

## Psychosocial issues in paediatric pulmonary hypertension using a Multidisciplinary approach

1<sup>st</sup> European Conference on Neonatal and Pediatric Pulmonary Vascular Disease  
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 Groningen, The Netherlands  
 University Medical Center Groningen

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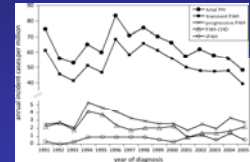


## Paediatric Pulmonary Arterial Hypertension (PAH)

Paediatric PAH is a rare disease<sup>1</sup>

Incidence: 3 /million children  
 Prevalence: 20 cases/million diagnosed with PAH

iPAH	0,7/million
PAH/CHD	2,2/million
other	PAH/CTD
	PAH/HIV
	Porto-pulmonary PAH
	PVOD



Availability of new medications

More knowledge, experiences and research

But little is known about the impact of PAH on children/families

<sup>1</sup> van Loon R L E et al. Circulation 2011;124:1755-1764



## Worldwide consensus:

Specialized centers to provide optimal care

Diagnosis

Treatment

Care



## National Network in the Netherlands

National Network for Pulmonary hypertension in childhood



7 University Medical Centers  
 2 Paediatric Cardiology Center  
 1 National Expertisecenter

Standard Diagnosis and Treatment of Pulmonary Hypertension in Children

Douwes, JM., van Loon, RLE, Rooftoof, MTR., Berger, RMF. Pulmonale arteriele hypertensie bij kinderen in Nederland. Ned Tijdschr Geneeskd.2011;155:A3901.



## Psychosocial problems and Optimal care

At diagnosis and during follow up:  
 Feeling overwhelmed  
 Worry / anxiety / uncertainty

Difficulties:  
 Medical treatment  
 Child's symptoms and/or disability  
 Family function

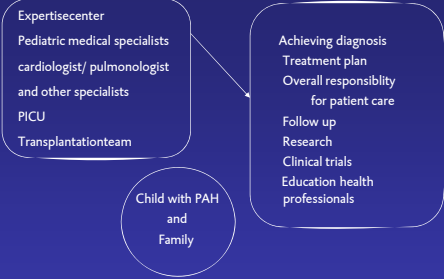
Rare disease      Complex care      Need for Multidisciplinary approach

Wryobeck JM, Lipso G, McLaughlin V, Riba M, Rubenfire M. Psychosocial aspects of pulmonary hypertension: a review. *Psychosomatics* 2007;48:467-475.

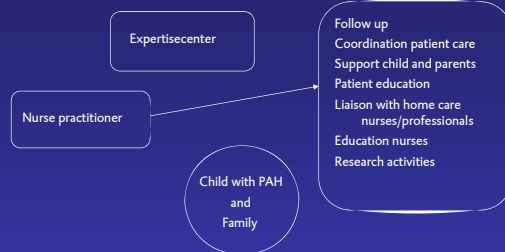
Ogawa, MT, Albrecht DA, Liu EY. Medical and non-medical considerations for the outpatient management of children with pulmonary arterial hypertension. *Progress in Pediatric Cardiology* 27 (2009)57-61.

Mullen MP, Andrus J, Labella MH, Forbes P, Rao S, Mc Sweeney JE, et al. QOL and Parental functioning in pediatric PH. Abstract presented at the 10th International PHA Conference and Scientific Sessions, June 22-24/2012.

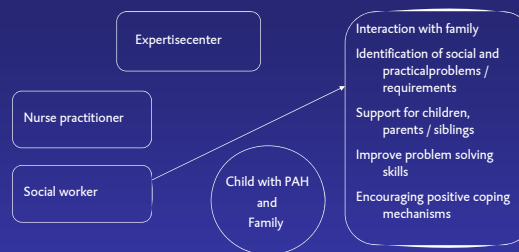
## Dedicated Health Care Team Expertisecenter

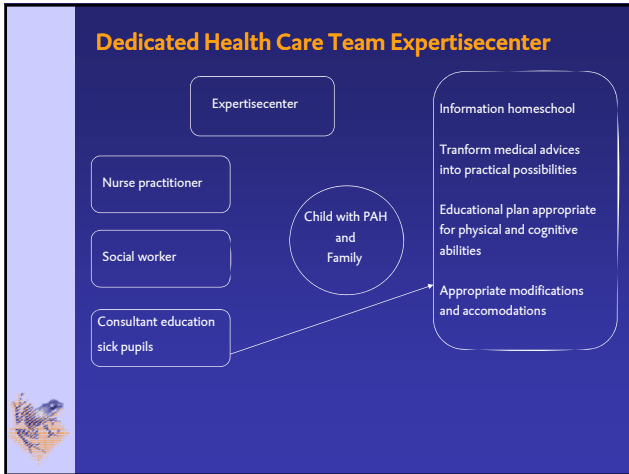


## Dedicated Health Care Team Expertisecenter



## Dedicated Health Care Team Expertisecenter





### Adult PH center

- VU Medical Center Amsterdam
- University Medical Center Groningen
- University Medical Center Maastricht
- St. Antonius Hospital Nieuwegein
- University Medical Center Nijmegen
- University Medical Center Rotterdam



### Case presentation:

The child newly diagnosed with  
paediatric PAH and his/her family

Ria Bakker / Sira Baars / Mirjam van Gent



### Case presentation:

A child with severe PAH on the PICU  
and screening for lungtransplantation

B. Wijnberg-Williams / G. Wildeboer



### Case presentation:

Transition of an adolescent with PAH

B. Coleman



## Contact

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