

Learning more about growth in CHARGE syndrome using photometry

During the international CHARGE conference, on the 28-29th of July we will be asking children with CHARGE syndrome and their parents to help us investigate **growth** in CHARGE syndrome.

Why are we collecting growth information?

By asking as many children with CHARGE syndrome as possible to join us, we hope to be able to make CHARGE syndrome specific growth curves indicating what is normal growth in CHARGE syndrome. We hope this will help us to provide even better care for children with CHARGE syndrome.

What else are we doing?

In addition to making growth charts, we want to find out more about body proportions of children with CHARGE syndrome at different ages. We use a new technique, photometry, to study body proportions. We are interested in the proportions of arms and legs versus the torso, and the torso versus height. With photometry, all we need are two pictures, taken with a regular camera. We can then use specialized computer software to determine all the measurements we need.

What will we ask of you and your child?

Your child must be able to stand upright to participate in this study. If you give your consent, we will take **two regular photographs**. Your child will be photographed wearing only undergarments. Of course, you will be present while we are taking the photographs.

Who are we?

The photometry has been developed by dr. W.J. Gerver, pediatrician-endocrinologist and Bas Penders, researcher, of the Maastricht University Medical Centre (MUMC+), interested in growth in genetic disorders.

During the CHARGE family weekend the photographs will be taken by Dieuwerke Dijk, researcher and resident in training to become a physician for people with intellectual disability at the University Medical Center Groningen (UMCG) and Erasmus Medical Center Rotterdam. She will be supervised by Gianni Bocca, pediatric endocrinologist and Conny van Ravenswaaij, professor in clinical genetics of the Dutch CHARGE center of expertise at the UMCG.

More information

If you have any questions, please do not hesitate to ask. We will wear a button indicating the growth study.

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This study has been approved by the MUMC+ institutional ethical review board.

