

The PATIENTS Program

at the University of Maryland
School of Pharmacy



AUGUST 2021



PATIENTS VOICE

Newsletter

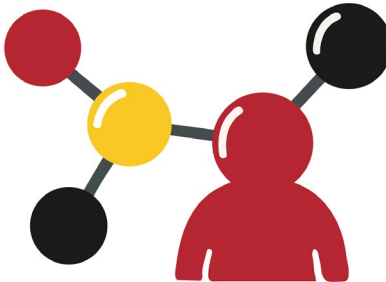
A Message from The PATIENTS Program

Fall is on the way!

Another season to work with
our community partners

While the fall season brings us closer to the end of the year, it is also a beginning. It is the start of a school year and another season to keep working with our community.

Although we have added web options as a way to bring the patient’s voice into research, what will never change is how we walk and work with the community.



Welcome to the

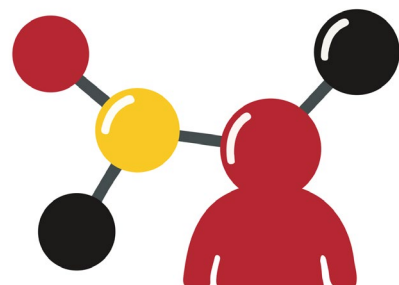
AUGUST 2021 ISSUE

PATIENTS Voice newsletter

In this issue we talk with Chauncey D. Whitehead, a fitness trainer and community advocate who works with the PATIENTS Program.

We are still connecting with the community with our Facebook Live events and have enjoyed talking with you (even if it is just in the comments section!)

As we keep working to bring the patient's voice into research, our work with the community won't change whether we are in person or virtual.



Welcome New Members to the **PATIENTS Team**

Meet **Mary Katherine (MK) Huffman**

MK is a **Postdoctoral Fellow** with the PATIENTS Program



Mary Katherine Huffman, PhD

Mary Katherine (MK) Huffman earned a PhD in both Health and Kinesiology/Gerontology from Purdue University. She is interested in helping people keep up good health behaviors for the long term. Using both qualitative and quantitative methods, her doctoral research looked at older adults' reasons for keeping up their physical activity. Also, MK earned a bachelor's degree in Mathematics from Virginia Tech and a master's degree in Kinesiology from UNC Greensboro.

Between completing her undergraduate degree and going to graduate school, MK gained industry experience working for Ernst & Young in Washington, DC. MK enjoys the learning process and she will always be a student at heart. She likes learning in her personal life as well – recently, she has started kickboxing and studying the Russian language.

MK joined the PATIENTS team in 2021 and is working with Professors C. Daniel Mullins and Joey Mattingly.

Meet Andrea Melgar Castillo

Andrea is a **Postdoctoral Fellow** with the PATIENTS Program



Andrea Melgar Castillo, PhD

Andrea earned her PhD in Interdisciplinary Biomedical Sciences from the University of Arkansas for Medical Sciences in 2021. She began her program in neuroscience. During her program she volunteered as an interpreter for Spanish speaking patients from disadvantaged backgrounds. As a result, she wanted a career focused on health equity and shifted her work to health services research.

For her postdoctoral research, Andrea talked to Veterans from southern states who had chronic pain and lost their pain medication after the Veterans Healthcare System put in place strict opioid prescribing policies. She wanted to know how these policies affected Veterans' lives: their pain level, relationships, mental health, and what they thought about providers. She also looked at differences in Veterans' experiences by race, biological sex, and if they lived in a rural neighborhood.

Andrea is originally from Panama City, Panama where she lived until she moved to Fayetteville, Arkansas. She graduated with a bachelor's degree in Biology from the University of Arkansas (Woo Pig Sooi!) in 2015.

At the School of Pharmacy, Andrea is working with Professors C. Daniel Mullins and Joey Mattingly. She brings to the PATIENTS program experience in collecting and looking at rapid qualitative data, as well as speaking both English and Spanish. She hopes to help the program work with more Latin/Spanish speaking communities in the Baltimore area.

In her spare time, Andrea likes exploring Baltimore City with her 'foster failure' Marvel, working out, reading, watching fútbol, and spending time with her friends.

Meet Kate Storm

Kate is a **Program Specialist** with the PATIENTS Program



Kate Storm

Kate oversees projects for the PATIENTS Program while working with team members and our partners on patient-centered outcomes research (PCOR) projects. She coordinates planning, tasks, helping the project take place, and looking at the results.

Kate holds bachelor's degrees in Environmental Interpretation and Media Studies and holds certifications in Change Management and Science

Communication. She is currently working on her Master of Health and Social Innovation, with a focus on utilizing games and interactive technology to impact mental health and health equity. Her background includes managing an FDA-funded project on drug compounding in the School of Pharmacy, fund-raising for STEM education, and establishing health, technology, and innovation partnerships and programs at a science center.

Kate is excited to be a member of the PATIENTS team, saying "Patient-centered outcomes research allows us to bring the community into research from the start to increase the researchers' impact while better serving our community."

Fond Farewell to Members of the PATIENTS Team

This month, we wish a fond farewell to two of our postdoctoral fellows:

Moaz Abdelwadoud, MD, DrPH, MPH

Moaz will be joining New York University School of
Global Public Health as Assistant Professor

Jasmine Cooper, MA, PhD

Jasmine will be joining Penn State Harrisburg School of Behavioral
Sciences and Education as an Assistant Professor of Sociology

To wish them goodbye, we created word art for each of them as a fun way to
let them know how we felt about our time working with them on the team.

We wish
t h e m

BOTH WELL!





Special Team News

Putting the Patient First



Dr. Sydnee Chavis, DMD
Clinical Assistant Professor
from the University of Maryland
Baltimore School of Dentistry

Dr. Sydnee Chavis, DMD, Clinical Assistant Professor from the University of Maryland Baltimore School of Dentistry, works with the PATIENTS Program as one of our faculty partners. She has been with the School of Dentistry for the past four years.

Through a clinic at the dental school, her focus is providing dental care to people with developmental disabilities or other special needs which makes getting dental care difficult.

She notes for these patients, their dental care is not simple as it is hard for these patients to take part in usual dental care tasks like sitting for a long

period of time with the mouth open. She adds it can be hard to find dentists who are willing or able to treat this community. As a result, those with developmental disabilities often don't get dental care.

While some patients may be sedated (asleep) during dental care, she wants to work with what the patient can tolerate to avoid sedation.

"Because of the extra time, resources, and risk for a patient to be asleep for dental care, we try to work with patients instead of putting them to sleep," she says. "We try to figure out what they can handle such as how long they can sit there with their mouth open."

She has worked with the PATIENTS Program on a research project that talks with patients when possible as well as caregivers of adults with special needs. "We want to understand what are the factors that influence their dental care and treatment," she says.

We want to understand what works well and what doesn't so our clinic can improve how we serve that community.

"We want to have a better patient-focused understanding to improve access as well as dental care for these patients."



Community Partner Spotlight

Helping the Community Improve Their Health



Chauncey D. Whitehead
PATIENTS Program
Community Partner

Chauncey D. Whitehead strongly believes in helping the community be physically fit “where they are at.” Chauncey, a fitness trainer, and community activist in Baltimore City, has been helping the community improve their health for the past 23 years.

“During the pandemic, we all needed something to do so every Sunday we walked in Druid Hill Park,” he says. “The community that walks together, talks together. Bringing the community together is my passion, my skill, and what I like to do.”

Chauncey also trains and works out with Ms. Ernestine Shepherd, who



is the World’s Oldest Female Body Builder at 85 years old!

He has also led fitness activities at PATIENTS Day, a day that talks about the work the PATIENTS Program does to bridge research and the community. He leads stretching exercises at PATIENTS Day and other events. He helps people get started with fitness and loves being the “go to” fitness guy!

By working with the PATIENTS Program, Chauncey can help bridge the community and research. Taking part in community walks helps researchers get to know the community.



“In the past, there has been confusion and distrust between the community and researchers,” he says.

“It helps to have the PATIENTS Program and the community work together to bridge that trust, starting with an activity everyone can take part in, like a walk. From an activity like walking together, a conversation can spark.”

The Next Community Walk

**Saturday, September 18th at
7:30 AM in Druid Hill Park**

The Baltimore Druid Hill Park Community Walkers meet at the tennis courts to start the walk. The next community walk will be Saturday, September 18th at 7:30am in Druid Hill Park.

For more information, feel free to reach out to Chauncey D. Whitehead on his Facebook page.

Celebrating Success

#ID@Home

June 23, 2021

In It for the Long Haul: How COVID-19 Patient Experiences Inform Infectious Disease (ID) Research

#ID@Home Virtual Conference a Success

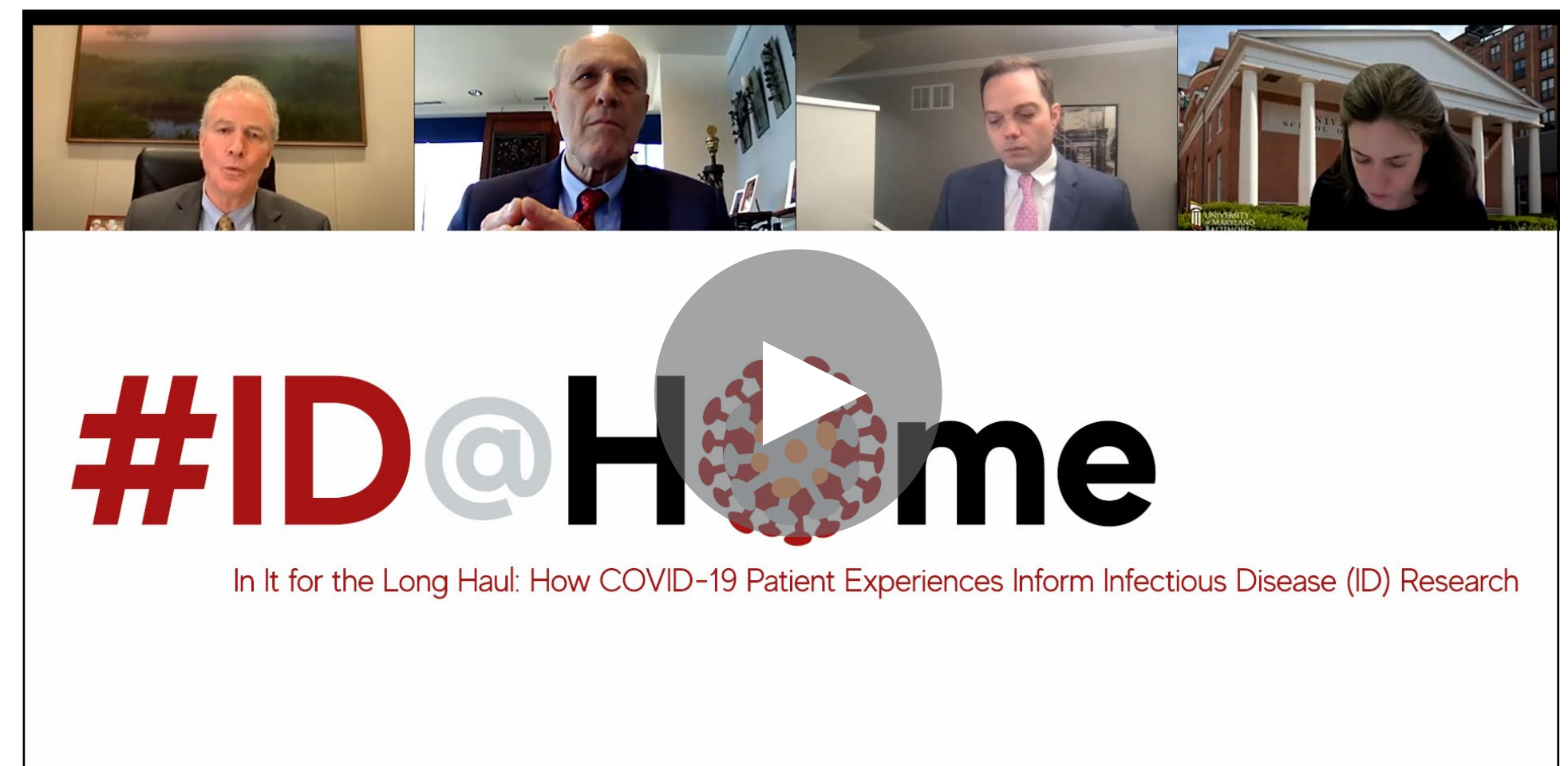
We are proud to share that more than 80 people joined us for the #ID@Home virtual conference on June 23, 2021! Thank you to everyone who logged on! We heard from six amazing speakers and had great talks about how to improve the future of patient-centered infectious disease research.

The first session was about how to engage with people virtually (online) during COVID-19. We heard from speakers who talked about outreach in the disability community and ethical patient sign-up for COVID-19 clinical trials. We also learned about patient-centered outcomes research (PCOR) from the conference sponsor, the Patient-Centered Outcomes Research Institute (PCORI).

Session two was about health system challenges during the pandemic. Speakers talked about hard situations faced by the lupus community during COVID-19, how issues such as lack of housing or education (social determinants) affected health, and long-haul COVID, which is when people have symptoms related to COVID-19 for a long time. Special guests University of Maryland, Baltimore President Bruce E. Jarrell and Maryland Senator Chris Van Hollen also shared their thoughts on the importance of patient engagement in research.

Check out our recap video below and stay tuned for information on how to watch the full conference.

PRESS PLAY TO WATCH THE RECAP





Get the Latest

Project Updates

We have been working hard with the community on our projects. Read about what is going on for each one!

Building Trust to Enhance Diversity in Aging Research

NIA R24

The project is in its **third and last year.**

The research team is working on a list and database where seniors can sign up and give information on the types of research in which they would want to take part. We are also looking for older adults with memory concerns and their care partners to talk to us. If you would like to take part, please call Rodney Elliott at 410-706-7312.

Building Trust to Enhance Diversity in Aging Research will give researchers more ways to work with a variety of senior communities that includes information from their culture. We learned about these ways from what seniors in our focus groups and interviews told us.

Communicating about COVID-19 Testing to Underrepresented Groups

The FDA COVID-19 testing project is in the final stages.

We reviewed the data and made an infographic of themes and recommendations about COVID-19 testing. The table of themes and recommendations was accepted by the community advisors and the FDA Co-Investigators. We are writing the manuscript and final report.

The infographic is a “give back” to give to the community. The “give back” talks about the project and gives information on what the study learned and why the project is important.

It talks about:

- **What we did**
- **How we did it**
- **What we learned**
- **Why it matters**

Communities and Universities Engaged to Fight COVID-19

(CUE COVID-19)

Our **community partners** **personalize the Community Think Tank** in their own unique way.

The team is working on making the structure of the Community Think Tank. Our community partners personalize the Community Think Tank in their own unique way. During Think Tank sessions, Principal Investigators will be invited to come and present their proposals for future projects and get feedback. The team is building an application for researchers to fill out and is working on the Think Tank’s rubric, that will help us grade researcher’s proposals as they present to the Community Think Tank.

COmmunity Based Development of CollaboRatIVE and Sustainable PartNerships in PCOR/CER

CO-DRIVEN

The community will benefit from this research by creating and building relationships.

The CO-DRIVEN team is happy to say that we held our first training on Monday, August 2nd from 5:30- 7pm, which took place on Zoom. For our first session we had 15 people sign up from the West Baltimore and UMB research communities. We are very excited to introduce the West Baltimore community to PCOR. CO-DRIVEN will give us the chance to learn from the community as we teach them about PCOR.

We want to
TRAIN YOU!

VIRTUAL TRAINING SESSION

Patient-Centered Outcomes Research/Comparative Effectiveness Research

WHAT YOU WILL LEARN...

Learn about how your community could add their voice to health research.



TRAINING OBJECTIVE:

To build meaningful partnerships while teaching the southwest community.

For more information or to sign up for a session,

Please contact **Karen Morales** at kmorales@rx.umaryland.edu

Sponsored by



The **PATIENTS** Program

at the University of Maryland
School of Pharmacy

Eugene Washington PCORI Engagement Award:

Capacity Building for a Learning PCOR System

The team is working on creating materials to share what they learned.

The team is in its last stages of creating materials and sharing what was learned over the two-year project period. This project ranks information from most important to least important, and shares PCOR evidence with all stakeholders – patients, care partners, clinicians, health systems and policymakers – so that they can take part in many projects and be in different parts of the research process, not just when they are a part of one PCOR study.

Eugene Washington PCORI Engagement Award:

DISRUPTS

The project will wrap up in August.

The DISRUPTS team is putting together the information they have learned from the project and talking about the best ways to share that information with the community. We are working on creating an infographic, which uses numbers and design to provide information.

The team is also working on a press release, which has information about the project to share broadly. We are also working on an abstract, which is short information about the project, and articles to send to journals. The journal articles and information will talk about how the results helped the community. A focus group is being created to keep their community a part of research in the North Country of New York. The project will wrap up in August.

PREP-IT Trial

PREP-IT

Our team has been busy this summer!

The Stakeholder Advisory Board (SAB) met at the end of June to talk about ways to share results and their unique experience with the broader community. The SAB was given a draft recipe that talks about the “ingredients” and “instructions” needed for a successful patient-centered trial.

Stakeholders will be asked in August to talk about the image currently being made, which will be used as a tool for sharing information. We are also looking at journals to send our co-authored article to by the end of summer. Our next SAB meeting will be in September, where we will plan our interactive sessions for the upcoming Investigator Meeting in December.

Prioritization of Comparative Effectiveness Research (CER)/ Patient-Centered Outcomes Research (PCOR) on Prostate Cancer Active Surveillance (AS):

Community Consensus Initiative

Everyone is very excited about this project.

The team is very excited as we are planning our two-day meeting for this project. The first stage of our planning is getting input on which topics everyone would like to focus on. If you want to, please fill out this BRIEF survey about topics that YOU think are important to the future use of Active Surveillance (AS) in the management of prostate cancer.

We are seeking input from patients, patients’ spouses/partners and supporters/caregivers, physicians, nurses, and others.

The link to the survey can be found here:

Click Here to Take the Survey!



PATIENTS Team Member Publications

PATIENTS Program team members have published articles!

Hillary Edwards, MPH, Director of Methodological Research and Evaluation

Michelle Medeiros, MS, MA, CCRP, Director of Research

C. Daniel Mullins, PhD, Executive Director

Publishing articles about our projects is just one way the PATIENTS Program shares the information they've learned from projects with the academic community.

Colloca L, Kisaalita NR, Bizien M, Medeiros M, Sandbrink F, Mullins CD. Veteran engagement in opioid tapering research: a mission to optimize pain management. *Pain Rep*. 2021 Jun 3;6(2):e932. doi: 10.1097/PR9.0000000000000932. PMID: 34104838; PMCID: PMC8177869.

Davies-Teye BB, Medeiros M, Chauhan C, Baquet CR, Mullins CD. [Pragmatic patient engagement in designing pragmatic oncology clinical trials](#). *Future Oncol*. 2021 Aug 2. doi: 10.2217/fon-2021-0556. Epub ahead of print. PMID: 34337970.

Hillary A Edwards, Jennifer Huang, Liz Jansky, and CD Mullins. [What works when: mapping patient and stakeholder engagement methods along the ten-step continuum framework](#). *Journal of Comparative Effectiveness Research* 2021 10:12, 999-1017

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Watch past episodes on our Facebook page



We hope you have enjoyed your summer, as much as we have enjoyed connecting with the community through our Facebook Live events!

On June 17, Miss Bj talked about thriving during a pandemic. She talked with Joyce Ashford, a mental health professional who provides mental health services at Miss Bj's clinic in West Baltimore. Joyce has a lot of love for West Baltimore. She attends church and has friends there, so she wants to support West Baltimore.

Joyce talked about work-related factors that can add to stress. Being worried about getting COVID-19, taking care of family while working, and having a lot of work to do can bring more stress.

“Signs that we are having trouble are trouble sleeping and feeling afraid for long periods of time,” Joyce said. “One client talked about depression as a black curtain coming down over their lives.”

She suggests thinking about how much symptoms like insomnia (which

means you can't sleep) or other sleep issues may mess with our daily life. If you feel down for longer than a few weeks, she suggests talking to a mental health professional.

She had some suggestions on helping our mental health:

- Take breaks from watching reading or listening to news stories
- Take care of your body
- Focus on your breath, eat well, exercise, get sleep, avoid alcohol and large meals before going to bed
- Make time to relax
- Connect with others, even if just by phone or text
- Connect with your community or faith-based organizations, like a church

Joyce also wants us to be kind to ourselves.

“Take the time to think about how you want to see your family and friends in a safe way,” she says.

“While you may not feel comfortable going with a friend to a movie, you might be ok with sitting outside and talking.”

On July 8th, Genevieve Polk, Assistant Director of Dissemination and Implementation at the PATIENTS Program, talked with Rodney about how the PATIENTS Program gets research information into the community after the community has taken part in a research study.

“Dissemination and implementation is just a fancy way of saying ‘talking and sharing,’ she says. “It’s about talking and sharing about the work we do at the PATIENTS Program.”

The PATIENTS Program connects with the community by supporting community partners with their events, such as helping with health screening events, which allows the PATIENTS Program to talk about who we are and what we do.

“We pride ourselves on working with the community at the start of a research study, asking what they think about the research, not halfway through or towards the end,” she says.

The community works with researchers on how to write the aims, or what the project wants to do, and making sure the information is written so everyone can understand it. “The community gets excited about taking part in the research because they understand it and they helped create the project,” she adds. “The community trusts us as we have been meeting and talking with them at the beginning, during, and end of the research project.”

At the end of a project, the PATIENTS Program creates “give backs,” which gives the information learned from the study back to the community. Give backs can be videos, flyers, or infographics.

“The goal is to have researchers do research that puts the patient at the center of the project,” she says. “The PATIENTS Program wants to be the bridge between research and the community and deliver the information to the community.”

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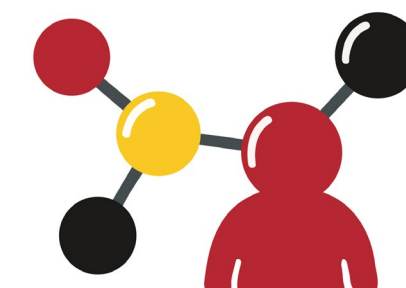


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SPREAD THE WORD

We want to get the word out! Feel free to share this newsletter to let others know about what the PATIENTS Program is up to in the community.

Share this newsletter





THANK YOU!

Thank you so much for your support to help
The PATIENTS Program build the four pillars required
to support a bridge to holistic health:

• **Physical Health** • **Mental Health** • **Spiritual Health** • **Financial Health**

Thanks to your generous support, we can continue to deliver on
our promise that our research results are translated into solutions that
improve the health of West Baltimore, Maryland, and beyond.

C. Daniel Mullins Dwyan Monroe Taih Craddock Matthew King
Eberechukwu Onukwugha Jennifer "Ayana" Harrison

Pillar Sponsors

Ellen H. Yankellow, BSP '73, PharmD '96



Significant Contributors

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