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,” 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 AANCART, and Joan Block, executive director of HBF (Aug. 7-8, 2012).

“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
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 Dr. Beasley (page 7), we recognize more must still be done, but we are proud that progress is being made.

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 hepbox.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.

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!
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 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.”

Hepatitis B Foundation’s 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, 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 hep bunited.org.
## HBV Compounds in Development

### FAMILY/DRUG NAME | MECHANISM | COMPANY | WEBSITE | STATUS, USA
--- | --- | --- | --- | ---
**INTERFERONS**
Pegasys (Pegasys 2a) | Immunomodulator | Genentech, South San Francisco, CA | www.gene.com | FDA Approved 2005
**NUCLEOSIDE ANALOGUES**
Epivir-HBV (Lamivudine) | Inhibits viral DNA polymerase | GlaxoSmithKline, Phila., PA | www.gsk.com | FDA Approved 1998
Hepsera (Adefovir Dipivoxil) | Inhibits viral DNA polymerase | Gilead Sciences, Foster City, CA | www.gilead.com | FDA Approved 2002
Baraclude (Entecavir) | Inhibits viral DNA polymerase | Bristol-Myers Squibb, Princeton, NJ | www.bms.com | FDA Approved 2005
Tyzeka (Telbivudine) | Inhibits viral DNA polymerase | Novartis, Switzerland | www.novartis.com | FDA Approved 2006
Viread (Tenofovir) | Inhibits viral DNA polymerase | Gilead Sciences, Foster City, CA | www.gilead.com | FDA Approved 2008
Clevudine (Levovir) | Inhibits viral DNA polymerase | Bukwang, Seoul, Korea | www.bukwang.co.kr | Approved in S. Korea
MIV-210 | Inhibits viral DNA polymerase | Medivir/Daewoong, S. Korea | www.daewoong.com | Phase II
Amdoxovir (DAPD) | Inhibits viral DNA polymerase | RFS Pharma LLC, Tucker, GA | www.RFSpharma.com | Phase II
Baraclude (Entecavir) | Inhibits viral DNA polymerase | Bristol-Myers Squibb, Princeton, NJ | www.bms.com | FDA Approved 2005
**NUCLEOSIDE ANTI-VIRALS**
Epivir-HBV (Lamivudine) | Inhibits viral DNA polymerase | GlaxoSmithKline, Phila., PA | www.gsk.com | FDA Approved 1998
Hepsera (Adefovir Dipivoxil) | Inhibits viral DNA polymerase | Gilead Sciences, Foster City, CA | www.gilead.com | FDA Approved 2002
Baraclude (Entecavir) | Inhibits viral DNA polymerase | Bristol-Myers Squibb, Princeton, NJ | www.bms.com | FDA Approved 2005
Tyzeka (Telbivudine) | Inhibits viral DNA polymerase | Novartis, Switzerland | www.novartis.com | FDA Approved 2006
Viread (Tenofovir) | Inhibits viral DNA polymerase | Gilead Sciences, Foster City, CA | www.gilead.com | FDA Approved 2008
Clevudine (Levovir) | Inhibits viral DNA polymerase | Bukwang, Seoul, Korea | www.bukwang.co.kr | Approved in S. Korea
MIV-210 | Inhibits viral DNA polymerase | Medivir/Daewoong, S. Korea | www.daewoong.com | Phase II
Amdoxovir (DAPD) | Inhibits viral DNA polymerase | RFS Pharma LLC, Tucker, GA | www.RFSpharma.com | Phase II
AG X-1009 | Pro-drug of tenofovir | Agenix, Australia | www.agenix.com | Phase I, China
**NON-NUCLEOSIDE ANTI-VIRALS**
NOV-205 (Bam 205) | Small molecule | Novelos, Newton, MA | http://novelos.com | Approved in Russia
LB80380 (ANA830) | Inhibits viral RNA polymerase | LG Life Sciences, Seoul, Korea | www.lgs.com | Phase II
Myrcludex B | Entry inhibition | Myr-GmbH, Germany | www.myrgmbh.de | Pending
HAP Compound (Bay 41-4109) | Inhibits viral nucleocapsid | A/Curis, Germany | www.aicuris.com | Phase I
REP 9AC | HBsAg release inhibitor | REPLiCor Inc., Montreal, Quebec | www.replicor.com | Phase I
Alinia (Nitazoxanide) | Small molecule | Romark Labs, Tampa, FL | www.romark.com | Pre-clinical HBV
**NEW!** ARC520 | RNAi gene silencer | Arrowhead Research, Pasadena, CA | arrowheadresearch.com | Preclinical
**NON-INTERFERON IMMUNE ENHANCERS**
Zadaxin (Thymosin alpha-1) | Immune stimulator | SciClone, San Mateo, CA | www.sciclon.com | Orphan drug approval in U.S. for liver cancer
CYT107 (Interleukin-7) | Immunomodulator | Cytheris, Paris, France | www.cytheris.com | Phase I/IIA
DV-601 | Therapeutic vaccine | Dynavax, Berkeley, CA | http://dynavax.com | Phase I
HBV Core Antigen Vaccine | Therapeutic HBV vaccine | Emergent Europe, UK | www.ebse.com | Phase I
**NEW!** GS9260 | TLR7 agonist | Gilead Sciences, Foster City, CA | www.gilead.com | Phase I
**NEW!** GI13000 | HBV antigen | GlobeImmune, Louisville, CO | www.globeimmune.com | Preclinical with Gilead
**POST-EXPOSURE AND/OR POST-LIVER TRANSPLANT TREATMENT**
HyperHEP S/D | HBV immunoglobulin | Talecris, RTP, NC | www.talecris.com | FDA Approved 1977
Nabi-HB | HBV immunoglobulin | Biotest, Boca Raton, FL | www.biotestpharma.com | FDA Approved 1999
HepaGam B | HBV immunoglobulin | Cangene, Ontario, Canada | www.cangene.com | FDA Approved 2006

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.
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 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.
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 pre-existing health conditions. The ACA also expands Medicaid eligibility, invests 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.

"The PPH Fund ... 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 hepunitedphiladelphia.org.
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 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.

Giving hope to millions is as easy as giving ... and we’ve made it even easier. Donate online at www.hepb.org.

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

Name__________________________________________________________
Address_______________________________________________________
City______________________________________________ State_____ Zip_____
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

Nov. 9-13 The Liver Meeting 2012
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

April 24-28 The International Liver Congress 2013
European Association for the Study of the Liver (EASL)
RAI Convention Centre
Amsterdam, The Netherlands
www.easl.eu

May 18-21 Digestive Disease Week (DDW) 2013
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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B Informed and all back issues are available online at www.hepb.org/newsletters.

Remembering
Dr. R. Palmer Beasley