The Patient Access Initiative hosted its inaugural summit in 2023. The summit convened a broad group of stakeholders, including patients, advocates and industry leaders. Former Health and Human Services Secretary Alex Azar was the plenary speaker for the event. Discussions centered around policy solutions to encourage early diagnosis and improve care for kidney patients.

**Screening and Testing**

Nine out of 10 people with chronic kidney disease are unaware they have it. Advocates noted that many people with chronic kidney disease die from cardiovascular complications before even getting a diagnosis.

**CHALLENGES**
- Lack of clear and actionable instruction for health care providers
- Poorly reimbursed genetic counselors

**SOLUTIONS**
- Develop U.S. Preventive Services Task Force recommendations on screening for chronic kidney disease
- Ensure that Medicare directly reimburses genetic counselors by passing the Access to Genetic Counselor Services Act

**Patient Education and Navigation**

Patient advocates identified patient education and navigation as major challenges. Many people at high risk aren’t aware of their risk factors and don't know when to ask for screening for kidney disease.

**CHALLENGES**
- Unclear coverage of genetic testing
- Health disparities, which result in lack of access to clinical trials, patient education and treatment options

**SOLUTIONS**
- Expand physician education programs
- Partner with community organizations to develop culturally competent educational materials
The Food and Drug Administration Approval Process

Patients and providers noted that many challenges stem from the U.S. Food and Drug Administration.

**CHALLENGES**
- High rejection rates for chronic kidney disease treatments
- Lack of input from patients and advocates at the FDA

**SOLUTIONS**
- Ensure sufficient nephrology expertise on the Cardiovascular and Renal Drugs Advisory Committee
- Include a kidney disease patient advocate as a permanent member of the Cardiovascular and Renal Drugs Advisory Committee

Coverage Issues

Coverage issues arise in several areas, including the Center for Medicare and Medicaid Innovation payment models and commercial health plan coverage.

**CHALLENGES**
- Lack of financial incentives for commercial insurance to prioritize early treatment
- Challenges for patients and providers as they navigate Center for Medicare and Medicaid Innovation models
- Limited access to treatments because of prior authorization, step therapy and high cost-sharing

**SOLUTIONS**
- Support value-based payment models so insurers can prioritize preventive care and improved health outcomes
- More opportunities for patients and providers to weigh in
- Utilization management reform to ensure timely access to treatment

With resolute policymaking and continued advocacy, stakeholders can shape a brighter future for people living with chronic kidney disease.

The Patient Access Initiative focuses on the patient and caregiver burden, regulatory challenges, and health insurance design to better understand and address issues faced by the kidney patient community.

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