

PATIENTS VOICE

February 2022 Issue

NEWSLETTER



Meet Our Community PartnerJanice Tufte

Facebook Live Highlights
Real Talk with Rodney & Bj's Corner

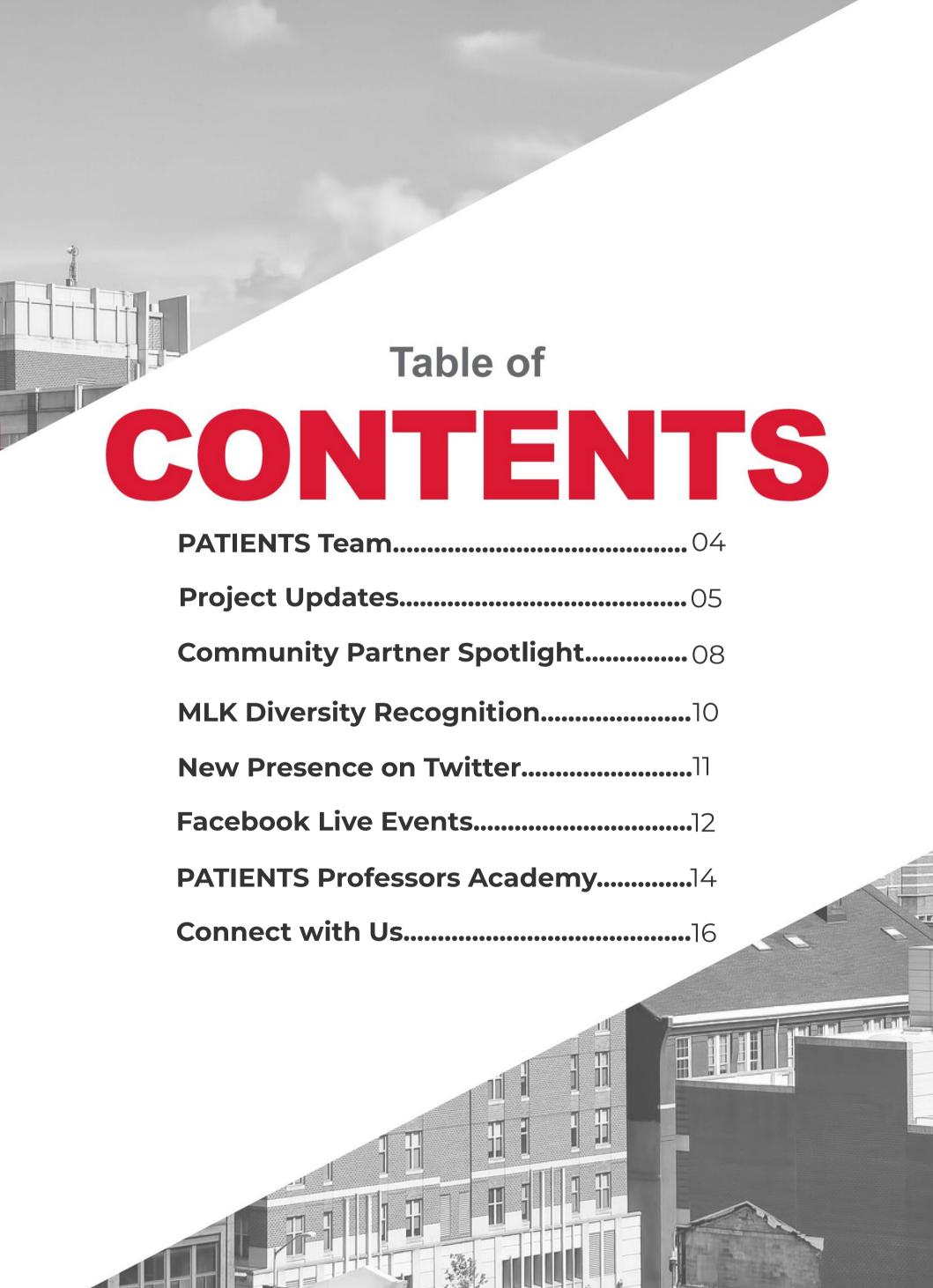
Next Steps for thePATIENTS Professors Academy





The start of a new year has us excited to work with our partners and community members. This spring we'll see the full launch of the PATIENTS Professors Academy, where 170 people will enroll to learn from our PATIENT Professors about working with the community on patient-centered outcomes research (PCOR).

PATIENTS Day will also be back this summer! PATIENTS Day has a collaborative vibe where all our partners come together to learn from each other. Everyone is welcome, so stay tuned for the date and more information. We can't wait to get this year started!



PATIENTS Team

Meet Thomas "Joe" Howarth

Joe is a Training Specialist with the PATIENTS Program



Joe Howarth comes from Northwest Indiana by way of Charlotte, NC where he worked as a community engagement liaison and educator at UNC Charlotte. During his time working with Charlotte neighborhoods on community and urban planning issues, he learned the value of listening to the stories and experiences of his neighborhood partners. This listening was invaluable in determining what the neighborhoods want to do

and what they wanted to change in their communities. This neighborhood level work led to teaching at the college level leading a course called Citizenship and Critical Community Service. This course pushed students to challenge how they think about race, class, and what it means to be a citizen.

"I'm most excited about working with the PATIENTS Program because of their commitment to justice and authentic community partnership," he says. "As a Training Specialist on the PATIENTS Professors Academy, I feel I can have a role in actually helping people live healthier lives and change how we do health research and provide healthcare."

Meet Adebukola "Ade" Oluyole

Ade is an Engagement Specialist with the PATIENTS Program



Ade grew up in Brooklyn, New York and spent the last few years in Albany, where she finished her Masters of Public Health degree and became a Certified Health Education Specialist. She enjoys traveling, exploring new cities, and spending time with her family and friends. Ade loves listening to music, especially Afrobeats because it allows her to stay connected to her Nigerian roots. As someone who likes new adventures, Ade

is excited to be in a new city and is looking forward to exploring all that Baltimore has to offer.

"I am excited about joining the PATIENTS Program and looking forward to engaging with the community and learning more about patient-centered research," she says.

PROJECT Updates

CEAL

NIH Community Engagement Alliance (CEAL)

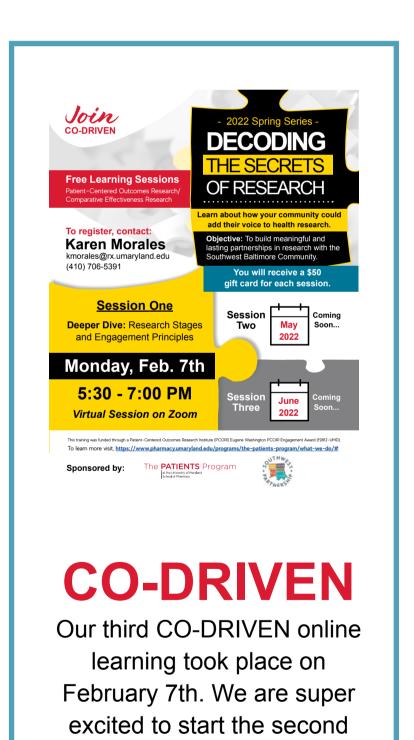
In December, we had a successful Community Think on Research with researcher Dr. Khanna and her team from the UMB School of Medicine. It was an engaging conversation between the researcher and our community leaders. The community leaders advised Dr. Khanna and her team on pieces of her research on COVID-19 where she can focus on the needs of the community in which she works.

COMMIT

COmmunity Mistrust and Measures of Institutional Trustworthiness

We received our funding from the NIH-National Institute on Minority Health & Health Disparity to start the project. This project wants to codesign a sustainable model for trustworthy CEnR partnerships to address Social, Ethical, Behavioral Indications (SEBI) of COVID-19 testing. The project will also create a Memorandum of Commitment (MOC) template for CEnR partnerships for COVID-19 testing to advance trust through trustworthiness, transparency, and respect.

Community Partner Mount Lebanon Baptist Church is working with CVS Health, a large retail pharmacy chain, to develop a workforce development center for a pharmacy technician training program that will be run out of MLBC's basement. We propose to leverage PATIENTS and UMB School of Pharmacy's longstanding partnerships with MLBC and CVS to conduct CEnR on SEBI factors. We had our kick-off meeting on February 10th to start planning the project.



year of the project.

Developing Provocative Questions:

The Prostate Cancer ACTIVE Surveillance Research Initiative

Over 100 people went to the two-day online conference for this PCORI funded project on Active Surveillance. The conference was a success as the people who attended enjoyed the conversations where patients led the dialogue and shared their experiences. We are working on video highlights of the conference and a list of provocative questions for future prostate cancer research.

NIA Bioethics Supplement

We are looking for older adults who have trouble with their memory and the people who take care of them to take part in interviews. These interviews will talk about what may get in the way of taking part in research and the best ways to get involved and interested in research. So far, we have talked to 3 older adults for this project.

NIA R24

Signing up for the NIA Registry gives you a chance to share what you think on health topics with others in and around your communities. The registry is growing and if you want to join, contact Rodney Elliott at relliott@rx.umaryland.edu.

PREP-IT

The PREP-IT Trial held its annual Investigator Meeting back in December, where patient representatives joined research coordinators and surgeons on a panel discussion about ongoing and steady patient stakeholder engagement in the study. We are starting the year off strong by developing our plans for 2022 hosting a Stakeholder Advisory Board meeting in mid-February.

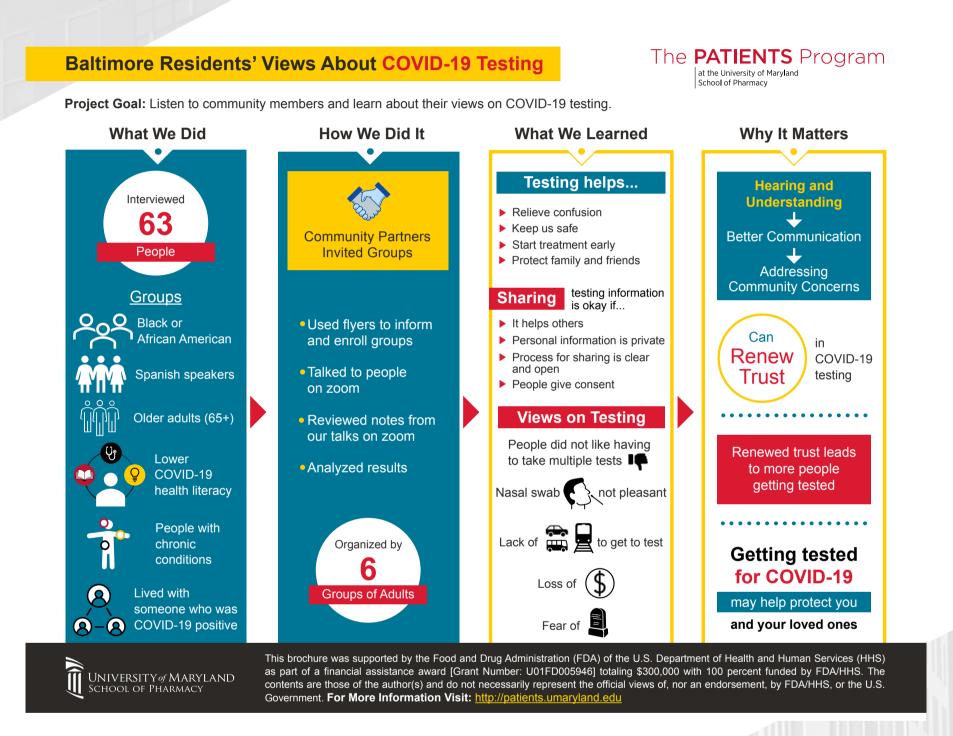
Rx-DEBT

Pharmacy Student and New Practitioner Educational Debt and Burnout

We want to learn how student debt may affect pharmacists' jobs and personal lives. We also want to know how pharmacy students and recent pharmacy graduates feel about the loan payment suspension period brought on by COVID-19. We have talked to 8 current pharmacy students and will start talking to recent pharmacy graduates soon.

The FDA One Health Initiative

We want to find and look at COVID-19 data. We want to know what the public thinks about COVID-19 and what it does to their pets and their environment. We are currently looking at information from the Advisory Committee, social media comments, and other FDA data about One Health. The information we learn from this study would be the basis for our focus groups. We will also test different messages to see if the public understands our research results.



Communicating About COVID-19 Testing to Underrepresented Groups

An important part of a research project is the "give back" to the community. The "give back" tells the community what we learned from the research project. The one-page of information for the project titled "Communicating About COVID-19 Testing to Underrepresented Groups" held with the Food and Drug Administration (FDA) talks about what community members think about COVID-19 testing.

COMMUNITY Partner Spotlight

Janice Tufte

Janice Tufte is a passionate patient advisor working to make health care more equitable for all. As the owner of Hassanah Consulting, she has served on many panels, committees, and projects in health services research and systems improvement work from local to international levels. One of her many volunteer roles is as a Patient-Centered Outcomes Research (PCORI) Patient Ambassador, where she brings the patient partner voice to many projects and conferences.

When and how did you first get involved with the PATIENTS Program?

I heard about the PATIENTS Program in 2014 when Dr. Mullins and Gail Graham presented at the PCORI Ambassador pre-conference Annual Meeting. I was very impressed with their level of community engagement work. Rather than doing studies on people, Dr Mullins and the PATIENTS Program team worked with the community to build trust and to learn from community members before working with them to develop research studies. The studies were designed with the community at the start of the grant writing process, not as an afterthought. This is one reason the PATIENTS Program has worked so well with institutions on studies across the nation.



Is there a project that you most enjoyed being a part of with the PATIENTS Program?

I have attended research conferences where the PATIENTS Program members were presenters. The INSPIRE Research project was one conference grant in 2015. I enjoyed attending the PATIENTS Program's PATIENTS Day in 2019 where I was able to meet many diverse stakeholders and learn more about specific PATIENTS Program projects and results. The skill learning and story experience focused presentations were an equal amount of community members and researchers and education-based institutional leadership. I was also able to meet many other patient partners.

Why do you continue to work with the PATIENTS Program?

I appreciate the PATIENTS Program's 10-step framework where patient partners work with researchers during the entire project, from choosing the topics to looking at project results. The deep community participation frameworks the research teams have developed and nurtured are exemplars in patient-centered research.

What are your future plans with the PATIENTS Program? Any involvement in potential projects?

I am looking forward to taking part in future projects for which we have applied for funding. We as a nation should support and fund projects that have positive impacts on the health and wellbeing of patient, clinician, and systems all.

I believe and continue to support the PATIENTS Program as their collaborative approach has emphasized the fact that individuals and communities should always have options to speak for themselves, especially to advance better health and wellness opportunities. All of us can learn from others, as we truly are never too old to learn new and more efficient ways to do health research.

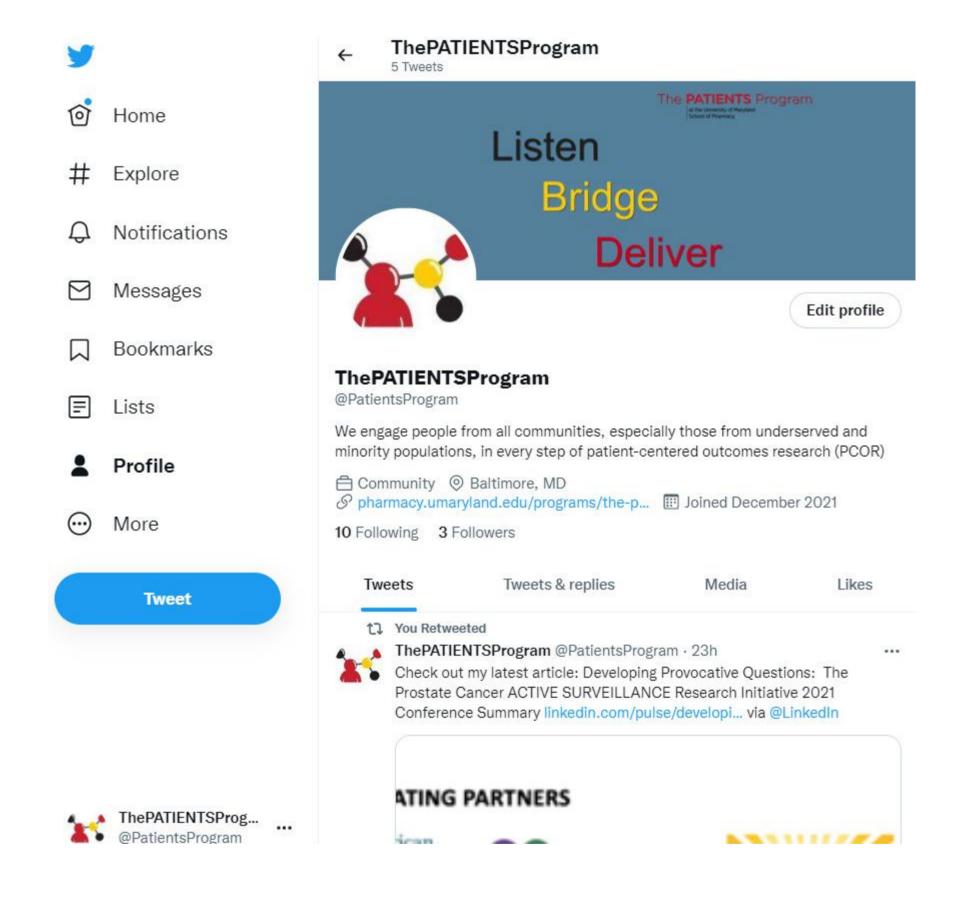


The PATIENTS Program is humbled and honored for our selection as a UMB Diversity Recognition Award Winner in the Outstanding Staff category. We were selected for our efforts to stay connected with the West Baltimore community during the COVID-19 pandemic, pivoting our engagement programs and outreach efforts to virtual platforms, such as Facebook Live.

We also helped address barriers to preventing city residents from receiving the COVID-19 vaccine, working with Mount Lebanon Baptist Church and Walgreens to administer first and second doses to several hundred people. We could not do the work we do without our partnerships and are grateful for those continued relationships.

Read more about the award here: http://news.pharmacy.umaryland.edu/patients-program-wins-umb-diversity-recognition-award/

Follow us on TWITTER



Check out new tweets about our projects and program updates!



FACEBOOK Live Events

What started out as our "pandemic pivot" has turned into another way we regularly talk with our community. The last several months saw many new guests on our Real Talk with Rodney Facebook Live event as well as Miss Bj's familiar face on Bj's Corner.

Be sure to click on any of the quotes from the guests below to watch their Facebook Live episode!



NaTasha Horton, MBA, Vice President, Community Development Manager with Truist Bank

"Truist has worksheets and tools to help with budgeting; while no one saved money for a pandemic, we can help you save money for a rainy day." NaTasha Horton from the September 23rd episode of Real Talk with Rodney where she talks about how Truist helps the financial health of the community.

Click here to watch the episode!



Barbarajean "BJ" Robinson- Shaneman, Senior Program
Specialist at the PATIENTS Program

"You will get the facts from me about a research project and where we are coming from; I have earned the community's trust so you can come talk to me. My clients trust me because they know I will protect them." Miss Bj from the October 7th episode of Bj's Corner on how COVID-19 affects your spirit.

Click here to watch the episode!



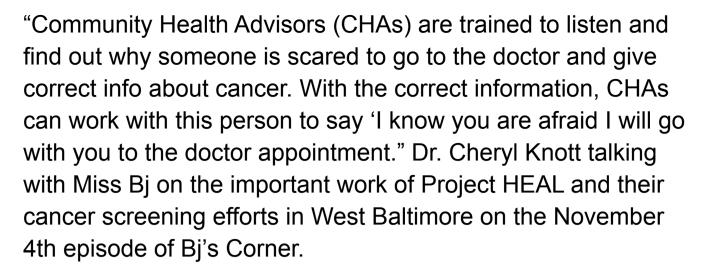
Joshua Harris, Founding Partner of Harris Branding and Associates

"My Grandmom taught me 'if it is to be, it is up to we,' in that not me as an individual but we as the collective as we all have a part in making change." Joshua Harris from the October 21st episode of Real Talk with Rodney, talking about the role of the community in the good physical, mental and financial health of Baltimore.

Click here to watch the episode!



Dr. Cheryl Knott, PhD, Professor in the Department of Behavioral and Community Health at the University of Maryland School of Public Health and Co-Director of the Cancer Control and Population Sciences Program at the University of Maryland Greenebaum Comprehensive Cancer Center.



Click here to watch the episode!



Alfred Diggs, Prostate Cancer Advocate, pharmacist, and Community Health Advisor with Project HEAL

"Men should get their regular prostate exam as it is better to put a finger in a hole that is already there than make a hole that isn't there." Dr. Alfred Diggs talking with Miss Bj about the importance of being checked for prostate cancer on the December 2nd episode of Bj's Corner.

Click here to watch the episode!



Deloris Mack, Mount Lebanon Baptist Church Credit Union

"As we have been around for 50 years, we are a trustworthy resource that takes care of the community. For our members who have direct deposit, we can pay their bills when they are due. That helps keep them in good standing and helps better their credit score." Deloris Mack with Mount Lebanon Baptist Church Credit Union on the December 16th Real Talk with Rodney.

Click here to watch the episode!

"Bartering is trading goods and services without using cash. For example, 'if you do my hair, I can do your taxes,' or 'if you can fix my car, I'll fix your Thanksgiving dinner.' Bartering can help get you what you need without spending money." NaTasha Horton from the November 18th episode of Real Talk with Rodney.





NaTasha Horton, MBA, Vice President, Community Development Manager with Truist Bank

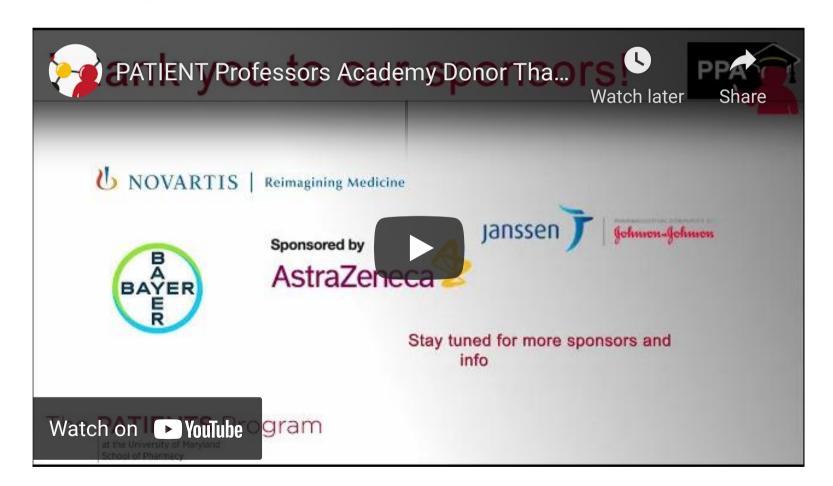


The PATIENTS Program has an advisory board of patient advocates to create and put on a five-week training academy. The training will use our successfully proven approach to continuous engagement in patient-centered research to improve health equity. The first Academy is planned for Summer 2022, and will include patients, caregivers, employees from government and the pharmaceutical industry, community leaders, and other stakeholders.

We are grateful for the support of our sponsors:

Novartis, Bayer Pharmaceuticals, AstraZeneca, and the Janssen Pharmaceutical Companies of Johnson & Johnson for their support of the PATIENTS Professors Academy.

Their support shows their commitment to patient-centered research.



Registration for the PATIENTS Professors Academy will open soon!

For more information about the PATIENTS Professors Academy, check out our website at: https://www.pharmacy.umaryland.edu/programs/the-patients-program/patients-academy/



Cynthia Chauhan



Gail Graham



Joshua Harris



Aurelia Laird



Dwyan Monroe



DeJuan Patterson



Del Price



Jeff Wells

THE PATIENTS PROFESSORS ACADEMY IS INFORMED BY AN ADVISORY BOARD

The Advisory Board includes other stakeholders who influence patients' health care decisions, such as community health care providers, community leaders, or policy makers.

Cynthia Chauhan, MSW, Patient Advocate

Gail Graham, Director of Mt. Lebanon Baptist Church HIV/AIDS Ministry-Outreach Services and HIV/AIDS Activist

Joshua Harris, Founding Partner of Harris Branding and Associates

Aurelia Laird, Former Director of Clinical and Community Research at Bon Secours Health System

Dwyan Monroe, Program Coordinator for Community Health Worker (CHW) Initiatives at the Institute for Public Health Innovation

DeJuan Patterson, MPA, Advisor, Advocate & Social Impact Consultant

Del Price, Community and Stakeholders Relations Consultant and Owner of DLP Communications



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