



Craniosynostosis Symposium

COMPREHENSIVE CARE, POLICY AND ADVOCACY

Craniosynostosis Symposium: Comprehensive Care, Policy and Advocacy

Thursday/Friday 14-15 March 2024

Collaborating Institutions

- HRAC Hospital de Reabilitação de Anomalias Craniofaciais - Bauru SP/ Brazil
- Boston Children's Hospital - Boston MA/ USA
- Necker Enfants Malades - Paris/ France

Location

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

Meeting Summary

This will be a 2-day meeting that focuses on craniofacial disorders in Brazil. It will have clinically focused morning meetings concentrating on syndromic craniosynostosis, including Apert syndrome. The morning sessions on both days will discuss the different protocol approaches in Brazil as well as Boston Children's Hospital and Necker Hospital in Paris as a means of comparing and contrasting different approaches. There will also be specialty-specific sessions that focus on sub-specialty care for all the different aspects of care of the complex syndromic craniofacial patient. The goals of the morning sessions include sharing clinical experiences and, more importantly, providing a framework for clinical and research collaboration in the future.

In the afternoon, on both days, the emphasis will shift to policy and advocacy. What is the present situation in Brazil regarding managing patients with craniofacial disorders (of all types, including craniosynostosis and other craniofacial conditions)? What are the barriers to care? Are there workforce, infrastructure, funding, policy, or governance issues that could be addressed? Is there a gap in the public/private



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management of this complex patient population? How can Brazil move forward and create universal access to safe, affordable care for patients with craniofacial disorders? What learning points are there from the recent successes seen in global surgery in terms of national approaches to surgical system strengthening? For the afternoon sessions, advocacy and policy experts from all aspects of Brazilian health care policy, delivery, and governance will be invited. We will also invite patient and family advocacy organizations and NGOs caring for patients with craniofacial conditions. The goals for this afternoon session include not only documenting the present issues related to the care of the complex syndromic craniofacial patient but also how this dialogue can bring about policy, legal, and governance changes in Brazil to provide safe, affordable, quality access to care for all patients and families with craniofacial conditions.

Chairmen:

John Meara

Nivaldo Alonso

Scientific Committee:

Cristiano Tonello

Melissa Zattoni Antoneli

Michele Madeira Brandão

Igor Cunha

Natalia Queiroz Jereissati

Mark Proctor

Partners:





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PRELIMINARY PROGRAM

DAY ONE

Thursday, March 14, 2024

MORNING SESSION

07:00 - 08:00	Registration
08:00 - 08:15	Opening Remarks Nivaldo Alonso / John Meara
08:15 - 09:00	Official Welcome - Nivaldo Alonso Carlos Gilberto Carlotti Junior (Dean USP) Suéllen Rosim (Bauru Mayor) Nisia Trindade de Lima (Minister of Health) Paulo Rebello (ANS Director)
9:00 - 10:15	Title: General Introduction
Moderators:	John Meara / Nivaldo Alonso
09:00 - 09:15	Overview of syndromic craniosynostosis Cristiano Tonello (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



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10:15 - 10:45	Coffee Break
10:45 - 13:00	Title: Surgical Management - Protocol Overview - Algorithm
Moderators:	Clarissa Turrer / Ricardo Oliveira
10:45 - 11:05	HRAC Cristiano Tonello Michele Brandao
11:05 - 11:25	BCH John Meara Mark Proctor Bonnie Padwa
11:25 - 11:45	Necker Eric Arnaud
11:45 - 12:05	Sobrapar Cassio Eduardo Raposo do Amaral Enrico Ghizoni
12:05 - 12:25	FMUSP-SP Hamilton Matushita Nivaldo Alonso
12:25 - 12:45	UNIFESP Sergio Cavalheiro Max Pereira SP
12:45 - 13:00	Q&A
13:00 - 14:00	Lunch



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DAY ONE

AFTERNOON SESSION

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

Moderators: Max Pereira / Enrico Ghizoni

14:00 - 14:15 Overview of Craniofacial Centers in Brazil
Nivaldo Alonso

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/PR

15:15 - 15:45 **Coffee Break**



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

Moderators: Nelci Zanon Collange / Melissa Zattoni Antoneli

15:45 - 16:05 A patient with Apert syndrome - João's Journey
Igor Cunha
Natalia Jereissati

16:05 - 16:25 BCH Boston
Jay Berry – by Zoom

16:25 - 16:45 Private Sector Brazil
Goldete Prizskulnik

16:45 - 17:05 Public Sector Brazil
Isabel Cristina Drago M. Salmen

17:05 - 17:25 France
Eric Arnaud

17:25- 17:45 **Round Table**

17:45 - 18:00 **Q&A**



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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 / Pedro Hamamoto

08:00 - 08:15 HRAC
Michele Brandão

08:15 - 08:30 SOBRAPAR
Enrico Ghizoni

08:30 - 08:45 BCH
Mark Proctor

08:45 - 09:00 Necker
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?
Vinícius Quintao HC - FMUSP

10:00 - 10:30 **Coffee Break**



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10:30 - 11:30 **Title: Dentistry, Orthodontic, Orthognathic Refinements**

Moderators: Renato Yaedu / Terumi Ozawa

10:30 - 10:45 HRAC USP
Adriano Porto Peixoto

10:45 - 11:00 BCH USA
James MacLaine

11:00 - 11:15 BCH USA
Bonnie Padwa

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

Moderator: Renato da Silva Freitas

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

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

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



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- 12:15 - 12:25 Psycho-social and Cognitive Considerations
Mariani Ribas HRAC-USP Neuropsychology
- 12:25 - 12:35 Genetic considerations in cognitive development
Luiza do Amaral Virmond HRAC USP
- 12:35 - 12:50 Virtual 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 Policies for the Treatment of syndromic craniosynostosis
Alfredo Borrero
- 14:30 - 14:45 Policies for the Treatment of Rare Diseases in Brazil
Jose Augusto Pupio Reis Jr
- 14:45 - 15:00 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 Priszkulnik



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- 15:00 - 15:45** **Title: Policy and Advocacy from the Society's perspective**
- Moderators:** Helena Romcy / Michele Brandao
- 15:00- 15:15 The Influence of Parents associations in health public policies
Graciela Mendanha Sobrinho
- 15:15- 15:30 High-Quality Information: role of Parents Associations.
Élida Brandão (@craniossinostosemcura- Instagram)
- 15:30 - 15:45 The journey from necessity to effective change in public changes.
Denise Rodrigues Eloi - ICOS
- 15:45 - 16:15** **Coffee Break**
- 16:15 - 16:45** **Title: Registration of patients with syndromic craniosynostosis:
how it is done and how to improve.**
- Moderators:** Eduardo Jucá / Claudia Rodriguez (rarascro)
- 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**
Nivaldo Alonso
John Meara



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