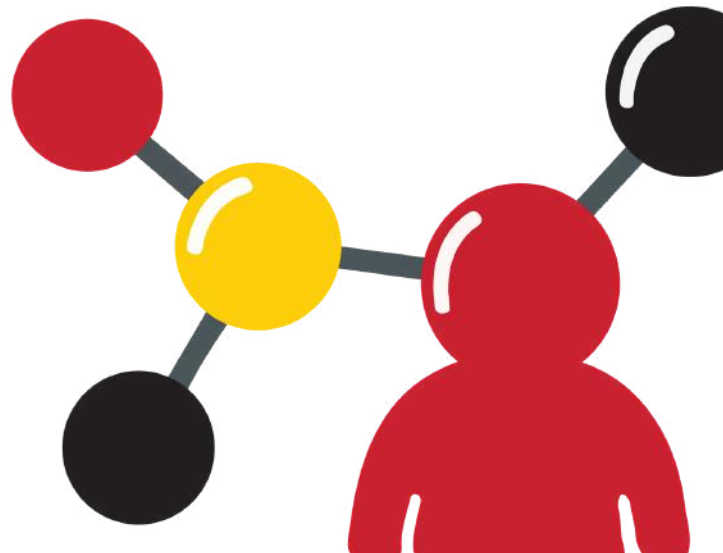


PATIENTS' Voices Newsletter

April 2021



UNIVERSITY
of MARYLAND
SCHOOL OF PHARMACY



A background image showing a group of people, mostly women, sitting around a large wooden table. They are working on laptops, looking at documents, and holding blue folders. The image is faded and serves as a backdrop for the text.

A Message from The PATIENTS Program

Spring is here, and with the new season comes a sense of rebirth and renewal.

We at the PATIENTS Program are working in a variety of life cycles for different projects. Some are coming to an end and we are looking forward to sharing results for our projects to the community. Many are just getting started or are well underway.

No matter the project, we at the PATIENTS Program are committed to being the bridge between research and the community. That promise is especially strong as we navigate our always changing world.

Happy Spring!

Meet Andrelle Mathelier

Andrelle Mathelier is a Program Specialist with the PATIENTS Program

Andrelle is responsible for overseeing projects for the PATIENTS Program, while working with team members and our partners to deliver effective patient-centered outcomes research (PCOR) research projects. She provides management, coordination, planning and evaluation of project deliverables.

In 2018, Andrelle graduated from Towson University with a bachelor's degree in Health Science with a track focused on Community Health.

Upon graduating, she worked for the State of Maryland Health Department, Behavioral Health Administration in their Service Access Practice and Innovation division for a little over two years.

During her time there she helped with the coordination, management, and execution of statewide Public Awareness projects. She helped to plan and create public health information projects designed to bring awareness and teach the public about topics, including preventing an overdose, mental health, and substance use disorders.

"I have a strong passion for public health and improving the lives of others," she says. "I am very excited to join the PATIENTS program."



Meet Eileen Eldridge



Eileen Eldridge is a Web Content Specialist with the PATIENTS Program

Eileen assists in developing multi-media materials for the PATIENTS Program and its clients, while working with team members and our partners to deliver effective patient-centered outcomes research (PCOR) findings to the community.

She assists in the implementation of web content strategies, promotional materials and other multi-media content to creatively design information. This information engages our internal and external clientele using photography, audio/visual and video production.

Eileen graduated from Morgan State University with a Bachelor's degree in Fine Art with a concentration in Graphic Design.

She has been with the University of Maryland Baltimore for a little over 4 years in the School of Medicine with the Office of Student Research. During her time there, she improved the quality and productivity of the OSR by partnering with the Director of the OSR and the OSR Team to enhance the team processes and procedures. She designed promotional materials and worked with other departments to better convey messages through web and digital media.

“I am passionate about problem-solving, helping others and being creative. I am excited to be part of the PATIENTS Program team. I get to combine and share my gifts, talents and experiences along with my passion of connecting with others to help build lasting relationships while positively impacting the community.”

CONGRATULATIONS TO ABISOLA ILUYOMADE



Abisola Iluyomade, Doctor of Pharmacy candidate, Class of 2021, completed a rotation with the PATIENTS Program. Below are her own words as to her post-graduation plans!

"I will be completing a post-graduate year 1 (PGY1) pharmacy residency at the University of Maryland Prince George's Hospital Center, where I will be trained in inpatient hospital pharmacy. This is a year long program that will prepare me to enter the field of health systems pharmacy or continue on to specialized training in an area of interest."

"As a resident, I will develop evidence-based therapeutic plans for patients and provide drug information and clinical recommendations to an interprofessional team."

"During my rotation with the PATIENTS program, I created an interview guide to perform qualitative research interviews with patients and stakeholders. I worked closely with PhD students, faculty, and members of the PATIENTS Program to derive core principles to include in a data use agreement for the NIA R24: Building Trust to Enhance Diversity in Aging Research patient research registry. I then compiled the data from the interviews and meetings with the team into possible principles and presented my findings to the team. This work really helped build my confidence in giving presentations to an interprofessional team, which I believe is a valuable skill that will help me during residency. I also gained very useful research experience that will be helpful when I complete my longitudinal research project during residency."

CONGRATULATIONS TO DR. LAURA GRESSLER

Congratulations to Dr. Laura Gressler, who successfully defended her dissertation titled "The Creation of Objective Performance Criteria and Generation of Predictive Models among Medical Devices in a Vascular Space."

Laura is an ORISE fellow at the Center for Devices and Radiological Health at the Food and Drug Administration. She is looking for a position in academia.

Laura shares her thoughts below about her time with staff with the PATIENTS Program, such as Bj Robinson-Shaneman, Senior Program Specialist, as well as some photos on the following pages.

"I started working with Ms. Bj when I first started as a PhD student. Some of the first events with her were the PowWows, church health fairs, school health fairs, and then the annual B'More Healthy Expo. During this time, BJ taught me how to talk to community members about research and their health. These experiences were instrumental during my first funded PCORI funded pilot project. I also helped Ms. Bj and Rodney during two PATIENTS Day events.

Overall, I cannot stress enough how much going into the community with Bj, Rodney, and the rest of the PATIENTS Program has taught me and how it has helped shape me as a researcher."



Dr. Laura Gressler, left, with Bj Robinson-Shaneman and at other community events.

The **PATIENTS** Program

at the University of Maryland
School of Pharmacy





What is a Community Research Think Tank?

The words “think tank” often brings up an image of a group of people at an upper management level of leadership dictating and guiding policy. The process of developing research programs also brings to mind a group of doctors and researchers developing a scientific protocol.

However, the PATIENTS Program has long championed the idea that the voice of the community must play an active role in the development of research studies. Historically, community members saw “helicopter research,” where doctors or researchers came in, took the information needed from a community, only to leave without sharing the results of the research with the community.

The PATIENTS Program has a long history of making sure the voice of the community is heard in research. Our prior work created tools to evaluate how to map evidence-based engagement strategies to specific research projects.

The results of that work allowed us to evaluate and “map” specific engagement strategies to specific populations (e.g. African Americans, elderly, Spanish Speaking, individuals with low literacy, people with physical impairments).

Last fall, the PATIENTS Program with the University of Maryland, Baltimore Institute for Clinical and Translational Research (UMB ICTR) hosted a Community Research Jam aka “The Dolphin Tank.” Researchers and community leaders came together to bridge the gap between research and community.

The Research Jam gave researchers a chance to hear from community leaders from West Baltimore about how to make their research projects more patient-centered and possibly more relevant to the communities they serve.

[Please read more about the event here.](#)

The PATIENTS Program is dedicated to furthering the idea of a “community research think tank,” where community leaders regularly work with researchers to co-develop culturally appropriate and patient-centered outreach and research efforts. Think tank advisors are community leaders who can guide research teams toward effective strategies. The PATIENTS Program has been approached by many researchers seeking to understand how to make their research more diverse and we guide them towards making their research more patient-centered, relevant, and diverse.

The community research think tank is just one of the innovative approaches that the PATIENTS Program uses to conduct research and teach others how to conduct patient-centered research.

Projects and Publications

The DISRUPTS project with St. Lawrence Health System

The PCORI Eugene Washington Engagement Award: DISRUPTS, is in its final phase. The PATIENTS Program continues to work with the research team of rural upstate New York's St. Lawrence Health System's (SLHS) Clinical and Rural Health Research Department to assist with doing Patient-Centered Outcomes Research (PCOR) in the North Country area in New York state. The group also got more funds from PCORI to look at best ways to teach the SLHS community about stopping the spread of COVID-19 through education sessions.

Projects and Publications

In the video below, hear an update from Carly Lovelett, Clinical Research Director at St. Lawrence Health System (SLHS), who leads the DISRUPTS project at SLHS.

To see any of the videos developed as part of the DISRUPTS project, please [click here](#).



Projects and Publications

Project: Building Trust to Enhance Diversity in Aging Research

Collaborators: National Institute on Aging

The project team is still talking to seniors about their thoughts about taking part in future research. The team also got more funding to interview seniors with memory problems. This new priority group brings the total priority groups to four priority populations: Black seniors, seniors who cannot leave their homes, seniors who have mobility, hearing or seeing problems, and seniors with memory problems.

This project will give researchers more culturally appropriate ways to work with with a variety of senior communities, based on what seniors in our focus groups and interviews share with our researchers.

Projects and Publications

The PREP-IT Trial

We held our last Stakeholder Advisory Board meeting on March 9th, where we talked about opportunities for stakeholders to take part in various forms of results dissemination and started creating a visual infographic. The infographic will show the patient/stakeholder perspective in taking part in the PREP-IT Trial.

We have submitted two abstracts to both the APHA Annual Meeting 2021, and PCORI Annual Meeting 2021. We are starting to write an article for an academic journal written by patient stakeholders, which will note how patients and stakeholders influenced a pragmatic clinical trial following the principles of the 10-Step CEnR/PCOR Framework for Continuous Patient Engagement.

Projects and Publications

Project Title: Eugene Washington PCORI Engagement Award: Capacity Building for a Learning PCOR System

The project team is currently creating a graphic that shares lessons learned with those who took part in the project and the broader community. We will share it later this spring.

Based on what we learned from the four deliberative engagement sessions that took place in 2020, the project team is also creating a draft framework of the essential components of a Learning PCOR System. This will be shared with the project's Stakeholder Advisory Board for review and approval later this spring.

This project prioritizes and interprets PCOR evidence for all stakeholders – such as patients, care partners, clinicians, health systems and policymakers – so that they can remain actively engaged across the many projects and at different stages of the research process, not just when they are involved in a PCOR study.

We are happy to announce that results from this project will be shared at the Academy Health ARM (Annual Research Meeting) conference in June 2021.

Projects and Publications

Conference Award Effort Kicked Off on April 1st

Dr. Mohummed Minhaj Siddqui, Associate Professor of Surgery in Urology at the University of Maryland Medical Center, heads a project titled “Prioritization of Comparative Effectiveness Research (CER)/Patient-Centered Outcomes Research (PCOR) on Prostate Cancer Active Surveillance (AS): Community Consensus Initiative.”

The project aims to support a national discussion and conference aimed at identifying evidence gaps to guide future research on the use of active surveillance to monitor low-risk prostate cancer. This approach will serve as an alternative to immediate treatment with surgery, radiation, or hormone therapy which all have potentially debilitating side effects.

At this time, we are in the very beginning stages. Our team will soon meet to determine the members of our Multi-stakeholder Advisory Board (MAB) who will help in the planning of the national discussion and conference.

Projects and Publications

Project Title: Communicating about COVID-19 Testing to Underrepresented Populations.

Collaborators: Center of Excellence in Regulatory Science and Innovation (CERSI) and The Food and Drug Administration (FDA)

The project wants to understand attitudes around testing for COVID-19 in six underrepresented populations and the willingness of these populations to share their testing data in national repositories.

Methods (How did we do it?):

We created an interview guide, participants screener, flyers, and translated these materials into Spanish. We secured Institutional Review Board (IRB) exemption. We worked with our community partners to get people to take part from the six underrepresented populations from greater Baltimore area. We interviewed 10- 11 people per underrepresented population using virtual focus group discussions and key informant interviews.

Projects and Publications

Communicating about COVID-19 Testing to Underrepresented Populations (continued)

The people who took part were:

1. African American across the adult age range with age-appropriate groupings.
2. Spanish-speakers across the adult age range with age appropriate groupings.
3. Older adults (aged 65 years and older).
4. Lower health and overall literacy.
5. People who have more than one chronic condition.
6. People who (are asymptomatic, meaning they don't show symptoms,) but have household members with COVID-19.

We removed personal information from the transcripts, and translated the Spanish transcripts into English to facilitate analysis. We used NVivo software to code data, explored emerging themes, and identified quotes supporting themes and sub-themes. We reviewed within and between groups and used the data saturation model to assess saturation among the six underrepresented population groups. We had two project status meetings. The most recent was held on March 17, 2021 in which all project partners were impressed at the progress made so far.

Projects and Publications

Communicating about COVID-19 Testing to Underrepresented Populations (continued)

We have also created a comprehensive dissemination strategy, and we presented an overview of the project at the School of Pharmacy Dean's Office virtual series for alumni and friends on December 10, 2020. The project team was accepted as a panelist at the May 17, 2021 ISPOR Virtual Annual Conference. Our community partner, Mr. DeJuan Patterson has also written a blog post on this project.

Community Benefit:

This research will give valuable information to the FDA. This may help the FDA make their communications clearer to the community. It may also help the FDA better understand ways to protect the health of underrepresented populations.

Projects and Publications



PATIENTS Program Team Members Continue to Publish Articles

Several staff members with the PATIENTS Program, along with community partners, have all recently authored articles published in a public health journals.

Please click on the article title below to read each article.

Pragmatic randomized trial evaluating pre-operative aqueous antiseptic skin solution in open fractures (Aqueos-PREP): the feasibility of a cluster randomized crossover study.

Managing work flow in high enrolling trials: The development and implementation of a sampling strategy in the PREPARE trial.

Patient and stakeholder engagement learnings: PREP-IT as a case study.

Meet Our Community Partner

Matthew H. King, MBA

President & Executive Director

Harlem Park Community Development Corporation

Over the years, the PATIENTS Program has worked closely with the Harlem Park neighborhood in Baltimore city to improve the health of the community and to bring their voices to research projects.

Matthew King, MBA, who serves as President and Executive Director of the Harlem Park Community Development Corporation (Harlem Park CDC) is the point person between the organization and the PATIENTS Program.



Matthew has served on panels at our PATIENTS Day events, talking about how communities can improve their engagement with large research institutions to make sure their voices are heard in research.

"Our organization takes on an inclusive and equitable development approach when it comes to creating a progressive environment design to enhance the community's quality of life," he says.

Meet Our Community Partner

Harlem Park CDC is committed to community-based initiatives that will provide upward mobility and improve the quality of life for all its residents. The organization has initiatives in place that revolve around healthy living, a 4H club, and a homeownership program.

During the pandemic, to deal with food disparities and lack of access to the vaccine, Harlem Park CDC launched a COVID-19 Rescue Response, where the organization provided the necessary supplies (facial masks and healthy food) to help them combat the coronavirus pandemic. The Harlem Park CDC is also working to organize a mobile COVID-19 vaccination effort for the neighborhood and is in the final design phase of creating the Harlem Park Neighborhood Plan, which will spark large-scale development within the Harlem Park Community.

The following photos are a snapshot of their successes with their response.



Meet Our Community Partner



Our Impact

Healthy Box Lunches Students & Elderly Served	735
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Boxes of Fresh Produced Provided	1,800
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Total Individuals Served during our Giveaway Series	7,200
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Total Number of Face mask Distributed	1,000
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Individual Hand Sanitizers Distributed	350
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"Harlem Park is an amazing neighborhood that has been hit with historical disinvestment as well as systemic racism," he says. "With high volumes of blighted homes and high poverty levels have impacted our resident's lives tremendously, but this is a community working towards a bright future by changing the impact from the creation of the highway to nowhere."

Meet Our Community Partner

GIVEAWAY MEMORIES



To learn more about Harlem Park CDC initiatives, to donate, or to volunteer click below to go to their website:

www.harlemparkcdc.org

Real Talk with Rodney and Bj's Corner

As we "spring" into Spring, our "pandemic pivot" Facebook Live events, Real Talk with Rodney and Bj's Corner, continue with a great lineup of guests and topics.

On February 25th, on BJ's Corner, Barbarajean "Miss Bj" Robinson-Shaneman, Senior Program Specialist at the PATIENTS Program talked with the PATIENTS Program post-doctorate fellow Dr. Jasmine Cooper about how fear can be a barrier to getting healthcare.

"If you have a question about the COVID-19 vaccine, or any health care question, be sure to advocate for yourself," she says. "Look up the information, go to your family doctor, or see what the CDC and FDA have to say about the topic. It is important to have knowledge to protect yourself and the community."



Real Talk with Rodney and Bj's Corner

Our conversations about the health of the community continued on "Real Talk with Rodney" on March 11th. The PATIENTS Program's Associate Director of Engagement Karen Morales hosted the event and spoke with Michelle Medeiros, Director of Research at the PATIENTS Program and Curtis Eaddy II, Marketing and Communications Director at the Southwest Partnership about the CO-DRIVEN project.



Curtis Eaddy
Marketing and Communications
Director at the Southwest Partnership

CO-DRIVEN stands for Community Based Development of CollaboRatIVE and Sustainable PartNerships in PCOR/CER- (CO-DRIVEN). Curtis, who was profiled in our recent February issue of the newsletter, is working with Michelle and the PATIENTS Program to foster a multi-stakeholder collaboration for Patient-Centered Outcomes Research (PCOR) with the Southwest Baltimore community.

To do this, we will work with The Southwest Partnership (SWP) to partner with the community to take part in research from choosing topics through returning results.

Real Talk with Rodney and Bj's Corner

The Southwest Partnership is an organization made up of seven neighborhoods and six institutions who work together to build community in Baltimore. They are residents, business owners, workers, visitors, church members and partners in the neighborhoods of Barre Circle, Franklin Square, Hollins Roundhouse, Mount Clare, Pigtown, Poppleton and Union Square.

Curtis appreciates the chance for the community to have a seat at the table when it comes to research.

"It's a great opportunity to come to our community to help think of research questions we may not know how to ask, and to understand research may not accepted by all," he says. "The PATIENTS Program can make research more approachable as they know it's a conversation with the community, not dictating to them, but amplifying the community's voice with this platform."



Real Talk with Rodney and Bj's Corner



BJ Robinson-Shaneman
Senior Program Specialist

On the March 25th BJ's Corner. Miss BJ spoke with Karen Morales about how community voices educate the PATIENTS Program.

She talked about the importance of trusted resources in the community and how those who run a research project need to show up in the community.

"My community trusts me, but if you want them to trust you, you need to be standing beside me to answer questions," she says.

Please "Like" our Facebook page and "Follow" us to get information about future Facebook Lives, which take place every other Thursday at noon.



