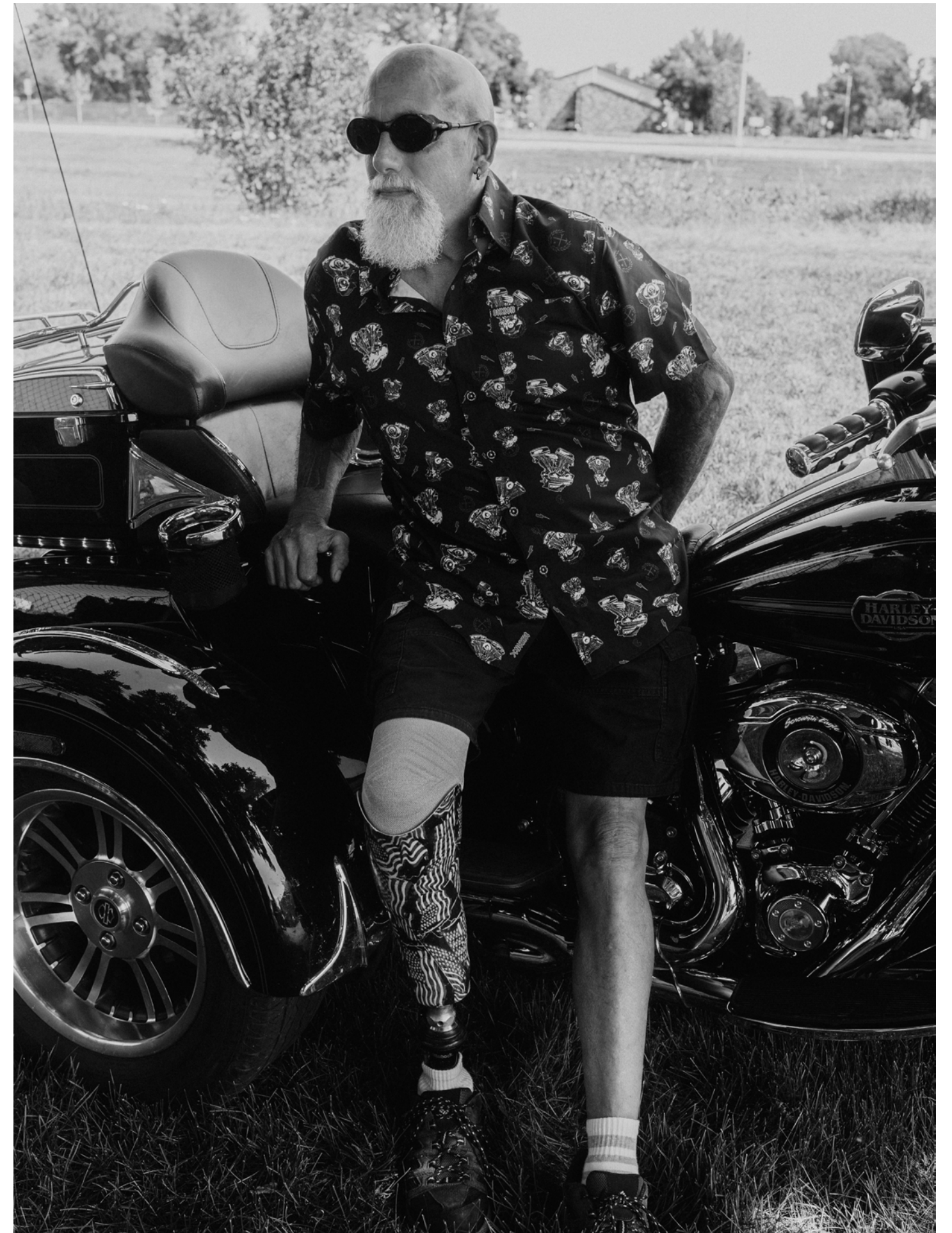
"I want them to see that I'm powerful and I can do what I want," Shade expressed. "I put my heart into working in sports and I achieved that goal, and I didn't let my disability get in the way of that." She also looks forward to seeing her friends express themselves in their own unique and empowering ways. "I can't wait to see it all come together."

Since her youth, treatments for SMA have come a long way. "I can do so much more." Since starting her treatment in 2018, she's seen a significant decrease in her symptoms' progression. It's helped her achieve whatever goals she sets her mind to – one of the biggest achievements, being an aunt to her nephews. "I want to be around to see them grow up," she mentions. If you ask Shade today, she'll tell you she's a confident person. "It took me a while to gain that confidence, but I'm pretty confident now." Being in a chair doesn't define who she is. "If we're just getting to know each other, as people, I don't even include my disability, because I don't find it to be that big of a deal."

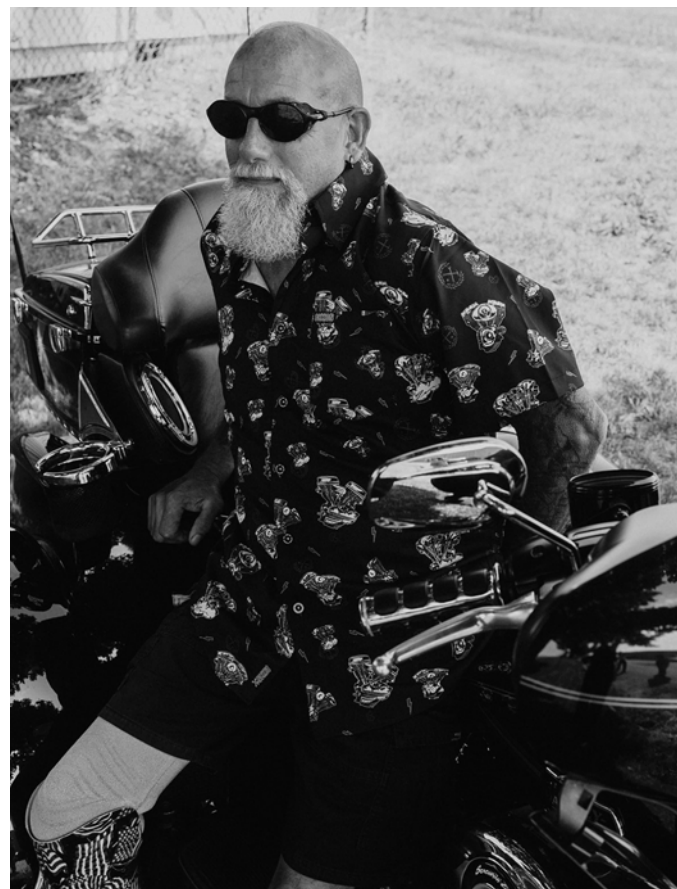
Stephen Bruggeman

**“I’m a very active veteran
for an amputee.”**

Since childhood, Stephen Bruggeman has always been a standup guy. “I answered the call of the Coast Guard in August of 1981.” Bruggeman grew up in a military family. His father served in the United States Marines. When Bruggeman turned 19, he followed in his footsteps and enlisted in the U. S. Military, specifically the Coast Guard. His intention was to serve his country for four years. “It was a great adventure,” states Bruggeman. “I went from 19 to 40 in a matter of no time. It was crazy.” But his plans were cut short roughly halfway through his tour. “I got shot in the upper thigh and the bullet went through and severed my sciatic nerve,” an injury sustained in an accident on the shooting range. “We were qualifying with M-16s,” he recalls. “I don’t know why this guy did it, but he didn’t put his safety on, and for some reason, he put his finger on the trigger, and it went off.” Bruggeman was 20 years old.



He was rushed to the hospital where he underwent over 13 hours of microscopic surgery, an Easter weekend he and his parents would never forget. "When they got a hold of my parents, they told them, 'Your son is in surgery. We don't know if he's going to live. If he does live, we don't know if he will keep his leg.'" He was released from the hospital about a month before his twenty-first birthday. "In the military, you can't show emotion," says Bruggeman. "You got to keep going, no matter the circumstances." Bruggeman remembers being in denial about his condition at first, eventually turning to drugs and alcohol to cope. "It affected me a lot. I never accepted it." Bruggeman states his biggest challenge wasn't the loss of use in his leg, but having to re-learn much of what he already could do before.



"I was paralyzed in my right leg below the knee. I couldn't move my toes. I couldn't control my foot." Due to various infections over the years, he decided it was time to amputate his leg. "I was in and out of the hospital all the time and I was just tired of it." Today, he wears a prosthetic leg and switches between using his wheelchair and walking. "If I wear pants, you couldn't tell I wear a prosthetic." Yet, it was the loss of his leg that inspired him to put his best foot forward. Through the Sioux Falls Veterans Affairs is where he found his love of adaptive sports. "They showed me sailing, kayaking, track and field, and that there were things out there."

What Sports do You Play?

"The VA has given me everything I need to play hockey, which is a big part of my life right now," mentions Bruggeman. "I love it and I can't get enough of it. The wife gets tired of listening to me talk about it," he laughs. He found his passion while attending a winter sports clinic in Snowmass, Colorado. "I learned how to downhill ski a two-track like everybody else." From golfing and downhill skiing to sled hockey and recumbent cycling, the Sioux Falls Veterans Affairs helps Bruggeman fund his adaptive activities; activities that have opened the door to a wider community. "It's really about a bunch of disabled people in the community together. It's fun and I love it."

What Are Some Common Misconceptions About Your Disability?

Bruggeman recalls a time where he was accused of faking his disability. "I pulled into a handicap parking spot, and I was wearing pants that day," he states. "I noticed a man pull around and park across me on the handicap spot on the other side." Bruggeman was confronted by the man upon entering the store. "He looks at me and says, 'Did you find a doctor to give you that handicap placard or what?'" Although reluctant, Bruggeman responded simply by pulling up his pant-leg and showing him his prosthetic leg. "His 85-year-old mother was pissed off at him," he laughs. "I don't have to show you anything. I don't have to explain anything to you. It is what it is."

In fact, Bruggeman doesn't mind the occasional questions about his leg, especially from kids. He says parents, however, will sometimes rip their kids away out of fear of offending him. "They think they're being polite by not letting their kids ask," he states. "But they're not really being polite. They're not letting the kid solve their curiosity." When it comes to his prosthetic leg, he says he's never ashamed to talk about it. "I'm proud of it. I

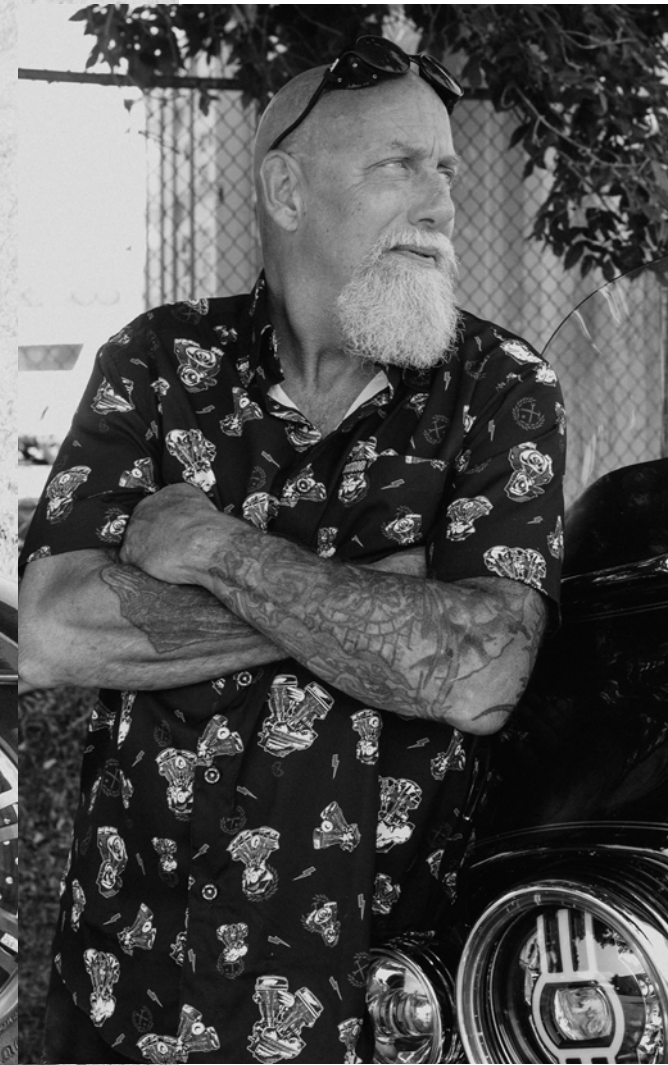
wouldn't draw attention to it if I wasn't." He has it decorated with the American flag when it's visible. "If you have to look at it, you might as well look at something," he smiles.

Why Did You Join This Show?

"To help promote disability awareness," said Bruggeman. "It needs to be known that just because I'm not in a wheelchair, doesn't mean I don't have a disability." He's grateful for the show pushing him out of his comfort zone. "I've never modeled before," he says. "It was kind of different and there were so many cameras and videos in one day; it was pretty crazy." He mentions his beard also got an overdue tune-up. "They turned my whiskers into a goatee, and my wife really likes where it's at." For his shoot, he took pictures on his three-wheeled motorcycle, otherwise known as a trike. "I'm really excited to see what this show is going to be like."

What do You Want People to Take Away from This Show?

"This guy is doing good," states Bruggeman in reference to himself. "Compared to where I was 30 years ago, I'm in a pretty happy spot right now." Bruggeman says that, even though, on the outside, it might not always look like he has a disability, that people should never assume anything. "I guess everybody has kind of like two lives." There are things the public sees and there are things they don't. "I still get PTSD and the phantom pain moments," he states. "In public, I won't let you see how bad it's really hurting, but you can't let it control you. You have to control it."



Today, Bruggeman enjoys retirement, living on disability through the military. But what he enjoys more, is spending it as a family man. "I have a great wife that's been with me for more than 30 years now. She's been with me through thick and thin." Together they have two kids and are also raising their two grandkids. "We've been raising them since they were two and three and they're 11 and 12 now." While life can often feel like you're stuck in the trenches, Bruggeman says it's important that you soldier on. "You have to make it better. You have to learn how to overcome and adapt and make things work for you."

TANA ZWART

“I’m always wanting to have more of an active role.”

From the moment she moved to Sioux Falls, South Dakota, in 2014, Tana Zwart wasted no time embracing her new community. “I like hanging out with friends and doing things downtown,” she states. “I love finding new places to eat and drink and all that good stuff.” Beyond exploring fun sights and locations, she balances her time by giving back. “I’m involved in a lot of nonprofits around town and different advocacy groups for folks with disabilities.” Most recently, she’s embraced her role as the Chair of the Disability Awareness and Accessibility Review Board (DAARB) for the City of Sioux Falls. “I’ve held that role for the last three now, so that’s been a new experience.”





Her passion for helping others started when she was young, around the time she was diagnosed with Facioscapulohumeral Muscular Dystrophy (FSHD). “It’s just a really long word that means facial muscles and upper arm muscles,” she laughs. Most people who develop FSHD are usually diagnosed later in their life. Zwart’s condition, however, was a rare case. “I was diagnosed in second grade.” A life-changing diagnosis that, at first, didn’t slow down an otherwise active childhood. “I was still walking and doing sports,” she recalls. “It wasn’t until about junior high that it started getting hard to walk, and I began using a scooter for longer distances.” An experience that came at an already difficult time. “You’re going through puberty and things are awful anyway and you don’t want to be different,” she says. “I had this very real disease that was making me noticeably different.”

Not only was this disease taking away her ability to walk, but it was also beginning to affect her passions. “My friends were still playing sports and I wasn’t anymore and that was very much my identity.” FSHD causes the muscles to progressively weaken, but it was through years of coming to understand her diagnosis where she found her strength. Zwart turned her attention to other interests, namely fashion. “That’s something I’ve been able to use in a lot of different ways; for comfort, for expression and it helped me cope.” Looking back on what she’s lost, Zwart says she’s grateful to have gained perspective. It’s that life experience that’s helped guide her mission for disability advocacy. “If you value people with disabilities, and want them in your community, you have to be actively and intentionally thinking about things like accessibility.”

What Are Some Ways You Advocate for People with Disabilities?

As Chair of the DAARB, she mentions her goal is to be a strong resource for the city. “We’ve been deciding what projects we want to take on and how we want to be involved in the community,” she states. She’s been behind major projects such as the ArtAbility show held every year and the disability awareness parking signs around town. She is also a member of the ADA30 Sioux Falls committee, and a board member of Rare by Design.

As a strong supporter of the Muscular Dystrophy Association since diagnosis, she’s had an active role in speaking, fundraising and event planning over the years in various capacities, both locally and nationally. From 2019-2020, she served as the MDA National Ambassador. “In my first year,” she states, “I went to Florida for a scientific conference. We also went to Washington, D.C. to advocate on The Hill. We talked with congressmen about different issues affecting our community, specifically accessible air travel.”

What Are Some Common Misconceptions About Your Disability?

“The loudest misconception is that I’m unfriendly or unhappy,” she mentions. “My disease affects my facial muscles, so I can’t really smile and show my teeth.” She says her condition mixed with her calm and introverted personality makes it easy for people to misjudge her. “It was a huge insecurity for me,” she says. “People say things like, ‘Why don’t you ever smile?’ or ‘What’s wrong with you?’” Over time, however, she learned to put less weight on other people’s words and more on what she loves about herself. “I learned a long time ago how to just be okay with people being wrong about me, because it is wrong,” she recalls. “I have a huge heart and a great sense of humor. You can fake a smile, but you can’t fake those things.”

Zwart says dating with a disability is also full of obstacles rooted in misconceptions. “Dating these days is hard to begin with, but add a disability/rare disease on top of that – wow.”

From inappropriate questions and comments to an underlying mentality that people with disabilities should be happy to get what they can get, Zwart says it gets defeating quickly. “The fact that individuals with disabilities can be intimate or equally contributing partners is still a hard concept for a lot of people. Combatting that is frustrating,” she states. “People with disabilities are equally (if not more) aware of their human needs just as much as they are aware of what they bring to the table. I mean, hello, I’m a great cook and get good parking,” Zwart jokes.

Why Did You Choose to Participate in the Show?

“It was actually a brainchild of me and Kendra,” she laughs. “We were trying to think of fun, interesting ways to reach the community.” It was during her time on the Disability Awareness Commission in 2015 that she met lifelong friend and fellow advocate, Kendra Gottsleben. “She asked me for my help on a project with the Center for Disabilities and then we just kind of became friends that way.” Flash forward to today, and they’ve collaborated on numerous projects, big and small, including Rare by Design’s The Style Show and now the Refocus exhibit. “We’re all so unique as human beings, and especially as people with disabilities,” she mentions. “Just to focus on the fact that we’re so complex and we’re not just our disability...this show is a really cool way to do that.” For her photoshoot, Zwart took the opportunity to express herself through her passion for fashion. “I’m not the loudest person, but I like to be loud with my clothes and my makeup.” Her outfit was bright and colorful with glamorous studs sparkling off her jacket and shoes. “It was just kind of obnoxious, which is what I like,” she laughs.



What Do You Want People to Take Away from This Show?

“I hope that I present myself as somebody who is stylish and takes pride in her appearance,” she states. “My wheelchair is part of me and my story, but it’s not 100% of who I am.” Beyond her looks, Zwart hopes people can see her strength and assurance underneath. “I am very empowered and able.” A sentiment she hopes people can find when they see every model on display. “I think if people can realize that disabilities are a

naturally occurring part of the human race, and we’re not just some “other” group of people, that would be a good start,” she says. “We’re all just people. We all have thoughts and feelings, goals and a purpose, only it’s in a world that isn’t made as accessible for us as it is for everyone else.”

Despite times when life takes things away, Zwart always finds a reason within herself and gives it her all. “I’m very fortunate to have had a lot of experiences.” That includes having a major role in the Refocus exhibit. “There’s just nothing like it around here, so I’m just really excited about it.” From advocating for disability access and awareness to exploring her passions without limitation, where some might see disability, she sees opportunity. “Because we’re in the Midwest, I think there’s an old school mentality and many misconceptions about disabilities still,” she mentions. “The Refocus exhibit is a really unique way to showcase people for who they are. You can tell people until you’re blue in the face, but to be able to SHOW what disability really is and rearrange those misconceptions... this show is something really special.”



KONI SIMS

“I try to speak up and make sure that people’s voices are heard.”

One look at Koni Sims, and it’s easy to see how much of an advocate she is for people with disabilities. “I serve on a national board for the blind and visually impaired,” she mentions. “I serve on state level and some local level boards and committees for the disabled.” Her drive to help stems from a young age. “I’ve been legally blind since birth.” She has the rare eye disease Aniridia, which causes partial or complete absence of the iris. Born in the small town of Groton, South Dakota, she grew up a “very strong Lutheran,” with an even stronger sense of self. “When I was 12, my parents told me that if I didn’t stand up for myself, no one else would.” Values that extend to the people around her. “I have friends and family that have mental and physical conditions,” she says. “When I advocate, I think about everyone.” When she finds time for herself, she usually spends it with her husband of over 30 years, Seth, who is deaf-blind.



Due to her strong faith, Sims amassed quite the cross collection over the years. “I love crosses.” On May 12 in 2017, that faith saved her life. It started as a typical day, with Sims going with her husband to a doctor’s appointment. “I don’t know why, but God told me to wear a special cross that day.” After the appointment, they decided to grab breakfast. “We were at 41st and Sheldon Lane, which is the “T” intersection right across from Perkins there on 41st Street, and it was busy.” As they were crossing Sheldon Lane to the Original Pancake House, an oblivious driver decided he could turn right into traffic and struck them. “He flipped me over the hood.” As he swung around the corner, her feet were crushed under the wheels. “He kept going, knocked down my husband.” She was then flipped to the ground. The driver dragged her into 41st street and stopped inches from her neck. “I can still see all the tread marks today. I could count them. He was seconds from beheading me.” Thankfully, a nurse and a couple citizens were nearby to help. As they waited with her for the ambulance to arrive, Sims recounts the nurse commenting on the cross around her neck, “God is here. He kept you safe.”

The accident left Sims with mobility issues and crushed feet. “They looked like hooves.” But you couldn’t crush her faith. “The doctors agree that there were angels holding the car up because I probably shouldn’t have made it.” Sims had a major back surgery. “They had to do a cage and four screws.” She suffered permanent damage to her feet and has nerve damage that has caused neuropathy to her feet and hands. “So, that’s when I ended up having to quit work. I tried going back and I couldn’t do it.” She officially retired in 2020. While the accident felt like a low point, Sims’ faith helped her see it as a blessing in disguise. She now focuses on advocacy full-time as a member of countless boards. “God was there to protect me and to guide me,” she states. “I wouldn’t be doing the advocacy work that I am today.”

What are Some Common Misconceptions About Your Disability?

“Sometimes, you feel like you can’t be yourself because people are judging you,” mentions Sims. “People think that, because you have low vision or you’re blind, you can’t do things,” a notion that’s even come up around family. Sims remembers a few instances with her mom when she offered to help her cook. “She would get worried sometimes because I’m left-handed.” A sentiment that has been expressed by other family members, as well. “They don’t let me do stuff in the kitchen because I might do it differently and they don’t feel comfortable around it.” Sims says that just because her way looks different doesn’t mean it’s wrong. “It’s my way of doing it.”



“I think all of us have a disability to some degree,” states Sims. “It’s just more noticeable on some of us.” It’s that separation, says Sims, that makes it tough to avoid glares from onlookers. In those times of self-doubt, she’s reminded of what she and other people, like her husband, have accomplished. “I look at my husband, he is totally blind—now is hard of hearing—and how he does landscaping and woodworking. He’s good because he does it by touch. It just takes him a little longer.” When a person with a disability – whether it be physical or mental – is presented with a challenge or opportunity, Sims asks that you reserve your judgement and give that person a chance. “If we can’t do it, or if we need help, then we will ask for help, but don’t just assume that we can’t do things.”



Why Did You Join This Show?

“I think doing this photoshoot is a wonderful way to show off who we are.” Sims’ first experience with modeling was in 2022, strutting the catwalk in Rare by Design’s The Style Show. “It was so fun.” She says her experience with Refocus allowed her to show off the “lighter side” of her personality. “I feel like I’m too serious, sometimes,” she expressed. “For my shoot, I played with the flowers and different things, and it was just kind of fun. It’s a side of me that people don’t always see. A more playful side.” For makeup, she asked the artists to accentuate her right eye with a creative, colorful design. “The artist was so good that I said she could do my makeup every day,” she smiles. “It was fun. It showed me with my cane, but it didn’t focus on the cane, and it just showed who I want to be, who I could be.”

What Do You Want People to Take Away from This Show?

“That we’re just like everyone else. I’m a whole person.” Sims feels that people who don’t often interact with people who have disabilities can be timid upon meeting them. “Getting to know individuals with disabilities might get people to think about being more involved in the disability world or advocacy work.” She wants people to understand that the real limits in life are the ones people put on themselves. “Whether you have a vision issue and use a cane, if you’re someone who has a wheelchair, you have Downs Syndrome or you are have hearing loss, you’re still a whole person.”

Since retiring, Sims serves on the Active Transportation Board (ATB), the Sioux Falls Pedestrian Planning Committee (PPC) and she was elected to the American Council of the Blind (ACB) board and still serves. She represents ACB on the International Code Council (ICC) and American National Standards Institute (ANSI). She was also President and now the current first Vice President and Past President of South Dakota Association of the Blind (SDAB). When she’s at home, the work doesn’t stop. “I like to be outside,” she states. “We have a house with lots of flowerbeds and I love to work on my flowers.” The latest project she and her husband completed was residing their garage, which Sims later repainted herself. “It’s therapeutic for me,” she says. “Just because you’re blind or visually impaired doesn’t mean you can’t get out there and do what you love.”

SCOTTY BRIGGS

“Just because he’s not always able to express his words, doesn’t mean he can’t do things.”

Scotty Briggs is a man of action. “He has been a swimmer for 20 years,” says his mother, Julie Briggs. “He also competes in track and field.” His love of sports has deep roots, as it began when he was young. He attended Roosevelt High School in Sioux Falls, South Dakota, where his love only blossomed. He would attend every event, something that he still does to this day. When he’s not cheering in the stands, he spends his time celebrating his family. “Those are some of his favorite people in his life.” Briggs recently celebrated his sister’s wedding over the summer. “He sort of stole the show from the bride and groom,” she laughs. “But that’s okay, they all expected it. That’s usually what happens.”





Briggs' mom states, "Scotty was born with Down Syndrome, and he was my third child and only boy. I've been in the field of working with disabilities for well over 25 years now," she says. "There are a lot of different abilities within individual disabilities." She mentions he's developed a unique way to communicate. In other words, he lets his actions do the talking. When he isn't competing, Briggs helps with Special Olympics South Dakota's fundraising efforts. "We do this fundraiser called Chase the Ace. Our CEO, Darryl Nordquist loves having Scotty there, because even though Scotty doesn't have a lot of words, he works that crowd and he's a great fundraiser."

Like most people, when Briggs is not out at sporting events, he's busy at work. He's employed by The Effortless Bow, a local business that specializes in handmade modern hair accessories. "Scotty assembles bows," says Briggs. "He also puts the orders together and gets them ready to be shipped out." Over half of the team is made up of individuals with disabilities. "He is working in a really cool, inclusive environment."

What is Working Like for Scotty?

The Effortless Bow was founded by Mary Spargur, a former Special Education teacher. “She knows how important it is for those with disabilities to be able to have opportunities,” Briggs’ mom states. The business’ mission is to create enjoyable and meaningful employment for adults with intellectual and developmental disabilities. “She has taught Scotty many skills. He’s done things like ironing, which I didn’t even know that he could do.” Briggs also assists The Effortless Bow at various art shows, where he drums up business and networks with potential customers. “He’s a good PR person. Scotty knows a lot of people,” she mentions.

What Are Common Misconceptions About Down Syndrome?

“People put limits on what people with Down Syndrome can do.” Briggs says that her son doesn’t let his situation stop him from being a part of society. “He does what he wants and loves life.” But, as we know, life presents its fair share of challenges. “Sometimes people will assume, ‘Oh, they’re always so happy.’ That’s not true. He has his times of frustration.” Frustration that stems from difficulties with communication and finding independence.

Because of his limited verbal skills, Briggs states that some people assume her son has lower intelligence. “That is such a misconception, because he is a very smart young man.” In fact, Scotty has very good handwriting and quite the artistic side. He can draw and he practices photography. His artwork has been featured in ArtAbility shows. “Our dining room table is also known as the ‘art table,’” she says. “It’s full of his artwork.”

Why Did You Join This Show?

“For many years, I’ve been an advocate,” mentions Briggs’ mom. “To be a part of this organization and to help others understand that he can do what everyone else can is something that I want him to be a part of.” For his shoot, Briggs wore the stylish suit he wore at his sister’s wedding. “He’s usually in sportswear, but he occasionally likes to dress up and look sharp,” she says. Having been a model in the past, Briggs was no stranger to flaunting his style for the camera. A big part of the fun, according to his mom, was seeing some of his old friends. “Any time Scotty’s happy and is comfortable, then of course that’s a wonderful thing for me to see him have good experiences.”

What do you Want People to Take Away from This Show?

“We just want people to know that there are not limitations for people with disabilities.” Briggs and his mom have worked with Rare by Design in the past. They feel this show is an excellent way to help reshape the public’s preconceived notions about people with disabilities. “We were honored to be a part of this project.”

“Yes, Scotty has Down Syndrome, but he is like everyone else and does things like everyone else.” From hanging out with family and making art to watching sports—and even competing himself—you’d be hard-pressed to find a dull day on Briggs’ calendar. When he enters a room, he is the light that burns brightest, bringing warmth and illuminating people’s lives. He’ll greet you with a genuine smile and perk you up with a hug. “Scotty loves people, and he enjoys meeting people,” she mentions. “He understands so much more than people give him credit for.” While Briggs might not always be able to express himself in words, with every kind gesture, hug and smile, his actions speak volumes.



Laura Hayne

“I’m very open to all types of people. Once I make connections, I’m very extroverted.”

Ever since she was a child, Laura Hayne has considered herself pretty flexible. “I was a gymnast.” She practiced gymnastics from ages eight to eighteen. In her sophomore year of high school, her parents bought a gymnastics for an extra practice,” she remembered. “I did a move I had done a million times.” What she didn’t know, is the gymnastics bar wasn’t fastened properly. “It basically sling-shotted me down to the floor.” She was eighteen when she broke her back.

“I couldn’t feel my legs,” recalls Hayne. “It felt like they were suspended up in the air.” Thankfully, she was with one of her coaches at the time. She was taken to the hospital. It wasn’t until after surgery when reality started to set in. “It’s really, really tough to go from able-bodied to disabled as a teenager.” But she didn’t go through it alone. During her time in the hospital, friends would often visit her throughout the day. “I had people there all the time.” But she wasn’t about to get too comfortable. “I was very determined to get out of the hospital,” she says.





Upon returning to normal life, she found herself faced with new obstacles. “Trying to socialize with people was hard. Nowhere was accessible,” both in the physical and emotional sense. “I was very good at hiding my emotions. That’s what I always did growing up with gymnastics.” Despite the occasional hurdle, Hayne found herself balancing life just fine over the years. “I’m a single mom. I have two kids: a son and a daughter.” As her kids enter their teen years, Hayne now searches for more activities. “I’m trying to find things to do for myself,” she states. “I want to get out into the world more.”

What New Things Are You Trying?

“I’ve just kind of been in my comfort zone the last few years.” Hayne says the COVID-19 pandemic left her a homebody. “I started going to a counselor and working on what I wanted to do.” She was encouraged to open a new chapter in her life and join a group that shares similar interests. This came to her when she found a book club. “It’s at a coffee shop in Tea, South Dakota, and I was like, ‘Oh, I can actually get there.’” The club was founded by a woman who began writing her own books during the pandemic, which sparked up an old idea of Hayne’s: writing a book about her life. “If I have questions, she’d be great to talk to about it.”

What Are Common Misconceptions About Your Disability?

“People are always very surprised when some of us drive,” she mentions. “When I first got hurt, that’s what people kept saying, ‘Oh, you’re going to need a van.’ But who wants to get a minivan at 18? I’m almost 46, and I don’t want one now,” she laughs. Despite having more accessibility in certain places, when she ventures out, Hayne says she can often feel like an outsider. “When I go out to things that commonly involve standing, you’re not going to see many other disabled people.”

Early in life, she was also advised to not get pregnant. “None of the doctors recommended that I have a baby,” she recalls. “They were scared because they didn’t know what would happen with somebody with a spinal cord injury having a baby.” Today, her son is seventeen years old.



Why Did You Join This Show?

“I don’t like pictures.” Hayne states modeling is out of her comfort zone, which is even more reason she pushed herself to do it. “It was so fun,” she says. “My hair was amazing. My makeup was awesome.” She did her photos in the style of a sexy librarian. “I told Hollie, ‘If you could make me look hot, that would be great,’ and it was great. I felt hot.” She got some early buzz after she shared a selfie online, receiving a ton of likes and positive comments.

What Do You Want People to Take Away from This Show?

“To see people and beauty in all different forms.” Hayne says, while disabled people aren’t often considered for this type of art form, she hopes this show will help break that negative stigma. “This is definitely a big step out of my comfort zone.” She’s excited to see everyone’s reactions to the gallery – from both the public and her fellow models. “I can’t wait to see what everything looks like,” she mentions. “It was really fun to see everybody getting ready.”

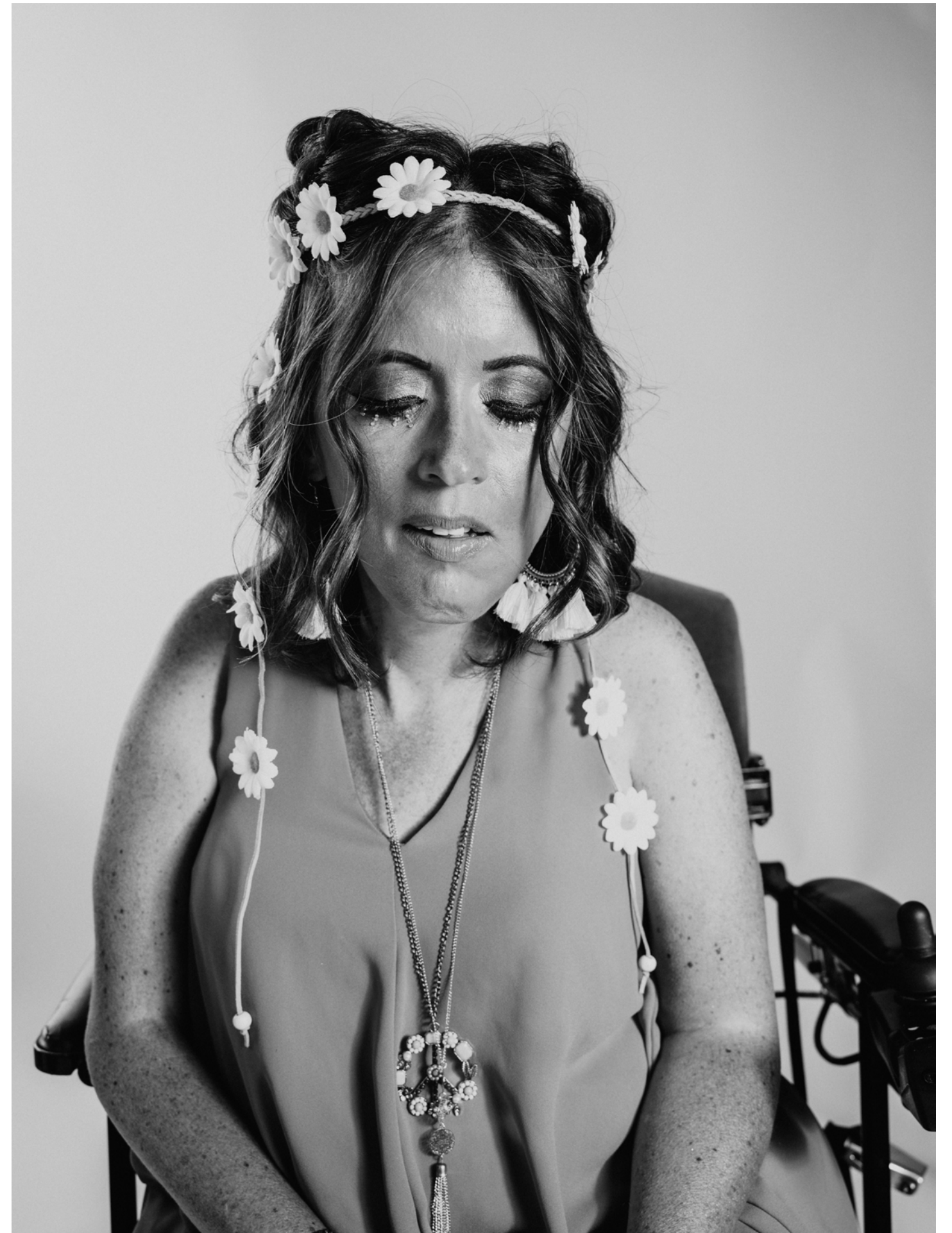
As for what’s next for Hayne, she says she’s staying flexible. “Getting out and doing more things is definitely on my schedule.” As she continues open herself up to new adventures, she asks others to do the same in regard to people who live with disabilities. Even though her situation may look different on the surface, if you look closer, you might find something in common. “I have a house, I take care of it,” she states. “I take care of my kids, and then I do pretty much everything that the average person does.” Whatever adventure comes next for Hayne, she knows it will be one for the books.

MELINDA PALLONE

“Your disability can either hold you back or you can keep pushing forward.”

For Melinda Pallone, those words are a way of life. She was born in 1979 with Merosin Deficient Congenital Muscular Dystrophy (CMD). “Which basically means that I don’t have protein on the edge of my cells like most people,” says Pallone. Since birth, she hasn’t been able to walk on her own, needing to rely on leg braces during most of her youth. “Then, during puberty, I grew faster than my muscles were strong, so my hips became uneven by the curve in my spine. So now I use a power wheelchair full time.”

While CMD may have caused her childhood to look different, her upbringing was anything but. “My parents, they never treated me like I should be doing anything less than my brother and sister, who fully walk.” Pallone recalls them having equal expectations and cites her mom being her “best friend” growing up. “They just wanted me to leave the house just like the other two,” she laughs.



And that she did. Upon graduating from high school, Pallone earned her bachelor's degree in Economics at Buena Vista University, her master's degree online from the New York Institute of Technology, and a number of program certificates and financial licenses in her work as a financial representative for eight years. It wasn't long after meeting her now husband, Steve, that Pallone gained a new-found passion for creativity, art, and sharing life skills for those with disabilities by working as an Independent Living Specialist/Advocate for a local Center for Independent Living. She and Steve have now been married for 13 years, have 3 children and currently live in Sioux City, Iowa. She continues her drive for sharing an unhindered life on her YouTube channel, "Melinda Speaks".

How Does Social Media Play an Important Role in Your Life?

"I create motivational videos [on YouTube] that push positivity," she says. Her latest video focuses on how life can be overwhelming and shares a personal story of a hard time she's overcome. "That's how I was raised, no 'poor me' or anything like that." She works with her son to run the channel. He often gives her feedback on her videos. "He 'critiques' them, I'll say that," she laughs. Pallone mentions that her son also teaches her how to edit the videos she creates. Her goal for the channel is to be a positive influence on those who might have trouble looking on the bright side. "I'm trying to show people that, no matter what you're feeling in life, a positive attitude can help get you through it."



What Are Common Misconceptions About Your Disability?

The first instance Pallone experienced a misconception was when she was nine or ten years old. "My mom and I were at Target, and I was in a manual wheelchair. This little boy was checking out my chair, and just saying, 'Hi,' to me and then, suddenly, his mom runs up, pulls him away and says, 'Get away from her; you might catch something.'" She says that was the 80s and that was the attitude many people shared.

Since adulthood, she feels society has grown beyond those extreme assumptions. "I didn't understand until I got older how parenting styles could be so different." In fact, people are often surprised at how capable she is. "They're shocked when I tell them that I drive, I went to college, I have my master's and all of that." People are also surprised when they discover that she's a mother. She experiences similar reactions from medical staff during appointments. "Sometimes, at the end of a session, the doctor or nurse will ask, 'Do I need to call you a ride?' And I tell them I drove myself, and they're like, 'Oh, you drive?' But I just put on that friendly face because I know they don't mean any harm."

What Motivated You to Be in This Show?

"I loved Rare by Design's runway show. I just thought that was so neat. Plus, who doesn't want to be a model? So, the fact that I could do that and be a part of something really important is really cool," Pallone states. When it comes to fashion, people that share her condition hardly have representation. "It drives me nuts that when you're shopping for dresses or pants or whatever, all of the mannequins are standing up. You never know what that dress looks like when they're sitting down, and it makes it kind of hard when shopping." This art exhibit was something she knew she could not miss out on. "To be a part of something that can be so life-changing and eye-opening for so many people is amazing."

How Does it Feel Being a Model?

"I've never done any modeling, so that was kind of cool," Pallone says. "When I went in, there was a lot of excitement right away. Everybody seemed really joyful and happy to be there." When it came time for makeup, she told the artists she wanted to go "all out." "I had jewels down my face, really done-up eyelids and fake lashes and fancy hair." For some of the photos she mentioned she wanted to separate herself a little bit from her wheelchair, so she slid forward and put her feet on the ground. She states her wheelchair is how she gets around, but it's not all of her.

What do you Want People to Take Away from This Show?

She doesn't want this exhibit to be seen as something only for people with disabilities. Pallone says, "We are not just a little corner of the world, we are part of the greater fashion industry. It doesn't have to be disabled people over here or just one disabled person on a commercial or something. It should just be intertwined. That's what I would like to see." She mentions that she wants people to understand that normalcy doesn't mean to ignore disabilities. "I have life goals and aspirations. I have a positive attitude, I'm intelligent and I have a lot to give the world."

Pallone's hope is that she can be a positive influence on those who feel they can't achieve their goals – a mission that reaches beyond YouTube. Her favorite quote by former NFL Player, Trent Shelton, helps illustrate this mindset: "Perspective can either be your power or your prison." Whether it's for her kids, her husband or strangers on the street, every day Pallone sets an example of how to push forward when life tries to push you down.



Jeremy Neuheisel

“You can lose things, but you can gain things, too. It makes you a stronger person.”

Jeremy Neuheisel has a hard time sitting still. “I’m usually always on the go.” Whether it’s being a friendly face as a HyVee greeter or an educator volunteering at the Butterfly House, he’s always exercising his unique talents. “I love learning,” he mentions. “I’m looking at taking a couple of college courses. Maybe Psychology or English.” He also attends Bible study, where he has embraced his spiritual side. It’s a passion that has helped him see the bright side of his physical limitations brought on by cerebral palsy. “I just like emotions and learning how to control them,” he states.



To help him get around, Neuheisel often receives help from his twin brother, who does not have a disability. "He can be very pokey," Neuheisel laughs. It's not always convenient, however, and can often lead to points of frustration. "One of my biggest flaws is my anger." Much of this comes from the struggles of forming a daily schedule, where he requires much help from others with certain tasks, such as applying his braces, meeting appointments or going to activities. "Sometimes, I feel like I can only do one or two things a day," he states. A situation made more difficult by his optic nerve atrophy, a condition that has affected his ability to see. "Whatever you see at 200 or 400 feet, I only see at 20 feet." In spite of this, he keeps looking on the bright side.

When life gets turbulent, Neuheisel practices mindfulness techniques to center himself. "I try to treat my mind like a plane," he says. "Planes can swerve all over, but if you imagine the plane smoothing out, then, eventually, YOU smooth out." But it's not just his mind he keeps in shape. Neuheisel spends a lot of his time keeping active. "I've been working out since I was 14." While in public school, Neuheisel says gym class didn't offer proper exercise options, so he needed to make time outside of school. "I was swimming maybe once a week and lifting weights twice a week." He followed this up with physical therapy every day, which, he says, didn't offer a ton of flexibility in terms of being social. That all changed when he went to the School for the Blind.



How Did the School for the Blind Impact Your Life?

"It's where I learned how to rely on myself," recalls Neuheisel. "In public school, I got stuck with other kids with disabilities, and the school thought it was more important for us to play games and follow rules, when I thought I should be exercising." At the time, he weighed 160 pounds. In his first year in a new environment, he slimmed down to 117 pounds on his own. It was the move from public school to the School for the Blind where Neuheisel was able to strike a balance between exercising his body and his mind. "It allowed me to do different activities." The looser schedule allowed him to travel to different schools for extra curriculars, like speech meets or student council. "If I hadn't moved to that school, I probably wouldn't be as active or willing to try different things as I am now."

What Are Common Misconceptions About Your Disability?

"I feel like sometimes people hold me up on a pedestal." Neuheisel says one of the misconceptions that he experiences most is people looking up to him because he maintains a positive attitude in spite of his disability. "I just think to myself, 'You don't have to appreciate me for working. I'm just trying to live my life.'" There have also been situations where comments have been made at the expense of his religious beliefs. "People have tried to tell me that if I believe in Jesus hard enough, I could walk," he recalls. "Then they follow it up by saying that then I could finally get a full-time job." In response to these comments, Neuheisel exclaims, "Working is overrated, and so is walking!" He laughs, "I've heard a lot of people complain about walking."

Why Did You Join This Show?

"I just thought it'd be cool to try and have a new experience." Neuheisel says the Refocus exhibit is the first time he's done any modeling. He wanted his photoshoot to reflect his love of physical fitness. "A lot of my pictures were tailored to exercises and holding weights a certain way." Long before he practiced mindfulness as a teen, he says he'd spend countless hours at the gym. "I love the feeling of being able to lift something heavy and feel powerful," he states. "Fitness gives me a something to strive for."

What do you Want People to Take Away from This Show?

"I hope people take away that we're not something to be pitied." Neuheisel says this show is a strong opportunity to show people the strength he and his fellow models possess underneath the misconceptions. "I would like for people to know that I am determined and I'm willing to help other people out if I can, emotionally," he mentions. "Help is more than just physical, it can be spiritual and emotional."

Neuheisel mentions that the weight of his disability can be a heavy lift at times. "I have coworkers that feel the need to tell me that they feel sorry for me," he states. "That doesn't do anything for me. It just makes me upset." But working out his body and his mind has given him a unique opportunity to flex his greatest strength. "It gives me confidence," he says. "I can be an ear to listen, give a kind word or send a prayer." Meaningful gestures, he believes, we can all exercise. "Be a good neighbor. Be the Mister Rogers."



KENDRA GOTTSLEBEN

“When life gives you lemons, you make the best lemonade possible.”

No matter how sour life can feel at times, you'll always find Kendra Gottsleben with a smile on her face. “I love helping others.” Born with the rare disease Mucopolysaccharidosis Type VI (MPS), Gottsleben says her situation is a rare case. “There are, as far as we know, about 100 people in the United States that have it.” An individual with MPS lacks the enzyme needed to cleanse their cells. “My cells are built up with this lovely, mucus-like substance,” she laughs. It's also resulted in her having a short stature. Despite her diagnosis at the age of 4, she says it wasn't until 5th grade when she began to notice her fellow classmates towering over her in height. “I must've been a naive kid because I just thought, ‘Oh, I'm really short,’” she chuckles. It wasn't until she was 12 when her parents informed her of her condition. “It was during a trip to the University of Minnesota, which is a specialty hospital for MPS. We would go there every summer for appointments and surgeries when needed.” While some might see this news as a limitation, Gottsleben found herself exposed to a world of opportunity.



“My disability has led my life professionally,” Gottsleben states. “I started a nonprofit and I help others with rare diseases and disabilities.” When she was 16 and in high school, she had the rare opportunity to take part in a clinical research trial for enzyme replacement therapy. “That’s an experience that not a lot of people have.” The therapy helped doctors build a case to go to the Food and Drug Administration (FDA) and develop a treatment for people with MPS Type VI. “That was the first time I’d ever met anybody else with my disability,” she recalls. “It was interesting because I grew up in Vermillion, South Dakota, and I was the only person in a wheelchair in middle school through high school.” Because her condition is so rare, the fact that a pharmaceutical company was doing research on it was, in her words, “a miracle.” During her diagnosis process, Gottsleben recalls that her doctors told her parents that she may not see the day treatments are approved. “Not only did I see the day,” she says. “I took part in getting it FDA approved so that when anybody is diagnosed, when a baby is born with MPS Type VI, they can start treatment right away.”

Today, Gottsleben is the Marketing Communications Specialist at the Center for Disabilities at the University of South Dakota Sanford School of Medicine in Sioux Falls. “I work with a broad audience of health care professionals, individuals with disabilities, families and all of that.” She’s been in the role for 13 years. Gottsleben also serves as the executive director of the local nonprofit Rare by Design, which she founded in 2021. It focuses on creating awareness, inclusion and representation for individuals with rare diseases and disabilities. It wasn’t until Gottsleben underwent open heart surgery when she decided to bring her dream to life. “I didn’t know if I was going to come out alive or not,” she remembers. “I needed to stop wondering and waiting for what the future might hold and put a plan into action.” She says that while her condition has given her some really neat opportunities, that doesn’t mean she hasn’t had her fair share of hardships. “I don’t focus on those,” she mentions, “I focus on the lemonade.”



What Lemonade Have You Made?

Gottsleben is an accomplished author and has published three books. Her first book – published in 2012 – *Live, Laugh, Lemonade: A Journey of Choosing to Beat the Odds* chronicles her life with MPS from childhood to graduating college. The book also contains poems that she has written throughout her life. She also wrote a children’s version of that story, called *Kendra’s Lemonade*. The book educates kids about MPS and how it’s okay to be different from others. “Everybody has something that makes them unique,” she mentions. Her third book, *Kendra’s Perfect Dance Routine*, was released in 2019. This story was inspired by her two years in dance class when she was in grade school. “[In the book] Kendra was sad because she wasn’t doing the moves like her classmates,” she explains. “She wanted to be perfect like everybody else, but she just couldn’t get it figured out. And then, she finally realizes that her perfect dance is her own, unique dance. It’s her way of doing it, that’s what makes it perfect.”

What Are Common Misconceptions About Your Disability?

“People have asked me, ‘What’s your life expectancy?’” Gottsleben says, when they hear the term rare disease, people often assume the worst. “I get where they’re coming from, because, when you have a rare disease, it’s a little different.” She reminds people that there’s no specific life expectancy with MPS Type VI, and the situation all depends on the type someone has. As far as she knows, her life expectancy is like anyone else’s with some lung and heart concerns. “I could cross the street and get hit by a car tomorrow.”

Whether it’s an injury or a rare disease, Gottsleben states that the line dividing people with and without disabilities is pretty thin. “Disability can happen to anybody no matter who they are or what they look like.” That is inevitable for everyone over time, it just has a different term. “We call it growing older,” she mentions. “You have to understand the actual definition of what a disability is. It’s not being able to use fine motor skills, or thinking processes. You experience hearing loss, etc. Those are all things that can happen when you get older.”

Why Did You Choose to Participate in This Show?

“I wanted to try to show that, despite being short and in my wheelchair, I am powerful and I have a different side.” Gottsleben has been in photoshoots before, mainly for pharmaceutical companies. “This was probably the most thrilling experience I’ve had,” she says. “I had been glammed up for some things, but this was like ten notches up.” For her photos, they were shot in a way that pulled focus away from her wheelchair, not to separate herself from it, but to remind viewers that, wheelchair or no, it’s Kendra who is front and center. “Because I am little, sometimes the wheelchair can like overtake me in photos,” she states. “I always tell whoever is taking photos, ‘Please make sure the wheelchair doesn’t look like it’s eating me,’” she laughs.

As one of the creators of the show, her experience with the shoot was quite unique. “It was just something that I kind of always dreamed of doing.” Her favorite part was seeing the happiness and comfort in her fellow models. “I feel joy when I see others experiencing things that: A. help with confidence, and B. they don’t get to do every day. There’s been nothing like this in Sioux Falls.”

What do you Want People to Take Away from This Show?

“There are hardships that come with having a disability,” mentions Gottsleben. “But there’s also a lot more to life than people think.” As the title of the show implies, Gottsleben hopes viewers will Refocus their initial perceptions at the show. “I hope they see that people can be married, you can have children, you can be an active community member, you can have a job, you can do a lot of things when you have a disability.” She also hopes to deliver a unique experience for everyone involved. “I love giving people experiences.”

“We’re all models,” she states. “I want people to feel how amazing they are for just who they are.” Gottsleben says that, without her disability, life would be quite different. “I’ve had a lot of cool, incredible experiences because of what I have. I would not be where I am today.” A life that she wouldn’t change for the world. “There are definitely times when I get frustrated with what I have,” Gottsleben admits. “But I count the more positive things because, at the end of the day, that’s what life is really about.” While some days life can be a lemon, Gottsleben reminds us that, with hard work and positive attitude, we too can stir up some sweet lemonade.



CONNOR ROEMAN

“I’m just an 18-year-old trying to have fun and live his best life, no matter his circumstance.”

It goes without saying that Connor Roemen is a bit of a daredevil. “My whole life I’ve been an adrenaline junkie,” he says. He loves his family, friends and playing sports. From skiing to tennis, name a sport and chances are he’s played it. And ever since he’s been in his wheelchair, his world has only gotten bigger. “About two years ago,” Roemen recalls, “I was injured in a car accident which left me paralyzed from my waist down.” He was riding with some friends around the lake. “The driver was speeding around a corner, lost control and then we went into the ditch and hit a tree.” At least, that’s what he was told happened. “I don’t remember about two hours before and about two days after the accident.”



When he came to, he had a feeling life would be different. “I kind of knew right away,” he states, “but I didn’t know I was paralyzed. I just knew I couldn’t move or feel my legs. I asked my mom, ‘Am I my paralyzed?’ and she didn’t want to say it, but I could tell by the sadness in her eyes.” Accepting and adapting to this change didn’t come easy. “At first, I was trying to come up with a way to try and change that situation, like, ‘What would’ve happened if I would’ve gone home from the lake that day like I had planned?’” Not long after, Roemen stopped dwelling on the past and turned to his faith to help him move forward. “God came down to me and said, ‘You’ll be okay, trust Me. I have good plans for you.’”

On the surface, this might seem like a life-altering event, but, if you ask Roemen today, he’ll tell you not much has changed. “I’m the same person as I was before my injury, but now, I just have to work harder to accomplish most things in life. Because of this, I have a much clearer mindset.” He mentions things that keep him going are God, his family, his friends and his community. “They’re always commenting on my social media or my parents’ social media posts saying, ‘What an inspiration,’ and ‘He’s so positive,’ and all these wonderful things and I don’t want to let them down.” He states he’s also encouraged by others with similar injuries. “I see people that are in the same boat with a broken back and in a wheelchair, but they’re still having fun.”

Do You Still Play Sports?

“Before my injury, I played football, basketball, baseball, golf, tennis, and I didn’t want to stop doing those. At first, I thought I had to stop,” Roemen said, but his disability has opened doors for him in the world of adaptive sports. Some of his favorite sports to play include wheelchair tennis, sled hockey and mono-skiing. He’s also looking to join wheelchair basketball. He mentions playing adaptive sports has also broadened his circle

of friends. “You step into this new world, and you meet other folks who have been through similar situations and you realize you are not alone.”

What Are Common Misconceptions About Your Disability?

“To be honest, around two or three years ago—my freshman or sophomore year—I would see a person in a wheelchair go by and wonder, ‘What happened to him’ or ‘What happened to her’ and think, ‘Oh, they’re not living a good life because they’re in a wheelchair.’ I felt sad for them,” he reflects. “Ever since my injury, I’ve realized that my life is still good. You might not be able to do the things you want to all the time, but it’s a new way of life and sometimes you discover something new about yourself.” And he hopes others who meet him can understand a similar lesson. “If I meet a stranger in Walmart,” he says, “they don’t know how to treat me. Unlike my friends, who treat me the same as they did before my injury, which I want them to do.”

When it comes to meeting others who don’t understand his condition and make comments, Roemen has learned to treat them with empathy. “Sometimes I’ll see little kids staring at me or they will say something to me. I let it go because I know I was in the same boat at one point, so I just try not to let that stuff get to me.”



Why Did You Join This Show?

“My mom came to me, and she was like, ‘Do you want to be a model for this event?’” He was interested despite having never modeled before. “I wanted some good pictures of me that I can just have and I may post on social media.” He says he wanted his photoshoot to have a casual feel. “I did mostly streetwear. I wore a sweatshirt and then a nice polo with some khakis. It was cool. Hollie was so good about it, she made the experience better because she knew what she was doing.” Roemen wants his photos to remind people that, at the end of the day, he’s just like any other young adult. “No matter your disability in life, you can still live a good life. Don’t let people bring you down because they don’t understand.”

What Do You Want People to Take Away from This Show?

“That your disability doesn’t define you.” No matter your shortcoming—disability or not—Roemen wants people to see this show and be motivated to let nothing hold them back. “But not just me,” he mentions. “I want people to know that one can endure anything if they just believe in themselves.”

Today, you can still find Roemen playing sports, hanging out with his friends, and just doing what he loves. Only this time, his circle has grown much wider. “I’ve made some good friends and a lot of connections along this journey that have made me who I am today,” he says. His next goal in life is to attend Augustana University in Sioux Falls, South Dakota, and major in Business Administration and Entrepreneurship in hopes to grow his brand, Endure Anything.



HAILEY BORK

**“I love fashion.
It’s part of my life.”**

When it comes to style, Hailey Bork is no stranger to posing for the camera or walking the runway. You might recognize her from Rare by Design’s first The Style Show, or you might have seen her on a billboard or two around Sioux Falls, South Dakota. “It’s my dream.” She first discovered her love of fashion online, where she learned how to channel her beauty through watching videos. This inspired her to join The Style Show and strut her stuff on the runway, an experience that Bork can only describe as nothing short of “amazing.”

When she’s not in the spotlight, you can find her working at the Yakkity Yak Coffee Shack, located inside the All-American Gymnastics Academy in Sioux Falls. She works there two days a week where she prepares food and makes smoothies for guests. “It’s good and fun,” Bork expressed.



Outside of work, Bork can be found doing any number of activities. "I love shopping, fashion, journaling, going to movies, the park, traveling and eating out." In the summer, she attends Creative Camp, a place where she can do arts and crafts. She has a deep love of animals and says her favorites are lions and tigers. Whenever she needs a break from her active lifestyle, she retreats to her parents' lake house on Lake Madison.

What Are Common Misconceptions About Your Disability?

A common misconception about adults who have Down Syndrome is that they cannot work or get jobs. A statement that holds some weight, if you ask Bork, "Finding a job. It's hard work." But she's pushed through and landed several jobs in and around Sioux Falls. She says one of her favorite parts of working at Yakkity Yak Coffee Shack is being part of a team and helping people who stop in.

What Was the Photoshoot Like for You?

"It was great to be in the photos." Bork describes her photoshoot like something out of a movie – literally. She drew inspiration from one of her favorites, *Twilight: Breaking Dawn*. "I wanted the 'Bella look,'" explained Bork. "I wore a beautiful, blue dress." They took her photos at the Outdoor Campus to replicate one of the scenes that took place in a forest. When asked about her experience with

getting her hair and makeup done, she described it in three words: "Great, fun and awesome." As a bonus, she got to flaunt her look to her boyfriend, as they went on a date right after the shoot.





What Do You Want People To Take Away From This Show?

Much like her favorite animals, lions and tigers, Bork wants people to notice her strength, courage, pride and fierce nature. She's also excited to see her fellow models express themselves, as she wants people to understand that their disabilities don't make them any less than other people; people with hopes, dreams and aspirations.

When she's not looking up the latest trends in the fashion world, Bork is looking toward a bright future. Her dream job is to work in a bridal shop so she can help women celebrate and look good for their special day. A day that she's been dreaming about for herself for quite some time. "My dream is to be a mom and have kids," she said. "I want to raise them and buy a house with my boyfriend." After marriage, she says they plan to honeymoon in Hawaii and own a red convertible. Because, for Bork, when you live life in the fast lane, there's no time to take it slow.

CAMERON HOVERSON

“Everybody’s disability is a little different.”

There’s a quote by the late singer, songwriter and musician Bob Marley that goes, “You never know how strong you are until being strong is the only choice you have.” It’s a choice that Cameron Hoverson makes every day of his life. “My spine is literally cut in half and there’s a titanium rod on each side that’s screwed in,” he explains. “There are two big anchor bolts that go into my pelvis, and that’s what kind of keeps me upright. It’s left me with a lot of chronic pain.” Hoverson says his disability came from a malignant tumor he had when he was 24 years old. “I was having a weird pain on my left side. I was walking, holding it and hunched over.” When he got it checked at the hospital, the doctors found the tumor on his hip and spine. “After an MRI and some X-rays, they realized that it was wrapped around my spinal cord.” It was a difficult time, as this news came shortly after Hoverson’s first daughter was born. “She was a little over a year old when they found the tumor.” On Monday, December 17, 2001 he went in for a biopsy. “The doctor said if it’s benign, they’ll take the tumor out in pieces. If it’s malignant, they’ll take it all out, along with everything around it.” The next day, he found out the tumor was malignant.



"I had a little more than 12 hours to deal with that," Hoverson remembers. "I showed up for surgery at 5 AM on the next day." Knowing what he had to do, Hoverson states the only choice he had at that moment was to be strong. "My folks were there, along with my wife and my daughter, so, pretty much, your only choice is to accept it and try and be strong for all of them." On the day of the surgery, Hoverson remembers waking up ready to face his new future. "I got up bright and early, put on a big smile and said, 'Let's go.'" He didn't wake up from surgery until a week later. The doctors reported that the tumor was "about the size of a cantaloupe," and what they cut out of Hoverson was roughly the

size of a football. "My mom said I looked like the Michelin Man," he chuckles. "Every square inch of my body was swollen." If they hadn't removed what they had, Hoverson says that he wouldn't be alive. "Even now, 20-some years later, they haven't found any chemo or radiation that will kill this cancer," he mentions. "So, they just cut everything around the tumor, including my spinal cord, muscle, bone and tendon. It didn't matter." Despite what he's lost, he couldn't be more grateful for what he's gained. "I've raised two kids. One wasn't even in the world before my surgery." His youngest had turned 18 around the time of this interview. "They're my favorite people in the world."

That's not to say Hoverson doesn't face challenges from day-to-day. As a result of the surgery, he uses a wheelchair to get around and often deals with chronic pain. "After several years, I had my leg amputated at the knee to try and cut down on some of the pain," he explains. "Before then, I had an orthotic brace that would lock into place when I stood up. Every step that I took, I had to lift that leg, which is paralyzed all the way up to my waist." To further help with the pain, he uses a pain pump, which feeds him a medication called Pre-Ult. "It's been really good for knocking the pain down enough where I can get back to work full time," he states. "I can also go out and enjoy life once in a while instead of going to the E.R. every six or eight weeks." One of the ways he's been able to get out is through adaptive sports.

How Did You Get into Adaptive Sports?

"One of my physical therapists at Sanford told me about a weekend where people could try adaptive hockey." It's a program put on by Team USA to generate and gauge interest in the sport. "I was like, 'I've got to see this,'" he recalls. "I went, got in a sled, got out on the ice and we had a good time. It was difficult to stay balanced at first, but it was fun." With the success of that weekend, his friend organized a nonprofit and earned a grant of \$25,000 from Labatt Beer to buy equipment and pay for ice time for that first year. "We started going and working out every week that whole winter long." When hockey season came to an end, however, Hoverson's newfound friendships were only beginning. One of his new friends runs a wheelchair basketball program in Sioux Falls. "He told me to meet him and that he would show me how to play basketball." Hoverson admits he was hesitant at first. "I had tried shooting baskets from my wheelchair before, and I couldn't even hit the rim with the ball. I was bad." But, after some dedicated practice, he overcame the odds. "It's just training the muscles like anything else." This inspired him to keep pursuing other adaptive sports, from tennis to pickleball. "Skiing is one that really, really excited me," he expressed. "I enjoy getting out on the mountain and just letting everything else go. It's fantastic. It's you versus Mother Nature."





What are Some Common Misconceptions About Your Disability?

“It’s hard to go a week where people don’t offer to help me,” Hoverson mentions. “Whether it’s getting in or out of my car or holding a door open for literally 30 seconds as I’m coming up the parking lot.” Despite that, he says he doesn’t expect people to help with every little thing, and, if he needs help, he’ll ask for it. But during the occasional situation where he’s right behind you entering a building, like anyone else, he states it’d be nice to be treated with common courtesy, like having the door held open.

“Another thing that genuinely shocks people is when I tell them how much wheelchair equipment costs,” he mentions. “They’re stunned when you tell them a manual wheelchair costs anywhere between \$6,000 or \$7,000 dollars.” He says that insurance also doesn’t pay for adaptive sports equipment. “It’s difficult to get insurance to pay for the chair that you need every day, let alone the ones that are for hobbies.” Another misconception, he states, is that just because his disability is visible, doesn’t mean anyone knows exactly what he’s going through. His chronic pain sometimes comes in the form of phantom nerve pain, which can cause the occasional spasm. “People just do not realize how painful chronic pain can be.”

Why Did You Join This Show?

“I was invited,” he chuckles. “I like Vicki too much to tell her no. She is one of the kindest, sweetest people I know. Also, her husband, Alma, is the guy that taught me how to ski.” Not having much experience outside of family photos, Hoverson spoke positively about his modeling session for Refocus. “It was nice getting to chat with people throughout the day. It was also a good excuse to get away from work,” he laughs. His past experience with taking photos left a lot to be desired, he says, as his disability can often make it difficult. “I’m standing there with my family, and I’m on crutches.” Sometimes, he’ll alternate and sit in his wheelchair. “But then, they’re all the way above and it looks weird. I just can’t stand up straight because of the way my back is screwed together, so my stance sticks out weird.” For his photoshoot, he chose to sit in his chair and show off his love of sports through pickleball. “The first shot, they told me to hit one, and so I served the ball and accidentally hit Hollie right in the knee,” he chuckles. “Luckily, it was a whiffle ball and she said it didn’t hurt, but I made sure to be more careful on the next one.”



What Do You Want People to Take Away from This Show?

“Everyone is unique, whether it’s their disability or personality.” Hoverson wants people to recognize that, while there are multiple people with disabilities in similar situations who share some day-to-day issues, no story is, ultimately, the same. This sentiment reflects his own personal experience. “Not everybody that has a spinal cord injury, like me, has chronic pain,” he mentions. “I thought that was just part of it when it first happened to me.”

Hoverson states he’s not sure what to expect at the Refocus show, but he knows it’ll be a moving experience for anyone who is not often exposed to the world of disabilities. While he still deals with pains of the past, Hoverson rests comfortably knowing his plans for the future. “I’m going to visit my oldest out at Washington State University in November,” he mentions. “We’re going to celebrate Thanksgiving and catch a football game.”

SOME WORDS

FOR O M

THE **FOLKS**

WHO MADE THIS

BOOK POSSIBLE

MAX HOFER

Max Hofer is a writer, actor, filmmaker and storyteller from Sioux Falls, South Dakota. He graduated from the University of South Dakota in 2018 with his bachelor's degree in media and journalism and a minor in film studies. He is a former journalist for KELOLAND News, where he won an Upper Midwest Emmy Award for his reporting. His short films have gone on to win awards at film festivals, both local and national. This is his first published book.

Having worked with both Untitled.io and Rare by Design in the past in different capacities, Hofer says he was excited when he heard about this show. "I was grateful they approached me about working on this book, despite never having written one before," he chuckles. "I have a couple family members with disabilities and they're some of the best people I know." Hofer says each interview proved to be an eye-opening experience. "There's so much I didn't know about the world of disabilities, and so much I wouldn't have thought of if not for these conversations."

"Everyone has a story to share," Hofer mentions. "It's my job to listen and help express them through their own words." The intention of this book is to grant readers more insight into the personal lives of the subjects featured in this show. "It's been a real privilege to sit down and hear their stories," states Hofer. "I was surprised at how comfortable and open many of them were with sharing their personal stories with me – both the highs and the lows."

Hofer says he hopes anyone who checks out this book takes the time to read and learn from these stories. "Especially those who don't think – or maybe even overthink – about people with disabilities," he mentions.

"These stories aren't just powerful, they're incredibly human. Even if your physical situation is different, there are a lot of emotional ones that are universal."

Keep up with Max's work by following him on social media:
Instagram: @macsofer
YouTube: Climax Productions

RARE BY DESIGN

Rare by Design is a local, grassroots nonprofit organization that works towards awareness, inclusion and representation for individuals living with rare diseases and disabilities. Founded on the belief that everyone should celebrate the rare that makes us all unique and extraordinary, they focus on living life positively. Rare by Design's projects strive to foster community engagement and challenge the status quo, while promoting human growth, self-advocacy and empowerment.

When developing or designing an event or experience, Rare by Design's philosophy is to find others who share the same values. That's what drew them to Untitled.io. The art nonprofit has been making a name for itself around the Sioux Falls area for their pop-up art shows. "When they agreed to collaborate with us, we were ecstatic," says Founder and Executive Director of Rare by Design, Kendra Gottsleben. "We knew this project would be innovative. Sioux Falls has never seen anything like it before."

The experience became more than the Rare by Design team could have even imagined, according to Gottsleben. She mentions the Refocus show has grown into something truly remarkable and significant, and she credits much of the show's success to the talent, skills and artistic perspective of artists like Untitled.io (Tyson Schultz, Levi Sternburg and Kenzie Shubert) and lead photographer Hollie Leggett. "With her past work, passion and connection to the disability space, there was no doubt in our minds that she was the right individual for the job." A feeling which was later proven right.

"Her enthusiasm, sensitivity and empathy allow her to tell these extraordinary stories of the human condition in a universal and authentic way."

-Kendra Gottsleben

Find out what's next from Rare by Design by following them on social media:
Website: rarebydesign.org
Facebook: Rare by Design
Instagram: @rarebydesign

UNTITLED.10

Untitled.10 is a visual art organization operating out of Sioux Falls, South Dakota. Their mission is to create art events in public spaces, giving new and emerging artists in the community a platform to share their artwork and their voices. They strive to be equitable, inclusive, and open minded in their process of representation of the talented artists in the community.

Their relationship with Rare by Design started in early 2023. They were approached off the heels of their exhibit, *The Blues*, about being consultants for Refocus. However, naturally, the conversation blossomed into a full-blown, collaborative partnership. “We all gelled together,” said Founder and co-organizer of Untitled.10, Tyson Schultz. “We all just wanted to work with each other, both as organizations and as individuals.

A huge benefit of this collaboration, Schultz explains has been the opportunity to learn about the others’ respective fields. “We’re learning more about the challenges individuals with rare diseases/disabilities deal with on the day-to-day.” He says it’s also an ample time to unite community members with skillsets, from writing to photography, to help push the show’s mission of giving each model their own platform. “Disabled people are part of our community,” says co-organizer Levi Sternburg. “They deserve the same level of dignity.”

“If there’s going to be any programming addressing disabilities,” mentions Sternburg, “the conversation should be led by people living with disabilities.” Through Refocus, Untitled.10 hopes this one-of-a-kind event can provide an empowering experience, learning opportunities and bridge a connection between community members of all kinds.

Find out what’s next from Untitled.10 by following them on social media:
Website: untitled10.com
Instagram: [@untitled.10.sf](https://www.instagram.com/untitled.10.sf)





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