

Alyssa

Meet 29-year-old Alyssa Miles, daughter of Henry and Elizabeth Miles. According to her mom, Elizabeth, Alyssa showed early signs of developmental delays at one and a half years of age. She started having seizures at 18 months and speech delay. Alyssa is globally-developmentally delayed with very little speech. At 25, she was diagnosed with Beta-propeller protein-associated neurodegeneration (BPAN), a very rare genetic disorder "Her disorder causes Parkinsonism and dementia, which will shorten her life span," said Elizabeth.

Alyssa was enrolled in the Stark County Integrated Preschool (SCIP) program at age 3 and then attended Plain Local Schools in the multiple disabilities program until she was 21. Alyssa loved getting on the bus and going to school. She had great teachers throughout her entire school career. Mrs. Fleming was her high school teacher and she flourished under her guidance. Alyssa loved going to the proms with her peers. The music, food, dancing and dressing up was a definite highlight.

"Alyssa is a huge Disney fan. She has been to Disney at least 25 times," said Elizabeth. "Her favorite time to go is the Christmas season. Disney has the Candlelight Processional performed by the orchestra and massed choir which tells the story of the birth of Jesus. She has to see it every night."

Alyssa's greatest strength is her smile and laugh. Her smile is contagious and makes everyone else smile.

In addition to her parents, Alyssa has a younger brother, Matthias (Matt). "He's 22 and a OSU graduate. He works for Pepsi







in Twinsburg," said Elizabeth. "Matt has played baseball since he was little. Alyssa loved watching her brother play. She had a special chair behind the backstop where she would sit and cheer. Matt still plays in a wood bat league and she is still his biggest fan."

"Alyssa's grandparents, Harry and Eleanor Schoger, are a huge influence in her life," said Elizabeth. "They have been a loving, caring support system throughout her life. Alyssa calls them pop pop and ma ma ma."

In addition to her family and traveling, Alyssa has participated in community activities much of her life. "She rode horses at Pegasus Farms from 6-years old until the COVID shut down the program. Annie was her horse and she loved riding," said Elizabeth.

"Alyssa learned to swim and went to the YMCA with Beth, her swim instructor and friend. Twice a week, Beth would pick her up from school or the Day Habilitation program and take her swimming. Again, COVID shut down her swimming," said Elizabeth. "During the shutdown, Alyssa's disorder progressed and she became non-ambulatory. She is no longer able to swim or ride horses."

Alyssa attends Jason's Place, a community provider, during the day. "It's the perfect place for Alyssa," said Elizabeth. "Melissa Haddock, owner, makes sure the clients' needs are met and incorporates their interests and likes into their day. Alyssa likes her peers and the direct support staff."

Recently, Alyssa's disorder has changed her life immensely. With the financial help from her Individual Options (IO) Waiver, every needed service was authorized to help Alyssa: Shared Living Services, Homemaker Personal Care (HPC), home









modifications and van modification/ equipment. "They are all separate available services through Alyssa's IO waiver," said Shelia Meyer, Stark DD Service and Support Administrator.

"She is no longer able to walk, use the restroom independently, and feed herself. Stark County DD helped to modify the house to accommodate her new normal," said Elizabeth. "A bedroom and bathroom had to be built on the first floor. The van was fitted with a seat that rotates out, lowers so she can be transferred easily and then returns to normal position. We are grateful for the Stark County Board of DD."

