

Final programme February 20

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Sunday March 8

1500	Registration open	
1700 - 1730	Opening Ceremony	
1730 - 1830	Session 1: Welcome	Chair: Victor Skrinska
1730 - 1800	O1. History of Newborn Screening; Newborn Screening and Public Health Infrastructure Initiatives	Jim Bonham (UK)
1800 - 1830	O2. Newborn screening in Cyprus O3. Selective Screening for Inborn Errors of Metabolism in Cyprus	Argyris Argyriou (Cyprus) Anthi Drousiotou (Cyprus)
1830 - 2000	Welcome reception	

Monday March 9

0800	Registration Open	
0900 - 1100	Session 2: Country reports	Chairs: Gerard Loeber/Tawfeq Ben Omran
0900 - 1100	O4. The Status of Newborn Screening Programs In The Countries of MENA Region, Report From Country Delegates Bahrain Egypt Iran Iraq Jordan Kuwait Lebanon Libya	tbc Heba Khafagy Farzad Kobarfard Roula Hamid Safwan Dababneh Amir Abdelazim Issam Khneisser tbc

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	Morocco Oman Palestine Authority Pakistan Qatar- Saudi Arabia UAE Yemen	Layachi Chabraoui Fathiya Al Murshedi Samir Khatib Hafsa Majid Victor Skrinska Ahmed Alfares Mohamed Salahedin Riad Ahmad Alshehari
1100 - 1130	Coffee (exact time depending on the number of country reports)	
1130 - 1230	Session 3: Challenges	Chairs: Issam Khneisser/Heba Khafagy
1130 - 1200	O5. Experiences, Hopes, Despair and Challenges to Implement Newborn Screening Programs In The Countries of the MENA Region.	Layachi Chabraoui (Morocco)
1200 – 1230	O6. The impact of consanguinity on the incidence of inherited metabolic disorders: challenges and opportunities.	Tawfeg Ben Omran (Qatar)
1230 - 1345	Lunch plus PerkinElmer-sponsored symposium, see invitation	
1345 - 1555	Session 4: Various conditions	Chairs: Victor Skrinska/Enzo Ranieri
1345 – 1405	O7. Congenital hypothyroidism screening	Farzad Kobarfard (Iran)
1405 – 1420	O8. Neonatal screening for congenital hypothyroidism: Experience from Morocco	Asmae Tantane (Morocco)
1420 - 1435	O9. Determining reference ranges for tT4 in dried blood samples of newborn screenings	Ralph Fingerhut (Switzerland)
1435 - 1455	O10. Congenital Adrenal Hyperplasia Screening	Toni Torresani (Switzerland)
1455 - 1515	O11. Cystic Fibrosis Screening	Ralph Fingerhut (Switzerland)
1515 – 1535	O12. Severe Combined Immunodeficiency Screening	Ghassan Dbaibo (Lebanon)

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1535 - 1555	O13. Newborn screening for SCID in the Polish-German trans-border area: experiences from the first year of collaboration.	Maria Gizewska (Poland)
1555 - 1625	Coffee, tea	
1625 - 1805	Session 5: Metabolic conditions	Chairs: Anthi Drousiotou/Issam Khneisser
1625 - 1645	O14. Aminoacidopathies, fatty acids and organic acid oxidation disorders screening using MS/MS, updates and new developments	Issam Khneisser (Lebanon)
1645 - 1655	O15. Phenylketonuria screening in the Republic of Kazakhstan	Alexandra Murtazaliyeva (Kazakhstan)
1655 - 1705	O16. Expansion of the Dutch Newborn Screening panel: the first months of screening for CPT-I, PA, MMA	Rose Maase (Netherlands)
1705 - 1725	O17. Lysosomal storage disease screening, update and latest	Rola Mitri (Qatar)
1725 - 1735	O18. Targeted-Population Screening for Mucopolysaccharidoses. Paving the way to newborn screening	Zoltan Lukacs (Germany)
1735 - 1745	O19. Screening and diagnosis of Lysosomal Storage Disorders using a two-tier screening strategy of enzyme activity and metabolites by tandem mass spectrometry (MS/MS)	Enzo Ranieri (Australia)
1745 - 1805	O20. Advances in treatment of Genetic Disorders: Lessons learned from Neuromuscular and Lysosomal Disorders	Tawfeg Ben Omran (Qatar)
Tuesday March 10		
0800	Registration open	
0900 - 1000	Session 6: Haemoglobinopathies and related conditions	Chairs: Kate Hall/Amal Saadallah
0900 - 0920	O21. Haemoglobinopathies Screening in MENA region	Mohamed Salahedin Riad (UAE)
0920 - 0940	O22. Haemoglobinopathies Methodology	Stuart Moat (UK)
0940 - 1000	O23. G6PD Screening	Issam Khneisser (Lebanon)
1000 - 1030	Coffee/Tea Break	

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1030 - 1150	Session 7: Follow-up and treatment	Chairs: Jim Bonham/Rodney Howell
1030 - 1050	O24. Follow-up on a positive screening result, practical issues	Victor Skrinska (Qatar)
1050 - 1110	O25. Follow-up on a positive screening result, clinical issues	Amal Saadallah (Saudi Arabia)
1110 - 1130	O26. Ethical Considerations in Newborn Screening	Ali Al Odaib (Saudi Arabia)
1130 – 1145	O27. The importance of cooperation between the public and private sectors in developing countries in the field of newborn screening	George Sahyoun (Jordan)
1145 - 1200	O37. Routine Newborn Screening of Newborns. Why can't ISNS & other International organisations make it mandatory in Asia? Newborn Screening: Why is Asia lagging behind & what can they do?	Kishore Kumar (India)
1200 - 1245	Meeting of the ISNS-MENA members and information on ISNS	Chair: Jim Bonham
1245 - 1400	Lunch plus Bio-Rad-sponsored symposium	
1400 - 1800	Session 8: Workshops	Chairs: Jim Bonham, Gerard Loeber
1400 - 1530 (Parallel Session)	<p>Group 1: Participants from countries with existing National NBS Programme</p> <ul style="list-style-type: none"> • Choosing conditions for inclusion in a newborn blood spot program • Managing a co-ordinated programme by the use of links to birth registers, KPIs and following up incidents. • The need to ensure blood spot quality • The practice of EQA and IQ • The importance of second tier testing • The benefit of gaining outcomes to help assess the effectiveness of screening • Maintaining confidentiality and public confidence in screening 	Moderators: Jim Bonham, Marleen Jansen, Christine Cavanagh, Stuart Moat, Kostas Petritis, Enzo Ranieri, Rose Maase, Rachel Knowles
	<p>Group 2: Participants from countries without National NBS programme</p> <ul style="list-style-type: none"> • NBS: A Primary Health Care Program • How to start? Forming a multidisciplinary group • Registering birth – old ways and new ways • Involving/engaging parents with NBS • Taking samples and transport to laboratory • Paying for programme 	Moderators: Gerard Loeber, Kate Hall, Ghassan Abdoh, Victor Skrinska, Maria Gizewska

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	<ul style="list-style-type: none"> • Deciding which conditions to include • Laboratory Infrastructure, Requirements and Instrumentations • Quality Considerations • Laboratory Accreditation • Confirmatory diagnostics • Involving/engaging Clinical professionals • Information to parents • Nutritional Interventions • Involvement of ISNS 	
1530 - 1600	Coffee, tea	
1600 - 1730 (Parallel Session)	<p>Group 1: Participants from those countries with National NBS Programme (continued)</p> <p>Group 2: Participants from those countries with no National NBS programme (continued)</p>	
1730 - 1800	Plenary discussion on results of the workshops	Chairs: Jim Bonham, Gerard Loeber
1900 - 2200	Conference Dinner	
Wednesday March 11		
0800	Registration open	
0900 - 1000	Session 9: Quality issues	Chairs: Rose Maase/Jamal Golbahar
0900 - 0920	O28. Quality assurance and quality control program for first tier and second tier testing.	Kostas Petritis (USA)
0920 - 0940	O29. Advances in Molecular technology for the follow up and second tier testing.	Vasiliki Chini (Qatar)
0940 - 1000	O30. Storage and use of residual newborn screening specimens	Rachel Knowles (UK)

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1000 - 1030	Coffee Break	
1030 - 1150	Session 10: Miscellaneous	Chairs: Gerard Loeber/Rodney Howell
1030 – 1040	O32. High incidence of congenital hypothyroidism in Pakistan calls for action: need of a national newborn screening program	Hafsa Majid (Pakistan)
1040 – 1055	O33. A comprehensive evaluation of the Hellenic newborn screening: new people, new technologies, new possibilities	Dimitrios Platis (Greece)
1055 – 1115	O34. PKU patients born before the era of population newborn screening: is it still possible to improve their life quality?	Maria Gizewska (Poland)
1115 – 1130	O35. IT infrastructure for screening, diagnosis and long-term follow-up for newborn screening in Sweden	Lene Sörensen (Sweden)
1130 – 1150	O36. The use of 2nd tier blood-spot metabolites by Tandem Mass Spectrometry (MS/MS) to reduce the false positive rate on routine Newborn Screening for Inborn Errors of Metabolism (IEM).	Enzo Ranieri (Australia)
1150 - 1215	General Discussion and Wrap up	Chair: Jim Bonham
1215	Closure	Victor Skrinska

Poster presentations

P1. Combined effect of gestational age and birth weight on metabolites related to inherited metabolic diseases in neonates
Ling Wang, Fang Yi, Chengdu Newgenegle Clinical Laboratory, Clinical department, Chengdu, China, People's Republic

P2. Should genetic markers be nominated for the new expanded NBS panel?
Adel Zeglam, Samira Tarhooni, Tripoli University Hospital, Pediatrics, Tripoli, Libya

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P3. Newborn Screening for G6PD Deficiency and the Mutational Spectrum in Vietnam

Quoc Hai Luyen, Bionet Vietnam, Newborn screening center, Ha Noi, 10000, Vietnam

P4. 14 Years experience in expanding Newborn Screening using MSMS and confirmation positive results in KFSHRC ,Saudi Arabia

Mohamed S Alamoodi, KFSHRC, Genetic, Riyadh, Saudi Arabia

P5. Development of a HILIC-LC-MS analytical method to screen pyridoxine dependent epilepsy from dried blood spot

Sudheer Moorkoth, Elizabeth Mary Mathew, Leslie Lewis, Pragna Rao, Manipal College of Pharmaceutical Sciences, Pharmaceutical Quality Assurance, Manipal, India

P6. An innovative SMA screening method directly from dried blood spots

Charlotte Vandermeulen, Axel Giltay, Liselot Detemmerman, LaCAR MDx, Molecular diagnostic, 4102 Liège, Belgium

P7. Development and validation of a spatially multiplexed digital microfluidics platform to screen for Biotinidase deficiency and galactosemia

Sandeep Kalelkar, Candice Brannen, Jon Washburn, Hari Patel, Anirudh Ullal, Sally Chopra, David Billings, Daniel Mun, Baebies, Newborn Screening, Durham, United States

P8. Determination of multiplex enzyme assay activities in DBS samples using NeoLSD KIT and LC-MS/MS.

Najah Obeidat, Esraa Okour, Jordan university of science and technology, Princess Haya Biotechnology Center, Irbid-Jordan, Jordan

P9. Quantitation of glycosaminoglycans in amniotic fluid by liquid chromatography tandem mass spectrometry: a potential tool for the rapid prenatal identification of MPS in pregnancies at risk

Francyne Kubaski, Rejane G. Kessler, Andryele Z. Machado, Inamara S. Moraes, Fernanda Medeiros, Fernanda Bender, Maira G. Burin, Kristiane Michelin-Tirelli, Dafne D.G. Horovitz, Anelise Barth, Robert W. Mason, Shunji Tomatsu, Roberto Giugliani, UFRGS/HCPA/INGAMEP, PPGBM, Porto Alegre, Brazil

P10. Biochemical and molecular characterization of CTNS mutations in Tunisian patients with cystinosis

Rouaida Gafsi, Latifa Chkioua, Azza Dandana, Wael Bahia, Hela Boudabous, Maroua Nouri Bouzaabia, Maissa Brahim, Neji Tebib, Khelifa Limem, Salima . Ferchichi, University of Monastir, Faculty of pharmacy, 5000 Monastir, Tunisia

P11. Profile of Mucopolysaccharidoses diagnosed at the Biochemistry laboratory in Farhat Hached Hospital – Sousse Tunisia

Wael Bahia, Azza Dandana, Zina Chamekh, Hela Boudabous, Maroua Nouri Bouzaabia, Maissa Brahim, Neji Tebib, Khelifa Limem, Salima Ferchichi, Farhat HACHED Hospital, Laboratory of Clinical Biochemistry, Sousse, Tunisia

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P12. The Metachromatic Leucodystrophy: Experience of laboratory of clinical Biochemistry In Farhat HACHED Hospital

Wael Bahia, Azza Dandana, Zina Chamekh, Hela Boudabous, Maroua Nouiri Bouzaabia, Maissa Brahim, Neji Tebib, Khelifa Limem, Salima Ferchichi, Farhat HACHED Hospital, Laboratory of Clinical Biochemistry, Sousse, Tunisia

P13. Clinical, biological and molecular profiles of Fabry disease in Tunisian families: A Case Report

Latifa Chkioua, Chaima Saheli, Hela Boudabous, Lamia Jaafoura, Salima Ferchichi, Neji Tebib, Sandrine Laradi, University of Monastir, Faculty of pharmacy, 5000 Monastir, Tunisia

P14. Gaucher disease in a Tunisian family

Azza Dandana, Wael Bahia, Zina Chamekh, Hela Boudabous, Maissa Brahim, Neji Tebib, Khelifa Limem, Salima Ferchichi, Farhat HACHED Hospital, Laboratory of Clinical Biochemistry, Sousse, Tunisia

P15. N370S (c.1226 A>G) mutation among Tunisian patients with Gaucher Disease

Azza Dandana, Wael Bahia¹, Zina Chamekh, Hela Boudabous, Maroua Nouiri Bouzaabia, Maissa Brahim, Neji Tebib, Khelifa Limem, Salima Ferchichi, Farhat HACHED Hospital, Laboratory of Clinical Biochemistry, Sousse, Tunisia