

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

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

Organization

Universitätsklinikum Tübingen, Calwerstraße 7,
72076 Tübingen

Participation Fee:

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

CME

CME-certified through LAEK Baden-Württemberg

Registration:

Only online registration possible at www.robin-sequence.de

Speakers

Abadie, Pr. Veronique, MD

Université Paris Descartes, CRMR "Syndromes de Pierre Robin et troubles de succion/déglutition congénitaux", Paris, F

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

Bacilliero Ugo, MD

U.O.C. Chirurgia Maxillo Facciale, Hospital Vicenza, Italy

Breugem, Corstiaan, MD

Plastic-Reconstructive and Hand Surgery,
Wilhelmina Children's Hospital, Utrecht, 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, FRCSC, 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

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

Römmler-Zehrer, Josephine, MD Parent of a Robin patient, Munich, D

Volz, Verena, Parent of a Robin patient, Freiburg, D

van Lieshout, Manouk, MD, Erasmus Medical Center, Dutch Craniofacial
Center, Rotterdam, NL

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 PhD

Dept. of Human Genetics, Heinrich-Heine-University, Düsseldorf, D

Speakers Tübingen University Hospital:

Kagan, Karl Oliver, MD, Dept. Gynecology and Obstetrics

Koos, Bernd, DMD, Polyclinic for Orthodontics

Krimmel, Michael, MD, Dept. Craniofacial Surgery

Poets, Christian, MD, Dept. Neonatology

Reinert, Siegmar, MD, DMD, Dept. Craniofacial Surgery

Wegmann, Ulrike, RN, Dept. Neonatology

Wiechers, Cornelia, MD, Dept. Neonatology

3rd International Robin Sequence Consensus Meeting

April 5-6, 2020



Invitation to the 3rd International Consensus Meeting on Robin Sequence

Dear Colleagues, dear Guests,

Following the first meeting in Utrecht, NL, 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 the beautiful south-west of Germany, where weather conditions can already be quite pleasant in April.

We are looking forward to welcoming you to Tübingen!



Prof. Dr. Christian Poets, MD



Prof. Dr. Dr. Siegmund Reinert, M



Prof. Dr. Bernd Koos, MD

Program April 5, 2020

08:30	Welcome and Introduction (C. Poets, D)
I	Building on Consensus I
08:45	Review of consensus from previous meetings and goals for present RS meeting (K. Evans, US; C. Forrest, CAN; S. Reinert, D)
09:05	<i>Discussion</i>
II	Genetics of Craniofacial development
09:15	Genetics of Mandibular Development (D. Wiczorek, D)
09:35	Genetic factors contributing to RS (J. Amiel, F)
09:55	<i>Discussion</i>
10:05	Coffee Break
III	Incorporating parents' and patients' voices
10:25	1. The importance of a prenatal diagnosis in RS (J. Römmeler-Zehrer, D)
10:40	2. What does tracheostomy mean to parents? (V. Volz, D)
10:55	3. Lobbying for Robin kids in the political arena (P. Pakter, CH)
11:10	<i>Discussion</i>
IV	Do results from diagnostic procedures inform treatment & prognosis?
11:20	Prenatal diagnosis (K. Kagan, D)
11:35	Upper airway endoscopy (D. Manica, BRA)
11:50	Polysomnography (K. Joosten, NL)
12:10	What are (better available) alternatives to PSG? (D. Gozal, US)
12:35	Jaw index (C. Wiechers, D)
12:50	MRI (C. Resnick, US)
13:05	Weight charts/Feeding Issues (U. Wegmann, D)
13:20	Panel Discussion: What do we consider essential diagnostic steps?
13:30	Lunch Break
V	Comparing sleep study results and growth using different therapeutic approaches in RS
14:20	Tübingen Palatal Plate (C. Poets, D)
14:40	Mandibular Distraction and Tongue-Lip Adhesion (R. Flores, US)
15:00	Weight gain following MDO: Indian experience (J. Murthi, IND)
15:20	Positioning (K. Waters, AUS)
15:40	Continuous Positive Airway Pressure (A. Amaddeo, F)
16:00	Nasopharyngeal Airway (C. Wallis, UK)
16:20	<i>Panel Discussion</i>
16:30	Break

Program April 5, 2020 *continued*

VI	Is there mandibular catch-up growth in RS, and which influence has myofunctional therapy?
16:50	Yes, there is (B. Koos, D)
17:05	No, there isn't (M. Krimmel, D)
17:20	Effects of MDO on mandibular growth (R. Reid, US)
17:50	<i>Discussion</i>
18:00	Program End Day 1

Program April 6, 2020

08:00	VII Free presentations I
VIII	Updated RS treatment protocols from around the world
9:30	Paris, F – CPAP (A. Amaddeo)
09:45	Seattle, USA – MDO (K. Evans)
10:00	Modena, IT – Mandibular Traction (U. Bacilliero)
10:15	London, UK – Nasopharyngeal Airway (C. Wallis)
10:30	Tübingen, D – Tübingen Palatal Plate (B. Koos)
10:45	Panel Discussion: Diagnostic approaches: Data dictionary/collection tools with sleep and feeding metrics (Wiechers, D)
11:00	Given the diversity in treatment approaches, what can we agree on? (Poets, D)
11:15	<i>Discussion</i>
11:30	Lunch Break
IX	Long-term outcomes in RS
12:30	Neuro- and Speech Development (V. Abadie, F)
12:50	Quality of Life (M. van Lieshout, NL)
13:20	<i>Discussion</i>
13:30	X Free presentations II
15:00	Coffee Break
15:20	XI Building on Consensus II <i>Panel Discussion</i>
16:20	Future Directions: How can we define a common data set to evaluate treatment effectiveness?
17:20	Program End Day 2

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