



READOUT: Cancer Support Community (CSC) | 2025 IRA Summit (September 25, 2025 | 9:00am – 3:00pm EST)

On September 25, 2025, the Cancer Support Community (CSC) brought together patient and caregiver advocates, policy experts, healthcare innovators, and thought leaders for the **2025 Inflation Reduction Act (IRA) Summit** to discuss key aspects of the IRA, unintended consequences on patient access and the healthcare delivery system, and future opportunities to engage with the Centers for Medicare & Medicaid Services (CMS).

The full-day event was headlined by **keynote remarks from Congressman Don Davis (NC-01)** about legislation to address unintended consequences of the IRA, a **fireside chat with the Centers for Medicare & Medicaid Services (CMS)** about the current status of IRA implementation, and a **legislative update from the Biotechnology Innovation Organization (BIO)**. The event featured three separate panel discussions that highlighted the IRA's impact on patients, and opportunities for engagement with CMS and the Trump Administration.

The summit represents a continuation of broader advocacy efforts that CSC has led, and will continue to lead, to drive a coordinated advocacy response around the ongoing drug price negotiation process. **CSC will continue to find opportunities to bring additional voices into the conversation as this effort evolves.**

Please let us know if you have any questions or if there is anything below we can expand upon.

Overview & Key Themes | CSC IRA Summit (9/25)

- **WHO:** CSC & Patient, Caregiver, Policy & Healthcare Experts
- **WHAT:** One-day summit convening patient and caregiver advocates, policy experts, healthcare innovators, and thought leaders to discuss the impacts of the IRA on patients, and opportunities for engagement with CMS and the Trump administration about the Medicare Drug Price Negotiation Program (MDPNP).
- **WHEN:** Thursday, September 25, 2025 | 9:00am – 3:00pm EST
- **WHERE:** Washington, D.C.

[Key Themes & Action Items](#)

Throughout the discussion, several action items emerged about the need to continue educating patients about the IRA and opportunities for engagement, and educate CMS on how patients will be impacted by unintended consequences of the program. To effectively engage with CMS, patient advocacy communities must:

- **Recommend the creation of a formal liaison at CMS for patient advocacy organizations to refer to for questions and information about Medicare negotiations and the implementation**



of negotiated prices. A liaison or ombudsman role at CMS dedicated to implementation of the IRA and price negotiations can help to promote transparency within the program.

- Support **education to inform patients about impacts on treatment access** as a result of the MDPNP and opportunities to share their experience with those impacts with CMS. Coordinate information sharing efforts across patient advocacy organizations to encourage engagement and amplify patient perspectives throughout Medicare negotiations.
- **Educate CMS** on the impacts of the IRA on the care delivery system to ensure continued patient access to treatments, while simultaneously advocating for legislative changes, such as pharmacy benefit manager (PBM) reform, to help ensure that patients have access to care.

Key Resources

Note: The below represents resources discussed during the event and is not comprehensive of all resources created by participating organizations.

- ProPublica (Report): [How Deeply Trump Has Cut Federal Health Agencies](#) | 8/21/25
- Ensuring Access through Collaborative Health & Patient Inclusion Council (EACH-PIC) (Report): [Patient Experience Survey: Prescription Drug Affordability and Unaffordability](#) | 8/4/25
- DLA Piper (Report): [Keeping watch on Medicare: Formulary assessment shows large declines in access for certain rare disease treatments](#) | 7/30/2025
- Caregiving in the US (Report): [Caregiving in the US 2025 Report](#) | 7/24/25
- Global Coalition on Aging (GCOA) (Report): [The Inflation Reduction Act & Small Molecule Development: Policy Brief](#) | 6/2025
- DLA Piper (Report): [Keeping watch on the Inflation Reduction Act: Medicare poses Part D formulary access challenges](#) | 4/14/2025
- DLA Piper (Report): [Keeping watch on Medicare: Access prescription drug plans and premiums](#) | 1/30/2025
- National Community Pharmacists Association (NCPA) (Report): [Report for January 2025 Survey of Independent Pharmacy Owners/Managers](#) | 1/27/25
- Pioneer Institute (Data Tool): [The Inflation Reduction Act \(IRA\): Impact on Medication Pricing, Spending, Affordability, and Access](#) | N/A

Actionable Next Steps | CSC IRA Summit (9/25)

- **Urge CMS to Establish a Dedicated Liaison for Patient Advocacy Groups.** CSC will advocate for CMS to establish a dedicated liaison for patient advocacy organizations to provide information on Medicare negotiations and implementation of negotiated prices, and to provide greater transparency into the program. CSC can coordinate across patient advocates and therapeutic alternatives on tactics to engage with CMS.
- **Develop Educational Toolkit on IRA and Medicare Drug Price Negotiation Program for Patients.** CSC will develop a toolkit template to educate patients on the IRA and Medicare negotiations, including a timeline for engagement, opportunities for alternative forms of



engagement, best practices for sharing patient stories, and how they may be impacted by the MDPNP. CSC can share the educational toolkit with patient advocacy organizations to customize for different therapeutic areas.

- **Coordinate Information Sharing to Amplify New Resources, Perspectives, and Research.** CSC will coordinate opportunities to share new resources, perspectives, and research that can be used in advocacy materials to build collaboration and alignment across groups.
- **Collaborate On & Coordinate Patient, Caregiver & Advocacy Comments on the IRA & MDPNP.** CSC will coordinate across stakeholder communities to showcase broad input and experiences across patient communities in public comments to CMS on the MDPNP, focusing on highlighting the IRA's impact on the care delivery system and patient access to treatments.
- **Convene Small-Group Meetings with CMS to Share Patient Perspectives Outside of Traditional Avenues for Engagement.** CSC will coordinate with patients, caregivers, and advocacy organizations across therapeutic areas to convene small, closed-door meetings with CMS to share input and perspectives about Medicare negotiations and access challenges that patients are facing as negotiated prices take effect.

Key Takeaways: Speaker Presentations & Panel Discussions | CSC IRA Summit (9/25)

[Keynote Address \(Congressman Don Davis \(NC-01\)\)](#)

- The Optimizing Research Progress Hope and New (ORPHAN) Cures Act ([H.R.946](#)), which was enacted as part of the One Big Beautiful Bill Act, represents the opportunity to amend the IRA through targeted legislative fixes.
- The Ensuring Pathways to Innovative Cures (EPIC) Act ([S.832/H.R.1492](#)) would amend the IRA to change the timeline on which small molecule drugs are eligible for negotiations. Currently, small molecule drugs, which play an important role in increasing treatment access and adherence, are eligible for negotiations four years sooner than large molecule drugs, threatening future innovation of those treatments.
- The Maintaining Investments in New Innovations (MINI) Act ([H.R.1672](#)) would amend the IRA to allow drug products with genetically targeted technology to be on the market for 11 years before becoming eligible for Medicare negotiations, incentivizing investment in these therapies, which are often used to treat life-threatening rare diseases.
- The Old Drugs, New Cures Act ([H.R.2542](#)) would carve out an exemption for “priority research” drugs to incentivize the development of new uses for existing drugs to treat conditions that disproportionately impact rural and low-income communities.

[Fireside Chat: A Conversation with CMS \(Lara Strawbridge | Acting Director, Medicare Drug Rebate & Negotiations Group, CMS\)](#)



- CMS has made changes to the patient engagement process throughout Medicare negotiations based on feedback received from the advocacy community during the first round of negotiations. CMS is open to continued feedback from patients and advocates on the formal patient engagement opportunities.
- The Trump Administration has expressed support for the Medicare negotiation program, but wants to find ways to improve the program, such as by implementing greater transparency throughout the process. There is interest from all layers of government to implement the program well.

Legislative Update: Supporting Patient Access to Innovative Treatments (Kristin Murphy | Vice President, Federal Government Affairs, Biotechnology Innovation Organization (BIO))

- Reconciliation packages, and other large pieces of legislation, are an opportunity to advocate for and pass smaller bills that can amend the IRA, such as the ORPHAN Cures Act that was included in the One Big Beautiful Bill Act.
- Patients in each congressional district face different challenges to access care. Understanding the nuances across districts and connecting the right patient story to each member of Congress is a critical part of engaging with lawmakers and championing bipartisan legislation. Patients, caregivers, and advocates can play a key role in fostering alignment among lawmakers on issues that matter most to the patient community.

Panel 1: Breaking Down Barriers to Patient Care

- Recent research shows that negotiated treatments are being put out of reach for patients and are increasingly subjected to increased rates of utilization management and placement on higher formulary tiers, primarily due to PBM practices and payers aiming to protect profits.
- CMS needs to be more present with patients, caregivers, and advocates throughout engagement on Medicare negotiations, and increase their attendance and role at patient engagement sessions, including patient-focused roundtables and town halls.
- Lawmakers must prioritize pharmacy benefit manager (PBM) reform to ensure that these entities do not continue to profit off of patients while also restricting access, by changing formulary tiers and using utilization management tactics. The rebate-based business model used by most PBMs allows them to find alternate avenues for profit on a drug with a Maximum Fair Price (MFP).

Panel 2: Paving the Way for Patient & Caregiver Engagement

- Education is critical to advance productive patient and caregiver engagement around the IRA, including educating patients of existing opportunities for engagement with CMS and the potential impacts on their access to care, and educating CMS about what matters most to patients and the need for continued improvement in those engagement opportunities.



- CMS must create inclusive avenues for patient engagement that are accessible to those who may not want to disclose their disease state publicly or do not have the ability to participate in virtual opportunities to ensure that all patients have an opportunity to engage with CMS throughout the negotiation process.
- CMS should establish a dedicated liaison for patient advocacy organizations who could help provide a clear pathway into CMS' decision-making process and facilitate greater transparency around the use of patient data and input, including the consideration of qualitative evidence.

Panel 3: Aligning Priorities Under the Trump Administration

- In conversations with the Trump Administration, it is important to emphasize that the MDPNP disincentivizes the innovation of small molecule drugs, which can have widespread impacts on patient access to treatments and negatively affect the United States' competitiveness in biomedical innovation.
- Identifying key themes, learnings, and overlapping priorities with the MAHA movement, such as a focus on chronic diseases and caregiving, will be valuable in finding alignment with the Administration and driving health policy solutions, given the broad support for efforts within that movement from grassroots communities.
- Highlighting individual patient and caregiver experiences and bringing data points to life are crucial to illustrate the impact of the MDPNP and encourage the development of patient-centered reform to the program.

Key Milestones: IRA & MDPNP | CSC IRA Summit (9/25)

- **September 30, 2025:** CMS publishes [final guidance](#) for IPAY 2028.
- **November 30, 2025:** CMS announces MFPs for the 15 drugs selected for negotiation for IPAY 2027.
- **January 1, 2026:** Negotiated prices for IPAY 2026 drugs become effective.
- **February 1, 2026:** CMS announces up to 15 additional drugs under Part D or Part B for potential negotiation for IPAY 2028.
- **February 28, 2026:** Negotiation begins for Part B drugs selected IPAY 2028.
- **March 1, 2026:** CMS publishes an explanation of the MFPs for the 15 drugs selected for IPAY 2027.
- **January 1, 2027:** Negotiated prices for the 15 IPAY 2027 drugs become effective.
- **January 1, 2028:** Negotiated prices for IPAY 2028 drugs become effective.