

## Daylight on diabetes drugs: Nevada bill would track insulin makers' profits

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Patients notched a rare win over the pharmaceutical industry this week when the Nevada Legislature revived a bill requiring insulin makers to disclose the profits they make on the life-sustaining drug. In a handful of other states, bills addressing drug prices have stalled.

Many of the 1.25 million Americans who live with Type 1 [diabetes](#) cheered the legislative effort in Nevada as an important first step in their fight against skyrocketing costs of a drug on which their lives depend. The cost of [insulin](#) medications has steadily risen over the past decade by nearly 300 percent.

Prominent patient advocacy groups, such as the American Diabetes Association, have maintained stony silence while diabetes patients championed the [bill](#) and lobbied the Legislature during this debate - a silence that patients and experts say stems from financial ties.

"Normally all of the patient advocacy groups rally around causes and piggyback on each other in a productive way - that's what advocacy groups are good at - but that hasn't been the case here," said Thom Scher, chief operating officer of Beyond Type 1, which does not accept donations from the pharmaceutical industry. Beyond Type 1 has not issued a formal opinion on the Nevada bill.

Many of the dozens of U.S. diabetes advocacy organizations, large and small, garner significant portions of their funding from insulin manufacturers. The Nevada bill also requires such organizations

operating in-state to disclose all contributions they receive from the pharmaceutical industry to discourage that sort of conflict.

In 2016, two of the "big three" insulin producers - Eli Lilly and Sanofi - contributed at least \$4.7 million to such national patient advocacy groups as the American Diabetes Association, Diabetes Patient Advocacy Coalition (DPAC), JDRF International and the Diabetes Hands Foundation, according to company disclosures. The third major insulin manufacturer, Novo Nordisk, does not disclose its charitable contributions.

The advocacy groups have taken no position on the Nevada legislation. Generally speaking, their advocacy focuses on pressuring insurers to pay the price of insulin, not protesting price rises.

Local diabetes groups, hardly free from conflicts with the pharmaceutical industry, have also stayed on the sidelines.

The Nevada Diabetes Association for Children and Adults officially issued a neutral opinion.

"The Nevada Diabetes Association supports regulations on medications. The problem with SB 265 is that it is not just regulating medication but the industry," said Executive Director Sarah Gleich.

The nonprofit does not list its fiscal sponsors on its website or most recent 990 tax form.

"We disclose what we have received, and the IRS does not require that we publicly publish from whom," Gleich said. "No one is giving out their invitation list to the party."

Gleich said the Nevada Diabetes Association receives table sponsorships

and supplies for camp programs from the [pharmaceutical industry](#) but "nothing that would make a dent on the budget." Auditing non-monetary donations in order to meet the bill's transparency requirement would be burdensome, Gleich said.

Membership dues accounted for only about \$6,000 of the group's \$320,000 in revenue last year, according to its latest tax form.

The American Diabetes Association - which operates a Nevada chapter - accepted at least \$3.9 million from Eli Lilly and Sanofi last year.

"The American Diabetes Association believes that no individual in need of lifesaving medications such as insulin should ever go without due to prohibitive costs," Michelle Kirkwood, its director of strategic communications and media relations, said in a statement. She would not say whether the nonprofit supports the bill.

Former American Diabetes Association president Larry Hausner wrote an op-ed in the Nevada Appeal opposing the legislation. "Caring for people with diabetes involves more than what they pay for insulin or another medication," Hausner wrote. "As a lifelong patient advocate, I know Nevadans expect more out of their elected officials."

Hausner, now the president of a consulting and public affairs firm, serves on the board of directors of Research!America, a nonprofit promoting increased federal funding for public health research, alongside Sanofi's president of global research & development, Elias Zerhouni.

The Diabetes Hands Foundation expressed neutrality on the bill. "This state priority in Nevada is a good step towards a larger conversation about the costs of chronic care conditions like diabetes," said the foundation's director of advocacy, Mandy Jones. "But it's hard to know

the particular outcome of this particular bill in the U.S. market."

JDRF International would not comment. DPAC deferred questions to the National Diabetes Volunteer Leadership Council.

Against the backdrop of silence from these patient advocacy groups, a community of [diabetes patients](#) on Twitter elevated the bill's profile around the hashtag #insulin4all, created by T1International, a group in the United Kingdom that does not accept pharmaceutical donations.

"People feel frustrated. At the federal level, we're not being seen because there's so much going on politically," said Erin Gilmer, a Colorado advocate with Type 1 diabetes. "It might have to be a state-by-state movement."

Sen. Yvanna Cancela, who sponsored the bill, said she believed requiring diabetes advocacy groups to reveal their sources of funding was key to understanding their positions and bringing prices down. "I believe there should be transparency across the health care system," Cancela said.

Gov. Brian Sandoval said Monday night that he intends to sign the bill, according to a Nevada Independent reporter. If the governor takes no action, the transparency rules become law. The bill, SB539, incorporates provisions of an earlier bill approved by the Legislature but vetoed by Sandoval. Sponsors stripped a controversial provision that would have required insulin manufacturers to warn patients 90 days before raising prices, which stoked concerns about drug stockpiling, The Associated Press reported Monday.

The Nevada bill "is definitely a step in the right direction," said Elizabeth Rowley, founder and director of T1International. "Almost anything requiring more transparency is incredibly important right now, especially at a time when almost all diabetes patient advocacy groups

take funding from drug and device companies."

Laura Marston, an advocate in Washington, D.C., with Type 1 diabetes, said that there is plenty of grass-roots support for legislation on insulin prices but that advocacy organizations are not listening to the right people.

"There should be more focus on the one thing we need to survive. ... Without insulin, I die a horrendous death in 12 to 24 hours," Marston said. "No grass-roots support? There's desperation."

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