

PORTING FAMILIES

We are hosting a series of major conferences focusing on Autism Spectrum Disorders. Renowned autism experts from across the country have been invited by ACC to share the latest research and treatment strategies.

Our Jamestown Campus

While the Anne Carlsen Center expands, we recognize the importance of our campus in Jamestown. Over the years, many children with disabilities have lived life to its fullest here, benefitting from our exceptional residential, therapeutic and educational services. For some students, this will continue to be the best fit for their needs and abilities.

“We look forward to seeing many more children blossom in the safe, secure and loving atmosphere the campus provides,” says Marcia Gums, ACC’s Chief Operating Officer.

The Journey Ahead

This expansion of ACC services will provide families across North Dakota with more choices. They will have additional resources available to them, as they search for help and hope.

“We recognize that each person has different needs and dreams for the future,” says Howell. “The Anne Carlsen Center has the depth of expertise and compassion to be a partner in life for so many. It is an honor to continue Dr. Anne Carlsen’s work, as we remain dedicated to nurturing abilities and changing lives.”



Hope at Last

ACC’s new outreach programs help family through troubled times

When it comes to play time, Jaxon and Jaleigh both go for books and puzzles. Here Jennifer helps Jaleigh with reading, while Dusty and Jaxon talk about how to put a puzzle together.

Jaxon and Jaleigh Schneider could be any other set of twins. They laugh, they cry, they scramble for toys, and capture your heart with their soft blue eyes.

But they are also miracles in their own way. Seeing them smile, move around their house, climb on their parents—all those everyday activities are hope fulfilled.

You see, 18 months ago, Jaxon and Jaleigh began their lives nine and a half weeks earlier than expected.

With the early start on life, came a series of medical emergencies. For a family excited for pregnancy and birth, there was also a fear that one or both of the children would not live past their original due date.

“You find out you are pregnant and you are so excited,” recalled Jennifer. “You bring home a perfect baby and life goes on.”

No one could have expected what the next year would bring.

Early Troubles

Confined to incubators and fed oxygen through respirators from birth, both babies suffered brain bleeds when they were one week old.

Premature babies are at an increased risk for brain bleeds, and the earlier a baby is born can often determine the severity of that bleed. Normally, premature babies have a grade I or II. Jaxon and Jaleigh suffered Grade III bleeds, identified by ventricles becoming enlarged by blood and often leaving a child with long-term brain injuries.

The babies were born at a hospital in Fargo, forcing the Jamestown couple to relocate temporarily with family in order to stay close to their children.

Dusty, who works in Valley City, made the 60-mile drive each morning and evening exhausted, but knowing the family depended on his income. Often fighting the temptation of sleep while on Interstate, Dusty felt guilty that he was abandoning his wife with the family’s problems. Both parents were finding hope to be, at times, a fleeting emotion. But the family found strength in each other.

“I’m not going to say it’s been easy on anybody,” said Jennifer. “It is exhausting. But you really learn to rely on each other, too.”

The medical emergencies continued to pile up. In September, Jaleigh needed surgery when the skull plates in her head had closed too soon. In October, Jaxon was

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suffering from what appeared to be a respiratory infection.

Unexpected Role Reversal

But after an ear, nose and throat doctor examined him, Jaxon was rushed into surgery. Not even a year old, his life was threatened again. Jaxon's airway was being restricted as scar tissue had formed around his trachea. The after-effect from the ventilator that had previously kept him alive was now threatening his life.

"The doctor told us on the outside Jaxon looks healthy," said Jennifer. "Until you listen to his lungs. He is a fragile little boy."

It was a dramatic role reversal for Jaxon and Jaleigh. Sister had been the fragile child, while brother was the stronger one, the tough one. Suddenly Jaxon wasn't the hearty one. After receiving the tracheotomy, Jaxon had to be admitted back into the hospital in November due to a respiratory infection.

"I thought we were past all the problems and ready to be a family," said Jennifer, adding that the respiratory issues explained some of the crying fits Jaxon had early on. "Last summer he was a cranky little boy. When we were thinking back, it made sense because he was having trouble breathing on his own and was compensating."

Time Running Out

Christmas marked one year since Jennifer took a leave from her teaching job. After 12 months, the family was starting to run out of time. Jennifer was in danger of losing her job, and the in-home nursing care they were counting on had been approved, but there was a gap between the hiring and training phases. Worse yet, Dusty had broken bones in both feet that were making it difficult to get through the workday and care for children who love to play in and outside of the house.

"Between the four of us, someone is always sick," said Dusty with a laugh. "I'm on light duty for six months."

Jaleigh was accepted into the Head Start program, but with Jaxon's trach, he could not follow his sister. It was then the family was put in contact with the Anne Carlsen Center for services for Jaxon.



The red hair and the baby blues are pretty difficult to resist. That is what the Center staff discovered when providing 18-month-old Jaxon with his care.

Initially, the family was reluctant to involve Jaxon with ACC, thinking he was not the type of child they helped.

"I said that more than once," said Jennifer. "He doesn't have to go to the Anne Carlsen Center. He's not that bad."

Jaxon plays with bubbles as part his speech therapy learning curriculum. Ann Albrecht, a therapist with the ACC, travels to see Jaxon and his sister, Jaleigh, each week.



Enter the Center

While Jaxon received in-home nursing care and some therapy, the family's proximity to the Jamestown campus made it easier to bring him into the Center throughout the week. This also gave Jaxon the chance to learn and play with the Center's youngest residents.

"Everyone was so nice. They'd take pictures of what they were doing in the class and send them home. You could just see he was so happy," said Jennifer. "I learned a lot."

Most of Jaxon's care revolved around prevention and not treatment, as he was sporting the trach in the middle of winter. Undaunted by the new surroundings, Jaxon's outgoing personality and captivating smile turned him into a bit of celebrity at the Center.

"The staff just loved him being there," said Jennifer. "He was in a stroller and would wave at everyone when we went down the hall. They loved it."

With Jaxon at the Center and Jaleigh with Head Start, Jennifer was able to return to her job and finish the school year. In April the family received the in-home nursing care they had been waiting for.

Hope For the Future

Jaxon, now without the trach, is spending all of his days at home, but that wasn't the end of the relationship between the Center and the family. A therapist visits the Schneider's house twice a week to help Jaxon and Jaleigh with speech and feeding development.

All of the health problems haven't gone away, but they aren't as life threatening as they had been. Jaleigh has had ear infections on and off since the start of the year, but after what the family has endured, everyone is ready for a dose of what every kid goes through.

"That is normal stuff," said Jennifer. "We can handle that."

"I think back to 12 or 13 months ago," said Dusty. "I never thought we'd be at this point."

Jaxon has started walking and was up to nine steps by the end of May. Jaleigh was right behind, figuring out the standing part, but not quite ready for those first unassisted steps.

"We didn't get the perfect dream, the perfect situation," Jennifer said. "But we wouldn't trade it for anything."