



# PATIENTS' Voices

a newsletter from the PATIENTS Program at the  
University of Maryland School of Pharmacy

July 2016

Meet the PATIENTS  
Program Team

Tips for Healthy Living

Feature Article

Get Involved

In the Community

#### Our Vision

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

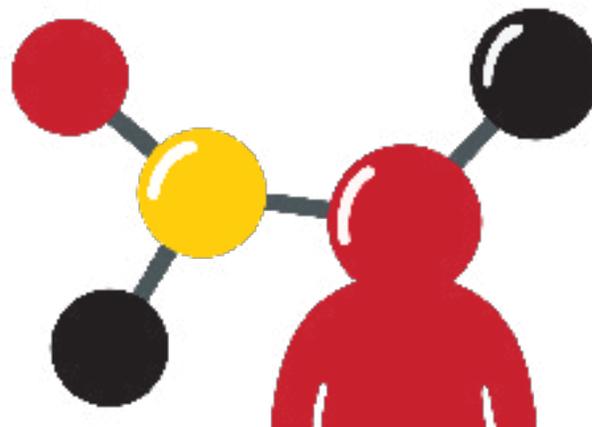
## Message from the PATIENTS Program Team

We're excited to re-launch the PATIENTS Program newsletter as a bi-monthly publication. Now, we'll include more health and wellness resources from our team, partners, and around the Web. You'll also find a list of events where the PATIENTS Program team will be out connecting with the community, and ways that you can become involved in helping us advocate for putting the voice of the patient at the forefront of clinical research.

In addition to the usual content on health living and a feature article on topics like diabetes, heart disease, and mental illness, the newsletter will include short interviews with members of the PATIENTS Program team. We want you to get to know us!

This newsletter is a resource for you, and we welcome all feedback on how to make it better. Email [patients@rx.umaryland.edu](mailto:patients@rx.umaryland.edu) to submit comments and ideas, or if you'd like to have an event listed in the newsletter.

Also, be sure to follow us on Facebook (@PATIENTSProgram) and YouTube (PATIENTS: Engaged in Research) for video content and informative interviews about health, wellness, and patient-centered medical research.



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As a member of the PATIENTS Program team since October 2015, Hillary Edwards brings a wealth of passion for making the program's vision a reality and the know-how for moving that mission forward. Her training at the University of Maryland School of Medicine's Master of Public Health program gives her a dynamic skillset in research ethics, community-based participatory research, and critical issues in global health.

Hillary's experiences in Campus Administration, the School of Medicine, and now the School of Pharmacy make her uniquely qualified to collaborate within the University and abroad. Most recently, Hillary was elected to UMB's Staff Senate, where she'll represent the School of Pharmacy on the highly-regarded, shared-governance leadership body.

## Meet the PATIENTS Program Team

Hillary A. Edwards, MPH

- Assistant Director of Program Management & Evaluation, PATIENTS Program, University of Maryland School of Pharmacy
- B.A., Business Management and Arts Administration, Goucher College
- Master of Public Health, University of Maryland School of Medicine

### **Q: What do you like most about working for the PATIENTS Program?**

A: I come to work every day because of our team. There's a 360-degree view on every project because of all of the different skills that everyone brings to the table. I'm in a sweet spot because I get to work with both researchers and the community. At the end of the day, I love that I've been able to contribute to the various projects in so many ways. From building research proposals to participating in community health fairs, I love seeing the PATIENTS Program building relationships and making an impact.

### **Q: How do you think your position can or will impact the community?**

A: I see the big picture, and I can help researchers understand what concerns people about getting involved in clinical research. I think it helps that I don't come from a strictly scientific background. Our [West Baltimore] neighbors have a lot of questions about the work we do and what's in it for them to contribute.

### **Q: What do you want people in the community to know about the PATIENTS Program?**

A: Because we are representatives of the university and we participate in research, people think of us as "the researchers." They think that we represent a research agenda. I want to separate us from that image. When the PATIENTS team is in the community it's not just to recruit patients.

We're not just a research entity—we're here to listen, serve and give the community a voice that is heard by the University and hold everyone accountable to address the issues that matter to the people of West Baltimore and beyond.

### **Q: What's your favorite healthy meal?**

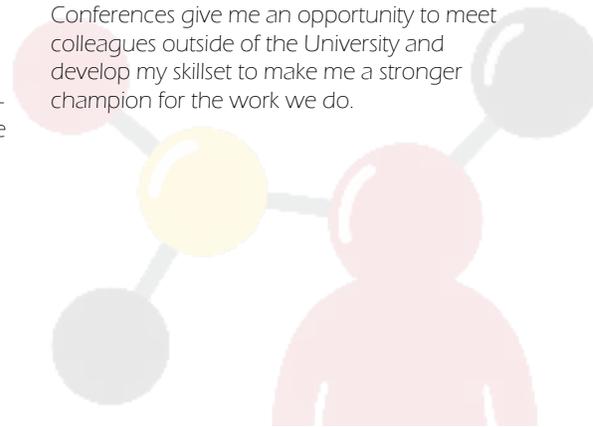
A: Kale salad with toasted nuts and dried fruit. It helps me feel more refreshed, especially after eating out a lot or traveling. I grow a huge garden, so I love pulling my own ingredients from there. I'm also saving money and reducing waste, which feels great.

### **Q: What's your guilty pleasure when it comes to food?**

A: Definitely mac and cheese—always and forever my comfort food! I've also been known to eat half a pint, okay, maybe a whole pint, of ice cream in one sitting.

### **Q: What is one of your professional goals for the next six months?**

A: I am eager to attend a professional conference coming up at the end of July. Conferences give me an opportunity to meet colleagues outside of the University and develop my skillset to make me a stronger champion for the work we do.



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## Did You Know?

Types of Clinical Trials

**Natural history studies** provide valuable information about how disease and health progress.

**Prevention trials** look for better ways to prevent a disease in people who have never had the disease or to prevent the disease from returning. Better approaches may include medicines, vaccines, or lifestyle changes, among other things.

**Screening trials** test the best way to detect certain diseases or health conditions.

**Diagnostic trials** determine better tests or procedures for diagnosing a particular disease or condition.

**Treatment trials** test new treatments, new combinations of drugs, or new approaches to surgery or radiation therapy.

**Quality of life trials** (or supportive care trials) explore and measure ways to improve the comfort and quality of life of people with a chronic illness.

(<https://www.nih.gov/health-information/nih-clinical-research-trials-you/basics>)

## Clinical Research: Myths vs. Facts

The terms clinical research and clinical trials often conjures up negative images for patients and caregivers. People recall stories of doctors treating patients like “lab rats” during studies, or participants in need of treatment who only receive placebos (treatments with no known active ingredients). And while there have been documented cases of such abuses, clinical research continues to be a key component in the development of the medicines and treatment we rely on today. Clinical trials are research tools for advancing medical knowledge, patient care, and policy development. They produce the best data available for health care decision making. Clinical research can also be a powerful platform for patients and caregivers to influence the way researchers and law makers approach treatment, care, and policies.

### What are clinical research and clinical trials?

The U.S. Department of Health & Human Services defines clinical research as “medical research that involves people to test new treatments and therapies” and clinical trials as “research study in which one or more human subjects are prospectively assigned to one or more interventions (which may include placebo or other control) to evaluate the effects of those interventions on health-related biomedical or behavioral outcomes.” (<https://www.nih.gov/health-information/nih-clinical-research-trials-you/glossary-common-terms>) These studies also may show which medical approaches work best for certain illnesses or groups of people.

### Myth: Clinical trials are not safe. I'd be gambling with my health if I signed up.

**Fact:** Many measures are in place to protect the safety of people who take part in studies—from careful study design to oversight by institutional review boards and periodic monitoring of study data by independent experts. Clinical study participants receive regular and careful medical attention and are closely observed for safety concerns.

During the study, researchers must inform you of any new risks, benefits, or side effects they discover. By taking part in a Phase III clinical study, you have the chance to try a new treatment that is generally not available outside of a clinical study. If the treatment is better than standard therapy, as a clinical study participant you may be among the first to benefit from it.

Visit the PATIENTS Program Facebook page (@PATIENTSProgram) for more information on clinical research myths and facts.

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## Fitness FAQs: Yoga

### **What is yoga? Where did it come from?**

The word yoga comes from Sanskrit, an ancient Indian language. It is a derivation of the word yuj, which means yoking, as in a team of oxen. In contemporary practice, this is often interpreted as meaning union. Yoga is said to be for the purpose of uniting the mind, body, and spirit.

### **How is yoga different from stretching or other kinds of fitness routines?**

Unlike stretching or aerobics, yoga focuses on more than just the physical aspects of an activity. It is unique because it promotes a connection between the movement of the body and the fluctuations of the mind to the rhythm of our breath. Connecting the mind, body, and breath helps to direct our attention inward. Your body will most likely become much more flexible by doing yoga, and so will your mind.

### **I'm not flexible. Can I do yoga?**

Absolutely! One of the best parts of yoga is the "come-as-you-are" nature of the practice. It's great for people with physical impairments or who're recovering from injury.

A good yoga instructor will ask about your possible limitations at the beginning of the class and offer suggestions for modifications. As with any routine, the more you practice, the more flexible you'll become. This newfound agility will be balanced by strength, coordination, and enhanced cardiovascular health, as well as a sense of physical confidence and overall well-being.

## Tips for Healthy Living

### **Don't Let Summer Cookouts Sabotage Your Healthy Lifestyle**

Whether you're managing your blood sugar, trying to lose weight, or just striving to make healthier choices this summer, navigating the cookout scene can be overwhelming. There is hope! Preparation is the key to enjoying the outdoor feasts this season while feeling good about the food choices you make. What should you do to prepare?

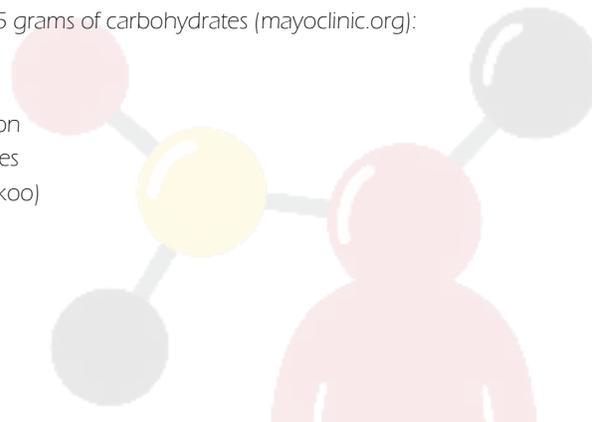
- Stay hydrated. Drink plenty of water throughout the day and leading up to the picnic.
- Start your day with a healthy habit like exercising to help maintain the day's calorie balance.
- Eat regular meals and snacks leading up to the picnic so that you are not starving by the time the food is served.
- Fill half your plate with veggies, add some protein off the grill, and compliment your dish with two spoons full of your favorite side dish. Most calories, sodium, and carbohydrates hide in the side dishes, so be mindful of going overboard.
- Unsure if there will be guilt-free veggies at the picnic? Bring your own veggie tray, salad, or marinated veggie kabobs to the party — just be sure to bring enough to share!

### **Enjoying Fruit While Managing Your Blood Sugar**

Warm weather means lots of luscious fruit. But if you have diabetes, you may be wondering how these seasonal treats can fit into your diet plan. According to the American Diabetes Association, fruits are loaded with vitamins, minerals, and fiber and should be a part of a diabetes-friendly diet — just keep track of them as you do with all carbs. The key is to keep an eye on portion sizes and to stay away from fruits canned in syrups or contained in other types of added sugar.

The following fruit servings contain about 15 grams of carbohydrates (mayoclinic.org):

- 1/2 medium banana
- 1/2 cup (83 grams) cubed mango
- 1 1/4 cup (190 grams) cubed watermelon
- 1 1/4 cup (180 grams) whole strawberries
- 1/3 cup (80 grams) cubed sapodilla (chikoo)
- 3/4 cup (124 grams) cubed pineapple



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## Opportunity: University of Maryland Health and Wellness Focus Group

The goal of this study is to understand what empowers people to take an active role in their health care.

### Who is eligible?

- Men and women ages 18 and older

### What do you have to do?

- Have brief phone eligibility screening
- Attend a 1 ½ hour in-person focus group (if eligible)
- Discuss why people are not active in their healthcare, how to encourage people to be more active, and what health care providers can do to help

### What do you get?

- You will receive a \$25 gift card for your time. All information is confidential.

If interested, contact Jennifer Huang at [JenniferHuang@Westat.com](mailto:JenniferHuang@Westat.com) or 301-610-5590.

## Get Involved

We invite you to take advantage of these exciting opportunities to participate in community-based groups created by partners and friends of the PATIENTS Program who are actively seeking input and feedback.

As always, feel free to reach out to the team at [patients@rx.umaryland.edu](mailto:patients@rx.umaryland.edu).

### Opportunity: B'more for Healthy Babies Focus Group

We need community input to figure out what programs and services would best meet community needs!

B'more for Healthy Babies will be coming to Mondawmin to help improve maternal health and birth outcomes. The University of Maryland Medical Center and the Schools of Medicine, Social Work, and Pharmacy have received funding from the Association of American Medical Colleges to implement this project.

### Who is eligible?

- Women (18 years and older) who are pregnant or were recently pregnant
- Partners (18 years and older) of women who are currently or recently were pregnant
- Grandparents who help out with young grandchildren

### What do you have to do?

- Have a brief phone call to determine your eligibility and contact information
- Attend a 90 minute in-person focus group to discuss healthy pregnancy and healthy birth outcomes

### What do you get?

Participants will receive a light meal and a \$20 gift card. All information that you share will be kept confidential and will not be linked to participants in any way.

If you are interested, please email [patients@rx.umaryland.edu](mailto:patients@rx.umaryland.edu) or call 410-706-8828.

### Opportunity: A Focus Group to Develop Questions about Taking Medications

The goal of this focus group is to get YOUR input on potential questions that will be used to determine if patients take their medications or not.

We want our questions to be the best possible, and with your help we can make that possible we need your help to do so.

### Who is eligible?

- Men and women ages 18 and older who are taking at least 1 prescription medication every day

### What do you have to do?

- Have a brief phone call to determine your eligibility and gather contact information
- Attend a 90 minute in-person focus group
- Discuss the questions we have written to determine if they are easily understood, relevant, and important to patients who are taking medications

### What do you get?

- All information is confidential and will not be linked to participants in any way.
- You will receive a \$20 gift card for your time and participation.

If interested please contact Brian Lindner by phone at 443-876-8275 or email at [blindner1@umaryland.edu](mailto:blindner1@umaryland.edu). If there is no answer by phone, please leave a message with your contact information.

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## Patient Advocate Spotlight: Cynthia Chauhan

Education, engagement, and advocacy are at the core of the PATIENTS Program, and Cynthia Chauhan's work exemplifies those values. As a breast cancer survivor and care giver for her husband, a kidney transplant patient, Cynthia provides a unique perspective for what it takes to develop successful clinical research that truly address the questions and needs of patients and their loved ones.

Ms. Chauhan's article, "Patients Views Can Improve Clinical Trials for Participants", was published in the April 2016 edition of The BMJ (formerly The British Medical Journal).

In the article, Ms. Chauhan writes: "including patients' voices from inception through to the completion of trials, as well as focusing on the emotional, social, and financial aspects of trial participation for patients, can make participation easier for more of us."

Read the full article at <http://www.bmj.com/content/353/bmj.i1922.full?ijkey=OHxCHmXvzbzI5Veq&keytype=ref>.

## In the Community

### Join Us for a Monthly Community Walk

The PATIENTS Program team will be out supporting the Baltimore Community Health Walkers for its 38th consecutive monthly walking event hosted by Chauncey "The Trainer" Whitehead and Ms. Ernestine Sheppard. The group is teaming up with the National Urban League's Conference walk, so it's sure to be a great crowd.

**Date and Time:** Saturday, August 6, 6:30 a.m. – 8:30 a.m. (registration from 6:00 a.m. – 6:30 a.m.)  
**Start Location:** Baltimore Convention Center, One West Pratt Street, Baltimore, MD 21201

For more information, contact Lynnee Roane, Assistant Director of Engagement, PATIENTS Program, at [lroane@rx.umaryland.edu](mailto:lroane@rx.umaryland.edu) or 410-706-5998.

### Upcoming Events

Below is a list of events where the PATIENTS Program community engagement team will be onsite to speak about health, wellness, and becoming a voice in research for health conditions that affect the lives of the community. Each event will include:

- blood pressure and diabetes monitoring and testing,
- information available about navigating health care services, insurance, and hospice care, and
- an HIV counseling and information station.

**Saturday, August 6, 2016: Church and Community Block Health Fair, 10:00 a.m. – 3:00 p.m.**  
St. Matthews Gospel Tabernacle Apostolic Faith Church  
1907-13 Rosedale Street, Baltimore, Maryland 21216

**Sunday, August 7, 2016: Hispanic Community Health and Wellness Fair, 10:30 a.m. – 4:30 p.m.**  
Patterson Park Recreation Center  
Baltimore, Maryland 21224

**Sunday, August 13, 2016: Back to School Event, 11:00 a.m. – 3:00 p.m.**  
St. James Pentecostal Church  
1432 Hollins Street, Baltimore, Maryland 21223

**Sunday, August 27, 2016: Affordable Care Act Event and 9th Annual Family and Community Outreach, 9:00 a.m. – 1:00 p.m.**  
The Reservoir at Druid Hill Park  
900 Druid Park Lake Drive, Baltimore, Maryland 21217