

Strengthening Newborn Screening in the Middle East and North Africa

13-15 November 2006

Palmeraie Golf Palace & Resort
Marrakech, Morocco

Agenda

12 November

20:00 – 22:00 Welcome Dinner

13 November

8:30 – 9:30 Morning Moderator: *Abdelaziz Sefiani, Morocco*
Welcoming Remarks and Introductions
Mohamed Cheikh Biadillah, Minister of Health, Morocco
Duane Alexander Director, NICHD/NIH/DHHS, USA
Christian Brechot, Executive Director, INSERM, France

9:30 – 10:10 Issues Unique to the Region
9:30 – 9:50 Genetic Disorders in Arabs
Ghazi Omar Tadmouri, Centre for Arab Genomic Studies, UAE
9:50 – 10:10 Consanguineous Marriages and Public Health in Morocco
Naima Lamdouar Bouazzaoui, CHU Ibn Sina –Rabat, Morocco

10:10 – 10:40 Break

10:40 – 11:10 Issues Unique to the Region – Continued
10:40 – 10:55 Ethical and Cultural Issues Relating to Genetic Research and Newborn Screening in the Islamic World
Iqtidar Khan, Department of Paediatrics, Aga Khan University, Karachi, Pakistan
10:55 – 11:10 Newborn Screening and Genomics Research in the Muslim World
Aida Al-Aqeel, Department of Paediatrics, Riyadh Armed Forces Hospital/ KFSH&RC, Riyadh Saudi Arabia

11:10 – 12:10 Pillars of a Newborn Screening System: From Theory to Practice
11:10 – 11:30 The Newborn Screening System: A Theoretical Framework
Michele Lloyd-Puryear, HRSA/DHHS, USA
11:30 – 11:50 A Newborn Screening System in Practice
Jean-Pierre Farriaux, past-President AFPDHE, France
11:50 – 12:10 Initiating Newborn Screening in Developing Countries: Challenges and Opportunities
Carmencita Padilla, NIH Philippines, Philippines

12:10 – 13:30 Lunch
Afternoon Moderator: *Brad Therrell, National Newborn Screening and Genetics Resource Center, USA*

13:30 – 16:00 Newborn Screening in the Region: Country Reports
13:30 – 13:35 Introduction
Bradford Therrell, National Newborn Screening and Genetics Resource Center, USA
13:35 – 13:45 Algeria: *Mohamed Tahar Hamlaoui, Réanimation Pédiatrique, CHU Hussein-Dey Algiers*
13:45 – 13:55 Bahrain : *Shaikha al Arrayed, Genetic Department, Salmaniya Medical Complex*
13:55 – 14:05 Egypt : *Randa Kamal Raouf, Institute of Post-graduate Childhood Studies, Ain-Shams University*
14:05 – 14:15 Iran : *Shahin Yarahmadi, Ministry of Health and Medical Education*
14:15 – 14:25 Iraq : *Ashwaq H. Abdulahad, Kurdish Regional Government*
14:25 – 14:35 Jordan : *Sana' Al Hait, Ministry of Health, Disease Control & Prevention*
14:35 – 14:45 Kuwait : *Omar Sherif, Ministry of Health Center for Medical Genetics*
14:45 – 15:10 Questions to session presenters

15:10 – 15:30 Break

15:30 – 18:20 Newborn: Screening in the Region - Country Reports (Continued)
15:30 – 15:40 Lebanon : *Khalid Yunis, Department of Pediatrics, American University of Beirut Medical Center*
15:40 – 15:50 Morocco: *Naima Lamdouar Bouazzaoui, CHU Ibn Sina –Rabat, Morocco*
15:50 – 16:00 Oman : *Surendra Nath Joshi, Child Health and Inborn Errors of Metabolism Sultan Qaboos University Hospital*

16:00 – 16:10	Pakistan : <i>Iqtidar Khan, Department of Paediatrics, Aga Khan University, Karachi.</i>
16:10 – 16:20	Palestinian Authority <i>Suhail Ayesh, Hebrew University & Al-Makased Hospital, Jerusalem</i>
16:20 – 16:30	Qatar : <i>Ghassan Mustafa Abdoh, Neonatal Intensive Care Unit, Hamad Medical Corporation</i>
16:30 – 16:40	Saudi Arabia <i>Mohamed Rashed, National Laboratory for Newborn Screening, King Faisal Specialist Hospital & Research Centre,</i>
16:40 – 16:50	Syria : <i>Adel Bakir, Atomic Energy Commission (AECS)</i>
16:50 – 17:00	Tunisia <i>M Habiba Bouhamed Chaabouni, Service de Maladies Congénitales et Héréditaires Hôpital Charles Nicolle, Tunis,</i>
17:00 – 17:10	UAE : <i>Mohamed Salah El-Din, National Screening Program for Woman and Child Health, Central Department of Maternal and Child Health, MOH,</i>
17:10 – 17:20	Yemen : <i>Ahmed Alshehari, Medical College at Thamar University</i>
17:20-18:00	Questions to session presenters

14 November

	Morning Moderator: <i>Peter van Dyck, HRSA, DHHS, USA</i>
8:30 – 9:15	Newborn Screening in Europe and the United States
8:30 – 8:40	Netherlands : <i>Gerard Loeber, ISNS & Natl. Inst Public Health, Bilthoven</i>
8:40 – 8:50	France : <i>Paul Czernichow, Department of Endocrinology, Growth and Gynecology Necker Hospital, Paris</i>
8:50 – 9:00	United States: <i>R. Rodney Howell, NICHD/NIH/DHHS</i>
9:00 – 9:15	Questions to session presenters
9:15 – 10:30	Surveillance, Epidemiology and Registries
9:15 – 9:30	The Use of the Danish Newborn Screening Register and Biobank in Routine and Research <i>Bent Nørgaard-Pedersen, Serum Staatens Institute – Copenhagen, Denmark</i>
9:30 – 9:45	Global Lysosomal Storage Disorders Registry Program <i>Marc Nicolino, Division of Pediatric Endocrinology and Metabolism, University Hôpital Debrousse, Lyon, France</i>
9:45 – 10:00	National Congenital Abnormalities Registry in UAE (1999-2004) <i>Mohamed Salah El-Din, National Screening Program for Woman and Child Health, Central Department of Maternal and Child Health, MOH, UAE</i>
10:00 – 10:15	The Catalogue for Transmission Genetics in Arabs (CTGA) <i>Ghazi Omar Tadmouri, Centre for Arab Genomic Studies, Dubai, UAE</i>
10:15 – 10:30	Discussion
10:30 – 10:50	Break
10:50 – 12:20	Range of Newborn Screening Technologies
10:50 – 11:10	Traditional Testing Techniques: bacterial inhibition, enzyme/fluorescence immunoassay, isoelectric focusing <i>Jean-Louis Dhondt, ISNS, AFPDHE, France</i>
11:10 – 11:35	Tandem Mass Spectrometry: Examining its capabilities; its variations & modifications <i>Mohamed Rashed, National Laboratory for Newborn Screening, King Faisal Specialist Hospital & Research Centre, Saudi Arabia</i>
11:35 – 11:50	Development of a Non-invasive Assay for Prenatal Diagnosis of Cystic Fibrosis by Genetic Analysis of Circulating Trophoblastic Cells Enriched by ISET <i>Patrizia Paterlini-Brechot, Laboratoire de Biochimie A, Hôpital Necker-Enfants Malades & INSERM, France</i>
11:50 – 12:05	Emerging Technologies in Newborn Screening <i>Michael Watson, American College of Medical Genetics, USA</i>
12:05 – 12:20	Discussion
12:20 – 14:00	Lunch
	Afternoon Moderator: <i>Mohammed Khattab, Pediatric Oncology, CHU Ibn Sina –Rabat, Morocco</i>
14:00 – 15:00	Issues around Quality Control and Quality Assurance
14:00 – 14:20	Assuring Quality in the Newborn Screening System <i>Bradford Therrell, NNSGRC, USA</i>
14:20 – 14:40	Quality Assurance Program for Newborn Screening Laboratories Worldwide <i>Harry Hannon, CDC/DHHS, USA</i>
14:40 – 15:00	Discussion
15:00 – 15:30	Break

- 15:30 – 16:10 Model Programs for Newborn Screening of Prevalent Conditions in the Region
 15:30 – 15:45 Newborn Screening for Congenital Hypothyroidism in Egypt:
 A Model Program for Developing Countries. *Ibrahim El-Nekhily, Children With Special Needs Department, Ministry of Health & Population, Egypt*
 15:45 – 16:00 Hemoglobinopathies (Sickle Cell Disease and the Thalasemias) *Shaikha Salim Al-Arrayed, Genetic Department, Salmaniya Medical Complex, Kingdom of Bahrain*
 16:00 – 16:10 Cost Effectiveness of G6PD newborn screening in Lebanese Males
Issam Khneisser, Newborn Screening Laboratory Medical Genetic Unit, Faculty of Medicine, Saint Joseph University, Lebanon
 16:10 – 17:25 Newborn Screening for Other Conditions in the Region
 16:10 – 16:25 Metabolic Conditions: PKU : *Layachi Chabraoui, CHU Ibn Sina –Rabat, Morocco*
 16:25 – 16:40 Challenges to Treatment of Inherited Metabolic Disorders: The Saudi Experience
Zuhair Al-Hassnan, Dept. of Medical Genetics, King Faisal Specialist Hospital & Research Center, Riyadh, Saudi Arabia
 16:40 – 16:55 Congenital Adrenal Hyperplasia, a Missed Diagnosis in Egypt
Nermin Salah El Din, Children Hospita , Cairo University, Egypt
 16:55 – 17:10 The Genetics of Hearing Loss in the Palestinian Population
Moiem Kanaan, Bethlehem University, Bethlehem, Palestinian Authority
 17:10 – 17:25 Sensory Disorders: Initiating a Hearing Screening Program in Morocco
Razika Bencheikh, CHU Ibn Sina- Rabat, Morocco
 17:25 – 17:45 Discussion
 17:45 – 18:55 Education and Outreach to Health Care Providers, Patients & Families
 Moderator: *James Hanson, NICHD/NIH/DHHS, USA*
 17:45 – 18:00 Initiation to Newborn Screening: Our experience of sickle disease
Mohamed Tahar Hamlaoui, Réanimation Pédiatrique, CHU Hussein-Dey Algiers, Algeria
 18:00 – 18:15 Education and Outreach to Health Care Providers, Patients & Families: French Experience
Gérard Bréart, INSERM, France
 18:15 – 18:30 Education Role of Genetic Centres: Moroccan experience
Abdelaziz Sefiani, Department of Medical Genetics, NIH Rabat Morocco
 18:30 – 18:45 A Bilateral Approach to Outreach and Advocacy in Genetics
Hanaa Rifaey, Genetic Alliance, USA
 18:45 – 18:55 Discussion

15 November

- Morning Moderator: *Layachi Chabraoui, CHU Ibn Sina –Rabat, Morocco*
 8:00 – 8:30 Financing Developing Newborn Screening Systems
 8:00 – 8:10 Financing Developing Newborn Screening Systems: A Saudi Experience
Nasser Al-Hamdan, Ministry of Health, Saudi Arabia
 8:10 – 8:20 Financing Developing Newborn Screening Systems
Kenneth Pass, Laboratory of Newborn Screening Technology Wadsworth Center, New York State Department of Health, USA
 8:20 – 8:30 Financing Developing Newborn Screening Systems: A Philippine Experience
Carmencita Padilla, NIH Philippines, Philippines
 8:30 – 9:15 Recent Advances Relevant to Newborn Screening of Conditions Prevalent in the Region
 8:30 – 8:45 Muscular Dystrophies in Arab Countries
Fayçal Hentati, Institut National de Neurologie, Tunisia
 8:45 – 9:00 Recent Advances Relevant to Screening of Congenital Cardiomyopathy in Lebanon
Fadi Bitar, Pediatric Cardiology Program, American University of Beirut Medical Center, Lebanon
 9:00 – 9:15 Newborn Screening for Fragile X Syndrome
Don Bailey, RTI International, USA
 9:15 – 9:30 Questions to morning session presenters
 9:30 - 10:30 Panel: Research and Infrastructure Needs to Strengthen Newborn Screening in the Region
 Moderator: *Fayçal Hentati, Institut National de Neurologie, Tunisia*
Hatem el Shanti, Division of Medical Genetics, University of Iowa Hospital & Clinics, USA
Moiem Kanaan, Bethlehem University, Bethlehem, Palestinian Authority
Ahmad Teebi, Cornell Medical College, Qatar & University of Toronto, Toronto, Canada
Khalid Yunis, Department of Pediatrics, American University of Beirut Medical Center
 10:30 - 11:00 **Break**

- 11:00 - 12:20 Opportunities for Research Collaboration and Research Training
 11:00 – 11:10 Fogarty International Center Research and Research Training Programs
Judy Levin, FIC/NIH/DHHS, USA
- 11:10 – 11:20 Opportunities for Research Collaboration in Newborn Screening at the National Institute of Child Health and Human Development
Danuta Krotoski, NICHD/NIH/DHHS, USA
- 11:20 – 11:30 Opportunities for Research Collaboration and Research Training in France
Arnold Munnich, Necker Hospital, INSERM, France
- 11:30 – 11:40 Opportunities for Research Collaboration and Research Training by the European Commission
Albrecht Jahn, Directorate General for Research, European Commission
- 11:40 – 11:50 Research Collaboration and Research Training in Europe
Jim R. Bonham, ERNDIM/EUGT, United Kingdom
- 11:50 – 12:00 Opportunities for Research Collaboration and Research Training
*Kenneth Pass, Laboratory of Newborn Screening Technology
 Wadsworth Center, New York State Department of Health, USA*
- 12:00 – 12:20 Discussion
- 12:20 – 13:45 Lunch**
 Afternoon Moderator: *Stéphane Roy, International Relations Department, INSERM, France*
- 13:45 – 15:15 Opportunities for Training in Newborn Screening
 13:45 – 14:00 An International Training and Support Program for Neonatal Screening in Developing Countries
Masaru Fukushi, Health Science Section, Sapporo City Institute of Public Health, Health & Welfare Bureau, City of Sapporo, Japan
- 14:00 – 14:15 Egypt Training Program for Primary Health Care Team on Neonatal Screening
Safa'a Abdel Fattah, Healthy Mother / Healthy Child Project, Ministry of Health & Population, Cairo, Egypt
- 14:15 – 14:30 French and European Training Opportunities
Arnold Munnich, Necker Hospital, INSERM, France
- 14:30 – 14:45 Newborn Screening Training in the USA
Jelili Ojodu, Association of Public Health Laboratories, USA & Bradford Therrell, National Newborn Screening and Genetics Resource Center, USA
- 14:45 – 15:00 Genetics Training in the USA
Michael Watson, American College of Medical Genetics, USA
- 15:00 – 15:15 Discussion
- 15:15 – 15:45 Break**
- 15:45 – 16:45 Summary of Meeting, Priorities and Next Steps
Brad Therrell and Session Moderators
- 16:45 – 17:00 Closing Remarks
Rajae El Aouad, INH-Rabat, Morocco

16 Novembre 2006

Réunion pour la création d'une Unité de Dépistage Néonatal au niveau de l'hôpital des Enfants Rabat