THE NEWSLETTER OF THE HEPATITIS B FOUNDATION FALL 2016

B INFORMED

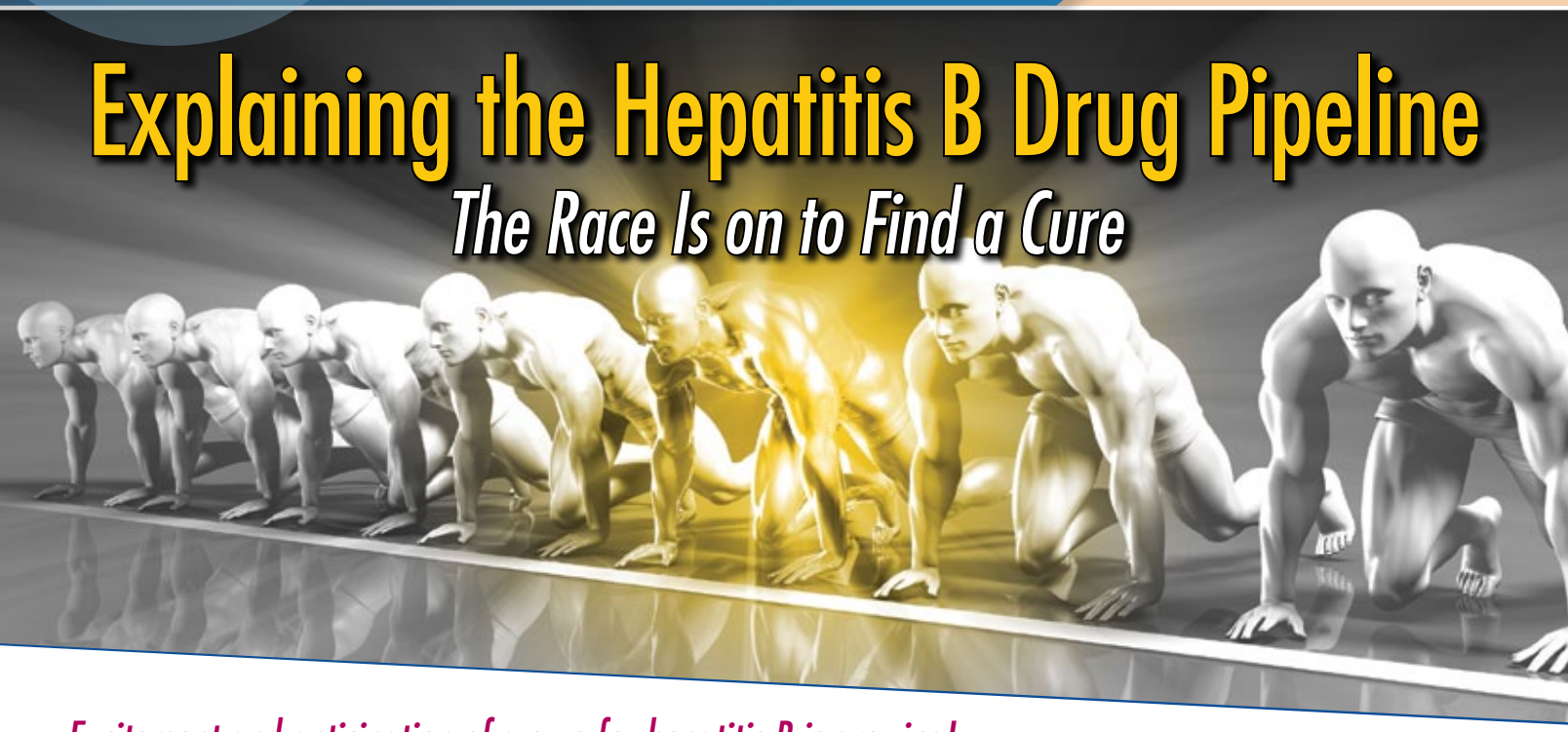
No. 70

INSIDE THIS ISSUE:

4 HBV Drug Watch Explodes
5 Hepatitis Delta Connect
6 Double the Federal Funding!
7 My Untold Story

Explaining the Hepatitis B Drug Pipeline

The Race Is on to Find a Cure



Excitement and anticipation of a cure for hepatitis B is growing!

This is due, in large part, to the success of hepatitis C being curable. Today the race is now on for the growing number of hepatitis B drugs in the pipeline to become the next cure.

We all want a cure, but the hepatitis B virus (HBV) is complicated and even the definition of 'cure' is being debated. A 'clinical cure' can be defined as *returning an individual with chronic HBV to the risk of serious liver disease to that of someone who has never been infected, or, at least, has had a 'resolved' infection.* But achieving that goal would take many years of therapy, so it is not practical to use it for evaluating a drug's effectiveness.

More realistic is a 'functional cure,' which declares success as *causing a sustained reduction in virus and other disease markers in the blood even after a drug is stopped.* In addition to suppressing or eliminating viral DNA, more ambitious goals for a functional cure call for loss of HBV surface antigen (HBsAg), appearance of HBV surface antibody (HBsAb), and silencing or eliminating cccDNA (covalently closed circular DNA), which is responsible for persistence of HBV infection even during prolonged antiviral therapy.

Suppression of these blood markers will most likely relate to, if not equal, a clinical cure and since these can be measured within years, if not months, of therapy, determining a drug's efficacy is possible. Whether or not all virological markers need to be stably suppressed to achieve meaningful clinical goals is being debated.

Although the approved oral antivirals do a good job of suppressing viral DNA levels, none of them reliably achieve the goal of 'functional cure.' They are also limited in achieving 'clinical cure' as defined above. Thus, there is still a need to develop new drugs that attack different pathways of the HBV life cycle to achieve a cure.

There are now more than 30 new HBV drugs in the pipeline that are different from the currently approved therapies (interferons and nucleos(t)ides). In general, the new drugs being developed to treat HBV can be divided into two general categories: direct acting that target the virus and indirect acting that target the human host.

Continued on page 3

*HBF celebrates **25 years** and is making hepatitis B history!* *Read more on page 8*

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.

Joan M. Block, Co-Founder and Executive Director

From the Editor's Desk

The People Challenge

The explosion in drug discovery around hepatitis B is truly exciting, yet challenging, with more than 30 new hepatitis B drugs in the pipeline. There is great expectation, and great optimism that highly effective new therapies will be available to manage chronic HBV infection over the next five years.

One of the most serious challenges in the development of new therapies, however, is finding people for the clinical trials. The problem seems paradoxical. There are more than 240 million people chronically infected with HBV worldwide, of which 2 million live in the U.S. But identifying those eligible and willing to enter clinical trials is a significant obstacle.

In the U.S., most patients do not know they are infected, and those who have been diagnosed are generally being treated already. Outside the U.S., the barriers are identifying patients and finding providers or medical centers that are able to conduct rigorous clinical trials.

To ensure the success of future hepatitis B clinical trials, programs are needed to improve hepatitis B screening and care. For example, *Hep B United*, the national coalition we started in 2012 that is focused on building community coalitions to increase screening rates (p. 6), and our new *Patient Storytelling Campaign* that is working with groups to use personal stories to raise the visibility of hepatitis B in high-risk communities and, thereby, stimulate testing (p. 5).

For the past 25 years, the Hepatitis B Foundation has found success in overcoming obstacles through partnerships. To paraphrase an African proverb, *"To go fast, go alone; to go further, go together."* Working together will be the key to solving the current people challenge for moving promising hepatitis B drugs into human clinical trials … and ultimately, a cure.

NEWS IN THE NEWS

HBF Congratulates Michael Sofia on the 2016 Lasker-Debakey Award!

The Hepatitis B Foundation is proud to recognize **Michael J. Sofia, PhD**, who received the ***2016 Lasker-DeBakey Clinical Medical Research Award*** for his role in the discovery of the cure for chronic hepatitis C. The Lasker Awards rank among the world's most celebrated scientific honors for biomedical research; in fact, 87 past Lasker awardees have gone on to receive the *Nobel Prize*.

Dr. Sofia received the *2016 Lasker-DeBakey Award* with **Charles Rice, PhD**, of Rockefeller University and **Ralf Bartenschlager, PhD**, of Heidelberg University, who were recognized for their work in developing systems essential to hepatitis C research. Dr. Sofia used these systems in developing his drug, sofosbuvir (Sovaldi®), while at Pharmasset, which was acquired by Gilead. His drug is now the backbone of Harvoni®, a 12 week course of treatment that cures almost 100% of HCV patients.

Today, Dr. Sofia has turned his attention to the unmet need of hepatitis B through his work as co-founder and chief scientific officer of Arbutus Biopharma, a company focused on HBV drug discovery. He also serves as a resident adjunct professor of the Baruch S. Blumberg Institute of the Hepatitis B Foundation. *"Hepatitis B is difficult, but we and the Blumberg Institute have brought together some of the best scientists in the world to achieve this goal. We have put the hepatitis B virus in our cross hairs, and we won't let it get away,"* he said.

The cure for hepatitis C is one of the greatest medical advances of our lifetime and Dr. Sofia is deserving of the 2016 Lasker Award. We now look forward to his encore for hepatitis B! Read more at *scientificamerican.com* and search '*2016 Lasker Award.*'

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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.

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Layout & Design: CP Printing Solutions

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Continued from page 1

Explaining the Hepatitis B Drug Pipeline

With more than 30 new HBV drugs in the pipeline, there is great hope that a 'functional' cure, if not a 'clinical' or complete cure, will be achieved through one of these promising strategies. This article provides a brief overview of the new direct acting (target the virus life cycle) and indirect acting (target the human host functions) drugs being pursued for hepatitis B.

NEW Direct Acting Antivirals

A greater understanding of the hepatitis B virus and proteins has enabled efforts to develop multiple direct-acting antivirals (DAAs), which are drugs targeted at specific steps within the HBV life cycle.

siRNA is short for "silencing" RNA, which are nucleotide drugs that interfere and cause the destruction of the viral RNA. Without viral RNA (which comes from cccDNA) there is no production of viral proteins. Thus, no RNA and no protein means no virus.	ARC-520 and 521 ARB-1467 ALN-HBV Hepbarna ARB 1740 Lunar-HBV
Tenofovir (TDF) Prodrugs are modified polymerase inhibitors (called 'NUCS') designed to get into the liver cells more easily and inhibit HBV. It is expected that TDF prodrugs will be used at lower doses with more suppression compared to current NUC drugs.	TAF CMX157
Entry Inhibitors interfere with HBV getting into liver cells via attachment to a specific viral protein called 'preS1' and a specific liver cell protein. Myrcludex B is the first drug that looks like preS1 and interferes with HBV attachment to the liver cell.	Myrcludex B
Capsid Inhibitors interfere with viral capsid formation, which is the protein shield that covers and protects the viral DNA. The capsid is made of pairs of HBV 'core' proteins or antigens, also called 'HBcAg,' which is needed to produce infectious virus.	NVR 3-778 GLS4 AIC 649 CpAMS AB-423
sAg Inhibitors interfere with the production of HBV surface antigen (HBsAg), which is needed for the virus to enter and exit the liver cell. HBsAg is found in the blood of most infected people and is, therefore, thought to play a role in maintaining the state of chronic infection by suppressing the immune system.	Rep 2139 Arbutus RO7020322 Blumberg 259
cccDNA inhibitors are considered the 'holy grail' for a cure, but remain very challenging. The chromosome of HBV persists in the nucleus of the infected liver cell as a small cccDNA molecule, which is the natural source of all HBV gene products. It lasts for a very long time, even after NUC drugs appear to be effective in suppressing the virus.	Arbutus
CRISPR/cas and "TALEN" are genome editing systems, which due to their low cost and simplicity have become powerful new tools for discovery. For HBV, these systems can be used to attack and destroy the cccDNA. A problem with these systems is getting them into the infected viral cell nucleus because they are not 'small molecule' drugs.	Cellectis Editas Intellia

NEW Indirect Acting Antivirals

The hepatitis B virus uses the human body as its host to grow, so indirect acting antiviral drugs are being developed that target host functions.

Therapeutic Vaccines use vaccine technology for treatment rather than prevention. These 'vaccines' are being used to stimulate immunity as a potential therapy since people living with HBV do not appear to have an effective immune response to the virus.	GS 4774 INO-1800 TG 1050 HepTcell TomegaVax HBV
TLR Agonists are targeting the 'toll-like receptors,' which are the 'sensors' that detect infectious agents and tell the cell to defend itself. A TLR 'agonist' is a drug that activates our innate immune system, which is our body's first line of defense against an infection.	GS 9620 RG7795 Arbutus
STING is an innovative approach that shows a small molecule 'Stimulator of Interferon Genes' can eliminate all detectable viral gene products. This has been done in tissue culture, which was confirmed by a small animal study.	Arbutus Blumberg Institute
SMAC Mimetics are a new class of drugs designed to induce programmed cell death (or 'apoptosis'). Use of this mechanism means HBV infected liver cells might be able to be pushed into apoptosis more easily than uninfected cells.	Birinapant
Cyclofillin Inhibitors are based on cyclophillins, a family of host cell proteins that help other proteins carry out their functions. They are also involved in the development of liver diseases such as HBV by helping the virus enter the liver cell. Inhibition of cyclophillins have been used to modify the immune system for therapeutic benefit and could be useful for HBV.	CRV 431

Combination is the Key

Most experts believe that a cure for HBV, functional or otherwise, will require at least two drugs. Perhaps a directing acting (DAA) will be taken with an indirect acting drug - the DAA will keep the virus suppressed while the immunomodulator 'educates' the immune system to recognize and take over suppression of the virus when the drugs are stopped.

Most logically, elimination of all markers, silencing cccDNA and loss of HBsAg with appearance of HBsAb, will come the closest to being a 'cure.' However, stable suppression of viral DNA after stopping a drug would be a big step forward, and if this is also accompanied by stable off-drug loss of HBsAg (and normalization of liver enzymes), the community would have lots to celebrate.

Although the future cannot be known, short duration of use, effective drugs that achieve at least a functional cure, and taken alone or in combination, are the goal and we are within reach of making hepatitis B history!

*Visit the **Hepatitis B Foundation Drug Watch** at www.hepb.org/drugwatch, which is followed by leaders in the field to monitor new drugs in the hepatitis B development pipeline.*

This article was written by Timothy M. Block, PhD, Co-Founder and President of the Hepatitis B Foundation and its Baruch S. Blumberg Institute

HBV DRUG WATCH

HBV Compounds in Development • FALL 2016

www.hepb.org/drugwatch

FAMILY/DRUG NAME	MECHANISM	COMPANY	WEBSITE	USA STATUS
Interferons	Mimic naturally occurring infection-fighting immune substances produced in the body			
Intron A *(Interferon alfa-2b)*	Immunomodulator	Merck, USA	merck.com	Approved 1991
Pegasys *(PegInterferon alfa-2a)*	Immunomodulator	Genentech, USA	gene.com	Approved 2005
Nucleos(t)ide Analogues	Interfere with the viral DNA polymerase enzyme used for hepatitis B virus reproduction			
Epivir *(Lamivudine)*	Inhibits viral DNA polymerase	GlaxoSmithKline (GSK)	gsk.com	Approved 1998
Hepsera *(Adefovir Dipivoxil)*	Inhibits viral DNA polymerase	Gilead Sciences, USA	gilead.com	Approved 2002
Baraclude *(Entecavir)*	Inhibits viral DNA polymerase	Bristol-Myers Squibb, USA	bms.com	Approved 2005
Tyzeka *(Telbivudine)*	Inhibits viral DNA polymerase	Novartis, Switzerland	novartis.com	Approved 2006
Viread *(Tenofovir)*	Inhibits viral DNA polymerase	Gilead Sciences, USA	gilead.com	Approved 2008
Levovir *(Clevudine)*	Inhibits viral DNA polymerase	Bukwang, S. Korea	bukwang.co.kr	Approved 2006 in S. Korea
Zadaxin	Immunomodulator	SciClone, USA	sciclone.com	Approved outside USA
DIRECT ACTING ANTIVIRALS	Targets the virus and interferes with specific steps in the HBV life cycle to prevent replication			
TDF Pro Drugs	Targets the virus and interferes with specific steps in the HBV life cycle to prevent replication			
TAF *(Tenofovir alafenamide)*	Prodrug of tenofovir	Gilead Sciences, USA	gilead.com	Phase III
CMX 157	Prodrug of tenofovir	ContraVir, USA	contravir.com	Phase II
Silencing RNA's (siRNAs)	Interferes and destroys viral RNA			
ARC 520	RNAi gene silencer	Arrowhead Pharmaceuticals, USA	arrowheadpharma.com	Phase II
ARB-1467	RNAi gene silencer (1.0)	Arbutus Biopharma, Canada	arbutusbio.com	Phase II
ARC 521	RNAi gene silencer	Arrowhead Pharmaceuticals	arrowheadpharma.com	Phase I
ALN-HBV	RNAi gene silencer	Alnylam, USA	alnylam.com	Preclinical
Hepbarna *(BB-HB-331)*	RNAi gene silencer	Benitec, Australia	benitec.com	Preclinical
ARB-1740	RNAi gene silencer (2.0)	Arbutus Biopharma	arbutusbio.com	Preclinical
Lunar-HBV	RNAi gene silencer	Arcturus, USA with Janssen of J&J	arcturusrx.com	Preclinical
Entry Inhibitors	Interferes with HBV getting into liver cells			
Myrcludex B	Entry inhibitor	Hepatera, Russia with MYR GmbH, Germany	myr-pharma.com	Phase II
Capsid Inhibitors	Interferes with the viral DNA protein shield			
Morphothiadin *(GLS4)*	Capsid inhibitor	HEC Pharma, PR China	pharm.hec.cn/en	Phase II
NVR 3-778	Capsid inhibitor	Janssen of J&J	janssen.com	Phase II
RO6864018	Undisclosed	Roche	roche.com	Phase II
AIC 649	Capsid inhibitor	AiCuris, Germany	aicuris.com	Phase I
JNJ56136379	Capsid inhibitor	Janssen of J&J	janssen.com	Phase I
HBV CpAM	Capsid inhibitor	Assembly Biosciences, USA	assemblybio.com	Preclinical
AB-423	Capsid inhibitor	Arbutus Biopharma	arbutusbio.com	Preclinical
HBsAg Inhibitors	Interferes with production of HBV surface antigen (sAg)			
Rep 2139	sAg inhibitor	REPLICor, Canada	replicor.com	Phase II
Rep 2165	sAg inhibitor	REPLICor	replicor.com	Phase II
RO7020322 *(RG7834)*	sAg inhibitor	Roche	roche.com	Phase I
Blumberg 259	sAg inhibitor	Blumberg Institute, USA	blumberginstitute.org	Preclinical
Antisense Molecules	Binds to the viral mRNA to prevent it from turning into viral protein			
IONIS-HBVRx *(GSK3228836)*	Viral protein inhibitor	Ionis Pharma with GSK	ionispharma.com	Phase I
IONIS-HBVLRx *(GSK33389404)*	Viral protein inhibitor	Ionis Pharma with GSK	ionispharma.com	Phase I
INDIRECT ACTING ANTIVIRALS	Targets the human immune system to attack the HBV virus			
Therapeutic Vaccines	Vaccine technology used to stimulate the immune system as a treatment			
GS 4774	Therapeutic vaccine	Gilead with GlobeImmune, USA	gilead.com	Phase II
INO-1800	Therapeutic vaccine	Inovio, USA	inovio.com	Phase I
HB-110	Therapeutic vaccine	Ichor, USA with Janssen	ichorms.com	Phase I
TG1050	Therapeutic vaccine	Transgene, France	transgene.com	Phase I
HepTcell	Therapeutic vaccine	Altimmune, USA	altimmune.com	Phase I
TomegaVax HBV	Therapeutic vaccine	TomegaVax, USA	tomegavax.com	Preclinical
Innate Immune Defense Pathway	Compounds that activate the innate immune system			
GS 9620	TLR-7 agonist	Gilead Sciences	gilead.com	Phase II
ARG7795 *(ANA773)*	TLR-7 agonist	Roche	roche.com	Phase II
SB9200	RIG -1 and NOD2 agonist	Spring Bank Pharmaceuticals, USA	springbankpharm.com	Phase II
Blumberg STING	STING agonist	Blumberg Institute	blumberginstitute.org	Preclinical
Host Acting Pathway	Compounds that induce programmed cell death (apoptosis)			
Birinapant *(TL32711)*	SMAC Inhibitor	TetraLogic, USA	tetralogicpharma.com	Phase I
EYP001	FXR agonist	Enyo Pharma, France	enyopharma.com	Phase I
CRV 431 *(CPI 431-32)*	Ciclofillin inhibitor	ContraVir	contravir.com	Preclinical
HEPATITIS DELTA VIRUS (HDV)				
Myrcludex B	Entry inhibitor	MYR-GmbH	myr-pharma.com	Phase II
Lonafarnib	Prenylation inhibitor	Eiger Biopharma, USA	eigerbio.com	Phase II
Pegylated interferon lambda	Immune response stimulator	Eiger Biopharma	eigerbio.com	Phase II
Rep 2139	HBsAg inhibitor	REPLICor	replicor.com	Phase II
ALN-HDV	RNAi gene silencer	Alnylam	alnylam.com	Preclinical

FOUNDATION AT THE FOREFRONT

Hepb.org Relaunches with a *NEW* Look!

The HBF is proud to unveil our new website, which has been redesigned to be mobile friendly and with a clean look and simple navigation. Our information remains as comprehensive and useful as ever, but we now feature new sections for easier accessibility: Newly Diagnosed, About Our Research Institute, Language Translations, Our Programs, and much more. For those who depend on our regularly updated *HBV Drug Watch*, Clinical Trials and Physician Directory, these pages are still available and growing. Our website is a work in progress and we welcome feedback from our readers!

Hepatitis Delta Connect Program Addresses Unmet Need

Hepatitis B Foundation HEPATITIS DELTA CONNECT An Online Patient Resource

Hepatitis delta is the deadliest form of viral hepatitis which occurs only in people already infected with hepatitis B. Yet, most people are unaware of the delta virus, let alone are being tested for it. Over the past 25 years, the HBF has helped reduce the burden of hepatitis B through its website, help lines and outreach programs. It is now time to also increase awareness about the need to test for hepatitis delta among hepatitis B patients since coinfection with this virus results in more serious and rapid liver damage. Our ***Hepatitis Delta Connect*** program will include a dedicated website, social media presence, webinars and other educational activities. **Visit *www.hepDconnect.org.***

HEPATITIS DELTA VIRUS (HDV) *FAST FACTS*

- There are 15 million people worldwide living with HDV
- Hepatitis B co-infection with HDV results in more serious and rapid liver damage
- The hepatitis B vaccine can prevent HDV
- HBV is most common in parts of Mongolia, Pakistan, Russia, Central Asia, Turkey, Africa, China, and South America
- There is no approved treatment for HDV, but there are 5 new promising drugs in human clinical trials. Visit us at *www.hepDconnect.org.*

NEW Hepatitis B Foundation Storytelling Campaign

The HBF recognizes that engaging community members in sharing their personal stories about hepatitis B is essential to reducing stigma, encouraging screening, and improving referral to care and services. The ***Hepatitis B Foundation Storytelling Campaign*** will use the real voices of everyday people living with or affected by HBV as a key component in our awareness and advocacy efforts. We will engage people to share their stories in short videos created during a digital storytelling workshop led by StoryCenter (formerly the Center for Digital Storytelling, a nonprofit organization that founded the global digital storytelling movement). These participants will then be trained to share their stories and videos to increase HBV awareness, screening and care in their local communities and nationally.
Our goal is to build a meaningful patient story bank that create a sustainable network of trained storytellers to put a compelling human face on the problem of hepatitis B and raise its visibility as an urgent public health priority. **Visit *www.hepb.org/storybank.***

CDC Awards Hepatitis B Foundation *NEW* 5-Year Cooperative Agreement

The HBF is pleased to have been awarded a second competitive five-year cooperative agreement with the Centers for Disease Control and Prevention (CDC) in recognition of its success in creating ***Hep B United***, a national hepatitis B coalition established in 2012 by the HBF in partnership with AAPCHO. This new CDC award will leverage the success of our first CDC cooperative agreement, and will enable us to further strengthen the national hepatitis B coalition through capacity-building, technical assistance, mini-grants, educational initiatives and working with the CDC to expand and promote its national multilingual ***Know Hepatitis B*** campaign.

Hep B United
hepbunited.org

It Takes a Coalition to Fight Hepatitis B

The 4th Annual *Hep B United National Summit* was held July 27-29 in Washington, DC with more than 70 participants from the 30 member local coalitions across the country, federal partners, and national nonprofit organizations.

Hep B United, a national coalition established by the Hepatitis B Foundation and AAPCHO in 2012, hosted its **4th annual *Hep B United National Summit i***n Washington, D.C., from July 27-29. This annual summit is the largest assembly of HBV leaders that gathers to discuss community-based screening, prevention and linkage to care strategies with the goal of eliminating hepatitis B. Key topics this year included building capacity and sustaining local hepatitis B coalitions, helping patients navigate complex insurance and health care systems, and launching the new *Know Hepatitis B* campaign materials developed by CDC and co-branded with ***Hep B United.***

To commemorate ***World Hepatitis Day*** on July 28, the HBF and AACPHO organized Hill Visits during the summit with more than 50 advocates visiting 25 Congressional offices to share their stories and concerns about the need for increased federal attention and funding to address the silent epidemic of hepatitis B *(read more below about the HBF Advocacy Agenda).*

A highlight of the annual summit is the presentation of ***Hep B Champion Awards*** by HBF, AAPCHO and the CDC to recognize community leaders who successfully collaborate to address hepatitis B in their communities.

This year's honorees included: **Alex Shirreffs, MPH**, Philadelphia Dept. of Health's Viral Hepatitis Prevention Coordinator; **Mohammed Abdul-Kadir, MPH, MSIS**, Coordinator of the Hepatitis B Coalition of Washington; **Nadine Shiroma**, a civil rights advocate from Seattle who has worked with HBF to eliminate HBV-related discrimination in the U.S., and; **Moon Chen, PhD**, Director of the Asian American Network for Cancer Awareness, Research and Training (AANCART) in Sacramento, CA.

Hep B United now has more than 30 community coalition members across the country located in 26 cities, 15 states including Washington, DC, and a collective reach to almost 5 million high-risk individuals.

The Hepatitis B Foundation is proud of the growth and expansion of this national coalition to help increase awareness about the urgency of making hepatitis B a national priority.

Capitol News

Hepatitis B Advocacy Agenda

Leading the Charge to Double the Money!

The Hepatitis B Foundation is leading the charge in a national advocacy campaign to ***Double the Federal Funding***, within five years, for hepatitis B and liver cancer research. With the downgrading of hepatitis B, evidenced by declining funds at the National Institutes of Health (NIH) and the CDC, a loud, strong and visible advocacy campaign is urgently needed. Washington leaders are listening. We have their ear.

This past June, HBF arranged for a Congressional letter, led by **Senator Maize Hirono** (D-HI), and **Congressmen Mike Honda** (D-CA) and **Mike Fitzpatrick** (R-PA) and **signed by 12 Senate and House of Representatives colleagues**, which was sent to **NIH Director Dr. Francis Collins** requesting the NIH to:

"…prepare a **professional judgment budget (PJB)** that lists and discusses the research and accompanying resources needed to meet the Hepatitis B Foundation's goal of a cure for hepatitis B and to significantly reduce deaths due to hepatocellular carcinoma from hepatitis B and other causes."

Over the last five years, funding for HBV research at the NIH has declined by almost 16%. It is now only $49 million. The PJB document, requested from the NIH before the end of this calendar year, will serve as the roadmap for our advocacy in Washington to ensure that the federal government prioritizes funding to realize our goal.

To further increase pressure on Congress, more than 50 community advocates were mobilized by the HBF on July 28, World Hepatitis Day, to make Hill Visits to 25 Congressional offices and advocate for increased funding to double NIH funding to $100 million for HBV to leverage new research opportunities to find a cure, as well as to improve HBV testing and treatment.

Advocates stressed the need for the National Cancer Institute to pursue better treatments for liver cancer and that the CDC should double its funding for direct HBV interventions. There is a lot to be done, but the Hepatitis B Foundation's new campaign is mobilizing Congressional champions and community advocates to focus on a clear goal – double the federal funds for hepatitis B!

We sincerely thank the RFS Family Foundation for making the lead donation to launch this advocacy campaign and the HBF Scientific and Medical Advisory Board members for their generous donations to support it.

This article was written by Alyson Lewis, Legislative Director of Madison Associates, Washington, DC.

SPEAKING PERSONALLY

From Ghana

My Untold Story

I used to hear people tell their stories about how they have received their breakthrough for their health-related issues and I marvel. I became so excited and wonder if I would ever meet such a breakthrough.

It was on one fateful day in 2007, during my 2nd year of education, when I decided to voluntarily donate blood to help save the lives of pregnant mothers who get complications during deliveries.

Confidently, I walked into the blood bank to get my blood tested. Everything was OK until the lab technician called out my name and told me they cannot let me complete the process because my blood was 'incompatible.' He handed me a fact sheet on viral hepatitis. I felt so confused and didn't know what to do. I thought I would be referred to see a physician for counseling but no, nothing.

Not knowing what to do, I decided to educate myself on the disease. So I went online, read through several articles and documents on hepatitis B and its management. I learnt about the need to avoid alcoholic beverages, smoking, and ensure I always eat a well-balanced diet to boost my immunity. I did this for close to two years.

Finally, somewhere in 2009, I took another test which revealed that I was in the chronic stage of the infection. Even the health professionals at that facility couldn't explain what that really meant. I got totally confused and didn't know if I was going to die or not.

I have been alive just by grace. I say this because, I do not show any sign or symptoms of the infection and this most times gives me hope. My last medical checkup was in 2010. I had my blood drawn and tested for liver function and HBV tests. The results were good.

Life afterwards has been manageable. I live in a community and country where the level of awareness of hepatitis B is very low. The majority of the people are ignorant about the situation. I have lost some family members as a result of the disease.

It was through my regular search for more information when I came across the Hepatitis Foundation of Ghana. I was so excited and impressed about their work and who they seek to represent. I read several of their works and felt they could help me transform the mindset of the people within my community and the nation as a whole.

I was happy about the swift response with which they responded to my mail and followed up with a call. I no longer feel left alone. I now feel I have someone whom I could call upon for any information or seek clarification concerning my situation. Not only me, but for my community too.

I know my story might not be so different from yours, or perhaps, yours might be worse than mine. I want to assure you that, there is always a way out! Seek information from the right source and be responsible for your life.

*This story was given to **Theobald Owusu-Ansah,** founder and president of **Hepatitis Foundation of Ghana**, who gave us permission to reprint it for our readers. Theobald started his foundation in 2007 after four of his family members died from hepatitis B. The Hepatitis Foundation of Ghana is a nonprofit patient advocacy organization that seeks to promote awareness, to educate the public about prevention and treatment options, and to provide care and support to the infected and affected people in Ghana. For more information, visit www.hepatitisghana.org.*

Giving hope to millions is as easy as giving … and we've made it easier.

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YES! I want to support the Hepatitis B Foundation with a tax-deductible gift.

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Signature_____ **We cannot process your donation without the security code.*

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Donations 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 PA Department of State toll-free within PA at 800-732-0999 or out-of-state at 717-783-1720. Registration does not imply endorsement.

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25 HBF CELEBRATES SILVER JUBILEE

Twenty-five years ago when the Foundation was started, there was no public awareness about hepatitis B and no place for patients to seek support. Nonprofit organizations didn't want to touch hepatitis B because it was an 'undesirable infectious disease.'

Public health experts said the vaccine would wipe it out in a generation so there was no need for a cure. Drug companies weren't conducting research because they didn't see a market. And policy makers didn't pay attention because they weren't hearing any noise.

Over the past 25 years, the remarkable scientific and medical advances that have been made prove hepatitis B is a problem that can be solved. There is a simple blood test, safe vaccine, good treatments, and a cure for hepatitis C. The race is now for a hepatitis B cure.

The Hepatitis B Foundation is proud to be an active partner in advancing the science and medicine of hepatitis B to fulfill our missing of finding a cure and improving the lives of those affected worldwide. In 1991, the foundation was started to help one family.

Today, we are reaching millions of families around the world through our comprehensive outreach, public health and patient advocacy initiatives. We are bringing hope through our dedicated research institute, the Baruch S. Blumberg Institute, which is one of the largest concentrations of nonprofit scientists working on hepatitis B and liver cancer.

As we celebrate our *Silver Jubilee*, our hope for the next 25 years is simple. We hope that a universal vaccination program will protect everyone, young and old. We hope that a complete cure is found that will benefit everyone with hepatitis B. *A world without hepatitis B would be the best gift of all.*

Calendar of Events

2016

Nov. 9
HBV Cure Workshop
Virology Education
Toronto, Canada
virology-education.com

Nov. 11-15
The Liver Disease Meeting
American Assoc. for the Study of Liver Diseases
Boston, MA
aasld.org

2017

Feb. 15-19
APASL 2017
Asian Pacific Association for the Study of the Liver
Shanghai, PR China
apasl2017.org

April 7
Crystal Ball Awards 2017
Hepatitis B Foundation
Lansdale, PA
hepb.org

April 19-23
International Liver Congress 2017
European Association for the Study of the Liver
Amsterdam, The Netherlands
easl.eu

May 6-9
Digestive Disease Week 2017
AASLD, AGA, ASGE, SSAT
Chicago, IL
ddw.org

July 28
World Hepatitis Day
World Hepatitis Alliance
Events around the world
worldhepatitisday.org

Sept. 3-7
International HBV Meeting
Hepatitis B Foundation
Washington, DC
HBVmeeting.org

Nov. 1-3
2nd World Hepatitis Summit
World Hepatitis Alliance
Sao Paulo, Brazil
worldhepatitissummit.org

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B Informed **and all back issues are available online at www.hepb.org/newsletters**

For More Information About Hepatitis B Foundation Programs

- **HBV Info & Support List … HBList.net**
- **HBV Clinical Trials … hepb.org/clinicaltrials**
- **HBV Drug Watch … hepb.org/drugwatch**
- **Hepatitis Delta Connect … hepDconnect.org**
- **Liver Cancer Connect … livercancerconnect.org**