

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

No registrations found.

<b>Ethical review</b>	Not applicable
<b>Status</b>	Pending
<b>Health condition type</b>	-
<b>Study type</b>	Observational non invasive

## Summary

### ID

NL-OMON21691

### Source

Nationaal Trial Register

### Brief title

Growing up with PAH, a QoL study

### Health condition

Pulmonary arterial hypertension

## Sponsors and support

**Primary sponsor:** Center for Congenital Heart Diseases

**Source(s) of monetary or material Support:** 3e geldstroom

## Intervention

## Outcome measures

### Primary outcome

Quality of Life in patients with pulmonary arterial hypertension

### Secondary outcome

Quality of Life in parents and siblings of patients with pulmonary arterial hypertension

## Study description

### Background summary

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.

### Study objective

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.

### Study design

First part: cross sectional study

Second part: prospective, longitudinal intervention study

### Intervention

First part: cross-sectional study with questionnaires.

Second part: psychosocial interventions.

## Contacts

### Public

Center for Congenital Heart Diseases, Beatrix Children's Hospital, University Medical Center Groningen, the Netherlands  
Meindina Haarman

0503613363

### Scientific

Center for Congenital Heart Diseases, Beatrix Children's Hospital, University Medical Center Groningen, the Netherlands  
Meindina Haarman

0503613363

# Eligibility criteria

## Inclusion criteria

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.

## Exclusion criteria

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

## Study design

### Design

Study type:	Observational non invasive
Intervention model:	Other
Allocation:	Non controlled trial
Masking:	Open (masking not used)
Control:	N/A , unknown

### Recruitment

NL	
Recruitment status:	Pending
Start date (anticipated):	01-07-2019
Enrollment:	200
Type:	Anticipated

### IPD sharing statement

**Plan to share IPD:** No

## Ethics review

Not applicable	
Application type:	Not applicable

## Study registrations

### Followed up by the following (possibly more current) registration

No registrations found.

### Other (possibly less up-to-date) registrations in this register

No registrations found.

## In other registers

Register	ID
NTR-new	NL7528
Other	METC UMCG : UMCG Research Register number: 201800785

## Study results