American Cancer Society
Cancer Action Network℠

Chairman Warrey, Vice Chairman Ostile, and Members of the Committee,

My name is Eniola Soetan, and I am a student at Dickinson State University as well as a volunteer with American Cancer Society Cancer Action Network. I am here to express my support for HB 1216.

As someone who has had to use my fair share of health care services, I know very well the burden that this can place on individuals, families, and entire communities at large. On top of having to deal with the physical, mental, and emotional stresses that come with living with an injury or illness that requires treatment, figuring out how to make the finances work adds another monumental layer of strain to an already very difficult situation.

Copay assistance programs are a very important facet of making sure that healthcare and treatment are accessible to those who need it. In many cases, copay assistance programs can be the difference between individuals achieving a functionable quality of life, or facing progressively worse prognosis leading to death.

Unfortunately, the advent of copay accumulator programs has undermined the lifesaving efforts of copay assistance. When copay assistance does not go towards a deductible, this functionally eliminates any form of assistance to the individuals and families who need it, while also creating a system in which the insurance companies essentially get paid twice.

Many potentially fatal diseases such as certain cancers and genetic disorders are now able to be treated thanks to the help of medical breakthroughs that help to keep people alive. Unfortunately, a lot of these medications are also extremely expensive.

Consider a family that has a child with type 2 spinal muscular atrophy for example, a disease that results in low muscle tone, muscle weakness, inability or difficulty to stand, walk, or sit upright without support, and weak respiratory muscles. This disease also leaves diagnosed individuals with a life expectancy of around 30 years or so[3]. Just to be able to perform simple daily life tasks, children with this disease will require assistive devices such as braces, orthotics, and wheelchairs, physical therapy or occupational therapy services, feeding tubes, and ventilators. If in a household with multiple guardians, one guardian will have to stay at home full time with the affected child, likely foregoing a source of income, and the child will also require some sort of in-home nurse or caretaker. In a single guardian household, this dilemma becomes even more complicated. Drugs that have been found to have a profound impact on the development of the disease have become available, but having a child with this disease is already an incredible financial demand on a family even without looking into these new drugs that have costs into the millions[2], with no guarantee that all of the necessary medical needs will have approved insurance claims.

Imagine a family who has been given a second shot at life with their child thanks to financial assistance with life-changing medication. Now imagine telling that same family that the assistance they received would not be going towards their deductible, that even though they qualified for assistance, they would still have to find a way to shell out more money in order to meet their deductible amidst extremely trying circumstances.

In adults, we often see individuals foregoing treatment all together due to an inability to afford it. According to the Kaiser Family Foundation, in 2023, 25% of US adults skipped or postponed treatment due to costs[3]. With many diseases, delayed treatment or lack of treatment worsens the prognosis of the disease quite drastically, eventually putting individuals in situations where they can hardly function on a day to day basis, let alone go to work to make some money. Diabetes can go from something easily manageable with regular insulin shots to a situation that becomes life threatening where amputations may be required. Cancer goes from an easily caught and treatable disease to a tragic and uncontrollable metastasis, all due to differences in treatment, and differences in the ability to access said treatment.

Copay assistance programs help to bridge the gap between individuals and the treatment they require so that you do not have to be rich or put yourself into insurmountable debt to be able to save yourself or a loved one's life. As someone who has lost a grandma to diabetes because of inadequate access to medication, and my own mom to cancer when I was 10 years old, this chance at life is a gift that I cannot imagine being ripped away from anyone.

In order to support and build on the great work of copay assistance programs, to improve healthcare accessibility, and ultimately to give as many people as possible a chance at life, and a high quality of life, I strongly urge the committee to give this bill a do pass recommendation.

Sincerely,
Eniola Soetan
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[1]- https://my.clevelandclinic.org/health/diseases/14505-spinal-muscular-atrophy-sma

[2] - https://www.drugs.com/medical-answers/zolgensma-expensive-3552644/

[3]-https://www.kff.org/health-costs/issue-brief/americans-challenges-with-health-care-costs/#:~:text=The%20cost%20of%20care%20can,28%25%20vs.%2021%25).