

ONE HUNDRED FOURTEENTH CONGRESS
Congress of the United States
House of Representatives
COMMITTEE ON ENERGY AND COMMERCE
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MEMORANDUM

September 6, 2016

To: Subcommittee on Health Democratic Members and Staff
Fr: Committee on Energy and Commerce Democratic Staff
Re: Hearing on “Examining Legislation to Improve Public Health”

On Thursday, September 8, 2016 at 10:00 a.m. in Room 2322 of the Rayburn House Office Building, the subcommittee will hold a legislative hearing titled “Examining Legislation to Improve Public Health.” The legislative measures under review at the hearing include H.R. 1807, Sickle Cell Disease Research, Surveillance, Prevention, and Treatment Act of 2015; H.R. 3952, Congenital Heart Futures Reauthorization Act of 2015; H.R. 1192, National Diabetes Clinical Care Commission Act; H.R. 1717, Sober Truth on Preventing Underage Drinking Reauthorization Act; and H.R. 3119, Palliative Care and Hospice Education and Training Act.

**I. H.R. 1807, SICKLE CELL DISEASE RESEARCH, SURVEILLANCE,
PREVENTION, AND TREATMENT ACT OF 2015**

A. Background

Sickle cell disease (SCD) is a group of inherited red blood cell disorders that affect about 100,000 Americans.¹ The disease causes red blood cells to change from their healthy round shape into a crescent or sickle shape. Sickle cell disease is a lifelong condition which can cause severe pain and other complications such as infection, organ damage, or stroke.

Sickle cell anemia is the most common and often the most severe form of sickle cell disease. Anemia occurs when there are not enough healthy red blood cells to carry a sufficient

¹ Centers for Disease Control and Prevention (CDC), *Sickle Cell Disease (SCD) Data & Statistics* (Aug. 31, 2016) (online at <http://www.cdc.gov/ncbddd/sicklecell/data.html>).

amount of oxygen throughout the body.² Red blood cells contain a protein called hemoglobin that is necessary for the circulation of oxygen throughout the body. Individuals with sickle cell disease are born with two abnormal hemoglobin genes, one from each parent. Individuals who inherit only one abnormal hemoglobin gene are carriers of the sickle cell trait and generally do not experience any complications.³

The treatment of sickle cell disease requires comprehensive and often costly care. Federal spending data shows that in 2005, medical expenditures for children with SCD averaged \$11,702 for children enrolled in Medicaid and \$14,772 for children with employer-sponsored coverage.⁴

In the United States, sickle cell disease most commonly affects blacks, due to the fact that the sickle cell gene is especially prevalent in families whose ancestors came from Africa.⁵ Symptoms of sickle cell disease often begin in children in their first year of life. Studies show that more than 90 percent of children with sickle cell disease in the United States and the United Kingdom survive into adulthood, however their life expectancy is still two to three decades shorter compared to the general population.⁶

Transitioning from pediatric SCD care to adult SCD care has shown to be associated with increased hospital admissions and medical complications for a variety of reasons. For instance, SCD poses greater risks in adulthood and there are typically fewer adult SCD programs available compared to pediatric programs. Furthermore, young adults may have greater difficulty practicing self-management of their disease.⁷

B. Sickle Cell Disease Treatment Demonstration Program

Section 712 of the American Jobs Creation Act of 2004 led to the authorization of the Sickle Cell Disease Treatment Demonstration Program. The law directed the Health Resources and Services Administration (HRSA) to make grants available to up to 40 entities for the purpose of improving the prevention and treatment of sickle cell disease.

² Mayo Clinic, *Sickle Cell Anemia Definition* (June 11, 2014) (www.mayoclinic.org/diseases-conditions/sickle-cell-anemia/basics/definition/con-20019348).

³ Mercy Mvundura et al., *Health care utilization and expenditures for privately and publicly insured children with sickle cell disease in the United States*, *Pediatric Blood & Cancer* (June 2009) ([www.ncbi.nlm.nih.gov/pubmed/19492318?log\\$=activity](http://www.ncbi.nlm.nih.gov/pubmed/19492318?log$=activity)).

⁴ *Id.*

⁵ CDC, *Sickle Cell Disease (SCD) Data & Statistics* (Aug. 31, 2016) (www.cdc.gov/ncbddd/sicklecell/data.html).

⁶ National Heart, Lung, and Blood Institute, *Evidence-Based Management of Sickle Cell Disease Expert Panel Report* (2014) (www.nhlbi.nih.gov/sites/www.nhlbi.nih.gov/files/sickle-cell-disease-report%20020816.pdf).

⁷ National Heart, Lung, and Blood Institute, *How Is Sickle Cell Disease Treated?*, (Aug. 2, 2016) (www.nhlbi.nih.gov/health/health-topics/topics/sca/treatment).

C. H.R. 1807, Sickle Cell Disease Research, Surveillance, Prevention, and Treatment Act of 2015

Representative Danny Davis (D-IL) and Representative Michael Burgess (R-TX) introduced H.R. 1807, the Sickle Cell Disease Research, Surveillance, Prevention, and Treatment Act of 2015 on April 15, 2015. This legislation would reauthorize the Sickle Cell Disease Treatment Demonstration Program; allow the Secretary of Health and Human Services to conduct or support research to help increase understanding of sickle cell disease; and create a grant program that would support states in conducting surveillance on the prevalence and distribution of the disease, conduct public health initiatives, or to identify and evaluate prevention and treatment strategies.

II. H.R. 3952, CONGENITAL HEART FUTURES REAUTHORIZATION ACT OF 2015

A. Background

Congenital heart diseases (CHDs), also referred to as congenital heart defects, are problems with the structure of the heart present at birth. Congenital heart defects are the most common type of birth defect, with approximately 40,000 babies in the United States born with a congenital heart defect each year.⁸ It is estimated that about one million children and 1.4 million adults in the United States live with congenital heart defects.⁹

Congenital heart defects range in severity and are generally diagnosed before or soon after birth. Some individuals are not diagnosed with CHD until later on in life. Health care professionals often do not know the cause of congenital heart disease. However, several genetic and environmental factors have been linked to the disease. For example, half of all babies with Down syndrome have a congenital heart defect and smoking during pregnancy may lead to certain congenital heart defects.¹⁰

As a result of advances in technology and treatments, babies born with congenital heart disease now have a far greater chance of survival. Today, a child born with a congenital heart defect has about a 90 percent chance of surviving, compared to only a 20 percent chance in

⁸ CDC, *Congenital Heart Defects (CHDs) Data & Statistics* (Aug. 1, 2016) (www.cdc.gov/ncbddd/heartdefects/data.html).

⁹ Suzanne M. Gilboa et al., *Congenital Heart Defects in the United States: Estimating the Magnitude of the Affected Population in 2010*, *Circulation* (July 5, 2016) (circ.ahajournals.org/content/early/2016/06/30/CIRCULATIONAHA.115.019307).

¹⁰ National Heart, Lung, and Blood Institute, *What Causes Congenital Heart Defects?* (July 1, 2011) (www.nhlbi.nih.gov/health/health-topics/topics/chd/causes).

1950.^{11,12} Individuals living with CHDs may be at risk of developing health problems such as heart failure, arrhythmias, stroke, or liver disease.¹³

B. The Congenital Heart Futures Act

The Congenital Heart Futures Act was first introduced in 2009, and passed as part of the Affordable Care Act in 2010. The bipartisan legislation established a National Congenital Heart Disease Surveillance System at the Centers for Disease Control and Prevention (CDC) and called for increased lifelong congenital heart disease research at the National Institutes of Health (NIH).

C. H.R. 3952, Congenital Heart Futures Reauthorization Act of 2015

Representatives Bilirakis (R-FL), Schiff (D-CA), and Holmes Norton (D-DC) introduced H.R. 3952, the Congenital Heart Futures Reauthorization Act of 2015 on November 5, 2015. H.R. 3952 builds on existing efforts by requiring the CDC to enhance and expand its research, surveillance infrastructure, and public outreach and education programs relating to congenital heart disease. The bill directs CDC to submit one or more reports to Congress on a cohort study to improve knowledge of the epidemiology of congenital heart disease across human lifespans. The report should consider the role of factors such as health care utilization, demographics, and outcome measures. The bill also directs CDC to implement an awareness, outreach, and education campaign for CHD.

III. H.R. 1192, NATIONAL DIABETES CLINICAL CARE COMMISSION ACT

A. Background

More than 29 million Americans are living with diabetes.¹⁴ Another 86 million Americans are living with pre-diabetes, which is characterized by elevated blood glucose levels.¹⁵ Total U.S. costs associated with diagnosed cases of diabetes totaled \$245 billion in

¹¹ National Heart, Lung, and Blood Institute, *Congenital Heart Disease* (Sept. 2011) (www.nhlbi.nih.gov/news/spotlight/success/congenital-heart-disease).

¹² CDC, *Congenital Heart Defects (CHDs) Data & Statistics* (Aug. 1, 2016) (www.cdc.gov/ncbddd/heartdefects/data.html).

¹³ CDC, *Congenital Heart Defects (CHDs) Living with a Congenital Heart Defect*, (May 18, 2016) (www.cdc.gov/ncbddd/heartdefects/living.html).

¹⁴ CDC, *Chronic Disease Prevention and Health Promotion: Diabetes* (July 25, 2016) (www.cdc.gov/chronicdisease/resources/publications/aag/diabetes.htm).

¹⁵ *Id.*

2012, including \$176 billion for direct medical costs.¹⁶ According to CDC, more than 20 percent of healthcare spending is for people with diagnosed diabetes.¹⁷

Diabetes is a group of diseases that can result from metabolic disorders. Diabetes is characterized by hyperglycemia or high blood glucose due to the body's inability to use blood glucose for energy.¹⁸ Metabolic disorders occur when there is a disruption in the human body's biochemical processes that recruit digestive system chemicals to convert food into energy by breaking food down into sugars and acids.¹⁹ There are different groups of metabolic disorders -- some affect the breakdown of amino acids, carbohydrates, or lipids while others affect the mitochondria, the parts of cells that produce energy.²⁰

There are two types of diabetes – Type 1 and Type 2. Type 1 diabetes occurs when the body does not produce insulin.²¹ Type 2 diabetes occurs when the body does not use insulin properly. Type 1 diabetes is most often diagnosed in young people while the more common Type 2 most often develops in middle-aged and older adults.²² Pregnant women can develop high blood glucose levels, referred to as gestational diabetes, when their bodies do not produce and use all the insulin needed for pregnancy.²³ Gestational diabetes generally goes away after pregnancy.²⁴

B. H.R. 1192, National Diabetes Clinical Care Commission Act

¹⁶ American Diabetes Association, *Statistics About Diabetes: Overall Numbers, Diabetes, and Pre-diabetes* (Apr. 1, 2016) (www.diabetes.org/diabetes-basics/statistics/?loc=db-slabnav?referrer=http://www.diabetes.org/diabetes-basics/gestational/what-is-gestational-diabetes.html).

¹⁷ CDC, *Chronic Disease Prevention and Health Promotion: Diabetes* (July 25, 2016) (www.cdc.gov/chronicdisease/resources/publications/aag/diabetes.htm).

¹⁸ CDC, *Glossary of Terms* (Oct. 29, 2014) (www.cdc.gov/diabetes/library/glossary.html#d).

¹⁹ Medline Plus, *Metabolic Disorders* (Aug. 23, 2016) (medlineplus.gov/metabolicdisorders.html).

²⁰ *Id.* For example, phenylketonuria or PKU is a type of metabolic disorder that affects the breakdown of amino acids. Individuals with PKU cannot process part of the protein phenylalanine which is present in most foods. Some other disorders result from when digestive organs become diseased or do not function properly.

²¹ American Diabetes Association, *Type 1 Diabetes* (www.diabetes.org/diabetes-basics/type-1/?loc=db-slabnav).

²² CDC, *Glossary of Terms* (Oct. 29, 2014) (www.cdc.gov/diabetes/library/glossary.html#d).

²³ American Diabetes Association, *What is Gestational Diabetes?* (June 20, 2014) (www.diabetes.org/diabetes-basics/gestational/what-is-gestational-diabetes.html).

²⁴ American Diabetes Association, *How to Treat Gestational Diabetes?* (Apr. 29, 2014) (www.diabetes.org/diabetes-basics/gestational/how-to-treat-gestational.html?loc=db-slabnav).

Representative Olson (R-TX) introduced H.R. 1192 on March 2, 2015. The original version of H.R. 1192 would have created a national commission focused on improving clinical care for individuals with diabetes and associated conditions. We expect the Committee to consider an amended version of H.R. 1192 which would create a national commission focused on improving clinical care for individuals with metabolic disorders. The commission would be comprised of governmental and nongovernmental members and charged with duties and responsibilities to improve Federal efforts relating to metabolic disorders. Under the bill, the commission is directed further to issue a final report not later than three years after the date of the Commission's first meeting.

IV. H.R. 1717, SOBER TRUTH ON PREVENTING UNDERAGE DRINKING REAUTHORIZATION ACT

A. Background

Although the number of underage youth who currently consume alcohol has declined since 2006,²⁵ alcohol remains the most commonly used and abused substance among youth.²⁶ According to the 2014 National Survey on Drug Use and Health, almost 23 percent of underage individuals were alcohol users and almost 14 percent were binge alcohol users.²⁷ In fact, individuals between the ages of 12 and 20 years old consume 11 percent of all alcohol consumed in the United States.²⁸

The use and abuse of alcohol by underage youth has negative consequences. Each year, approximately 4,300 deaths occur due to underage drinking.²⁹ Underage drinking can also lead to a disruption in the normal growth and sexual development of youth, memory problems, and changes in brain development that may have life-long effects.³⁰ Underage drinking is also associated with school problems, such as truancy and poor grades, and social problems such as fighting.³¹ Underage drinking can also place young people at increased risk of future alcohol

²⁵ Substance Abuse and Mental Health Services Administration (SAMHSA), *Behavioral Health Trends in the United States: Results from the 2014 National Survey on Drug Use and Health* (Sept. 2015) (www.samhsa.gov/data/sites/default/files/NSDUH-FRR1-2014/NSDUH-FRR1-2014.pdf).

²⁶ CDC, *Alcohol and Public Health: Fact Sheets – Underage Drinking* (Nov. 12, 2015) (www.cdc.gov/alcohol/fact-sheets/underage-drinking.htm).

²⁷ SAMHSA, *Behavioral Health Trends in the United States: Results from the 2014 National Survey on Drug Use and Health* (Sept. 2015) (www.samhsa.gov/data/sites/default/files/NSDUH-FRR1-2014/NSDUH-FRR1-2014.pdf).

²⁸ *Id.*

²⁹ CDC, *Alcohol and Public Health: Fact Sheets – Underage Drinking* (Nov. 12, 2015) (www.cdc.gov/alcohol/fact-sheets/underage-drinking.htm).

³⁰ *Id.*

³¹ *Id.*

dependence. In fact, youth who begin drinking before age 15 are six times more likely to develop alcohol dependence later in life than individuals who begin drinking at or after age 21.³²

B. Authorization of Sober Truth on Preventing (STOP) Underage Drinking Act

The Sober Truth on Preventing (STOP) Underage Drinking Act became law in 2006. According to the Substance Abuse and Mental Health Services Administration (SAMHSA), almost 30 percent of underage individuals were current alcohol users and 19 percent were binge alcohol users that year.³³ The STOP Act was the nation’s first-ever comprehensive legislation to combat underage drinking.³⁴ The STOP codified establishment of the Interagency Coordinating Committee on the Prevention of Underage Drinking and a national media campaign to prevent underage drinking, authorized a community-based coalition enhancement grant program to prevent underage drinking, authorized grants directed at preventing and reducing alcohol abuse at colleges and universities, and required the Secretary, subject to appropriations, to increase data collection and research on underage drinking.

C. H.R. 1717, Sober Truth on Preventing (STOP) Underage Drinking Reauthorization Act

Rep. Roybal-Allard (D-CA) introduced the STOP Underage Drinking Reauthorization Act on March 26, 2015. The legislation would reauthorize the community-based coalition enhancement grant program, the Interagency Coordinating Committee on the Prevention of Underage Drinking, the national media campaign to prevent underage drinking, and epidemiologic studies on excessive drinking and alcohol use through FY 2020. H.R. 1717 would also reauthorize the grant program directed at colleges and universities by restructuring the grant program to support partnerships between community coalitions and colleges and universities. The STOP Reauthorization Act would further authorize the Administrator of the Substance Abuse and Mental Health Services Administration to award “enhancement grants” to assist pediatric provider organizations in reducing underage and college student drinking, by promoting effective practices in reducing underage drinking, including screenings and brief interventions.

V. H.R. 3119, PALLIATIVE CARE AND HOSPICE EDUCATION AND TRAINING ACT

A. Background

³² *Id.*

³³ SAMHSA, *Behavioral Health Trends in the United States: Results from the 2014 National Survey on Drug Use and Health* (Sept. 2015) (www.samhsa.gov/data/sites/default/files/NSDUH-FRR1-2014/NSDUH-FRR1-2014.pdf).

³⁴ SAMHSA, *STOP Act Legislation* (Oct. 27, 2015) (www.samhsa.gov/underage-drinking-topic/stop-act-legislation).

Palliative care is delivered to improve the quality of life of patients who have a serious or life-threatening disease.³⁵ Palliative care can be given throughout an individual's experience with a serious disease – starting as early as diagnosis through the end of life.³⁶ It is intended to prevent or treat the symptoms and side effects of a disease and its treatment rather than cure or treat the disease.³⁷ Palliative care may be provided by a number of health care professionals, including doctors, nurses, and social workers and is often delivered by a palliative care team.³⁸ Health care providers can specialize in palliative care. Those palliative care specialist specialize in treating the symptoms, side effects, and emotional problems experienced by patients.³⁹

Hospice care is delivered at the end-of-life to help individuals who are dying have peace, comfort, and dignity.⁴⁰ Typically, individuals receiving hospice services are expected to live 6 months or less.⁴¹ Hospice care is intended to control pain and other symptoms to allow a person to remain as alert and comfortable as possible.⁴² Hospice services also can be provided to support a patient's family.⁴³ According to the National Hospital and Palliative Care Organization, an estimated 1.6 to 1.7 million people in the U.S. received hospice services in 2014.⁴⁴ Hospice care is generally provided through team-based care, which can include the patient's personal physician, hospice physician, nurses, hospice aides, social workers, bereavement counselors, clergy or other spiritual counselors, trained volunteers, and speech, physical, and occupational therapists.⁴⁵

B. H.R. 3119, Palliative Care and Hospice Education and Training Act

Reps. Engel (D-NY), Reed (R-NY), and Cleaver (D-MO) introduced the Palliative Care and Hospice Education and Training Act on July 21, 2015. The goal of this legislation is to improve education, healthcare professional training, and research into palliative care and hospice care through grant programs that create Palliative Care and Hospice Education Centers, support projects to fund training of physicians who plan to teach palliative medicine, and which promote

³⁵ National Cancer Institute, *Palliative Care in Cancer* (Mar. 16, 2010) (www.cancer.gov/about-cancer/advanced-cancer/care-choices/palliative-care-fact-sheet#q1).

³⁶ *Id.*

³⁷ *Id.*

³⁸ *Id.*

³⁹ *Id.*

⁴⁰ Medline Plus, *Hospice Care* (Mar. 25, 2015) (medlineplus.gov/hospicecare.html).

⁴¹ *Id.*

⁴² *Id.*

⁴³ *Id.*

⁴⁴ National Hospice and Palliative Care Organization, *NCPO's Facts and Figures Hospice Care in American* (2015) (www.nhpco.org/sites/default/files/public/Statistics_Research/2015_Facts_Figures.pdf).

⁴⁵ *Id.*

the career development of academic hospice and palliative care physicians in addition to non-physician health professionals entering the field of palliative care. H.R. 3119 would make changes to certain existing nurse workforce programs to advance hospice and palliative care nursing. This legislation would allow HHS to award grants and enter into contracts with supporting entities, such as medical and osteopathic medicine schools, teaching hospitals, and graduate medical education programs, for developing and implementing programs that train and educate individuals in providing palliative care in health-related education, hospice, home, or long-term care settings. Finally, H.R. 3119 would require the Agency for Healthcare Research and Quality to develop a national palliative care education and awareness campaign and make changes to expand national research programs in palliative care at the National Institutes of Health.

VI. WITNESSES

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