Knights of the Roundtable

Under the direction of Martha Saly, the National Viral Hepatitis Roundtable (NVHR) and its 200-plus member organizations continue to make the fight against hepatitis B and hepatitis C a major priority. Here, Saly provides an inside look at NVHR and the noise the coalition is making to end these largely silent epidemics.

December 8, 2011 By Tim Horn

Tell us a bit about the National Viral Hepatitis Roundtable. When was it founded, and what was the impetus for its creation?

In 2003, four or five organizations and some folks from the U.S. Centers for Disease Control and Prevention came together to develop a plan for the elimination of viral hepatitis in the United States. In the process, other groups were brought to the table to work on the plan, which resulted in the roundtable growing to about 70 organizations. The plan, called “Eliminating Hepatitis: A Call to Action,” was published in April 2006, and although it never got a lot of traction, it did start the ball rolling on a strong advocacy agenda. Today, NVHR has more than 200 member organizations.

NVHR director Martha Saly.

That’s amazing. There’s definitely a lot of strength to be gained in numbers. Can you tell us a little more about your membership and how the roundtable works?

Our membership is incredibly diverse. We have very small grassroots community groups. We also have large nongovernment organizations, university medical centers and national associations. Local, state and federal government organizations and for-profit companies may also join NVHR as associate members. However, they don’t have voting privileges. We have an 11-member steering committee that is elected from among our voting members to serve three-year terms. Presently, about 80 percent of our members are voting members and 20 percent are associate members.

Let’s talk a little about the U.S. Department of Health and Human Service’s Action Plan for the Prevention, Care and Treatment of Viral Hepatitis. The development of a strategy to curtail the hepatitis B and C epidemics in the United States was a long time coming! What role did NVHR assume in its development?

In 2010, NVHR was a sponsor of the Institute of Medicine report, “Hepatitis and Liver Cancer, a National Strategy for the Prevention and Control of Hepatitis B and C.” That report pointed out the deficiencies in awareness and education about viral hepatitis and the disparities in access to care and treatment associated with the stigmatized communities affected by hepatitis B and C. As an outcome to that report, Dr. Howard Koh, the assistant secretary for health, convened a working group to develop the HHS action plan. During the development of the plan, we had a number of opportunities to submit comments and provide feedback to the working group.

Are there any particular objectives outlined in the action plan you're particularly keen on?

I guess I would have to say that I am keen on all of the objectives outlined in the plan, but I am also concerned about how and when these objectives will be implemented, given that there is no funding attached to this plan.

One thing that stood out to me was that there didn't appear to be a clear recommendation promoting universal hepatitis C testing, much like is in now in place for HIV. This is curious, given that such a large percentage of people living with hepatitis C virus (HCV), particularly those of baby boomer years, don't know they're infected. Compound this with a recent report, indicating that testing all U.S. baby boomers for HCV would help identify more than 800,000 people living with the virus, or roughly 86 percent of those who are infected and at risk for potentially fatal liver disease but don't yet know it. Does the action plan go far enough in promoting HCV testing?

While the action plan may not spell it out in detail, the CDC has convened a group of experts, including some members of the NVHR steering committee, that is working to revise hepatitis C testing guidelines, and I believe that an age-based testing recommendation will be introduced early next year.

Saly (left) with musician Gregg Allman and Caring Ambassadors Program co-founder and executive director Lorren Sandt, following the Tune in to Hep C benefit concert at New York's Beacon Theatre on July 27, 2011.

You mentioned that there's no funding attached to the action plan. Is there any indication that Congress is committed to coming up with the money needed to step up prevention, care and treatment programs?

The fact that there is no funding associated with the action plan is, of course, extremely troubling to viral hepatitis advocates. On the plus side, the Viral Hepatitis Testing Act of 2011 was recently introduced in the House of Representatives by California Congressman Mike Honda and Louisiana Congressman Bill Cassidy and in the Senate by Massachusetts Senator John Kerry. This bill has a $90 million price tag, which seems like a small amount, but not in the current environment, I'm afraid.

And if it doesn't pass?

Well, it will still serve to educate our representatives about the issues associated with chronic viral hepatitis. We also have a great champion in Congressman Hank Johnson, from Georgia, who himself has been treated for hep C and is committed to shedding light on this disease.

Yes, Congressman Johnson's personal history and steadfast support make him an incredibly valuable ally. Speaking of treatment, it's clear we're entering a long-awaited renaissance, at least for hepatitis C. The protease inhibitors have improved genotype 1 HCV cure rates, and the sheer number of promising compounds in development is amazing. The question is, Where are we with access? Are people who need these meds getting them?

I believe we have good and bad scenarios here. The drug makers are bringing a lot of needed attention to hepatitis C to get at-risk folks tested and into care. Plus, a lot of people who already know they’re infected are looking at the benefits of the new drugs.

The difficult part, however, is that we still do not have enough providers to treat hepatitis C. What’s more, the new drugs require expertise and may be too challenging to prescribe in primary care settings. And of course, the cost of treatment is completely out of reach for many who need it. Don’t forget, the new drugs are in addition to the previous standard of care, pegylated interferon and ribavirin, not in place of these drugs, so the cost is only getting higher.

NVHR Steering Committee and participating members, from left to right, Chris Taylor, Rachel McLean, Ryan Clary, Lorren Sandt, Tracy Swan, Martha Saly, Michael Carden, Jeff Caballero and NVHR administrative coordinator Mimi Schott.

Let’s talk a bit about the Affordable Care Act, a.k.a. health care reform. If it isn’t reversed before it is fully matured in 2014, do you anticipate that it will do away with a lot of the treatment access issues facing people living with viral hepatitis?

I can only hope so! Having guaranteed access to care is a good thing, right? But we don’t have a clear picture of the level of care folks with hepatitis B and C will have in a managed care system. I am encouraged by a letter signed last week by more than 50 members of Congress asking the Secretary of Health, Kathleen Sebelius, to include HIV and viral hepatitis care as essential health benefits under the provisions of the Affordable Care Act in order to ensure access to care and medications for people with these chronic conditions.

Go to NVHR.org *for more information.*

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