Florida Viral Hepatitis Council meeting
July 17-18, 2007
LifeLink HealthCare Center, Tampa

Council members:
Debbie Barnes
Dr. Chen
Dr. Johanson
Deborah Orr
Bob Keane
Michael Amidei
Cindy McLaughlin
Jennifer Bourgeois
Chester Grabowski
Maureen Merckle
Mike Jolly

Guests:
Nosipho Beaufort
Lucretia Jones
April Crowley
Phil Reichert
Kathy Cavanaugh (GSK)
Marc Konechy (Valeant)
Peggy St. Croix (Roche

July 17, 2007

Michael Amidei proposed provisional approval of the minutes for the last meeting. Seconded. Minutes were provisionally approved by the council.

Phil Reichert attended the Patient Care Planning Group (PCPG) meeting last week and presented on the **Florida Viral Hepatitis Council (**VHC) and the Hepatitis Prevention Program (HPP). The leaders of the three planning groups (VHC, Prevention Planning Group (PPG), PCPG) should meet annually. **Meghan Boyter** is the liaison for all three groups. HPP staff try to attend all the meeting as part of goal to integrate hepatitis into other programs.

Reichert attended the Hepatitis Foundation national meeting in early June to see if it would be useful to bring some of those speakers to Florida. **Dr. Melissa Palmer** presented at the conference – good presentation with a lot of slides and a lot of discussion of Hepatitis B treatment and management. **Debbie Barnes** stated that talks are in progress with Valeant to get Dr. Palmer as keynote speaker for the next statewide conference. The Hepatitis Foundation meeting also had parents of children with hepatitis B (children adopted from China or children of immigrants, primarily) and discussed changes in testing. Also discussions about how to treat non-responders. Lack of understanding of universal precautions – reluctance among doctors to treat people with hepatitis who have not disclosed. One of the co-founders of the Hepatitis B foundation said they expect five (5) new drugs on the market for hepatitis B (HBV).

Drugs focus on attacking certain points of the HBV life cycle (similar to modern HIV/AIDS drugs). The hepatitis virus can survive outside of the body for two weeks and is still infectious. 80% of all liver cancer in the world is caused by HBV, and HBV is very underreported.

Chester Grabowski was at a meeting in DC last week and people report that local doctors within ethnic groups are sitting on large pools of HBV patients and not treating them based on old guidelines that didn't advise aggressive treatment if ALTs are normal and they appear healthy. Are also using old data and drug treatment guidelines.

Hepatitis B foundation will be publishing a paper in the *Journal of Viral Hepatitis* re: improving hepatitis surveillance.

Discussion of Title I and II and care consortiums

Hepatitis Program legislative budget request (LBR) – have asked for $4 million dollars every year to provide enhanced testing for hepatitis C patients. Has never gotten out of Florida Department of Health (DOH). Planning on meeting with Surgeon General **Dr. Viamonte-Ros** to discuss the program and present its needs.

Funding issues – working on a Centers for Disease Control and Prevention (CDC) grant. CDC gave $68K towards hepatitis C coordinator. This year, there will be a hepatitis specific grant. Can apply for 5K – 150K. Grant application is due August 31, 2007. Built in $10K to support an educational conference next year.

The 317 program had an overlap of money with extra funding ($400K) for hepatitis B vaccine (FL received $2.5 million total). 317 vaccine is being used in STD clinics for at risk patients. CDC may make 317 money ($) available next year.

In the process of reducing the budget by 10% ($300K). Can't touch the money that goes to the 15 funded counties for this year. If there is an additional reduction next year, may have to cut some counties. Will have to reduce vaccine $ and lab $ for this year – doesn't leave much for subsequent cuts.

Risk assessments – **Andi Thomas** developed a universal risk assessment form last year. Every program uses a different risk assessment form. 1628 form is used for HIV/AIDS. Had a hepatitis section added to the 1628 form. Ten counties will continue to use the separate hepatitis risk assessment form. Ultimate goal is to reduce the amount of paperwork for county health departments. Phil distributed copies of the new 1628, Thomas's form and the hepatitis risk assessment form.

Dr. Viamonte-Ros sent out email regarding reducing travel and monitoring purchases. Suspended all special pay increases and review all contracts for possible reductions. All programs have been asked to look at their budgets and remove 10%.

Reichert distributed a copy of *Public Health Reports* – there is an article on Florida's hepatitis integration efforts.

At the last meeting, discussed goals, objectives, and unmet needs. Were able to fund two more health departments (Orange and Duval). The hepatitis hotline was funded until a few years ago – no longer exists. Able to use that money for other things, such as hepatitis C home test kits.

Would like to break up into workgroups and write position papers.

Comprehensive plan discussion:

Would like to break up into three groups to come up with action steps under the objectives. CDC cooperative agreement asks that you develop a plan and/or maintain a plan.

Reichert distributed copies of the new draft of the comprehensive plan.

Group 1 does Goal 1-2, Group 2 – Goal 3-4, Group 3 – Goal 5-6.

Idenix project ended last week – no longer viable.

FHVC openings, nominations, openings, and bylaws; educational materials – April Crowley

Reviewed changes to the bylaws that were suggested at the last meeting.

18 out of the 20 positions are filled.

Need at least 4 community members – right now only have 1 community member. Have people who are on the council that are representing CBOs (although they are infected also). Do we want 4 people from the community just as consumers? There is a problem getting people because some community members may not want to disclose in order to get time off from work and some people may not be able to afford the trip. Some people can overlap in roles – but want to make sure that the Council is inclusive.

Need two academic/research people (only 1 now). Shift Chester Grabowski and Mike Jolly from medical section to academic/research.

No one representing the Veterans Administration (VA) – need to recruit someone. Michael Amidei has someone from the VA who is interested in joining the Council. Dr. Bridget Morgan at James Hailey VA in Tampa.

Also, need to represent people from across the state. The group meets in Tampa because ALF is here, but need to get Council members from outside of Tampa as well.

Anyone can nominate anyone, but have been appointing people too often. Need to go back to nominating and voting on new council members. Council has agreed to doing nominating and voting on new members on a quarterly basis. April could do a statewide press release about the Council and announcing availability for nominations, directing them to a website. Would also

increase the number of guests. After some discussion, it was decided that a press release is not a good idea for this particular venue.

Michael Amidei – if you invite people then set up a slate of people to vote on who may not be selected. Need to do something for people who are not elected to allow them to participate in the council.

Debbie Barnes– also have rules about missing meetings to remove people from the council.

If we open up to more guests – need to have rules and restrictions for guests. Also need to restrict our interactions with pharmaceuticals companies and they should not be included in meeting business

Chester Grabowski motioned to add the following to the bylaws any conversations specific to developing ideas and discussing topics related to the Council be limited to the voting members of the Council only. Welcome guests in an observation position for the consultation of the Council)

Mike Jolly supports Mr. Grabowski – felt that they should not have been involved in the conversation because there was a change in the conversation. There are ways to have them in the room without having them actively involved in the conversation.

Peggy St. Croix – was at a meeting where a person said that the drug companies pay the FDA. Had to speak up to clarify the process. Drug companies are getting bad press right now.

Jolly – publicity is justified because of shady practices.

Debbie Barnes and **Cindy McLaughlin**– corporate entities should not be involved in those discussions.

Amidei called the question.

Council voted to support the motion.

Amend the motion to state "voting members, including the Co-chairs and facilitator"

Council unanimously voted to amend the motion.   Note: We follow *Roberts Rules of Order*, and as part of that, the co-chairs and/or facilitator need to recognize guests who wish to speak.

Discussion of who should be the back up for the Co-chairs of the Council. Who should be the backup if Phil Reichert is absent from the meeting?

Don't need to set up a back up because the Council can vote.

Michael Amidei voted to accept the by laws, Grabowski seconded. Council voted unanimously to pass.

Educational Materials:
A new hepatitis C brochure from ETR is now available in both English and Spanish. Contact **April Crowley** if you would like to receive them. There is room on the brochures to add local contact information.

In the process of revising the ABC viral hepatitis charts to make them more consumer friendly.

The CDC educational material website is up again and materials can be requested from them.

Break for lunch. Will reconvene at 12:45.

Jennifer Bourgeois acknowledged the meeting sponsors for the meeting. Debbie Barnes also acknowledged the contributions if the pharmaceutical companies in providing patient assistance programs. Phil Reichert acknowledged Jennifer and the American Liver Foundation (ALF) for providing assistance and support for setting up the meetings.

Reminder to submit agenda items for inclusion at the meeting.

Deborah Orr

Got Ryan White $ from Orange County Health Department (CHD) to work within the immunology clinic with people who have been diagnosed as HCV positive to do education, counseling, and link with case management. Had a lot of people who were HCV positive that were not considered ready for treatment. Works with them to help stay compliant with treatment-does psych assessments and referrals as well.

The goal is to start a Hepatitis Service Center (similar to the AIDS Service Organization). Received money from Roche to do hepatitis education. Working closely with April to find ways to work together to access the most resources. Working with pharms that are interested in gaining access to methadone clinics. Also working on a case finding project. Also working to unify with indigent health care services to work on providing more unified care and linkage with case finding program. The CHD will make some resources available. Need help for the uninsured and the underinsured.

Debbie Barnes

We know there is a need to provide more education to the medical professional community. Spoke to Hope King (from the CDC) at the conference and she said that she would take back the possibility of requiring hepatitis education for physicians. Ran into stigma with a different doctor. There are a lot of doctors and dentists who will not see people who are HCV infected. There is also a stigma against the uninsured.

April gets a lot of calls from dentists who have been vaccinated against HBV but are still reluctant to treat. Also shows an ignorance of universal precautions.

Are there spikes in hepatitis among returning soldiers? Don’t know yet – things have changed.

Are there spikes in hepatitis among Hurricane Katrina first responders? None detected. State epidemiologist stated that there was very low risk of hepatitis because it is not endemic, also the vaccine does not provide instant protection. The vaccine was made available anyway.

Make a point of educating your doctors as they come into contact with them.

There is a high level of ignorance among primary physicians. Not much screening is being done in general, particularly with hepatitis or HIV.

Are your screenings being covered by Medicaid/care? Never had a lab test kicked back.

What can be done to address this?

ACTION: Can we draft a letter or recommendation requiring hepatitis education for the medical community?

Could have recommendations for education for health care providers in general – even just attached to the HIV requirement.

Can write a position paper, promote it and send it to the Board of Medicine, Board of Nursing, Board of Dentistry, all of the licensed boards, Department of Professional Regulations, and/or Florida Medical Association.

Could there be online education?

Also, AHA provides standard education portions via video or DVD. Something that could required on new licensures and then have others complete with three years.

Patient Care Planning Group

No longer doing FCPG. PCPG met last week and did Bureau update. Discussed 2006 reauthorization of Ryan White. There were changes and line items had to be eliminated. Almost finished with contract changes. MAI grant was submitted requesting $1 million. Grants will be awarded in September.

The AIDS Drug Assistance Program (ADAP) applied for a supplemental award and did not receive it. Were able to use carryover $ to meet the gap.

FTE profile data update – Lory Maddox presented surveillance data to explain how to plan money using data.

Area 1 presentation.

PCPG members worked on their implementation plans for integration into the big plan and presented on their status.

Developed minimum standards of care guidance years ago. Group is currently working on a disaster preparedness guide for consumers. There is a Patient Care meeting Sept 24-26 in Tampa. Next PCPG meeting is November 15-16 in Tampa.

Patient Care is funded by HRSA. Prevention and Early Intervention are funded by CDC.

AICP is very efficient.

The #1 killer of AIDS infected patients is liver disease.

Michael Amidei

FLASH sees a lot of nonresponders who have no place to go. Have to take a look at the protocols. Hoping to gain insight and philosophies for that group. He has spent the last three months focusing on homelessness. Passed out HUD document re: local homeless population.

Also beginning to see more data on mental illness among the homeless. Also data on homeless with HIV/AIDS and hepatitis – difficulty with adherence.
Also the very young and senior categories of homeless are increasing.

Due to budget cuts, will have to seek additional help from churches going into the winter season.

People are being told that they do not need to worry about their hepatitis C. Coinfected people are being told not to worry about the hepatitis because the HIV will kill them first. Need more education.

Mike Jolly – There is hope for people with hepatitis C. Expect to see HCV go away within the next 20 years because of the many advances in medical technology.

Need to provide help for all people who are infected. May not be able to resolve the major life issue but can still give some help

Also, non responder is hard to define because not everyone gets the best treatment or the most aggressive treatment.

Many who have heard the horror stories do not want to know their status.

Hepatitis is very much at the same place as HIV/AIDS was in 1985.

Have to provide information and education for those who are diagnosed so they can challenge their doctors with information.

There is a relationship between depression and drug/alcohol use.

Can refer people to Chance Center support group meetings (information on www.chancecenter.org)

Inequity with Medicaid among what they approve even though (Infergen) is on the formulary.

Would it be possible for one doctor's office to contact another to get best practices for approval? Yes, but Medicaid should have a standard procedure for approval. Even VA doesn't have a standard formulary.

ACTION: Motion to draft a paper recommending that Medicaid uniformly approve FDA approved medication for nonresponders to Pegylated interferon (which is Infergen).

Asking for consistency in authorizing the medication AND not making medical recommendations when there is a recommendation based upon clinical trials. The FDA approved dosage is 3X per week and but the scientifically backed recommendation (and what is usually prescribed) is daily.

How useful is a position paper from this group if this is part of a bigger problem? Well, there is nothing to lose.

Who do we address about getting vaccines covered by Medicaid for adults? Vaccines are viewed as a childhood thing.

Keane seconded the motion.

ACTION: Should invite people from Medicaid to attend the next meeting. – FVHC will email questions in advance through Deborah Orr.

Valeant can supply the studies and product information for the dosage.

Also, there is a recommendation to revaccinate people with HIV because relevant t-cells may be lost to the disease.

Discussion of the plan

Goal 3, Objective E.

- looked at the cost of A,B, and Twinrix
  - Due to budget cuts, not sure that will be able to increase the number of vaccine given.
    - May have to change the per county allotment in July of 08 – currently the counties do not order their allotment.
    - The amount in the goal is based upon the current usage.
  - Will the health department adopt the accelerated Twinrix dosage?

            - That may work for certain people, but is not for everybody – most advisable for substance abuse clinics, jails, or travelers (who do not fall under 09)
                - Would be appropriate for CFDFL – could use 09 vaccine with that schedule.
            - Is there any info on the response without the 4th dose?
                - That information is available – will bring it tomorrow.
        - State pharmacy and CDC are changing to a decentralized system.

Objective F

- maintain contact with Bureau Chief and division Director
- Can there be a strong comment to the CHDs?
    - Can there be a strong algorhythmic guideline to standardize the CHDs?
    - Group discussed creating standard policy and procedures for the hepatitis program.
        - Phil – the main issue is making sure that people are comfortable discussing hepatitis along with STDs, family planning and/or HIV.
        - Decisions for testing are based on the risk assessment – can treat an STD with symptoms and no test results – can't refer HIV/AIDS unless positive test result.
        - For CHDs – see it as extra work, so they won't do it.
        - Have there been any audits to see if people have adopted the recommendations?
            - Have been tracking the information and don't have the data here.
        - Can the CHDs be standardized as far as providing services and access charge?
            - Can't
        - Age limits are missing drop outs. DOH TCL (testing, counseling, and linkage) programs are including test kits and are trying to provide some hepatitis education.
        - ACTION: Can put out a letter from division director with recommendations for procedures or addresses on a biweekly call.
            - Can director speak about the issue on the CHD conference call or Epi conference call?
        - CHDs do not have enough staff to follow up on all hep C cases.
        - Recommend that HPP has a presence at Florida Association of Drug and Alcohol Abuse (FADAA) and Mental health conferences.

Objective G:

- Include dissemination of information

Objective H:

- Meet and report on collaboration with internal partners.

Objective J:

- Meet report on collaboration with external partners
    - Does VHC count? Yes, but can also include one on ones/phone call/email

Objective K:
- Discussion re combining with Objective M
- If you are doing technical assistance (TA), there should be follow up to check on progress and the usefulness of the TA and training.
    - Hepatitis TA is proactive to help maintain their program. Most of the nonfunded CHDs don't know the program and are not familiar with the staff.

Objective L:

Tomorrow – will resurrect the old position papers and complete.

Objective M: (combine with K?)

Objective O: Discussion about combining with F
- Convert to action statement under F.

Review a copy of the plan and email April AND Phil with your changes and/or approval.

Each Council member present was assigned a section to review tonight and bring back changes tomorrow.

Closing – Phil

Discussion of today's products
Discussion of tomorrow's agenda

Initiative and responsibilities of the hepatitis prevention program.

Putnam County has a high hepatitis rate – probably due to a small population and concentrated small number of cases.

HPP wants people to be able to call someone in their own county and get information and assistance.

Amidei – A lot of clients who are coinfected are confused about viral loads and what the hepatitis one means.
- There is a new standard – above 400K IUs is a high load and probably will change to 200K. It is a negative predictor, but depends on other factors.

July 18, 2007

Reviewed past position papers.
Proposed to break down into two groups and work on two position papers during the meeting.

Will work on the Medicaid topic and the education for the medical community.

The Medicaid paper will need to go to the division director, the Surgeon General and the Secretary of AHCA.

Will work on the wording for distribution and promotion. Distributed a sample position paper.

Dr. Johansen completed a position paper supporting Medicaid coverage of hepatitis vaccine for adults.

Need to develop a simple format for position papers.

Introduction
Body
- Data
- Background
Recommendation

Deborah Orr will take over work on substance abuse position paper that Barbara Rush had worked on.

Medicaid paper – Reichert, Jolly, Grabowski, Johanson

Education – Chen, Amidei, Barnes, McLaughlin, Orr, Merckle, Bourgeois

Discussion of the Hepatitis Educational Conference

So far, HPP has received a lot of positive feedback. Had about 200 people there. 3-4 breakout sessions at a time.

Orr – felt that the conference successfully appealed to both case managers and doctors/nurses

Good feedback re: Andi's Basic Hepatitis

Discussion about doing it again next September (during 08/09 fiscal year).

Please make suggestions for speakers for next year's conference – both keynote and breakout speakers.

Thanks to HPP and Jennifer for all of the hard work on the conference.

Need to have a higher private presence – with invitations and better publicity. Can use DOH to get mailing lists for health care professionals.

Problems attracting private industry because conference is during working hours. Possibly should do a Friday – Saturday conference. Just need to set the dates and location as early as possible for a save the date distribution.

Do a save the date three months out. The American Association for the Study of Liver Disease (AASLD) conference is in early October. The American College of Gastroenterology (ACG) conference is the second week of October. Mid-September is better. Also, Jewish holidays are in September.

Have access to expert speakers through Lifelink – Chester Grabowski and Mike Jolly know all the experts.

Opening and closing plenary session – did that work?

Need to offer partial CEU/CME credits for the conference – have to work out the paperwork issue.

Also will need to solicit information.

Can we ask the AIDS Institute for assistance with organization help? That is possible.

American Liver Foundation

ALF Walk is on Saturday.

Salute to Excellence dinner is on July 17 @ Embassy Suites Downtown.

On August 25th, they will be doing screenings with the Chance Center

The AIDS Institute (TAI)

Passed out information from Carl Schmid.
Added Jason Kennedy as a contact person.
What things would you like focus on regarding advocacy, policy, and/or education that TAI can help with whether in Florida or national? Respond to Carl or Jason.

Is HRSA getting more money to treat hepatitis in its clinics? Encouraging treatment in community health clinics and incorporating hepatitis screening. No news about any new money.

Also have a monthly issue – did a hepatitis issue in March (handouts).

New project – women's issues initiative. Launched in May with a focus on HIV/AIDS, hepatitis, etc relating to women.

Is there any state legislation in the works? Didn't bring information.

Are there any hepatitis-friendly state legislators? – Can get that information.

Is there information about hepatitis C and the Care Councils? It was suggested that more people who are co-infected participate on the Care Councils.

Can they develop more information to distribute to the case managers? With coinfection – focus on disability in terms of which infection you are recognized as having first.

- Should be eligibility criteria in place
- Possibly for the conference – do a breakout on eligibility criteria for case managers.

What happened to the faith based initiatives?
- the people that were part of TAI trainings did follow ups

Unfinished business

Next meeting probably will not be until January

ACTION: forward details of substance abuse position paper to Cindy McLaughlin and Deborah Orr

Have discussed having a position paper from the group encouraging additional funding for LBR. – Dr. nelson authored a position paper on additional funding for hepatitis labs.

Had to cut labs and cut vaccines with the hopes that can make up the difference with 317 $. Do need funding for vaccines.

Best to have a position paper signed from the council regarding funding in time for meetings with the Florida Surgeon General.

Should have a workshop on the position paper with a subgroup of volunteers of the committee – within the next month or so.

Would like to work on the LBR position paper for the last 30 minutes of the meeting.

Developed the LBR position paper.

ACTION: Phil will edit the draft position papers and forward to the Council.

Sept 22- Chance Center fundraiser featuring Phil Reichert as keynote speaker

Is there a National Hepatitis testing Day? No. May 19th is World Hepatitis Day and March 18 is Hepatitis Day at the Florida Capitol.

January 08 – Next FVHC meeting
Motion to adjourn the meeting
Seconded
Meeting was adjourned.