25 Years of the Ryan White CARE Act

POZ contributing writer Shawn Decker gives a firsthand account of a White House special event.

September 23, 2015 By Shawn Decker

Ryan White

On September 9, The White House hosted a special event to commemorate the 25th anniversary of the Ryan White CARE (Comprehensive AIDS Resource Emergency) Act. Jeanne White-Ginder, mother of the late Ryan White, the bill's namesake, and Andrea White, his sister, were in attendance. Many of the people responsible for the landmark legislation joined them, including key politicians Senator Orrin Hatch (R–Utah) and the lead author of the bill, former Democratic Congressman Henry Waxman.

Reflecting on the domestic HIV/AIDS landscape before the CARE Act passed in 1990, Hatch explained, "HIV/AIDS was woefully underfunded...Medicaid required AIDS patients to be totally disabled before they could qualify for benefits."

Waxman, whom Hatch affectionately referred to as "the toughest little bugger I've ever known," also spoke about the early days of the epidemic. "We had people in the Republican administration who knew what was going on...and wanted to do the best they could to fight the disease and not the people who have it...but we also had a president (Ronald Reagan) that wouldn't say the word 'AIDS' until his last year in the presidency." He stated that HIV/AIDS is a "nonpartisan" issue, praising Hatch for his help in making the CARE Act a reality and also giving former President George W. Bush props for PEPFAR (President's Emergency Plan for AIDS Relief), which provides global funding, calling it "the greatest accomplishment of his administration."

But the former congressman's biggest accolade was reserved for Tim Westmoreland, who worked closely with Waxman on the issue of HIV/AIDS. Westmoreland served as counsel to the Subcommittee on Health and Environment and spearheaded dozens of congressional hearings, each one slowly chipping away at the apathy and hysteria that surrounded the topic of HIV/AIDS. "Tim Westmoreland was the great hero of this legislative battle."

"New rumors and guesses and wild ideas were coming up every day as we tried to investigate this," Westmoreland said, at times appearing visibly shaken by his recollections of the resistance they faced. "[We got] responses that were sometimes crazy and that were sometimes cruel." Giving real-life examples of what people with HIV were dealing with, he underlined why

government help was so desperately needed. “People lost their jobs, and their health insurance…Children were thrown out of school. Reputable pundits were writing about quarantines and requiring tattoos — and I don’t mean fringe pundits, it was in The New York Times.”

Donning a vintage 1990 bomber jacket that she’d bought two nights before at an AIDS auction, former head of the AIDS Action Council Jean Flatley McGuire discussed the role of community-based activism, giving a special shout out to ACT UP as she talked about all of the moving parts that came together in making the CARE Act possible: “We had many great leaders and collaborators in Congress and on the outside: in the executive agencies, in business, in the arts, in all sectors. It was a very rich time.”

The occasion was bittersweet, both a celebration of a bipartisan victory that currently serves over 500,000 Americans living with HIV but also a moment to reflect on the life of Ryan White, who passed away just four months before the bill was passed.

“I wanted him to believe that somehow, some way, he’s going to be around,” White-Ginder said. “He said, ’Mom if I could live five years, they’ll have a cure by then. They’re really working hard on it.” Well, he lived five and half years.“ She also talked about Ryan’s sense of humor, and how he forced a conversation on her about what he wanted to be buried in — including his Oakley sunglasses, to prevent people from seeing whether his eyes were moving in the casket. ”He’d only been to one funeral when he was little,“ Jeanne said. ”I guess that’s what he did."

Ryan contracted HIV through blood products used to treat the blood-clotting disorder hemophilia. He was kicked out of school in his hometown of Kokomo, Indiana, as a result of his HIV-positive status. His mother began a lengthy legal battle to get him readmitted and, though it worked, the family relocated about 30 miles away. The town of Cicero, Indiana, welcomed them with open arms, and the high visibility of the care, combined with Ryan’s charming personality, made him a much-needed spokesperson for people living with HIV. Ryan’s call for compassion for everyone, regardless of how they contracted HIV, opened hearts and minds to the medical reality of living with the virus, while also alleviating unnecessary concerns about transmission.

Senator Joe Donnelly (D–Indiana) spoke about Ryan’s continued influence in his home state. “Ryan set the example…In the Indiana Hall of Fame, no one’s higher at the head of the class than Ryan.”

In March of 1990, Ryan White attended an Oscar party to benefit children with illnesses, which was hosted by Ronald and Nancy Reagan. It was his last public appearance. During his week-and-a-half-long hospitalization in Indianapolis before passing, he was surrounded by loved ones, among them Elton John, who feverishly answered the countless incoming calls for Ryan. When the late Democratic Senator Ted Kennedy called, John patched him through. Kennedy informed White-Ginder that the legislation they’d been working so hard on would be named in Ryan’s honor.

After Ryan’s death, White-Ginder was inundated with requests to speak on behalf of the CARE Act in DC, including Kennedy, but ultimately it was Hatch’s relentlessness that carried the day. “’I’ve got 25 senators lined up,’” White-Ginder said, doing her best impersonation of Hatch, “’and I won’t

take no for an answer!’” When she expressed concerns about her lack of political savvy, Hatch softened his approach. “’Just be a mom. Everybody has a mom. Tell these senators what it was like to watch your child live and die with this disease.’”

The encouragement worked and, like the Ryan White CARE Act itself, White-Ginder has been doing her part in helping to improve the lives of people with HIV for a quarter of a century. When she stood up to speak, everyone cheered; Ryan’s influence and spirit were palpable. As White-Ginder began to speak, she turned her gaze to Andrea White. “I’m the mother of Ryan White, but I also have a beautiful daughter who was very much a part of our story, and lived the story along with Ryan and I, but she was very much left out of the story. I’m just a mom, but a mom that’s been blessed by two wonderful children.”

Click here to read a message from President Obama recognizing the 25th anniversary of the Ryan White CARE Act. Click here to read an article by Shawn Decker on the importance of remembering Ryan White.

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