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EXTENSION OF REMARKS RECOGNIZING IGA NEPHROPATHY AWARENESS DAY

HON. TED W. LIEU
OF CALIFORNIA

IN THE HOUSE OF REPRESENTATIVES
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Madam Speaker, I rise to recognize May 14th as IgA Nephropathy Awareness Day. IgA Nephropathy (IgAN) is a rare autoimmune disease that causes a person's immune system to attack the kidneys. Fewer than 200,000 people are diagnosed with this incurable condition per year in the United States, yet it is one of the most common diseases affecting the kidneys other than those caused by high blood pressure or diabetes.

IgA Nephropathy is a condition in which an abnormal build-up of a protein called immunoglobulin A (IgA) causes the immune system to attack the kidneys, often leading to kidney damage and failure. The cause of abnormal IgA build-up in patients with this condition is unclear, though it is likely due in part to genetic factors. While IgA Nephropathy impacts women and men of every ethnicity, it is most prevalent in those from Asian backgrounds. In fact, kidney failure among Asian Americans is 5 times more likely to be the result of IgA Nephropathy than among Caucasians, and 15 times more likely compared to African Americans.

Although IgA Nephropathy can develop at any age, the National Organization for Rare Disorders (NORD) notes that it most often affects younger Americans, usually appearing between the teen years and the late 30s. Furthermore, according to the IgAN Foundation, as many as half of those affected by IgAN will develop end-stage kidney disease and eventually require dialysis or a kidney transplant.

As is often the case with rare diseases, the diagnostic journey to IgA Nephropathy tends to be long. There are usually little or no immediate signs and symptoms. The disease causes inflammation that can trigger complications, including high blood pressure and chronic kidney disease. In fact, many patients are not diagnosed until they show some of these complications and blood or protein in the urine.

IgA Nephropathy was first identified in 1968, and it is viewed as a condition without a cure. While some patients have been able to delay kidney decline and failure through lifestyle changes, supplements, and medication, many others have seen no effective treatments whatsoever.

We believe this is about to change. The FDA approved the first-ever medication for IgA Nephropathy in late 2021. Another drug is currently under FDA review with more therapies in phase 2 and 3 trials. Additionally, a growing number of clinical trials are underway.

These advancements in IgA Nephropathy treatment provide hope for so many patients struggling with this chronic disease. It's important we help raise awareness of this condition to counter the fear and uncertainty that can come with an IgA Nephropathy diagnosis. More needs to be done to develop the means for patients to manage their conditions and live normal lives even while dealing with this cruel disease.

I also want to salute by name the IgA Nephropathy Foundation. On May 14, 2004, Bonnie Schneider and her husband established the IgA Nephropathy Foundation from their home. Eddie, their 13-year-old son, had been recently diagnosed with the condition, and they saw firsthand the unmet need for answers, resources, and a supportive community for individuals with IgAN and their families.

In addition, I am proud to say that California's 33rd Congressional District is fully engaged in this effort, as IgA Nephropathy Foundation Board Secretary Mary Schneider is from Venice in my district.

So on May 14th, the 18th anniversary of its founding, the IgA Nephropathy Foundation and the entire IgAN community and partners will come together to raise awareness about this disease, while celebrating the strength of those warriors who battle it every day. Their hope is that this important day will drive people to check their risk and recognize symptoms, improve awareness among primary care physicians, build a stronger network of support for patients, and encourage further research to find effective therapies and, one day, a cure.

Madam Speaker, I want to thank the IgA Nephropathy Foundation for creating this important day of awareness. I am proud to stand with the brave Americans and their families who must battle this disease and who continue in their efforts to educate the public on IgA Nephropathy. On May 14th, we honor them and all their efforts as we recognize IgA Nephropathy Awareness Day.