

Navigating assistance system

Hanover mother of boy with heart problem gathered valuable guidance and information through Partners in Policymaking

By Ed DuBois, Wright County Journal-Press

When Treynor Smith was just three days old, he and his parents were flown from Brookings, S.D. to the University of Minnesota Hospital. Treynor underwent his first of many surgical procedures seven days after his birth.

He was born with a condition called truncus arteriosus. His mother, Amy Smith, explained that the pulmonary artery and the aorta divide in most infants as they grow and develop in the womb.

"Treynor's pulmonary artery and aorta never did that," Amy said. "There was a hole between the left and right sides of the heart, and there was one tube (vessel) where the pulmonary artery and aorta should have been located."



She recalled Treynor appeared to be "pink and healthy."

"We would never have known about the heart problem if it had not been detected during an ultrasound examination," Amy said.

Today, her five-year-old boy loves T-ball, and after getting home from preschool, he likes being outside with the family's faithful dog, Zoey, as well as several pet cats. Still recovering from his very serious heart condition, he looks and acts like most five-year-old boys, but he will need to undergo more surgical procedures, and he hasn't quite completed his transition from a feeding tube to eating and drinking like most of us.

Navigating assistance

The family is living in Minnesota now. Between Treynor's Valentine's Day birth in South Dakota five years ago and his present day activities in Hanover, Amy and her husband, Clint Smith, have been navigating through a world with which most people are quite unfamiliar. Fortunately, most people do not need government agencies that can help out with medical costs and things like transportation to faraway hospitals, training services for parents of children with special needs, a nurse to help out at home, and more.

Amy said you can feel very isolated and lost in that world. Where do you go? Who do you see? What's the best way to proceed?

The answers to such questions were found through a program called Partners in Policymaking. Amy is a recent leadership graduate of the program, which was introduced by the Minnesota Governor's Council on Developmental Disabilities in 1987. Since then, over 900 Minnesotans have completed the program and over 27,000 have participated in Partners programs offered worldwide.

Amy said one of the greatest benefits of the program was connecting and starting relationships with others who have common experiences. Her classmates were a great source of information and insight.

According to a recent Partners news release, she recommends the program to other parents so they can become more aware of the possibilities for their children.

"When you don't even know the questions to ask, you do not realize that you have options," Amy said.

"You can feel like an island (before entering the program), but with this group of people, you learn from those who already understand," she told the Journal-Press.

Ag teachers

The first time she learned about Partners in Policymaking was when she was in South Dakota. She was a member of the South Dakota State University faculty, and her husband, Clint, was teaching at a nearby high school.

Today, Amy is a member of the agriculture education faculty at the University of Minnesota. She said she is a teacher of ag teachers. Clint is an agriculture teacher at Rockford High School.

Amy and Clint met in Iowa when they were both attending an agriculture teachers' conference. They later married in Missouri before moving to South Dakota. They have lived in Hanover since the spring of 2014.

Expectant parents

Amy recalled that before knowing about Treynor's congenital heart defect, she and Clint were like most expectant parents.

"They usually want to know if it's a boy or a girl so they know what color to paint the newborn's bedroom. That was suddenly not important," she said.

A cardiologist confirmed the heart problem.

During the quick trip to Minneapolis just days after Treynor was born, a former student took care of the house in South Dakota (as well as Zoey) and substitute taught for Clint. The Smith family was in the Twin Cities six weeks as Treynor recovered from surgery and his parents learned about dealing with feeding issues. Many infants with serious heart issues never get a chance to learn to feed.

Because Treynor had a feeding tube almost since birth, he never learned to take food orally. Now he is more interested in food after seeing his friends at preschool eat food.

An occupational therapist and a speech therapist have helped Treynor get over an aversion to drinking from a cup. His visits with the therapists were called "Food Camp" to help make them more positive and fun. Amy explained the speech therapist was involved because many of the muscles used for speech are also used for eating.

"They are tied closely together," she said.

Some give up

Through Partners in Policymaking, Treynor's parents learned about programs that have helped get Treynor ready to start school. Through Partners, they were able to arrange to get intensive feeding training at the University of Iowa, for example.

"People with less access and knowledge about programs and agencies struggle with finding help. Some never get the help they need. They give up out of frustration," Amy said.

From September to May, Amy took part in the Partners eight-month leadership training program. She was in the 33rd class, and the weekend sessions took place at a hotel near the Mall of America.

Participants learn how to become knowledgeable, confident and effective advocates for themselves, their children and others with disabilities.

Amy feels strongly about helping provide access to and knowledge about available services.

"Streamlining access to services is important to me," she said.

The systems in place for gaining access to services can be different from county to county and from state to state. Partners helps you find your way. You can learn the meaning of the

terminology used by the service providers, and you can learn who to see and the best questions to ask.

Partners helps understand how it all works, Amy said.

Camp Courage

One of the programs that helped Treynor is True Strides, a horse riding therapy service available at Camp Courage near Maple Lake.

"The social and emotional benefit of True Strides was huge," Amy said. "Treynor is going again this summer."

Through Partners, she has been able to get in touch with key leaders in the school system and help work toward positive change for kids with special needs.

Treynor goes to preschool in the morning. Back at home, he receives care from an LPN (licensed practical nurse) until his parents get home. Amy said Treynor and the LPN, Tammy, are "best buddies."

The Partners Program

"Graduates report that they gained a greater understanding of disability law and policies and increased their self confidence in advocating for their needs," said Colleen Wieck, executive director of the Governor's Council. "Many have become leaders in their own communities as they speak up for people with disabilities."

"This program is based on the belief that systems change is best brought about through the efforts of those most affected by them, and we seek to arm these individuals with the tools needed to be successful in the public policy arena," said Wieck.