



4th International Robin Sequence Consensus Meeting



Thursday April 3
Friday April 4
2025

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

Preliminary **PROGRAM**

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Preliminary program



Véronique Abadie



08h00 Welcome coffee.



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.

Morning
9h00-13h00

Chairmans :

Jeanne Amiel
Hossein Khonsari

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



Prenatal imaging.



09h00 Imaging criterias for prenatal screening of RS.
(speaker being identified)



09h20 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.



09h40 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.



10h00 Discussion and toward a consensus for prenatal strategies (imaging and genetics) when RS is prenatally suspected ?
(pair of geneticists and obstetrics, being identified)



10h30 Coffee break.



Post-natal imaging: interests and technics.



11h00 Classical radiography and CT scan in RS analysis.
(speaker being identified)



11h20 Photo 3D - Mandibular catch-up growth in Robin infants treated with the Tübingen Palatal Plate.
Cornelia Wiechers, Tubingen, Germany.



11h40 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.
(Team from Seattle, USA, speaker being identified)



13h00 Lunch on site.

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After-noon
14h00-18h00

Chairmans :

Brigitte Fauroux

Christian Poets

Respiratory evaluation and treatment.



Evaluation of respiratory obstruction.

- 14h00 How to score breathing in children under one year of age : why is it a challenge.
Brigitte Fauroux, Paris, France.
- 14h30 How to score sleep studies in infants with Robin sequence : MOAI vs. MOAHI.
Christian Poets, Tubingen, Germany.
- 14h50 Sleep polysomnography vs gazometry .
Lucie Genet, Sonia Khirani, Paris, France.
- 15h00 PSG vs sleep PG.
Laurianne Coutier, Lyon, France.
- 15h10 Difference in analyses and treatment of upper airway obstruction in Robin sequence in different countries in Europe.
Nathaniel Sullivan and Corstiaan Breugem, Amsterdam, Nederlands.



15h20 Coffee break.



Treatment.

- 15h45 Prone position in RS, theoretical aspects.
Catherine de Blacam, Ireland.
- 16h00 Sleep recording in prone versus supine position.
French group experience, Paris and Lyon.
- 16h10 TPP experience out of Germany : France and US.
France and US : Hye Ran Choo, Kelly Evans, Barbara Sheller, Agnès Giuseppi and Arnaud Callies.
- 16h30 NPT experience.
(UK experience, speaker being identified)
- 16h45 Place of CPAP in RS treatment.
Brigitte Fauroux, Paris.
- 17h00 Surgical experience, TLA and MCO: advantages and disadvantages.
Roberto flores, NY USA.
- 17h30 Discussion and ERN guidelines for respiration investigation and treatment.
(speaker being identified)



18h00 End of the day.

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Morning
09h00-13h00

Chairmans :
Arnaud Picard
Kelly Evans

After-noon
14h00-17h00

Chairmans :
Cortiaan Breugem
Véronique Abadie

What is new in RS, what has changed in 3 years ?



Physiopathology, diagnosis, nutrition. (09h00 - 10h30)



Is the brainstem involved in RS ?

Dysrobin: Laurianne Coutier, France.



How to move forward in genetics exploration in isolated RS : help from families.
(speaker being identified)



Catch-up growth in Robin Sequence really matters .

Koen Joosten, Nederlands.



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.



10h30 Coffee break



Outcome, surgery. (11h00 - 13h00)



Facial growth in RS, from infants to adolescents, long term outcome for patient treated with neonatal MDO.

Marcus Vinicius Martins Collares, Porto Alegre, Brazil.



Facial growth in RS, from infants to adults, impacts of non-invasive methods for treating respiratory obstruction.

Silvia Mueller-Hagedorn, Friburg, Germany.



Functional Outcome after primary palatal surgery.

Arnaud Picard, Paris.



Risk of respiratory worsening after secondary pharyngoplasty.

Corstiaan Breugem, Amsterdam.



13h00 Lunch



Free communications. (14h00 - 16h00)



Networks. (16h00 - 16h40)



Rare disease in other countries.

model of France (Nicolas Leboulanger)

model of UK (speaker, Canada, USA, EUROCAT, ERN CRANIO, Irene Matijssen).

16h45

Conclusion and perspectives. (16h45)



17h00 End of the day.