

blisters on the skin, eyes, throat, and internal organs. Children with EB are often called “butterfly children” because their skin so fragile. As with most rare diseases, EB can vary in progression and severity among its various types and subtypes.

The most severe form of EB, recessive dystrophic EB, puts children at especially high risk for infection. Typically, even a mild localized trauma can cause skin to fall off, leading to open sores that do not heal, which cause indescribable pain and agony. In addition to the risk of infection, other conditions associated with EB include cancer, heart failure, malnutrition, and foot and hand deformities.

I have heard the heartbreaking stories of children with this form, such as Rafi Kopelan and Jackson Silver of New York City and Mikey Fullmer of Irvine, California. Imagine being eight years old, unable to play soccer or swim, covered in bandages, enduring regular painful vinegar and bleach baths, and fighting through the discomfort to eat and breathe. This has been a reality for kids like Rafi, Jackson, and Mikey.

New York City is home to two of the three leading patient advocacy and research organizations representing the EB community—debra of America and the EB Research Partnership. I would like to recognize the tremendous impact both organizations, as well as the Los Angeles, California based EB Medical Research Foundation, are having on the community. Due to their efforts, several drug manufacturers are currently in the research and development phase for various treatments for EB—from topical creams to protein replacement therapies.

The Rare Pediatric Disease Priority Review Voucher Program has been instrumental in creating an incentive for these companies to finally allocate resources to investigating potential solutions for children with EB beyond pain management and wound care. But more progress is needed. Further research is necessary, for example, to develop interventions against a particularly virulent form of squamous cell carcinoma in EB patients, which has a mortality rate approaching 90 percent.

Congress has long supported EB research funding through the National Institutes of Health, which has helped lay the foundation for these existing development programs. Reauthorizing the Rare Pediatric Disease Priority Review Voucher Program, however, is a critical way of providing the necessary incentives to ensure children like Rafi, Jackson, and Mikey will soon benefit from this important research in the form of FDA-approved therapies.

We must not let this deadline slip and this important program expire, and I hope all my colleagues recognize the urgency of this issue.

#### PERSONAL EXPLANATION

#### HON. JAMES A. HIMES

OF CONNECTICUT

IN THE HOUSE OF REPRESENTATIVES

*Thursday, July 14, 2016*

Mr. HIMES. Mr. Speaker, on July 13, 2016, I was unable to be present to cast my vote on amendments Number 76 and Number 78 to H.R. 5538, the Department of the Interior, Environment, and Related Agencies Appropriations Act, 2017. I wish to reflect that had I

been present for roll calls No. 453 and 454, I would have voted “nay.”

#### RECOGNIZING POTTSTOWN SUPERINTENDENT DR. JEFFREY R. SPARAGANA

#### HON. RYAN A. COSTELLO

OF PENNSYLVANIA

IN THE HOUSE OF REPRESENTATIVES

*Thursday, July 14, 2016*

Mr. COSTELLO of Pennsylvania. Mr. Speaker, I rise today to recognize Pottstown School District Superintendent, Dr. Jeffrey R. Sparagana, as he prepares to retire after a career in education spanning more than four decades.

For the past 23 years, Dr. Sparagana has held a variety of teaching, administrative, and coaching positions in the Pottstown School District. He was appointed superintendent in December 2012, demonstrating outstanding leadership during what his colleagues described as “the most tumultuous period of change” in the District’s 177-year history. It was a period that saw the District revise attendance boundaries, close one elementary school and renovate four others, and realign the Middle School to include fifth grade. Innovation, a commitment to academic excellence and accountability and an incredible ability to collaborate with teachers, parents and the community were hallmarks of Dr. Sparagana’s tenure. Those traits undoubtedly contributed to Pottstown earning national accolades for its PEAK program, which ensures students start kindergarten properly prepared for a lifetime of learning. Pottstown students also benefit from a healthy living program, one of just 20 comprehensive high school programs in the Commonwealth of Pennsylvania, virtual and alternative learning academies for customized instruction and an active Foundation for Pottstown Education, which provides supplemental funding for unique educational opportunities.

Despite the tremendous demands as the top educator in a district with 3,200 students, Dr. Sparagana always was an engaged citizen and made countless positive contributions to the greater Pottstown community. He is a past president of the Pottstown Area Industrial Development organization, helped facilitate quarterly joint meetings with the District and Pottstown Borough Council and fostered partnerships with Montgomery County Community College and The Hill School, resulting in Pottstown CARES days during which more than 600 volunteers pitch in on an array of projects in the community.

Mr. Speaker, I ask that my colleagues join me in expressing gratitude for Dr. Jeffrey R. Sparagana’s more than 40 years of outstanding service as an educator and genuine passion for ensuring that each student in the Pottstown School District has the opportunity to learn and develop into a responsible, engaged citizen and offering best wishes for a long, healthful retirement.

#### S CORPORATION MODERNIZATION ACT

#### HON. DAVID G. REICHERT

OF WASHINGTON

IN THE HOUSE OF REPRESENTATIVES

*Thursday, July 14, 2016*

Mr. REICHERT. Mr. Speaker, yesterday, Representative RON KIND and I reintroduced the S Corporation Modernization Act to reform and repeal unnecessary rules and limitations on S Corporations. This bill supports growth in communities across the country and builds upon last year’s success. With broad bipartisan support in December, Congress passed the Protecting Americans from Tax Hikes (PATH) Act that provided permanent built-in gains tax relief for S Corporations. The legislative history of this provision makes clear that Congress intended this permanent relief for built-in gains to also apply to Real Estate Investment Trusts (REITs) and mutual funds.

#### HONORING MARALIN NISKA

#### HON. JANICE HAHN

OF CALIFORNIA

IN THE HOUSE OF REPRESENTATIVES

*Thursday, July 14, 2016*

Ms. HAHN. Mr. Speaker, I rise today to honor the memory of Maralin Niska who passed away at home in Santa Fe, New Mexico on July 9, 2016. Maralin sang leading roles with both the Metropolitan Opera and the New York City Opera and was widely known as one of the greatest talents of her generation. She was not only an acclaimed soprano, she was a devoted teacher who loved sharing her passion with admirers and her community.

Born in San Pedro, California, on November 16, 1926, Maralin Niska showed early promise as a musical student. In her youth, she performed as a young soloist in the First Presbyterian Church of San Pedro as well as with the Los Angeles Philharmonic. Despite the advice of teachers and friends, she refused to go to Europe to study and build a career. She told the New York Times, “I’ve never even been to Europe, and I don’t have any desire to go . . . I’m still one of the few holdouts who are truly American in training, experience, everything.” She never wavered in her love for her community and country. Ms. Niska completed her degree at the University of California, Los Angeles (UCLA), in English literature and continued to study voice at the University of Southern California (USC) and UCLA. All the while, she continued to sing as a resident soloist at several community churches.

Ms. Niska had a rewarding career in education and was a Torrance elementary school teacher for seven years, while continuing to perform for local opera companies and the community. She loved teaching, and appreciated all students at whatever level they could achieve. In 1968, Ms. Niska sang the title role in *Madama Butterfly* for the opening of the new house at the Santa Fe Opera. After retiring in Santa Fe, Ms. Niska continued her passion for teaching and maintained a private vocal studio. There, she taught Master Classes to aspiring students who shared her love for music. The Arizona Daily Star even wrote that Ms. Niska left “most of the traditional diva