

Dear chromosome 6 parents,

Groningen,
January 17th, 2014

The first update of 2014!

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

If you have ideas on what is interesting to hear for the next update, do not hesitate to send us an email.

Money matters

The money generously donated by your group, allows Barbara to work on the project one day a week until June 2014. We want to spend the money, which you were able to collect through all kind of amazing initiatives, as efficiently as possible.

In the meanwhile we are working on a grant proposal, but the selection procedure for a grant takes a long time. Therefore we will not know on short-term whether our proposal will be granted or not.

If the proposal is granted we will not only continue collecting and analyzing information on chromosome 6 patients, but we will also design an interactive website that will contain detailed information on chromosome 6 anomalies, including recommendations for surveillance, for families and professionals. In this project we will work together with, amongst others, Unique and of course with your group represented by Pauline Bouman. If the project is granted we will need your help to make a website that really suits your needs!

Chromosome 6 research video

We have been contacted by Mrs McPherson, who suggested making a video that can be used in fund raising initiatives for the chromosome 6 research. We are very enthusiastic about this great idea! With a video explaining what chromosome 6 abnormalities are and why further research is needed we might be able to reach far more parents and investors. We want to thank Mrs McPherson warmly for this initiative and of course we will assist her whenever necessary.

Twitter

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

New webpage

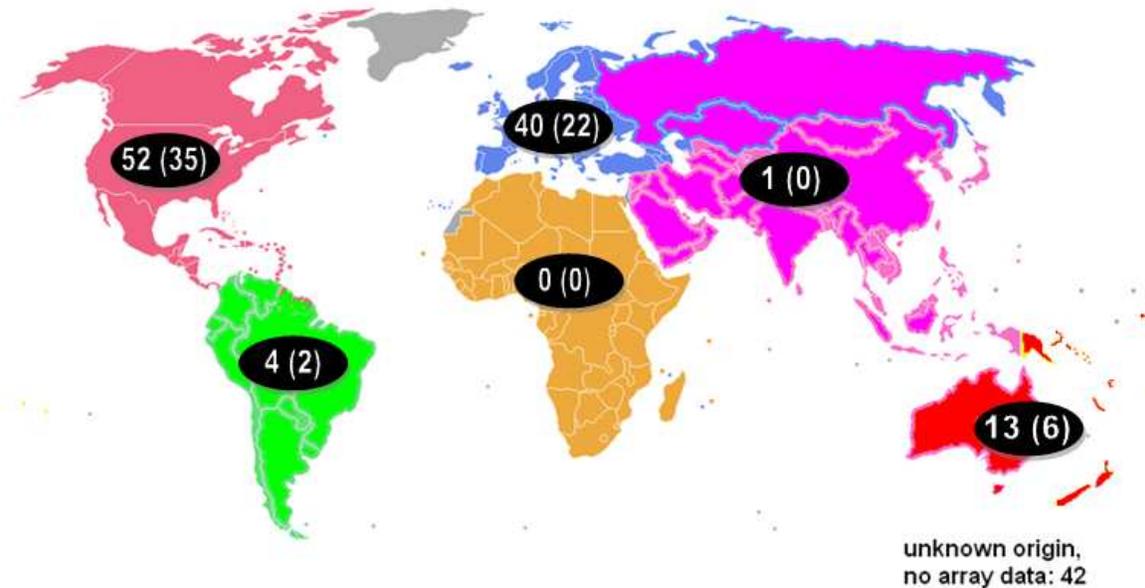
We are continuously improving our website. It contains information about the study, a letter from parents about the importance of the research, and information about fundraising for the chromosome 6 foundation.

http://www.rug.nl/research/genetics/research/chromosome_6/

Number of participants

Through Pauline Bouman we heard that parents want to know how many participants there are and what the distribution over the globe is (see figure). The numbers in the figure are not the most recent numbers, but they give a good impression.

Number of people who responded
(number of participants with complete data)



Over 200 parents have shown their interest in our study by sending an email. Almost one hundred of them have returned the questionnaire and consent forms. We have 66 'complete' 6q files and ten complete 6p files. Complete files are files with the questionnaire and array results (microarray, SNP array or array-CGH).

The study will remain open for new applications as long as we can finance Barbara, so if you are interested in the study please let us know!

Kind regards,

Barbara Frentz and Prof. dr. Conny van Ravenswaaij-Arts,
Department of Genetics, UMC Groningen
Chromosome6@umcg.nl