

**National HIV/Hepatitis C Coinfection Coalition
Meetings with Senate H.E.L.P. Committee members and House Committee on
Energy and Commerce: Subcommittee on Health**

February 14, 15 and 16, 2005

Steering Committee Report

Members in Attendance: Dave Cavanaugh; Jules Levin; Jim Driscoll; Michaela Leslie-Rule and Beri Hull.

Monday February 14, 2005

10am

Juleigh M. Nowinski, Legislative Correspondent
Senator Barack Obama (D-IL)

This meeting was primarily dedicated to education Ms. Nowinski about the problem of Hepatitis C for those coinfecting with HIV. We discussed the possibility of Senator Obama releasing a statement suggesting Congressional support for inclusion of Hepatitis C language in the Ryan White Care Act. Such a statement would be drafted in cooperation with Senator Durbin's office and will be discussed later in the reauthorization process.

Senator Obama has an existing relationship with AIDS Foundation Chicago and has been involved in health care issues at the Illinois State level throughout his political career. It would be useful to provide Obama's office with Illinois (or Chicago) specific data regarding HIV infection and substance abuse.

11am

Dr. Rodney Whitlock and Honey Smith (Legislative Aid – replacing Dr. Whitlock on Health care issues)
Representative Charles Norwood (R-GA)

Whitlock agrees that more attention needs to be directed towards coinfection. No timeline has yet been set in the House (regarding a bill). Whitlock thinks the most effective way to incorporate HCV information is through education. "If we can win on education, we may be able to succeed in mandating RW to address HCV." Key members on reauthorization will be Pitts (PA) and Bono (CA). The House probably won't move on RW until after the NIH budget is through. The President's budget might force congress' hand – meaning the House would have to move sooner than the Subcommittee would like. Norwood is specifically interested in formula changes regarding the South East (that the new infection numbers and population affected be reflected in the formula for funding disbursement). Another concern for Norwood is Standard of Care. **Following

this meeting we were informed that Honey Smith will be replacing Dr. Whitworth on health care issues for Rep. Norwood.

1pm

Savitri Singh

Rep. Millender-McDonald D-CA(37)

Ms. Singh is already familiar with the coinfection issue because of meetings the Coalition held with her last spring. Savitri would like another copy of the language (MLR emailed her), so that she can circulate it and discuss it with other Democrats in the House. She would like to discuss the issue with Rep. Waxman's office (they have worked before on HIV issues and have a good relationship). Savitri reviewed the language with us during the meeting, describing the legislative process for RW reauthorization and proposing report language as a necessary "backup" to changes in the law.

Her questions: Who on the Republican side in the House will lead on the language? Have we considered Committee Report Language – in the event only a portion of the language is included, or if Hepatitis C is mentioned only a few times?

3pm

Katherine Haley and Matthew Acock (Acock is the new Health Legislative Aid for Senator Hutchison) Haley and Acock will work together on Ryan White issues Senator Kay Hutchison (R-TX)

Hutchison is the lead in the Senate on the Hepatitis C Surveillance and Reporting bill introduced last year. Ms. Haley doesn't know whether the bill will be reintroduced this year. The bill requires 90 million to authorize for the first year, increasing each additional year as necessary. Ms. Haley agrees that more education on HCV coinfection opens the door to testing and treatment funding in the future. In such a tight budget year the importance of focusing on education is crucial. Hutchison is definitely interested in healthcare issues, but is not sure yet whether she will be working to incorporate new language into Ryan White CARE Act.

Tuesday February 15 2005

11am

Katherine Martin

Rep. Mary Bono (Palm Springs, CA)

Bono will be leading the Ryan White Bill in the House. She will be working with Pitts (PA). If Bono and Pitts can find consensus on a RW bill (amendments), the likelihood it will be approved in the House is high – Bono is more moderate and Pitts is conservative.

In the Senate – Coburn and Enzi want control of the bill in the Senate: Enzi will get undoubtedly get control of it because he has more experience and is the current chair of the Senate HELP committee.

Rep. Bono is very interested in co morbidities of HIV, most specifically Syphilis – because Palm Springs is affected at epidemic proportions. “70% of Palm Springs AIDS population is Gay and 45% of the population is transient.” Their EMA does not receive adequate funding because many of the individuals who access services there are residents of other counties or states. Bono is increasingly interested in Hep C coinfection and knows the CARE Act very well (as does Katherine Martin).

Following the State of the Union address, Bono’s office wrote a letter to the administration (Secretary Thompson) requesting that co morbidities receive more attention and pleading their case. Bono will be working to include co morbidities in the CARE Act – we should follow up in a few weeks. Deal wants to have a bill in the committee (Commerce and Energy) by July. Ed Towns and Waxman will be involved.

Her question: What are the positions of AIDS Action and CAEAR Coalition?

12pm

Ann Gavaghan

Senator Hillary Clinton (D-NY)

In lieu of coinfection prevalence data, are there specific examples (nationally) that we can cite of instances in which people did not receive appropriate care for their HCV while accessing services through Ryan White? Or cases in which there have not been enough resources (i.e., ADAP. support services) to address needs of coinfecting individuals?

What should the standard of care for HIV include? When we say “HIV Care Management” how should this include hepatitis C coinfection? Can we demonstrate the need to incorporate HCV management in rural areas in addition to urban areas? Clinton’s office is concerned with changes in the epidemic (the South Eastern region of the U.S., African Americans and women) in addition to the needs of HIV-positive individuals in NY State.

Clinton’s role in reauthorization will deal primarily with NY State’s rising rate of infection. Last year NY State had the highest number of HIV positive persons, and 20% of all new HIV infections occurred there. NY has a good HIV standard of care (in comparison to other parts of the country). Clinton would like NY’s standard of care and existing care models maintained, and may not support overwhelming formula changes in the CARE Act.

Clinton’s office already sent a letter to the administration (after the President’s budget was announced) stating the need for increased money for Hepatitis C. Ann can provide us with a copy of that letter. Ann agrees with Senator Enzi’s timeline (a Senate draft of the bill by May).

2pm

Rachel Nuzum, Winston Public Health Policy Fellow
Senator Jeff Bingaman (D-NM)

The reauthorization discussion has just begun. An internal meeting of senatorial staff members was held and facilitated by HRSA. Deborah Parham (?) presented the President's principles for reauthorization based on the State of the Union Address and emphasized his commitment to seeing Ryan White reauthorized this year. The president wants congress to focus on evidence based life-extending care; a) drugs; b) labs and; c) Primary care. The President would also like to see greater flexibility for states and municipalities to address their 'location specific' AIDS related needs.

It is possible that the president is setting the stage for a debate about spending (caps) for ADAP and support services. There is more research defending the efficacy of drugs and labs, and less proving that support services are tantamount to treatment adherence (explicitly).

During the meeting of staff (mentioned above) Heather Langdon, Sen. Schumer's office (NY), asked whether HCV coinfection would be included in HRSA's recommendations for RW reauthorization. Deborah Parham said that HRSA is still in discussions about the restructuring of RW and she does not yet know what will be included in their request/statement.

Possible Democratic players include – Barack Obama. Bingaman primarily interested in services that accompany primary care.

Her Questions: Is NM a state that covers HCV drugs in their ADAP formulary?

3pm

Page Kranbuhl (Health Policy Advisor)
HELP Subcommittee on Children and Families
Senator Lamar Alexander (R-TN)

Doesn't know where Alexander stands yet on reauthorization. Enzi's office (Shana Christoff) is just beginning to educate staffers – with hearings once per week/month on Ryan White issues. Alexander may be a proponent of formula changes for S.E. states to better reflect the impact of new HIV infections in that part of the country. Alexander is less likely to champion or lead an amendment to the bill – and more likely to support another senator's amendment. **Shana is putting together a list of community organizations that want to be in the "loop" regarding reauthorization. We should call her and find out whether the Coalition can be a part of that list.**

Republican Players – Enzi and Frist (Liz Hanlan is Frist's Aid dealing with RW)

4:30pm

Karen Nelson
Representative Henry Waxman D-CA(30)
2204 Rayburn House Office Building

A brief meeting in which Ms. Nelson took our language for review with the Representative. She will contact us if Representative Waxman is interested in taking a lead on this issue.

Wednesday, February 16, 2005**10am**

Dena Morris
Senator Durbin (D-IL)
332 Dirksen Senate Building

Dena Morris was extremely happy with the language the Coalition has provided and was specifically interested in the 'education' components proposed. She is interested in working with Senator Barack Obama's office and together they could make suggestions to the Democrats on the Senate H.E.L.P. Committee regarding Hepatitis C coinfection. Later in the reauthorization process (when a bill goes to committee) Durbin's office may be able to take a more active role.

Her questions: How receptive have other members of the health committee been on including HCV educational measures in the existing CARE Act?

12:15pm

Keysha Brooks Coley
Senator Mikulski (D-MD)
503 Hart

The Senate bill will definitely lead for reauthorization. Most Democratic members of the Committee will be engaged in the process but the lead will come from Enzi's office. Mikulski represents Baltimore constituents and is aware of the hepatitis C problem specifically intravenous drug users. Mikulski will be 'nailing down' her issues for Ryan White within the next month, and expects RW bill to be drafted in H.E.L.P. committee before the August recess. Kennedy staffers are working closely with all Democrats on H.E.L.P., specifically over issues of funding redistribution (taking money from HOPWA for ADAP etc.) and Block grants. Both areas are seen as potential battleground between the Democrats and the Republicans.

1:15pm – 1:45pm

Sekemia Mwonyonyi
Senator Dewine (R-OH)
140 Russell (1st Floor)

Mwonyonyi was not particularly informed about how Dewine would be active on Ryan White. I will schedule an additional meeting with Aby Kraal (who attended the Dec. briefing for senate staffers on RW), who works on the Committee staff for Dewine, during the Coalition's next visit to the hill.

2pm

Jenny Hansen
Senator Burr (R-NC)
B40C Dirksen

**No comments

3:15pm

Anna K. Mitchell, Legislative Correspondent
(Working with Jen Vesey on Ryan White reauthorization)
Senator Rick Santorum (R-PA)

Jim Driscoll has an existing relationship with Anna Mitchell. She is informed about HCV issues. She does not have a timetable yet for the Senate Bill on RW – although it is a priority given the President's State of the Union address. The White House will probably defer to the Senate for a timeline on the Hill.

ADAP will be the primary concern from Senator Santorum, and his office will be working to get the ADAP financial structure reworded so that it can be handled in the Finance committee (Santorum's committee). Ms. Mitchell thinks Sen. Dianne Feinstein might weigh in on RW even though she is not on the H.E.L.P. committee. It is important that all changes to the CARE Act supported by Santorum, can be proposed as 'cost-neutral.'