The New National Voice of People with HIV is...

May 24, 2013 By Mark S. King

At a recent town hall forum in Washington, DC for people living with HIV, the very idea of what it means to be positive -- and who is our national voice of advocacy -- was questioned. With the demise of The National Association of People with AIDS (NAPWA) earlier this year, it's an important conversation to have.

The forum, sponsored by the Federal AIDS Policy Partnership, a coalition of AIDS-related organizations and interests, didn't bear much fruit in terms of hearing the feedback of people living with the disease. The event was lightly attended in person, with most of those living with HIV present representing some organization or another, and the online viewers had technical problems and, presumably as a result, contributed very little.

The most compelling minutes of the event, to me at least, were courtesy of the sheer audacity of former administrators from NAPWA (like Frank Oldham, pictured above), who made a pitch for their new HIV advocacy venture. After bankrupting a multi-million dollar agency and charges of financial malfeasance, you'd think they would opt for a lower profile. In this video episode of My Fabulous Disease, I take them to task and even provide a dramatic reenactment of some of their organizational negotiations. I can't wait for you to see it.

The day following the forum I attended a scheduled meeting of the the Federal AIDS Policy Partnership (FAPP), and heard excellent presentations on the state of Ryan White during healthcare reform (iffy but hopeful), and how we as people with HIV can best navigate Obamacare (tip: go directly to www.HIVHealthReform.org and get educated).

In light of the town forum they hosted, I also strongly encouraged FAPP to add seats on their body specifically for people with HIV -- or for representatives from coalitions for people with HIV -- so there would be voices of people with HIV that wore no other hats or were tied to other agencies or agendas. I look forward to giving you an update on whatever steps they might take in this regard.

Thanks for watching, and please be well.

Mark

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