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# PATIENTS NEWS

October 2014

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## News



### Researchers of the Year

C. Daniel Mullins, PhD, and Robin Newhouse, PhD, RN, MS, NEA-BC, FAAN, have been chosen as UMB's 2014 Founders Week Researchers of the Year for developing a collaborative program that engages patients as advisors in designing research on health issues important to patients. [More](#)

### Researcher of the Year Lecture

On October 13, Drs. Newhouse and Mullins delivered this year's Researcher of the Year lecture. They gave an unorthodox and very engaging presentation by inviting fellow colleagues to the podium and by

Dear John,

The PATIENTS Program celebrated its first anniversary of AHRQ funding on September 29 with a number of achievements:

- supported 21 CER/PCOR proposal submissions, of which 5 received funding
- funded 2 pilot projects
- received new funds from the Dean of the School of Pharmacy
- developed 4 training webinars
- cataloged 43 training materials
- developed a website
- issued 2 e-newsletters
- participated in community health fairs and walks
- participated in a "reverse site visit" in Cambridge, MA, hosted by our partner PatientsLikeMe

As we go forward, we plan to transition from a first-year focus on enhancing collaborations with our partners, to a second-year expanded focus on more direct patient engagement.

With input from communities of patients, we hope to identify research questions that are meaningful and important, and we hope to put forward more winning proposals.

We also plan to continue producing and cataloging:

- high-quality training materials and resources for those of us engaged in CER/PCOR research
- accessible health videos and information for patients and caregivers in the community

I look forward to another transformative year!

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 Gail Betz

starting and ending the presentation with the voice of the patient.

## Champions of Excellence



CHAMPIONS OF EXCELLENCE | PATIENTS PROGRAM

### Partnering with PATIENTS

When patients have a role in designing the research, those results mean more to them and they are able to make treatment decisions that advance their own health priorities. [More](#)

## Featured Videos



April 28, 2014 -- Members of the program's internal and external steering committees gather at the School of Pharmacy to discuss progress, share experiences, and begin shaping the next phase of this groundbreaking initiative. [Read](#)

## 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](#).

My name is Gail Betz and I am a visually impaired librarian at the University of Maryland, Baltimore's Health Sciences and Human Services Library.

I was diagnosed with Stargardt's disease 8 years ago, and since then I graduated from college, got married, got a Master's degree, relocated, and ran one marathon and many half marathons.

I love to teach, and have taught in an elementary school, a middle school, in special education, and at two universities. I have also relinquished my driver's license, seen countless doctors, and purchased glasses much thicker than I am comfortable wearing in public.



## Training and Resources

### Interview with Patient Advocate and Representative Gail Betz



In this 8-minute interview, Gail Betz shares her experiences as a visually impaired patient and gives advice to PCOR researchers and patients who would like to be engaged in research as advisers and collaborators. She also answers questions about the reasons people with impairments are under-represented in clinical trials and the benefits from engaging patients in research.

### PatientsLikeMe Data Capabilities Overview Wednesday, June 25, 2014



On June 25, our partner PatientsLikeMe provided information in a webinar presentation about their capabilities and interests for collaboration. Now you can watch the webinar recording, which is available under [PCOR / Resources](#) our website.

PatientsLikeMe® is a patient network that improves lives and a real-time research platform that advances medicine. Through the network, patients connect with others who have the same disease or condition and track and share their own experiences. In the process, they generate data about the real-world nature of disease that help researchers, pharmaceutical companies, regulators, providers, and nonprofits develop more effective products, services and care. With more than 250,000 members, PatientsLikeMe is a trusted source for real-world disease information and a clinically robust resource that has published more than 40 peer-reviewed research studies.

## Activities and Accomplishments

**Members travel to PatientsLikeMe headquarters for in-depth look at the organization's services and to share guidance on future research and collaborations.**

**By Malissa Carroll**  
**Friday, September 19, 2014**

Six members from the PATIENTS program at the University of Maryland School of Pharmacy traveled to the headquarters of PatientsLikeMe - one of the program's community partners - in Cambridge, Mass., to conduct the program's inaugural partner site visit from July 16-18. The visit, which showcased the capabilities and culture of PatientsLikeMe, is part of the program's ongoing effort to support bi-directional learning among its researchers and community partners. [More](#)



## Featured Article

### My Experience at the PatientsLikeMe Site Visit

**By Dr. Joseph Richardson**  
**Tuesday, August 25, 2014**



Hello!

I'm [Joe Richardson](#) and I work with young Black men who are the victims of violent injury to reduce repeat violence-related trauma. My research focuses on issues of race and poverty, specifically issues which impact the lives of young Black men.

In July 2014, I visited PatientsLikeMe (PLM) for a three-day site visit as part of the bi-directional educational commitment of the PATIENTS program. I presented with Daniel Mullins on the engagement of individuals who are typically underrepresented in the research process. Specifically, I highlighted the methodological issues that I encountered while conducting a clinical ethnography of Black male victims of violent injury/trauma on a level II trauma unit at Prince George's Hospital Trauma Center, with special emphasis on concerns other researchers may need to consider when conducting research among vulnerable populations.

I was also able to bring my insight into a group discussion on qualitative research techniques, specifically ethnography, clinical observations and in-depth interviews.

In addition to sharing my own experiences, I took away a better understanding about the way in which qualitative data is collected and stored on the PLM platform and the logistics of conducting online surveys. I also had the opportunity to interact with two active PLM community members who demonstrated the broad spectrum of ways in which individuals can connect

and share information and experiences on the platform. This is especially important as I feel that access to, and the appropriate use of, online patient forums and other technological advances, have the potential to open the door to better engaging African-American men in the research, not only as participants, but as partners throughout the entire process. Because low-income young Black men are often estranged from traditional healthcare systems, it is critically important that they are knowledgeable of and empowered to engage and navigate the healthcare system.

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