WORKSHOP:

NEWBORN SCREENING IN MINAS GERAIS:
new perspectives on Hereditary Metabolic Diseases and Primary Immunodeficiencies

August, 14 - 15th, 2014 - Belo Horizonte, Minas Gerais, Brazil.
The State of Minas Gerais Department of Health established a partnership with the Federal University of Minas Gerais State (UFMG), Brazil, through the Center of Newborn Screening and Genetic Diagnostics of the Faculty of Medicine from UFMG - Nupad – aiming at implementing newborn screening throughout the State in 1993. In 2001, due to the nationalization of the Newborn Screening Program by the Ministry of Health, Nupad was enrolled as technical reference for conducting the Newborn Screening Program in Minas Gerais, Brazil.

Newborn screening has become a successful public health program in the country and Minas Gerais turns out to be an example in particular. Early diagnosis of diseases, potentially severe and disabling, has assured that thousands of patients have the right to a better life. Since its founding, Nupad has worked diligently to assure early diagnosis of diseases that have treatment, seeking to minimize damage, improve the health and optimize the use of public resources.

In order to study the possibilities of increasing the number of the screened diseases by Minas Gerais Newborn Screening Program, specifically hereditary metabolic diseases and primary immunodeficiencies, Nupad will hold a workshop and other activities on August 13-15, 2014. The event will be supported by the Ministry of Health and will feature several international speakers, who have extensive experience on the discussing topics, as well as guests from the Ministry of Health and the State of Minas Gerais Department of Health.

**VENUE:**

**Boulevard Plaza**

Av. Getúlio Vargas, 1640 – Savassi, Belo Horizonte, Minas Gerais, Brasil.
## WORKSHOP PROGRAM

**AUGUST 14\textsuperscript{th}, 2014  Thursday**

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<tr>
<th>Time</th>
<th>Event</th>
<th>Speaker/Coordinator</th>
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<tr>
<td>08:00am - 08:45am</td>
<td>ATENDEE REGISTRATION</td>
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<td>08:45am - 09:15am</td>
<td>OPENING SESSION</td>
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<tr>
<td>09:15am - 09:45am</td>
<td>MINI-CONFERENCE: Newborn Screening in Minas Gerais prospects for expansion and international cooperation</td>
<td><strong>José Nelio Januario</strong>&lt;br&gt;Faculty of Medicine, Federal University of Minas Gerais (UFMG), Brazil</td>
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<tr>
<td>09:45am - 10:05am</td>
<td>ROUND-TABLE DISCUSSION Newborn screening for rare diseases advances and prospects in the Unified Health System (SUS).</td>
<td><strong>Ana Lúcia Starling</strong>&lt;br&gt;Faculty of Medicine, Federal University of Minas Gerais (UFMG), Brazil</td>
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<tr>
<td>09:45am - 10:05am</td>
<td>The National Policy on Comprehensive Care for People with Rare Diseases in Unified Health System (SUS).</td>
<td><strong>Pollyanna Almeida Santos</strong>&lt;br&gt;Ministry of Health</td>
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<tr>
<td>10:05am - 10:25am</td>
<td>Newborn Screening in Brazil.</td>
<td><strong>Ana Stela Goldbeck</strong>&lt;br&gt;Ministry of Health</td>
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<td>10:25am - 10:45am</td>
<td>Unified Health System (SUS) Ordinance 199/2014 for rare diseases in the context of newborn screening in Minas Gerais.</td>
<td><strong>Representative / State of Minas Gerais Department of Health</strong></td>
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<td>10:45am - 11:05am</td>
<td>Center for Biological Tissues (Cetebio) and transplantation of hematopoietic stem cells in Minas Gerais.</td>
<td><strong>Júnia Guimarães Mourão Cioffi</strong>&lt;br&gt;Minas Gerais State Department of Health / Hemominas Bank Blood Foundation</td>
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<td>11:05am - 11:20am</td>
<td>COFFEE-BREAK</td>
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<td>11:20am - 12:00am</td>
<td>DISCUSSION</td>
<td><strong>Marcos José Burle de Aguiar</strong>&lt;br&gt;Faculty of Medicine, Federal University of Minas Gerais (UFMG), Brazil</td>
</tr>
</tbody>
</table>
AUGUST 14TH, 2014  Thursday

12:00pm - 2:00pm  •  LUNCH

2:00pm - 3:00pm  •  CONFERENCE:
Newborn screening for hereditary metabolic diseases and primary immunodeficiencies in the United States.

LECTURER:
Mei Baker
University of Wisconsin - USA

COORDINATOR:
Marcos Borato Viana
Faculty of Medicine, Federal University of Minas Gerais (UFMG), Brazil

3:00pm - 3:40pm  •  CONFERENCE:
State of art: the use of tandem mass spectrometry (MS / MS) in newborn screening for metabolic diseases.

LECTURER:
Victor Raul de Jesus Miranda
CDC- Atlanta - USA

COORDINATOR:
José Nelio Januario
Faculty of Medicine, Federal University of Minas Gerais (UFMG), Brazil

3:40pm - 4:00pm  •  COFFEE-BREAK

4:00pm - 4:40pm  •  CONFERENCE:
Strategies and analytical systems available for the laboratory diagnosis of primary immunodeficiencies in newborn screening.

CONFERENCISTA:
Francis Lee
CDC- Atlanta - USA

COORDINATOR:
Dora Mendez del Castillo
Center of Newborn Screening and Genetic Diagnostics (Nupad) of the Faculty of Medicine from Federal University of Minas Gerais (UFMG), Brazil.

4:40pm - 5:00pm  •  GENERAL DISCUSSION:
Additional questions and conclusions of the day.

COORDINATOR:
Francisco José Penna
Faculty of Medicine, Federal University of Minas Gerais (UFMG), Brazil.
AUGUST 15TH, 2014  Friday

09:00am - 10:00am  •  CONFERENCE:
Treatment and follow-up of the primary immunodeficiencies in newborn screening context.

CONFERENCISTA:
John Sleasman
University of Wisconsin-USA

COORDINATOR:
Jorge Andrade Pinto
Faculty of Medicine, Federal University of Minas Gerais (UFMG), Brazil.

10:00am - 10:20am  •  COFFEE-BREAK

10:20am - 11:50am  •  ROUND-TABLE DISCUSSION
Newborn screening for rare diseases advances and prospects in the Unified Health System (SUS).

COORDINATOR:
Rocksane de Carvalho Norton
Faculty of Medicine, Federal University of Minas Gerais (UFMG), Brazil.

10:20am - 10:50am  •  LECTURE:
Newborn screening for hereditary metabolic diseases and primary immunodeficiencies in the state of Wisconsin (USA) dilemmas and lessons learned.

LECTURER:
Mei Baker
University of Wisconsin-USA
Wisconsin State Laboratory of Hygiene-USA

10:50am - 11:20am  •  LECTURE:
Expanded newborn screening for hereditary metabolic diseases in Portugal: dilemmas and lessons learned.

LECTURER:
Hugo Rocha
National Institute of Health - Portugal

11:20am - 11:50am  •  DISCUSSION

COORDINATOR:
Rocksane de Carvalho Norton
Faculty of Medicine, Federal University of Minas Gerais (UFMG), Brazil.

11:50am - 1:30pm  •  LUNCH

1:30pm – 2:50pm  •  COLLOQUIUM:
Newborn screening for hereditary metabolic diseases and primary immunodeficiencies in Minas Gerais: reflections and possibilities.

COORDINATOR:
Representative / State of Minas Gerais Department of Health
### AUGUST 15th, 2014  
**Friday**

#### 1:30pm - 1:40pm
- **Expanded newborn screening for metabolic diseases and the Unified Health System (SUS) Attention Network: possible strategies.**
  
  **José Nelio Januario**
  Faculty of Medicine, Federal University of Minas Gerais (UFMG), Brazil.

#### 1:40pm - 2:00pm
- **Full or reduced panel to metabolic diseases by tandem mass spectrometry (MSMS) in Minas Gerais? General Impressions.**
  
  **Mei Baker**
  University of Wisconsin - USA
  Wisconsin State Laboratory of Hygiene - USA

  **Victor Raul de Jesus Miranda**
  CDC-Atlanta-USA

#### 2:00pm - 2:10pm
- **Primary immunodeficiencies and the Attention Network in Minas Gerais: Possible Strategies.**
  
  **Jorge Andrade Pinto**
  Faculty of Medicine, Federal University of Minas Gerais (UFMG), Brazil.

#### 2:10pm - 2:20pm
- **Transplantation of hematopoietic stem cells for primary immunodeficiencies: feasibility in Minas Gerais.**
  
  **Jorge Andrade Pinto**
  Faculty of Medicine, Federal University of Minas Gerais (UFMG), Brazil.

#### 2:20pm - 2:40pm
- **Newborn screening for primary immunodeficiencies in Minas Gerais: impressions and general considerations.**
  
  **John Sleasman**
  Duke University - USA

  **Francis Lee**
  CDC- Atlanta - USA

#### 2:40pm - 2:50pm
- **Ordinance 199/2014 in the context of the State Attention Network: general considerations.**
  
  **Marcos José Burle de Aguiar**
  Faculty of Medicine, Federal University of Minas Gerais (UFMG), Brazil.

#### 2:50pm - 3:00pm
- **PLENARY SESSION**
  
  *General assessment and next steps.*

#### 3:00pm - 3:20pm
- **CLOSING SESSION**
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FOR FURTHER INFORMATION

- Support to events and local training services – SATE
  Phone: (+55 31) 3244-6443 and (+55 31) 3244-6444

- Section of translation and Internacional Relations - SETRI
  Phone: (+55 31) 3409-8936

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