



South Dakota Possibilities 2023

Enlightened Vision

A collection of photographs
shows us a better way to see

**South Dakota
Possibilities 2023**

A publication by the
Center for Disabilities

Eric Kurtz, Ph.D.
Executive Director,
Center for Disabilities

Arlene Poncelet
Executive Director,
South Dakota Council on
Developmental Disabilities

Principal Writer
Peter Carrels

Managing Editor
Kendra Gottsleben

Photography
Untitled.10
Holly Leggett
Eric Dalseide

Design
Eric Dalseide

Center for Disabilities
Health Science Center
1400 W. 22nd St., Sioux Falls, SD 57105
Phone: 605-357-1439
Fax: 605-357-1438
cd@usd.edu
usd.edu/cd
X: @CD_SouthDakota
Facebook: CDSouthDakota
YouTube: /Center4Disabilities

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University of South Dakota
Sanford School of Medicine

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Welcome

to Our Eighth Edition of
South Dakota Possibilities!

Contents

3 From the Executive Director

4 Improving Access in the
Black Hills

8 Photo Exhibit Presents
Lasting Messages

18 Addressing Children's
Mental Health Needs

20 Profile of an Active
Advocate

24 Lessons Learned by
a Loving Mother



Center for Disabilities

A University Center for Excellence in Developmental Disabilities Education, Research and Service

Dear Friends and Colleagues,

As South Dakota's University Center for Excellence in Developmental Disabilities (UCEDD) Education, Research and Services, we are tasked with improving the lives of individuals and families across our great state. Our vision is that through collaborative efforts, all people can achieve independence, self-determination, productivity, and community inclusion.

We know these are big goals, and the challenges are complex. We also know that this work involves important collaborations with many partners, including individuals and their families, and numerous healthcare, education, human service, employment, government, and community-based organizations. These collaborations are central to achieving our mission of improving the quality of life and community inclusion for individuals with developmental disabilities and their families.

Inside this publication, we are proud to provide powerful examples of resiliency, resolve, and success by South Dakotans. Read on and you will find stories of independence, perseverance, optimism, and dedication to pursuing one's life goals. We feel deep gratitude and respect for those individuals touched by our collaborative work and who have offered to share their personal stories with you.

South Dakota has an abundance of amazing individuals and organizations who work tirelessly to help us achieve our mission to improve the lives of people with disabilities and their families. The possibilities are endless, and the potential is great!

On behalf of the faculty and staff at the Center for Disabilities, thank you for taking the time to learn more about our work, and we look forward to our continued collaborations.

Sincerely,
Eric G. Kurtz, Ph.D.
Executive Director
Center for Disabilities





Promoting Awareness
and
Elevating Access

Few places in the United States carry more cachet as a tourism destination than the Black Hills of South Dakota. People from across the country, even the world, visit this oasis of rugged and pastoral beauty. They come to see massive stone sculptures, free ranging bison and sprawling caves. In 2021, almost four million people visited the Black Hills. Those visitors contributed more than \$300 million to South Dakota's economy. There is a growing permanent population in the region, where more than 125,000 people call the Black Hills their home.

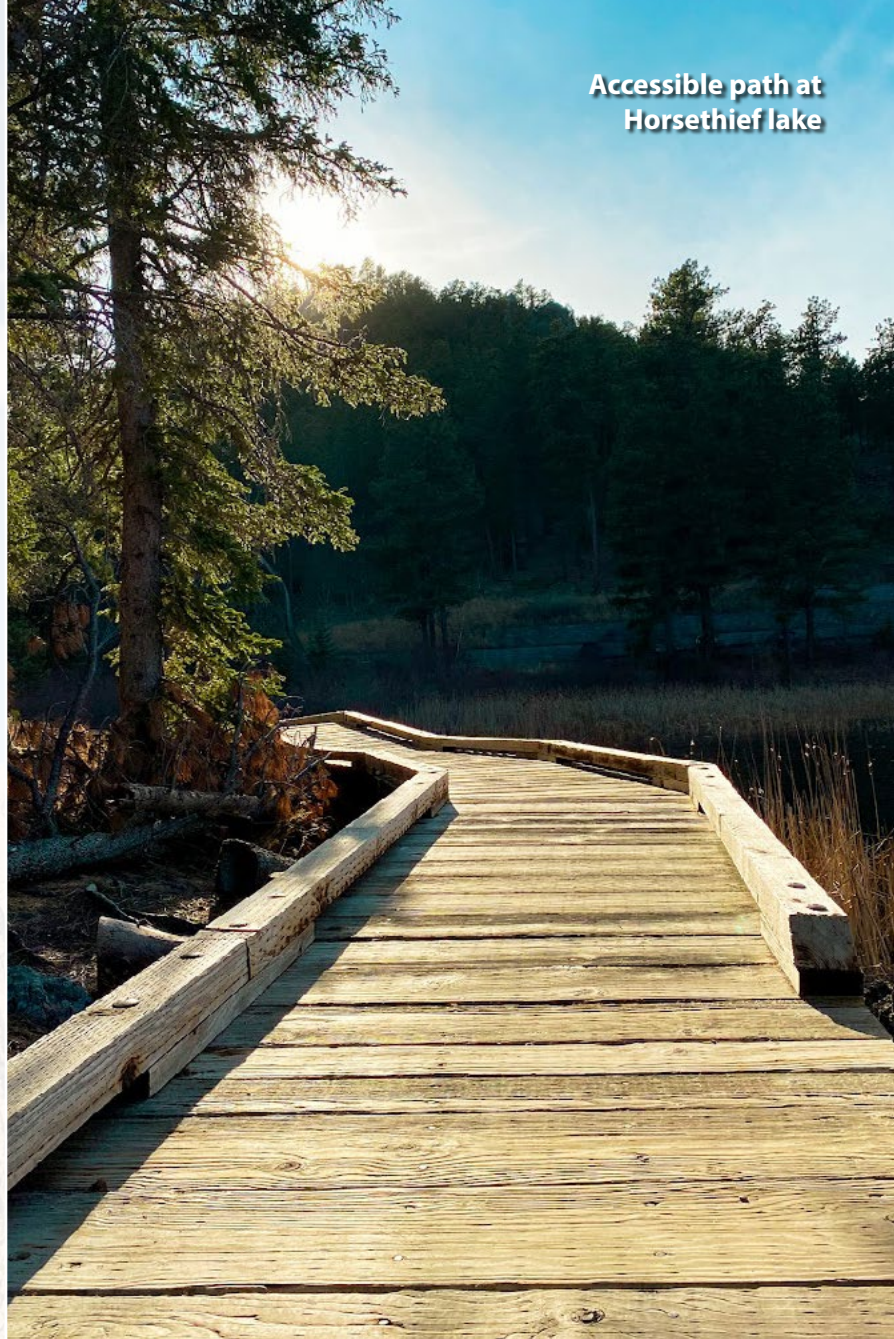
All visitors need to eat and sleep, and there's no shortage of restaurants and hotels. But which ones are accessible to those with a mobility disability? What about outdoor destinations and convention facilities? What about gift shops, art galleries, bookstores and so many other businesses frequented by visitors, and by locals, too?

About 12% of the overall population has a mobility disability and most use a wheelchair or crutches. Nearly 11% live with serious hearing or vision issues.

Wouldn't it be useful if information about access to businesses and destinations was available from a single source? Wouldn't visitors who come to the Black Hills benefit from this type of advance knowledge?

Of course they would, says Kelsey Stine of Rapid City. Stine, a wheelchair user, grew up in Rapid City and understands tourism and the unique needs of people with disabilities. She decided to fill a void and in 2021 began an effort to educate visitors about access availability and businesses about how to better accommodate those with disabilities.

Stine recognized that travelers are typically unfamiliar with accessibility conditions in unfamiliar places. She was made acutely aware of this situation when she and her mother faced barriers while vacationing with the rest



An elevator moves visitors to the second floor of a Rapid City art gallery.



A Black Hills restaurant designates parking spaces.



Photos courtesy of Kelsey Stine

of their family, including her dad and an older sister.

“I have muscular dystrophy,” explained Stine. “The disease started showing when I was four years old. I walked until I was 13.” Stine, now in her 30s, added that her mother also has the genetic disease.

“As I grew up,” Stine recalled, “I noticed some businesses were more aware than others about access for all.” The American Disabilities Act was new, she explained, and society was just starting to understand the importance of accommodating people with disabilities. Stine learned which businesses offer ramps, wide doorways, accessible bathrooms, low tables and other features that allow her visits.

After graduating from Stevens High School in Rapid City, Stine attended and graduated in 2014 from Black Hills State University, earning a degree in mass communications with an emphasis on graphic design. She then worked as a website designer, social media manager and marketing coordinator before taking the plunge to open her own advertising business, Vela Creative Company. That was in 2019.

Two years later, Stine launched an accessibility awareness project. She established Accessible Black Hills, an enterprise aimed at providing useful information to those with disabilities. “Accessible Black Hills started as an Instagram post about accessibility issues,” said Stine. “Then people started contacting me to find out about different businesses and whether they were accessible or not.”

Special emphasis was to deliver information to those planning to travel to the Black Hills. From her own experiences as a traveler, Stine knew that this knowledge

would allow all visitors to better plan their vacations. She designed a website offering this information to both visitors and Black Hills residents. Her experience in advertising and marketing benefited this awareness campaign.

On the Accessibility Black Hills website, suggestions to improve access are described and businesses offering access are showcased. Stine especially enjoys highlighting locally owned businesses. She also solicits volunteers to survey area businesses. Using a checklist, the volunteers document accessibility features as well as identify areas needing improvement. Stine is always searching for local partners to help with all aspects of the organization, including spreading the word about Accessible Black Hills.

Stine has already performed countless site visits to help businesses improve access, and she assists businesses find funding to undertake improved access. She partnered with a local tourism promotion organization, Visit Rapid City, which resulted in a more comprehensive checklist for businesses to perform self-assessments.

“This project keeps growing,” Stine exclaimed. “I need to evolve the purpose of what we do and maintain our relevance.” One planned component of her growing service is to develop an app for hand-held devices that provides accessibility information businesses and people need. The app, produced in collaboration with Visit Rapid City, will also make it simpler for volunteers and the public to add useful information to the Accessible Black Hills website.

“I view myself as an entrepreneur,” said Stine. “Entrepreneurs solve problems. And that’s what we’re doing.” •

To learn more about Accessible Black Hills, go to accessibleblackhills.com or contact Stine at kelsey@accessibleblackhills.org.

Enlightened

Vision

A collection of photographs titled “**Refocus**”
informs, educates and celebrates.



Koni Sims

A rare eye disease, aniridia, rendered Sims legally blind since birth. And in 2017, an auto-pedestrian collision crushed her feet and seriously injured her back, causing permanent mobility issues. That condition forced retirement from her job. Sims then became a state and national advocate for others with disabilities, especially those who have vision loss. "I think all of us have a disability to some degree," said Sims. "It's just more noticeable on some of us."



Kayley Shade

Born with spinal muscular atrophy, Shade has been a wheelchair user all her life. She's also been a football fan since she was young, and she has turned that passion into a career. Shade expanded an internship for the Sioux Falls Storm into work as the media director for the Indoor Football League. New treatments have decreased her symptoms and raised her ambitions. "It took me awhile to gain confidence," she explained, "but I'm more confident now."



About the Exhibit

The idea for a photo exhibit featuring people living and thriving with rare diseases and disabilities originated with the Sioux Falls organization, Rare by Design, a non-profit group that initiates and sponsors events intended to promote public awareness and community engagement as well as self-advocacy and empowerment.

Kendra Gottsleben is the founder of Rare by Design, and she and the organization had specific objectives for the photos and exhibit. "Our mission with this project, and with other projects we pursue," she noted, "is to bridge

the gap between initial perceptions and the rich human experiences that lie beneath visible disabilities." Gottsleben, who serves as the marketing communications specialist at the Center for Disabilities, explained that people with visible disabilities often face immediate assumptions and judgements due to their conditions. "This is a reality they cannot conceal," she said.

It was the marriage between Rare by Design with Sioux Falls-based visual arts organization Untitled.10 that firmed up the exhibit plan. Untitled.10 promotes emerging



Alma Stewart

Stewart was paralyzed from the chest down as the result of a motorcycle accident. An ardent hunter, angler and outdoor sports enthusiast, Stewart also works as a volunteer coach to those interested in adaptive sports. He is married to Vicki Stewart.

artists with an emphasis on art that is equitable, inclusive and open-minded.

The result of this collaboration is an inspiring and stimulating collection of photographic images. Each model portrayed has their own unique and compelling story, but all models are bound by common traits: Fortitude, perseverance, creativity, positivity. The power and trajectory of this exhibit only begins with photography. There is so much more to be learned by the viewer. For example, what path led each model to a photo session? These stories are captured in a book

created by Untitled.10 and written by Max Hofer that shares the same name as the title of the exhibit.

The over-arching theme of this collection of images is not vague or abstract. All of us can inspire the rest of us, and in many ways, for many reasons. Meaningful art proposes that we pay close attention to the world around us, to those around us. Lasting art suggests that we be perceptive and sensitive to those messages delivered by voices spoken and unspoken.

Vicki Stewart

Stewart has osteogenesis imperfecta, also known as 'brittle bones disease'. A graduate of Augustana University, Stewart serves as executive director of Employment Disability Resources in Sioux Falls. Her interests include national and international travel and music. Her husband, Alma, is also featured in the exhibit. "Unfortunately," said Stewart, describing common reactions to those with disabilities, "people look at what we can't do instead of what we can do."



Scotty Briggs

Special Olympian Scotty Briggs competes as a swimmer and in track and field. Born with Down syndrome, Briggs works at The Effortless Bow, in Sioux Falls. He has developed a deserved reputation as a successful fundraiser for the South Dakota Special Olympics.



Hailey Bork

Bork acknowledges a common misconception is that adults who have Down syndrome cannot find or perform employment. Bork now works at the Yakkity Yak Coffee Shack in Sioux Falls, where she prepares food and creates smoothies. Her active life includes shopping, fashion, journaling, movies, traveling, visiting parks and lakes and patronizing local restaurants. Bork's dreams include marrying her boyfriend, a Hawaiian honeymoon, having children, and owning a home and a red convertible.



Melinda Pallone

Pallone was born with merosin deficient congenital muscular dystrophy, and used leg braces to walk until puberty, when she became a wheelchair user. Pallone pursued higher education and earned bachelor's and master's degrees. She works as an independent living specialist/advocate at a Center for Independent Living in Sioux City, Iowa. She and her husband have three children.



Connor Roeman

The youngest model in the exhibit, Roeman was paralyzed from the waist down two years ago as the result of being a passenger in a car accident. Before the crash, Roeman participated in a variety of sports and was known as a daredevil. He decided he wouldn't allow the mishap to change him, and he has become a competitor in adaptive sports, including wheelchair tennis, sled hockey and mono-skiing. "I'm the same person I was before my injury," he explained, "but now, I just have to work harder to accomplish most things in life. Because of this, I have a much clearer mindset." Roeman's future plans include attending Augustana University and majoring in business administration and entrepreneurship. He'll use that education to advance his brand, Endure Anything.



Jeremy Neuheisel

Cerebral palsy and optic nerve atrophy don't stop Neuheisel from rigorous exercise routines. Between swimming, lifting weights and physical therapy, Neuheisel fits in time to work as a greeter at HyVee and an educator volunteering at the Butterfly House.

Kendra Gottsleben

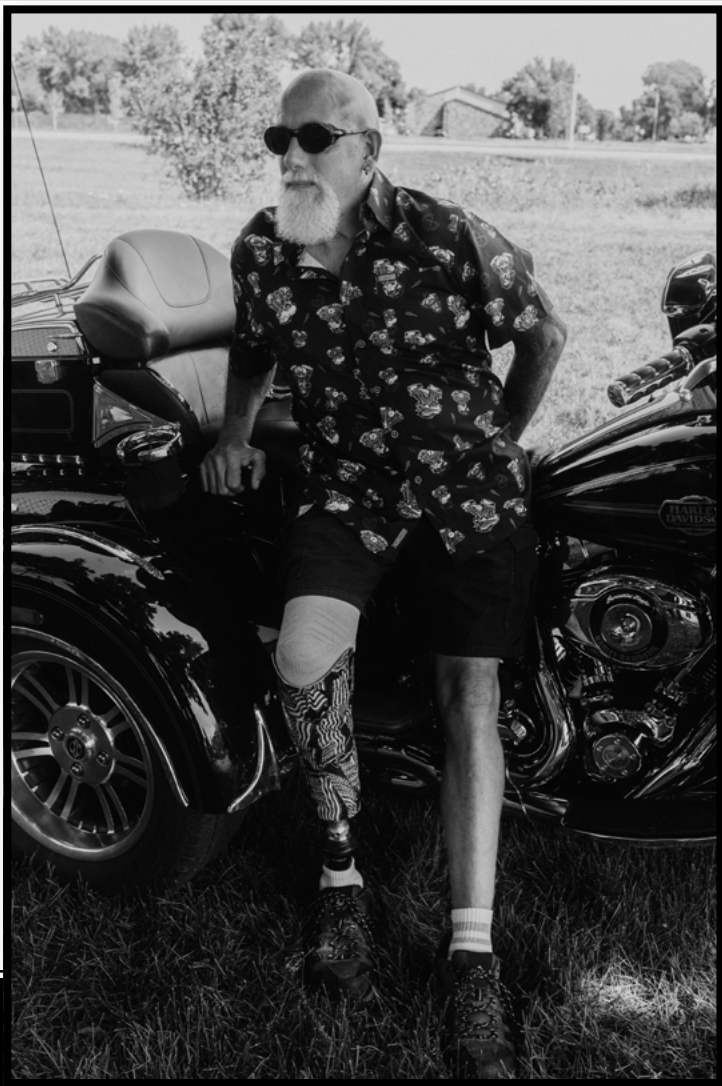
Gottsleben was born with a rare disease called mucopolysaccharidosis type VI. Only about 100 people in this country have this disease. Gottsleben has also experienced open heart surgery. She is the founder of Rare by Design, has authored three books and works for the Center for Disabilities within the University of South Dakota's Sanford School of Medicine.



Tana Zwart

Zwart was diagnosed with facioscapulohumeral muscular dystrophy at a young age. A college graduate, Zwart has opened her own graphic design business and volunteers in various leadership roles in Sioux Falls.





Stephen Bruggeman

At age 20, serving in the U.S. Coast Guard, Bruggeman was seriously injured by an M-16 bullet carelessly discharged by a military comrade during weapons practice. The leg was later amputated. Thanks to encouragement and training by U.S. Veterans Affairs in Sioux Falls, he now pursues adaptive sports, such as downhill skiing, golf, recumbent bicycling and sled hockey.



Cameron Hoverson

A malignant tumor wrapped around Hoverson's spinal cord required major surgery when Hoverson was 24 years old, married and had a one-year-old daughter. That procedure removed parts of Hoverson's spine, as well as muscle, bone and tendons. He later had one leg amputated to reduce chronic pain. Hoverson has now raised two children and enjoys adaptive sports. Fellow exhibit model Alma Stewart taught Hoverson how to snow ski.

Laura Hayne

At age 18, Hayne broke her back in a gymnastics accident. Recovery was difficult, but Hayne is now a single mother with two children. She is also a member of a local book club and is considering writing a book about her life.



About the artist

A graduate of Sioux Falls Washington High School, Hollie Leggett attended South Dakota State University for two years before transferring to the Minneapolis College of Art and Design, in Minneapolis, Minnesota. There, she studies and explores multi-media approaches to communication.

This is her first solo exhibition, and the scope and theme of the project presented special demands. “I was unsure about stepping into this space,” Leggett explained, “because I do not have a rare disease or disability.” Leggett was aided in her understanding of people with disabilities by a younger brother who has cerebral palsy. Watching him face challenges and learning about those challenges helped Leggett prepare for and capture poignant images.

Leggett also possesses an artist’s sensitivity and sensibility. “We worked hard to become acquainted,” said Leggett, describing interactions with the models preceding the actual photo sessions. “I understand that being in front of a camera reveals our vulnerabilities. I wanted the models to feel comfortable, and we crafted photos that showed the models in situations and experiences they were comfortable in.”

Following much advance preparation, each of the 14 models was photographed during a long, single-day session. While it was a busy, hectic day, it was also an enjoyable experience for everyone involved. “We had fun, a good time, almost like a party,” said Leggett.



It was a celebratory atmosphere on Oct. 21, 2023, when the exhibit's models, their families and friends, and the collective of committed individuals involved in making the exhibit a reality gathered at Monick Yards, an event center near downtown Sioux Falls. As many as 200 people attended the event, and they heard expressions of gratitude by representatives from Untitled.10 and Rare by Design. Artist Hollie Leggett also spoke. "I worried I wasn't up to the job," she admitted. "But the models helped me through the process. They are my heroes."

"What could be a better way to build a stronger community than a project like this?" said Rare by Design spokesperson Tana Zwart. "Disabilities are a naturally occurring aspect of the human race. That's how this exhibit presents people with disabilities."

The opening event



Thanks to Untitled.10 for their help with copy and photos. The *Refocus* book can be viewed online at un10sf.com/event/refocus/



BUILDING A NETWORK TO ADDRESS A CRISIS IN CHILDREN'S MENTAL HEALTH

The Center for Disabilities has announced a new statewide program to address the rising number of mental health cases involving children and youth in South Dakota.

“Young people in our state are experiencing significant mental health care needs, which are exacerbated by a chronic shortage of health care and mental health professionals and numerous barriers to accessing care,” said Eric Kurtz, Ph.D., executive director of the Center for Disabilities. “We need to build capacity in our existing health care workforce, and also build that workforce.”

Kurtz led an effort to establish the new program, called Pediatric Mental Health Care Access (PMHCA). A critical aspect of this undertaking, said Kurtz, is to provide specialized training to existing health care providers to better equip them to recognize, diagnose, refer and treat young people with significant mental health needs. The program will also offer specific consultations to health care providers needing expert guidance. Trainings will be virtual, and typically offered once per month, and same-day provider-to-provider consultations

will be available. “We’re assembling an expert team of behavioral health professionals to provide these consultations,” Kurtz explained.

Training sessions will be accessible online via the University of South Dakota’s Extension for Community Healthcare Outcomes (ECHO) video-conferencing platform. The Center for Disabilities will manage those trainings and content with input from program partners.

Those partners are members of a broad and impressive coalition. Kurtz identified and acknowledged the University of South Dakota Sanford School of Medicine, Avera Health, Sanford Health, Horizon Health, South Dakota Department of Health-MCH Title V Program, South Dakota Department of Social Services-Division of Behavioral Health, Helpline Center, Urban Indian Health, and Monument Health as playing cooperative and participatory roles in the program.

Partners will not only serve as advisors to the program, they will also champion the program within their own systems and networks.

“This ambitious and vitally needed program couldn’t proceed without the expertise of our partners,” said Kurtz. “I am grateful and deeply impressed with the commitment each of our partners has already demonstrated.”

Training programs within PMHCA will eventually be offered to students in various aspects of health care at South Dakota institutions. Teachers and others working in the state’s schools and educational system will also have opportunities for specialized training.

Another PMHCA objective is to build and maintain a statewide pediatric behavioral health resource website.

The U.S. Department of Health and Human Services Health Resources and Services Administration (HRSA) has provided \$2.1 million to this new program. The program’s first components were launched in October 2023. •







Tana Zwart, Committed Advocate

Progress doesn't happen by accident; ask Tana Zwart. She'll tell you about the many meetings she attends and the countless conversations and decisions she has experienced about matters related to helping people with disabilities.

Zwart is no stranger to community activism and volunteerism. As a youngster she first learned to give her time to good causes. Now, in her 30s, she serves as chair of the Disability Awareness and Accessibility Review Board (DAARB) for the City of Sioux Falls, South Dakota. She is also involved in other organizations as a volunteer, including the Muscular Dystrophy Association (MDA). Five years ago, she served as a national ambassador for that organization. She currently contributes to the Center for Disabilities' Consumer Advisory Committee.

"There are many people who volunteer to help address the needs of people with disabilities," Zwart explained. "I have evolved in my roles. Since moving to Sioux Falls nine years ago, I've been able to learn more about different disability issues. I've grown more comfortable working on issues related to people with disabilities."

Zwart was diagnosed at age seven with facioscapulohumeral muscular dystrophy (FSHD), the third most common myopathy, affecting about 1 in 20,000 people. Individuals with FSHD show progressive weakness and atrophy of facial, shoulder and upper arm musculature.

"I have always been resilient," said Zwart. "It was a long road to diagnosis that ended with a series of many tests at the

Mayo Clinic. My parents never coddled me, and I had an amazing support system, including my parents, my grandparents, family members, even the community. When I reached middle school, I started feeling the effects of the disease. By the time I was a senior in high school I was using a scooter for mobility.” She now uses a wheelchair.

Zwart’s involvement as a volunteer supporting those with muscular dystrophy started when she was growing up in Edgerton, Minnesota. “My family and I were involved in fundraisers, and I appeared on local MDA Jerry Lewis telethon broadcasts,” she noted. “We felt like it was our way to do something about something we couldn’t really do anything about. It was turning a negative into a positive.”

Between her fifth and sixth grade years, Zwart attended MDA summer camp. “It was eye-opening,” she explained. “I was the only kid in my community with a disability, let alone muscular dystrophy, so going to that camp where there were so many others with disabilities helped me feel that it was okay just to be who I was.”

As chair of Sioux Falls’ DAARB, Zwart has opportunities to make a difference in her new community. One of the organization’s important initiatives is to encourage respect for parking spaces designated for individuals with disabilities. “People parking in these restricted spaces continues to be a problem,” reported Zwart. “We are placing a second and more personal sign below the disabled



Avery Hill is featured on a “Think of Me” public awareness sign with her mom, Mindy Hill.

parking signs that request thoughtfulness and compliance with the signs.” The public awareness project, according to Zwart, features an image of a local model, accompanied by the messaging, Think of me—Keep it free.

Zwart also has a direct hand in helping organize ArtAbility, an annual show hosted by DAARB. This exhibit features artists with disabilities from the Sioux Falls area and across the state. The event is typically held each April, and last year more than 90 pieces

of art were displayed. “Creativity doesn’t have limitations,” said Zwart. “The artists have a myriad of disabilities, and they do art in a variety of mediums.”

Another accessibility cause Zwart has embraced relates to air travel. “We need greater access on commercial flights for people in wheelchairs,” she explained. Zwart has lobbied in Washington, D.C. for supportive legislation and holds out hope for legislation now being considered.

Zwart was a perfect fit for her volunteer work with Rare by Design, a Sioux Falls-based

nonprofit that expands public awareness and inclusion for individuals with rare diseases and disabilities. The organization, led by Center for Disabilities Communications specialist, Kendra Gottsleben, uses special and creative events like fashion shows and art exhibits to celebrate the unique and positive characteristics of each and every person.

“Tana is a community leader and a real asset to our organization,” stated Gottsleben. “She brings experience and enthusiasm to our mission.” Zwart, likewise, is grateful for opportunities to serve the organization.

“Rare by Design is rewriting narratives commonly held about people with disabilities,” said Zwart. “I am especially excited about serving on the board of this organization.”

Zwart attended Southwest Minnesota State University in Marshall, where she studied graphic design, literature and creative writing. She now freelances as a self-employed media manager, focusing on nonprofits and the arts. “I like the variation of what I do and who I work with,” she explained.

Blending her skills and advocacy, Zwart has been able to make a difference for many on many fronts: board member, volunteer, lobbyist, community leader and activist. Her contributions range from fundraising to aid science and research, to raising the profile of people with disabilities.

“My involvement has been rewarding for many reasons,” said Zwart. “I have met many amazing people through my work. Most importantly, we are seeing changes for the better for those with disabilities.” •



Paul TenHaken, Sioux Falls mayor, presented Zwart with his proclamation designating October as Disability Employment Awareness Month for the City of Sioux Falls.

Photos courtesy of Tana Zwart



Inès White and her family. Standing, left to right, is oldest daughter, Allie Riddle, daughter Katie and son Sam. Seated, from left to right are Allie's daughter, Emma, Inès, Allie's son, Wyatt and Inès' husband, Chris.

A Mother's LOVE

Inès White, a mother of three from Vermillion, South Dakota, and her husband, Chris, have experienced profound challenges and joys as they faced medical conditions regarding two of their three children that changed their family life. As her children dealt with their diseases, White developed a deep admiration for them. “Watching my children face their conditions,” she reflected, “has been inspiring.”

Sam, their only son, was born in 1992. At age two, he started showing signs of developmental challenges. White suspected a hearing problem, and a local physician agreed. But White’s sister-in-law had familiarity with autism and suggested testing for the disorder. The confirmed diagnosis was known as Aspergers syndrome at the time, a condition within the autism spectrum disorder (ASD).

Despite his challenges, Sam graduated from high school with an impressive 3.6 GPA. “His resilience and intelligence shone through,” White explained. “He has a photographic memory.”

The White’s third child, Katie, is six years younger than Sam. As a little girl she demonstrated physical characteristics that initially stumped doctors, and her family subsequently embarked on a 16-year search for answers. Katie, too, showed autistic tendencies and faced difficulties with growth and development. It wasn’t until the family

lived to St. Louis, Missouri, that a physician diagnosed her with Myhre syndrome, a rare genetic disorder with only 200 documented cases worldwide. Today, Katie is the only person in South Dakota with this condition. Myhre syndrome is life-threatening and can cause stiffening and thickening of organs and muscles in the body.

After learning about her daughter’s rare condition, White became part of the tight-knit Myhre syndrome community, and soon after its inception, in 2019, she became a board member of the Myhre Syndrome Foundation. “We’re all there for each other,” White explained. “Sadly, we have lost members of our small community. It’s devastating to all of us when this happens, which is why we are so determined to find a path to treatments.”

White’s resolve to provide her children with as many everyday life experiences as possible became her guiding light.

Sam has forged meaningful connections and friendships in the Vermillion community with his gregarious and affectionate personality. He works in the food service industry at the University of South Dakota and maintains his health through long walks.

Katie confronted different obstacles due to Myhre syndrome, including struggling with mobility issues and the constant risk of weight gain. The family installed a backyard

swimming pool, where Katie has dedicated herself to regular exercise. “She’s working hard on weight management, better nutrition and her heart is good right now,” White explained.

Inès White’s personal journey and how it led her back to Vermillion is an integral part of this story. Her mother was a young woman living in Belgium when she watched a touring rodeo from the United States. Included in the rodeo troupe was a distinguished Native American from South Dakota named David Beautiful Bald Eagle. In addition to competing in the rodeo, Bald Eagle performed traditional Sioux dances. White’s mother and Bald Eagle met and eventually married. When White was seven years old, she and her family moved from Europe to Eagle Butte, South Dakota.

After graduating from high school, White enrolled at the University of South Dakota, where she participated in cross country, track and field, and Reserve Officers’ Training Corps (ROTC). She became the first member of her family to graduate from college. Following a long military career, White now works for a leading consulting organization providing high-level scientific, technical and analytic expertise to the U.S. government and military. In 2020, White was the commencement speaker at USD’s fall graduation.

The family resided in communities around the country and the world and could have chosen to live anywhere before they decided to return to Vermillion, the place Inès has long called her hometown. Vermillion is not only where White earned her college degree, it is where she met her husband. Returning to Vermillion, White explained, proved to be an ideal choice.

“Vermillion is a perfect place for my children,” declared White, who works remotely and travels the globe to fulfill

defense institution-building assignments. “The Vermillion community is safe and friendly, and the people here have been remarkably supportive.

“Sam loves everyone in Vermillion, and everyone loves Sam,” continued White. “Katie is less social than Sam,” White explained, “but she has figured out how to co-exist with her syndrome. She is very aware of Myhre, and her threshold for pain is amazing. Although she doesn’t show much emotion, she pays close attention to how I become emotional over her.”

Katie has chosen to speak to groups about her disease, serving on panels, answering questions and raising awareness.

White has a special fondness for the Myhre Syndrome Foundation and the organization’s objectives, including connecting families and informing the public about Myhre syndrome. “I have come to understand how difficult it is for people and families, including me, to deal with their children who have the syndrome,” she acknowledged. “I have learned that because Myhre is so rare and complicated, the medical community has limited knowledge regarding how to help Katie. Teaching people about the disease is something I am passionate about.”

Despite the demands of an international job and supporting her family, White is dedicated to helping others who face the challenges of children with complex needs. “It’s not always easy fighting for a cause, but I want to be active, give back, and make a difference. I feel like it’s who I am.”

“My children are brave and resilient,” White declared. “I love and admire them; they have taught me so much. I’m a better person and mother because of what we’ve all been through together.” •

To learn more about Myhre Syndrome, visit www.myhresyndrome.org

The Center for Disabilities would like to thank all the businesses, organizations and individuals who connected us with the extraordinary people featured in this publication.



UNIVERSITY OF
SOUTH DAKOTA
SANFORD SCHOOL OF MEDICINE

Center for Disabilities

1400 West 22nd Street • Sioux Falls, SD