

Honoring Christian Pueschel's Legacy

I would like to express my sincere gratitude to the NDSC for the opportunity to address the banquet audience this evening. Please permit me to say a few words about my son, Chris, and how his extraordinary life had a profound impact on my life in general and on my professional career in particular.

Chris was born on July 25, 1965; and after a fulfilled and prolific life, he died August 9, 1998, a day I shall never forget. Some of you may recall that a few hours after Chris' passing on, I stood in front of the audience of the 1998 NDSC Convention to present a plenary session. To say the least, it was one of the most arduous and painful tasks in my life.

Going back some 34 years ago, like many expectant parents, my wife and I had been looking forward to the birth of a healthy baby. However, our dreams soon were shattered when we found out that Chris had Down syndrome. But after this initial traumatic experience, our sadness and concerns were soon transformed into joy and true happiness because his smiles and his pleasant personality conquered our hearts, and thus we started to celebrate Chris' life. In spite of the bleak prognosis given by his doctors, his steady developmental progress and his determination to overcome adversity were exhilarating and inspiring.

I could tell you many exciting stories about my son, however, I would rather dwell on Chris' legacies and also let you know what I have learned from other children during my professional life, for I had the very privilege of caring for literally hundreds of persons with Down syndrome during the past 30 years. These children taught me about their human qualities, the enormous contributions they can make to society, and their passion for life.

They also taught me that special children are no different from other children in their needs, only in the manner by which they express them and that they are not different from others in their rights, only the way they learn and use them.

Moreover, I learned from Chris and from other individuals with Down syndrome that there is a goodness, kindheartedness, humanity, and magic in our children that must be protected and never be betrayed.

My friends, we must preserve this humanity and these human values in a world whose forces and pressures tell us to always believe in technological solutions. I believe that there is a need to return to the fundamentals of existence, the pursuit of truth, the reverence of life, and the unselfish concern for human dignity. Reverence of life and an appreciation of the significance of each individual human being, including our children with Down syndrome, must be the cornerstone of any enduring society.

This may be a profound statement, and some may not agree with me in this regard, in particular, those professionals who tell us that prenatal diagnosis will identify most fetuses with Down syndrome and that subsequent abortion of those fetuses will "take care of all problems." We have to ask ourselves, does this new technology in prenatal diagnosis, and the shift toward viewing affected fetuses as disposable, deter physicians from their primary mission to be healers and preservers of life?

I feel strongly that there has to be respect for the sanctity of life and for the dignity of any human being, for this is Chris' legacy. My son taught me that every person with Down syndrome is a unique and most valuable human being. And, if one believes that human life is infinite in value, then one must believe that the sanctity of life is bound to be unaffected by either intellectual or physical

impairments.

In my view, the value of people with Down syndrome is intrinsically rooted in their very humanity and in their uniqueness as human beings. If individuals with Down syndrome have the intrinsic value and the rights of human beings, they indeed can reach a point of significant fulfillment.

Another one of Chris' legacies: When it comes to life, there are no limits. Thus, I do believe in the tremendous potential that can be reached if we are sincere in providing these individuals with optimal medical care, as well as with excellent educational, vocational, and recreational services and if we are dedicated to enhancing the fullness of life for every person with Down syndrome.

It is imperative that we as parents, professionals, and friends of persons with Down syndrome affirm the absolute fullness of their humanity and the absolute worth and significance of their lives. Let us recognize our children for their beauty, their compassion for life, and for their humanizing influence on society.

-- Speech presented by Dr. Siegfried Pueschel at the 1999 NDSC Annual Awards Banquet held in Pittsburgh, PA.