



# PATIENTS NEWS



January 2015

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## News

### M-CERSI Conference on March 9, 2015

On March 9, 2015, the University of Maryland Center of Excellence in Regulatory Science and Innovation (M-CERSI) Conference on Patient-Focused Drug Development will bring researchers, academics, clinicians, patients, and caregivers (and other key stakeholders) together to discuss the nature of patient-focused drug development (PFDD), components of successful PFDD, and current PFDD initiatives from the FDA, patient advocacy groups, and pharmaceutical companies. The conference will also focus turning challenges within PFDD into opportunities for growth, and the conference deliverables will include a patient engagement rubric for PFDD.

The conference will be held at the Hyatt Regency in Bethesda. Registration is free. For more information, or to register, visit: [link](#)

## Featured Videos



This video provides information to assist subcontractors on grant proposals and contracts awarded to the University of Maryland Baltimore.

## Champions of

Dear Reader,

Authentic and impactful patient and community engagement in health-improving research is best facilitated by strong partnerships with institutions that serve these populations. The University of Maryland PATIENTS Program reflects an incredible diversity of partnering institutions that have spent the first year building a sound infrastructure to conduct patient-centered outcomes research (PCOR) in a bidirectional learning atmosphere. This solid foundation will allow us to work collaboratively in our second year and beyond to leverage our infrastructure to conduct PCOR.

Quite simply, the patient is the center of patient-centered outcomes research - which is why this second year of the PATIENTS program is all about reaching out to patients, finding out what their health care concerns are and getting them invested in research and informed decision making. We have taken some steps forward by hiring Laverne McNeal as our community outreach coordinator and by working with our partners on training activities and grant proposals. Now it is time to get the word out to a broader audience - those patients and caregivers who will benefit from our work. As always, we rely on our steering committees to offer us feedback on how we can make our efforts more visible.

I am looking forward to the year ahead, to hearing - and sharing - the patient's voice.

Sincerely,

C. Daniel Mullins, PhD  
PATIENTS Program Director  
Chair, Department of Pharmaceutical Health Services Research  
University of Maryland School of Pharmacy

## The Voice of the Patient

### My Story

By *Jacqueline Williams*



A few years ago I left the corporate world and decided to take a different path. I had been practicing yoga for several years and always thought about how rewarding it would be to teach. I was so busy changing my life that I didn't notice that my parents were getting older. Last year my dad had a stroke and now he is living in a nursing home. Our roles have changed and now I am one of his caregivers. I spend a lot of time making sure that his physical and emotional needs are met. This means working with the health care providers at his facility to ensure that his treatment and care plans are fulfilled. My two siblings and I also believe it's important to try and visit our father every day.

It's easy to get so caught up in caring for a

## Excellence



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## About PATIENTS

Launched in September 2013, the PATIENTS program aims to build the necessary infrastructure to empower patients to propose questions about their health care concerns and actively participate in studies to answer them. Funded through a grant from the Agency for Healthcare Research and Quality (grant # R24 HS22135-01), the program contributes to the University System of Maryland's "MPowering the State" initiative by combining the expertise of leading researchers from the University of Maryland, Baltimore and the University of Maryland, College Park through innovative partnerships with patient communities and health care systems. Together, we work to ensure that patients, health care providers, and other partners are actively engaged in research. To learn more about us, check out our [website](#).

loved one that you forget to make sure that your own needs are being met. When you burn the candle at both ends, you can burn out. It's especially important for caregivers to care for ourselves so our physical and mental health doesn't falter. I always eat lots of fresh fruit and vegetables to keep colds and flu at bay. I also get plenty of protein to keep myself strong enough to face daily challenges. I meditate and practice yoga about five times per week and highly recommend yoga and meditation as a way to ward off stiffness and injuries. Practicing yoga and meditation can also bring more peace and balance into your day to day activities. Yoga doesn't have to mean a bunch of complicated poses. You can start by closing your eyes, taking deep, slow breaths and practicing good posture for ten or fifteen minutes a day. People often carry tension in the body and hold their breath without even realizing it. Yoga is a wonderful way to unite the mind, body and spirit.

Being a caregiver can become stressful and sometimes lead to using food or other substances as forms of comfort. Adopting a healthy lifestyle can help to avoid this behavior. It's been my experience that people who are struggling this way will appreciate a supportive hand extended in loving kindness. You can research and discuss treatment options with your loved one and help them take the steps needed to move forward. Remind them of how important they are, especially to the people they care for. Help them to recognize the triggers that lead to the addictive behavior and work with them to come up with healthy, positive activities to replace the unhealthy ones. Exercise can keep the mind and body strong and alert as you transition out of negative, addictive behaviors. Also, if it proves necessary, you can help your loved one find a therapist or support group.

Fortunately, we live in a time when helpful information is a lot more accessible; however, being responsible for someone else's care and wellness still comes with many challenges. As a caregiver, my biggest request of the medical community is availability. I realize that doctors are extremely busy and sometimes under stress but no one wants to feel forgotten or ignored. Even if the communication can't be face to face, an email, call or text can go a long way towards making caregivers and their loved ones feel more secure. In the meantime, take care of yourself and the ones you love.

## Training and Resources

### Meet The New Team Members

The PATIENTS team is proud to welcome two new team members:



LaVerne McNeal, our new community outreach coordinator, has served as a case manager for women and children in crisis and she brings her passion for helping others to PATIENTS. She'll work to strengthen and develop collaborations within our communities. Her experience includes traditional and new media relations, publicity and brand management for not-for-profit organizations and businesses.



Laura Bogart, our new writer, comes to us from LifeBridge Health, where she served as the editorial manager, coordinating marketing efforts for internal and external campaigns. She'll be using her marketing and media expertise to help develop overall communication and outreach. Laura will also be assisting on proposals.

## Activities and Accomplishments

### PATIENTS in the Media

C. Daniel Mullins, PhD, joined trainer and fitness activist Chauncey Whitehead on the Marc Steiner show on Jan. 8. Together, they talked about the ways in

which patients can become more active and empowered in their health care, and offered tips for Baltimoreans who want to prioritize fitness well beyond the gym rush of early January.



Whitehead talked about the community walks he co-leads with the celebrated "Mama Ernestine Shepherd," who has held the Guinness Book of World Records title of World's Oldest Female Bodybuilder. Once a month, people of all ages and fitness levels from the community gather in Druid Hill Park to walk, share stories, and make new friendships. "The community that walks together, talks together," says Whitehead. [link](#)

## Featured Article

### PATIENTS Site Visit Brings PCOR Experts and Community Partners Together

On Jan. 12, 2015, some of the brightest minds in patient-centered outcomes research (PCOR) braved icy weather in Baltimore to attend the second site visit of the PATient-centered Involvement in Evaluating the effectiveNess of TreatmentS (PATIENTS) program at the University of Maryland School of Pharmacy. Researchers, clinicians, and community health advocates came together to celebrate accomplishments made in the program's first year, discuss some of the most important issues in PCOR, and to chart a course for PATIENTS' year two.



PATIENTS, created in 2013 with a five year, \$5 million grant from the Agency for Healthcare Research & Quality (AHRQ), used year one of the program to integrate the members of its internal and external steering committees and to invite collaboration between key stakeholders. These collaborations have the power to develop and sustain lasting partnerships across local, regional, and national communities of patients and providers. Year two is targeted toward patient outreach - one of the PATIENTS program's chief aims is to help patients feel more educated and empowered about their health care choices, and to become more active in clinical research.

"When patients are involved in research, they can help ensure that the questions driving research will be meaningful to them," explains C. Daniel Mullins, PhD, professor and chair of the Department of Pharmaceutical Health Services Research at the School of Pharmacy and director of the PATIENTS program. "We want researchers to understand the value of having patients and other stakeholders involved in every stage of research, from trial designs to sharing information with the community."

The site visit's morning agenda was focused on survey and interview results collected by Westat, the project's internal evaluator, which were presented by Paula Lipman, PhD, senior study director. These surveys and interviews, which were conducted with members of the steering committees, showed that the group has faith in PATIENTS' "strong, stable leadership," and that they were pleased with PATIENTS' initial outreach and communications efforts: launching a website, an e-newsletter, and e-briefs geared toward engaging PATIENTS' partners and steering committee members. Westat recommended expanding these forums to include topics that are more pertinent to patients' interests and concerns -- an approach that was heartily endorsed by the attendees, many of whom spoke about a greater need for health literacy within the communities they serve.



Marcy Fitz-Randolph with Pastor Franklin Lance

Making PCOR more impactful for patients and providers requires versatility, and finding creative ways to engage new communities was the subject of two interactive panel discussions. Franklin Lance, D.Min, pastor of Mt. Lebanon Baptist Church in Baltimore, teamed with Marcy Fitz-Randolph, research client manager at PatientsLikeMe, to talk "high touch vs. high tech" approaches to PCOR. Afterward, Wanda Miller, director of Nursing and Patient Care Services at Riverside Health System, and Samuel Ross, MD, CEO of Bon Secours Baltimore Health System, presented "PCOR Across Diverse Health Care Delivery Systems," which offered insights into the unique challenges and opportunities of delivering health care within rural and urban communities.



Samuel Ross with Wanda Miller

Participants enjoyed talks on training and stakeholder engagement, as well as updates on the status of PCOR sub-projects funded through the PATIENTS grant. Robin Newhouse, PhD, RN, NEA-BC, FAAN, professor and chair of the Department of Organizational Systems and Adult Health at the University of Maryland School of Nursing, and Wanda Miller shared their enthusiasm for the work they've completed on project one, titled "Improving Heart Failure Outcomes in Rural Hospitals." Susan dosReis, BSPHarm, PhD, associate professor in the Department of Pharmaceutical Health Services Research at the School of Pharmacy, discussed the work to be done on project two, which seeks to establish methods to help family members and caregivers choose the best care options for their loved ones.

The patient's voice was always present throughout the day. Patient advisor

Daniel Frye, JD, executive director of the New Jersey Commission for the Blind and Visually Impaired and member of the PATIENTS program's external steering committee, spoke about his involvement in making the PATIENTS website more accessible for visually-impaired people (VIPS). He also talked about collaborating with fellow VIP patient advocate Gail Betz, and members of the PATIENTS team on a manuscript that will offer researchers insights on engaging VIPs in clinical trials.

One of the undeniable highlights of the visit was the chance to hear living legend Miss Ernestine Shepherd, who was named the Oldest Performing Female Bodybuilder by the Guinness Book of World Records, talk about her personal commitment to fitness at any age. Each month, Miss Ernestine leads a community walk through Druid Hill Park; representatives from PATIENTS make a point of joining her to show support and share the program's message.



Miss Ernestine Shepherd

"Listening to engaged members of the community, like Miss Ernestine, and to the patients who've been so generous with their experiences, really reminds us why PCOR is so important," says Dr. Mullins. "Achieving, and sustaining, good health has the power to transform individuals and build better communities. After all, that really is the ultimate goal of the PATIENTS program."

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