Report of attendance at the conference

“Strengthening Newborn Screening in the Middle East and North Africa”

13th-15th November 2006

Attended by:
Dr. Jim Bonham
Member of ERNDIM Board and Representing EUGT
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The meeting was extremely well attended with more than 130 delegates attending from 35 countries (see enclosure A).

Day 1

The morning of the first day included useful presentations outlining the cultural and religious context common to genetic screening in Muslim countries. The afternoon was occupied with country reports illustrating the current screening activities in the Arab countries represented.

Day 2

The day began with reports of the current status of screening in Europe and the USA and continued with a review of the registers, biobanks and the newborn screening technologies available.

In the afternoon quality assurance aspects were considered and a description of some model programmes in operation in North Africa and the Eastern Mediterranean were considered.

Day 3

In the morning, financial and funding aspects were considered drawing upon the experience in both developed and developing countries.

The discussion then moved to funding and facilitating research in which there was an opportunity to present the potential contribution from ERNDIM and links with the Eurogentest project (see enclosure B).

The afternoon concentrated on training opportunities for all members of the multidisciplinary teams involved in screening

The culmination of the meeting was a clear declaration of intent to develop screening within the North African/Eastern European Mediterranean area (see enclosure C). Further meeting will be planned to develop this network.

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Research Collaboration & Research Training in Europe

Dr J R Bonham, UK

Topics to be covered

- Introduce some of the Societies involved
- What do they provide?
- Information resources
- Potential for partnership

Organisations involved in Europe

- **ERNDIM – www.erndim.unibas.ch**
  Largely works in EQA, 250 participating labs mainly in the field of IEM's with some relevance for screening eg phenylalanine.
  Organises schemes, education and standard setting.
- **Eurogentest – www.eurogentest.org**
  Standard setting and education. EU funded to agree standards of practice and quality across the EU 25. Broad definition of genetics, molecular genetics, cytogenetics and biochemical genetics, hence the screening implications

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Organisations involved in Europe

- **International Society for Neonatal Screening – Europe – www.isns-neoscreening.org**
  The society has the objective of promoting the carrying out of appropriate screening for foetal, neonatal and infant sicknesses and disorders, world-wide.
  a. developing, coordinating and maintaining practice and quality standards;
  b. carrying out or commissioning scientific research and the enlargement of scientific knowledge concerning neonatal screening by means of meetings, symposia, discussions, reports and publications;
  c. contributing to development and teaching;
  d. harmonizing screening programs, methods and protocols.

National Societies

- DGNG, Germany – www.screening-dgns.de
- AFDPH, France – www.afdphe.assoc.fr
- SEQC, Spain – www.seqc.es/semc
- UKNSLN, UK – www.newbornscreening.org
- Portugal – www.diagnosticoprecoce.org

Related Societies

- SSIEM - www.ssiem.org
  - IMD's but a lot of screening emphasis
- MetBioNet - www.metbio.net
  - A National IMD/Screening alliance
- Other National IMD Societies eg BIMDG

Regulatory bodies and agencies

- UK newborn Screening Program centre - www.newbornscreening-bloodspot.org.uk
- UK NEQAS - www.ukneqas.org.uk
- Clinical Pathology Accreditation - www.cpa-uk.co.uk

How does it work in practice?

- Most societies promote and organise meetings to discuss scientific issues and present research findings and discuss audit findings
- Overarching regulation is provided by country law guided by International standards eg Eurogentest and accreditation eg CPA informed by EQA (NEQAS,CDC,ERNDIM, audit data etc)

Where can we go from here?

- Access to information – free
- Membership of EQA schemes – reduced fees
- Exchange visits
- Partnership support
- Joint applications for research

Enclosure C

Newborn Screening in the
Middle East
and North Africa

Marrakech Declaration
15-11-2006

The international community has achieved a point as which important results in infant survival and the reduction of neonatal morality. In view of the United Nation's Convention on the Rights of the Child (1989) governments must now focus increased attention on assuring our children's optimal development and to put in place policies to ensure that tomorrow's adults are as free as possible from disability that will limit their achieving their potential. This is facilitated by early screening for congenital genetic disorders that are responsible for major disability; if not treated early, the costs of treatment of preventable disability are prohibitive for the society and the lives of children and their families are tragically and unnecessarily limited. Systematic newborn screening for these genetic disorders is thus a necessity for public health programs based on the means available.

Participants of the first meeting of "Strengthening Newborn Screening in the Middle East and North Africa" recognize that our children's health is a high priority for our countries. Newborn screening is an important tool in the prevention of disease and disability in our children and thus should be a key part of a comprehensive public health system in all of our countries. Each country should prioritize the panel of genetic disorders and system of care that is appropriate to their situation.

Based on the meeting's deliberations, the following recommendations have received high priority:

- Encourage all countries to develop policies and provide necessary support to establish a systematic national newborn screening program within the context of a global national policy for children's health that will provide access to all newborn infants in these countries and provide follow-up services. Such services should integrate both public and private health care delivery systems.
- All countries in the region should screen for at least one condition develop a national model program that takes into account all aspect for post-testing care.
- Establish national research priorities around newborn screening, through culturally relevant and ethical strategies.
- Reduce disability and death by assuring that the children identified as having screening positive for a genetic disorder have the opportunity to a good quality of life through access to medical treatment including behavioral, physical therapeutic interventions as well as assistive technology in order to preserve healthy development and improve autonomy and independence.
- Develop population studies to determine the incidence of genetic disorders in the region and consider linking to national databases with standardized measurements. Clearly population genetics data needs to be accumulated country by country as it is anticipated that each country will have unique disorders related to their own population.
- Begin regionalization and cooperation among countries by sharing of expertise, information, and other resources.
- Develop training programs that focus on role-specific activities that build the interdisciplinary teams needed for newborn screening systems of care.
- Stimulate regional research capacity that addresses the specific conditions of priority to the Middle East and North Africa.

In view of all of the above recommendations, the attendees recognize the need for establishment of collaborative, cooperative networking to facilitate the development of a newborn screening system for all nations.

In order to develop such a collaborative network it would be of value to:

- Hold annual meeting assess country advances.
- Develop smaller focused meeting on issues of particular importance (e.g. training).
- Establish structures for increased communication across the region including a regional website and biennial regional meetings.
- Establish an advisory committee to set up an agenda for addressing the recommendations identified above.
- Establish working groups that can implement identified priorities.