POZ

Hey, HIV Advocates: Talk Nerdy to Me!

Why we need Black people in the halls of HIV research conferences—and what they must be able to do when there.

November 17, 2016 By Matthew Rose

The longer I work in this field, the more I just want you to talk nerdy with me. I get excited when someone can mix the language of the layperson with highly scientific and technical terms. When you can effortlessly say “These antibodies persist like the good stank of your grandma’s pork rinds,” I get a chill.

Advocates are so often tasked with the role of translator, usually needing to understand and speak to several distinct and overlapping groups of people with differing levels of comprehension. We are tasked with teaching each side how best to speak with and understand one another. It is a challenging task to ensure ideologies are not lost in translation. The implications and effects of this impaired translation are far-reaching and long-lasting, and they impact the health of whole communities. Further, while many advocates are called, few are able to stand and cover the gaps between science and community.

Some advocates must bear the arduous task of understanding the 56 PowerPoint slides deck. The P values, confidence intervals, the study design that create clues and mechanics that are built into the scheme that explains why the studies’ statistical power makes sense for proving scientific questions and mandates. If that all sounded Greek to you, it just highlights my point. This is the language that gives power to science, the ability to shape a study that proves evidence for funding taht can affect the lives of millions. It is not enough to have researchers that look like us. We must also ensure liaising the information, breaking down the knowledge, and holding research studies accountable to the diversity of the community most deeply impacted by this epidemic. If we are not intentional with this sharing and translating of information to our communities, we risk being left behind with our unique experiences ignored and forgotten.

Know that speaking to your community is not enough. We must embody the mantra “nothing about us without us.“ A colleague of mine made an astute observation about a recent research conference we were attending. Rob’s piece asks the very simple question: Where are all the African-Americans. How do you protect the lives of those in need when they are not in the rooms where power is gathered and decisions are made. If members of the community are not included in research from the outset, the input is left out of the conversation. The further down the research pipeline community input is added, the less the community can influence the process and have their concerns truly addressed.

We need more people that ask folks (advocates) to “talk nerdy to me.” We need these individuals at meetings, understanding and giving input. These advocates need not understand every detail of the science, but they should understand the basic concepts, what research studies are trying to figure out, and how this research may impact the health outcomes of the community. There must be more Black people in the halls of research conferences asking key questions and demanding that the research agenda not move forward without an answer. Knowing that in doing so they protect the health and well-being of future generations of their community. The end of the epidemic can only come when we start listening and understanding one another to a much greater degree.

Working to identify strategies that will meet the needs while integrating the experiences and unique patterns that make up the Black experience in America requires more people who are willing to have someone talk nerdy to them.