



Craniosynostosis Symposium

COMPREHENSIVE CARE, POLICY AND ADVOCACY

SCIENTIFIC PROGRAM

DAY ONE

Thursday, March 14, 2024

07:00 - 08:00 Registration

MORNING SESSION

08:00 - 08:15 Opening Remarks

Nivaldo Alonso and John Meara

08:15 - 09:00 Official Welcome

8:15 - 8:20 Cleide Carrara - HRAC/USP Superintendent

8:20 - 8:25 Danilo Arruda - HCB Director

8:25 - 8:30 Tales De Nadai - USP Bauru Medical School Coordinator

8:30 - 8:40 Paulo Rebello - ANS Director

8:40 - 8:50 Natan Monsores - Rare Diseases Coordinator, Ministry of Health

8:50 - 9:00 José Augusto Pupio Reis - Federal Deputy

9:00 - 10:15 Title: General Aspects of Syndromic Craniosynostosis

Moderators: John Meara / Cristiano Tonello

09:00 - 09:15 Overview of syndromic craniosynostosis
Nivaldo Alonso (HRAC-USP)

09:15 - 09:30 Genetics in syndromic craniosynostosis
Nancy Nakata (HRAC-USP)

09:30 - 09:45 Prenatal Diagnosis
Victor Bunduki (USP-SP)

09:45 - 10:00 Craniofacial Biology Research
Matt Harris (Harvard Medical School) - by Zoom

10:00 - 10:15 Potential CRISPR based treatment therapy
Danny Balkin (Harvard Medical School) - by Zoom

10:15 - 10:45 Coffee Break (*10:15 – Authorities and Speakers Official Photo)

10:45 - 13:00 Title: Surgical Management Algorithm - Protocols Overview

Moderators: Clarissa Turrer / Ricardo Oliveira

10:45 - 11:05 Hospital for Rehabilitation of Craniofacial Anomalies - Brazil
Cristiano Tonello / Michele Brandão

11:05 - 11:25 BCH - Boston Children's Hospital - USA
John Meara

11:25 - 11:45 Necker - Enfants Malades Hospital - France
Eric Arnaud

11:45 - 12:05 Sobrapar Hospital - Campinas - Brazil
Cassio Eduardo Raposo do Amaral / Enrico Ghizoni



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- 12:05 - 12:25 FMUSP-SP Medical School - Brazil
Hamilton Matushita / Nivaldo Alonso
- 12:25 - 12:45 UNIFESP - São Paulo Federal University - Brazil
Sergio Cavalheiro / Max Pereira
- 12:45 - 13:00 Q&A**

13:00 - 14:00 Lunch

DAY ONE - AFTERNOON SESSION

14:00-15:15 Title: The challenges to provide optimal care for patients with syndromic craniosynostosis

Moderators: Pedro Hamamoto / Enrico Ghizoni

- 14:00 - 14:15 Craniosynostosis and endoscopic treatment: BCH experience.
Mark Proctor
- 14:15 - 14:30 How to improve syndromic craniosynostosis patient treatment in Brazil. "What do we have, what we don't"?
Eduardo Jucá, President of SBNped
- 14:30 - 14:45 Challenges to treat syndromic craniosynostosis in the Northeast of Brazil
Marcelo Lins, Recife- PE
- 14:45 - 15:00 Challenges to treat craniosynostosis in the South of Brazil, at the University
Marcus Collares, Porto Alegre-RS
- 15:00 - 15:15 Challenges to treat syndromic craniosynostosis in the South of Brazil
Renato da Silva Freitas, Curitiba-PR

15:15 - 15:45 Coffee Break

15:45 - 18:00 Title: The first year: multidisciplinary care for the neonate and infant with craniosynostosis.

Moderators: Adriano Yacubian / Nelci Zanon

- 15:45 - 16:05 Patient's experience in the Boston Children's hospital (EUA)
Jay Berry – by Zoom
- 16:05 - 16:25 Where and how to get access to a craniofacial reference center
Natan Monsores
- 16:25 - 16:45 Patient's experience in the French Public Sector
Eric Arnaud
- 16:45 - 17:05 Patient's experience in the Brazilian Private Sector
Goldete Prizskulnik
- 17:05 - 17:25 Patient's experience in the Brazilian Public Sector
Isabel Cristina Drago M. Salmen
- 17:25 – 17:45 High-Quality Information: role of Parents Associations.
Élida Brandão (@craniossinostosestemcura- Instagram)

17:45 – 18:00 Round Table



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DAY TWO

Friday, March 15, 2024

MORNING SESSION

8:00 - 09:00 Title: Neurosurgical Management: Chiari and Hydrocephalus

Moderators: Franklin Rocha / Nelci Zanon

08:00 - 08:15 Hospital for Rehabilitation of Craniofacial Anomalies - Bauru - Brazil

Michele Brandão

08:15 - 08:30 Sobrapar Hospital - Campinas - Brazil

Enrico Ghizoni

08:30 - 08:45 BCH - Boston Children's Hospital - USA

Mark Proctor

08:45 - 09:00 Necker - Enfants Malades Hospital - France

Eric Arnaud

9:00 - 10:00 Title: Anesthesia Protocols

Moderators: Claudia Marquez Simões / Fernanda Leite

09:00 - 09:15 Hemorrhage management and transfusion strategies

Susan Goobie BCH USA – by Zoom

09:15 - 09:30 Global Anesthesia training

Craig McClain BCH USA – by Zoom

09:30 - 09:45 Anesthesiology approaches and local block in craniofacial surgery

Luciano Brandao HRAC USP

09:45 - 10:00 The “frequent flyer” surgical kid: do we need to be concerned with the anesthesia related neurotoxicity?

Vinicius Quintão HC - FMUSP

10:00 - 10:30 Coffee Break

10:30 - 11:30 Title: Dentistry, Orthodontics and Orthognathic Refinements

Moderators: Renato Yaedu / Tiago Turri

10:30 - 10:45 Hospital for Rehabilitation of Craniofacial Anomalies - Brazil

Adriano Porto Peixoto

10:45 - 11:00 Boston Children's Hospital - USA

James MacLaine

11:00 - 11:15 Boston Children's Hospital - USA

Bonnie Padwa

11:15 - 11:45 Title: Apert's hand

Moderator: Nivaldo Alonso

11:15 - 11:30 Apert Hand - USP/SP - Hugo Nakamoto

11:30 - 11:45 Apert Hand - BCH/USA - Brian Labow



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11:45 - 13:00 Title: Multidisciplinary approach in the treatment of patients with syndromic craniosynostosis

Moderators: Sergio Cavalheiro / Cynthia Martins Rocha

11:45 - 11:55 Airway in Syndromic Craniosynostosis - Crouzon Syndrome
Cristiano Tonello

11:55 - 12:05 Airway in Syndromic Craniosynostosis - Apert Syndrome
Ricardo Oliveira

12:05 - 12:15 Ophthalmologic Management
Isabella Parizotto

12:15 - 12:25 Psycho-social and Cognitive Considerations
Mariani Ribas

12:25 - 12:35 Genetic considerations in cognitive development
Luiza do Amaral Virmond

12:35 - 12:50 Mixed reality - Hololens in syndromic craniosynostosis planning
Mauricio Yoshida

12:50 - 13:00 Q&A

13:00 - 14:00 Lunch

DAY TWO - AFTERNOON SESSION

14:00 - 15:00 Title: Policy and advocacy from the professional perspective

Moderators: Mark Proctor / Patrícia Dástoli

14:00 - 14:15 Experience in Global Surgery
John Meara

14:15 - 14:30 Global Surgery: Ecuadorian Experience
Alfredo Borrero

14:30 - 14:45 Are syndromic craniosynostosis considered rare diseases according to Brazilian legislation? Benefits of laws for people with rare diseases that can benefit children with CS.
Goldete Prizskulnik

15:00 - 15:45 Title: Policy and Advocacy from the Society's perspective. The Patient's Journey.

Moderators: Helena Romcy / Melissa Antoneli

15:00- 15:15 A patient with Apert syndrome - João's Journey
Igor Cunha / Natalia Jereissati

15:15- 15:30 The Influence of Parents associations in health public policies
Graciela Mendanha Sobrinho (Apert's Brazilian Society)

15:30 - 15:45 The journey from necessity to effective change in public changes.
Denise Rodrigues Eloi - ICOS

15:45 - 16:15 Coffee Break





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16:15 - 16:45 Title: Registration of patients with syndromic craniosynostosis: how it is done and how to improve.

Moderators: Eduardo Jucá / Claudia Rodriguez

16:15- 16:30 Mapping to know! How is syndromic craniosynostosis registered?
What statistics do we have?

Miyuki Goto, Consultant for the Brazilian Medical Association

16:30 - 16:45 Model of a platform for registering rare diseases applied to syndromic craniosynostosis

Sandra Facincone. Medtech rarascro.com

16:45 - 17:15 Round Table

17:15 - 17:30 Closing ceremony and Commitment (*Group photo)

Nivaldo Alonso and John Meara

Location:

University Theater of Bauru Dental School, University of São Paulo (FOB-USP), Bauru – Brazil.

Chairmen:

John Meara

Nivaldo Alonso

Scientific Committee:

Cristiano Tonello

Melissa Zattoni Antoneli

Michele Madeira Brandão

Igor Cunha

Natalia Queiroz Jereissati

Mark Proctor

Parceiros e Patrocinadores:



**Patient
Specific
Planning**



DePuy Synthes



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