WELCOMING CHARLOTTE BETH STONE

HON. JOHN L. MICA

OF FLORIDA

IN THE HOUSE OF REPRESENTATIVES

Friday, July 10, 2015

Mr. MICA. Mr. Speaker, as I rise today, it is my pleasure to announce the birth of Charlotte Beth Stone on June 3, 2015 at Virginia Hospital Center in Arlington, VA.

Charlotte is the daughter of Kevan Stone, my Special Projects Director, and Alexis Rice. Friends since High School in West Palm Beach, Florida, Alexis and Kevan married years later in Washington, D.C. at the historic Willard Hotel in May of 2014.

On this happy occasion, I ask my colleagues to join me in extending our warmest congratulations and wishes to the Stone and Rice families for continued health and happiness.

PERSONAL EXPLANATION

HON. MARK DeSAULNIER

OF CALIFORNIA

IN THE HOUSE OF REPRESENTATIVES

Friday, July 10, 2015

Mr. DeSAULNIER. Mr. Speaker, I regret that I was unable to vote on Friday, July 10 as I was attending the memorial services of a dear friend in my congressional district.

Had I been present, I would have cast my vote in support of H.R. 6, the 21st Century Cures Act, even though I am disappointed that the Republican Majority included last minute and unnecessary policy riders. I am cosponsor of the underlying bill which would encourage biomedical innovation and the development of new treatments and cures (Roll Call #433).

I would have also cast my vote in support of the amendment introduced by Representatives BARBARA LEE, JAN SCHAKOWSKY, and YVETTE CLARKE to H.R. 6, the 21st Century Cures Act. This amendment would remove harmful policy riders that aim to undermine women's access to reproductive health services from this otherwise noncontroversial, bipartisan effort. As a longtime supporter of a woman's right to access comprehensive reproductive healthcare, I oppose the inclusion of these unnecessary policy riders in this important bill (Roll Call #432).

I would have cast my vote in opposition to the Brat/McClintock/Garrett/Stutzman/Perry Amendment to H.R. 6, which would have turned the NIH and Cures Innovation Fund into a discretionary spending program, leading to immense uncertainty which would undercut the Fund's effectiveness and NIH's ability to maximize its work (Roll Call #431).

CONGRATULATING MARY AGEE ON HER RETIREMENT FROM NORTHERN VIRGINIA FAMILY SERVICE

HON. GERALD E. CONNOLLY

OF VIRGINIA

IN THE HOUSE OF REPRESENTATIVES

Friday, July 10, 2015

Mr. CONNOLLY. Mr. Speaker, I rise today to congratulate Mary Agee of Fairfax, Virginia on her retirement after 43 years at Northern Virginia Family Service (NVFS).

Since its founding by community volunteers in 1924, NVFS has addressed the growing needs of communities throughout our region. NVFS works to improve the lives of its clients through a variety of programs in five mission initiatives: housing, child and family enrichment, health access, emergency assistance, and workforce development.

Ms. Agee began her career with the organization as a Family Counselor in 1972 and since 1988 has served as Executive Director and then Chief Executive Officer. Four decades of service to our community cannot be fairly summarized in one statement, but just a few examples illustrate the tremendous impact Ms. Agee's efforts have had on the lives of Northern Virginia families.

When she was named Deputy Director in 1978, NVFS had 11 staff, five of whom were full-time, and a budget of $187,000. Today, the nonprofit organization has 350 employees, approximately 3,600 volunteers, an operating budget of $32 million and offices in Arlington, Fairfax, Prince William and Loudoun counties, as well as the cities of Alexandria, Manassas and Manassas Park. NVFS is now the largest private, nonprofit human service organization in Northern Virginia. Each year, nearly 34,000 individuals and families turn to NVFS to find housing and emergency services, early childhood programs, health & mental health services, workforce development programs, legal assistance, anti-hunger programs, and intervention and prevention programs.

Additionally, NVFS has played a role in stabilizing families affected by national crises. After the tragedy of 9/11, NVFS lead the Survivors' Fund Project, providing direct assistance and long-term case management services to local victims, their families, and first responders. Ms. Agee considers this her proudest moment. In partnership with the Red Cross, NVFS led the Katrina Project for evacuees from New Orleans who relocated to our region. The success of this first-ever collaboration led the Red Cross to establish similar contracts across the nation.

Through Ms. Agee, NVFS has earned a reputation as a leader in the community by supporting community partnerships, taking a leadership role in multi-agency service delivery for clients, and working collaboratively with other human services agencies on advocacy issues. On an individual level, Ms. Agee has served as an inspiration and mentor to many in the human services community. She carefully works with colleagues to develop their strengths and to nurture relationships that benefit the community and people in need, rather than any particular organization. I had the great pleasure of collaborating with Ms. Agee during my 14 years on the Fairfax County Board of Supervisors. Her leadership was invaluable when the County launched homeless prevention and affordable housing initiatives during my tenure as Chairman, and she, along with the entire team at NVFS, was an invaluable partner for the County's many human service programs to assist our neighbors most in need.

Mr. Speaker, I ask my colleagues to join me in thanking Mary Agee for a lifetime of service to our community and in congratulating her on her retirement. When I was Chairman of the County Board, we often joked when retirement announcements like this were made that we should pass an ordinance not allowing such talented and dedicated people to leave public or community service, and I certainly wish that was the case here. I wish Mary and her family all the best in this next chapter of her life.

21ST CENTURY CURES ACT

SPEECH OF

HON. GUS M. BILIRAKIS

OF FLORIDA

IN THE HOUSE OF REPRESENTATIVES

Thursday, July 9, 2015

The House in Committee of the Whole House on the state of the Union had under consideration the bill (H.R. 6) to accelerate the discovery, development, and delivery of 21st century cures, and for other purposes:

Mr. BILIRAKIS. Mr. Chair, on a personal level, I have family members who have suffered with Parkinson's—I witness this debilitating disease through them. It is hard to see. Few things in America are truly ubiquitous—diseases, sadly, are one of those things.

In addition to the struggle chronic and rare disease patients face, physicians, researchers, clinicians, and medical device companies (among others) deal with an outdated and overly burdensome regulatory structure. These regulations stifle the development of new cures and treatments, whether they are drugs, biologics, or devices.

Given the reality, we have to ask: how can we get cures and treatments to the people who desperately need them?

That is the question the 21st Century Cures Initiative was created to answer. The 21st Century Cures Initiative is a bipartisan undertaking by members of the Energy and Commerce Committee to help our healthcare innovation infrastructure thrive and deliver more hope for all patients. This is a tremendous undertaking, and is much easier said than done.

It is about finding new ways to drive innovation. In addition to adequate funding and resources, we need to think critically about structural changes to streamline and modernize our health care system. We need to rethink what we have been doing and how we are doing it for the 21st Century.

This is what 21st Century Cures Initiative is giving us: an opportunity to address some of the structural barriers to new cures and promote new ways to incentivize developments. The 21st Century Cures Initiative has examined and seeks to accelerate the complete cycle of cures—from discovery to development to delivery and back again to discovery. This has resulted in the 21st Century Cures Act—a culmination of over a year's worth of engaging with patients, researchers, physicians, government, and private entities.

This year included numerous hearings and roundtables in Washington D.C. As legislators, we worked tirelessly to engage all stakeholders from across the spectrum. The only way we can answer the question—how do we get better cures and treatments?—is to work with everyone involved in the American health care system.

I am proud that I was able to have several provisions that were included in the final version of the Cures Act. These provisions will help to change the lives of patients in small to larger ways. I want to take a moment and highlight some of the provisions and some of the people that helped shape the policy.

Rare diseases are not a rare problem. Nearly 30 million Americans—1 in every 10 people—are living with a rare disease.

That is why I introduced the OPEN Act—the Orphan Product Extensions Now Act. It was included as a provision of the 21st Century Cures Act.

My bipartisan bill has the potential to help millions of people by incentivizing the testing of mainstream drugs—or repurposing them—to treat rare diseases and pediatric cancers, and it was included as a major provision in the 21st Century Cures Act.

The OPEN Act would unlock a new world of potential treatments—it would put FDA-approved, safe, and effective treatments "on-label."

Through the 21st Century Cures Act, Congress has a chance to come together to make a real difference in the lives of the 160 million Americans who suffer from a rare or chronic condition, as well as the family members and friends of all those afflicted.

The OPEN Act is one provision in the 21st Century Cures Act, but it is one I am proud to have authored, and one I believe will make a substantial difference in the lives of a lot of people.

I want to take this opportunity to thank all the people who helped make the OPEN Act a reality, and who fought for this legislation to be in the 21st Century Cures Act.

Julia Jenkins, Max Bronstein, Andy Russell, Harry Sporidis, Tim Perrin, everyone at the EveryLife Foundation for Rare Diseases, and the other 155 rare disease groups that supported the OPEN Act:

National MPS Society, With Purpose, National PKU Alliance, Taylor's Tale, RASopathies Network USA, Kids v Cancer, Let Them Be Little X2 Inc., Info and Resources for Idiopathic Pulmonary Hemosiderosis (IPH-NET), Noah's Hope, Mary Payton's Miracle Foundation, Hope4Bridget Foundation, Batten Disease Support & Research Association, Cure Sanfilippo Foundation, Beyond Batten Disease Foundation, Drew's Hope Scientific Research Foundation, International Pemphigus and Pemphigoid Foundation (IPPF), Cure AHC, Autoinflammatory Alliance, MLD Foundation, Fabry Support & Information Group, Children's PKU Network, FMD Chat;

National Tay-Sachs & Allied Diseases Association (NTSAD), Little Miss Hannah Foundation, Rare Disease United Foundation, Global Genes Project, Fibromuscular Dysplasia Society of America (FMDSA), Lymphatic Malformation Institute, Mastocytosis Society, EB Research Partnership, BRBN Alliance, Jonah's Just Begun, Abigail Alliance for Better Access to Developmental Drugs, Hannah's Hope Fund, GNE Myopathy International, The Ryan Foundation, Organic Acidemia Association, Cardio-Facio-Cutaneous International, NGLY1.org, Gwendolyn Strong Foundation, POMC Island One boy an Ocean of friends, Gene Giraffe Project, International FOP Association, Aware of Angels;

CureCADASIL, GT23 FOUNDATION, Desmoid Tumor Research Foundation (DTRF), The Association for Glycogen Storage Disease, Gene Spotlight Inc., Amyloidosis Foundation, Heriditary Neuropathy Foundation, Relapsing Polychondritis, Klippel-Feil Syndrome Freedom, CureDuchenne, Prader-Willi Syndrome Association, Bert's Big Adventure, Parent Project Muscular Dystrophy, Sarcoma Foundation of America, The Nicholas Conor Institute, Luck2Tuck Foundation, Team Sanfilippo Foundation, The Rally Foundation for Childhood Cancer Research, CARES Foundation, Inc., Help Extinguish Hunter Syndrome, Sephardic Health Organization for Referral & Education, Hunter Syndrome Research Coalition;

The Kortney Rose Foundation, Saving Case & Friends, Phelan-McDermid Syndrome Foundation, The Children's Medical Research Foundation, Inc., Cure SMA, Narcolepsy Network, Celiac Support Association, Caleb's Crusade Against Childhood Cancer, International Waldenstrom's Macroglobulinemia Foundation (IWMF), PKD Foundation, EDSers United Foundation, Choroideremia Research Foundation, Inc., Genetic Alliance, The Life Raft Group, The Will Luthcke Foundation, Angioma Alliance, Smashing Walnuts Foundation, Castleman Disease Collaborative Network/Castleman's Awareness & Research Effort, The GIST Cancer Awareness Foundation, The Truth 365, The Arms Wide Open Childhood Cancer Foundation, Sophia's Fund;

Journey4ACure, Princesses on a Mission, Inc., Noah's Light Foundation, Pediatric Cancer Foundation, West Virginia Kids Cancer Crusaders, Inc., Bear Necessities Cancer Foundation, A Kids' Brain Tumor Cure, RARE Science, Inc., ISMRD (the International Advocate for Glycoprotein Storage Diseases), Hermansky-Pudlak Syndrome Network Inc., Run4Rare, A–T Children's Project, The Global Foundation for Peroxisomal Disorders, The Adult Polyglucosan Body Disease Research Foundation (APBDRF), Alexa Nawrocki Pediatric Cancer Foundation, Beckwith-Wiedemann Children's Foundation International, The Brooke Healey Foundation, Talia's Legacy Children's Cancer Foundation, The Rare Childhood Cancer Advocacy Group, Alex's Army Childhood Cancer Foundation, The Catherine Elizabeth Blair Memorial Foundation, Stillbrave Childhood Cancer Foundation;

Cures Within Reach, ALL4Trey, Team Sabrina, Sofia's Hope, Inc., ALL4Trey, Delainee's Battle, Joey's Wings Foundation, The Bozeman 3, Team Ashley Bragg, Cole vs Cancer, Dominick One in a Million, Samuel Szabo Foundation, Wilms Tumor Survivor Group, Aiden's Army, Sofia's Hope, Inc., Mikey's Way Foundation, Team Serena, Supporting Our Cancer Kids, The Champ's Corner, Habitat for Hope, Ali's Angels Foundation, Gold Rush Cure Foundation;

Sickle Cell Warriors, Inc., The Rare Cancer Research Foundation, Carson Leslie Foundation, Amyloidosis Research Consortium, Pulmonary Fibrosis Advocates, The Coalition for Pulmonary Fibrosis, Mytonic Dystrophy Foundation, LMSarcoma Direct Research Foundation, BioPontis Alliance for Rare Diseases, Foundation for Ichthyosis & Related Skin Types, Inc., 5p-Society, The Santonio Holmes III & Long Foundation, National Fragile X Foundation, National Organization for Rare Disorders (NORD), OsteoPETrosis Society, Curing Retinal Blindness Foundation, The MAGIC Foundation, Cure HHT, DEFY Foundation, Chase After a Cure, DC Outreach Inc., Children's Cardiomyopathy Foundation, and the Bridget the Gap—SYNGAP Education and Research Foundation.

These groups' grassroots efforts were instrumental in the effort to get the OPEN Act in the 21st Century Cures Act.

I would like to thank all the participants of the two 21st Century Roundtables I held in my District in August of 2014. Your input was vital in the early stages of drafting the 21st Century Cures Act, and I will be forever appreciative:

Dr. Wayne Taylor, on behalf of the Leukemia and Lymphoma Society;

Mrs. Colleen Labbadia, on behalf of the Parent Project for Muscular Dystrophy (PPMD);

Ms. Patricia Stanco, MHS, on behalf of the ALS Association Florida Chapter;

Ms. Ashleigh Pike and Ms. Beth Pike—dysautonomia patient advocates;

Dr. Samantha Lindsay, on behalf of the Alpha–1 Foundation;

Ms. Janice Starling, on behalf of the American Association of Kidney Patients;

Mr. and Mrs. Michael and Gretchen Church, on behalf of the Parkinson's Action Network;

Dr. Clifton Gooch, FAAN, Professor and Chair, Department of Neurology, University of South Florida;

Dr. Dave Morgan, CEO and Director of USF's Byrd Alzheimer's Institute;

Dr. Richard Finkel, Chief Neurologist at Nemour's Children's Hospital;

Mr. Geary A. Havran, President of NDH Medical, Inc., and Chairman, Florida Medical Manufacturers Consortium (FMMC);

Ms. Lisa Novorska, CFO, Rochester Electro-Medical, Inc.;

Dr. Thomas Sellers, MPH., Center Director and Executive Vice President for Moffit Cancer Center;

Dr. Glen Hortin, Clinical Pathology Medical Director for the Southeast Region, for Quest Diagnostics.

Additionally, I want to thank Nick Manetto from PPMD and USAgainst Alzheimer's, Miriam O'Day from the Alpha–1 Foundation, John DeMuro from Moffitt, Monica Richter from USF, Jennifer Sheridan from PAN, Gary Dessatti, John Ray from FMMC, and Erin O'Malley and Virginia Biggar from USAgainstAlzheimer's.

I would also like to thank Candace Lerman, Laura Milford, and Max Schill. They are all rare disease patients and advocates who I have had the pleasure of meeting. Their in-person advocacy and their dedication to improve the lives of everyone with a rare disease is admirable. I am truly grateful to their contribution and support of this legislation.

I also want to recognize Noah Coughlan and Jonny Lee Miller. Noah is a young man who ran across the country—over 3,000 miles—three times to raise awareness for rare diseases. This is a feat achieved by very few, and is a tremendous physical feat demonstrating his dedication to this cause. Jonny Lee Miller is an actor and advocate who runs ultra-marathons to raise money and awareness for rare diseases.

To everyone else who was involved, supported the OPEN Act, tweeted about it, posted about it on Facebook, or advocated on behalf of the 30 million Americans with rare diseases, I sincerely thank you from the bottom of my heart.

Additionally, the 21st Century Cures Act includes another one of my bills, H.R. 2298, the Patient Safety and Prescription Drug Abuse Prevention Act. I began work on this bill three years ago, after a prescription drug abuse hearing. The problem was apparent, and a fix was desperately needed.

This provision will create a drug management program within Medicare to use the same tools used in Medicaid, TRICARE, and private insurance to deal with the growth in prescription drug abuse.

The Substance Abuse and Mental Health Administration (SAMHSA) estimates that there are 15.3 million Americans over the age of 12 that "used prescription drugs non-medically in the last year." USA Today reported that in 2012, the average number of seniors misusing or dependent on prescription pain relievers in the past year grew to an estimated 336,000, up from 132,000 a decade earlier, based on data from SAMHSA. Addiction does not recognize age, race, ethnicity, or income. Anyone could be susceptible including seniors.

The U.S. Department of Health and Human Services' Office of the Inspector General has recommended that Medicare have this type of a program. In a hearing, the Center for Medicare and Medicaid Services' Principal Deputy Administrator stated that they supported this policy, but needed a statutory change in the law to create such a program.

A change to the Medicare program is a herculean task. I want to thank some of the people that supported this provision and helped get this legislation over the finish line. Lindsay Berman from the Pew Charitable Trusts, Jerry Steffl, Jonathan Heafitz, Gary Kline, Sergio Santiviago, Richard Hoar, Heather Cutler, Nelson Bunn from the Major County Sheriffs Association, and Chuck DeWitt from the Major Cities Chiefs Association.

PERSONAL EXPLANATION

HON. LUIS V. GUTIÉRREZ

OF ILLINOIS

IN THE HOUSE OF REPRESENTATIVES

Friday, July 10, 2015

Mr. GUTIÉRREZ. Mr. Speaker, I was unavoidably absent in the House chamber today because I was at the 5th U.S. Circuit Court of Appeals hearing in New Orleans, LA, on President Barack Obama's immigration executive actions.

Had I been present, I would have voted "nay" on roll call vote 431.

I would have voted "yea" on roll call vote 432 and in favor of the Lee/Schakowsky/Clarke Amendment which would have struck from the underlying bill controversial policy riders that will undermine a woman's right to choose. This amendment would have protected women's health care choices and was especially vital to low-income and minority women's health.

I would have voted "yea" on roll call vote 433 in support of H.R. 6, the 21st Century Cures Act.

RECOGNIZING THE 2015 INSTITUTE FOR EXCELLENCE IN SALES & BUSINESS DEVELOPMENT LIFETIME ACHIEVEMENT WINNER MARK WEBER

HON. GERALD E. CONNOLLY

OF VIRGINIA

IN THE HOUSE OF REPRESENTATIVES

Friday, July 10, 2015

Mr. CONNOLLY. Mr. Speaker, I rise to recognize the recipients of the Lifetime Achievement presented by the Institute for Excellence in Sales & Business Development (IES&BD). The Institute was created to foster excellence in business sales and development practices and to help organizations maximize their efforts. This annual award recognizes individuals, teams, and organizations throughout the United States who demonstrate exemplary performance through leadership, risk taking, innovation, vision, and customer development.

The 2015 IES&BD Lifetime Achievement Award honoree is Mark Weber of NetApp, a data management and cloud storage provider based in Vienna, Virginia. With over 30 years of experience in technology sales and engineering, Mr. Weber is a proven leader in Information Technology with particular expertise in serving the public sector.

Mr. Weber began his career as a federal account manager for Hewlett-Packard and later joined Sun Microsystems where he managed a diverse portfolio and served in a variety of positions including regional executive director for federal, state, and local government sales.

At NetApp, as Senior Vice President for the Americas, Mr. Weber leads sales, channels, engineering, professional services, business development, finance, operations, and marketing across North America, South America, and U.S. Public Sector. Prior to his current role, Mr. Weber served as the President and General Manager of NetApp U.S. Public Sector for ten years. He was responsible for managing and developing government business at the federal, state, and local levels in addition to higher education and teaching hospitals.

Under his leadership, NetApp's Vienna office was ranked in the top 10 for the best places to work in D.C. for the sixth time by the Washington Business Journal as well as repeatedly listed in the Washingtonian's Best 50 Places to Work issue.

Mr. Weber's professionalism has earned him the respect and admiration of his peers. In 2014 he was recognized by the Wash100 Exec Ranks as an Innovative GovCon Technologist & Business Leader. He was also awarded the FedScoop50 Industry Leadership award in 2012 and 2013 and the Federal Computer Week's Federal 100 Award in 2011. Within NetApp, he has received the Club Award for nine straight years and is frequently recognized as Sales Leader of the Year within the larger organization.

Mr. Weber sits on the Advisory Council for the Department of Business & Economics at Catholic University in Washington, D.C., and is a board member of the Virginia Tech Science and Engineering Regional Growth Enterprise (VT-SERGE).

Mr. Speaker, I ask my colleagues to join me in recognizing Mark Weber for his many contributions to the federal IT procurement field and on congratulating him on receiving the 2015 Institute for Excellence in Sales & Business Development Lifetime Achievement Award.

21ST CENTURY CURES ACT

SPEECH OF

HON. TERRI A. SEWELL

OF ALABAMA

IN THE HOUSE OF REPRESENTATIVES

Thursday, July 9, 2015

The House in Committee of the Whole House on the state of the Union had under consideration the bill (H.R. 6) to accelerate the discovery, development, and delivery of 21st century cures, and for other purposes:

Ms. SEWELL of Alabama. Mr. Chair, today I stand in strong support of the 21st Century Cures Act. This bipartisan bill gives our nation's best and brightest the tools they need to understand—and eventually defeat disease—and reauthorizes both the National Institutes of Health (NIH) and the Food and Drug Administration (FDA).

The 21st Century Cures Act has the potential to accelerate the discovery of drugs for life-threatening illnesses; repurpose drugs found ineffective for one condition and test them on another; promote an interoperable health system; enhance telehealth practices; and advance the development of more targeted, personalized treatments.

My district, the 7th Congressional District of Alabama, is home to the University of Alabama at Birmingham, the Southern Research Institute, and the University of Alabama. NIH funding is critical to the continuing vitality of these three leading institutions, as well as to the region.

The prospect of this act alone provides hope. Hope that cures can be discovered, hope that one day no diagnoses indicate inevitable ailment or death, and hope that one day treatments will yield more reward than risk.

Despite the potential of this bill, there are two amendments that threaten that hope and essentially aim to inhibit the health of several Americans. First, the Hyde Amendment has reared its ugly head yet again. It is a harmful and discriminatory bill that prevents women from making their own healthcare decisions. Further, it serves as a stark contradiction to efforts geared toward providing health positive resources for all.

Second, the Brat amendment aims to convert the federal funding of the NIH and the FDA from mandatory to discretionary. Such a transaction would stifle the progress both federal agencies have already made and will continue to make. It will singlehandedly reverse the trajectory of medical progress and halt further research efforts.

With only 5 percent of rare diseases having an FDA-approved treatment, it would be a gross understatement to say our medical systems have failed to keep pace. Viruses and diseases will not wait for us to catch up; they will mutate, grow ever more virulent, and continue to impact our public health. We need to leverage our investments to make potentially game-changing strides in treatment. We need 21st century solutions for 21st century threats.

An investment in health affects more than our physical well-being, and the 21st Century Cares Act reflects this. H.R. 6 is not only a health bill; it is a jobs bill. Our country has been the leader in both the medical device and biopharmaceutical industry for decades, helping us become the core of global medical innovation. This puts a target on our backs, as China and other countries have attempted to attempt to claim this role and thus, our jobs. U.S. medical device-related employment totals over 2 million jobs, and the U.S. biopharmaceutical industry is responsible for over 4 million U.S. jobs. NIH funding currently supports over 400,000 jobs at research institutions across the country, including jobs for young and upcoming scientists. Without this funding, our jobs are out there for the taking. Without this funding, the thousands of jobs in my district provided by the University of Alabama at Birmingham, the Southern Research Institute, and the University of Alabama are not safe. The policies in this legislation will help us fight off foreign competitors and allow us to continue innovating, so we can all protect medical jobs in our districts and add more.

We must get serious about addressing the unmet medical needs of the American people.