

Down Syndrome does not define who I am as a person :

October is Down syndrome Awareness Month! What does Down Syndrome mean? The syndrome was discovered by John Langdon Down, a British physician who described the condition for the first time in 1866. The syndrome is also known as trisomy 21, because individuals with Down syndrome have an extra chromosome, a third copy of chromosome 21. That extra chromosome is the one key trait that makes us a group. However, all individuals with Down syndrome are not alike. Each one of us is one of a kind while sharing in the same humanity and condition with many others with intellectual challenges or not. Each one of us is a member of a unique family with all of the hereditary traits of many generations.

When I was ten years old, I had my tonsils taken out and as we were going to the hospital, I asked my mother: “Will I get rid of the Down syndrome thing too?” She responded: “It is something that stays with you all your life, but it does not stop you from having dreams and being successful”. She was right and as my life unfolded, I wanted to live the idea of “boldly going where no other person with Down syndrome has gone,” to borrow from Star Trek. I let myself dream big and then bigger. I dared to dream of work that mattered. I dared to dream of advocating for a whole world of people with Down syndrome and other disabilities . I dreamed of being on Capitol Hill, saying the words that changed hearts and minds and laws.



You can learn more about my work in advocacy in my book: “More Alike Than Different: My Life With Down Syndrome.”

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By daring to dream, I found many of my goals turning into accomplishments. In my life, I have learned that the barriers of low expectations aren't real. In a way, they mark the limits of imagination. If someone hasn't seen or heard of someone doing something, maybe they think it can't be done. Having an extra chromosome, having Down Syndrome creates challenges for us. I have had my share of struggles: physical, social, and intellectual. I try not to be discouraged by the difficulties that I face. Having Down syndrome is not easy as our health is at risk. Our immune system is fragile. While the medical profession and researchers have made some progress making it possible for us to live beyond the age of 25 which what was predicted when I was born; "It is not enough to live longer, we need to prosper" as Officer Spock says.

During this month of October, let us celebrate all of the individuals with Down syndrome and their families. What I am today has been shaped by my family and the people I have met in my life. My personal experiences influenced my growth and the man I am today. Being included in everything—family life, school, sports, work—has given me chances to grow as a person that would have been hard to imagine when I was born in 1977. Our extra chromosome unites us as a group to advocate for better health, education, employment and a full inclusive life but it does not define us as an individual person.



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