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# Reflections of a Hepatitis C Advocate

## Long time health advocate Bill Remak's reflections on the 2015 AASLD and hepatitis C advocacy

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Bill Remak

After three days of attending activities and symposium sessions at the 2015 AASLD Liver Meeting, I was thoroughly exhausted. On Monday evening, I found myself at the Marriott Marquis Hotel in San Francisco at a meeting titled, *Beyond the Walls of the Clinic: The Importance of Collaboration with Community Organizations to Address Viral Hepatitis*.

The meeting that evening was different. It was sponsored by advocates fighting viral hepatitis rather than the usual meeting fare of doctors and researchers. I wanted to hear their concerns, strategies and ideas about the current landscape and what goals they were thinking about for the future. The mood seemed to be upbeat and hopeful. I noticed that there were providers, public health officials, policy wonks, health consultants, patient advocates, hospital systems and representative from several non-profit organizations from across the US and abroad.

I listened carefully to the presentations, the questions and comments that came from several persons, and observed the audience reactions in the room. I noticed some hope, frustration and the occasional "deer in the headlights" look. Few were fiddling with their smart phones, either texting or reading their emails. I took notes and found some of the statistics alarming that showed how much work had to be done, but also showed that real, positive outcomes were being achieved. A sense of optimism was present, but it was unclear exactly how we would get the job done unless we were unified in our efforts. This made very reasonable sense to me.

What was not clear was where the leadership was and where it came from. "Who" was actually the one listening. Some individuals received generous applause and praise, while others were ignored. It did not appear as an act of humility nor conducive to a positive united effort. It seemed like some were vying for a stake at the table of advocates. It was not entirely comforting. The tone seemed to me to alienate some folks in the room. A patient advocate friend of mine from India, I had invited to attend with me, appeared confused.

I sat there thinking and listening. I had survived nearly 50 years so far with hepatitis C, struggled and suffered immensely over the years with cancer, diabetes, two liver transplants and chronic kidney disease, advocating for all people with hepatitis and helping organize chronic disease organizations and provider associations throughout California to work together. Our team was working to resolve the system and policy dysfunctions impacting our access to quality care, never giving up and always knowing about the lives and loved ones lost...I felt numb and tired. All Lives Matter! Those that had paved the way, did monumental work should never be forgotten. They did not die in vain. Doctors, researchers and advocates that I and many others had known and are no longer with us would be happy to know how far this battle has gone and their efforts made a difference in getting us to this point. A sign of respect speaks volumes.

Forty-eight hours before, my eldest daughter had given birth to her second son and my fourth grandchild. I felt blessed to still be alive to have the joy of this experience. It reminded me that all the lives we save have loved ones and families. We must for the sake of human decency address all human beings suffering the agony of these diseases and others for the good of our society, if we are to flourish on this planet. That is what is special and sometimes different about our species. Drug addicts, prisoners, mentally ill, immigrants, people of color, poor people, rich people, other religions, all human beings matter. The word “those people” in reference to people with a disease or that are different than you are, disgusts me beyond words. We are people not “aliens” from another planet. Lives Matter! We are all people and no one is enjoying the devastation illness brings to our lives. I invite those that are so lofty in the correctness of their opinions to have the courage to walk in the shoes of a person that is suffering from viral hepatitis for just one day! Compassion, listening and understanding goes much farther if it is honestly and truly genuine in nature.

Those that are fortunate to have come through this illness and are now cured, have been given a second chance and take nothing for granted. Looking back is not an option but we must learn that the road to real success does not happen in a vacuum and the building capacity will require thinking that embraces those in society that are in the same boat traveling against the current to survive and escape falling onto the rocks and drowning.Those of us that are aging gracefully with viral hepatitis and of those of us that are getting treatment or have been cured, ask that the younger advocates, researchers and providers listen to us and embrace our experience. Many lessons have been learned. Wisdom is sometimes acquired by education and sometimes through hardship. When we are gone, you will have this burden entirely on your shoulders. Carry it with compassion. All Lives Matter! Take this to a higher plateau! Elimination or eradication of these diseases will require even more dedication and innovations than we have now.

*Bill Remak is the Chairman of the California Hepatitis C Task Force and current chair of the National Association of Hepatitis Task Forces. He is also one of founding board members of the California Chronic Care Coalition. He serves on the boards of several national, state and community health service foundations and advises state and federal agencies on issues related to chronic diseases and health innovations. He is a frequent speaker at universities and his articles have appeared widely in nationally known publications. He resides in the North San Francisco Bay Area in California.*

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