

NYC HEPATITIS B COALITION • 2012-2013 EVALUATION FINDINGS

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Coalition History, Mission & Operations

The NYC Hepatitis B (HBV) Coalition was founded in 2009 by the NYC Department of Health and Mental Hygiene (DOHMH) and NYU's Center for the Study of Asian American Health B Free CEED. The Coalition's mission is to coordinate efforts to prevent, manage and reduce HBV among all residents of NYC. The coalition seeks to foster an inclusive collaboration among all stakeholders to advance HBV awareness, screening, access to care, and vaccination through education, outreach, advocacy and support of research.

Current Status of the NYC Hep B Coalition

- **Funding & Support:** The Coalition has always remained unfunded.
- **In Person Meetings** take place 3-4 times a year in a central location in NYC. **Location** is selected based on community request, neutrality, no cost & accessibility to public transportation.
- **Meeting Structure:** Begins with introductions and announcements, followed by 2-3 presentations (Core content: Program presentation; New information/resources & Advocacy); and ends with discussion. Meetings are focused on provision of tools directly beneficial to members' work.
- **Leadership:** Organized & coordinated by DOHMH and a planning committee. As of Fall 2013, there is a community based lead organizer.
- **Online Network** increases reach and includes those who cannot attend in person:
 - **Meeting Highlights** (meeting notes) with program contact info sent out after every meeting
 - **Monthly NYC Hep ABC Newsletter** summarizes resources of previous and following month including: events, advocacy, training, resources, news, publications, funding & jobs
 - **Website:** www.nychebpc.org. Central hub of Coalition activities & resources.
 - **Facebook:** NYCLiverHealth; **Twitter:** @hepatitisNY; **Linked-In:** 'NYC Hep B & C Community Coalitions'

2012-2013 NYC HBV Coalition Evaluation

Purpose

- Document and evaluate the Coalition's outcomes and achievements.
- Use findings to improve the future functioning of the Coalition.
- Share lessons learned in HBV coalition building with other affected regions.

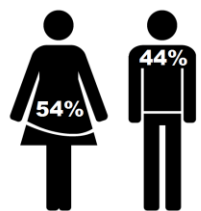
Methodology: Graduate student evaluator examined qualitative and quantitative data using grounded theory from: online & paper surveys (n=27), member interviews and focus groups (n=5), meeting logs, and online webpage and social media analytics.

Findings

Reasons Members Participate

- To learn about hepatitis resources in the community (85%)
- To connect with other organizations working on hepatitis (78%)
- To learn more about hepatitis (56%)
- To learn about best practices (33%)
- To conduct outreach for a program (44%)
- To conduct outreach for an event (22%)
- Other (15%)

Member Demographics



Average age : 33
(Age range: 20-47)
58% Asian
29% White
8% Black
4% Pacific Islander
32% Foreign-born

Member Organization Characteristics

- **34 active member organizations in 2012** alone.
- Predominant populations served: HBV; Immigrants, & Asians
- **Top sectors represented:** Health Center (25%); Hospital (17%); Community based organization (16%); Government (13%); Research (13%); Health Business (8%); Student (4%) & Advocacy (4%)

Member Roles Within Organization

- Program Administrator (74%)
- Outreach Worker (28%)
- Health Business (19%)
- Patients & Advocates (15%)
- Health Educator (15%)
- Researcher (15%)
- Medical Provider (MD, NP, PA, RN) (11%)
- Government Employee (8%)
- Health Care Support (Social work, mental health, care coordination, navigation) (7%)
- HBV tester (4%)
- Association Member (4%)
- Other (4%)

Member Participation

On average members have participated in the Coalition for **2 years** (Range = 1- 66 months)



93% Attend Meetings



85% Read E-mails



63% Access Website



37% Access Facebook (348 fans)



15% Access Linked-In (225 members)



Unk% Access Twitter (305 followers)

Meeting Attendance

- **In 2012: 53 members attended** at least one meeting in that year (active members)
- Meeting attendance at meetings was 17 members in 2012, & 28 members in 2011.

Barriers Meeting Attendance

- Taking time out of work schedule to attend meetings (41%); Time of meetings (15%)

Member Satisfaction

- 88% of members believe the mission is currently being met
- Meeting format: 88% are satisfied with introductions, 84% are satisfied with presentations, and 60% are satisfied with the discussions
- 84% of members find the 'Meeting Highlights' (minutes) to be helpful to their work
- 84% of members find the monthly newsletters to be helpful to their work

Coalition Achievements

- New resources identified or created and disseminated continuously
- New partnerships formed continuously
- Jobs & Internships identified and filled by network members
- Funding resources disseminated and secured (ex. Recent funding of African Services Committee for CDC HBV Testing & Linkage to care in Immigrant communities)
- Annual 'Hepatitis Health Care Access Training'
- Supports Advocacy Groups & Initiatives
- Trainings Developed: (ex. Patient Navigation)
- 2010 NYC Hep Legislative Awareness Breakfast
- Annual World Hepatitis Day Awareness Event
- 2010 launched Online Viral Hepatitis Services Locator
- 2012 www.NYCHEPBC.org Website launched
- 2012 Team HBV NYC founded
- And many more

Coalition Organization Challenges

- Frequent staff turnover: emerging leaders leave
- Few staff members devoted/funded to work on HBV
- HBV programs have lost funding
- Challenging personalities and old feuds have been disruptive to coalition functioning and advocacy efforts
- Few patients willing to disclose status and become advocates
- Extreme cultural diversity within affected population

Overcoming challenges

- Select dates & times for quarterly meetings a year ahead
- Continue to seek & engage potential patient advocates
- Identify funding for a community based HBV Advocacy position

Member Suggestions for future meeting topics:

- Healthcare access for undocumented immigrants
- Plan events (screenings & press conferences)
- Funding opportunities
- Policy & Advocacy