Experience of a Maternal and Neonatal Network in a Developing Country

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National Collaborative Perinatal Neonatal Network (NCPNN)

Bettering the attribute of medical care in virtue of healthy Mothers and Newborn Infants through a coordinated program of Research and Scholarship

Definition and Objectives

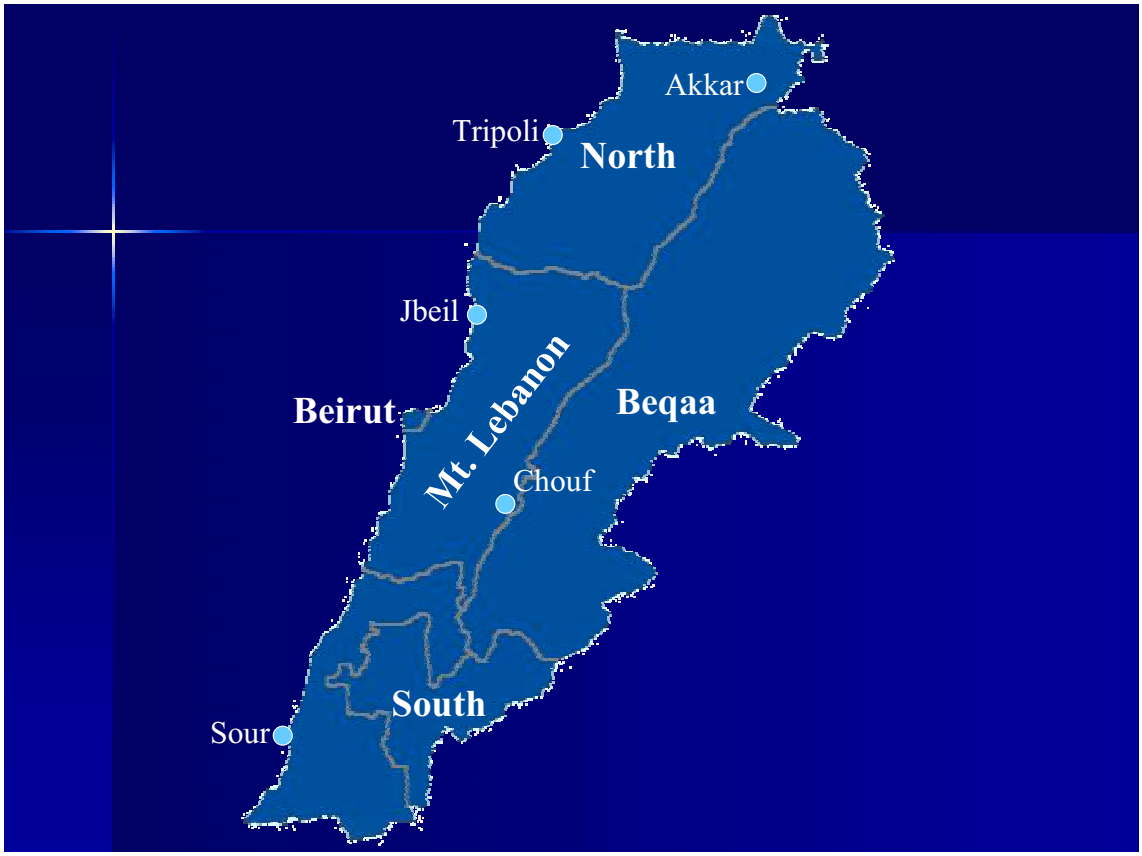
- DEFINITION: Non-profit voluntary collaboration of health professionals whose aim is to assess, improve and refine the proficiency of perinatal and neonatal care through the establishment of an integrated maternal and perinatal neonatal database
- OBJECTIVE: The network constitutes an infrastructure for conducting collaborative, multicenter and multidisciplinary research projects including prospective studies, intervention studies, clinical trials and quality improvement.

Definition and Objectives

- OBJECTIVES : The database project. Continuous prospective data collection of consecutive newborn admissions (and their mothers) to NCPNN participating centers.
- Thirteen Lebanese hospitals, with an estimated 13,000-14,000 deliveries per year.

NCPNN Member Hospitals
(in order of starting date)

1. American University of Beirut, Medical Center
2. Najjar Hospital
3. Middle East Hospital
4. Hotel Dieu de France Hospital
5. Rassoul Aazam Hospital
6. Sahel General Hospital
7. Rizk Hospital
8. St. Georges Hospital
9. Makassed General Hospital
10. Notre- Dame de Secours (Jbeil)
11. Riyak Hospital
12. Bekaa Hospital
13. Nini Hospital (Tripoli)



Physicians Investigators
(in alphabetical order)

Alia Aaraj (RAH)
Mona Alameh (SGH)
Hanane Balataji (Beqaa)
Marie-Claude Faddous (NDS)
Sana Elias (Nini)
Amir El Zahr (Riyak)
Mohammad Itani (Najjar)
Imad Melki (HDF)
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Yolla Nassif (St. Georges)
Hassan Fakhoury (Makassed)
Faysal Shatila (MEH)
Imad Shokr (MEH)
Gerard Wakim (Rizk)
Khalid Yunis (AUBMC)

Data Collectors (in alphabetical order)

1. Rima Abou Ahmad (Bekaa)
2. Salwa Alawiyya (Makassed)
3. Rania Beyrouti (Nini)
4. Samar Bou Deeb (Nini)
5. Jihane Cheaib (RAH)
6. Rima Cheaito (MEH)
7. Fatmeh Farhat (Najjar)
8. Faten Fouaani (Riyak)
9. Mervat Hawwari (Makassed)
10. Siham Hazimeh (MEH)
11. Iman Jammoul (RAH)
12. Ismat karaki (Bekaa)
13. Loubna Zreik (Riyak)

NCPNN Coordinating Center: AUB

- Project director: Khalid A. Yunis, MD
- Co-investigators:
  Mustafa Khogali, MD
  Hala Tamim, PhD
- Project Statistician: Ghina Mumtaz, MSc.
- Project Coordinator: Pascale Nakad, BSc.
- Research Assistants:
  Ban Al Sahhab, BSc
  Bassima Dergham, BSc
  Dania Abi Haydar, BSc.
  May Kassar, BSc.

NCPNN main funding agencies

- World Health Organization (WHO)
- Lebanese National Council for Scientific Research (LNCSR)
- Medical Practice Plan (MPP), AUBMC
- University Research Board (URB), AUB
- Chairman's fund at Pediatrics Department, AUBMC
- Abbott Laboratories
- Nestle
- Pfizer
- Bledina
- Iyamed

Need of a network

- Lebanon: Lack of an adequate health care infrastructure
- Lack of national statistics
- Estimates are based on ad-hoc surveys rather than on a continuous surveillance system
- Need such a network that would provide reliable and continuous data on maternal and child health indicators, the basis for policy making

NCPNN Database Project: Data Management (1)

Data collection & auditing:

- Research Assistants, Nurses and Midwives collect data prospectively at NCPNN centers. Baseline data collection is achieved on all live births, stillbirths and mothers.
- Collected data sent routinely to the NCPNN coordinating center .
- Data auditing and cleaning are performed on a regular basis

NCPNN Database Project: Data Management (2)

Data entry, cleaning & analysis:

- Computerized database at the Coordinating Center.
- Data entry: Research assistants and students.
- Data cleaning & analysis: NCPNN Project Statistician.
- Confidentiality: Each hospital is assigned a specific code.

NCPNN Database Project: Data Reporting

- Annual reports are generated periodically by the NCPNN Coordinating Center.
- The General Report summarizes the combined data from all NCPNN centers over a specified period of time.
- The Individual Reports present data from each NCPNN center, for comparative purposes.

Published & accepted manuscripts by the NCPNN (1)

1. Maternal predictors of small-for-gestational age in uncomplicated births. *Int J Gynaecol Obstet*, 2002; 79(1): 33-5
2. Cesarean route of delivery and hyaline membrane disease: a hospital based case-control study in greater Beirut. *Pediatric & Perinatal Epidemiology*, 2003
3. Consanguinity and apnea of prematurity. *American Journal of Epidemiology* , 2003
4. Risk factors for fetal growth restriction in the absence of maternal complications. *American Journal of Perinatology* , 2003

Published & accepted manuscripts by the NCPNN (2)

5. Impact of maternal age on preterm delivery and low birthweight: a hospital-based collaborative study of nulliparous women in Greater Beirut. *Journal of Perinatology* , 2003
6. Household Crowding Index: a correlate of socioeconomic status, inter pregnancy spacing and birth outcome in an urban setting. *Journal of Epidemiology and Community Health* , 2003
7. Low socioeconomic status and neonatal outcomes in an urban developing population. *Journal of Maternal-Fetal and Neonatal Medicine* , 2003

NCPNN
Some of three years Data

April 1st 1999-March 31st 2002

Results
1. Admission characteristics

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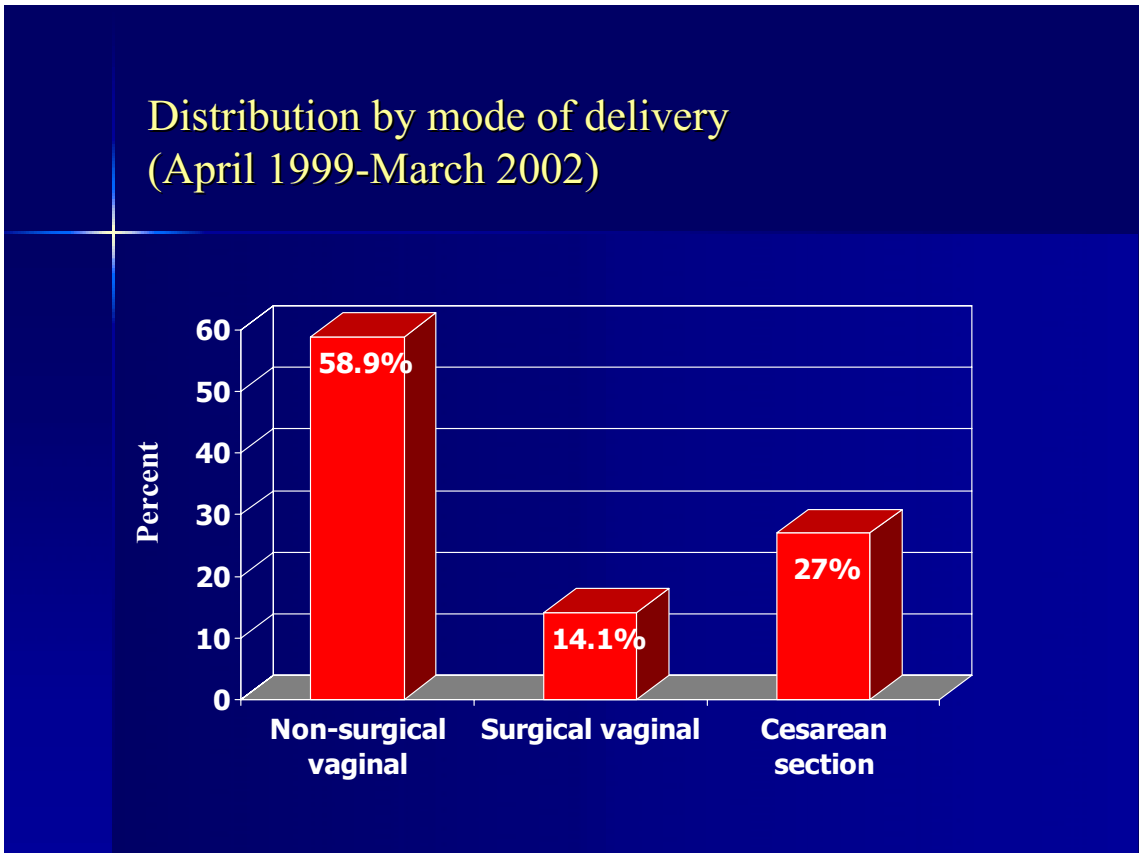
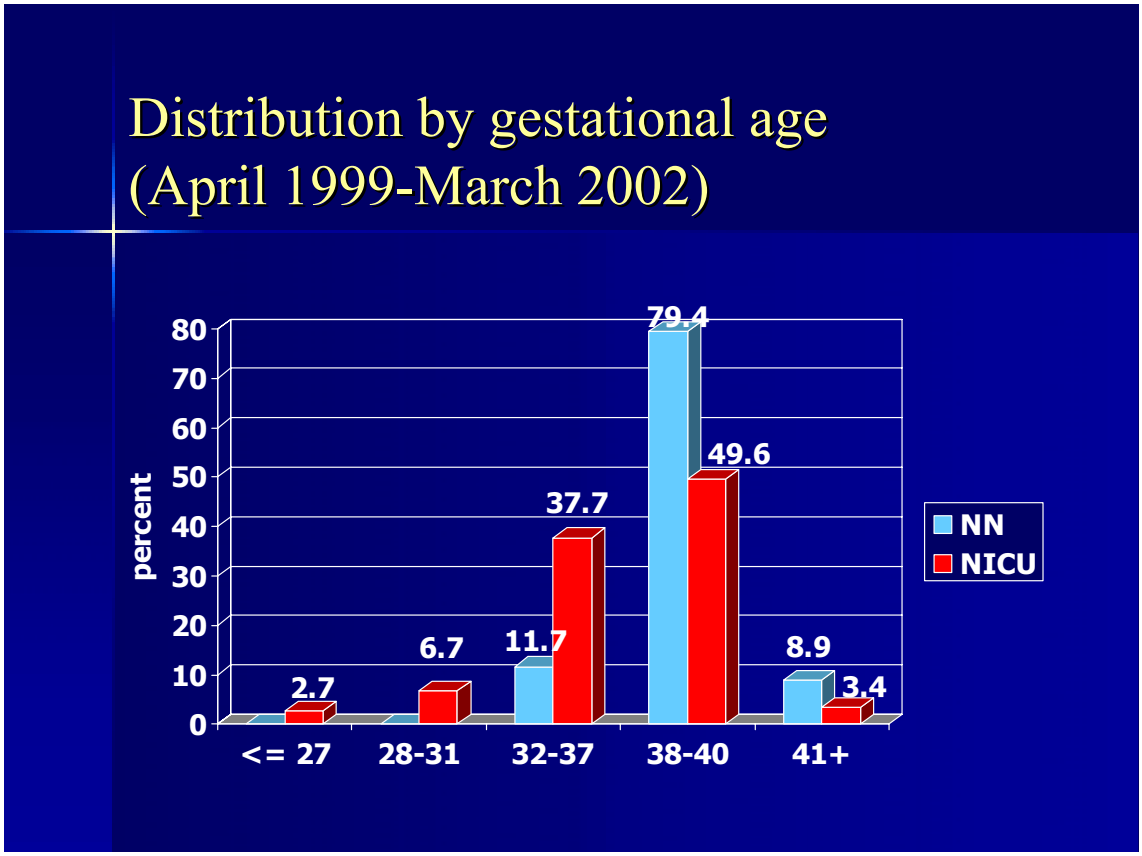
- 28,908 live births admitted to nine NCPNN centers:
  - 24,807 (85.8%) NN
  - 4,101 (14.2%) NICU
- M/F sex ratio = 1.04
- Gestation:
  - 25,020 singleton births
  - 1,288 (4.9%) multiple births (1,115 twins, 157 triplets or more, 16 unknown gestation)

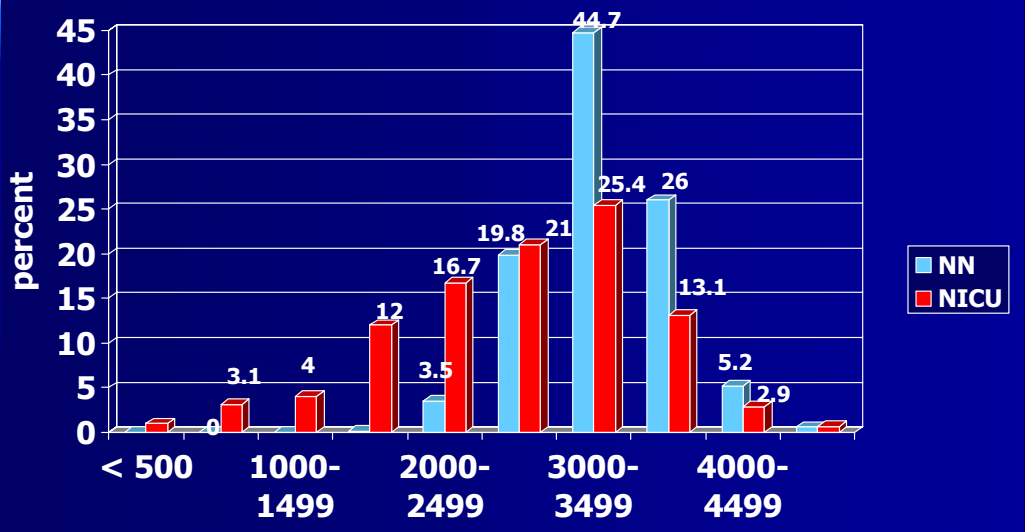
Admission characteristics (cont'd)

- Mean gestational age = 38.7 ± 2.0 weeks
  - NN: 39.1 ± 1.4
  - NICU: 36.7 ± 3.6
- Mean birthweight = 3,197.1 ± 547.9 grams
  - NN: 3,275.7 ± 445.0
  - NICU: 2,706.8 ± 810.9
- Prematurity rate: 8.6%
  - NN: 4.0%
  - NICU: 38.7%
- LBW rate: 8.2%
  - NN: 3.6%
  - NICU: 36.8%


Distribution by mode of delivery
(April 1999-March 2002)
Percent
60
50
40
30
20
10
0
58.9%
14.1%
27%
Non-surgical vaginal
Surgical vaginal
Cesarean section

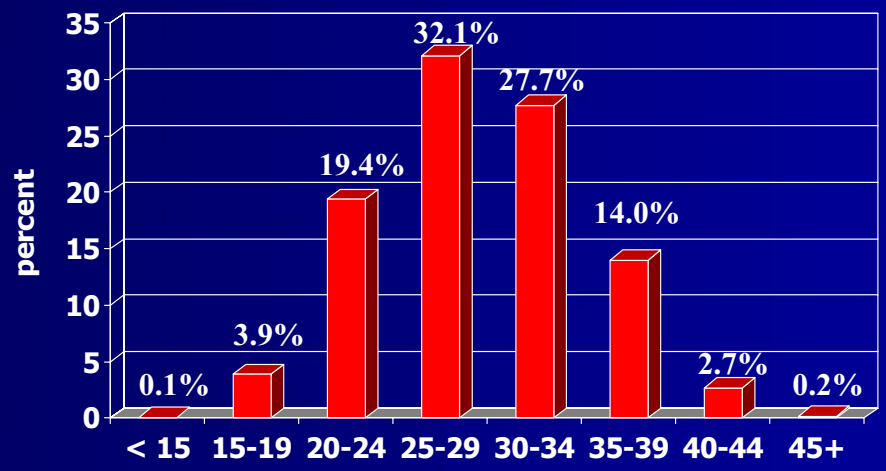

Distribution by gestational age
(April 1999-March 2002)
percent
80
70
60
50
40
30
20
10
0
2.7
6.7
11.7
37.7
79.4
49.6
8.9
3.4
<= 27
28-31
32-37
38-40
41+
NN
NICU

Distribution by birth weight (April 1999-March 2002)



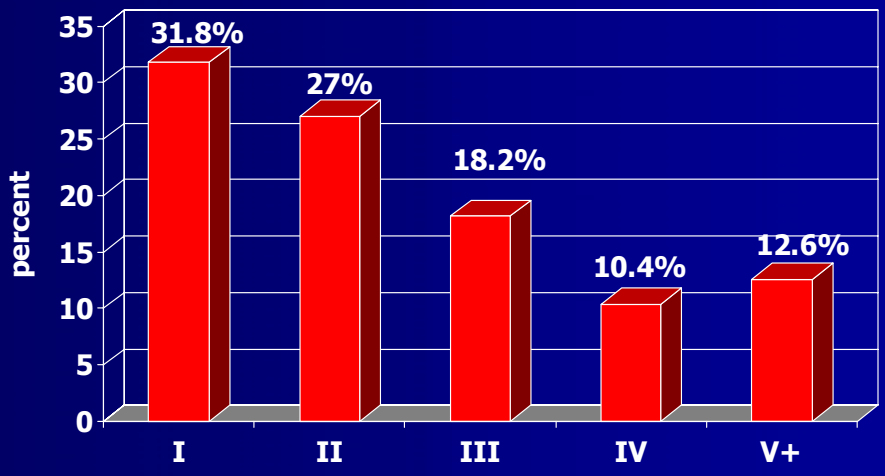
(Results cont'd)
2. Maternal characteristics

Distribution by maternal age (years) (April 99-March 2002)



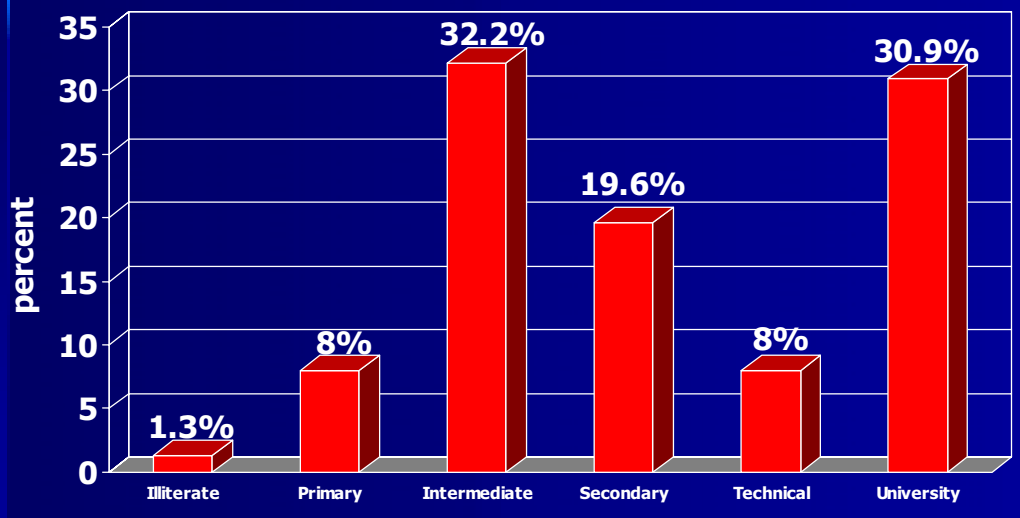
Mean (SD) = 28.84 (5.59) years

Distribution by gravidity (April 1999-March 2002)

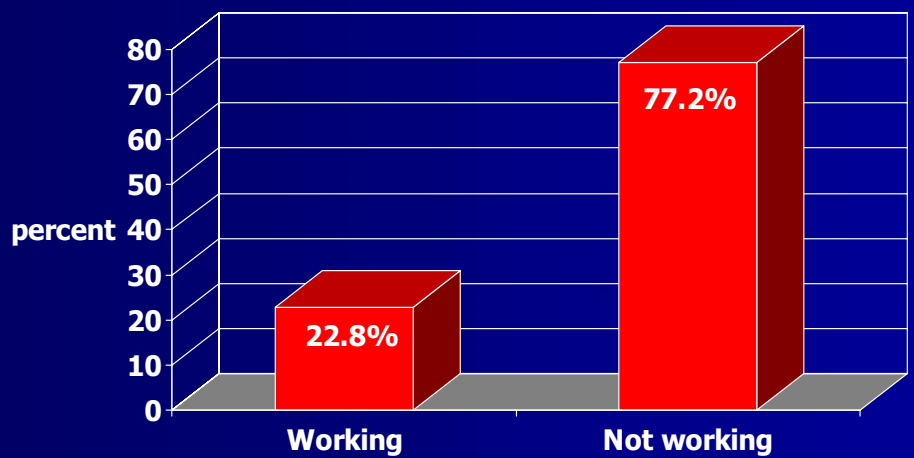


Mean (SD) = 2.59 (1.73)

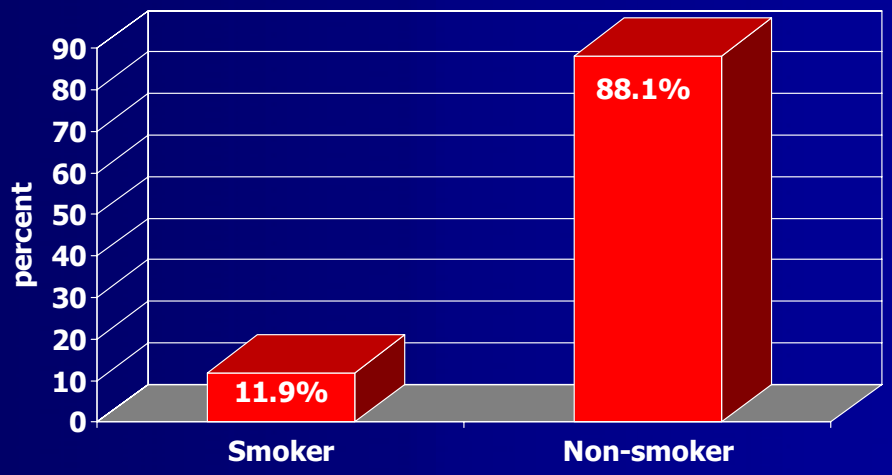
Distribution by maternal education
(April 1999-March 2002)



Distribution by maternal work status
(April 1999-March 2002)



Distribution by cigarette smoking status (April 1999-March 2002)

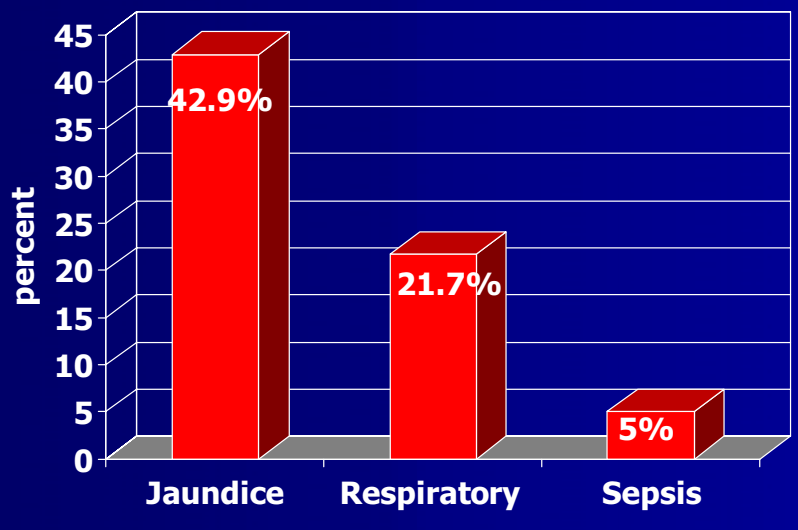


Maternal characteristics (Cont'd)

- Mean number of **prenatal visits** = 9.14 ± 2.58
- Mean number of **U/S** = 4.36 ± 3.16
- **Pregnancy complications**: 3,255 (11.3%) of mothers
- Antenatal **steroids**: 552 (2.1%) of mothers
- Antenatal **antibiotics**: 9,385 (35.3%) of mothers

(Results cont'd)
3. Morbidity and Mortality

NICU major morbidities



Rates of congenital malformations (2000-2001)

- Overall rate = 2.7%
- CHD = 11.5 ‰
- Musculoskeletal = 5.3 ‰
- Cleft lip/palate = 1.2 ‰
- Genitourinary = 5.5 ‰
- Chromosomal abnormalities = 1.9 ‰

Mortality in the NICU

- 281 (6.9 per 100) NICU admissions died before discharge.
  - 53 (18.9%) died within first 24 hours of life
  - 157 (55.9%) died within the first week of life
  - 211 (75.1%) died within the first month of life
- Survival rate increased with increasing BWT and GA.

Current projects

1. The Study on Morbidity and Mortality among Newborn Babies, Infants and Under Five Year Old Children in Greater Beirut
2. Consanguinity and congenital malformations: A study of prevalence and association in the Lebanese population
3. Group B streptococcal colonization of pregnant women and neonates in Lebanon
4. Intervention to reduce C-section rate

Genetic diseases in the Mediterranean area

Prof. Antonio Cao
Istituto di Neurogenetica e Neurofarmacologia – Consiglio Nazionale delle Ricerche - Cagliari

Populations living in the Mediterranean basin have a high incidence of a number of genetic diseases, among which the most common are the α and β thalassemias, G6PD deficiency, Familial Mediterranean Fever and Wilson disease (table). In the Mediterranean populations the high frequency of heterozygous α and β thalassemia and G6PD deficiency is related to the protective effect of these conditions vis a vis Plasmodium-Falciparum Malaria.

Wilson disease in all the world populations including the Mediterranean is very heterogeneous at the molecular level. Each population usually show a set of population-specific-mutation. In all the Mediterranean origin populations as well as in other populations excluding Sardinians, the most common allele in H1069Q; in Sardinians, however, a Sardinian-specific-mutation, the –441 del 15 is very common and account for more than 65% of the mutant alleles (fig. 1).

G6PD deficiency at the molecular level is relatively homogenous because the Mediterranean variant is largely predominant. However, with a lower frequency, G6PD Seattle, G6PD Union and G6PD A^- have been also detected (fig. 2).

As for as α-thalassemia is concerned, the large majority of the mutant alleles results from heterozygosity or homozygosity for the –3.7 single α globin gene deletion. Large deletion, involving both in cis α-globin genes, are rare. This finding explains why in Mediterranean populations fetal hydrops, which result from the lack of all 4α-globin genes, is very uncommon and HbH disease (which is produced by the deletion of three out of four α-globin structural genes) is observed with a relatively high frequency.

In the Mediterranean populations 47 β-thalassemic mutations have been so far detected. The large majority of these mutations are Mediterranean-specific as they occur rarely in other populations (fig. 3). In each Mediterranean-population from 1-6 mutations are prevalent, accounting for the large majority of the defect in the β thalassemic chromosomes. The other mutations are, however, rare. The distribution and incidence of the different mutations varies in the various populations. On the whole, the codon 39 non sense mutations is predominant in the Western part of the Mediterranean basin, whereas the β^+-IVS-1 nt 110 is the most common β thalassemic allele in the Eastern part.

As in other populations, also in the Mediterranean the β-thalassemic alleles are divided into two groups i.e those lacking totally the β-globin gene production (β°- thalassemia) and those associated with a variable residual production of the β chains from the β locus (β^+ Thalassemia). The large majority of these defects are point mutation or deletion of one nucleotide or oligonucleotides. Large deletions, however, are relatively uncommon.

According to the pathogenic mechanism, the β-thalassemia mutations are subdivided in the following categories: gene-deletions, promoter mutations, splicing abnormalities, polyadenylation signal mutations, initiation codon mutations, mutations leading to premature terminations which includes non sense and frameshift mutations, termination codon mutations and mutations resulting in the production of unstable globins (fig. 4).

Homozygosity or compound heterozygosity for β-thalassemia may results in the severe transfusion-dependent form, dubbed thalassemia major, or more rarely, in a less-severe non-transfusion-dependent variety which is referred to as thalassemia intermedia. Patients with thalassemia major are

homozygotes or coumpound heterozygotes for a severe mutation (characterized by absent or very low production of β-globin chain) and have not inherited any of the known ameliorating factors. Patients with thalassemia intermedia are genotypically homozygotes or heterozygotes for β-thalassemia. In homozygotes the molecular mechanisms resulting in the production of a mild phenotype are homozygosity or compound heterozygosity for mild or silent alleles (characterized by a consistent residual output of β-globin chain), coinheritance of a genetic factor such α-thalassemia or hereditary persistence of fetal Hb (HPFH), which are able to reduce the extent of α/nonα globin chain imbalance. In the β-thalassemia heterozygotes, the β-thalassemia intermedia phenotype may results from the coinheritance of the triple-α globin gene arrangement or from the presence in heterozygosity of a mutation leading to the production of a hyperunstable β-globin (fig. 5).

In addition to coinherited α-thalassemia or HPFH, the clinical phenotype of homozygous β-thalassemia can be modified also by a number of inherited and environmental factors. Among the inherited factors a very interesting modifying gene is the UGT1A, which shows a polymorphism in the TATA promoter. The presence of the TA_7/TA_7 configuration instead of the TA_6/TA_6 in normal individuals gives rise to an increase of plasma indirect bilirubin, without any other associated symptoms, which is dubbed Gilbert's syndrome. The coinheritance of Gilbert syndrome with homozygous β-thalassemia is able to determine an increase of serum indirect bilirubin and my also rise the risk of developing gall stones (fig. 6).

In a number of Mediterranean populations with a high incidence of β-thalassemias such as Cypriotes, Greeks and Italians, programs of population screening, genetic counselling and prenatal diagnosis have been introduced since the early seventies. Those programs led to a continuous increase in the knowledge of β-thalassemia by the population and resulted in a consistent decrease of the birth rate of thalassemia major (fig. 7).

In the field of therapy, the major advance of the last years has been the introduction of bone marrow transplantation (BMT) from HLA identical siblings. BMT carried out in patients without major complications and specifically patient exempt from iron overload and liver fibrosis may led to disease-free survival of around 95% (fig. 8).

In the traditional management a marked improvement was realized by the introduction in chelation therapy of diferiprone (which is administered by the oral route), especially in combination with desferrioxamina B, which led to an increase in the compliance and therefore in the reduction of the extent of iron accumulation.

A number of potentially useful iron-chelators are in phase II trial or in the process of development.

Future prospects are concentrated in the development of a safe gene therapy. Recent progress in this field has been obtained by using lentiviral vectors in the thalassemic mouse.

Suggested reading

Weatherall DJ, Clegg JB. *The Thalassemia Syndromes*. 4th edn. Oxford: Blackwell Science, 2001.

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Stamatoyannopoulos G, Majerus PW, Perlmutter RM et al. *The Molecular Basis of Blood Diseases*. Philadelphia: Saunders, 2001.

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Huisman THJ, Carver MFH and Baysal E. A syllabus of thalassemia mutations. *The Sickle Cell Anemia Foundation, Augusta, GA, USA* 1997; (http://globin.cse.psu.edu).

Thein SL. Structural Variants with a β-Thalassemia Phenotype. In: Steinberg MH, Forget BG, Higgs DR et al. *Disorders of Hemoglobin: Genetics, Pathophysiology, and Clinical Management*. Cambridge: Cambridge University 2001: 342-55.
Cao A. *Phenotype. Genotype relationships in Mendelian Disorders: The example of β-Thalassemies.* Ital J Pediatr 2002; 28:440-52.
Weatherall DJ. The Thalassemias. In: Stamatoyannopoulos G, Majerus PW, Perlmutter RM et al. *The Molecular Basis of Blood Diseases*. Philadelphia: Saunders, 2001:183-226.
Cao A, Galanello R, Rosatelli MC. Prenatal Diagnosis and screening of the haemoglobinopathies. In: Rodgers GP, ed. *Bailliere's Clinical Haematology* 1998; Vol 11:215-238.

Tab. Frequent Mediterranean diseases

- η-thalassemias
- ζ-thalassemias
- G6PD deficiency
- Familial Mediterranean fever
- Amyloid Polyneuropathy
- Myoclonic Epilepsy of Unverricht-Lundborg
- Polycystic Kidneys disease
- Fragile Mental Retardation 1
- Glycogen storage disease type III
- Wilson disease
- Type 2 Vitamin D-dependent Rickets
- Crutzfeldt-Jacob disease
- Laron dwarfism
- Familial cold autoinflammatory syndrome
- Gilles de la Tourette syndrome
- Adenosine deaminase deficiency
- Kaposi sarcoma
- Tyrosinemia type I
- Susceptibility to multiple sclerosis
- Inflammatory bowel disease

Fig. 1

Fig. 2

G6PD deficiency variants in Mediterranean populations

G6PD Mediterranean

G6PD^{-}

G6PD Seattle

Union

Fig. 3 **Heterogeneity of hemoglobinopathies in Mediterranean**

η-thal alleles (47)

5 - CT	-90 T	-101 T
8/9 + G	-88 A	-92 T
30 C	-88 T	UTR +10-T
1-1 A	-87 G	+ 33 G
1-2 A	-87 T	2-844 G
1-2 G	-87 A	AATAAG
1-5 C	-86 A	
1-5 T	-31 C	
1-110 A	-30 A	
1-116 G	-30 C	
1-130 C	6 - A	
39 T	8 - AA	
37 A	27 T	
44-C	1-5 A	
54-T	1-6 C	
59-A	2-1 A	
7-C	AACAAA	
2-705 C	AATGAAA	
2-745 G		
2-843 G		
2-844 A		
2-850-G		
2-850 C		

ζ-thal alleles (18)

-ζ(3.7) initiation cd ACCATG⇓ - - CATG	$-\zeta^{3.7}$
ζ2 ATG⇓ ACG	$-\zeta^{4.2}$
ζ1 ATG⇓ GTG	$-\zeta^{3.7}$ Hb Hasharon
ζ2 cd 29 T⇓ C (Agrinio)	$-(\zeta)^{20.5}$
ζ2 IVS1 (-5nt)	--MED-I
ζ2/ζ1 cd 110 C⇓ A (Petah Tikva)	--MED-II
ζ2 cd 142 T⇓ A (Icaria)	$-(\zeta)^{5.2}$
ζ2 polyA ATAA⇓ ATGA	--(MA)
	--(CL)
	--(CAL)

ι-thal alleles

-65 A⇓ G
-55 T⇓ C
cd 4 C⇓ T
cd 27 G⇓ T
Corfù –7.2 Kb

Hb Lepore

ιη-thal alleles

Sardinian Sicilian
Spanish
Turkish
Macedonian

HPFH

-196 Av C ⇓ T HPFH –4
-117 Av G ⇓ A HPFH –5

Structural variants

HbS
HbC
HbD Punjab
HbO-Arab

Fig. 4

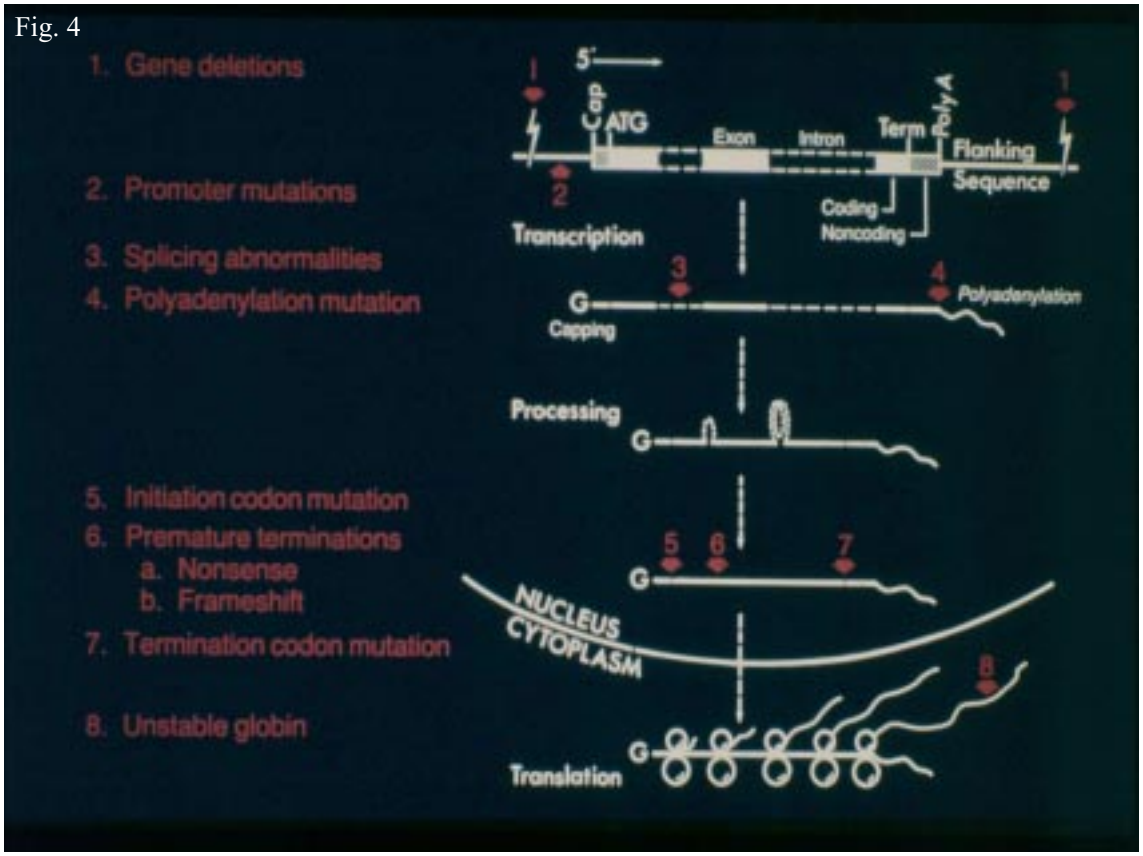


Fig. 5 **Mechanisms of η thalassemia intermedia**

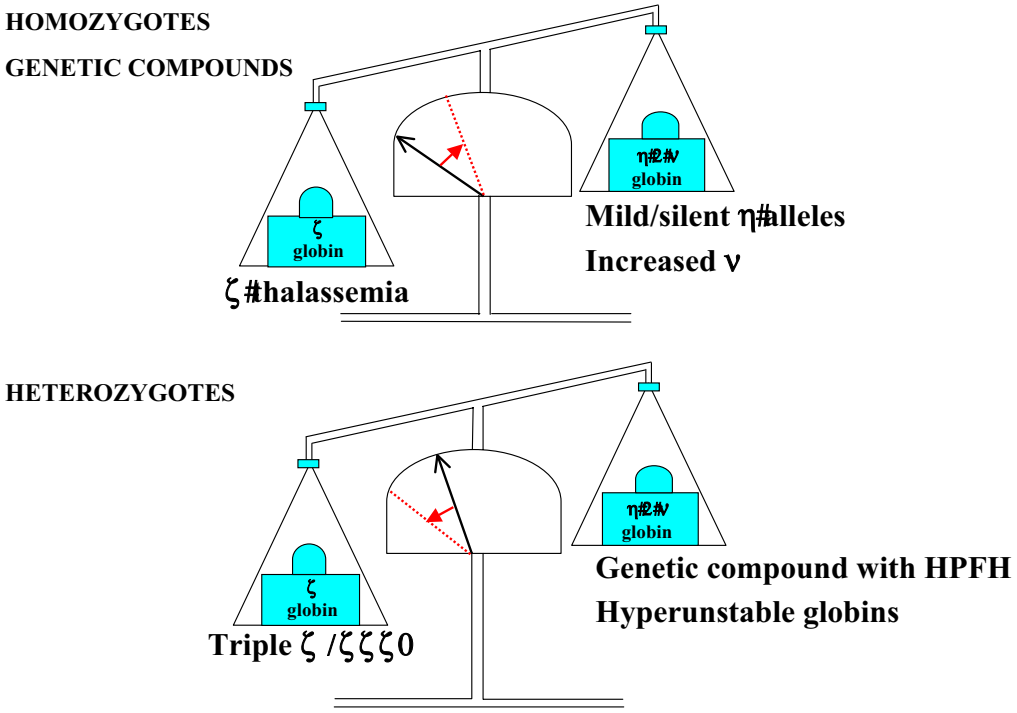


Fig. 6 **bilirubin data from η°-thalassemia intermedia patients**

UGT1A*1 Genotype	No.	Bilirubin (σmol/L) Tot	Ind
$(TA)_6/(TA)_6$	13	39.1∂19.1*	28.2∂15.8*
$(TA)_6/(TA)_7$	14	49.5∂22.1*	36.6∂19.6*
$(TA)_7/(TA)_7$	7	117.0∂53.9*	102.1∂47.3*

*p<0.0005[referred $(TA)_7/(TA)_7$ **vs** $(TA)_7/(TA)_6$ and $(TA)_6/(TA)_7$]

Fig. 7

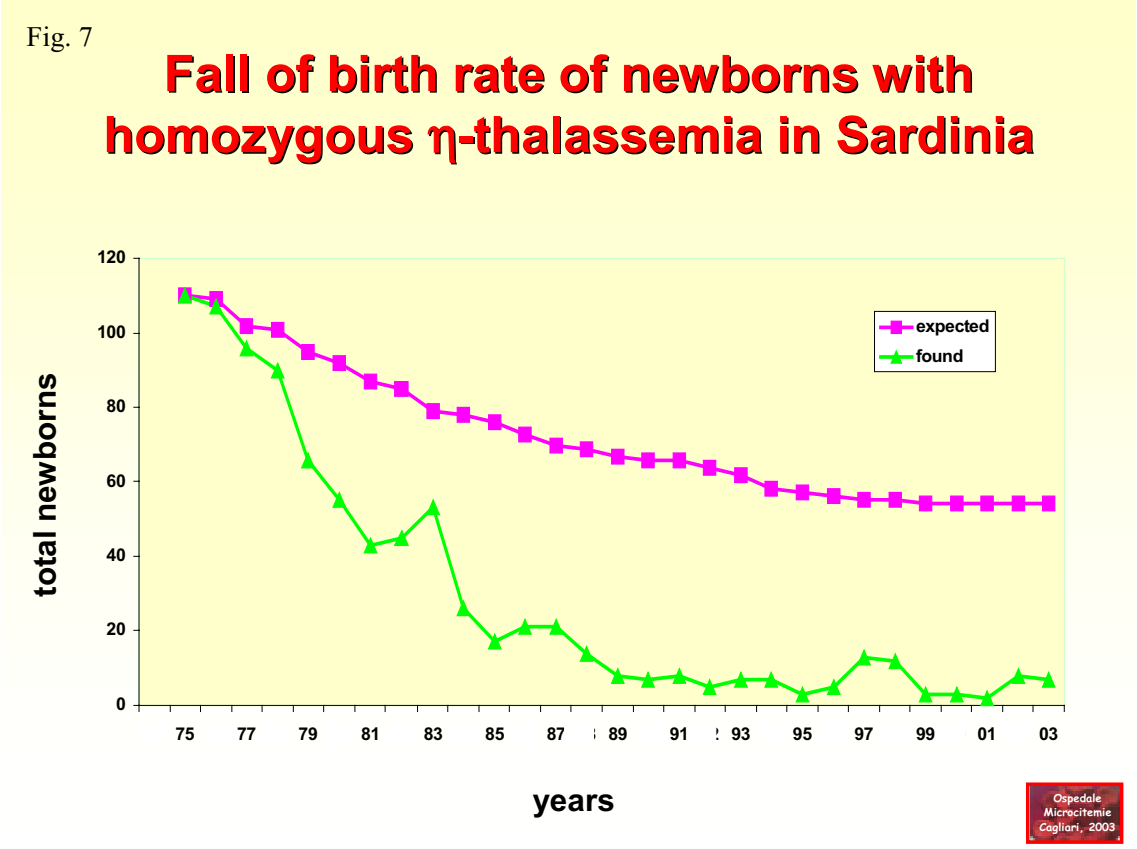
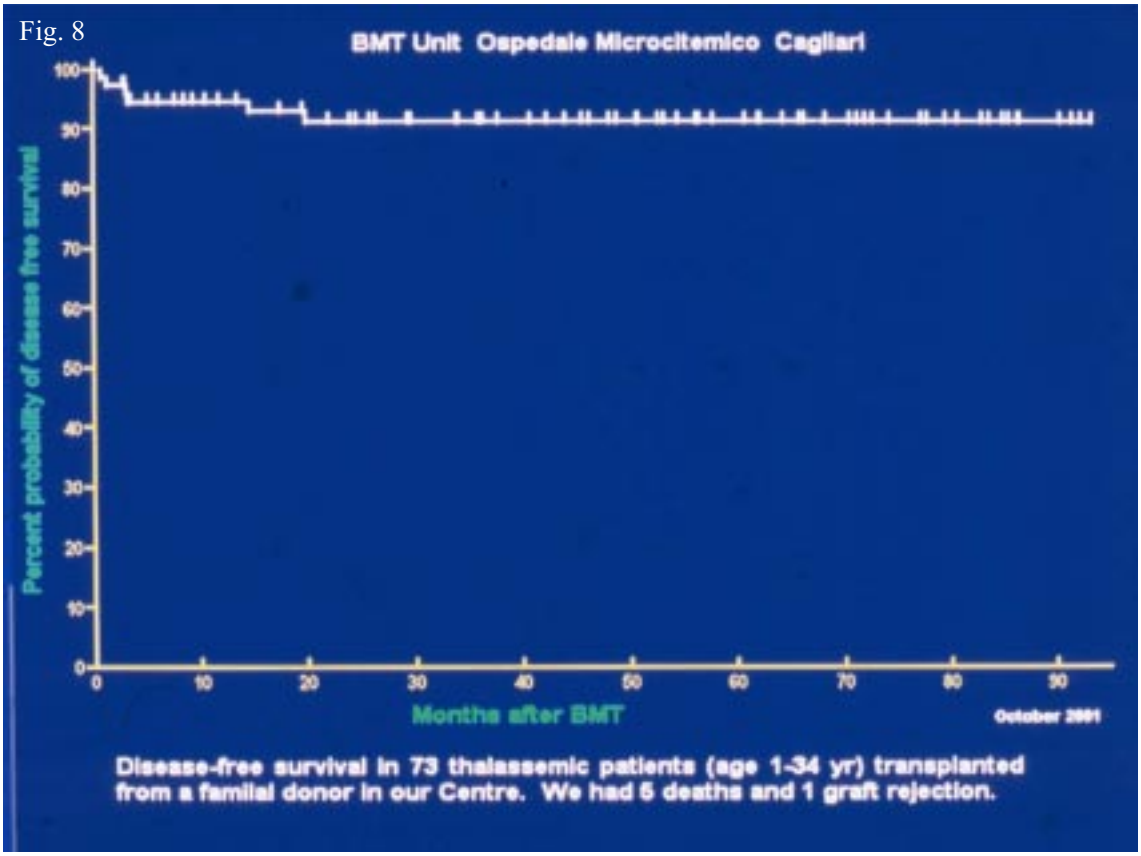

Fall of birth rate of newborns with homozygous η-thalassemia in Sardinia
total newborns
120
100
80
60
40
20
0
75
77
79
81
83
85
87
89
91
93
95
97
99
01
03
years
expected
found
Ospedale Microcitemie Cagliari, 2003

Fig. 8


BMT Unit Ospedale Microcitemico Cagliari
Percent probability of disease free survival
100
90
80
70
60
50
40
30
20
10
0
0
10
20
30
40
50
60
70
80
90
Months after BMT
October 2001
Disease-free survival in 73 thalassemic patients (age 1-34 yr) transplanted from a familial donor in our Centre. We had 5 deaths and 1 graft rejection.

Molecular Defects in the GH/IGF-I Axis in the Mediterranean Area

Zvi Laron, M.D.
Endocrinology & Diabetes Research Unit, Schneider Children's Medical Center of Israel, WHO Collaborating Center for the Study of Diabetes in Youth, Sackler Faculty of Medicine, Tel Aviv University, Israel - Fax:972-3-9222996; e-mail:laronz@clalit.org.il

Due to the high degree of consanguinity in the populations surrounding the Mediterranean sea and those of the Middle East, the incidence of hereditary disease is also high. Among those are also endocrine diseases. Advances in laboratory technology in the last 15-20 years have enabled to diagnose the pathology at the molecular level of a large series of endocrine diseases occurring in childhood and have offered the possibility of prenatal diagnosis.

Forthwith an overview of the presently recognized molecular defects along the GH/IGF-I axis.

GHRH Gene Defects: Although isolated GH deficiency (IGHD) owing to complete or partial absence of GHRH has been diagnosed by indirect methods, no patients with a GHRH gene deletion or mutation in the GHRH gene have been described so far.

GHRH Receptor Gene Mutations in Man: The finding of an inactivating mutation in the little (lit) mouse suggested that similar defects may occur in man. So far four kindreds have been described, three originating from the Indian peninsula and one from Northeast Brazil. The first described patients by Wajnrajch et al. are Indian Moslems and originate from Bombay. They belong to a very consanguineous kindred of which two cousins, a boy (age 16 yr) and a girl (3.5 yr) were investigated. Both were very short (-4.2 and -7.4 height SDS), and had frontal bossing and truncal obesity, the typical phenotype of severe isolated GH deficiency (IGHD) or GH resistance (Laron syndrome).

Molecular Defects in the Human GH Gene and Hormone: Abnormalities in the structure of the hGH molecule or GH gene deletion have been suspected to occur in humans for some time, but could not be proven until adequate laboratory methods were developed and the right patients found. A seemingly innocuous defect is the omission of exon 3, which causes the production of 17 Kd hGH. HGH-N gene deletions are being diagnosed more and more frequently in patients with hereditary IGHD from consanguineous families. A classification attempt has been made as shown below in Table 1

Table 1: Isolated Growth Hormone Deficiencies (IGHD)

Category	Inheritance	GH-RIA
IGHD IA	Autosomal recessive	Absent
IGHD IB	Autosomal recessive	Absent/low
IGHD II	Autosomal dominant	Low
IGHD III	X-linked	Low

Growth Hormone Deficiency Owing to Mutant Human Growth Hormone: Although the existence of short stature due to biologically inactive growth hormone had been postulated, the case was only proven recently. Takahashi et al. (Japan) reported the first documented patients.

Molecular Defects of the Human GH Receptor (Laron Syndrome): The first description of patients with this syndrome was made by Laron et al. in 1966 who subsequently reported 22 patients in 1968. The patients resembled phenotypically those with IGHD but had excessively high circulating GH levels, and very low serum IGF-I (sulfation factor) generation, which did not respond to administration of exogenous GH.

In 1989 Godowski et al. characterized the genomic organization of the GH-R gene and reported two patients from the Israeli cohort who were homozygous for the deletion of exons 3, 5 and 6. In the same year Amselem et al. using the newly developed polymerase chain reaction (PCR) methodology described several point mutations in patients with Laron syndrome. So far 53 molecular defects have been described.

Treatment: The only possible therapy is administration of IGF-I, which has been practiced by us since 1988 and subsequently by three other groups in the US, Ecuador and Europe. IGF-I stimulates linear growth, but is less efficient than hGH in the treatment of IGHD.
There are many patients with this syndrome in Mediterranean and Mid-Eastern countries, but only few are treated by IGF-I.

Defects of the IGF-I Gene and Receptor: Only one patient with a defective IGF-I gene has been described so far. In 1996 Woods et al. described a very short 15.8 yr old boy.

IGF-I Resistance: Very few reports of short children fit this category, and so far no convincing evidence of a true homozygous IGF-I receptor defect has been reported.
Table 2 presents a summary of the similarities and differences between patients with molecular defects in the hGH or IGF-I genes or their receptors

Table 2:

Characteristics	GHRH-R Gene Mutation	hGH-I Gene Deletion	hGH-I deletion or Mutation GHBP-	hGH-I deletion or Mutation GHBP+	Post hGH-R Mutation GHBP+	IGF-I Gene Deletion	IGF-1-R Mutation
Dwarfism	+	+	+	+	+	+	+
Short at Birth	+	+	+	+	+	+	+
Small cranium	+	+	+	+	+	+	+
Acromicria	+	+	+	+	+	+	?
Obesity	±	+	+	+	-	-	+
Small genitalia & Testes	+	+	+	+	+	+	?
Serum hGH	↓	↓	↑	↑	↑	↑	↑
Serum IGF-I	↓	v↓	v↓	v ↓	v↓	v↓	↑
Serum insulin	↓	↓	↑	↑	N	?	↓

V = very

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The Foundation of Child Neurology and Establishment of the Institute for Child Development in Slovenia

Neubauer David

Background: Like all the small, oddly shaped European countries that emerged from the shadow of so-called Eastern block in the last decade of the 20th century, **Slovenia** has needed to work hard to establish its place on the International stage. This has certainly been something of a challenge, on account of the country's tiny population (just 2 million), and its diminutive size (20.000 km^2) not to mention its shape (Slovenia has a hen-like shape).[1] Slovenia, the first of the former Yugoslav Republics to become independent (June 25th, 1991), is slightly smaller than New Jersey, though it has considerably more mountains – about a third of the country consists of Alps, which are shared with Austria and Italy - and rather much less beach (the coastline is only 29 miles long) which is squeezed between Italy and Croatia, with whom it has a contested boarder. The Project of Slovenian distinctiveness was surely not helped when a year after its independence, Slovakia made its own declaration of statehood, thus confusing those casual watchers of the World Scene who were still having trouble distinguishing between Latvia and Lithuania. Slovenia has, however, a reputation disproportionately large for its size when it come to the world of ideas. Slovenia has a rich history of famous people (however some of them visted it only for a very short time, like James Joyce, who stepped out of the train in the capital Ljubljana by mistake, thinking he is in Trieste), is producing extremly good winesorts and is well known by its wintersport champions and football players. There here also been famous poem writers (as France Preseren), architects (as Joze Plecnik), scientist (as Jozef Stefan) and also historians (as Janez Vajkard Valvasor). And Slovenia also has a very rich history of non-governmental organizations (NGO).

The development of **NON-GOVERNMENTAL ORGANIZATIONS** in Slovenia can be traced back to the emergence of various communities in the 7th and 8th centuries and continued with guilds, religious charity organizations and foundations in the 14th century, the first workers' movements in the first half of the 19th century, the first legal regulations (the 1867 Law on the Right of Association and Societies and Political Societies) and over 1,700 cooperatives that existed before the World War II. The year 1974 was an important cornerstone in the development as the new Societies Act was adopted this year. This was the start of the process of the NGOs funding. However due to ineffectual state support these organizations were small and lacking mass support. After the year 1980 many new social movements emerged (peace, environmental, human rights, spiritual and other movements), and some of their members joined the political sphere later on (!); yet the others remained active on the NGO level. Unlike in the other transition countries independence did not lead to a mass emergence of modern NGOs (with the exception in some areas as sport, culture and social care). The expectations of many that the introduction of democracy would help to increase civil society's impact on political decision-making and consolidate civil society did not occur. As a result many of the issues that NGOs have dealt with in the past still remain.

It is important to read the next chapter to understand why all the trials to make healthy foundation for quality decision-making in Slovenia have (until now) not yielded much success.

Objectives: As in other countries, the NGO sector in Slovenia is diverse, heterogeneous and filled with organizations with hugely varied goals, structure and motivations.[2] The characteristics that are usually shared by NGOs are: they are formed voluntarily, they are not created to generate personal profit, are independent (in particular from government, political parties and/or commercial organi-

zations) and are aimed to act in a public arena on concerns and issues related to weel being of people, specific groups of people (e. g. children) or society as a whole. The most common forms of NGOs in Slovenia are societies (other forms amount to only around 3% of the total). There are around 15,000 societies registered, and 350 religious communities, more thab 100 foundations and around 200 private institutes. The sports (28%) and culture (12%) are among the most common areas represented. Social field is less well represented (only around 3%), however you can find some strong NGOs in that field, some of which will have a public benefit status. There is quite a lot of organizations which exist only on paper but are not working in practice. Employment in the societies is small and amounts to around 0.4% of all employed people in Slovenia, however the highest proprtion of the employed in the societies is in the organizations for disabled (around 15%), which shows the special interest of this field. There are around 91% of societies (and 81% of foundations) without employed staff. There exist no statistical data about the number of part time workers, but in some instances the number might be quite high. Only 20% of the societies will have an annual budget above 13,000 Eur, while the total income of NGOs in Slovenia is around 2% of GDP (around 215 million Eur). One fourth of this sum comes from the state budget. The development of NGOs is one of the more important tasks for Slovenia in its process of harmonization with the EU and Slovenian NGOs wish to play a more important role in this process. Slovenian NGOs are also interested to be more involved in the activities of NGO networks within the EU. Some major NGOs in Slovenia have already good contacts, but most of the rest do not have the capacity to be active at the European level. Around 50% of NGOs expect better environment for their work after joining the EU.
Regarding the legislation the main problems are related to the public benefit status, the procedure to obtain such status and the consequences of it. Another problem is lack of private foundations that can't be established by the law (only foundations in public interest can). Next probem is the lack of stimulating tax legislation enabling private sector (organizations and corporations) to support NGOs. There is also lack of legislation on information, consultation and co-operation. All these make the NGO life difficult since state administration hardly understands the meaning of principles of open government or civil dialogue. Regarding the NGO capacity main problems remain in the extremly low employment rate in NGOs as it is very hard to assure working places within NGOs since the flow of income is not sustainable (e.g lack of long term contracts). Good candidates hardly see the NGOs as an alternative to the state administrator or commercial sector and voluntary work is not stimulated enough and not regulated properly either. All mentioned problems are results of the lack of government strategy to define NGOs as one of the priorities for social and economic development of Slovenia. Co-ordination of the activities regarding the NGOs in state administration is missing and partial solutions within the state administration usually create only new problems. Hopefully the government will sign the agreement act on collaboration with interested NGOs in 2004. After that the final strategic step should be the adoption of National Programme on NGO Development in Slovenia.

Methods: The Foundation of Child Neurology in Slovenia has been established in 1997 on the initiative of the Department Child, Adolescent and Developmental Neurology at the Childrens' Hospital Ljubljana.[3] As a non-governmental institution it aimed primarily to improve the quality of the functional diagnostics in child neurology that is to support financially the purchase of costly modern equipment, which could not be supplied from the regular hospital budget. Such equipment was aimed at better detection and diagnostics of sleep disturbances, cardiorespiratory abnormalities during sleep, sensorial deficits and cognitive (dys)functions as well as more complex epilepsy diagnostics. During the period 1997-2003 the foundation participated in financing or has financially completely supported the purchase of the following: digital EEG machine, machine for evoked potentials-sen-

sory electroencephalography, cardiorespiratory monitor, oximetry device, videoEEG and ambulatory EEG machine in a sum mounting over 100,000 Eur. The money was collected either by the financial donations of large Slovenian Enterprises and corporations (Mobitel, A-Banka, SCT) or direct donations of the particular machines (HermesPlus and Vasco). Some money was collected by individual donations during different campaigns also supported by some enterprises (e.g. Mercator).
On the other hand we felt that the standard of care at both inpatient units (for infants and toddlers and schoolchildren and adolescents respectively) should be improved in view of more children (and their parents) friendly hospital. This can be achieved only through additional financial support for improvement of the living conditions (proper climatization, sleeping chairs for the parents staying overnight at the bed) as well as donations (e.g. toys, computer games, books, TV and music sets). Until now through direct donations from various small enterprises the two departments (for infants and toddlers and for schoolchildren and adolesecnts) have been adapted and the condions were improved, however still much has to be achieved (especially regarding climatization and very crowded conditions as well as co-sleeping beds for parents).
Foundation has recently participated at the educational level in the field of child neurology: support of visits from outstanding lecturers from abroad, financial support of education abroad of young researchers, co-organization of symposia and congresses and publishing several booklets on special topics of child neurology and neurophysiology. Its president is also one of the board members of IPOKRaTES which is an International non-profit, non-governmental organization for postgraduate seminars in the field of pediatrics and especially child neurology, neonatology and developmental pediatrics with the head ofice in Mannheim, Germany. Under the educational tasks is also the running of webpage for ICNA (International Child Neurology Association) which has been successfuly done by prof. Velickovic Perat, Head of our Developmental Department.
Since December 5th, 2000 the foundation has become one of the 11 constitutional members of the Association of Slovene Foundations. The president has become also one of the Board members of the Association and has also participated in some of the joint meetings with the Legal Information Center for NGOs Slovenia. It is since that time that the awareness of the position of Child Neurology Foundation within other societies and NGOs, and especially sharing the same problems with other members of different kinds of NGOs, has raised enormously. We have also become aware that long term startegic plans should be developed and pushed forward as the main goal for future efforts and strategies of our Foundation.

Results: It is tradionally throughout Europe and USA that the institutes of child health are the leading tertiary centers for complex management and care of children and adolescents, especially those with developmental impairments/neurological disabilities and handicap. Such institutes, which are more or less independent and supported by different grants, non-profit and non-governmental organizations and individual donations as well as charity foundations. They are internationally recognized institutions dedicated to improve sick child's and adolescent's quality of life through excellent (and frequent multidiciplinary) patient care, special education, research and professional training. Its clinical programs are interdisciplinary designed, tailored to the individual needs of each child and adolescent, and services include different subspecialized units and outpatient clinics, offer home and community programs and services to assist families. On the other hand they are the mainstream educational institutes in the scope of childhood neurological and developmental disabilities. They are also the leading research institutions in the field of child's normal and abnormal development. Among such well established and renowned institutions (among many others which are also famous) are The Institute of Child Health (ICH) in London and Kennedy Krieger Institute (KKI) in Baltimore. Such institutions are always clinically supported by the governmental hospital facilities and partly

also by its staff. In the case of ICH this is The Great Ormond Street Hospital and in the second case it is the Johns Hopkins University Childrens' Hospital. These institutes employ their own staff, majority of whom are paid by different grants as the researchers or from funding as well as the staff from the university hospitals and school of medicine. Some occasional staff members (or part time workers) are from other institutions (e.g. faculty of sciences).

In former Yugoslavia there were two well-known and established institutions in Belgrade and in Zagreb and both are even now working perfectly and even in Zagreb, Croatia they have extended the scope of research and scientific work and formed Croatian Institute for Brain Research, while on the educational and clinical level they have established The Academy of Child's Development. In Slovenia there has not been such an institution until now and the activities of clinical work, research and education were mainly performed on the individual initiatives from the staff of the Department of Child, Adolescent and Developmental Neurology, University Childrens' Hospital Ljubljana and partly from other institutions involved in the field of child's development and neurorehabilitation. It is aimed that such an institute would also co-ordinate all activities in the field.

On the other hand there have been already 10-year long efforts to persuade responsible adiministrators at the Ministry of Health, Slovenia to bulid a New Pediatric Hospital (NPH). The efforts have been implemented through an NGO, named Foundation for building of New Pediatric Hospital. It seems that now agreement has been reached and that the works will start to build NPH, however to much lesser extend that it has previously been planned. The minimizing of the surface area will primarily reduce the outpatient care, research and teaching facilities.

Department of Child, Adolescent and Developmental is at present located on four different locations and it is aimed that all outpatient, multidisciplinary clinical, neurodevelopmental teratment as well as educational and research facilities would be placed on one location as the part of the newly formed Institue of Child Development. The ideal place for such an institute would be already existing building in Ulica Stare pravde 4 (formerly called Town Childrens' Hospital) where now are located: child neurology outpatient unit, developmental psychology unit, neurodevelopmental tretament unit and inpatient department of child nephrology whicih will be moved out of the building when NPH will be built. This place is located in a peaceful place just below the Castle hill and has good parking facilities and is also adjacent to the buliding where many of the NGOs, associated with the child's health and wellbeing, are located (Ulica Stare pravde 2).

The formation of the Institute of Child Development has been designed by:

Department of Child, Adolescent and Developmental Neurology, University Childrens' Hospital Ljubljana and its Units, especially: Center for Developmental Neurology and Unit for Neurodevelopmental Treatment (NDT-Bobath Center), Center for Child & Adolescent Epilepsy Care, Unit for Neuropsychology and Unit for Developmental Psychology; Foundation of Child Neurology, Slovenia; Foundation League Against Epilepsy, Slovenia; Child Neurology Society, Slovenian Medical Association; Postgraduate Courses on Child Neurology, Medical Faculty of Ljubljana University

The possible co-partners of the Institute of Child Development would be:

Other clinical departments (specialized in different fields of child's care, management and rehabilitation) of the University Medical Center, Ljubljana; Dispansaries for Developmental Neurology throughout Slovenia (22 units); Medical Faculty of Ljubljana University and its Institutes (especially those in the field of Neurosciences); The Oncology Institute Ljubljana; The Institute for Rehabilitation, Ljubljana; The Institute Josef Stefan, Ljubljana and The Town of Ljubljana; Ministry of Health, Slovenia; National Health Insurance Company, Slovenia; different NGOs; donators and funds; EU projects.

Such an Institute would include:

Clinical programs:

- Outpatient programs: multidisciplinary care of children with cerebral palsy (CP), developmental disorders and autism, comprehensive epilepsy care and management of drug resistant epilepsies (including multidisciplinary teams for possilble epilepsy sugery or other non-medical techniques); neurodevelopmenatl treatment, neuropscyhology;
- Preventive programs: registries for »at risk children« and for cerebral palsy, registry for epilepsy; early recognition and screening of possible developmental disorders; partnership with NGOs in the field of disabilities and handicap;
- Community programs: cooperation and interdisciplinary board meetings with the dispansaries for Child Developmental Neurology throughout Slovenia; partnership with community programs and instructions for proper management and care of disabled;
- Diagnostic programs (incl. the Hospital daycare Units):
  - development of different neurophysiological laboratories (some already existing) e.g. sleep laboratory, noninvasive EEG diagnostics, evoked potentials, cardiorespiratory studies;
  - development and standardization of neurocognitive tests, developmental psychological batteries;
  - GM (general movement) laboratory and follow-up of special groups of »at risk« newborns;
  - advanced neuroimaging programs (MRI, MRS, fMRI) with particular interest in developmental pediatrics and child neurology research

- Day-care admissions for children and adolescents who need diagnostics and management of their chronic condition (e.g epilepsy, cerebral palsy, cranio-facial abnormalities, sleep disorders, multiple malformations and/or handicap).
- Therapeutic programs: neurodevelopmental treatments (Bobath); follow-up of different treatment approaches in CP children (variuos medications, botulinum toxin, intrathecal baclofen, additional surgical procedures); different multidisciplinary board meetings;
- Possible private consulting rooms for offering second opinion in the fields of developmental pediatrics, child neurology, neuropsychology and developmental psychology (especially for those children and parents coming from the countries of former Yugoslavia) and giving neurodevelopmental treatment and possiblew arrangements for further physiotherapy, rehabilitation and other porcedures (different spa treatments, electrical stimulation, biological currents, etc) for referrals from abroad

Research programs:

Pediatric neurophysiology, pediatric neuropsychology and advanced neuroimaging research.
Autism and neuropsychiatric disorders research.
Epilepsy comprehensive care and management of associated cognitive impairments.
Cerebral palsy and other movement and developmental coordination disorders research.
Learning and other cognitive disorders, mental retardation/developmental disabilities research.
Molecular neurosciences and neurobehavioral research.
Rehabilitation research.
Extramural research: in co-operation with dispansaries for developmental neurology throughout Slovenia

Educational programs:

Neuro-developmental treatment programs: Bobath International, Bobath for babies, Bobath for physicians;
Postgraduate Courses in Child Neurology (Medical Faculty Ljubljana)

Postgraduate Course on Mother and Child Care (Medical Faculty Ljubljana and Institute of Health, Ljubljana)
IPOKRaTES Seminars on Child Neurology, Child Development and Neonatology
Short courses (with international participation and domestic experts) on the selected topics in Child and Developmental Neurology (e.g neuromuscular, epilepsy, neonatal seizures, clumsy child etc) and the organization of International Congresses within the scope of Child Development and Pediatric Neurosciences.

Continuing Professional Development and publications:
Organization of Ground Rounds (incl. participation of those experts at different other fields of neuroisciences) at the inpatient department, outpaient and daycare units
Organization of regular clinical-case conferences;
Organization of regular meetings of Society of Child Neurology;
Offering possibilities for postgraduate studies in the field of Dveleopmental Pediatrics and Child Neurology for pediatricians from former Yugoslav republics
Publications of Child Neurology Library booklets;
Other publications in
the field of child and developmental neurology;
Regular updating of Foundation of Child Neurology webpage with a special »corner for parents«
Regular updating of ICNA (International Child Neurology Association) webpage.

Conclusions: The program would include only the tertiary care regarding the interdsciplinary as well as individual clinical work (»different subspecialities according to the child's needs at one place«). The team sessions and board meeting would all take place only at the institute. Such an institute would cover and supervise also the work of dispansaries in the field (developmental neurology outpatient clinics) and would offer clinical, multidisciplinary and educational (CPD) help.The institute would take over the comprehensive care programs, such as comprehensive epilepsy care and comprehensive neuro-developmental treatment and habilitation of children with cerebral palsy and developmental disabilities. It would aim at individual child needs and parents education according to the child's condition and social conditions. There would also be regular board meetings for individual children and adolescents where it should be decided about further management and care, and given opinion on additional investigations and treatments abroad. The institute could offer private consultations and second opinion for the children and their parents, referred from abroad, especially from the former Yugoslavia, as well as mediating different treatments for those interested from abroad. At the same time the institute can offer also postgraduate training for the pediatricians from former Yugoslavia, interested in the field of developmental pediatrics and child neurology. The institute would take care about research activities in the field as well as about educational programs, postgraduate courses and education for parents, and community care programs. The institute would support different NGOs and develop all forms of cooperation and programs within the field. The institute would take care about good clinical practice principles, ethics, proper medicines for children and adolescents, guidelines and clinical pathways (algoritms) in the field of developmental pediatrics and child neurology.
Finally, Slovenia has been for a long time lacking such an institute and there would be expected definite final benefit of forming such an institute which could also more clearly present and control the consumption of different financial and personnel resources in the field of developmental pediatrics and child neurology.

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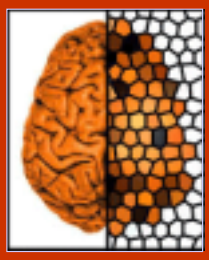
The Child Neurology from Slovenia and from Kuwait – two decades of shared & mutual experiences and co-operation



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Past two decades


Kuwait


Ljubljana

- **In the year 1985/86 the exchange programme started, based on previous Agreement Act between University Medical Centre Ljubljana and Ministry of Health, Kuwait (from 1979)**

Past two decades

Kuwait

Ljubljana

- **In the year 1985/86 the exchange pediatric programme started between:**
- ***Pediatric Department, Al Sabah Hospital, Kuwait***
- ***University Childrens' Hospital Ljubljana, Slovenia***

Past two decades

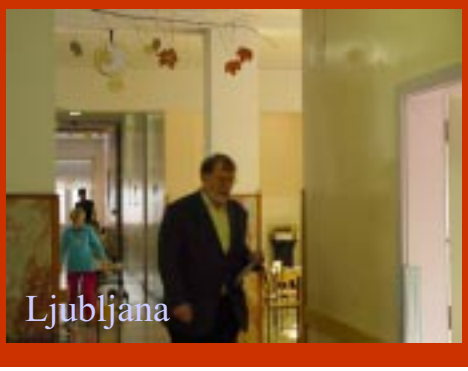
Kuwait

Ljubljana

- **The programme initially included clinical experiences and experts' exchange in the field of Child & Developmental Neurology of:**
- ***Pediatric Neurology Unit – NBK since 2001***
- ***Department of Child, Adolescent & Developmental Neurology***

Past two decades


Kuwait


Ljubljana

- There has been also the exchange of patients, especially those who were in need of complex diagnostics and treatment, mainly (re)habilitation


physiotherapy

Past two decades


Kuwait


Ljubljana

- There has been also the exchange of training & education as 5 pediatricians from Kuwait were trained at University Childrens Hospital Ljubljana and their Board Examinations were approved by
- **KIMS – Kuwait Institute of Medical Specialisation**

Past two decades


Kuwait

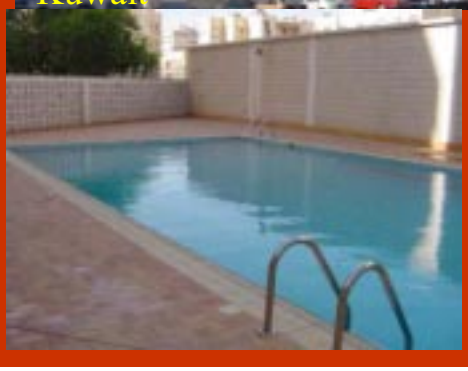

Ljubljana

- There has been also the exchange of consultants:
- 4 consultant Child Neurologists and
- 4 consultants in Pediatric Intensive Care

were regulary coming (for a period of 4 – 6 months) to visit Childrens' Department in Kuwait:

Past two decades

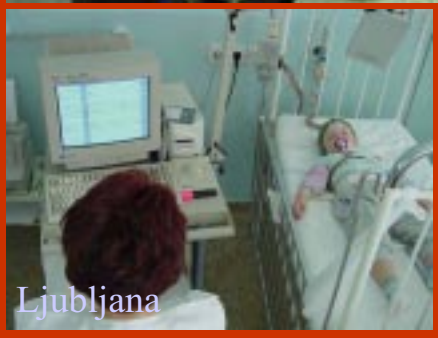

Kuwait



- and ..

who were given full accomodation and transportation facilities

Past two decades



- There has been also the exchange of special postgraduate programmes:
- In the fields of pediatric neurophysiology (EMG, EEG and Evoked Potentials) and
- PICU specialities care (CFM and ECMO)

What we have accomplished

- shared participation at
- 14 International Scientific medical congresses, conferences and seminars

What we have accomplished

- **shared authorship in 18 articles published in International Scientific Medical Journals** (mainly SCI and CC journals)

What we have accomplished

Dr Vesna Zeljic, Kuwait and prof Lily Dubowitz, London at Bled IPOKRaTES in 2001

Alec Hoon, Baltimore, USA in 2003

- **We have succesfully co-organized 3 International IPOKRaTES seminars with distinguished guests from USA, EU and Arab Countries**

What we have accomplished

VideoEEG in Kuwait

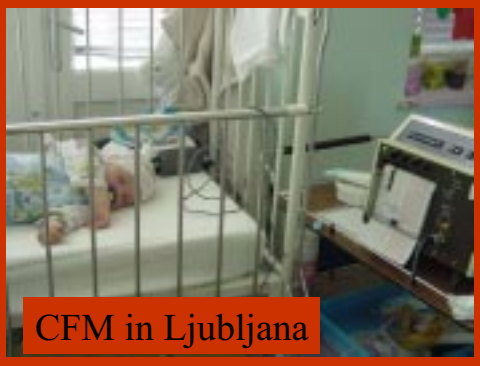
VideoEEG in Ljubljana

- **successful introduction of new methods, diagnostic techniques and treatment regimes**

Videoelectroencephalography

What we have accomplished

CFM in Kuwait



CFM in Ljubljana

- **successful introduction of new methods, diagnostic techniques and treatment regimes**

CFM- cerebral function monitor

What we have accomplished

- **successful introduction of new methods, diagnostic techniques and treatment regimes**

GMFCS – Gross Motor Function Classification System
(originally introduced by Palisano et al. *DMCN; 1997*)

What we have accomplished

- **successful introduction of new methods, diagnostic techniques and treatment regimes**

CRG – CardioRespiroGraphic studies and diagnostics

What we have accomplished

- **successful introduction of new methods, diagnostic techniques and treatment regimes**

Epilepsy treatment regimes: new AEDs-antiepileptic drugs introduction

What we have accomplished

- **successful introduction of new methods, diagnostic techniques and treatment regimes**

Buccal midazolam and rectal diazepam for treatment of status epilepticus during childhood & adolescence

Future perspectives

- Further widening of scope of collaborative studies, especially in the fields of (developing) modern diagnostic & therapeutic techniques

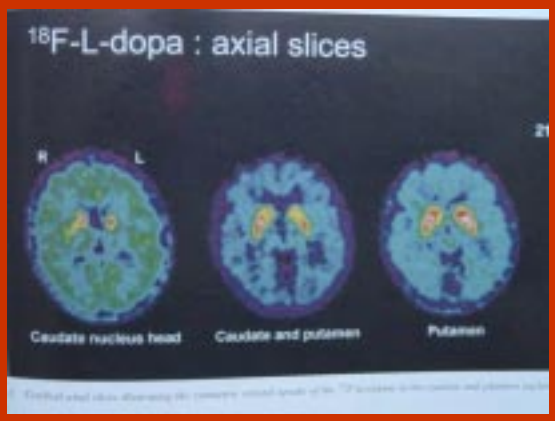
Videotelemetry & epilepsy surgery

Future perspectives

Further widening of scope of collaborative studies, especially in the fields of developing modern diagnostic & therapeutic techniques

VNS - Vagal Nerve Stimulation

Future perspectives



- Further widening of scope of collaborative studies, especially in the fields of developing modern diagnostic & therapeutic techniques

New imaging techniques – PET studies

Future perspectives

- Further widening of scope of collaborative studies, especially in the fields of developing modern diagnostic & therapeutic techniques

New cognitive techniques – visual, sensory, memory, etc.

Future perspectives

- Further widening of scope of collaborative studies, especially in the fields of developing modern diagnostic & therapeutic techniques

ABC Movement test for Developmental Coordination Disorders (DCD)

Future perspectives

- Educational "free-flow"

Co-organization of IPOKRaTES Seminars and other meetings and exchange of postgraduate students

…also aimed at: friendship and bilateral understanding

in Kuwait…

… also aimed at: friendship and bilateral understanding

and in Slovenia

Addendum

The Foundation of Child Neurology and Establishment of Child Development Institute in Slovenia

by

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Objectives

- Foundation of Child Neurology (http://animus.mf.uni-lj.si/neurology/)

has been established to support:

- on financial
- technical
- parental support
- and educational level

Department of

Child, Adolescent & Developmental Neurology at University Childrens' Hospital Ljubljana, Slovenia

Already done…

/since est. in 1997/

at the promotion of new videoEEG

- New digital EEG machine (20.000 Eur)
- Machine for evoked potentials (30.000 Eur)
- videoEEG (40.000 Eur)
- Ambulatory EEG (30.000 Eur)

Short term plans (2004-2006)

- New machine for videotelemetry
- Polysomnograph for sleep studies
- Interactive website for parents Q & A
- Organization of international symposia and meetings
- Editing booklets on special topics in child & adolescent neurology

Long term plans (2006 -)

- Establishment of the
- INSTITUTE OF CHILD DEVELOPMENT in Slovenia

INSTITUTE OF CHILD DEVELOPMENT

- Multidisciplinary outpatient care
- Preventive programs (in cooperation with NGOs)
- Community programms (+ NGOs)
- Diagnostic programs on outpatient basis

INSTITUTE OF CHILD DEVELOPMENT

- Daycare therapeutic programs and short term admissions
- Private consulting rooms
- Research programs
- Educational programs
- CPD programs and editorial work

INSTITUTE OF CHILD DEVELOPMENT

- Already existing location at the place of old Town Hospital for Sick Children
- Approx. Cost:

10 million Eur

INSTITUTE OF CHILD DEVELOPMENT

Thank you !