

# Newborn Screening in Lebanon

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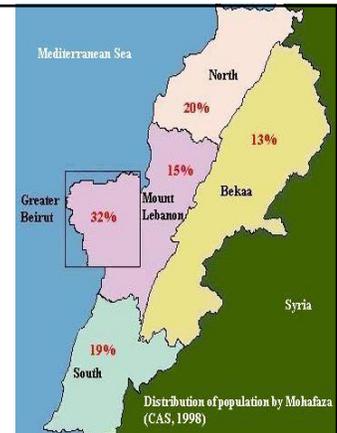


## Population

- Estimated pop: 4 million inhabitants (last census: 1932)
- 74,000 births per year (CAS, 2005)
- Rate of population increase: 1.65% yearly (CAS, 2000)
- Fertility rate: 2.2 (UNICEF, 2003)

## Consanguinity (UNICEF, 2000)

- Overall: 25%
- First-cousin: 15%



## Genetic conditions in Lebanon

### Prevalence: (MOD, 2006)

- Dominant single gene disorders: 7‰ live births
- Recessive single gene disorders: 10.8‰ live births
- Chromosomal abnormalities: 4.2 ‰ live births
- X-linked single gene disorders: 1.3 ‰ live births

### Most common disorders:

- Thalassemia
- G6PD deficiency
- Familial hypercholesterolemia
- Non-syndromic hearing loss
- Familial Mediterranean fever
- Familial hypercholesterolemia
- Mitochondrial Disease



## Genetic conditions in Lebanon

- Infants identified with a genetic condition are usually followed by their individual pediatrician and admitted to various hospitals
- One center specialized in Thalassemia care, one for sickle cell anemia and few others for children with disabilities.



## Genetic conditions in Lebanon

### Resources for newborns identified with genetic condition:

- No significant resources
- Limited help through the Ministry of Health & the Ministry of Social Affairs
- Various NGOs mainly for children with developmental disabilities



## Newborn screening in Lebanon

- In Lebanon: Lack of a national programme for neonatal screening
- Lebanese government / Pediatric Society: Screening for phenylketonuria and hypothyroidism included in the individual infant's health record
- Screening strategies are left to individual practices at the organization and physician levels



## Newborn screening in Lebanon

- AUH: since 1992, screen for CH, G6PD & PKU
- USJ in collaboration with 40 hospitals in Lebanon: since 1996, screen for CH, G6PD, PKU & GALT
- International Atomic Energy Agency (IAEA) project in Lebanon
- Some hospitals screen only for CH
- 60% of hospitals do not screen for any genetic condition



## Ten-years experience of systematic screening at AUBMC & USJ

- 126,190 newborns screened for PKU, TSH and G6PD (January 1996-December 2005)
  - AUBMC: 16,190 newborns
  - USJ with 40 hospitals: 110,000 newborns
- 110,000 newborns screened for Galactosemia



## Ten-years experience of systematic screening at AUBMC & USJ

Results: (N=126,190)

- 6 case of phenylketonuria
- 4 case of hyperphenylalaninemia
- 76 cases of permanent type congenital hypothyroidism, incidence of 63:100,000
- 419 cases of complete G6PD deficiency, incidence of 33:10,000
- 3/110,000 cases of galactosemia



## Newborn screening in Lebanon

- Suggested conditions to be included as a first step in a newborn screening program:
  - Congenital Hypothyroidism
  - G6PD deficiency
  - Congenital hearing loss
  - PKU
  - Classical Galactosemia
  - Sickle cell disease
  - Cystic Fibrosis



## Newborn screening in Lebanon

- Barriers to establishing a NBS program:
  - Financial burden
  - Failure of the MOH to implement nation-wide programs
  - Difficulty in establishing adequate follow-up services
- Needed:
  - Government issuing and implementing a legislation reinforcing NBS in all institutions
  - Collaboration of MOH with academic institutions



## NBS Needs Assessment

- Questionnaire developed in partnership between the NCPNN and the MOD
- Questionnaire entails two sections to be filled by:
  - Pediatrician / Neonatologist
  - Head of Laboratory
- Pilot testing: 15 NCPNN member hospitals



### Birth defects surveillance in Lebanon

- No national birth defects registry
- Through the National Collaborative Perinatal Neonatal Network (NCPNN)
- The database system established by the NCPNN provides a basis for creating a **hospital-based birth defects registry**



### Birth defects surveillance in Lebanon

- NCPNN:
  - Currently 17 hospitals, urban and rural
  - Average 15,000 admissions/year
  - Rate of malformations 2.9%
- Trained personnel for data collection, auditing and analysis
- Access to medical records
- About 96% of deliveries occur in hospitals
- Continuous growth of the network will insure a more complete national coverage and a better representation of the Lebanese population



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