



**3<sup>rd</sup> International  
Robin Sequence  
Consensus Meeting**

April 3-4, 2022



**Universitätsklinikum  
Tübingen**

## Invitation to the 3<sup>rd</sup> 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 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 3<sup>rd</sup> 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 is also possible). However due to the unclear future development of the current pandemic, this will be organized as a hybrid meeting, where all presentations can also be attended online. To facilitate participation by our colleagues from North and South 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? (D. Manica, 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 (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 (C. Wallis, United Kingdom)

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

03:15 p.m. Continuous Positive Airway Pressure (A. Amaddeo, Italy)

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 (A. Amaddeo, Italy)

## Program - April 4, 2022

11:35 a.m. The Seattle Children's Hospital approach centered on MDOs (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, UK)

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**  
*Katharina Peters, DMD*
- 12.15 p.m.     **TPP going digital II: CAD / CAM Workflow of TPP production**  
*Alexander Xepapadeas, MA*
- 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.     **Timing and procedural aspects of cleft closure in RS**  
*Siegmar Reinert, MD, DMD*
- 03:45 p.m.     **Long-term orthodontic treatment in RS**  
*Christina Weise, MD, DMD*
- 04:15 pm     **Conclusions and Farewell**  
*Bernd Koos, DMD*  
*Christian Poets, MD*  
*Siegmar Reinert, MD, DMD*

## Speakers

**Abadie, Pr. Veronique, MD**

Université Paris Descartes, CRM R "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

**Ammadeo, Allessandro, MD**

S.O.C. Pediatria d'Urgenza e Pronto Soccorso, IRCCS Burlo Garofolo, Trieste, IT

**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

**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

**Manica, Denise, MD**

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

**Mathijssen, Irene, MD**

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

**Murthy, Jytsna, MD**

Cleft and Craniofacial Center, Dept. of Plastic Surgery, Sri Ramachandra University, Chennai, India

**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

**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**, Department of Neonatology  
**Kagan, Karl Oliver, MD**, Department of Gynecology and Obstetrics  
**Koos, Bernd, DMD**, Polyclinic for Orthodontics  
**Krimmel, Michael, MD**, Department of Craniofacial Surgery  
**Poets, Christian, MD**, Department of Neonatology  
**Quante, Mirja, MD**, Department of Neonatology, Sleep Laboratory  
**Reinert, Siegmar, MD, DMD**, Department of Craniofacial Surgery  
**Sorg, Anna-Lisa**, Department of Neonatology  
**Wegmann, Ulrike, RN**, Department of Neonatology  
**Wiechers, Cornelia, MD**, Department of 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](http://www.robin-sequence.de)



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