

# THE POLICY ISSUE

SEPTEMBER 2024



**Tigerlily**  
Foundation  
*Beauty. Strength. Transformation.*

## The Policy Issue

Make your voice heard! It's that time of year again – our annual Hill Day is just around the corner with two special virtual events! This isn't just another advocacy event – it's a powerful opportunity for you, the patient advocate, to directly influence the policies that impact your life and the lives of millions living with chronic illness. This newsletter will equip you with everything you need to make your Hill Day experience a success, from crafting your message to connecting with your elected officials. Remember, patient voices are the driving force behind impactful legislation. Let's join forces and make a difference together!



## We're excited to announce the 2024 EmPOWER Ball Honorees!



These incredible individuals are making significant impacts in advocacy, research, and their fields and beyond in the pursuit of health equity and addressing health disparities.

### Join us in celebrating:

- ★ **Mandi Pratt-Chapman, MA, PhD, Hon-OPN-CG**
- ★ **Dr. Sara Horton, MD**
- ★ **Nadine Barrett, PhD, MA, MPH**
- ★ **Sherri Neal Crowley**
- ★ **Michelle Anderson-Benjamin, MHA**
- ★ **Tameka Johnson**
- ★ **Sigourney Bonner**
- ★ **Jade Curtis**
- ★ **Catrina Marcell**
- ★ **Kim Rhoads, MD, MS, MPH, FACS**
- ★ **Gary Puckrein, PhD**

Mark your calendars for October 19th at the Waldorf Astoria in Washington DC!

Let's come together to pay tribute to patients, healthcare providers, and leaders while fundraising to improve the lives of young women with cancer and bridging the gap in health disparities.

**Secure your tickets today!**

## Join us at the Second Annual BEACON Symposium!



**October 19, 2024 | 9:30 AM - 2 PM**  
Waldorf Astoria, 1100 Pennsylvania Avenue, NW  
Washington, DC 20004

The **Tigerlily Foundation's Second Annual BEACON Symposium** is defining what nirvana looks like for patient-centric care in the real world by bringing patient advocates, health systems, providers and science together to co-create better solutions today.

This year's panels will address

**Panels at the Second Annual BEACON Symposium will include:**

- **Accelerating Access to Diverse Trials: Putting Our Money Where Our Mouth Is**
  - » What we can do to support equitable trials and patient participation to ensure better treatment options for all.
- **Policies for Affordable Drugs for Patients: Inflation Reduction Act, Affordability Boards and Upper Payment Limits—Oh My!**
  - » What's going on with prescription drug cost reduction efforts and how do we ensure meaningful patient benefits to support health equity.
- **Accessing Science Through Health Literacy: The Power of Knowledge is Meant for All**
  - » Addressing and avoiding collateral damage of insufficient communication and education for better health outcomes and reducing health disparities.

Together, we are the **BEACON** of hope and light that drives us forward to health equity.

[\*\*Register and learn more about BEACON here!\*\*](#)

[\*\*Watch our BEACON 2023 Highlights here!\*\*](#)

## HEAL Policy COE Updates

Policy Advocacy in Action Webinar: Prescription Drug Affordability Boards



# Advocacy in Action: PRESCRIPTION DRUG AFFORDABILITY BOARDS (PDABs)

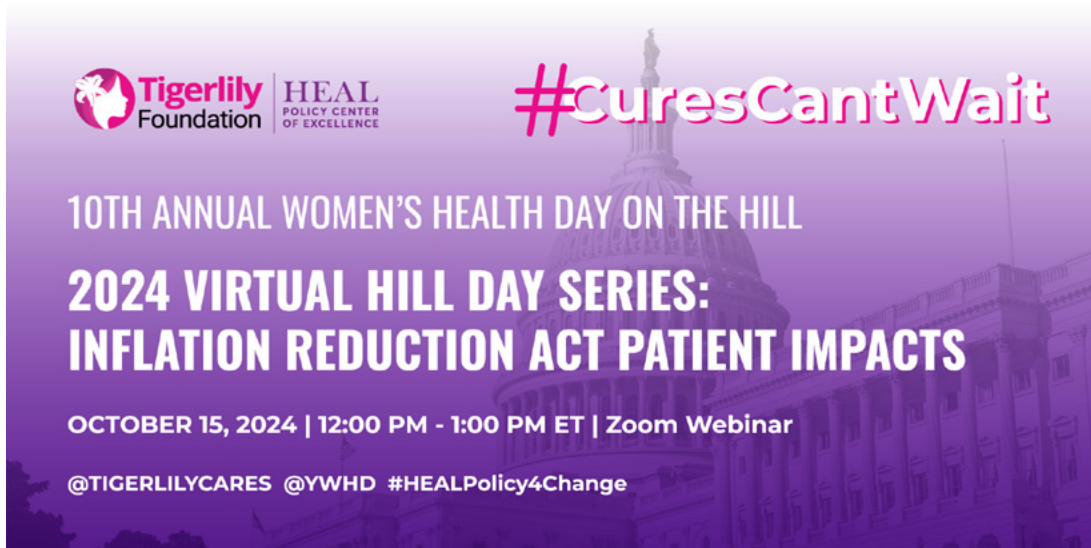
Educational Series & Advocate Engagement

Calling all advocates! Join us for an engaging webinar on September 25, discussing Prescription Drug Affordability Boards (PDABs) and how you as an advocate can meaningfully engage in them to ensure patients are receiving their intended benefits.

PDABs are state government-appointed boards that have the authority to review prescription drug costs and determine if they present an affordability challenge for patients. These boards are formed by policymakers and do not include patient, provider, or caregiver representatives who experience the real-world impact of treatments but can use tools to implement pricing restrictions that can actually hinder access to treatments for patients. The webinar will provide an overview of PDABs, the states they have been implemented or introduced and tools to help amplify your voice and thoughts on this issue. Together we can speak up to protect access and innovation for patients!

[Click here to register](#)

## 2024 Virtual Young Women's Day on the Hill Series: IRA Reform



**Tigerlily Foundation** | **HEAL**  
POLICY CENTER OF EXCELLENCE

**#CuresCantWait**

10TH ANNUAL WOMEN'S HEALTH DAY ON THE HILL

**2024 VIRTUAL HILL DAY SERIES:  
INFLATION REDUCTION ACT PATIENT IMPACTS**

OCTOBER 15, 2024 | 12:00 PM - 1:00 PM ET | Zoom Webinar

@TIGERLILYCARES @YWHD #HEALPolicy4Change

Tigerlily's Women's Health Day on the Hill is going virtual! Join us on October 15th for our 2024 Virtual Hill Day Series to discuss some of the unintended patient impacts of the Inflation Reduction Act (IRA) and ways we can address them to ensure equitable treatment and access to treatment for patients. Tigerlily Foundation, advocates, policy-makers and patient and provider stakeholder groups will come together to learn about the landscape of the Inflation Reduction Act (IRA), unintended policies that threaten access to lifesaving medicines, The Ensuring Pathways to Innovative Cures (EPIC) Act, the ORPHAN Cures Act and how YOU can raise your voice in the discussion.

[Click here to register](#)

### Statement for the Record for Senate Finance Committee, September 17, 2024, Full Committee Hearing "Lower Health Care Costs for Americans: Understanding the Benefits of the Inflation Reduction Act"

Tigerlily submitted an official statement for the record to the Senate Finance Committee ahead of the September 17th hearing on Lowering Health Care Costs for Americans: Understanding the Benefits of the Inflation Reduction Act (IRA) in support of the ORPHAN Cures Act, H.R. 5539/S. 3131, to ensure rare disease treatments—like ovarian, cervical and fallopian tube cancer— research and development, including treatments for common cancer treatment side effects and permanent side effects—like neuropathy, kidney disease and liver disease—remain incentivized equally to non-rare disease treatments.

[Read the full letter here!](#)

## 2024 Virtual Young Women's Day on the Hill Series: Clinical Trial Modernization Act



#Research4All

10TH ANNUAL WOMEN'S HEALTH DAY ON THE HILL

### 2024 VIRTUAL HILL DAY SERIES: CLINICAL TRIALS MODERNIZATION ACT

SAVE THE DATE: **October 30th, 2024**

@TIGERLILYCARES @YWHD #HEALPolicy4Change

Save the date to join us on October 30th for the second series of our 2024 Virtual Hill Day Series to discuss the Clinical Trials Modernization Act! We will be discussing the aims of the Clinical Trial Modernization Act to provide education on clinical trials to our communities, better patient support for trial participants and design for more diverse clinical trials to meet patient treatment needs.

Registration is coming soon! Please check the [HEAL Policy Center of Excellence](#) page on the website in October to register. We look forward to seeing you there!



## Preserving Accessibility & Incentives for Development of Small Molecule Medicines

Tigerlily was honored to join our partner’s National Minority Quality Forum’s webinar on September 13th for an important discussion about the issues surrounding needed reform to the Inflation Reduction Act (IRA) to provide parity for large molecule and small molecule drug development and access. On this webinar, Tigerlily’s Founder, CEO and President Maimah Karmo joined moderator Candace DeMatteis, Policy Director at Partnership to Fight Chronic Disease and panelists Rosa Mendoza, Founder, President & CEO of ALLvanza and Michelle Sie Whitten, Co-Founder, President & CEO of Global Down Syndrome Foundation to provide the patient perspective on this issue and the fixes the Ensuring Pathways to Innovative Cures (EPIC) Act.

The Inflation Reduction Act (IRA) includes a provision that could hinder drug innovation, especially when it comes to small molecule drugs, which are often developed in pill form. These drugs are uniquely designed to enter cells more easily due to their lower molecular weight, targeting molecules like proteins inside the cells and, in many cases, killing cancer cells. This is a significant advantage compared to large molecule drugs, which have a harder time penetrating cells due to their size.

However, under the current structure of the IRA, small molecule drugs are unfairly disadvantaged. While biologic drugs are given 13 years before they face price controls, small molecule drugs are only granted 9 years. This arbitrary difference threatens the development of innovative treatments like oral chemotherapy, which is critical for cancer patients. The Ensuring Pathways to Innovative Cures (EPIC) Act seeks to correct this by extending the exemption for small molecule drugs to 13 years, aligning them with biologics. This change is vital to ensure continued investment in the research and development of small molecule therapies, so that patients can access groundbreaking treatments that can save lives.

[Click here to watch the full webinar](#)



## Bridging the Gap: Exploring the Health Equity Implications of the 340B Drug Pricing Program



The graphic features the National Minority Quality Forum logo on the left and the Center for Sustainable Health Care logo on the right. The title is centered in blue text. Below the title is a blue button with white text for the live event date and time, and a registration link. Five circular headshots of speakers are arranged in two rows, each with their name and title below.

**NATIONAL MINORITY QUALITY FORUM** | **Center for Sustainable Health Care**  
Quality and Equity

### Bridging the Gap: Exploring the Health Equity Implications of the 340B Drug Pricing Program

**JOIN US LIVE AUG. 9 AT 12 PM ET**

**REGISTER NOW: [BIT.LY/NMQF0809](https://bit.ly/nmqf0809)**

**Jen Laws**  
President & CEO  
Community Access  
National Network

**Rev. Kimberly Williams**  
Executive Director  
Choose  
Healthy Life

**Lizzie Wittig**  
Director, HEAL Policy  
Center of Excellence  
Tigerlily Foundation

**Dr. Ifeoma Udoh**  
Executive Vice President  
Policy, Advocacy and Science  
Black Women's Health Imperative



**Robin Strongin**  
Senior Director, Health Policy  
National Consumers League

Tigerlily was honored to join our partner's National Minority Quality Forum's webinar on August 9th for an insightful webinar on the 340B Drug Pricing Program and its impact on health equity. On this webinar, Tigerlily's Director of HEAL Policy Center of Excellence and National Programs Lizzie Wittig joined moderator Jen Laws, President & CEO of the Community Access National Network and panelists Dr. Ifeoma Udoh, Executive Vice President for Policy, Advocacy, and Science of the Black Women's Health Imperative, Rev. Kimberly Williams, Executive Director of Choose Healthy Life and Robin Strongin, Senior Directory of Health Policy at the National Consumers League to discuss how the 340B Program, despite being designed to support vulnerable populations, inadvertently contributes to provider consolidation, increases costs for patients, and negatively affects the quality of life of those it aims to help.

[Watch the full webinar here](#)



## Tigerlily is gearing up for Breast Cancer Awareness Month!



### TIGERLILY FOUNDATION

#### OCTOBER: BREAST CANCER AWARENESS MONTH

##### KEY DATES & EVENTS

10/1	Start of Breast Cancer Awareness Month
10/2	National Previvor Day
10/2	2024 Virtual Hill Day Series: Inflation Reduction Act Patient Impacts
10/2	Navigating the Costs of Breast Cancer Care Webinar with Aimee Hoch
10/10	World Mental Health Day
10/13	Metastatic Breast Cancer Awareness Day
10/13	Tigerlily's MY LIFE Is My Legacy 5 Year Anniversary
10/18	National Mammography Day
10/19	Tigerlily Foundation's BEACON Symposium & Annual EmPOWER Ball
10/23	MY LIFE Perkatory Virtual Event
10/25	Pull Up A Seat: BCAM Edition
10/30	2024 Virtual Hill Day Series Clinical Trials Modernization Act

At Tigerlily, every day is dedicated to breast cancer awareness, but October is a special time to come together and make a difference. We're thrilled to unveil our calendar of special dates and events for the upcoming Breast Cancer Awareness Month. We can't wait for you to join us in DC and be a part of the movement—let's unite in the fight and support each other!

Follow us on social media to keep up with our Breast Cancer Awareness Month content and events!

-  @tigerlily\_foundation
-  @tigerlilyfoundation
-  @tigerlilycares
-  @tigerlilyfoundation
-  @tigerlilyfoundation

# Pull Up A Seat: Breast Cancer Awareness Month Edition: Empowering Black and Brown Communities through Health Equity, Clinical Research, and Patient Advocacy



Join Tigerlily Foundation on October 25th for a #PullUpASeat BCAM Edition! This powerful event will be co-hosted by patient experts and is dedicated to amplifying underrepresented women's voices. We'll dive into crucial topics such as enhancing diversity in clinical trials, ensuring equitable health treatments, and addressing disparities that contribute to higher mortality rates among Black women.

This 2-hour conversation from 12pm – 2pm will focus on empowering Black and Brown communities through health equity, clinical research, and patient advocacy. Let's work together to build a more inclusive and just healthcare system.

[Click here to register!](#)

## Navigating the Costs of Breast Cancer Care October 2 @ 8:00 pm - 9:30 pm



**Tigerlily  
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### Navigating The Costs of **BREAST CANCER CARE**

Presented by: **Aimee Hoch, LSW, OSW-C, FACCC**  
**October 2 | 8-9:30PM EST**



A breast cancer diagnosis and treatment not only pose both physical and emotional challenges but can also have a significant financial impact. Understanding how to manage and navigate the costs associated with care can help reduce financial distress and help an individual focus on their recovery.

This presentation is designed for both patients and caregivers. It will provide an overview of the potential costs associated with breast cancer care, insights about how insurance coverage works, and will provide participants with the knowledge and resources to navigate those costs from diagnosis through treatment and survivorship.

Aimee Hoch, LSW, OSW-C, FACCC, is a Masters Level Social Worker with 20 plus years of experience in both healthcare and behavioral health. Her practice is focused on oncology, specifically addressing financial toxicity.

Aimee earned her MSW from Fordham University Lincoln Center and is a licensed social worker. She is a Certified Oncology Social Worker.

Aimee is a Financial Navigator for the Cancer Program at Grand View Health where she created and implemented the Financial Navigation program in 2018. She is a consultant for the Cancer Support Community Helpline as a Financial Navigation Specialist. Aimee is an active member of the Association of Cancer Care Center's (ACCC) Financial Advocacy Network Advisory Committee, Initiatives Task Force, and has been recognized as a Fellow for the organization. She is a member of the Medical Advisory Board at Living Beyond Breast Cancer. Aimee was selected for the Cancer X Moonshot 2024 Mentor cohort. She speaks about financial toxicity and the role of financial navigation in cancer care.

[Click here to register!](#)

## Welcome to our Newest ANGEL Advocates!



WE ARE  
THE CHANGE

Tigerlily Foundation ANGEL Advocates



**Andrea Hans**  
Trainer



**LaToya Cauley**



**Charnita Alexander**



**Hope Brewer**

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Cohort 31 was trained by Andrea Hans and graduated August 29, 2024.

Welcome to the ANGEL family:

LaToya Cauley – Chicago, IL

Charnita Alexander – Loganville, GA

Hope Brewer – Lawrenceville, GA

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## Advanced ANGEL Trainings for September

A purple rectangular graphic with white text and illustrations. At the top, it says 'ANGEL Advocacy Training Program'. Below that, a quote reads: 'Tigerlily's mission is to educate, advocate for, empower and support young women before, during and after breast cancer.' To the right of the quote is an illustration of two women sitting on a white sofa, talking. The woman on the left is wearing a pink top and blue pants, while the woman on the right is wearing a pink top and yellow pants. In the bottom left corner of the graphic is the Tigerlily Foundation logo, which features a stylized tiger head in a circle and the text 'Tigerlily Foundation' with the tagline 'Keep Strength. Find Purpose.'

**ANGEL Advocacy Training Program**

*Tigerlily's mission is to educate, advocate for, empower and support young women before, during and after breast cancer.*

 **Tigerlily Foundation**  
Keep Strength. Find Purpose.

Register for our advanced ANGEL training sessions for this month!

We're offering

**Module 7: Disparities in Healthcare.**

If you'd like to register,

email [amanda.e@tigerlilyfoundation.org](mailto:amanda.e@tigerlilyfoundation.org).



**Wednesday Sept 18th 6:30-8PM EST with Vickie Williams**

**Thursday Sept 19th 8-9:30PM EST with Maricia Cole**



## ANGELs in the Community

### Hey Cousin Cultural Fest 2024



**August 11<sup>th</sup>:** The intent of Hey Cousin Cultural Fest was to bring together the community as they highlight and showcase the beauty of Black culture. They desire to create a platform for organizations to showcase, educate, and raise awareness to support the community work they complete throughout the year.

***The Hey Cousin Culture Fest is organized by Diggin Her Roots Boutique and JanaeDanielle Consulting & Design.***

**ANGELs in attendance:** Neosho Ponder & Angel Thompson

### Black Nurses Rock Back-to-School Health Fair



On August 24<sup>th</sup>, Black Nurses Rock Back-to-School Health Fair was held at the Washington View Apartments in DC. Over 100 community members attended, and ANGEL Lead Neosho Ponder spoke to the attendees about the importance of breast cancer screening and self-advocacy through her own cancer journey. DMV-area ANGEL, Jennifer Dean, joined Neosho in staffing our table and they both enjoyed a great day of passing on Tigerlily's mission! This was the first of many events that we will be in collaboration with Black Nurses Rock at the apartment complex.



## Support our RAISE Platform!



### RAISE

Tigerlily Foundation has partnered with The WITT Group to create the RAISE (Resources and Assistance for Support and Empowerment) platform! RAISE is a patient-driven tool that makes it easy for a patient to share their financial and non-financial needs, but more importantly makes a patient's needs visible to friends, family, and donors that are willing and able to provide support.

If you or a loved one has heard the words “you have cancer,” you know the heartbreak, fear and uncertainty this diagnosis brings. **This month, we're leveraging our community to help patients get the non-clinical support they need as they go through treatment so that we can ease the fear and offer comfort and strength every step of the way.**

The support of people like you can ease the burden of those struggling with everyday needs, which often prevent them from focusing on what is most important - their health.

We have implemented a program, **RAISE**, to enable you to directly support our patients. Will you help us impact the lives of those fighting their battle with Cancer? [SUPPORT A PATIENT](#) Thanks for being on our team.

With past support, we have over 380 patients on RAISE, and have raised over \$13,000 for them, which has had a real and meaningful impact on every cancer patient's experience.

#### **Every gift makes a life-changing difference.**

100% of your donation goes to the patient and can make a powerful impact:

- **Daily Life:** \$30 could fund childcare for a patient, so that they don't have to miss treatment if they need someone to watch their children
- **Housing:** \$50 could help cover lodging expenses or mortgage payments for patients whose medical bills make paying rent a challenge
- **Health:** \$100 could support a patient's ability to co-pay insurance or pay for medication
- **Transportation:** \$47 could provide parking, gas, or rideshare support for patients who need transportation to and from treatment
- **Every patient you see on RAISE has been VERIFIED as a real patient going through treatment... so you know your support is making a real impact on those in need.**

[SUPPORT A PATIENT](#) A guide for the journey

A cancer journey is difficult, but thanks to our RAISE platform, every patient can ask for help without feeling guilty, and YOU have the opportunity to support them in a truly meaningful and impactful way. Our RAISE platform gives you the ability to support REAL patients, with REAL needs, and make a MEANINGFUL difference in their lives.



## A SPECIAL THANK YOU TO OUR HEAL POLICY CENTER OF EXCELLENCE SPONSORS

Supporting Tigerlily's policy work!

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Daiichi-Sankyo

**sanofi**

*Lilly*



**MERCK**

**Seagen**