

Post-Conference Workshop (with local speakers):
The Tübingen Approach to RS Treatment
April 7, 2020

- 09:00 a.m. **Introduction and Overview**
Bernd Koos, DMD, orthodontist
- 09:30 a.m. **Polysomnographic findings in RS: Implications for treatment**
Mirja Quante, MD, neonatologist & sleep specialist
- 10:00 a.m. **Evolution of the Tübingen Palatal Plate (TPP) treatment approach**
Margit Bacher, DMD, orthodontist
- 10:30 a.m. **Coffee Break**
- 11:00 a.m. **TPP going digital I: First experiences with intraoral scanning**
Karin Frank, DMD
- 11:30 a.m. **TPP going digital II: CAD / CAM Workflow of TPP production**
Alexander Xepapadeas, MA
- 12:00 p.m. **Variations in Syndromic RS: Modifications to the TPP**
Silvia Müller-Hagedorn, MD, DMD, orthodontist
- 12:30 p.m. **Insertion and endoscopic evaluation of the prototype TPP**
Cornelia Wiechers, MD
- 01:00 p.m. **Pitfalls during TPP treatment**
Joerg Arand, MD
- 01:30 p.m. **Lunch**
- 02:00 p.m. **Nursing with, and maintenance of, the TPP**
Regina Iffländer, RN, Petra Knechtel, RN
- 02:30 p.m. **The role of speech therapy and feeding training during TPP treatment**
Bärbel Grandke, speech therapist
- 03:00 p.m. **Timing, procedural aspects and results of cleft palate repair in RS**
Siegmar Reinert, MD, DMD
- 03:30 p.m. **Long-term orthodontic treatment in RS**
Christina Weise, DMD
- 04:00 pm **Conclusions and Farewell**
Bernd Koos, DMD, Christian Poets, MD, Siegmar Reinert, MD, DMD

Speakers

- Abadie, Pr. Veronique, MD; Amaddeo, Alessandro, MD**
Université Paris Descartes, CRMR "Syndromes de Pierre Robin et troubles de succion/déglutition congénitaux", Paris, F
- Amiel, Jeanne, PhD**
Embryologie et Génétiques des Malformations Congénitales, Paris, F
- Bacher, Margit, DMD**, Orthodontist, Tübingen, D
- Bacilliero Ugo, MD**
U.O.C. Chirurgia Maxillo Facciale, Hospital Vicenza, Italy
- Breugem, Corstiaan, MD, PhD**
Plastic Surgeon, Emma Children's Hospital, Amsterdam, NL
- Dulfer, Karolijn, PhD**
Erasmus Medical Center, Dutch Craniofacial Center, Rotterdam, NL
- Evans, Kelly, MD, FAAP**
Seattle Children's Hospital, University of Washington, USA
- Flores, Roberto L., MD**
Dept. of Plastic Surgery, New York University Langone Medical Center New York, USA
- Forrest, Christopher R., MD, MSc, FRCS, FACS**
Plastic & Reconstructive Surgery, University of Toronto, CAN
- Gozal, David, MD**
Department of Pediatrics, MU Women's and Children's Hospital University of Missouri School of Medicine, Columbia, MO, USA
- Joosten, Koen FM, MD**
Department of Pediatrics, Intensive Care Unit, Erasmus Medical Center, Sophia Children's Hospital, Rotterdam, NL
- Manica, Denise, MD**
Otolaryngology & Head & Neck Surgery, Hospital de Porto Alegre, BRA
- Müller-Hagedorn, MD, DMD**
Polyclinic for Orthodontics, Rostock, D
- Pakter, Phillipe, Esq**, Parent, Lausanne, CH
- Reid, Russel R., MD PhD**
Cleft and Craniofacial Services, Section of Plastic Surgery, The University of Chicago Medicine & Biological Sciences, Chicago, USA
- Resnick, Cory, MD**
Department of Plastic and Oral Surgery, Boston Children's Hospital, Boston, MA, USA
- Römmeler-Zehrer, Josephine, MD**
Parent of a Robin patient, Munich, D
- Volz, Verena**, Parent of a Robin patient, Freiburg, D
- Wallis, Colin, MD**
Respiratory Pediatrics, Great Ormond Street Hospital, London, UK
- Waters, Karen, MD**
Pediatric Sleep Medicine, Westmead Children's Hospital, Sydney, AUS
- Wieczorek, Dagmar, MD**
Dept. of Human Genetics, Heinrich-Heine-University, Düsseldorf, D
- Yingqiu, Cui, MD**
Department of Oral and Maxillofacial Surgery, Guangzhou Women and Children's Hospital, Guangzhou, Guangdong, PRC

Speakers Tübingen University Hospital

- Arand, Joerg, MD**, Dept. Neonatology
- Frank, Karin, DMD**, Polyclinic for Orthodontics
- Grandke, Bärbel**, Speech Therapy Centre
- Iffländer, Regina, RN**, Dept. Neonatology
- Kagan, Karl Oliver, MD**, Dept. Gynecology and Obstetrics
- Knechtel, Petra, RN**, Dept. Neonatology
- Koos, Bernd, DMD**, Polyclinic for Orthodontics
- Krimmel, Michael, MD**, Dept. Craniofacial Surgery
- Poets, Christian, MD**, Dept. Neonatology
- Quante, Mirja, MD**, Dept. Neonatology, Sleep Laboratory
- Reinert, Siegmar, MD, DMD**, Dept. Craniofacial Surgery
- Wegmann, Ulrike, RN**, Dept. Neonatology
- Weise, Christina, DMD**, Polyclinic for Orthodontics
- Wiechers, Cornelia, MD**, Dept. Neonatology
- Xepapadeas, Alexander, MA**, Polyclinic for Orthodontics

Organization

Centre for Cleft Palate and Craniofacial Malformations,
Tübingen University Hospital,
Calwerstrasse 7,
D-72070 Tübingen, Germany

Participation Fee (Main conference):

€ 210 (if registered prior to Feb 1, 2020, otherwise € 250)

Participation Fee (Workshop):

€ 100 (if registered prior to Feb 1, 2020, otherwise € 120)

CME

CME-certified through LAEK Baden-Württemberg

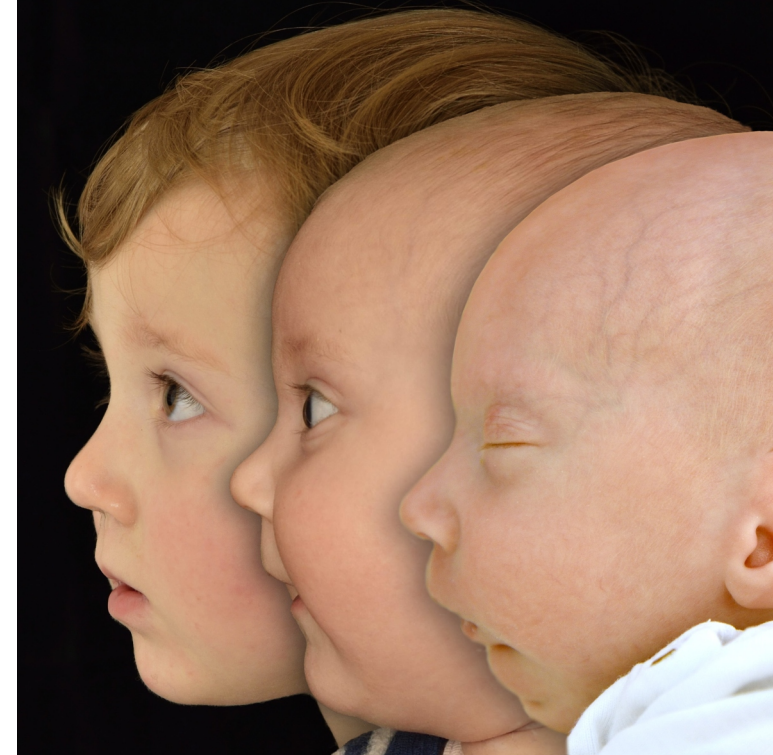
Registration only possible online at:

www.robin-sequence.de

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Universitätsklinikum
Tübingen



3rd International Robin Sequence Consensus Meeting

April 5-6, 2020

Invitation to the 3rd International Robin Sequence Consensus Meeting

Dear Colleagues, dear Guests,

Following the first meeting in Utrecht, Netherlands, and the second in Toronto, Canada, the Tübingen team took up the challenge of hosting the third International Consensus Meeting on Robin Sequence (RS) in Tübingen, Germany.

As true for many rare conditions, treatment approaches for RS vary considerably, as randomized controlled trials are difficult to perform. Evidence for different treatments, however, can also be based on cohort studies. This requires agreement on the relevant outcomes tested in such studies, i.e. the definition of a common data set to be used in future clinical studies on RS.

The latter will be the main subject during the upcoming 3rd international RS meeting. We expect renowned speakers from around the world to present their latest data with a focus on a quantification of sleep-related upper airway obstruction and failure to thrive as the two most relevant early outcomes in RS. Also, is there mandibular catch-up growth in RS? What is the long-term outcome and quality-of-life after the various interventions used, and what do parents think?

Whichever approach is being taken, RS treatment requires a team approach, and this is not only reflected by our organizing committee, but also by the faculty of this meeting.

Tübingen is an old medieval university town (the university was founded in 1492) located in Germany's beautiful South-West, where weather conditions can already be quite pleasant in April (but wet and cold weather conditions are also possible).

We are looking forward to welcoming you to Tübingen!



Prof. Dr. Christian Poets, MD



Prof. Dr. Dr. Siegmund Reinert, MD, DMD



Prof. Dr. Bernd Koos, DMD

Program - April 5, 2020

08:30 Welcome and Introduction (C. Poets, Germany)

I Building on Consensus I

08:45 Review of consensus from previous meetings and goals for present RS meeting (C. Breugem, Netherlands; C. Forrest, Canada; S. Reinert, Germany)

09:05 *Discussion*

II Genetics of Craniofacial development

09:15 Genetics of Mandibular Development (D. Wiczorek, Germany)

09:35 Genetic factors contributing to RS (J. Amiel, France)

09:55 *Discussion*

10:05 *Coffee Break*

III Incorporating parents' and patients' voices

10:25 1. The importance of a prenatal diagnosis in RS (J. Römmeler-Zehrer, Germany)

10:40 2. What does tracheostomy mean to parents? (V. Volz, Germany)

10:55 3. Lobbying for Robin kids in the political arena (P. Pakter, Switzerland)

11:10 *Discussion*

IV Do results from diagnostic procedures inform treatment & prognosis?

11:20 Prenatal diagnosis (K. Kagan, Germany)

11:35 Upper airway endoscopy (D. Manica, Brasil)

11:50 Polysomnography (PSG) (K. Joosten, Netherlands)

12:10 What are (better available) alternatives to PSG? (D. Gozal, USA)

12:35 Jaw index (C. Wiechers, Germany)

12:50 Magnetic resonance imaging (C. Resnick, USA)

13:05 Weight charts/Feeding Issues (U. Wegmann, Germany)

Program - Continuation April 5, 2020

13:20 Panel Discussion: What do we consider essential diagnostic steps?

13:30 *Lunch*

V Comparing sleep study results and growth using different therapeutic approaches in RS

14:20 Tübingen Palatal Plate (C. Poets, Germany)

14:40 Mandibular Distraction and Tongue-Lip Adhesion (R. Flores, USA)

15:00 Risk factors of prolonged mechanical ventilation in infants with Pierre Robin sequence after mandibular distraction osteogenesis (C. Yingqiu, China)

15:20 Positioning (K. Waters, Australia)

15:40 Continuous Positive Airway Pressure (A. Amaddeo, France)

16:00 Nasopharyngeal Airway (C. Wallis, United Kingdom)

16:20 *Panel Discussion*

16:30 *Break*

VI Is there mandibular catch-up growth in RS, and which influence has myofunctional therapy?

16:50 An orthodontist's view (B. Koos, Germany)

17:05 A maxillofacial surgeons's view (M. Krimmel, Germany)

17:20 Effects of MDO on mandibular growth (R. Reid, USA)

17:50 *Discussion*

18:00 *Program End Day 1*

Program - April 6, 2020

08:00 **VII Free presentations I**

09:00 *Coffee Break*

Program - Continuation April 6, 2020

VIII Updated RS treatment protocols from around the world

09:30 Paris, France – CPAP (A. Amaddeo)

09:45 Seattle, USA – Mandibular distraction osteogenesis (K. Evans)

10:00 Modena, Italy – Mandibular Traction (U. Bacilliero)

10:15 London, UK – Nasopharyngeal Airway (C. Wallis)

10:30 Tübingen, GER – Tübingen Palatal Plate (B. Koos, C. Poets, S. Reinert)

10:50 Panel Discussion: Diagnostic approaches: Data dictionary/collection tools with sleep and feeding metrics (C. Wiechers, Germany)

11:05 Given the diversity in treatment approaches, what can we agree on? (C. Poets, Germany)

11:20 *Discussion*

11:30 *Lunch*

IX Long-term outcomes in RS

12:30 Neuro- and Speech Development (V. Abadie, France)

12:50 Quality of Life (K. Dulfer, Netherlands)

13:20 *Discussion*

X Free presentations II

15:00 *Coffee Break*

XI Building on Consensus II

Panel Discussion

16:30 Future Directions: How can we define a common data set to evaluate treatment effectiveness?

17:30 *Program End Day 2*

Additionally: Poster viewing throughout meeting. Authors should be present during lunch break on day 2