



The International 22q11.2 Foundation Inc.

Hi, My name is Carol Cavana and I am a founding board member, Secretary and Past Chair of The International 22q11.2 Foundation. I would like to wish the International 22q11.2 Foundation a Happy 15th Anniversary. I am a proud parent of a remarkable nineteen-year-old son, Louis, with 22q deletion syndrome.

Over nineteen years ago, my son, Louis, was diagnosed with the 22q Deletion Syndrome. At that time, I remember feeling isolated and uncertain. Isolated because my son had a condition that was not well known in the medical community and little was known of the many associated medical problems along the developmental continuum. Back in 2003, a small group of parents and a local professional, concerned about individuals affected by the chromosome 22q11.2 deletion, sat around a kitchen table in suburban Philadelphia and brain stormed about how they might help. From this initial meeting and in an attempt to be as inclusive as humanly possible, The International 22q11.2 Foundation, Inc. was born.

When my son was diagnosed in 1998 I felt alone, devastated and uncertain what the future would hold for him. As a parent I wanted to do everything possible to give my child the best outcome in life. I asked myself so many questions, why did this happen? Did I do something? Could I have done something different and so many more? I cried for weeks thinking why me?

Well I can say Louis is a nineteen-year young man still in High School doing **AWESOME!!!** Now I say that in a way that our 22q community will understand. Louis has had eighteen surgeries beginning at the age of three months and on. He has extreme learning disabilities in reading, writing and math. One thing that impresses me so much about him is his persistence to achieve the things he loves and this is what drives him to do better.

He enjoys sports through the Special Olympics such as basketball, swimming, and track and tried speed skating. When he sets his mind to something he is determined to accomplish that goal. He has many gold and silver medals to show his dedication to the sport.

Along this journey, I hope I have made some impact on the 22q community with my work and friendships I have made through the years through the foundation. What I wish most is that 22q becomes a household name; nineteen years later I'm still explaining what 22q is, but boy has our foundation come a long way!

Carol Cavana
Founding Board Member, Secretary, Past Chair and Proud Parent

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