

Ellie's Story



Ellie Venue is named after the most brave little girl, born with a very rare 22q11.2 micro chromosome duplication, she has fought through and survived several operations to save her life since birth, including two open heart surgeries of which the first at only two months of age and the second when she was 10 months old.

“Almost two years ago I sat in an ICU’s waiting room with my husband next to me as doctors and genetic specialists briefed us about the surgeries she’s going to have to get and the conditions she most likely are going to have to grow up with (89% of having autism etc.) For the most part they used the phrases, ‘do not expect her to be a highly active, normal child’, always take three steps forward and four steps backwards’. Then they came to a little girl who we called Ellie.

The genetic specialist described her to us as ‘highly special needs’ with “extreme bodily deformities” to parents who were, in so much words, in denial. And I’m glad we were, because since then she has showed amazing strength and power. Fighting

through so much, surprising so many with her abilities and showing the world an angel-heart filled with so much love and hope and an amazing sense of humour, a golden little smile and laugh.

I decided that apart from the data on her 5 pages long diagnosis, I would toss the rest of the interpretations about my daughter out the window because I believe she is capable of so much more!”

A true story from inspirational parents of Ellie, Pieter and Bianca, that encourages us to do aim higher, believe more, and assume the best in all of our kids, because they are the future.