

**Third Conference of the MENA Initiative: Future Directions in Developmental Disabilities: Prevention,  
Screening, and Treatment**  
April 27, 2010 - April 29, 2010  
Doha, Qatar

<b>Scientific Program</b>
<b>April 26th, 2010</b>

**19:00      Opening Reception**

<b>Day 1</b>	<b>April 27</b>
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**Session 1      Newborn Screening (NBS) in the MENA Region**

<b>Organizers</b>	<b>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)</b>
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<b>Chairs</b>	<b>Ibrahim Al Janahi, HMC (Qatar) and Gerard Loeber, International Society for Neonatal Screening, (ISNS, Netherlands)</b>
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<b>8:15</b>	<b>Welcome Hamad Medical Corporation Shafallah center NICHD</b>
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<b>8:25</b>	<b>History of the MENA NBS Initiative Danuta Krotoski (NICHD, USA)</b>
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<b>8:35</b>	<b>Intersection of public health and NBS Brad Therrell (USA)</b>
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<b>9:05</b>	<b>Status of NBS within MENA: analysis of 2010 Country Situation Survey Ahmad Teebi, Weill Cornell Medical College (Qatar)</b>
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<b>9:15</b>	<b>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.</b>
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<b>Chair</b>	<b>Tawfeg Ben Omran (Qatar) Issam Khneisser St. Joseph's University (Lebanon) Georg Hoffman, University of Heidelberg (Germany)</b>
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**Ghassan Abdoh, Hamad Medical Corporation (Qatar), Nawal  
Maksheed (Kuwait)**

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| <b>10:00</b> | <b>Strategies used to prioritize conditions for national NBS panels</b> 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) Shaikha Al-Arrayed, Ministry of Health (Bahrain) Mounia Bouabdellah, Instiitue National d'Hygiene ( Morocco), Ali Odaib, King Faisal Specialist Hospital & Research Center (Saudi Arabia) Georg Hoffman, (Germany)  |
| <b>10:45</b> | <b>Break</b>   |
| <b>11:05</b> | <b>Challenges for patient follow-up</b> The goal of this roundtable is to learn how countries have addressed patient follow-up from the perspective of different specialties. Chair: Mohammed Rashed (Egypt) and Gerard Breart (France) Speakers: 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) Ali Mgadmi, Tripoli Medical Center (Libya)   |
| <b>11:45</b> | <b>The Hemoglobinopathies: a model for developing a regional provider and research network and addition to newborn screening panels</b> 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 Hospital (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, |

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**University of Pennsylvania (USA)**

<b>12:15</b>	<b>Early Detection of Hearing Loss Screening for hearing loss in Qatar. Dr Khalid Abdul Hadi, HMC (Qatar), Screening for hearing loss in Morocco. Razika Bencheikh, Centre Hospitalier Universitaire Ibn Sina (Morocco)</b>
<b>12:45</b>	<b>Lunch</b>
<b>13:30</b>	<b>New technologies and research opportunities in NBS Chairs: Agyab 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)</b>
<b>14:15</b>	<b>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 &amp; Research Centre (Saudi Arabia) Pascale Karam, American University of Beirut (Lebanon); Michele Puryear, Health Resources and Services Administration (HRSA, USA)</b>
<b>15:00</b>	<b>Break</b>
<b>15:25</b>	<b>Workshops to update National Plans of Action Chairs: Peter Van Dyck, HRSA (USA) and Hilal Al Rifai, HMC (Qatar)</b>  <b>A: Countries starting NBS programs Algeria, Jordan, Libya, Morocco, Syria, Tunisia, Kuwait, Pakistan, Yemen Moderators: Brad Therrell (USA) and Tawfeg Ben Omran</b>

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**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)**

<b>17:45</b>	<b>Report back on workshop outcomes</b>
<b>18:15</b>	<b>Adjourn</b>
<b>Day 2</b>	<b>April 28</b>
<b>Session 2</b>	<b>Genetic and Developmental Disorders in the MENA Region</b>
<b>Organizers</b>	<b>Haitham El-Bashir, HMC (Qatar); George Jesien, Association for University Centers on Disability (AUCD, USA); Andy Shih, Autism Speaks (USA); Melissa Parisi (NICHD, USA)</b>
<b>Chairs</b>	<b>Haitham El Bashir (Qatar) and Andy Shih (USA)</b>
<b>8:15</b>	<b>Recent advances in diagnosis and treatment for developmental disabilities: an overview Melissa Parisi (USA)</b>
<b>8:25</b>	<b>Early diagnosis of autism and related developmental disabilities Mayada Elsabbagh, Birbeck College (United Kingdom)</b>
<b>8:45</b>	<b>Screening approaches for developmental delay Habiba Chaabouni, Hôpital Charles Nicolle (Tunisia)</b>
<b>9:05</b>	<b>Screening for language delay and speech and language impairments Judy Reilly, San Diego State University (USA)</b>
<b>9:25</b>	<b>Genetic and metabolic approaches to screening for developmental disorders beyond the newborn period Hatem El Shanti, Shafallah Genetics Research Center (Qatar)</b>

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<b>9:35</b>	<b>Discussion</b>
<b>9:45</b>	<b>Break</b>
<b>10:05</b>	<b>Status of Developmental Disorders in the MENA region Eric Fombonne, McGill University (Canada)</b>
<b>10:25</b>	<b>Status of screening for developmental disorders in MENA: Country presentations Moderator: Amin Badii, HMC (Qatar) and Buadoion Forgeot D'Arc (France)</b>
<b>Algeria</b>	<b>Ould Taleb, Hospital Drid Hocine</b>
<b>Bahrain</b>	<b>Ementhal Al Jishi, Salmanya Medical Center</b>
<b>Egypt</b>	<b>Randa Kamal Raouf, Ain-Shams University</b>
<b>Iran</b>	<b>Roksana Sasanfar, Harvard University</b>
<b>Iraq</b>	<b>Mahjoob Al Naddawi, Baghdad University</b>
<b>Jordan</b>	<b>Amira Al Asmari, University of Jordan</b>
<b>Kuwait</b>	<b>Amal Al Wadaani, Kuwait Medical Genetics Center</b>
<b>Lebanon</b>	<b>Khalid Yunis, American University of Beirut</b>
<b>Libya</b>	<b>Adel Zeglam, Al Khadra Hospital</b>
<b>Morocco</b>	<b>Abdelaziz Sefiani, Institut National d'Hygiene</b>
<b>Oman</b>	<b>Surender Nath Joshi, SQ University</b>
<b>Palestine</b>	<b>Jumana Odeh, Palestinian Happy Child Center</b>
<b>Qatar</b>	<b>Haitham El-Bashir, Hamad Medical Center</b>
<b>Saudi Arabia</b>	<b>Mohamed Al Dosari, King Faisal Specialist Hospital &amp; Research Centre</b>
<b>Syria</b>	<b>Waddah Orabi</b>

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<b>Tunisia</b>	<b>Ahlem Belhaj, Hôpital Charles Nicolle</b>
<b>UAE</b>	<b>Bushra Al Mulla, Dubai Early Childhood Developmentl Center</b>
<b>Yemen</b>	<b>Ahmed Al-Sherhari, National Committee on Genetic Diseases</b>
<b>12:30</b>	<b>Lunch</b>
<b>Session 3</b>	<b>Developing Partnerships with Patient, Parent and Community Groups</b>
<b>Organizers</b>	<b>Ali El Mgadmi, Tripoli Medical Center (Libya); Gerard Loeber (ISNS); Natasha Bonhomme, Genetic Alliance (USA); James Hanson (USA)</b>
	<b>Chairs : Ali Mgadmi, (Libya) and Gerard Loeber (ISNS)</b>
<b>13:30</b>	<b>Stages and elements in development of NBS programs: relationships to parental efforts and advocacy opportunities James Hanson (USA)</b>
<b>13:40</b>	<b>The diagnostic odyssey George Jesien (USA)</b>
<b>13:50</b>	<b>Prevention and treatment research opportunities at the community level Andy Shih (USA)</b>
<b>14:00</b>	<b>The role of family and consumer advocacy in support of NBS and developmental disorders Natasha Bonhomme (USA), Regional Representatives</b>
<b>14:30</b>	<b>Break</b>
<b>14:50</b>	<b>Workshops: challenges to implementing early screening of genetic and developmental disorders</b>
	<b>Chairs : Andy Shih (USA) and Haitham El-Bashir (Qatar)</b>
	<b>Workshop 1 Moderators (measurement instruments) Judy Reilly, Randa Kamal Raouf</b>
	<b>Workshop 2 Moderators</b>

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	<b>Workshop 3 Moderators</b>
<b>17:00</b>	<b>Break</b>
<b>17:20</b>	<b>Workshop Summary and Discussion</b>
<b>18:30</b>	<b>Adjourn</b>
<b>Day 3</b>	<b>April 29</b>
<b>Session 4</b>	<b>Developing Infrastructure for Services and Translational Research: From Bench to Bedside</b>
	<b>Organizers: Hatem El Shanti (Qatar); Habiba Chaabouni (Tunisia); James Hanson (USA); Khalid Yunis, American University of Beirut (Lebanon)</b>
	<b>Chairs: Hatem El Shanti and</b>
<b>8:00</b>	<b>Research and infrastructure support for NBS and developmental disorders James Hanson (USA)</b>
<b>8:10</b>	<b>Considerations in developing interoperable informatics systems Clement McDonald, National Library of Medicine, NIH (USA)</b>
<b>8:30</b>	<b>Linking NBS to Electronic Health Records Kari Klossner, Perkin Elmer (Finland)</b>
<b>9:00</b>	<b>Surveillance of rare conditions and developmental disabilities Segolene Ayme, Orphanet, INSERM (France)Ibrahim Al Janahi, HMC (Qatar)</b>
<b>9:10</b>	<b>m-Health: intersection of health and communication/ IT technologies Mitul Shah, WestWireless Health Institute (USA)</b>
<b>9:30</b>	<b>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)</b>

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<b>10:15</b>	<p><b>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)</b></p> <p><b>Autism Speaks Global Autism Public Health Initiative, Andy Shih (USA) Fogarty International Center Programs, Judy Levin (USA) INSERM-MENA cooperation, Gerard Bréart, INSERM (France)</b></p>
<b>11:00</b>	<b>Break and Workshops</b>
<b>11:15</b>	<p><b>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</b></p>
<b>13:00</b>	<b>Lunch</b>
<b>14:00</b>	<b>Reports from Workshops on Research and Infrastructure, Education and Training</b>
<b>15:00</b>	<b>Conference Closing</b>