Newborn Screening in the MENA Region

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MENA region
MENA Demographic

- Region of the Middle East and North Africa (MENA) consists of more than twenty countries
- Population of the region is about 400 million,
- An estimated 10 million newborns per year
- Significant diversity between the countries in relation to population size, per capita income, health system, insurance coverage and differences in the stages of epidemiological transition.
- High rates of consanguinity and first cousin marriages, genetic disorders are relatively common.
- In the past decade, reducing mortality rate lead to growing recognition in the MENA region of the value of NBS
MENA demographic

- NBS role in preventing or ameliorating:
  - Intellectual and physical disability
  - Neurologic damage
  - Death in conditions amenable to screening, particularly in those conditions in which treatment is simple and relatively inexpensive.
Efforts in the region
Efforts

• United Nations family as World Health organization (WHO)
• Technical cooperation (TC) programme of International Atomic Energy Agency (IAEA)
• Japan international cooperation agency (JICA)
• Centers for Disease Control and Prevention (CDC)
• National Institute of Health (NIH), International Society for Neonatal Screening (ISNS), and others, aimed to Strengthen NBS in 2006, to partnerships for sustainable NBS infrastructure and research opportunities in 2008 and 2010.
Newborn Screening Grows Up

It started with one test, in one state. But technological advancements, increased awareness, and federal action in recent years have spurred sharp growth in the average number of conditions states include in their newborn screening programs.
To screen or Not to screen
(Wilson & Jungner criteria)

- Knowledge of the disorder and its natural history
- Availability of, access to treatment
- “simple” test
- Follow up of “screen positive” newborns for confirmatory testing, introduction and monitoring of treatment
- The principles as outlined earlier were acceptable to the consumer — the “target population”.

MENA ISNS participation in 2016

- Increasing number of participants from 2014 (20 members) to 31 members in 2016.
Material and Methods

Assessing NBS data infrastructure was based on recent papers and personal contacts with members of:

- ISNS MENA region
- Middle East Metabolic Group (MEMG).

We will present the results for screening overview for:

At least one condition (generally congenital hypothyroidism CH)

Other conditions (using MS/MS)
CH Screening
National programs

• Many countries have a wide coverage exceeding 90 percent. A national program for at least one disease:
  • Bahrain,
  • Egypt,
  • Israel, Palestinian Territo (Occupied),
  • Qatar,
  • Saudi Arabia
  • United Arab Emirates
  • Jordan
  • Bahrain (for sickle cells)
Soon National program

• Other countries have completed pilot studies for at least one condition and anticipate expansion to national programmes. These countries include:
  • Lebanon
  • Oman (the treated metabolic cases did a song to the Prince in order to proceed forward)
MS/MS screening
Quality Assurance

Improving and Assuring Newborn Screening Laboratory Quality Worldwide: 30-Year Experience at the Centers for Disease Control and Prevention

Víctor R. De Jesús, PhD, Joanne V. Mei, PhD, Carol J. Bell, BS, MT (ASCP), W. Harry Hannon, PhD


External quality assurance programme for newborn screening of glucose-6-phosphate dehydrogenase deficiency.

Chiang SH¹, Fan ML, Hsiao KJ.
NSQAP program
NSQAP 2013 participants (courtesy of CDC)
Saudi Arabia

- Started three decades ago (Mohamad RASHED big role)
- MS/MS developing methods
- National TSH program
- Regional leaders
- Limited panel of MSMS
- Research done of G6PD & Sickle cells screening
- More than 20 publication related NBS on DBS
- Many publications of other type of screening. Like hearing....
LSD NBS in SAUDI ARABIA started in 2007-2008


Qatar

- Supported with heilderberg.
- Homocystinuria screening with expanded panel on MSMS
- Still collaborating with Germany: platforms and know how acquired


Lebanon

- Started in late 1995 by private efforts community based universities
- 20,000 newborns yearly were screened in 2006 at time of expansion to MSMS
- Currently 40,000 yearly benefit from screening in 2016.
Lebanon 2007

**International support**

- **Hamburg Metabolic Laboratory**
  (Sample analysis & training)

- CDC training & QA/QC (NSQAP)

- Region4genetics
  (Mayo Clinic training & sample exchange program)

• 2008: ISNS Dussault medal award
الكشف المبكر عند الولادة منذ 1995

من أجل صحة جيدة لأطفال لبنان

من 18 عامًا، من مجمل 25000 طفل خضعوا لهذا الكشف المبكر، 1600 حالة شُخصت وهم جميعًا يتمتعون بصحة جيدة وتنوعًا حياة أفضل.

إن احتمال إصابة طفلك بإحدى هذه العوامل هو احتمال ضئيل جداً، إلا أنه لا يمكن التنبؤ لوجود هذه العوامل عند الولادة أو تجنب حصولها عند الطفل، لأنها عوامل خلقية أو وراثية، ولذلك تجري التحاليل لجميع الأطفال عند الولادة. إن هذه الكشف المبكر عند الولادة، بواسطة إجراء التحاليل الخصية المناسبة، "Test de Guthrie" قد بدأ العمل به منذ أكثر من خمسين عامًا في معظم بلدان العالم.

إذا أردتم الحصول على المزيد من الإيضاحات حول أهمية إجراء هذه التحاليل، استشيروا طبيب أطفالكم.
maktadır

الكشف المبكر والعلاج عند الولادة لبعض العاهات، يقي من التخلف العقلي أو الجسدي، من خلال الدماء، ومن الموت المبكر إن التحليل المحتوي للمحمية صغييرة من دم طفلكم يمكن من إعلام طبيبك، وإفادتك بالسرعة اللازمة عن الوضع الصحي غير الظاهر لطفلكم، في حال إصابة المولود الجديد بإحدى العاهات الثلاثية والعشرون التالية على الأقل:

1 - نقص هورمون الغدة الدرقية

2 - نقص G6PD

3 - زيادة سكر الحليب

4 - مشاكل الحوامض الأممية (8 أمراض)

مركز الكشف المبكر
كلية الطب - جامعة القديس يوسف
هاتف: 02163824170 - 02163803141
متشفي 2007 - 1 محرم 1428
Lebanon 2010

2000 samples
Damasus
Beirut
Baghdad
Tripoli

121 cases
IMD

12 MMA, 5 PA
4 ChC def.
1 BKT
4 4VA, 3
Blotinase.
1 GAL I 3 MCC

14 PKU, 3 HPA
9 M3UJ
20 tyr-1
1 tyr-II

28 CAD
2 VLCAD
9 MCAD

10 urea cycle
defect
(ASA & CII)
10 HCY, 2
MAT III
2 NKHG

5 CPT-I
1 CPT-II
Lebanon 2014

- Support to other pilot programs and services to: Iraq, Oman, Yemen, Libya, Tunisia and Morocco (this latter supported by Orphan)
Lebanon 2016

• We are providing MSMS screening 2nd opinion/diagnosis to centers in:
  – Oman
  – Morroco
  – Lybia (two centers)
  – Tunisia
  – Vietnam
  – Iraq
  – Egypt
Prevalence of G6PD deficiency and knowledge of diagnosis in a sample of previously unscreened Lebanese males: clinical implications

Issam Khneisser, Salim M Adib, Jacques Loiselet and André Mégarbané

Cost-benefit analysis of G6PD screening in Lebanese newborn males.

Khneisser I1, Adib SM, Loiselet J, Megarbane A.
Sickle cells screening experiences

• UAE has nationalized NBS screening of sickle-cell diseases.
• Bahrain started in 2007
• Saudi had pilot studies
Challenges and opportunities

- A comprehensive NBS programme begins with the test itself and with its reliability. Laboratories, pediatricians and parents must be confident that the test results are accurate and that disorders are not missed.

- Additionally, NBS is not only a test but also a comprehensive system of education, screening, follow-up, diagnosis, treatment or management and evaluation that must be institutionalized and sustained within public health systems.
challenges

• Even with current **man-made calamities** and key challenges in the area, regional co-operation in training and research among countries could occur through sharing expertise, information and other resources. Parents, pediatric health-care providers and policy makers should be educated about available NBS services in a nation.

• Cost-effective NBS studies

• Every newborn in this region deserves access to NBS, diagnosis, treatment and the best quality of life.
New challenges

• More expansion in use of MS/MS technology implicate finding of cases that have no cure and incorporation of molecular testing.
• To limit storage and research of collected samples and tailoring parental permission.
• Additional implications for public health and policy.
2016 BUDGET CUT

• Saudi arabia: Newborn screening budget cut by 25%
• Iraq: pilot newborn screening in baghadad and karbala stopped after three of leasing contrat.
Conclusion

• No doubts improvement had been made since:
  - Marrakech meeting 2006
  - Saadallah et al. 2007
• Reported in Terrell et al in 2015
• But this is only a milestone towards full NBS coverage for all babies in the region
Perspectives challenges 4th ISNS-MENA?

• The NIH/NICHD had the major role both in finance and efforts in the previous meetings of 2006, 2008.

• In 2010 the funding was provided by Supreme Council of Health, Qatar.

• With the limitation in resources due to the worldwide macro economic status and due to the political instability in the region, the ongoing challenge is to secure sponsorship both in finance and in planning.
acknowledgment

• Gerard Loebor,

Euroscreening, Paris 2005

• Amal Saadallah & Brad Therrell