

The California Hepatitis C Alliance

Improving Policy, Improving Practice

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The California HCV Alliance is Born!

Well, it's official. After 2 highly successful Hepatitis C Disparities conferences, the first in Sacramento on May 9th and 10th and the second in Los Angeles on June 29, HCV organizations across the state have officially joined forces to advocate for sound HCV policies in California. With this newsletter, we'll keep you posted on upcoming Alliance activities, as well as relevant hepatitis policy-related events in California and the nation at large.

HCV Disparities: A Call to Action, Sacramento, May 9/10, 2006

True to its title, Day 1 focused on the call, and Day 2 focused on the action. Day 1 presentations delineated the scope and consequences of HCV disparities and approaches to overcoming them. Speakers were John Ward (CDC), Michael Dimitt (consultant, Assembly budget committee), Adele James (CA Endowment), Glenn Backes (legislative polymath), and the disparities panel members: Jaime Ordonez, Richard Darling, Joseph Bick, Lorenzo Rossaro, and Diana Sylvestre. Conference attendees then divided into 6 brainstorming groups to develop a dream list of HCV policies for the coming 5 years in the state of CA, a list which, as delineated below, was integrated with one from Southern CA and will serve as the template for our future policy efforts.

Disparities Conference Day 2 began with briefings of legislative staff by conference organizers Diana Sylvestre, Martha Saly, Alan Franciscus, and Glenn Backes. Legislative attendees included Tia Orr, Consultant, Legislative Black Caucus and staff to Asm. Mervyn Dymally of LA; William Sánchez,

Consultant, Office of Senator Martha Escutia of LA, Latino Caucus, Roger Dunston, Consultant, Senate Health Committee, Andrew Langley, staff to Asm Gloria Negrette McLeod of Chino.

Participants at the legislative session also included: Jack Lewin, MD (CEO, CA Medical Association); Robert Harris, legislative advocate; Pat Powers (CHI); Ken Morgan (CA HCV Task Force); Michael Ninburg (National Hepatitis C Advocacy Council); Neva Chaupette, MD; Rob Kidney (National Association of Community Health Centers); Carol Craig; Libby Guthrie; Jaime Ordonez, MD (Yolo County Health Department); Donna Geiger; Kelli Zirbes; Sherry Ziegler; Richard Darling; Peter Simpson; David Kilburn; Jean Yokotobi; Maria Bannister; and Sedrick Spencer.

Thanks to the participants the reception from legislative staff was surprisingly positive. They specifically noted that they had not been aware of the impact of HCV on the State and encouraged attendees to consider introducing a funding request for a "liver wellness" plan in the budget, which ultimately proved impossible due to the imminent budget deadline, and also to consider introducing hepatitis legislation in the coming year.

With this encouragement, conference attendees reconvened and agreed that the best approach would be to unite our diverse organizations, comprising the spectrum of expertise in HCV, into a single unifying organization called the California Hepatitis C Alliance. Its final structure awaited input from the many Southern CA HCV agencies that were not able to attend.

HCV Disparities II, Los Angeles, June 29, 2006

An additional 68 people attended the second organizational meeting in Los Angeles, a condensed version of the Sacramento conference that brought the perspectives of Southern California to the table. Speakers at this conference included Alberto Mendoza, cochair of the LA HCV Task Force; Diana Sylvestre; Martha Saly; Eve Rubell, Homeless Health Care Los Angeles and LA HCV Task Force; Carol Craig, CA Hepatitis C Resource Center; and Danny Jenkins, Cri-Help and incoming chair of the LA Task Force. As in Sacramento, attendees were divided into workgroups to develop the Southern CA version of legislative policy goals and summarized these goals after reconvening. The goals of the newly organized HCV Alliance were discussed prior to closing the meeting, and all attendees were encouraged to join the HCV Task Force of LA.

The California HCV Alliance

Admittedly still a work in progress, the principal goal of this new alliance of organizations is to advocate for sound HCV policies as a unified voice. The main work of the organization will be to structure these advocacy efforts for its diverse participants. Member organizations will be asked to send at least one member to Sacramento each year to participate in legislative advocacy efforts, and individual members will be asked, at a minimum, to visit at least one local legislator each year. It is hoped that funding will be obtained to host quarterly meetings.

Legislative Action Plan

Based on the input of conference participants, our action plan for California will include the following items:

1. Public Awareness Campaign. It was agreed that advocating for a multicultural media campaign to educate the public and fight stigma will be a key legislative goal.

2. Information Clearinghouse. A centralized web-based clearinghouse for hepatitis education materials and referrals, to be used by professionals as well as those affected, is a clear need.

3. Surveillance. It was agreed that CA needs improved surveillance to better assess

the impact of HCV on its citizens as well as to measure the impact of future policy efforts, and that hepatitis C should be given an official home, perhaps within the Division of Communicable Disease Control.

4. Education. The dismal lack of HCV knowledge in professionals as well as patients contributes to stigma, poor outcomes, and ongoing disease transmission. It was agreed that HCV education should be mandatory for physicians and other healthcare workers, first responders, prison workers, inmates, and school children. A number of other professional groups and high risk groups were also considered important targets for these efforts.

5. Testing and Vaccination. It was agreed that free HCV testing and counseling should be made available to all high-risk Californians, and that mandatory opt-out testing should be instituted in the prison system. Hepatitis A and B vaccinations should also be made available statewide to all high-risk individuals regardless of insurance status.

Next Steps

1. Membership. We are still small. And we are all volunteers. But our impact will depend upon our size and our unity. As we organize our membership and our legislative efforts, we will need help reaching new interested members that would like to participate in HCV advocacy efforts. Spread the word, it will be fun! If you are aware of other HCV organizations or individuals that would like to join, pass on a copy of this newsletter and have them join our email list by contacting us at hcvalliance@sbcglobal.net.

2. Advocacy. We have chosen Friday, **October 20** as a local Hepatitis C Advocacy Day. Mark your calendars!!! State Legislators will be in their home districts, and this represents an opportunity to organize our first unified advocacy efforts and to teach advocacy to those who have never done so. We will be seeking volunteer schedulers to help organize local meetings with key legislators. If you can assist, please contact us at hcvalliance@sbcglobal.net.

3. Website. Carol Craig has generously offered to help us put this together—it will be a great central contact point. Stay tuned....

4. Wanna submit an article? Just email it, again, to hcvalliance@sbcglobal.net.