

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
8h00-13h00

Chairmans :
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).

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After-noon
14h00-17h00





Chairman :
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 Végas, 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.



19h00 Gala dinner at the Restaurant Le Ciel de Paris.

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Morning
09h00-13h00

Chairmans :
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 experience out of Germany : France and US.
Hye Ran 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)

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After-noon
14h15 - 17h30

Chairmans :
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.

- 15h00 Catch-up growth in Robin Sequence really matters.
Koen Joosten, Rotterdam, the Netherlands.

- 15h20 Functional Outcome after primary palatal surgery.
Arnaud Picard, Paris, France.



- 15h50 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 Matijsshen, 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.