



HCV and Patient Advocacy

Editor's Message

By John Loofbourow, MD



THANKS TO THE SSVMS SPRIT PROGRAM, I have become aware of the Hepatitis C Support Project in Sacramento. This non profit organization was started in 1997 by people with Hepatitis C (HCV) "to provide unbiased information, support, and advocacy to all communities affected by HCV," including physicians.

On November 1, the 1st Annual Conference on Primary Care for Hepatitis C and Liver Diseases, was held at Sacramento's Hyatt Regency. Course Director was Lorenzo Rossaro, Chief of Gastroenterology and Hepatology at UC Davis; Co-Course Directors were Alan Franciscus of (appropriately) San Francisco, a patient in the Hepatitis C Support Program; and Donna Geiger, from a gastroenterology/hepatology group in Marin.

Among 172 registered attendees, 66 were physicians, chiefly in primary care. The majority were non-MD medical professionals and HVC patients, consistent with the origins, thrust and ethic of advocacy. What made the course most interesting and significant was the interaction of attendees, who rarely strayed from the concerns of patients and primary care givers.

Medicine is not a static art or science. From a primal veneration of those who speak with gods, to the guild-oath of Hippocrates, to Maimonides, Galen, on, on to the present, we note the growing possibility for people to seize more and more control over their own lives and their own illness. User groups and advocacy orgs are just another locus along that continuum.

Given email, the web, and multiple options for care, patient networking is the most rational way to deal with the complexities of illness, in a fragmented array of "providers," medical industrialists, and government programs. For physicians, it is most efficient and effective to work with patients who are knowledgeable and responsible about their disease. That is the ideal result of advocacy by and with patients.

Kaiser's Model: Gayle Witt, RN, works with MaryPat Pauley, MD, at Kaiser Sacramento. They have established an integrated program for HCV including: screening; patient education by Gayle and staff; GI evaluation, further evaluation and biopsy if desired so decisions can be taken by and with the patient about treatment; ongoing management by GI in case of treatment, or by primary care when treatment is not appropriate or not desired. Using rough numbers, at the last screening 600 HCV infected patients were identified. Of them, 440 took Gayle's class, 120 were biopsied and 96 are being treated. This is only one of many "user groups" for Kaiser patients.

Private Practice Model: Todd Wise, an internist in private practice in Portland, gave the opening presentation at the HCV symposium. He works within a complex network that requires: ongoing training of his office staff who triage, educate, and help manage treatment; a consultation and referral network for biopsies, psych, cardiology, surgery, and treatment of complex cases; an ongoing relationship with a dependable and reliable pharmacy, and a lab, to assure accuracy and consistency; and association with an advocacy groups.

Advocacy Model: The Sacramento HCV Support Group was instrumental in organizing the conference. Log on to www.hcv.org to see what options patients have, or, frankly, to refresh your knowledge of HCV. If you link your way through this site, which was built by Franciscus, I believe you will be amazed at its depth and detail.

Consultant Model: UC Davis Course Director Rossaro and Staff were ideal sponsors and consultants for a course like this. They were always there to respond, but never heavy handed. They listened as much or more than they spoke. The result was an informative and spirited exchange of information and ideas among those most intimate to the HCV problem; just what the patients and the primary care docs ordered.

An aspect of medicine that has always been difficult for me is that many patients expect a miraculous "healing," after they have abused their bodies and continue to do so.

So I enjoyed it when the Jesus, of the well known musical, *Jesus Christ, Superstar*, screams at the multitude begging to be healed:

"Heal Yourselves!!!"

Local advocacy groups, of an inclusive and integrative nature, like the HCV Support Group, are the natural children of the information age. I emphasize local, because when organizations grow to resemble the AARP, NRA, or Sierra Club, they tend to become part of the problem.

Local advocacy implies physicians are a vital, but not unique, resource for individual patients in managing disease. Such groups offer patients a way to inform themselves about the nature of their illness, the options open to them, and, not least, the opportunists in commerce, in government, and in the professions who may not always keep the patient's best interest foremost.

A Bauerism — one of those piquant comments from nonogenarian physician Herbert Bauer — is that, "Medicine is a branch of public health."

Perhaps the patient advocate would say, in like manner, "Medicine is a branch of self care."

Not bad ideas; their time will come.

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