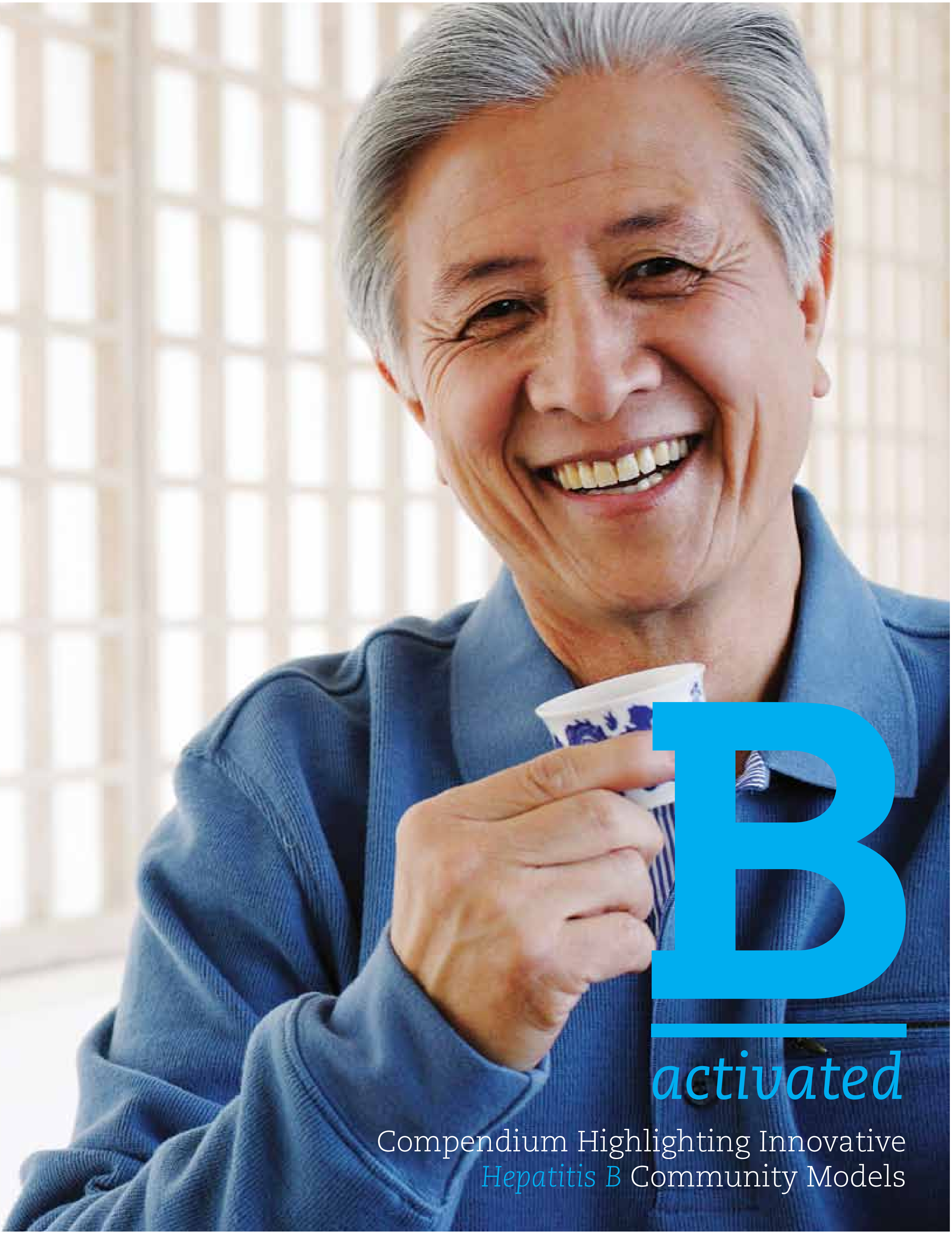

B
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Compendium Highlighting Innovative
Hepatitis B Community Models

The B Activated Program

The Association of Asian Pacific Community Health Organizations (AAPCHO), with funding from the Office of Minority Health (OMH), launched the B Activated Program for hepatitis B in 2008. The goal of the B Activated Program is to increase the capacity of local grassroots organizations to participate in policy advocacy and media outreach activities to raise awareness of the disease, and to align national goals and strategies that address chronic hepatitis B. The National Goals and Strategies were developed by the National Taskforce on Hepatitis B Expert Panel in 2008 and funded by the OMH.

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Acknowledgements

We acknowledge the staff at each participating community health center and participating AAPCHO staff for contributing their invaluable time, expertise, and insight to assemble this compendium.

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Asian Health Services
Oakland, CA

Asian Human Services, Inc.
Chicago, IL

Asian Pacific Health Care Venture, Inc.
Los Angeles, CA

Hepatitis B Foundation
Doylestown, PA

Hepatitis B Initiative of Washington, D.C.
Washington, D.C.

International Community Health Services
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B activated : Table of Contents

AAPCHO

Dear Reader,

Hepatitis B is a serious and costly epidemic affecting millions of people in the United States. The disease's impact has been disproportionately severe among Asian American, Native Hawaiian, and other Pacific Islander (AA&NHOPI) communities.

The Association of Asian Pacific Community Health Organizations (AAPCHO) has helped to address the problem of hepatitis B among these medically underserved communities through its national hepatitis B program. AAPCHO's hepatitis B program assists community health centers (CHC) and community-based organizations (CBO) in developing programs that educate and engage AA&NHOPI communities, health care providers, and policy makers about hepatitis B in new and culturally sensitive ways.

To help community members address hepatitis B through policy, media, and educational programs, we created this three-part publication entitled, *B Activated Resource Guide: Increasing Hepatitis B Awareness, Prevention, and Management in Asian American, Native Hawaiian, and Pacific Islander Communities*.

Part one is the *B Activated Compendium Highlighting Innovative Hepatitis B Community Models*. The compendium consists of case studies highlighting the standard practice of care of six CHCs and CBOs across the country working to address hepatitis B in AA&NHOPI communities. The goal is to capture the innovative strategies used by these organizations, as well as the challenges each experienced. These case studies are not a prescription for success but tools to generate ideas to develop your own hepatitis B services and activities.

Part two is the *B Activated Hepatitis B Needs Assessment Report*. The needs assessment report explores hepatitis B prevention and care activities that exist in CHCs serving AA&NHOPI communities. The report also surveys medical providers for their perceptions and expressed need for resources to enhance their efforts in the prevention and management of hepatitis B.

Lastly, part three is the *B Activated Hepatitis B Policy Advocacy & Media Outreach Toolkit*. The toolkit is a useful tool to help you in your advocacy and outreach efforts at your local, regional, and national levels of policy and media. A wide-range of information and resources are found throughout the toolkit.

We hope that this resource guide will be both useful and helpful in your organization's efforts to build its capacity to raise national and local awareness about the devastating impact of hepatitis B among AA&NHOPI communities.

Hepatitis B is a significant problem within our communities. However with increased awareness, preventative measures such as screening and effective management of the disease, many AA&NHOPIs can continue to live long and healthy lives. Thank you for your commitment to engage in the collective effort to address and eliminate hepatitis B.

Sincerely,

Jeffrey B. Caballero, MPH
Executive Director

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AAPCHO

The Association of Asian Pacific Community Health Organizations (AAPCHO), founded in 1987, is a nonprofit national organization dedicated to promoting advocacy, collaboration, and leadership that improves the health status and access of Asian Americans, Native Hawaiians, and other Pacific Islanders (AA&NHOPI) within the U.S., its territories, and freely associated states.

AAPCHO's membership includes 27 community-based organizations, 19 of which are community health centers (CHCs) located in communities with high concentrations of medically underserved AA&NHOPIs. AAPCHO's members serve over 350,000 patients annually and provide community-responsive, culturally and linguistically appropriate services to AA&NHOPI sub-populations in more than 15 languages.

AA&NHOPI and Hepatitis B

Hepatitis B is one of the most common infectious diseases both nationally and abroad. The hepatitis B virus (HBV) is 100 times (100x) more contagious and robust than HIV, and often goes undetected.[1] HBV is most commonly spread from an infected mother to her infant at birth but can also spread through contact with infectious blood, semen, and other body fluids from having sex with an infected person and/or sharing contaminated needles for drug injection or tattooing.

HBV attacks the liver, leading to chronic (lifelong) infection, cirrhosis (scarring) of the liver, liver cancer, liver failure, and even death. Tragically, chronically infected persons only learn of their status when they develop symptoms of liver cancer and liver disease later in life. Chronic hepatitis B is a leading cause of liver cancer, with one out of four cases resulting in death. Over 5,000 deaths in the U.S. are attributed to chronic hepatitis B infections.

- An inexpensive and simple blood test is the only way to diagnose for hepatitis B infection.
- HBV virus is preventable with an effective and safe vaccine.

Up to 12 million (1 out of 12) people in the U.S. are infected with HBV, with roughly two million chronically infected. Nationally, Asian Americans (AA) account for more than 50% of chronic HBV cases. In addition, AAs have a high prevalence of chronic hepatitis B and a high incidence rate of liver cancer but are poorly informed about the transmission, prevention, symptoms, risk factors, and occurrence of chronic HBV. Many AA&NHOPIs continue to suffer needlessly from this silent but deadly disease due to primary care providers' and the general public's alarmingly poor knowledge and awareness about hepatitis B.

In January 2010 the Institute of Medicine (IOM) released a report, which claimed that current efforts to stem hepatitis B in the United States are not working. The IOM identified key focus areas and offered specific recommendations to ensure that viral hepatitis services are comprehensive on all levels including clinical settings. Recommendations included increasing resources for prevention and treatment, strengthening vaccination requirements, and developing a comprehensive public awareness campaign to help further bring attention to this preventable disease.

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[1] Center for Disease Control and Prevention website - http://www.cdc.gov/hepatitis/ChooseB.htm. Accessed June 1, 2010.

Medical and work loss costs for HBV-related conditions total more than $700 million per year in the United States. Hepatitis B treatment is estimated at $2.5 billion per year. In 2000, the lifetime cost of hepatitis B was approximated at $80,000 per person or more than $100 billion. This cost is expected to increase more than 2.5 times over the next 20 years.[8]

Recent count shows that there are 12 million (about 5%) AA&NHOPIs residing in the U.S. The AA&NHOPI population is projected to reach 20 million by 2020 and approximately one out of every 10 Americans will be of Asian or Pacific Islander descent by 2050. According to the U.S. Bureau of the Census, from 1990-2000 the Asian population in the U.S. increased by 48%, while the Native Hawaiian and Pacific Islander population increased by 9%. The AA&NHOPI population is also extremely diverse, consisting of at least 49 ethnic groups and numerous sub-groups that speak over 100 different languages and dialects. The history, experiences, and cultures of these communities, among AA&NHOPIs born here and outside of the U.S., are equally diverse and distinct.

The most successful and effective hepatitis B interventions for AA&NHOPIs are those interventions that acknowledge their diversity and distinction. Hepatitis B intervention strategies—health education material or community outreach including advocacy and communications—are most effective if they accentuate and integrate AA&NHOPIs culture and language.

One in 10 AA&NHOPIs in the U.S. suffer from chronic hepatitis B.[2]

Up to 20,000 women in the U.S. who give birth each year have chronic HBV infection; more than half of these women are AA&NHOPIs.[3]

Marshallese in Arkansas have high prevalence of perinatal HBV infection.[4]

Infants infected at birth have a 90% chance of developing chronic hepatitis B.[5]

AAs are 6 to 13 times more likely to die from liver cancer than Caucasians (Vietnamese Americans 13x higher, Korean Americans 8x higher, and Chinese Americans 6x higher).[6]

Liver cancer is the third leading cause of cancer death among AA&NHOPIs.[7]

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[2] IOM Report Brief - http://www.cdc.gov/hepatitis/IOMnews.htm - Accessed May 2, 2010. [3] Asian Liver Center - http://liver.stanford.edu/Education/faq.html - Accessed May 2, 2010. [4] Fischer G et al,An investigation of perinatal hepatitis B virus infections among a high-risk population: the delivery hospital as a safety net. Accessed June 16, 2010 at http://journals.lww.com/pidj/Abstract/2009/07000/An_Investigation_of_Perinatal_Hepatitis_B_Virus.6.aspx. [5] World Health Organization website - http://www.who.int/mediacentre/factsheets/fs204/en/. Accessed June 1, 2010. [6] Edwards B, Brown M, Wingo P et al. Annual Report to the Nation on the Status of Cancer, 1975-2002, Featuring Population-Based Trends in Cancer Treatment. J Natl Cancer Inst 2005; 97: 1407-1427. Available at http://jncicancerspectrum.oxfordjournals.org/cgi/content/full/jnci;97/19/1407 [7] Office of Minority Health website - http://minorityhealth.hhs.gov/templates/browse.aspx?lvl=2&lvlid=190. Accessed May 2, 2010. [8] Asian Liver Center - http://liver.stanford.edu/Education/faq.html - Accessed May 2, 2010.

The B ACTIVATED Program

AAPCHO, with funding from the Office of Minority Health (OMH), launched the B Activated Program for hepatitis B in 2008. The goal of the B Activated Program is to increase the capacity of local grassroots organizations to participate in advocacy and media activities to raise awareness of the disease, and to align national goals and strategies that address chronic hepatitis B. The National Goals and Strategies were developed by the National Taskforce on Hepatitis B Expert Panel in 2008 and funded by the OMH. Eleven project sites participated in the B Activated Program's community engagement and mobilization activities (six contributed to this compendium and are marked with an asterisk below):

Asian Health Services*
Oakland, California

Asian Human Services Inc.*
Chicago, Illinois

Asian Pacific Health Care Venture, Inc.*
Los Angeles, California

Asian Week Foundation
San Francisco, California

Chinese American Medical Society-Mid Atlantic Chapter
Wheaton, Maryland

Hepatitis B Foundation*
Doylestown, Pennsylvania

Hepatitis B Initiative of Washington, D.C.*
Washington, DC

International Community Health Services*
Seattle, Washington

Lowell Community Health Center
Lowell, Massachusetts

San Francisco Hep B Free Campaign
San Francisco, California

University of Pennsylvania–Asian Health Initiatives
Philadelphia, Pennsylvania

AAPCHO staff worked with project sites to strengthen their capacity in the following areas: policy advocacy, media campaign, community outreach and education, and hepatitis B prevention education and evaluation. These advocacy and media components are vital parts of a hepatitis B program to raise awareness about this devastating epidemic, and to encourage prevention, diagnosis, and treatment.

Each of these organizations has a long history of providing services to AA&NHOPI communities. Project site activities were tailored based on their organizational and staffing capacities, as well as the community served. All project sites conducted activities that were culturally and linguistically appropriate to ensure that interventions were effective and beneficial to AA&NHOPI communities. Each project site conducted its activities with the overall goal of increasing the target population's awareness of hepatitis B prevention and management efforts. AAPCHO staff also worked extensively with project sites to conduct policy advocacy and media campaigns, and in establishing methods that would allow the sites to determine if an intervention was adequate and effective.

Cultural Tailoring

Due to the diversity of the AA&NHOPI population, a single model of intervention for hepatitis B education, outreach, and management would be ineffective if applied to all B Activated project sites. Therefore, staff worked with each project site to individually develop programs that would more adequately meet the needs of each AA&NHOPI population. Though project site programs differed widely, they all shared common themes:

1. Incorporating culturally and linguistically appropriate materials and interventions;
2. Outreach with bilingual/bicultural health outreach workers; and
3. Partnerships with key individuals/organizations in the AA&NHOPI community.

These common patterns represented key elements contributing to the success of each project site's hepatitis B efforts. Integrating cultural aspects of each specific AA&NHOPI group was critical to ensuring that the program's messages regarding prevention and self-management were understood and well-received. For instance, many sites translated necessary education materials and conducted hepatitis B workshops strictly in the language spoken by their target audiences. This type of cultural tailoring enabled sites to communicate program messages effectively among AA&NHOPIs who were monolingual or limited English proficient. In other instances, using outreach workers familiar with the audience's culture and language was also very important to sites' outreach efforts. For some project sites, bilingual/bicultural health outreach workers were critical in building trust with community members and were vital to the recruitment of participants for hepatitis B education activities.

B Activated project sites also developed partnerships with community organizations, media sources, and community leaders to increase the community's awareness of hepatitis B in AA&NHOPI communities. For instance some project sites collaborated closely with local ethnic media outlets through radio programs, press releases, and the dissemination of health education messages in the audience's native language, reaching an even larger audience than originally anticipated. This type of outreach encouraged community members to visit their health care provider and participate in hepatitis B education workshops.

Although all project sites had unique challenges and differences in carrying out their program activities, each site tailored their interventions to meet the needs of the community they served, not only through the translation of hepatitis B materials, but also through multi-faceted approaches that involved forging critical partnerships with the AA&NHOPI community as a whole.

B

activated : Asian Health Services

Asian Health Services
818 Webster Street
Oakland, CA 94607
www.asianhealthservices.org

Program Goal

To increase awareness among underserved Asian and Pacific Islander immigrant and refugee communities about the hepatitis B virus and to increase community capacity to advocate for culturally competent strategies addressing Hepatitis B virus.

Asian Health Services

Asian Health Services (AHS) started in 1974 as a one-room clinic in Oakland Chinatown staffed completely by student volunteers and community activists. Today AHS provides over 97,000 medical and dental visits to 20,725 patients annually and is a nationally recognized comprehensive community health center model, for serving a primarily low-income, Limited English Proficient (LEP) population. AHS offers a continuum of care from primary health care services to perinatal workshops, dental services, health education, teen clinic, client advocacy, youth services, and nutrition, behavioral health and insurance counseling for low-income Asian and Pacific Islander (API) communities in Alameda County. AHS' mission is to serve and advocate for the API community by ensuring access to health care services regardless of income, insurance status, immigration status, language or culture. As an important part of its mission, we provide services in English and eight Asian languages: Cantonese, Vietnamese, Mandarin, Korean, Khmer (Cambodian), Mien, Tagalog and Lao.

AHS has a long history of not only providing comprehensive health care home for API community members but also in leading outreach, and advocacy efforts in the community. Over the past 35 years, AHS has earned the trust of and built strong relationships with many of the API communities in Alameda County.

Activities and Strategies

The goal of AHS' hepatitis B program is to increase awareness among underserved API immigrant and refugee communities about the hepatitis B virus (HBV) and to increase community capacity to advocate for culturally competent strategies addressing HBV.

In order to increase community awareness and advocacy capacity, AHS utilized its Patient Leadership Councils (PLC). The goal of the PLCs is to improve culturally appropriate health care access for the API community by training volunteers to provide peer health education and navigation services, and to conduct advocacy activities on behalf of their community's needs. AHS proposed to utilize PLCs to build a foundation of knowledge and attention regarding hepatitis B in the Asian American community and to engage in hepatitis B advocacy activities. Members of the PLCs are trained by Community Health Advocates (CHAs), during monthly leadership trainings and educational workshops. The three strategies used to accomplish their goal are:

1. Conduct presentations and outreach activities led by CHAs and PLC leaders: AHS identified four key PLC members to assist in leading HBV outreach activities. AHS developed a one-hour community education curriculum, "Hepatitis B and the Asian Community." The curriculum included a pre and post test designed to evaluate the knowledge base of HBV before and after the presentation. A total of 16 workshop presentations on HBV were conducted and reached 516 community members. The HBV education workshops were conducted in Cantonese, Mandarin, Vietnamese, Korean and Khmer. Results from the pre and post tests indicated that 14% of workshop participants correctly answered the pre-test questions regarding prevalence, transmission, potential risks, and prevention and diagnosing hepatitis B. On the other hand, there was a significant 72% increase in knowledge with 86% of participants correctly answering the same post-test questions.

2. Facilitate PLC meetings and trainings related to hepatitis B: AHS' community educational curriculum on HBV was piloted with five PLCs with at least 100 members participating in the trainings. Among the five PLCs, an average of 93% answered post-test questions correctly. Throughout the trainings, PLC members expressed appreciation for the gained HBV knowledge, which resulted in 14 members agreeing to support AHS' hepatitis B education and advocacy efforts. Out of the 14 who originally committed to co-facilitate and/or assist with community workshop presentations and disseminate HBV materials, 12 members actually carried through with their participation. AHS intends to work with the 12 PLC members and build their capacity to be key community educators on hepatitis B advocacy issues.

3. Participate in collaborative hepatitis B efforts with other community based organizations and media: AHS participated in numerous venues that spoke to the awareness of hepatitis B such as the Huong Viet, a Vietnamese language school and a Vietnamese weekly radio talk show. AHS was also able to share their community education curriculum on HBV with other community health centers across the country and with the Refugee Community Liaison at the Fresno County Department of Social Services. As a result of their increased efforts for hepatitis B, AHS partnered with the Hepatitis B Project of the University of California, Berkeley to host their clinic as a weekly site for community drop-in for HBV screening and vaccinations. During this time, AHS joined forces with the newly established Alameda County Hep B Free campaign, which was modeled after the San Francisco Hep B Free campaign. The partnership aimed to eliminate hepatitis B and liver cancer in Alameda county.

Lessons Learned

1. We learned that it was difficult to reach some agencies when trying to utilize materials they had already developed. Because of this challenge, we proceeded to develop and translate our own materials. Rather than continue to contact the agencies, we decided to identify other curriculum options and integrated the translation process into our efforts. Additionally, the hiring of a volunteer undergraduate intern proved extremely useful, as that individual could focus on researching existing materials that were evaluated and deemed appropriate. We found that for this type of project, interns are a great source of talent.

2. We learned that while engaging our LEP patient population, there were two significant barriers we were encountering with our hepatitis B advocacy efforts: a) a very low level of awareness of hepatitis B and its disproportionate impact in the API community, and b) a lack of advocacy campaign materials in Asian languages. Through these instances we learned that engaging LEP immigrant community members requires that they first have a basic understanding of hepatitis B and its impact In addition, the lack of API language materials on hepatitis B advocacy efforts is challenging if you are conducting outreach in LEP communities.

3. We learned that when conducting community outreach and encouraging individuals to get screened or vaccinated, you should first ensure that your facility can accommodate an influx of patients prior to conducting outreach.

Recommendations

1. Student groups and volunteers can be an important resource for HBV and other health education activities. Student groups and internship programs can enhance staff efforts and simultaneously provide students with a learning community.

2. Engaging LEP API immigrants in HBV advocacy efforts first requires raising their level of awareness regarding HBV and the disproportionate impact HBV has on API communities. HBV advocacy efforts require a two-pronged approach of education regarding HBV as a health issue and as an advocacy issue.

3. Organizations should engage LEP API immigrants in HBV advocacy efforts. This requires that the creation of API language material (in written and/or internet format) be budgeted and planned for.

B

activated : Asian Human Services, Inc.

Asian Human Services, Inc.
2838 W. Peterson Avenue
Chicago, IL 60659
www.ahschicago.org

Program Goal

To develop strategic programs and events that increase hepatitis B awareness, screening, immunization, and access to care among low-income and uninsured Asian and other Pacific Islanders.

Asian Human Services, Inc.

Founded in 1978, Asian Human Services, Inc.'s (AHS) mission is to provide client-centered, quality, and compassionate services to Asian and Pacific Islander (API) immigrants and other underserved communities so that they can fully participate in society, prosper, and thrive. Asian and Pacific Islander (API) immigrants and refugees face many challenges including lack of comprehensive insurance coverage, limited access to health information due to cultural and language barriers, and social isolation. AHS services are delivered through seven program areas at five different sites: nationally accredited and state Medicaid Certified Mental Health Services (CARF), award winning community health programs, a Family Health Center, employment and youth services, family literacy, Passages Charter School (from pre-K through 8th grade), and a pro bono legal clinic. In the 2009 program year, AHS, multilingual and multicultural staff provided services to nearly 17,000 clients. AHS Community Health Program has extensive experience in implementing successful health and safety education activities that address specific issues within the immigrant and refugee communities.

Activities and Strategies

The goal of AHS' Hep B Smart Project is to develop strategic programs and events that increase hepatitis B awareness, screening, immunization, and access to care among low-income and uninsured API. This project targets diverse API immigrants and refugees living in Chicago and its suburbs, specifically in the community areas of Uptown (Little Saigon), Edgewater, Rogers Park, Lincoln Square, Armour Square (Chinatown), and Albany Park. It also targets API social service providers and local policy makers in order to build advocacy capacity in API communities surrounding hepatitis B and related health issues. The five strategies used to accomplish this goal are:

1. Identify and create a local network of partners in API communities in Metropolitan Chicago: AHS recruited 14 local partners/supporters and convened quarterly API Hepatitis B Advocacy Taskforce meetings. Among the local partners identified are workers and community health advocates from the local health department, churches, and API social service organizations and community centers. The goal of the taskforce was to develop a working policy and advocacy agenda, and to provide action steps to address hepatitis B issues. We conducted a SWOT analysis and brainstormed ideas on ways to outreach to the community and provided locations and participants to do hepatitis B outreach, education, and/or screening. This taskforce created a potential hepatitis B network in Metropolitan Chicago to advocate for state and national policy changes.

2. Utilize local media channels to disseminate information to the community on hepatitis B: AHS created an "AHS Community Health: Hepatitis B" Facebook page, where hepatitis B news, event announcements, and factoids are posted. Members can communicate with each other by posting helpful information that others in the network can read. We also developed a PSA on hepatitis B risk factors, access to care, and language resources. The message was reviewed and translated in other API languages with the help of the Taskforce members. The article was then sent to AHS' and the Taskforce's media contacts, and printed in different API ethnic newspapers. At the National Hepatitis B Taskforce meeting, AHS will be receiving a media release regarding the efforts on passing the Viral Hepatitis and Liver Cancer Control and Prevention Act in to the U.S. Congress. With the Taskforce's media contacts and translation capacity in place, this media release and any hepatitis B-related messages will be promptly distributed throughout the year to the at-risk API community.

3. Partner with national API organizations to provide advocacy training to API community leaders and providers, as well as local partners: AHS asked AAPCHO to provide advocacy training on hepatitis B and health-related issues. AHS will also create a web-based legislation alert and invite local Asian ethnic organizations to sign on. In addition, AHS and Taskforce members will conduct a minimum of one legislative visit during the program year. On May 19, 2010, we attended the World Hepatitis B Day event and visited members of Congress in Washington, D.C. We met with staffers from the offices of Sen. Dick Durbin, Sen. Arlen Specter, Sen. Kay Hagan, and Rep. Lois Capps. AHS will utilize information it received at AAPCHO's advocacy education training and related webinars, with taskforce members. The information will also be useful in future legislative visits.

4. Conduct a community survey to develop baseline data that assesses the knowledge and access to screening and care in the target community: AHS created the API Hepatitis B Community Needs Assessment Survey in January 2010. The survey is designed to gather information on hepatitis B rates and service needs in the API community. The results of this survey will help us develop and implement hepatitis B programs. AHS emailed the survey to the Taskforce members for review and dissemination. Our goal is to collect a minimum of 100 surveys for the program year. So far, we have collected 105 surveys.

5. Build outreach screening capacity in API communities and communicate with local health departments to provide screening kits: AHS worked with local organizations in API communities and encouraged them to provide screening to 40 API clients, and refer those who tested positive to AHS Family Health Center or CORE Center for treatment and follow-ups. AHS lined up several screening events in the different API communities during the program year: gathered necessary screening equipment (i.e., butterfly needles, vacuum tubes, etc.), contacted a laboratory to test blood, and calculated the cost for screening. AHS is also contacting pharmaceutical companies and applying for small grants to help pay for tests and equipment.

Lessons Learned

1. We learned that meeting in-person once every three months is not adequate to have an effective taskforce. Staying in contact via email is the best way to communicate with members, share updates, announcements, screening events, news reports, and reminders of timelines and priorities. We also conduct individual meetings with Taskforce members when they cannot attend the meeting so we can get their input. We must have realistic expectations as to what Taskforce members can and cannot do because we ask them to add extra tasks to their everyday responsibilities.

2. We learned that the Taskforce can effectively disseminate any hepatitis B information in the community by posting messages on Facebook, distributing email reminders, passing

out flyers at member agencies, and sending out a media release to local outlets. Word-of-mouth is the "traditional social network" and the most effective way in reaching some refugee groups and older members of the API community who have difficulty with navigating the internet. Thus, we continue providing hepatitis B awareness workshops at different API community sites. Furthermore, developing a media message that can be translated to different API languages is not simple. The age and educational level of our audience, and the difficulty in providing accurate translations from English into API languages, should be considered. Finding a better way to explain the core concepts of hepatitis B by using culturally appropriate images and less medical terms is helpful when conducting outreach.

3. We learned that the advocacy training and materials provided by AAPCHO before our Capitol Hill visits were very helpful. We will be able to utilize the skills and materials we acquired when we schedule face-to-face meetings with local legislators.

4. We learned that the AHS staff and Taskforce members were effective in conducting the needs assessment surveys. They were able to reach those API clients that we would not be able to reach due to language barriers and trust issues. Having realistic expectations on how many surveys the Taskforce could collect was helpful because we did not want to overwhelm them. We also created an Excel worksheet that made entering data and creating a report much easier.

5. We learned that collaboration and leveraging local resources was key to building an effective hepatitis B screening program. We partnered with organizations that provided the screening and vaccines. We conducted outreach, organized the event, and recruited nurses. We also provided educational services and follow-up phone calls to people who were screened. We learned that providing hepatitis B education in the community created a greater sense of awareness and urgency to get screened. If clients were interested in screening, we collected their names and referred them to our AHS Family Health Center for screening.

Recommendations

We believe that the Taskforce is still in its infancy and that it has the potential to help build a bigger hepatitis B prevention and treatment infrastructure in Chicago. Our vision is to have a citywide hepatitis B program, similar to what they have in San Francisco and Philadelphia. In order for that to happen, the taskforce should take the first step in starting a legislative committee that advocates for such a program. AHS staff and Taskforce members recommended meeting at least four times a year. The strong coordination of programs and resources was very beneficial in the API community.

B

activated : Asian Pacific Health Care Venture, Inc.

Asian Pacific Health Care Venture, Inc.
1530 Hillhurst Avenue
Los Angeles, CA 90027
www.aphcv.org

Program Goal

To increase the quality of life of and improve access to care for Los Angeles County's Asian American, Native Hawaiian, and other Pacific Islander communities affected by hepatitis B through advocacy, prevention, education, and research.

Asian Pacific Health Care Venture, Inc.

Asian Pacific Health Care Venture, Inc. (APHCV) is a 501(c)(3) nonprofit community health center established in 1986. Our mission is to advocate for and to provide quality health care services to all persons in a culturally competent manner. APHCV offers services with a particular focus on low-income families and underserved Asian American, Native Hawaiian, and other Pacific Islander (AA&NHOPI) communities within its catchment area and other regions of Los Angeles County. APHCV offers a full range of primary medical services, as well as various enabling services. APHCV provides multilingual and multicultural health care support in more than 14 languages. APHCV's current service area includes Hollywood, Mid-Wilshire, North Hollywood and its surrounding communities: Silver Lake, Echo Park, Glendale, and the greater Los Angeles downtown area which also include Thai Town, Historic Filipinotown, and Little Tokyo.

APHCV has been involved in hepatitis B research, and screenings, and education and awareness campaigns since the early 1990s, specifically through grants from the California Community Foundation and the Office of Minority Health. Before APHCV delivered direct clinical services, we oversaw other API health providers in Los Angeles County in the provision of community health research, advocacy, provider recruitment, health care services, and health education, including comprehensive hepatitis B outreach and education. Among the first ever API in-language hepatitis B health materials were developed through this API health coalition. We targeted hard-to-reach communities at the time when the LA County Department of Health Services Hepatitis B Program only had two Asian-speaking staff to cover the entire county. APHCV and member clinics joined forces with LA County to form the API Hepatitis B Coalition, which over the years, changed and grew with help from local, state, and national hepatitis B leaders and advocates. It most recently was renamed the Hep B Free Coalition to mimic the successful hepatitis B campaign in San Francisco. APHCV is proud to have been an active member of the Hep B Free Los Angeles (LA) Coalition, formerly known as API Hepatitis B Coalition almost since its inception. Hep B Free LA expanded its network to now include Hep B Free Orange County (OC) and Hep B Free Long Beach/South Bay (LB/SB).

Activities and Strategies

The mission of the Hep B Free Coalition is to increase the quality of life and improve access to care for Los Angeles County's AA&NHOPI communities affected by hepatitis B through advocacy, prevention, education, and research. The following are three strategies we used to work towards this goal:

1. Build capacity within the Coalitions for advocacy: Coalition members want to make local legislators aware of the impact hepatitis B has within AA&NHOPI communities. The most pressing advocacy issue was garnering Congressional support for HR 3974, the Viral Hepatitis and Liver Cancer Control and Prevention Act of 2009, which was released in October 2009. This bill aims to amend the Public Health Service Act to direct the Secretary of Health and Human Services to establish, promote, and support a comprehensive prevention, education, research, and medical management referral program for viral hepatitis infection that will lead to a reduction in the disease burden associated with chronic viral hepatitis and liver cancer. To attain our goal in generating congressional support for HR 3974, we used several strategies:

a. Established an advocacy team to lead Hep B Free's advocacy effort. Members within the coalition were recruited to be part of the "Advocacy Team," which is chaired by community advocates from APHCV and Asian Pacific American Legal Center (APALC). Members of the Advocacy Team consist of representatives from Hep B Free member community-based organizations whose common goal is to educate and bring awareness of hepatitis B to the community and elected officials.

b. Created a legislative packet or folder to be used during legislative visits. The team decided to keep the folders general (it had no reference to any particular city or area) so more advocates would be able to use it. It simply stated the main tenets of the Hep B Free campaign: "Be Tested. Be Vaccinated. Be Treated. It could save your life! – Hep B Free Campaign." The following were the contents of the packet:

- Hep B Fact Sheet includes some statistical data about the disease and brief statements regarding hepatitis B transmission, testing, vaccinations, and prevention
- Hepatitis B Data and Statistics shows the rate of Asians who suffer and die from liver cancer in Los Angeles County
- Whittier Daily News article highlights the story of the late San Gabriel Mayor Chi Mui who died from liver cancer just a month into his position. Mayor Mui had hepatitis B and the article emphasized how Asians are disproportionately affected by this disease and are at greater risk of developing liver cancer
- Disproportionate Funding Graph for Viral Hepatitis and Burden of Disease Data showing the disparity of funding available for viral hepatitis relative to numbers of people living with chronic hepatitis B and C compared to the amount of funding for HIV/AIDS and the number of people living with HIV/AIDS.
- Hep B Free Coalition brochure explaining who we are as a coalition, our mission, supporters, and what we want to accomplish
- Hep B Free ASK Sheet asking legislators to co-sponsor HR3974, the Viral Hepatitis and Liver Cancer Control and Prevention Act of 2009

c. Conduct legislative visits with community partners. The main goal of the legislative visits was to get Congress members to co-sponsor HR3974 to give it as much support and chance as possible to make it out of committee for a vote. We utilized the Congressional target list given to us by the AAPCHO Hepatitis B Policy Fellow and focused on local legislators we could realistically visit. We started with Congress members with whom our Advocacy Team members were a constituent or already had a relationship with a particular office. The Team planned to have at least two to four people participate in each visit and have at least one constituent and/or advocate to speak about either a personal story or professional encounter with those affected with hepatitis B. The group met approximately thirty minutes prior to each meeting to plan and strategize the visit consisting of the following components: introduction of the Hep B Free Campaign, presentation of data (or lack thereof), a personal story and finally, the ask. The team generally brought two legislative packets or folders, one to present to the Field or Legislative Representative during the meeting and the other one to leave for the Congressmember. During the meeting, each member of the group, as planned, discussed the contents of the legislative folders.

Several local legislative visits were scheduled by the Advocacy Team. The first was with the Legislative Representative of Congresswoman Loretta Sanchez, (47th District). Succeeding legislative visits were completed thereafter: Henry Waxman, (30th District); Adam Schiff, (29th District); Ed Royce, (40th District); and Brad Sherman, (29th District). Each of these visits were made with the Congress members' Field Representative. We are encouraged that more and more Congress members continue to sign on, however, we continue to plan more visits with the following legislators to get more support:

John Campbell (48th District), Dana Rohrabacher (46th District), Grace Napolitano (38th District), David Dreier (26th District), and Linda Sanchez (39th District).

After the visits, we made sure to conduct follow-up phone calls, send e-mails or letters to congress members to thank them after each visit. The Advocacy Team also plans to thank local Congress members who have already signed on to HR3974.

2. Utilize ethnic media to increase hepatitis B awareness in the community: The Coalition held its 2nd Annual Hep B Free Awareness Day press event on May 20, 2010 (one day after World Hepatitis Awareness Day) at St. Mary Medical Center in Long Beach, CA in which several key speakers were on hand to deliver important hepatitis B information to the community, including the relationship between hepatitis B and liver cancer–diseases that disproportionately affect AA&NHOPIs–and the available Hep B Free community programs and screening events. Patient advocates also shared their stories about how hepatitis B has affected their lives. Several ethnic newspapers (i.e., Balita Media, Thai Town USA, Philippine News, etc.) as well as television media (LA Channel 18 and IPTV) supported the Coalition's press event and were utilized to disseminate the information. Hepatitis B screening tests were made available to the members of the press as well as those in attendance. The positivity rate from that press event screening was surprisingly much higher than most screening events at approximately 20%. It emphasized the importance of having the community tested for this disease.

Awareness events, such as the press conference, reach beyond community members but can result in the direct allocation of resources. The Centers for Disease Control and Prevention, recognizing all the work that Los Angeles Hep B Free Coalition has been able to accomplish in such a short amount of time, allocated one-time funding of $30,000 to LA County (via the Coalition) for hepatitis B screenings and confirmatory studies for the community.

3. Collect patient stories: We have begun the process of collecting stories to document and share the experiences of those living with or who have a family member with hepatitis B. Data and statistics alone tell an incomplete story of how this disease has affected the AA&NHOPI community. The everyday struggles and triumphs of those directly affected by the disease can really touch and educate individuals. Patient stories can encourage more people at risk to be screened. Treatment success stories can also be encouraging for those newly diagnosed. We try our best to include a patient or patient advocate during our legislative visits to share the human effect of hepatitis B with our legislators and to emphasize how their support for a policy change truly affects the lives of individuals and their constituents.

Lessons Learned

1. Given the time commitment and other responsibilities individuals have, we learned to be realistic in how many people can be recruited to make the visits. The interest was there, but we found that those who were the most willing and ready to participate in the visits were those who have done many of them before (of which there were a limited few). The Advocacy Team did not anticipate the difficulty of trying to schedule visits with Hep B Free Coalition members, while taking their other work priorities into consideration, especially when advocacy is usually not in their job description.

2. The majority of the legislative representatives have heard of chronic hepatitis B and C but were not aware of the facts regarding the benefits of screenings, vaccinations, or treatment. They wanted to see numbers of individuals affected by hepatitis B in their district. This was the perfect opportunity to mention the fact that there is no comprehensive surveillance system in place to capture chronic hepatitis B prevalence and how much it is needed. It gave us yet another reason to have them support HR3974. The best we could do is to give them an approximate number of 10% of their districts' AA&NHOPI population as being affected by hepatitis B.

3. It is imperative to utilize ethnic media contacts to spread the Hep B Free campaign. Our staffs' close relationship with the media has been key in letting them know about our press events, screening events, and general information about hepatitis B which translates into media coverage that reaches thousands of individuals.

Recommendations

We learned that many members within the Coalition had little to no experience in conducting advocacy activities. Conducting an annual advocacy training during a coalition meeting would be very helpful for new members and to serve as a refresher for seasoned members.

1. Create a "How To" binder to make legislative visits simpler and easier to coordinate, including how to avoid typical failures in any advocacy campaign (e.g., challenges of recruiting people to participate).

2. Create an Advocacy Coordinator position within an agency to be able to coordinate all the logistics of planning visits, developing materials, and keeping up-to-date with the constantly changing political environment surrounding health issues.

3. Create a centralized list of all the hepatitis B-related advocacy websites; we learned very quickly that there are several advocacy websites in which one can send a form letter to their legislator, specifically for hepatitis B. It was difficult to keep track of them all and to promote any one of them not knowing which was the best and all-encompassing.

4. Create a National Hep B Free headquarters or umbrella organization to oversee and coordinate all Hep B Free Campaign efforts throughout the nation. Under this umbrella, make the Hep B Free Campaign artwork/images centralized and available for other groups across the nation to be able to access and customize them easily for their own use.

B

activated : Hepatitis B Foundation

Hepatitis B Foundation
3805 Old Easton Road
Doylestown, PA 18902
www.hepb.org

Program Goal

To help reduce hepatitis B and liver cancer health disparities, and to mobilize the community and key policy makers to address these diseases as urgent public health priorities.

Hepatitis B Foundation

The Hepatitis B Foundation (HBF) is a nonprofit organization dedicated to finding a cure and improving the lives of those affected by hepatitis B worldwide through research, education and patient advocacy. HBF's commitment includes funding-focused research, promoting disease awareness, supporting immunization and treatment initiatives, and serving as the primary source of information for patients and their families, the medical and scientific community, and the general public.

HBF was started by two couples living in New Hope, PA in 1991. HBF was formed in response to a young family, affected by hepatitis B, with nowhere to turn for information or support. The family experienced not only professional and personal discrimination, but they were dismayed to learn there was no organization dedicated to finding a cure for hepatitis B. With the help of committed individuals and the strong support of Dr. Baruch Blumberg, who won the Nobel Prize in Medicine for his discovery of the hepatitis B virus, the founders have successfully grown HBF from a kitchen grassroots effort into a professional organization with global reach.

The Hepatitis B Foundation is a leading research and disease advocacy nonprofit organization with a 20-year track record of success and experience in addressing the challenges for those who are affected by hepatitis B worldwide. It brings hope by funding its own research institute in the pursuit of a cure; hosting national and international scientific meetings focused on hepatitis B; awarding research fellowships and scholarships to recruit and retain promising scientists; and sponsoring high school and college summer research internships to help build the ranks of future scientists. HBF's public health research program conducts community-based research and contributes to the body of knowledge through publications and presentations at professional conferences.

Finally, HBF's advocacy program has helped to raise the profile of this overlooked disease through Congressional Briefings it has hosted since 2005; serving on the executive committees of the National Viral Hepatitis Roundtable and the National API Task Force on Hepatitis B; advocating for the first Institute of Medicine report on Hepatitis and Liver Cancer; and helping to draft and secure support for the Viral Hepatitis and Liver Cancer Prevention and Control Act 2009 (HR 3974). Additionally, HBF partners with the National Institute of Health, as an officially designated partner of the Centers for Disease Control and Prevention, and works with organizations outside the U.S. to leverage its efforts worldwide.

Activities and Strategies

The overall goals of the HBF's B Activated project were to reduce hepatitis B and liver cancer-associated health disparities through increased education and screening among high-risk Asian and Pacific Islander (API) populations. Locally, we strived to develop an advocacy strategy for the city of Philadelphia to make hepatitis B and liver cancer a public health priority by increasing screening and vaccination

rates, and enlisting community leaders to actively participate in local and national advocacy efforts. Our target audiences included Philadelphia city and health officials, hospitals and academic institutions, Community Based Organizations (CBO) that serve high-risk API immigrant and refugee communities in Philadelphia, health care providers that serve API communities, primary care physicians, and media (ethnic and mainstream). In order to achieve our stated goals, we devised the following strategies:

1. Coalition Building: We adopted best-practices and lessons learned from the successful San Francisco "Hep B Free", which included community organizing and coalition building by reaching out to potential partners in the public and private sectors. Project staff visited over 35 CBOs (i.e. health clinics and social service providers that serve API communities) and 5 city-wide cultural events to offer in-person and in-language education to partners and community members. As a result, we signed 40 partner organizations to formally participate in the Hep B Free Philadelphia education and advocacy campaign, which kicked off on June 15, 2010 with the Health Commissioner and a Mayoral Proclamation that was widely covered by both print and TV media outlets.

2. Partner Development: For each partner organization, we strived to help them identify what resources and services (i.e. translation, legal, medical, and other types of assistance) they can contribute to help advance the campaign's goals of increasing screening and vaccination rates in the high-risk ethnic communities. We helped each organization determine how they could best participate in the campaign by using existing resources and minimizing burden.

3. Bringing Together Experts: HBF convened a two-day workshop to improve screening rates for hepatitis B among high-risk API ethnic groups across the U.S. We brought together a group of 10 primary care providers (PCPs) that included experts from internal medicine, family medicine, OB/GYN, pediatrics, nurse practitioners, and physician assistants. The goal was to develop a simple, one-page medical flowchart created by and for PCPs to alert them to ensure they test high-risk individuals, order appropriate blood tests, correctly interpret results, and take the right action for follow-up care or referral to a liver specialist. After vigorous discussion about the barriers to HBV screening and management in the primary care setting, the flowchart and consensus recommendations have been summarized and submitted to the Journal of Family Practice for publication. Once accepted, a multi-faceted dissemination plan to integrate the medical flowchart into PCP practice across the U.S. will be launched.

Lessons Learned

1. We learned that community organizing and coalition building is a time-consuming process, and from our own experience, can take many years. CBOs often face constraints such as lack of staffing and resources, which can be a barrier to partnership development and active coalition participation. During this economic downturn, many CBOs have downsized or suspended programmatic activities. We have learned that it is important to reach out to one key person at a CBO who has a leadership role in the organization. Multiple site visits and meetings are necessary to offer staff education, introduce the idea of the campaign, and emphasize how the CBO can participate without burdening their existing resources. Through persistent and open communication, we were able to increase awareness of the unmet needs surrounding HBV and liver cancer. This led to motivated partners, who now actively participate in the campaign.

2. We learned that there are many barriers to recruiting health care and corporate partners. The lack of knowledge about the devastating effects of HBV on API communities can only be overcome by in-person visits and informal education. However, corporate and professional partners need to know more specifically how they will benefit by joining the campaign. For example, GlaxoSmithKline (GSK), headquartered in Philadelphia and manufacturer of one of the two approved hepatitis B vaccines, has pledged to help promote the campaign through their sales force in 2011 because they see the campaign as an opportunity to demonstrate good corporate citizenship and that it aligns with their goal of promoting vaccination. Focusing on the win-win proposition is a necessary step for successfully recruiting commercial partners.

3. We learned how to work strategically with partners to ensure they feel able and motivated to support the campaign and assume responsibilities within their capacity. By inviting every stakeholder to participate in the campaign, sending out continuous reminders and encouragements, publishing names and affiliations in meeting minutes and press releases, and recognizing the contributions of every partner, we have been able to stimulate active participation in the monthly planning calls, attendance at public events such as the press launch at City Hall, and volunteerism at education and screening events. In any city there are many different research and advocacy agendas, some of which overlap or compete. In Philadelphia, we spent an enormous amount of time nurturing relationships, building trust, and reassuring partners that the Hep B Free Philadelphia campaign would complement their individual research, community, and advocacy projects.

4. We learned that cultivating champions, particularly high profile community and professional leaders, is vital to the success of an awareness and advocacy campaign. Such individuals can make significant inroads into new or difficult to reach communities and can be extremely influential at many levels. Philadelphia, however, has a generally low awareness and knowledge about hepatitis B among CBOs and the community at-large, and we found that this can make it difficult to recruit champions. Additionally, many of the individuals and organizations we work with are apprehensive at the thought of meeting with legislators and city officials. We have found willingness for sign-on letters but less willingness for in-person visits. This apprehension is primarily due to lack of experience with the advocacy process. A user-friendly advocacy tool kit would be ideal to improve participation and reduce anxiety by helping people understand why the process is important and how it is accomplished.

5. We learned that provider barriers continue to be a challenge to improving HBV screening rates and care in the U.S. Through this project, HBF has become acutely aware of the multitude of provider barriers to HBV screening. These include limited time during office visits to address hepatitis B risk, reluctance to refer to specialists because they do not want to potentially lose their patients, and compensation barriers (i.e. insurance refusal for testing). It will take a comprehensive, multi-pronged, multi-year effort to begin to alleviate some of these barriers to promote HBV screening in the U.S. We believe that our new medical flowchart for primary care providers can play an important role in improving HBV screening.

Recommendations

1. When dealing with disease-specific coalition building, it is important to remember that there can be little knowledge and understanding about the disease within affected communities and organizations that serve these groups. For example, it is vital to improve awareness and knowledge about HBV if we hope to motivate and mobilize people to join our campaign. It is also important to remember that most individuals and CBOs have little experience with advocacy and can be overwhelmed by their perception of the process, which can be overcome through education.

2. Community-based HBV campaigns, such as Hep B Free Philadelphia, must include strategies to educate our partners about why hepatitis B is such a serious public health concern. One strategy that we found effective is to make the clear link between HBV and liver cancer at all educational opportunities. HBV might not seem to be an urgent health issue on its own, but when people are able to make the connection with a deadly cancer, it enhances the perceived importance of the disease and the need to take action.

3. Having knowledge of the political and leadership environment within a city is vital before starting an HBV campaign. There are likely some key individuals who can be cultivated as champions. It is important to make clear that one's goal is not to overburden already resource-stretched organizations. Rather a multi-level approach with many partners each contributing what they can is essential; members from the community, health care, academia, government, media, and corporate sectors should all be involved. Each organization can have an important role to play, and as a campaign leader, it is our job to help identify their strengths to ensure sustainability of the campaign.

4. Finally, it is important to remember that we want to reduce the health disparities associated with HBV and liver cancer in API communities without perpetuating stigma or discrimination. Media and advocacy campaigns need to find a way to improve awareness and screening efforts without sending the message that HBV is only a problem in API or immigrant communities.

There are many potential barriers to a community-based HBV awareness and advocacy campaign, including low knowledge and lack of resources. Solutions should encompass inclusive, multi-phased and well-planned strategies to help overcome these barriers and build the infrastructure needed. The primary goal of our awareness and advocacy campaign is to help reduce HBV and liver cancer health disparities and to mobilize the community and key decision-makers in the city to address these as urgent public health priorities.

B

activated : Hepatitis B Initiative of Washington, D.C.

Hepatitis B Initiative of Washington, D.C.
1725 I Street NW, Suite 300
Washington, D.C. 20006
www.hepbinitiative.org

Program Goal

To build a coalition in the Greater Washington, D.C. area that supports hepatitis B and C activities and legislation.

Hepatitis B Initiative of Washington, D.C.

The Hepatitis B Initiative of Washington, D.C. (HBI-DC) is a nonprofit organization with 501(c)(3) status. The Hepatitis B Initiative (HBI) was formerly known as Hepatitis B Education and Prevention in Boston, a volunteer organization that Leslie Hsu, along with a small group of medical and public health students, formed to reduce and eliminate hepatitis B infection among Asian Americans. The HBI expanded its service model to the D.C. metropolitan area through HBI-DC.

The goal of HBI-DC is to eliminate hepatitis B disparities in Asian and Pacific Islander (API), and other at-risk communities. HBI-DC organizes free education, screening, and vaccination events at locations where high-risk communities gather. HBI-DC strives to promote activities that increase awareness about this deadly but silent disease. To better manage fiscal and manpower resources, HBI-DC partnered with faith-based organizations, education and research institutions, community-based organizations, pharmaceutical companies, government agencies, and dedicated volunteers.

HBI-DC's successful faith-based model is replicated on a national level in partnership with AAPCHO and the Asian Pacific Islander American Health Forum. A guidebook was developed for a faith-based organization to perform a screening and vaccination event on their own.

Activities and Strategies

HBI-DC's goals for the B Activated program were:

1. Organize a formal network of Hepatitis B stakeholders in the greater Washington, D.C. area (D.C., Virginia, Maryland) that supports hepatitis B and C legislation:

HBI-DC's key strategy was to build a coalition in the Greater Washington, D.C. area that supported hepatitis B and C activities and legislation. HBI-DC tapped into its existing network and cadre of community activists to accomplish this. HBI-DC also organized meetings to get key stakeholder buy-in and commitment to participate in a coalition.

HBI-DC convened five meetings in the greater D.C. area. The organization created a listerv that served as a communication vehicle for all participants. The meetings were attended by over 50 participants including physicians, community-based organizations, public health officials, pharmaceutical agents, advocacy trainers, government officials, national viral hepatitis partners, and community activists. The meeting also featured guest speakers such as Dr. Sam So, the Director of Asian Liver Center at Stanford University. These events allowed participants to network, share and exchange materials and information, and build relationships with one another.

2. Coordinate and participate in advocacy activities at the local, state, and national levels: HBI-DC worked with AAPCHO's Hepatitis B Fellow in Washington, D.C. to capitalize on advocacy opportunities, including legislative visits to Congressional members.

HBI-DC also participates in the National Taskforce on Hepatitis B monthly conference calls. The calls focus on APIs and allow participants to update one another on current hepatitis B activities. The calls were also a good networking opportunity and allowed participants to learn from one another.

HBI-DC also participated in AAPCHO's Community Engagement and Mobilization Events at World Hepatitis Day events in Washington, D.C. The events included a briefing, a rally at Capitol Hill, and legislative visits. The legislative visits provided an excellent opportunity to educate policy makers and their staff about the impact of hepatitis B on API and other at-risk communities in their states. HBI-DC visited Sen. Webb of Virginia, Sen. Barrasso of Wyoming, and Sen. Shaheen of New Hampshire.

Other activities related to legislative visits included calling and following-up with key local, state, and national legislators; drafting sign-on letters; sending email alerts to encourage legislators to support HR. 3974; and using social networking tools such as Facebook, Twitter, and YouTube.

3. Continue to implement and strengthen hepatitis B screening and data collection: HBI-DC's free hepatitis B screening events were in alignment with the Centers for Disease Control and Prevention's screening protocols, as well as the Institute of Medicine's Report's recommendation. Screening events occur where high-risk communities gather, such as places of worship, ethnic festivals, ethnic stores and shops, and family gatherings. HBI-DC along with the Chinese American Medical Society - Mid Atlantic Chapter, conducted a screening event with members of the Senate and House of Representatives. To date HBI-DC organized over 10 screenings. The organization continues to implement the Institutional Review Board- approved standard format to collect demographic data at these screening events. HBI-DC also partners with John Hopkins University to analyze data from these screenings. Lastly, HBI-DC presented a poster entitled "Hepatitis B Virus Infection among Asian and African Immigrants in the Baltimore Washington Metropolitan Areas," at the American Public Health Association's Annual Meeting in Denver, CO in November 2010.

Lessons Learned

1. Coalition Building: Organizing and building coalitions provide great networking opportunities at our meetings but most importantly coalitions help strengthen the voice of API communities. Participants overall felt the meetings were valuable but that they were also time-consuming because of the need to do follow-ups and develop interesting and innovative programs for the meetings.

2. Advocacy: National policy must change for our efforts to make a significant impact. However, an organization should be prepared and anticipate the energy and time required to call and email members of Congress and their staff.

3. Screening Guidelines: Screening results proved the importance of addressing this disease and the impact it has in the underserved API communities. Funding to ensure project sustainability is a major challenge.

4. Workforce: Managing and operating a nonprofit organization is a significant challenge for one person because there is so much to do. Funding for workforce development will ensure that this important work continues and is sustainable. In these tough economic times, it is critical to establish and develop relationships with partners to share fiscal and manpower resources.

Recommendations

HBI-DC is dedicated to building an infrastructure that integrates resources, creates partnerships, mobilizes communities, and leads coalitions committed to HBV education, prevention, and treatment in targeted communities.

HBI-DC strongly believes that an ongoing, collaborative approach is needed to effectively reduce and eliminate hepatitis B. This approach was formalized when HBI-DC founded the "Hep B Free DC Network" in 2009, a consortium of stakeholders from Virginia, Washington, D.C. and Maryland who share a common goal of reducing and eliminating hepatitis B. These meetings have provided a forum for health care providers, public health professionals, researchers, and community health advocates to network, share ideas and best practices, and exchange hepatitis B-related information on medical care, screening, vaccination, health education, and other services.

The greatest concern we are currently facing is our inability to obtain or access adequate funding to sustain the continuity of work. This is a great health disparity, our work is only restricted to our funding. Thus, our recommendation would be to secure more funding resources to sustain our activities.

B

activated : International Community Health Services

International Community Health Services
720 8th Avenue South
Seattle, WA 98104
www.ichs.com

Program Goal

To raise community awareness about chronic hepatitis by developing a program that would expand the current local infrastructure to support a Seattle-King County community awareness campaign targeting the general public, and Asian American, Native Hawaiian, and other Pacific Islander and immigrant and refugee communities.

International Community Health Services

In 1973, a group of dedicated volunteers established International Community Health Services (ICHS) as a small storefront clinic to ensure that the low-income, elderly, and limited English-proficient (LEP) Asian residents of Chinatown and Beacon Hill of Seattle, Washington could access affordable and linguistically-competent medical care. In the 36 years since its founding, ICHS has grown into a state-of-the-art community health center with two full-service primary care clinics in the International District and Holly Park neighborhoods of Seattle. In addition to primary medical and dental care services, ICHS offers traditional Chinese medicine, breast and cervical cancer screenings and referrals, behavioral health services, laboratory and pharmacy services, health education, and other services, in over 15 languages and dialects. Services are focused on education, prevention, and early intervention. Because of the high rates of chronic hepatitis B within the primary patient populations served by ICHS, the clinics have always been involved in cutting edge programming that increased screening, vaccination, and treatment for patients with chronic hepatitis B. In 2009, ICHS served a total of 17,260 patients, the vast majority of whom were low-income, uninsured/underinsured, limited English-proficient Asian Americans, Native Hawaiians, and other Pacific Islanders (AA&NHOPIs). Despite the well-documented need for affordable, accessible health care for AA&NHOPIs, ICHS is the only community health center in Washington that specifically aims to serve medically-underserved Asian American, Native Hawaiian, and other Pacific Islanders (AA&NHOPIs) in Seattle and King County.

Activities and Strategies

Inspired by the success of the San Francisco Hep B Free campaign, and to continue to meet the hepatitis B health disparity needs of AA&NHOPIs, ICHS began planning for a Seattle and Puget Sound area adaptation of this project in the fall of 2008. Since the Hepatitis B Coalition of Washington State (HBCW) shared ICHS' goal of raising community awareness about chronic hepatitis, ICHS solicited their co-leadership in developing a program that would expand the current local infrastructure to support a Seattle-King County community awareness campaign targeting the general public and Asian American, Native Hawaiian, and other Pacific Islander and immigrant and refugee communities by mobilizing stakeholders including, but not limited to, health care providers, employers, mainstream and ethnic media, community organizations and other groups, including academia and young people.

To meet this goal we employed two main strategies.

1. Build community capacity using a community-based engagement model to strengthen the role of grassroots organizations, to identify community needs, issues, and assets, and to develop a shared agenda.

2. Exchange skills and knowledge with the community to promote community-based policy change by convening multiple stakeholders for media events as well as disseminating in-language media resources such as brochures, PowerPoint presentations, and ads in local, ethnic media.

ICHS and HBCW staff and volunteers convened a Hepatitis B Community Engagement work group to develop community mobilization and engagement strategies that would help address unique knowledge needs, cultural and physical barriers to testing and treatment, and to provide insight on how to better tailor a media message to reach these populations. A total of 26 community conversations were conducted, with 18 in a "Talking Circle" format, and eight as one-on-one key informant interviews. Traditionally Talking Circles are group discussions intended to give all participants an equal opportunity to voice their opinions. Although a traditional format was not utilized, the group facilitators captured the spirit of Talking Circles as much as possible by promoting respectful and open discussion among participants and encouraging all individuals to contribute to the discussion. These community conversations were conducted with diverse AA&NHOPI and East African community groups and individuals. Community groups were selected based on accessibility and willingness to partner. Each group was capped at 15 participants, lasting one and a half to two hours, included at least a facilitator and note taker; interpreters were utilized when appropriate. All conversations were kept confidential.

To exchange ideas and skills, ICHS and HBCW staff and volunteers convened a one-time media event targeting AA&NHOPI and broader refugee and immigrant community members and local media to share what was learned during the community engagement conversations. Additionally, participants received electronic copies of ads, brochures, PowerPoint presentations, a copy of the full report, and a sample press releases for local, ethnic media. Each of these educational tools were informed by the information we learned during the community engagement project. Since this one time media event, efforts have been made to return to the communities that participated in the community engagement project to share the outcomes and to mutually develop next steps for each community.

Lessons Learned

In total 194 individuals participated in these community conversations, representing a wide range of ethnicities and ages. Participants and key informants were 56% female and 44% male. Ages ranged from under 21 to 80 with fairly equal distribution between age groups. Through these community engagement talking circles and interviews, we learned a lot about the communities that we were trying to mobilize, which helped us develop ongoing media and advocacy programs and tools.

1. Knowledge

- Misconceptions about the disease are high within the communities.
- In some languages other than English, hepatitis B is often identified by its symptoms rather than being called hepatitis B.
- Some participants incorrectly assumed that immigration policies required immigrants to be tested for hepatitis B prior to entering the U.S.
- Many community members and some service providers incorrectly assumed that testing for chronic hepatitis was part of a routine medical exam or any blood test.
- Most community groups knew that a vaccine for hepatitis B existed, however there was confusion about whether or not the vaccine was good for life.
- One participant shared his confusion about why one family member with chronic hepatitis B might be on medications while another is not.

2. Barriers

- Hepatitis B does not have a sense of urgency about it.
- There is generally minimal or no taboo regarding discussion of hepatitis B symptoms, but there is a reluctance to discuss hepatitis B as a sexually transmitted disease.
- Hepatitis B is not given adequate attention at medical visits by both patients and medical providers.
- Cost and lack of insurance often prevent people from getting tested.
- Cultural barriers between the medical provider and patient can contribute to inadequate and inaccurate communication about hepatitis B.
- Comprehensive hepatitis B education and case management by medical providers is also limited by resources and tight budgets.

3. Strategies

- Partner with communities; outreach and education are more effective when the community members are personally involved and invested.
- Personalize hepatitis B; emphasize that it affects everyone in the family, and that protecting oneself is a step towards protecting one's family.
- Emphasize that testing and vaccination are preventive measures that save money over time.
- Use messages that are short and simple.

In general, both service providers and community members believed that hearing about hepatitis B from a medical provider reinforced its significance. Multiple communities support and encourage cross-generational approaches to education and family based education about hepatitis B. Service providers and community members agreed on many successful strategies: using community events to raise awareness, conducting outreach to places of worship, using multiple forms of media (e.g. DVDs, ads, articles, radio, and TV), developing in-language brochures and handouts and adding social elements like food and activities into educational events.

Additionally, throughout this entire project, we were reminded that community mobilization and engagement takes time, patience, and relationship building. In order to successfully recruit members of each language/ethnic group, we relied on the leadership and expertise of community members within those respective communities to guide us.

Finally, we are always reminded and humbly admit that even when you try to be fully culturally competent and sensitive to language needs and demands, it is often difficult to get it "perfect" and due to limited resources (including time and funding) we were forced to choose which languages would be translated first, rather than meet all communities' needs at the same time.

Recommendations

The participants and the work group that implemented these conversations developed many pro-active and solution-oriented ideas to help reduce the hepatitis B health disparity for several high-risk communities.

1. Key Messages for Everyone

- Know your hepatitis B status. Get tested.
- Talk with your family, friends, neighbors and medical doctors about chronic hepatitis B. Help them understand the importance of hepatitis B.
- Get trained on hepatitis B prevention, testing, and treatment. Organize and conduct hepatitis B presentations and events.
- Identify someone or become the "face" of hepatitis B (for your communities) on materials or in a media campaign.
- Educate your local and state elected officials about chronic hepatitis B, especially in supporting related legislation.
- Clarify misconceptions and myths about hepatitis B if/when you encounter them.
- Display and distribute hepatitis B materials at your offices, churches, and other gathering locations.

2. Key Messages for Service Providers

- Test your patients.
- Check if your clinic has a policy to test and educate patients and their families who are at increased risk for chronic hepatitis B.
- Educate your colleagues about chronic hepatitis B, especially those with direct access to patients and communities experiencing a hepatitis B disparity.

The community conversations provided valuable input and ideas on how to engage and mobilize different communities regarding hepatitis B. The insights from these conversations were immediately used to develop new multi-lingual educational resources, such as brochures, advertisements, posters, and PowerPoint presentations. Furthermore, these insights will be useful in developing future strategies and tools to help educate different communities about hepatitis B.

Common Acronyms

AA&NHOPI - Asian American, Native Hawaiian, and other Pacific Islanders

API - Asian and Pacific Islander

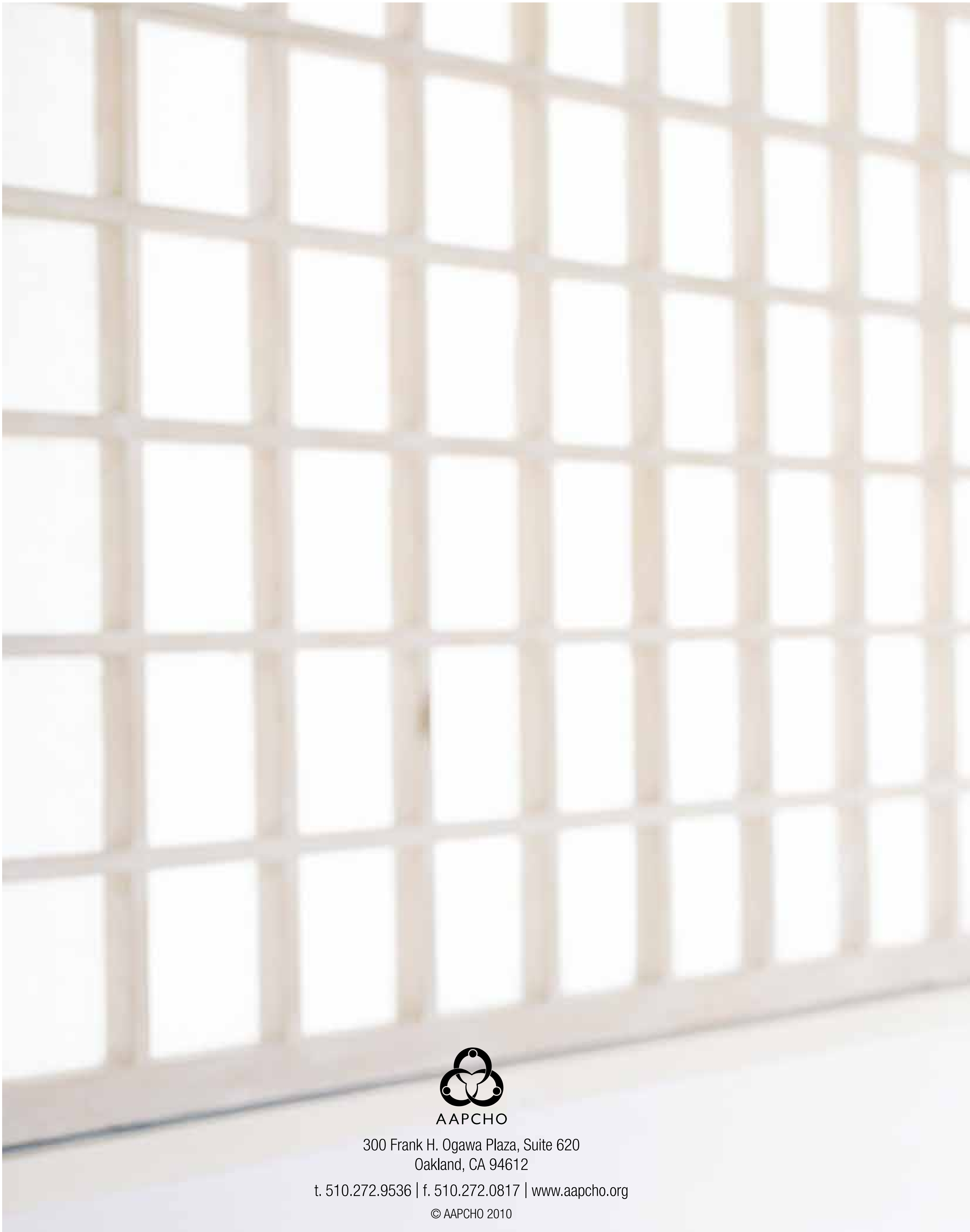
CDC - Centers for Disease Control and Prevention

CBO - Community-based Organization

CHC - Community Health Center

HBV - Hepatitis B Virus

IOM - Institute of Medicine



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