the association's fifth president in 1991. During that time, over four decades of service, Jim and the PMTA have worked on behalf of the Pennsylvania trucking industry, fighting to preserve and strengthen the industry, and protect and promote its jobs. Whether that meant impacting legislation before the Pennsylvania General Assembly, or marching through the halls of Congress to meet with members and staff of the Pennsylvania delegation, Jim and the PMTA's voices were always respected. Without question, during my time representing the 9th Congressional District of Pennsylvania, and serving as Chairman of the House Transportation and Infrastructure Committee, Jim has been the face of trucking and a trusted advisor on the safe and efficient operations of the industry.

Mr. Speaker, it has been a privilege to work with Jim, and I thank him for his decades of service to the PMTA. While he will be truly missed, the Pennsylvania trucking industry will be forever grateful for his tireless leadership and service on their behalf. I wish Jim and his wife Linda the very best in whatever their futures may hold.

URGING IMMEDIATE REAUTHORIZATION OF THE RARE PEDIATRIC DISEASE PRIORITY REVIEW VOUCHER PROGRAM

HON. MICHAEL T. McCAUL

OF TEXAS

IN THE HOUSE OF REPRESENTATIVES

Thursday, July 14, 2016

Mr. MCCAUL. Mr. Speaker, I rise today to urge immediate reauthorization of the Rare Pediatric Disease Priority Review Voucher Program before it expires at the end of this fiscal year. Simply put, this program has proven to save the lives of children. My colleague and dear friend from North Carolina, Mr. BUTTERFIELD, and I have introduced legislation that would make it permanent. Last July, thanks to the leadership of Committee on Energy and Commerce Chairman FRED UPTON and his staff and advocates like Nancy Goodman, who is the founder and Executive Director of Kids v. Cancer, this Chamber passed an amended version of this initiative as part of H.R. 6, the 21st Century Cures Act. This program is a crucial incentive—in addition to the Orphan Drug Act—for drug manufacturers to make the significant investment in developing therapies for rare pediatric diseases, including pediatric cancers and lysosomal storage disorders.

When we were considering H.R. 6 last July and again in recognition of National Neuroblastoma Awareness Day last September, I came to this Floor to speak about the positive impact the Rare Pediatric Disease Priority Review Voucher Program has had on children with neuroblastoma. Because of the limited market incentives available prior to the creation of the program, biopharmaceutical companies had been unwilling to risk investing in research and development for a therapy that treats this extremely rare and devastating pediatric cancer. The Rare Pediatric Disease Priority Review Voucher Program proved to be the necessary incentive for United Therapeutics to satisfy this unmet need with the development of Unituxin. In March 2015, this therapy received Food and Drug Administration ("FDA") approval for children with high-risk neuroblastoma. Unituxin was the first drug that FDA approved for this condition and only the second FDA-approved therapy for pediatric cancer. Upon its approval, FDA awarded Unituxin the second voucher from this program.

As the chairman of the Childhood Cancer Caucus, I recognize the importance of this therapy to the community, especially to children like four-year-old Rex Ryan from Austin in the 10th District of Texas. Diagnosed with high-risk neuroblastoma at 17 months old, Rex's parents Leslie and Casey enrolled him in the clinical trial for Unituxin at Children's Blood and Cancer Center at Dell Children's Medical Center of Central Texas in Austin. Rex is a neuroblastoma survivor because of this new drug, which would not have been developed without the voucher program. After witnessing the direct impact Unituxin has had on Rex and his parents, it would be unconscionable for Congress to allow this program to expire. As I have previously described, the hope afforded by the Rare Pediatric Disease Priority Review Voucher Program extends to other conditions as well.

Nearly two years ago, I came to this Floor to speak about the value of the program just after BioMarin Pharmaceuticals sold the first voucher from this program for $67.5 million, which the company immediately reinvested to build a clinical laboratory on its campus in San Rafael, California. The laboratory is a critical component of its development of a gene therapy platform for hemophilia A, which is showing promising early data in eight patients. BioMarin received this first voucher for developing a therapy for Morquio A syndrome, which is also known as mucopolysaccharidosis ("MPS") type IV. Unfortunately for the millions of children affected by one of the nearly 7,000 rare diseases without a treatment, such as several of the other types and subtypes of MPS, including Sanfilippo syndrome and Sly syndrome, politics have hampered Senate negotiations on its larger innovation package, which is putting the program in jeopardy.

Patients like eight-year-old Beckett Weldon, who is from Cypress in the 10th District of Texas, cannot afford for Congress to allow this program to lapse. Beckett suffers from SYNGAP1-related intellectual disability, which is an ultra-rare and severely disabling, genetic neurological disorder. Approximately two-thirds of the children with this condition have some form of epilepsy. Other symptoms include hypotonia, behavioral disorders, language impairment, and oral dyspraxia. Beckett began his four-year diagnostic odyssey at 4 months old, when he began missing milestones his twin sister Pyper was meeting. After visiting 19 specialists and several diagnostic tests, Beckett received his diagnosis.

Only recently identified, SYNGAP1-related intellectual disability has no FDA-approved treatment. Beckett's parents Monica and Chris hope to change that for this community. Less than two years after Beckett's diagnosis in 2012, Monica Weldon—with the help of Global Genes—founded Bridge the Gap-SYNGAP Education and Research Foundation, which is a member of the National Organization for Rare Disorders ("NORD"). Due to Monica's efforts, the Foundation was one of twenty rare disease patient organizations selected in April to develop natural history studies with the assistance of NORD and supported in part by a cooperative agreement with the FDA. The Bridge the Gap-SYNGAP Education and Research Foundation is also hosting the first ever SYNGAP1 International Conference November 30–December 1, 2016 at Texas Children's Hospital in Houston in an effort to bring together families, researchers, and clinicians to foster a collaborative environment that will lead to the development of treatments and ultimately a cure for the condition.

As the SYNGAP1 community initiates these efforts toward treatments and a cure, it is critical that the Rare Pediatric Disease Priority Review Voucher Program be available as an incentive for manufacturers to consider investing in therapies for this condition. Congress must continue to help sick children and their families find treatments by extending this valuable program.

TRIBUTE TO MINERVA CRANTZ ALLEN

HON. MICHAEL M. HONDA

OF CALIFORNIA

IN THE HOUSE OF REPRESENTATIVES

Thursday, July 14, 2016

Mr. HONDA. Mr. Speaker, I rise today to recognize Minerva Crantz Allen, a bilingual Native American educator, linguist, and poet. It is my pleasure to commend Minerva for her lifelong commitment to preserving the Assiniboine (Nakoda) tradition, heritage, and culture. Her civic accomplishments for the Native American people truly make her the embodiment of leadership and service.

Minerva was born in the spring of 1934 on the Fort Belknap Indian reservation, in North-central Montana. Her grandfather instilled in her at an early age the importance of education for her future. The daughter of a French Chippewa father and an Assiniboine-Gros Ventre mother, Minerva spoke her native languages, but also taught herself English by singing songs with the Presbyterian ministers' wife. Minerva's grandmother, aunts and uncles still conversed in the Sakoda language, because of their culture and belief system.

Growing up was hard, not only because of the Great Depression. Minerva hid her language, culture and religion, and was scared of being turned into the law. Minerva thrived on following her passions, despite the sacrifices. At thirteen years old, she was sent to attend Indian Boarding School at Flandreau, South Dakota. Minerva was a very outgoing member of the student body—a cheerleader, Homecoming Queen, playing football and basketball. Despite the death of her grandfather and her parents' divorce, she went on to obtain a bachelor's degree from Central Michigan University, a master's degree from Northern Montana State College, and completed additional coursework a Weber State College.

Minerva has proven herself time and again, holding various critical positions with the Hays' Lodge Pole school system. As the Head Start director for eight years, Minerva helped to establish the first Foster Grandparent Program, bringing grandmothers and grandfathers into the classroom to teach the students their language and culture. She has written several books that translate Indian history and folklore into English, and she has published two books of her own poetry which are used widely in Montana.