



**3rd International
Robin Sequence
Consensus Meeting**

April 3-4, 2022



**Universitätsklinikum
Tübingen**

Invitation to the 3rd International Consensus Meeting on Robin Sequence

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 the effectiveness of different treatments, however, can also be gained from 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 the 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 is also possible). Due to the unclear future development of the current pandemic, we will organize this as a hybrid meeting, where presentations can also be attended online. For those attending the conference in Tübingen, we will need proof of a full immunization status for SARS Cov-2 (or recent (<6 months) recovery from this infection). To facilitate online participation by our colleagues from South and North America, we will start late in the morning (European time).

We are looking forward to welcoming you to Tübingen (or remotely at your desktop)!



Prof. Dr. Christian Poets, MD

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

Prof. Dr. Bernd Koos, DMD

Program - April 3, 2022

09:45 a.m. Welcome and Introduction (C. Poets, Germany)

I Building on Consensus I

10:00 a.m. Review of consensus from previous meetings and goals for present RS meeting
(C. Breugem, Netherlands; C. Forrest, Canada; S. Reinert, Germany)

10:30 a.m. *Discussion*

II Genetics of Craniofacial development

10:45 a.m. Genetics of Mandibular Development
(D. Wiecek, Germany)

11:05 a.m. Genetic factors contributing to RS (J. Amiel, France)

11:25 a.m. *Discussion*

11:35 a.m. **Coffee Break**

III Do results from diagnostic procedures inform treatment & prognosis?

11:50 a.m. How can we increase rates of prenatal diagnosis for RS? (K. Kagan, Germany)

12:05 p.m. How to grade findings obtained during upper airway endoscopy? (C. Schweiger, Brasil)

12:20 p.m. Polysomnography (PSG) results in RS babies
(K. Joosten, Netherlands)

12:35 p.m. What are (better available) alternatives to PSG?
(D. Gozal, USA)

12:50 p.m. Can weight trajectories inform about severity of phenotype in RS? (C. Resnick, USA)

01:05 p.m. Feeding Issues in RS infants (U. Wegmann, Germany)

01:30 p.m. **Lunch**

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

02:15 p.m. Positioning (K. Waters, Australia)

02:35 p.m. Nasopharyngeal Airway (F. Abel, United Kingdom)

02:55 p.m. Tübingen Palatal Plate (C. Poets, Germany)

03:15 p.m. Continuous Positive Airway Pressure
(V. Abadie, France)

03:35 p.m. Mandibular Distraction and Tongue-Lip Adhesion
(R. Flores, USA)

Program - April 3, 2022

03:55 p.m. Risk factors for prolonged mechanical ventilation in infants with Robin sequence after mandibular distraction osteogenesis (C. Yingqiu, China)

04:15 p.m. *Panel Discussion*

04:35 p.m. ***Coffee Break***

V Incorporating parents' and patients' voices

04:55 p.m. The importance of a prenatal diagnosis in RS (J. Römmler-Zehrer, Germany)

05:10 p.m. What does tracheostomy mean to parents? (V. Volz, Germany)

05:25 p.m. Lobbying for Robin kids in the political arena (P. Pakter, Switzerland)

05:35 p.m. *Discussion*

05:45 p.m. ***Coffee Break***

05:55 p.m. Presentation of an European RS Register (A.-L. Sorg, C. Wiechers, both Germany)

06:15 p.m. Current state of developing an intentional guideline for RS treatment. (I. Mathijssen, Netherlands)

06:35 p.m. Panel Discussion – How can we agree on a common data set to evaluate treatment effectiveness? (Moderators: K. Evans, USA, C. Poets, Germany)

06:55 p.m. ***Adjournment (End of Day 1)***

08:30 p.m. ***Dinner at the “Kelter” (Schmiedtorstrasse 17)***

Program - April 4, 2022

VI 10:00 - 11:00 a.m. Free Presentations I

11:00 a.m. ***Coffee Break***

VII Updated RS treatment protocols from around the world

11:15 a.m. The French approach relying on CPAP (B. Fauroux, France)

Program - April 4, 2022

11:35 a.m. The Seattle Children's Hospital's approach to RS (K. Evans, USA)

11:55 a.m. Mandibular Traction – The Modena experience (U. Bacilliero, Italy)

12:15 p.m. Using the Nasopharyngeal Airway in RS infants (F. Abel, United Kingdom)

12:35 p.m. The Tübingen Protocol (C. Wiechers, Germany)

12:55 p.m. *Panel Discussion: Given the diversity in treatment protocols – what can we agree on?*

01:15 p.m. **Lunch (with Poster walk; Moderator: C. Weise, Germany)**

VIII Is there mandibular catch-up growth in RS?

02:15 p.m. An orthodontist's view (B. Koos, Germany)

02:30 p.m. A maxillofacial surgeon's view (M. Krimmel, Germany)

02:45 p.m. Effects of MDO on mandibular growth (R. Reid, USA)

03:00 p.m. *Discussion*

03:15 p.m. **Coffee break**

IX Long-term outcomes in RS

03:30 p.m. Neuro- and Speech Development (V. Abadie, France)

04:00 p.m. Quality of Life in RS children (K. Dulfer, Netherlands)

04:30 p.m. *Discussion*

04:45 p.m. **Coffee Break**

X 05:00 - 7:00 p.m. Free presentations II

06:00 p.m. *Panel Discussion – Can we agree on a common way forward? Goals for the next congress*

06:45 p.m. Farewell (C. Poets, Germany)

07:00 p.m. **Adjournment**

Additionally: E-Posters will be available throughout the meeting.

**Post-Conference Workshop (with local speakers):
The Tübingen Approach to RS Treatment
April 5, 2022**

- 09:45 a.m. **Introduction and Overview**
Bernd Koos, DMD, orthodontist
- 10:15 a.m. **Evolution of the Tübingen Palatal Plate (TPP) treatment approach**
Margit Bacher, DMD, orthodontist
- 10:45 a.m. **Polysomnographic findings in RS: Implications for treatment**
Mirja Quante, MD, neonatologist & sleep specialist
- 11.15 a.m. **Coffee Break**
- 11.45 a.m. **TPP going digital I: First experiences with intraoral scanning**
Christina Weise, MD, DMD
- 12.15 p.m. **TPP going digital II: CAD / CAM Workflow of TPP production**
Alexander Xepapadeas, MSc
- 12:45 p.m. **Lunch**
- 01:15 p.m. **Insertion and endoscopic evaluation of the prototype TPP**
Conny Wiechers, MD
- 01.45 p.m. **Pitfalls during TPP treatment**
Joerg Arand, MD
- 02:15 p.m. **Variations in Syndromic RS: Modifications to the TPP**
Silvia Müller-Hagedorn, MD, DMD, orthodontist
- 02.45 p.m. **Nursing with, and maintenance of, the TPP**
Regina Iffländer, RN, Petra Knechtel, RN
- 03:15 p.m. **The role of speech therapy during TPP treatment**
Bärbel Grandke, speech therapist
- 03:45 p.m. **Timing and procedural aspects of cleft closure in RS**
Siegmar Reinert, MD, DMD
- 04:15 p.m. **Long-term orthodontic treatment in RS**
Christina Weise, MD, DMD
- 04:45 pm **Conclusions and Farewell**
*Bernd Koos, DMD,
Christian Poets, MD,
Siegmar Reinert, MD, DMD*

Speakers

Abadie, Pr. Veronique, MD

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



Abel, Francois, MD

Respiratory Pediatrics, Great Ormond Street Hospital, London, UK



Amiel, Jeanne, PhD

Embryologie et Génétiques des Malformations Congénitales, Paris, F



Bacilliero, Ugo, MD

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



Breugem, Corstiaan, MD

Department of Plastic Reconstructive and Hand Surgery, Emma Children's Hospital, University of Amsterdam, NL



Dulfer, Karolijn, MD

Erasmus Medical Center, Dutch Craniofacial Center, Rotterdam, NL

Evans, Kelly, MD, FAAP

Seattle Children's Hospital, University of Washington, USA



Fauroux, Pr. Brigitte, MD

Pediatric noninvasive ventilation and sleep unit Paris University EA 7330 VIFASOM (Vigilance Fatigue Sommeil et Santé Publique), Necker University Hospital, Paris, F



Flores, Roberto L., MD

Department 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



Speakers

Mathijssen, Irene, MD

Department of Plastic and Reconstructive Surgery and Hand Surgery, Erasmus Medical Center, Rotterdam, NL



Pakter, Phillipe, Esq,

Parent, Geneva, 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



Römmmler-Zehrer, Josephine, MD

Parent of a Robin patient, Munich, D



Schweiger, Cláudia, MD

Otolaryngology & Head& Neck Surgery, Hospital de Porto Alegre, BRA



Volz, Verena,

Parent of a Robin patient, Freiburg, D



Waters, Karen, MD

Pediatric Sleep Medicine, Westmead Children's Hospital, Sydney, AUS



Wieczorek, Dagmar, MD

Department of Human Genetics, Heinrich-Heine-University, Düsseldorf, D

Yingqiu, Chi, MD

Department of Oral and Maxillofacial Surgery, Guangzhou Women and Children's Medical Center, Guangzhou Medical University, Guangzhou, China

Speakers Tübingen University Hospital

Arand, Joerg, MD,
Dept. Neonatology



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



Quante, Mirja, MD,
Dept. Neonatology, Sleep Laboratory



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



Sorg, Anna-Lisa,
Dept. Neonatology



Wegmann, Ulrike, RN,
Dept. Neonatology

Wiechers, Cornelia, MD,
Dept. Neonatology



Organization

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

The symposium will take place as a hybrid event, but we encourage you to participate in person if at all possible!

The participation fee for online participation is the same as for onsite participation!

Participation Fee (Main conference):

€ 210 (if registering prior to Feb 1, 2022, otherwise € 250)

Participation Fee (Workshop):

€ 100 (if registering prior to Feb 1, 2022, otherwise € 120)

CME: CME-certified through LAEK Baden-Württemberg

Registration:

Only online registration possible at

www.robin-sequence.de



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