




## National Neonatal Screening Program in UAE (1995-2005)

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**The United Arab Emirates**

POPULATION : 3,769,080 , BIRTH RATE : 65,000  
CONSANGUINITY RATE : 54% , FIRST - COUSIN : 35%




## Start

The program started by screening for :

- Phenylketonuria in **January 1995**.
- Congenital hypothyroidism in **January 1998**.
- Sickle cell disease in **January 2002 & March 2005**.
- Congenital Adrenal Hyperplasia in **January 2005**.




## Protocol

The following protocol covers all stages of the screening program:

- a. Invitation for screening : NS Form
- b. Specimen collection :  $\geq 72$  hours , Heel Prick
- c. Laboratory analysis : Delfia Fluorometric , HPLC  
UK NEQAS
- d. Follow up of positive cases : Recall System
- e. Management of affected infants
- f. Systematic evaluation of all phases of the program




## Evaluation

- A- Coverage (% uptake).
- B- Timeliness of the screening program indicators (age of sampling , time of delivery of the specimen to Lab , time taken by the lab to produce the result , age of recall and age of treatment initiation) .
- C- Unsatisfactory Specimen Quality.
- D- Indicators for evaluation of validity of test (recall rate, the apparent sensitivity, specificity and positive predictive values).
- E- Follow up results

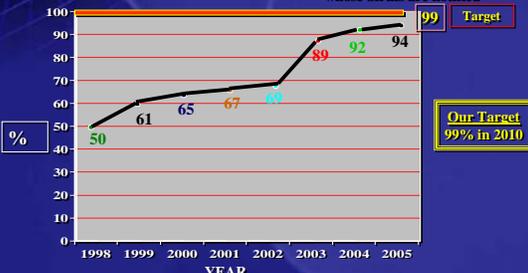
**Compared to the international standards**




## Results

% Uptake (Coverage):

Our results: Target: 99% of liveborn infants whose births are notified



Year	% Uptake
1998	50
1999	61
2000	65
2001	67
2002	69
2003	89
2004	92
2005	94
Target (2010)	99

Fig 1: -% Uptake in UAE during 1998,1999, 2000 , 2001 , 2002 , 2003 , 2004 and 2005 compared to the international standards

### PKU

Categories	Borderline Ph 3-4 mg/dl		Abnormal Ph >4 mg/dl		Total
	No	%	No	%	
	Classical PKU	-	0.0%	26	
Benign Hyperph	8	12.5%	2	7.1%	10
Transient	3	4.7%	-	0.0%	3
False +ve	53	82.8%	-	0.0%	53
Total +ve screening	64	100%	28	100%	92

Table (1): Follow up of positive screened PKU cases (JAN 1995 - DEC 2005)  
(n=385,135)

### Congenital Hypothyroidism

Categories	Border TSH 10-25mU/L		Abnormal TSH >25mU/L		Total
	No	%	No	%	
	Confirmed	11*	11.7	177	
Transient	38	40.4	9	4.6	47
False+ve	40	42.6	4	2	44
Failure to recall	5	5.3	7	3.6	12
Total +ve Screening	94	100%	197	100%	291

\*6 cases were defaulters infants whose ages are more than one month when screened.  
Table (2): Follow up of positive screened Congenital Hypothyroidism cases (JAN 1998 - DEC 2005).  
(n=368,993)

### Sickle Cell Hb

Type	Hb Diseases		Hb Carriers	
	No Identified	Prevalence/ 100	No Identified	Prevalence/ 100
1- Sickle Hb	83*	0.06%	1154	0.9%
2- Non-Sickle Hb : Hb C	5	-	42	0.03%
Hb D	35	0.03%	487	0.38%
Hb E	1	-	10	-
3- Unidentified band	-	-	7**	-

\* Sickle Cell Diseases: include 75 cases confirmed as homozygous SS and 8 cases confirmed as S/B; - thalassemia.  
\*\* 2 diagnosed as Hb O Arab by family study  
Table (3) : Prevalence of confirmed sickle cell diseases, non-sickle hemoglobinopathies and hemoglobinopathy carriers during JAN 2002- DEC 2005  
(n=128,148).

### Congenital Adrenal Hyperplasia

	Term	Preterm	All newborn
Screened population (n)	9,421	569	10,000
Recalls (n)	9	16	25
Recall rate	0.1%	2.8%	0.25%
CAH confirmed (n)	3	1	4
False positive recalls (n)	6	15	21
Positive predictive value	33%	6%	16%

Table (4): Follow up of positive screened Congenital Adrenal Hyperplasia (JAN 2005 - DEC 2005).

### Follow up results :

Since the implementation of the program (from January 1995 until DEC 2005) : **385,135 infants** were screened with relative incidence of :

- **1:1963** for *congenital hypothyroidism* (188 cases were prevented from mental retardation).
- **1:14,812** for *classical PKU* (26 cases were prevented from mental retardation).
- **0.06%** for *sickle cell disease* (83 cases) and **0.9%** for *sickle cell trait* (n=1154) in our program .

\* Pilot study of *congenital adrenal hyperplasia* : 4 cases (3 males & 1 female) with the classic type .

### Future Plans

- \* **Increase the uptake rate** to reach 99 % by the year 2010 .
- \* **Additional of others tests to the program:**
  - Maple syrup urine Disease (MSUD)
  - Galactosemia
  - Tandem Mass Spectrometry
  - Hearing NS

