

Florida Viral Hepatitis Planning Group (VHPG) Meeting
Tampa, FL
Thursday, July 21, 2016, 8:30am – 5:00pm

| Members | Guests |
|---|---|
| April Crowley – Public Health Co-Chair | Allison Ruby - Merck |
| Enid Santiago-Cruz | Anthony DeMeis - AbbVie |
| Mike Jolly – Community Co-Chair | Timothy Norton - Gilead |
| Robert Wallace | Scott Gauron - AbbVie |
| Gordon Licata | Terry Steffes - AbbVie |
| Michelle Scavnicky | Sheila Alaghemand - Pinellas CHD |
| Elizabeth Simoes | Maura Comer – HQ-Bureau Com Disease |
| John-Mark Schacht | Rick Mendiola – Orasure Technologies |
| JoAnne Lamb | Allison Liby-Schoonover - Metz, Husband, |
| Kim Saiswick | & Daughton |
| Susanne Crowe | |
| Pam Langford | |
| Phil Styne | |
| Patrick Roberts | |
| Dianne Carden Glenn | |

Mike Jolly welcomed everyone. All members and guests introduced themselves. Since Phil Reichert retired, we are currently lacking a public health co-chair. April Crowley will fill in for now. The following members have also retired and dropped off the VHPG: Charles Dennis and Dr. William Chen. Welcome new members Dianne Carden Glenn and JoAnne Lamb. Patrick Roberts is filling in for Cindy McLaughlin from Lakeview Center in Pensacola.

April Crowley narrated a PowerPoint presentation that she and Jessi Dyer put together for Phil Reichert's retirement party. The new program manager for the Hepatitis Prevention Program (HPP) is **Tom Bendle**, who has worked at the Florida Department of Health (DOH) in Immunizations and HIV/AIDS. He has also been responsible for the distribution of the rapid hepatitis C tests since January of 2015. His bio was included in the handouts.

April went over the bylaws and stated this is one of the first times in history we actually have enough members in almost every category.

- Community members (infected or affected). Required: four. Current: four
- Clinical or medical services, at least two, we have five.
- Public Health at least four, we have five.
- Other Governmental, at least two, we have two.
- Associations/CBOs, at least three, we have four.
- Academic Research is the only area we're lacking since Dr. Chen retired. Also, Mike Jolly is closing his research program.

April talked about the grant from the Centers for Disease Control and Prevention (CDC) that funds the program manager's position. One week after Phil retired, the funding opportunity announcement came out. A lot more testing is required and the funding amount is reduced. The

grant has been filled out, the narrative has been written, and it was submitted ahead of schedule to the CDC.

Robert Wallace (Dr. Bob): Founder of Love the Golden Rule, a free clinic that treats hepatitis C (HCV), addiction and obesity. Dr. Bob gave an update on all the medications to treat HCV:

- Zepatier
- Harvoni
- Viekira Pak
- Epclusa was just approved by the FDA on June 23rd. It treats all genotypes.

Treatment has greatly improved with no (or very little) side effects. For most patients, it is one pill a day, and some have even cleared the virus after four weeks. Interferon is no more! Dr. Bob sees as many as seven new HCV cases per month. Unfortunately, there is still a stigma attached to HCV. Many health care providers do not realize there is a cure. We need more education about this disease.

Dr. Bob sees four new patients a day. He and Gordon Licata are working with Bio-Collections to get viral loads and genotyping done. It's \$90.00 for a viral load and \$230.00 for genotyping. A lot of his patients don't qualify for Medicaid or the Affordable Care Act (ACA).

Gordon Licata – HepatitisMain started with two people, a website and a phone. When he connected with Dr. Bob, he was given an office, a phone and a doctor! Once Dr. Bob thinks patients are ready for treatment, Gordon gives them the medications. So far, they have treated 170 people, and, 30 are currently on treatment. Refills come directly to their office. They help people who never thought they could be treated. These are the people they really reach out to.

One of the complexities is that the drug companies who provide the meds want to know how many people are living in the household, along with an annual income. Most of the people they treat don't have any income. If a patient is still using drugs or drinking alcohol, they don't treat. They do work with them to get recovered and to be clean and sober prior to treatment. A big part of sobriety is being accountable, committed, honest, open-minded and willing.

Susanne Crowe provided an overview of the Bureau of Public Health Laboratories (BPHL). There are three locations:

- Jacksonville, established 1903
- Tampa, established 1910
- Miami, established 1914

Their services include clinical laboratories, environmental laboratories, bioterrorism defense program, chemical threat program and testing. They provide testing for hepatitis A, B and C, including the confirmation testing for HCV.

Maura Comer:

- Gave an update on the Young Adult Project and hepatitis surveillance
- Florida now has a case definition for perinatal HCV
- Incubation period for HCV has changed from six months to 12 months

Lunch

Michelle Scavnicky, The AIDS Institute (TAI)

- Integrated Plan
- U.S. Health & Human Services (HHS) is updating “Viral Hepatitis Strategy” Fall of 2016
- TAI has a Testing Coverage Guide
- TAI has two hepatitis congressional briefings, House and Senate

John-Mark Schacht Presented on Pre-Exposure Prophylaxis (PrEP) and Non-Occupational Post-Exposure Prophylaxis (nPEP) for HIV. He handed out the HIV Strategic Plan for 2016 – 2018, which is a set of recommended goals, objectives, strategies and steps to improve and increase Florida’s capacity to support and implement PrEP and nPEP services.

Maura Comer gave a summary on the HCV Rapid Tests:

- 4,262 tests completed
- 4,335 Risk Assessments received
- 736 reactivities (as of 7/19/16)
- 589 confirmatory tests (RNA testing)
- Of those, 382 were positive, 189 negative and no results for 18.

Mike Jolly and April Crowley facilitated a discussion about writing position papers.

- **Kim Saiswick** – Something in the line of statistical data increase – increase access to hepatitis testing and access to care. Three sentences, three bullets and one conclusion.
- **Pam Langford** – Know Your Status. Getting tested begins with you.
- **Dr. Styne** thinks personal responsibility is a great idea.
- **John-Mark** – If the goal is to influence policy with the legislature that is more of marketing campaign and has nothing to do with position papers. The paper should state the problem and the proposed solutions. Also, we (public health employees) cannot lobby. We can advocate. **Lobby**: “I want you to vote on this bill.” **Advocate**: Provide information & stats
- **Dr. Styne** – We think the state should have a social awareness program and the theme should be centered on getting individuals to request testing. The reason for this is due to the prevalence and treatability of hepatitis.
- **John-Mark** that would be the solutions once we figure out the “problem.”
- **Dr. Styne** – Part of that request would be the availability of testing and reduce barriers.
- **Elizabeth Simoes** – Last year, it took the VA months to prepare for a talk before the U.S. Senate in Washington regarding HIV and hepatitis C. We had to use facts in black and white. With the Florida Legislature, you have to provide facts. The VA got over \$700 million from the Affordable Care Act. Bay Pines received \$26 million to treat hepatitis C.
- **Mike** - Disseminate and education, base dissemination on facts.
- All in agreement – Mike – Idea is to have 2 working groups
- **John-Mark** is willing to volunteer for the writing and putting the data together in a logical format
- **Dr. Bob** is always up to try and help.
- **April** – Dr. Wallace and Dr. Styne would be the best ones to sign the papers.
- **Mike** – Maura help with statistics – **Maura** – I can get data but only for about 1.5 years since we just started

- **John-Mark** – Ready for when legislature meets again (March). Maura – JoAnn and Enid can help her. Mike –Kim – add more and tweak it.

Kim:

- ❖ Need the number of Floridians at risk
- ❖ Cost of care for un-diagnosed hepatitis C to Floridians = \$
- ❖ Cost of care for diagnosed hepatitis C to Floridians = \$
- ❖ Statistical data gathered in the State of Florida between 2015 and 2016 indicates _____
- ❖ Increased rates of hepatitis C in the State of Florida, as evidenced by the
 - CDC's Youth Survey and Hepatitis Surveillance Project
 - Number of HCV positives =
 - Florida's 10-County Pilot Hepatitis-C testing project
 - Number of HCV positives =

Call to Action:

- ❖ Increase Education on Hepatitis-C for all Floridians regarding risk and availability of testing and treatment
- ❖ Increase access to Hepatitis-C testing for all Floridians
- ❖ Increase funding to support Hepatitis-C for treatment and care

Mike – Help with cost, drug treatment, labs, liver transplant, morbidity and mortality, overall cost of hepatitis C. We should send two papers to the legislature since we haven't done any since 2009.

The day ended with **April** showing samples of all of the hepatitis educational materials that are provided at no cost by the Hepatitis Prevention Program.

Adjourned at 5:00 PM.

Tampa, FL
Friday, July 22, 2016, 8:30am–11:30am

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| Kim Saiswick | Maura Comer – HQ-Bureau Com Disease |
| John-Mark Schacht | Rick Mendiola – Orasure Technologies |
| JoAnne Lamb | Kristen Hoover – Transplant Institute |
| Susanne Crowe | Peggy St. Croix – Transplant Institute |
| Pam Langford | |
| Philip Styne | |
| Patrick Roberts | |
| Dianne Carden Glenn | |

The following were voted in as new members:

- **Maura Comer**
- **Patrick Roberts**
- **Peggy St. Croix**

Dr. Wallace is the new Community Co-Chair and **April Crowley** is the Interim Public Health Co-Chair

Pam Langford and **Dianne Carden Glenn** provided details about their March trip to Washington, DC for “Hepatitis on the Hill,” a constituent-based advocacy event focused on hepatitis B and hepatitis C federal policy issues.

- Asked for support of Viral Hepatitis Act of 2018, which authorizes \$80 Million over three years
- Increase in funding from CDC, \$ 5 million
- Visited offices of Senators Bill Nelson and Marco Rubio and Representative David Jolly

John-Mark provided an update on the HIV Prevention Program.

Mike Jolly – Back to the two Position Papers –

- **Kim** will be lead on one with **Mike** helping with dollar amounts, **Maura** and **Joanne** on data and **Enid** with whatever else is needed.
- **John-Mark** will be lead on the other paper with **Dr. Wallace**, **Patrick** and **Pam** on his team. Hope to have completed by the end of the calendar year.
- **Susanne** will represent lab on both groups.

Much discussion ensued about the group trying to meet in person twice a year. Due to budget constraints and travel restrictions, it's not feasible. Suggestions were made to have meetings via Skype or Webinars.

Michelle proposed that **Michael Ruppal** with The AIDS Institute could provide a webinar on how the legislature works and what kind of facts and information they consider. **Rick Mendiola** offered to host the technology.

John-Mark something to think about would be to add the position statements to the Action Plan.

Mike – Perhaps skype in November. Work on a physical meeting either in Tampa or Orlando next year.

April – Meeting Minutes approval from last meeting

Next physical meeting proposed for second week in January possibly in Tallahassee, pending Michael Ruppal's recommendation on Legislature.

Adjourned at 11:30 AM.