



Project chromosome 11q duplication started!

Does your child have a partial trisomy (duplication) on the long arm of chromosome 11? Please join <https://www.facebook.com/groups/chromosome11qplus/> (restricted group). We are updating now the project to collect genetic, clinical and developmental information on children with a duplication 11q. We hope to report results in 2017 and 2018.

Are you not on Facebook yet and do you want to know more? Or: do you not want to join Facebook? Please contact me via [e-mail](#).

Annet van Betuw

What do we know about duplications on 11q (11q+)?

Summary: In 2016 and 2017 we will carry out a project to collect genetic, clinical and developmental information of children with a duplication of a part of chromosome 11q. It will be reported in 2017 and 2018.

The American and European Chromosome 11 groups have been very important in collecting knowledge on deletions and duplications. In 1998 American and European parents started cooperation with the university of Catania (It). In the period 2002 to 2004 the European Chromosome 11q network (now European Chromosome 11 Network) has been collecting a lot of information on genetic, clinical and developmental problems of children with a deletion or duplication on chromosome 11q. There were and are more deletions than duplications (partial trisomy). Duplications tend to be more complex in the development of a child. The relatively low number of children with a duplication and this complexity made it problematic to answer questions of parents on what to expect of the development of their children.

Now we are 12-14 years further in time. Genetics developed and our knowledge developed as children grew up. We know now about 42 children with a chromosomal duplication on 11q mainly in Europe and the USA. Therefore we expect that we are now better capable to produce together an overview of chromosomal characteristics, the complications in the development of the children and life expectancy.

Therefore we, prof Dr Teresa Mattina and Dr Cristina Gorgone of the University of Catania (It), Annet van Betuw and Rob Jongman, parents of the 11q+ child (†2000), who was the instigation for the 11q-network, decided to take action. We will

- bring together the information that was available in 2004,*
- update this with your help, if you are willing to spend the time and*
- ask other parents to join this project.*

We hope that this might help you to organise your lives with your children better. It might help the parents with young children in the questions they can expect in the coming years, in consulting and instructing doctors and caretakers and in organising their life as well.