

# Diabetes Beyond Insulin: Successful State Strategies

Pennsylvania Representative Donna Oberlander,  
Women In Government State Director (Moderator)

George Huntley, Chief Executive Officer, Diabetes Leadership Council  
and Diabetes Patient Advocacy Coalition

Erika Emerson, Chief Policy Officer, Diabetes Leadership Council and  
Diabetes Patient Advocacy Coalition



*#AccessToHealthCare*



# Diabetes Beyond Insulin: Successful State Strategies

Women in Government  
Leadership & Innovation Summit Orlando  
November 18, 2022

# INTRODUCTIONS

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**GEORGE HUNTLEY**  
CHIEF EXECUTIVE OFFICER



**ERIKA EMERSON**  
CHIEF POLICY OFFICER

# PEOPLE WITH DIABETES, PARENTS & ALLIES



**Former leaders of national diabetes organizations provide policy expertise for lawmakers & advocates**

## NATIONAL LEADERSHIP & NETWORKS

- American Diabetes Association
- Association of Diabetes Care & Education Specialists
- Certification Board for Diabetes Care and Education
- Children with Diabetes
- Diabetes Dietetic Practice Group of the Academy of Nutrition and Dietetics
- Diabetes Patient Advocacy Coalition

## MEDICAL & SCIENTIFIC EXPERTS

- Diabetes Care & Education Specialists
  - Dietitian
  - Pharmacist
  - Registered Nurse & Dietitian
- Dietitian
- Internal Medicine & Diabetes Specialist
- Pediatric Endocrinologist
- Research Scientist and Professor of Molecular Physiology and Biophysics

# AGENDA

**DIABETES 101**

**RAPIDLY CHANGING LANDSCAPE**

**FACTORING FOR INFLATION**

**SUCCESSFUL STATE STRATEGIES**

**Q&A**



# DIABETES 101

40% OF AMERICANS ARE DIRECTLY IMPACTED BY DIABETES

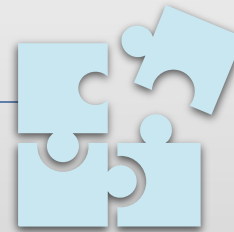
- 37 million **have diabetes**
- 96 million **have prediabetes**



Affects how the body converts food into energy



Recognized disability under federal ADA & IDEA laws

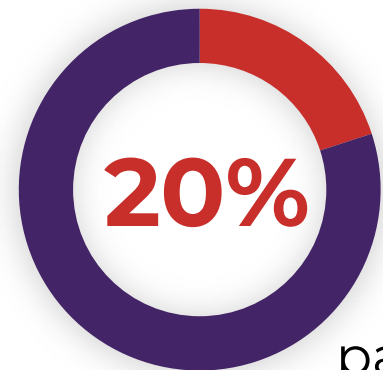
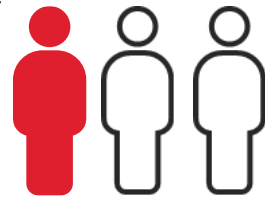


No cure (yet) but innovation is reshaping the diabetes management & prevention landscape

# INSULIN IS THE KEY

**INSULIN ACTS LIKE A “KEY” TO LET BLOOD SUGAR INTO THE CELLS TO USE FOR ENERGY**

**1 in 3** adults with diabetes require insulin daily



Of U.S. insulin prescriptions cost patients more than \$35

**5-10% TYPE 1**

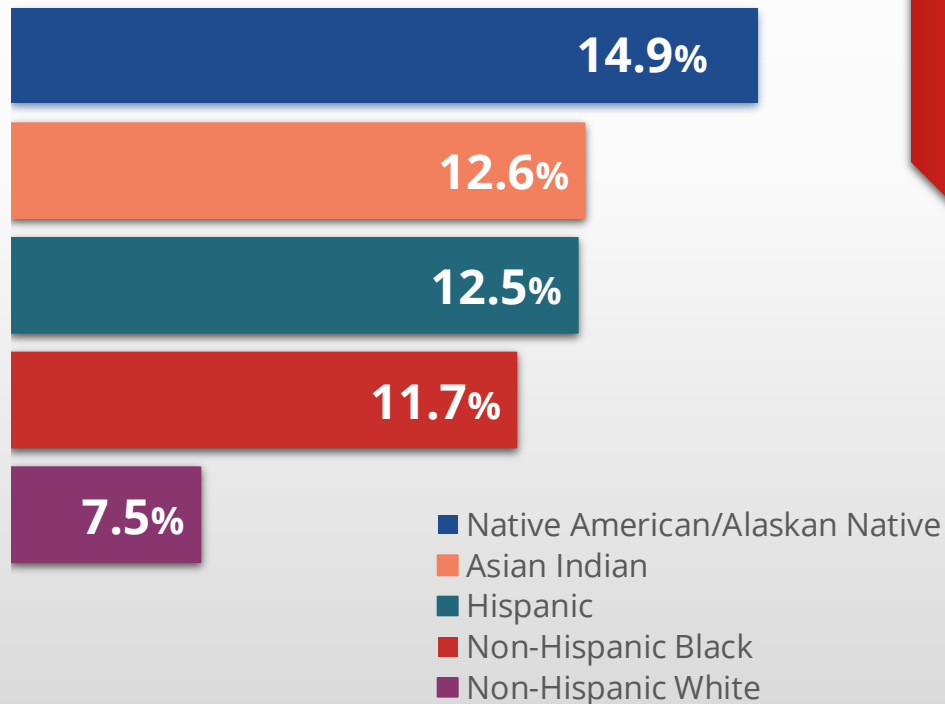
Autoimmune  
Can't produce insulin

**90-95% TYPE 2**

Metabolic  
Insulin deficient or resistant

# DIABETES DISPARITIES PERSIST

## PERCENTAGE OF DIAGNOSED DIABETES IN U.S. ADULTS BY RACE/ETHNICITY<sup>1</sup>



## PEOPLE OF COLOR WITH DIABETES ARE LESS LIKELY TO

- Be prescribed a CGM
- Be prescribed an insulin pump
- Receive education regarding newer diabetes technology
- Have access to newer diabetes technology (due to cost/coverage)
- Be prescribed newer types of insulin and glucagon medications

## AND MORE LIKELY TO

- Develop complications including damage to nerves, eyes and kidneys
- Be frequently hospitalized for severe high or low blood sugar levels
- Be hospitalized due to COVID-19 or die from it



# DIABETES ACCESS & AFFORDABILITY

## DIABETES REQUIRES MORE THAN INSULIN

- 24 hours a day
- 7 days a week
- 365 days a year

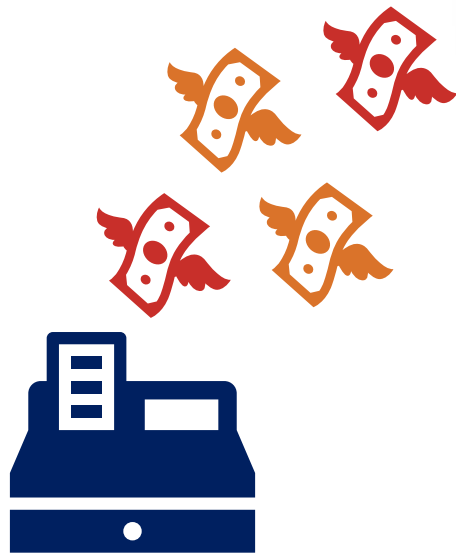
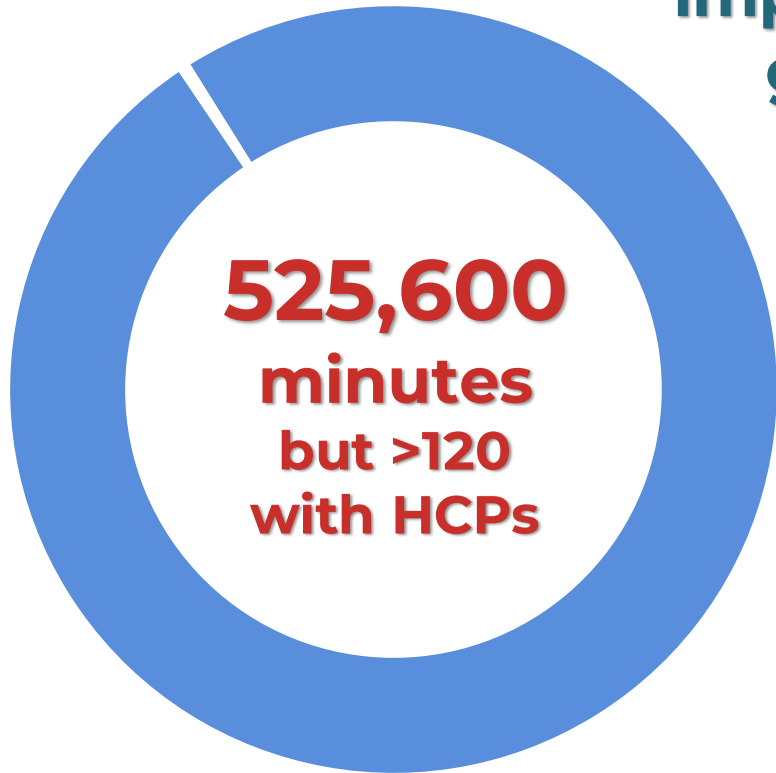







Image credit: Carter Clark for Beyond Type 1

# DIABETES IS NOT ONE-SIZE-FITS-ALL

## 42 FACTORS impact blood glucose



The 42 Factors graphic is used with permission from The diaTribe Foundation. To learn more go to [diaTribe.org/42FactorsExplained](https://diaTribe.org/42FactorsExplained)

FOOD 	BIOLOGICAL 
<ul style="list-style-type: none"> <li>↑↑ 1 Carbohydrate quantity</li> <li>→↑ 2 Carbohydrate type</li> <li>→↑ 3 Fat</li> <li>→↑ 4 Protein</li> <li>→↑ 5 Caffeine</li> <li>↓↑ 6 Alcohol</li> <li>↓↑ 7 Meal timing</li> <li>↑ 8 Dehydration</li> <li>? 9 Personal microbiome</li> </ul>	<ul style="list-style-type: none"> <li>↑ 20 Too little sleep</li> <li>↑ 21 Stress and illness</li> <li>↓ 22 Recent hypoglycemia</li> <li>→↑ 23 During-sleep blood sugars</li> <li>↑ 24 Dawn phenomenon</li> <li>↑ 25 Infusion set issues</li> <li>↑ 26 Scar tissue / lipodystrophy</li> <li>↓↓ 27 Intramuscular insulin delivery</li> <li>↑ 28 Allergies</li> <li>↑ 29 A higher BG level (glucotoxicity)</li> <li>↓↑ 30 Periods (menstruation)</li> <li>↑↑ 31 Puberty</li> <li>↓↑ 32 Celiac disease</li> <li>↑ 33 Smoking</li> </ul>
MEDICATION 	ENVIRONMENTAL 
<ul style="list-style-type: none"> <li>→↓ 10 Medication dose</li> <li>↓↑ 11 Medication timing</li> <li>↓↑ 12 Medication interactions</li> <li>↑↑ 13 Steroid administration</li> <li>↑ 14 Niacin (Vitamin B3)</li> </ul>	<ul style="list-style-type: none"> <li>↑ 34 Expired insulin</li> <li>↓↑ 35 Inaccurate BG reading</li> <li>↓↑ 36 Outside temperature</li> <li>↑ 37 Sunburn</li> <li>? 38 Altitude</li> </ul>
ACTIVITY 	BEHAVIOR & DECISIONS
<ul style="list-style-type: none"> <li>→↓ 15 Light exercise</li> <li>↓↑ 16 High-intensity &amp; moderate exercise</li> <li>→↓ 17 Level of fitness/training</li> <li>↓↑ 18 Time of day</li> <li>↓↑ 19 Food and insulin timing</li> </ul>	<ul style="list-style-type: none"> <li>↓ 39 More frequent BG checks</li> <li>↓↑ 40 Default options and choices</li> <li>↓↑ 41 Decision-making biases</li> <li>↓↑ 42 Family and social pressures</li> </ul>

*The arrows show the general effect these 42 factors seem to have on blood glucose based on scientific research and/or our experiences at diaTribe. However, not every individual will respond in the same way, so the best way to see how a factor affects you is through your own data: check your blood glucose more often with a meter or wear a CGM and look for patterns.*



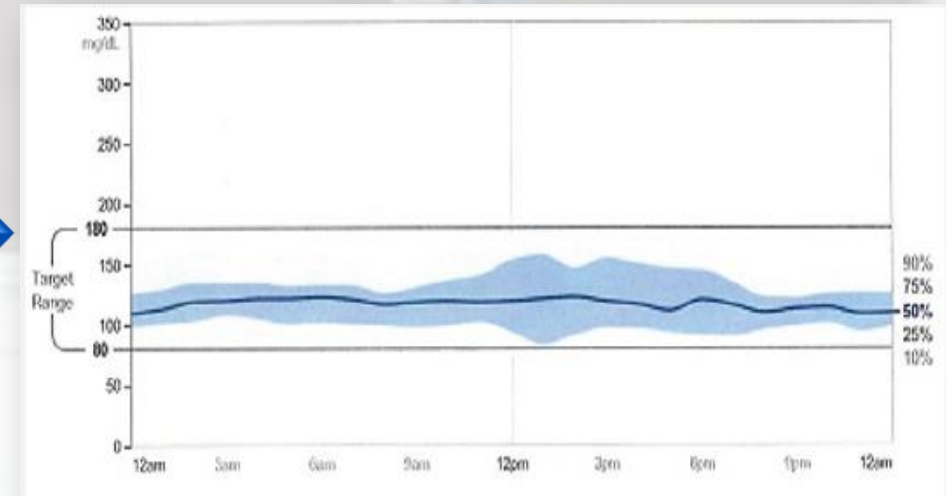
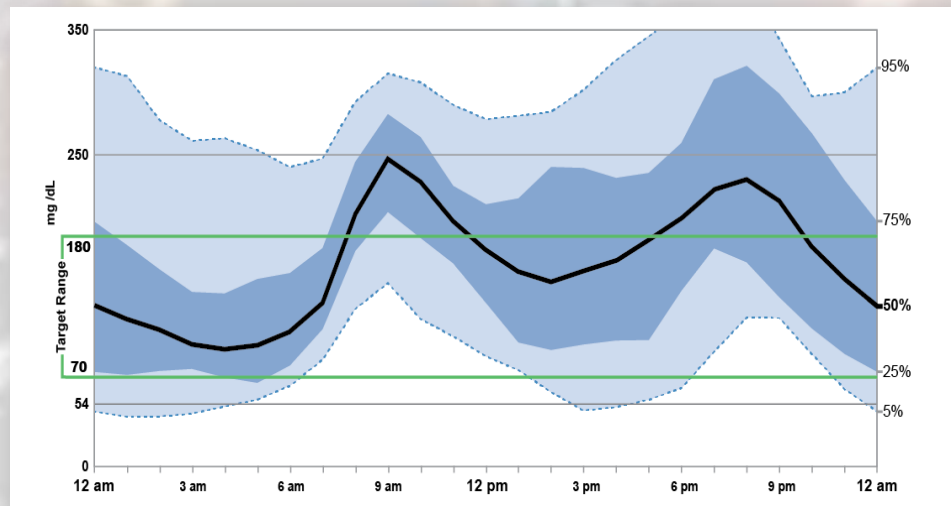
# RAPIDLY CHANGING LANDSCAPE

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# INNOVATION IS RESHAPING DIABETES CARE

STANDARDS OF CARE NOW AIM TO EQUIP PEOPLE WITH DIABETES WITH **TOOLS AND INFORMATION** NEEDED TO SUPPORT SELF-MANAGEMENT DECISIONS **IN REAL TIME**

*Outcomes improve when they have the right mix of medicines, devices, knowledge and skills to tightly manage blood sugar levels*



# CRITICAL DIABETES TECHNOLOGIES

Smart pens coming soon!

## GLUCOSE MONITORING



## INSULIN ADMINISTRATION



## CONNECTED INSULIN DELIVERY SYSTEMS



# NEW GLUCAGON RESCUE OPTIONS

FIRST THERE WAS



NOW THERE IS



**MORE OPTIONS FOR BETTER:**

- ✓ **Awareness**
- ✓ **Preparedness**
- ✓ **Emergency intervention**

# NEW OBESITY & T2 DIABETES TREATMENTS

Current obesity treatment coverage is largely limited to bariatric surgery. Newer medications offer less expensive and less invasive options<sup>1</sup>



**80-98% of dieters regain their lost weight<sup>2</sup>.** Medications and accompanying behavioral treatment may help address unmet medical needs for people wanting to avoid costly surgery and long-term complications of obesity and diabetes

1. Partnership to Advance Cardiovascular Health. [https://static1.squarespace.com/static/56e6efdb5559866c54beb696/t/60ccb8b8838f3b6afccd1d4a/1624029373909/PACH\\_Obesity\\_WhitePaper\\_June2021.pdf](https://static1.squarespace.com/static/56e6efdb5559866c54beb696/t/60ccb8b8838f3b6afccd1d4a/1624029373909/PACH_Obesity_WhitePaper_June2021.pdf)
2. Wing RR, Phelan S. Long-term weight loss maintenance. Am J Clin Nutr 2005;82(suppl):222S-5S. doi:10.1093/ajcn/82.1.222S

~\$35 CivicaRx insulins expected in 2024

# MORE INSULINS – MORE SAVINGS?

## FIRST THERE WAS




**\$275**

insulin lispro injection  
100 units/mL



**\$289**

insulin aspart injection 100 Units/mL



**\$284**

insulin glargine injection 100 Units/mL

## NOW THERE IS



**\$233**

insulin lispro  
injection 100 Units/mL



**\$82**


Insulin Lispro  
Injection



**\$145**

Insulin Aspart  
Injection

One 10 mL, multi-dose vial  
100 units/mL (U-100)  
Rx only




**\$73**

NovoLog<sup>®</sup>  
insulin aspart injection 100 Units/mL



**pens**

basaglar<sup>®</sup>  
(insulin glargine)  
injection  
100 Units/mL



**\$270**

Semglee<sup>®</sup>  
(insulin glargine-yfgn) injection  
100 units/mL (U-100)



**\$99**

Insulin Glargine  
(insulin glargine-yfgn) Injection  
100 units/mL (U-100)



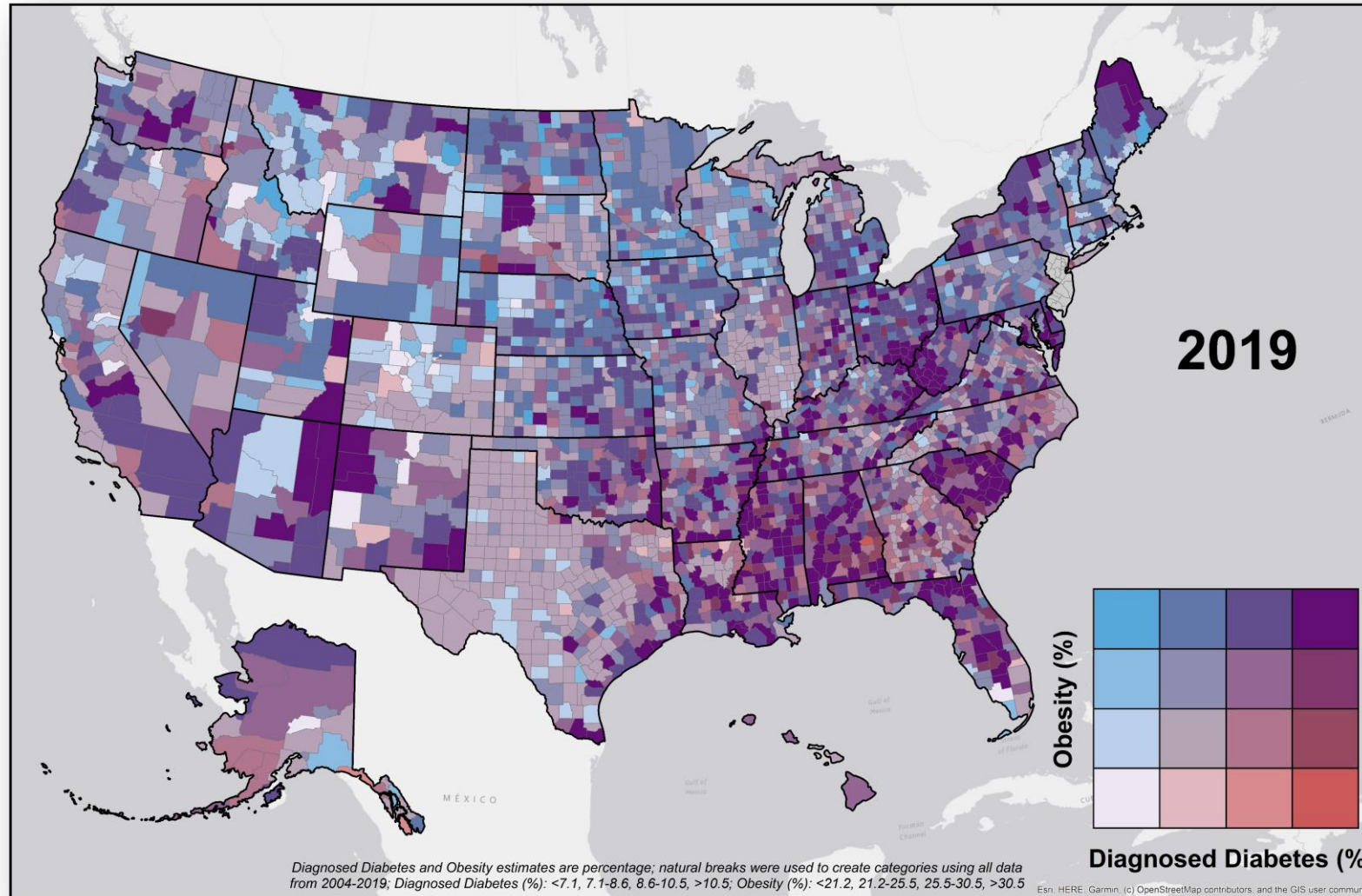


# FACTORING FOR INFLATION

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- Obesity & Diabetes
- Diabetes Costs
- Prescription Drug Rebates

# DIABETES & OBESITY EPIDEMIC



**42% of U.S. adults reported unwanted weight gain in the first year of the pandemic**

**29 pounds gained on average**

**10% gained more than 50 pounds**



# DIABETES STRAINS FAMILY BUDGETS

**2.3x higher** average annual health costs for a person with diabetes<sup>1</sup>



**\$7,151**  
WITHOUT  
DIABETES



**\$16,752**  
WITH  
DIABETES

*“Few, if any, chronic disease patients will spend as much money in your pharmacy as a person with diabetes”*

Average spend = **\$10,000** over a 3-4 year period

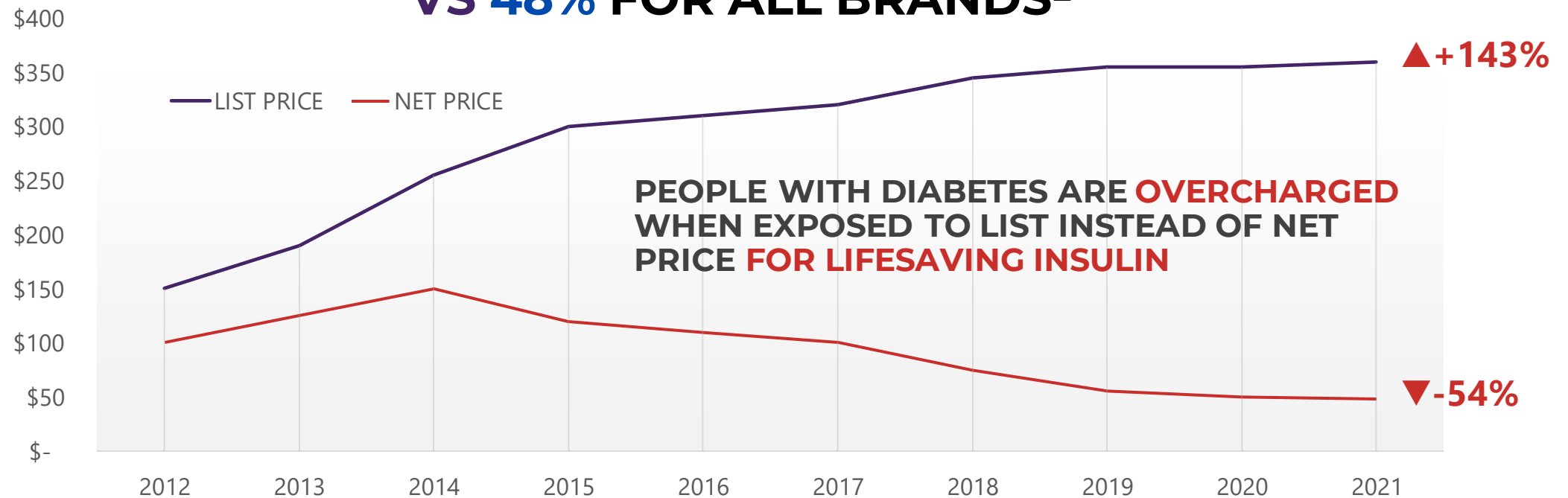
- Prescriptions
- Supplies
- OTC items
- Vaccinations

1. American Diabetes Association. <https://doi.org/10.2337/dci18-0007>

2. Meece J. Being the go-to pharmacy for diabetes care. Drug Store News, January 25, 2019. <https://www.drugstorenews.com/insights/being-the-go-to-pharmacy-for-diabetes-care/>.

# REBATE INFLATION ISN'T HELPING PATIENTS

## INSULIN REBATES CAN EXCEED 80%<sup>1</sup> VS 48% FOR ALL BRANDS<sup>2</sup>



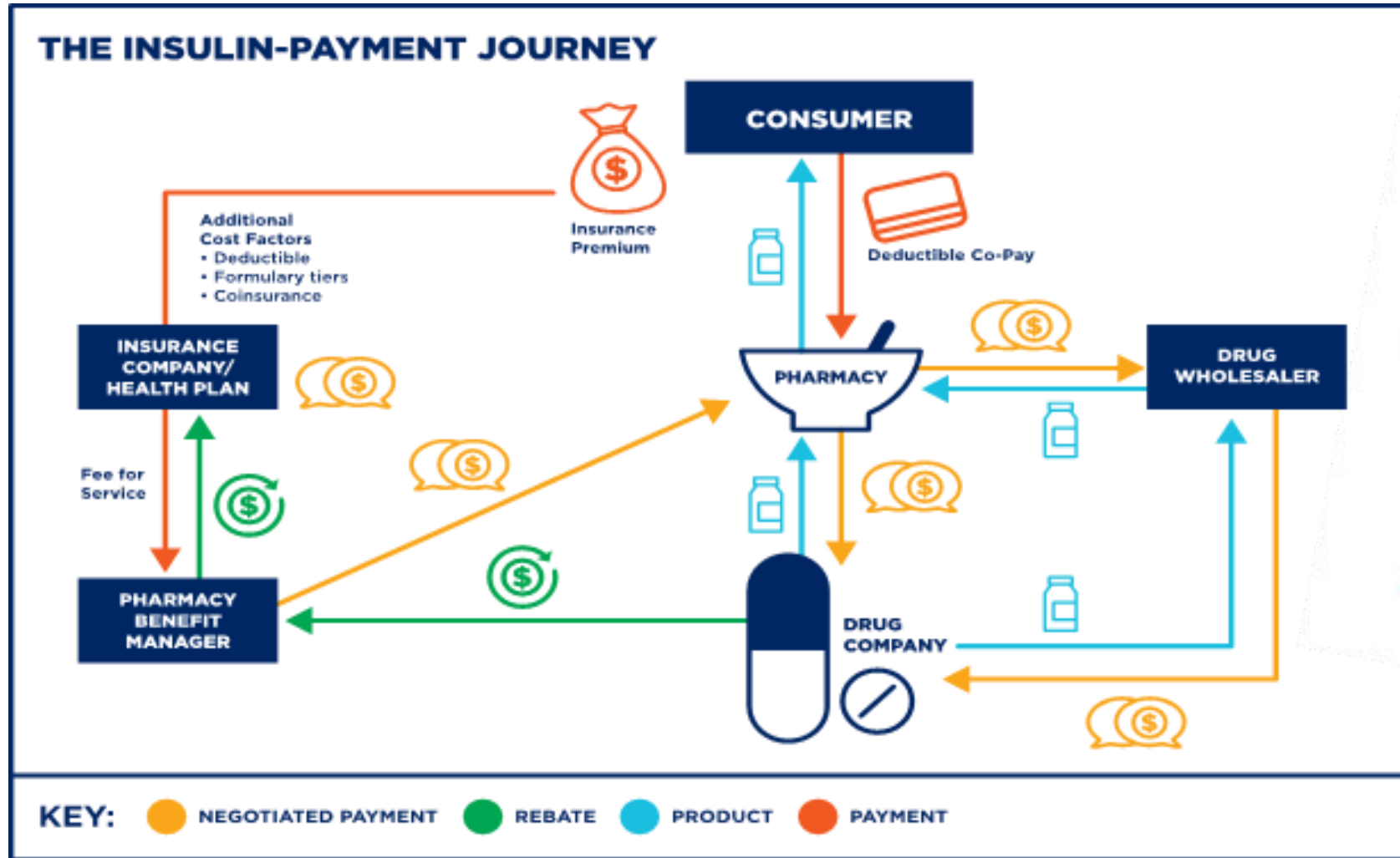
1. U.S. Senate Finance Committee on Finance. Insulin: examining the factors driving the rising cost of a century old drug. January 14, 2021.

[https://www.finance.senate.gov/imo/media/doc/Grassley-Wyden%20Insulin%20Report%20\(FINAL%201\).pdf](https://www.finance.senate.gov/imo/media/doc/Grassley-Wyden%20Insulin%20Report%20(FINAL%201).pdf).

2. Kakani P, Chernew M, Chandra A. Rebates in the pharmaceutical industry: evidence from medicines sold in retail pharmacies in the U.S. March 2020. NBER Working Paper 26846. <https://www.nber.org/papers/w26846>.

3. Sanofi 2021 Pricing Principles Report. March 3, 2021 <https://www.sanofi.us/en/pricing-principles-report>. Sanofi is a member of the DLC Industry Advisory Board.

# WHAT NEEDS TO CHANGE: A FLAWED SYSTEM



# STATE SUCCESS STORIES


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# STATE LEGISLATION SCORECARD

DIABETES  
PATIENT  
ADVOCACY  
COALITION

## STATE-SPECIFIC LOOK AT LEGISLATIVE PROGRESS ON DIABETES ACCESS & AFFORDABILITY

### OKLAHOMA LEGISLATION SCORECARD

- DIABETES ACTION PLAN
  - DIABETES CAUCUS
  - INSULIN COPAY CAP
  - DIABETES SUPPLIES COPAY CAP
  - COPAY ACCUMULATOR BAN
  - FIRST DOLLAR COVERAGE FOR DIABETES
  - REBATE PASS-THROUGH
  - ADULT MEDICAID COVERAGE FOR CGMS
  - CHILD MEDICAID COVERAGE FOR CGMS
  - EMERGENCY ACCESS TO INSULIN (KEVIN'S LAW)
- 

### NEW YORK LEGISLATION SCORECARD

- DIABETES ACTION PLAN
  - DIABETES CAUCUS
  - COPAY ACCUMULATOR BAN
  - INSULIN COPAY CAP
  - DIABETES SUPPLIES COPAY CAP
  - REBATE PASS-THROUGH
  - ADULT MEDICAID COVERAGE FOR CGMS
  - CHILD MEDICAID COVERAGE FOR CGMS
  - FIRST DOLLAR COVERAGE FOR DIABETES
  - EMERGENCY ACCESS TO INSULIN (KEVIN'S LAW)
- 

# SUCCESS FACTORS: PATIENT ASSISTANCE

## NAVIGATORS & HOLISTIC HELP

### AVOID PATIENT COST BARRIERS

- No cost to access program
- No cost for donated products
- No “spread” on discounted products

### BROAD, EQUITABLE ELIGIBILITY

### STAKEHOLDER ENGAGEMENT

**STATE HEALTH SOLUTIONS**

### Person-Centered Prescription Assistance

ADDRESS SYMPTOMS & UNDERLYING CAUSES

States are stepping up with novel approaches to improve prescription drug access. Effective prescription assistance programs center on people rather than product. They help people with chronic conditions like diabetes access needed medications, medical devices and supplies, then connect with other supports to meet their unique needs and circumstances.

- 1 NAVIGATORS PROVIDE HOLISTIC HELP**  
People who struggle with prescription costs are likely experiencing other hardships. Trained program navigators help to identify and address unmet needs, including prescription assistance.
- 2 BRIDGE RESOURCE GAPS**  
Raise awareness and utilization of existing public and private assistance sources. Connect people and programs, then fill gaps rather than duplicate efforts.
- 3 AVOID PATIENT COST BARRIERS**  
People already struggling with prescription costs should not be asked to pay for assistance program access or donated products, or pay a mark-up or spread on discounted products.
- 4 HAVE BROAD, EQUITABLE ELIGIBILITY**  
Avoid ID requirements and eligibility criteria that may disproportionately exclude people of color, low wage earners, disabled individuals and other underserved communities.
- 5 APPROPRIATE ADEQUATE STATE FUNDS**  
Omitting critical program elements to avoid a fiscal note undermines reach and utilization. New programs require funding to support public awareness campaigns, navigator training and support, and impact reporting.
- 6 ENGAGE COMMUNITY STAKEHOLDERS**  
Each state's health care and community service ecosystem is unique. Engage medical societies, charity clinics, non-profit organizations, faith communities and other stakeholders to help develop and implement statewide solutions.
- 7 IDENTIFY THE RIGHT PROGRAM ADMINISTRATOR**  
New programs need a "home" in the right state department or agency to be successful. What works in one state may not work in another. Identify the agency with resources and expertise to provide person-centered assistance.

**DIABETES LEADERSHIP COUNCIL** [LEARN MORE](https://diabetesleadership.org)  
Visit [diabetesleadership.org](https://diabetesleadership.org)  
or email [contact@diabetesleadership.org](mailto:contact@diabetesleadership.org)

### BRIDGE RESOURCE GAPS

- Leverage existing public and private resources
- Avoid program duplication

### ADEQUATE APPROPRIATIONS

- Public awareness
- Navigator training and support
- Impact reporting

### EXPERIENCED PROGRAM ADMINISTRATION





# KENTUCKY PATIENT ASSISTANCE PROGRAM

NAVIGATORS & HOLISTIC HELP



AVOID PATIENT COST BARRIERS

BRIDGE RESOURCE GAPS



BROAD, EQUITABLE ELIGIBILITY

ADEQUATE APPROPRIATIONS



STAKEHOLDER ENGAGEMENT

EXPERIENCED PROGRAM ADMINISTRATION



STATE HEALTH SOLUTIONS

## Kentucky Prescription Assistance Program

KPAP: THE SMALL PROGRAM WITH A BIG IMPACT

**SPOTLIGHT:** Prescription Drug Affordability  
**SOLUTION:** Enable and expand community-based efforts to enroll eligible Kentuckians in prescription assistance programs

**LEGISLATIVE LEGACY**

- Introduced by Jimmie Lee, Kentucky Representative and chair of the Appropriations and Revenue Committee
- Cabinet for Health and Family Services annual line item of \$600K
- Bipartisan support from both chambers and every Kentucky governor since the program launched in 2009

**RECIPE FOR SUCCESS**

- Expand local capacity without duplicating efforts
- Partner with individuals and organizations already active in underserved communities, including county health departments, hospitals, food pantries and faith-based organizations

**HOW IT WORKS**

- KPAP supports a statewide toll-free hotline and licenses software that identifies free or reduced cost prescription programs offered by manufacturers, retailers and other sponsors
- Callers are connected with a local KPAP volunteer advocate
- KPAP's trained advocates serve as navigators, helping Kentuckians enroll in prescription assistance and find other needed support
- The service is free to patients
- Read all about KPAP at: <https://chfs.ky.gov/agencies/dph/dpqi/hcab/Pages/kpap.aspx>

**ANNUAL SUCCESS METRICS**

- \$43 million** in free or reduced cost prescriptions
- 70x** return on the state's investment
- 3700** people assisted
- 200** KPAP trained advocates serving all 120 counties

**DIABETES LEADERSHIP COUNCIL**

**LEARN MORE**  
Visit [diabetesleadership.org](http://diabetesleadership.org) for model bills and other tools for legislators and health advocates



# STATES CAN HELP CLEAN UP THIS MESS



# HOW INSURANCE USUALLY WORKS

List Price

Negotiated plan discount

Patient share before meeting deductible

## Summary of a claim for services on January 6, 2022

for services provided by QUEST DIAGNOSTICS INC.

Amount Billed	\$775.09	This was the amount that was billed for your visit on 01/06/2022.
Discount	\$688.54	<b>You saved \$688.54.</b> Your plan negotiates discounts with health care professionals and facilities to help you save money.
What my plan paid	\$0.00	Your plan did not pay any of the amounts billed. This could be because you haven't met your deductible yet or your plan doesn't cover the services you received.
What I Owe	\$86.55	This is the amount you owe after your discount, what your plan paid, and what your accounts paid. People usually owe because they may have a deductible, have to pay a percentage of the covered amount, or for care not covered by their plan. Any amount you paid when you received care may reduce the amount you owe.
You saved	<b>89%</b>	You saved \$688.54 (or 89%) off the total amount billed. This is a total of your discount and what your plan paid. To maximize your savings, visit <a href="#">questdiagnostics.com</a> or call customer service to estimate treatment costs, or to compare cost and quality of in-network health care professionals and facilities.

# HOW PRESCRIPTION COVERAGE WORKS\*

Patient share before meeting deductible

Someone else keeps this

*"Pharmaceuticals are the only part of the U.S. health care system in which the difference between list and net prices is monetized as rebates and redistributed to intermediaries"*

Adam Fein  
Drug Channels Institute

Summary of a claim for services on January 6, 2022

for services provided by **THE PHARMACY WE OWN AND MAKE YOU USE**

Amount Billed      \$775.09      **A NUMBER WE CAN MAKE UP**

Discount              \$688.54      **ANOTHER NUMBER WE CAN MAKE UP**

What my plan paid      \$0.00

What I Owe              **\$775.09**

You saved



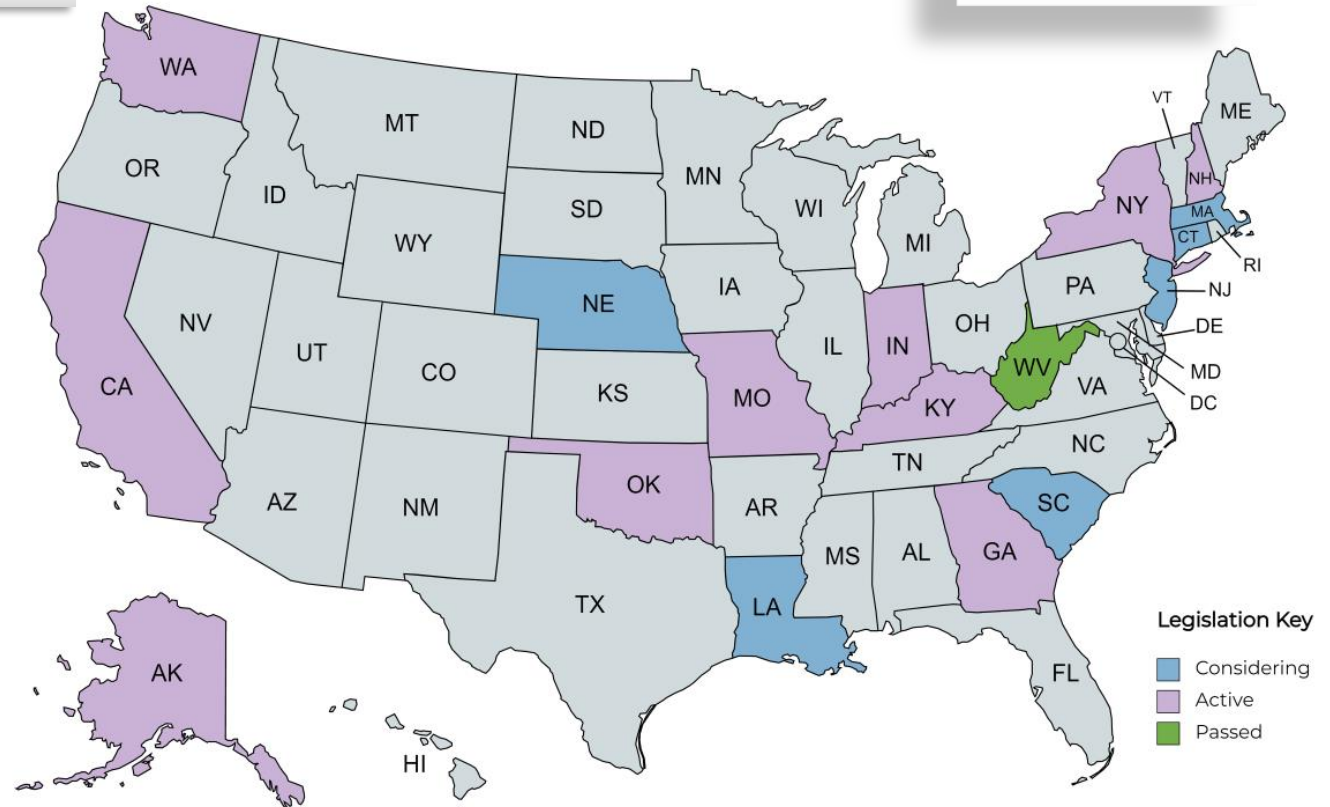
**\* WITHOUT REBATE PASS-THROUGH (i.e., parity with other plan discount sharing)**

# 2022 REBATE REFORM LANDSCAPE



## REBATE PASS THROUGH

- WV became the first state to require a rebate pass through in 2021
- Included in the 2021 CSG Shared State Legislation docket (Health, 08-42-01)
- 15 states introduced rebate pass through bills in 2021
- Several other states have expressed interest. Member organizations in the **Patient Pocket Protector Coalition (PPPC)** are urging bill sponsorship



As of June 1, 2021



# PPPC MEMBER ORGANIZATIONS



COLLEGE  
DIABETES  
NETWORK



on your own but not alone™



Association  
of Women in  
Rheumatology



**NAMI**  
National Alliance on Mental Illness

Oklahoma



Children with Diabetes®  
[www.childrenwithdiabetes.com](http://www.childrenwithdiabetes.com)

## Supporting Organizations

American Diabetes Association  
Arthritis Foundation  
PBM Accountability Project  
Patients Rising

AIDS-CT  
Alliance for Transparent and Affordable Prescriptions  
Lower Out of Pocket Costs Coalition

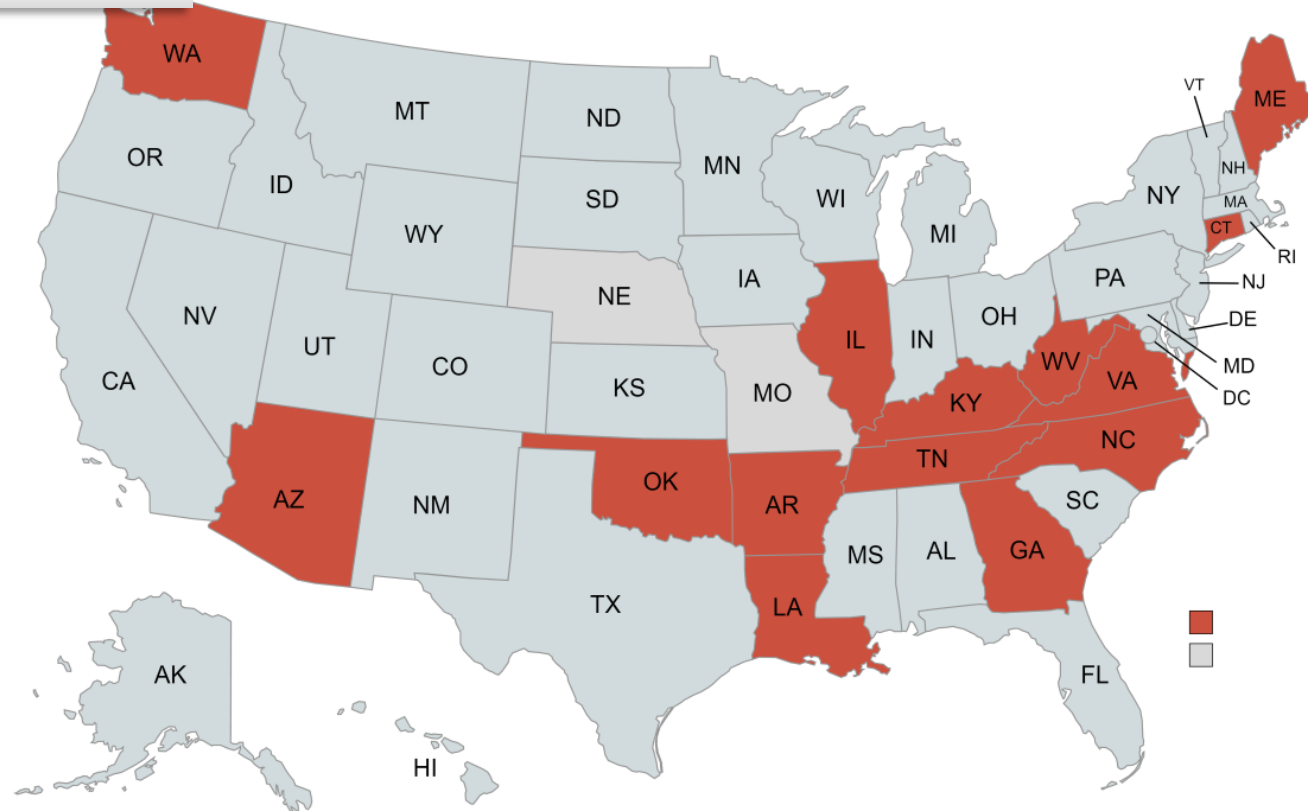


# ELIMINATE THE 'COPAY SURPRISE'



## COPAY ACCUMULATOR BAN

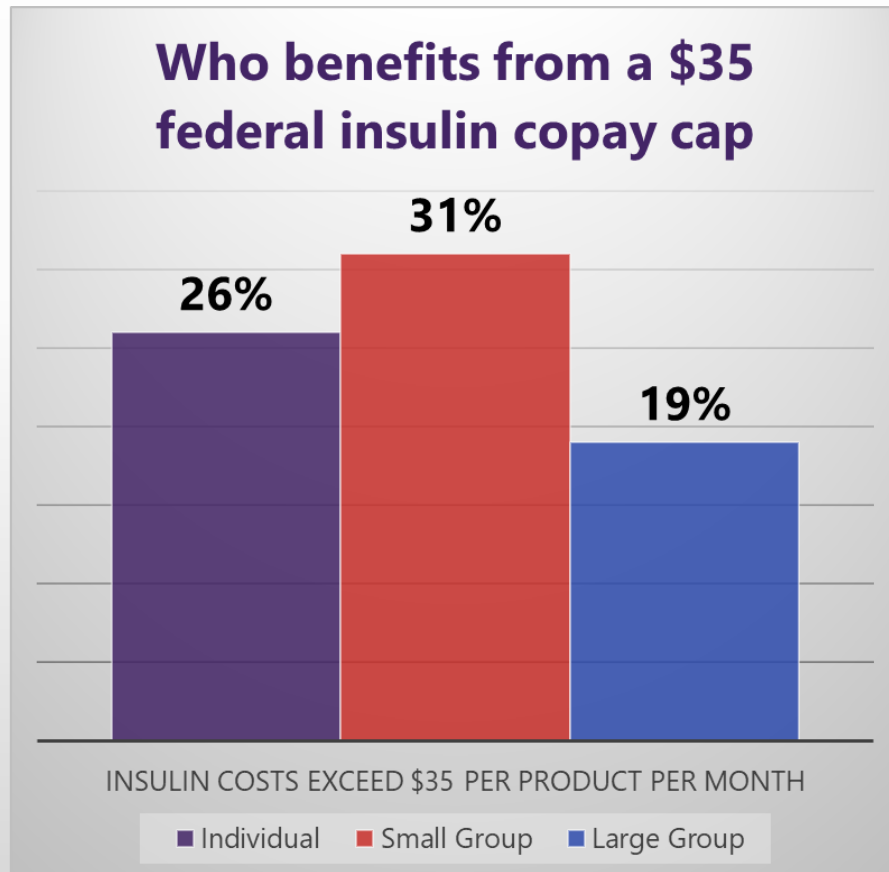
- Reduce consumers' drug costs by requiring health plans to count **all payments made by or on behalf of patients** toward annual cost sharing requirements
- 14 states have enacted bans to date
- Bipartisan bicameral Help Ensure Lower Patient (HELP) Copays Act introduced in 2021
- DLC, DPAC & HIV+Hepatitis Policy Institute litigation ongoing



# COPAY CAPS ARE VITAL PIECES OF THE PUZZLE

## ✓ INSULIN & SUPPLY CAPS

**20+ states** now have \$25-\$100 monthly insulin caps in place  
**2 states** (CT & DE) have caps on diabetes supplies



## HIGHEST RATIONING RISK





# EMERGENCY INSULIN: KEVIN'S LAW



## EMERGENCY DISPENSING



- Allows a pharmacist to dispense emergency insulin supply under a lapsed prescription when the prescriber can't be reached
- Named after Kevin Houdeshell of Ohio
- Passed in 18 states so far but others may allow emergency dispensing
- Variables include:
  - Medications included (insulin, others)
  - Supply dispensed (30-day for insulin)
  - Who pays for the emergency supply
  - Annual usage limits
  - Referrals provided



**THANK YOU**

[contact@diabetesleadership.org](mailto:contact@diabetesleadership.org)

[diabetesleadership.org](http://diabetesleadership.org)