BINFORMED

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Hepatitis B: Is a Gure Possible? CURE

AHEAD

With the momentum growing around hepatitis B drug discovery research, how far are we from a cure?

Closer than ever, according to Timothy Block, PhD, president and co-founder of the Hepatitis B Foundation and its research arm, the Baruch S. Blumberg Institute.

He points out that hepatitis C, initially thought to be incurable, can now be cured with new combination treatments. "Hepatitis B is in a similar position," Block believes.

And the need for a cure has never been greater, with over 240 million people living with chronic hepatitis B infection worldwide, resulting in 1 million deaths per year from related

liver failure and liver cancer.

"Treatments are available," explains Block, "but we have become a little too comfortable with the seven medications that are currently approved for use." While these drugs are effective, the interferons have many side effects and the oral antivirals require lifelong use. Moreover, they work in only about half of the infected population, and reduce the rate of death due to liver disease by only about 40 to 70 percent.

For those who benefit from treatment, the antiviral drugs prove that medications can be effective. However, there are

millions who do not benefit and are still left vulnerable. "We should not accept that a significant number of people will still die from hepatitis B-related complications despite taking the current drugs," Block declares.

What would a cure look like?

The current antiviral agents are similar and combinations do not offer any advantage. They have limited effectiveness against cccDNA, the seemingly indestructible "mini-chromosome" of the hepatitis B virus that continues to produce virus particles in infected liver cells, even in people being treated.

A cure, therefore, would have to destroy or silence cccDNA and provide long-term protective immunity. Because one-drug treatments can lead to drug resistance, a cure would almost certainly involve combination therapy.

With the recent advances in hepatitis B research, scientists are optimistic that another big leap in the search for a cure is possible if other complementary drugs can be found.

The Baruch S. Blumberg Institute of the Hepatitis B Foundation is at the forefront of research efforts to discover such new drugs.

Continued on page 3

A NOBEL CHALLENGE MET!

The Hepatitis B Foundation raises \$3 million to recruit top scientific talent!



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.

Read more on page 8



Joan M. Block, Co-Founder and Executive Director

The Hepatitis B Foundation thanks

everyone who contributed to our

Annual Fund Appeal in 2015. We

sincerely appreciate your support and donations to help us continue our

public health and patient advocacy. All

donors are recognized in our Annual Report 2015, which is available on our

website at hepb.org. Thank you!

valuable work in research, outreach,

From the Editor's Desk LATE BREAKING NEWS!

Elimination of Hepatitis B and C is Possible in the U.S.

n this newsletter we are pleased to report that a cure for hepatitis B is truly within reach (page 1); the growing momentum around hepatitis B is garnering both national and international attention (page 6); and that liver cancer is also gaining increased visibility (pages 2, 7).

So the release of a new report on April 11 – Eliminating the Public Health Problem of Hepatitis B and C in the United States - by the National Academies of Sciences, Engineering, and Medicine is very timely. This is the first of a two-phase study, and was commissioned by the CDC, Division of Viral Hepatitis, and the U.S. Dept. of Health and Human Services, and the Office of Minority Health to determine the feasibility of national elimination of hepatitis B and to describe barriers to meeting

this goal.

The Consensus Committee determined that "hepatitis B and C could both be eliminated as public health problems in the United States, but that this would take considerable will and resources." The second report, to be released in 2017, will outline a strategy for meeting the goals discussed. With this clear call to action, the Hepatitis B Foundation looks

forward to working with all its national and international partners to turn up the advocacy volume around hepatitis B to ensure that there is both the political will – and the resources – needed to truly relegate hepatitis B to the history books.

IN THE NEWS

Journal of the National Cancer Institute Publishes Consensus Recommendations to Improve Liver Cancer Screening and Treatment

The Journal of the National Cancer Institute, a respected source of peer-reviewed content on cancer research and treatment, has published the Hepatitis B Foundation's paper, "Hepatitis-Associated Liver Cancer: Gaps and Opportunities to Improve Care" (April 2016). The article describes the conclusions reached by thought leaders in liver cancer who were convened by the Hepatitis B Foundation in March 2015 for its bi-annual Princeton Workshop (B Informed, Spring 2015). The workshop focused on how to improve screening and care for those with liver cancer related to chronic hepatitis B infections and identified gaps and limitations in current approaches to detecting and treating primary liver cancer (hepatocellular carcinoma, HCC) and to define research priorities and opportunities for advocacy.

Liver cancer is the second leading cause of cancer deaths worldwide, and the second deadliest cancer in the U.S. (with a 5-year survival rate less than 15%). Earlier diagnosis, therefore, must be substantially improved since effective treatment for advanced disease is still lacking.

Hepatitis B is the primary cause of liver cancer worldwide and the global burden of primary liver cancer is increasing because, too often, the disease does not present clear, recognizable symptoms. Thus, increasing provider awareness, better definition of at-risk populations, and improved screening can ensure earlier diagnosis and intervention, with more lives saved. Hepatitis-Associated Liver Cancer: Gaps and Opportunities to Improve Care. McMahon B, Block J, Block T, Cohen C, Evans A, Hosangadi A, London WT, Sherman M. J National Cancer Institute. 108(4):djv359; doi: 10.1093/jnci/djv359 (April 2016 print issue).



HBF convened a group of the nation's leading experts at its Princeton Workshop to discuss improving liver cancer screening and treatment. Standing L to R: Joan Block, HBF; Xin Wei Wang, NCI; Tim Block, HBF and Blumberg Institute; Brian McMahon, Alaska Native Medical Center and CDC; Edith Mitchell, Thomas Jefferson U.; Yujin Hoshida, Mt. Sinai; Ying-Hsiu Su, Blumberg Institute; Hashem El-Serag, Baylor; W. Thomas London, HBF and Fox Chase Cancer Center; Morris Sherman, U. Toronto; Chari Cohen, HBF; Michael Soulen, U. Pennsylvania; Jo Ann Rinaudo, NCI; Anand Mehta, Drexel U.; Alison Evans, Drexel U.; Tim Greten, NCI; Kirti Shetty, Johns Hopkins U.; Stuart Gordon, Henry Ford Health Systems; and Anu Hosangadi, HBF. (March 2015)



HEPATITIS B FOUNDATION

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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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*Baruch S. Blumberg, MD, DPhil HBF Co-Founder & Distinguished Scientist *In Memoriam

Editor – Joan Block Managing Editor - Anu Hosangadi Contact - Editor@hepb.org

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Hepatitis B: Is a Cure Possible?

Blumberg Institute at the forefront

Blumberg scientists have played a key role in increasing understanding of the virus life cycle and are recognized leaders in drug discovery research that also includes designing and developing assays to screen for new drugs.

"With our Drexel University colleagues, we are among the first, if not the only group, to identify a small molecule that inhibits hepatitis B virus cccDNA formation," Block notes. This is significant because inhibition of cccDNA is considered essential in achieving a complete cure. Block is confident that a drug with this mechanism will eventually become available (see sidebar).

In 2015, the Blumberg Institute licensed several of its discoveries to Arbutus Biopharma, the first company solely dedicated to hepatitis B drug discovery, and signed a three-year research agreement to work on novel approaches to developing a hepatitis B cure. "This unique partnership will allow us to move our discoveries more rapidly from the lab to the clinic," Block explains.

Adding to its drug arsenal, Blumberg researchers have used computer modeling to design and produce targeted drugs against hepatitis B and liver cancer. In another innovative approach, researchers

are screening plant and fungal extracts from its Natural Products Collection, donated by Merck & Co. in 2011, and have already discovered two potential drugs that are active against hepatitis B.

Getting close to the finish line

"There has never been more optimism than right now that a cure is within reach," says Block. "This is the goal of the Hepatitis B Foundation, so we are all very excited."

Blumberg researchers are building on recent discoveries that have heightened the momentum around finding a cure for hepatitis B and liver cancer: new screening methods to search for effective drugs; new ways to treat hepatitis B using different approaches to shut down the virus; a new blood biomarker that aids in the early detection of liver cancer; and a promising drug that selectively kills liver cancer cells in animal studies.

"The years that we all have spent working towards a cure for hepatitis B have laid the groundwork for this final phase," said Block. "We are committing everything we have, every resource at our disposal, to developing the therapies that will ultimately improve the lives of all people living with hepatitis B worldwide and ultimately relegate hepatitis B to the history books."



Baruch S. Blumberg Institute HBV Research Pipeline

The Baruch S. Blumberg Institute (BSBI) of the Hepatitis B Foundation is leading the charge in developing innovative new therapies against hepatitis B. Among the products in the pipeline:

cccDNA Inhibitors

We are among the first, if not the only group, to identify the first small molecule inhibitor of HBV cccDNA, which has now been made highly active and is licensed to Arbutus Biopharma for further development.

Capsid Inhibitors, "YES Kinase" Inhibitors

We are using high-throughput screens and computer modeling to design and produce targeted drugs that include capsid inhibitors for HBV and "YES kinase" inhibitors for liver cancer.

Immune System Activators

We have developed a new HBV drug that works by activating an infected liver cell's own immune system, which has been shown to be effective in animal studies.

Natural Antiviral Agents

We have screened thousands of plant and fungal extracts from our extensive Natural Products Collection and identified two new leads that show potential activity against HBV.

Blumberg Institute Develops New Academic Partnerships to Expand Its Research

Forging new academic partnerships, the Baruch S. Blumberg Institute of the Hepatitis B Foundation will be offering innovative opportunities to deliver life science graduate programs to expand its research training programs and impact.



BSBI partners with The Commonwealth Medical College to offer a graduate program. Standing (L-R): Mr. Wayne Yetter, Founding CEO of AstraZeneca and CEO of Novartis, USA; Dr. John Kulp, assistant professor and director of Academic Programs, Blumberg Institute; Dr. W. Thomas London, vice-chairman of Blumberg Institute Board of Directors; Dr. Timothy Block, co-founder and president, Blumberg Institute; and Dr. Steven Scheinman, president and dean, TCMC. (January 2016)

Blumberg Institute Partners with U. Penn's Graduate Chemical Sciences Program

A new partnership between the Blumberg Institute and the University of Pennsylvania will bring high-caliber research support to the Institute while giving Penn graduate students in the Master of Chemical Sciences program the opportunity to be mentored as they secure real-world research experience at the Institute to enter or advance in the chemistry profession.

Blumberg Institute and TCMC Partner for a Master Degree in Biomedical Sciences

The Blumberg Institute has partnered with The Commonwealth Medical College (TCMC) to offer a 16-month Master of Biomedical Sciences (MBS) program for working professionals. Leveraging the impressive scientific faculty of the Blumberg Institute with TCMC's successful MBS program, students will be trained at the Institute where they'll be well prepared for further graduate or medical studies, or careers in biotechnology, pharmaceutical and life science companies.



SPRING 2016 HBV Compounds in Development www.hepb.org/drugwatch

FAMILY/DRUG NAME	MECHANISM	COMPANY	WEBSITE	STATUS, USA
INTERFERONS Mimic naturally o	ccurring infection-fighting immur	ne substances produced in the body		
Intron A (Interferon alfa-2b)	Immunomodulator	Merck, Whitehouse Station, NJ	merck.com	FDA Approved 1991
Pegasys (PegInterferon alfa-2a)	Immunomodulator	Genentech, South San Francisco, CA	gene.com	FDA Approved 2005
NUCLEOSIDE ANALOGUES Interf	ere with the viral DNA polymeras	e enzyme used for hepatitis B virus reproduction		
Epivir-HBV (Lamivudine)	Inhibits viral DNA polymerase	GlaxoSmithKline, Phila., PA	gsk.com	FDA Approved 1998
Hepsera (Adefovir Dipivoxil)	Inhibits viral DNA polymerase	Gilead Sciences, Foster City, CA	gilead.com	FDA Approved 2002
Baraclude (Entecavir)	Inhibits viral DNA polymerase	Bristol-Myers Squibb, Princeton, NJ	bms.com	FDA Approved 2005
Tyzeka (Telbivudine)	Inhibits viral DNA polymerase	Novartis, Switzerland	novartis.com	FDA Approved 2006
Viread (Tenofovir)	Inhibits viral DNA polymerase	Gilead Sciences, Foster City, CA	gilead.com	FDA Approved 2008
Clevudine (L-FMAU)	Inhibits viral DNA polymerase	Bukwang, South Korea Eisai, Japan	bukwang.co.kr	Approved in S. Korea 2006 (Levovir)
Tenofovir alafenamide (TAF)	Prodrug of tenofovir	Gilead Sciences, Foster City, CA	gilead.com	Phase III
CMX157	Prodrug of tenofovir	ContraVir Pharmaceuticals, Edison, NJ	contravir.com	Phase II
AGX-1009	Prodrug of tenofovir	Cinkate Pharma, Oak Park, IL (licensed from Agenix)	cinkate.com	Phase I, China
NON-NUCLEOSIDE ANTIVIRALS	Interfere with proteins involved in	n viral reproduction		
Myrcludex B	Entry inhibitor	Hepatera, Russia with Myr-GmbH, Germany	myr-pharma.com	Phase II for HBV & HDV
ARC-520	RNAi gene silencer	Arrowhead Pharmaceuticals, Pasadena, CA	arrowheadpharma.com	Phase II/III
NVR 3-778	Capsid inhibitor	Novira Therapeutics, Doylestown, PA	noviratherapeutics.com	Phase IIa
Morphothiadine mesilate (GLS4)	Capsid inhibitor	Sunshine Lake Pharma of HEC Pharma, China	hecpharm.com	Phase II
IONIS-HBVRx	Antisense drug	Ionis Pharma (with GSK), Carlsbad, CA	ionispharma.com	Phase II
SB 9200 HBV	RIG-1 and NOD2 agonist	Spring Bank Pharma, Milford, MA	springbankpharm.com	Phase II
Rep 2139-Ca	HBsAg release inhibitor	REPLICor Inc., Montreal, Canada	replicor.com	Phase II
ARB-1467	RNAi gene silencer	Arbutus Biopharma, Canada	arbutusbio.com	Phase II
Birinapant (TL32711)	SMAC inhibitor	TetraLogic, Malvern, PA	tetralogicpharma.com	Phase I/IIa
AIC 649	Capsid inhibitor	AiCuris, Germany	aicuris.com	Phase I
EYP001	FXR agonist	Enyo Pharma, France	enyopharma.com	Phase I
IONIS-HBV-LRx	Antisense drug	Ionis Pharma (with GSK), Carlsbad, CA	ionispharma.com	Phase I
ALN-HBV	RNAi gene silencer	Alnylam, Cambridge, MA	alnylam.com	Preclinical
ARB-1740	RNAi gene silencer	Arbutus Biopharma, Canada	arbutusbio.com	Preclinical
CpAMS	HBV Core Protein	Assembly Biosciences, New York, NY	assemblybio.com	Preclinical
CPI-431-32	Cyclophilin inhibitor	Ciclofilin Pharma, San Diego, CA	ciclofilin.com	Preclinical
Hepbarna	RNAi gene silencing	Benitec, Australia	benitec.com	Preclinical
ARC-521	RNAi gene silencer	Arrowhead Pharmaceuticals, Pasadena, CA	arrowheadpharma.com	Preclinical
NON-INTERFERON IMMUNE ENI	HANCERS Boost T-cell infection-f	ighting immune cells and natural interferon producti	on	
ABX 203	Therapeutic vaccine	ABIVAX, France	abivax.com	Phase Ilb/III
GS-4774	Therapeutic vaccine	Gilead Sciences with Globelmmune, Louisville, CO	gilead.com	Phase II
GS-9620	TLR-7 agonist	Gilead Sciences, Foster City, CA	gilead.com	Phase II
RG7795 (formerly ANA773)	TLR7 agonist	Roche, Switzerland	roche.com	Phase II
INO-1800	Therapeutic vaccine	Inovio, Blue Bell, PA	inovio.com	Phase I
NCT01641536	Therapeutic vaccine	Ichor Medical Systems (with Janssen), San Diego, CA	ichorms.com	Phase I
TG 1050	Immunotherapeutic	Transgene, France	transgene.fr	Phase I
ARB-1598	TLR9 agonist	Arbutus Biopharma, Canada	arbutusbio.com	Phase I
Hepatitis Delta Virus (HDV) Dru	g Watch			
Myrcludex B	Entry inhibitor (targeting NTCP)	Hepatera, Russia with Myr-GmbH, Germany	myr-pharma.com	"Orphan drug" in US Approved in Europe
Lonafarnib	Prenylation inhibitor	Eiger BioPharmaceuticals, Palo Alto, CA	eigerbio.com	Phase II for HDV
Rep 2139-ca	HBsAg release inhibitor	REPLICor, Canada	replicor.com	Phase II for HDV

Thank you to Timothy Block, PhD (HBF President), Brent Korba, PhD (Georgetown U) and Raymond Schinazi, PhD (Emory U and RFS Pharma) for their regular review of the HBF Drug Watch.

For More Information... ■ HBV Clinical Trials hepb.org/clinicaltrials

- Resource Round-Up hepb.org/resources
- Liver Cancer Drug Watch livercancerconnect.org
- HBV Info & Support List (adults) HBList.net
- HBV Adoption List (parents) groups.yahoo.com/group/hbv-adoption/info

HBF Forefront

Hepatitis B Foundation Hits Nearly \$125,000 Monte Carlo Jackpot!

Celebrating its first 25 years, the Hepatitis B Foundation is confidently betting on finding a cure in the next 10 years!

undreds of leaders from academia, industry, government and the community showed their support and played their hand at the casino-themed Crystal Ball, the Foundation's signature annual fundraiser, on Friday, April 8, at the Warrington Country Club in Warrington, PA.

The highly successful event raised an unprecedented near \$125,000 to help fund the Foundation's valuable research, outreach, public health, and patient advocacy programs.

Dr. Bud Tennant was presented with the 2016 Baruch S. Blumberg Prize, the Hepatitis B Foundation's highest honor, in recognition of his pioneering

woodchuck animal model for work on developing the the study of hepatitis B virus (HBV). While on the faculty of Cornell U. College of Veterinary Medicine, he was contacted by Dr. Blumberg's group regarding a new virus infecting woodchucks that was closely related to human HBV. He was instrumental in identifying, testing and maintaining a colony of woodchucks for use in HBV research, in conjunction with the NIH. Over the next 31 years, the woodchuck model was used on nearly every drug licensed by the U.S. FDA for HBV treatment and for most of the potential HBV drug candidates.

Mr. Renold Capocasale



was honored with the 2016 Community Commitment Award for his contributions to improving the community at large through his significant scientific accomplishments in pharmaceutical research and development. After 20 years in big pharma, he launched his own company FlowMetric, Inc., at the HBF's biotech center in

Major sponsors included Presenting Sponsor *Univest*; Platinum Sponsors Arbutus BioPharma, Contravir Pharmaceuticals, Gilead Sciences and Novira Therapeutics; Diamond Sponsors Arrowhead *Pharmaceuticals* and *Dynavax*; and Emerald Sponsors Allure West, deArt Folio, FlowMetric, Fulton Bank, Furia Rubel, High Swartz LLP, Inovio Pharmaceuticals, and Janssen Pharmaceuticals.



Dr. Bud Tennant (2nd from right) receives the HBF 2016 Baruch S. Blumberg Prize at the Crystal Ball for his pioneering work in developing the woodchuck animal model for hepatitis B research. L to R: Dr. Timothy Block. HBF president and co-founder: Dr. Thomas London, HBF board vice-chair; and Mrs. Jean Blumberg, wife of the late Dr. Blumberg (April 8, 2016).



Mr. Renold Capocasale (left) receives the **HBF 2016 Community Commitment Award** from Mr. Joel Rosen, HBF board chairman, for his scientific accomplishments and active involvement in nonprofit organizations that are both improving lives and enriching communities.



Capitol News

HEP ON THE HILL Raises Awareness

n Tuesday, March 8, the Hepatitis B Foundation joined over 120 advocates on Capitol Hill in Washington, DC, to deliver an impassioned plea to their Congressional representatives: increase federal funding to address the silent epidemic of HBV and HCV!

Sharing personal stories of how family, friends and loved ones have been touched by hepatitis, advocates made the case during their visits to member offices that investment in prevention, education, and screening programs is urgently needed to turn the tide.



Distinguished Bruce Witte Lecture 2016



Antonio Bertoletti, MD, (left) Professor, Duke-NUS Medical School, Division Emerging Infectious Diseases, Singapore, with *HBF co-founders* Jan and Paul Witte, delivered the 2016 HBF Distinguished

Bruce Witte Lecture on the role of the immune system in hepatitis B infection. (March 3, 2016)

Hepatitis B Foundation and Hep B United partners make Congressional visits during Hep on the Hill.

Standing (L-R): Binh Tran, APHF, Maureen Kamischke,, HBF manager of Outreach and Social Media; Dr. Chari Cohen, HBF director of Public Health; Chris Kukka, HBF blog writer; Kate Moraras, HBF senior program director; and Karen Jiobu, AACS. (March 2016)

Good News in Bad Nauheim The 2015 International HBV Meeting



Dr. Dieter Glebe (on stage), co-chair of the 2015 International HBV Meeting, kicks off the meeting in Bad Nauheim, Germany. (October 4-7, 2015)

he 30th International HBV Meeting, organized by the Hepatitis B Foundation in October 2015, was co-chaired by Drs. Dieter Glebe (Giessen U., Germany) and

HaiTao Guo (Indiana U., former faculty member at Drexel U. Medical School and the Baruch S. Blumberg Institute).

And the news at the meeting was

pretty good, not bad! In German, "bad" means "bath" and the almost 400 delegates did share some very clean data during the 246 oral and poster presentations.

The meeting kicked off with a clinically oriented symposium on hepatitis B virus (HBV) drugs that are in human trials. This is significant because the worlds of clinical and basic science do not often overlap. Bringing together leading molecular biologists, clinicians, and drug development professionals, the symposium aimed to accelerate the process of drug discovery to clinical use.

Some of the drug development highlights include identification of new small molecule inhibitors of the HBV entry receptor (NTCP), a comprehensive map of HBV cccDNA, and the intriguing finding that the core antigen may not be needed for the formation of cccDNA.

One group showed that a capsid protein inhibitor, known to work in mice, is also effective in

people! Several groups presented new data on the mechanism of immunosuppression, including the encouraging news that the immune response can be restored after antiviral therapy.

Dr. Peter Revill and his Australian and European colleagues issued an impassioned plea to the HBV research community to identify research priorities and mobilize a grassroots appeal to policy makers and funding agencies worldwide.

African delegates described the serious public health problem of chronic HBV infection and liver cancer in sub-Saharan Africa.

The consensus was to pursue international initiatives to call for increased funding and attention to address the global problem of HBV (see below).

The research momentum is definitely picking up for HBV, so there are great expectations for the next meeting, which will be held Sept. 21-24, 2016 in Seoul, Korea.

GROWING International Collaboration AROUND HEPATITIS B

International Coalition to Eliminate Hepatitis B Virus (ICE-HBV) Proposed

At the 2015 International HBV Meeting in Bad Nauheim, Germany (see above) leading scientists met with the Hepatitis B Foundation to discuss creating an International Coalition to Eliminate Hepatitis B Virus (ICE-HBV) based on the success of the ANRS "HBV Cure" program (see on right). Drs. Peter Revill, Barbara Testoni, Stephen Locarnini and Fabien Zoulim outlined an initial strategy to achieve its ambitious international goals.

The ICE-HBV coalition would function as a multidisciplinary International Working Group with representatives from academia, industry, and the HBVaffected community. The initiative would establish subgroups in

virology, immunology, innovative tools, and clinical trials. These four pillars of HBV research would drive hepatitis B cure programs in a coordinated approach across the world.

ICE-HBV would be established and organized under the auspices of the International HBV Meeting, a proposal strongly supported by the Hepatitis B Foundation, which serves as administrator and coordinator of the annual meeting.

With plans to promote dedicated HBV cure programs worldwide, the Hepatitis B Foundation will be inviting interested stakeholders to comment on the ICE-HBV proposal in the near future. Stay tuned!

French National Agency Launches **HBV-Cure Program**





The French National Agency for Research on AIDS and Viral Hepatitis (ANRS) recently created the "HBV Cure" program to promote basic and translational science studies and shape the organization of hepatitis B virus (HBV) research in France.

The program also intends to foster international collaborations in HBV research, as has been implemented with the HIV Cure Initiative.

After launching in 2014, the program organized the first scientific workshop in 2014 in Paris to bring together researchers, clinicians and pharmaceutical companies to define the current state-of-theart and unanswered questions in HBV science. The program's goal is to develop a concerted strategy towards an HBV cure.

SPEAKING PERSONALLY

You Have Three Months to Live

By Frank Gardea



In 2008-2009, during routine testing before surgery, I found out I had hepatitis and liver cirrhosis. It was a double whammy because they told me that

chronic hepatitis and cirrhosis put me at high risk for liver cancer.

Then the abdominal pain started. I suffered for almost three years and was in and out of the emergency department. They could not pinpoint the cause of the pain. When they finally diagnosed my liver cancer, the tumor was over 8 cm. I was of course angry. Why didn't they catch my cancer earlier? I was hospitalized for over a week and then referred to the oncology department.

That's when they told me,

"You have 3 months to live."

I was not a candidate for a liver transplant and one of the doctors didn't even want to give me a referral to a hepatologist because she thought I was too far gone.

I went home and binge-watched YouTube videos on liver cancer. I found out that far too often, by the time liver cancer is diagnosed, it's too late.

Another doctor later referred me to UCLA, one of the top liver cancer centers in the country. At my first appointment, I was seen by Dr. Richard Finn, a leading liver cancer expert who was part of a team of health care professionals taking care of me. They never once said I was beyond hope.

The following week, the tumor burst and I was admitted to the center. I realized I was dying. They did a procedure called TACE that saved my life. I was put

on an oral targeted therapy, which, in combination with the TACE, caused the tumor to shrink.

Fulltime job

Life definitely changed for me. I had a small company that I had to pretty much shut down. I fell behind on my mortgages but was able to work out agreements to get them modified.

Being a patient now became my fulltime job.

I spent most of my time negotiating insurance plans, figuring out medical costs, and going for medical visits. My friends put me on their private insurance plan for 2 years, and then I got my own insurance through the Affordable Care Act. Without that insurance, I would not have been able to survive.

Staying positive

It's hard to stay positive when you know you have a tumor inside you that's killing you. It's not just financially but also emotionally draining. I go for mental health therapy because I get so depressed. Being sick, not being as physically active as I want, and coping with the side effects of the drugs can get overwhelming.

Be your own advocate

The most important thing I have learned is that I have to educate myself about my disease and be prepared when talking with my doctor. I had to become my own advocate, asking questions and being persistent about getting the care I need.

I am not out of the woods yet, but I have a lot to be thankful for. I have now lived three years longer than expected, thanks to my care team. They say I am one of their success stories!

I have joined a cancer support group so I can share my experience. Maybe I can help somebody.



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

Make a secure donation online at www.hepb.org

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A NOBEL CHALLENGE: Mission Accomplished!

he Hepatitis B Foundation (HBF) successfully completed its "Nobel Challenge" campaign, raising more than \$3 million to further its mission to eliminate the deadly hepatitis B virus.

The funds are being used to recruit and retain top scientific talent from around the world for the HBF's Baruch S. Blumberg Institute to accelerate the pace of research for a hepatitis B cure.



Hepatitis B Foundation Board Directors and senior staff celebrate completing the \$3 million Nobel Challenge campaign to fund research at the Baruch S. Blumberg Institute. (November 2015)

"Our goal is not merely to support the development of treatments for hepatitis B or to raise awareness about this serious liver disease. Our ultimate goal is to eradicate hepatitis B, to relegate it to the history books," said **Dr. Timothy Block**, president and co-founder of the HBF and the Blumberg Institute. "We are recruiting the world's finest minds in science and medicine to work fulltime on finding a cure for hepatitis B. The extraordinarily successful fundraising campaign will power our efforts to do precisely that."

Named for Dr. Baruch S. Blumberg, the Nobel Prize-winning discoverer of the hepatitis B virus, and co-founder of the Hepatitis B Foundation, the Institute now funds the largest concentration of nonprofit scientists in the United States working on the challenge of hepatitis B and liver cancer.

The success of the Nobel Challenge fundraising campaign, which will be leveraged for new federal grant funds and additional philanthropic contributions, allows the Blumberg Institute scientists to concentrate fully on discovering breakthrough therapies for hepatitis B that will result in human clinical trials within the next three years.

With promising drugs in the research pipeline (see page 3), the HBF and the Blumberg Institute are establishing relationships with companies that can take their discoveries from the lab to the clinic, where they can ultimately benefit people worldwide.



National Hepatitis Testing Day

Centers for Disease Control and Prevention Testing events across the U.S. cdc.gov/hepatitis hepbunited.org

May 31

3rd ANRS HBV Cure Workshop

French National Agency for Research on AIDS and Viral Hepatitis Paris, France anrs.fr

July 27-29

Hep B United National Summit

Hepatitis B Foundation and AAPCHO Washington, DC www.hepbunited.org

July 28

World Hepatitis Day

World Health Organization Events held around the world worldhepatitisalliance.org

September 21-24

International HBV Meeting

Hepatitis B Foundation Seoul, South Korea HBVmeeting.org

November 9

International Hepatitis B Cure Workshop 2016

Virology Education Toronto, Canada virology-education.com

November 11-15

The Liver Meeting 2016

American Assoc. for the Study of Liver Diseases Boston, MA aasld.org

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