Issue No. 1 2016 February



Health Policy Update

Liver Matters for Advocates

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-releasepresidents-budget-fails-address-severity-viralhepatitis-epidemic

Learn more about NIH's budget request for FY 2017 by viewing their Budget Slides here: http://www.nih.gov/sites/default/files/aboutnih/nih-director/budget-requests/fy17-budgetrollout-slides-20160209.pdf

POLICY READS & OTHER RESOURCES

FDA Sign Up for Information on Advisory Committees

http://www.fda.gov/AdvisoryCommittees/ Calendar/default.htm

NCI Council of Research Advisors

http://deainfo.nci.nih.gov/advisory/ncra/ncra.htm

CDC Viral Hepatitis (includes CMS letter to State Medicaid Directors) http://www.cdc.gov/hepatitis/index.htm

NASTAD Health System Integration

https://www.nastad.org/blog/introducingnastads-health-systems-integration-team

Legal Epidemiology

http://www.cdc.gov/phlp/news/current.html

CONTENT CONTRIBUTIONS WELCOME!

Contact policy@globallliver.org to send relevant content for our next issue.

GLI Health Policy Update is a monthly online newsletter produced by the Global Liver Institute. Contact policy@ globalliver.org for more information. Follow us on



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

NGOS

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 Crver, 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-achievementfor-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-workinggroup-submissions

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 vfortheEliminationofHepatitisBandC.aspx

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/

On February 11th, the National Hispanic Medical Association: Viral Hep in Hispanics is held their 4th and final Hepatitis C and Hispanics Leadership Summit. The summit aims to continue its discourse on barriers to and necessary strategies for programs that

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FOR YOUR CALENDAR

Feb 29 Rare Disease Day marks the ninth international Rare Disease Day coordinated by EURORDIS. This year the theme is 'Patient Voice' which recognizes the crucial role that patients play in voicing their needs and in instigating change that improves their lives and the lives of their families and carers. Click here to learn more on how to raise awareness of this event.

March 3-4 AASLD/FDA PSC meeting

March 6-7 Digestive Disease National Coalition The 2016 DDNC Public Policy Forum will be held Sunday, March 6 and Monday, March 7 in Washington, DC. Join patients, health care providers, industry representatives, lawmakers and their legislative staff for two days of educational programs, legislative updates and advocacy training. Click here to learn more.

March 14 NPC Webinar: 2:00 - 3:00PM ET NPC Webinar: 2016 CFR and the Environment for Health Care Decision-Making. Click here for details.

March 17 Webinar: How PCORI Is Changing Healthcare. Click here for details.

April 6 AASLD Liver Capitol Hill Day

April 16-20 American Association for Cancer Research (AACR) Annual Meeting, New Orleans http://www.aacr.org/Meetings/Pages/MeetingDetail.aspx?EventItemID=63&DetailItemID=36 6#.VsUcuVLG8y9

UNOS meetings

https://www.unos.org/events/list/?tribe paged= 3&tribe event display=list March 7, RVA Career Expo 10am-2pm, Glen Allen, VA March 8, Annual Meeting of Members 11:00 am - 11:30 am, Richmond, VA March 8, OPTN/UNOS Histocompatibility Committee Teleconference, 12-1pm March 8, OPTN/UNOS UNOS Ad hoc Disease Transmission Advisory Committee Teleconference, 4-5pm March 9, OPTN/UNOS Region 9 Meeting New York, NY

GRANT OPPORTUNITIES

PCORI Engagement Awards:

http://www.pcori.org/content/engagementaward-application-process

Intercept's Practice to Policy Health **Awards Program:** March 4th deadline www.interceptpracticetopolicy.com



Richard Wolitski, Acting Director, Office of HIV/AIDS and Infectious Disease Policy, HHS

Don Graves, JD. Domestic Policy & Economic Advisor, VP Biden – in charge of Moonshot http://www.statnews.com/2016/02/10/bidengraves-cancer-moonshot/

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/



🏝 G L O B A L

Starting on February 16th, the World Hepatitis Alliance Tools for Change is launching a three-part webinar series to provide quidance 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: http://worldhepatitis alliance.org/en/tools-change-webinarseries-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.aasld. org/events-professional-development/ aasld-fda-primary-sclerosing-cholangitisgreat-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 patientfocused@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, gastroparesis and ulcerative colitis in adults and children.

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

Friedan 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 Friedan State's address here: http://www.publichealthnewswire.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?s cid=su6501a6.htm w