

Children with trisomy 13 and 18 and their families are happy

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Children with trisomy 13 or 18, who are for the most part severely disabled and have a very short life expectancy, and their families lead a life that is happy and rewarding overall, contrary to the usually gloomy predictions made by the medical community at the time of diagnosis, according to a study of parents who are members of support groups published today in *Pediatrics*. The study was conducted by Dr. Annie Janvier of the Sainte-Justine University Hospital Center and the University of Montreal with the special collaboration of the mother of a child who died from trisomy 13, Barbara Farlow, Eng, MSc as the second author.

The study interviewed 332 parents who live or have lived with 272 children with trisomy 13 or 18. It turns out that their experience diverges substantially from what [healthcare providers](#) said it would be, according to which their child would have been "incompatible with life" (87 %), would have been "a vegetable" (50 %), would have led "a life of suffering" (57 %) or would have "ruin their family or life as a couple" (23 %).

It should be noted that trisomies 13 and 18 are rare chromosome disorders that are most often diagnosed before birth and sometimes after. Children who have received these diagnoses generally do not survive beyond their first year of life, while some who do have severe disabilities and a short life. When trisomy 13 or 18 is diagnosed before birth, many parents decide to interrupt the pregnancy, whereas others choose to carry it to term and in such cases [miscarriages](#) are common.

As children with trisomies 13 or 18 generally receive [palliative care](#) at birth, some parents who opt to continue the pregnancy or desire life-prolonging interventions for their child encounter the [prejudices](#) of the [medical system](#). In this regard, the parents interviewed in the study consider that caregivers often view their child in terms of a [diagnosis](#) ("a T13", "a lethal trisomy") rather than a unique baby.

"Our study points out that physicians and parents can have different views of what constitutes quality of life," states Dr. Annie Janvier, a neonatologist and co-founder of the Master's program in Pediatric Clinical Ethics at the University of Montreal. In fact, over 97% of the parents interviewed considered that their child was happy and its presence enriched the life of their family and their life as a couple regardless of longevity. "In the medical literature on all handicaps, disabled patients – or their families – rated their quality of life as being higher than caregivers did," adds Dr. Annie Janvier.

Parents who receive a new diagnosis of trisomy 13 and 18 and join a parental support group often acquire a more positive image of these diagnoses than the predictions made by the medical profession. In fact, according to the parents interviewed, belonging to a support group helped them view their experience positively. "Our research reveals that some parents who chose a path to accept and to love a disabled child with a short [life expectancy](#) have experienced happiness and enrichment. My hope is that this knowledge improves the ability of physicians to understand, communicate and make decisions with these parents," concludes Barbara Farlow.

Given the rarity of trisomy 13 or 18 cases (one case out of approximately every 10,500 births), the parents were recruited through online [support groups](#) that parents often join after receiving the physicians' diagnosis. Dr. Annie Janvier and Barbara Farlow sometimes give joint talks on the subject of trisomies 13 and 18.

Provided by University of Montreal

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