

Hepatitis C Global Foundation (HCGF) 5th Annual Conference San Francisco, CA: 2-5 August, 2001

*Alan Franciscus: Editor-in-Chief, HCV Advocate;
Patty Perkins: Independent Health-care Consultant*

Your ever intrepid travelers report once again from a first-rate hepatitis C (HCV) conference. This is one of the most patient-centered forums we have attended and/or where we have presented in the last year. The “Global” conference, as we’ve come to call it, has always been hosted in the San Francisco Bay Area (our home region), so we were happy to attend a local event for a change. This conference is the largest US-based training program (over 450 attendees over 4 days) exclusively devoted to HCV and one where academics, policymakers, frontline health-care workers, and patients can mingle freely and share ideas. The Exhibit Area included booths and materials from non-profits, drug treatment providers, nutritional supplement companies, and the major pharmaceutical company providers of HCV treatments, but no talking livers or flaming stomachs as we reported from DDW in May! There is something for everyone at this event. Unfortunately, because your reporters also were on HCSP table duty, presenting or moderating several panels over the four-day period, we could not cover as much as we might have. Our apologies for some obvious bias in this reporting.

Day 1: **Patient Training**

At the last moment one of us (PP) was asked to cover Carol Craig’s (“Back-to-Life” Orange County, California and Study Director, HALT-C, VA Medical Center, UC Irvine, CA) Patient Training during the Thursday morning session. Carol had e-mailed first-rate educational handouts and overhead materials and with the wonders of Kinko’s and conference organizers, a worthwhile training was salvaged and presented. While conference organizers had indicated that there would be 22 people in the room, 54 conferees attended this session, including many front-line health-care workers themselves infected with HCV and eager to learn new skills they could bring back to their patients and/or clients. Worried that there would be some overlap with earlier epidemiology discussions that same morning, this training concentrated on how to develop your own HCV health plan and an advocacy plan for your client. Matthew Dolan, a UK-native and author of “The Hepatitis C Handbook” provided valuable commentary on how complementary care modalities--acupuncture, herbs, Qi Gong--are more widely accepted as part of HCV treatment planning and even embraced as part of care delivery within the British National Health Service (NHS). A lively discussion ensued around cost of HCV treatments, US patients, particularly substance abusers, having access to such modalities, and ways of teaching patients this form of self-care. Cultural and regional differences on how these modalities are embraced among California’s many ethnic groups were also discussed. Several participants from Los Angeles and the San Joaquin Valley mentioned working with local herbalists in the Latino and Hmong communities to ensure patient safety since many herbal remedies are toxic to the liver. Matthew Dolan took several additional questions about this topic in the hallway after this training, and before and after his Friday book signing. Additional questions along this theme arose during the advanced counselor training on Sunday. More about this later.

Physician and Nurses Track

This track was originally divided between MDs and NPs/RNs. One of us, AF, was one of the two track chairs for the nurses’ training, along with Stanford nurse, Lucinda Porter, RN. We have noted that nurses, particularly advanced practice nurses—NPs--generally prefer being included in tracks with primary care or specialist physicians. Important news to know for other agencies planning future community training events. Your reporters were running other morning sessions and were unable to attend these events. However, “Global” provided some comments and additional commentary was offered by speaker Dr. Dan Ciccarone.

HCGF Chief Executive, Joey Tranchina, who also serves as the Executive Director of APAN, San Mateo (CA) County's first and only syringe exchange program, moderated the morning portion of this training. Speakers included: Dr. Joanne Imperial from Stanford Medical Center; Dr. Luther Virgil, an HIV physician who provides care to the IDU community in Wash., DC, and Dan Ciccarone, MD, MPH from UCSF's Urban Health Study. The latter group had recently published a commentary piece in the July 19, 2001 edition of *New England Journal of Medicine*, entitled "Is it justifiable to withhold treatment for hepatitis C from illicit-drug users?" Thus, the concentration of this track centered on issues in screening, management, and treatment issues for in and out of treatment drug users. This turned out to be a standing-room-only session, with the audience offering several concrete examples of their concerns in providing care to this community, particularly in how to provide symptom management for depressive symptoms, known to be widespread among IDUs **even before** initiating interferon-based treatment.

PP attended the afternoon portion of the MD training offered by California Pacific Medical Center (CPMC) San Francisco hepatologist Adil "Ed" Wakil. Dr. Wakil is an excellent speaker, gave an outstanding overview of domestic and international HCV epidemiology, co-infection treatments, the latest in pegylated treatments, the particulars around liver biopsy, and some commentary about organ transplant, including living liver donor transplants. For regular readers of www.hcvadvocate.org, much of this was familiar news, though the commentary on side effect management and treatment pre-post transplant was valuable new information.

Friday, August 3rd

Corrections and Hepatitis C Track

As we all know, HCV in prisons is at epidemic proportions with an estimated 1.25 million prisoners in the U.S. infected with HCV. While a couple of sessions dealt with this issue, it is clear that much more attention needs to be focused at this conference and others. It should be noted that Hepatitis C Global Foundation is to be commended for including this in their program because it is generally excluded from other conferences. Hopefully, next year we will see expanded sessions on this theme.

AF attended a very good session on 'Facing Hepatitis C Within a Correctional Setting' that was moderated by Brenda Goldhammer. The first presenter was Katie Kramer from Centerforce, who spoke on the model plan to support and educate prisoners in San Quentin, CA. It really is a great program that provides peer education and support on HIV and HCV. Unfortunately, this model is only available in a couple of prisons in California. Next, Phyllis Beck spoke on her independent efforts in Oregon State Prison to help support and educate prisoners on HCV issues. Probably the most enlightening speaker was a former prisoner with HCV who talked about his prison experience.

Afternoon Plenary Session

The afternoon harm reduction plenary showcased both the work and international photography of Global CEO Joey Tranchina and Dutch academic and former Lindesmith Center/DPF scholar Dr. Jean Paul Grund, who now lives in Frankfurt, Germany. Much of Dr. Grund's recent work has centered on harm reduction and HIV risk reduction strategies and interventions for IDUs in Russia and the Ukraine, and his German research group is now adding HCV to their intervention package. Dr. Grund interspersed photographic slides with reports on how changes in availability of illicit drugs and shifts in drug using practices (more needle sharing) has resulted in escalating infection rates of both HCV and HIV. He cautioned the audience that the former Soviet Union's move to take a more interdiction as opposed to drug treatment approach to deal with illicit drug use already is having negative public health consequences to at least Russian and Ukrainian drug users. Joey Tranchina's photography, entitled "Moi vacance en Barcelone" or "My vacation in Barcelona" was equally hard-hitting. Designed to display the settings in which illicit drug use actually occurs, the photo series, recently taken in an outdoor drug market in Barcelona, was incorporated within a vignette of shots taken at a San Juan Puerto Rico shooting gallery in 1995. The photos served as a harsh reminder that risk reduction strategies employed for HIV may not be robust enough to withstand the much harder HCV, and that provision of sterile injection equipment needs to include sterile wipes, cotton, cookers, and water. An earlier

Friday session offered by NYC Positive Health Project Director, Jason Farrell, touched upon strategies for introduction of these materials among US syringe exchange participants in five regions. Most of the question and answer period was devoted to this discussion for both domestic US and international settings.

Research Track

A SF-based epidemiology research presentation concluded the Friday afternoon research track. Dr. Tomas Aragon of the SF Department of Public Health illustrated available serodata from several Bay Area data sources and discussed the department's strategies for outreach to hard-to-access communities. Dr. Kellogg, also of DPH, presented HCV seroprevalence data from one of SF's largest HIV Anonymous Test Sites (ATS), one serving primarily non-IDU men who have sex with men (MSM). Rates of HCV were low in this cohort, providing additional evidence that sexual risk practices among MSM do not contribute to higher HCV rates than infection rates observed among the heterosexual population. Concerns arose on how future testing will be provided in the County, how to leverage existing resources, and who will and how will HCV treatment services be provided to the already large cohort of SF County's HCV infected IDU community. Some answers to this were offered in the special advanced counselor training on Sunday, August 5.

Counseling & Support Track

AF conducted a Counseling & Support Workshop moderated by Lorren Sandt. The objective of this session was to help counselors understand the challenges facing recently diagnosed HCV positive people. The majority of the workshop consisted of role playing exercises to acquaint the participants with the emotional complexities of a person newly diagnosed with HCV to effectively counsel HCV+ individuals get to the next step of living with HCV. Here is how it worked: one person would 'play' the HCV positive patient and the other person would be the counselor for the first exercise and then the roles would be reversed for the next role playing. The groups were given five minutes to complete the counseling session and afterwards we would compare notes about the techniques employed. The second round was a case presentation of a person that was newly diagnosed. The room was divided into five groups and each group presented a group consensus on counseling techniques. The third and final round was a 'make up your client' where the entire room would create a fictional client. It was definitely a very complex person that we all came up with, but many of us agreed that the person depicted was not at all that unusual from the clients we see everyday. The solutions and people in this session were very creative, but practical.

The techniques we used in this session are great exercises because you can really gain some helpful techniques from the entire group to be put to good use in the real world. The passion and enthusiasm was apparent – the room was at full buzz in a very short period of time. These individuals involved in counseling should really be commended. Counselors have one of the most difficult jobs in the HCV world and are definitely down in the trenches.

AF and PP employ these techniques in all of our HCV and HIV/HCV trainings and are one of the most valuable tools to help people understand various aspect of HCV. If you would like more information about our HCV and HIV/HCV coinfection training sessions, please contact Alan Franciscus at sfhepcat@msn.com or Patty Perkins at perkybella@aol.com.

Saturday, August 4

PP attended the session on drug treatment and HCV with several keynote national and state speakers, including Dr. Henry "Skip" Francis, Chief of CAMCODA (Center on AIDS and Other Medical Consequences of Drug Abuse) of NIH/NIDA; Warren Hewitt, MS, Senior Planning Officer, AIDS Coordinator of Research; CSAT/SAMSHA (federal agency in charge of funding drug and alcohol treatment and prevention of drug addiction); and Rebecca Mora, Director of the Quality Assurance Office of Alcohol & Drug Programs (ADP), the State of California Division of Health Services (DHS). The government talks are always an informative view of where federal and state dollars are likely to emerge for new diseases. Dr. Francis is a gifted and funny speaker. His comments touched upon difficulty with medication adherence for TB or HIV medications, and the how lessons learned in these fields will inform the delivery of HCV services to in and out of treatment

drug users. He talked about shifting the paradigm about how diseases of drug users are treated by seeing drug use as a chronic disease, similar to diabetes, with both biological and environmental components. Joanna Buffington MD, MPH from the CDC's Viral Hepatitis Division, made several key suggestions about the importance of Hepatitis A and B vaccination, highlighting a recent hepatitis A outbreak among a group of Native American IDUs in the Plains states, one that could have been averted easily with more widespread vaccination efforts. CSAT's, Warren Hewitt reminded the audience that we sometimes forget that IDUs include non-heroin users, and that shifting patterns of methamphetamine use and more "muscling" (subcutaneous injection use of speed) puts this group at high risk for HCV. He also expressed concern about not tracking the non-injector population; particularly crack cocaine users, who were long ignored in the early days of the HIV-IDU interventions, at great costs to public health. Mr. Hewitt mentioned that CSAT had recently lost one of their own staff members to complications from a failed liver transplant and that liver disease has become a personal priority of CSAT's leadership. Finally, Rebecca Mora from the State of California ADP/DHS, discussed: the upcoming State RFA (funding application due on 8/29/01); changes in federal and state regulations for narcotic treatment providers will likely mandate provision of at least voluntary HCV testing at all drug treatment sites; and the hope that the State RFA will result in funding at least one annual training-of-trainers program so existing drug treatment counselors can incorporate HCV education and advocacy as part of overall treatment planning.

Women & HCV

PP and AF attended this lunch-time Sat., 8/4/01 session, which included well-known speakers Dr. Norah Terrault from UCSF and SAGE Executive Director Norma Hotaling. Another session that outgrew the size of its room, Dr. Terrault gave the audience an update on what's known and not known about HCV risk and treatment issues specific to women throughout their life-course. The good news is that women seem to do better on HCV treatment than men, though it is not known if their disease course is less advanced or treatment more successful due to generally lower rates of alcohol consumption through their life-course. Risk of maternal-fetal transmission appears to be low but can occur (5%) and is significantly higher in settings of HIV-HCV co-infection. Once again, a lively discussion erupted over the burning question: is HCV an STD or can it be sexually transmitted? The jury appears to still be out on the latter question. But Dr. Terrault gave several cautionary recommendations which have been published in the *HCV Advocate* previously: (1) among monogamous heterosexual partners where one partner is HCV+ the other is not, no changes recommended; (2) among non-monogamous partners, condom use should be urged; (3) women should not have unprotected vaginal intercourse during their menstrual cycle; (4) condom-only anal intercourse; (5) presence of genital lesions--herpes or warts may enhance transmission; (6) transmission more likely from infected male to female, HCV seems to be more highly concentrated in semen than in vaginal secretions, but role of high viral titers may be the most significant issue here.

The remainder of the speakers, Ms. Hotaling, and a team that included Sarah Weinberg and Carol Francois, have all worked together either at SAGE in San Francisco or through the SF County Jail system. Most of the remaining discussion centered around developing innovative risk reduction programming for HCV+ women, particularly geared to women in the sex-for-money or sex-for-drugs trade. Issues around how women negotiate safer drug use and needle sharing were reviewed, and concerns about escalating violence against women in disclosing their HCV status were discussed. The team believed that the best approach is a holistic team, consisting of: non-MD case manager who can serve as the woman's primary care or primary medical advocate. Complementary or alternative medical providers appear to be taking up this role at least in San Francisco. Additions of crisis intervention, social support, and programs that offer emotional stability, counseling for extended family members, education for employers, and support groups that are sensitive to both race and class will all go a long way in fostering and sustaining self-esteem and self-advocacy for HCV+ women.

Alternative & Complementary Treatment Track & HIV/HCV Co-infection

Misha Cohen, L.A.c., who also presented on a comprehensive Chinese medical approach to managing HIV/HCV coinfection, moderated this session. Misha gave an excellent overview of HIV/HCV coinfection as well as how to help people with HIV/HCV coinfection manage their disease and help with treatment side

effects from HIV and HCV medications using herbs, acupuncture, Qi gong and other non-Western therapies. Next Michelle Kuppich, RD spoke on the nutritional aspects for people with HIV/HCV coinfection. Imagine the difficulty of good nutrition while taking HIV medications! Throw in a bad liver and you can imagine how difficult it is for the provider and patient to stay on top with a healthy diet! The issues are too complex to delve into with this short piece, but Michele consented to writing an article for the *HCV Advocate* website on nutritional recommendations for people with HIV/HCV coinfection. Stay tuned, the article will be coming your way shortly. The last speaker was yours truly (AF) and I talked about the need for support groups and my experience facilitating a 12-week HIV/HCV coinfection support group in collaboration with UCSF's AIDS Health Project. I shared my thoughts about the support group, which for me was a truly remarkable experience. The medical and psychological needs for people living with these two life-threatening illnesses are not completely understood or acknowledged and more of these types of support groups are needed. What was remarkable to me about this group was the general lack of knowledge about HCV by the group members. Clearly, the HIV and the HCV communities need to concentrate more energy to educate medical professionals and their clients about these two diseases.

Day 4: Advanced Counselor Training

On Sunday OASIS (Oakland, CA) staff, Dr. Diana Sylvestre and Physician Assistant Barry Clements, OASIS Advisory Board Member and your reporter, Patty Perkins, and VAMC-SF, pharmacologist and Chief of Viral Hepatology Research, Dr. Steve Rossi, offered a six-hour training. For regular readers of the *HCV Advocate*, the March 2001 issue included a story about the OASIS program.

Combating the deafening noise and amplifiers of post-Vatican II music church service in the room next door, your reporter (PP) woke up this Sunday morning crowd with a rendition of a gospel version of "You've got to Luv your Livah," which included an audience refrain. Copyright Patricia Perkins, yes, I write music, too!! Neither the Staple Singers nor Aretha Franklin have any worries here, but PP's Southern roots showed all day and when the crowd looked sleepy after Krispy Creme treats were depleted, she would offer another chorus of Gospel public health! Again, conference organizers had promised an audience of 31, the morning count included 57 persons. Quick review of standard epidemiology and epidemiology of HCV in drug users was followed by Dr. Rossi's outstanding presentation and review of the mechanics of how interferon works in the body, along with some updated information on the new pegylated products. PA Barry Clements provided some great tips on how to refer patients, establishing a referral network, and ideas for setting up on-site support networks in drug treatment facilities, a topic he had covered in much more detail in a Friday, August 2nd talk. Finally, Dr. Sylvestre, an engaging and lively speaker even without Gospel tunes, provided a great case study example and got the class to almost teach itself. She concluded with some inspiring combination therapy end-of-treatment response data among a cohort of Bay Area methadone maintenance patients OASIS has been following for the past 18 months. These studies are ongoing, now include use of the pegylated interferon and ribavirin combination, and include collaborations with Bronx and Philadelphia programs. The Q&A for this session was an ongoing afternoon event and spilled out into the lobby area. In March 2002, OASIS will be co-sponsoring, with the Bay Area Chapter of the American Liver Foundation, its second special two-day training on HCV issues in drug users, with CME and CEUs for medical providers, social workers, and counselors. Lessons learned in providing this training were as valuable to the speakers as we believe our presentations were to the audience. Thanks, from PP and the other speakers. Look for future announcements about this winter training on www.hcvadvocate.org.

Finally, one of the most important benefits of this conference was the ability of the community to come together. This was evident with the various community coalitions that held meetings during the conference. The National HCV in Prison Coalition held a meeting to strategize on actions to bring about more awareness to the plight of HCV in prisons. Workgroups were established to help with Treatment, Care, Protocols, Political Points and Education. Another community meeting was held on advocacy & activism and strategies to help bring about more awareness and services for people living with HCV. Lastly, The National Hepatitis C Advocacy Coalition held a meeting to discuss various national strategies and action steps to be taken in the near future.

We will be hitting the road shortly for more conferences and trainings. If you are in the area, please look us

up. Look for more co-reporting from the next BIG liver conference in Dallas ---AASLD in early November.

Until then, we both wish you prosperity, happiness and a healthy liver!

Peace.

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