

Prevention, Screening and Treatment of Developmental Disorders in the Middle East and North Africa (MENA) Region

April 26-29, 2010

Draft Agenda (3-22-2010)

April 26

19:00 Opening Reception

Day 1: April 27

Session 1. Newborn Screening (NBS) in the MENA Region

Organizers: Brad Therrell, University of Texas Health Science Center at San Antonio, (UTHSCSA, USA); Tawfeg Ben Omran, Hamad Medical Corporation (HMC, Qatar); Mohamed Rashed, Pharmagene (Egypt); Tiina Urv, National Institute of Child Health and Human Development (NICHD, NIH, USA)

Chairs: Ibrahim Al Janahi, HMC (Qatar) and Gerard Loeber, International Society for Neonatal Screening, (ISNS, Netherlands)

8:15 Welcome

*Hamad Medical Corporation
Shafallah Center
NICHD*

8:25 History of the MENA NBS Initiative
Danuta Krotoski (NICHD, USA)

8:35 Intersection of public health and NBS
Brad Therrell (USA)

9:05 Status of NBS within MENA: analysis of 2010 Country Situation Survey
Ahmad Teebi, Weill Cornell Medical College (Qatar)

9:15 Strengthening NBS through cooperative efforts across sectors (roundtable)
The goal of this roundtable discussion is to identify and discuss cooperative efforts within and outside the region to strengthen NBS.

Chair: Tawfeg Ben Omran (Qatar)

International and regional newborn screening cooperative efforts: Lebanon's experiences, Issam Khneisser

Georg Hoffman, University of Heidelberg (Germany)

Qatar,

Nawal Maksheed (Kuwait)

10:00: Strategies used to prioritize conditions for national NBS panels
The goal of this roundtable is to examine how countries identify and prioritize conditions for NBS.

Chair: R. Rodney Howell, NICHD (USA)

Michelle Puryear, Health Resources and Services Administration, (USA)

Mohamed Salah Riad El Din, Ministry of Health (UAE)

Saudi Arabia,

Bahrain,

Morocco,

10:45 Break

11:05 Challenges for patient follow-up

The goal of this roundtable is to learn how countries have addressed patient follow-up from the perspective of different specialties.

Chair:

Mona Hafez el Nakam, Ministry of Health and Population (Egypt)

Bassam Y. Abu-Libdeh, Makassad Hospital (Palestinian Authority)

Shahin Yaramadi, Ministry of Health and Medical Education (Iran),

Qatar,

11:45 The Hemoglobinopathies: a model for developing a regional provider and research network and addition to newborn screening panels

Chairs: Mohamed Abulaban, HMC (Qatar) and Hani Atrash, Centers for Disease Control and Prevention (USA)

Speakers: CDC/EMRO Collaboration to strengthen NBS for hemoglobinopathies in the Middle East. Hani Atrash (USA)

A model for integration of screening, molecular validation and comprehensive clinical care in Oman. Salam Al Kindi, Sultan Qaboos University Hospita (Oman)
France-Oman collaboration in Hematological disorders Rajagopal Krishnamoorthy, INSERM (France)

Screening for Hemoglobinopathies in Jordan Sana' Al Hait, Ministry of Health (Jordan)

Partnerships for developing screening for sickle cell disease in Ghana Kwaku Ohene-Frempong, University of Pennsylvania (USA)

12:15 Early Detection of Hearing Loss

Screening for hearing loss in Qatar: Dr Khalid Abdul Hadi, HMC (Qatar)

12:45 Lunch

13:30 New technologies and research opportunities in NBS

Chairs: Ajjab Almarri, HMC (Qatar) and James Hanson, NICHD (USA)

Speakers: Luminex technologies—Kenneth Pass, New York State Laboratory (USA)

Digital microfluidics—Vamsee Pamula, Advanced Liquid Logic (USA)

High throughput technologies for hemoglobinopathies—Shoaib AlZadjali, Sultan Qaboos University Hospital (Oman)

DNA-based screening for cystic fibrosis and cytomegalovirus (CMV)—Zafar Nawaz, HMC (Qatar)

MS/MS Technologies—Jan Ostrup, Perkin Elmer (Finland)

Natural history studies—Tiina Urv, NICHD (USA)

14:15 Ethical issues associated with NBS

The goal of this roundtable is to discuss issues such as informed consent, privacy, cultural considerations, long term storage of blood spots and their utilization for research.

Chair: Mumtaz Wassef

Speakers: Zuhair Al Hassnan, King Faisal Specialist Hospital & Research Centre (Saudi Arabia); Pascale Karam, American University of Beirut (Lebanon); Michele Puryear, Health Resources and Services Administration (HRSA, USA)

15:00 Break

15:25 Workshops to update National Plans of Action

Chairs: Peter Van Dyck, HRSA (USA) and Hilal Al Rifai, HMC (Qatar)

A: Countries starting NBS programs

Algeria, Jordan, Libya, Morocco, Syria, Tunisia, Kuwait, Pakistan, Yemen

Moderators: Brad Therrell (USA) and Tawfeg Ben Omran (Qatar)

B: Countries with existing NBS programs—Integrating new technologies into NBS programs

Bahrain, Egypt, Iran, Lebanon, Oman, Palestine, UAE, Saudi Arabia, Qatar

Moderators: Mohamed Rashed, Pharmagene (Egypt) and Kenneth Pass (New York State Laboratory, USA)

17:45 Report back on workshop outcomes

18:15 Adjourn

Day 2: April 28

Session 2: Genetic and Developmental Disorders in the MENA Region

Organizers: Haitham El-Bashir, HMC (Qatar); George Jesien, Association for University Centers on Disability (AUCD, USA); Andy Shih, Autism Speaks (USA); Melissa Parisi (NICHD, USA)

Chairs: Haitham El Bashir (Qatar) and Andy Shih(USA)

- 8:15 Recent advances in diagnosis and treatment for developmental disabilities: an overview
Melissa Parisi (USA)
- 8:25 Early diagnosis of autism and related developmental disabilities
Mayada Elsabbagh, Birbeck College (United Kingdom)
- 8:45 Screening approaches for developmental delay
Habiba Chaabouni, Hôpital Charles Nicolle (Tunisia)
- 9:05 Screening for language delay and speech and language impairments
Judy Reilly, San Diego State University (USA)
- 9:25 Genetic and metabolic approaches to screening for developmental disorders beyond the newborn period
Hatem El Shanti, Shafallah Genetics Research Center (Qatar)
- 9:35 Discussion
- 9:45 Break
- 10:05 Status of Developmental Disorders in the MENA region
Eric Fombonne, McGill University (Canada)
- 10:25 Status of screening for developmental disorders in MENA: Country presentations
Moderator: Amin Badii, HMC (Qatar) and Gerard Breart (France)

Algeria:	<i>Ould Taleb, Hospital Drid Hocine</i>
Bahrain:	<i>TBD</i>
Egypt:	<i>Randa Kamal Raouf, Ain-Shams University</i>
Iran:	<i>Roksana Sasanfar, _____</i>
Iraq:	<i>Mahjoob Al Naddawi, Baghdad University</i>
Jordan:	<i>Amira Al Asmari, University of Jordan</i>
Kuwait:	<i>Laila Bastaki, Kuwait Medical Genetic Center</i>
Lebanon:	<i>Khalid Yunis, American University of Beirut</i>
Libya:	<i>Adel Zeglam, Al Khadra Hospital</i>
Morocco:	<i>Abdelaziz Sefiani, Institut National d'Hygiene</i>
Oman:	<i>Surender Nath Joshi, SQ University</i>
Palestine:	<i>Jumana Odeh, Palestinian Happy Child Center</i>
Qatar:	<i>Haitham El-Bashir, Hamad Medical Center</i>
Saudi Arabia:	<i>Mohamed Al Dosari, King Faisal Specialist Hospital & Research Centre</i>
Syria:	<i>TBD</i>
Tunisia:	<i>Ahlem Belhaj, Hôpital Charles Nicolle</i>
UAE:	<i>Bushra Al Mulla, Dubai Early Childhood Developmentl Center</i>
Yemen:	<i>TBD</i>

12:30 Lunch

Session 3: Developing Partnerships with Patient, Parent and Community Groups

Organizers: Ali El Mgadmi, Tripoli Medical Center (Libya); Gerard Loeber (ISNS); Natasha Bonhomme, Genetic Alliance (USA); James Hanson (USA)

Chairs: Ali Mgadmi, (Libya) and Gerard Loeber (ISNS)

13:30 Stages and elements in development of NBS programs: relationships to parental efforts and advocacy opportunities

James Hanson (USA)

13:40 The diagnostic odyssey

George Jesien (USA)

13:50 Prevention and treatment research opportunities at the community level

Andy Shih (USA)

14:00 The role of family and consumer advocacy in support of NBS and developmental disorders

Natasha Bonhomme (USA), Regional Representatives

14:30 Break

14:50 Workshops: challenges to implementing early screening of genetic and developmental disorders

Chairs: Andy Shih (USA) and Haitham El-Bashir (Qatar)

17:00 Break

17:20 Workshop Summary and Discussion

18:30 Adjourn

Day 3: April 29

Session 4: Developing Infrastructure for Services and Translational Research: From Bench to Bedside

Organizers: Hatem El Shanti (Qatar); Habiba Chaabouni (Tunisia); James Hanson (USA); Khalid Yunis, American University of Beirut (Lebanon)

Chairs: Hatem El Shanti and _____

- 8:00 Research and infrastructure support for NBS and developmental disorders
James Hanson (USA)
- 8:10 Considerations in developing interoperable informatics systems
Clement McDonald, National Library of Medicine, NIH (USA)
- 8:30 Linking NBS to Electronic Health Records
Kari Klossner, Perkin Elmer (Finland)
- 9:50 Surveillance of rare conditions and developmental disabilities
Segolene Ayme, Orphanet, INSERM (France)
Ibrahim Al Janahi, HMC (Qatar)
- 9:10 m-Health: intersection of health and communication/ IT technologies
Mitul Shah, United Nations Foundation (USA)
- 9:30 Training
This roundtable will highlight regional and international training models and opportunities.
Regional activities *to be identified*
NIH Training Opportunities—*Judy Levin, Fogarty Center, NIH (USA)*
Training programs that linking health services and research—*George Jesien (USA)*
- 10:15 Models for international cooperation and collaboration (roundtable)
Opportunities for research collaboration with Qatar—*Hareth Al-Kater, HMC (Qatar)*
Newborn Screening Translational Research Network—*Michael Watson, American College of Medical Genetics (ACMG, USA)*
Rare Diseases Clinical Research Network—*Melissa Parisi (USA)*
EU Capability Project —*Irmgard Nippert, Universitaetsklinikum Muenster (Germany)*
Autism Speaks Global Autism Public Health Initiative—*Andy Shih (USA)*
Fogarty International Center Programs—*Judy Levin (USA)*
INSERM-MENA cooperation—*Gerard Bréart, INSERM (France)*
- 11:00 Break and Workshops
- 11:15 Workshop topics
Integration of communication, informatics and new technologies into NBS and developmental disabilities
Human capacity needs and training programs
Priorities for international research cooperation
- 13:00 Lunch

14:00 Reports from Workshops on Research and Infrastructure, Education and Training

15:00 Conference Closing