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
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 Kholy, 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*