

2nd Conference of the Middle East and North Africa Newborn Screening Initiative: Partnerships for Sustainable Newborn Screening Infrastructure and Research Opportunities of the Middle East and North Africa

12-14 April 2008
J.W. Marriott Cairo
Cairo, Egypt

Agenda

12 April

9:00 – 9:45 **Welcoming Remarks and Introductions**

Nasr Al Sayed, Egypt
James Hanson, USA
Christine Chirol, France

9:45 – 10:15 **Plenary Presentation**

The Importance of National Newborn Screening Programs
Mohamed Rashed, Egypt

10:15 – 10:40 **Break - Sponsor:** *HVD Life Sciences*

10:40 – 12:20 **Basic Aspects of Newborn Screening Programs**

Session Chairs: *James Hanson, USA*
Nadia Badrawi, Egypt
Esmat Mansour, Egypt

10:40 – 10:55 Overview of Newborn Screening System and Infrastructure
Bradford Therrell, USA

10:55 – 11:10 Legislative and Policy Issues
Carmencita Padilla, Philippines

11:10 – 11:35 Integrating Research and Research Linkages
R. Rodney Howell, USA

11:35– 11:50 Ethical, Legal and Cultural Considerations
Gerard Loeber, Netherlands

11:50– 12:20 Discussion

12:20 – 13:20 **Newborn Screening in the Middle East and North Africa**

Session Chairs: *James Hanson, USA*
Isis Ghaly, Egypt
Rabah Shawky, Egypt

12:20 – 12:35 Overview of Newborn Screening Systems within Middle East and North Africa: Analysis of Country Situation Survey

Ibrahim El Nekhely, Egypt
Sorrel Namaste, USA

12:35 – 12:50 Discussion

12:50 – 13:05 Report from the Congenital Hypothyroidism Working Group
Bradford Therrell, USA

13:05 – 13:20 Discussion

13:20 – 14:50 **Lunch – Sponsor:** *Luminex*

14:50 – 18:30 **Workshop on Developing a National Plan of Action**

Session Chairs: *Peter van Dyck, USA*

Hamed El Khayat, Egypt

Mohamed Salah El Kholy, Egypt

14:50 – 15:00 Introduction

Peter van Dyck, USA

15:00 – 17:00 Concurrent group discussions to develop draft national action plans

Group 1: Develop a pilot program for countries that have not begun or provide limited newborn screening

Randa Kamal, Bradford Therrell, Carmencita Padilla, Ben-Omran Tawfeg, Sorrel Namaste

Group 2: Develop a national program for countries that have not begun or provide limited newborn screening

Habiba Chaabouni, Jean-Louis Dhondt, Gerard Loeber, Michele Hindi-Alexander

Group 3: Expanding a national program for countries that have established national newborn screening programs

Ahmad Teebi, Mohammed Rashed, Joanne Mei, Danuta Krotoski

17:00 – 17:30 **Break – Sponsor:** *HVD Life Sciences*

17:30 – 19:30 Presentation from Small Groups to Develop a National Plan

17:30 – 19:30 Group 1

17:40 – 17:50 Feedback

17:50 – 18:00 Group 2

18:00 – 18:10 Feedback

18:10 – 18:20 Group 3

18:20 – 18:30 Feedback

18:30-19:30 **Poster Reception - Sponsor:** *HVD Life Sciences*

13 April

8:30 – 12:30 **Workshop on Developing a National Plan of Action (Continued)**

Session Chairs: *Peter van Dyck, USA*

Hamed El Khayat, Egypt

Mohame Salah El Kholi, Egypt

8:30 – 10:30 Concurrent group discussions to develop draft national action plans
(Continued from Day 1)

10:30 – 11:30 **Poster Session and Break - Sponsor:** *HVD Life Sciences*

11:30 – 12:00 Presentation from Small Groups to Develop a National Plan

11:30 – 11:40 Group 1

11:40 – 11:50 Group 2

11:50 – 12:00 Group 3

12:00 – 12:30 Discussion

12:30 – 13:00 **Closing Remarks by Policy Maker**

Nasr El Sayed, Egypt, Hatem El Rouby, Egypt

13:00 – 14:20 **Lunch**

14:20 – 15:40 **Panel on Building Partnerships and Collaborations**

Session Chairs: *Sana Al Hait, Jordan*

Amal El Beshlawy, Egypt

Mohsen El Alfy, Egypt

14:20 – 14:30 Newborn Screening Outreach Program for Physicians in
Saudi Arabia

Zuhair Al-Hassnan, Saudi Arabia

14:30 – 14:40 INSERM and Morocco Scientific Collaboration: Laboratory for
Research on the Genetics of Developmental Disabilities in Children

Aziz Sefiani, Morocco

Stanislas Lyonnet, France

14:40 – 14:50 Qatar and Germany Laboratory Partnership

Ghassan Abdoh, Qatar

14:50 – 15:00 Newborn Screening Community Awareness Campaign: The
Philippine Experience

Carmencita Padilla, Philippines

15:00 – 15:40 Discussion

15:40 – 16:00 **Break – Sponsor:** *HVD Life Sciences*

16:00 – 17:30 **Congenital Hypothyroidism**

Session Chairs: Ahmad Teebi, Qatar

Samia El Temtamy, Egypt

Mona Attya, Egypt

16:00 – 16:20 Treatment for Congenital Hypothyroidism

Thomas Foley, USA

16:20 – 16:30 Congenital Hypothyroidism Screening to Assess Iodine Deficiency

Michael Zimmermann, Switzerland

16:30 – 16:40 Iodine Deficiency in Egypt

Randa Kamal, Egypt

16:40 – 17:30 Discussion

19:30-22:00 **Dinner Reception- Sponsor:** *PerkinElmer*

Abou El Sid Restaurant

157 at 26th of July St. Zamalek

Meet in the lobby at 19:30

14 April

8:00 – 9:30 **Training Panel on Performance Standards and Quality Assurance**

Session Chair: Jean-Louis Dhondt, France

8:00 – 8:10 System Indicators and Program Evaluation/Audit

Bradford Therrell, USA

8:10 – 8:20 Performance Evaluation and Assessment Scheme (PEAS) for the Philippines

Carmencita Padilla, Philippines

8:20 – 8:30 Developing Iranian Program Activities with a Performance Evaluation and Assessment Scheme

Shahin Yarahmadi, Iran

8:30 – 8:40 Developing Laboratory Quality Assurance with Emphasis on Congenital Hypothyroidism

Anne Green, United Kingdom

8:40 – 8:50 International Screening Laboratory Proficiency Testing

Joanne Mei, USA

8:50 – 9:30 Discussion

- 9:30 – 9:45 **Break – Sponsor:** *SHS International*
- 9:45 – 11:45 **Discussion Panel on Developing Research Infrastructure:
From Bench-to-Bedside**
Session Chair: Stéphane Roy, France
- 9:45 – 9:55 Use of Residual Dried Blood Spots for Research: Practical and Ethical Considerations
Bent Nørgaard-Pedersen, Denmark
- 9:55 – 10:05 Informatics and Data Systems
Nick Waddell, United Kingdom
- 10:05 – 10:15 Bahrain-Oman-Qatar. INSERM partnership on Haemoglobinopathies
Salam Al Kindi, Oman
Krishnamoorthy Rajagopal, France
- 10:15 – 10:25 Developing a National Collaborative Translational Research Infrastructure
Michael Watson, USA
- 10:25 – 10:45 New Newborn Screening Technology: Luminex
Raj Asundi, USA
- 10:45 – 11:05 New Newborn Screening Technology: Advanced Liquid Logic
Vamsee Pamula, USA
- 11:05 – 12:00 Discussion
- 12:00 – 12:15 **Closing Remarks**
James Hanson, USA
Ibrahim El Nekhely, Egypt