

Drum Roll, Please!

June 2022 Caregiver of the Month, Justin Cartmell
Missouri Department of Health and Senior Services



Justin is a committed father to his son, Patrick, who was diagnosed with DeSanto-Shinawi Syndrome, a rare neurodevelopmental disorder before his 1st birthday. Shortly after Patrick was born, it became obvious he was experiencing global developmental delays, trouble sleeping and difficulties with communication. In addition, Patrick was diagnosed with Autism Spectrum Disorder (level 3), characterized by severe challenges in social communication as well as extremely inflexible behavior. Children with level 3 autism are nonverbal and have the use of only a few words of intelligible speech. Initiation of social interaction is very limited, as well as response to others. Patrick was almost two before he started to walk.

Now, Patrick is almost five years old. Over the past few years, Patrick has engaged in extensive therapies, including Applied Behavioral Analysis (ABA) as well as Physical, Speech and Occupational Therapy. During some weeks, Patrick has participated in 40 hours/week of therapies with lots of trips back and forth to therapy sessions. Patrick is currently attending summer school in preparation for starting pre-Kindergarten this fall.

Patrick is fascinated with YouTube videos and can navigate a device independently. He has used apps such as Endless Alphabet to help with communication and learning. Patrick learning some sign language. Much like a typical kid, Patrick enjoys Cheetos, yogurt, fruit, spaghetti and macaroni and cheese. He shares a love of chocolate kisses with his grandmother, Rita, who lives on the same property.

Patrick loves the outdoors and any ride he can get, whether that be in a car, truck or on a lawn mower. He has sensitivity to sounds, lights and movements which proves challenging in many situations. Patrick is an only child. He loves to play and watch the neighbor kids outdoors. Patrick is a “people watcher.”

Justin describes Patrick as very active but easily fatigued. Patrick has trouble sleeping and is sometimes up during the night 3-4 hours at a time. Patrick is generally happy and easy-going however he often

becomes frustrated due to his inability to speak. Patrick can be rambunctious. He requires supervision and oversight during both the day and night (when he is awake) and needs redirection by someone to help him stay on task. Out of frustration, Patrick can become self-abusive and will sometimes bite his hands and fingers.

As a result of Patrick's condition, Justin chose to give up his 25-year family lawn care and landscaping business. Justin knew he would be needed at home and home is exactly where he has invested his time and energy. Justin also assists in caring for his wife on a daily basis who has a neurological disease and helped care for his father who recently passed away.

Due to the caregiver demands, Justin has not been able to pursue traditional work opportunities but instead turned his efforts towards permaculture gardening. As Justin describes, "a permaculture garden is a design that mimics nature so that you can garden organically, encourage the right wildlife and have a low-maintenance yard all in one hit."

Justin's passion for gardening has evolved into a healthy source of food for his family. Gardening has become an opportunity for Justin to not only pursue his love of nature and grow produce but provides favorable circumstances to interact with Patrick while providing the care he needs. Justin's latest project was grafting tomato plants. Patrick had a hand in helping dad by decorating the grow tent with Grandma Rita's trinkets. Patrick collected a number of items, such as cards and crystals, and placed them carefully and discreetly along the top of the tent, poking some through the vents. Justin later found a tomato plant severed by playing card. Luckily, the plant survived and is producing some small tomatoes.

Justin credits Patrick's mother, Liz, for her commitment to Patrick, stating she is really thorough at handling a lot of tasks related to Patrick's care, such as paperwork and medical information. Also, the family receives support from other family members including Patrick's grandparents who recently bought Patrick a trampoline. Patrick's two aunts are supportive as well, Destiny and Chrishna.

Justin is a musician who played the drums for over 30 years. He explains he "hasn't done much of that" since Patrick was born. He dreams of playing the drums again and would really like to teach Patrick how to play.

Justin grew up learning a strong Midwestern work ethic from his dad. Justin always considered himself a self-reliant person and admits he had to change his thinking that was so engrained from childhood. Relying on others to provide the necessary services for Patrick's habilitation has been invaluable. Justin states that it has been challenging to accept help for Patrick – state and public resources such as Medicaid, Social Security – and most importantly, services and treatment from the medical community. Justin remarked, "I always wanted to do my part and not be a burden on the system."

In addition to gardening, Justin plays video games to unwind and relax. His advice for other caregivers is "don't feel alone – there are others out there and lots of people going through the same things."

About 1 in 150 babies is born with a chromosomal condition. Justin hopes for genetic testing to be widely available for infants so that parents can get a medical diagnosis as early as possible – to get early education, treatments and interventions for their children.

Justin is a member of the Desanto-Shinawi Syndrome advocacy group. He is exploring the possibility of pursuing a degree in horticulture.