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# PATIENTS' **Voices**

a newsletter from

The **PATIENTS** Program

at the University of Maryland  
School of Pharmacy



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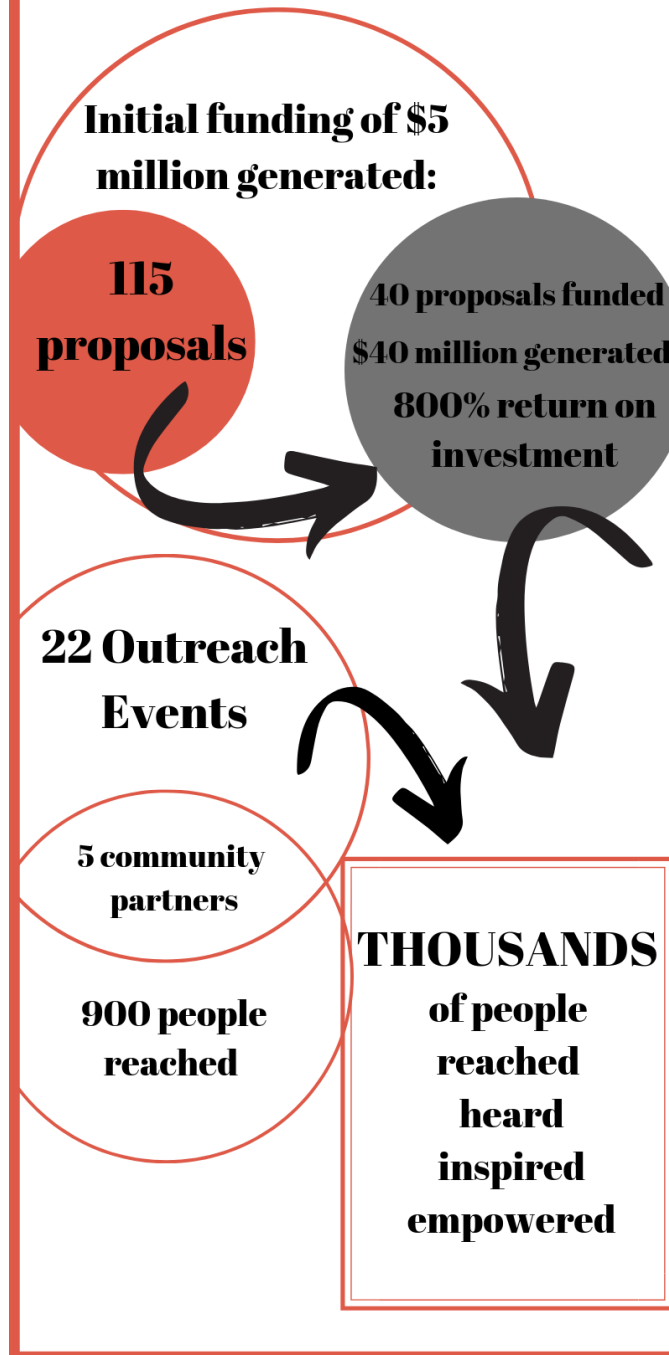
## Message from The PATIENTS Program



# PATIENTS

Patient-centered Involvement in Evaluating the Effectiveness of Treatments Program

[www.patients.umaryland.edu](http://www.patients.umaryland.edu)



Sustainability is a vital component of The PATIENTS Program. Sustainability in our partnerships, our programs and our community. This commitment to sustainability supports our mission to empower patients to propose questions about their health care concerns and actively participate in studies to answer them. Sustainability in all that we do drives us towards listening to the voices of patients, acting as a bridge between research and the community and delivering critical solutions that serve the community. Sustainability is also the underlying thread of all programs, events, and initiatives featured in this issue.

In this issue we spotlight the efforts of program partner Center for Medical Technology Policy (CMTP) in their latest initiative to make sure the voice of the patient is front and center regarding developing core outcome sets in clinical trials for sickle cell disease.

Be sure to take a look at our featured videos, which include Rodney Elliott learning all about Traffic Light Eating with Board Certified Health & Wellness Coach Amy Abell as well as how Officer Johnson makes each Friday a very Happy Friday.

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

Happy Summer!

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## The Voice of the Patient was Heard at the Making Learning Healthcare Systems More Patient-Centered Conference

The Making Learning Healthcare Systems More Patient-Centered conference on the morning of May 31st was well attended. This half-day conference allowed community members and researchers from across the nation to come together and discuss the work that is being done in the Patient Centered Outcomes Research (PCOR) field. Attendees had the chance to network and hear from 11 submitted poster abstracts at the start of the day, followed by three workshop sessions. Each session hosted multiple researcher and patient advisor pairs from different health and research institutions. The dialogue around how research has changed and how to push the needle forward in the direction of more patient involved research was fruitful. Funding for this conference was made possible in part by (1R13HS026092-01) from the Agency for Healthcare Research and Quality (AHRQ).



If you missed out on attending this year, you're in luck! We will be hosting the conference again next year. Look out for more details to come in 2020.

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## PATIENTS Day a Success!



Attendees enjoy the health fair.



University of Maryland President Jay Perman with Officer Johnson who brightens our day by wishing us a "Happy Friday!" every Friday.

Approximately 150 individuals representing a mix of local community participants and researchers from Baltimore and across the country attended PATIENTS Day on Friday, May 31st at the University of Maryland BioPark. The event featured panel presentations from PATIENTS program partners as well as an interactive health fair. Health fair vendors were



on hand to support attendees in our mission to improve health and quality of life for individuals and their communities.

As always, the voice of the patient is first, so the day began with a panel presentation titled "Patient and Community Voices" featuring Patient Advisor Ms. Cynthia Chauhan and long-time partner of The PATIENTS Program, Rev. Franklin Lance.

Other panel topics included learning from our "PATIENT" Professors as well as our "PATIENT" pioneers, and concluding with an informative discussion surrounding healthy neighborhoods: food deserts vs. food swamps.

Highlights of the day included a vigorous stretch break led by Mr. Chauncey Whitehead and the 83-years-young Ms. Ernestine Shepherd as well as a yoga break led by Ms. Jacqueline Williams. Attendees left the event via a closing line dance with the Het Heru Healers. If you didn't get a chance to join us, be sure to visit The PATIENTS Program You Tube channel to view the full sessions.

A special thank you to Natalie Eddington, PhD, FAAPS, Dean, University of Maryland School of Pharmacy; Jay Perman, MD, President, University of Maryland, Baltimore; and Jane Schaab, MBA, Associate Vice President for Economic Development, University of Maryland, Baltimore, whose community engagement message within their opening remarks resonated with our attendees. We are grateful for Dean Eddington's words praising "The PATIENTS Program's commitment to listening to the voice of the community, bridging research and the community, and delivering solutions that are important to the community."

We also extend a great big THANK YOU to all of our partners, volunteers, and supporters who contributed toward making this event a huge success. Don't miss out on PATIENTS Day next year! Be sure to follow us on Facebook and subscribe to our You Tube channel to stay connected to receive updates. We can't wait to see you next year!



Ending the day with a line dance with the Het Heru Healers.

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# Meet the Newest Members of The PATIENTS Team

## Meet The PATIENTS Program's Postdoctoral Fellow Jasmine Cooper and Research Assistant Derek Edwards

### **Jasmine Cooper, Postdoctoral Fellow**

Jasmine K. Cooper, Ph.D. is the newest postdoctoral fellow with The PATIENTS Program. She earned an M.A. and Ph.D. in Sociology at Michigan State University. Additionally, she holds a B.S. in African American Studies, earned at Eastern Michigan University. Her experience in qualitative research and background studying intersecting structured racial, gender, and economic inequality collectively prepared her for this new position with The PATIENTS Program Team.

Since 2011, she has overseen undergraduate courses in Sociology, Women's & Gender Studies, and Africana Studies, at Michigan State University, Virginia Commonwealth University, Rowan University, Central Michigan University (Global Campus), and two Pennsylvania-area community colleges. In Fall 2018, she completed a semester-long lectureship in the Department of African American Studies at Princeton University, where she oversaw two preceptorial sections.



### **Derek Edwards, Research Assistant**

Derek Edwards, B.S. is a second year pharmacy student and research assistant with The PATIENTS Program at the University of Maryland School of Pharmacy.

Derek received his Bachelor of Science in Physiology and Neurobiology from the University of Maryland, College Park in May of 2018. Drawing on his experience in a diverse range of community and institutional pharmacy settings, Derek hopes to apply his empathic spirit and patient-centered mindset towards facilitating the objectives of The PATIENTS Program.

Following graduation, Derek aims to complete a PGY-2 in palliative care and pursue a career in palliative care pharmacy.



Welcome Jasmine and Derek!

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## Projects and Publications Update

### PREPARE Patient Partners Present at PATIENTS Program Events

Two of our patient advisors, Debra Marvel and Jeffrey Wells, co-presented their poster entitled "Patient Engagement in Orthopedic

Trauma Research -Lessons Learned" at the Making Learning Healthcare Systems More Patient-Centered Conference. Following the conference, they also attended PATIENTS Day where Debra and Jeff sat on one of the panel discussions during the day. We are thankful for their contribution to the PREPARE team, but also their involvement in sharing their story with the West Baltimore community.

## Partner Spotlight: Center for Medical Technology Policy (CMTP)

**A Major Initiative of CMTP is Partnering with Sickle Cell Disease Association of America, Inc. to Develop a Core Set of Outcomes for Clinical Trials**

The Green Park Collaborative (GPC), a major initiative of the Center for Medical Technology Policy (CMTP), is partnering with Sickle Cell Disease Association of America (SCDAA), to develop a core set of outcomes to be used in clinical trials of new therapies for sickle cell disease. This initiative, coreSCD, will engage patients, clinicians, regulators, payers, health technology assessment groups, product developers, and other key stakeholders in a structured consensus process to develop the core outcome set.



CMTP is an independent, non-profit 501(c) (3) organization, and home of the Green Park Collaborative (GPC), that works to make health care more effective and affordable by improving the quality, relevance, and efficiency of clinical research. CMTP is also a partner of The PATIENTS' Program's in our efforts to engage patients in research.

"Sickle cell is a disease area demonstrating a lot of clinical development activity," Ellen Tambor, MA, Research Director at CMTP, explains. "There is a large benefit to getting all the stakeholders together, especially patients, to create an alignment of outcomes across all clinical trials." Patient participation is evident as the initiative has patient representatives on the advisory committee as well as the stakeholder panel. "Efforts are

being made to try to tip the scale towards the patients regarding input for core outcomes because historically when core outcome sets have been developed, it's been mostly by clinicians or academics," Ellen explains. Results for the initiative are expected in December 2019.

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## Press Play: Featured Videos on The PATIENTS Program YouTube Channel



**Traffic Light Eating On Your Next Shopping Trip.**

### **Feature: Traffic Light Eating**

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.



**PAVE ING the Way in Value Assessment**

### **Feature: PAVE-ing the Way to Value Assessment**

Patient-Driven Values in Healthcare Evaluation (PAVE) brings together patients and other stakeholders to co-produce reliable and meaningful value assessments to support patient-centered health care decision-making. In this [video](#) PAVE stakeholders discuss important elements to cost-effectiveness analyses, how the PAVE approach is different



from typical cost-effectiveness, and how this research can be used in medical decision-making. To learn more about PAVE go to <https://www.pharmacy.umaryland.edu/ce>.



**Happy Friday!**

**Feature: Happy Friday!**

Fridays at the University of Maryland, Baltimore are special when Officer Johnson shares her beautiful smile and message.



**PATIENTS Day 2K19**

**Feature: PATIENTS Day 2K19**

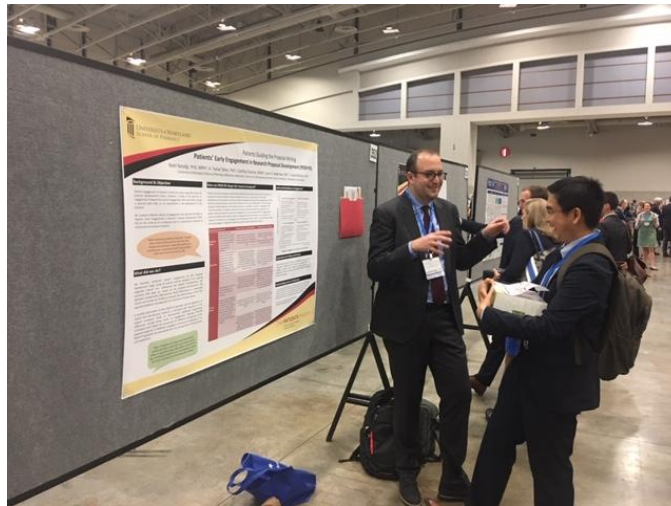
PATIENTS Day was a huge success with our wonderful speakers, informative panels, and amazing vendors. Check out this short video of the highlights from the day. Stay tuned for our panel videos on PATIENT Professors, PATIENT Pioneers, and Healthy Neighborhoods. Please subscribe to our YouTube channel, like our FaceBook page @PATIENTSProgram, and to learn more about The PATIENTS Program go to <http://www.patients.umaryland.edu/>.

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**The PATIENTS Program Presents Poster Sessions at  
the Annual Research Meeting (ARM) of  
AcademyHealth**

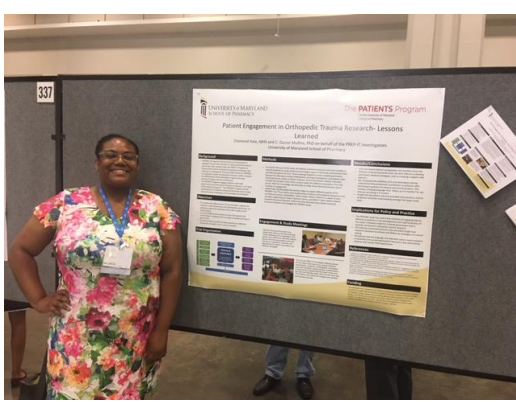


Pictured L to R: Patient Advisor Janice Tufte along with Nabil Natafqi and Diamond Hale. Also pictured below: Nabil, Diamond and Olayinka presenting at their poster sessions.



The PATIENTS Program had a strong presence in this year's Annual Research Meeting (ARM) of AcademyHealth that took place in the nation's capital, Washington, DC between June 1 and 3. Nabil Natafqi, Olayinka Ladeji, and Diamond Hale presented on three different projects on two days (see below). Our team had excellent interactions and discussion with various attendees of the annual meeting who come from across the nation and represented diverse backgrounds including patients and patient advocates, health services researchers, policymakers, and other stakeholders.

1. Poster Session on 6/1 in the State Health Research & Policy IG titled "Evaluating Receptivity to Implementing a Learning Health Care Community" by Nabil Natafqi
2. Poster Session on 6/2 titled "Evaluating Receptivity to Implementing a Learning Health Care Community" by Olayinka Ladeji
3. Poster Session on 6/2 titled "Patient Engagement in Orthopedic Trauma Research - Lessons Learned" by Diamond Hale
4. Poster Session on 6/2 titled "Patients' Early Engagement in Research Proposal Development (PEER-PD): Patients Guiding the Proposal Writing" by Nabil Natafqi



## The PATIENTS Program Steering Committee



The PATIENTS Program Steering Committee met on Thursday, May 30, for a day-long meeting to discuss the recent achievements of the program and planning for future initiatives. The day started out with The Patient Voice, featuring Dwyane Monroe. The Steering Committee, which is comprised of PATIENTS program partners such as the Association of Black Cardiologists, Bon Secours Baltimore Health System, Center for Medical Technology Policy, The Hope Institute, and Mount Lebanon Baptist Church, participated in breakout sessions designed to further develop strategic planning around engagement and dissemination and implementation. We thank all of our leadership members who participated in the day's activities.

## The Patient's Voice is Being Heard in Medical Journals

Congratulations to patient advisors Cynthia Chauhan and Gail Graham, who recently co-authored articles in medical journals!

Cynthia Chauhan, along with co-authors Justin Beklman, C. Daniel Mullins, and Nabil Natafqi, authored a paper titled "Patients' Early Engagement in Research Proposal Development (PEER-PD): Patients Guiding the Proposal Writing." The paper compares three levels of patient engagement and describes patients' early engagement in research proposal development process and its contemporary relevance to clinical and


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

What's in a name? In her article, patient advisor Gail Graham describes the impact that the name of a health center can have on an individual's likelihood of seeking treatment. Click [here](#) to read Gail Graham's story of how your voice matters.

Congratulations again!

## Stay Connected

View our videos on 

 Like us on Facebook

## Our Vision

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