

Oral Testimony of Jeanne White
Before the
Senate Committee on Health, Education, Labor, and Pensions
March 2, 2000

Good morning, Mr. Chairman, Senator Kennedy and distinguished members of the committee. My name is Jeanne White. I am the mother of two beautiful children - my daughter Andrea, and my late son Ryan. On behalf of Ryan, AIDS Action and the men, women, children and families affected by this deadly disease I am here to thank the United States Congress for your support of the Ryan White CARE Act.

As I walked to the hearing room this morning, it brought me back to a time ten years ago. 1990 was a difficult year for my family. My son Ryan was in the fight of his life against the HIV disease he had contracted as a result of the use of Factor VIII to treat hemophilia. Across the nation, families like mine were hoping against hope for a miracle to end this dreadful illness.

Shortly after my son passed away in April 1990, Senator Kennedy contacted me about naming a bill after my son, called the Ryan White CARE Act. A few days later, Ryan died. All my hopes of Ryan beating the odds, finding a cure, and praying for miracles were gone. The "whys" and "hows" could not be answered. I felt depressed, I wanted to cry and feel sorry for myself. But, I had a powerful support team that wasn't going to let me silent. Senator Kennedy called to try to get me to come to Washington to urge Congress to pass the Ryan White CARE Act to help individuals living with HIV/AIDS with no where else to turn. I was reluctant.

If you've every lost a loved one you know how painful and draining it can be. Senator Kennedy told me that I shouldn't be afraid, that I was just a mom talking to people about what it was like to watch my children live and die from HIV/AIDS. He said, "We have twenty-three Senators we'd like you to approach." I was very reluctant, because I felt like it was always Ryan people wanted to hear, and not me. I felt I wasn't smart enough. I was concerned that I would hurt the "cause" instead of help it. Senator Orrin Hatch reassured me. He told me "You're a strong woman, represent the voice of mothers. I know you can do it."

I then thought of something Ryan had said that gave me the strength to come to Capitol Hill. He said, "I'm not afraid of dying...it's how you live your life that counts." If Ryan hadn't been afraid of dying, then how could I be afraid of 23 Senators? Well, I went to Washington and, one by one, met with the Senators. I asked them to support my boy's bill. Going to DC was the best decision I could have made. For the first time, I felt like I could continue Ryan's legacy and make a difference.

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I hope that trip to Washington helped pass the original CARE Act. I hope it helped give back something to all the wonderful people whom stood by us and helped us in our struggle. So many sons and daughters have died. Ryan would want us to help those who are alive today.

He would want us to provide the treatments that he did not live long enough to benefit from. The legacy my loving, understanding, wise son has left me is this: we must do everything we can to help each and every person who has HIV and AIDS.

I'm so honored that Congress named this bill after Ryan. My boy once said to me, "Mom, I want to be the first kid with AIDS to speak out, fight back and win." Members of the committee, my son gave me the courage to continue this battle - to fight until no mother has to feel the pain of the loss of a child to AIDS.

While this legislation could never replace my son or the emptiness I still feel today from that loss, I am happy that a program named after Ryan has benefited hundreds of thousands of men, women, children, and families living with HIV and AIDS.

Even in this bright era of hope, it sometimes seems like the darkest days are still with us. Unfortunately, others still face the fear, the pain, and the discrimination that Ryan knew oh so well. I witnessed first hand the ravages of this disease. I know the terrible toll HIV and AIDS has taken on mothers, fathers, sisters, brothers, grandpas and grandmas everywhere.

Ryan was a mover and shaker -- he was the first national voice on AIDS. He was strong but he was still a boy. As a mother sometimes I just wanted to reach out and do what moms do best -- make everything better. I tried but as his health deteriorated it became clear that a mother's love would not save him from this disease. The doctors told me Ryan only had 3 months to live and he lived for 5 ½ years. I am grateful for every moment of the 18 years I shared with Ryan.

The CARE Act makes real Ryan's dream of compassion for people living with this disease. It provides care, drugs, and services to those who face the same struggles as my late son. Ryan never understood those who wanted to deny care to people with AIDS - now the CARE Act ensures that more people have access to care and services.

This disease affects all kinds of people - black, white, brown, young, old, rich, poor, Republican and Democrat. We must make sure this program stays strong so that the people living with HIV and AIDS can live as long as possible. As a mother dedicated to seeing our sons and daughters with HIV are taken care of, I urge you to reauthorize the CARE Act as soon as possible. It is what Ryan would want us to do.