

to pay the rent. Today, the successor to First National maintains that branch and the relationship with the community, so wise was Bev's investment of time and energy in the economic development of this little town.

Grass never grew under her feet and, to prove the point, in 2000 she accepted the position as chief financial officer at San Francisco Brannan Street Wholesale Florist Incorporated. This is a very large wholesale operation in San Francisco, and a perfect work environment given Bev's love for flowers, particularly roses. Bev is an avid gardener and the roses in her garden look like award winners. It was also a natural transition from working with the coastside's farmers, many of whom sold their product at this facility. However, Bev never severed her relationship with coastside businesses and charities.

Whether it's Farm Day, the Pumpkin Festival, Dream Machine, the Harbor Lights Boat Lighting Contest or any other signature event on the coast, Bev was present and most likely running the show. Several of these events served as fundraisers for charities, and Bev was always serving food, pouring drinks, or raising money. She also used the bully pulpit of the Chamber of Commerce to promote tourism so that her customers and our residents could thrive during good times and survive as recessions came and went.

Throughout her time on the coast, and although she worked full time, she found time to volunteer long hours. She served on the board of directors of the San Mateo Event Center. For 12 years, she served on the board of directors of the Half Moon Bay Chamber of Commerce. Since 1992 she has been the chair for Mel Mello Farm Day, a delightful annual luncheon that has brought together farmers, small business owners and community leaders for 50 years. It is one of my favorite events of the year and I always cherish spending that day with Bev. She is the main engine behind this elaborate luncheon, complete with local recipes for artichokes and Brussels sprouts. So ubiquitous is Bev's presence that the Chamber created an award to be given to a community leader. It's named the Bev Miller Community Service Award. A true civic volunteer, she also served on the board of her homeowner's association and keeps her home as immaculate as her garden. She is known for constantly redecorating her house. Bev simply can't sit still and is always in motion.

One of the most difficult but important jobs in any community is serving on the board sofa nonprofit for disabled seniors. Bev served on the board of the Coastside Adult Day Health Center, a remarkable institution that has provided loving care for the elderly for decades. She was a judge for the Harbor Lights Boat Lighting Contest, served on the Dream Machine Committee, and always was the first volunteer to arrive at the Pumpkin Festival and the last to leave. Hundreds of thousands visit the festival each year. If you run a non-profit organization, you clearly want Bev on your board.

Madam Speaker, I ask the House of Representatives to rise with me to celebrate the joy of life (*goie de vivre*) of Bev Miller. She's leaving the coastside and will be dearly missed. She is returning to Spokane unleashing an immediate rise in energy and optimism once she enters its community hall or local government center. She will stay en-

gaged in any town that she calls home. Service to others is in her DNA and I wish her all the best in the next chapter in her life. I, along with countless coastsideers, will deeply miss her.

HONORING 50 YEARS OF SERVICE
BY CROWDER INDUSTRIES

HON. BILLY LONG

OF MISSOURI

IN THE HOUSE OF REPRESENTATIVES

Monday, September 9, 2019

Mr. LONG. Madam Speaker, I rise today to honor the 50 years of service by Crowder Industries of Newton County, Missouri.

In August of 1969, Crowder Industries opened its doors in Newton County. Its mission was simple: provide meaningful employment to disabled citizens. Since then, hundreds of people have come through its doors and received the opportunity to work in and serve their community.

Today, Crowder Industries works in areas such as assembly, packaging services and cardboard production for its community partners, providing not only employment for those with disabilities, but also serving the community, and helping other local businesses. Crowder Industries currently employs 110 people, most of whom have some disability. These hard-working employees work alongside people who provide vital support for the process and keep the company functioning smoothly.

The success of Crowder Industries is in large part due to the support of the Newton County community, and local businesses. They provide Crowder Industries with the resources it needs to fulfill its mission.

Madam Speaker, Crowder Industries has spent the last 50 years striving towards a goal. It was formed with the idea that everyone should be able to have meaningful employment. Its motto is, "Our People Make the Difference." Crowder Industries has fulfilled its mission and its motto. Its work has bettered the citizens of Newton County, and all southwest Missouri, and I can think of no greater honor than to recognize Crowder Industries achievements here.

INTRODUCTION OF THE RARE DISEASE
ADVANCEMENT, RESEARCH, AND EDUCATION (RARE)
ACT, H.R. 4228

HON. ANDRÉ CARSON

OF INDIANA

IN THE HOUSE OF REPRESENTATIVES

Monday, September 9, 2019

Mr. CARSON of Indiana. Madam Speaker, I am pleased to reintroduce the Rare Disease Advancement, Research, and Education (RARE) Act. This important, bipartisan legislation will address many of the issues facing rare disease patients and families. I am pleased that this legislation has been endorsed by 139 patient groups and cosponsored by a number of my colleagues from both sides of the aisle. But most importantly, this legislation will make a meaningful difference in the lives of those struggling with rare diseases by using increased research to

help provide more accurate diagnoses and increased treatment options.

During my time in Congress, I have been honored to represent and meet with many brave Hoosier families that are struggling with rare diseases. I have been moved by their courage. Their strength in the midst of trying conditions is not only inspiring, but also instructive. They have educated me and my colleagues about the necessity of increased research and rare disease surveillance in order to provide more treatment options and better diagnoses.

One family in Indiana, the Meggenhofens, exemplify the challenges of accurately diagnosing and treating rare diseases. Jocelyn Meggenhofen was born with Leukodystrophy, an extremely rare brain disease that causes delays in cognitive development and poor motor skills. After years of seizures, misdiagnoses of a brain tumor, and denials from residential facilities, Jocelyn was finally able to receive the correct treatment. Her struggles were not over: the Meggenhofen's health insurance would not cover room and board for an inpatient stay at a facility in New Jersey and her school in Hancock County would not approve Jocelyn's education at the facility. However, despite being told by doctors that she wouldn't live past her fifth birthday, Jocelyn, now 15, has received treatment at Riley Children's Health hospital in Indianapolis and continues to fight her disease.

In another example, Derrian Baker in Merrillville, Indiana suffered from Prader Willi Syndrome, a very rare genetic disorder. During his short life, Derrian and his family struggled to receive the necessary treatment after being denied an inpatient stay for treatment at the Children's Institute in Pittsburgh. Derrian passed away at the age of 26, underscoring the severity and high morbidity of many rare diseases if they cannot be treated.

Unfortunately, the plights of people like Jocelyn and Derrian are not uncommon: Nearly one in ten Americans live with one or more of the roughly 7,000 known rare diseases. These largely inherited diseases—defined as affecting 200,000 or fewer people—often lack substantive research investments and treatment options. In particular, African-Americans are especially vulnerable to certain rare diseases, including Sickle cell disease and beta-thalassemia. Specifically, the blood disorder Sickle cell disease affects 73 out of every 1,000 African American babies versus only three out of every 1,000 Caucasian babies.

While rare diseases cross the medical spectrum, individuals with rare diseases face some common challenges. Largely due to their limited patient population size, these individuals may have difficulty obtaining an accurate diagnosis, finding physicians or treatment centers with expertise in their disease, and ultimately finding appropriate treatment options and cures. Moreover, it can be difficult to find patients for treatment studies, underscored by the example of Maria Isabel Bueso, who came to the U.S. from Guatemala in order to participate in a clinical trial. Thanks to her participation, a treatment for her rare disease, Mucopolysaccharidosis VI, was approved. Maria now faces the possibility of deportation because the current administration eliminated a program that allows immigrants like Maria to stay in the country while receiving lifesaving medical treatment. Frighteningly, roughly 90 percent of rare diseases still lack a treatment