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*“My good friend and a trailblazer for Lyme Disease patients”*

## Pat Smith’s transformational, extraordinary work

Mr. Speaker, I would like to take a moment to recognize the incredible life and the amazing contributions of my friend Pat Smith, who passed away peacefully on August 17<sup>th</sup>. Tomorrow, September 7<sup>th</sup> there will be a “Celebration of Life” to honor and pay tribute to the remarkable Pat Smith.

Pat Smith’s extraordinary work for patients, caregivers, and Lyme-literate doctors around the country has been **transformational**. An incredibly well-informed and tenacious leader, Pat fought effectively and relentlessly for greater diagnosis, treatments, and outcomes for Lyme patients.

Because of Pat Smith, legislation to better meet the needs of Lyme patients is now the law of the land.

I first met Pat in 1992 and from that moment on, my understanding, advocacy and legislative work for Lyme patients—and frankly the work of this chamber—was substantially and positively influenced. She was an outstanding collaborator. She did meticulous research and was painstakingly honest, reliable, and hardworking—often to the chagrin of the Lyme deniers.

A widely-respected straight shooter, Pat did not mince words as she and I worked

together—along with other Lyme victims and family caregivers—calling on all public, medical and insurance industry officials to be forthright and dedicated in fighting Lyme and saving lives.

More than 30 years ago, Pat Smith came to one of my town hall meetings in Wall, New Jersey and shared with me the plight of those suffering from chronic Lyme—including her two daughters.

Shortly after, Pat and I sat down with the top leaders at the Centers for Disease Control and the National Institutes of Health, who were polite but highly dismissive of our concerns surrounding the recommended treatment for Lyme.

Pat was brilliant in that meeting. She told them how CDC’s “recommendation” for prescribing up to a mere one month’s worth of antibiotics was being used by health insurance companies as the ceiling for what was covered. Even if the patient had Lyme for five years, only one month of Doxycycline was covered.

The feds said it wasn’t their intention to limit health insurance coverage, but they didn’t fix the problem either.

If you knew Pat, you knew that answer would not suffice.

Already the founder and President of the Lyme Disease Association (LDA), Pat embarked on a personal and compassionate mission across the nation to educate and help spread awareness of this terrible disease; how to prevent it; and how to properly diagnose and treat it. She built synergistic coalitions around the country that worked relentlessly in support of Lyme research and to advance diagnosis and treatment for patients.

Beyond the working coalitions, Pat organized 22 national, scientific conferences and shared her wealth of knowledge at hundreds of government, business and school events.

She provided both oral and written expert testimony in support of national and state laws and physicians' right to fully treat Lyme in numerous states, including our own.

When Pat brought her renowned expertise, passion and admirable no-nonsense demeanor to Washington, people listened.

At my request, Pat testified before Congress and provided critical insights for substantive reform and federal Lyme programs. And she skillfully made her case each year during the congressional appropriations process, ensuring that Lyme Disease programs—and patients—finally got their due, or close to it.

Pat also served two terms as a public member of the US Department of Health and Human Services' Tick-Borne Disease Working Group—a working group created by legislation she and I worked on together and helped shepherd into law.

The Working Group reports, mandated by Congress, represent a true landmark in their far-reaching coverage of the persistent symptoms and persistent illness suffered by Lyme Disease patients and the

need for enhanced understanding of Lyme disease-associated chronic illness. And the reports referenced many published studies of Chronic Lyme Disease.

The groundbreaking content of the Working Groups' reports—and their positive impact on Lyme patients and Lyme study—are due in no small part to 2-term WG member Pat Smith.

Under Pat's leadership, LDA provided 127 research grants that have been acknowledged in 62 scientific journals.

Working with author Amy Tan, she created LymeAid 4 Kids—a program that offers critical support to children with Lyme who come from families that face financial challenges. To date, this amazing initiative has provided more than \$475,000 for diagnosis and treatment for children in need.

Naturally inquisitive and loaded with "street smarts," Pat also continued to study and probe the origins of Lyme and the impact defense bioweapons experiments on ticks may—or may not—have had on Lyme's epidemic growth in the U.S.

Pat Smith's unyielding commitment to improving the federal response to Lyme disease has made a huge difference and has offered so much hope for Lyme patients across the country.

She demanded fairness and honesty and never asked anybody to give more or do more than she—and her husband Rich—gave and did for the cause of conquering Lyme.

I will greatly miss my good friend, Pat Smith, a trailblazer for Lyme Disease patients. Pat and I share a birthday, a last name and a thirst for justice for patients with Lyme. For Pat, and in her honor, our fight will continue.

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