

Hepatitis B Cure Campaign 2020 Progress Report

Introduction

The World Health Organization (WHO) has set 2030 as a goal for the elimination of viral hepatitis. This calls for 90% and 65% reductions in new viral hepatitis infections and death, respectively. Currently, the strategies towards this goal include a combination of prevention through vaccination for hepatitis B, increased testing with linkage to care, and increased use of curative treatments for hepatitis C virus and viral suppression with current hepatitis B antivirals. While this is a laudable goal, these strategies alone will not get us to global elimination. There are 292 million people worldwide chronically infected with hepatitis B and up to 2.2 million in the U.S. Current treatments are not curative, they require long-term antiviral therapy, and they are not recommended for all those chronically infected. Curative therapies for hepatitis B are critically needed to help reach global elimination goals, and to save lives.

In 2016, the Hepatitis B Foundation launched the <u>Hepatitis B Cure Campaign</u>, to promote and advocate for an aggressive and vigorous research agenda to find a cure for chronic hepatitis B infection. With a renewed scientific interest and recent advances in technology, there is increasing optimism in the scientific community that a cure is possible. The goal of the *Cure Campaign* is to create a sense of urgency and political will to significantly increase federal funding opportunities for hepatitis B cure research.

The *Hepatitis B Cure Campaign* is a unique program ensuring that the 292 million people with chronic hepatitis B are not forgotten. For the past 29 years, the Hepatitis B Foundation has remained a constant voice advocating to prioritize hepatitis B and the people impacted worldwide, and we will remain committed to advocating for a cure for as long as that voice is needed.

This report outlines the 2020 activities, progress and successes of the Hepatitis B Cure Campaign.

Strategies

The *Hepatitis B Cure Campaign* takes a multi-faceted approach. This includes:

- Developing report language and meeting with legislators and federal leaders at the NIH, CDC and FDA throughout the year.
- Convening scientific, public health and clinical leaders to discuss innovative approaches to finding a cure and improving treatment access for people with hepatitis B.
- Hosting public awareness events around the U.S., including Congressional briefings, to promote awareness and engagement, and keep hepatitis B in the federal spotlight.
- Publishing scientific papers, letters to the editors, white papers, and position pieces regarding hepatitis B screening, vaccination and treatment.
- Conducting policy and economic analyses on matters relevant to hepatitis B treatment research and access.
- Communicating findings through professional conferences and meetings, e-newsletters, and social media.
- Growing a grassroots movement to respond to Calls to Action pertaining to hepatitis B.



As the COVID-19 pandemic grew throughout 2020, we transitioned our *Cure Campaign* and public policy and activities to virtual, but did not reduce any of our activities. In fact, we pushed through to ensure that those with hepatitis B and liver cancer remained a priority group for federal research and policy — and we are working to ensure that those with hepatitis B and liver cancer have the information and support they need to navigate the COVID-19 pandemic. Below, you can find updates on our 2020 activities and outcomes examples of our public policy and *Cure Campaign* outcomes and activities:

Federal Funding for Hepatitis B and Liver Cancer

 HBF continued to advocate for increased federal funding through NIH and CDC for

hepatitis B and liver cancer, through report language, and virtual Congressional visits and letters to Congressional champions throughout the year. We were instrumental in the CDC Division of

Viral Hepatitis receiving an additional \$500,000 for FY22.

• In July 2020, we hosted a Hepatitis B Week of Action. Every day for a week, we worked with partners to conduct advocacy events. These included hosting virtual meetings with legislators and staff, conducted letter writing campaigns to prioritize hepatitis B and liver cancer research, and hosted educational and training webinars for over 300 advocates and partners.



NIH FUNDING FOR HEPATITIS B RESEARCH

Although hepatitis B is preventable and treatable, there is still no cure for this disease. In addition to the devastating toll on patients and their families, ignoring hepatitis B costs the U.S. an estimated \$4 billion per year in medical costs. Yet, the NIH will spend only \$66 million in FY 2021 on hepatitis B research.

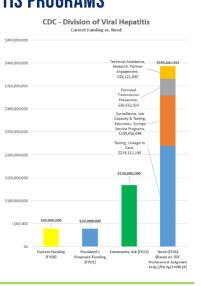
- Without early diagnosis and intervention, 1 in 4 people chronically infected with HBV will die prematurely from cirrhosis, liver failure, or liver cancer.
- Despite the availability of 7 approved medications to manage chronic HBV infection, none are curative, most require lifelong use, and they only reduce the likelihood of death due to liver disease by 40-60%.
- There are exciting new research developments and opportunities in the field that make finding a cure very possible.
- The hepatitis B research community convened a virtual consensus conference to prepare a <u>Roadmag for a Cure</u> that identifies the most urgent research questions that must be answered to find a cure for hepatitis B, and a panel of experts developed a professional judgment budget.

In order to pursue the critical research opportunities identified in the Roadmap for a Cure and to help eliminate hepatitis B once and for all, we recommend increasing NIH funding for hepatitis B research by an average of \$38.7 million a year for 6 years, or \$232.3 million total over 6 years.

CDC FUNDING FOR VIRAL HEPATITIS PROGRAMS

CDC's viral hepatitis prevention and surveillance programs are severely underfunded and underprioritized.

According to a December 2016 professional judgment budget, a comprehensive, national program to eliminate viral hepatitis, including hepatitis B, would require approximately \$3.9 billion over 10 years. The current CDC funding level for viral hepatitis is only \$39 million.



• We continue to make strides in ensuring that both hepatitis B and liver cancer are represented in the Department of Defense biomedical research (DOD) funded programs. In 2020, we successfully advocated, for the fifth year in a row, for hepatitis B to be included in the DOD Peer Review Medical Research Program and liver cancer to be included in the DOD Peer Review Cancer Research Program. The opportunities for submitting research proposals open spring 2021, and the HBF will be disseminating the opportunities widely through our networks, to academic and nonprofit researchers. This continues to be an important source of funds furthering cure research: since its initial inclusion, over \$4.1 million has been

awarded to hepatitis B grants and over \$21 million has been awarded for liver cancer research.



• In 2019, HBF successfully advocated for the creation of a think tank to strategically implement hepatitis B cure research. The Trans-NIH Hepatitis B Working Group, created in 2019, published the first <u>Strategic Plan to Cure Hepatitis B</u>, creating a blueprint for additional research funding. In 2020, we advocated for the Working Group to continue their work together, for the Strategic Plan to be funded at the federal level, and for the NIH to provide updates on progress towards implementing activities of the plan.

Addressing Hepatitis B Discrimination

- In January of 2020, HBF co-hosted a meeting with the HHS Assistant Secretary for Health and CDC Director, outlining our top federal hepatitis B priorities, and urging them to take action. In response, the HHS Assistant Secretary for Health designated hepatitis B-related healthcare discrimination as a top 2020 priority for HHS. We worked with HHS Office of Infectious Disease and HIV/AIDS Policy (OIDP) throughout 2020. In November 2020, this work culminated in an officially signed and updated letter confirming that healthcare students and professionals in the U.S. cannot be discriminated against. This is a big win, as we still receive 15-20 discrimination complaints each year.
- In 2020, we also completed a template health care school admissions model policy, based on CDC guidelines, for healthcare professions programs, to be used as a guide to managing healthcare students who have hepatitis B.

State-Level Elimination Work

 In 2020, HBF advocated for inclusion of hepatitis B in state viral hepatitis elimination plans, and provided technical assistance and training to partners around the U.S. to engage in state-wide elimination planning. We also co-chair the PA Elimination Plan and the PA Hep Free advocacy coalition.

Vaccine Advocacy

In 2020, HBF created a new full-time position dedicated to prevention policy. The Prevention Policy Manager represents hepatitis B at national and state immunization coalitions, attends and provides written and oral comments at ACIP meetings, drafts vaccine-



related policy papers and report language, analyzes state and federal vaccine policy, partners with high-risk communities to discuss vaccination strategies, and provides education and awareness about the importance of universal adult hepatitis B vaccination in the U.S.



On April 30, 2020, which is designated Adult Hepatitis B Vaccination Awareness Day, HBF hosted
a Congressional Briefing to educate legislators and staff on the importance of vaccinating adults
for hepatitis B. We had over 50 legislative staff and partners attend.



A REPORT ON HEALTH INSURANCE TRENDS IN THE UNITED STATES THAT MAY INCREASE THE COST OF HEPATITIS B TREATMENTS

Treatment Access

- We completed an analysis of 68 health insurance plans in 24 states and developed a new tool for all people with hepatitis B in the U.S., to help them choose a health insurance that would cover their hepatitis B antiviral medications, to avoid having to pay thousands of dollars out of pocket. The tool, Health Insurance Costs Impacting Shoppers Living with Hepatitis B, is available online and is being disseminated through partners in 22 states around the U.S.
- HBF supported legislation, including the Liver Act, to improve access to hepatitis B screening, care and treatment.

Plans for 2021

- HBF will continue to advocate for increased federal funding for hepatitis B and liver cancer. This will include writing and submitting report language for FY22, conducting virtual Hill Visits with Congressional champions, meeting with NIH and CDC leaders, and hosting virtual advocacy events in July and throughout the year.
- HBF is focusing on providing advocacy and support, and creating a national movement to support CDC/ACIP

publishing and implementing universal hepatitis B vaccination, and universal hepatitis B screening guidelines. It is time we had national hepatitis B screening and vaccine guidelines that will be more effective in improving rates of hepatitis B testing and adult vaccination in the U.S.

- HBF will continue to support legislation that will improve vaccination, screening, care, and quality of life for those at risk for, or living with, hepatitis B.
- HBF has launched a statewide grassroots advocacy training and engagement program. We are
 training patients, advocates, providers and researchers to become local advocates for hepatitis B,
 addressing key goals within their city/state. We will be training them on how to advocate for
 support from city councils and state legislatures, completing statewide viral hepatitis elimination
 plans, change policy and practice to improve vaccination rates, and address barriers to treatment
 access in their state.
- HBF will continue to work on hepatitis B discrimination issues associated with drug access and healthcare students/professionals. We will be convening a new working group of medical and nursing students throughout the U.S. to help put pressure on health professions schools to abide by the ADA guidelines and implement appropriate policies for health care students with hepatitis B.