

PATIENTS voice

NEWSLETTER

Late Summer 2022 Issue

Community Partner Asma Ali



Project Highlights Newest Projects and Facebook Live Events

PATIENTS Professors Academy Graduate Experiences and More

2022 PATIENTS Day Photos and Special Highlights

MEET The PATIENTS Team

We are proud to welcome new staff to the PATIENTS Program. Click on their name below to learn more about their role in the PATIENTS Program.



Patrice Forrester, PhD, MSW Postdoctoral Fellow

Learn more about her role!



Jodi-Ann Haynes, BS Graduate Student

Learn more about her role!



Gabriel Henderson, BS Graduate Student

Learn more about his role!



Abdou Simon Senghor, PhD

Postdoctoral Fellow

Learn more about his role!



Tuador Wikina, BS Graduate Student

Learn more about her role!



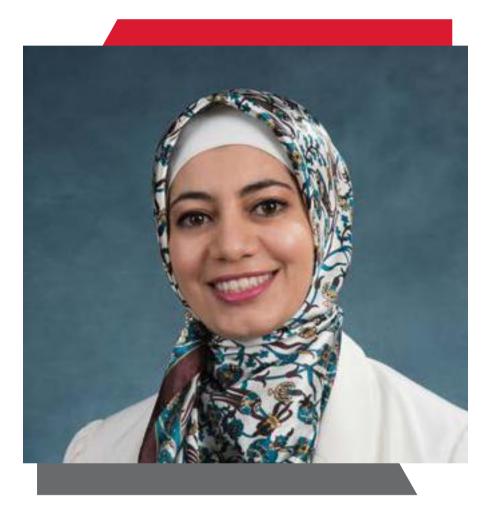
Courtney Wittstadt, BS, MPH Graduate Student

Learn more about her role!



COMMUNITY Partner Spotlight

Asma Ali



Asma Ali, PharmD, PhD, is a Palestinian American researcher whose direct encounter with patients as a clinical pharmacist made her understand the importance of having patients at the center of research to improve health outcomes and health equity. She is also a graduate of the inaugural cohort of the PATIENTS Professor Academy (PPA.) The PPA is a free, 5-week online program with interactive components led by our patient advisors and content experts.

Asma is currently a T32 Postdoctoral Research Fellow at UW-Madison. She serves as a PI on a university funded grant leading community engaged research with a racially diverse marginalized population. This project is based on building a sustainable partnership with two community-based organizations. Asma recognizes how the participation of different stakeholders from the community including patients, clinicians, and refugee coordinators has been monumental for the success of the project to achieve its objectives. While Asma's ongoing goal is to help improve health outcomes and health equity in the United States, her long-term goal is to utilize her expertise to help communities all over the world including the Middle East and Africa regions.

What made you want to take part in the PPA?

I am currently leading my first community engaged research project and it has been

a learning experience. The PPA was timely for me to gain more in-depth knowledge about different aspect of community engaged research from renowned experts in the field. What stood out to me within the structure of the program is the diversity of the PPA students, especially the inclusion of patients. I have been excited to share and discuss with the PATIENT Professors my experience in working with a diverse marginalized community.

Also, learning how to best handle challenges within community engaged research has been monumental for my work. One of the main learning objectives that I wanted to gain from the PPA was how to make my community engaged research sustainable. The knowledge and experience that I gained from my participation in the Academy has greatly exceeded my learning expectations.

Was there a topic covered by the PPA that you found most compelling? If so, why?

In my opinion, all topics covered in the PPA were set in a way that are complementary to one another. Even within each topic you attend the seminar with specific learning expectation, but you leave surprised and with more eagerness to learn and explore further. For instance, during the second week's topic "Responsible and Patient-Engaged Conduct of Human Research & Patient-Centered Outcomes Research" the discussion went off to emphasize the importance of sustainable community engagement.

Panelists described how communities notice helicopter research and how transparent communications play an integral role in building trustworthy partnerships. Another example is the third week's topic "Patients 10 Step Framework & Evaluation Technique" in which the selection of speakers was unique and creative. The inclusion of the patient advisor Dan Frye with Daniel Mullins when explaining the 10-step framework, forces the researchers to think creatively in an inclusive way in terms of the patients that they look to engage in the next research.

Were there any obstacles to taking part or unexpected challenges?

Other than finding enough time to read the material and go through the resources provided, there have been no challenges. The PPA provides important resources and tools that help prepare students before the seminar and to use later on.

How do you plan to use what you'ver learned through the PPA?

I have already started using what I am learning from the PPA in my current projects. We are re-opening some discussions with our community partners to ensure that we are having transparent communications about expectations and sustainability of work. My participation in the PPA will also benefit my future work and career tremendously. I now have the knowledge and the skillset of keeping patients and stakeholders at the center of the research by using the 10-step framework to improve health equity.

Specifically, I will use this knowledge in developing a patient-centered outcomes measure targeted for the marginalized patient population that I work with. I am confident of my ability to choose the most appropriate method of engaging patients within the specific research step within the project. The PPA equipped me with innovative ideas of disseminating findings to the community and patient partners.

I would like to greatly thank Dr. Mullins, Dr. Howarth, the great team behind this program, and all my colleague PATIENT Professors for this unique learning opportunity. I encourage future PATIENT Professors to pay close attention to the readings, resources, and seminars. All the details within the program are there for a reason. It is obvious that advisors of this program have worked hard and thought meticulously about what to include, why, when, and how.

PATIENTS Professors Academy

This summer, the PATIENTS Program held its inaugural PATIENTS Professors Academy (PPA), a free, virtual 5-week program with interactive components led by patient advisors and content experts.

Click the link below to read more about the program and the experiences of its first graduating class.

Click Here to Read The Full Article!

SUMMER 2022 JULY & AUGUST ROUNDTABLE SERIES

- The National Institute on Minority Health and Health Disparities Research Framework: What Does it Mean for the Future of Minority Health?
- Payer Roundtable: How Is the Payer Industry Meaningfully Engaging Patients?
- Health Literacy, Institutional Review Boards, Consent Forms, and You
- Evaluation: A Core Element of Community Engagement
- FDA Perspectives on Patient Engagement in Medical Product Development

- Religious Leader Panel: How Faith Leaders and Communities Play a Key Role in Community Health and Patient Engagement
- Community Engagement in Our Own Words
- Dissemination, Implementation, and Return of Results to Participants and Communities: Closing the Loop in Stakeholder-Engaged Research
- Patient Advisor Preparation: What to Know When You Have a Seat at the Table



Reflections From PATIENTS Professors Academy Graduates



Brian Gutierrez

Patient Advocate - Spina Bifida

"The PATIENTS Professors Academy gave me the foundation of having a patientcentered perspective on how to best serve and advocate for the needs of the Spina Bifida community that I have been blessed to be a part of."

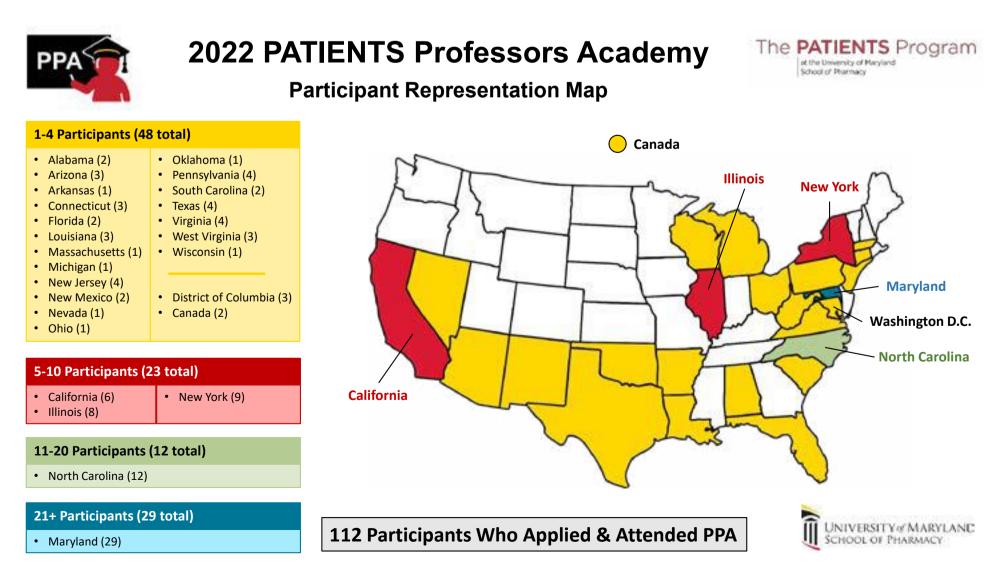


Anil Kochhar

Caregiver and Lead Medical Device Reviewer

"The Patients Professors Academy (PPA) provides patients and caregivers a tangible approach to integrate patients/caregivers, and their inputs, into the development of healthcare research studies. In addition, the PPA created a forum for patients/caregivers to collaborate and build more momentum towards developing a patient-centered healthcare system."

<u>Click here to hear PPA graduate Sandy Powell talk about</u> <u>her experiences with the PATIENTS Professors Academy</u>



PATIENTS Professors Academy Graduates

Claudia Alberico *Carolyn Alexander *Asma Ali Adriana Argaiz Tanisha Armstrong *Kathy Arriola *L. Marie Asad Kenneth Baxter Cherif Boutros *Imani Bryan *Luis Buenaver *Nicole Bullock *Royce Burruss *Darryl Cannady *Taneal Carter Valerie Carvajal *Gerard Charlot **Courtney Christian** *Jeanette Coffin *Timothy Cole *Jennifer Cook *Wesley Correa *Cheryl Courtlandt Talia Curhan

*Karen Cushnyr *Karen Dates Dunmore *Sheree Daugherty *Lenora Davis *Yvette Davis *Kelly Doran *Anjanette Elligan *Tiffany Encarnacion *Brian Englum Jeannie Farnsworth *Jennie Flanagan Italia Folleco *Patrice Forrester Joseph Gallo *Stuti Ganatra *Kyungsook Gartrell Britt Gayle Martin Gewirtz *Tracy Gray *Tanikka Green-Akrie *Brian Gutierrez *Krista Highland *Elita Hill *Jocelyn Holmes

Felicia Houston *Tess Hudson Melissa James *Rozmin Jiwani *Gabrielle Jones *Lawrence Jones II *Anil Kochhar *Dana Kontras *Elaine LaLone *Marcie Lambrix *Renee Leverty Markham Luke *Sally Mannix *Rubi Mar *Denise Marksberry *Mattie Marshall *Juana Mata *Estela Mata-Carcamo *Mariam Mauzi *Kelly McGlothen-Bell *Marik Moen *Celene Moorer *Surachat Ngorsuraches *Mallory Nickles

*Nneka Onwudiwe *Barbara Palmer *Heather Phipps *Sandra Powell **Raymond Puerini** Nicholas Robert *Kimberly Richardson *Belinda Rogers *Jayashri Sankaranarayanan *Lisa Schill *Susan Schwartz *E. Michael D. ("Mike") Scott *Abdou Senghor *Monica Still *Caroline Swift *Nancy Thomas Myeisha Thompson *Phyllis Tyler Fanta Waterman *Marianne Weant *Renee Willmon *Terri Winston *Howard Wolinsky *Donald Young

*Honors Students

Thank you to our sponsors!

We are grateful for the support of our sponsors Novartis, Bayer Pharmaceuticals, AstraZeneca, the Janssen Pharmaceutical Companies of Johnson & Johnson, PhRMA, Eli Lilly, Sanofi, Pfizer, and Truist, Bank and CareFirst BlueCross BlueShield for their support of the PATIENTS Professors Academy. Their support shows their commitment to patient-centered research.

For more information about the PATIENTS Professors Academy, go to:

https://www.pharmacy.umaryland.edu/programs/the-patients-program/patients-academy/

2022 PATIENTS DAY

On PATIENTS Day, we welcomed nearly 200 community members, researchers, supporters, and community partners to our fourth PATIENTS Day on August 16. We enjoyed a day of learning about patient-centered outcomes research thanks to our panelists, sponsors, and patient partners. Thanks to everyone who took part in the health fair as well.

Click Here to Read More About The Day!

Check Out Highlights



Check out this short video that celebrates the collaborative spirit of PATIENTS Day!

In case you missed the event, we livestreamed the day!

Click here to watch the livestream



Attendees visit the health fair



PATIENTS Day attendees enjoy a stretch break



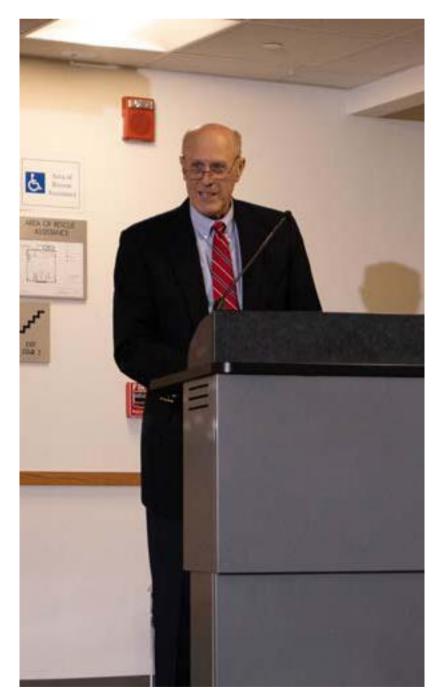
Rev. Dr. Franklin Lance, Mt. Lebanon Baptist Church, President and CEO of Parks & People (R) greets Fitness and Wellness Coach Chauncey Whitehead



Bishop William Thomas, St. Matthew's Gospel Tabernacle Apostolic Faith Church provided opening remarks as the patient and community voice



L to R: Panelists for the Community Think Tank panel: Andrelle Mathelier, Program Specialist, the PATIENTS Program; DeJuan Patterson, MPA, Advisor, Advocate & Social Impact Consultant; Jennifer Ayana Harrison, Founder, Wellness Coach, Ayana Wellness Spa and Educational Resources; and Joey Mattingly, PharmD, MBA, PhD, Director of Operations, the PATIENTS Program



University of Maryland, Baltimore President Bruce E. Jarrell, MD, FACS, welcomes the attendees





L to R: Panelists for the Four Pillars of Health panel: Chauncey Whitehead, Fitness and Wellness Coach; Curtis Eaddy II. Business Relationship Manager, Southwest Partnership; Ericka Lewis, PhD, LMSW, Assistant Professor, University of Maryland School of Social Work; NaTasha Horton, MBA, Vice President – Community Development Manager, Truist; Rev. Dr. Franklin Lance, Mt. Lebanon Baptist Church, President and CEO of Parks & People

Chauncey Whitehead and Daniel Mullins, PhD, Executive Director of the PATIENTS Program, led the attendees in a stretch break



HIGHLIGHTS Our Newest Projects

Check out highlights of our newest projects and our Facebook Live events!

New Projects

Read all about the trusted partnership between the PATIENTS Program and Mount Lebanon Baptist Church with their latest project, <u>"COmmunity Mistrust and Measures</u> of Institutional Trustworthiness (COMMIT.)

Read about how the PATIENTS Program and our partners are working towards health equity in COVID-19 vaccine trials in another project, "<u>COMmunity Mistrust</u> and Institutional Trustworthiness to Advance Health EQuity Research" (COMMIT-EQ). COMMIT-EQ is supported by the Food and Drug Administration (FDA), the governmental regulatory body that oversees the regulation of testing, vaccines, and treatment approval.

Facebook Live Events

We've enjoyed talking with our guests and hearing from you on our Facebook Live events, Real Talk with Rodney and BJ's Corner! Click on the links to the playlists below to see Rodney Elliott, Engagement Specialist, talk about our latest topics, the CO-DRIVEN project and the PATIENTS Professors Academy. During these past few months on BJ's Corner, our own BJ Robinson-Shaneman, Senior Program Specialist, talked about partnerships in the community and the importance of lived experience.

Real Talk with Rodney Episodes

BJ's Corner Episodes

4

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