

November 6, 2019

Chairwoman Brenda Landwehr
Special Committee on Medicaid Expansion
Re: Medicaid Expansion

Chairwoman Landwehr and Committee Members:

I often hear the term “able-bodied adult” when talking about KanCare Expansion. Well, I was one of those “able-bodieds,” except my body isn’t always so able. I am living with multiple sclerosis (MS), an unpredictable, often disabling disease of the central nervous system. MS interrupts the flow of information within the brain, and between the brain and body. Symptoms range from numbness and tingling to blindness and paralysis. While each individual with MS is impacted differently by the disease, a growing body of evidence indicates that early and ongoing treatment with a disease modifying therapy (DMT) is the best way to modify the course of the disease, prevent the accumulation of disability, and protect the brain. Ongoing access to these medications is essential for people with MS to be able to live their best lives

I began experiencing symptoms in 2013, when I was a student at Wichita State University. I began experiencing numbness in my legs and trouble walking. Then, my speech became slurred. I began falling on campus as I tried to walk between my classes. The scariest part was that despite working, I couldn’t afford health insurance. After receiving an MS diagnosis, I was faced with having to find a way to afford this very expensive disease. In 2019, the average wholesale price of MS disease modifying therapies alone was \$88,853.

After my diagnosis in 2014, I began sharing my story about being an uninsured college student living in the KanCare gap. In 2015, I testified in front of the House Health Committee and shared my experience. It was scary and intimidating, but I felt like it was important not just for me, but to improve the lives of other Kansans facing devastating diagnoses and uncertain futures. Representative Dan Hawkins chairs the committee and was pleasant to me throughout the process. That’s why I was surprised by a personal attack he made against me during a Topeka Capital Journal podcast on the topic of KanCare Expansion in 2018.

Representative Hawkins shared his memory of a college student with MS testifying in front of his committee (me) and how “she could have easily received care through WSU’s health plan.” This is a logical question to ask, and I wish he would have asked me about the health plan during the committee hearing, instead of using it to discredit me years after the fact.

University health plans are not equipped, nor are they intended to treat expensive chronic illness. Remember those expensive prescription drug costs? The WSU plan required a 30% co-pay, an out of pocket cost of over \$25,000. Prescription drug costs, deductibles, and the premium itself was not within my financial capabilities and I made too little, oddly enough, to qualify for a

marketplace plan subsidy. Community health centers do not provide specialty health care, like neurology care, so that wasn't an option. This is what it is like to live in the KanCare gap.

During the same podcast, Hawkins went on to say that I had "an expensive cell phone" and that his father imparted wisdom upon him when he was a young man to prioritize health insurance, implying I should follow his dear old dad's advice. Chair Hawkins certainly should recognize that times have changed. Cell phones have replaced land lines and are necessary as the main source of contact for school and work. Insurance access and affordability have also changed since he was a kid and for many people, it is entirely unaffordable on a limited budget. This is exactly why Kansas needs KanCare Expansion. Expansion would allow chronically ill people who have complex healthcare needs to continue to work, attend college and contribute to society.

The good news is that I'm a high school Physics teacher now, and I have health insurance. It's been almost 5 years since I shared my story and the legislature have failed to support KanCare expansion. It makes me worried for other young, uninsured Kansans facing devastating diagnoses. Kansas should be a place that does everything it can to provide for its most vulnerable citizens. Instead, it continues to amass missed opportunities to join the 37 states who have chosen to expand their programs. I respectfully request the Senate Select Committee on Medicaid Expansion support of expansion with **no barriers and no delays**.

Sincerely,

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