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Thank you, Chairman Heinrich, Vice Chairman Schweikert and distinguished members of the Joint Economic Committee for inviting me to testify on behalf of the American Diabetes Association (ADA) regarding the cost of living with diabetes. We appreciate you considering this important topic at this critical time.

The ADA is the nation's leading voluntary health organization fighting to bend the curve on the diabetes epidemic and help people living with diabetes thrive. For 80 years the ADA has been driving discovery and research to treat, manage and prevent diabetes, while working relentlessly for a cure. We help people with diabetes thrive by fighting for their rights and developing programs, advocacy and education designed to improve their quality of life.

Today I would like to take this opportunity to describe and offer context for some of the most significant drivers of cost increases for people living with diabetes and the work ADA is doing to make managing diabetes more affordable and prevent costly adverse outcomes.

More than 37 million Americans live with diabetes, and nearly 100 million Americans have prediabetes, making diabetes is the most expensive chronic condition in the United States—people with diabetes account for $1 of every $4 spent on health care in the country and nearly one-third of Medicare drug spending. People of color and other underserved populations—those who lack access to adequate health insurance coverage, health care services and the tools they need to manage their diabetes—bear a disproportionate share of patient cost burdens. That's because 18 percent of Black Americans, 17 percent of Latino Americans and nearly 15 percent of Native Americans have diabetes, compared to seven percent of white Americans. Because diabetes diagnoses are less likely when people have access to resources, diabetes prevalence is inversely related to household income—individuals who earn less than $30,000 per year are three times more likely to have diabetes than those who make more than $80,000. Lower-income Americans in both rural and urban areas are also more likely to develop diabetes, experience complications from poorly managed diabetes and die younger than higher-income Americans.

To address these social and economic barriers to the appropriate providers, tools and services for diabetes management, the ADA launched our Health Equity Now in 2020. The ADA's Health Equity Bill of Rights guides our work to consider the social determinants of health that lead to a higher prevalence of diabetes and worse health outcomes. The pillars of our actions are built on this foundation.

The ADA has identified several major drivers of the high cost of care for people with diabetes and ways Congress can address them. Some of these include:

High Rates of Complications and Hospitalizations

Having health insurance is the strongest single predictor of whether adults with diabetes will receive high-quality health care services. The 27.5 million uninsured Americans have a higher likelihood of having undiagnosed diabetes because they are 60 percent less likely than insured individuals to have regular office visits with a physician, prescribed 52 percent fewer medications, and have 168 percent more emergency room visits. Diabetes-related amputations are a particularly expensive complication that requires significant health care resources and time in the hospital. A foot or leg amputation costs $30,000 to $60,000 in initial hospital costs, with an additional $40,000 to $60,000 in follow-up care in the three years post-surgery. These costs do not consider lost employment, or additional costs of mental health and other services commonly required by amputees.

These disparities became even more acute during the recent pandemic and consequent economic downturn. Americans with diabetes and other related underlying health conditions were hospitalized with COVID-19 six times as often and died of COVID-19 12 times as often as those who did not have diabetes. One in 10 coronavirus patients with diabetes died within one week of hospital admission. And Americans with diabetes accounted for 40 percent of COVID-19 fatalities nationwide, despite making up just 10 percent of the U.S. population at the time. While we are still learning about the relationship between COVID-19 and diabetes, we know that unmanaged diabetes—whether a lack of medication use or missing doses—is a key factor in COVID-19 severity and complications, and an important indicator of whether someone with diabetes and COVID-19 is likely to have a longer hospitalization.

Comorbidities, Including Obesity

People with undiagnosed diabetes are more likely to develop comorbidities—from kidney failure to coronary artery disease—increasing costs and severely limiting their ability to get healthy. More than 85 percent of people with type 2 diabetes have overweight or obesity. Similarly, research shows that people with type 1 diabetes are at a growing risk for obesity and related health conditions including heart disease, stroke, and 13 types of obesity-cancer. ADA understands the urgency of responding to the obesity epidemic to improve the health of millions of Americans particularly those with or at risk for diabetes. There is strong and consistent evidence that obesity management can delay the progression from prediabetes to

type 2 diabetes and is highly beneficial in treating type 2 diabetes. Effective weight management can lead to type 2 diabetes remission.

Obesity exacerbates or causes over 200 medical disorders resulting in declining physical, mental and emotional health and physical mobility. The Centers of Disease Control and Prevention identified that obesity also increases the risk of severe illness from COVID-19 and triples the risk of hospitalization. Mirroring trends with diabetes, obesity has a greater impact on people of color, with lower incomes and education levels. Over 49 percent of Black adults and over 45 percent of Hispanic adults, compared to over 40 percent of white adults have obesity.

The ADA recognizes that obesity is a common, chronic, progressive and relapsing disease with many medical, physical, and psychosocial issues. People with obesity deserve the access to person-centered, effective interventions available to treat to their disease and support healthy weight management as detailed in our 2023 Standards of Care. In addition to supporting access to healthy food and nutrition outlined above, we encourage Congress to help prevent diabetes by addressing the obesity epidemic:

- Improve Medicare beneficiaries' access to effective weight management services by updating the intensive behavioral therapy (IBT) benefit and allowing access to anti-obesity medications currently prohibited. Medicare's position and coverage restrictions are an outlier among other federal health care programs. The Department of Defense, Veterans Health Administration and the Office of Personnel Management provide access to a comprehensive obesity benefit across the continuum of care for enrollees. Unfortunately, state health care programs including Medicaid and State Employee Health Plans indicate Medicare's restrictions as rationale for non-coverage.
- Support access to preventive services for recommended by the United States Preventive Task Services (USPSTF) for state Essential Health Benefit (EHB) benchmark plans. In 2018, USPSTF recommended that "clinicians offer or refer adults with a body mass index (BMI) of 30 or higher to intensive, multicomponent behavioral interventions." Ensuring that EHB plans not only offer by provide access to these preventive services can reduce disparities and lead to better health outcomes for people with diabetes, at risk for diabetes and with comorbidities including obesity.

The Cost of Prescription Drugs

The increasing cost of prescription drugs has created an outsized burden on the diabetes community and the U.S. health care system writ large. For people with diabetes, many of whom rely on insulin and other expensive medications to manage their condition, this financial barrier can mean the difference between life and death. The price of insulin has roughly tripled in the past decade, increasing from less than $100 for an average vial in 2009 to nearly $300 for the same vial today, even though today's insulin is nearly the exact same product as it was 10 years ago. Americans spend more treating diabetes than any other chronic condition; that people with diabetes in the U.S. spend two and a half times more on health care than those who do

not have diabetes; and that one in four insulin-dependent Americans report rationing their insulin supply due to the cost of the drug and financial difficulty.

Currently, pharmacy benefit managers (PBMs) and other drug middlemen function at the center of the pharmaceutical supply chain, acting as intermediaries between insurers, manufacturers, and pharmacies. Health insurers hire or own PBMs to handle benefits for their health plans, who then develop lists—or formularies—of the drugs and devices the health insurer will cover. PBMs negotiate prices with drug makers for the products covered on the formulary, and as part of this process, manufacturers offer rebates to PBMs in exchange for preferred formulary placement. As a result, the actual price the PBM pays is lower than the list price. Because what the consumer pays at the pharmacy counter is based on the list price, not negotiated price, it is not clear how, if at all, rebates negotiated by PBMs benefit patients. More fundamentally, there is troubling evidence that current incentives for PBM formularies to favor the most high- cost drugs and devices may encourage the exclusion of lower-cost drugs and devices, putting more affordable options out of reach for our community.

The system in place has created perverse incentives and led to increased costs to consumers, negotiated by PBMs for prescription drugs should be shared with consumers, and those with unusually high launch prices where other lower-cost options are available, should be subject to a full pass-through of rebates to consumers so that they are not given preferential treatment that limits or blocks access to lower-cost options.

Limiting cost-sharing is another important way Congress has and can continue to help people with diabetes who are insulin-dependent. As a result of the ADA's leadership in advocating for state and federal limits on cost-sharing for insulin, 25 states and the District of Columbia have already enacted co-pay caps. We know that limits on cost-sharing for insulin can provide immediate, noticeable financial relief to patients. California Senate Bill 90 would cap out-of-pocket costs for insulin at $35 per month for state regulated plans and offer patients currently paying above the cap a 67 percent reduction in cost-sharing, from an average of $88 per prescription to $20 per prescription. The analysis estimated a 10 percent decrease in diabetes-related emergency room visits, which could reduce emergency room costs by more than $2.4 million in the cap's first year should the state enact it.

Given that people with diabetes typically require more than one medication to manage their diabetes and other comorbidities, we hope to see Congress take additional steps this year to make prescription medication and supplies for people with diabetes more affordable, especially for those who lack health insurance coverage. Our priorities include:

- Building on the $35 monthly co-pay cap that began with the Senior Savings Model in 2021 and culminated in the permanent Medicare co-cap in the Inflation Reduction Act by enacting a national insulin co-pay cap for commercial insurance plans so more Americans with diabetes can benefit from reduced cost-sharing regardless of the type of insurance they have.

- Increasing transparency throughout the pharmaceutical supply chain, including efforts to shed light on pricing practices, improve accountability in the pharmacy benefit manager (PBM) market, and ensure that rebates are benefiting patients and not artificially inflating prices or limiting patient options.
- Speeding competitive generic drug and biosimilar alternatives to market by, among other things, addressing loopholes in our patent system that allow manufacturers to stave off competition.
- Cracking down on insurance practices that push patients to choose between quality and affordability, including prior authorization and step therapy (or "fail first") policies that force patients to try the least expensive drug in a class first, even if their prescribing physician believes a different therapy is in the patient's best clinical interest.
- Increasing oversight and regulation of specialty drug tiers used by insurers that shift the cost-sharing burden disproportionately onto patients with rare and/or chronic conditions who rely on these medications.

Limitations on Access to Diabetes Technology

Thirty-one percent of individuals with diagnosed diabetes—or more than 10 million Americans—are treated with insulin and stand to benefit from a continuous glucose monitor (CGM). We know that access to CGMs in this population means better glycemic control. And poor glycemic control can lead to dangerous health outcomes—including heart failure, myocardial infarction, and death—not to mention increased costs as a result of hospitalizations for and treatment of these cardiovascular complications.

For millions of people living with diabetes, CGMs provide significant, potentially life-changing benefits for diabetes management and in turn for avoidance or delay of serious co-morbidities, hospitalizations and even death. A CGM provides much greater detail to patients and their health care providers than traditional blood glucose meters do regarding an individual's blood glucose levels, offering opportunities to analyze patient data more granularly than was previously possible and providing additional information to aid in achieving glycemic targets. CGMs also provide biofeedback in real time, allowing individuals with diabetes to modify their diet and insulin dose as needed in consultation with their health care provider. As a result, individuals with Type 1 and Type 2 diabetes who get a CGM are shown to have less hypoglycemia, and they experience a reduction in their average blood glucose (A1C).

Given what we know about the benefits of CGM access and the deadly impact of poorly managed diabetes in communities with limited access to health insurance coverage and the health care system, the ADA commissioned a study on the relationship between insurance coverage, age, geography and race to identify where the greatest barriers to CGM access are. The data show that the people who are least likely to get a CGM are people of color, low-income individuals who rely on Medicaid, and people who live in states with some of the highest rates of diabetes. The study found that poorer, older Americans of color are the least likely group to get CGMs.

In particular, three troubling trends emerge from the data:

Individuals covered by Medicaid are the least likely to get a CGM, especially if they are people of color. Income is the first hurdle to getting a CGM. The greatest access barrier shows up when we combine income with race. Individuals enrolled in Medicaid who take insulin are two to five times less likely to get a CGM than those who have a commercial health insurance plan. And the CGM access gap between Medicaid and commercial insurance plans is bigger for people of color than it is for white Americans. States with higher rates of white Americans enrolled in Medicaid have better CGM access than states with higher rates of black Americans, where Medicaid coverage of CGMs is abysmally low. Hispanic individuals are also less likely to get a CGM if they are covered by Medicaid than a commercial health insurance plan.

Where people with diabetes live is a major factor in how likely they are to get a CGM. Data show that people with diabetes covered by Medicaid living in poorer states and in more rural areas are less likely to get a CGM. Medicaid utilization of CGMs is consistently lowest in the Southeast. Texas, Arkansas, Louisiana, Mississippi, Alabama and South Carolina all have state poverty rates higher than the national average of 11.4 percent, and all states in this region have a diabetes mortality rate greater than 20 percent. Arkansas and Louisiana have a diabetes mortality rate greater than 30 percent, and in Mississippi more than 40 percent of deaths in 2020 were attributable to diabetes.

Young people are more likely to get CGMs than older Americans with diabetes are. Insulin-dependent children younger than 18 who have diabetes are significantly more likely to get a CGM than people with diabetes between the ages of 45 and 64 with diabetes are. For example, people with diabetes aged 18 or younger are 3.5 times more likely to get a CGM if they have commercial insurance than if they are covered by Medicaid. Individuals with commercial insurance between the ages of 19 and 44 are 4.3 times more likely to get a CGM, and individuals between the ages of 45 and 64 are 2.5 more likely to get a CGM.

For low-income people with diabetes who rely on Medicaid, the diabetes management technology they need may not be covered adequately, or at all. Because Medicaid coverage is often determined on a state-by-state basis, there are wide discrepancies in diabetes technology access from one state to another. Given both the short- and long-term health benefits of using a CGM for those with poor glycemic control, federal and state government officials can and should take steps to drive improved and more uniform coverage policies for diabetes technology and supplies within Medicaid as a vital health equity measure. Given the significant variation in Medicaid coverage between states—and the correlation between states with low CGM utilization and high diabetes prevalence—the onus is really on states to do more to make sure their Medicaid programs are allowing enrollees to access diabetes management technology. For example, states can promote CGM access by making them available through as many channels as possible, including both mail-order and local pharmacies, to increase access for the diverse populations that can benefit from CGMs.

As with prescription drugs, manufacturers of CGMs, insulin pumps and supplies typically pay rebates to middlemen like PBMs to carry their products, and the rebates similarly have a market-distorting impact that inherently reduces access to lower-priced, more cost- effective devices. Individuals who access diabetes technology across insurance coverage types often pay more for their devices as a result of rebates negotiated by pharmacy benefit managers. Opportunities to expand PBM rebate reform in the diabetes technology and supplies categories are meaningful, in much the same way they offer the promise of less burdensome costs in the prescription drug market. Diabetes device focused PBM rebate reform can bring needed pricing transparency, reduce costs at the counter and improve patient access to this vital technology.

Increase in Diabetes Diagnoses

Several factors are contributing to the growth of the diabetes population in the United States. Overweight and obesity are proven risk factors driving as many as 53 percent of new cases of type 2 diabetes each year. Additionally, rates of both type 1 and type 2 diabetes have increased as a result of COVID-19 infections.

Over the next 40 years, we are expecting a dramatic increase in the number of young people under 20 who have type 2 diabetes in the U.S.—as much as a 70 percent increase by 2060 according to recent studies. The projected number of young people with both type 1 and type 2 diabetes is expected to surpass 500,000 by 2060, putting significantly more pressure on the health care system as corresponding rates of insulin dependence and hospitalizations increase the cost of managing diabetes and treating complications. Data show that these increase in diabetes prevalence is likely to place a much higher burden on Black, Latino, Asian, Pacific Islander and Native American youth. Globally, the situation is much worse. Researchers believe every country in the world will see rates of diabetes—predominantly type 2 diabetes—rise over the next three decades, potentially doubling from 529 million people to 1.3 billion people by 2050.

Conclusion

Thank you for the opportunity to testify before the Joint Economic Committee on the cost of diabetes. The ADA looks forward to continuing to work with Congress to enact the proposals outlined above to address health inequities, reduce costs to patients, and help Americans with diabetes access the tools, medications, and services they need to stay safe and healthy.