Diverse Patient Engagement In Rare Diseases

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Challenges faced by underserved members.

Before discussing diverse patient engagement, it’s important to understand the systemic issues faced by underserved communities.
Challenges to Diversity in Rare Diseases

❖ Systemic Discrimination
❖ Cultural Barriers
❖ Lack of Representation in Rare Disease Spaces
❖ Lack of Diversity in Clinical Trials
❖ Lack of community health providers
❖ Unconscious Provider Bias
❖ Language Barriers
❖ And more
Consequences of Disparities and Need for Inclusion

- According to a 2018 presentation by the MRCT Center, participation by Black or African American participants in cardiovascular disease and oncology clinical trials was 3%.

- This is compared to the 13.4% of Americans that identify as Black or African American.
Consequences of Disparities and Need for Inclusion

- In study published in the Academic Emergency Journal, **women waited an average 16 minutes longer**, 65 minutes to 49, to receive an opioid analgesic for acute abdominal pain compared to men.

![Graph showing average wait-time in minutes for administration of opioid analgesics in the ER]

- Women waited 65 minutes on average, while men waited 45 minutes.
Patient Empowerment

The EveryLife Foundation Mission

EveryLife Foundation for Rare Diseases

Because Every Life Matters
The EveryLife Foundation for Rare Diseases is a 501(c)(3) nonprofit, nonpartisan organization dedicated to advancing the development of treatment and diagnostic opportunities for rare disease patients through science-driven public policy.

“We do not speak for patients. We provide the training, education, resources, and opportunities to make their voices heard. By activating the patient advocate, we can change public policy and save lives.”

– Julia Jenkins, Executive Director
Rare Disease Week on Capitol Hill
2020 was our ninth and most successful year!

900+ patients, caregivers, researchers, and other advocates joined us for at least one event during the week!

**Who:** Rare disease patients, caregivers, and other advocates including physicians

**What:** Series of events aimed at empowering patients

**Where:** Washington, D.C.
Creating spaces at events for diverse community focus.

Planning how best to use our scholarship and stipend programs.

Increasing outreach to states with diverse patient populations.

Performing outreach to diverse populations and rare disease organizations.

Setting goals for diverse community outreach.

Creating resources and models for rare disease organizations.
Strategies For Inclusion

- Developing a diverse staff and board that includes underserved communities
- Enable feedback by diverse communities
- Setting quantifiable goals for inclusivity and diversity
- Offering multi-lingual language options for event and project materials
- Creating materials designed with accessibility and inclusivity in mind
Thank you!

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What are Patient Organizations Doing to Enhance Inclusion Research and Patient Outreach?

JEANNE REGNANTE
CHIEF HEALTH EQUITY OFFICER
LUNGEVITY FOUNDATION
How Did I Get Here?

Started March 2020

Inspired by many...
What is LUNGevity Foundation's Health Equity Goal?

Our goal is to improve the lives and outcomes of all people impacted by lung cancer; We created a Health Equity and Diversity Initiative to ensure that all people diagnosed with lung cancer have access to optimal care.
African American Patient with Lung Cancer - ILCSC, Aug. 2020 (chat)

“Wow- I had no idea that there was an issue with African Americans not being included in lung cancer clinical research.”
PHEN began partnering with churches in 2009 with its “Annual Father's Day Rally" and has since worked with more than one thousand churches nationwide. PHEN expanded its partnership initiatives to include Educational Symposiums (2013), The Daddy’s Boys Stage Play (2017), and Social Media Initiative (2018). These efforts are aimed at educating and mobilizing men, women, and communities in the fight against prostate cancer.

Social Media Initiative
PHEN uses social media to provide live online monthly educational programs with church partners via Facebook Live. This initiative allows churches to outreach to their members with expert prostate cancer presentations and provides PHEN with the ability to bring prostate cancer educational programs into most every community on a continuing basis.
How Did You Get Buy In From Your Organization?

• “What Matters” Awareness Training X 3 over two months, staff surveys

• Health Care Disparities
• Health Equity
• Cancer Continuum of Care
Disparities Exist Throughout the Lung Cancer CA Continuum of Care

**INEQUITABLE HEALTH OUTCOMES**

The age-adjusted lung cancer incidence rate among black men is ~32 - 51% higher than for white men.

The five-year survival rate for lung cancer is over 20% lower for black Americans than for white Americans.

Income and education levels are also highly correlated with lung cancer mortality.

**RISK FACTORS FOR DISEASE**

Black smokers are 20% more likely to have lung cancer than white Americans who smoke the same amount

**TIMELY SCREENING AND DIAGNOSIS**

Black Americans are far more likely to have a late-stage diagnosis than white Americans.

Patients on Medicaid wait 5 times longer to see an oncologist than patients on private insurance.

**FOLLOW-UP WITH SPECIALIST**

Black Americans are 20-70% less likely to receive life-saving treatment than white Americans.

**HIGH-QUALITY CARE**

Patients from communities with household incomes below $30K are 25% likely to die within 30 days of lung surgery than wealthier patients.
Historical Injustices

**THE TUSKEGEE STUDY OF UNTREATED SYPHILIS IN THE NEGRO MALE**

In 1932, the Public Health Service, working with the Tuskegee Institute, began a study to record the natural history of syphilis in hopes of justifying treatment programs for blacks. The study initially involved 600 black men – 399 with syphilis, 201 who did not have the disease.

[Source: https://www.nih.gov/tuskegee/timeline.html]

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**HE LA**

HeLa cells are the first immortal human cell line. The cell line grew from a sample of cervical cancer cells taken from an African-American woman, Henrietta Lacks, on February 8, 1951. The lab assistant responsible for the samples named cultures based on the first two letters of a patient’s first and last name, thus the culture was dubbed HeLa. In 1952, Theodore Puck and Philip Marcus cloned HeLa (the first human cells to be cloned) and freely donated samples to other researchers. The cell line’s initial use was in cancer research, but HeLa cells have led to numerous medical breakthroughs and nearly 31,000 patents.

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**WHERE WAS HENRIETTA LACKS TREATED FOR HER CANCER?**

A pop-up Health Equity Quiz Break

**WHO WAS THE PRESIDENT THAT APOLOGIZED TO PATIENTS AND THEIR FAMILIES?**

A pop-up Health Equity Quiz Break

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**PUTTING PATIENTS FIRST**

National Health Council

Celebrating 100 Years
The Science of Cancer Health Disparities in Racial/Ethnic Minorities and the Medically Underserved

Successful implementation of implicit bias awareness training to support a lung cancer patient organization’s health equity strategy

Presenter/Lead Author: Jeanne M. Regnante
Chief Health Equity and Diversity Officer
LUNGevity Foundation
Chicago, IL

Co-Authors: Cheri Freeman-Watkins, Results One LLC; Barbara Netter, LUNGevity Foundation; Kim Alfonso, Results One LLC; Andrea E. Ferris, LUNGevity Foundation
Our Staff Asked Me to Consider...

Commitment to an Expanded Patient Definition:

• “We have huge gaps as an organization to provide the services underserved populations need. We have not been focused on smokers, or people with lung cancer who may not be highly educated and motivated”

Educational Materials

• “Our materials are too complicated; not culturally sensitive or health literate. They are too rich with information- use difficult terms; because we are driven by data and science… we need to develop this capability”

Community Engagement

• “We need to develop a community-based organization network…. we need connectivity with trusted leaders in high risk cancer communities who are engaging with vulnerable populations to learn from them and understand what patients need”

“AMPLIFY WHAT WE DO”
Communities, Who Are They and Where are They... Access to Care

Vulnerable Lung Cancer Communities

- Abstract: Clinical Trial.gov CT overlap with Prevalence of REMGs with Lung CA
- Abstract: Lung Cancer Screening Center COE overlap with REMGs with Lung CA

REF: 2016 Medicare FSS- NMQF
Lung Cancer Index [database]
What Is Meant By Health Literacy?

- Health literacy is a critical enabler to engage and involve patients in their health care and the health of those who they care for.
- Patients are often presented with an overwhelming amount of information that is distributed in an uncoordinated and inconsistent manner.
- Low health literacy is one of the social determinants of health associated with cancer-related disparities.
- Expanding partnerships with community-based organizations and consumers addresses unmet needs associated with cancer disparities.
NCI CC Leaders in Community Outreach, Engagement and Equity (Total N= 71)

• Build trusted community-academic partnerships that can reduce barriers and improve standard of care for vulnerable cancer communities
• Education about cancer prevention and control
• Opportunities for regular screenings and early detection
• Supportive services for treatment and survivorship including biomarker testing
• Programs for those struggling to access or afford care (SDOH)
• Listen to patient’s cancer concerns and partner in research and programs that address their most pressing needs
• Partner with LUNGevity Foundation for lung cancer patient expertise, education, research, program reach, CBO partner access, advocacy

Rickie Brawer, PhD, MPH, MCHES
Lorna McNeill, PhD, MPH
Karriem Watson, DHSc, MS, MPH
Build Sustainable Models

Development of an Actionable Framework to Address Cancer Care Disparities in Medically Underserved Populations in the United States: Expert Roundtable Recommendations

Stakeholders who implement this framework.
- Health care leaders, patient advocate groups,
- Community outreach leaders, community-based organizations, lay, nurse and clinical navigators, researchers, industry, government and policy leaders

Medically underserved populations.
- Racial/ethnic minority groups, rural populations, aged, adolescent/young adult, LGBTQ, differently abled, immigrants and refugees, and under and unserved communities

What strategies do US cancer centers use to optimize recruitment of racial and ethnic minority groups into clinical trials?

How Can We Make Cancer Clinical Trials More Diverse & Inclusive?

(Submitted JOP, Sept 2020)
What I Have Learned

• Cultural humility everyday; ongoing implicit Bias training is critical
• There is hope for lung cancer patients; they don’t think so
• “Patient Friendly” Education is lacking ---patients/caregivers need to understand standard of care in order to advocate for themselves
• The way to reach the community IS the community – this is the trusted way to reach patients for more timely screening.. inclusion in research
• We must be expert in lung cancer disparities at a state/county for each REMG and low SES whites to be able to address disparities
• Cancer Continuum of Care: Focus early efforts on early detection/screening and treatment/inclusion in clinical trials
• “All stakeholder” sustainable US models are needed

Do the work with community partners, then recognize & share best practice efforts nationally.
Our Vision and Strategy

Secure the **trusted** engagement and partnership of lung cancer communities to achieve health equity and equalize disparities for all.

**WHAT MATTERS?**

- DATA ON DISPARITIES
- GEOGRAPHY
- COMMUNITY ENGAGEMENT
- HEALTH LITERACY
- SOCIAL DETERMINANTS OF HEALTH (SDOH)
- FEAR AND HESITATION IN RESEARCH
- RACISM IN HEALTH CARE
- MODEL DEVELOPMENT

**Focus on Community**

Enable Trusted community partnerships in high risk geo locatons.
Focus on PF education.

**Address Disparities**

Establish LUNGevity as the expert on disparities across the lung cancer care continuum for vulnerable populations in high risk geo locations.

**Model Development**

Drive successful US models of community and patient engagement for vulnerable lung cancer patients and their care partners.

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PUTTING PATIENTS FIRST

NATIONAL HEALTH COUNCIL

Celebrating 100 Years
#ALLTOGETHERNOW!

"No one can whistle a symphony. It takes a whole orchestra to play it."
— He Luccock
Thank you!

Jeanne Regnante
Chief Health Equity Officer
LUNGevity Foundation