

# HBV Perinatal Programs

Gaps and opportunities



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# Two perspectives

## Academic public health science

- *Transmission studies*
- *Define/discover barriers*
- *Design and evaluate interventions*

## Non-profit organization

- *Aid individuals in need*
- *Raise awareness*
- *Advocate for systemic changes*



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### Top Stories

**CDC Expands Hepatitis B Testing Recommendations**  
Sept. 19 - The CDC today issued new recommendations designed to increase routine hepatitis B testing in the U.S. and new guidance for the medical management of individuals chronically infected with hepatitis B. [Read Full Article.](#)

**Nokia Still in Court Over Alleged HBV Discrimination**  
Sept. 19 - The Beijing Yirenping Centre, one of China's most highly visible watchdogs on HBV, has called for Nokia to honestly face the problem of workplace discrimination. [Read Full Article.](#)

**Researchers Invigorate "Exhausted" Immune Cells**  
Sept. 19 - Researchers have found a novel tool that may advance the development of new therapies for diseases such as HIV, hepatitis B and C, and cancer. [Read Full Article.](#)

**Epidemiology of HBV in Truck Drivers in Brazil**  
Sept. 19 - Research findings confirm truck drivers in Brazil are at high risk for HBV and the importance of a

**Please visit our newest CME course**  
**Hepatitis B Clinical Consults**  
Key issues surrounding screening, diagnosis, and treatment of the Hepatitis B virus in Asian Pacific Islander communities.

**Hepatitis B Foundation** **PODCAST DIRECTORY**

**ONE IN TWENTY** *Watch our video*  
Learn how the Hepatitis B Foundation is bringing hope to millions of people worldwide.

**Language Chapters**  
We have created unique language chapters providing culturally sensitive information on hepatitis B. You will need to have the various language fonts installed on your computer in order to view these pages.



# HBF Programs

- HBF Research Institute for Drug Discovery
- Outreach, Education and Patient Support
- Public Health Research
- National Advocacy



# HBF Outreach, Education and Public Health

- ✓ Comprehensive Web Site
- ✓ Phone and Email Help Lines
- ✓ Annual Patient Conference
- ✓ Free Print and Online B Informed Newsletter
- ✓ Free monthly e-Newsletter
- ✓ Research Training Internships
- ✓ Community Education and Screening Programs
- ✓ Public Health Research Projects and Publications



# The power of anecdotes

- ▣ HBF phone and e-mail counselors often hear from the newly-diagnosed with chronic HBV
  
- ▣ Two recent calls from women diagnosed during pregnancy illustrate some of the difficulties frequently encountered by HBV-infected mothers

# Case #1

- ❖ Foreign-born mother of three in her mid-30s
- ❖ Told during her first pregnancy (12 years ago) that she is HBsAg+
- ❖ Understood at the time that she was a “healthy carrier” who required no follow-up
- ❖ No care for HBV in intervening years, no education about transmission to others
- ❖ “Rediagnosed” recently because of GI symptoms, recommended liver bx
- ❖ Patient distressed, believes death is imminent

# Case #2

- ❖ New mother, tested HBsAg+ in 3<sup>rd</sup> trimester
- ❖ Baby given appropriate prophylaxis at birth
- ❖ Mother understood primary care doc's instructions as:
  - ❖ Do not touch or hold the baby
  - ❖ Get her affairs in order, prepare for death

# Outcomes for cases 1 and 2

- ▣ HBF counselors helped both women with
  - Emotional support
  - Education about disease transmission to family and household contacts
  - Finding a liver specialist for ongoing care
  
- ▣ For both women, multiple calls were required
  
- ▣ Note these women are the tip of an iceberg, not representative

# The public health science perspective

- Are these two isolated cases? Have the barriers they have encountered been documented on a population level?
- Most studies in perinatal HBV infection have focused on transmission to the infant
  - Issues with care of infected mother have not routinely been addressed in published studies
  - Provider education/communication issues mostly ignored

# HBF 2007 Patient Conference in Philadelphia Chinatown

- Session presented in Mandarin
- 69 participants, 97% infected or there to learn to help infected family member
- Motivation for attending session:
  - 79% to learn about treatment options
  - 61% to learn about prevention
  - 37% to learn about disease management

# HBV 2007 Patient Conference (cont'd)

- ▣ Of those infected with HBV:
  - 38% under care of liver specialist
  - Barriers to finding care:
    - ▣ 32% "I do not know how to find a liver specialist"
    - ▣ 32% lack of/inadequate health insurance
    - ▣ 28% "language barriers"

# From recent screening/education event

- Event held in Chinatown, presentations in Mandarin
- 100% (24) participants foreign-born ethnic Chinese (China, Indonesia, Vietnam, Hong Kong)
- Generally low income, low education
- 100% reported no regular medical provider
- None reported previous HBV testing or immunization
- 2/24 (8%) HBsAg+ at screening
- 4/24 still susceptible (HBsAg-, anti-HBs-)

# What next?

- Make getting the health of infected mothers a priority

AND

- Collect data, document barriers, publish results
  - Barriers to public health research
    - \$\$\$, privacy, expertise

# Other research priorities

- Predictors of failure after perinatal prophylaxis
- Effectiveness of anti-viral treatment during pregnancy
  - Transmission
  - Mother's infection
- Provider education needs
  - Hep B vaccine birth dose
  - Managing chronic infection