BACK TO SCHOOL 2025

NDVS/SB OUTREACH NEWSLETTER

NDVS/SB provides individualized services and resources to infants, children, and adults with visual impairment to empower them in achieving their goals.

Taking CHARGE

Ryder at the CHARGE Conference in Phoenix.

Not many teens would say that the highlight of their summer was attending a conference, but that's exactly how 16-year-old Ryder Schlafman-Hieb feels. Ryder, who is starting her junior year at Carrington High School this month, attended the CHARGE Syndrome Conference in Phoenix, AZ, at the end of July with her mom, her TSVI Lanna Slaby, and Lacey Long, the Director of the North Dakota Dual Sensory Project. Ryder was born with CHARGE Syndrome, which stands for **C**oloboma, **H**eart defects, **A**tresia choanae, **R**etarded growth and development, **G**enital and/or urinary abnormalities, and **E**ar abnormalities and deafness. These characteristics vary widely among individuals and not every person will have all the features that make up the acronym. In Ryder's case, CHARGE Syndrome has caused vision loss, hearing loss, and other physical issues, but, more importantly, she said, "it has offered me opportunities to meet new people." This summer was no exception, as Ryder met hundreds of individuals of all ages who have CHARGE Syndrome, as well as professionals, including those who are researching CHARGE Syndrome and people working for the CHARGE Foundation.

Ryder has attended this conference, which is held every odd year, in the past but had missed the last two that were held. "It was great to be back," she said. "The conference always has great food, and it is a well-planned conference," she explained. "I especially enjoy the planned evening events, and on Saturday night, there is always a CHARGE-a-palooza, and the theme this year was Glow Night!"

Besides the fun and socializing, Ryder learned more about her condition. "I think a person forgets how much the CHARGE Syndrome Foundation does throughout the year," she said. "There are a number of research projects in the works to help with various issues that one with CHARGE can face."

She also learned skills that will help her throughout her life. "One of the sessions I attended was called, 'Understanding Financial Tools for

continued on page 2

Right: Lacey, Ryder, Ryder's mom Kaylee, and Lanna enjoying Glow Night.

continued from page 1

Individuals with Disabilities: Public Benefits, Specials Needs Trusts, and ABLE Accounts,'" she shared. This session "helped me understand how these various financial tools can help me."

Ryder also had the opportunity to present at the conference. "I presented on the technology I use to access my school work," Ryder explained. "I wanted to give people some ideas or recommendations on technology that they could use to help them." Ryder felt her presentation went well, with one person even commenting that it was one of the best sessions she attended at the conference this year.

Ryder is already looking ahead to the next conference in 2027 in Dallas, where she'd like to present again. "I'm thinking my topic could be transition as I'll be a high school graduate by then," she said. After graduation, Ryder wants to attend college and pursue a career in law enforcement. She believes that attending this conference where she can learn about her own disability helps her become a better advocate for herself. She encourages other students with CHARGE Syndrome and their parents to attend the conference as well. Doing so "would allow them to connect with other parents in person and make a real connection with others," she explained. "Knowledge is Power!"

Above: Lanna, Ryder, Kaylee, and Lacey

The Power of Connecting and Learning: Why families should consider attending a conference on their child's disability

NDVS/SB Regional Coordinator Lanna Slaby and Director of the ND Dual Sensory Project Lacey Long both attended the CHARGE Syndrome Conference with Ryder this summer. While it is not unusual for either of them to attend a summer conference, it was a different experience to attend a conference with a student and her parent, and on a specific disability. Both, however, found it incredibly beneficial. "I enjoyed learning information specific to the diagnosis," Lacey said. "For example, at the CHARGE Conference, there were sessions with an ophthalmologist discussing vision loss related to CHARGE and an audiologist discussing hearing loss. The information that they shared would not have been shared anywhere else." Lanna appreciated that the networking opportunities and the information learned benefits both you and your students. "The knowledge gained from a conference provides professional growth, and therefore better advocacy for your student," she explained. Lanna, Lacey, and Ryder all agree that there are life-changing benefits by attending a conference about your child's specific diagnosis. For more reasons why to consider attending one, read Lanna's and Lacey's answers on our website.