

# PARIS 2025 - Wednesday April 2nd

## 4th International Consensus Meeting on Robin sequence

### Welcome Cocktail diner



18h30

From 18h30, private tour of the Antoine Bourdelle museum, one of the last vestiges of the Parisian artists' studios in the Montparnasse district at the beginning of the last century, followed by the welcome cocktail dinner, open to all participants.

# PARIS 2025 - Thursday April 3rd

## 4th International Consensus Meeting on Robin sequence

### Program



Pr Véronique Abadie



08h00

Opening of the conference.



08h30

Welcome and Introduction.

Véronique Abadie and the organization team.



08h40

Review from previous meetings and goals of the current meeting.

Corstiaan Breugem, Christopher Forrest and Kelly Evans, Christian Poets, Véronique Abadie.

## Imaging in the diagnosis and treatment of RS: toward a consensus

Morning  
08h00 - 12h45

Chairpersons :

Jeanne Amiel

Hossein Khonsari



### 1. Prenatal imaging.



09h00

Imaging criterias for prenatal screening of RS.

Judy A Estroff, pediatric radiologist, Boston, Massachusetts, USA.



09h30

Agreement between pre and post-natal diagnosis of RS : role of MRI and genetics.

Tiana Rasoarahona, Laurent Salomon, David Grevent, Jeanne Amiel, Tania Attié-Bitach, Véronique Abadie, Paris, pediatrics, obstetrics, genetics and radiology, Paris, France.



09h45

Is prenatal MRI useful for predicting neonatal distress and respiratory obstruction during the first semester of life ?

Briac Thierry, Maelys Leger, David Grevent, ENT, pediatric radiologist, Paris, France.



10h05

Discussion and toward a consensus for prenatal strategies (imaging and genetics) when RS is prenatally suspected ?

Jeanne Amiel, Genetics, Paris, France.



10h30

Coffee break.



### 2. Post-natal imaging: interests and technics.



11h00

Photo 3D - Mandibular catch-up growth in Robin infants treated with the Tübingen Palatal Plate.

Cornelia Wiechers, Tübingen, Germany.



11h25

How facial landmarks and AI may help for phenotypic characterisation of RS: example for Stickler and Kabuki syndrome.

Hossein Khonsari, Quentin Hennoch, Olivier Lienhard, Paris, France.



11h55

Characterizing Mandibular Morphology in Robin Sequence - A 3D Statistical Shape Analysis.

Khalid El Ghouli et al, Rotterdam, the Netherlands.



12h15

4D TDM for dynamic upper airway evaluation in children with RS.

Michael Barbour, Seattle, USA, Jake Dahl, Kansas City, USA.



12h45

Lunch on site (12h45 - 14h00).

# PARIS 2025 - Thursday April 3rd

## 4th International Consensus meeting on Robin sequence

### Program



After-noon  
14h00 - 17h00

Chairpersons :  
Corstiaan Breugem  
HyeRan Choo

- 14h00 Facial growth in RS, from infants to adolescents, long term outcome for patient treated with neonatal MDO.  
Marcus Vinicius Martins Collares, Porto Alegre, Brazil.
- 14h20 Facial growth in RS, from infants to adults, impacts of non-invasive methods for treating respiratory obstruction.  
Silvia Mueller-Hagedorn, Freiburg, Germany and Necker Hospital, Paris, France.
- 14h40 Cephalometric Analyses on Craniofacial and Upper Airway Growth in Infants with Robin Sequence treated with Stanford Orthodontic Airway Plate: 1-Year Follow-Up.  
HyeRan Choo, Stanford, California, USA.
- 15h00 Discussion and toward a consensus about imaging in the follow-up of patients with RS.  
Hossein Khonsari and the ERN group on craniofacial imaging, Paris, France.



15h30 Coffee break.

### 3. Free communications.

- 15h45 Genetic aspects of the Robin sequence: challenge for the diagnosis and its implication for treatment and genetic counseling.  
Roseli Maria Zechi-Ceide, Nancy Mizue Kokitsu-Nakata, Siulan Vendramini-Pittoli, Maria Leine Guion-Almeida, São Paulo, Brazil.
- 16h15 Oral phenotype in SatB2 syndrome.  
Nancy Vegas, Paris, France.
- 16h30 Supporting parents at home with Robin Sequence and a Nasal Pharyngeal Airway : Parental experiences within North London.  
Helen Robson, Paul Ramsey, UK.
- 16h45 Comparative effectiveness of pre-epiglottic baton plates and mandibular distraction in infants with Robin sequence.  
Cory Resnick et al, Boston, Massachusetts, USA.
- 17h00 End.

# PARIS 2025 - Friday April 4th

## 4th International Consensus meeting on Robin sequence

### Program









Morning  
09h00 - 13h00

Chairpersons :  
Brigitte Fauroux  
Christian Poets

#### Respiratory evaluation and treatment.






#### 4. Evaluation of respiratory obstruction.

-  09h00 How to score breathing in children under one year of age : why is it a challenge ?  
Brigitte Fauroux, Paris, France.
-  09h30 How to score sleep studies in infants with Robin sequence : MOAI vs. MOAHI.  
Christian Poets, Tübingen, Germany.
-  09h50 PSG vs sleep PG.  
Laurianne Coutier, Lyon, France.
-  10h10 Place of nocturnal transcutaneous gas exchange in children with RS.  
Sonia Khirani, Lucie Genet, Lucie Griffon, Véronique Abadie, Brigitte Fauroux, Paris, France.
-  10h30 Difference in analyses and treatment of upper airway obstruction in Robin sequence in different countries in Europe.  
Corstiaan Breugem, Nathaniel Sullivan, Amsterdam, the Netherlands.
-  10h45 Coffee break.



#### 5. Treatment.

-  11h15 Prone position in RS; theory and practice.  
Catherine de Blacam, Dublin, Ireland.
-  11h35 25 years of national experience of prone positioning as first step treatment for respiratory obstruction in RS : incident, ALTE, death ?  
Pauline Adnot, Véronique Abadie, for the French RS network, Paris, France.
-  11h50 TPP/OAP experience out of Germany.  
HyeRan Choo, Kelly Evans, Barbara Sheller, Agnès Giuseppi and Arnaud Callies.
-  12h20 Place of CPAP in RS treatment.  
Brigitte Fauroux, Paris, France.
-  12h40 Surgical experience : neonatal TLA and MDO for children with RS : advantages and disadvantages.  
Roberto Flores, New-York, USA.
-  13h00 Lunch on site. (13h00 - 14h15)

# PARIS 2025 - Friday April 4th

## 4th International Consensus meeting on Robin sequence

### Program



After-noon  
14h15 - 17h30

Chairpersons :  
Arnaud Picard  
Kelly Evans

- 14h15 Synthesis of the morning and ERN guidelines for respiration investigation and treatment.  
Eppo Wolvius, Rotterdam, the Netherlands.



#### 6. Physiopathology, nutrition, surgery, etc ...

- 14h45 Is the brainstem involved in RS ? Results of heart rate analysis Dysrobin.  
Laurianne Coutier, Lyon, France.
- 15h05 Succimetry in newborns with Robin sequence : preliminary results.  
Luc Marlier, Strasbourg, France.
- 15h20 Catch-up growth in Robin Sequence really matters.  
Koen Joosten, Rotterdam, the Netherlands.



- 15h45 Coffee break.

- 16h10 Risk of respiratory worsening after cleft palate closure.  
Corstiaan Breugem, Amsterdam, the Netherlands.

#### Networks for Rare disease in different countries.

- 16h30 Model of France.  
Nicolas Leboulanger, Paris, France.
- 16h50 ERN CRANIO.  
Irene Mathijssen, Rotterdam, the Netherlands.
- 17h00 Families' association, organization and testimonies.  
Delphine Vissac, Fernando de Pablo Cabrera, Association Tremplin syndrome de Pierre Robin, France.
- 17h20 Conclusion and perspectives: Organization team.



- 17h30 End.