

Dear chromosome 6 parents,

Groningen,  
February 17<sup>th</sup>, 2014

A new update on what we are doing at the moment and what we intend to do in the future with the chromosome 6 study.

### **Money matters**

The grant proposal was submitted last week. The selection procedure for this grant takes several months. Therefore we will not know on short-term whether our proposal will be granted or not.

It really would be great if we get this grant because that would allow me to spend more time on the chromosome 6 research project. In that case, I will be able to expand my work from collecting data to analyzing all information and writing the first papers in order to make the information available to the medical community. Moreover, the grant will enable us for the next period of three years to build an interactive website with detailed information on specific chromosome 6 anomalies, and to study what the impact of such a website for families is.

See please, let us all keep our fingers crossed!

### **Twitter**

You can now follow the Chromosome 6 research on Twitter! - @c6study

### **Chromosome 6 research webpage**

The chromosome 6 research webpage begins to take shape. On this webpage there is information about the study, a letter from parents about the importance of the research and information about fundraising for the chromosome 6 foundation. The advisory board for the chromosome 6 project also presents themselves on our website. This board consists of both parents and professionals and we really would like to invite you to meet them on our website. [http://www.rug.nl/research/genetics/research/chromosome\\_6/](http://www.rug.nl/research/genetics/research/chromosome_6/)

### **Translations**

Thanks to Lisa and her aunt a Portuguese translation of the questionnaire and study information is now available! So we invite all Portuguese speaking families to contact us if they want to participate in our study.

The study is still open for new applications, so if you are interested in participating in the study please let us know! Questionnaires are available in English, Dutch and Portuguese.

If you have questions or ideas on what is interesting to discuss in the next Facebook update, or if you have ideas for our study, do not hesitate to send us an email.

Kind regards, also on behalf of Prof. dr. Conny van Ravenswaaij-Arts,

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