

FREE

Volume 8 : Issue 6 / PCWSN.com

Parenting

Children with Special Needs

FINDING YOUR PLACE

Transitioning to Adulthood



Sign On
to Sign Language

KC is Tops
for Best Place to
Live with Disabilities



**Playing
Softball**
with One Arm.
You Bet!

KC's Only Pediatric Health and Services Resource Guide

FINDING YOUR PLACE IN THE WORLD



Tips for transitioning services for adult children with special needs

By Tracy Bennett

Even adults with special needs are somebody's child. And those parents share common challenges with parents of young children with special needs: feelings of isolation from other adults, caregiver burnout, struggles with personal and marital well-being, worry and concern for the future of their child. Age 18 isn't necessarily a magic number for that special needs person, but in the eyes of the law and society, it is. Parents must plan for what happens next. This is a story, yet without an ending, of one such family's journey from childhood to adulthood.

Although life has not gone as planned for Terri and Steve Wynne of Lee's Summit, they will tell you that their son has taught them more about strength and courage than they have taught him. "Life doesn't have to be picture perfect to be happy," says Terri.

Jeremy is their 31-year-old son. At age 7, he began exhibiting symptoms of what would eventually be diagnosed as Early Onset Generalized Dystonia, a neurological disorder that affects muscle groups. By the age of 9, Jeremy was in a wheel chair. "At age 15, he spent most days curled up, muscles contorted in painful spasms," says Terri. It was at this time that he had Deep Brain Stimulation (DBS) surgery to implant two stimulators in his brain, which run off of two generators in his chest. The purpose is to block neuro transmissions causing the muscles to tense. He was one of the youngest patients to undergo this surgery at the time. The generators have to be replaced about every 18 months, and rarely do they need to be replaced at the same time. "I've lost track of how many surgeries Jeremy has had," said Terri.

Despite learning disabilities, the loss of fluent speech, and the constant pain that Jeremy experiences, his love of sports, positive attitude and sense of humor, is how others will describe him. So much so, that he has become something of a local celebrity around Blue Springs High School, where

he attended through the age of 21. You may have seen a story about him on Fox 4 News in 2015. Jeremy is quite possibly the Blue Springs Wildcats football team's biggest fan. Head Coach Kelly Donahoe was instrumental in bringing Jeremy out of the stands and onto the sidelines as the team's honorary 12th man. That has included invitations to join the football powerhouse at two State Championships games and being the recipient of championship rings along with the rest of the players. Today you'll still see him on the sidelines. In fact, that's where he was headed the Friday evening this fall when I interviewed his parents.

A PLACE IN SOCIETY

As individuals with special needs grow up there is a shift that occurs in the way society views them, say Terri and Steve. "No longer cute and little, strangers just seem to ignore them. It's harder to get respite care for adults than it is to get a babysitter for a child," says Terri.

"People with special needs just want to be treated like everyone else. They don't want to be ignored. I've found that as Jeremy has gotten older, other adults don't know what to say or are uncomfortable. I suspect Jeremy's biggest disappointment and challenge is to be accepted by his peers," says Steve.

In this way, young people may be more welcoming and less judgmental. "I have been impressed the most by the players and students at Blue Springs," says Steve. "High school kids get a bad rep that may be undeserved. It's amazing the compassion the football players have shown to Jeremy over the years, even in the heat of the battle during a game they pause to include him," says Steve.

And it's not just at school. Jeremy is no longer a student but current and former players will drop by his house for a swim in the family pool



The Wynne family includes Jeremy, parents Terri and Steve, and brothers Josh and Zach and their families. Every other year they meet up to attend the Royals Spring Training in Arizona.

Erin Longshore/Erin Longshore Photography

Go WILDCATS!



Super fan
Jeremy Wynne loves to support the Blue Springs Wildcats Football team, and they in turn, love Jeremy, who watches the game from the sidelines as honorary 12th man. He's traveled with them to state championships, they frequently pop in to visit him at home, and each year they honor their most deserving players with the Jeremy Wynne Scholarship Award.

See more about Jeremy and the Wildcats on Fox4kc.com.

or to eat pizza. Another who went on to play for K-State brought Jeremy his jersey from the Liberty Bowl as a gift. Last year, the whole team came out to support Jeremy and the Exceptionals softball team. The Exceptionals is a league for physically or mentally challenged individuals. Terri and Steve have coached a team for many years.

The friendships and camaraderie resulting from Jeremy's unique relationship with the Blue Springs Wildcats started with just one person. His freshman year at the high school, one football player regularly paused to hold the door for him. Then Coach Donahoe altered the course of Jeremy's life. "This man has a great heart and passion for others. He was tuned into Jeremy," says Steve. That prevailing attitude comes from the top down, according to Steve, starting with the superintendent of the school district.

CHALLENGES INTO ADULTHOOD

It's not by chance that the Wynnes ended up in the Blue Springs School District. Soon after Jeremy's diagnosis, they wanted to move back to the Kansas City area to be near Terri's family so they could be part of Jeremy's support system. Before they moved Terri interviewed school districts on both the

Kansas and Missouri sides of the state line. Some didn't even call her back. Ultimately, they were impressed with Blue Springs' willingness to listen, their thorough review of Jeremy's records, and their proactive suggestions for how they could best serve him.

Although no longer a student, continuing to keep Jeremy happy and healthy remains the ongoing goal for his parents. That means finding programs beyond school to provide him with structure and social activities. These days, Jeremy attends Developing Potential, Inc., (DPI) a day program for adults with developmental disabilities.

DPI serves about 150 individuals from three locations in Lee's Summit, Independence, and Kansas City. Many patrons have significant mobility challenges and need individual attention at meal times. Through the use of individual, personalized development plans that integrate the Gentle Teaching philosophy, participants are able to work with staff in a safe and medically supported environment. Services focus on building skills related to health and physical fitness, personal expression, communication, and socialization.



DECKER
INTEGRATED
ORTHOTICS • PROSTHETICS

LOREN J. DECKER, CP



PERSONAL CARE from OUR FAMILY to YOUR FAMILY

We will treat your family
with the same care we
treat our own families!

Orthotic Services

Pediatric Orthotics
Scoliosis Bracing
Custom Leg Braces
Custom Knee Braces
Off-the-shelf Bracing & Splinting
Spinal Bracing
Club Foot Bracing

Prosthetic Services

Pre-surgical Counseling
Post-operative Fitting
Upper & Lower Extremity Prosthesis
Partial Hand & Foot Prosthesis
Pediatric Prosthetics
Myo-Electric Prosthetics
Bionic Knee and Foot Prosthesis

We are committed to providing patients with the highest quality orthotic and prosthetic care through Decker Intergrated Orthotics & Prosthetics.

8931 W.

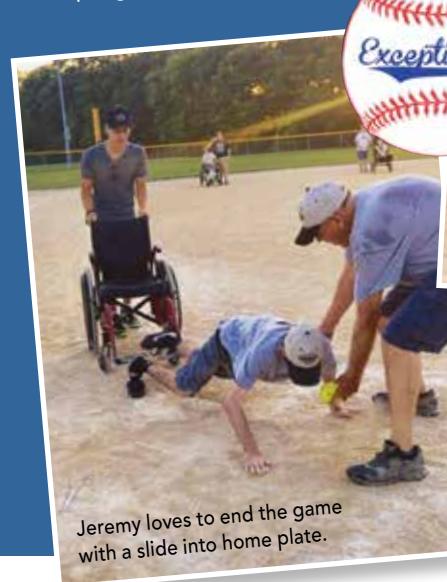
75th St. | Overland Park, KS 66204

913.341.2661

www.deckeriop.com

THE EXCEPTIONALS SOFTBALL LEAGUE

Sterling Farber started **The Exceptionals** softball league 26 years ago for individuals with special needs. Ages 5 to adult participate on either coach pitch or tee ball teams, playing games every Monday in May and June at Hidden Valley Park in Blue Springs.



Jeremy loves to end the game with a slide into home plate.

In the 1990s, the league started with just 18 players and has grown to include more than 200. Volunteer "buddies" assist players so that parents can watch the game. Learn more on Facebook@exceptionalsoftball or call Sterling Farber at 816-694-4838.

According to Jeremy, what he likes best about DPI are the friendships he has made and the staff. He also likes the Halloween and Prom dances. Terri explains that the small class sizes group people of similar age and abilities. They often discuss current events, the weather, and Jeremy has been given the opportunity to be the "sports announcer." Field trips and activities keep things interesting.

For those who are capable, the program includes assistance in finding a job, maintaining personal finances, and achieving self-reliance. According to DPI literature, over the next 20 years the number of people with disabilities is expected to double. Currently 54 million Americans live with disabilities. While about 20% of those are actively seeking employment, jobs for individuals with disabilities have not kept pace.

"DPI engages with area business to find ways to help them meet their business goals by thinking differently about employing individuals with disabilities," says Amy Cox, Development Director at DPI.

Cox encourages families to start the planning process early as a child is approaching adulthood. "In Missouri, start by contacting the Kansas City Regional Center, Missouri Department of Mental Health at 816-889-3400 to begin the intake and assessment process when the child is 14 to 15 years old. The process of assessment, approval, identifying services and service providers, and being on waiting lists can take several years," she says.

In addition, Terri recommends making use of the resources available to you at school while your child is still enrolled in high school. Often the high school will assign a transition coordinator to facilitate this and guide you to government assistance and services available for adults. "Waiting

lists are quite long so get your name on some early," she says.

She also suggests that parents start with finding an attorney that specializes in elder care who can assist you with applying for guardianship when your child turns 18, developing a special needs trust, and writing a will that accounts for who will take over guardianship after you and your spouse are gone. "We're still grappling with how to make it financially possible for Jeremy to remain in our home after we are gone, but if not, what residential care facilities are available," says Terri.

GOING THE DISTANCE

The Wynnes bring the wisdom of hindsight and 33 years of marriage to the situation of caring for an adult child with special needs. Terri says reliance on God for strength is at the core of their marriage. And it's also about the simplest of things: spending time on yourself by exercising and eating well.

"We're in this together," she says. "We try not to focus on what we can't do, but instead on what we can do together. Many of our friends are empty nesters. We won't ever be empty nesters, and be able to retire and travel." But Terri and Steve can meet for lunch while Jeremy is at

Developing Potential, they try to go on a date at least once a month, and a couple of times a year they get away for a weekend. As a family, they go to Royals games and every other year they meet up with their other adult children and their families for Royals Spring Training in Arizona.

That's not to say that Steve and Terri don't wish for a break now and then, as do all caregivers, which as we age may include senior parents, a spouse, plus adult children with special needs. While friends will offer to help, Terri says what's most helpful is when someone is specific. "Don't just say 'call if you need anything,' but be proactive and say I'm coming over on a certain day at a certain time, so you can get out."

"I'm proud of Jeremy for his attitude about life. He has taught me so much," says Steve. "It's hard for a parent to know your child is in pain, but he just grits his teeth and doesn't complain." Meanwhile, he has made meaningful connections with Wildcats football players and others. "With his eyes and his smile...he touches people," said Steve.

Tracy Bennett is a freelance writer and owner of Mighty Mo Media Partners, a public relations, media strategy, and event planning company. She specializes in connecting small businesses to media outlets, especially in niche or trade industries. She is mother to two teenagers, one of which has ADHD.

Contact her at tbennett@mightyomedia.com.

Cover and Family Photos: Erin Longshore is a portrait photographer that has been photographing families around the Kansas City Metro area for the past six years. As owner of Erin Longshore Photography, she specializes in families, newborns, births, and high school seniors. Erin resides in Olathe, Kan., with her husband and three sons.

elongshorephoto.com



Medical Rehabilitation • Therapeutic Preschool • Employment Services

We provide developmental, educational, and therapeutic services for children and adolescents, from birth to 18 years, with special needs.

- ABA Services
- Assistive Technology
- Aquatic Therapy
- Driving Evaluation
- Early Education
- Early Intervention
- First Time Job Placement
- Individualized Programs
- Intensive Services (up to 5 days a week)
- Occupational, Physical, and Speech Therapies



Call for information on programs and after hours therapy opportunities.

Medical Rehabilitation tel: 816.751.7700

Therapeutic Preschool tel: 816.756.0780

www.abilitykc.org

Ability KC brings together Rehabilitation Institute of Kansas City and Children's Therapeutic Learning Center.

Was your Baby in the NICU?



Find out why

Every year shortly after delivery, thousands of children are admitted to Neonatal Intensive Care Units. Often doctors or hospitals are too busy to review the records and tell you why this happened to your baby. We can help you obtain the records and find the answers.

DOCTORS who are also LAWYERS Advocates for Children



CULLAN & CULLAN M.D., J.D.

FREE CONSULTATION

MISSOURI **816.861.7600**

KANSAS **913.649.7600**

www.doctorspracticinglaw.com

The choice of a lawyer is an important decision and should not be based solely upon advertisements. Attorney meetings by appointment only. Neither the Supreme Court nor The State Bar Association reviews medical or medical legal certifying organizations.

