August 24, 2020

Director Matt Damschroder
Ohio Department of Administrative Services
Chair, Prescription Drug Transparency and Affordability Council
30 East Broad Street, 40th Floor
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via email – mariah.halleck@das.ohio.gov

Dear Director Damschroder and Members of the Prescription Drug Transparency and Affordability Council:

Whereas my ability to join the final Council meeting this Wednesday is uncertain, I am hopeful you will accept these written comments as you consider the development of your final report to Governor DeWine, the General Assembly, and the Joint Medicaid Oversight Committee.

People with diabetes are facing a crisis.

Of the 34.2 million Americans with diabetes,\(^1\) about 6.8 million use insulin.\(^2\) Right here in Ohio, nearly 4.3 million people have or are at risk for diabetes.\(^3\) Many people with diabetes need insulin to live and to avoid devastating complications that include blindness, kidney failure, lower limb amputation, heart attack, stroke, and even death. For them, the cost has spiraled out of control and is beyond the reach of many.

Insulin prices have tripled between 2002 and 2013\(^4\) and have doubled since then\(^5\) - for a medicine that is nearly 100 years old. There have been incredible advances in research and development and technology that have improved the lifespan and quality of life for those with diabetes, but the formula for insulin has not changed significantly since the 1990s.

Without insulin, people with diabetes die and scaling back on insulin can lead to costly and sometimes deadly complications. People with diabetes can require as much as two to four vials of insulin per month. So, when deductibles are high, even people with insurance end up paying upwards of $1,200 per month simply to live or they’re rationing their insulin, either taking less than the dose they have been prescribed or skipping doses altogether, which may lead to deadly complications and high costs to the state. Research conducted for the American Diabetes Association (ADA) has shown that, for one in four insulin users, cost has impacted their use, causing them to ration their insulin.\(^6\)
The American Diabetes Association is the nation’s leading voluntary health organization fighting to bend the curve on the diabetes epidemic. As a leader in the insulin affordability discussion, we consistently hear from people with diabetes who struggle to afford their life-sustaining insulin.

ADA, through the work of its Insulin Access and Affordability Working Group, reached a number of conclusions that have been published in the journal *Diabetes Care*:

- The current pricing and rebate system encourages high list prices.
- There is a lack of transparency throughout the insulin supply chain.
- People with diabetes are financially harmed by high list prices and high out-of-pocket costs.
- Patient medical care can be adversely affected by formulary decisions.
- The regulatory framework for development and approval of biosimilar insulins is burdensome for manufacturers.

After further study, ADA released a public policy statement that included key recommendations such as:

- Increasing pricing transparency throughout the insulin supply chain,
- Lowering or removing patient cost-sharing for insulin, and
- Increasing access to health care coverage for all people with diabetes.

**Recommendation #1 - Increasing pricing transparency throughout the insulin supply chain.**

Transparency is at the forefront of any recommendations to address the high cost of insulin. This representation of the complexities of the insulin supply chain shows the numerous stakeholders involved in the delivery of insulin as well as the multiple opaque transactions between and among these stakeholders.
It is unclear precisely how the dollars flow and how much each intermediary in the insulin supply chain profits. This lack of transparency clouds the true cause of higher prices. In order to better understand the role of each link in the supply chain, there must be full transparency.

To accomplish this, ADA recommends:
- requiring all entities in the insulin supply chain to report certain pricing, sales, and profit data to a designated state agency,
- compiling the information in an aggregated report and providing it to the state legislature and insurance commissioner’s office, and
- publishing the report on the agency’s website.

**Recommendation #2 - Lowering or removing patient cost-sharing for insulin.**

The American Diabetes Association has joined with other diabetes stakeholders to support state legislation to cap the amount a patient with diabetes pays each month for their insulin. This would apply to all state-regulated commercial health insurance plans.

In May of last year, Colorado became the first state in the nation to enact an insulin co-pay cap bill. The law:
- caps co-pays for insulin at $100/month, regardless of the type of insulin or the number of vials a patient requires and
- calls on the Colorado Attorney General to investigate the rising prices of insulin in the state and make recommendations to the General Assembly for further action.

Soon after Governor Polis signed the bill in Colorado, other state’s legislators began exploring the possibility of replicating the bill in their own states.

Insulin co-pay cap laws have now been enacted this year in Illinois, New Mexico, Maine, West Virginia, Utah, Washington, New York, Virginia, New Hampshire, Delaware, and Connecticut.

In Ohio, Rep. Beth Liston and Sen. Hearcel Craig are the primary sponsors of HB 387 and SB 232, respectively. Each bill seeks to establish a monthly co-pay cap on insulin. Separate legislation, HB 385 and SB 231, would require the Attorney General to investigate and report on the pricing of insulin.

Whereas only sponsor testimony has been heard on each bill, ADA will continue to work with the legislature to enact insulin co-pay cap legislation.

Some states have also taken action to exempt insulin from the deductible, an action ADA also supports.
A related recommendation is to include the value of drug manufacturer coupons toward a patient’s out-of-pocket cost obligation. Whereas ADA recognizes that cost-sharing coupons are not a long-term solution to prescription drug affordability issues, they can be essential to ensuring individuals with high cost-sharing requirements are able to afford medications their providers deem necessary, including insulin, for which there is no generic available.

This type of legislation has already been enacted in Arizona, Illinois, Virginia and West Virginia. House Bill 469, sponsored by Rep. Susan Manchester, is an example of legislation supported by ADA.

Finally, Medicare coverage can be a guide for states as they consider coverage decisions. With the announcement earlier this year that the Part D Senior Savings Model will limit the cost of insulin for participating seniors to a maximum of $35 for a 30-day supply, we urge Ohio and insurance plans doing business in the state to follow suit.

**Conclusion**

It’s time to reduce the financial burden on the state and on Ohio diabetes patients who need insulin. People with diabetes - Ohioans with diabetes - are sometimes forced to choose between insulin and rent or between insulin and food to survive.

The American Diabetes Association believes that no individual in need of life-saving medications should ever go without due to prohibitive costs or accessibility issues.

On behalf of the nearly 4.3 million people with or are at risk for diabetes, we urge this Council to issue a report urging the General Assembly to increase pricing transparency throughout the insulin supply chain and lower or remove patient cost-sharing for insulin.

Thank you very much for the opportunity to submit these written comments. Please let me know if you have any questions at all.

Sincerely,

Gary Dougherty
Director, State Government Affairs

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4. Diabetes Care 2018;41:1299–1311 | [https://doi.org/10.2337/dc18-0019](https://doi.org/10.2337/dc18-0019)
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