B

Informed

Hep B United National Summit Making More **NOISE**!

INSIDE

- 2 CDC Updates HBV Recommendations for Health Care Workers
- 5 B Informed Patient Conference for Parents
- 6 HBF Receives CDC Grant
- **7** Loss of an Older Brother



Cause for a Cure

The Hepatitis B Foundation is a national nonprofit organization dedicated to finding a cure and improving the quality of life for those affected by hepatitis B worldwide through research, education and patient advocacy.

With nearly 1 in 10 Asian-Americans suffering from chronic hepatitis B—and the incidence of hepatitis-related liver cancer rising in the United States—there is a critical need to combat this hidden epidemic. Thus, the Hepatitis B Foundation (HBF) and the Association of Asian Pacific Community Health Organizations (AAPCHO), with the support of the U.S. Department of Health and Human Services' (HHS) Office of Minority Health, launched *Hep B United* this year as a new national campaign to highlight hepatitis B and liver cancer.

"The primary purpose of *Hep B United* is to develop a community response to the hepatitis B–related goals of the HHS Hepatitis Action Plan. The campaign will empower local coalitions that are working to increase prevention, screening, and access to care and treatment, particularly for Asian communities disproportionately impacted," said **Joan Block**, HBF executive director.

The first *Hep B United* National Summit was held August 7-8, 2012, at the HBF's headquarters in Doylestown, PA, in partnership with AAPCHO. Key federal partners and leaders from 14 community coalitions across the United States were convened to develop a strategic road map to optimize the efforts of local coalitions and strengthen partnerships with federal agencies to reduce the burden of hepatitis B.

"Hep B United aims to increase coordination of federal plans for enhancing private-public partnerships to address hepatitis B. We also want to implement joint federal and local efforts to advance the HHS Hepatitis Plan,"



Hep B United's First National Summit, led by **Dr. Moon Chen**, professor at UC Davis Cancer Center and director of AANCART, **Jeff Caballero**, executive director of AAPCHO, and **Joan Block**, executive director of HBF (Aug. 7-8, 2012).

explained **Jeff Caballero**, executive director of AAPCHO. "The goal is to strengthen local coalitions' capacity," he emphasized.

A rousing kickoff for the summit was given by **Moon Chen**, **PhD**, **MPH**, professor at UC Davis Cancer Center and director of the Asian American Network for Cancer Awareness and Research and Training (AANCART). "First, we need to make more NOISE," exhorted Dr. Chen.

"We have to recognize the need, opportunity, importance, sustainability, and endurance for addressing hepatitis B," Dr. Chen explained. "Just as smallpox was eradicated, we also now have the same parallels for success for hepatitis B. With the current political support and a good vaccine and effective treatments, eradication of hepatitis B is do-able, and opportunities like this only come once in a while."

Continued on page 3

Remembering R. Palmer Beasley, MD. Read more on page 3



From the Editor's Desk

Joan M. Block, Co-Founder and Executive Director

Pillars of Strength

The two biggest giants in the hepatitis B arena have unquestionably been Nobel Laureate **Dr. Baruch Blumberg**, who discovered the hepatitis B virus, and **Dr. R. Palmer Beasley** (page 3), who proved the virus could be transmitted from mother to newborn and definitively linked the virus to primary liver cancer.

As observed by HBF president **Dr. Timothy Block** during the ceremony where Dr. Beasley was presented with our 2010 Distinguished Scientist Award, "We are honored to have the two big B's in hepatitis with us tonight—Drs. Beasley and Blumberg—who together represent the two pillars upon which all current hepatitis B science and medicine is based."

While the hepatitis B community mourns the passing of these two remarkable pioneers, we continue to build on their legacy to achieve their goal—the elimination of hepatitis B.

To this end, our research is focused on finding a cure and developing early detection biomarkers for liver cancer. We co-organized with AAPCHO the first *Hep B United* National Summit (front page), and focused our annual *B Informed Patient Conference* on the needs of children with hepatitis B (page 5). Our public health program received a major boost of confidence and funds from a CDC grant (page 6), and the urgency of our mission is highlighted by the poignant story of one family's loss (page 7).

Building on the collective accomplishments of Drs. Blumberg and Beasley, the two strongest pillars of our community, we recognize more must still be done, but we are proud that progress is being made.

PLEASE HELP US SAVE LIVES!

We will be screening 1,000 at-risk individuals for hepatitis B. But we need your help to cover the lab costs. Please donate to our **2012 Annual Fund Appeal**. *Thank you!*



We are a national nonprofit organization dedicated to finding a cure and improving the quality of life for those affected by hepatitis B worldwide.

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In the News

CDC Updates Recommendations for Health Care Workers and Students with HBV

On July 6, 2012, the CDC updated its 1991 recommendations for the management of hepatitis B—infected health care workers and students. Based on the medical advances over the past 20 years, the new recommendations state that HBV infection alone should not disqualify someone from studying or practicing a health care profession. Patients do not need to be informed of a health care worker's infection status, and an expert review panel should monitor infected health care professionals as needed, with infectivity determined by viral load rather than e-antigen status. HBF is proud to have played a major role in advocating for these updated recommendations (see Spring 2012 *B Informed* at *hepb.org/newsletter*). The CDC recommendations are available at *cdc.gov/mmwr/pdf/rr/rr6103.pdf*.

CDC Recommends HCV Testing for Boomers

All U.S. baby boomers should get a one-time test for the hepatitis C virus, according to the CDC. One in 30 baby boomers—the generation born between 1945 and 1965—has been infected with hepatitis C, and most don't know it. The CDC estimates that the new recommendation could identify more than 800,000 additional people with hepatitis C. Read more at cdc.gov/nchhstp/newsroom/2012/HCV-Testing-Recs-PressRelease.html.

Hep B United National Summit

With encouragement to make more NOISE, the two-day *Hep B United* Summit got off to a fast start. On the first day, the group was challenged with the question, "What can be done better as *Hep B United* rather than alone?" This provided a clear focus for the vigorous discussions, sharing of experiences and promising practices, and breakout sessions.

The summit was organized around three of the six topic areas outlined in the HHS Hepatitis Action Plan: community and provider education, screening and linkage to care, and elimination of vaccine-preventable hepatitis. The goal was to coordinate the *Hep B United* road map with the HHS plan, which will help ensure the sustainability and endurance of local and national efforts around hepatitis B.

As a national community-based response to the HHS Hepatitis Plan,



First Hep B United National Summit held August 7-8, 2012, at the HBF in Doylestown, PA. Attendees included representatives from the Hepatitis B Foundation, Association of Asian Pacific Community Health Organizations, key federal agencies, and leaders from 14 community coalitions across the United States. For a full listing of the coalition partners, see *hepbunited.org*.

Hep B United's strategic road map will serve to optimize limited resources, empower and build the capacity of local hepatitis B coalitions, and strengthen federal partnerships. Additionally, the road map will facilitate public-private partnerships and leverage synergies and opportunities to increase testing, vaccination, and linkage to care efforts. These actions are needed to help reduce

the burden of, and ultimately eliminate, hepatitis B.

"We can do so much more together than alone, which is why *Hep B United* is an important next step in the national fight against hepatitis B and liver cancer," said Ms. Block.

For more information about *Hep B United* and to find local hepatitis B coalitions across the country, visit *hepbunited.org*.

Remembering Dr. R. Palmer Beasley:

A Giant in Hepatitis B Research

The Hepatitis B Foundation mourns the passing of **R. Palmer Beasley, MD**, a true loss to the global hepatitis B community. Dr. Beasley's groundbreaking research in hepatitis B and his numerous scientific contributions included the identification of mother-to-infant transmission and the fatal link between HBV and liver cancer.

Through decades-long research conducted in Taiwan, Dr. Beasley and colleagues showed that the hepatitis B vaccine could successfully prevent the spread of the virus and, therefore, the liver cancer that it caused. He worked tirelessly to persuade the World Health Organization to include the HBV vaccine

in its global recommendations for immunizations, thereby saving millions of lives worldwide.

Dr. Beasley was the Ashbel Smith Professor and Dean Emeritus at the University of Texas School of Public Health. He also served as chair of the Institute of Medicine (IOM) committee that published the landmark IOM report on Hepatitis and Liver Cancer in 2010.

In recognition of his scientific research and advocacy efforts, Dr. Beasley was awarded the King Faisal International Prize in Medicine, the Charles S. Mott Prize, and the Maxwell Finland Award for Scientific Achievement.

In 2010, Dr. Beasley received the



R. Palmer Beasley (right) and **Baruch Blumberg** (left) enjoy a light moment during the HBF's 2010 award ceremony honoring Dr. Beasley.

Hepatitis B Foundation's Distinguished Scientist Award. At the award ceremony, Nobel Laureate **Dr. Baruch S. Blumberg,** who discovered the hepatitis B virus, observed that "there are at least a million people alive today who would otherwise not be here if not for Dr. Beasley's pioneering research in hepatitis B."

HBF Drug Watch

HBV Compounds in Development

www.hepb.org/drugwatch

egasys (PegInterferon alfa-2a) Immunomodulator Genentech, South San Francisco, CA www.gene.com FDA Appr UCLEOSIDE ANALOGUES Interfere with the viral DNA polymerase enzyme used for hepatitis B virus reproduction Divir-HBV (Lamivudine) Inhibits viral DNA polymerase GlaxoSmithKline, Phila., PA www.gsk.com FDA Appr Repsera (Adefovir Dipivoxil) Inhibits viral DNA polymerase Gilead Sciences, Foster City, CA www.gilead.com FDA Appr Reraclude (Entecavir) Inhibits viral DNA polymerase Bristol-Myers Squibb, Princeton, NJ www.bms.com FDA Appr Rezeka (Telbivudine) Inhibits viral DNA polymerase Novartis, Switzerland www.novartis.com FDA Appr Rerad (Tenofovir) Inhibits viral DNA polymerase Gilead Sciences, Foster City, CA www.gilead.com FDA Appr								
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Sincere thanks to **Timothy Block, PhD** (Drexel U. College of Medicine, Philadelphia, PA), **Nat Brown, MD** (Presidio, San Francisco, CA), **Brent Korba, PhD** (Georgetown U. Medical Center, Rockville, MD), and **Raymond Schinazi, PhD** (Emory U. Medical School, Atlanta, GA) for their regular review of the HBF Drug Watch.

For More Information...

- HBV Clinical Trials @ www.hepb.org/clinicaltrials
- Resource Round-Up @ www.hepb.org/resources
- Hepatitis B Info and Support List @ www.hblist.org
- HBV Adoption Support List @ http://health.groups.yahoo.com/group/hbv-adoption/

HBF at the Forefront

B Informed Patient Conference Focuses on Parents and Children

Maureen Kamischke, HBF Social Media Manager

The Hepatitis B Foundation's *B Informed Patient Conference* was held May 19th in Philadelphia, PA, and was a wonderful opportunity for parents of kids with HBV to hear from pediatric medical experts in the field. It was also a great opportunity to forge lasting relationships with other parents dealing with the same concerns. I couldn't help but be impressed with a parent who spent 10 hours on a bus, each way, to make it to the conference. Clearly, she wanted to be there!

Two nationally renowned pediatric liver specialists—Karen Murray, MD, of Seattle's Children's Hospital, and Barbara Haber, MD, formerly of Children's Hospital of Philadelphia—presented medical updates to the more than 60 parents attending. Dr. Haber covered the global burden, transmission, vaccination, and monitoring of HBV. Dr. Murray focused on management and treatment, which included sharing that pediatric clinical trials are under way through the NIH HBV Clinical Research Network.

Treatment is always a hot-button issue for parents. There are worries about kids in the immune tolerant stage (e.g., high ALT and DNA levels) who are not usually treated, concerns with starting and stopping antivirals in kids, and the side effects of interferon therapies. Both doctors addressed parents' concerns about their kids' risk of liver cancer as they progress into adulthood.

W. Thomas London, MD, HBF board member and medical advisor, and one of the world's leading HBV experts, joined Drs. Haber and Murray during the "Ask the Experts" panel discussion. They answered parents' questions about nutrition (there is no special diet and multivitamins are fine, but mega-vitamins are not) and the use of over-the-counter drugs (ibuprofen and acetaminophen are



Maureen Kamischke, HBF social media manager, and **Eileen Beck**, HBF volunteer, assist at the Hepatitis B Foundation's Patient Conference (*May 19, 2012*).

usually fine, but caution is needed when combining OTC drugs that may contain acetaminophen). Parents wanted to know about monitoring, since adoptive children have no family records, and therefore do not know if they are at increased risk for liver cancer. The panel agreed that monitoring every six months or even once a year was adequate based on their child's liver health.

Paul Cohen, Esq, Jenei & Cohen, P.C., spoke to parents about the legal aspects of disclosure, especially on school health forms and camp registrations, which is a huge concern for parents. He explained that court decisions about what and whether to disclose vary from state to state and even from district to district. Disclosure, therefore, remains a private family issue, and parents need to think carefully before revealing their child's medical information.

A session led by **Carol Cobb-Nettleton**, **DSW**, gave parents an opportunity to share their personal experiences and challenges, including the loneliness some feel and the differences between families with children who are being treated and families with children who are not.

Since 2001, the HBF's annual *B Informed Patient Conference* continues to be the

only national meeting that brings together patients and families affected by hepatitis B. This year, the focus on parents provided a wonderful opportunity for folks to connect with others who share the same fears and hopes, and in the process to form lasting friendships.

The expert medical presentations from the 2012 Patient Conference are available at *youtube.com/hepbfoundation*.

Editor's Note: Download the national pediatric recommendations for the screening, care, and treatment of children with HBV that were developed by the Hepatitis B Foundation with an expert panel of the nation's leading pediatric liver specialists and published in Pediatrics and Hepatology at hepb.org/patients/children_and hepatitis b.htm.

2012 Bruce Witte Distinguished Lecturer



Snorri S. Thorgeirsson, MD, PhD, (far right) delivered the HBF's 11th annual Bruce Witte Lecture on June 8, 2012. As head of the Center of Excellence in Integrative Cancer Biology and Genomics, National Cancer Institute, NIH, Dr. Thorgeirsson is a leader in the field of liver cancer. His presentation, "Deconstructing Liver Cancer: From Genome to Stem Cells", was well received by the audience, which included HBF co-founders Paul and Janine Witte (center), who established the named lecture in honor of Paul's son in 2001.



What Does the ACA Mean for the Hepatitis B Community?

Alyson Haywood Lewis, Madison Associates, Washington, D.C.

In a historic ruling on June 28, 2012, the U. S. Supreme Court upheld the Patient Protection and Affordable Care Act, the 2010 health care reform law commonly referred to as the ACA. The law's goals are to increase the number of Americans covered by health insurance and provide new protections for people who have health insurance.

Although the ACA continues to be a controversial political issue, many provisions have already been implemented and others are scheduled to go into effect in 2014.

What does the ACA provide?

Some ACA provisions already in place include extending coverage for young adults on their family insurance plans up to age 26 years, prohibiting the denial of children's coverage for pre-existing conditions, and ending lifetime and most annual dollar limits on care. ACA also gives patients free access to recommended prevention services, such as mammograms and colon cancer screenings.

In 2014, other provisions will take effect, including the individual mandate,

which requires all Americans to obtain health insurance or pay a tax penalty. States are required to establish health care "exchanges," where people may buy health insurance.

What is the impact of the ACA for people with hepatitis B?

Many of the provisions included in the ACA will greatly benefit Americans infected with hepatitis B, especially the provision that will bar insurance companies from discriminating based on preexisting health conditions. The ACA also expands Medicaid eligibility, invests

"The PPH Fund ... offers the most promise for the hepatitis B community."

in community health centers, and provides funding to broaden the health care workforce. However, it is the Prevention and Public Health (PPH) Fund that offers the most promise for the hepatitis B community.

What is the Prevention and Public Health (PPH) Fund?

The PPH Fund was established to expand prevention and public health programs. The Fund aims to both improve health and limit health care costs by allowing patients to see their health care professionals earlier, rather than waiting for treatment until they are sicker and care is more expensive. The legislation appropriates more than \$15 billion for prevention activities over the next 10 years. The Department of Health and Human Services (HHS) released \$500 million in PPH funds in 2010; another \$750 million was released in 2011, and \$1 billion was released in 2012.

What about hepatitis prevention projects?

The expanded coverage provided by the ACA will help with the screening, testing, and vaccination components in the HHS National Viral Hepatitis Action Plan. Americans who are currently uninsured or underinsured will gain greater access to comprehensive prevention and treatment services for viral hepatitis.



HBF Receives \$125,000 CDC Grant Award for Screening Project

The Hepatitis B Foundation is pleased to announce a \$125,000 CDC grant award to support its public health program in Philadelphia. We were selected, along with Seattle, as one of two demonstration sites in the United States to document our education, screening, and linkage to care efforts.

The CDC grant will help us further build on the success of our citywide coalition—*Hep B United Philadelphia*—that was established in 2010. A key aspect of this CDC collaboration involves continued engagement with community and city leadership to improve access to care for both prevention and

treatment, particularly for underserved high-risk groups, such as Asian Pacific Islanders and African immigrants.

Over the next 12 months, the HBF will work with local coalition partners to screen 1,000 high-risk adults and navigate people into care for either vaccination or medical evaluation. We will share our best practices with the CDC as it develops guidelines for other groups across the United States to use in the future.

For more information on *Hep B United Philadelphia* and its more than 60 coalition partners, visit *hepbunitedphiladelphia.org*.

Speaking Personally

Preventable Loss of an Older Brother

John Moon

A frantic call from my sister-in-law shattered what would have otherwise been an enjoyable Labor Day weekend in 2010. She anxiously told me that my brother, Dan, would be undergoing an emergency procedure on his liver.

Dan had gone to the ER because of acute abdominal pain, which had been bothering him, along with nausea, for the past several months. This time, the doctors finally took an X-ray and found a large lump in his liver. Ultimately, they decided not to operate, but to wait until after Labor Day to conduct more extensive tests.

This was the beginning of the most heart-wrenching six months for our family.

On Tuesday, the doctors informed us of the worst: Dan had stage four liver cancer that was inoperable. He had about six months to a year to live. The news was devastating and totally unexpected, since Dan was an otherwise very healthy 47-year-old architect, avid skier, husband, and father of an 18-year-old son.

We had no idea he had chronic hepatitis B, which the doctors explained was the likely cause of his cancer. The next six months for our family were a blur of raw emotions, anguish, false hopes followed by deeper disappointment, and an outpouring of love. It was hardest for my parents, who had immigrated to the United States 37 years ago from Korea to give their children a better life.

For me, it was the most intense period of my life as I saw the older brother whom I loved—the one who taught me how to ride a bike, who always gave me thoughtful Christmas gifts, and so many other fond memories—physically deteriorate so quickly. Yet he fought on and remained optimistic for us during that excruciating period.

On March 6, 2011, Dan passed away surrounded by our loving family.

Naturally, my thoughts went to how his death could have been prevented. The more I found out about the lack of public awareness of hepatitis B, the more anguished I became knowing that Dan's death could have been delayed or prevented.

There was a total lack of awareness by both Dan's physicians and our family. Dan had had regular physical examinations during his 40s, but had never been tested for hepatitis B, although we were in a high-risk category because we had immigrated from Korea.

Dan had developed the classic symptoms of liver disease (fatigue, lack of appetite, abdominal pain) as early as



The author (left) with his older brother Dan.

nine months previously. Yet his doctors misdiagnosed him, even though these were telltale symptoms and he was in a high-risk category. Our family also did not know of our high-risk status, so we could not be effective patient advocates.

As a result, I have taken an active role to improve public awareness and knowledge of this devastating disease. I share our family's story with the hope that through greater awareness among the physician and Asian Pacific Islander communities, those at risk may be better diagnosed and have better access to preventive treatment.

Through this, I hope that the loss of my brother could have some redemptive value so that other families do not have to experience this tragedy.

PLEASE GIVE GENEROUSLY TO OUR ANNUAL FUND

so that we can continue our mission to find a cure and help affected families worldwide. **Thank you!**

Giving	hope to	millions	is as e	asy as	giving	and	we've	made
it even	easier.	Donate o	nline a	at www	.hepb.	org.		

Yes! I want to support the Hepatitis B Foundation's Cause For A Cure! Enclosed is my tax-deductible gift.

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Name	
Address	
	StateZip
Please charge my gift to my credit card:	☐ MasterCard ☐ Visa
Card #	3-Digit Security Code*
Name on card	Exp. Date
Signature	

*Located on back of credit card; we cannot process your donation without this number!

Make check payable to Hepatitis B Foundation and mail to: 3805 Old Easton Road, Doylestown, PA 18902

Contributions will be acknowledged in our annual report unless otherwise requested.

A copy of the official registration and financial information may be obtained by calling the Pennsylvania Department of State toll-free within PA at 800-732-0999 or out-of-state at 717-783-1720. Registration does not imply endorsement.

Calendar of Events 2012-2013

2012

The Liver Meeting 2012 Nov. 9-13

> American Association for the Study of Liver Diseases (AASLD)

Hynes Convention Center

Boston, MA www.aasld.org

Dec. 5-8 **Asian Pacific Digestive Week**

Congress Gastroenterological

Association of Thailand

Queen Sirikit National Convention Center

Bangkok, Thailand http://apdw2012.org

2013

March 7-10 APASL Conference 2013

Asian Pacific Association for

the Study of the Liver

Suntec Singapore International Convention Centre, Singapore www.apaslconference.org

The International Liver Congress 2013 April 24-28

European Association for the Study

of the Liver (EASL) **RAI** Convention Centre Amsterdam, The Netherlands

www.easl.eu

Digestive Disease Week (DDW) 2013 May 18-21

AASLD, AGA, ASGE, SSAT

Orange County Convention Center

Orlando, FL www.ddw.org

May 19 National Hepatitis Testing Day

Centers for Disease Control and Prevention

Activities across the USA www.cdc.gov/hepatitis

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Dr. R. Palmer Beasley **нешешрекид**



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