


PATIENTS' Voices

a newsletter from the PATIENTS Program at the
University of Maryland School of Pharmacy



Message from the PATIENTS Program Team

As part of The PATIENTS Program mission that "Patients and stakeholders are heard, inspired, and empowered to co-develop patient-centered outcomes research (PCOR)", we've spent hours in the community conducting one-on-one interviews, as well as getting footage of events and programs that enhance and support our mission. But, more importantly, we've captured numerous personal stories from patients and caregivers, researchers, and community advocates, who give greater insight into what PCOR looks like in the "real world", along with the successes and challenges related to engaging the health care system and living their best lives.

In this issue of PATIENTS' Voices, we're featuring some of that video content, highlighting personal stories that many of our readers can relate to. You'll find valuable wellness tips that promote active and healthy lifestyle choices. The videos featured in this month's newsletter are just a small sample of what we've collected while out and about in the community. Be sure to subscribe to the [PATIENTS YouTube channel](#), PATIENTS: Engaged in Research to view additional information. You'll receive notifications of new content as it becomes available and you can also follow our [@PATIENTSProgram page](#) on Facebook where we also share video content on a regular basis.

We're also excited to announce the launch of our new Learning Health Care Community research project funded by Merck & Co Inc. Investigator Studies Program. For the next 18 months, we'll engage patients, caregivers, providers, and researchers from west Baltimore and across the country to gather and analyze information with the intent of achieving a more equitable health care system.

As always, we welcome your feedback on how to make this newsletter a better resource for you. Feel free to email us at patients@rx.umaryland.edu to submit your comments, suggestions, and ideas.

Meet the PATIENTS Team

PATIENTS Program Team Members and Advocates Talk About the Myths and Facts of Medical Research



B.J. Shaneman, PATIENTS Community Outreach Coordinator, is a registered nurse and long-time community advocate for patients throughout Baltimore City. In this video, B.J. talks about the myths related to medical research that prevent many people from participating, and gives the facts about what it means to be a part of the research process.

A First-Hand Story of PCOR's Positive Impact in the Community

Each year the PATIENTS Program holds a leadership meeting to provide updates on program activities and receive feedback and guidance from its board members and advisors. As is customary with each formal PATIENTS Program gathering, the recent gathering started with a personal account of how a patient-centered approach impacts lives.



Listen as Tanya Alexander, breast cancer survivor and PATIENTS advocate, describes her health care journey and her take on the benefits of research in her community.



The PATIENTS Program Launches a New Study to Increase Patient-Health System Collaboration and Promote Greater Health Equity in West Baltimore

On September 8, 2017, The PATIENTS Program at the University of Maryland, School of Pharmacy, held its first advisory board meeting to launch a research study with a broad goal of increasing collaboration between patients and provider health systems, and to promote greater health equity in the west Baltimore community.

The \$349,000 study, "Co-developing Sustainable Learning Health Care Communities (LHCC) using Community-Based Participatory Research", funded by Merck & Co Inc. Investigator Studies Program, will engage patients, caregivers, providers and researchers from west Baltimore and across the country to gather and analyze information.

According to the study's Principal Investigator, Professor C. Daniel Mullins, "The learning healthcare system model is an excellent way to assure that evidence-based treatments

are used by patients and their health care providers; however, the current implementation approach requires patients to enter into a healthcare system to be active participants. We hope to learn from patients and community members how we can build upon innovations and lessons learned from learning healthcare systems, while engaging patients earlier on in the process. That way, we can prevent - rather than just effectively treat - illness and disease."

[read more](#)

PCOR in Action

The idea of patient-centered outcomes research (PCOR) may be too complicated for people who don't work in health-related jobs, which is why PATIENTS enlists community members to tell their stories and what PCOR looks like in everyday life.



What happens when a University of Maryland researcher and a parent of an autistic child work together to help other parents navigate day-to-day care decisions? Hear Danielle Strobeck and Gloria Reeves, MD explain the real-world benefits of putting patients first in the research process.



One of the best ways to make a patient's journey from illness to health even more impactful is to use that knowledge to help others. PATIENTS partner Jeff Wells recounts his story of moving from patient to research advisor.

Tips for Healthy Living

Fitness Fun: Chair Yoga

Certified yoga instructor and west Baltimore community member, Jacqueline Williams of City Bliss Yoga, shares a 15-minute chair yoga routine to help reduce stress and increase strength and flexibility.



Check out more short clips of Jacqueline demonstrating yoga postures that lengthen and strengthen the body.

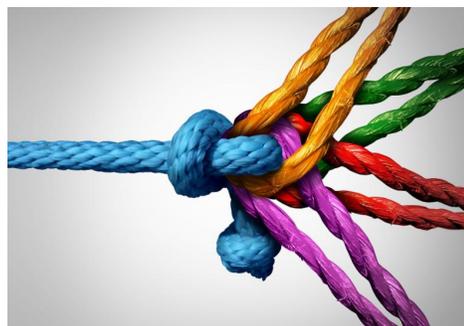


Tackling Food Deserts in the Park Heights Community



Nutrition is the cornerstone of any solid health regimen, but what happens when you live in a neighborhood without access to grocery stores that sell fresh fruits and vegetables? Watch as members of the The Park Height Community Health Alliance discuss the importance of turning a half-acre lot in their west Baltimore community into an urban oasis that grows organic produce.

Partner Spotlight: Mount Lebanon Baptist Church Changes Lives through Its HIV/AIDS Ministry



website: <http://www.mtlebanonbaptist.org/>

Facebook: <https://www.facebook.com/Mt-Lebanon-Baptist-Church-113844961979377/>

Founded in 1924, Mount Lebanon Baptist Church continues to serve as a pillar of spiritual guidance and community advocacy in west Baltimore's Mondawmin community. Under the leadership of Reverend Franklin Lance, D. MIN, the church provides support through innovative programs like its HIV/AIDS Ministry and Domestic Violence Ministry.

Gail Graham, a member of Mount Lebanon Baptist Church and the face of the church's HIV Ministry, has been living with HIV for the past 20 years. Partnering with other-faith based organizations, as well as community programs like PATIENTS, Gail continues to advocate for prevention, early detection, and support for those living with HIV/AIDS.

Gail Shares Insights on Living with HIV/AIDS



In the Community

Community Health: A Holistic Approach

Healthcare isn't always about patients and doctors and hospitals. It's about viewing health and wellness through a wider lens of public policy and community access. The following videos examine health from a variety of perspectives.



Youth Police Dialogue Circles

Building trust and repairing relationships require open dialogue. Community Mediation shares some insight on how to rebuild the conversation between Baltimore's youth and police.

PATIENTS Talk to Seniors at the Enoch Pratt Free Library

The PATIENTS Program's Tracy Rice and BJ Shaneman were invited to the Enoch Pratt Free Library's Orleans Street Branch. They had the opportunity to present at the Harry and Jeanette Weinberg Seniors Program to many seniors in the community. This program has been reaching out to Baltimore's patriachs for several years, keeping them informed and connected.



Molding Young Men from the Inside Out

Project Pneuma helps young men in Baltimore City develop focus and structure in a loving, nurturing environment. Under the leadership of project founder Damion Cooper, these young men have the opportunity to grow into healthy men and leaders in their communities. The PATIENTS Program gives a look inside a life-changing program.

Using Acupuncture to Aid in Addiction Recovery

The Penn North Recovery Acupuncture program gives community members recovering from substance abuse an

opportunity to experience the mental and physical health benefits of the ancient eastern medical practice of acupuncture.



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Our Vision

Patients and stakeholders are heard, inspired, and empowered to co-develop patient-centered outcomes research.