

Amplifying Patient Voices in Market Access:

Insights from DKI Health's Patient and
Caregiver Advisory Roundtable



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It sounds obvious: patients should have power in choosing treatments that are best for them. But in reality, they face opaque prescription drug prices and a payment system seemingly designed to confuse rather than cover them.

DKI Health met with our Patient and Caregiver Advisory Council to learn from their experiences and their ideas for how patients' voices can be heard in drug pricing, reimbursement, and market access.

PAYER RESTRICTIONS IMPACT PATIENTS' WELL-BEING

Payers in the United States (including health insurance companies and government agencies) use numerous tools to restrict patient access to medicines. Such “utilization management” measures can burden healthcare providers, impact patient care, and result in negative patient outcomes. These include:

- **Prior Authorization** requires providers to justify their prescription or patient treatment before it is covered. This often involves significant paperwork, lab tests, or other proof of need—and creates more work for already overwhelmed provider offices.¹

For example, among patients who were prescribed a class of medicines to lower cholesterol (LDL) levels called PCSK9 inhibitors, 80% were initially denied coverage by their health insurers.² Such denials, delays, and frustrating back-and-forth communication patients must often manage can lead them to abandon or find alternatives to their best course of care.

“The PCSK9 prior authorization process was complicated, and the denial rate was high, often without a clear reason for denial. Clinics faced with the administrative burden of re-application were not inclined to prescribe...the situation is better now, as patient and physician outcry has led to lower prices, and it is no longer a specialty pharmacy requirement.”

-Sue Koob, CEO, Preventive Cardiovascular Nurses Association



- **Step Therapy** requires patients to try a medicine that the payer prefers—often an older treatment, or one for which the payer has negotiated a lower cost—and fail on that treatment before they can receive the medication they and their prescriber want.³ This may also lead to disease progression, new symptoms, side effects, and other poor results for patients—and higher treatment costs.⁴

Sickle cell disease patients face significant unmet needs, and until recently had few options for treatment. While recent approvals of Adakveo and Oxbryta have offered patients hope, lagging access has left hopes unfulfilled: a recent survey of Medicare providers found more than half place access restrictions (step therapy and/or prior authorization) on Adakveo, and more than 80% restrict Oxbryta.⁵



“Patients with Sickle Cell Anemia are first prescribed Hydroxyurea. Even when it is sometimes proven to be ineffective drug for months, it takes time before patients are allotted a different or tweaked treatment plan to increase their livelihood and reduce their Sickle Cell crisis.”

-Alisha Lewis, Founder and CEO, Genèsic Nonprofit Organization

- **Copay Accumulators** block copay assistance from counting towards a patient’s out-of-pocket maximum or deductible, undermining the intent and value of programs that millions of Americans rely upon to afford their medications.⁶



“Patients... feel frustrated when they discover they need to pay the full deductible after their copay assistance runs out, leading to interruption and/or discontinuation of their treatment.”

Jen Grand-Lejano
Government Relations Director, American Cancer Society Cancer Action Network

SUPPORT THE WHOLE PATIENT AND FIND A TRUE ALLY

Two opportunities our advisors shared for patient engagement on access are:

Empower patients through education on treatment pricing, the stakeholders involved, and patients' influence in the system.

Support access across the treatment journey, as patients must navigate utilization management on more than drugs.

"The more literate patients are, the more power they have to fight for access to their medication... one of the of the biggest problems for our patients was not understanding the system at all....it would be great if pharmaceutical companies could bring more of this."

"Epilepsy patients who take anticonvulsants may need further hemispherectomy procedures, which require payer approval in advance. It would be great if, besides supporting prior authorization or step therapy applications for anticonvulsants, pharmaceutical companies could also help patients with their access to hemispherectomy procedures."

-Phil Gattone, President, Elevate for Impact



CONCLUSION

It is said that knowledge is power—and if patients are to have power in choosing treatments that are best for them, they need and deserve the knowledge to make those choices. DKI Health believes that stakeholders who recognize the untapped power of patient voice in market access, and who provide the right tools and education to empower patients, will see gains well beyond what they invest.

U.S. LEGISLATION ON DRUG ACCESS UNDER CONSIDERATION

The Safe Step Act:⁷ Introduced in 2021 and endorsed by more than 200 patient advocacy groups⁸, would require group health plans to provide certain step therapy exemptions and make clear the process for gaining an exemption. The Act's design is similar to laws passed in 36 states (as of February 2023).

"It is not safe or fair for patients to be forced to use medications that don't work for them simply because of insurance companies' protocols that do not take the patient's unique health needs into account... My bill (The Safe Step Act) will help patients get the medicine they need to live healthy, productive lives."

Congressman Raul Ruiz, M.D.



The Help Ensure Lower Patient Copays Act:⁹ Introduced in 2021 and supported more than 75 national patient and provider advocacy groups,¹⁰ would address copay accumulators by requiring group and individual health plans to apply payments made on behalf of plan enrollees toward plan's cost-sharing requirements. The Act's design is similar to laws passed in 16 states (as of February 2023).



"These practices (copay accumulator) target the most financially vulnerable patients and erode coverage for preexisting condition... If enacted, this legislation would bring much-needed relief by ensuring that all payments—whether they come directly from the patient or with the help of copay assistance—count towards patient out-of-pocket responsibility."

-Kollet Koulianos, Senior Director of Payer Relations, National Hemophilia Foundation

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