

**Comments for Externally Led Patient-Focused Drug Development Meeting for Hepatitis B
June 9, 2020**

Comments were submitted via email from June 1-June 30, by people worldwide living with chronic hepatitis B and/or their family members. Comments were in response to 8 discussion questions, to supplement the testimony from the June 9th PFDD meeting. All submitted comments are listed below, organized by question.

TOPIC 1 DISCUSSION QUESTIONS

1. How have physical symptoms or liver disease associated with chronic hepatitis B impacted your daily life, and what has had the most significant impact?

<p>Maureen from Maryland</p>	<p>Symptoms for my daughter included extreme fatigue and joint pain due to her extensive fibrosis. In my work talking to others living with chronic hepatitis B, I hear about everything from fatigue to digestive system issues and terrible anxiety related to living with a chronic Hepatitis B. What is heartbreaking is that many are not properly managed by a knowledgeable health care professional, so they have no idea if the symptoms they are experiencing are due to their Hepatitis B or something unrelated.</p>
<p>Neha from Kenya</p>	<p>I have had 2 types of treatment. I have had antivirals, which were tenofovir and Vemlidy, as well as interferon injections to manage my hepatitis B viral load.</p> <p>Living with the interferon therapy was a nightmare, and the side effects were a disaster. I was in bed the majority of the time due to the fatigue and body ache and got osteoporosis.</p> <p>I would like to mention that on the side I started taking milk thistle and had a great change in my diet. Loads of vegetables, fruits, and gluten-free food helped me with better blood work and viral load.</p> <p>I have been on treatment for 7 years. My treatment was done in India for 5 years because in my country (Kenya) medical services for hepatitis B are pathetic. But recently, I have been going to Thailand for my treatment which has finally made my viral load undetectable.</p>
<p>Kim from Minnesota</p>	<p>My father had diabetes, so we thought the signs and symptoms he had were due to that. It wasn't until he had tremors that we looked deeper, which lead us to a liver biopsy. It was at this point that he was diagnosed with hepatocellular carcinoma due to the hepatitis B virus.</p>
<p>Bulus from Nigeria</p>	<p>In 2019, when it was discovered that fibrosis had started, I had poor appetite, and I was immobile. I could feel right-sided upper abdominal pain.</p> <p>However, today I occasionally still feel mild upper abdominal pain that is short lived, as well as right apex fingernail pain.</p>

Espi from Florida	For me, fatigue and insomnia have the most significant impacts.
Karin from California	I was diagnosed at age 35 with chronic hepatitis B virus (acquired at birth) which had already progressed to cirrhosis. I have never experienced any symptoms that I could clearly associate with my hepatitis B virus. However, whenever I have experienced physical symptoms, such as bone loss, difficulty gaining back weight after an illness, or difficulty building muscle when working out, it left me wondering how much of these issues were due to, or exacerbated by the condition of my liver. I have suffered more pain and discomfort from unrelated illnesses than many people because the risks of using medications with cirrhosis have generally kept me from resorting to using any of them. Also, as a survivor of breast cancer, the risk of developing liver cancer looms even larger than with my HBV alone, as both conditions carry an increased risk.
Manoj from India	I received my hepatitis B diagnosis during another surgery without any symptoms showing. I was shocked and stressed. Other tests were conducted, and I finally started medicine on recommendation of a doctor, to avoid any complications.
Imelda from California	<p>Fatigue has been the primary physical complaint, followed my strong joint pain.</p> <p>I have always been a very energetic active person, but about 6 years ago I was feeling way too tired around 2-3 PM, and unable to continue with my daily activities. I had to force myself to lie down. I used to cry, feeling helpless, distressed, and very much alone. I immediately recognized that this was not normal, but my doctors and family members will associate this with overworking myself rather than with my illness.</p> <p>I am currently taking tenofovir alafenamide and it has proven to be effective suppressing the virus.</p>
Eduardo from the Philippines	I was diagnosed with hepatitis B virus in 2015. I don't feel any severe symptoms, but sometimes I get so self-conscious about my own condition (especially my skin). People who knew my condition would always say that I am not really sick. But I already got a second opinion and was tested, and the virus is still reactive. I am now taking a medication since the last time I got checked my viral load was really high. One thing that bothers me is that my condition itself holds me back in continuing my teaching profession. I am scared to be known by everybody. I once tried applying for a teaching position abroad, but I was rejected due to my condition. Thank you so much for hearing me out!
Patrick from the Philippines	Right now, I suffer joint pain and back pain due to my hepatitis B virus. I never take any pain reliever, I use pain killer to lessen the pain.
Victor from Nigeria	The challenge in living with the hepatitis B virus right now is insomnia and indigestion.

Bright from Maryland	I was on Entecavir which was manageable for me as I took other medications. Early this year, my medication was switched to Vemlidy. It is very hard to manage because I have some medications that I have to take on an empty stomach; but I have to take Vemlidy with food. This has impacted my morning routine and sleep. I am not a breakfast person. This is a huge inconvenience especially if you are taking some medications that require you to take with food and others on an empty stomach both in the morning.
Mohammed from Illinois	I, like others, used to have lots of fatigue, but after 6 months of treatment - it went away.
Sungviel from Ghana	The joint pain and fatigue associated with the disease is very painful.
Solomon from Ghana	I experience abdominal pains, nausea, and vomiting. I have fear and anxiety towards dating, termination from work, developing cancer and dying prematurely. Currently, I only use diet management and physical activity to treat without any drug. I want a complete loss of surface antigens. For a route of administration of medication, I will tolerate oral intake or IV.
Paul from California	The hepatitis B virus has caused cirrhosis, fatigue, muscle degeneration, abdominal pain, itching, digestion and excretion problems, vasculitis, portal hypertension, esophageal varices just to name some of the main issues.
Yvonne from Australia	Before I was on treatment, I had on and off fatigue for years. I didn't make the connection with hepatitis B because I didn't know much else and thought that it was normal when having babies.
Innocent from Tanzania	None. I have not experienced those kinds of symptoms.
Raj from California	I have not had any physical symptoms or physical impact associated with chronic hepatitis B. The most significant impact for me personally is mentally being aware of being a carrier of the disease which could shorten my life.
Randall from London	I had fatigue and jaundice, which stopped once I was on antiviral treatment. Because of the jaundice, people used to always say "you look like you've been in the sun" or "Have you been on holiday? Because your face looks really tanned."

2. What impact has your diagnosis had on your personal, social, and professional life?

Rukundo from Uganda	Living with hepatitis B has greatly affected my life. I am not allowed to work in some organizations like Uganda Wildlife authority, I can't work in United Arab Emirates countries, some institutions segregate, and I had to lie to get a vacancy. I can't freely associate with people when they come to know I have it. I am even a laughingstock to some of my relatives. But however many the challenges, I have decided to continue with my medication no matter what people are saying about me. I wish those infected could be treated as normal human beings since we can't transmit the disease when we are on medication, especially on issue of close contact like shaking hands and hugging, among others.
W.L. from California	Isolation. As someone living with hepatitis B for 26 years, I feel I'm going through it alone. The health community group emphasizes on public awareness, vaccination, and prevention but they do little for people living with the disease. There's no dedicated support group for hepatitis B. The ones I found are for hepatitis C and liver cancer, so I don't fit those "disease" categories. The American Liver Foundation has information about hepatitis C, cancer, and transplants, but little for hepatitis B. So, having hepatitis B feels like a marginalized experience.
Ian from the UK	I think we all put a stigma in our heads because of the virus. Feelings of being dirty and doing something wrong are hard to get rid of. It's stopped me applying for jobs over the years, and hiding it for 25 years in my current employment. I'd love to "come out" but people don't understand the disease, and then you are stigmatized.
Tamba from Liberia	Living with hepatitis B as a poor person in a poor country with no adequate health care service is like living a life in hell, because even if the services and proper medication are available, I wouldn't have the financial strength to continue or buy my medication. I can't get into a relationship now with any woman because of this unexpected situation surrounded by poverty and poor health facilities.
Raj from California	Often, I feel shame in sharing my diagnosis to friends, family, or co-workers. Even though I understand that this disease is no fault of my own, as I've had it since birth, I still feel a stigma when sharing my story. Socializing can often be difficult also as I often must explain why I'm not drinking alcohol.
Bulus from Nigeria	I was diagnosed with hepatitis B in 2009, at that time I was only making sure I eat a good diet which was not good enough. It was not until 2019 that I was seriously sick.
Ravi from India	I am not able to concentrate on my career.
Karin from California	Generally, I have been fortunate enough not to have been impacted hugely in my professional life, because I was employed in state service with good medical insurance

	<p>when I was diagnosed. But I have been unable to secure long term care insurance, and I decided against making a job change partly because of the increased challenge in obtaining adequate health insurance, especially with HBV, at a reasonable cost in the private sector compared to my government employment.</p> <p>In my personal life, my sister, who was also diagnosed with hepatitis B virus as a result of my urging her to be tested, has become a partner in learning about treatments and making decisions regarding our condition. My mother, from whom we acquired our HBV, has had a difficult time acknowledging the seriousness of this disease and has been quite dismissive of our efforts to pursue diagnostics and treatment, although she did agree to being tested and facilitated the rest of the family getting tested.</p>
Tenzin from India	<p>As a teenager until now I didn't face many problems, and I was treated equally in schools. People didn't really care about it. But what worries me the most about living with the chronic Hepatitis B in India is whether I can get admission in the college and job that I want to do, (I want to be a chef). If I do get in, maybe I will be treated differently. These things disturb me a lot.</p>
Barbara from the Philippines	<p>Being a carrier of chronic hepatitis B is more challenging in my part, because I experience being rejected in my work just because of this. I want to study or work abroad, but especially because I am a health worker, there is a stigma. In some other countries I'm not allowed to work or migrate as a health worker who has such a disease.</p>
Daniel from Ghana	<p>Relationships, finances, isolation and cutting off lots of food have been my major concerns. My hope is that the scientific and medical community comes out with a potential and lasting cure.</p>
Anonymous from Canada	<p>I experience mental fear, the feeling of being weak, anxiety about dating, and I gave up alcohol.</p>
Ayodele from Nigeria	<p>Social discrimination is everywhere in Nigeria. The moment you're diagnosed with hepatitis B virus, then you're cut off the world. So, a cure is the only solution.</p>
Victor from Nigeria	<p>In Africa, the stigma is there and very high. That is why people don't come out to speak about it, and I think the whole world is not doing much about the hepatitis B virus. Also, in my country testing is very expensive and viral load test is up to \$150. As such, this makes it difficult to go for testing regularly.</p>
Neha from Kenya	<p>There is a lot of stigma in my community. I would love to share my story and help people, but I still have not managed to come forward to help due to the stigma. The scary part is that if I ever come out in the open my family members shall face issues. There are so many children who have HIV from the country I come from who are so mistreated that it feels sad</p>

	<p>that we live in such a world. People still don't know the difference between HIV, HepB, and HepC so there is a lot of misinformation regarding them.</p> <p>As I had said earlier, my social life was halted. Since I was diagnosed, we had not even told people apart from my main family members. Unfortunately, there is a stigma about this illness. But luckily, I work in our own family business, so I was fine missing work, especially when I was unwell at the time. The best part is that my husband and my family are very supportive in this journey, which makes it very easy for me to tackle.</p>
Alan from Australia	<p>For me, another worry would be transference to non-family members. Situations such as passing onto prospective partners, visiting dentist, being in a car accident or something so innocuous as having a bloody nose can be worrisome.</p>
Patrick from the Philippines	<p>Many members of our society still suffer discrimination in the workplace, or even from their families.</p>
Gugsa from Minnesota	<p>I hope people living with hepatitis B who are facing prejudice, stigma, discrimination, and harassment get helped.</p>
Sarah from Canada	<p>The most acute impact to my life from Hepatitis B was when I was seeking housing during one summer's stint in another city. I considered it my responsibility to disclose to my potential hosts that I have hepatitis B, since my understanding was that a risk factor to transmitting hepatitis B was living with someone who has the disease. Several families with young children did not feel comfortable hosting me, which is completely their prerogative. However, it still hurt, and I experienced anxiety entering other social situations out of fear that I would impose risk to those around me.</p> <p>Having hepatitis B has not affected my daily life very much and I have received very good treatment here in Canada (drug prescription, quarterly blood tests and biannual ultrasounds) and I am grateful for that. But I would love to have treatment or research that would give me more ease of mind that I am not presenting a high risk of transmission to those around me.</p>
Maureen from Maryland	<p>Figuring out how to cope with my daughter's diagnosis was challenging. It was very isolating as I had few people to talk to about my concerns and fears for her future. Despite an effective vaccine, I vacillated between feeling empowered by the Hepatitis B vaccine and being afraid someone may not have completed the series or was a non-responder.</p> <p>Working with the Hepatitis B Foundation I have heard from thousands over the years that were left at the altar, some afraid to even consider dating, and others who found out about it when they attempted to go to school or seek employment in-country or overseas. Love is lost, dreams are shattered and there is great shame associated with having this disease. The worst are mothers that learn about their hep B infection while they are pregnant, not with</p>

	their first child, but the 2 nd or 3 rd , wondering if they have transmitted the virus to their older children. It's heartbreaking.
Karin from California	I have been unable to secure long term care insurance and I decided against making a job change partly because of the increased challenge in obtaining adequate health insurance, especially with hepatitis B virus, at a reasonable cost in the private sector compared to my government employment.
Priyanka from India	Hepatitis B is psychologically very hurtful - it is killing me every day - please find a cure.
Ahn from California	I just wanted to strongly emphasize that the antiviral medication prescribed to patients for chronic hepatitis need to be taken for a very long time. A fatal mistake made by my mother's doctor was taking her off entecavir after nearly three years of drug treatment albeit the fact that she was doing so well while on it and without any side effects. Seven months later, she passed away from liver failure.

3. What worries you most about living with chronic hepatitis B?

Neha from Kenya	My biggest fear is passing on the Hepatitis B virus to my children if I ever get pregnant. I am advised not to get pregnant at the moment, but it is heartbreaking for me hearing that as I love children. Every single day I have to worry.
Karin from California	<p>To this day, it weighs on me to think about how many people I might have innocently and ignorantly infected, both as a child and as a young adult. Much later, after my chronic hepatitis B diagnosis, and learning more about the disease, I was very concerned about having transmitted the virus to my daughter, members of my family, and others, but fortunately I had not infected any of them and by that time the HBV vaccine had become available.</p> <p>My biggest concern now, is the elevated risk of liver cancer, especially after having also had breast cancer. Almost equally concerning is the osteoporosis I have developed, probably accelerated by taking tenofovir for 10 years and the likelihood of needing to restart antiviral treatment at some future point increases my concern that bone loss might become my most serious issue.</p>
Abdul from Nigeria	After it was confirmed that I am hepatitis B positive, I took a couple of clinical tests, except one (viral load) — it cost 20,000 Nigerian naira. I have begged the doctors severally to work with the tests I was able to afford but they refused. I am a student and self-sponsored; I just fear I'm too close to my grave day after day. I sleep and wake up every day with so much fear.

Shamuna from Ghana	I worry about dying prematurely and not being able to marry and raise my own family, and also who will take care of my sick parents if I die prematurely.
Felicia from Ghana	I'm afraid to die early because of hepatitis B virus, so please help me out by curing this disease.
Mercy from Ghana	My fear or worries of hepatitis B is that maybe I could develop liver cancer.
Kenneth from Uganda	<p>There has been a huge challenge in the management of hepatitis B in Africa where the majority of patients are not put on treatment which leaves them asking why not, yet they are infected. The majority have been lost to follow-up because they never come back to health facilities because they may be asymptomatic for very long time. Those who come back and still are not given any help as they expect never come back again. We see a danger in the case they could be developing the complication due to lifestyle. Couldn't the "test and treat strategy" help to avoid these cases lost to follow-up as to some, coming back to pick up their refills is enough incentive to get them back for review and follow up?</p> <p>What's your thought on this as we wait for a cure that everyone is anxiously waiting for?</p>
Tamba from Liberia	Hepatitis B drugs are expensive and poor people like us are finding it difficult to pay for our treatment. Is the cost of medication going to be reduced for poor patients or are their plans to make the treatment free like the tuberculosis drugs?
Anonymous from Canada	I worry about cirrhosis.
Kus from India	I have a fear of dying or cancer.
Imelda from California	<p>I have been living with hepatitis B probably my whole life, but I wasn't diagnosed with it until about 25 years ago. But it was not until 4 years ago that I began treatment to suppress it.</p> <p>The preventive measures can be a burden for many, having to check for quantities and liver panels and ultrasounds every 6 months can be a financial burden.</p> <p>This disease is serious and if not properly cared for can lead to serious consequences. My mother died from liver cancer and cirrhosis. My main concern is that with the virus being so contagious and damaging why not enough is done to educate and prevent transmission.</p>
Omotobi from Atlanta, Georgia	My doctor told me there is no cure for the virus, and that it can lead to liver damage, liver cancer, and death. My children are not happy. My family told me I don't need treatment now, I'm not at the level yet. I'm fine, my liver shows no signs and my hepatitis B viral levels stay in the same range. But I can't sleep, I always have sleepless

	<p>nights thinking about my life. I use Google for research and reach the same answer. I don't know when or how long to get medical treatment, or if I should go the herbal way since there's no cure, or try my own science with God's help to wait it out. I still have children, I'm just 55. I really want to know the cure, not just medicine to try to clear it out. My family, children, and I are worried and crying. Thanks, this organization is God blessed. So, at this point I can take any medicine but I'm not getting it until I need to.</p>
Lynette from Massachusetts	<p>I worry about having no insurance or no money to continue to get the medicine for the rest of my life.</p>
James from Kenya	<p>Getting drugs is a big problem, in Kenya no priority is given to this disease and people die every day without being diagnosed in villages. The government has no plan for dealing with this condition and it is left to traditionists to deal with it as witchcraft.</p>
Maureen from Maryland	<p>Although my daughter is one of the lucky ones that recovered from chronic hepatitis B, I still worry about whether or not this disease will reactivate later in her life. When her anti-HBs titers were tested for college, they were in the thousands, and I know it is not completely gone despite her being HBsAg negative, HBsAb positive and with an undetectable viral load. It's disconcerting knowing this virus is integrated into the DNA of her hepatocytes with the possibility of reactivation and the more remote chance of liver cancer in the future.</p> <p>From the people I hear from across the globe, I feel their anguish, wondering if they'll be there for their children or if they'll be able to support them. Others worry if they'll ever meet someone that will accept them with their diagnosis. Those that are diagnosed early cope with facing their own mortality at such a young age. There is fear and grieving over the loss of a carefree life they see their peers living. They are isolated and lonely as they wait for the "ticking bomb" in their bodies.</p>
Joan from Pennsylvania	<p>I started on lamivudine but developed drug resistance so had to change to tenofovir. But when I developed osteoporosis as a result of tenofovir, I switched to Vemlidy to decrease my risk of further bone loss. So, I'm currently on my 3rd anti-HBV antiviral and am worried that if there's no cure in the near future, I may run out of options.</p>
Maxwell from Ghana	<p>Mentally I am not completely stable knowing I am hepatitis B positive and it can lead to other health complications.</p>
Jason from New York	<p>What worries me about living with chronic hepatitis B is developing cancer or not being able to live long enough for scientists to find a cure.</p> <p>Although new exciting treatments to sustain healthy life are terrific, a cure is much more satisfying. I look forward for the cure to eradicate the fear.</p>
Yahaya from Nigeria	<p>The fear to disclose my status because of stigmatization.</p>

Raj from California	My greatest fear is dying of liver cancer. My mother, who also had chronic hepatitis B, passed away at 64 to liver cancer 5 years ago. The idea of leaving my family behind and specifically my young twins scares me deeply.
Yvonne from Australia	The only thing that worries me is the residual risk of developing liver cancer that remains even with low viral load. My life goal is to meet my grandchildren and hopefully see them grow up too!
Sungviel from Ghana	What worries me is the fears of developing liver cancer and probably dying at the end because they say it has no cure but can only be managed.
Espi from Florida	I worry most about liver cancer, dying prematurely, transmitting it to loved ones, and increased bone loss from antiviral treatment due to osteopenia.
Innocent from Tanzania	I have a lot of fear surrounding dating and relationships. I feel badly that I will be rejected because of my condition. I am worried about cancer and dying prematurely.
Dora from Alaska	In 2015, I received the devastating news that I had cancer of the liver. It wasn't a total surprise, but it was terrible news nonetheless. I don't remember the exact measurements of the tumor, but I remember it started off by just being a dot on the image that I was shown. Within 3 months, the dot became the size of a dime and in January of 2016, I had surgery to remove my tumor. I am happy to say that today here I stand cancer free telling my story to help educate others who were in my shoes.
Alhassan from Ghana	I have a fear of developing liver cancer and dying prematurely. The high cost of medications and too many food restrictions at a tender age also affect me.

4. Have you ever felt stigma and/or discrimination because of your chronic hepatitis B diagnosis, and if so, could you share an experience with us?

Adeiza from Nigeria	<p>I'm losing hope because of stigmatization. My income is spent on laboratory investigation, medications, and inflated consultation fee. My job is not secure because of my status.</p> <p>I just need someone to tell me that everything is going to be okay.</p>
Maureen from Maryland	Yes, we have experienced stigma. We disclosed my daughter's status for the early intervention program because she was undergoing treatment with interferon and she was in pain. We were refused services by some of the staff and were asked to change home schools. The principal resented that I involved a civil rights attorney to protect my daughter's information from being shared with other staff. As a result, her IEP from Kennedy Krieger was denied, so she was refused services, and I felt she was assigned

	<p>inferior teachers. More significantly, I felt that there were people that knew about her status, and that she dealt with a more quiet form of rejection or discrimination – a fear of hugging her, having a mother rush up to ensure she did not touch the toe of her baby or breathe over his carriage. There were numerous, hushed experiences.</p> <p>One young woman I consulted with learned of her infection when she became pregnant with her first child. Her mother-in-law told her she could come back to the family’s home after she was cured. Her mother sold her wedding jewelry to pay for her daughter’s viral load test. She is such a smart young woman, married to an ignorant man unwilling to even listen or support his wife.</p>
Barbara from the Philippines	<p>Being infected is challenging because I experience being rejected from my work. I am a health worker. There is stigma and some countries do not allow people with hepatitis B to work or immigrate there.</p> <p>When it comes to treatment, hopefully there will be a cure.</p>
Dee Lee from China	I have felt stigma and discrimination all my life in every corner of China.
Mai from Pennsylvania	I have not felt stigma, but my own family suggest that I should not disclose my condition to anyone outside of the family for fear of being ostracized.
Anonymous from Canada	I haven’t felt stigma, but that's because no one knows about my diagnosis. I am sure the stigma will be there if I disclose my diagnosis.
James from Kenya	I beg for any assistance from the foundation for me and my family to earn a dignified living with my young family of two kids and spouse as I struggle to fight negative branding, stigma and discrimination even from my own family members, here in rural Kenya.
Patrick from the Philippines	I have been diagnosed since 2006, I was discriminated against when applying here in local employment and even abroad. I’m doing an online freelance job to support my family.
Farul from Indonesia	Sometimes we face discrimination to get a job because of chronic hepatitis B.
Ian from the UK	I have been diagnosed since 1985 and the knowing you have it never leaves you. It makes me feel "dirty" is a great description and having to hide it from friends and colleagues has also impacted my private life. People don't understand what it is, so I feel better not telling them.

Rukundo from Uganda	Living with hepatitis B has greatly affected my life. I am not allowed to work in some organizations like the Uganda Wildlife Authority, and I can't work in United Arab Emirates countries. Some institutions segregate and I had to lie to get a vacancy. I can't freely associate with people when they come to know I have it. I even am a laughingstock to some of my relatives. But however many the challenges, I have decided to continue with my medication no matter what people are saying about me. I wish those infected can be treated as normal human beings since we can't transmit the disease when we are on medication especially on issue of close contact like shaking hands and hugging among others.
Innocent from Tanzania	I worry a lot about dating and relationships. I feel badly that I will be rejected because of my condition.
Maxwell from Ghana	I will say it is painful that people discriminate against us.
Tenzig from India	Living with chronic hepatitis B in India worries me - I don't know if I can get admission to college or a job (I want to be a chef). And if I do get into school, maybe I will be treated differently. This disturbs me a lot.
Karin from California	I have had the experience twice of seeing a doctor for my HBV and being greeted with the comment "You're not Asian!" It seems the expectation in the United States is, that if one has chronic HBV, one must be Asian.

TOPIC 2 DISCUSSION QUESTIONS

5. What are you currently doing to help manage your symptoms and your condition?

Jin from Maine	<p>I have had hepatitis B since birth - I am 27 - and recently gave birth to my first child. I have never required treatment, only monitoring, but as you know it is critical to make my OB/GYN aware of my infection to step up monitoring for ALT flares etc., and to ensure the immunization birth dose for my child. I found my OB/GYN quite unaware of hepatitis B, and monitoring requirements for women during pregnancy.</p> <p>There remains a lack of education/information about Hepatitis. If we had not been highly informed about hepatitis B and provided AASLD information on best practices for monitoring etc., my provider would have been totally unaware about how to handle my infection.</p> <p>I realize we need to be our own advocates, but this shows a breakdown in hepatitis B awareness, and an awareness of the importance of linking OB/GYN patients to treatment should they begin to experience liver damage during pregnancy.</p>
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	<p>I gave birth six months ago, and I still have not had my ALTs tested since birth. This results from ignorance, my being overwhelmed as a new mother, and of course COVID-19, which has cut into much preventive care including immunizations.</p> <p>I have been adamant in making sure my daughter has received her hep B immunizations - with or without COVID-19 barriers - but I want to underscore I made this happen because we know an unusual amount about hepatitis B. If English were my second language or if I were not aware that my hepatitis B status was not shared with my OB/GYN, my care would have been very different.</p>
Raj from California	<p>I take my Viread medication daily. I exercise regularly and have recently stopped drinking alcohol. I get my blood work checked every 6 months along with a bi-annual Ultrasound and yearly MRI. I try to recognize that each day is a gift so I'm driven to extract the most out of the time that I'm here.</p>
Christian from Nigeria	<p>Adjusting to a life of eating meals without oil was not easy but I am coping well now. Lifestyle changes can help.</p>
Bulus from Nigeria	<p>What is seriously helping me now is taking vegetables and fruits like beet roots, carrots, cabbage, broccoli, apples, lemons, etc.</p> <p>I also do exercise occasionally and I sleep for the minimum period of 8 hours.</p>
Anonymous from Canada	<p>I have regular check-ups.</p>
Halit from Belgium	<p>I do physical exercise.</p>
Maureen from Maryland	<p>Despite recovery from chronic infection, my daughter has chosen to abstain from alcohol, which is a good decision, though I think it sometimes makes her feel left out since many of her friends are going to bars and drinking. Even though she has recovered, it hangs over her.</p>
Yvonne from Australia	<p>I have been on tenofovir for almost 10 years and it's working very well. My viral load has become undetectable and I have noticed a clear improvement in energy levels. I feel well most of the time so rarely do anything extra to manage the condition. I know I should exercise more. I do a bit of yoga but am generally quite lazy physically (maybe an old habit). My diet is healthy, I don't drink alcohol (apart from the occasional tiny sip of red wine from my husband's glass) and I have no issues with weight. Overall, I feel great!</p>

Karin from California	<p>After 10 years of successful viral suppression and reduction of ALT/ AST to low normal levels, I stopped treatment and have continued doing fine without medication for 5 years now. I have continued with my decades long protocol of high intensity cardiovascular exercise, a whole food, low saturated fat diet, nutritional supplements (including milk thistle), and abstention from alcohol.</p> <p>I am monitoring my condition with lab work, ultrasound and Fibroscan imaging. I am also beginning to experiment with meditation and other stress reduction modalities. I consider this approach to be beneficial to my overall health, rather than just for managing my HBV, especially as I approach more advanced age.</p>
Anonymous from California	<p>I was diagnosed with hepatitis B about 40 years ago. I have been taking anti-virals since 2000 and am currently taking Vemlidy. A couple of years ago, during a sonogram, two +1cm lesions were discovered on my liver. They currently are classified as stable, LIRAD 3. All of my lab results are normal. In addition to taking Vemlidy, I exercise at least 30 minutes each day, maintain a healthy diet, abstain from alcohol and get plenty of sleep. I see a hepatologist at UCSF and have quarterly CT scans and lab tests. Is there anything else I should be doing?</p>

6. If you are currently taking a prescribed medication for hepatitis B, how do you feel it's affecting your daily life?

Joan from Pennsylvania	<p>Taking an antiviral has definitely improved my life - less fatigue, less worry about being "infectious," and more hopeful that I won't get liver cancer. The only downside, however, is that I have to see my doctor every 6 months for blood tests and an ultrasound. When I was working fulltime, taking time off was a hassle and all the co-pays related to the visit, blood tests and ultrasounds took its financial toll. In addition, every visit was anxiety-provoking because I always wondered if "this visit" would be where I learned that I had liver cancer. Chronic hepatitis B is very much like living with a time bomb!</p>
Lynette from Massachusetts	<p>I found out that I have hepatitis B when I was at high school in Taiwan. I started to take Baraclude 0.5mg once a day when my Fibroscan score was at 10.2 in 2016. After taking Baraclude for one year, the Fibroscan score was down to 9.3 in 2017. In 2018, my Fibroscan score was down to 5.2. My virus load now is undetectable from over 19,000 back in 2016. I had a chemotherapy treatment due to breast cancer for three months, my GI doctor was monitoring my GOT and GPT for me. All the blood work results turned out to be normal. The only side effect I had was sensitivity to my right abdomen. I set the alarm clock to take my medicine every night. I had a good experience with Baraclude. I discussed the choice of the medicine with my GI doctor in Boston and my doctor in Taiwan to make sure Baraclude has the least side effects, such as damage to my kidney</p>

	<p>and causing the loss of bone density. I am very appreciative of my GI's help for not giving up on me when I wasn't ready to take the medicine.</p>
<p>Maureen from Maryland</p>	<p>My daughter spent 6 months on interferon as a baby, which made it very challenging to navigate her cycle of uncomfortable side effects and nearly impossible to travel. Taking an antiviral was much easier, though she hated the taste of the pediatric liquid formulation.</p> <p>Based on the people I hear from daily; many are unhappy being on lifetime treatment for hepatitis B. Reliable access to affordable medication is very concerning. Those in need of treatment worry about being a burden to their family.</p>
<p>Ian from the UK</p>	<p>I tried interferon and was unable to cope on it. If I knew before I started it how bad the side effects were, I would not have started. I also feel it has affected me permanently since I tried it.</p> <p>The physical side effects of long term entecavir used to worry me. I've developed more aching joints as I've gotten older, and I worry, "is this an effect of the medication?" I have had nearly 40 years of not being "healthy" and feel robbed of a normal life.</p>
<p>Raj from California</p>	<p>The medication is not affecting my daily life in a big way. It's a single pill taken daily which controls my virus load. It's a reminder each day of how I can control this disease and it gives me the opportunity to live a long healthy life.</p>
<p>Paul from California</p>	<p>I am currently on Vemlidy for treatment and numerous other medications for issues related to hepatitis B virus and cirrhosis. Although, I was told there would be little to no side effects with Vemlidy, I was sort of 'brain dead' for 3 months afterward. I could not think, process, remember, I was irrationally emotional, couldn't speak properly, etc. It took another 6 months after the initial first 3 months to start getting back memory and vocabulary. It also caused digestive issues. I still live with these issues on a little less scale with the help of more medications. My quality of life plummeted once I started treatment. I know treatment was necessary and inevitable but the issues and effects after the fact are just as detrimental; not just physically but mentally and emotionally.</p>
<p>Yvonne from Australia</p>	<p>I already had early cirrhosis by the time I made it to a specialist for the first time. I have been taking tenofovir for 10 years. Treatment (Tenofovir) has literally saved my life. Being on Tenofovir is not affecting my life much and I have a positive attitude of gratitude. I have no side effects and the 6-monthly visits to the specialist clinic are easy because I work at the hospital. Cost is also not an issue because here in Australia, it is heavily subsidized by the government as part of the Pharmaceutical Benefit Scheme. Of course, I would much prefer a drug that could cure me so I wouldn't have to be on medication long-term (I never say lifelong because I believe a cure will be found in my lifetime).</p>

Espí from Florida	Taking antiviral medication gives me peace of mind, reduces the risk for liver cancer, is a possible life saver, will increase my longevity. Unfortunately, it means a lifetime on drugs (not a cure), has side effects and has an exorbitant cost (I felt the need to mortgage my house to pay).
Bulus from Nigeria	I was placed on tenofovir disoproxil fumarate 300mg but was difficult to adhere to the drug because of initiation side effects. I was later placed on Tenofovir alafenamide 25mg.

7. What do you consider the most important benefits of an ideal treatment?

Lindsey from Kentucky	<p>A cure would be ideal. But a ‘functional’ cure would be welcome too. Something that would make passing hepatitis B virus onto others no longer a risk and would also reduce the chance of cirrhosis and liver cancer - even if not completely removing the virus. And it would do so with limited side effects whether they are used long-term or short-term. Preferably short-term use, perhaps no longer than 6 months of treatment.</p> <p>Treatment should not cause financial stress and burden. Having a chronic and contagious illness can cause anxiety and stress which can lead to inflammation and disease progression. Having to pay high insurance rates and co-pay for the rest of your life is a true burden. Having private insurance does not guarantee affordable drug costs.</p> <p>No one should have to choose between paying for food/rent or a lifesaving drug.</p>
Chris from Maine	<p>I am the parent of a child with chronic hepatitis B. The ideal treatment for hepatitis B would act similarly to the current treatment for hepatitis C -- completely eradicating the virus.</p> <p>Any treatment that would require ongoing/indefinite regimen of pills (similar to current HIV treatment) would be ineffective in resource-poor regions and countries without access to universal health coverage, including the United States.</p> <p>Many people living with hepatitis B would not qualify for Medicaid or SSI, as is the case with many people living with HIV. This leaves a large percentage of minority and marginalized Americans without access to or ability to afford long-term treatment.</p> <p>Also, many who live with hepatitis B in the United States are immigrants or second-generation individuals who face health equity issues, including a lack of health insurance, unemployment, language barriers that limit access to treatment, lack of paid sick leave, income disparities, and an immigration status that stops many from seeking care out of fear of deportation.</p>

Jin from Maine	<p>As you consider treatment/drug development, you must take into consideration the economic and race-based barriers that persist in this country and prevent people from getting the health care they need.</p> <p>Any drug treatment must be accessible across all ethnic/racial groups, affordable, and its delivery mode must be adapted to all individuals and regions.</p>
Mai from Pennsylvania	<p>For me, loss of surface antigen and a reasonable price would be top priority. Taking treatment for less than a year with minimum side effects is ideal.</p>
Anonymous from Canada	<p>For me, loss of surface antigen.</p>
Tim from UK	<p>My latest blood tests have shown an increase in ALT and the doctor wants to put me on Entecavir in order to decrease the viral load in my body but I am worried about going on this lifelong treatment because I learnt this could cause a life threatening damage to the liver via a condition called lactic acidosis.</p> <p>I am still trying to get my mind around the benefits of this treatment if it doesn't prevent the complication of chronic hepatitis B (cirrhosis or liver cancer).</p>
Kus from India	<p>For me, loss of surface antigen would be important.</p>
Halit from Belgium	<p>A treatment that can help me live longer to see my children grow. I want to stay alive, cancer free.</p>
Maureen from Maryland	<p>Outcomes are significantly better for those with loss of surface antigen, and it truly impacts the quality of life of those living around the world that face stigma and discrimination as a result of being Hepatitis B Surface Antigen positive. However, if durable loss of hepatitis B viral DNA were accomplished with a reasonable, finite treatment, that would go a long way for people living with chronic hepatitis B. Hopefully this would decrease stigma and discrimination assuming this treatment were accessible to all in need. A sterilizing cure, eliminating covalently closed circular DNA and concerns with liver cancer, would be ideal, but likely not feasible at this time.</p>
Julius from Uganda	<p>I would consider the most important benefit of hepatitis B treatment to be the loss of surface antigen, and only taking my pills for a limited period of time like a year.</p>
Raj from California	<p>For me, an ideal treatment would be one that gives me a functional cure: one that reduces the viral load to undetectable levels and protects my liver from inflammation, scarring, fibrosis, and cirrhosis. It would also lower the probability of liver cancer.</p>

<p>Ronald from California</p>	<p>Ideal treatment: It must be affordable...one pill taken only once...(or if not possible, then one pill taken daily for one month)...resulting in the loss of Hepatitis B surface antigen and normalization of ALT / AST levels and reversibility of any fibrosis...all of which are sustained as a cure forever...</p>
<p>Stephen from Australia</p>	<p>Overall, an ideal treatment would be an affordable treatment, finite in time involving taking a pill, that will lead to at least a functional cure.</p> <p>The loss of hepatitis B surface antigen is ideal. In China, a citizen would be required to take blood tests throughout their life, from entry to kindergarten, education, job applications, and annual medical checkups by employers. Even though there are recent rules to protect medical privacy and to forbid discrimination against HBV persons in education and employment, these are frequently ignored by hospitals, schools, and employers. So, if a person tested positive for HBV, they may not be able to get an education or employment. Also, older generations have a prejudice against HBV, so when it comes to marriage which often requires consent by the parents, this can be a real barrier.</p> <p>A significant reduction in the risk for hepatocellular carcinoma is also very important.</p>
<p>Karin from California</p>	<p>After many years of living with the hepatitis B virus with no treatment options, my perspective is that the options available today have made a huge positive impact. But an ideal treatment would need to be more affordable, time limited to preferably less than three months, with no serious side effects, and made available worldwide. Most importantly, an endpoint of surface antigen seroconversion and ideally also loss of covalently closed circular DNA would be the most desirable.</p> <p>The ideal treatment would be designed specifically for the Hepatitis B virus, and undergo rigorous testing, including dosing studies that would allow a more individually “tailored” prescription, rather than a “one size fits all” for multiple viral diseases approach as we've seen with some other antiviral medications that were rejects from HIV drug development. The ideal treatment might need to be two or more separate treatments for people in various stages of HBV progression.</p>
<p>Rapaheljude from Lagos</p>	<p>Hepatitis B has been a long-neglected illness. The world at large has many who are infected, yet the only available tests and treatment are too expensive to patients. These drugs should be made available as other drugs used for chronic sickness and even made to be free so that many can access it.</p>

Alhadi from Nigeria	To think I will have to take my medicine daily prevented me from traveling to places for fear of running out of drugs where they are not available. The cost is too much, please do find a cure and make it affordable to the poor.
James from Nigeria	It's not been easy for me since I tested positive for the hepatitis B infection. Fake drugs are everywhere, and I don't know the right one to take. I am just hoping to be free from this.
Honesty from Nigeria	Living with chronic hepatitis B is not easy. The cost of the available medication for treatment is not encouraging. Most people with chronic hepatitis B end up not receiving treatment due to the high cost of available drugs for treatment which in turn leads to increase in viral load of the carrier and also increase in spread of the virus. It will be a great achievement if Hepatitis B drug is given free as that of HIV/AIDS. It will go a long way in making treatment accessible to those who cannot afford the present cost of treatment thereby placing more people on treatment and at same time reducing the spread of the virus due to adequate treatment given to the carriers. Thanks for your consideration.
Innocent from Tanzania	Losing surface antigen or seroconversion is all I need right now.

8. If you were to enroll in a clinical trial for an experimental hepatitis B medication, what routes of administration and what length of treatment would you be willing to accept? What side effects, if any, would you be willing to tolerate?

Victor from Nigeria	I think if life insurance is given to patients with the hepatitis B virus for drug trials a lot of people will be willing to take trial drugs since most patients are adults who have dependents.
Halit from Belgium	Any length would be okay as long as the clinical trial gives me the confidence that my life is not in danger.
Joe from California	Having spent much of the last 7 years in a clinical trial on the opposite side of the country from my home, it would be so much easier if some of the testing or some of the trial visits could be conducted at a cooperating research institution close to home rather than at the main research institute that requires 12 hours of travel one way.

<p>Maureen from Maryland</p>	<p>When my daughter was being treated, her situation was grim and debating treatment and associated side effects was not an option. She needed treatment.</p> <p>A pill or combination of pills taken daily for a finite period of time is optimal. Injectables which can be self-administered are also reasonable. Infusions and the time and travel necessary, make it much less tolerable. ALT flares would be acceptable and expected, as monitoring should ensure patient safety. Hopefully, symptoms would wane with the course of treatment and be tolerable. Long term protocols would be challenging if symptoms kept an individual from working and participating in daily life activities. There would need to be a high probability for a functional cure.</p>
<p>DeWayne from Georgia (U.S.)</p>	<p>I would be willing to participate in a clinical trial if it will help me live longer, even if for one or two years. Because that is more time to spend with my child and wife. My goal is to see my child graduate and to be able to take care of himself.</p> <p>For this goal, I am willing to accept any route of administration and any side-effects, including mild side effects, like headache and mild nausea, or moderate – mild to moderate flu-like symptoms, or fatigue for a couple of days.</p> <p>This all depends on whether this is just another anti-viral, or a new therapy that would achieve at least functional cure. I would do anything that can help prolong my life, and also help find a cure for this disease.</p>
<p>Chris from Maine</p>	<p>According to the AMA, "There is widespread and persistent under-representation of minority communities in national clinical trials." This lack of representation could have direct implication on the efficacy of future hepatitis B treatments.</p> <p>To increase representation in hepatitis B clinical trials, "trusted sources must be enlisted to help educate and recruit under-represented groups; and barriers like transportation, time off work, and childcare must be addressed to ensure full participation."</p> <p>Time and effort must also be made to involve physicians serving these historically under-served communities who are at high risk of hepatitis B in America, including Asian and Pacific-Islander and African immigrant families, who have staff who speak appropriate languages to fully inform them of all aspects of a clinical trial.</p>
<p>Raj from California</p>	<p>I would be open to any route of administration for a long duration (+1 year) with the caveat that the treatment would not be worse than the disease. I'm not willing to</p>

	<p>participate if there is a risk or probability of the treatment making me sick or causing my disease to accelerate. I would be willing to accept mild side effects as long as they do not negatively impact my long-term liver health.</p>
Karin from California	<p>It would depend very much on what the expected end point of the new medication would be. Temporary ALT flares, and transient, reasonably tolerable side effects would be a worthwhile price to pay for a treatment that results in surface antigen seroconversion or even permanent suppression of liver inflammation after cessation of treatment.</p> <p>But after having lived with Hepatitis B for 65 years, I would not want to endure any significantly uncomfortable side effects or take risks of long-term side effects.</p> <p>If I were younger or in a position of having less secure medical insurance, I would be willing to take somewhat more risks for a chance at a complete cure. The type of and length of administration would be a very secondary consideration for me. I would patiently take a daily medication that led to surface antigen seroconversion for several years if necessary.</p>
Innocent from Tanzania	<p>I am more than willing to participate in clinical trial and will bear any risks of side effects.</p>
Mai from Pennsylvania	<p>Less than a year and minimum side effects are ideal.</p>
Anonymous from Canada	<p>Routes and length don't matter much, as long as I am able to work normally I can take treatment.</p>
Kus from India	<p>I will tolerate anything any as long as side effects don't affect work.</p>
Stephen from Australia	<p>Practical aspects of the trial - the methods of delivery of the trial drugs, how often, and for how long would influence a patient's decision. Not all patients can afford the time required off work.</p> <p>The financial aspect - since drugs like PegIFN are very expensive in China, many patients are enticed by the promise of free Interferon treatment and would join a trial involving Interferon. The promise of frequent tests during the trial is also attractive to a patient who cannot afford some of the medical tests or drugs.</p>

The medical benefits - in Australia, patients are usually under the care of HBV specialists who would have a good history of the patients. Invitations to a clinical trial are usually initiated by the specialists who are able to explain the medical pros and cons to the patients. So, patients would rely on and are heavily influenced by their doctor.

Also, most Chinese patients I know are averse to being a "guinea pig". They would weigh the cost and benefit of the clinical trial before deciding.