Neurodevelopmental outcome and quality of life in infants with (congenital) liver disease

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Infants with congenital liver disease and/or who underwent a liver transplantation < 5 year will have more neurodevelopmental problems and an impaired quality of life at school age when compared to healthy peers.

Ethische beoordeling	Positief advies
Status	Werving gestart
Type aandoening	-
Onderzoekstype	Observationeel onderzoek, zonder invasieve metingen

Samenvatting

ID

NL-OMON27464

Bron
NTR

Verkorte titel
COLINO

Aandoening

Neurodevelopmental outcome
Congenital liver disease
Biliary Atresie
Liver transplantation
Behavioural problems
Quality of life

Neurologische uitkomst
Ontwikkelingsproblemen
Kwaliteit van leven
Aangeboren leveraandoeningen
Galgangatresie

Ondersteuning

Primaire sponsor: -
Overige ondersteuning: MLDS

Onderzoeksproduct en/of interventie

Uitkomstmaten

Primaire uitkomstmaten

Neurodevelopmenatal outcome
Quality of Life

Toelichting onderzoek

Achtergrond van het onderzoek

Background

Congenital liver disorders often present shortly after birth, and in a large number of infants this leads to a liver transplantation before the age of 18 years. Previous studies showed that children who underwent a liver transplantation often have neuropsychological developmental problems. Recently we performed a pilot study in which the neuropsychological development at school age (6-12 years) in children with biliary atresia was examined. This analysis showed that these children achieve poorer results in motor, cognitive and behavioral tests compared to their healthy peers. The reason for these developmental problems is still unclear.

Methods

All children born in the Netherlands and Denmark with congenital
liver disease will be asked to undergo validated neuropsychological tests, at different ages (3 months post-term, 18 months and between 6 and 12 years old). The results of these tests

are correlated with different clinical parameters and risk factors to identify those children at high-risk for developmental problems.

Expected results

We expect to give an overview of the neuropsychological development of children born with congenital liver disease at school age. And furthermore to identify risk factors, in this population, for impaired neuropsychological development. Early identification of those infants at high risk for developmental problems may give us the ability to provide extra guidance or treatment in order to promote their quality of life and social participation.

Doel van het onderzoek

Infants with congenital liver disease and/or who underwent a liver transplantation < 5 year will have more neurodevelopmental problems and an impaired quality of life at school age when compared to healthy peers.

Onderzoeksopzet

School age (6-12 years of age)

Onderzoeksproduct en/of interventie

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Contactpersonen

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Deelname eisen

Belangrijkste voorwaarden om deel te mogen nemen (Inclusiecriteria)

- All infants with congenital liver disease in the Netherlands.

- All infants who had a liver transplantation < 5 year in the Netherlands.

Belangrijkste redenen om niet deel te kunnen nemen (Exclusiecriteria)

- Deceased infants.

-Neurodevelopmental sequelae due to other problems (e.g. syndromal)

Onderzoeksopzet

Opzet

Type:	Observationeel onderzoek, zonder invasieve metingen
Onderzoeksmodel:	Anders
Toewijzing:	N.v.t. / één studie arm
Blindering:	Open / niet geblindeerd
Controle:	N.v.t. / onbekend

Deelname

Nederland

Status:	Werving gestart
(Verwachte) startdatum:	01-09-2016
Aantal proefpersonen:	75
Type:	Verwachte startdatum

Ethische beoordeling

Positief advies

Datum:	25-10-2016
Soort:	Eerste indiening

Registraties

Opgevolgd door onderstaande (mogelijk meer actuele) registratie

Geen registraties gevonden.

Andere (mogelijk minder actuele) registraties in dit register

Geen registraties gevonden.

In overige registers

Register	ID
NTR-new	NL6060
NTR-old	NTR6207
Ander register	UMCG Research Register : 201600843

Resultaten