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# Down Syndrome and Congenital Heart Disease: A Personal Story

*Written by Doug Rothenbush, father of Jenna*

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My daughter Jenna, who is now 19 years old, was born with tetralogy of Fallot, a serious heart condition that required her to undergo open-heart surgery when she was just three months old. At seven years old, she had another surgery to replace a pulmonary valve that had been only partially functional after her first operation. Jenna was also born with long QT syndrome, a heart rhythm condition that we later discovered was inherited from me.

**Approximately half of all infants born with Down syndrome also have significant heart diseases and defects, like Jenna.** Thanks to dedicated research and skilled medical professionals, Jenna has received outstanding care, which has allowed her to grow into a vibrant young woman who actively participates in dance, gymnastics, and cheerleading. **However, despite her current good health, Jenna's condition will require lifelong cardiac care to ensure that her heart remains healthy and functional.**

That is why efforts like those at the Centers for Disease Control and Prevention (CDC) to support research that improves survival rates for children born with congenital heart disease/defect (CHD), prevents premature death and disability, and enhances the quality of life for the 2.5 million Americans living with CHD is so important to me and my family.

These important efforts are authorized by the Congenital Heart Futures Act which was first passed in 2010 and has been reauthorized several times since. For families like mine, this continued research is vital, as it ensures that doctors are equipped with the knowledge and resources needed to provide the best care possible throughout Jenna's life.

Supporting continued investments in CHD research and awareness is not just about securing a healthier future for my daughter; it's about giving hope to every child and family affected by congenital heart disease. By investing in research and public health programs, we can continue to improve the quality of life for millions of people and ensure that children like Jenna have the opportunity to live long, healthy, and fulfilling lives.



*Jenna today*



*Jenna, 3 months old*



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