



**PATIENT ACCESS**  
*for a*  
**HEALTHY TEXAS**

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*Working together for a healthy Texas*

**ADVOCATE TOOLKIT**

86<sup>th</sup> Texas Legislature  
2019

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Welcome!

## PATIENTS NEED THE RIGHT MEDICINE AT THE RIGHT TIME AND THE RIGHT PRICE

With strong bipartisan support, Texas legislators have passed laws over the past 15 years to protect some of our state's most vulnerable Texans by ensuring they have access to the medicine their doctor determines is best for their care and well-being. The Patient Access for a Healthy Texas coalition – comprised of patient advocates, health care professionals, business organizations, and Texans like you – is dedicated to preserving these protections and breaking down the barriers that continue to delay patients from obtaining their prescriptions and treatments in a reasonable and affordable way.

In our latest survey, we heard your concerns and have focused our advocacy efforts for the 86<sup>th</sup> Legislature on reducing the cost of prescription drugs and ensuring that pharmacy benefit managers (PBMs) “share the savings” with consumers. Patients have watched in frustration as necessary medications continue to skyrocket in price, and even with health insurance, these barriers to entry reduce access to many of the most medically necessary treatments that Texans rely on to manage their conditions.

Consider the statistics. Health insurers are shifting costs onto the patient through deductibles, increased use of coinsurance, and extra tiers of prescription drugs, even as rebates and discounts to entities like health insurance companies average 40 percent of the list price of medicines (and totaled \$150 billion in 2017 alone). PBMs negotiate some of these savings, but patients are the ones left on the hook for them.

**In 2019, patient and health care groups are joining together to urge Texas lawmakers to defend patient protections, establish transparency that allows patients to “follow the money,” and put the money that PBMs save back into patients’ pockets. The inability to pay for important medication can be life-altering – if not life-threatening – and vulnerable patients deserve peace of mind knowing that they’re getting the savings they were promised.**



## ABOUT THE ISSUES

### PHARMACY BENEFIT MANAGERS

A pharmacy benefit manager (PBM) acts as a third-party administrator between insured patients and their health plans, and they are, at the most basic level, responsible for processing prescription drug benefits. PBMs retain a percentage of the fees paid for prescription drugs, and from the creation of the first PBM in 1968 through today, their role in the healthcare marketplace has greatly expanded from their original purpose as a transaction manager.

PBMs argue that they play a vital part in ensuring that prescription drug costs remain low for insured patients. Because PBMs now handle the vast majority of health plans for consumers (with the three largest PBMs covering 78% of the market, or 180 million enrollees), they wield outsize influence with drug companies by maintaining **formularies** (a list of prescription drugs approved for reimbursement by a particular PBM) through which the PBM can negotiate rebates, threaten to drop certain medications from their formulary, and otherwise regulate the prescribing behaviors of physicians and the ability of consumers to obtain certain prescription medications.

### THE PROBLEM

Whether patients save any money at all through PBMs is in serious doubt. Consumer savings are often considered “trade secrets” and therefore aren’t disclosed to the public, and studies have determined that the prices of many drugs – including cancer medication and the top 20 most prescribed Medicare Part D program drugs – have continued to increase in price faster than the general inflation rate. Some large employers, like Coca-Cola and Amazon, have begun breaking ties with PBMs over “existing marketplace practices that are costly, wasteful, and inefficient.”

These marketplace practices result in profit for the PBM at the expense of the patient through methods such as:

- Markups on the list price – the PBM pays a lower price to the pharmaceutical company for a medication but charges health insurance companies a higher price



than the PBM paid, the costs of which are often shifted to the patient through higher deductibles and coinsurance;

- Charging fees to pharmaceutical companies to list their products on a “preferred” formulary, thereby directly influencing which drugs patients on a particular health insurance plan are most likely to be able to afford;
- Requiring patients to order their drugs through a mail order pharmacy (generally through a “mandate” to health insurance companies) that is maintained by the PBM, promising savings that are oversold or nonexistent.

**As a result, patients are left carrying the burden of higher insurance rates, higher drug costs, and savings that never materialize. Insurers should share more of these rebates with patients. Providing more information and access to discounted prices at the point-of-sale could dramatically lower patients’ out-of-pocket costs and increase access to important medications for patients.**

Be wary of bills that claim to bring transparency to the system without including meaningful reforms or useful information. We will be monitoring any introduced legislation to ensure that patients receive the tools and empowerment they deserve to take control of their healthcare decisions. As we continue through the legislative session, please use this toolkit and other resources provided on the Patient Access for a Healthy Texas website to help educate legislators, staff, and other advocates about the need for all Texans to be able to access the right medications at the right time.



## SAMPLE TESTIMONIAL

### Tim Revell & Family

#### Leander, TX

- “When you consider that the expected lifespan of a child with Duchenne is 20 to 25 years, days are like years for us. We’ve got enough roadblocks in our life, so having to mess around with struggling to get the right medicines approved is not something we enjoy or have time for.”



#### Their Story

Tim and Laura Revell’s precious boys both have Duchenne muscular dystrophy, the most common form of this genetic disorder, which causes progressive muscle degeneration and weakness. Twelve-year-old Timothy Revell was diagnosed with Duchenne on his second birthday. Coincidentally, Timothy’s younger brother, nine-year-old Andrew, was diagnosed on his fifth birthday. The boys’ medicines include human growth hormone (HGH), as well as common drugs for osteoporosis, high blood pressure, ace inhibitors, and other heart medications. The process for purchasing their medicines is complex and can be frustrating.

As a self-proclaimed ‘Dad advocate’ who volunteers with CureDuchenne and who refuses to take no for an answer when it comes to his boys, Tim believes that in his family’s case, time is life. The average lifespan of someone who has Duchenne muscular dystrophy is typically 20 to 25 years.

The Revells have to go out of state – to Ohio – for their sons’ primary care. In order to use Medicaid to obtain the HGH they need – which their Ohio-based endocrinologist prescribed – prior authorization has to come through an approved Texas pediatrician. So, Tim must first find an appropriate local pediatrician, who must then fill out the prior authorization paperwork and jump through all the hoops to get the HGH covered.

Despite these many challenges, Tim continues to work hard to provide a normal upbringing for his sons. He strongly believes that it should be painless and affordable to obtain life-saving prescriptions and works tirelessly to tear down the barriers to his children’s care – and to the care of millions of Texans.



## SOCIAL MEDIA CHEAT SHEET

Social media is one of the most effective tools in telling your story. Use this cheat sheet as you post on social media, share your thoughts, and repost important information that all advocates should see when talking about access to prescription medications for all Texans.

### SAMPLE POSTS

“I have joined a coalition of everyday Texans, patient advocates, health care professionals, and business organizations committed to public policy that ensures access to prescription medications and healthcare treatments for all Texans. Join us! @PatientAccessTX #txlege”

“Share this post if you agree all Texans should have access to all of their medications. I am a partner with @PatientAccessTX to ensure this fundamental right is preserved. #txlege #patientaccess”

### HASHTAGS

#PatientAccessTX  
#patientaccess  
#txlege  
#texasHHSC  
#patientadvocate

### FOLLOW US

Facebook: [facebook.com/TxPatientSafety](https://facebook.com/TxPatientSafety)

Twitter: [@PatientAccessTX](https://twitter.com/PatientAccessTX)

YouTube: [YouTube.com/PatientAccessTX](https://YouTube.com/PatientAccessTX)

If you are planning any social media activities, including blog posts about patient access issues, please let us know. Please feel free to contact Taylor Ward at (512) 236-1001 or [taylor@jhlcompany.com](mailto:taylor@jhlcompany.com) with any questions.



## WAYS TO ENGAGE

Patient Access for a Healthy Texas champions are critical to raising awareness about the need for ensuring patient access in Texas and there are many ways you can help spread the word. Please let us know how you'd like to help.

- Provide a written testimonial
- Testify at legislative committee meetings
- Attend in-person meetings with legislators
- Send emails to legislators
- Make phone calls to legislators
- Participate in Patient Access for a Healthy Texas events
- Support Patient Access for a Healthy Texas on digital media
- Become a Patient Access for a Healthy Texas spokesperson
- Submit an opinion editorial or letter to the editor about Patient Access for a Healthy Texas to your local newspaper

Are there other ways you'd like to promote Patient Access for a Healthy Texas that aren't listed?

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Name: \_\_\_\_\_

Email: \_\_\_\_\_

Phone: \_\_\_\_\_

Address: \_\_\_\_\_

Please fill out the form and return to Taylor Ward at [taylor@jhlcompany.com](mailto:taylor@jhlcompany.com). For questions please call (512) 236-1001.

We look forward to working with you throughout this campaign and thank you again for your commitment to ensuring patient access in Texas by sharing news about Patient Access for a Healthy Texas with those in your community.



## SHARE YOUR STORY

Patient Access for a Healthy Texas champions are critical to raising awareness about the need for ensuring patient access in Texas. If you have had an experience with patient access issues in Texas and would like to share your story with us, please use the form below.

Name: \_\_\_\_\_

Email: \_\_\_\_\_

Phone: \_\_\_\_\_

Address: \_\_\_\_\_

Circle One: Patient Physician Caretaker Other: \_\_\_\_\_

Please tell us about your experience with patient access issues in Texas.

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