



# Understanding and Combating HBV-Related Stigma and Discrimination

November 1, 2017

# Hep B United: A National Coalition



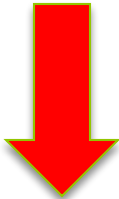
[hepbunited.org](http://hepbunited.org)



***Dedicated to reducing the health disparities associated with hepatitis B by increasing awareness, screening, vaccination, and linkage to care for high-risk communities across the United States.***

- 30+ local coalitions & national organizations that focus on the Asian American & Pacific Islander communities.
- Voices for local and national advocacy

# Stigma

- We know that many populations impacted by HBV face stigma.
  - Stigma is defined as a “mark of disgrace,” either real or perceived, that sets someone apart from others.
  - Those that feel stigma can feel shame, hopelessness, loneliness, social isolation, and much more.
- 
- This can lead to being treated differently from others in one’s family and community, discrimination, etc.

# Speakers

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Charles B. Wang Community Health Center

## **Beverly Quintana**

Communications Manager

Association of Asian Pacific Community Health Organizations  
(AAPCHO)





# Addressing HBV Stigma

At Charles B. Wang Community Health Center (CBW)

A Federally-Qualified Health Center in New York City

Janice Lyu

Senior Hepatitis B Program Associate



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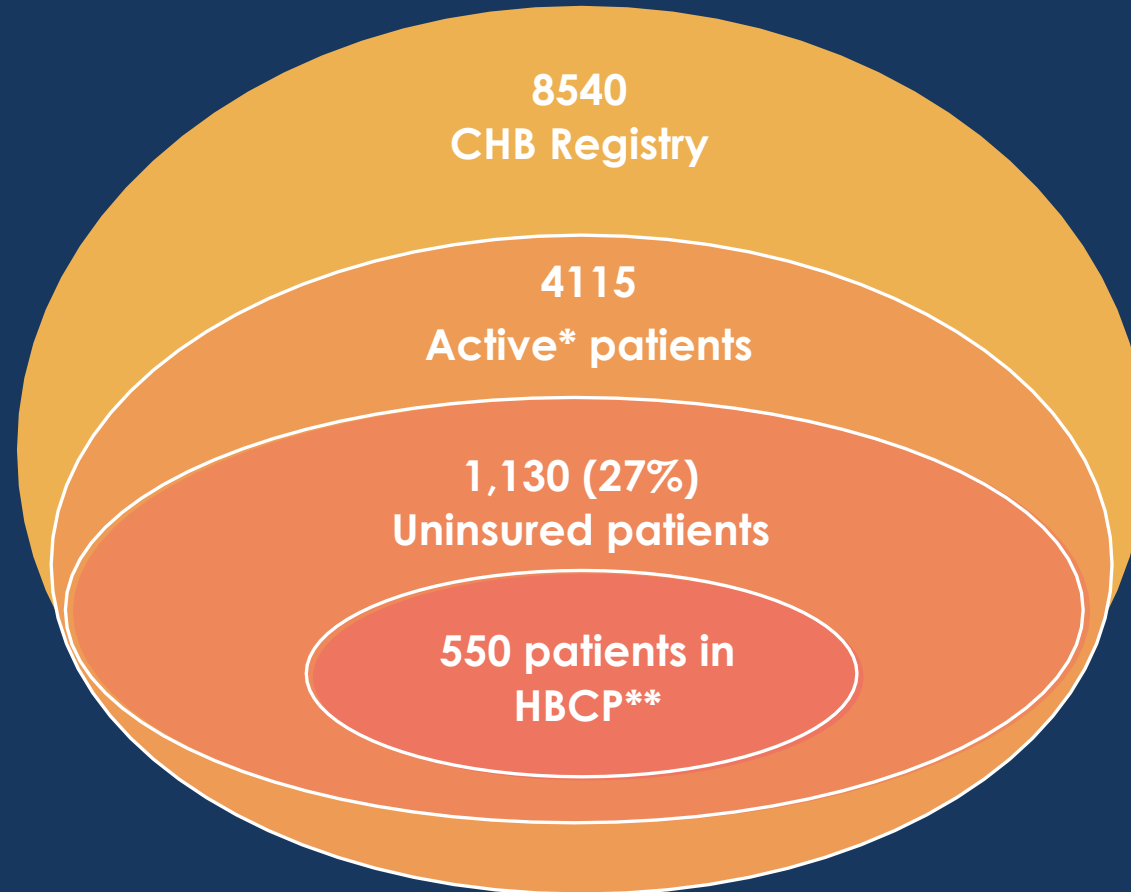


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- Federally Qualified Health Center
- NCQA level 3 Patient-Centered Medical Home
- Multidisciplinary care- primary care (adult, pediatric, OB/ GYN), mental health, specialists, optometry, dental, social work
- 4 clinical sites across Chinatown, Manhattan and Flushing, Queens
- Serve more than 50,000 patients and 275,000 service visits in 2015
- Focus on medically underserved and Asian Americans
  - Staff fluent in many languages, including Mandarin, Cantonese, Taishanese, Shanghainese, Fujianese, Vietnamese, and Korean
- Research and Evaluation Department
- Health Education, Marketing & Communications Departments



# How many chronic hepatitis B (CHB) patients do we see?



\*Active CHB patients were seen for an annual physical or follow-up visit from 9/1/15 to 9/1/2017  
\*\*HBCP = Hep B Care Program for high risk uninsured CHB patients include care management and subsidized imaging tests



# Hepatitis B Programs

- Hepatitis B Care Program (HBCP) *est. 2009*
  - Case management for high-risk uninsured adult patients with HBV
  - Over 550 patients (Manhattan and Flushing) enrolled
  - Patients are referred by providers and found using internal HBV registry report
  - High-risk enrollment criteria:
    - On treatment
    - Have family or personal history of HCC or cirrhosis
    - Meet other high risk HCC screening criteria (Asian M > 40yo, Asian F > 50yo, African/Black > 20yo)



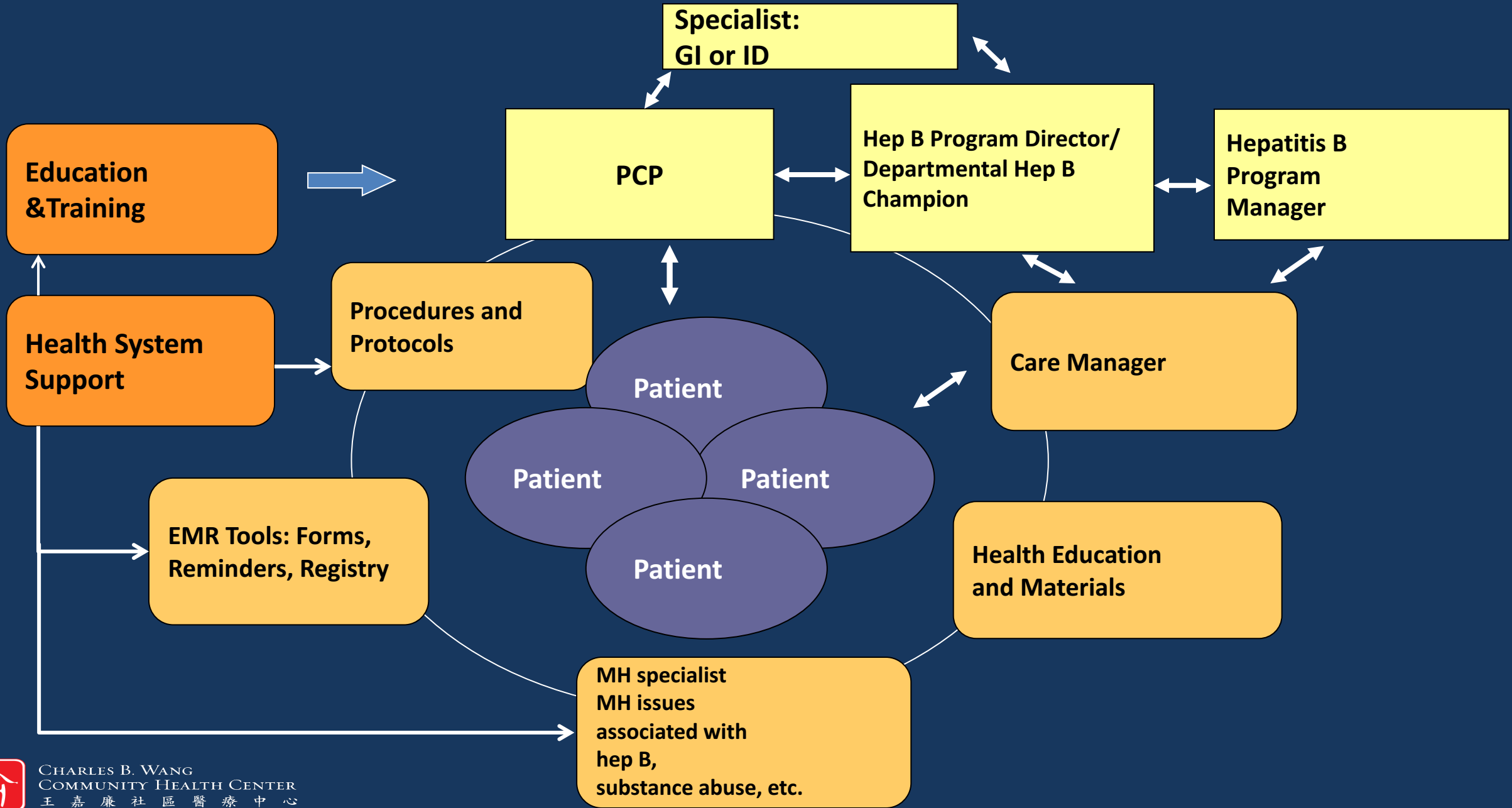
# Hep B Moms Program

- Goal to prevent perinatal transmission and fill the gaps between transitions of care (OB/HBV provider/Delivery hospital/Pediatrician)
- Tested early in pregnancy and assessed for existing care and if not, referred to CBW IM
- Patients are identified from Women's Health OBGyn Care Management report run biweekly
  - Care Manager provides face-to-face counseling
  - Links patients to hepatitis B care during and after pregnancy





# Overview of Primary Care Model for Hepatitis B Care at CBWCHC



# HBV Stigma at CBW

## Cause:

- Lack of knowledge and misconception
- Having no visible chronic hepatitis B symptoms

## Effect:

- Neglecting care
- Lack of communication
- Making assumptions and suspecting
- Fears



# Protocols and Education for Providers

**Medical Protocol Portal**

	ALT ULN = 19 if female; 30 if male	HBV DNA (IU/mL)	Interval management	Treatment (Tx)
HBsAg + w/o cirrhosis <sup>1</sup>	< 1 x ULN <i>Immune-tolerant phase</i>	Optional for trend	q3-6mo ALT, q6-12mo HBsAg	Consider tx if F3+ AND age > 40yo
	1-2 x ULN		q3mo ALT, q6mo HBsAg, consider liver elastography	Consider tx if F2+, age > 40 or FHx HCC
HBsAg - w/o cirrhosis <sup>1</sup>	> 2 x ULN <i>Immune-active phase</i>		q1-3mo ALT, HBsAg, liver elastography opt	Tx if persistent <sup>2</sup>
	< 1 x ULN <i>Inactive CHB phase</i>	< 2000	q3mo ALT and HBV DNA x 3, then q6-12mo if stable HBsAg q1-2y for clearance	None
	1-2 x ULN	2000-20,000	q3mo ALT and HBV DNA Consider liver elastography if persistent	Consider tx if F2+, age > 40 or FHx  Tx if persistent <sup>3</sup>

**PROCEDURE:**

**I. SCREENING AND VACCINATION**

The standard of care at CBWCHC is to provide hepatitis B screening and vaccination as part of routine preventive care. Review of hepatitis B risk factors, vaccination history, family history and serologic HBV screening tests, if indicated, should occur during initial and annual physicals.

**A. Screening for HBV:** In accordance with 2008 CDC guidelines [1] and the 2014 USPSTF recommendation [2], the following groups should be screened for HBV infection:

- Persons born in countries with high (>8%) or intermediate (>2%) HBV prevalence (see table 1 and Figure 1)

Table 1: Areas of high and intermediate prevalence of HBV

- Asia (All)
- Africa (All)
- The Caribbean (Antigua and Barbuda, Dominica, Grenada, Haiti, Jamaica, St. Kitts and Nevis, St. Lucia, and Turks and Caicos Islands)
- South America (Ecuador, Guyana, Suriname, Venezuela; and Amazonian areas of Bolivia, Brazil, Colombia, and Peru)
- Central America (Guatemala and Honduras)
- North America (Alaska natives and indigenous populations in northern Canada)
- Middle East (All except Cyprus and Israel)
- Western Europe (Malta, Spain, and indigenous populations in Greenland)
- Eastern Europe (All except Hungary)
- South Pacific Islands (All except New Zealand)

Figure 1: Geographic distribution of chronic hepatitis B virus (HBV) Infection - 2006

- Updated Guidelines and Protocols Uploaded on Central Medical Protocol Portal
- Monthly Internal Medicine/ Provider meetings
- Monthly Hepatitis B Collaborative meetings
- CME Providers Education Seminars/ Training





# Hep B Education Reminders in EMR

Pre Diabetes | DM | **Hepatitis B** | HTN | Hyperlipidemia

Explained to pt that HBV is a chronic disease

**Patient education given on:**

- F/U MD regularly
- Avoid liver injury
- Avoid self medication
- Avoid transmission factor
- Household screening
- Signs and Symptoms of Flare
- Antiviral medication compliance (if pt taking)

**Hep B Self-management Support Resources**

- Discussed Hep B Self-management Support
- Healthy Lifestyle
- Advised tobacco cessation

Pt verbalized understanding and educational pamphlet give

Comments:

Prev Form (Ctrl+PgUp) | Next Form (Ctrl+PgDn)

Documents

- Flowsheet
- Orders
- Histories
- Protocols
- Graphs
- Handouts
- Registration

Uptodate

Chart Desktop

Chart

Chart Reports

Chart LinkLogic

Scheduling

Previous HepB Tracker Status: renewed and given (12/28/2016 2:44:11 PM)

HepBTracker:

OB Visit	11/27/2015 3:22 PM	IMFU: Urgent care--
PED Encounter	11/18/2015 5:02 PM	IMFU: Urgent care--left thumb injury, right hand pain
	10/08/2015 4:47 PM	IMFU: urgent care- left eye redness
	10/04/2015 11:02 AM	IMFU: f/u HepB, Flu vax given
	06/28/2015 4:20 PM	IMFU: f/u HepB, Hyperlipidemia, Abnormal TSH
	06/03/2015 10:31 AM	IMNursing: TST reading - negative
	05/31/2015 2:55 PM	IMAPE: IPE, tdap, pneumovax (DOH) & "T" card given

Doc ID: 75 Properties: IM FU Visit at C\_IM\_4 on 09/10/2016 10:07 AM

**Hepatitis B**

**Patient education given on:**

F/U MD regularly: Need to have bloodwork routinely to monitor viral load and liver health

Avoid liver injury: Avoid alcohol and smoking, healthy diet and adequate rest

Avoid self medication: Herbal supplements and OTC meds may harm liver, notify MD if taking

Avoid transmission factor: Do not share toothbrushes, razors, nail clippers, or any other object that could possibly become contaminated with blood.

Household screening: Household contacts and family should be screened and vaccination if needed

**Healthy Lifestyle:** Be physically active and adequate rest

**HepBTracker:** patient did not bring tracker to visit 09/10/2016

Pt verbalized understanding and educational pamphlet given By: AM



# Care Manager Duties

- Create a safe environment for patients to raise questions/ fears/ concerns about HBV
- Assess knowledge about HBV
- Phone or in-person HBV education and case management
- Work with provider for optimal treatment plan
- Monitor patient's HBV visits and their progress using database
  - Track patient's blood work and follow up appointment dates
- Re-engage non-adherent patients
  - Call if did not show up or canceled appointment
  - Provide education and reschedule appointment
- If unable to reach by phone, send HBV specific reminder letter Track HCC U/S screening referrals
  - Assist in scheduling appointment
  - Assist in follow up imaging if needed (CT or MRI)
- Track staging fibrosis referrals (Elastogram/Fibroscan)
- Record patient's treatment status in database
  - Assist in applying for medication through Patient Assistance Program
  - Check that patient is adherent to medication



# Household Contact

- Weaved into care manager's and provider's HBV education
- Ask about family history/ status of household contacts
- Encourage communication with family and friends
- Encourage households to get screened
  - Offer 1<sup>st</sup> time screening for free



# Patient HBV Education Tools/ Resources

## 乙型肝炎病毒 (HBV) 血液測試結果 YOUR HEPATITIS B VIRUS (HBV) BLOOD TEST

日期 Date	乙肝表面抗原 HBsAg Hepatitis B Surface Antigen	如果這項測試結果呈陽性 (+), 表明你已經感染了乙肝病毒。 If this test result is positive (+), it means that you are infected with the hepatitis B virus.
日期 Date	乙肝表面抗體 HBsAb Hepatitis B Surface Antibody	如果這項測試結果呈陽性 (+), 表明你對乙肝病毒產生免疫力。 If this test result is positive (+), it means that you are immune to the hepatitis B virus.
日期 Date	乙肝 "e" 抗原 HBeAg Hepatitis B "e" Antigen	如果這項測試結果呈陽性 (+), 通常表明你血液內的病毒數量較高。你把病毒傳染他人的機會較高。當 "e" 抗原呈陽性, 通常稱為 "大三陽"。 If this test is positive (+), it often means the amount of virus in your blood is higher. You may be more likely to spread the virus to others. When "e" antigen is +, it is often described as "big three positive."
日期 Date	乙肝 "e" 抗體 HBeAb Hepatitis B "e" Antibody	如果這項測試結果呈陽性 (+), 表明你的血液內病毒數量較低。當 "e" 抗體呈陽性 (而 "e" 抗原呈陰性), 通常稱為 "小三陽"。 If this test is positive (+), it can mean that the amount of virus in your blood is lower. When "e" antibody is + ("e" antigen is -), it is often described as "small three positive."



### 治療記錄

醫生將根據你的檢查報告、健康情況與家族史來決定你是否需要治療。

### TRACK YOUR TREATMENT

Your doctor will decide if treatment is needed based on your test results, health condition and family history.

藥物名稱 Medication Name	劑量 Dosage	開始日期 Start Date	結束日期 End Date

## 接受檢查, 瞭解肝臟狀況 TESTS TO CHECK THE HEALTH OF YOUR LIVER

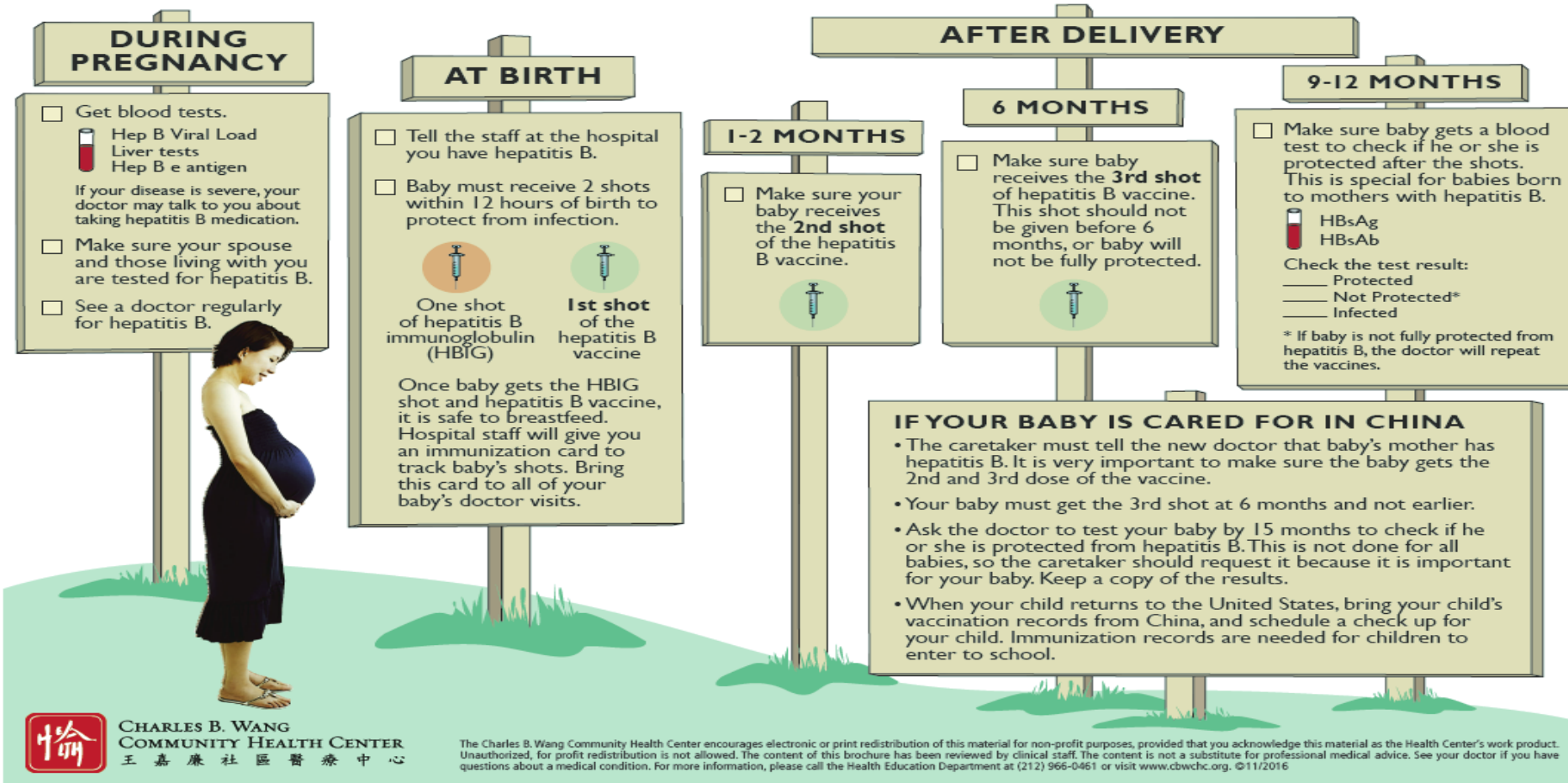
日期 Date	轉氨酶水平 ALT (U/L)	肝功能測試能夠衡量你的肝臟發炎的程度。假如結果呈上升, 就表明你的肝臟已經受到影響。 Liver function tests measure inflammation in your liver. If the result is elevated, it means your liver is affected.
日期 Date	乙肝病毒含量 HBV Viral Load (IU/mL)	這項測試能夠顯示你血液內乙型肝炎的病毒含量。如果病毒含量開始上升, 醫生會進一步觀察你的健康狀況。 This test shows how much hepatitis B virus you have in your blood. If your viral load starts to increase, your doctor will need to monitor you carefully.
日期 Date	纖維化評分 Fibrosis Score	它估計肝臟中的疤痕形成量, 數值範圍由 F0 (正常) 到 F4 (肝硬化)。它估計了肝臟中疤痕的數量, 範圍由 F0 (正常) 到 F4 (肝硬化)。 It estimates the amount of scarring in the liver from a scale of F0 (normal)- F4 (cirrhosis).
日期 Date	超聲波 Ultrasound	這能夠幫助檢測肝硬化或肝癌。 It can help detect cirrhosis or cancer in the liver.
日期 Date	甲胎蛋白 AFP (ng/mL)	這項測試能夠幫助檢測肝癌。 This test can help detect liver cancer.
日期 Date	甲型肝炎抗體 Hepatitis A Ab (Hepatitis A Antibody)	如果這項測試結果呈陽性 (+), 表明你對甲型肝炎產生免疫力。 If this test result is positive (+), it means that you are immune to the hepatitis A virus.
日期 Date	丙型肝炎 Hepatitis C	如果這項測試結果呈陽性, 表明你感染了丙型肝炎病毒。 If this test is positive, it means that you are infected with the hepatitis C virus.



# Hep B Mom Roadmap

## IF YOU HAVE HEPATITIS B, PROTECT YOUR BABY USE THIS CHART TO TRACK YOUR CARE AND YOUR BABY'S CARE

If you have hepatitis B, the virus can be transmitted to your newborn through your blood at birth. The baby can then carry this serious disease for a lifetime. To prevent infection, make sure your baby is protected with immunizations. Also, see your doctor regularly to take care of your hepatitis B and avoid liver damage.



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**Protecting Your  
Baby From Hepatitis B**  
What Pregnant Women Need to Know

CHARLES B. WANG COMMUNITY HEALTH CENTER  
王嘉廉社區醫療中心

Hepatitis (HEP-ah-TY-tis) B is a serious liver disease caused by infection by the hepatitis B virus. If not cared for or treated, a hepatitis B infection can lead to cirrhosis (liver scarring), liver damage, and liver cancer.

Hepatitis B is called the "silent killer" because most people with the disease do not know they have it until they develop serious problems. People with hepatitis B can spread the virus to others even if they do not have any symptoms.

**Why should I be concerned about hepatitis B?**

Asians are at high risk of getting infected. About 75% of people with chronic hepatitis B infection in the world are Asian.

Among Asians, the most common way the virus spreads is from mother to baby. If a mother has hepatitis B, her blood and body fluids are likely to infect her baby during birth.

**Even if a mother does not have hepatitis B, her child can still get infected by:**

- Contact with infected blood and body fluids through breaks in the skin, such as bites, cuts, or sores.
- Contact with objects that have blood or body fluids on them such as toothbrushes or razors.
- Having sex without a condom with someone who has hepatitis B when the child grows up.

**Hepatitis B virus is NOT spread by:**

- Sharing food or drinks
- Sharing eating utensils or cups
- Sneezing or coughing
- Kissing or hugging
- Saliva, sweat, tears, urine, or stool



# Thank you!

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## Understanding and Combating Stigma: A Toolkit for Improving Care and Support for People Affected by HBV

November 1, 2017

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Beverly Quintana, Communications Manager, AAPCHO



# About the Association of Asian Pacific Community Health Organizations (AAPCHO)

- National association of 33 community health organizations serving **Asian Americans, Native Hawaiians and Pacific Islanders (AA&NHPIs)**
  - 28 of which are Federally Qualified Health Centers (FQHCs)
- Dedicated to **improving the health status and access** of these medically underserved communities

# AAPCHO Hepatitis B Activities Overview

1. Increase awareness about the impact of hepatitis B on AA&NHPs and other at-risk populations, through **thought leadership and advocacy** work with:
  - Hep B United coalition
  - AAPCHO member health centers and broader network
2. Develop and disseminate **resources and tools** to improve hepatitis B prevention, care and treatment

# Hep B United and AAPCHO Network

- Hep B United
  - National coalition raising profile of hepatitis B and liver cancer as an urgent public health priority
  - National Summit, coalition-building, mini-grant program, webinars
  - Meetings with policymakers
  - #justB Story campaign to combat stigma
- AAPCHO network
  - Community health centers
  - National and local CBO partners



# New Toolkit to Address HBV-Related Stigma

## *Understanding and Combating Stigma: A Toolkit for Improving Care and Support for People Affected by HBV*

<http://bit.ly/HBVStigmaToolkit>

- Curriculum to help community-based organizations and health facilities work with patients, staff and community members to combat and address stigma and discrimination experienced by people living with or most vulnerable to the hepatitis B virus (HBV)
- Acknowledgements and thanks to **contributing reviewers**



# What's in toolkit and why was it developed?

- Collection of **participatory educational exercises**
  - Learner-centered, participatory approach
  - Built around discussion and small group activities
- The aim of these exercises is to facilitate open discussion on HBV-related stigma and what we can all do to promote a change in attitude and practice



**PARTICIPATORY  
LEARNING**

**PICK AND  
CHOOSE**

**START WITH  
YOURSELF**

# Who can use this toolkit?

- Anyone can use this toolkit.  
You might be a:
  - HBV health care provider or educator
  - Community member or member of a community-based group
  - Someone living with or who knows someone who is affected by HBV (partner, child, parent, or friend)
  - Someone who can use the materials in this toolkit to adapt them for use to train other groups (media, policymakers, other community based organizations, etc.).
- Currently being pilot-tested by AAPCHO and Hep B United partners

## Five Steps to Stop HBV Stigma



### KNOW THE FACTS

Even if you know about HBV, make sure you understand how HBV is transmitted, who is at risk, and how effective care and support is implemented for people affected by HBV. *Learn the facts and address the myths (Appendix 4).*



### BE MINDFUL OF YOUR ATTITUDES AND BEHAVIOR

Prejudices and judgmental thinking about how those affected by HBV should not speak about their illness are learned and often commonplace. Family, friends, society and the media reinforce these attitudes and behaviors. *We can change our thinking and recognize people not as labels but as unique individuals.*



### CHOOSE YOUR WORDS WISELY

The way we speak can affect how other people think and speak. *Use accurate and sensitive words when talking about people at risk for or living with HBV. Understand that they might not want to disclose their status, and try to understand why.*



### EDUCATE OTHERS

Take opportunities to share facts and positive attitudes about people affected by HBV. *If people present information that is not true, share correct information. Let them know that their negative words and misinformation affect people at risk for or living with HBV, and contribute to false notions.*



### TAKE ACTION

Increase awareness about HBV-related stigma and how stopping it could benefit public health overall. *If you witness a person living with or affected by HBV experiencing discrimination, speak up. We can help make sure that those affected by HBV are treated equally and with respect.*

Excerpt: Short Intro →  
Straight to Modules

## HBV, Stigma and At-Risk Groups

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## Combating HBV Stigma in a Health Care Setting

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## Table of Contents

Introduction

MODULE A - Understanding and Confronting Stigma

MODULE B - More Empathy and Less Fear

MODULE C - “Us” vs. “Them”

MODULE D - Understanding Stigma in  
Your Family and Community

MODULE E - Combating Stigma in a Health Care Setting

MODULE E - Taking Action to Combat Stigma

APPENDICES



# Excerpt: More Facts, Stats and Tools in Appendix

## HEPATITIS B

KNOW HEPATITIS B

### Are You At Risk?

#### What is Hepatitis B?

Hepatitis B is a liver disease. It is caused by the Hepatitis B virus. For some people who get Hepatitis B, the virus stays in the body, causing a lifelong illness. Hepatitis B can cause serious health problems over time. These problems can include liver cancer and liver failure.

#### How is Hepatitis B spread?

Hepatitis B is spread when someone comes in contact with blood from a person who has the disease. Most people born in China and other Asian countries who have Hepatitis B were infected as infants or young children. Hepatitis B can be passed from an infected mother to her baby at birth or from a family member to young children.

Hepatitis B is not a genetic disease. People also do not get Hepatitis B from sharing meals, bowls or utensils with someone who has the disease. Hepatitis B is not spread through breastfeeding, hugging, kissing, holding hands, coughing, or sneezing.

#### How common is Hepatitis B?

Hepatitis B is very common in China and other Asian countries. Approximately 1 in 12 Asians are living with Hepatitis B, but most people do not know it.

#### What are the symptoms of Hepatitis B?

Most people who have Hepatitis B do not know they have it. The disease does not always cause symptoms. Hepatitis B can stay hidden in the body. Many people can live with Hepatitis B for 20 years without feeling sick. Still, liver damage from the disease can take place during this time.

#### How serious is Hepatitis B?

Hepatitis B can become very serious. For some people, this disease leads to liver damage, like liver failure or cancer.

#### How do people get Hepatitis B?

A Hepatitis B blood test that Doctors do not test.



#### Why should I get tested?

Getting tested There are treat serious liver da can also keep c are always test members who protect them f Hepatitis B test Hepatitis B can cannot be firec

#### How is Hepatitis B spread?

People who ha knowledgeable that will slow c before taking a the liver or cau by your doctor

## Protect Your Baby for Life

### Hepatitis B and Your Baby



#### Why should pregnant women be concerned about Hepatitis B?

Hepatitis B is a contagious liver disease that can be easily passed from a pregnant woman to her baby at birth. Fortunately, there is a vaccine to prevent babies from getting Hepatitis B.

#### How is Hepatitis B spread?

Hepatitis B is spread when blood, semen, or other body fluids from a person with the Hepatitis B virus enter the body of someone who is not infected. The virus is very infectious and is easily spread to others. This can happen through:

- An infected mother passing it to her baby at birth
- Sex with an infected person
- Direct contact with blood from an infected person, even in tiny amounts too small to see

#### What is Hepatitis B?

"Hepatitis" means inflammation of the liver. Hepatitis B is a liver disease that results from infection with the Hepatitis B virus. Some people are able to fight the infection and clear the Hepatitis B virus. For others, the virus remains in their body and becomes a chronic, or lifelong, illness. Over time, Hepatitis B can cause serious health problems.

#### How serious is Hepatitis B?

As many as 1 in 4 people with Hepatitis B develop problems including liver damage, liver failure, and Every year, approximately 3,000 people in the Unit Hepatitis B-related liver disease.

Prevent Hepatitis B. Get your baby vaccinated.

#### How common is Hepatitis B?

It is estimated that 350 million people worldwide a people in the United States are infected with Hepa 1,000 pregnant women that give birth each year, 1 Hepatitis B.

#### Are babies at risk for Hepatitis B?

Yes. When a pregnant woman has Hepatitis B it ca to her baby. Babies and young children can also g close contact with family members or others who r Infants who become infected with Hepatitis B hav developing a lifelong, chronic infection.

#### Are pregnant women tested for Hepatitis B?

Yes. Many women do not know they are infected, s Hepatitis B often have no symptoms. As a result, a are given a blood test for Hepatitis B as part of their prenatal care. The test is usually performed during the first prenatal visit. If a woman has not received prenatal care, then she will be tested at the hospital before she delivers her baby.

#### Why are women tested for Hepatitis B?

Pregnant women are routinely tested for Hepatitis B, along with other diseases. These tests are done to find health problems that can be prevented or treated in both a woman and her baby.



TRUE

FALSE





















### HOW WELL DO YOU KNOW

## HEPATITIS B

1. Hepatitis B is spread through direct contact with infected blood.
2. Hepatitis B cannot be spread through the air.
3. Hepatitis B cannot be spread through sharing meals, bowls or utensils with someone who has the disease.
4. 1 in 12 Asian Americans has Hepatitis B.
5. Many people with Hepatitis B don't have symptoms and don't look or feel sick.
6. A Hepatitis B blood test is the only way to know if you are infected with the virus.
7. The CDC recommends that people born in Asia or the Pacific Islands be tested for Hepatitis B.
8. Treatments are available that can help prevent serious liver damage from Hepatitis B.
9. Most people infected with Hepatitis B were infected at birth or in early childhood.
10. Hepatitis B is the leading cause of liver cancer among Asian Americans.

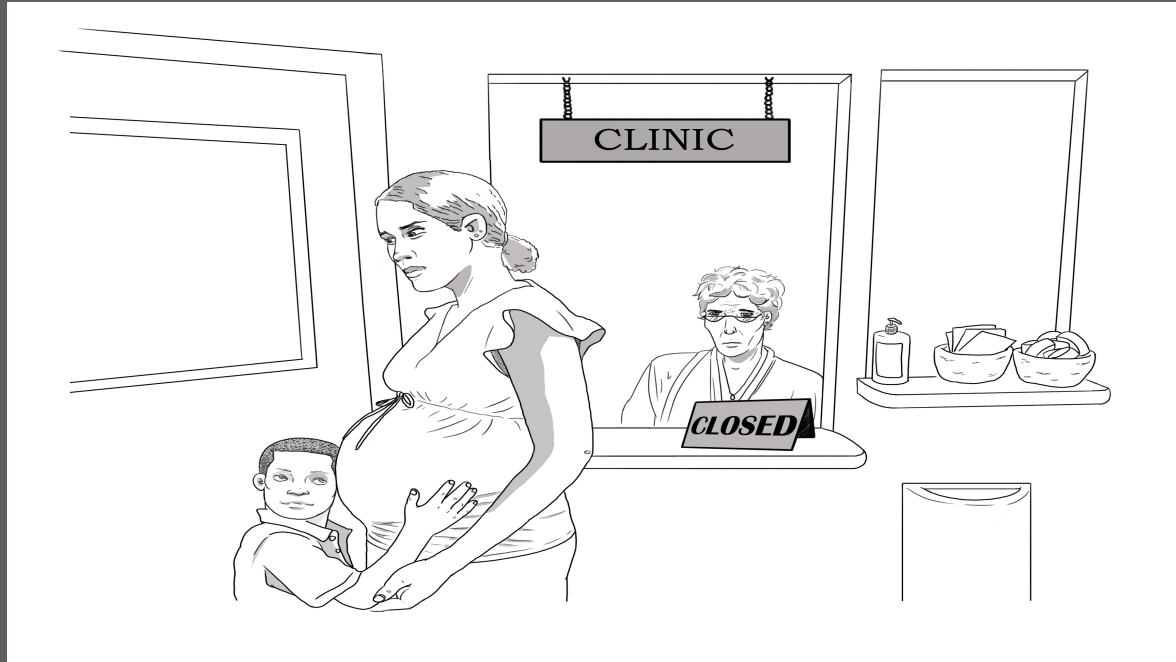


U.S. Department of Health and Human Services  
Centers for Disease Control and Prevention





# Excerpt: “Combating Stigma in a Health Care Setting” Module



## Exercise E2 – Seeking Health Care with HBV



### ACTIVITIES

#### OBJECTIVES :

- Participants will be able to:
  - Better understand the perspective of people living with HBV
  - To describe the impact of healthcare workers' behaviors on HBV-positive patients' health and well-being



#### TIME :

1-2 hours



#### MATERIALS :

- Scenario examples on cards or signs
- Flipchart sheets
- Notepads
- Pens and markers

- Distribute scenario examples (see below) on cards or display case studies on signs.
- Ask participants to write one response for each case study, saying:
  - What is your reaction to these scenarios? How do they make you feel?
  - Would you change anything that happened? How?
- Report back to the group and note key points on flipchart.
- Ask participants to briefly describe a situation they have witnessed or experienced at their own health care facility where they or a patient was treated poorly because they were HBV-positive/had hepatitis B; discuss:
  - How did you react?
  - Looking back, would you change anything that happened? How?

#### Scenario Examples

##### Example 1:

A woman came to the hospital in labor. At a certain point in her care, her doctor found out that she was HBV positive/had hepatitis B and refused to assist the delivery. He didn't say anything to her, he just left the hospital. She was forced to seek care elsewhere.

##### Example 2:

A man came to the health clinic because he had a cough that would not go away. He worried all the way there about telling the nurse that he had hepatitis B. He thought they might tell him to go away. In the end he told her, and she praised him for doing so, as it was important for the staff to know this. She treated him just like she would any patient, with dignity and respect, in a caring manner.

# Excerpt: “Understanding Stigma in Your Family and Community” Module



## Exercise D1 – Stigma in the Household



### ACTIVITIES

#### OBJECTIVES :

- Participants will be able to:
- Understand forms of stigma in a household with a person living with HBV
  - Identify ways to address stigma and create a healthier and more supportive household environment



#### TIME :

1 hour



#### MATERIALS :

- Selection from stigma pictures (Appendix 1)
- Notepads
- Pens and markers

#### Breakout Groups:

- Divide participants into groups and give each group a picture.
- Ask the group to write down notes to answer and discuss:
  - “What do you see in the picture? What do you think is happening? Does this happen in your family/household?
  - How does it affect you? How does it affect the people living with HBV in your house?
  - What can you do to address this stigma and create a more supportive household?
  - As a person living with HBV, how would you want your family members to treat you and make you feel comfortable?
- Report back to the group.

#### Summary:

Explain how stigma in the family/household takes many forms including isolation, blaming, and judging those living with HBV. The first step to combatting stigma is to identify and acknowledge it, then work together to solve it.

#### Some examples of stigma in the household:

- Separation of utensils—plates, cups, spoons.
- Burn or discard clothing and other things used by person living with HBV
- Physical isolation (e.g., forced to sleep alone or in a separate room).
- Minimum physical contact. No hugging. Told not to touch/play with children.
- Treated as a burden (e.g., extra money needed for treatment, extra time for care and management).
- Judging, Blaming, Condemning. Made to feel s/he has disgraced family.
- Partners/spouses of people living with HBV are assumed to be HBV positive.
- In-laws blame spouse for HBV (HBV exaggerates tensions with in-laws).

# Thank You

Understanding and Combating Stigma: HBV Toolkit

<http://bit.ly/HBVStigmaToolkit>

[HBVStigmaToolkit@aapcho.org](mailto:HBVStigmaToolkit@aapcho.org) - *feedback for improvements appreciated!*

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Thank You!

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