

PATIENTS' Voices

a newsletter from

The PATIENTS Program

at the University of Maryland
School of Pharmacy

Message from The PATIENTS Program

**LISTEN.
BRIDGE.
DELIVER.**

"Listen, Bridge, Deliver" is the core driver of The PATIENTS Program. According to Dr. C. Daniel Mullins, PhD, professor and chair of the Department of Pharmaceutical Health Services Research (PHSR) at the School of Pharmacy and Executive Director of The PATIENTS Program, "We must listen to the residents of West Baltimore, and bridge the gap between the health needs of patients and the ability of our campus to work with local residents to meet those needs." He went on to add "together, we can deliver solutions to the most challenging health problems that West Baltimore faces. The University of Maryland is here to listen, to bridge, and to work in authentic partnership with the West Baltimore community to deliver solutions." This issue features our latest efforts to bridge those partnerships in our community.

To keep our program efforts progressive and sustainable, we have secured a new collaborative initiative that promises to continue our work to make sure the patient's voice is front and center. Read about our new partnership with Johns Hopkins University through a

Our longtime partnerships are consistently what drives our work forward. Check out our efforts in the community with our participation in the Mt. Lebanon Baptist Church annual Back to School Community Fair. Our outreach team is busy making connections in West Baltimore neighborhoods.

Be sure to take a look at our featured videos, which include the panel presentations from PATIENTS Day. Two of our videos have been recognized with accolades -- we are so excited to share our successes with you!

Our community is the driving force behind our work, so we always welcome your feedback on how to make this newsletter serve you better. Feel free to email us at patients@rx.umaryland.edu to submit your comments, suggestions, and ideas.

At a Glance

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Meet the Newest Members of The PATIENTS Team

Meet the Three PharmD Students Who Were On Rotation at The PATIENTS Program This Summer

Annette Yoo

Annette Yoo worked on an independent project within NIA R24 (Participant Diversity in Aging Research), specifically focusing on the motivating factors of the elderly population to participate in research and their clinical implications.

"I learned how to communicate with patients from their eye level," she says. "I've learned that researchers tend to use 'our' language rather than catering to the community and even one word can shift the entire meaning." She will graduate in Spring 2020.



Rosina Annan

Rosina Annan worked on the project titled "Social Entrepreneurism; Its Impact and How It Is Measured with Emphasis on 'Pharmapreneurism' as It Applies to Patients in West Baltimore."

"I learned the necessary skills and strategies that will enable me to be an innovative pharmacy entrepreneur in the years to come," she says. She will graduate in Spring of 2020.



Jeidimar Miranda

Jeidimar Miranda worked with the MDEpiNet project which is an initiative of the FDA to better understand the safety and effectiveness of medical devices that are currently on the market.

"During my time at The PATIENTS Program I learned more about the work that is done 'behind the scenes' as well the impact that this program have in the research community," she says. She will graduate in Spring of 2020.



Meet the Summer Intern with The PATIENTS Program

Ashley Russell

Ashley Russell spent the summer with us as an intern with The PATIENTS Program. She notes:

"My time working with The PATIENTS Program through the Summer Bioscience Internship Program was an experience that I will cherish and remember as I continue to work towards a career in the medical field. This experience was unique for me, as it was my first time working in an office setting, a deviation from my usual clinical internship work. I had the opportunity to learn about Patient-Centered Outcomes Research (PCOR) and how The

PATIENTS program has integrated PCOR into the West Baltimore community. With this, I also learned the value of culturally sensitive language and how language from research institutions can be perceived by the general public. Prior to my internship at The PATIENTS Program, I conducted health research in Baltimore, but never thought to include PCOR as a part of my research process. Knowing what I know now about PCOR and seeing its positive impacts in the community, I intend to integrate it into my future research projects. Apart from the valuable lessons and concepts that I learned at The PATIENTS Program, I was very lucky to be surrounded by a group of friendly, intelligent, and professional staff members who were more than happy to give me the opportunity to work with them and introduce me to new concepts."



Projects and Publications Update

A Learning PCOR System to be Developed This Fall

The PATIENTS Program will kick off a new initiative to develop a "Learning PCOR System." A Learning PCOR System generates PCOR evidence, synthesizes PCOR evidence from the peer-reviewed literature and other reliable sources, and prioritizes and interprets PCOR evidence for patients, health care providers, payers, policymakers, and other stakeholders so that they remain actively engaged across the PCOR continuum -

not just when they are involved in an individual PCOR study.

A Learning PCOR System would have the capacity for authentic shared learning across PCOR studies and incorporation of patient preferences, and cultural norms within a healthcare delivery context. In a Learning PCOR System, emerging evidence would rapidly be returned to patients and their health care providers, communities, and stakeholders who could benefit from the information to make better-informed decisions about the healthcare choices patients face every day. The project will have a deliberate focus on underrepresented populations, building upon prior work with diverse populations. We propose to continue building relationships, trust, and credibility within our Learning PCOR System that partners with community-based health systems and African-American, faith-based, and impairment populations. The project will build upon and coordinate with other related efforts and will include findings from other PCORI-funded projects.

PREP-IT Team Serving as a Co-Presenter As Well As Receiving National Recognition

The PREP-IT team has been working hard internally to plan for our next steps within the project. Our Patient Partners have been co-presenting along with Clinical Research Coordinators (CRC) on the topic of consent and follow up. These conversations have been fruitful and engaging as we begin to think about the critical role of CRCs and the patient-centered approaches to consenting. We have received great news from the Patient-Centered Outcomes Research Institute (PCORI). PCORI would like to showcase the video "PREP-IT Team Defines Patient-Centered Outcomes Research" (please see the "Press Play" section to watch this video) on a national platform as a resource to educate others on PCOR. This video was produced by our very own Eric Kettering!

Notice of Award Received for Second Year of FDA Grant

On Monday August 12, 2019, The PATIENTS Program received the official Notice of Award

(NOA) for the second year (Phase 1b) of the U.S. Food and Drug Administration (FDA) funded project: "Improving FDA Health Communications with Older Women Regarding FDA-Regulated Products." This project is supported by the University of Maryland Center of Excellence in Regulatory Science and Innovation (M-CERSI) collaboration with FDA which assesses the safety, efficacy, quality and performance of FDA-regulated products. The goal of this project is to explore health information-seeking needs, intentions, and behaviors of older women, identified as 38 years old or older, as well as barriers they face in their attempts to access a range of FDA-regulated products modes of communication.

To achieve this goal, in the first year (Phase 1a), The PATIENTS team, in collaboration with Westat, conducted 13 focus group discussions in the Baltimore-Washington Metropolitan Area with older women in three generation groups: 38- 53, 54-72, and 73 - 90 years old. Participants engaged in discussions about the following FDA-regulated products: drugs, vaccines, medical devices, and food package labels.

The purpose of Phase 1b focus groups is to expand the focus group discussions and explore new topics with women in other locales and demographics across the United States. We want to enrich our understanding of women's health seeking intentions and behaviors focusing on health communications associated with drugs and vaccines. We will employ broader recruitment strategies and engage national level partners to cover the four regions of the nation, while covering urban and rural settings in each of these regions. We will also explore a wider array of factors that comprise socioeconomic status; and include more diverse racial and ethnic groups of women.

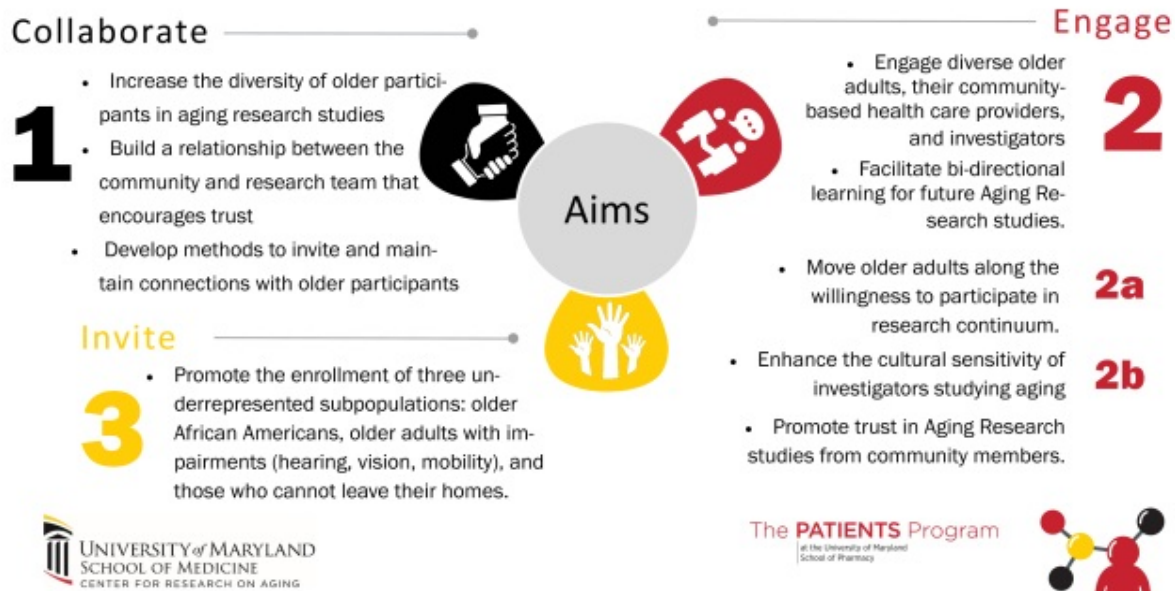
By the end of Phase 1b, important and relevant items identified from the focus groups conducted in first two years will be identified to inform the development of Phase 2 nation-wide survey of this project.

The National Institute on Aging R24 Initiative: Examining Diversity, Recruitment and Retention in Aging Research

Examining Diversity, Recruitment, and Retention in **Aging Research**

R24 AG063728-01

The PATIENTS Program and the Center for Research on Aging at the University of Maryland strive to "develop a population of diverse community members ready to engage in [National Institute on Aging] funded clinical research studies." We will identify and disseminate efficient methods for recruitment/retention of diverse populations so that others involved in Aging Research may utilize the methods to increase diversity of underrepresented populations in their settings.



The PATIENTS Program is thrilled to be a contributing player in the National Institute on Aging (NIA) R24 Initiative: Examining Diversity, Recruitment and Retention in Aging Research. Stay tuned for more information regarding this exciting initiative!

The overarching project objective is that, through work with community allies, we can reduce health disparities of diverse groups of older adults. In doing this, we can address barriers to elderly residents taking part in health research.

1. First Aim: Create a partnership between the community and research team that builds trust, invites older residents to engage in research and maintain relationships with them, and increase diversity in studies of aging
2. Second Aim: Help older people, their doctors, and researchers learn from each other.
 - a. Help older people be comfortable being in research
 - b. Help researchers earn the trust of older people they study
3. Third Aim: Encourage older adults to join research studies using ethical methods. Focus our efforts on the following groups:
 - Older African Americans
 - Older adults with impairments (hearing, vision, mobility)
 - Those who cannot leave their homes

Future (long-term) Objectives: Create a database that includes older and underrepresented community members by inviting older residents to engage in research and maintain relationships with them. Have researchers and older residents learn from each other to

reduce current health disparities and prioritize the most important healthcare topics for the community.

On August 7, 2019, The PATIENTS Program was excited to kick-off the NIH National Institute on Aging - R24 study (see photos below) to identify evidence-based recruitment methods that are effective and efficient in recruiting and retaining underrepresented populations in clinical trials.



Press Play: Featured Videos on The PATIENTS Program YouTube Channel

The PATIENTS Program Videos are Getting Awards and Recognition!



Traffic Light Eating On Your Next Shopping Trip.

Feature: Traffic Light Eating

This video has been accepted for screening at the 2019 Global Public Health Film Festival during the American Public Health Association's 2019 Annual Meeting and Expo in Philadelphia! The video addresses how your voice is important for your health and your loved ones. [This video](#) can help you become a smart shopper by using the Traffic Light Eating System. Visit Amy Abell at <https://amyabellwellness.com/> to take charge of your health.



PREP-IT- Team Defines Patient-Centered Outcomes Research

Feature: PREP-IT- Team Defines Patient-Centered Outcomes Research

PCORI has announced they are linking our video as a resource on their website. Click [here](#) to learn more about this study.

Patient-Centered Outcomes Research, PCOR, at its best is hard to define. It may look different in every study. PREP-IT stakeholders, such as patient advisors, research coordinators, and surgeons, define PCOR and how it affects the PREP-IT study.

PATIENTS Day 2K19 Panel Videos

PATIENTS Day 2K19 was a resounding success and we deeply appreciate all of our presenters who took the time to share critical information with our attendees.

Below please enjoy the panel presentations from PATIENTS Day 2K19!



Learning from our PATIENTS Professors

Learning from our PATIENTS Professors

PATIENTS Day 2K19's first-panel featured PATIENTS Professors discussing our 10 Step framework detailing how the voice of the patient or stakeholder can be included in the research process. Del Price and Dywan Monroe share their experiences shaping research.



PATIENTS Pioneers, PATIENTS Professors

PATIENTS Pioneers, PATIENTS Professors

PATIENTS Day Panel 2 discussion includes our PATIENTS Professors Debra Marvel and Jeff Wells who helped researchers like Dr. Gerard Slobogean design and conduct one of the largest Orthopedic Surgery Studies in the country. Having your voice be heard is vital for your health. Gail Graham has been a key advisor to The PATIENTS Program and has an article published in the British Medical Journal. Click [here](#) to read the article.



Healthy Neighborhoods vs Food Deserts and
Food Swamps Preview

Healthy Neighborhoods vs. Food Deserts and Food Swamps

Did you know that The U.S. Department of Agriculture estimates that 23 million people, including more than 6 million children, live in food deserts that are more than a mile from a supermarket? Research shows that access to fresh and healthy foods is one of several factors that can contribute to better eating habits and positive health outcomes, including decreased risk for obesity, heart disease, high blood pressure, stroke, and other diet-related

diseases. PATIENTS Day panel 3 discussed access to healthier food options in West Baltimore, how businesses can thrive and serve as an anchor to the community, and celebrated individuals and groups breaking down obstacles and providing fresh fruits and vegetables to the community.

UMB Partners with Johns Hopkins University for Clinical and Translational Science Award (CTSA)



Baltimore's two most powerful research institutions are forging an alliance around science. With Johns Hopkins University as our partner, University of Maryland, Baltimore has just won a coveted Clinical and Translational Science Award (CTSA) from the National Institutes of Health (NIH). These awards support a nationwide network of top-tier medical research institutions, called "hubs," that work together to improve the translational research process so that more treatments can get to more patients more quickly. There are about 60 of these hubs across the country, a testament to the selectivity of the program and to the outstanding quality of the UMB application. The CTSA brings a significant amount of money into UMB -- around \$9 million over five years. The PATIENTS Program is proud to be a part of the Community and Collaboration Core.

Click [here](#) to read more about this exciting partnership!

In The Community



On Saturday August 17, 2019, The PATIENTS Program hosted a table at Mt. Lebanon Baptist Church annual Back to School Community Fair. This is an event where the church opens its doors to the congregation and the surrounding neighborhood. The youth in attendance were given book bags filled with school supplies. They played on the newly developed Church Park. Everyone in attendance enjoyed grilled food and fresh produce all free of charge. The PATIENTS program was one of the many health vendors that shared information on health awareness and prevention. We were able to engage over 100 people and provide them with information on Patient Centered Outcome Research (PCOR). It's always a pleasure

participating in an event with Mt. Lebanon Baptist Church, a staple in the West Baltimore community and a strong and positive partner of The PATIENTS Program.

The PATIENTS Program Featured in The Baltimore Times



The Baltimore Times featured an article in the August 16th issue of the publication about the work of The PATIENTS Program. The article spotlights our mission and accomplishments while introducing our program to the publication's readership.

Click [here](#) to read the article.

Share Your Voice Regarding the Transformation of Lexington Market

Make sure your voice is heard regarding the upcoming transformation of Lexington Market, which has served as a hub for the past several decades. Participation is the right and responsibility of every Baltimorean to ensure Lexington Market continues to serve the needs of the community.



In an effort to continue the conversation about the future of the market, a town hall meeting is scheduled for Wednesday, October 9th, 2019 from 6-7:30pm at Lexington Market. Or, participate in the online survey to make sure your thoughts and ideas are a vital part of this transformation. Make sure your thoughts and ideas play a part in the future of Lexington Market!

Click [here](#) to RSVP to the town hall meeting or to take part in the survey.

The PATIENTS Program is Now On LinkedIn!


The PATIENTS Program can now be found on LinkedIn! Click on the "View our profile" button below to connect with us to learn about new and ongoing initiatives as well as to stay up to date on all the latest news and information.



View our profile on
LinkedIn

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Our Vision

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