My Journey in Advocacy with my Heart Leading the Way

Charlotte Woodward, Transplant Recipient and NDSS Staff Member

My name is Charlotte Woodward. I was born with Down syndrome and a significant heart condition, which is common – approximately 50% of babies who are born with Down syndrome have some sort of heart condition. I had four open-heart surgeries, three when I was a baby, and one when I was ten years old. As I grew, my heart struggled to support my body. As the struggle worsened, my cardiologist determined that there was nothing more that could be done surgically to help me and that **I was in dire need of a life-saving heart transplant.**

I never dreamt that I would need an organ transplant! I felt overwhelmed when I was told that I needed a new heart. My cardiologist was concerned that he might face resistance from the transplant team when he presented my case to them, and said that he might have to “go to bat” for me.

Fortunately, my transplant team looked beyond my Down syndrome diagnosis and saw me for who I am, someone who was deserving of the same opportunity for a lifesaving organ transplant just like anyone else. They advocated for my right to be considered for a transplant just like anyone else. On January 30, 2012, I received a healthy new heart and have been in excellent health ever since. I am very, very grateful for the generosity of my heart donor and her family, and for the willingness of my transplant team to provide me with the opportunity to receive this life-saving gift.

Receiving a life-saving heart transplant has enabled me to pursue my dreams and goals. Since having my heart transplant, I graduated from college and began my career working at the National Down Syndrome Society. I have been able to travel and to live a very healthy and fulfilling life!

When I learned that people with disabilities are denied life-saving organ transplants because of institutional bias and prejudice and discrimination, I became determined to work towards ensuring that right for everyone with disabilities. The result of that determination is federal legislation that is before both the United States Senate and House of Representatives that bears my name, the Charlotte Woodward Organ Transplant Discrimination Prevention Act!

People with Down syndrome and those with other disabilities have inherent value and worth and deserve to have the same access to life-saving organ transplants just like everyone else.

Please help us by supporting my bill. Together, we can make sure that no person ever loses their life again to this type of discrimination again and that all people get the same opportunity that I have.

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