Marrakech Declaration

15-11-2006

The international community has achieved important advances in infant survival and the reduction of neonatal mortality. As a consequence, 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 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 will be prohibitive for society and the lives of children and their families will be tragically and unnecessarily limited. Systematic newborn screening for these genetic disorders is, thus, a necessity for public health programs based on the resources 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 and develop a national model program that takes into account all aspects 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 screened 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 genetic 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 meetings to assess country advances
- Develop smaller focused meetings 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.