

## EXTENSIONS OF REMARKS

HONORING THE LIFE AND LEGACY  
OF MR. WILLIE LEE LAWSON III

**HON. ALCEE L. HASTINGS**

OF FLORIDA

IN THE HOUSE OF REPRESENTATIVES

*Tuesday, October 27, 2020*

Mr. HASTINGS. Madam Speaker, I rise today to honor the life and legacy of my dear friend and pillar of the South Florida community, Mr. Willie Lee Lawson III. Willie sadly passed away on September 29, 2020. He will be deeply missed by those who knew and loved him. He was born in Americus, Georgia, to parents who instilled in him the importance of serving his community at an early age. Eventually, Willie and his family moved to Pompano Beach, Florida, where he would start to put those lessons to use as a community advocate.

Willie was a selfless leader who served multiple terms as the President of the Miami-Dade and North Broward County NAACP, respectively, and as the Chair of the Minority Business Council, New Alliance of Interactive Leaders & Supporters (NAILS) Founder & President, Advanced Certified Toastmaster, and committee leader for First-Time Homebuyers Program.

His dedication and passion for his community and colleagues was perhaps only outdone by the love he felt for his family. However, even here, Willie took the knowledge and love that came from being a parent and husband and used it to support the people around him. Whether it was a parent in need of help with a child who was in legal trouble, an employee who was wrongfully terminated from their job, or Black children in need of support in school, Willie always made time for anyone who needed his help.

Madam Speaker, I extend my heartfelt condolences to Willie's wife, Marie; and his children, Kimberly, Keisha, Miraj, and Willie. I pray they find comfort during this extremely difficult time. Willie will be dearly missed.

NATIONAL SPINA BIFIDA MONTH

**HON. LUCILLE ROYBAL-ALLARD**

OF CALIFORNIA

IN THE HOUSE OF REPRESENTATIVES

*Tuesday, October 27, 2020*

Ms. ROYBAL-ALLARD. Madam Speaker, I rise today to commemorate October as National Spina Bifida Awareness Month; and to pay tribute to the numerous individuals and their families across our country living with this condition.

Spina Bifida is the nation's most common permanently disabling birth defect compatible with life. According to the March of Dimes, about 1,645 babies are born with this condition in the United States each year, with the prevalence being highest in the Hispanic population. Known as a neural tube defect, Spina Bifida stems from a hole in the spinal cord that

occurs because the spinal column fails to close properly during development in the womb; and, therefore, this condition impacts virtually every major organ system in the body. Children born with Spina Bifida typically undergo dozens of surgeries before they become adults. Adults living with Spina Bifida face a myriad of physical and mental health complications, as well as other challenges, such as unemployment and limited access to quality primary and specialty care.

Over the last three decades, we have made some strides in preventing the birth defect and managing the care of those born with this condition. In response to research that showed the incidence of Spina Bifida could be reduced by up to 70 percent with the addition of folic acid in a woman's diet, the United States Public Health Service recommended that all women of childbearing years should take 400 micrograms of folic acid daily to prevent having a pregnancy affected by a neural tube defect. Based on this recommendation, I introduced the Folic Acid Promotion and Birth Defects Prevention Act, which was passed into law as part of the Children's Health Act of 2000. This Act authorized a program within CDC to provide professional and public education for folic acid awareness. In 1998, the U.S. Food and Drug Administration required that folic acid be added to enriched grain products such as bread, pasta, rice, and cereal to increase the likelihood that women would have sufficient folic acid in their diet before becoming pregnant. And, in 2016, after years of advocacy with the FDA and the corn masa industry, folic acid fortification of corn masa flour was finally begun to target Hispanic communities that consume more corn masa products than grains. But there is still much work to be done to ensure adequate consumption of this critical nutrient that can prevent neural tube defects.

There are currently an estimated 166,000 individuals in the United States living with Spina Bifida, approximately 65 percent of whom are adults. This disease is now witnessing its first generation of adults, an incredible milestone, considering that the original designation of Spina Bifida as a childhood condition meant that the vast majority of children born with this condition did not experience life beyond youth. And while a generation of adults is an achievement worth celebrating, unfortunately there remain many unmet needs and additional health challenges affecting this medically fragile population.

As individuals develop, their clinical needs change, as should the type of care, and often the type of medical professional they see for that care. One of challenges faced by adults with this condition is that while we have a coordinated system of care designed to treat children with Spina Bifida in the United States, there is no equivalent for adults. Thus the "graduating child" enters into a very fractured medical system where individuals struggle to find physicians willing to provide treatment. Unfortunately, many of these physicians lack basic knowledge of this complex condition,

and hence thousands of young to middle-aged adults are left with few options other than to seek care in the emergency room, while some continue to see their pediatric care team at Spina Bifida Centers, which are designed for children.

In recent years, the Spina Bifida community has seen a growing incidence of sudden death in its over 25 population. There is speculation that this sudden loss of life has something to do with the central nervous system, but the cause or causes remain unknown. There has been much energy and resources devoted to ensuring that people with Spina Bifida can experience full lives that are not cut short by this condition. As such, we must explore and understand this sudden death phenomenon so we can reverse this troubling trend. Moreover, we must support—and expand investment in—research to address other issues related to Spina Bifida and associated secondary and co-morbid conditions, such as hydrocephalus, latex allergy, neurogenic bladder, developmental delay, and impaired executive functioning.

The CDC's National Spina Bifida Program is the sole federal program tasked with improving the care and outcomes for people with Spina Bifida. In 2008, the Spina Bifida Program created a National Spina Bifida Patient Registry (NSBPR) to collect the scientific data needed to evaluate existing medical services for spina bifida patients, and to provide clinicians, researchers, patients, and families a "window" into what care models are effective and what treatments are not making a measurable difference. Building on this in 2014, the Spina Bifida Program funded the development of a Spina Bifida Collaborative Care Network (SBCCN) to identify and to disseminate "best practices" for the care of people with Spina Bifida at all ages. These programs are continuing to improve quality-of-life and outcomes for people with this birth defect, but their full potential has been constrained due to flat federal funding over the last six years. Additional funding could expand the number of clinics participating in the registry, and increase the amount of information reported, which in turn, will provide further insights into how to continue to improve care and outcomes for people with Spina Bifida.

People with Spina Bifida deserve no less than the rest of us as we age. During a lifetime, someone with Spina Bifida will face at least a \$1,000,000 in medical expenses, including multiple surgeries, and most can expect to spend much of their lives in a wheelchair or walking with braces. We must ensure that adults with Spina Bifida can receive evidence-based medical care tailored for their condition and receive that care in age-appropriate, non-emergency settings. I call upon my Congressional colleagues to prioritize increased funding for the CDC Spina Bifida Program to ensure that it will be poised to best guide the health care community in optimal treatment options for people living with Spina Bifida.

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