Developing patient-centred care for counselling prospective parents faced with a prenatal diagnosis of CDH: outcomes important to parents, patients and their families

We are currently inviting parents who have had a prenatal diagnosis in their unborn child of CDH to participate in part II of the patient centred care study.

The purpose of this research is to understand the outcomes relevant for prenatal counselling for CDH, important to parents, patients and their families. Therefore, we are inviting parents who have had a prenatal diagnosis of CDH (moderate or severe) in their child during pregnancy, regardless of the subsequent decisions made (fetaltherapy/ FETO, postnatal treatment, termination of pregnancy), between 2011 and 2021.

Through this study, we hope to further improve the care offered to the parents to meet their unique needs. This information will be used to develop a questionnaire for the evaluation of future clinical care for parents of an unborn baby with CDH.

The research will be carried out through interviews via video-call (Skype, Zoom, Facetime or equivalent) or telephone. A researcher who has a lot of experience with this subject will talk to you and / or your partner to find out more about the outcomes that are according to you most relevant in prenatal counseling.

If you wish to participate, you will be invited for an interview at a suitable time determined by you. The interviews will last 30 to 60 minutes. At the end of the interview, parents will be asked whether they wish to be contacted later to review the questionnaire to assess clinical care that would be developed from this research. You

are free to decline participating further.

Contact the investigator directly: neeltje.crombag@kuleuven.be

Principal Investigators Prof. Jan Deprest

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If you wish you may discuss participation with your GP

This project is based in KU Leuven, Belgium and received ethical approval of the ethics committee of the UZ Leuven (S64933)