Hep on the Hill: A Time to Unite!

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“Let’s have everyone introduce themselves. Tell us who you are and why you’re here today."

It’s Hepatitis on the Hill 2016, and I’m praying that we can get through a hundred conference participants’ introductions in sixty minutes and stay on time. Instead, I completely lose track of time as participants relay stories of diagnoses, denial of treatment, liver transplants, and health disparities tangled up in the narrative of hepatitis in their communities.

This March, Capitol Hill saw the largest constituent-based event for hepatitis advocates in the country, known as Hepatitis on the Hill. The event, coordinated by Hep B United (HBU), the Hepatitis Appropriations Partnership (HAP), and the National Viral Hepatitis Roundtable (NVHR), brought advocates working in both pandemics to ground zero (Washington, DC) for national advocacy.

After a long day of Hill visits, participants trickled into the reception room for a debrief session, riding the momentum from the day. Between collapsing into chairs and grabbing water, constituents swapped stories about the reactions from the legislative staff.

“I could tell she didn’t really care, but I kept telling my story! I was going to make her hear me!”

“On our way out, one staffer told us her aunt had died of hep C.”

“Our group did so well - I think my legislator’s going to sign the letter!”

The letter the constituent is referring to was one of the “asks” participants presented to their legislators. There were two separate letters circulating in the House and Senate, asking representatives to support increased funding for the Division of Viral Hepatitis at CDC in the Fiscal Year 2017 Appropriations Bill. The other request was that legislators support the modified syringe language included in the FY 2016 Appropriations Bill, which allows syringe service programs to use federal funds to support organizational efforts, though not to specifically purchase syringes.

The most poignant part of the debrief session was the camaraderie between group members. After an exhaustive seven-hour day of Hill visits, many hep B and hep C advocates had their routine down pat. One constituent described their visits as a relay, where a hepatitis C advocate began the meeting and then “handed it off” to the hepatitis B advocates to tie everything together.

Hepatitis on the Hill was intended to bring hep B and C constituents together in an advocacy setting and say, “We need a strategy for our visits. What’s the common thread between our stories?”

During the two-day conference, I saw advocates from Washington state planning to collaborate on events when they returned home, and Pennsylvania constituents learning more about hepatitis B initiatives in their state. I watched California advocates greet people who had become their friends after so many years working on these initiatives.

I watched advocates find the common thread.

It can be exhausting to work in these movements, particularly when the obstacles seem insurmountable. Yet from where I stood, advocates finally had a shared space where they could exchange stories of hardship, success, and lessons they had learned. With all the energy in the room, I can only hope this experience rejuvenated advocates to continue this important work in their communities!

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Check out the Hepatitis Appropriations Partnership and Hep B United to get involved!

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