Meeting Date: Wednesday, June 5, 2013; 5:30pm – 7pm
Meeting Location: Philadelphia Department of Public Health, 500 S. Broad St
Organizations in Attendance: ACT UP, American Liver Foundation, Crosslink Medical Services, Do One Thing, Drexel School of Medicine, Drug Policy Alliance, Genentech, Health Federation, Hepatitis B Foundation/Hep B United, HepTREC, Jansen, Jefferson University, Kadmon, Merk, OraSure, Philadelphia Department of Public Health, Prevention Point Philadelphia, Temple University Hospital, Vertex

WELCOME & INTRODUCTIONS

Thirty-five people were in attendance at the June 5th HepCAP meeting representing 19 agencies! Did you see HepCAP in the news in May? City Paper interviewed HepCAP’s co-chairs and highlighted the Do 1 Thing campaign, which is doing HIV and hep C testing in Southwest Philly. Check out the article here: http://ph.ly/SsvZ7

REVIEW: LOCAL HEPATITIS AWARENESS MONTH EVENTS

Several community partners provided an overview of their activities to raise awareness and get people tested for hepatitis B and C during May.

Love Your Liver Info Table; Science Festival Carnival: On Saturday, April 20th, HepCAP and Hep B United partners joined forces to educate thousands of people at the Philadelphia Science Festival’s Carnival on the Ben Franklin Parkway, which brought together over 150 exhibitors in celebration of science. Kids were invited to decorate their own construction paper livers with arts and crafts supplies, the Hep B Foundation’s O’Liver mascot made an appearance, and adults were given information about hepatitis B and C. Over 400 paper livers were decorated at the Carnival!

To kick off June, HepCAP had a message scrolling across the top of the PECO Tower for three nights (May 1-3): May is Hepatitis Awareness Month! www.phillyhepatitis.org. Check out a YouTube video of the message lighting up the Philly skyline:

- PECO Message on You Tube: http://ph.ly/4mFhy

Hepatitis B Foundation/Hep B United: Hep B United reported on several events that they hosted in May. Most notable was the completion of a year of community screening events: from May 2012 through May 2013, 1,000 individuals, mostly from Asian American communities, were screened for hepatitis B. Infected individuals were linked to care and the Philadelphia Department of Public Health (PDHP) partnered with the campaign to provide vaccines to people lacking hep B immunity.

On Friday, May 17th, Hep B United hosted their annual awareness-raising rally with community partners. This year’s event was held on the “Rocky Steps” of the Philadelphia Museum of Art.

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The group ran up the steps to signify surmounting the challenges of hepatitis B. At the top the group was joined by O’Liver and a breakdancing group. Back at the bottom of the stairs, Philadelphia City Councilman David Oh presented Hep B United Partners with a Hepatitis Awareness Month Proclamation. On the evening of May 17th, Hep B United also had an awareness message scrolling on the Philly skyline. For three nights, the top of the tower featured this message: B A Hero – Get tested! www.hepb.org.

Finally, to celebrate the end of a successful month, on June 1st Team Hep B Heroes competed for the second year in the Independence Dragon Boat Regatta. Before the regatta, heroes had the chance to practice their skills at four practices held throughout May. Hep B Heroes placed 24th out of 64 teams and over 25 partners turned out to row and enjoy a beautiful day by the Schuylkill River.

Daniel was asked to talk about the importance of student involvement in Hep B United activities. He said students play a very important role in Hep B United activities. Students from Temple, Penn, Drexel, and Jefferson all participate in Hep B United. Many of them are members of their schools’ Asian Pacific American Medical Student Association (APAMSA) groups. Students from all of the local schools meet about every two months to discuss priorities and plan activities. They are a constant presence at Hep B United events and bring new ideas and energy to the coalition. Even though there is turnover when working with a student population, Hep B United has not had a problem replenishing the coalition with new students. The students also benefit from being part of the coalition; last year Philly students presented a poster at the national APAMSA conference to show the impact of students on the campaign and vice versa.

Daniel was also asked how far in advance the Hep B Foundation began planning its annual rally. He said they start thinking about the next one immediately after May ends. Paperwork for Parks and Rec permits are filed by February and all the details are in place by April.

Check out media coverage of the hep B events:

- Hep B Rally on WPVI 6: http://ph.ly/yfj0z
- Hep B Rally on WNBC 10: http://ph.ly/Nm8yW
- Dragon Boat Race Day on FB: http://ph.ly/FU8IR

**American Liver Foundation:** The Mid-Atlantic Division of the American Liver Foundation reported on several events. On April 23, ALF had its annual Flavors fundraiser at Loews Hotel. CBS was the media sponsor and several hospitals and pharmaceutical companies participated by buying tables. On May 11, ALF had its annual Liver Life Walk at Memorial Hall in Fairmount Park. Over 386 walkers and runners representing 46 teams came out in rainy, overcast weather to raise over $75,000. Both events helped raise money and awareness for ALF.

HepCAP and ALF partnered up to receive a Hepatitis Awareness Month Proclamation from City Councilwoman Marion Tasco’s office. The proclamation was presented to HepCAP and ALF representatives at a City Council hearing on May 23rd by Councilwomen Maria Quiñones-Sánchez, Cindy Bass, and Blondell Reynolds-Brown. At the Proclamation presentation, Stacey and Ivory gave brief speeches to provide council members with a background on hepatitis C in Philadelphia. They also left info packets for each of the council members. Ivory noted that other groups who received proclamations brought a crowd of supporters and suggested that next year HepCAP should organize a bigger presence at the presentation to show City Council the size of HepCAP’s force.

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Philadelphia Hepatitis Outreach Project (P-HOP): Overall in May, P-HOP tested 135 people for HCV; 14 people tested positive for HCV antibodies. On May 17th P-HOP hosted a Hispanic Hepatitis Awareness Day Health Fair in Norris Square in Kensington. The key partners who helped P-HOP organize this event were Kensington Hospital and Congreso. P-HOP also received support from Councilwoman Quiñones-Sánchez’s office, which helped cover the cost of renting the park. Over 40 vendors came to the park to offer health and wellness resources and information. P-HOP also provided a moon bounce for the kids, a cotton candy machine, and healthier snacks like bottles of water and fruits. Out of 52 people tested for HCV, 11 tested positive for HCV antibodies. HPV vaccines and HIV/STD testing were also available at the health fair. While 192 people checked into the health fair, P-HOP estimates 300-400 people actually walked through the health fair throughout the day. P-HOP thinks the community partnerships were a great strength of the health fair and next year they would like to do deeper outreach in the community to get even more people to attend and get tested.

Crosslink Medical Services: On May 19th Crosslink hosted a screening event targeted at the Egyptian community in Montgomery County, which has limited resources to address hepatitis: 103 people were tested with the help of 50 volunteers who assisted with the actual testing and registration. The event took about 5 months for Crosslink founder Sandra Khalil to plan. She had assistance from a number of HepCAP partners including Sameh Bektor, the PA state Viral Hepatitis Prevention Coordinator; P-HOP and Prevention Point. Crosslink’s aim is to incorporate medical technology into the non-profit world.

Lessons Learned: A huge component of the success of Philadelphia’s Hepatitis Awareness Month events were partnerships and collaborations between agencies. Alex remarked on how great it was to see HepCAP partners supporting each other and helping Hepatitis Awareness Month grow bigger each year in Philadelphia. She also pointed out the impressive reach of events into many different communities – awareness events that reached the general public, targeted testing among underserved communities, and outreach to policy makers. Her suggestion was that activities like the Liver Walk or community events could be opportunities for HepCAP members to take on a leadership role. For example, the Liver Life Walk would be a great opportunity for HepCAP to have a team and raise its profile if someone would be willing to coordinate the team. HepCAP could keep Hepatitis Awareness Month as an agenda item at all future meetings so that by January the group is ready to start assigning tasks for May 2014.

HEP C IN THE NEWS

Stacey and Alex provided updates on recent hepatitis C news.

Conference Updates: Stacey summarized important research that was presented at EASL’s International Liver Congress and the Digestive Disease Week conference. Some of the most important updates related to new drugs that will be on the market within the next year. Gilead’s Sofosbuvir and Johnson and Johnson’s Simeprevir will be the next new hep C drugs to reach the market. Stacey also presented a study that showed when people on hep C treatment – including people who were on opioid maintenance - attained SVR, they showed improved

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quality of life and productivity. This shows that getting people treated and linked to care is not just important for health outcomes related to hep C but because it can lead to improved wellness in other areas of people’s lives.


These websites provide good summaries from hepatitis-related conferences and on hepatitis news in general:


**CDC Reports in MMWR:** CDC recently published two articles of note in MMWR.

  - [http://www.cdc.gov/mmwr/preview/mmwrhtml/mm6218a4.htm?s_cid=mm6218a4_w](http://www.cdc.gov/mmwr/preview/mmwrhtml/mm6218a4.htm?s_cid=mm6218a4_w)

  Approximately half of reported hepatitis C cases in the US had only a HCV antibody test and the other half had a positive RNA test to confirm a chronic infection. Part of this may be because negative RNA results are not reportable but another reason is because people are not getting their positive antibody test followed up by a confirmatory test. This data was based on surveillance data collected between 2005 and 2010 from seven jurisdictions across the US. Alex pointed out that the CDC’s hepatitis surveillance grants were redistributed in October 2012; Philadelphia was selected as a new hepatitis surveillance site. She noted that because Philadelphia has this grant, it means data from our city will contribute to future CDC reports, which is exciting because the City is doing a good job positioning itself as a jurisdiction ready to lead the charge against hepatitis C.

- **Testing for HCV Infection: An update of guidance for clinicians and laboratorians**
  - [http://www.cdc.gov/mmwr/preview/mmwrhtml/mm6218a5.htm](http://www.cdc.gov/mmwr/preview/mmwrhtml/mm6218a5.htm)

  In order to improve the identification of chronic infections and link more chronically infected people into care, CDC updated their hepatitis C testing guidance to emphasize the importance of following a positive antibody test with a confirmatory RNA test. Alex showed a DRAFT of the updated CDC screening algorithm (see attached).


**UPDATES & ANNOUNCEMENTS**

**Grants.** Alex and Stacey announced two grant applications they worked on that would support HepCAP activities.

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• CDC, National Center for HIV/AIDS, Viral Hepatitis, Sexually Transmitted Diseases and Tuberculosis Prevention, Public Health Conference Support. This would support a hepatitis conference that would have several different tracks: one for support staff/community based agencies, one for primary care/community health care providers, and one for hepatitis specialists. The conference would build capacity of providers to understand hepatitis, integrate more hepatitis activities into their services, and improve collaboration between agencies providing services at different points of the hepatitis service continuum.

• CDC, Viral Hepatitis Networking, Capacity Building and Training. This grant would support the HepCAP Clinician Education project, which will use current hep C treatment specialists to build the capacity of primary care practices to test more people and to understand the process of linking a positive individual to hepatitis care and treatment. Because CDC is looking for a broad reach with this limited grant (up to 5 projects will be funded overall), Stacey and Alex were figuring out how to make our local project scalable in a way that would make it competitive for the grant.

Other miscellaneous updates included:

• T-Shirts. HepCAP shirts have been ordered! Alex showed a sneak peek of the design. Come to our next meeting at 5:30pm on August 7th to get your HepCAP shirt!

• PhillyHepatitis.org. The online hepatitis resource guide for Philadelphia is nearing completion! Alex reported that PDPH has been working with a web designer to develop the website, which will have basic hepatitis information, links to other useful hepatitis websites, and a searchable map of hepatitis services in Philadelphia.

• October HepCAP Meeting: The Hepatitis C Mentor and Support Group. Alex announced that the Hep C Mentor and Support group project has funding to visit areas that are interested in offering more hepatitis support groups to patients. Ronni Marks will be coming from New York to attend the HepCAP meeting and share some experience about her work establishing support groups and conducting hepatitis advocacy work in New York. The day after the HepCAP meeting, Ronni will do a training for sites interested in establishing patient support groups. She prefers to train sites that have someone with a clinical background who can serve as a facilitator and/or advisor.

Please contact Alex Shirreffs at 215-685-6462 or alexandra.shirreffs@phila.gov if you have edits to these notes or feedback about HepCAP.

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Hundreds of livers later...

ALF: City Council Proclamation

Liver love

Olliver and some adoring fans
Updated CDC Testing Algorithm

- MMWR: Evaluation of hep C virus infection testing and reporting – 8 US sites, 2005-2011
  - "Approximately one-half of persons newly reported with HCV to state or local health departments did not have a report of a positive HCV RNA test; thus, it was not possible to determine whether the reports indicated past resolved infection or current HCV infection."

- Testing for HCV Infection: Guidance for Clinicians and Laboratorians
  - Persons with reactive results after HCV antibody should be evaluated for the presence of HCV RNA in their blood.

Sneak Peek: HepCAP Shirts!
CrossLink Medical Resources*

National Hepatitis Testing Day
May 19, 2013

Who we are

- Public charity, nonprofit corporation - Health and Patient Advocacy
- Website: www.crosslinkmed.org
- Started organization in February 2011 in Montgomery County, PA
- Vision - transform global healthcare navigation and delivery by advocating on behalf of patients and simplifying their journey to health and well-being.

Mission

To connect individuals with the global healthcare community through a central, integrated, and personalized approach, leveraging the available resources and expertise of:

- health and patient advocacy organizations
- patient support networks
- outreach programs
- research institutions
- pharmaceutical and biotechnology companies
- government programs

NATIONAL HEPATITIS TESTING DAY MAY 19

- Priority of testing - Egyptian immigrants
- Egypt has highest prevalence of HCV worldwide, 15% infection in 2008, Journal of Viral Hepatitis 2012
- Tested 103 people whose country of origin is from Egypt
- Included testing of people born in the US/Egyptian-American and those born in Egypt
Can you help locate funding?

- Need funding to sustain
- Need volunteer grant writers to locate seed funding
  - Grant challenges for start-up organization
- Need volunteer physician to represent organization
- Currently, all volunteer based
- Future - Technology and Innovation

Next steps

- Funding
- Confirmatory testing
- Link to care, GT4 HCV treatment
- Many more Egyptians to be tested

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