

# INTERIM JOINT COMMITTEE ON BANKING AND INSURANCE

## Minutes of the 1st Meeting of the 2019 Interim

August 21, 2019

### Call to Order and Roll Call

The 1st meeting of the Interim Joint Committee on Banking and Insurance was held on Wednesday, August 21, 2019, at 10:00 AM, in Room 149 of the Capitol Annex. Representative Bart Rowland, Chair, called the meeting to order, and the secretary called the roll.

Present were:

Members: Senator Jared Carpenter, Co-Chair; Representative Bart Rowland, Co-Chair; Senators Julie Raque Adams, Tom Buford, Rick Girdler, Christian McDaniel, Morgan McGarvey, Dennis Parrett, Albert Robinson, Brandon Smith, and Reginald Thomas; Representatives Terri Branham Clark, Joseph M. Fischer, Deanna Frazier, Jim Gooch Jr., Kathy Hinkle, Dennis Keene, Adam Koenig, Derek Lewis, Sal Santoro, Dean Schamore, Wilson Stone, Ken Upchurch, and Rob Wiederstein.

Guests: Gary Dougherty, Director, Government Affairs and Advocacy, American Diabetes Association; Angela Lautner, Chapter Leader, and Angie Summers, Kentucky #insulin4all; George Huntley, Treasurer and President-Elect, National Diabetes Volunteer Leadership Council; Stewart Perry, Interim Chief Executive Officer, Diabetes Patient Advocacy Coalition; Allison Lile, Healthcare Data Administrator, Office of Health Data and Analytics, Kentucky Cabinet for Health and Family Services; Nancy Galvagni, President; Chuck Warnick, Vice President, Data Analysis and Planning; Melanie Moch, Director, Data Collection and Training; and Carl Herde, Vice President of Finance, Kentucky Hospital Association.

LRC Staff: Jessica Sharpe, Breanna Miller, and Dawn Johnson

### Insulin Access and Affordability in Kentucky

Gary Dougherty, Director, State Government Affairs and Advocacy, American Diabetes Association (ADA) said many people with diabetes struggle to afford insulin, a life sustaining medication. Between 2002 and 2013, the average price of insulin almost tripled. Nearly 30 million Americans have diabetes, of which, 7.5 million rely on insulin. Approximately 567,000 adult Kentuckians have diabetes. In 2016, the ADA Board of Directors passed a resolution requesting increased transparency in pricing along the insulin supply chain to ensure no one is denied affordable access to insulin. The resolution requested congressional hearings to identify reasons for the significant cost increase and to

ensure affordable access. At the same time, the ADA created a website, [makeinsulinaffordable.org](http://makeinsulinaffordable.org), with a grassroots petition for affordability, a forum for patient stories, and links to published research. The Insulin Access Affordability Working Group, formed in 2017 to assess the problem, concluded that the current pricing and rebate system encourages high list prices. It identified a lack of transparency throughout the insulin supply chain that allows high list prices and high out-of-pocket costs. Patient medical care can be adversely affected by formulary decisions, and the development and approval of biosimilar insulin is burdensome for manufacturers. The group recommended increased pricing transparency, lowering or removing patient cost-sharing, streamlining the biosimilar approval process, and increasing access to health care coverage for all people with diabetes. Following the 2016 resolution, Congress has held more than a dozen hearings on insulin affordability with the ADA testifying at many of them.

Last year, the ADA launched [www.insulinhelp.org](http://www.insulinhelp.org) to provide resources, including links to insulin manufacturers who may offer immediate assistance, for those struggling with insulin costs and links to local community health clinics or pharmacies that may offer access to free or reduced-fee insulin. Mr. Dougherty said the ADA strongly supports the Insulin Price Reduction Act sponsored by the U.S. Senate Diabetes Caucus. Mr. Dougherty noted that Kentucky Representative Danny Bentley introduced 2019 Regular Session House Bill 502 on price transparency by diabetes drug manufacturers and pharmacy benefit managers (PBMs). The ADA recommended additional language to include all entities in the supply chain. They recommend legislation that requires reporting from health plans and pharmacies. In May 2019, Colorado became the first state to enact an insulin co-pay cap bill that caps co-pays at \$100 per month, regardless of type of insulin or number of vials required. The Colorado bill also calls for the state attorney general to investigate the rising prices of insulin in the state and make recommendations to the General Assembly. Mr. Dougherty said Representative Bentley has prefiled a bill similar to Colorado that caps insulin copays at \$100 per month. Seventeen states have introduced or are considering similar legislation.

The ADA supports efforts at the state and federal levels of government to ensure access to adequate and affordable healthcare, including making insulin affordable and accessible for all who need it. They recommend requiring entities in the insulin supply chain to report pricing, sales, and profit data to a designated state agency. This would apply to insulin manufacturers, PBMs, pharmacies, and health plans. Information would be compiled in an aggregated report and provided to the state legislature and insurance commissioner. It would also be available to the public. They recommend lowering or removing patient cost sharing for insulin by capping copays for insulin and exempting insulin from deductibles. The ADA recommends ensuring that the value of copay assistance programs is applied toward a patient's deductible. This is in response to individuals using copay coupons to help pay for expensive medications.

Angela Lautner, Chapter Leader, Kentucky #insulin4all and Angie Summers shared their stories of living with diabetes and the difficulties of affording insulin. Ms. Summers explained that even though she had insurance through her full-time employer, the cost of insulin increased from \$35 to over \$400 per month. After rationing insulin for years due to the high cost, Ms. Summers suffered severe, permanent medical issues.

Ms. Lautner said Kentucky #insulin4all is a grassroots organization created to raise awareness of the rising cost of insulin. She explained the difficulty of affording insulin, having been laid off from her employment four times. In 2017, the specific insulin she must use was being removed from her insurance formulary due to costs. Last year, she purchased insulin in Canada for \$22 while the cost in Kentucky was over \$300. When questioned about rising costs, manufacturers identify insurance plans and PBMs for increased list prices, while one suggested generic competition would help lower prices. Ms. Lautner said there is no generic equivalent for the insulin she uses. She said people are dying due to insulin unaffordability. Ms. Lautner asked that the General Assembly address insulin price transparency across the entire insulin supply chain and pass Representative Bentley's proposed legislation that caps copays to ensure every person with diabetes has access to affordable insulin, including those on high deductible health plans, the uninsured, and those on multi-state insurance plans.

Stewart Perry, Interim Chief Executive Officer, and George Huntley, President Elect, National Diabetes Volunteer Leadership Council (NDVLC) spoke on insulin affordability. Mr. Huntley said that high insulin costs often leads to rationing. With one in three people with diabetes requiring insulin, the high cost affects a large segment of the population. As high deductible health plans have increased, deep systemic problems in the country's health system has resulted in costs being shifted to the patient. Often, medical and pharmacy costs are now part of the deductible. There has been a shift from flat copays to coinsurance as list prices skyrocket. There are too many middlemen. The consumer is not getting the benefit of the negotiated value of the pharmaceutical discounts and rebates that are part of their health plan. Patients are paying list price with the difference going to the PBM. He said the sick are subsidizing the healthy.

Mr. Perry said that while manufacturing costs of insulin have changed little, there are now multiple people, including PBMs, the insurance plan, and the employer, involved in the process causing insulin prices to skyrocket. Mr. Huntley said a study by NDVLC comparing insulin health plan cost versus online purchasing identified a \$100 to \$200 online purchasing price savings for one vial of insulin. Going outside the health plan to purchase insulin is not viable for the consumer since payment does not go toward the health plan deductible. To address the issue, the NDVLC recommends understanding and maximizing coverage, asking for cash prices, using retail discount programs, enrolling in manufacturer discount or patient assistance programs, checking prices at member warehouses, using a community health center low-cost health provider, talking to employers about insulin costs, and talking to a patient diabetes care team about lower cost

options. Mr. Perry said the state can help by eliminating consumer exposure to excess cost burden by requiring first dollar coverage for insulin and other medical necessities and addressing rebate pass throughs, prohibiting pharmacy gag clauses, dictating that all payments count toward deductibles and out-of-pocket maximum, and improving consumer access to medically appropriate treatment by clearing the appeals process with quick adjudication. He noted that the number of drugs added to exclusionary formularies has increased 86 percent. He also recommended that the prescriber should prevail in non-medical switching, fee-only PBM contracts, and meaningful transparency reporting.

In response to Chairman Rowland's question, Mr. Perry said it would be difficult to estimate out-of-pocket expenses for diabetes treatment as health plans differ significantly.

Senator McDaniel said small employers are limited in healthcare options and must choose from available plans. Mr. Huntley said an employer can work with their PBM or consultant to design their plan. Senator McDaniel said certain private employers are under pre-Affordable Care Act guidelines to provide a more cost effective health plan.

Senator McDaniel said the Colorado copay cap model is flawed as it shifted the balance of the cost to Medicaid. No accountability was introduced into the system, they simply substituted the state as the payer. He cautioned that the legislation could potentially be an incentive for other drugs as well. Mr. Dougherty said he does not disagree and would support language changes to the Colorado bill.

Senator Smith said he sponsored a bill in 2005 to address the issue of drug rebates being directed toward the consumer in an attempt to offset manufacturing costs, but the bill did not advance. In response to Senator Smith's question, Mr. Perry said even though internet access has made rebate coupons more accessible, they can be hard to find and they do expire. The main problem is the rebates and coupons do not count toward a deductible, copay, or coinsurance. Ms. Lautner said people should not be forced to search for coupons for life-saving insulin.

Representative Koenig said that while he favors a more hands-off approach on this type of issue, it would be helpful if entities practiced self-transparencies so better decisions could be made by the legislature while being less invasive to businesses.

In response to Senator Thomas' comment, Mr. Perry said community health centers receive favorable drug pricing through the federal 340B Drug Discount Program that gives some access to medications at a lower cost. He suggested changing income qualifications to use the programs would be a positive step. Mr. Perry said that would need to be done on the federal level. Mr. Smith said it should not matter who is paying for a medication for deductible consideration but trying to get PBMs and insurance companies to agree would most likely require legislation. Ms. Lautner said there are income restrictions with faith pharmacies and free clinics so many people who are employed will not be helped.

Representative Gooch said health plans copay requirements have changed significantly. He said, previously, there was a monetary benefit for a healthy person to take a high deductible plan that allowed savings to cover future events. Now high deductible plans are being used because people cannot afford anything else.

### **Hospital and Ambulatory Facility Price Transparency Initiative**

Allison Lile, Healthcare Data Administrator, Office of Health Data and Analytics, Kentucky Cabinet for Health and Family Services explained that the Office of Health Data and Analytics was recently established from an agency reorganization. They are currently reviewing and evaluating statutes and regulations to see how they apply to the new office. With regard to the part of Kentucky's health data collection law relating to health care cost and quality, the agency previously used resources from the federal Agency for Health Care Research and Quality, including a tool to create a consumer website showing costs and quality, but that website is no longer available. Referring to a PowerPoint, Ms. Lile presented an example of a quality indicator map using diabetes as it specifically related to long-term complications for something that could have been prevented had the person received well-regulated care. She noted that the indicators do not necessarily mean good or bad, they are a comparison to national benchmarks. She said the office publishes several annual reports.

Nancy Galvagni, President, Kentucky Hospital Association (KHA) said the KHA has been working on price transparency and understands the need for consumer access to better information when deciding where to have their services. The KHA has been partnered with the cabinet for over 20 years. It collects Kentucky hospital billing data. The KHA has a contract with the Cabinet and provides the Cabinet with information as well. Since 2005, they have released comparative charge information on inpatient services, which is available on their website. The KHA wants to get the word out that this information is available. Work is ongoing to make the website more consumer friendly and provide more outpatient service information. Melanie Moch, Director of Data Collection and Training gave an overview of the KHA's Consumer Price Transparency website, which includes pricing point information, quality information, hospital information from the CMS quality metrics, health care community and outreach events, and a "frequently asked questions" page to serve as a starting point for consumers.

Carl Herde, Vice President of Finance said there is a push for hospitals and insurers to publish agreed upon rates. He noted that many insurance contracts have confidentiality agreements. He said the agreed upon payment amount is a small part of the information sought; actual insurance coverage is what is important. Disclosing the payment information that hospitals have with payers will not get the information that consumers seek. That information comes from the insurer. The hospital is just one piece of the care of the patient.

Responding to Representative Stone's question, Mr. Herde said most hospitals are working toward supplying procedure-specific cost information but often it is the insurance coverage that determines costs. Most hospitals will work with consumers to get an idea of where they stand. Representative Stone said it would be helpful if hospitals could submit basic procedure pricing that can then be used with the consumer's insurance coverage.

In response to Representative Wiederstein's question about whether the KHA would support an all-payer claims database in Kentucky, Ms. Galvagni said there is an interest, and the KHA collects billing data, but collecting payment and adjustment data would be a huge undertaking. Mr. Herde said there is a significant difference between charges and actual payments. Collecting payment data would be better than charge data but it still would not provide enough information to pass on to the consumer. Insurance coverage plays a monumental role.

In response to Chairman Rowland's question, Mr. Herde said most insurers provide consumers with online insurance data tracking, with hospital billing data provided.

There being no further business, the meeting adjourned at 11:55 AM.