



## THE IMPACT OF COVID-19 ON PEOPLE LIVING WITH HEPATITIS B IN THE U.S.



**Kate Moraras, MPH**, the Hepatitis B Foundation's deputy director of public health, recently wrote a guest blog for the National Foundation for Infectious Diseases highlighting the impact of the COVID-19 pandemic on people with hepatitis B in the U.S.

[nfid.org/2021/05/20/the-impact-of-covid-19-on-people-living-with-hepatitis-b](https://nfid.org/2021/05/20/the-impact-of-covid-19-on-people-living-with-hepatitis-b)

Many have faced increased challenges in accessing medical care and treatment due to delayed appointments and de-prioritization of routine hepatitis or primary care services, according to Ms. Moraras.

Not only have patients had to adjust to telemedicine, but they also experienced difficulty getting antiviral refills and disruptions in mail-order delivery.

Others have had trouble navigating specific health information related to COVID-19 for people with liver disease and concerns related to the safety and efficacy of

COVID-19 vaccines for people living with hepatitis B and liver disease.

The past year also has been particularly challenging for community-based organizations (CBOs) that provide direct public health services such as HBV education, screening, and vaccination. A 2020 survey conducted by Hep B United and several partners (the National Association of State and Territorial AIDS Directors, HepVu, the National Viral Hepatitis Roundtable, the Hepatitis Education Project and the National

Association of County and City Health Officials) found that nearly two-thirds of CBOs providing viral hepatitis services received inadequate or no funding to adapt during the pandemic. Many CBOs were not able to offer hepatitis testing, vaccination, or community outreach, and more than half had to furlough or lay off staff.

Despite these challenges, organizations have adapted resources and programs to the new reality. Creative strategies include an increased social media presence for hepatitis B awareness, contactless hepatitis B lab testing, client outreach and follow-up via phone calls and

email, distribution of hepatitis B materials alongside COVID-19 education, and hosting drive-through educational events, among others.

If the COVID-19 pandemic has shown us anything, it is the dedication, passion, and resilience of under-resourced CBOs to persevere in the most challenging times and continue their mission to eliminate viral hepatitis.

**“Infectious diseases and public health threats, including hepatitis B, do not disappear during pandemics, but instead are exacerbated...”**

**Find more about COVID-19 and Hepatitis B at [www.hepb.org](http://www.hepb.org).**

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### LEARN MORE ABOUT HEPATITIS B

The Hepatitis B Foundation recommends three steps to help protect against hepatitis B:

- 1 Get tested:** Hepatitis B can easily be detected with a quick and simple blood test, often available for free or reduced cost at a healthcare professional's office or clinic.
- 2 Get vaccinated:** There are safe and effective vaccines that can provide lifelong protection from the virus. All newborns should receive hepatitis B vaccination at birth, and vaccination is also recommended for older children and adolescents who were not previously vaccinated or infected.
- 3 Get treated:** If you test positive for hepatitis B, talk with a healthcare professional who is knowledgeable about hepatitis B for regular monitoring and to find out if treatment is appropriate to help reduce the risk of further liver damage.

The national Hep B United coalition, led by the Hepatitis B Foundation in partnership with AAPCHO, provides culturally and linguistically responsive hepatitis B education, prevention, and treatment services to highly impacted populations—communities that often experience inequities in healthcare access.

**Learn more at [www.hepbunited.org](http://www.hepbunited.org).**

# WE'VE PLANNED A WEEK OF ACTION RIGHT UP TO WORLD HEPATITIS DAY



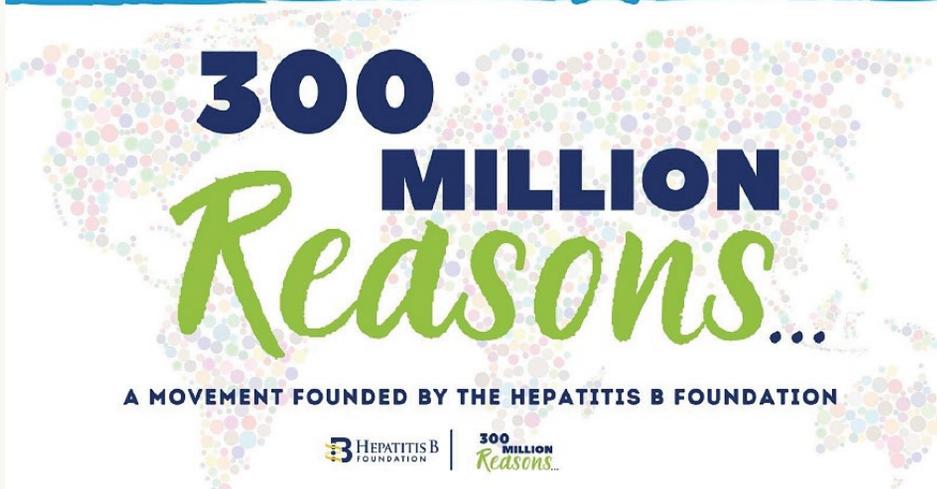
The Hepatitis B Foundation and Hep B United invite our community—people living with hep B, their families and friends, caregivers, health care providers, experts and other advocates—to take part in our week of action, starting July 21.

The goal is to encourage advocacy, raising awareness and lifting up the voices of our global community about the need for universal testing and adult vaccination in the United States, increasing birth dose vaccination worldwide, combatting stigma and discrimination and other advocacy priorities. The aim is to share our messages with government officials and elected leaders.

To help, we've created a new campaign, which is detailed in the adjacent article, **300 Million Reasons** campaign launched to boost advocacy communications," that also is being launched this month.

## 300 Million Reasons

THERE ARE ALMOST 300 MILLION PEOPLE LIVING WITH HEPATITIS B WORLDWIDE.



The **300 Million Reasons** campaign is a movement to improve awareness about hepatitis B and liver cancer worldwide, to promote engagement of key stakeholders, and to empower people impacted by hepatitis B to become vocal advocates. There are almost 300 million people around the world living with chronic hepatitis B infection, and we want to make sure every voice is heard.

We're launching 300 Million Reasons in conjunction with World Hepatitis Day to honor those living with hepatitis B and those engaged in hepatitis B prevention, patient care, research and advocacy.

**You can learn more about the 300 Million Reasons campaign by visiting [www.hepb.org/300millionreasons](http://www.hepb.org/300millionreasons) and on social media by following the Hepatitis B Foundation and #300MillionReasons.**



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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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### In Memoriam

Baruch S. Blumberg, MD, DPhil (2011)  
HBF Co-Founder and Nobel Laureate  
Bud Tennant, DVM (2016)  
HBF Scientific Advisory Board  
W. Thomas London, MD (2017)  
HBF Board of Directors  
Paul Witte (2021)  
HBF Co-founder

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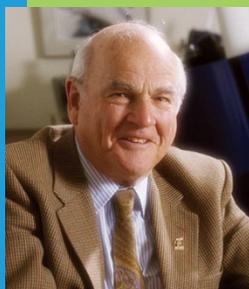
Layout & Design: CP Printing Solutions

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It is not intended to serve as medical advice or endorsement of any product or company. Readers should discuss all personal medical questions and decisions with a qualified health care provider.

## WHY IS WORLD HEPATITIS DAY ON JULY 28 EVERY YEAR?

People and organizations across the globe who care about viral hepatitis observe World Hepatitis Day on July 28 every year. That's the birthday of the late Dr. Baruch S. Blumberg (1925-2011), whose name is on our research arm, the Baruch S. Blumberg Institute. Not only did he discover the hepatitis B virus, Dr. Blumberg and colleagues invented the first vaccine for hep B. Because the virus so often leads to liver cancer, their invention effectively was the first "anti-cancer" vaccine. In 1976, Dr. Blumberg was awarded the Nobel Prize.



Baruch S. Blumberg, MD, DPhil

### Find Your Why for B Day!



Celebrate World Hepatitis B Day on July 28 by asking yourself an important question:

**"Why should I give to the Hepatitis B Foundation?"**

Your why may be the almost 300 million people living with hepatitis B today, or maybe just a person you love who has the disease. Your why may be the need to fight the ever-present stigma those with hepatitis B face or the need to find a cure. Or maybe you understand the need for more research and better treatment options for those living with hepatitis B.

Here's how Catharine Williams, one of our Board of Directors, expressed her Why: "Hepatitis B should not derail anyone's life. The Hepatitis B Foundation and Blumberg Institute are changing the outcomes for people living with the disease. They are the change agents for this diseases."

So, we ask you to Find Your Why for World Hepatitis Day, July 28, which we're making an annual giving day for our organization. Whatever your why is, you can make an immediate impact in these areas and more with a donation today. Please give from your heart to help someone else's liver.

**Please donate today!**

**Go to:** [www.hepb.org/whd](http://www.hepb.org/whd).

**Or contact Jean Holmes:**

[jean.holmes@hepb.org](mailto:jean.holmes@hepb.org),  
215-489-4946.

**Or mail your check to Hepatitis B Foundation,**  
3805 Old Easton Road,  
Doylestown, PA 18902

Thank you!

## Podcasts are hugely popular, and now we have one!



"**B Heppy**" is the name of our new podcast, which we launched this spring! You can find our B Heppy podcast on [www.buzzsprout.com](http://www.buzzsprout.com) and there is a link on the homepage banner on [www.hepb.org](http://www.hepb.org). You can also find B Heppy wherever you normally listen to podcasts.

**Robert G. Gish, MD**, a top specialist who has been treating hepatitis B patients for many years, is the featured guest in episode #1. In another, co-founders **Joan Block** and **Jan Witte** talk about the Foundation's 30-year history and **Dr. Chari Cohen** provides HepB 101, a highly educational and understandable presentation. In a very new edition, you can hear about the All of Us Research Program with **Thaddeus Pham** from Hep Free Hawai'i and **Beatrice Zovich** from the Hepatitis B Foundation.

## AASLD award to Joan and Tim Block

Hepatitis B Foundation co-founders **Joan Block, RN**, and **Timothy M. Block, PhD**, received a very significant honor last fall during the annual meeting of the American Association for the Study of Liver Diseases (AASLD).

The Blocks were honored with the AASLD's inaugural Distinguished Advocacy Service Award, which "recognizes service provided to the hepatology community over an extended period that raises awareness or garners public and federal legislative support and promotes liver health and quality patient care."

The award was presented by **T. Jake Liang, MD**, chief of the Liver Diseases Branch, National Institutes of Health, who will be presenting the award.

"The Hepatitis B Foundation has grown from a one-person crusade to a well-funded multi-tier organization with a large staff and deep influence in the advocacy community,"



**Tim and Joan Block, co-founders, Hepatitis B Foundation**

Dr. Liang wrote in his nomination. "It has effectively represented and advocated for patients with chronic hepatitis B and raised prominent awareness of the disease by implementing innovative educational, patient-oriented, community-based and public health programs."

Family/Drug Name	Mechanism	Company	Website	USA Status
<b>Interferons</b>				
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	genentech.com	Approved 2005
<b>Nucleos(t)ide Analogues</b>				
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
Baraclade (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
Vemlidy (TAF or Tenofovir Alafenamide)	Prodrug of tenofovir	Gilead Sciences, USA	gilead.com	Approved 2016
Levovir (Clevudine)	Inhibits viral DNA polymerase	Bukwang, S. Korea	bukwang.co.kr	Approved 2006 in S. Korea
Besivo (formerly ANA 380/LB80380)	Inhibits viral DNA polymerase	Ildong Pharma, S. Korea	ildong.com/en	Approved 2017 in S. Korea
Zadaxin	Immunomodulator	SciClone, USA	sciclone.com	Approved outside USA
ATI-2173 (Clevudine pro drug)	Inhibits HBV polymerase	Antios Therapeutics	antiostherapeutics.com	Phase II
<b>DIRECT ACTING ANTIVIRALS</b>				
Targets the virus and interferes with specific steps in the HBV life cycle to prevent replication				
<b>Silencing RNA's (siRNAs)</b>				
Interferes and destroys viral RNA				
VIR-2218	RNAi gene silencer	Vir Biotech, USA	vir.bio	Phase II
RG6346 (DCR-HBV5)	RNAi gene silencer	Roche, Switzerland, with Dicerna	roche.com	Phase II
JNJ-3989 (ARO-HBV)	RNAi gene silencer	J&J, Arrowhead Pharmaceuticals, USA	arrowheadpharma.com	Phase II
AB-729	RNAi gene silencer	Arbutus Biopharma, USA	arbutusbio.com	Phase I
BB-103	RNAi gene silencer	Benitec, Australia	benitec.com	Preclinical
ALG-125097	RNAi gene silencer	Aligos Therapeutics, USA	aligos.com	Preclinical
<b>Entry Inhibitors</b>				
Interferes with HBV getting into liver cells				
Hepcludex (Buleviride formerly Myrcludex B)	Entry inhibitor	Hepatera, Russia with MYR GmbH, Germany	myr-pharma.com	Phase II
<b>Capsid or Core Inhibitors</b>				
Interferes with the viral DNA protein shield				
Vebicorvir (ABI-H0731)	Capsid inhibitor	Assembly Biosciences, USA	assemblybio.com	Phase II/III
Morphothiadin (GLS4)	Capsid inhibitor	HEC Pharma, PR China	pharm.hec.cn/en	Phase II
JNJ 56136379	Capsid inhibitor	Janssen, Ireland	janssen.com	Phase II
ABI-H2158	Capsid inhibitor	Assembly Biosciences	assemblybio.com	Phase II
EDP-514	Capsid inhibitor	Enanta Pharma, USA	enanta.com	Phase II
RG7907	Capsid inhibitor	Roche, Switzerland	roche.com	Phase I
QL-007	Capsid inhibitor	Qilu Pharmaceuticals, PR China	qilu-pharma.com	Phase I
ABI-H3733	Capsid inhibitor	Assembly Biosciences, USA	assemblybio.com	Phase I
ZM-H1505R	Capsid inhibitor	ZhiMeng Biopharma, PR China	core-biopharma.com	Phase I
ALG-000184	Capsid inhibitor	Aligos Therapeutics, USA	aligos.com	Phase I
B-836	Capsid inhibitor	Arbutus, USA	arbutusbio.com	Phase I
VNRX-9945	Capsid inhibitor	Venatorx, USA	venatorx.com	Phase I
GLP-26	Capsid inhibitor	Emory University, USA	emory.edu	Preclinical
<b>HBsAg Inhibitors</b>				
Interferes with production of HBV surface antigen (sAg)				
Rep 2139	sAg inhibitor	REPLICor, Canada	replicor.com	Phase II
Rep 2165	sAg inhibitor	REPLICor, Canada	replicor.com	Phase II
ALG-10133	sAg inhibitor	Aligos Therapeutics, USA	aligos.com	Phase I
<b>Antisense Molecules</b>				
Binds to the viral mRNA to prevent it from turning into viral protein				
IONIS-HBVRx (GSK 3228836)	Prevent viral protein production	Ionis Pharma with GSK, USA	ionispharma.com	Phase II
ALG-020572	Prevent viral protein production	Aligos Therapeutics, USA	aligos.com	Preclinical
<b>Gene Editing</b>				
Intended to destroy or repress HBV DNA				
EBT107	CRISPR/Cas 9	Excision Bio, USA	excisionbio.com	Preclinical
HBV	ARCUS platform	Precision Bio, USA	precisionbiosciences.com	Preclinical
<b>IMMUNOLOGICALS</b>				
Targets the human immune system to attack the HBV virus				
<b>Therapeutic Vaccines</b>				
Vaccine technology used to stimulate the immune system as a treatment				
NASVAC	Therapeutic vaccine	CIGB, Cuba	cigb.edu.cu/sobre-cigb/	Phase III
GS-4774	Therapeutic vaccine	Gobellmune with Gilead, USA	globeimmune.com	Phase II
HepTcell	Therapeutic vaccine	Altimmune, USA	altimmune.com	Phase II
VBI-2601 (BRIL-179)	Therapeutic vaccine	VBO Vaccines, USA	vbivaccines.com	Phase II
VTP-300	Therapeutic vaccine	Vaccitech, USA	vaccitech.co.uk	Phase I/II
CVI-HBV-002	Therapeutic vaccine	Cha Vaccine Institute, S. Korea	en.chavaccine.com	Phase I/II
AIC 649	Therapeutic vaccine	AiCuris, Germany	aicuris.com	Phase I
HB-110	Therapeutic vaccine	Ichor Medical Genexine, USA	ichorms.com	Phase I
JNJ 64300535	Therapeutic vaccine	Janssen, Ireland	janssen.com	Phase I
CARG-201	Therapeutic vaccine	CaroGen, USA	carogencorp.com	Phase I
Chimigen HBV	Therapeutic vaccine	Akshaya, Canada	akshayabio.com	Preclinical
HBV	Therapeutic vaccine	HOOKIPA Pharma, Austria, with Gilead	hookipapharma.com	Preclinical
TherVacB	Therapeutic vaccine	Helmholtz Zentrum Muenchen, Germany	dzif.de/en/hepatitis	Preclinical
PRGN-2013	Therapeutic vaccine	Precigen	precigen.com	Preclinical
ISA104	Therapeutic vaccine	ISA Pharma, The Netherlands	isa-pharma.com	Preclinical
VRON-0200	Therapeutic vaccine	Viron Therapeutics, USA	viriontx.com	Preclinical
HBV Vaccine	Therapeutic Vaccine	Clear B Therapeutics, USA and Australia	clearbtherapeutics.com	Preclinical
<b>Innate Immune Defense Pathway</b>				
Compounds that activate the innate immune system				
Selgantolimod GS9688	TLR-8 agonist	Gilead Sciences, USA	gilead.com	Phase II
RG7854	TLR-7 agonist	Roche, Switzerland	roche.com	Phase I
SBT 8230	TLR-8 agonist	Silverback Therapeutics, USA	silverbacktx.com	Preclinical
YS-HBV-002	Activator of TLR3, RIG1, MDA5	YiSheng Biopharma, China	yishengbio.com	Preclinical
<b>Monoclonal Antibodies</b>				
Neutralize or bind the HBV proteins to reduce infection				
GC1102	Monoclonal antibody	Green Cross, South Korea	globalgreencross.com	Phase II
Vir-3434	Monoclonal antibody	Vir Biotech, USA	vir.bio	Phase I
<b>Checkpoint Inhibitors</b>				
Stimulate exhausted T-cell recognition of HBV-infected cells				
ASC22	PDL1 inhibitor	Asclepis Pharma, PR China	asclepis.com	Phase II
GS 4224	PDL1 inhibitor	Gilead, USA	gilead.com	Phase I
<b>Other Immunologicals</b>				
IMC-H109V	T-cell Receptor	Immunocore	immunocore.com	Phase II
LTCR-H2-1	T-cell Immunotherapy	Lion TCR, Singapore	liontcr.com	Preclinical
<b>Additional HBV Drugs Investigated</b>				
APG-1387	Apoptosis inducer	Ascentage, PR China	ascentagepharma.com	Phase II
EYP001	FXR agonist	Enyo Pharma, France	enyopharma.com	Phase I
HBV	MicroRNA	Regulus Therapeutics, USA	regulusrx.com	Preclinical
ENOB-HB-01	Gene modified cell therapy	Enochian BioSciences, USA	enochianbio.com	Preclinical
GV1001	"Novel peptide"	GenVax & KAEL, South Korea	genvax.com	Preclinical
CP101	Oral probiotic	Finch Therapeutics, USA	inchtherapeutics.com	Preclinical
EDP-721	RNA destabilizer	Enanta Pharma, USA	enanta.com	Preclinical
DF-006	Small molecule	Drug Farm, Shanghai	drug-farm.com	Preclinical
ASC42	FXR agonist	Asclepis, Hong Kong	asclepis.com	Preclinical



**Thomas Tu, PhD**, created an online community to address isolation, loneliness, and a need for connection—the often hidden symptoms of hepatitis B. People newly diagnosed with

hepatitis B are left with a lot of unanswered questions and limited support. Dr. Tu, an Australian scientist living with hepatitis B has created a growing online community supporting people living with hepatitis B to connect with people going through the same experiences and offer advice and support.

Our partners at World Hepatitis Alliance sat down with Dr. Tu to find out more.

The Hepatitis B Foundation is proud to partner with Dr. Tu in leading and growing this community.

## What motivated you to set up hepBcommunity.org?

When the doctor first broke the news to me about my diagnosis when I was 14, I was filled with a lot of emotions. I couldn't absorb anything else except "You're stuck with this the rest of your life." when I went home from the doctor, I realised I hadn't absorbed anything else he had told me. So, I did what many people do; I went online and searched for information. I wanted to find a community of people going through the same thing, and I couldn't find anything.

I could only find medical information, and that was all that was there. I realised then there was an additional problem with just Googling it: there are many scams and lots of people selling fake cures, and some people sharing well-intentioned but ill-informed information.

To learn more about it, I went to university, got a degree in biomedical science, and did a PhD in hepatitis B research. Years later, I saw an article about WHA president Su Wang speaking about living with hepatitis B and read about Joan Block, one of the founders of the Hepatitis B Foundation in the USA. They both were speaking publicly about their own hepatitis B experience. I felt I should be doing that too, so that spurred me to ratchet up my advocacy work.

I decided to look online again for a community. Almost 20 years after I first looked, there was still no online forum supporting people living with hepatitis B and connecting them with accurate

# THERE'S A NEW FORUM IN TOWN

HepBcommunity.org 

information from experts. I realised that as someone with a scientific background and as someone living with hepatitis B, I could make the connections to create a forum.

## How does the forum work?

Privacy was a big concern when setting up the forum because stigma is a huge issue for people living with hepatitis B. We allow people to post anonymously if they feel uncomfortable about being identified.

We also have several other measures to protect people's privacy. You have a username that can be anything you want; it can be your name or one you choose; you don't need to share your location or anything like that. Your email address is never shown publicly.

I also wanted the forum to be able to identify people that were trustworthy sources of information. So, we have a verification process for clinicians and nurses to be verified as health experts. They are on the forum to answer questions and give good advice about health guidelines and treatment options.

We also have verified scientists on the forum to explain to people what is coming in terms of a hepatitis B cure and other scientific and technical issues around hepatitis B. People can then ask questions and engage in the science of hepatitis B, like how the virus works and how people are developing new cures.

The site is entirely free and open to join; you just need an email address to register. People looking for advice can quickly get it. It is even free for people to read if you aren't comfortable with registering yet, so you can read answers to questions other people have asked.

We have around 400 members from around the world at the moment, and they are starting conversations and participating in community discussions. For me, it is really rewarding to see people being supported by their peers. When I was struggling with the emotions of being diagnosed, I wish I had this type of group to offer me advice and support.

## What are your hopes for the forum?

I hope this will get to a critical mass of users, encouraging offshoot movements and empowering societal change from the bottom-up. One thing I'd like to see is the coming together of multiple stakeholders, all sharing and learning from each other. A lot of the conversations in the clinical field and science are happening without the input of people affected by viral hepatitis; I would like to see the forum becoming a place where a strong patient voice can be harnessed to facilitate discussions. As a scientist, myself I know many scientists that have worked in the field for decades and they have never spoken to someone living with hepatitis B and never heard about how it is affecting their day to day lives. That connection can really focus the scientist in their work to use their knowledge and research to make a difference and combat the problems that have been highlighted to them.

Most importantly, I want people living with Hepatitis B to feel supported and empowered. I hope this community can act like a family for people living with hepatitis B, particularly if they cannot be completely open with people close to them. People deserve to be supported. I hope the loneliness and the shame people experience from hepatitis B can be alleviated by this community connection.

## How can people sign up?

I want to encourage everyone to join the forum by registering at [www.HepBcommunity.org](http://www.HepBcommunity.org). The stronger the community can become, the more influential the forum can be, the more people we can help. If you're an expert, please join so that you can share your knowledge and so that you can listen and learn about the problems people living with hepatitis B face.

Contact [info@hepbcommunity.org](mailto:info@hepbcommunity.org) for any comments or queries.

*[Note: This article was contributed by our valued partners at the World Hepatitis Alliance, and originally published in the March/April issue of HepVoice.]*

HEPATITIS DELTA VIRUS (HDV)	A virus that co-infects people already infected with HBV		
<b>Hepcludex</b> ( <i>Bulevirtide formerly Myrcludex B</i> )	Entry inhibitor	Gilead, USA	gilead.com
<b>Lonafarnib</b>	Prenylation inhibitor	Eiger Biopharma, USA	eigerbio.com
<b>Pegylated interferon-lambda</b>	Immune modulator	Eiger Biopharma	eigerbio.com
<b>REP 2139</b>	HBsAg inhibitor	REPLICor, Canada	replicor.com
<b>Ezetimibe</b>	NTCP inhibitor	Ziauddin University Hospital, Pakistan	zu.edu.pk
<b>JNJ-3989</b> (73763989)	RNAi gene silencer	Janssen	janssen.com
<b>GI-18000</b>	Immune Response Stimulator	GlobeImmune, USA	globeimmune.com
			EU approved 2020
			Orphan Drug Phase III
			Phase III Ready
			Phase II
			Phase II
			Phase II
			Preclinical

# HEPATITIS B FOUNDATION LAUNCHES WORLD'S FIRST REGISTRY OF DISCRIMINATION AGAINST PEOPLE LIVING WITH HEPATITIS B

People globally who are living with hepatitis B often experience discrimination in a variety of ways, including denial of access to employment and education, even in the U.S., and the Hepatitis B Foundation has launched the world's first initiative to track and analyze that discrimination.

We announced the **Hepatitis B Discrimination Registry**, which is a permanent and sophisticated database, in May 2021, with a worldwide communications campaign to encourage patients to share their stories of hepatitis B related discrimination anonymously. To date, more than 140 people have done so.



**Chari Cohen, DrPH, MPH**, the Foundation's senior vice president, said the primary means for collecting patients' accounts will be the Foundation's brief online survey, which will be supplemented over time with patient interviews.

"We appreciate that so many people living with hepatitis B have responded so quickly, taking time to share with us their stories," Dr. Cohen said. "The Foundation hopes the registry will provide us with the much-needed documentation to demonstrate that discrimination is a significant human rights violation for those living with hepatitis B that impacts all aspects of life. To our knowledge, no worldwide discrimination registry exists for individuals living with hepatitis B, and we intend to fill this gap."

Along with asking people living with hepatitis B to complete the survey, the Foundation is asking their families, health care providers, advocates, government leaders, other nonprofit organizations and academia to

help raise awareness about the new registry, particularly in regions with high infection rates.

The Hepatitis B Foundation has successfully worked to improve protections against discrimination in the U.S., such as winning inclusion of hepatitis B as a protected condition under the Americans with Disabilities Act (ADA) in 2013.

The Discrimination Registry's data will be used to develop policy and advocacy efforts intended to eliminate hepatitis B-related discrimination in the future. The Foundation will share the data through reports that will include high-level information (country-level, type of discrimination, etc.) on what is reported through the Registry. No identifiable information submitted by a person experiencing discrimination will be made available under any circumstances. The Foundation's public health staff, which regularly publishes articles in scholarly journals, will publish analyses of the data.

Discrimination against people living with hepatitis B has been documented in the U.S. and many other countries and anecdotally reported through the Foundation's social media channels and consultation lines with more frequency. But a greater number of discrimination reports may not mean the incidence is rising, according to **Catherine Freeland, MPH, PhD(c)**, public health program director at the Hepatitis B Foundation, who is leading the Registry project.

"The increase is probably because more people are coming out and talking about discrimination, and improved access to technology—more people around the world have access to the internet, social media and email—make it easier for people to find us and share their stories," Ms. Freeland said.

According to the Foundation, discrimination is defined as the unjust, unfair or prejudicial treatment of a person on the grounds of their hepatitis B status. In other words, being treated differently because of one's hepatitis B infection. People with hepatitis B often face discrimination in many ways: denied employment or education, treated unfairly while at work or in school, not allowed to enter certain countries, not permitted to serve in the military or treated unfairly by health care providers and institutions.

## Our hepatitis B clinical trial finder



Search for hepatitis B clinical trials

Start

powered by antidote

The future is promising for people with chronic hepatitis B, thanks in a part to advancements in medical science and new drugs now in development. Before being approved to use, every new drug must go through a testing process, which involves three-phase clinical trials, to evaluate its safety and effectiveness.

The Hepatitis B Foundation has partnered with Antidote, a company that connects patients with research opportunities, to **offer the Clinical Trial Finder, which can connect you with hepatitis B, hepatitis D, or liver cancer clinical trials near you in 60 seconds!** You don't need to input your email address to use the Finder, but if you do, you can receive updates on new clinical trial opportunities near you as they open. To access the Clinical Trial Finder, visit the Clinical Trials page on our [website](#). You also can contact us at [info@hepb.org](mailto:info@hepb.org) if you have any questions.



Volunteering for a clinical trial can be very valuable. Expensive blood work, treatment medications and doctor's visits are usually provided free for those accepted into a study. Clinical trials also provide the opportunity to potentially benefit from the latest advances in medical science.

The U.S. National Library of Medicine manages [www.clinicaltrials.gov](http://www.clinicaltrials.gov), a large website which can help you find clinical trials around the world.

## More Than B celebrates people living with hepatitis B

Building on the success of our **#justB Storytelling** campaign, we created a spinoff with a different twist: people living with hepatitis B talking about the fun and rewarding aspects of their lives that make them **#MoreThanB**.

One of our first **#MoreThanB** stories was submitted by **Espi**.

"I am 80 this year and live a happy healthy life with hepatitis B. I maintain my fitness routine and eat healthy. My passion for worldwide travelling and exploring different places took me as far as Ushuaia (end of the world) Argentina, Australia, Russia, and Asia. Also, I enjoy and have lots of fun ballroom dancing, swimming, studying & practicing Spanish conversation. Doing volunteer work for AAUW Diversity Committee discussion group and fundraising for Dollars for Scholars is rewarding and enhances my interest in social issues."

You can follow **#MoreThanB** on our social media, where we share new stories regularly.



## Successful Gala launches 30<sup>th</sup> Anniversary Celebration

Our Annual Crystal Ball Gala on April 30 was a huge success as a fundraiser and, though a virtual, online-only event, it was a great way to kick off the Foundation's 30<sup>th</sup> Anniversary celebration.



Live on the Gala webcast, **Chari Cohen**, our senior vice president, and our mascot **O'Liver** encouraged supporters to join in the fun.

The event also brought in more than **\$150,000** in pledges, which is a new record for our annual fundraiser. Of course, all of those funds will go to supporting public health, advocacy and research activities of the Hepatitis B Foundation and Blumberg Institute.

You can watch a recording of the event on the Gala website, [hepbgala.org](http://hepbgala.org). It includes a new, nine-minute feature video (at 22:50 of the recording) that provides a rich view of our history.



Your gift gives hope to millions affected by hepatitis B.

Make a secure donation online at [www.hepb.org](http://www.hepb.org)

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

Name \_\_\_\_\_

Address \_\_\_\_\_

City \_\_\_\_\_ State \_\_\_\_\_ Zip \_\_\_\_\_ Email \_\_\_\_\_

Donation Amount:  \$25  \$50  \$100  Other \$ \_\_\_\_\_

Please charge my gift to my credit card:  Mastercard  Visa  American Express  Discover

Name on Card \_\_\_\_\_ Exp. Date \_\_\_\_\_

Card # \_\_\_\_\_ Security Code\* \_\_\_\_\_

Signature \_\_\_\_\_

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

Please make check payable to: **Hepatitis B Foundation**

Use remittance envelope or mail to: **3805 Old Easton Road, Doylestown, PA 18902 USA**

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.

## Hepatitis B by the numbers



### Around the world...

- Hepatitis B is **one of the most common chronic infections worldwide.**
- Almost **300 million** people are living with a chronic hepatitis B infection.
- Each year about **884,000** people die from hepatitis B.



### In the United States...

- Almost **2 million** Americans are chronically infected.
- About **70%** of people living with hepatitis B in the U.S. don't know they are infected.
- More than **50%** of Americans with chronic hepatitis B infections are of Asian and Pacific Islander descent; hepatitis B is the #1 health disparity for Asian Americans and Pacific Islanders.
- **Thousands** of Americans die each year from hepatitis B.

**YOU  
COULD  
WIN A  
\$25 GIFT  
CARD!**

We at the Hepatitis B Foundation want to know your thoughts about this newsletter, so we can make improvements.

Five people who complete our five-minute online survey will be chosen at random to receive a \$25 gift card!

To fill out the survey, please go to:  
[www.hepb.org/reader-survey](http://www.hepb.org/reader-survey).

Thank you!

## Calendar of Events

### 2021

**JULY 28**  
World Hepatitis Day



**SEPT. 26-30**  
International HBV Meeting  
Toronto, Canada  
[hbvmeeting.org](http://hbvmeeting.org)

**OCT. 14 (3 p.m.)**  
Bruce Witte Lecture  
Harvey Alter, PhD, Nobel Laureate  
"Making Hepatitis B Virus History"  
Doylestown, PA  
[hepb.org](http://hepb.org)

**NOV. 2-4**  
Hep B United Summit  
(virtual)  
[hepbunited.org](http://hepbunited.org)

**NOV. 10**  
International Workshop on HBV Cure  
(virtual)  
[academicmedicaleducation.com/hbv-cure-2021](http://academicmedicaleducation.com/hbv-cure-2021)

**NOV. 12-15**  
The Liver Meeting  
Anaheim, CA  
[aasld.org/event/liver-meeting](http://aasld.org/event/liver-meeting)

### 2022

**APRIL 1**  
Hepatitis B Foundation Gala  
Warrington, PA  
[hepb.org](http://hepb.org)

**JUNE 8-10**  
World Hepatitis Summit  
Bangkok, Thailand  
[worldhepatitisummit.org](http://worldhepatitisummit.org)

## For More Information About Hepatitis B Foundation Programs

- HBV Info & Support List ... [HBList.net](http://HBList.net)
- HBV Clinical Trials ... [hepb.org/clinicaltrials](http://hepb.org/clinicaltrials)
- HBV Drug Watch ... [hepb.org/drugwatch](http://hepb.org/drugwatch)
- Hepatitis Delta Connect ... [hepDconnect.org](http://hepDconnect.org)
- Liver Cancer Connect ... [livercancerconnect.org](http://livercancerconnect.org)

## Find HBF on social media:



This issue of *B Informed* and all back issues are online at  
[www.hepb.org](http://www.hepb.org)

