Statement of Alvin C. Powers, MD
On Behalf of the Endocrine Society
Energy & Commerce Oversight & Investigations Subcommittee
Insulin Affordability Hearing
April 2, 2019

Thank you, Chairwoman DeGette, Ranking Member Guthrie, and members of the Oversight & Investigations Subcommittee for the opportunity to speak to you today about the rising cost of insulin and provide a physician's perspective on the scope of the problem of insulin affordability and the challenges this creates. My name is Alvin C. Powers and I am a physician-scientist. I am here representing the Endocrine Society. With over 18,000 members, the Endocrine Society is the world's oldest and largest organization of scientists devoted to hormone research and physicians who care for people with hormone-related conditions like diabetes. While we hear from our members about many different clinical and research issues, one causing the greatest concern for their patients is the rising cost of insulin. We commend the subcommittee for its efforts to shed light on this important issue.

As Director of the Vanderbilt Diabetes Center and Chief of the Vanderbilt Division of Diabetes, Endocrinology, and Metabolism, our health care providers and I have many patients who struggle to afford their insulin. The need to address this growing problem is urgent. People are rationing their insulin, and forgoing other necessities, such as food and rent. This leads to serious health problems, unnecessary complications, and hospitalizations. While I live in the "Diabetes belt" in Tennessee, the story is no different in Colorado, Kentucky, or elsewhere in the United States. The subcommittee has convened this hearing because insulin is unique in the broader context of the drug pricing debate and I want to highlight a few of the reasons why.

- First, millions of Americans take insulin to manage their diabetes. Of the more than 30 million with diabetes, more than 7 million use insulin to control their blood sugar and reduce the risk of life-altering complications such as dialysis, amputation, and heart disease. Patients with Type 1 Diabetes require insulin to survive. There is no other life-sustaining drug used by so many people who would die in a matter of days if they cannot afford it.

- Second, the price of insulin has tripled over the past 15 years. It is difficult to understand how a drug that has remained unchanged for almost two decades continues to skyrocket in price. In 2017, expenditures on insulin reached $15 billion and three of the top ten medication costs were for different types of insulin.

  What does this mean for a patient? A vial of insulin can now cost a patient more than $300 dollars and many patients require multiple vials each month. This can mean hundreds—or thousands—of dollars in monthly out-of-pocket costs. While nearly one-quarter of individuals on insulin live below the poverty line, it is not only the low-income or those without insurance who struggle with the cost of insulin. Some of the recent, tragic stories reported in the media involve people who are employed and have insurance, but also have high-deductible health plans and must pay the full list price for this life-saving medication. For many, this is simply not possible.

- Lastly, insulin has been around too long for this problem to be so pervasive. We are approaching the centennial of insulin's discovery in Toronto in 1921. After the scientists isolated insulin and saw its miraculous effects on individuals with type 1 diabetes, Frederick Banting, one of insulin's co-discovers said "Insulin belongs to the world, not to me." They sold the patent for $1 each to the University so that all patients who needed it would have access. However, exactly the opposite has happened—at least in the United States.

Patients and physicians face additional challenges because of failures to make the cost of insulin transparent, a lack of ability to know what the out-of-pocket costs will be, and limited options for low-cost solutions. I'd like to provide some context for these challenges by describing a typical patient visit. I'm seeing one of my patients who has type 1 diabetes and requires injections of a long-acting and a short-acting insulin each day. I prescribe both types of insulin but I do not know how much my patient will pay for her insulin because electronic health record systems do not provide patient-specific benefit information and I have no way of knowing what her out-of-pocket cost will be. At the pharmacy, she learns that she owes more than $1200 for 4 vials per month. Why? Because it's January, she is on a high deductible plan, and she is now responsible for the list price of the medication—a price she cannot afford. This scenario could be true for many working Americans and many in this room who have high-deductible health plans. In the best-case scenario, she calls my office and admits that she cannot afford her insulin. In the worst case, she rations or forgoes her insulin altogether.

My staff and I are constantly looking for options to make insulin more affordable such as patient assistance programs, but these are often restrictive, difficult to navigate for the patient and the provider, will not result in the patient going home with insulin that day, or even that week, and are not a long-term solution.

Our insulin supply system is broken, unfair, and dangerous. Our patients deserve better. Here are my thoughts about the insulin supply chain:

- Insulin is a life-saving medication that millions of our citizens must take every day.
- List prices for insulin continue to increase each year.
- No one understands the rising cost of Insulin - there is a lack of transparency in how drug prices are negotiated.
- Rebates between manufacturers, pharmacy benefit managers, and health plans are not passed along to consumers.
- Patients increasingly have high deductible health plans, dramatically increasing their out-of-pocket costs for life-saving medications like insulin.
- Patient Assistance Programs are complicated, difficult to navigate, and overly restrictive.
- Physicians are unable to access real time information about what their patients will pay for their medications like insulin.

- Thus, patients and physicians cannot have informed discussions about the cost of insulin.
- Regulatory systems and patent extensions restrict the introduction of more generics.
- And, until recently, pharmacists could not advise patients about less expensive options.

Addressing the rising cost of insulin is a priority for the Endocrine Society and are working with other organizations interested in this problem. We recently released a position statement outlining ways that stakeholders can improve its affordability. Many of our recommendations focus on opportunities to reduce out-of-pocket costs for patients while policies are formulated to lower the actual price of insulin. These recommendations include increasing transparency, limiting cost-sharing to a co-pay, integrating real time benefit information into EHRs, and ensuring rebates are passed along to patients without increasing out-of-pocket costs.

I am hopeful that by discussing the critical issue of insulin affordability, we can begin to identify additional solutions and make insulin affordable to our patients. If we can make progress on the insulin pricing and affordability, I think this can be extrapolated to other drugs. I look forward to working with the subcommittee as it moves forward in addressing this important issue.