

Growing up with pulmonary arterial hypertension, a Quality of Life Study

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Based on clinical experience in our multidisciplinary team caring for children with PAH and CHD, we expect that children with PAH and their families suffer from decreased psychosocial QoL compared to healthy norms. We expect psychosocial...

Ethische beoordeling	Niet van toepassing
Status	Werving nog niet gestart
Type aandoening	-
Onderzoekstype	Observationeel onderzoek, zonder invasieve metingen

Samenvatting

ID

NL-OMON21691

Bron

NTR

Verkorte titel

Growing up with PAH, a QoL study

Aandoening

Pulmonary arterial hypertension

Ondersteuning

Primaire sponsor: Center for Congenital Heart Diseases

Overige ondersteuning: 3e geldstroom

Onderzoeksproduct en/of interventie

Uitkomstmaten

Primaire uitkomstmaten

Quality of Life in patients with pulmonary arterial hypertension

Toelichting onderzoek

Achtergrond van het onderzoek

The primary objective of the proposed project is to investigate the Quality of Life (QoL) of children with PAH and the psychosocial and social impact of the disease. Further, the secondary objective is to study the impact on family life, parents and siblings of a child with PAH. Third, we will offer psychosocial interventions for patients (and their parents/siblings) to assess whether improved QoL can be achieved.

Doel van het onderzoek

Based on clinical experience in our multidisciplinary team caring for children with PAH and CHD, we expect that children with PAH and their families suffer from decreased psychosocial QoL compared to healthy norms. We expect psychosocial intervention programs to improve QoL in these children and their families.

Onderzoeksopzet

First part: cross sectional study

Second part: prospective, longitudinal intervention study

Onderzoeksproduct en/of interventie

First part: cross-sectional study with questionnaires.

Second part: psychosocial interventions.

Contactpersonen

Publiek

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Wetenschappelijk

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Meindina Haarman

Deelname eisen

Belangrijkste voorwaarden om deel te mogen nemen (Inclusiecriteria)

Patients with Pulmonary Arterial Hypertension:

- Age 5-18 years
- Patients with Pulmonary Arterial Hypertension: diagnosis confirmed according to the standards of the National Expertise Center for Pulmonary Hypertension in Childhood in the University Medical Center Groningen, Groningen, the Netherlands

Parent(s) of patients with Pulmonary Arterial Hypertension:

- Parent of a child with Pulmonary Arterial Hypertension with a confirmation of the diagnosis according to the standards of the National Expertise Center for pulmonary hypertension in childhood in the University Medical Center Groningen, Groningen, the Netherlands

Siblings of patient:

- Age 5-18 years
- brother or sister of patient with Pulmonary Arterial Hypertension: diagnosis confirmed according to the standards of the National Expertise Center for Pulmonary Hypertension in Childhood in the University Medical Center Groningen, Groningen, the Netherlands.

Belangrijkste redenen om niet deel te kunnen nemen (Exclusiecriteria)

A potential subject who meets any of the following criteria will be excluded from participation in this study:

Patients with pulmonary arterial hypertension

- age > 18 years of age
- age < 5 years of age
- not familiar with the Dutch language

Parents:

- not familiar with the Dutch language
- Being under examination for non-diagnosed disease at time of investigation

Siblings

- not familiar with the Dutch language
- Being under examination for non-diagnosed disease at time of investigation
- < 5 years of age

Onderzoeksopzet

Opzet

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

Deelname

Nederland	
Status:	Werving nog niet gestart
(Verwachte) startdatum:	01-07-2019
Aantal proefpersonen:	200
Type:	Verwachte startdatum

Voornemen beschikbaar stellen Individuele Patiënten Data (IPD)

Wordt de data na het onderzoek gedeeld: Nee

Ethische beoordeling

Niet van toepassing	
Soort:	Niet van toepassing

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
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NTR-new	NL7528
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Ander register METC UMCG : UMCG Research Register number: 201800785

Resultaten