

Dear 'Chromosome 6' parents,

UMCG, Groningen
April 14, 2014

This is an update on the chromosome 6 study to inform you about what we are doing at the moment and what we intend to do in the future.

Money matters

Our C6 grant proposal was submitted 5th February and in March we received critical comments on it from three independent reviewers. Two out of three reviewers rated our proposal as 'excellent' and one as 'sufficient'.

We were asked to respond to the reviewers' comments, and we emphasized the importance and feasibility of this research project. We are now waiting for the final decision and will hear in June whether our proposal will be successful for a grant or not.

In the meantime, the University Medical Centre Groningen (UMCG) and the Chromosome 6 Foundation have started a funding webpage at *JustGiving*: <https://justgiving.nl/en/charities/388-umcg-chromosome-6-research>. This has already proved to be a great success: within a few days €400 was raised.

Progress

Our work on the chromosome 6 data is progressing slowly and steadily. At the moment we are working on the first paper, and have several ideas for more articles. We are working hard to make our information available to the medical community.

The grant we have applied for would enable us to build an interactive website with detailed information on specific chromosome 6 anomalies, so that parents and health care professionals would be able to find the information they need.

Number of participants

The number of participants in the study is still increasing: over 210 parents have shown their interest in our study by sending us an email! Half of them have returned the questionnaire and consent forms.

We now have 71 complete 6q files and 12 complete 6p files. Complete files have both a filled-in questionnaire and the child's array results (microarray, SNP array, or array-CGH).

The study is still open to new patients, so if you are interested in the study please let us know!

Do send us an email if you have any questions or ideas on what it would be interesting to discuss in our next Facebook update, or if you have ideas for our study!

With best wishes,

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