

INSIGHTS



Family reflections: Charlotte's loving heart

Charlotte Woodward¹ and Darcy Woodward¹✉

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I would like to begin by stating that it is the greatest of honors to be the mom of my beloved Charlotte! She is truly my heart's delight!



Charlotte was born in Miami, Florida in December 1989. As a healthy 25-year-old with no pregnancy complications, I was given standard prenatal care and no diagnostic testing.



Within minutes of her birth, I was told that Charlotte had been born with Down syndrome and that she would most likely never learn to read or write and could expect to work in a sheltered workshop—where she would be paid subminimum wage—when

she was older. Soon after, I was told that she had also been born with a significant heart condition—an atrial ventricular septal heart defect—which would require surgery to correct. Approximately 50% of all infants born with Down syndrome are born with a heart condition.



Had Charlotte been born prior to the late 1980s, we may have been advised to place Charlotte in an institution, and doctors may have refused to provide lifesaving surgery due to her Down syndrome diagnosis. I am thankful that medical care was offered to Charlotte, and I would never have considered abandoning my precious daughter.

We were fortunate to soon be connected with Dr Welton Gersony, chief of the Division of Pediatric Cardiology at Columbia Presbyterian Hospital in New York City, and Dr Jan Quaegebeur, a pediatric cardiologist who was new to the hospital at that time and known for his innovative surgical techniques. Dr Quaegebeur performed successful open-heart surgery on Charlotte when she was 5 months old, and we were ecstatic and believed that all would be well henceforth. At a follow-up visit to assess Charlotte's heart, we were told that another surgery would be required to

¹Fairfax, VA, USA. ✉email: info@pedres.org

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address issues with her mitral valve. Dr Quaegebeur performed that open-heart surgery when Charlotte was 9 months old, but unfortunately Charlotte continued to experience mitral insufficiency, which coincided with a diagnosis of failure to thrive. By the time Charlotte was 18 months old she weighed only 12 pounds, despite aggressive attempts to try to help her to gain weight. At that time, Dr Quaegebeur performed Charlotte's third open-heart surgery, implanting an artificial mitral valve. We were told that Charlotte was the first baby in the United States to receive the particular valve implanted, of a size that would hopefully last her a very long while. We were thrilled that immediately following her third surgery Charlotte began to grow and thrive and flourish and hoped that the artificial mitral valve and the required daily regimen of taking Coumadin would ensure that Charlotte would lead a healthy, happy life. Unfortunately, by the time she was 10, Charlotte required replacement of the original artificial mitral valve with one that was larger—this time, we were told that the new valve should be large enough to last her a lifetime.

When Charlotte was born and first opened her eyes, she looked at the world with great curiosity and I was determined to help her learn as much as possible about the world. Despite the doctors' dire predictions about her capabilities and her future, she has always excelled and not only learned to read and write at a very young age, but recently graduated from George Mason University, *summa cum laude*, with a Bachelor of Arts in Sociology with a concentration in Inequality and Social Change. During her senior year, she was the recipient of GMU's 2021 Outstanding Sociology Undergraduate Award. As a budding sociologist, she examines the structural and systemic inequalities in society that affect the lives of people with disabilities, and as an advocate and a valued employee at the National Down Syndrome Society—first as the Community Outreach Associate and currently as the Education Program Associate—she uses this knowledge to raise awareness about these inequalities and to affect positive change.

While in college, Charlotte began to experience episodes of vasovagal syncope and would collapse and faint after physical exertion; as these episodes became more and more frequent, her cardiologist, Dr Frank Galioto, determined that there were no further surgical options available to improve her heart function, and that she was in need of a heart transplant. Fortunately, the transplant team at Inova Fairfax Hospital in Fairfax, Virginia considered Charlotte an excellent candidate for the lifesaving procedure, and on January 30, 2012, Charlotte received her healthy new heart. She has been in excellent health ever since, and we are all so very, very grateful for the generosity of her heart donor and her donor's family, and for the willingness of her medical team to provide Charlotte with the opportunity to receive her lifesaving gift.

Too often, people with disabilities are denied lifesaving organ transplants because of institutional bias and prejudice and discrimination in the medical field against people with intellectual and developmental disabilities and other disability

conditions. Charlotte is a fierce advocate for people with disabilities and as a result of her advocacy there is currently bipartisan legislation before both the House and the Senate of the U.S. Congress that bears her name and aims to prevent such discrimination: the Charlotte Woodward Organ Transplant Discrimination Prevention Act.

I would not change a single thing about Charlotte! She brings so much joy to all who know her, and she has opened the eyes of so many to the abilities that people with Down syndrome have and to their contributions to the world. However, I very much wish that she did not have to undergo all of the many, many medical procedures her heart condition required. We are so thankful that researchers are exploring the connection between Down syndrome and the extra copy of the 21st chromosome that those with Down syndrome have and accompanying heart conditions, and hope that they will prioritize this research. We are hopeful that information about the link will be found and that in the future heart conditions can be prevented in people with Down syndrome, and that if a person with Down syndrome does have a heart condition, those in the medical field will recognize the inherent worth and value of people with Down syndrome and will treat them with the dignity and respect of which all people are deserving.

In Charlotte's words:

As a person with Down syndrome who has gone through all the things that my mom has described, what is important to me is that people with Down syndrome who are self-advocates should have a seat at the table when medical decisions—including decisions about research—are being made about them. I also urge researchers to be inclusive of people with Down syndrome in their research studies, and to look beyond their own lived experiences in order to see the lived experiences of people with Down syndrome. Another thing that is important to me is that people with Down syndrome are not defined by their diagnosis. Having a disability is a natural part of life. People with disabilities are more alike than different. People with disabilities, including those with Down syndrome, have the right to be proud of who they are, to be treated with dignity and respect, and to be included. Thank you to all the researchers who are doing such important work—you are making the world a better place for everyone!

COMPETING INTERESTS

The authors declare no competing interests.

ADDITIONAL INFORMATION

Correspondence and requests for materials should be addressed to Darcy Woodward.

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