

H.B. 135 Written Testimony
From Marian Russell
June 9, 2015

Chairman Derickson, Ranking Member Howse, and Members of the House Community and Family Advancement Committee, my name is Marian Russell and I am the sibling of an Ohioan with Down syndrome. Please accept this written testimony in support of H.B. 135, which seeks to restrict abortion of babies with Down syndrome.

I would like to share my family's story so that you can see the real human side of Down syndrome. Too often people with Down syndrome become defined by their debility. Not often enough do people see value through the eyes of compassion. Well I hope the story of my brother Rick will prove there is value in life. For it pains me to think that a baby with Down syndrome deserves less love or worse does not deserve a chance to love.

My brother Richard Jay Lutzke was born December 28, 1955 with Down's syndrome, and is the second of four children. Rick developed his fine motor skills, talking and walking at a slower pace than most children, but he was a happy, good-natured child and developed a great sense of humor. Our love for him was unconditional.

He was treated the same as my siblings and I as far as discipline was concerned, and his early childhood was much the same as any other child. The neighborhood children accepted him. He started school at age 7 and attended public school in a class for special needs children. He had a good understanding of the English language before he started school. While in the primary grades he learned how to swim, and to this day he is an excellent swimmer. As far as we were concerned he was a normal kid and every bit apart of the family.

We had no way of knowing during our childhood what a positive impact Rick would have on our life experience. I certainly had no inclination what a ripple effect he would have on my life and the lives of my children. I have learned so much from him including patience and compassion. The first major lesson came when I was on a swimming field trip in the fourth grade. As we got ready to jump in the pool a boy in my class said, "Look at the retards!" I looked up and the first person I saw was Rick. My heart sank and his comment stung. I was upset that I could not protect him and saddened that Rick's feelings were hurt. I wanted to defend him; for this was not some random animal this was my brother. I would have to come to grips with society view of Rick just as Rick would have to come to grips with discrimination. It is not easy explaining why. To this day, Rick gets very upset by the "R-word" because he knows the term is derogatory.

My parents looked for better ways to provide for Rick just as most parents do for their children. In 1967 we moved to the Toledo, OH area from Cleveland and immediately began exploring ways our family could live a full life with Rick by our side. Lucas County was more advanced in providing services for the developmentally disabled at that time, and our father got involved almost immediately as many parents do. Likewise, our mother joined a parent support group and helped at special events just as she did with the rest of us kids at our events. Our family continued to stay involved and our

father, Gerald Lutzke, was a board member for LARC (Lucas Co. Association for Retarded Children and eventually became LARC President. He was always involved with numerous fund raising projects all to raise money for people like my brother Rick. And when there was an issue on the ballot you could find us painting and distributing yard signs as well as standing at the polls on Election Day. It was through this work that we learned the value of community and public service in spite of painful lessons interacting with the public.

Our parents were very careful when deciding about Rick's future. They wanted him in an environment that would be a good fit. After graduating with a limited diploma in 1976, Rick went to work at the sheltered workshop, Lott Industries. His job gave him a sense of worth and a new avenue to make friends. Even though Rick seemed happy, he never stopped exploring the world just as you and I would.

When he was around 30, Rick moved to a group home through *Community Residential Services*. His IQ increased 4 points when given more responsibility such as taking the bus and making purchases with the money he earned. He moved to an apartment and had a roommate for many years. Only recently have health issues caused him to move back into a group home environment where he is happy and meeting new friends—all at the age of 59.

As I raised my own children, I noticed more and more Down's syndrome children being integrated into the public school classrooms and not segregated as in the past. This produces higher functioning citizens but there is a much wider acceptance from the other children. Many obtain jobs in the community, participate in church life and live productive lives. More has changed in my lifetime for people with Down's syndrome than ever before. Research continues regarding the how and why this syndrome occurs. I am happy they have Rick in their lives because they have learned some of the same lessons that I had learned.

My children are now adults, some with their own children, and Rick continues to bring character to an otherwise boring and cruel world. I fully expect my grandchildren will learn the same values that my children and my siblings and I have learned from Rick. In the past two-years together as a family we have had to bury both my parents and my brother who was killed tragically in a traffic accident. Rick has taken their deaths very hard but had never lost his charming smile. We continue to learn from him and these recent events have shown us that his tears are not caused by grief or sorrow; rather they are a result of love.

In consideration of H.B. 135, I ask that you consider my brother Rick. I hope you see that his life is not defined by Down syndrome, but is instead defined by the priceless value he brings to this world. Rick is truly loved by our family and we cannot imagine a world without him. It pains me to think that so many babies with Down syndrome are thrown away as if they have no value. I hope you see all the positive ripple effects these babies could have, and I humbly ask you to vote "yes" for H.B. 135—not out of compassion but out of love.

Thank you.