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HOUSE DEMOCRATIC POLICY COMMITTEE

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House of Representatives
COMMONWEALTH OF PENNSYLVANIA

HOUSE DEMOCRATIC POLICY COMMITTEE HEARING

Topic: Rising Costs of Prescription Drugs

Haverford Township Building – Havertown, PA

September 11, 2019

AGENDA

2:00 p.m. Welcome and Opening Remarks

2:10 p.m. Panel One:
- Dr. Kevin Caputo, President and Chief of Behavioral Health, Crozer-Keystone
- Ashlie Van Meter, Senor Director of State Affairs, Association for Accessible Medicines
- Aali Javid, Board Member, Philadelphia Association of Retail Druggists
- Lauren Rowley, Vice President of State Affairs, Pharmaceutical Care Management Association
- Kristen Hathaway, Vice President of State Affairs, America's Health Insurance Plans

2:40 p.m. *Questions & Answers*

3:00 p.m. Panel Two:
- Ray Landis, Advocacy Manger, AARP Pennsylvania
- Patrick Keenan, Director of Consumer Protection and Policy, Pennsylvania Health Access Network

3:10 p.m. *Questions & Answers*

3:30 p.m. Panel Three:
- Audrey Farley, PhD, Leader, PA Chapter of #insulin4all
- Brian Hegarty, Writer/Editor/Content Strategist, Insulin Nation
- Adriana Richard, Member, #insulin4all
- Alison Hardt, Partner of Person with Type 1 Diabetes

3:50 p.m. *Questions & Answers*

4:10 p.m. Closing Remarks

PARD
An Association of Community Pharmacies

Established 1898

Editorial Board Discussion

Pa. Medicaid program is being overcharged by the MCO's and PBM's = About $200 - $300 Million dollars/year because:

Spread Pricing – Stores paid one price by the PBM and the PBM bills the MCO a much higher price – The MCO's use the higher figures in their calculation of the Capitation. The spread is being shared by the PBM and MCO through their "proprietary" contract. Legislation has been initiated to stop this practice.
Ohio audit calculated they paid $245 Million more than they should in 2018 & have now moved to one PBM for all Medicaid patients using a pass-through plan rather than a Spread Pricing plan.

Formulary – Using amount of rebate negotiated from the manufacturer in their decision of what should & should not be on formulary –

Example – The MCO Keystone First administered by Perform Rx (PBM) – mandates the use of BD brand for insulin needles – Price per hundred for BD product is about $50.00 – Also available are needles from several manufacturers that cost the stores $8-$10.
No legislation can stop this because this is proprietary & only the Auditor General or Attorney General can stop this by auditing these practices. Legislation has been initiated to stop this practice.

Pricing – PBMs reimburse drug ingredient cost by using Maximum Allowable Cost (MAC) and no one knows how they calculate these MAC prices. PBMs admitted at Senate hearings last year that they do not know what Independent pharmacies pay for drugs. We think they are using prices they see in their mail-order facilities which our stores cannot obtain as mail-order is a preferred "class of trade: according to manufactures.

We are trying to get DHS to mandate the use of NADAC pricing which is used in the Fee for Service Medicaid program, but they say that they cannot mandate pricing schedules in the $3.5 Billion Medicaid program in Pennsylvania. WHY NOT?

So, stores are losing money on ingredient cost on 25-30% of prescriptions they fill and the PBMs are paying dispensing fees of $0 - $.25 which does not even cover the cost of a bottle or vial. By Medicaid regulations, a store cannot refuse to fill an Rx for a Medicaid member because of price or because the member "says" they cannot afford the copay (RIDICULOUS).

2200 Michener Street | Suite 10 | Philadelphia, PA 19115 | 215-464-9690 |
www.pardrx.com | melb@pardrx.com

Pennsylvania Pharmacists Association

Support the Medicaid Reform and Transparency Package

The Medicaid Reform and Transparency Package addresses much needed changes to ensure fairness and transparency in the pricing reimbursements and other practices of Pharmacy Benefit Managers (PBMs) as fiscal stewards of taxpayer money.

- HB 941, sponsored by Rep. Doyle Heffley (R-122) and Rep. Robert Matzie (D-16) requires transparency in the Pharmacy Benefit Managers (PBMs) dealings with the Managed Care Organizations and the Department of Human Services. Almost 90 percent of Pennsylvania Medicaid patients are served by managed-care companies that contract with the state. In turn, those companies contract with PBMs for the management of their pharmacy programs. This legislation would require transparency between the payments from the MCOs to the PBMs and then to pharmacies. This legislation would also ensure fair reimbursement rates for commtrnity pharmacies.

- HB 942, sponsored by Rep. Seth Grove (R-196) would add one member from all four caucuses and two additional community pharmacists to the Pharmacy & Therapeutics Committee (P&T). The P&T committee establishes the drug formulary lists for the Medicaid program.

- HB 943, sponsored by Rep. Valerie Gaydos (R-44), would remove gag clauses in Medicaid. When PBMs contract with pharmacies, many times the contracts contain gag clauses, which prohibit a pharmacist from disclosing information to their patients that could substantially reduce the patient's out-of-pocket costs for their prescription medications. Additionally, some PBMs are prohibiting pharmacists from disclosing information to legislators and other officials and this bill would prohibit those gag clauses as well.

- HB 944, sponsored by Rep. Jonathan Fritz (R-111), would allow the Auditor General to audit all contracts between the Department of Human Services and the Managed Care Organizations as well as the contracts between the MCOs and the PBMs.

- HB 945, Conflict of Interest legislation, would prevent a Managed Care Organizationfrom using a Pharmacy Benefit Manager for Medicaid if the PBM is pan of a larger company that also owns retail pharmacies.

For More Information Contact: Pennsylvania Pharmacists Association, 508 North Third Street, Harrisburg, PA 1-71-01

PCMA

Finding the Formula for Drug Savings

Lauren Rowley
Senior Vice President, State Affairs

Why are we here?

Modern Healthcare

The leader in healthcare business news, research & data

Drug prices rise as pharma profit soars

By Alex Kacik | December 28, 2017

(Updated on Dec. 29)

The amount of money people spend on prescription drugs has over the past three decades as pharmaceutical sales and profi ballooned, according to a government report.

STAT

Several drug makers just raised their prices by nearly 10 percent, and buyers expect more price hikes

By ED SILVERMAN / JANUARY 2, 2018

Several drug makers celebrated the new year with substantial single-digit price hikes, while a new survey indicated that prices for brand-name medicines are expected to rise 3 percent ...

The New York Times

Humira's Best-Selling Drug Formula: Start at a High Price. Go Higher.

By DANNY HAKIM JAN. 6, 2018

prescription drug in the world. You may have

an with rheumatoid arthritis can wash her puppy
h colitis can stroll happily through a fair packed

The Washington Post

Pharma, under attack for drug prices, started an industry war

By Carolyn Y. Johnson

It's not easy to get Americans mad at a behind-the-scenes industry they've barely even heard of, but pharmaceutical companies have spent most of this year trying.

"Who decides what you pay for your medicines? Not who you ... in a radio spot ...

THE WALL STREET JOURNAL.

BUSINESS | HEALTH CARE

Cancer Drug Price Rises 1,400% With No Generic to Challenge It

Lomustine among 319 drugs with expired patents but no copies; FDA trying to boost competition

By Peter Loftus

Dec. 29, 2017 7:00 a.m. ET

Since 2013, the price of a 40-year-old, off-patent cancer drug in the U.S. has risen 1,400%, putting the life-extending medicine out of reach for some patients.

... and Hudgins ... ustine has no generic ...

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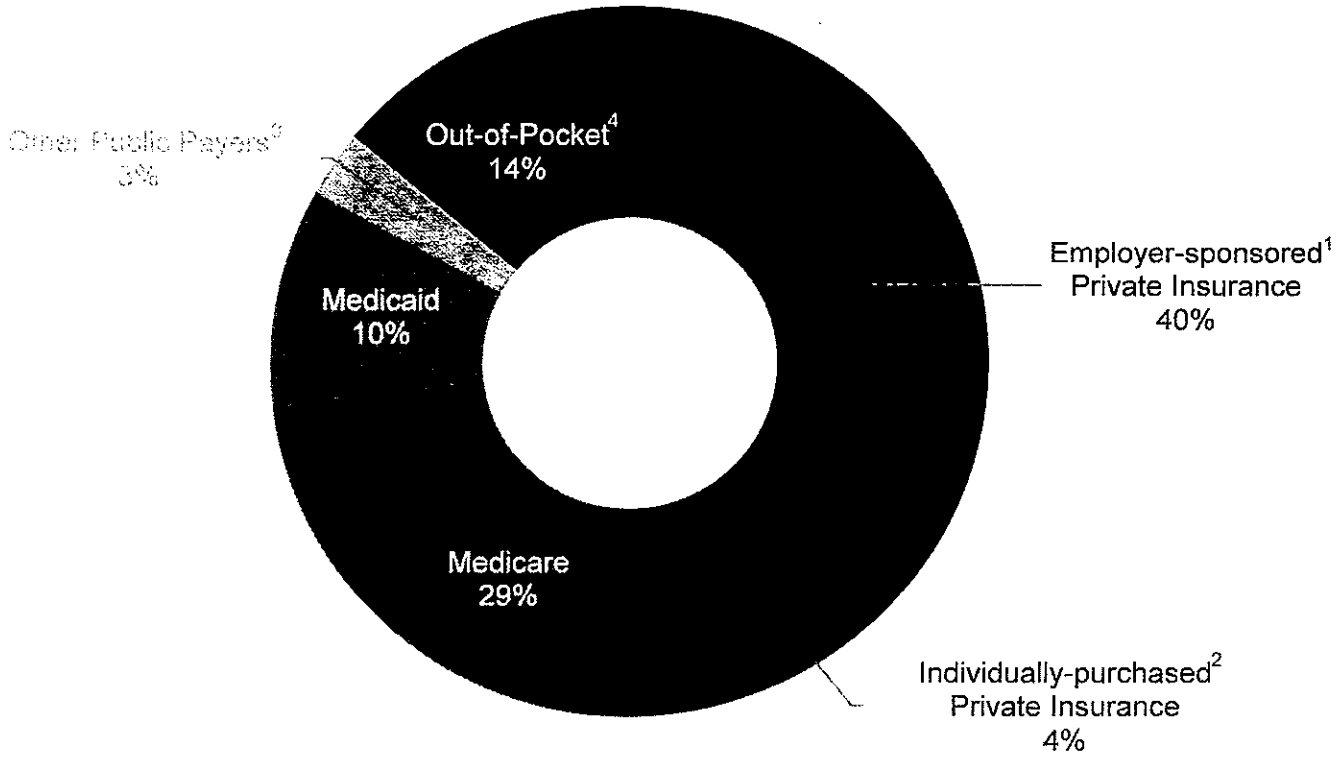
Who Pays for Prescription Drugs?

Source of Payment for Outpatient Prescription Drug Expenditures, 2016



1. Includes workers' compensation and Pembroke Consulting estimates for employer share of private insurance.
2. Includes those with Medicare supplemental coverage and all individually purchased plans, including coverage purchased through the Marketplaces. Figure reflects Drug Channels Institute estimates for prescription drug spending for individually purchased private insurance.
3. Includes Children's Health Insurance Program (Titles XIX and XXI), Department of Defense, Department of Veterans Affairs, Indian Health Service, workers' compensation, general assistance, maternal and child health, and other federal, state, and local programs. Other federal programs include OEO, Federal General and Medical, Federal General and Medical NEC, and High Risk Pools under ASA. Other state and local programs include state and local subsidies and TDI.
4. Consumer out-of-pocket expenditures equal cash-pay prescriptions plus copayments and coinsurance.

Source: Drug Channels Institute analysis of National Health Expenditure Accounts, Office of the Actuary in the Centers for Medicare & Medicaid Services, December 2017. Totals may not sum due to rounding. Data exclude inpatient prescription drug spending within hospitals and nearly all provider-administered outpatient drugs.

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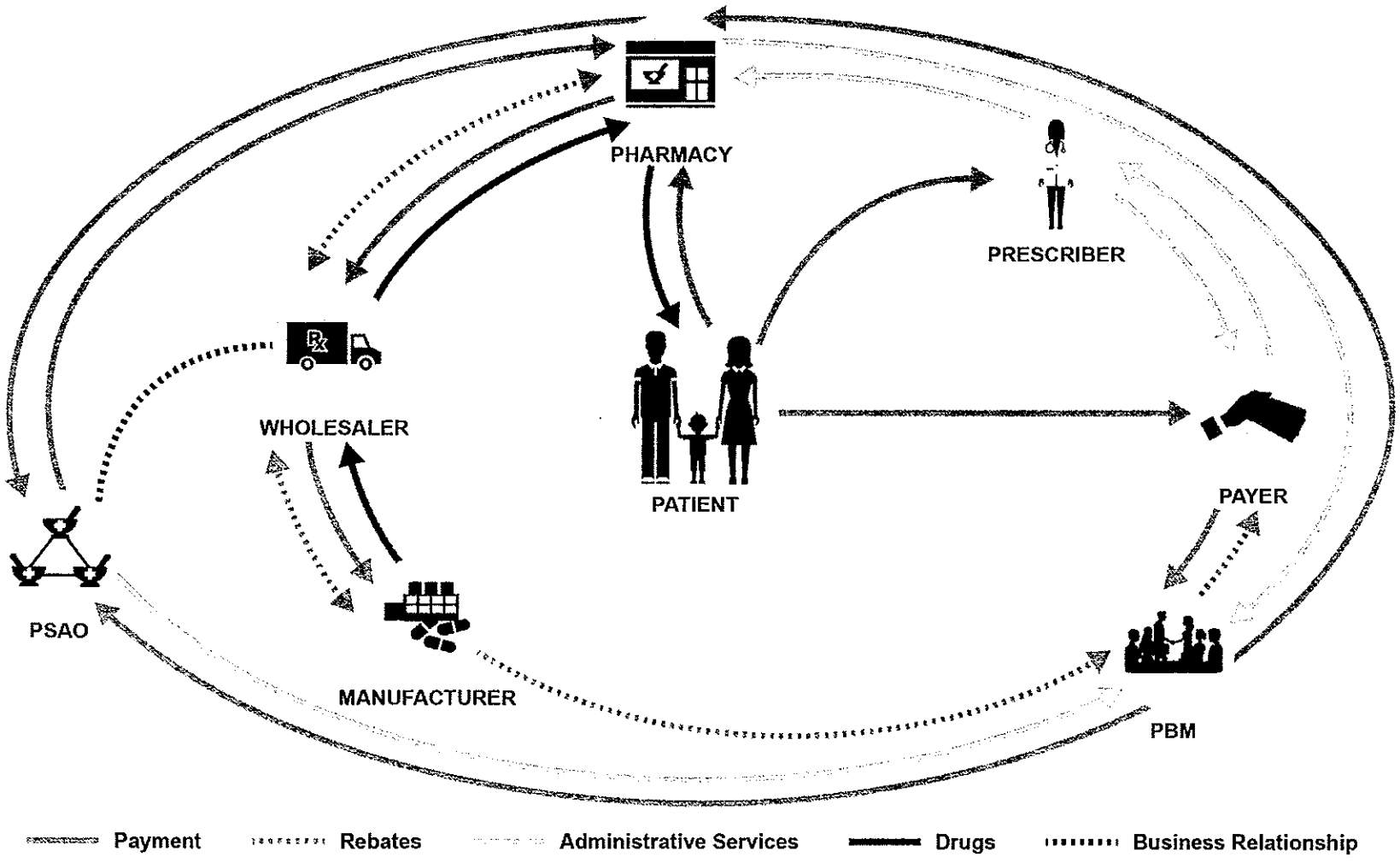
Flow of Goods, Transactions & Services



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What Role Does a PBM Serve?

- Pharmacy benefit managers (PBMs) negotiate on behalf of plan sponsors and administer the outpatient prescription drug portion of the health care benefit, in a high-quality, cost-effective manner.
- PBMs aggregate the buying clout of millions of enrollees, enabling plan sponsors and individuals to obtain lower costs for prescription drugs. PBMs are expected to save Pennsylvania patients and payers $28.5B over 10 years.[1]
- PBMs are the only check in the retail Rx drug supply chain against drug makers' power to set and raise prices.

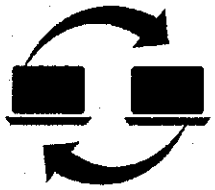
1 Visante, Generating Savings for Plan Sponsors, Feb. 2016, available at: - https://www.pcmanet.org/wp-content/uploads/2016/08/visante-pbm-savings-feb-2016.pdf

Why Do Plans Hire PBMs?

- PBMs help save plans 40-50% over unmanaged benefit, increase adherence.[1]
- Reduce medication errors through use of drug utilization review programs.
  - Over next 10 years, PBMs will help prevent 1 billion medication errors.[2]
  - Improve drug therapy and patient adherence, notably in the areas of diabetes and multiple sclerosis.[3]
- Manage programs to address opioid use issues.

1 Visante, Return on Investment on PBM Services, Nov. 2016.
2 Visante estimates based on IMS Health data and DUR programs studies.
3 Visante estimates based on CDC National Diabetes Statistics Report 2014 and studies demonstrating improved adherence by 10+%).

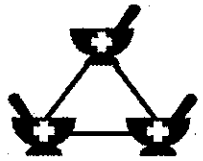
Pharmacy Benefit Management Services



Claims Processing

Price, Discount and Rebate Negotiations with Pharmaceutical Manufacturers and Drugstores

Formulary Management



Pharmacy Networks

Mail-service Pharmacy

Specialty Pharmacy

Drug Utilization Review

Disease Management and Adherence Initiatives

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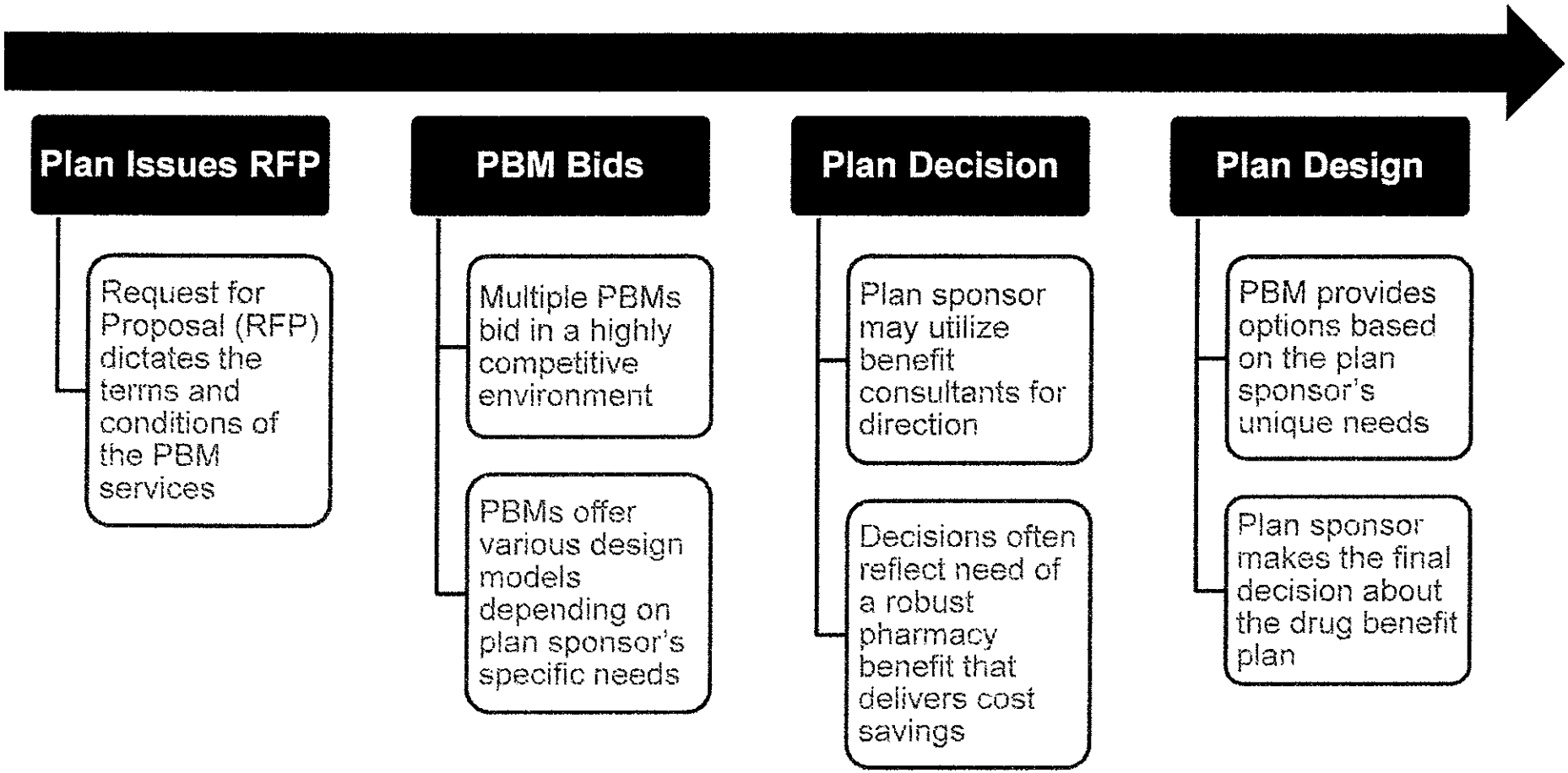
How Plans Hire PBMs: RFP Process



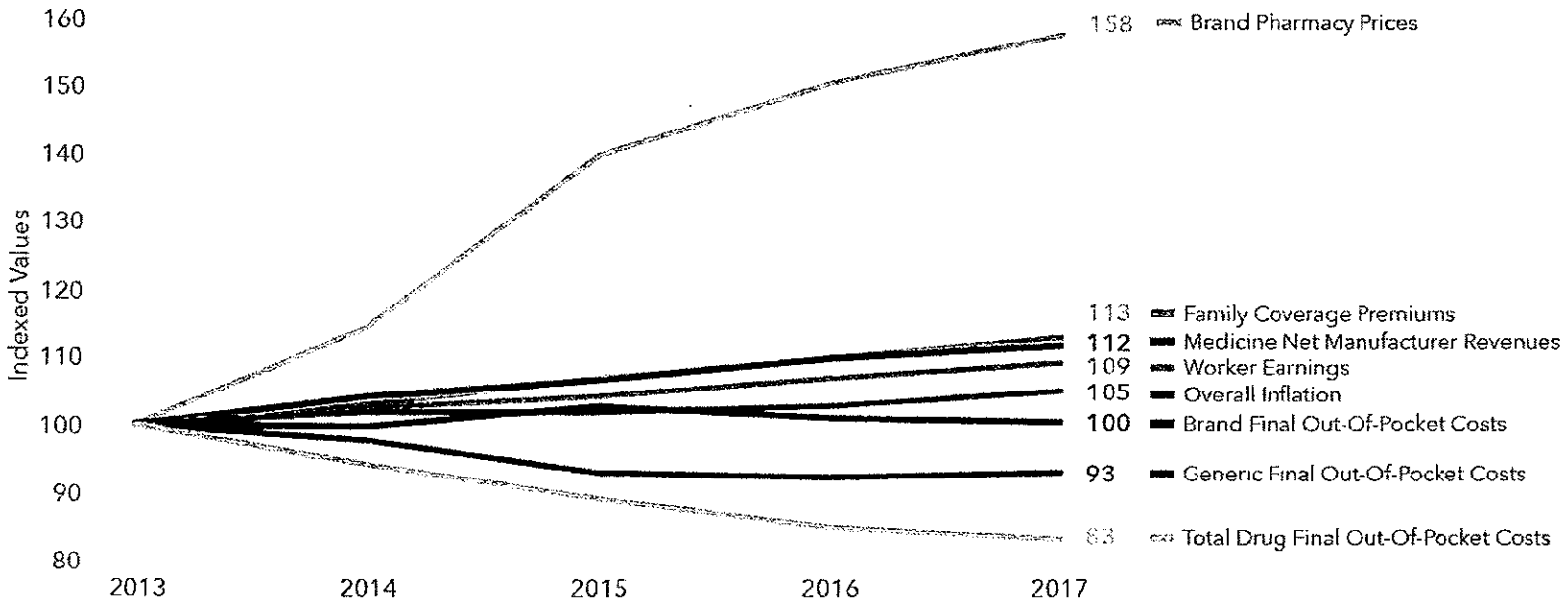
PBM – Plan Contracts

- PBMs offer various design models depending on a plan's specific needs:
  - Plans choose how to compensate PBMs: traditional/spread, pass-through/fees, rebate share.
  - Performance guarantees and audit rights protect plans and ensure transparency.
  - On average, more than **90%** of rebates negotiated by PBMs are passed through to plan sponsors.[1]
- The plan sponsor always has the final say when creating a drug benefit plan.
- Things not determined by a PBM: benefit design, cost sharing levels, deductibles, etc.

1. The prescription Drug Landscape, Explored. Pew Charitable Trust 2019.

Brand Drug Prices Increased 58% 2013-2017

Changes in Healthcare Costs or Cost Drivers 2013-2017, Indexed (2013 Values + 100)



Source: IQVIA Institute. *Medicine Use and Spending in the U.S.: A Review of 2017 and Outlook to 2022*, April 2018. Kaiser/HRET Survey of Employer-Sponsored Health Benefits, 2017; IQVIA Formulary impact Analyzer (FIA). IQVIA Institute, December 2017.

Chart notes: Indices sourced from Kaiser/HRET Employer Survey4 include: family coverage, premiums, workers earnings, overall inflation. Brand, generic and total final out-of-pocket costs and brand pharmacy prices are for commercially insured, Medicare Part D and cash payment types sourced from IQVIA Formulary Impact Analyzer. All charted values are indexed to set their 2013 value equal to 100.

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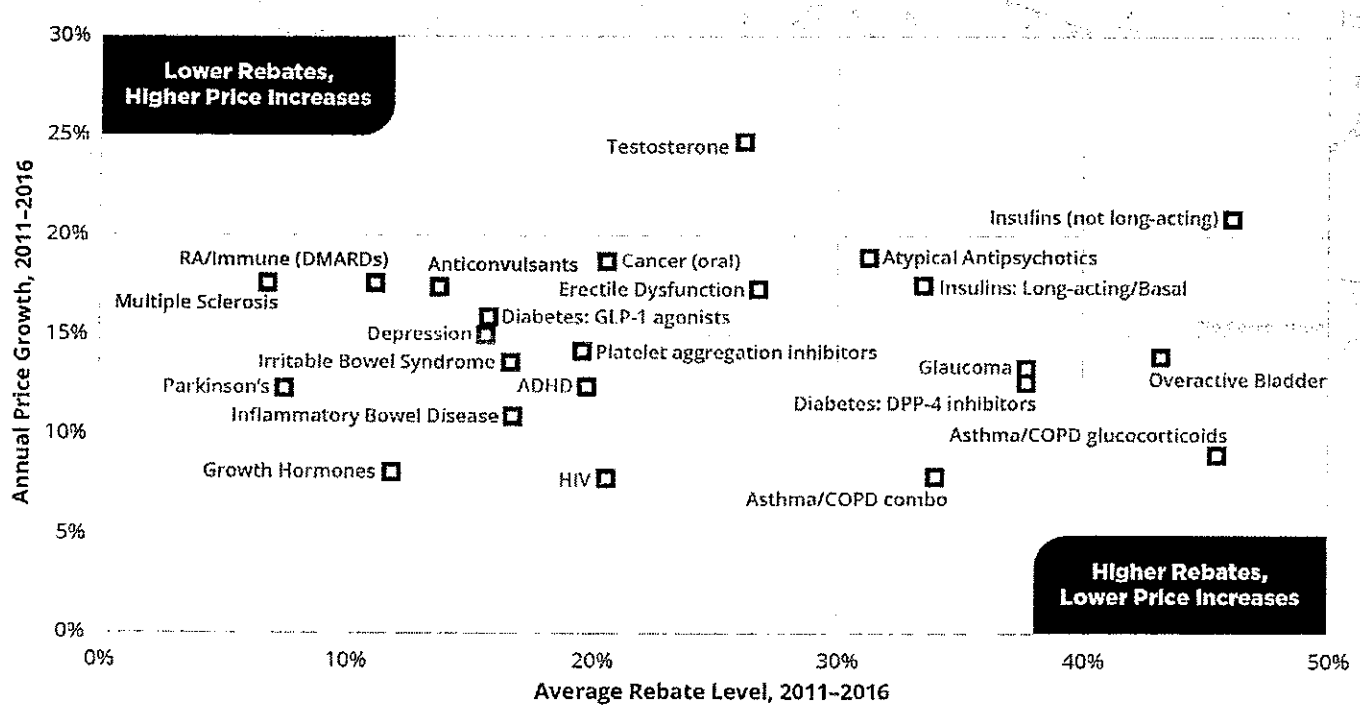
How PBMs Drive Savings and Quality: Manufacturers

- PBMs are able to bring volume to manufacturers and in some cases, obtain price concessions.
- Rebates reduce the net cost of drugs for payers, **but they aren't available on all drugs**—only where there is competition.
  - 90% of drugs dispensed are generics, with little-to-no rebate in commercial programs.
  - In Medicare Part D, 64% of brands were not eligible for rebates.[1]
  - PBM clients get the vast majority of the rebates.[2, 3]
- Rebates help reduce premiums & cost-sharing, and revenue is included in MLR calculation.
- Plans have no alternative tool at this time that is *as* effective at forcing manufacturers to compete, bringing down the net cost of drugs.

[1]Milliman, "Prescription Drug Rebates and Part D Drug Costs." (July 2018); [2]U.S. Government Accountability Office, "Medicare Part D: Use of Pharmacy Benefit Managers and Efforts to Manage Drug Expenditures and Utilization." (July 2019); and [3]Pew Charitable Trusts, "The Prescription Drug Landscape, Explored." (March 2019).

Study Shows No Correlation Between Drug Rebates and Price Increases



Major Findings:

- **No correlation** between drug prices and PBM/payer rebates
- Cases exist of higher-than-average price increases with relatively low rebates
- Cases exist of lower-than-average price increases with relatively high rebates
- Drugmakers are **increasing prices regardless of rebate levels**

Study: Top 200-self-administered, patent-protected, brand-name drugs in 23 major drug categories examined.

Source: Visante, *No Correlation Between Increasing Drug Prices and Manufacturer Rebates in Major Drug Categories*. (April 2017).

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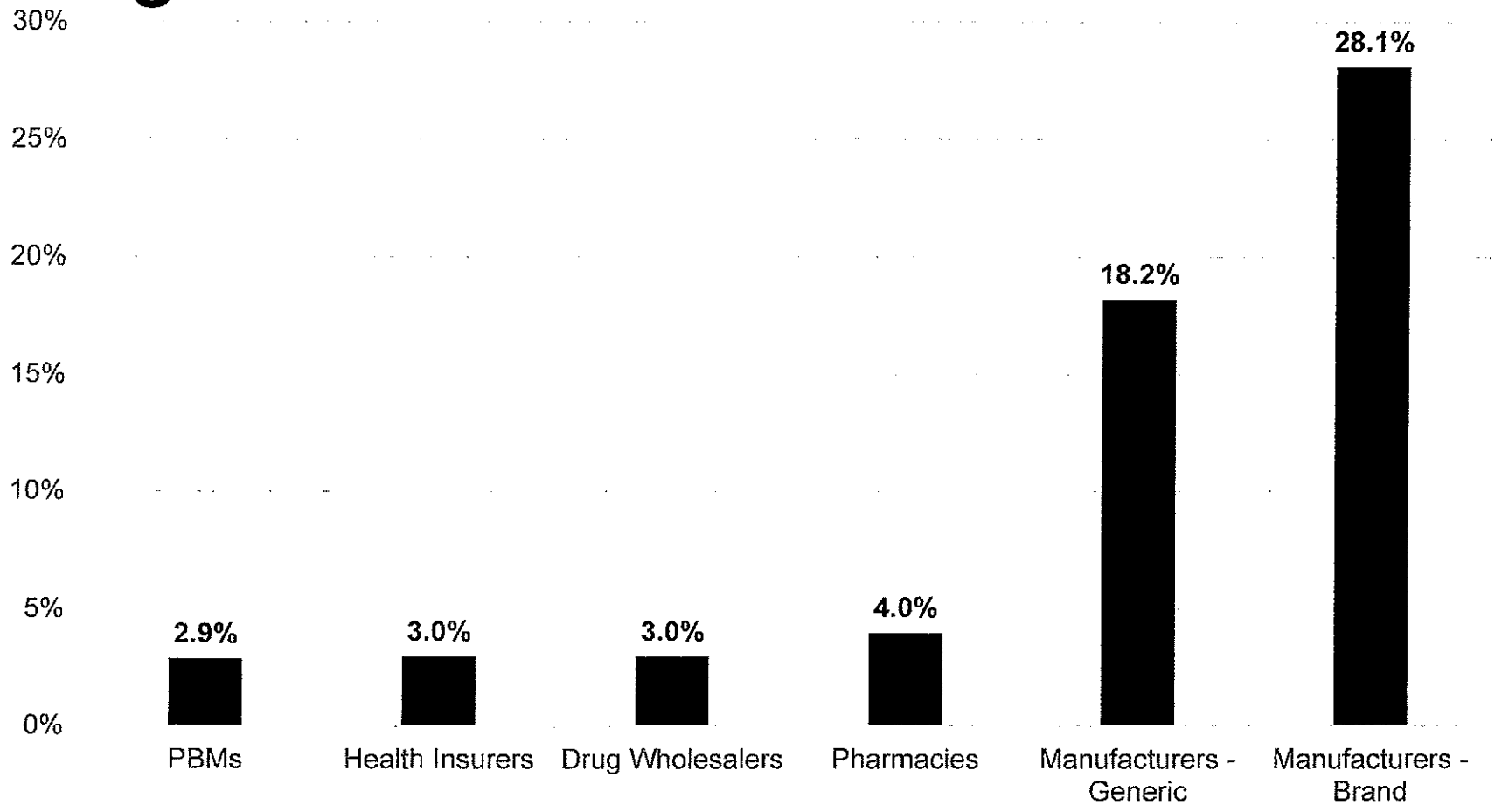
How PBMs Drive Savings & Quality: Pharmacy Networks

- Plans need a broad variety of pharmacies for adequate networks, and expect pharmacies to compete on both price and quality.
- PBMs:
  - Contract with a variety of pharmacies (typically through PSAOs) to ensure a robust network for health plan enrollees to access.
  - Efficiently process claims, provide real-time reimbursement information and timely payment.
  - Audit pharmacies for fraud, waste and abuse.

Pharmaceutical Supply Chain Profit Margins



Source: *The Flow of Money Through the Pharmaceutical Distribution System.* Schaeffer Center for Health Policy & Economics, University of Southern California. June 2017

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Questions?

Appendix:
Insulin in the Prescription Drug Marketplace

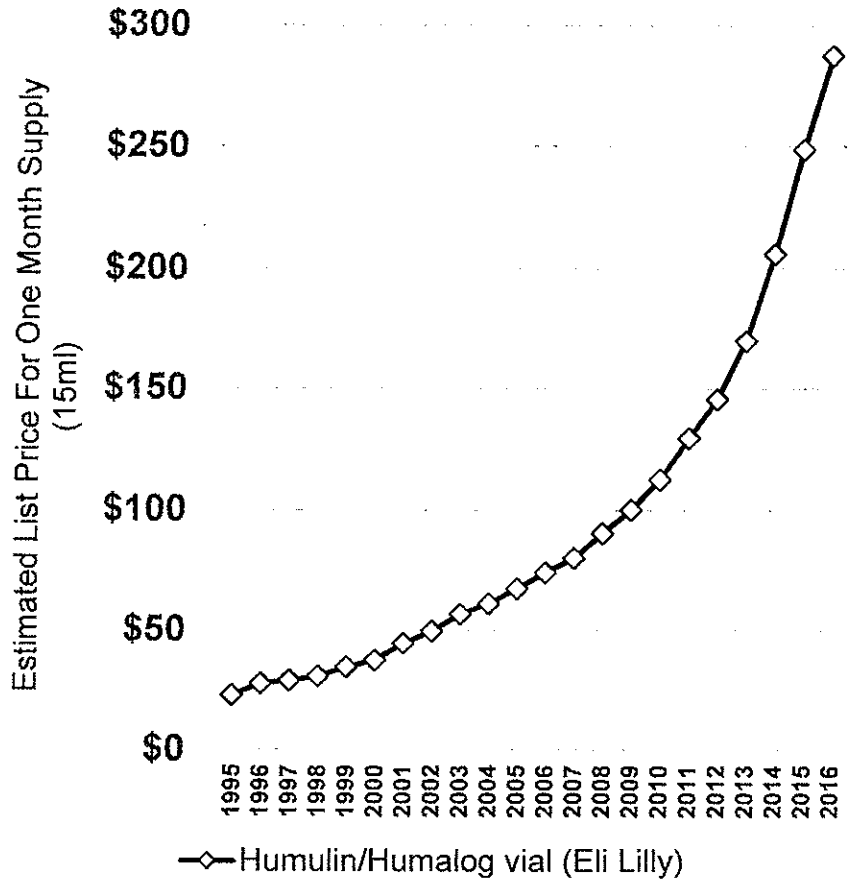
Introduction: Types of Insulin

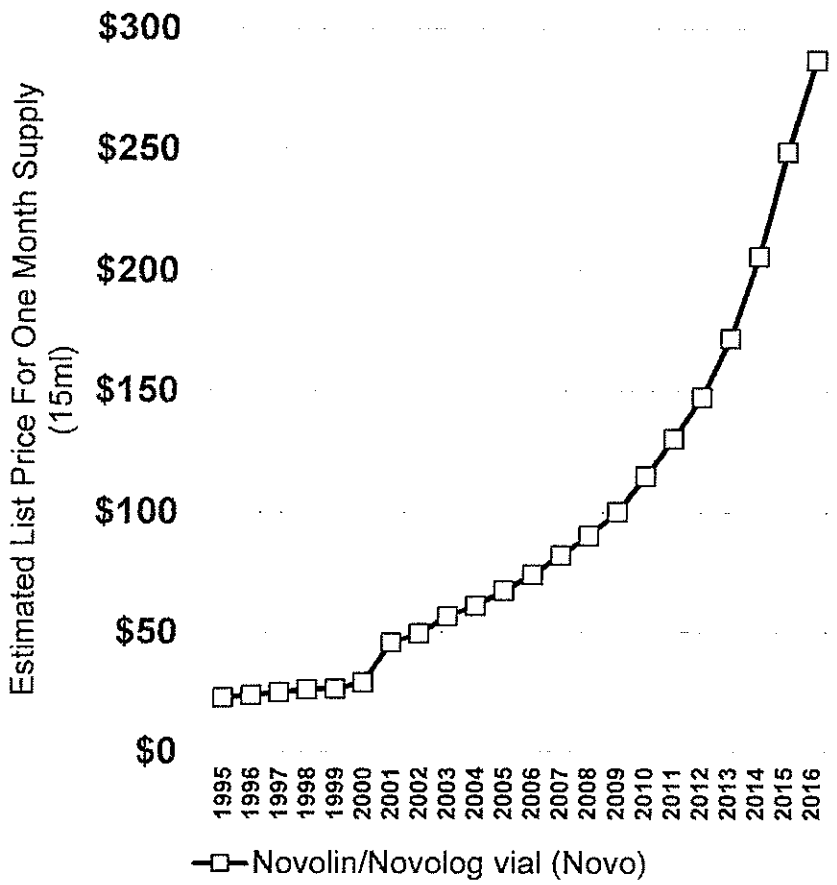
Types of Insulin	Brand Names
Rapid-acting: Usually taken before a meal to cover the blood glucose elevation from eating. This type of insulin is used with longer-acting insulin.	**Humalog** **Novolog** **Apidra**
Short-acting: Usually taken about 30 minutes before a meal to cover the blood glucose elevation from eating. This type of insulin is used with longer-acting insulin.	**Humulin** R (regular) **Novolin** R (regular)
Intermediate-acting: Covers the blood glucose elevations when rapid-acting insulins stop working. This type of insulin is often combined with rapid- or short-acting insulin and is usually taken twice a day.	**Humulin** N (NPH) **Novolin** N (NPH)
Long-acting: This type of insulin is often combined, when needed, with rapid- or short-acting insulin. It lowers blood glucose levels when rapid-acting insulins stop working. It is taken once or twice a day.	**Lantus** **Levemir** **Toujeo** **Tresiba** **Basaglar** (Lantus follow on)

Cost Driver: Manufacturer Price Increases

- Insulin prices have increased more than 10-fold since 1985. Prices have escalated more dramatically during the past 10 years.
- Prices for Humulin/Novolin have increased from approximately $25 per prescription in 1985 to nearly $300 in 2016.
- Prices for long-acting insulins have increased from about $100 per prescription in 2007 to nearly $400 in 2016.
- During the past 20 years, new insulin competitors have entered the market, but nearly always at higher prices than the existing market.
- Only recently have two lower cost follow-on insulins entered the market.
- During the past 10 years, gross sales for insulins have increased significantly due entirely to price increases, while overall utilization/prescription volume has remained flat.

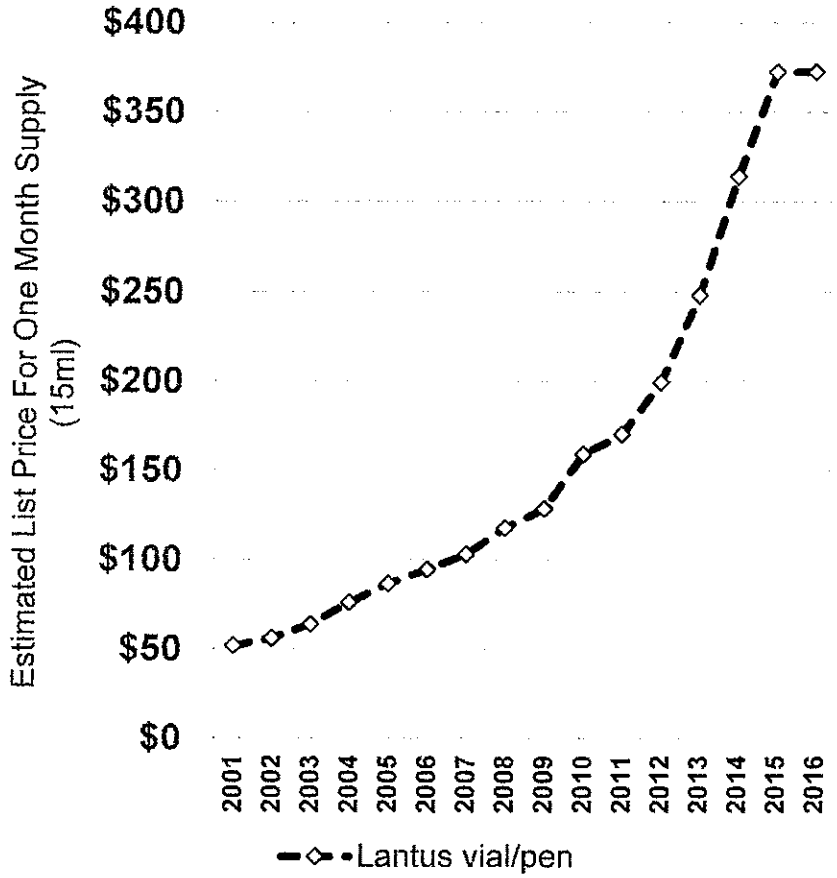
Humulin and Novolin: Large Manufacturer Price Increases

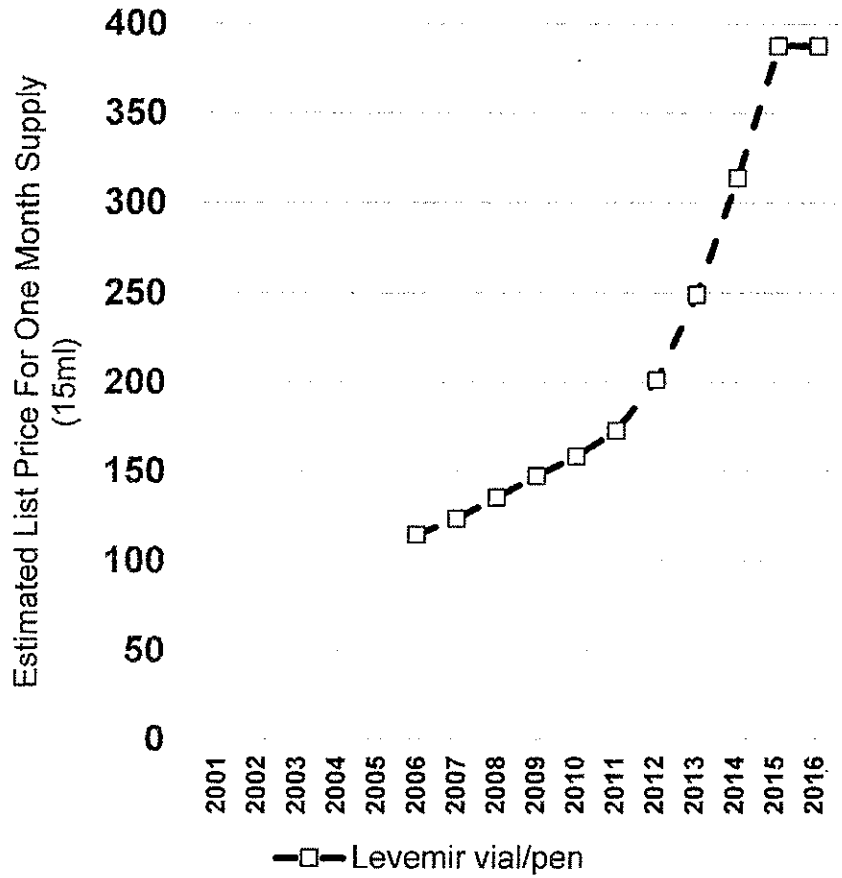




Source: Visante analysis of Medispan data.

Lantus and Levemir: Large Manufacturer List Price Increases

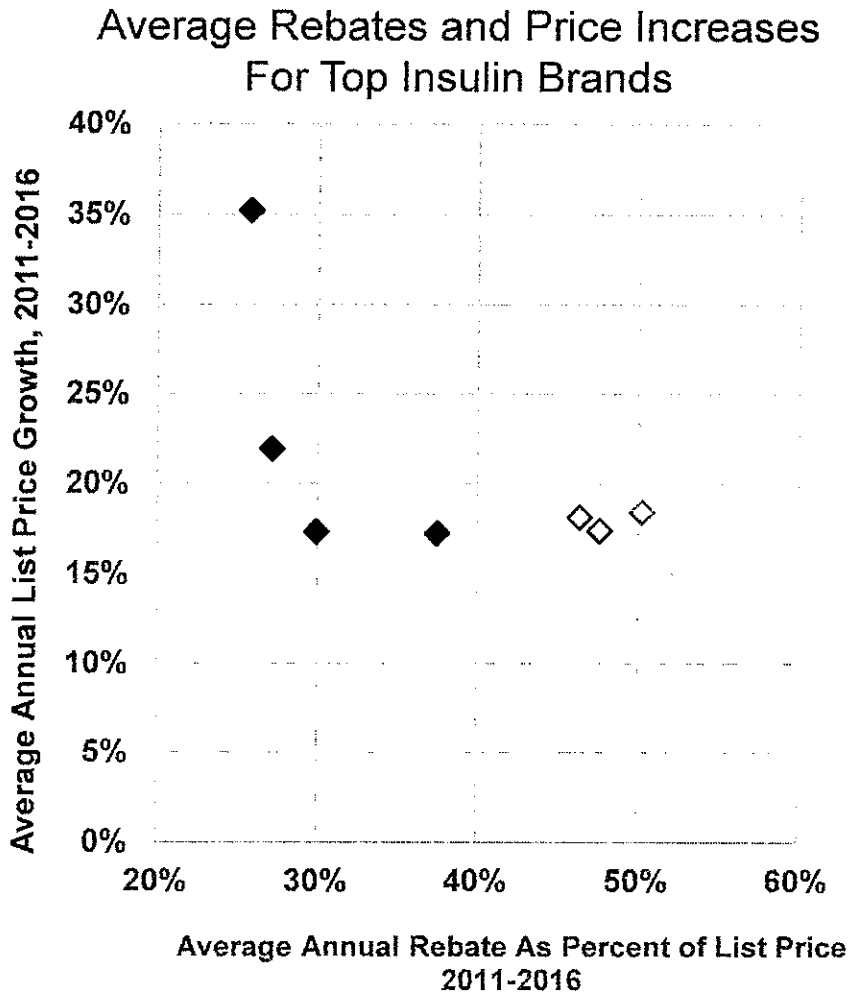




Source: Visante analysis of Medispan data.

Top Insulin Brands: No Correlation Between Rebates and Price Increases

- **Among insulin products ranked within the top 200 brand drugs by 2016 sales, there is no correlation between the growing prices set by drugmakers and the average rebate levels that they negotiate with PBMs.**
- Top Insulins with lower average rebates (in red) have actually had *higher* annual price growth during the 2011-2016 period.
- Top insulins with higher average rebates (in blue) have had only average price increases.
- A similar analysis across all top 200 drugs also shows no correlation between rebate levels and list price growth.*



** "Increasing Prices Set by Drugmakers Not Correlated with Rebates," Visante, 2017.*
Source: Visante estimates and analysis of SSR Health data, 2017.

Cost Driver: Manufacturers Raise Prices and Extend Patents by Delivering Product in Pens

Brand	Year Pen Launched	Estimated Monthly Price (15ml) In Year Pen Was Launched		Increased Price With Pen
		Vial	Pen	
Humulin	1999	$28	$55	96%
Humalog	2000	$44	$73	66%
Novolog	2001	$60	$75	25%
Levemir	2006	$100	$129	29%
Apidra	2009	$129	$166	29%
Lantus	2009	$139	$179	29%

Source: Visante analysis of Medispan data

Cost Driver: Manufacturers Develop New Brands that are Combinations of Older Drugs

- Pharmaceutical manufacturers have long used multi-drug combination products as an effective strategy to extend the life of older brand drugs.
- Two new insulin combination products launched in 2017:
  - Soliqua: A combination of insulin glarine and lixisenatide launched in January 2017.
  - Xultrophy: A combination of insulin degludec and liraglutide launched in May 2017.

Cost Driver: No Generic Insulins Have Been Available to Compete With Brands

- Unlike most other therapeutic classes, no generic insulins have been developed.
- Humulin and Novolin have been on the market since the 1980's. All other traditional drugs from the 1980's have gone generic long ago, and are now selling for pennies on the dollar.
- Tale of Two Diabetes Drugs:
    - Monthly prescriptions for two market leading diabetes drugs, Glucophage and Humulin/Novolin, each cost roughly the same amount in 2002: $50.
    - Glucophage was an oral diabetes drug that went generic in 2002, the generic rapidly gained more than 90% of the market, and the price for generic Glucophage (metformin) today is only $4 per prescription.
    - With no generics, the price for a monthly Humulin/Novolin prescription has increased to almost $300 today.

Access to Insulins: Formularies

Background on Formularies

- To create and manage formularies, payers and PBMs rely on panels of experts called Pharmacy and Therapeutics (P&T) Committees. These committees, made up of physicians, pharmacists, and other clinicians, evaluate clinical and medical literature to select the most appropriate medications for individual disease states and conditions.
- A number of cost-saving elements are then factored in, such as formulary tiers and step therapy, to encourage the most clinically appropriate and economically sound therapies. The effective use of formularies can minimize overall medical costs, improve patient access to more affordable care, and provide patients with an improved quality of life.

Specific to Insulins

- Generally accepted clinical guidelines for treatment of both type 1 and type 2 diabetes suggest when and how to use insulins, but do NOT favor one brand over another.
- P&T Committees for PBMs, health plans, hospitals and health systems have universally determined:
  - Humulin/Humalog and Novolin/Novolog are therapeutically equivalent and can compete for preferred status on formularies.
  - Likewise, long-acting insulins are therapeutically equivalent and can compete for preferred status on formularies.

TESTIMONY OF RAY LANDIS

ADVOCACY MANAGER

AARP PENNSYLVANIA

REGARDING PRESCRIPTION DRUG PRICING

BEFORE THE PENNSYLVANIA HOUSE DEMOCRATIC POLICY COMMITTEE

SEPTEMBER 11, 2019

HAVERTOWN, PENNSYLVANIA

Good afternoon and thank you for the opportunity to be here today. I am Ray Landis, Advocacy Manager at AARP Pennsylvania, representing the 1.8 million members of AARP in the Commonwealth

We're here today because Americans are struggling with rising prescription drug prices. That's why AARP, our friends at the Pennsylvania Health Access Network, patients, hospitals, regulators, and politicians are all raising their voices for change.

The bottom line is Americans pay more for brand name prescription drugs than individuals in other nations, and every year the prices keep rising at an astronomical pace, making it harder and sometimes impossible for families and those with limited income to afford the medicines they need.

How bad is the problem? The average annual cost of prescription drug treatments increased 58% between 2012 and 2017, while the annual income for Pennsylvanians only increased 10.4%. As a result, families are taking matters into their own hands, An AARP survey showed 23% of Pennsylvania residents stopped taking medication as prescribed due to the cost. Prescription drugs don't work if patients can't afford them.

That's why AARP in March launched a national campaign called Stop Rx Greed to persuade federal and state lawmakers to take action to curb soaring prescription drug prices.

The root cause of the problem is clear: the high prices of prescription drugs set by pharmaceutical companies when they first come on the market, which then increase faster than inflation year after year. In fact, the average drug price increase in the first six months of 2019 was 10.5% -- five times the rate of inflation.

It's time for all of us to take action. There are potential solutions. So far this year, 29 states have passed 47 new laws aimed at lowering prices for prescription medications. Pennsylvania needs to join that list.

We should remember that Pennsylvania has been a leader in helping our citizens get the medications they have needed to maintain their health. Our pharmaceutical assistance programs, PACE and PACENET, have been, and continue to be, the most comprehensive in the nation. Before the creation of Medicare Part D they provided the only way many older Pennsylvanians above income eligibility limits for Medicaid got any help with prescription drug costs and today they still aid hundreds of thousands. I would be remiss if I didn't mention the urgent need to continue to utilize lottery funding for PACE and PACENET and other programs that help Pennsylvanians remain at home and in their communities and stay off Medicaid. But the constant increases in the cost of prescription medications mean our lottery dollars aren't going as far as they could or should.

That brings me to our key recommendation in the effort to address high prescription drug costs – let's not to lose sight of the forest for the trees. For example, yes, we want to see drug prices reduced at the cash register for consumers. But we don't want insurance premiums for prescription drug coverage to skyrocket and become unaffordable for consumers as pharmaceutical companies attempt to rake in profits in a different way. We must tackle this

problem in a comprehensive manner and remember the root cause is that pharmaceutical companies are getting away with charging too much for their products.

We all need and value the products that pharmaceutical companies develop. But drug companies have gotten away with running up the prices of their medications for too long. It's time to Stop Rx Greed. And the time to act is now. We're currently working with the Pennsylvania Health Action Network to draw more attention to the high costs of prescription drugs in a series of town hall events we'll be holding across Pennsylvania this fall, which actually started yesterday. We're pleased the House Democratic Policy Committee is also focusing on the issue and we look forward to continuing to work with you to bring down the costs of prescription drugs for Pennsylvanians.

Pennsylvania Health Access Network
Stronger Voices for Better Health

Testimony on the Rising Cost of Prescription Drugs to the House Democratic Policy Committee

Given by Patrick Keenan, Director, Consumer Protections & Policy
September 11, 2019 in Havertown, PA

Good afternoon Representative Zabel and members of the committee. Thank you highlighting the very real problem that too many Pennsylvanians are unable to afford the medications they need. Our organization is on the frontlines of this crisis. Each year, we answer nearly 10,000 calls and regularly engage consumers from 61 of Pennsylvania's 67 counties. Over the past several years, we have noted an alarming trend that more and more people are sacrificing their savings, or not eating or heating their homes in order to pay for medications.

We were fortunate to partner with Altarum's Healthcare Value Hub, through the support of the Robert Wood Johnson Foundation, to conduct the first-ever Pennsylvania-specific survey of healthcare affordability late last year. We hope to repeat this survey in the near future. We captured data representing all Pennsylvania adults across insurance types and have been able to generate regional reports for five parts of the state. It comes as no surprise that half of Pennsylvania's adults have had a healthcare affordability burden in the last year. This means they struggled to pay bills, went uninsured due to high premium costs, or failed to get the care they needed due to costs. For a majority of Pennsylvanians, some part of our current system did not work for them in the past year, jeopardizing their health, financial stability, employability, or family life.

Prescription drug costs were a main driver of affordability burdens:

- 1 in 5 did not fill a prescription due to cost.
- 1 in 6 skipped doses or cut pills in half to save money.
- 2 in 3 are worried that the prescriptions they need will become unaffordable in the future.

The struggle to pay for prescription drugs and other healthcare costs has a real-world implication on our families and friends:

- 15% of Pennsylvania adults have been contacted by a collection agency in the last year
- 12% used up all or most of their savings.
- 10% were unable to pay for basic necessities like food, heat, or housing
- 7 to 8% either racked up large amounts of credit card debt or borrowed money

Given these numbers, it's no surprise that 9 out of 10 adults, across party lines, support a broad array of solutions. Specifically, on prescription drugs, with overall support at 90%, 88% of Republicans, 92% of Democrats, and 89% of Independents said the government should require drug companies to provide advance notice of price increases and justify those increase. Similarly, with overall support at 88%, 86% of Republicans, 91% of Democrats, and 86% of Independents said the government should set standard prices for drugs to make them affordable.

The report concludes with the following: "The high burden of healthcare affordability along with high levels of support for change suggest that elected leaders and other stakeholders need to make addressing this need a top priority." We urge you to take these matters seriously.

There are key steps that we can take now. We know that prescription drug prices are high and rapidly increasing, and that this is have devastating consequences on our residents. The fact is that we cannot answer why those prices are rising. Texas this year passed one of the most comprehensive transparency laws in the country. It joins states like California, Oregon, Maine, Nevada, Connecticut, and Louisiana that have similar measures. Transparency gives us critical information from the manufacturers of pharmaceuticals that allows us examine cost drivers and avoid speculation. It pulls back the curtain on questionable practices and abuse. Pennsylvanians deserve to know why their drugs cost so much, and this is analogous to what we already do in insurance, hospitals, and public utilities. Representative DeLuca has offered House Bill 568, which is currently in the Insurance Committee, to bring this commonsense approach to Pennsylvania.

Transparency answers a lot of questions, but does not lower prices. This year, we saw Maryland and Maine become the first states to pass Prescription Drug Affordability Boards, bodies of experts that review the available information on drug prices and determine whether or not certain drugs are creating affordability burdens. Eventually, after carefully considered processes are established, these boards are likely to have the ability to impose upper payment limits on purchasers of drugs, which would be the maximum amount an entity in that state would be allowed to pay for a drug subject to that limit. This would be the first real attempt to bring down the prices individuals eventually pay at the pharmacy counter. We are strongly optimistic that the precedent set in these states can be readily applied to other states as well.

There are other actions we could take. Pennsylvania could create an assessment on profits that exceed certain limits akin to the Medicaid Drug Rebate Program. It could examine importation. The key consideration here though is to ensure that whatever solution is pursued, it goes to the heart of the problem: the drug manufacturers themselves. Manufacturers have abused the public trust and need to be held accountable for many unexplained anomalies in their pricing. Regarding co-pay caps, it is critical to understand how premiums or other out-of-pocket costs would change, and what the totality of these implications would be for consumers. Solutions need to avoid creating more affordability burdens, and policy makers should examine how plans arrive at cost sharing structures. Let's be perfectly clear that the biggest driver of costs comes from the artificially high, unsubstantiated prices set by the drug manufacturers themselves that often abuse patent protections or use tactics like "greening" and "pay-for-delay" to convey near monopolistic power on them at the expense of consumers.

As you have heard before, prescription drugs don't work if people can't afford them. We appreciate the attention you bring to this issue. Thank you again for your time and look forward to your questions.

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My name is Audrey Farley, and I am the leader of the Pennsylvania chapter of #insulin4all, a group of volunteers dedicated to improving access to insulin. I am also the mother of a child with Type 1 diabetes and a historian who has extensively researched the commercial history of insulin.

I have firsthand knowledge of the impact of insulin and diabetes costs on families. When my daughter was first diagnosed (while we were living in Maryland), we paid more than $500 a month for medicine and supplies *with* insurance. Here in Pennsylvania, we pay nothing, thanks to the medical assistance program afforded to residents under 18 with a chronic condition. But I know the day will come when my child no longer qualifies for this assistance and that, if action isn't taken now, she may find herself among those who can't afford the medicine she needs to survive. Without insulin, my child would likely die within days.

As the leader of the #insulin4all chapter in Pennsylvania, I am routinely contacted by adults across the state who are desperate for insulin. They may be rationing until their next paycheck, perhaps because they had an expected cay payment that month. According to a Yale study, 1 in 4 diabetics have admitted to rationing insulin, which can lead to serious or even fatal complications. I have friends who have buried their children due to insulin rationing.

Often, critics, including policymakers, blame these individuals for their deaths, rather than finding ways to support them. Echoing the talking points of the drug industry, these critics say that diabetics should do one of three things: 1) just go the emergency room for insulin, 2) just go to Walmart for an older, cheaper version known as "human insulin," or 3) just call the manufacturer's patient assistance program.

None of these are solutions to the insulin crisis. An emergency room visit will leave someone with a bigger bill than insulin, with no promise of gaining the next vial. "Walmart insulin" or human does not work for all Type 1 diabetics. According to a class action lawsuit filed in the 1990s, five percent of diabetics experience severe low blood sugars, seizures, loss of consciousness, or even death while taking drug. (When it was initially released, human insulin was the eighth most reported drug for adverse reactions.) Patient assistance programs are difficult to qualify for, and they don't last forever. Eventually, beneficiaries will find themselves in the same dilemma: unable to afford life-sustaining insulin.

Drugmakers Eli Lilly, Novo Nordisk, and Sanofi like to point fingers at pharmacy benefit managers (PBMs) for the high price of insulin. While PBMs aren't innocent, manufacturers are primarily responsible for inflated prices; they only have colluded to fix insulin prices for nearly a century, since insulin's discovery. (The first anti-competitive lawsuit was brought against insulin manufacturers decades ago.) It is manufacturers that hold hostage an entire patient community for a drug that was discovered, not in Pharma labs, but in a public university, by a man who wanted it to be available to all in need.

For this reason, I believe legislative action should target insulin manufacturers, in addition to providing immediate relief to diabetics in need, especially the uninsured. State-level action might include drug price transparency legislation, allowing for the importation of insulin, or an anti-competitive lawsuit brought by the office of the Attorney General. To provide immediate relief to diabetics, lawmakers might consider expanding medical assistance to adult diabetics or subsidizing the cost of insulin for PA residents. It is time to take action to protect diabetics AND hold the drug industry accountable for its century-long abuse of this patient community.

Allison Hardt
Statement for September 11 hearing for rising drug costs

My partner Matthew was diagnosed with type 1 diabetes at the age of 7, in 1985. We are here today because the price of insulin has changed dramatically since that time. A few things about type 1 that have not changed: there is no cure for type 1 diabetes. There is no amount of dieting or exercise that can change having Type 1 diabetes. Anyone can get Type 1 diabetes, and many, like Matthew, are the first in their families to be diagnosed with it. Though most people are children when they are diagnosed, you can develop Type 1 diabetes later in life. Most importantly to today's conversation, the only way to stay alive as a Type 1 diabetic is to take insulin daily.

In 2015, Matthew went to our local CVS to pick up his insulin prescription. Earlier in the month, he had had a bad case of the flu. Despite getting the flu shot every year, he still gets it like clockwork every winter--being Type 1 means a weaker immune system than a healthy adult.

For those who don't know, illness is extremely disruptive to blood sugar levels and can cause extreme fluctuations that require doses of insulin well beyond what one might take during a typical day. For Matthew, a normal day means taking about 46 units, with a pen lasting about 5 days. During a bout with the flu, he can use nearly 100 units, meaning a pen will only last about 2 days.

When he went to CVS that day, Matthew's prescription was 2 days shy of being eligible for refill. The pharmacist informed him that because insurance would not cover it until 48 hours later, he would need to come back at that time. The other option was to pay the out-of-pocket cost for the 2 boxes of 5 pens each, for $750 each or $1500 total. With his insurance, the cost was $82 per month.

Matthew asked if there were any samples he could have, to get him through the 2 day period until his insulin would again be covered. The pharmacist said the only options were to talk to his doctor or go to the public health clinic run by the department of health, where he would have unknown wait times and could not be guaranteed they would provide insulin, let alone the type he was taking, since he had insurance. Matthew called his doctor's office but was unable to get through to his doctor--when he asked about samples, the doctor's office told him to ask the pharmacy.

To reiterate, he was insured, had his prescription, had a primary health care provider who was a specialist at Penn Medicine, and had been diagnosed as a Type 1 Diabetic since 1985, yet was unable to get his insulin due to the insurance company's rigid policy.

So, needing insulin and feeling desperate, Matthew turned to Craigslist. He search insulin, found a guy selling Novolog pens that his uncle no longer needed due to switching insulins, met him in a Wawa parking lot, gave him $20, and got the insulin he needed.

He took this risk because not all insulins are the same. He needed the insulin that his body was used to, that his doctor had prescribed. The type of insulin that a type 1 diabetic takes is determined by their doctor, and is different for each patient. Different insulins have different side effects and metabolizing times, and it is dangerous to switch insulins without consulting a doctor and monitoring closely. The insulin sold at Walmart for $25 is human insulin, while many diabetics have now switched to synthetic insulin, and these are not interchangeable because synthetic insulin has much more predictable rates of absorption. This was publicized widely earlier this summer by The Washington Post in the story of Josh Wilkerson, who aged off of his father's insurance and could no longer afford the synthetic insulin he had been taking. He tried to save money by using the $25 human insulin, but could not afford the test strips that would help him accurately monitor his blood sugar. He died after going into a diabetic coma less than a year after he lost his insurance coverage.

Our Wawa parking lot story is one of many stories from the past decade in which Matthew has taken extreme measures to secure insulin in the instance of shortfalls, despite having insurance and current prescriptions. These include getting insulin from an online pharmacies based in Turkey and India, and having French diabetic friends in Paris bring extra when they visit the US, all to maintain a small stockpile just in case he gets the flu, has his bag stolen (we live in Philly), experiences a highly stressful week, or any of the other myriad of reasons he might exceed their monthly prescribed doses.

For the majority of his time as a Type 1 diabetic, these measures were not necessary. For nearly two decades, if Matthew needed to supplement his monthly supply of insulin due to illness, extra stress, or any other of the myriad reasons prescribed amounts are not adequate, it was an additional $25-$40.

NovoLog, the type of insulin that Matthew currently takes, **increased** in list **price** by 353% from 2001 to 2016.

When he returned from teaching English in South Korea in 2004, just 15 years ago, and was without health insurance, Matthew paid $27 a vial for 3 vials of insulin, a total monthly cost of $82. This is less than what he pays today per month *with* his health insurance.

What I hope I have shown today is that even with the proper paperwork, the prescriptions, the insurance, it is still possible for type 1 diabetics to find themselves in life or death situations, faced with taking risks that unnecessarily compromise their health, all because drug companies have been allowed to profit off of this illness. For a type 1 diabetic, insulin is more vital to living than water--the average person can live without water for 3 days, but diabetic ketoacidosis, the inevitable result of missing insulin, is fatal within 24-48 hours. When Frederick Banting sold the patent for insulin to the University of Toronto for $1, he said it was because insulin was for the world. It is shameful that drug companies have been permitted to play with loopholes in the US patent system and effectively monopolize production for profit of a drug that is more vital than water for 1.25 million Americans. We must continue to address the root cause of this problem, the unnecessary inflation of insulin prices, as we move forward with legislation.