FY 2017 Budget impact on Liver Diseases

The Federal budget is a manifestation of our national priorities. The Fiscal Year 2017 Budget proposal by the White House does provide increased funding for both CDC and HRSA’s viral hepatitis activities, but in no way matches the scope of the epidemic across the country. For additional analysis and information:

Georgetown University Law Center O’Neill Institute on FY17 Budget and Viral Hepatitis: http://www.oneillinstituteblog.org/5433-2/

NVHR on FY17 Budget and Viral Hepatitis: http://nvhr.org/content/nvhr-press-release-presidents-budget-fails-address-severity-viral-hepatitis-epidemic


POLICY PERSPECTIVE

Welcome to the inaugural issue of the Global Liver Institute (GLI) Health Policy Update. GLI is committed to providing the entire liver community with tools to help elevate liver health, liver diseases, and liver patients to the top of the public health agenda commensurate with our prevalence and impact. Improving outcomes for people at risk for or currently living with more than 100+ different types of liver disease will be the culmination of advances in both the clinical and legal realms. This monthly update is intended to curate events, opportunities, and resources around liver health policy, broadly defined, to assist long-serving advocates and empower new ones. Please let us know if you find this of value and let us know if there is a policy event or issue that we should feature in the next issue. We can be reached at policy@globalliver.org.

Donna R Cryer, JD
President & CEO, Global Liver Institute

ON THE HILL

The Veteran’s Administration is the largest treater of Hepatitis C in the nation. The FY16 omnibus bill approved includes $3 billion allocated towards treating veterans with hepatitis C over the next two years. You can learn more about this unprecedented Hep C campaign for Veterans at Viral Hepatitis and Veterans http://thehill.com/blogs/congress-blog/healthcare/264727-historic-achievement-for-veterans-in-the-fight-against

Chronic care stakeholders across the United States have submitted their Chronic Care innovations and recommendations to improve care for Americans battling chronic conditions. To learn more about each individual submission, please visit: Senate Finance Committee Chronic Disease Working Group http://www.finance.senate.gov /legislation/details/chronic-care-working-group-submissions

Think about the Link’s virally-Induced Cancers Campaign has been launched to raise awareness of prevention strategies focused on: human papillomavirus (HPV), hepatitis B and hepatitis C. The campaign aims to increase people’s understanding of the link between viruses, certain cancers and how to reduce the risk that these viruses will lead to cancer. To learn more about the campaign and how to join, visit PreventCancer.org http://preventcancer.org /news-releases/prevent-cancer-foundation-launches-think-about-the-link-campaign/

Strategy for the Elimination of Hepatitis B and C is moving forward after conducting a two-phase meeting to develop reports on the feasibility of elimination, and a strategy to reach the goals identified in the elimination plan. To learn more about the upcoming reports, please view: IOM Viral Hepatitis: http://iom.nationalacademies.org/Activities/PublicHealth/NationalStrateg yfortheEliminationofHepatitisBandC.aspx

NGOS

The Institute of Medicine is entertaining several ongoing and potential upcoming studies to address a portfolio of liver diseases. The Committee on a National

continued →
educate on prevention and treatment of Hep C. In addition, the meeting will review recommendations from the previous summits. To learn more about the event and how to participate, visit: http://nhmamd.org/index.php/programs/hepatitis-c

In conjunction with Rare Disease Day on Monday, February 29, 2016, the National Organization for Rare Disorders (NORD) will host State House Events in 35 states, to provide the rare disease community the opportunity to meet with their state’s elected officials and advocate for legislation that directly affects the community. A full list of the current states participating and registration information is available on NORD’s website.

America’s Health Insurance Plan’s (AHIP) has launched Medicare Advantage Care Coordination (MACC) Task force. The MACC is a collaborative effort aimed to identify and raise awareness of best-in-class care coordination practices and policies. To learn more, visit: http://medicarechoices.org/partners/

GLOBAL

Starting on February 16th, the World Hepatitis Alliance’s Tools for Change is launching a three-part webinar series to provide guidance to patient advocates on tools available to effectively lobby for change. The webinar is focused on viral hepatitis but can be applied to any disease area. To learn more about the webinar topics and register, please visit: worldhepatitisalliance.org/en/tools-change-webinar-series-enhance-power-patient-advocacy

HHS NEWS

FDA

WATCH: American Association for the Study of Liver Diseases (AASLD)/ U.S. Food and Drug Administration (FDA) Conference on Trial Design and Endpoints for Clinical Trials in Adults and Children with Primary Sclerosing Cholangitis (PSC). The conference will be on livestream on March 3-4. To access the livestream, visit: https://www.aasl.org/events-professional-development/aasl-fda-primary-sclerosing-cholangitis-great-program

To expand the number of disease areas addressed in the Patient-Focused Drug Development initiative (PFDD), the U.S. Food and Drug Administration (FDA) welcomes patient advocacy organizations to organize externally-led PFDD meetings.

The FDA recommends submitting a Letter of Intent (LOI), guidelines for which are available here. If your organization is interested, please submit your LOI to patientfocussed@fda.hhs.gov. To read more about the externally-led PFDD meetings, please visit the FDA’s website.

NIH

JOIN: Friends of National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) Coalition has been formed to elevate the profile of NIDDK’s robust research portfolio which supports large-scale research projects in the areas of intestinal stem cells, gene therapies, gastroapiesis and ulcerative colitis in adults and children.

To join the Friends of NIDDK, please contact Jonathan Heppen at jonathan.heppen@dbrc.com or Jerrica Mathis at Jerrica.mathis@dbrc.com.

The National Institutes of Health (NIH) will host Rare Disease Day at NIH, on Monday, February 29, 2016, from 8:30 AM – 3:30 PM, EST in Bethesda, MD. At this event, panelists will aim to raise awareness about rare diseases, affected patients, and address challenges faced in the rare disease community. Additional information about this event is available here. If you would like to participate, please register here. Please note, the event is free to attend.

CDC

Frieden State of Public Health 2016, addresses the need for attention on threat of vector-borne diseases and the impact of climate change on states. His message missed the opportunity to highlight the crucial need for more targeted prevention and treatment efforts towards viral infections impacting Americans such as hepatitis B and C. You can read more on Frieden State’s address here: http://www.publichealth-news.org/?p=14449

The CDC released their Morbidity and Mortality Weekly Report (MMWR) focused on the Hepatitis A virus (HAV), titled Progress Toward Eliminating Hepatitis A Disease in the United States. The report examines the temporal association of Advisory Committee on Immunization Practices (ACIP)-recommended Hep A vaccination and disparities in cases of HAV disease and on seroprevalence of HAV-related protection. You can read the article in full on the CDC website: http://www.cdc.gov/mmwr/volumes/65/su/su6501a6.htm?chid=su6501a6