

INITIATION TO NEWBORN SCREENING : Our experience of sickle disease

M.T Hamlaoui- N Benmouffok

*Pediatric Intensive Care Unit
Algiers*

- ▶ Neo-Natal screening not compulsory in Algeria
- ▶ Care of patients and family based on sickle disease model
- ▶ **INFORMATION +++++**
family shed light on metabolic disorder
- ▶ Several **STEPS** well defined for succes

RECOGNISING OF DISEASE

- ▶ Diagnosis positive : DIFFICULT and COMPLEX
- ▶ FINE CLINICAL TEST (detailed family history)
- ▶ ALL ACTORS :
 - ◆ Initial training validated
 - ◆ Periodic upgrade
- ▶ POLES OF REFERENCE
- ▶ COMPETENCES NETWORKS (guidelines, consensus)
- ▶ PRIVATE and PUBLIC SECTOR

ANNOUNCEMENT

- ▶ Parents, sib-ship, circle of acquaintances
- ▶ **HUMANISME** and **RESPECT** (time, area)
- ▶ Based on **RELIABLE, SUCCESSFULL, IRREFUTABLE biological test++++++**

TREATMENT and CARE

- ▶ **To treat ≠ To prescribe :**
 - ◆ drug lack or not produced
 - ◆ prohibitive prices of drug
 - ▶ **Cost of monitoring and checking biological tests**
 - ▶ **Reduce the costs**
 - Attenuate the unfairness
 - Disponibility of drugs
- } **in the region and country**



ACCOMPANIMENT and SUPPORT

- ▶ **Health Staff (multidisciplinary team) :**
 - recognizing of genetic speciality
 - education + training of primary health workers
 - integration of genetic services into primary health care systems
 - more emphasis or practical guidelines for approach common genetic and metabolic disorders
- ▶ **Associative movements**

▶ **Public authorities :**

education of public (mass media campaigns with respects religious beliefs)
initiation of screening programme and anomalies birth registries
introduction of new technology
framework with another staff
definition of ethical, legal, religious and cultural factors in formulating genetic services(prenatal genetic diagnosis and termination of foetus affected by genetic or congenital disorder)

PREDICTIVE MEDICINE

- ▶ Requires other actors than public health
- ▶ Era of GENOMIC INVENTORY :
 PREDICTIVE MEDICINE
- ▶ Science and Ethics :
 Human well-being with account socio-cultural realities

CONCLUSIONS

- ▶ Born without risk:
first order of contemporary perinatal medicine
right of unborn child
- ▶ Neo-natal screening
protect child from real or potential handicaps
- ▶ Screening programme depends on many factors
political, economic, social, educationnal
- ▶ Benefice of national and regional framework