

## Proponent Testimony – House Bill 177

Good Morning Chairman Lipps and members of the House Public Health Policy Committee. My name is Dr. Alique Topalian. I am a Research Scientist in Cancer Survivorship and Supportive Services. I am involved in several cancer nonprofits nationally, throughout Ohio, and here locally in Cincinnati. I am a daughter, fiancée, sibling to 5, and aunt to 11.

I am also a two-time Acute Myeloid Leukemia (AML) survivor.

At the age of four in 1998 I was diagnosed with AML for the first time. Back in the 90s this was a very hard disease to treat in children and I was given a 13% chance of survival without a bone marrow transplant and 20% with a transplant. I was lucky and went into remission with experimental chemotherapy.

Going through this at such a young age I knew I wanted to devote my life and career to the healthcare field. Helping my family found the Armenian Bone Marrow Donor Registry and becoming involved in cancer advocacy and volunteer work at the age of 7. I then went on to get my BA in psychology, followed by my Master of Public Health and my PhD in Health Promotion and education in 2020.

Less than a year after completing my PhD, my AML relapsed, the first ever person to relapse with AML after 22 years. This time my odds were a bit different, since I could not find a close enough bone marrow match, I received a 20% chance survival with transplant and a 70-80% chance of survival with chemotherapy and immunotherapy. However, only about 15% of people diagnosed with AML will survive for 5 or more years after diagnosis.

A bone marrow transplant is considered “curative” treatment lowering the odds of relapse, since I could not find a match, I am very high risk for relapse. Because of this I am now on a maintenance chemotherapy drug given orally, 14 days on treatment, 14 days off treatment for the foreseeable future. This drug costs \$50,482.81 per month before insurance. With my insurance from a private employer, the drug costs \$10,669.71 per month. This is approximately 1/5 of my annual income.

I was thankful that I qualified for two copay assistance programs, one from the drug maker, and one from the specialty pharmacy that makes my drug cost \$0.00 per month. However, last year my copay assistance ran out in November. I had no way to afford this medication that is keeping me alive, working, and contributing to society. Luckily, the specialty pharmacy let me start my co-pay assistance for the new year of 2023 early. However, I am now waiting to see when this will expire this year and unsure of what costs I will be left with or if someone would start my assistance again early for next year.

This is a new drug, with no options for generic replacements. Being on an oral form of this drug has given me the ability to return to work since I am not tied to the hospital for infusions and having extreme reactions such as loss of blood counts and the inability to be in public due to my immune counts being so low. The ability to fight cancer recurrence in a way where patients are able to maintain a quality of life, contribute to the economy, and help others in our state and nation is imperative.

In addition to this, my health insurance plan has implemented a copay accumulator adjustment program, so the copay assistance that I’m using to help me afford my medication does not count towards my deductible or out of pocket maximum. Both of which would have been covered within two months of payments for this medication. Because of that since the beginning of 2023 I have already paid

over \$6,000 in additional health care costs which could have been avoided if the copay assistance used to pay for my medication counted towards my out-of-pocket costs.

how am I supposed to live and make financial decisions if I never know when I may lose my copay assistance and therefore access to my lifesaving drug.

I am here, working, advocating, and helping others because I was able to survive and now thrive with this oral chemotherapy.

Thank you Chairman Lipps and members of the House Public Health Policy Committee for considering this important legislation. I urge you to pass House Bill 177.

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