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IMPACT REPORT



Tigerlily
Foundation

Dear Friends,

I am thrilled to share with you the Impact Report from our inaugural BEACON Symposium, a momentous event that stands as a testament to our collective commitment to addressing the disparities in breast cancer care and outcomes. As the President & CEO of Tigerlily Foundation, it is my privilege to share with you the insights, initiatives, and next steps outlined in this report, all which stem from our unwavering dedication to empowering patients, advocating for change, and fostering collaboration across sectors.

In the wake of George Floyd's murder in 2020 combined with the impact of the COVID-19 pandemic, we saw a global outcry for racial justice, and significant resources started being allocated towards addressing health equity. Despite these investments, nearly five years later the landscape remains largely unchanged, with persistent systemic barriers to health improvement for BIPOC communities. Despite the efforts of dedicated individuals and organizations, there has been little tangible progress in dismantling these obstacles and achieving equitable health outcomes.

As a breast cancer survivor, patient advocate and leader of Tigerlily Foundation, deeply involved in this work for nearly two decades, I find myself questioning the sustainability of our efforts. BIPOC patients, advocates, and community leaders, pour their time and expertise into initiatives aimed at improving health outcomes, yet the fundamental challenges persist and there remains a power imbalance between patients and systems, industry organizations and policy structures - meaning that the power is still not in the hand of the patient - we are still in many ways at the mercy of systems, structures and organizations whose founding leaders established and maintained the very barriers we are still working to eradicate today. The disparity in resources allocated to smaller, Black-led organizations compared to their larger, white-led counterparts highlights a systemic imbalance that echoes historical injustices. It's concerning to witness a pattern where marginalized communities are expected to shoulder the burden of affecting change,

while those in positions of power benefit disproportionately. This imbalance evokes uncomfortable parallels with past injustices, where the labor of the oppressed fueled the prosperity of the privileged. While we are proud to work alongside many allies who are doing the right thing, there are still many bad actors, who support the status quo - a product of this status quo is the billions of hours and dollars spent on talking, developing competing advisory boards, and furthering an agenda that does not balance out to the benefit of BIPOC patients, communities and advocacy groups supporting these populations.

We cannot afford to continue these discussions without concrete action. Every day that passes without meaningful change, lives are at stake. It's time to move beyond dialogue and actively dismantle the structures perpetuating health disparities. The urgency of this moment demands swift and decisive action. How many more lives must be lost before we prioritize action over rhetoric? This is the impetus from which the BEACON symposium was born.

Designed to go beyond discussing the well-documented barriers and issues our communities and patients face, The BEACON Symposium focused on sharing best practices, thoughts and ideas for moving forward in health equity now and re-imagining the systems that control patients' care - with their real-world experience and needs in mind. The BEACON Symposium emerged from patient insights - patients wanted to curate an authentic patient-designed event, highlighting challenges facing individuals and communities impacted by breast cancer, including systemic barriers, lack of access to quality care, and disparities in outcomes - but with a focus on solutions, not simply reiterating the problems, statistics and terms that we have come to hear so often. Our aim was clear: to convene a diverse array of stakeholders - patients, advocates, healthcare providers, policymakers, and more - to collectively confront these challenges and chart a path toward a future, led by patients, moving towards a future where every individual receives equitable care and support.

In this report, you will find a comprehensive overview of the insights gleaned from the symposium, the initiatives proposed, and the impactful next steps identified by the esteemed speakers and participants.

From empowering generational health conversations to advocating for the integration of community health workers, to enhancing safety and support in clinical trials to addressing financial toxicity, the BEACON Symposium sparked vital discussions and laid the groundwork for meaningful action. As you peruse this report, I invite you to reflect on the collective impact we can achieve when we come together with a shared purpose.

The BEACON Symposium was just the beginning – now, it is incumbent upon us to translate our insights into tangible change, to advocate for policies that prioritize patient-centered care, and to forge partnerships that amplify the voices of those affected by breast cancer.

Next steps will be to implement recommendations – led by patients, in collaboration with our stakeholders. I am immensely proud of the strides we have made together, and I am confident that with continued collaboration and dedication, we will continue to make meaningful progress toward our shared goal of health equity for all. Thank you for your unwavering support and commitment to this work.

We look forward to continuing to work with you to serve as beacons of light, eradicating the darkness of health inequities in our world.

A handwritten signature in dark ink, appearing to read "Taen". The signature is fluid and cursive, with a large loop at the end.

President & CEO Tigerlily Foundation

2023 BEACON SYMPOSIUM PANELISTS AND SPEAKERS



Pamela L. Barnes

MA, Director, Federal Strategic Alliances, Bristol Myers Squibb



Eucharia Borden

MSW, LCSW, OSW-C, FAOSW, Vice President of Programs and Health Equity, Family Reach



Shonte Drakeford

MSN, CRNP, AGNP-C (She/Her), Metastatic Breast Cancer Patient Advocate, Tigerlily ANGEL Advocate



Christian Dauphin

Caregiver and Husband of Dr. Lori L. Wilson



Asma Dilawari

MD, Medical Oncologist, Clinical Reviewer, U.S. FDA Division of Oncology 1, Breast



Ann Fonfa

Founder/President/Volunteer, Annie Appleseed Project



Pierce Gould

Associate Managing Director, Press Ganey Life Sciences Division



Regina Hampton

MD, FACS, Chief of Breast Surgery, Luminis Health



Sara Horton

M.D., Executive Director of Access and Diversity, Quantum Leap Healthcare



Jazmine A. Lampkin

BSN, RN, Tigerlily ANGEL Advocate

2023 BEACON SYMPOSIUM PANELISTS AND SPEAKERS CONTINUED



Rachel Landauer

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



Lyndsay Levingston

Founder,
SurviveHER



Neha Shah Londoño

Director, Global Clinical Trial Diversity, Equity, & Inclusion, Seagen



Christina Mackey

M.A., M.Ed, Breast Cancer Survivor, Tigerlily ANGEL Advocate & Trainer



Linda Murakami

Head of Health Equity, Patient Engagement and Policy, Amgen



Mandi L. Pratt-Champman

PhD, Associate Director, Community Outreach, Engagement, and Equity, GW Cancer Center



Valencia Robinson

Co-founder,
Women of Color Wellness Alliance



Kawana Rucker

BCHC & PA, Tigerlily ANGEL Advocate Lead, DMV Area



Lisa Simms Booth

Executive Director, Smith Center for Healing and the Arts



Keisha Stephney

Patient Advocate, Founder/CEO, Peach'd Pink Project, Tigerlily ANGEL Advocate Lead, Bay Area, CA



Kendal Whitlock

Digital Optimization, RWE Clinical Trials, Walgreens

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OVERVIEW:

The challenge

Still there persists to be pervasive disparities in breast cancer care and outcomes that continue among communities, particularly those of marginalized backgrounds. Despite advancements in medical science, access to quality care remains unequal, with barriers such as inadequate education, limited access to healthcare services, and systemic inequities exacerbating the burden of breast cancer.

The organization

Tigerlily Foundation (Tigerlily) is a national women's health and oncology organization providing education, awareness, advocacy, and hands-on support to young women, before, during and after cancer, with a vision to end disparities of age, stage and color. We focus on health, wellness and risk reduction as a lifestyle—supported by traditional and integrative medicine. Through our programs, we seek to educate and empower women of all backgrounds, including those at heightened risk, those facing health disparities, and those with less access to care. We strive to improve quality of life and end isolation among cancer patients and survivors.

The approach

The inaugural BEACON Symposium marked a groundbreaking milestone in health equity. As the first-of-its-kind symposium focused on the patient experience, led by patients, and featuring patient advocate expert speakers (including Tigerlily ANGEL advocates), BEACON illuminated the path toward a more inclusive and empowering healthcare landscape. The symposium aimed to address these challenges by fostering dialogue, collaboration, and innovation to drive systemic change. By bringing together patients, advocates, healthcare providers, policymakers, and other stakeholders who typically do not have the opportunity to be at the table together to co-create solutions, BEACON sought to dismantle barriers, advocate for patient-centered approaches, and ultimately strive towards a future where every individual facing breast cancer receives equitable care and support. This report encapsulates the transformative dialogue and insights shared at the symposium, highlighting its profound impact on communities, healthcare providers, systems, pharmaceutical companies, and other stakeholders.

INSIGHTS & HIGHLIGHTS:



Empowering Generational Health Conversations:

Speakers highlighted the importance of breaking the cycle of secrecy surrounding family health histories, particularly in Black families. Commitments were made to initiate conversations about family history, including cancer, AIDS, and other health issues, empowering future generations with knowledge and awareness.

INSIGHTS & HIGHLIGHTS CONTINUED:

Multi-Generational Health Education:

Speakers and audience members stressed the need for comprehensive health education spanning generations, emphasizing early detection, holistic approaches to health, and reframing breast cancer as a chronic, manageable condition rather than a terminal illness.

Integration of Community Health Workers (CHWs):

Integration of CHWs into healthcare systems, particularly cancer centers, to provide personalized support and navigation tailored to individual patient needs is essential. Collaborations between patient advocates and CHWs were highlighted as crucial for enhancing patient comfort and understanding.

Educational Initiatives in Schools:

Discussions underscored the importance of reintroducing health education, including nutrition and cancer awareness, into school curricula. Efforts were proposed to partner with schools in the District of Columbia to implement comprehensive health education programs.

Expanding Access to Breast Health Services:

Leveraging existing resources such as prenatal mobile units, delegates advocated for expanding access to breast health services for women under 40. Strengthening trusted networks and community partnerships was emphasized to disseminate resources and support for financial toxicity.

Enhancing Safety and Support in Clinical Trials:

Discussions highlighted the need for enhanced safety protocols and patient support in clinical trials. Innovations such as oncopharmacist connections and patient-centered trial designs were proposed to improve the patient experience and ensure safety.

INSIGHTS & HIGHLIGHTS CONTINUED:

Addressing Financial Toxicity:

Panelists emphasized the need to address financial toxicity beyond insurance coverage, advocating for policy changes to support patients through Medicare/Medicaid and alleviate unmet basic needs.

Empowerment through Patient-led Programs:

Programs led by and for patients have proven to be mutually empowering, fostering better-tailored support for communities and individuals, ultimately leading to greater success in addressing healthcare challenges.

Criticality of Early Detection:

Personal testimonies underscored the critical importance of early detection, emphasizing its role in saving lives and providing individuals with crucial second chances.

Integrative Healthcare and Wellbeing:

The symposium underscored the importance of holistic, personalized treatment plans that prioritize both physical and emotional wellbeing, alongside efforts to mitigate financial toxicity.

Community Engagement and Collaboration:

Collaborative partnerships between healthcare providers, community organizations, faith-based groups, and insurers were highlighted as essential for delivering patient-centered care and addressing systemic barriers.

NEXT STEPS:



Policy Advocacy and Coalition Building:

BEACON Symposium outcomes serve as a model for innovative policies and partnerships between hospitals, community organizations, and advocacy groups. The symposium's impact extends to diverse representation in policy-making and a redefined approach to community outreach, including mapping across patient advocacy groups to assess the wide depth of services and form a patient-led, cross industry supported coalition to meet community-focused and national needs.

To learn more about Tigerlily's policy work, email HEAL@TigerlilyFoundation.org or visit <https://heal.tigerlilyfoundation.org/>.

NEXT STEPS CONTINUED:

Educational Initiatives and Provider Training:

Next steps include expanding health education initiatives in authentic community settings, educating providers on best practices, and engaging insurance agencies to address systemic barriers. To access Tigerlily's patient-facing and provider-facing Barrier Toolkits, visit <https://tigerlilyfoundation.org/barrier-toolkits/>.

Patient-Centered Innovations:

The symposium's impact extends to clinical trial design and patient navigation, with calls for policy changes to incorporate patient feedback, empower patient advocates, and improve access to supportive services. In addition, a call to promote awareness of umbrella services for covering out-of-pocket costs in clinical trials, ensuring equitable access for patients and navigators.

Financial Support and Access:

Efforts underway to raise awareness of financial support options for clinical trial patients need to be continued and integrated and supported by health care systems and continued advocacy for comprehensive coverage of alternative therapies and integrative health services is essential.

Strengthening Community Partnerships:

Collaboration with community-based and faith-based organizations continues to need to be prioritized, ensuring patient-oriented support and connectedness throughout the cancer journey. We need to create community-specific frameworks to overcome barriers and support local groups to do the work where they live, work and are trusted.

NEXT STEPS CONTINUED:

Policy and Advocacy Initiatives:

Advocate for patient-informed controls on AI in healthcare and policy changes that prioritize patient outcomes, including personalized treatment plans and integrative healthcare services. This includes ensuring AI in healthcare is assessed for bias and any biases in programming removed to promote health equity.

Industry Engagement and Education:

Encourage greater involvement of pharmaceutical companies, insurers, and other stakeholders in patient-centered dialogues, facilitating mutual learning and adaptation to evolving healthcare needs.



PANEL SUMMARIES:



Panel 1: Health Equity with the Patient as the Leader – A Paradigm Shift

Panelists: PAMELA L. BARNES, MA, Director, Federal Strategic Alliances, Bristol Myers Squibb | LYNDSEY LEVINGSTON, Founder, SurviveHER | MANDI L. PRATT-CHAPMAN, PhD, Associate Director, Community Outreach, Engagement, and Equity, GW Cancer Center | KAWANA RUCKER, BCHC & PA, Tigerlily ANGEL Advocate Lead, DMV Area | KEISHA STEPHNEY, Patient Advocate, Founder/CEO, Peach'd Pink Project, Tigerlily ANGEL Advocate Lead, Bay Area, CA.

PANEL SUMMARIES CONTINUED:

Expert BEACON Panel Findings

This panel discussed transformative approaches to healthcare centered around patient empowerment and community engagement. The discussion highlighted leveraging digital platforms and social media for innovative outreach strategies that bridge cultural gaps and foster community connections. It emphasized the importance of equipping patients with essential information, financial literacy, and the ability to ask pertinent questions before meeting with their oncology team, with trained patient advocates and survivors playing a crucial supportive role. The future of healthcare was envisioned to involve integrating patient-led programs and health coaches alongside traditional medical approaches, fostering holistic care and empowerment. Initiatives like employee-based resource groups were showcased as effective in informing pharmaceutical companies about designing clinical trials that better suit the needs of diverse populations, including those with disabilities. Collaborative partnerships between patient advocacy groups and pharmaceutical companies demonstrated effective models for driving policy change and community engagement. Efforts to address social determinants of health (SDOH) were deemed essential and need to be integrated at the pharmaceutical and Contract Research Organization (CRO) level.

The importance of empowering individuals to use their advocacy voice was emphasized, leading to meaningful changes such as influencing employer health plans to prioritize health equity. Initiatives like community-centered events and support programs were highlighted for meeting the diverse needs of patients beyond breast health. Sustainable change requires partnerships and funding support to drive initiatives such as training advocates through projects like the Community Health Worker Project at GW. Advocates play a crucial role in advocating for comprehensive data collection and continued investment in research to drive evidence-based decision-making. There's a call for a paradigm shift in research compensation, questioning why patients are compensated for research participation while community leaders providing input and

PANEL SUMMARIES CONTINUED:

Expert BEACON Panel Findings

support are not similarly compensated. Overall, the panel underscored the need for a holistic approach to healthcare that prioritizes patient empowerment, community engagement, and collaborative partnerships to drive meaningful change and improve health equity.

BEACON Recommendations:

1. Patients/survivors/thrivers are trained as Community Health Workers (CHW) and embedded within cancer centers to help patients enter and navigate care through survivorship. Peer navigators and CHW should be asked for their insights on how the health system or cancer center should address and prioritize SDOH distress for the population they all serve.
2. Pharmaceutical and Contract Research Organization (CRO) should have specific plans to address social determinants of health (SDOH) before, during and after clinical trials and leave something behind.
3. Influence employer health plans to address health equity. Work with Employee business groups to enable and influence change within a corporation.
4. Community Events with trusted CBOs/FBOs and lifestyle organizations should be offered on continuum of care subjects that focus on the health of young BIPOC women beyond and including breast cancer. e.g. topics like right to have a choice to participate in a clinical trial, mental Health in the community, genetic testing and biomarker testing, vaccines and cancer care, fertility and cancer care, bone health and cancer care etc.

PANEL SUMMARIES CONTINUED:



Panel 2: What Nirvana Looks Like for BIPOC Patients & Clinical Trials

Panelists: CHRISTIAN DAUPHIN, Caregiver and Husband of Dr. Lori L. Wilson | SARA HORTON, M.D., Executive Director of Access and Diversity, Quantum Leap Healthcare Collaborative | CHRISTINA MACKEY, M.A., M.Ed, Breast Cancer Survivor, Tigerlily ANGEL Advocate & ANGEL Trainer | NEHA SHAH LONDOÑO, Director, Global Clinical Trial Diversity, Equity, & Inclusion, Seagen | KENDAL WHITLOCK, Digital Optimization, RWE Clinical Trials, Walgreens.

PANEL SUMMARIES CONTINUED:

Expert BEACON Panel Findings

The panel shed light on innovative approaches to improve the clinical trial experience for BIPOC patients. Panelists highlighted the transformative impact of initiatives like ANGEL training, advocating for its widespread availability to empower patients from the onset of their diagnosis. They emphasized the crucial role of accessible support systems, such as Oncopharmacists, in managing treatment side effects and fostering enduring patient-physician relationships. Innovation in clinical trial models was discussed, emphasizing the incorporation of patient empowerment and shared decision-making into standard practice. The importance of a strong patient village, personalized treatment approaches, and financial toxicity considerations were underscored. Panelists advocated for true collaboration between patients, advocacy organizations, and healthcare stakeholders to inform culturally appropriate and community-based approaches. Initiatives like Seagen's support for community empowerment and engagement were highlighted as examples of progress. The need for policy changes to support patients, including addressing non-monetary barriers to participation, was emphasized, along with the importance of diverse representation in clinical trials. The discussion called for proactive efforts to bridge gaps in access to research, empower patients through dedicated support systems, and foster collaboration between stakeholders to ensure equitable and inclusive clinical trial experiences for all.

BEACON Recommendations:

1. A third-party patient navigator should be assigned to each patient and would not be associated with the hospital or sponsor so they can provide resources from anywhere without any barriers.

PANEL SUMMARIES CONTINUED:

BEACON Recommendations continued:

2. Remove caps and other restrictions for financial assistance to patients participating in clinical trials for non-clinical items, including the IRS tax to clinical trial participants on any stipends over \$600. Post meeting note: See new 2024 bill HR 7090.

3. All Patients should be given a respectful choice to participate in a clinical trial. The choice is the goal.

4. Remove restrictive regulations and educate IRBs so sponsor can support patients/clinical trial participants to ensure trial adherence with transparency.

5. Trial sponsors should build ways to address SDOH barriers in their clinical trial budgets and partner authentically with existing patient advocacy groups to do so versus with other industry organizations or agencies. It is also recommended that this be part of FDA guidance moving forward.

6. CROs and sponsors to partner with patient organizations to optimize community engagement plans and patient insights before, during and after the trial.

PANEL SUMMARIES CONTINUED:



Listening Session 1: Re-imagining our Healthcare System - Patient Innovation

Presenters: JAZMINE A. LAMPKIN, BSN, RN, Tigerlily ANGEL Advocate | REGINA HAMPTON MD, FACS, Chief of Breast Surgery, Luminis Health-Doctors | PIERCE GOULD, Associate Managing Director, Press Ganey Life Sciences Division

PANEL SUMMARIES CONTINUED:

Expert BEACON Presenter Summaries

The first presentation, delivered by Jazmine Lampkin, emphasized the importance of equitable healthcare for all individuals, regardless of race or background. Mrs. Lampkin highlighted the critical need for healthcare providers to listen to their patients, referring them to relevant support organizations, and developing personal relationships beyond medical records. She shared a poignant personal story underscoring the consequences of delayed diagnosis, stressing the vital role of attentive and culturally competent care. Additionally, Jazmine called for patients to take an active role in their healthcare, advocating for transparency and collaboration with providers. Ultimately, she urged collective action to improve outcomes, particularly for Black and Brown women facing cancer.

Regina Hampton's presentation highlighted shifts in healthcare, particularly in breast cancer care, focusing on patient navigation and survivorship. Dr. Hampton also emphasized the evolution from nurse navigators to peer navigators, recognizing the need for broader support networks. She stressed the importance of transitioning patients from constant medical care to survivorship, facilitating a return to a new 'normal' life. Survivorship care plans were discussed as tools to guide non-oncology providers in post-treatment care, aiming for a smooth transition while still ensuring ongoing monitoring. Challenges such as limited resources and delayed access to screenings were acknowledged, with a call for collaboration between survivors and healthcare providers to address these issues.

The final presentation, by Pierce Gould, focused on the intersection of healthcare, patient experience, and clinical trials. Pierce highlighted the importance of patient-centric approaches in shaping future healthcare. He discussed Press Ganey's role in measuring patient experience through surveys, revealing insights into trust and respect within healthcare.

PANEL SUMMARIES CONTINUED:

Expert BEACON Presenter Summaries Continued

settings. He also emphasized efforts to bridge gaps between healthcare and science, particularly in clinical trial processes, by prioritizing patient input and engagement. Pierce shared success stories of initiatives aimed at improving patient-centered care and enrollment in clinical trials. Additionally, he called for industry-wide action to prioritize patient-centricity and invited collaboration to further this goal. The presentation concluded with a thought-provoking question on the need for standardized measurement to gauge progress in becoming more patient-centric as an industry.

BEACON Recommendations:

1. Prioritize Equitable Healthcare by supporting initiatives that focus on addressing healthcare disparities faced by Black and Brown women, such as increased funding for community health programs and outreach efforts.
2. Require providers to enhance patient-provider communication through the adoption of proven patient-centered communication practices, including active listening, empathy, and cultural competence training as well as fostering trust and collaboration in healthcare decision-making.
3. Shift to include patient education in appointment or follow up discussions to include their rights and the importance of taking an active role in their healthcare, including advocating for transparency, collaboration, and access to relevant support organizations.
4. Advocate for the implementation of survivorship care plans to guide patients through the transition from active treatment to post-treatment care, addressing challenges such as limited resources and delayed access to screenings.

PANEL SUMMARIES CONTINUED:

BEACON Recommendations Continued

5. Guidelines and requirements to include of patient input in the design and implementation of clinical trials, prioritizing trust, respect, and patient-centered care throughout the trial process in addition to supporting initiatives aimed at improving patient engagement and enrollment in clinical trials, including efforts to bridge gaps between healthcare and science.

6. Industry partners and stakeholders to collaborate to develop standardized measures for assessing patient experience and patient-centricity in healthcare settings as well as advocating for the use of these measures to gauge progress and identify areas for improvement in becoming more patient-centric as an industry.

PANEL SUMMARIES CONTINUED:



Panel 3: Policy Interventions in Health Equity & Models for Success

Panelists: EUCHARIA BORDEN, MSW, LCSW, OSW-C, FAOSW, Vice President of Programs and Health Equity, Family Reach | RACHEL LANDAUER, Clinical Instructor, Center for Health Law and Policy Innovation of Harvard Law School | LINDA MURAKAMI, Head of Health Equity, Patient Engagement and Policy, Amgen | VALENCIA ROBINSON, Co-founder, Women of Color Wellness Alliance.

PANEL SUMMARIES CONTINUED:

Expert BEACON Panel Findings

This panel highlighted crucial policy strategies for advancing health equity and patient-centered care. Speakers emphasized the importance of meeting individuals where they are by understanding their unique circumstances, particularly in addressing unmet basic needs beyond the symptoms that many times come out as financial burdens but finding the root causes and addressing these issues through policy change. Family Reach's approach was spotlighted as a model for policies for hospitals to partner with community organizations, incentivizing programs that address basic needs to sustainably support patients. The panel stressed the significance of coalition building with diverse community and advocacy groups to elevate the patient voice and consider all intersecting factors impacting health. Moreover, they underscored the necessity of diverse patient representation in policy-making, especially amplifying the voices of those with metastatic breast cancer. Discussion also delved into the current federal landscape, highlighting recent reimbursements for community health workers (CHWs) and navigators, with a call to expand this support across payors. Ultimately, the panel emphasized that effective policy must be informed by the real experiences of patients, highlighting the crucial role of patient advocacy in shaping meaningful change.

BEACON Recommendations:

1. Understand the new federal standards for reimbursements for CHW and navigators and move towards implementation.
2. Develop accessible resource hubs for patients in high-risk cities so that resources and programs are accessible in one place for support personnel. and for patients and caregivers.
3. Policy changes needs to be driven with patient advocates and patient stories first.

PANEL SUMMARIES CONTINUED:



Listening Session 2: Innovations in Risk Reduction: Health Education versus Treating Chronic Disease

Panelists: ASMA DILAWARI MD, Medical Oncologist, Clinical Reviewer, U.S. FDA Division of Oncology 1, Breast Malignancies | SHONTE' DRAKEFORD, MSN, CRNP, AGNP-C (She/Her), Metastatic Breast Cancer Patient Advocate, Tigerlily ANGEL Advocate | ANN FONFA, Founder/President/Volunteer, Annie Appleseed Project | LISA SIMMS BOOTH, Executive Director, Smith Center for Healing and the Arts.

PANEL SUMMARIES CONTINUED:

Expert BEACON Panel Findings

This panel underscored the critical need for authentic community outreach and education to mitigate health risks and tackle chronic diseases effectively. Panelists emphasized the importance of redefining what constitutes genuine community engagement, advocating for initiatives that extend beyond traditional health fairs to reach individuals where they are, including local clinics, grocery stores, salons, and community events like homecoming weekends at colleges. Furthermore, there was a call to better educate healthcare providers, particularly primary care practitioners, on best practices and resources for early interventions. Incorporating insurance agencies into these efforts was highlighted as crucial, as they often present barriers to accessing care and coverage. The panel also emphasized the importance of patient education and holistic care, including mental, spiritual, and psychosocial support, alongside physical health. Collaboration and integration were stressed as essential components of innovation, with a focus on patient navigation and integrative oncology. Simple, community-based practices and lifestyle changes were promoted as key to preventive medicine. Additionally, there was a call to involve regulatory agencies like the FDA in facilitating faster implementation of changes that benefit patients, alongside urging patients and advocates to engage in driving these transformative initiatives forward.

BEACON Recommendations:

1. Establish a comprehensive community health education and outreach program that leverages existing community resources and partnerships.
2. This program could focus on training primary care providers in underserved communities on best practices for early interventions and holistic patient care, including mental, spiritual, and psychosocial support.

PANEL SUMMARIES CONTINUED:

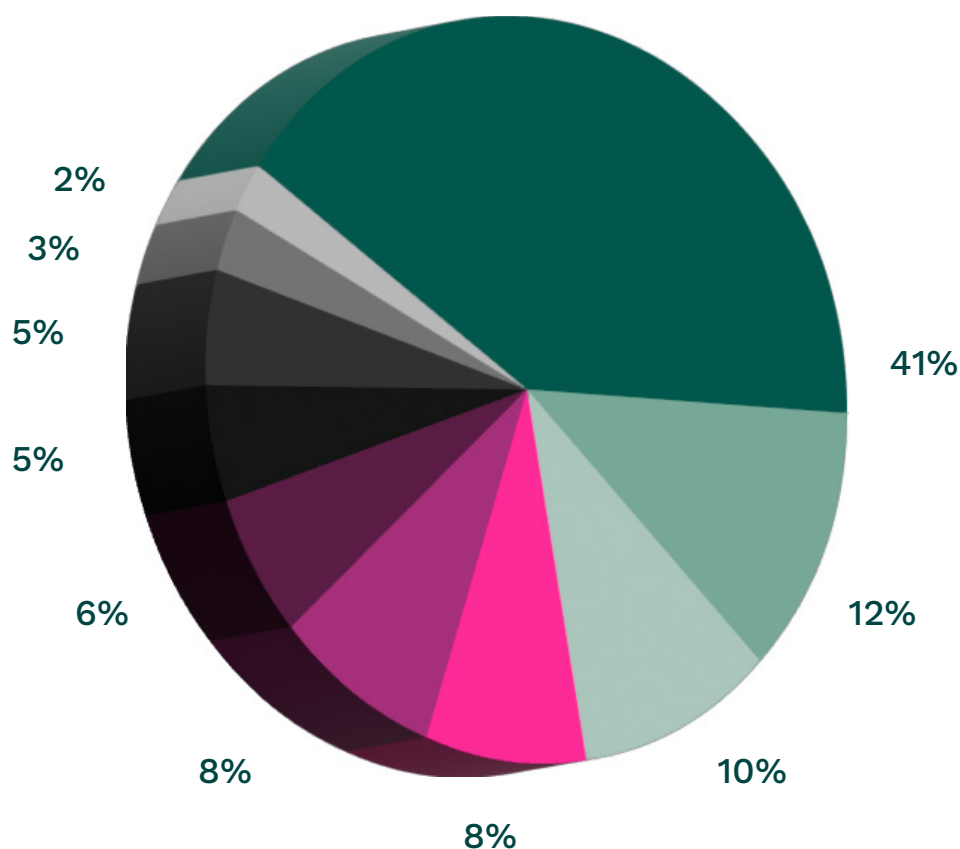
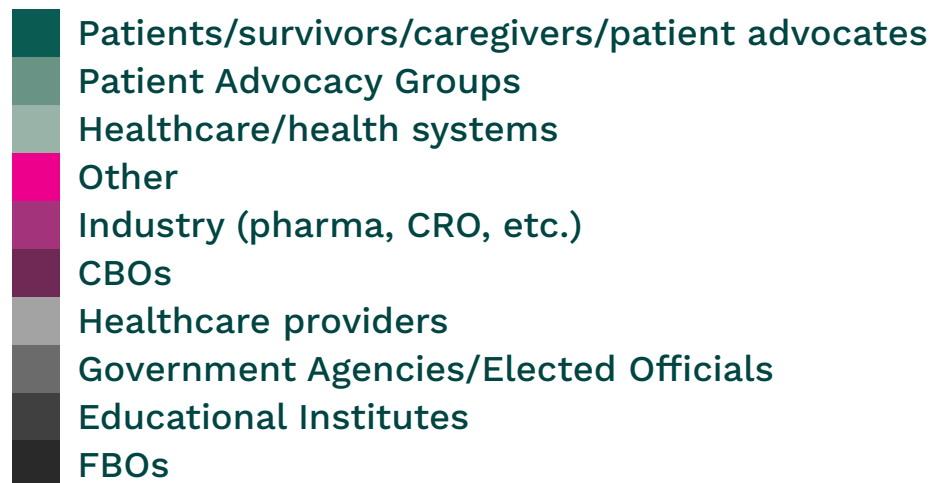
BEACON Recommendations Continued:

3. Additionally, it could involve collaboration with local businesses, clinics, and community organizations to host regular health education events in accessible locations such as grocery stores, salons, and community events. Insurance agencies could also be engaged in these efforts to provide guidance on navigating coverage and accessing resources.

By implementing such a program, communities could benefit from improved access to education, resources, and support, ultimately leading to better health outcomes and reduced chronic disease burden.

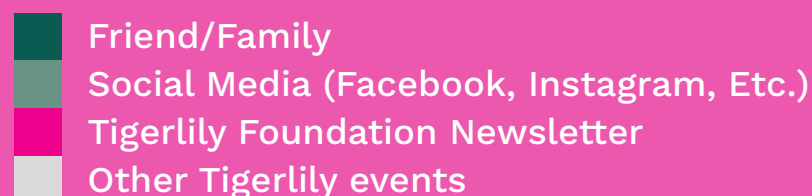
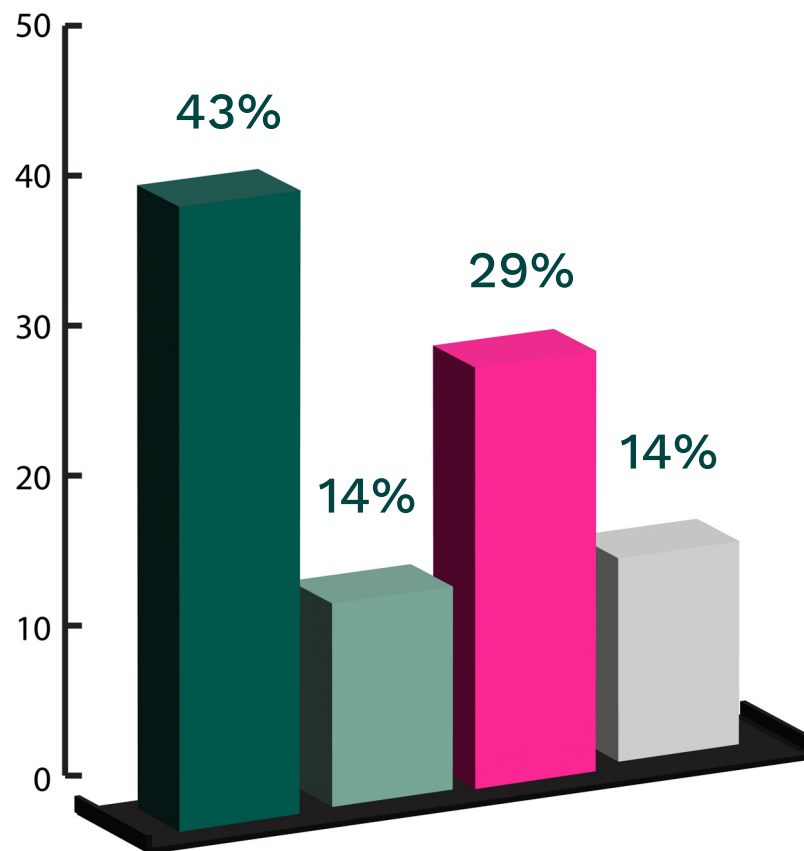
COMMUNITY REPRESENTATION:

Registered: 172



SURVEY RESPONSES:

How respondents heard about the event:



SURVEY RESPONSES CONTINUED:

How respondents most benefited from the event:

	50%	Learned the importance of knowing their family health history
	67%	Learned signs and symptoms of breast cancer
	50%	Learned the importance of being a self-advocate
	67%	Learned about resources to overcome barriers
	50%	Learned information they plan to share with family or community
	17%	Learned information they plan to share or ask their doctor about

SURVEY RESPONSES CONTINUED:

How likely respondents are to attend Tigerlily events in the future:

100% Very likely

How likely respondents are to recommend the event:

100% Will recommend

Overall, how respondents rated the event:

17% Met expectations

83% Exceeded expectations

Tigerlily's 2023 BEACON Symposium Attendee Feedback



“Just incredible-the best conference I’ve been to since my diagnosis 11 years ago.”

“Just great panelists and amazing audience participans. I’m looking forward to the next one.”

“There is nothing more important than hearing from patients, about patients, for patients! BRAVA!”

I walked away from [the BEACON symposium] amazed. That was THE best conference I have ever had the pleasure of attending.”

“So upbeat, full of hope, empowerment, and reduction of fear.”

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