

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.

Family Weekend Wrap-Up "There's Nothing We Can't Do in 2022!"

Family Weekend 2022 was a huge success, thanks to the hard work of the NDVS/SB Family Team, the incredible speakers, and the amazing families who attended! We asked the Vetsch family from Devils Lake to share a bit about why they attended and what they learned.

Who attended Family Weekend?

Myself (Sarah), my husband Joe, our daughter Josephine (Josie) age 10, son Tristan age 8, and son Harrison age 4. Our oldest son Collin was unable to attend with us. My son Tristan has an incredibly rare genetic recessive disease called Alstrom Syndrome which causes cone-rod dystrophy leading to progressive vision loss and several other physical manifestations.

What services does your family receive from NDVS/SB?

Tristan receives outreach services from NDVS at his school in Devils Lake from his wonderful TSVI Kathy Grzadzielewski, as well as from Tracy Wicken for technology assistance. Tristan also attends the short-term programming held on-site in Grand Forks at NDVS/SB which he very much enjoys.

Why did you decide to attend Family Weekend this year?

Mostly we wanted to connect with other families who might be like ours, or in the "same boat" as us so to speak. Having a child with a visual impairment can be extremely isolating, so it was nice to be in a place where everyone understands our situation to a degree. We also went so that we may learn as much as we can to improve the educational outcomes for Tristan and give him what he needs to have a more successful and independent future.

We attended Family Weekend when it was in Grand Forks in 2019. We chose to come back again this year with hopes to meet new friends and keep learning the best ways we can help Tristan to thrive. But especially for Tristan to make new friendships. He loves having friends and being a friend, but he does struggle with making friendships.



The Vetsch family includes (clockwise from far left) Collin, Sarah, Joe, Josie, Tristan, and Harrison.

Josie and Harrison both knew that this was a special weekend for Tristan, and I think that in and of itself is important. They know things can be extra hard for Tristan and understand that he deserves a special weekend that is sort of all about him. It's also an opportunity for them to see other children with vision impairments so they know their brother isn't alone and to see other children who have vision impaired siblings, so they know they aren't alone either.

What advice would you give other families who have a child who is visually impaired?

I would tell other families to hang in there, as cliché as that sounds. There are good days and bad days. I feel that being a mother to a vision impaired child has given me the ultimate "vision" as a human being. Tristan's achievements astound me on a daily basis. I would also tell other parents that while it is so incredibly important to focus on the future, your child's future, it is just as equally important to enjoy today. Let them be kids.

I know I need to take my own advice as well. Let them make the mess...swim in the pool... make the friends. And whether we want to be or not, we are our children's advocate in everything. Their success depends on our efforts, so we must learn where to funnel those efforts that are over and above just being a parent, which isn't easy!

Check out pictures from Family Weekend on the next page!



On Friday evening, families enjoyed pizza and cookies while getting to know each other. After dinner, they played accessible games with Trampes Brown, the President of the North Dakota Association of the Blind.

Left, a young boy throws a dart at the audible dart board.

Below, a group of parents and children try out blind soccer.



On Saturday, there was plenty of tactile fun for the kids and fantastic speakers for the parents. The children enjoyed visits from a miniature therapy horse, turtles, and insects!

Neva Fairchild, Trampes Brown, and Tara Tompai shared their knowledge with the parents, who also had a chance to get to know and learn from each other. The winners of the NDSB Foundation's Card Contest were honored at the luncheon hosted by NDSB Foundation President Julie Anderson.

We're already looking forward to next year's Family Weekend and hope you are too!



Second picture from top, Regional Coordinator Melissa Snyder helps a young boy pet a turtle. A young girl pets therapy horse Comet with some encouragement from Comet's keeper, Terry. Neva Fairchild shared her personal story and advice with parents.



Above, this girl's beautiful painting was created with maggots! Yes, maggots.

Below, NDSB Foundation President Julie Anderson congratulates one of the Card Contest winners.



save the date

FOR FAMILY WEEKEND 2023

MARCH 31 – APRIL 1

BISMARCK, ND

**THE NDVS/SB OUTREACH STAFF WISH YOU A WONDERFUL SUMMER
LEARNING, PLAYING, AND ENJOYING THE SUNSHINE!**