

On June 30, 2017, the [National Center for Advancing Translational Sciences](#) at the [National Institutes of Health](#) held its inaugural [NCATS Day: Partnering with Patients for Smarter Science](#) to collectively discuss ways for improved patient inclusion in NCATS' [translational science](#) activities. The [Northwestern University Clinical and Translational Sciences](#) Institute is supported by funding from NCATS and was pleased to have staff from the [Center for Community Health \(CCH\)](#) and [Center for Clinical Research \(CCR\)](#) participate. CCH also supported the attendance and participation of one of our patient advocacy partners, Candace Henley, Founder and Chief Surviving Officer of [The Blue Hat Foundation](#), a faith-based, colorectal cancer organization whose mission is to educate, raise awareness, and provide resources to the medically underserved.



Here's Candace's recap:

The day started with opening introduction of Christopher P. Austin, M.D., Director, NCATS. When Christopher began to speak I started taking notes because I was like "wow, he gets it, he is speaking my language" and as an advocate and cancer survivor, you yearn for the medical and scientific community to catch up and understand the needs of the patients and the need to have patients as partners to help the medical and scientific community to see us as patients with lives and not subjects.

I wrote down some key points he said that were impactful to me and set the tone for my expectation of what the day would be like.

- The status quo is simply not acceptable for any disease
- We fail to ask the people this is designed to help what they want, referring to (ACA debate, repeal and reform)
- If Healthcare is a consumer good, why would you exclude the consumer?

There was a case-study in Translational Science Collaboration presentation, The Alpha 1 Project, Inc, that highlighted an effective NCATS-patient advocates collaboration. *Alpha-1 Antitrypsin Deficiency (Alpha-1) is a genetic (inherited) condition passed from parents to their children that may result in serious lung or liver disease.* Once again, I was inspired by the presentation and success that was reported and the difference the collaboration made in the lives of patients and science.

Next, the participants broke into 6 groups of two brainstorming sessions which were designed to share information and opportunities for patient engagement and identify patient partner interests and needs to be match with NCATS programs. During these sessions, we were asked for our perspectives on what was missing in patient collaboration, how it can be better, and a list of necessary actions. In each and every discussion, I drove home the need to make sure the information is patient friendly and not too scientific and the need for access for patients in medically underserved communities which include neighborhood hospitals and clinics that may not be associated with a scientific hospital. Far too often information on clinical trials and new advances in treatment and technology are not quickly available to patients that live in rural America or use low-income community clinics and hospitals. These discussions are great to have but they must be inclusive to ALL walks of life. Otherwise, what's the point?

As a patient advocate, I found the meeting to have important intentions and meaning, however, I would have liked for it to have had more content about how to engage and collaborate with patients to partner for smarter science. I found

that some attendees were new to advocacy and used the day as a platform to voice their feelings of being ignored due to having a rare disease and not offering realistic suggestions about how to make effective change.

The Welcome address by Dr. Austin, was spot on and if our conversations had been centered around his speech, it would have set the tone and course of the discussions. But I left the day longing for a dialogue that was more patient engagement focused and had more detailed information on how to be engaged with various NCATS programs. I did have the opportunity to meet other great advocates that are doing great work on behalf of other patients, family members and friends that are fighting diseases and using their voices for change. I truly hope to have another opportunity to add my vast experience as a cancer survivor and advocate to advance patient understanding and collaboration in the future.