

Hepatitis C Advocacy in California

Presentation for the
Hepatitis Leadership Corp
July 15, 2015



- Began in 2006
 - Now a program of Project Inform
- Alliance of more than 100 organizations dedicated to reducing the scope and consequences of the hepatitis B and C epidemics in California.
- CalHEP members include public health organizations, community-based organizations, clinics and health care agencies, county hepatitis task forces, and others committed to viral hepatitis prevention, care, advocacy, and education.
- CalHEP's work focuses on:
 - Advocating for sound policies
 - Promoting evidence-based education
 - Broadening access to services

CalHEP Advocacy in 2014-2015

- Focused on hepatitis C virus (HCV) this year
 - ▣ State budget advocacy
 - ▣ Treatment access advocacy



Californians with Hepatitis C




- 750,000 Californians estimated to be living with HCV

Budget Advocacy (for FY 15-16)

- CalHEP proposed use of state general funds:
 - \$600,000 for rapid HCV test kits
 - \$3M for Syringe Exchange & Disposal Supply Clearinghouse
 - \$5M for HCV Linkage to and Retention in Care Demo Projects
- State budget approved:
 - \$3M annually for Syringe Exchange & Disposal Supply Clearinghouse
 - \$2.2M a year for 3 years for HCV Linkage to and Retention in Care Demo Projects

How We Advocated with the Legislature

- Developed written justification for and description of our proposals and sent to relevant legislative staff
- Met with relevant legislative committee staff
- Testified in relevant legislative committee hearings
- Met with co-chair of budget conference committee



- Brought people who have had HCV, providers, and other advocates.
- As much as possible, brought constituents.
- Had lobbyist follow up regularly with relevant offices.

How We Advocated with the Governor

- Had community members call the Governor's office in support of the budget proposals
- Had lobbyist meet with Governor's staffer
- Submitted a sign-on letter to the Governor
 - ▣ Included "egg heads"
 - Individual HCV experts, clinicians, researchers, academics
 - ▣ Included organizations from around the state

Treatment Access Issues & Advocacy

State Public Payers Rationing Care

- Medi-Cal and ADAP had treatment utilization policies that limit access to new medications
 - Medi-Cal & ADAP authorized treatment ONLY for people with advanced liver disease (i.e., F3-F4) or certain extrahepatic conditions
 - Medi-Cal prohibited treatment for people who use drugs or alcohol unless they have six months of abstinence or are “actively engaged in drug treatment”
- These requirements are purely rationing and cost-containment measures
 - Not based on the FDA-approved labels, clinical evidence, or guidance developed by the American Association for the Study of Liver Diseases/Infectious Diseases Society of America



Medi-Cal Managed Care Issues

- One-third of Californians have Medi-Cal
 - 75% are in "managed care" plans, rather than "fee-for-service"
- Managed care plans instituting additional restrictions beyond the treatment utilization policy
 - e.g., limiting to one specialist in an entire county, requiring abstinence only, denying every initial request, refusing to allow infectious disease or primary care docs to prescribe

Utilization of Hep C Drugs in Medi-Cal is Low

- Only 1.07% of the estimated 200,000 Medi-Cal patients living with hepatitis C treated in calendar year 2014
 - ▣ Medi-Cal Managed Care = 1719 beneficiaries
 - ▣ Medi-Cal Fee-for-Service = 430 beneficiaries

Letter to State Office of AIDS re: ADAP

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June 20, 2014

Karen Mark, MD, MPH
Chief of the Office of AIDS
California Department of Public Health

SENT VIA EMAIL: Karen.Mark@cdph.ca.gov

RE: Draft ADAP Prior Authorization Policy for Sofosbuvir & Simeprevir

Dear Dr. Mark,

Project Inform, which represent constituents at risk for and living with the hepatitis C virus (HCV), are pleased that the State Office of AIDS is promulgating guidelines outlining the ADAP treatment policy for the lifesaving medications sofosbuvir and simeprevir. We appreciate that ADAP is adding this important drug to the formulary, especially given Gilead's refusal to provide appropriate supplemental rebates to ensure affordability.

Utilization of Hep C Drugs in ADAP is Low

- The State Office of AIDS (OA) estimates that 12% of ADAP clients are co-infected with HCV (~4000)
 - OA estimates 32.4% of the co-infected clients have stage F3 or F4 liver disease, and 10% of ADAP's co-infected sub-population with stage F3 or F4 disease will be treated for hepatitis C each fiscal year (FY).
 - OA estimates 69 clients will be treated for HCV in FY 14-15
 - OA estimates 135 clients will be treated for HCV in FY 15-16
 - These estimates mean utilization will only be 5% total over two FYs for all co-infected patients in ADAP.
- Of special concern because HCV progresses more rapidly in people with HIV.

Covered California & Commercial Payers

- Covered California is state exchange
- Tiering of drug formularies (tier 1 is low-cost generics, tier 4 is “specialty” or high-cost drugs)
- All new hepatitis C drugs are on highest tier in every Covered California plan
- Cost-sharing up to 30% on these medications
- Many Covered California and private payers are engaged in similar rationing as the public programs

Positive Changes Spurred by Advocacy

- **Medi-Cal:** New Hep C Treatment Utilization Policy, effective July 1, that allows for treating F2-F4, as well as many people regardless of “F score,” including people with certain extrahepatic conditions, co-occurring conditions, and certain populations at high risk for transmitting the virus to others
- **ADAP:** Released new policy for FY 15-16 to treat all regardless of “F score”
- **Covered California:** Instituting cost-sharing cap on “specialty” drugs in new plan year
 - Most people will pay ~\$250 per drug per month
 - Platinum plan is \$150 per drug per month, Bronze plan is \$500 per drug per month

How We Advocate for Improved Tx Access

- **Public Comment to Department of Health Care Services (Medi-Cal) and Office of AIDS (ADAP)**
 - Project Inform coordinated and submitted sign-on letters in response to DHCS and ADAP proposed hepatitis C treatment utilization policies, providing public comment that included suggestions for how the policies could be improved and aligned with clinical best practices and professional guidelines.
 - In order to inform these comments, Project Inform consulted with experts in the field of treating hepatitis C, including hepatologists, infectious disease doctors, and primary care clinicians who have been treating hepatitis C for a number of years.

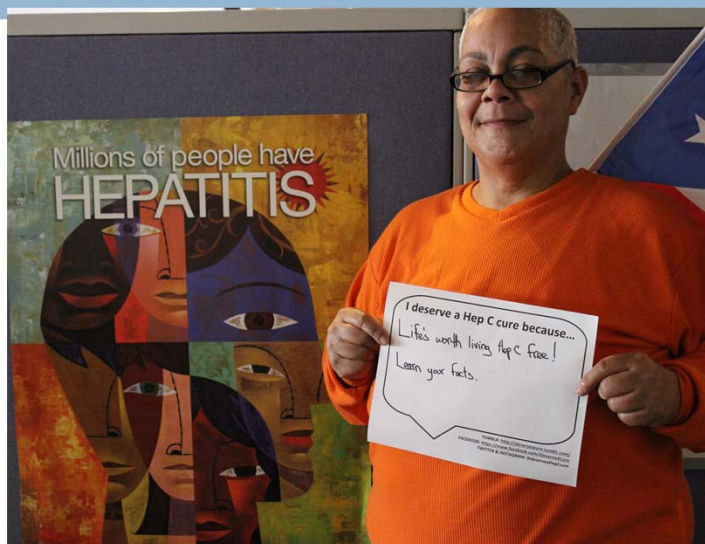
How We Advocate for Improved Tx Access

- **Consulting with Clinicians about “On the Ground” Access Issues**
 - Medi-Cal beneficiaries account for one-third of Californians. Of the 11 million people receiving Medi-Cal benefits, 75% are in “managed care” plans.
 - Project Inform partnered with the National Health Law Program (NHeLP) and the Health Consumer Alliance (HCA) to track these issues and work to have them reported to DHCS. This is an ongoing area of advocacy.

How We Advocate for Improved Tx Access

- **Meetings with DCHS**
 - Started in response to original policy
 - Now an ongoing area of advocacy as we bring clinicians to DHCS to explain the issues they are seeing on the ground
- **Participation on Advisory Committees**
 - Covered California Specialty Drug Work Group
 - Governor’s High-Cost Drugs Work Group
 - Medi-Cal Managed Care Advisory Group

Building a Movement to Cure All*



*Thanks to Daniel Raymond at Harm Reduction Coalition for coming up with this phrase

Discussion and Questions



Contact Information



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