



4th International Consensus Meeting on Robin sequence



Thursday April 3rd
Friday April 4th
2025

Imagine Institute - Necker University Hospital
24 boulevard du Montparnasse
75015 Paris, France

PROGRAM

RELATIONS MÉDICALES

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PARIS 2025 - Wednesday April 2nd

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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 who wish to attend.

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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



1. Prenatal imaging.



09h00 Imaging criterias for prenatal screening of RS.
Judy A Estroff, pediatric radiologist, Boston, 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.



09h50 Is prenatal MRI useful for predicting neonatal distress and respiratory obstruction during the first semester of life ?
Maelys Leger, David Grevent, Briac Thierry, ENT, pediatric radiologist, Paris, France.



10h10 Discussion and toward a consensus for prenatal strategies (imaging and genetics) when RS is prenatally suspected ?
Jeanne Amiel, Genetics, Paris, France.



10h45 Coffee break.



2. Post-natal imaging: interests and technics.



11h15 Photo 3D - Mandibular catch-up growth in Robin infants treated with the Tübingen Palatal Plate.
Cornelia Wiechers, Tübingen, Germany.



11h45 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.



12h15 4D TDM for dynamic upper airway evaluation in children with RS.
Michael Barbour, Seattle, USA.



12h45 Lunch on site (12h45 - 14h00).

Morning
8h00-13h00

Chairmans :
Jeanne Amiel
Hossein Khonsari

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After-noon
14h00-17h30

Chairman :
Corstiaan Breugem

-  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, Friburg, 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, US.
-  15h00 **3. Free communications.** *(on progress)*
 - Nurses' experience with NPT at home. (UK experience, speaker being identified)
 - SatB2 ? Nancy Végas.
 - Hyoid bone ?
 - Parents' experience.
-  17h30 End of the day.
-  19h30 Gala dinner.

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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, Tubingen, Germany.
-  09h50 PSG vs sleep PG.
Laurianne Coutier, Lyon, France.
-  10h10 Sleep polysomnography vs gazometry .
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, Nederlands.
-  10h45 Coffee break.



5. Treatment.

-  11h15 Prone position in RS; theory and practice.
Catherine de Blacam, Ireland.
-  11h35 25 years of national experience of prone positioning as first step treatment for respi-
ratory obstruction in RS : incident, ALTE, death ?
Pauline Adnot, Véronique Abadie, for the French RS network.
-  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, NY 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, Nederlands.



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

- 14h50 Is the brainstem involved in RS ? Dysrobin.
Laurianne Coutier, Lyon, France.
- 15h10 Catch-up growth in Robin Sequence really matters.
Koen Joosten, Nederlands.
- 15h30 Functional Outcome after primary palatal surgery.
Arnaud Picard, Paris, France.
- 15h50 Risk of respiratory worsening after secondary pharyngoplasty.
Corstiaan Breugem, Amsterdam, Nederlands.
- 16h10 How to move forward in genetics exploration in isolated RS : help from families.
(speaker being identified).
- 16h30 Networks for Rare disease in different countries.
Model of France : [Nicolas Leboulanger](#).
ERN CRANIO : [Irene Matijssen](#).
Other model ?
- 17h00 Conclusion and perspectives.
- 17h30 End of the day.