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THE MOST IMPORTANT PEOPLE

## Just living life

Parenting a child with special needs can be challenging and rewarding

## Valentines on a budget

Celebrating love while not spending a lot of cash

## Children and pets

Don't make a snap decision when adding a pet to the household

## Can you pay for me now?

Pre-pay or long-term contract, we discuss cell phone plans

# Special assignment

Parenting a child with special needs can be challenging and rewarding

By **TAMARA CLYMER** ❖ Photographed by **TODD WEDDLE**

**W**hen Tanner Hrenchir was born on that cold, snowy March day in 1982, his parents were thrilled. Sure, he was a few weeks early, but even at just 5 pounds and 19 inches, he was everything Jerry and Wanda had hoped for.

The little guy was healthy, had light brown hair and hazel eyes and was so good natured he rarely cried.

They were in love.

Tanner stayed in the hospital for several days, gaining weight and growing stronger, but on day nine, just as his new parents were getting ready to take him home, the doctor came in with devastating news.

"He told us he thought he had Down's," Wanda remembers. "He asked us if we knew what that meant. I said 'yes', but my husband said, 'no.'"

"He's going to be retarded," the doctor said. The crude bedside manner left the couple stunned. The pair quietly picked up their son, got in the car and drove home.



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Interviewed by **TODD WEDDLE**

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Please see **Page 14**



Wanda and Jerry Hrenchir show a picture of their three children, including Tanner (center), who has Down syndrome.

Genetic testing later confirmed the doctor's fear. Tanner had Down syndrome, a disorder caused by an extra chromosome in Tanner's DNA. Down syndrome is one of the most common genetic birth defects, affecting more than 3,000 babies a year in the United States. Unfortunately, while most of the stigma associated with the disease had subsided by the 1980s, doctors still weren't optimistic about Tanner's chances for a good quality of life.

"We took him in for his first checkup, and he told us everything he wouldn't do," Wanda recalls. "'He won't do this, or this or this,' he said. 'But the one positive is, Downs are very loving.' And there we sat, just totally shocked."

Without a recommendation on where to go for support and what to do to help their son, the couple was left to figure out how to help Tanner on their own. Once again, they took their son home and spent the next 12 months getting used to the idea of having a child with Down syndrome, telling only their family and close friends about his challenges. All the while they did the best they could to help Tanner reach developmental milestones on his own timetable.

"Nobody told me to exercise him and to do this and that to make the muscles in his neck stronger," Wanda remembers. "I thought what I mainly had was a cerebral palsy child. I had no idea what to do with him. No idea. So I treated him like you would a normal baby."

According to the U.S. Department of Health and Human Services, almost 13 percent of American kids born each year have some type of special need. And whether it's Down syndrome, cerebral palsy or another condition, parents are often unprepared emotionally for the challenges they're about to face.

Minnie Bray works with children and families who are still coming to terms with their new diagnosis. The United Cerebral Palsy speech pathologist says the process is similar to the grieving process.

"You lost the baby that you thought you were going to have, the future and things that you had dreamed about for your child," she says. "Just going through those initial grief stages and then sorting out where you go from there, some of that gets very overwhelming for parents."

But once the initial shock wears off, Minnie says parents often discover their children aren't so different after all.

"Once the dust settles, they start to see the similarities rather than just the differences," she says. "That's a big milestone in everyone's life — finding out that they are more



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like other children than they are different and accepting the differences and appreciating all of the good things."

It took awhile for that dust to settle for Cynthia Long. When her daughter, Elizabeth, was born five years ago, no one noticed anything different about her little girl. It wasn't until Elizabeth started missing developmental milestones that Cynthia became worried.

"She wasn't crawling or doing things that normal babies would do," she says. "So we took her to the genetics doctor at Children's Mercy."

That's when doctors discovered Elizabeth had 18-D Deletions Syndrome. It's a form of leukodystrophy, a rare genetic disorder that affects the central nervous system.

As recently as 50 years ago, children like Tanner and Elizabeth received next to no developmental care. Today, many disabilities are discovered before babies are even born, which means therapy can begin almost the moment the infant leaves the hospital.

Once Elizabeth was diagnosed, therapy began immediately. Now she has four years of training under her belt.

"She has come a long way due to her speech, physical and occupational therapy," Cynthia says. "We started that before she was a year old through UCP (United Cerebral Palsy). They've done a great job. If it wasn't for them, she probably wouldn't be where she is today."

"When we go in and work with families, we offer ideas and strategies that sometimes seem overwhelming," Minnie explains. "What we try to remember as professionals and remind parents is that they need to take care of themselves first. You really have to take care of yourself and find out what works best for your family."

And by taking care of themselves, they're able to keep up their stamina for one of their most important jobs: acting as an advocate for their child — working with health care professionals to get the services their child needs, all while



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And by taking care of themselves, they're able to keep up their stamina for one of their most important jobs: acting as an advocate for their child — working with health care professionals to get the services their child needs, all while

keeping a positive attitude.

“I think it's important to develop and foster those good professional relationships, whether it be with early intervention therapists or with school district therapists,” she says.

Wanda took her job as Tanner's advocate seriously. With the help of a preschool teacher, they started getting Tanner the services he needed and worked with school administrators to give their son the best educational experience possible.

“It was a continual fight all the way through school,” Wanda says. “We went round and around his whole four years of high school. I'm sure they just hated to see me walk in. I was nice ... but firm.”

Another one of his biggest supporters was his little sister. Katie Hrenchir says despite Tanner's developmental challenges, the pair had a typical brother-sister relationship.

“We had fights just like anybody else, except everybody felt sorry for Tanner,” she says, laughing.

But she wouldn't stand for anyone else fighting with him. After an incident with some school bus bullies, she became one of Tanner's biggest supporters.

“I remember coming home when they made him cry,” she says. “I was crying and I went to mom and I was like, ‘Mom they're making fun of him and it's making me so sad.’ She did not sympathize with me. She looked at me and said, ‘Katie, you've got to stand up for him. He's a little different, but he's special.’ She wanted me to stand up for him and that was probably the best advice I could have ever had. So from then on, I did stand up for him.”

Now at 27 years old, Tanner is doing great. He works part time at the Doniphan County Sheltered Workshop, waters plants at a local gardening center in the spring and is a Special Olympics athlete, competing in basketball, track, bowling, flag football and softball. And if that wasn't enough, Tanner also helps his dad on the family farm.

“I've been helping my dad for a long time and we always take care of the hay,” Tanner says with a wide grin. “Dad and I are best friends.”

He lives at home, in his own apartment of sorts. Besides the farm work, he helps with laundry, setting the table and fixing a meal every now and then. Wanda says he's pretty self-sufficient and probably just sticks around for a little extra TLC.

“He hasn't shown any desire to go to the apartments in Wathena,” his mom says. “If he doesn't want to, that's fine.”

“If I get married I might,” Tanner says.

“Yes,” she answers with a smile. “That's a dream of his, to get married.”

## Take care

Caring for someone with special needs, either as a child or adult, can be difficult. The national Centers for Disease Control and Prevention offers the following tips on ways to help you and those you care for stay healthy and safe.

- **Be informed** — Study up on your child's condition and special needs from a variety of reliable sources. Take a look at employee benefits and insurance policies to determine what is covered and what isn't for your circumstances. If you don't have them, research what local, state and federal benefits are available.

- **Get support** — Don't be afraid to ask friends and family to help as needed. A local or online support group can not only help you connect with people who share your experience, it also can combat isolation and fear that caregivers can experience. Find out what services are available through public and private organizations.

- **Be an advocate** — You can be your child's best advocate, and effective advocates tend to be more successful at getting better service. Don't be afraid to ask questions, inform other caregivers of any special circumstances, document your child's medical history and keep the information current. Talk to your employer about your circumstances and limitations. Be familiar with the Americans with Disabilities Act, the Family Medical Leave Act, and other state and national laws and how they apply to your situation.

- **Be empowering** — Focus on what your child can do. Be sure to celebrate milestones. Empower them by allowing them to engage as much as possible with others. When appropriate, teach them to be as independent and self-assured as possible.

- **Take care of yourself** — Don't let caregiving consume your entire life — it isn't healthy for you or those you care for. Balance is key with reasonable expectations. Take care of yourself by following your personal interests or, when possible, delegate some caregiving tasks to others so you can take a break. Even short walks or a relaxing bath can make a big difference. When possible, take longer breaks by getting away for a weekend with your friends or spouse.

- **Keep balance in the family** — Don't forget about your other family members. Special-needs children require extra care and attention, but don't let it be at the expense of the rest of the family. Pay extra attention to the needs of your other children as well.

— [www.cdc.gov](http://www.cdc.gov)