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IMPACT REPORT



Tigerlily
Foundation

HEAL
POLICY CENTER
OF EXCELLENCE

Dear Tigerlily Community,

In a time of profound uncertainty—as we witness alarming rollbacks in healthcare protections, cuts to vital safety net programs, and the erosion of hard-won diversity, equity and inclusion initiatives—our 2025 BEACON Symposium was not just an event. It was a necessary declaration. It was our collective stand against the currents that threaten to leave the most vulnerable behind.

This year, our gathering brought renewed urgency. The conversations in the room—on drug pricing, safety net programs, the need for community health workers and the power of ALL of our voices—were not merely academic. They were a strategic response to the real-world forces creating greater disparity and hardship for the patients and families we serve. The knowledge shared here is our armor; the connections forged, our network of resilience.

But the symposium was only the beginning. It was the ignition.

The true measure of our success will be the work that follows. The energy in that room must now translate into unwavering action in our communities, in legislative halls, and across social platforms. We must be louder in our advocacy, more innovative in our solutions, and more relentless in our pursuit of equity. And those are the commitments we make at Tigerlily. The feedback from attendees—with so many expressing a newfound passion to get involved—tells me you are with us.

The beacon is not a symbol of a distant hope; it is a signal for immediate, collective action. Our BEACON Symposium will honor that definition. Thank you to every speaker, partner, and advocate who helped light it. The challenges before us are significant, but our resolve is greater.

Now, let us go forward and do the work.

With determination and in solidarity,



Maimah Karmo

President & CEO Tigerlily Foundation

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2025 BEACON SYMPOSIUM PANELISTS AND SPEAKERS



Mistress of Ceremonies

Kimberly Aldridge

PhD, Health Care Executive and Patient Advocate



Moderator

Maimah Karmo

President & CEO, Tigerlily Foundation

NAVIGATING THE CROSSROADS: DRUG PRICING POLICY, INNOVATION, AND UNINTENDED CONSEQUENCES FOR CANCER PATIENTS



Erica Fae

Content Creator, Published Author, MBC Survivor,
Tigerlily ANGEL Advocate



Olivia Backhaus

Staff Attorney, Aimed Alliance



Thomas L. Johnson

Executive Director, Alliance to Save America's 340B Program
(ASAP 340B)

THE NEW FRONTLINE: COMMUNITY NAVIGATION BRIDGING CARE AMID FUNDING CUTS



Jennifer Dean

Breastivist, Tigerlily ANGEL Advocate



Leticia Boughton Price, CHW, LCSW

Co-Executive Director, Illinois Community Health
Worker Association



Rachel Landauer

Clinical Instructor, Center for Health Law and
Policy Innovation of Harvard Law School

OUR POWER, OUR VOICE: DEFENDING HEALTH EQUITY IN A CHALLENGING POLITICAL CLIMATE



Marquita Goodluck

Published Author, Breast Cancer Survivor, Tigerlily
ANGEL Advocate



Shyrea Thompson

Founder & Principal, IRIS Collaborative



Veronica Robinson

Patient Rights Advocate, Sr. Advisory to HELA100,
Great Granddaughter of Henrietta Lacks



INTRODUCTION

Tigerlily Foundation’s 2025 BEACON Symposium, themed **“From Policy to Practice: Safeguarding Patient Access in a Shifting Landscape,”** marked another pivotal moment in our ongoing commitment to advancing health equity through patient-driven collaboration. Building on the momentum of the 2023 symposium, which laid the groundwork for identifying systemic barriers, and the 2024 gathering, which shifted the focus toward co-creating actionable, patient-centered solutions, this year’s event centered on translating policy insights into tangible practice.



In a time of evolving political and economic pressures—including funding cuts, policy rollbacks, and growing inequities in care—the 2025 BEACON Symposium convened a diverse coalition of patients, survivors, advocates, policymakers, healthcare professionals, and industry leaders. Together, we explored how to protect and expand patient access in an increasingly complex landscape, emphasizing real-world application and sustainability.

Where the 2023 symposium highlighted the “why” and the 2024 event advanced the “how,” the 2025 dialogue focused on the **“what now”** — equipping attendees with the tools, networks, and resolve to implement change in their communities and beyond. This report captures the insights, outcomes, and collective calls to action that emerged from three dynamic panels, reflecting Tigerlily’s unwavering belief that patients must lead the way toward a more equitable and compassionate healthcare system.

SYMPOSIUM HIGHLIGHTS

Panel 1: From Policy to Practice

Navigating the Crossroads: Drug Pricing Policy, Innovation & Unintended Consequences for Patients.

Key Insights:

- **Prescription Drug Affordability Boards (PDABs)** were criticized for inefficiency and lack of patient representation. States like Maryland have spent millions without achieving patient savings.
- **The 340B Program** was highlighted as an essential but misused safety-net program, with hospitals spending funds on non-patient-centered expenses (e.g., capital projects, advertising) rather than drug discounts for patients or direct patient support.
- **Patient Advocacy** emerged as critical, especially in storytelling and social media outreach to humanize policy issues and drive grassroots engagement.

Attendee Takeaways:

- Ask healthcare facilities if they are 340B providers.
- Use social media to simplify and amplify complex policy topics.
- Demand patient representation on PDABs and other regulatory boards.

“

Financial debt is like the last thing you think you're gonna face when you're trying to just heal from something that's trying to kill you.”

Erica Fae,

Stage 4 Breast Cancer Survivor, Creative Director, ANGEL Advocate



“

340B should not be part of an earnings call for a hospital system... but that's what's happening.”

Thomas Johnson,

Executive Director, ASAP 340B

Panel 2: The New Frontline: Community Navigation Bridging Care Amid Funding Cuts

Key Insights:

- Community Health Workers (CHWs) and Patient Navigators are vital in guiding patients through complex systems, especially amid Medicaid cuts and work requirement proposals.
- Policy Gaps include inconsistent reimbursement for CHWs and navigators, with only some states (e.g., Illinois) moving toward Medicaid-funded certification programs.
- Private and philanthropic funding can bridge gaps while state and federal policies evolve.

Attendee Takeaways:

- Advocate for Community Health Worker (CHW) and navigator reimbursement in Medicaid/Medicare.
- Support training and certification programs for patient navigators.
- Leverage community partnerships to sustain navigation services during funding transitions.



“

Community navigation for me turned scary and isolation into connection and clarity.”

Jennifer Dean,
*Tigerlily ANGEL Advocate
and Breast-avist*

“

*Nothing about us without us.
[Community Health Workers] should be in places and spaces where they feel heard, seen, and valued.”*

Leticia Boughton Price,
*Co-Executive Director, Illinois
Community Health Worker Association*

Panel 3: Our Power, Our Voice: Defending Health Equity in a Challenging Political Climate

Key Insights:

- **DEI Rollbacks** and federal funding cuts threaten progress in cancer research, clinical trial diversity, and patient advocacy.
- **Storytelling as Advocacy** must be protected and compensated; patients should vet organizations and negotiate terms before sharing their experiences.
- **For ethical patient engagement**, partners need to use a framework that includes:
 - 1) A relational call to **know the patient as a person**,
 - 2) The work-focused conversation, and
 - 3) A follow-up to **show how the patient's input was used and credited**, ensuring respect beyond transaction.

Attendee Takeaways:

- Staying consistent with what matters to the patient community.
- Vet organizations before sharing your story; request compensation and set boundaries.
- Build coalitions across disease areas to amplify advocacy impact.
- Prioritize mental and emotional health to sustain long-term advocacy work. “Relax, Relate, Release” (RRR) Retreat Model is a specific, replicable model for advocate sustainability designed to combat burnout and weathering through community care, healing, and restoration.
- Reframe advocacy- not just accessing a seat at existing tables, but dismantling inequitable systems and building new, community-owned platforms and coalitions (exemplified by the Henrietta Lacks Advancing Cancer Research Act's passage).

“

We made so much progress... in scientific spaces, in research. And in one fell swoop, all of that has now been challenged. This is the fight of our lifetime... it's impacting cancer research, clinical trial diversity, and patient advocacy.”

Shyrea,

Founder & Principal, IRIS Collaborative

“

“We don’t have to be the topic of discussion at the table... Our family worked hard to dismantle those tables that are not built for us and build new ones.”

Veronica,

Lacks Family Advocate & WHO Ambassador

“

If you see someone and you see a potential advocate in them... throw them in somewhere. Without her story, without stories like hers... we would be silenced.”

Marquita,

Breast Cancer Survivor & ANGEL Advocate



RECOMMENDATIONS

To translate discussion into practice, the audience and speakers concluded we must commit to the following:

1 Amplify Patient Voices in Policy Making

- a) Demand patient representation on PDABs, hospital boards, and policy committees.
- b) Train patients to tell their stories effectively and safely, with compensation and respect.

2 Advocate for Sustainable Navigation Funding

- a) Push for state and federal policies that reimburse CHWs and patient navigators as essential parts of healthcare.
- b) Encourage private and philanthropic investment in navigation pilot programs.

3 Increase Transparency & Accountability

- a) Require 340B-covered entities to publicly report how funds are used and support legislation that ties 340B savings to direct patient assistance.
- b) Require PDABs and drug pricing policies to work in the real world to lower prices for patients first.

4 Leverage Digital Advocacy

- a) Use social media to educate and mobilize communities on drug pricing, clinical trials, and policy changes.
- b) Develop shareable content that simplifies complex healthcare topics.

5 Foster Cross-Sector Collaboration

- a) Build coalitions among advocacy groups, healthcare providers, policymakers, and industry partners.
- b) Create resource-sharing networks to avoid duplication and maximize impact.

6 Prioritize Advocate Well-Being

- a) Encourage self-care, mental health support, and sustainable workloads for patient advocates.
- b) Establish mentorship programs for new advocates navigating policy spaces.

CONCLUSION

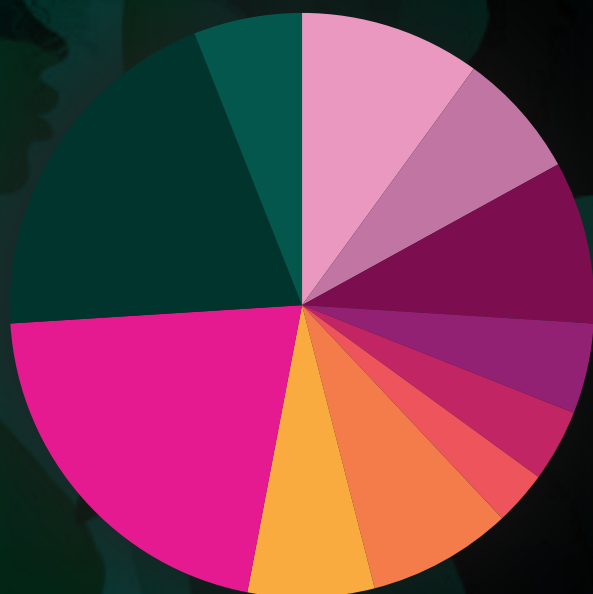
The 2025 BEACON Symposium reinforced that patient-centered advocacy is not only necessary—it is transformative. By uniting voices across sectors, we can confront inequities, influence policy, and ensure that no patient must choose between treatment and financial ruin. Together, we move from policy to practice—transforming dialogue into action, and advocacy into access.



COMMUNITY REPRESENTATION

BEACON Symposium Registrant Breakdown

Registrants



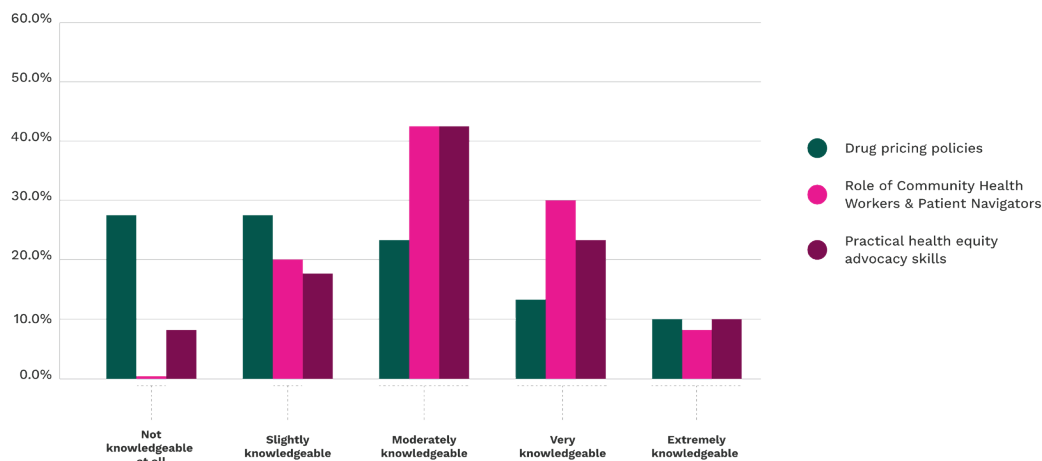
- Advocacy Group
- Faith Based Organization
- Healthcare Provider
- Patient/Survivor/Thrivor/Previvor
- Caregiver
- Government Agency
- Industry/Pharma
- Scientist/Researcher
- Community Based Organization
- Health System/Payor
- Patient Advocate

ATTENDEE FEEDBACK & INSIGHTS

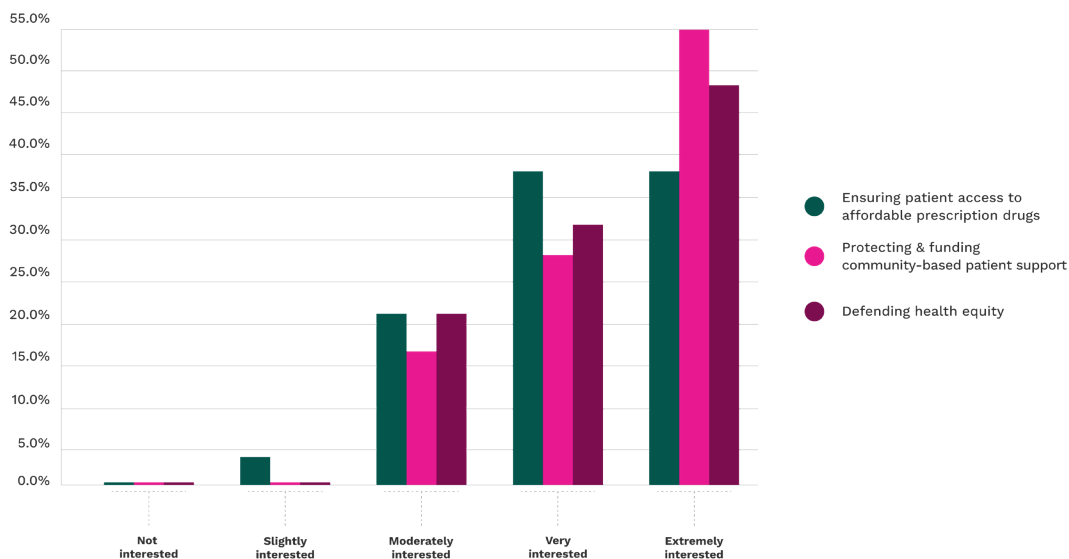
Pre-Event Survey Highlights:

- Many attendees reported limited prior knowledge of drug pricing policies (340B, PDABs) but high interest in advocacy.
- Top reasons for attending: to learn how policy affects patients, build advocacy skills, and support their communities.

Attendees' reported knowledge levels



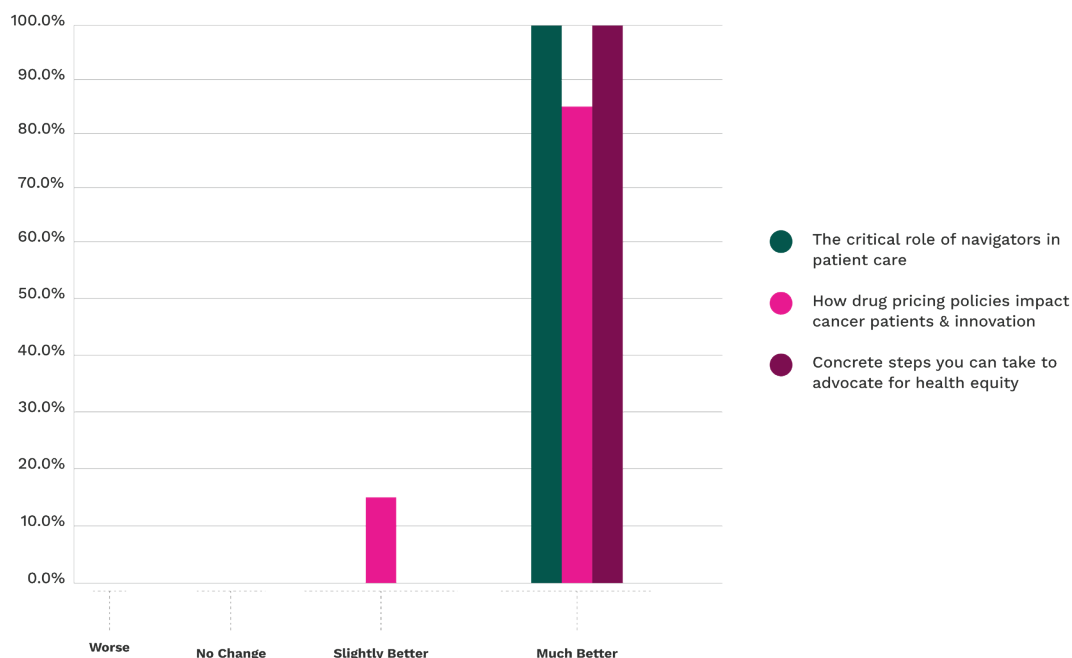
Attendees' reported interest level in advocating on discussion topics



Post-Event Survey Results:

- **93%** of respondents rated their understanding of drug pricing, navigation, and advocacy as “much better” after the symposium.
- **96%** reported being “likely” or “very likely” to take new advocacy actions (e.g., contacting legislators, using social media).
- Attendees highlighted the 340B program and navigation resources as the most impactful takeaways.

Attendees' reported level of understanding after BEACON discussion



ATTENDEE FEEDBACK

Tigerlily's 2025 BEACON Symposium Attendee Feedback



Leading Transformative Healthcare with Patients

The symposium was very educational and informative. I learned so much.

My passion to advocate for change was reignited. Thank you!

Thank you to the Tigerlily team for an engaging and inspiring day of purpose!

I am so glad that I was in the room. I enjoyed hearing from and talking with other advocates and passionate women who are actually doing the work and shedding light on the things that matter most.

This was a great symposium overall. Again, thank you.

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