BDAND
Bleeding Disorders Alliance of North Dakota

"When a bandage is not enough, we're here."

Emily Ouellette
HB 1216 Testimony
ND House Industry, Business, and Labor Committee Hearing
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Thank you, Chairman Warrey and the Committee, for hearing our testimony, and thank you to Representative Karls for once again working to protect North Dakota patients' access to lifesaving drugs with HB 1216.

My name is Emily Ouellette. I speak for the community I serve professionally as Executive Director of the Bleeding Disorders Alliance of North Dakota. I also have a personal connection. My husband and nephew, who grew up in Devils Lake, have severe hemophilia.

Hemophiliacs need specialty medicine that they self-infuse 1-3 times per week at home, costing $350,000 to $1,000,000 per year. There are no generic options. This medicine prevents internal bleeds. When patients get their medicine in January, they often reach their deductible immediately. Can you imagine needing to pay your full deductible in one payment at the beginning of the year every January to receive medicine that allows you to safely work or go to school? It is important that our patients access their medicine without financial barriers, so organizations like ours as well as some manufacturers offer financial assistance.

Recently, insurance companies have implemented Copay Accumulator programs where they accept the patient assistance money, but don't count it toward the patient's deductible. Think of it this way, a college student has a $10,000 tuition bill and a $5000 scholarship. The University accepts the $5000 scholarship, but still makes you pay the full $10,000 bill, you know so the student has "skin in the game". The school receives $15,000. Is that fair? This is happening to patients all over the US. It needs to stop. With these programs, hardworking families struggle to access their medication. They take out loans or ration doses and risk permanent joint damage.

Currently, 1 out of 3 health insurance plans in North Dakota have a copay accumulator program in place. I hope you will pass this bill to prevent all insurance companies from harmfully surprising North Dakota patients. We can join the 21 states who have passed legislation to ensure patients can utilize copay assistance programs as they were intended.

Access to medication allows people like my husband to continue being a contributing member of society, raising a family, and holding a job. It allows my 12 year old nephew to stay in school and be able to participate in Tae Kwan Do. The treatments are available. They cost a lot, but these patients are well worth the cost. The system is broken - high drug costs and various other practices make it difficult for patients to navigate their health care. This is making it even harder.

Health plans will tell you patients are driven to high cost name brand drugs. Patients with bleeding disorders do not have a generic option. They will tell you we have no skin in the game, no personal costs - we still pay our premiums, multiple doctor visits, lab work, and ancillary supply costs. Health plans still determine their formulary, and patients must still go through the utilization processes they've put in place. I know North Dakota takes pride in being a business-friendly state and some may be concerned about costs to employers. Employers will lose employees if they cannot stay healthy.

Copay assistance doesn't only provide financial relief, it improves adherence, leading to better clinical outcomes. I hope you will protect North Dakota patients in the rare disease community by supporting HB 1216. We want all payments to count, made BY the patient or on BEHALF of the patient.

Thank you.

*AIDS Institute Study – https://aidsinstitute.net/documents/TAI-2024-Report-2.27.pdf

*Global Healthy Living Foundation - https://ghlf.org/copay-assistance-protection/