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Written Testimony of
Stephanie Coleman
Submitted to Kansas Senate Committee on Public Health and Welfare

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Dear Chairwoman Beverly Gossage and other members of the Committee,

Thank you for the opportunity to submit written testimony regarding SB 287, a bill to add developmental disabilities, including Autism Spectrum Disorder, to the Kansas silver alert plan.

I work with families after they receive an Autism Spectrum Disorder diagnosis for their child in Kansas through Kansas Leadership Education in Neurodevelopmental and related Disabilities (Kansas LEND) at the University of Kansas Medical Center. I am also a parent of a 27-year-old young man with autism. To be clear, while my experience is divided between professional and personal, I am here as a private citizen today providing this testimony. My experience covers the lifespan of individuals.

Senate Bill 287 amends the pre-existing Kansas silver alert plan to include vulnerable persons including those with a developmental disabilities, such as Autism Spectrum Disorder who are age 18 and up. Currently, the system works by establishing public notice that disseminates information regarding a missing elderly person who may have dementia. The public notice allows state-wide coordination with all relevant departments within the state to work together to find the missing elderly. It relies on working with local law enforcement, news media, and the public to provide information on the missing elderly with the goal of locating the person before serious harm.

Research shows that individuals with Autism tend to ‘wander’ similar to individuals with Alzheimer’s or Dementia¹. The term "wander" is used to describe the act of moving without a specific destination or clear purpose, indicating a lack of self-awareness on the part of the person. The Centers for Disease Control and Prevention reports that one in 44 children have autism spectrum disorder and that more than half, or about 60%, were reported to wander². Over a five-year period, a third of those with Autism who did wander ended up in harm's way and needed serious medical intervention or, sadly, died. This is often due to individuals being drawn to water or areas of high traffic³. **There have been many times when my son has wondered, it started long before he was even diagnosed with Autism. When he was 3 we found him up in a tree over a creek with just his t shirt and diaper on, the rest of his clothes made a trail down the creek. I can't tell you how thankful I was that the creek was low that day. The next day, I signed him up for swimming lessons. Another time, we found him in the**

¹ Solomon, Olga, and Mary C. Lawlor. "Beyond V40.31: Narrative phenomenology of wandering in autism and dementia." *Culture, medicine and psychiatry* 42, no. 2 (2018): 206. <https://doi.org/10.1007/s11013-017-9562-7>.

² Centers for Disease Control and Prevention. "Disability and Safety: Information on Wandering (Elopement)." 2019. <https://www.cdc.gov/ncbddd/disabilityandsafety/wandering.html>.

³ McIlwain, Lori, and Wendy Fournier. "Mortality & Risk In ASD Wandering/Elopement 2011-2016". *National Autism Association* (2017). <https://nationalautismassociation.org/wp-content/uploads/2017/04/NAAMortalityRiskASDElopement.pdf>

basement of a new house that was being built, he fell and there was no way out for him. As he got older, he has gotten lost in the woods, fallen out of a tree and couldn't move, thankfully he was alright, taken off in the middle of the night just to walk and come home to tell me stories of people who had stopped to talk to him, I can't imagine if any of those people had more sinister ideas. I believe we were blessed with good outcomes because we were quick to notice him gone and had others there to help us go look for him. I get calls from frantic parents who have had this happen to them and what they can do to keep it from happening again, probably at 8-10 a year. On social media, I see pleas to share a post every single day of an adult with Autism that has gone missing across the country. The sooner, the local law enforcement and their partners can go looking for them the better chance of a positive outcome. Therefore, it is critical that individuals with Autism be included in the emergency response system.

We look forward to working with Kansas to make this necessary change. Thank you for considering my testimony as this bill moves forward. If you have any questions, please contact me as mymj@live.com.