

### ***She is Mine!***

February 2022 Caregiver of the Month, Charlessa Grime  
Missouri Department of Health and Senior Services



Ceirney, the younger of two siblings, was diagnosed with Rett Syndrome at an early age. Rett Syndrome is an extremely rare neurological disorder that primarily occurs in girls. It can lead to severe impairments and affects nearly every aspect of an individual's life. When Ceirney was a young girl, she went to pre-school through the second grade. She was a spunky and sassy young girl. When she started having behavioral issues, she was diagnosed with Rett Syndrome. Ceirney attended a state school in a neighboring county until the age of 21. She is now 23 years old.

Charlessa stated it was heartbreaking to watch her daughter go from a vibrant, active young girl to suffering the loss of speech and the inability to feed herself. Charlessa has devoted her life to Ceirney's care. She is a single mother and solely responsible for Ceirney's physical and emotional needs. Charlessa assists with all aspects of Ceirney's care including bathing, dressing, preparing and feeding her meals (she is on a special diet), and anything else Ceirney may need. Ceirney gets overheated easily so it is important to stay vigilant to monitor her in warm weather conditions.

Although Ceirney is nonverbal, she communicates in many ways. She understands everything that is said and responds by using various facial expressions such as smiling and frowning. She uses noises to convey her wishes and needs. She loves a good party and gets excited when she sees people, especially her older brother who lives in Kentucky. She likes to flirt and interact with many different people. She also enjoys watching television and movies. Charlessa said that jelly beans are Ceirney's favorite snack and help with getting her to settle down if she is overwhelmed in certain situations.

Through the Senate Bill (SB) 40 Board, Ceirney is able to attend a day program five days a week for persons with developmental disabilities. There, she is involved with various activities such as helping with holiday decorations, sorting rags and assisting in delivering meals with the Meals on Wheels program. Charlessa states Ceirney's favorite part of the day is the bus rides to and from the day

program. Being a part of this program allows Charlessa the opportunity to work outside of the home. Charlessa has two paid caregivers that help with Ceirney's care in the afternoon until she gets home from work.

Charlessa has some health issues that make caregiving a challenge. She has diabetes and is dealing with some long-term effects of COVID-19. Additionally, Charlessa lost her husband to COVID in 2020. She always loved to make her own greeting cards but has found that difficult to do since her husband passed. Charlessa participates in a Rett Syndrome support group on Facebook and relies on in-home services to provide the best possible care to Ceirney. Also, she has family and some very good friends that help out when needed.

Charlessa stated patience is the key to supporting Ceirney. She has learned to "go with the flow" and will simply hold Ceirney if something is wrong. It is hard to know exactly what is going on because Ceirney is unable to communicate verbally. Charlessa is constantly learning the various signs and signals that Ceirney exhibits so she can better help her when situations arise. Charlessa also stated Ceirney is capable of more than she ever thought possible and never takes anything for granted. "Each day is a blessing. For having a daughter who is nonverbal, she speaks to me in a manner that only a mother of a special needs child can understand. She is special, she is loved and she is mine!"