



31 October- 1 November 2014

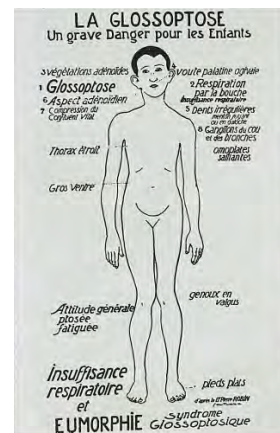
De Driehoek, Utrecht, The Netherlands

Welcome

Dear Colleagues,

Today we are pleased to welcome you in Utrecht, the Netherlands, for a meeting called:

***“Diagnosing, analyzing and treating Robin sequence:
A Consensus meeting”.***



After the successful 12'th International Congress on Cleft lip/palate and Related Craniofacial anomalies in Orlando, USA in May 2013, the idea arose to initiate a congress about Robin sequence. A group of enthusiastic physicians formed an organizing committee and subsequently, the first ever congress specific for Robin sequence, was initiated.

Robin sequence or syndrome is one of the best-known descriptions in our field. Despite our enthusiasm in trying to find better treatment options, it is well known that Robin sequence is still associated with significant morbidity and even mortality.

There will be three main goals for this congress

- 1. Try to get consensus about the definition used*
- 2. Hope we can get units to start collaboration for future studies.*
- 3. Get an update on research specific for Robin sequence*

We hope this meeting will also provide an impetus for further research and make new friendships. Please also visit our beautiful city Utrecht if you have time (www.visit-utrecht.com).

Yours sincerely,

Corstiaan Breugem
Pediatric Plastic Surgeon

On behalf of the organizing committee

Marie-José Van den Boogaard (Clinical Genetics)
Sarah Haverkamp (Speech- and language pathology)
Gijs van Haften (Molecular Biology)
Marvick Muradin, (Maxillofacial surgery)
Gilleen Nolst Trenite (Plastic Surgery)
Emma Paes, (Plastic Surgery)
Henriette Swanenburg de Veye (Psychology)
Marjan Rebergen (Secretary)

Faculty:

Veronique Abadie (Pediatrics, Paris, France)
Els-Marie Andersson (Orthodontics, Oslo, Norway)
Margit Bacher (Orthodontics, Tuebingen, Germany)
Marie-José Van den Boogaard (Clinical Genetics, Utrecht, The Netherlands)
Corstiaan Breugem (Plastic Surgery, Utrecht, The Netherlands)
Peter Don Griot (Plastic Surgeon, Amsterdam, The Netherlands)
Kelly Evans (Pediatrics, Seattle, United States)
Peter Farlie, (Research Institute, Melbourne, Australia)
Brigitte Faroux (Pediatrics, Paris, France)
Charles Filip (Plastic Surgeon, Oslo, Norway)
Chris Gordon (Clinical Genetics, Paris, France)
Gijs van Haften (Molecular Biology, Utrecht, The Netherlands)
Sarah Haverkamp (Speech- and language pathology, Utrecht, The Netherlands)
Robert Havlik (Plastic Surgeon, Indianapolis, USA)
Raoul Hennekam (Pediatrics Translat. Genetics, Academic Medical Center, Amsterdam, The Netherlands)
Paul Hong (Ear-Nose and Throat Surgeon, Halifax, Canada)
Koen Joosten (Pediatrics, Rotterdam, The Netherlands)
Mikihiko Kogo (Maxillofacial Surgery, Osaka, Japan)
Petra Lemmers, (Pediatrics, Utrecht, The Netherlands)
Marvick Muradin, (Maxillofacial surgery, Utrecht, The Netherlands)
Jyotnsa Murthy (Plastic surgery, Chennai, India).
Christian Poets (Pediatrics, Tuebingen, Germany)
Howard Saal (Clinical Genetics, Cincinnati, USA)
Rona Slator (Plastic Surgery, Birmingham, United Kingdom)
Geoffrey Sperber (Faculty of Medicine & Dentistry, Edmonton, Canada)
Sunjay Suri (Orthodontics, Sick Kids, Toronto, Canada)
Henriette Swanenburg de Veye (psychology, Utrecht, the Netherlands)
Marie-Paule Vazquez (Plastic Surgery, Paris, France)

FRIDAY 31 OCTOBER 2014

07:45- 17:00

Registration

08:30 - Welcome: Introduction and aim

Corstiaan Breugem

A. Diagnosis: Part 1 (Chair: Howard Saal, Arnaud Picard)

08:40 - Embryological aspects

Current understanding of embryology of the face with special reference to mandible and velopharyngeal musculature

Geoffrey Sperber

08:55 - Current etiological overview

Summary of current developmental and genetic perspectives

Peter Farlie

09:10 - Pathogenetic approach

Mechanisms: malformations vs dysostosis vs sequence

Raoul Hennekam

09:25 - Literature review on current definitions

Summary of and consensus on current definitions

Marie-José van den Boogaard

09:35 - Defining **micrognathia**

How can we objectively describe the size of a mandible?

Marvick Muradin

09:45 - Mandibular outgrowth controversy

Summary of controversies and misunderstandings with regard to outgrowth of mandible in Robin sequence

Sunjay Suri

09:55 - Discussion

10:25 - Defining **glossoptosis**

How can we describe the glossoptosis encountered in Robin sequence?

Jyotsna Murthy

10:35 - Discussion

10:50 – 11.10 Coffee

A. Diagnosis: Part 2 (Chair: Christian Poets, Veronique Abadie, Sunjay Suri)

11:10 - Defining **breathing problems (OSAS)**

Koen Joosten

Objective description of obstructive sleep apnea syndrome in Robin sequence

11:20 - Discussion

11:50 - **Feeding problems**

Describing feeding problems

Kelly Evans

12:00 - Discussion

12:20 - **Cleft palate**

Describing the cleft palate

Mikihiko Kogo

12:30 - Discussion

12:45 - 13:45 Lunch

Afternoon session

B. Treatment (Chair: Paul Hong, Rona Slator, Lucienne Speleman)

13:45 - Necessary **special investigations**

What investigations are ideal?

Christian Poets

14:00 - Discussion

14:40 - **Nasopharyngeal airway** as a treatment option

Advantages and disadvantages?

Rona Slator

14:50 - Discussion

15:05 - **Mandibular distraction** as a treatment option

Advantages and disadvantages?

Robert Havlik

15:15 - Discussion

15:30 - **Tracheostomy** as a treatment option

Advantages and disadvantages?

Paul Hong

15:40 - Discussion

15:55 - 16:15 Coffee

16:15 - **Tongue-lip adhesion** as a treatment option Peter Don Griot
Advantages and disadvantages?
16:25 - Discussion

16:40 - **CPAP** as a treatment option Brigitte Fauroux
Advantages and disadvantages?

16:50 - Discussion

17:00 - **Palatal Plate therapy** as a treatment option Margit Bacher /
Advantages and disadvantages? Siegmar Reinert

17:15 - Discussion

**17:20 – 18:30: Summary of morning session (Chair: Veronique Abadie,
Corstiaan Breugem, Raoul Hennekam)**

“Plenary Discussion on defining Robin sequence”

19:30 Dinner

SATURDAY 1 NOVEMBER 2014

**C. Treatment algorithms (Chair: Marvick Muradin, Jyotsna Murthy, Charles
Filip)**

09:00 Consequences of CO₂ retention and hypoxemia in young
children Petra Lemmers

Algorithms in opting management strategies from 3 hospitals

09:20 Seattle (Kelly Evans)

09:30 Birmingham (Rona Slator)

09:40 Cincinnati (Howard Saal)

09:50 Discussion

10:40 – 11:00 Coffee

D. Long-term outcome (Chair: Kelly Evans, Marie-José van den Boogaard)

11:00 - Cognition

Long term outcome of cognitive function

Veronique Abadie

11:15 - Discussion

11:25 - Speech and VPI

Long term outcome of speech

Charles Filip

11:40 - Discussion

11:50 - Teeth

Teeth anomalies and dental development in Robin sequence

Els-Marie Andersson

12:05 - Discussion

12:15 – 13:15 Lunch

E: Genetic analysis (Chair: Els-Marie-Andersson, Peter don Griot, Robert Havlik)

13:15 - Genetic analyses

What genetic analysis is mandatory in children with Robin sequence?

Chris Gordon

13:30 - Genetic diagnosis in a large Dutch cohort of Robin sequence patients

Hanneke Bassart

13:35 - PRS – not just mandibular hypoplasia and cleft palate

Rod Hunt

13:40 - Pierre Robin sequence in the Brazilian Database on orofacial clefts

Vera Lucia Gil-da Silva-Lopes

13:45 - Testing for myopia in PRS

Serryth Colbert

13:50 - Discussion

E. Open Papers

14:05-15:30 Open session papers

- 14:05 - Thirty year management of Robin Management Marilyn Cohen
- 14:10 - Airway management in syndromic and non-syndromic Robin sequence. Rimante Seselgyte
- 14:15 - Incidence and treatment of patients with Pierre Robin Hallvard Vindeness
- 14:20 - Outcome of mandibular distraction for the management of neonates and infants with micrognathia and upper airway obstruction JM Shand
- 14:25 - Respiratory support in children with Robin sequence. Manouk van Lieshout
- 14:30 - A multidisciplinary protocol to allow early palate repair in Robin sequence. *EC Francis*

14:35 Discussion

- 14:45 - Prevalence and patterns of permanent tooth agenesis in white patients with non-syndromic Robin sequence. Greg Antonarakis
- 14:50 - Tooth agenesis in Robin sequence patients Daan van Nunen
- 14:55 - Damage to tooth buds after distraction osteogenesis Emma Paes
- 15:00 - Mandibular growth and it's consequences in patients with isolated Pierre Robin sequence analysis in mixed dentition Marcus Collares
- 15:05 - Anesthetic neurotoxicity and the developing brain: an update Jurgen de Graaf
- 15:10 - Airway dysfunction in cleft palate and Robin sequence: lessons from comparative anatomy David Orr
- 15:15 - Obstructive sleep apnea in Robin sequence Andreaja Eberlinc
- 15:20 - Feeding protocol for infants with Pierre Robin Kelly Mabry

sequence following mandibular distraction.

15:25 - Parents' experiences of Robin sequence:
a UK multi-centre perspective.

Karine Latter

15:30 Discussion

15:45 – 16:00 Coffee

16:00-16:30 Discussion (Chair: Kelly Evans, Howard Saal, Marie-Paul Vazquez)

16:30 Closing remarks

Corstiaan Breugem

Endorsements:

Austrian Cleft Palate Craniofacial Association
American Cleft Palate Association
American Association of Pediatrics
Craniofacial Society of Great Britain and Ireland
Canadian Society of Otolaryngology
Dutch Cleft Palate Craniofacial Association
Dutch Association of Oral and Maxillofacial Surgery
Dutch Association of Plastic Surgeons
Dutch Society of Speech and Language pathology
Dutch Society for Clinical Genetics
European Society of Pediatric Otorhinolaryngology
German Cleft Lip and Palate Craniofacial Association
Indian Society Of Cleft Lip Palate & Craniofacial Anomalies.

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Social Program:

Friday 31 October 2014:

Congress dinner: “Academiegebouw Utrecht”

An exclusive Congress Dinner will be held in the impressive “Academiegebouw Utrecht” next to the Dom Tower in the city center of Utrecht. This building is used by the University of Utrecht for ceremonial activities (such as PhD defences), but also for orations and congresses. The main part of the building dates back to 1462.

Delegates that indicated during the registration process that they were coming to the dinner are welcome to come.

Address: Academiegebouw Domplein 29 3512 JE Utrecht

Dress Code: Casual chic

Time: 19:30 – 23:00



