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# PATIENTS' Voices

a newsletter from

## The PATIENTS Program

at the University of Maryland  
School of Pharmacy



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## Message from the PATIENTS Program Team

We didn't take much of a vacation this summer. In fact, the PATIENTS Program team spent time preparing for PATIENTS Day 2018, our second-ever community health fair, where we bring together researchers, community members, health professionals, and representatives from community advocacy groups to share information and learn from each other about the work we must do to move toward creating a better, healthier Baltimore. The team also continued conducting and supporting research projects like the Learning Health Care Community and the Radcomp breast cancer treatment studies.

In this issue of PATIENTS' Voices, we'll provide an update on those projects and introduce you to a new study we're conducting to help the Food and Drug Administration communicate more effectively with women.

Be sure to check what's playing on the [PATIENTS YouTube channel](#), where you can find videos of the panel discussions from PATIENTS Day and other great stories from members of our community.

As always, we welcome your feedback on how to make this newsletter better. Feel free to email us at [patients@rx.umaryland.edu](mailto:patients@rx.umaryland.edu) to submit your comments, suggestions, and ideas.

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## Meet the PATIENTS Team

PATIENTS Day 2018



Last month the team hosted [PATIENTS Day 2018](#), an interactive health fair that offered attendees an opportunity to learn from, and teach each other, how to create and sustain health for individuals and communities in Baltimore. The theme was "Your Health. Your Voice", and nearly 200 community members, health care providers, and researchers came together at the University of Maryland BioPark for panel

discussions on a broad range of topics that impact community health, such as fitness and nutrition, education, financial health, and gun violence.

If you didn't get a chance to join us, be sure to visit the [PATIENTS YouTube channel](#) and listen in on the full sessions.

[View the full panel discussion:](#) The Impact of Gun Violence on the Health of Baltimore's Residents, Neighborhoods, Education, and Economy.

[View the full panel discussion:](#) Research from the Community Perspective-Real Talk about the Good, the Bad, and the Impact of Health Research.



Patient advocate, Del Price, delivers opening remarks



Rodney Elliott, PATIENTS Program Engagement Specialist

Do you have suggestions for next year's PATIENTS Day or want to learn more about how you or your organization can participate? [Email our Engagement Specialist](#), Rodney Elliott, or call 410-706-3839.

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## Projects and Publications Update

**The Learning Health Care Community Study Nears the Final Interviews and Focus Group Sessions, Moving Into the Analysis Phase**

Principal Investigator: Daniel C. Mullins, PhD (University of Maryland, Baltimore)

After completing the pilot phase of the Learning Health Care Community (LHCC) study in June, the research team used their observations and



feedback from those sessions to revise and improve the interview guides for an experience better suited to the needs of community members and other participants. The team also generated a short report summarizing the main findings of the pilot phase, which included a qualitative analysis of the interview and focus group transcripts.

The LHCC study gained momentum throughout the summer, with the completion of 14 focus groups and eight key informant interviews. Researchers captured feedback from various stakeholders including patients, community leaders, residents, healthcare providers, and others vested in healthcare delivery in West Baltimore--a total of 89 study participants as of early August. Moving into the fall, the LHCC research team will finalize transcripts of focus group and interview recordings and move forward with the qualitative data analysis.



Take a look inside of some of the LHCC focus groups.

In addition, LHCC research team member Nabil Natafqi and community health advocate Gail Graham co-authored an article, ["A Call to Build Learning Health Care Communities"](#), which combines research and first-person narrative to make the case for creating and sustaining a new framework for community participation in the complete health care cycle. [Read the full article.](#)

If you are a healthcare professional, healthcare administrator, payer of healthcare (e.g. work at a public or private health insurer,) policymaker, or employer, there's still time to share your insights and perspectives. Visit the [LHCC webpage](#) to submit a request to participate, call us at 410.706.3839 or email [patients@rx.umaryland.edu](mailto:patients@rx.umaryland.edu).

### About the Learning Health Care Community Study

Funded by Merck & Co. Inc. Investigator Studies Program, "Co-developing Sustainable Learning Health Care Communities (LHCC) using Community-Based Participatory Research", aims to increase collaboration between patients and health care systems and promote greater health equity across the local area. The Learning Health Care Community model shifts from relying on natural outgrowths of patient interactions with providers and health systems at large, to a deliberate, proactive focus on co-learning practices based on trust and engagement by all community stakeholders.

### **PATIENTS Program Team Continues Collaboration with Cancer Research Advocacy Groups to Promote RadComp Study**

Principal Investigator: Justin E. Bekelman, MD (University of Pennsylvania)

PATIENTS Program team members Chinwe Ebonine and Anna Hung collaborated with cancer research advocacy group Facing Our Risk of Cancer Empowered (FORCE) to expand the promotion of the RadComp study. The team hopes to increase awareness of the study and reach prospective participants through its recent inclusion on FORCE's website. FORCE is a nonprofit organization whose mission is to improve the lives of individuals and families affected by hereditary breast, ovarian, and related cancers.

To further bring awareness to the study, Chinwe Ebonine and PATIENTS Program Student Research Assistant Nirmen Mahal, along with Melissa Sakow of SHARE Cancer Support and RadComp Trail Engagement Coordinator, Dana Goodlett, teamed up to co-author a blog post about how women who have been diagnosed with breast cancer can approach their doctors about participating in clinical trials. Visit the [SHARE website](#) or the [Radcomp website](#) to read the post.

Watch a short video of Kim Wright, a breast cancer survivor, fierce advocate, and valued stakeholder member of the RadComp study trial, as she shares her treatment experience, advocacy work, and offers advice to others dealing with breast cancer.



Kim Wright: A Survivor's Story

For more information about the RADCOMP study, visit the [PATIENTS website](#) or [YouTube channel](#).



### Get Involved: You Can Help the Food and Drug Administration Learn How to Better Communicate with Women

The PATIENTS Program at the University of Maryland, School of Pharmacy will be conducting a research study to learn how the U.S. Food and Drug Administration (FDA) can improve health communications about the products (food, drugs, devices, vaccines, etc.) they regulate to women aged 38 and over.

- If you join the study, you'll be a part of a focus group of 8-10 women.
- The focus group will last about two hours, and you will receive a \$40 gift card as a token of appreciation.

To learn more or to participate, contact The PATIENTS Program at 410.706.0529 or email [patients@rx.umaryland.edu](mailto:patients@rx.umaryland.edu).

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## Community Spotlight: University of Maryland School of Medicine to Offer a Free Mini-Med School This Fall



**When:** Tuesdays, Oct. 16 - Nov. 13, 2018

6:00 - 8:00 pm (Doors Open at 5:30)

**Location:** SMC Campus Center, Elm Ballroom

621 W. Lombard Street, Baltimore, Maryland 21201

**Website:** <http://www.medschool.umaryland.edu/minimed/>

**Phone:** 410.706.7508

Mini-Med School is a tuition-free lecture series provided by the University of Maryland

School of Medicine faculty. During this time community members will learn about certain diseases and their prevention, and how to improve their overall health and well-being. The program began 17 years ago with a session for adults, teaching them about important health issues. It has now expanded to include adult seniors and local city youth.

More than 400 Baltimore area residents annually attend Mini-Med School. Presented by faculty physicians, Mini-Med School lectures are designed to be casual, fun, and informative, while focusing on health care issues that are important to everyone.



## Press Play: Featured Video on the PATIENTS YouTube Channel



### Family Mediation for Co-Parents of Children with Illnesses

Co-parenting can be a challenge in general, but what happens when separated parents have to raise a child with a chronic health issue? In this video, members of the Community Mediation Maryland team provide free mediation to support parents in making hard decisions, work through conflict, and develop a collaborative plan of action.

[Watch excerpts of a mediation session.](#)

### Feature: Dispelling Myths about Medical Research

Leading up to PATIENTS Day, we asked some of the PATIENTS Program community partners and advocates to dispel common myths associated with medical research. [In this short clip](#), Pastor Franklin Lance of Mont Lebanon Baptist Church gives his take on one of the most prevalent misconceptions. [Watch now.](#)



### Feature: The Learning Health Care Community and the Doctor/Patient Relationship

Bi-directional learning--patients learning from doctor and doctors learning from patients--is a cornerstone of an effective learning health care community.

[In this video](#), Doctor Sean Holmes and Darryl Brodie share their unique perspective on the doctor/patient relationship.

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## Our Vision

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