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The International 22q11.2
Deletion Syndrome Foundation, Inc.

Dear Friend,

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 Deletion Syndrome Foundation, Inc. was born.

At that time, many of the founding families shared their feelings of isolation and uncertainty – isolation based on the fact that very few professionals, medical and school personnel alike, or lay persons had ever even heard of the 22q11.2 deletion, not to mention the confusion surrounding the numerous clinical names used to describe the same condition, and uncertainty surrounding the long term outcome for their children.

Thankfully over time the chromosome 22q11.2 deletion syndrome has gained momentum in terms of recognition and much has been discovered about this condition. For example, we now know that the 22q11.2 deletion is the most common microdeletion syndrome in man affecting one out of every 2,000-4,000 newborns (and this may well be an underestimate!). We know that it is found in 1 in 68 children born with heart defects and it is the most common cause of syndromic cleft palate. We also know that it can cause many other problems such as immunodeficiency leading to difficulty fighting infection and autoimmune disease; issues with feeding and growth; hearing loss; breathing difficulties; kidney and spine differences; autism, learning disabilities and behavioral differences. But we also now know that there is wide variability amongst individuals with the deletion so that some have all of these issues and others have almost none. This confounding fact alone, which is quite unique as chromosomal syndromes go, continues to challenge us to support identification, appropriate clinical care, and research studies towards a cure so that all whom need help are found and thereafter treatment plans to improve the long-term quality of life for those affected by the deletion are in place.

Based on these ambitious goals, the Foundation has evolved into a tax-exempt nonprofit organization dedicated to:

“Improving the quality of life for individuals affected by the 22q11.2 deletion syndrome through family and professional partnerships”

As a fellow parent, formerly frightened and alone, I ask that you consider making a tax-deductible donation to the Foundation to help us reach these goals. Please understand that no amount is too small. Alternatively, might you consider hosting a fund raiser in your own area. A bake sale, a walk or bike ride? The possibilities for supporting awareness and concurrently contributing to education, clinical care and research are endless. We can't do this alone and your support won't go unnoticed; in fact it will help ensure a brighter, healthier future for all!

Sincerely,

Carol Cavana

Parent, Founding Member and Board Chair
