Community genetic program in Bahrain 1984-2010

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SMC
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-The hereditary disease program started in Bahrain in 1984;

-in 1991 a National Committee for prevention of Genetic disease was formed to plan the control program of these diseases in the country.

The strategic goals were:

-to reduce the incidence of hereditary diseases in Bahrain,

-and to improve the standard of management and treatment of patients suffering from these diseases.

The Campaign to control SCD included:

Bahrain successfully implemented the campaign to control Sickle cell disease.

The campaign included education and public awareness campaign,

screening of different categories, e.g.

Antenatal, carriers, students, premarital newborns, prenatal screening, newborn screening followed by genetic counseling.

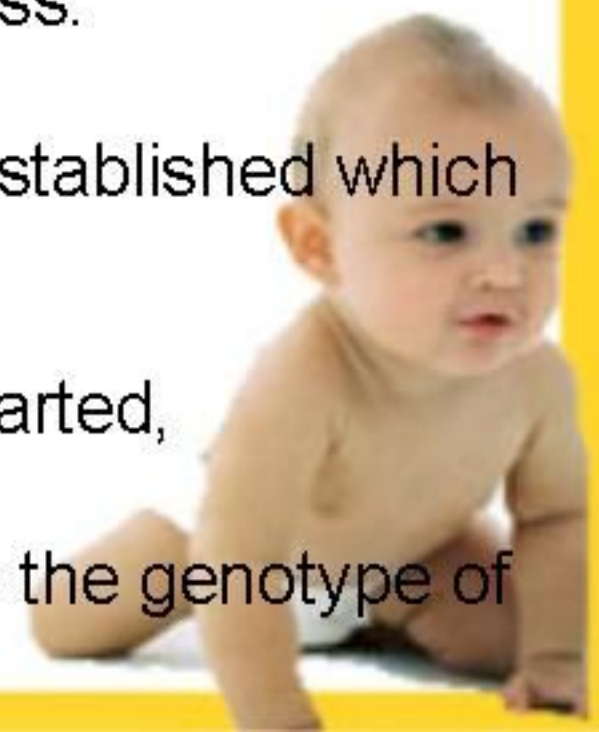
Information booklets were prepared and distributed widely in schools and to the public in an attempt to increase awareness.

In 1991, the Bahrain Hereditary Anemia Society was established which strengthen these efforts .

In 1993, a premarital counseling (PMC) service was started,

and in 1998, a student-screening project began.

A molecular laboratory have been established to study the genotype of the difficult cases



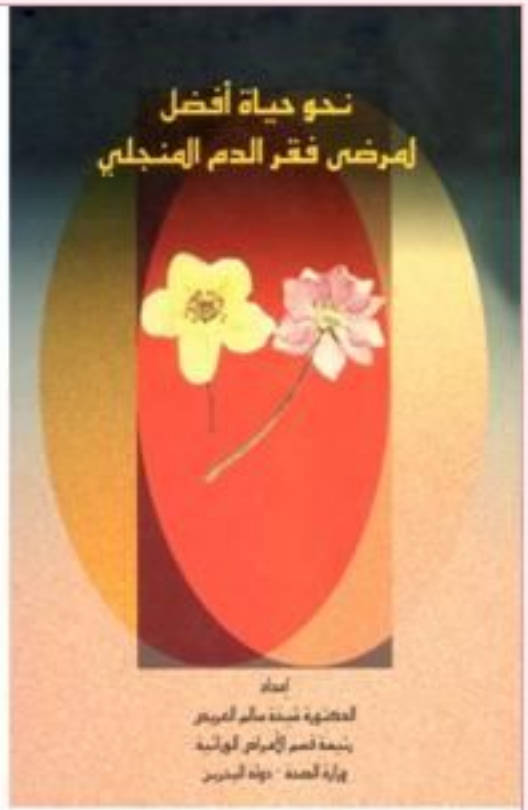
Health Education Programme

A comprehensive health education programme Has been launched , to increase public awareness of the diseases and methods to avoid them.

This programme used the media and target key opinion leaders in society. In schools and other public places

The programme included:

- General publicity campaign through periodic education programmes. presentations , leaflets and booklets ,etc


نحو حياة أفضل
لمرضى فقر الدم المنجلي
إعداد
الدكتورة شيخة سالم العريفي
رئيسة قسم الأمراض الوراثية
وزارة الصحة - دولة البحرين


مملكة البحرين
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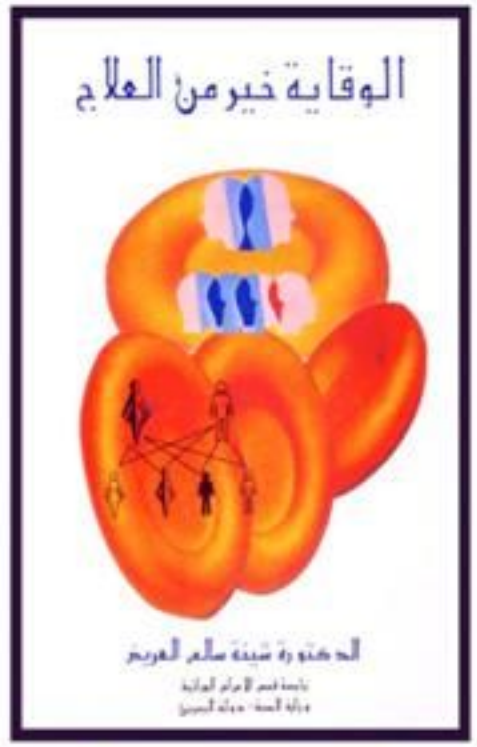
حقائق عن مرض
الثلاسيميا
إعداد الدكتورة شيخة سالم العريفي
قسم الأمراض الوراثية بمجمع السلمانية الطبي


الوقاية خير من العلاج
الدكتورة شيخة سالم العريفي
رئيسة قسم الأمراض الوراثية
وزارة الصحة - دولة البحرين


حقائق عن
أمراض الدم الوراثية
الجمعية الأهلية لأمراض الدم الوراثية في البحرين
BAHRAIN NATIONAL HEREDITARY ANAEMIA SOCIETY


مع تحيات
الجمعية الأهلية لأمراض الدم الوراثية
في البحرين
الجمعية الأهلية لأمراض الدم الوراثية في البحرين
BAHRAIN NATIONAL HEREDITARY ANAEMIA SOCIETY


مملكة البحرين
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الفحص قبل الزواج
لأجل جيل سليم


مملكة البحرين
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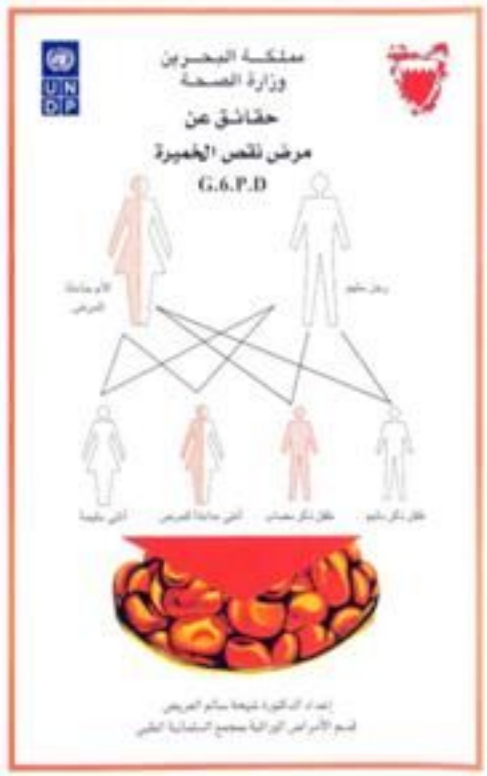
حقائق عن
فقر الدم المنجلي
إعداد الدكتورة شيخة سالم العريفي
قسم الأمراض الوراثية بمجمع السلمانية الطبي


مملكة البحرين
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مرض نقص الخميرة
G.6.P.D
إعداد الدكتورة شيخة سالم العريفي
قسم الأمراض الوراثية بمجمع السلمانية الطبي

screening for Genetic Blood diseases

To raise awareness about genetic blood diseases, and to identify carriers

1- Antenatal screening

2-Premarital counseling

3- Screen school leavers (11-12 graders)

4- Screen children at school entry (6 years

5- prenatal testing.

6- Cascade Screen

7- New born screening

Result:

These efforts continued for the past 24 years.

It had tremendous effect in reducing the prevalence of Genetic Blood Diseases (GBD) among the newborns,

from 20 /1000 to 6/1000,

with 60-70% decline .

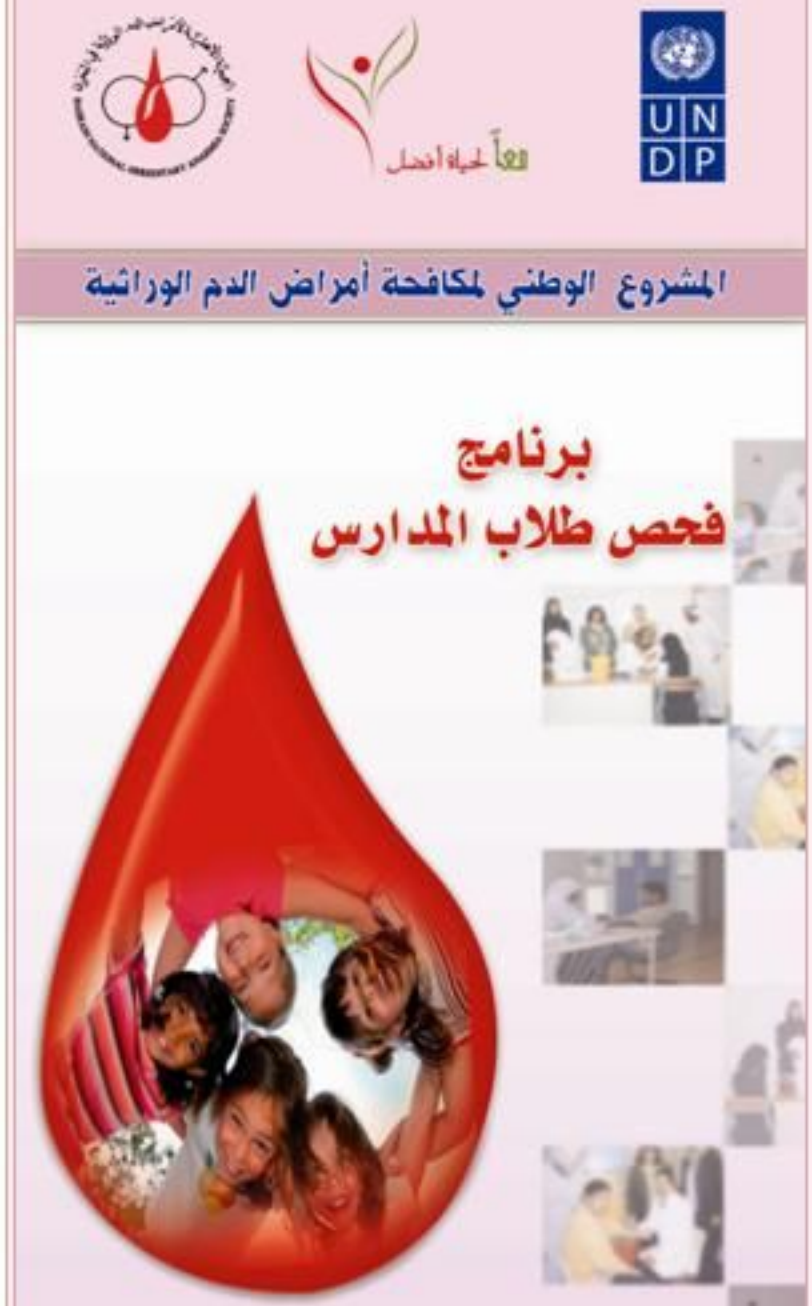
Consanguinity rate also declined gradually due to increase awareness about genetic diseases.

The total consanguinity rate and the first cousin marriages rate.

in 1990 were 39% and 24%. Respectively, while it became 20% ,and 11% in 2007 with 66% decline.

Discussion:

During the screening campaign the ELSI measures were taken care of, such as:
equity,
informed consent,
privacy,
confidentiality
and to prevent stigmatization and discrimination



المشروع الوطني لمكافحة أمراض الدم الوراثية

برنامج
فحص طلاب المدارس

إذا كنت مريضاً أو حاملاً للمرض فتأكد من ارتباطك بشخص سليم

مـع تحيـات

اللجنة الوطنية لمكافحة الأمراض الوراثية في البحرين

1- student screening for GBD

The project started in 1999 as collaborative project between MOH, MOE. It was partially funded by NGOs.

- The target group was all students at high school(11 grade students).
- It is now in its twelfth year.
- More than 66,000 students were screened for genetic blood diseases.
- A card with the results was given to each student.
- The project has been very popular among students and families,
- it resulted in tremendous raise in the awareness among the community.

-The aims included:

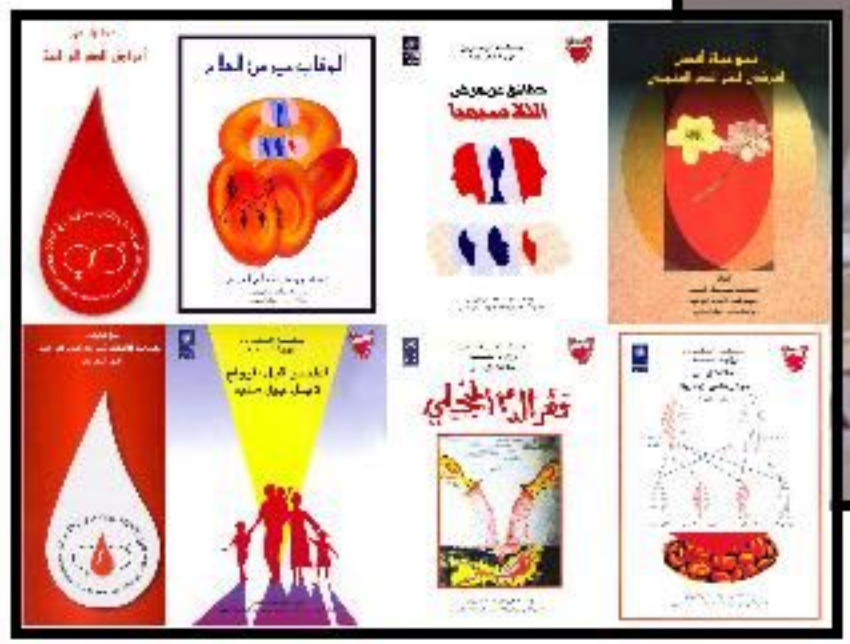
1- Raising awareness among the youth in Bahrain about hereditary anemia.
-Aiming at empowering them to take the right decision to prevent these diseases in their future families.
2-Determining prevalence of the common genetic blood disorders among Bahraini secondary school students.

-Permission for screening was taken from parents.

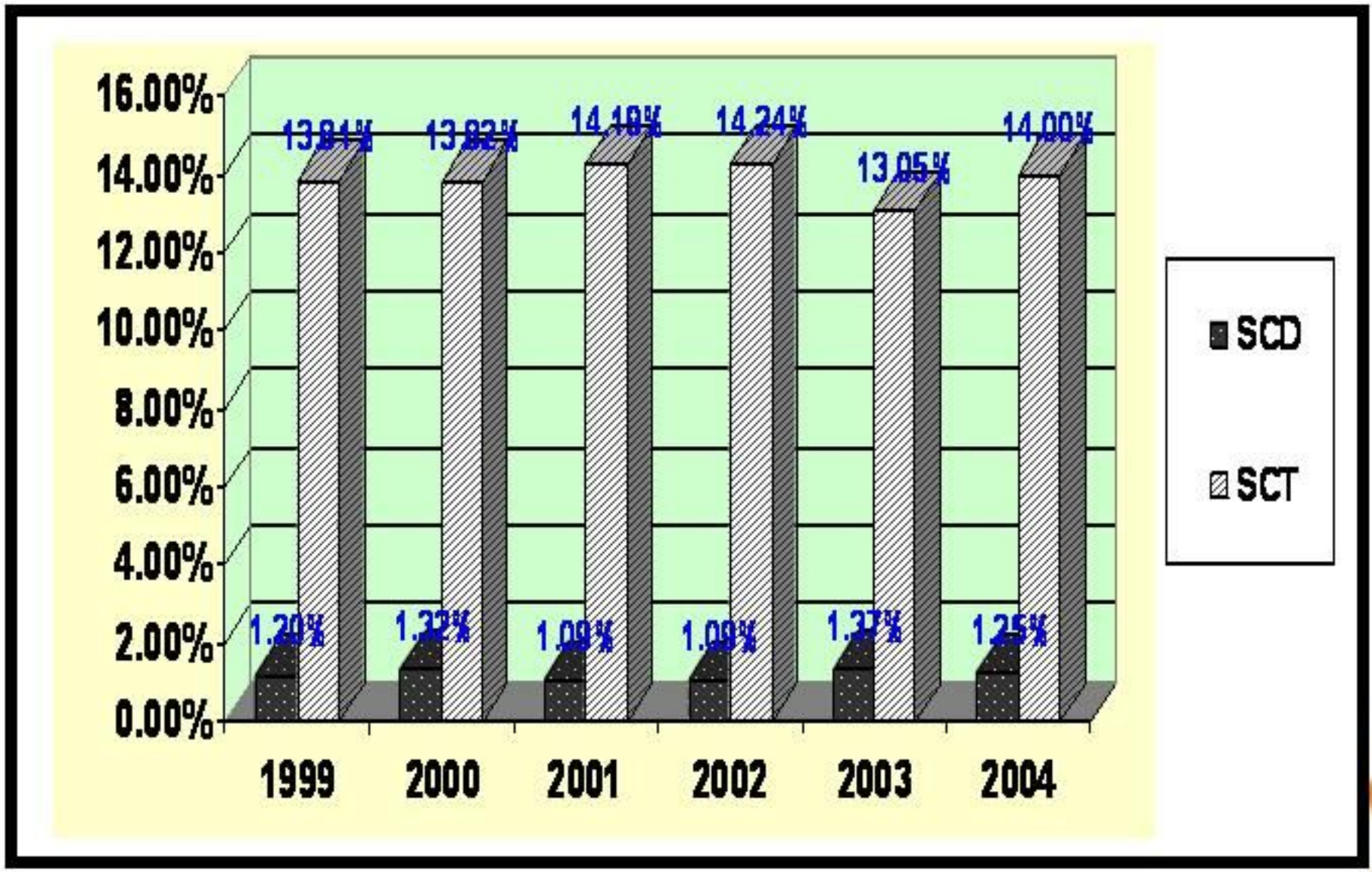
-positive response found in 80-85% of families every year.

The students were fully informed about these diseases through educational sessions.

Privacy was provided as cards with test results were given to students in a sealed envelope, and were delivered via their school, to be opened at home. In order to protect privacy, confidentiality, and prevent stigmatization.



Prevalence of Sickle Cell Disease



أهداف

المشروع الوطني لمكافحة أمراض الدم الوراثية

- رفع وعي المجتمع عن أمراض الدم الوراثية .
- التأكيد على أهمية الفحص قبل الزواج .
- إعطاء كل طالب بمرحلة الثاني ثانوي بطاقة تعرفهم عن وضعهم الوراثي لأمراض الدم الوراثية .

إذا كنت مصابا أو حاملا للعامل الوراثي فتأكد من ارتباطك بشخص سليم

المشروع الوطني لطلبة المدارس لمكافحة أمراض الدم الوراثية

قسم التثقيف الصحي


UNDP
الفحص قبل الزواج
مفتاح لأسرة آمنة
بدأ بيد نحو مستقبل أفضل لأولادنا
مع تحيات
اللجنة الوطنية للأمراض الوراثية في البحرين

2-Premarital Counseling:

The Genetic unit and the MCH department worked jointly to establish the service of premarital counseling in 1992.

- Training courses were organized for all doctors in HC.

-A specific risk assessment sheet was issued.

- Clients were provided with personnel cards with the laboratory results.
- During the first few years the service was voluntary, only 20% of the married couples went for premarital counseling.

On 22 June 2004 His Majesty King Hamad bin Isa Al Khalifa issued

low No 11 on premarital examination for both genders.

"Any citizen about to get married, even if the spouse is non-Bahraini, must undergo a premarital checkup, which includes some hereditary, infectious and other diseases according to regulation issued by H.E. the Mi of Health".

إلزامية الفحص قبل الزواج

إذا كنت مصابا أو حاملا للعامل الوراثي فتأكد من ارتباطك بشخص سليم

المشروع الوطني لطلبة المدارس لمكافحة أمراض الدم الوراثية

قسم التثقيف الصحي

صدور المرسوم الملكي رقم (11) لسنة 2004م

وينص على :

- تتولى وزارة الصحة بوضع الضوابط والتعليمات التي تمكنها من تقديم خدماتها بيسر وكفائة وسرية تامة في مجال الفحص الطبي
- وضع البرامج اللازمة لتوعية وتوجيه المقبلين على الزواج
- يجب على المقبلين على الزواج ان يخضعوا للفحص اجباريا ولو كان احد الأطراف غير بحريني

KINGDOM OF BAHRAIN
MINISTRY OF HEALTH

مملكـــــة البحـريـــــن
وزارة الصحـــــــة

Premarital Examination Certificate شـهادة الفحـص الطـبي قبل الـزواج

Certificate No. / رقـم الشـــهادة

According to the law No. 11 for 2004 issued on June 22, 2004 on mandatory premarital examination for both genders before getting married, the following partners were examined:

استنادا إلى المرسوم بقانون رقم (11) لسنة 2004م الصادر بتاريخ 6/22/ 2004م بشأن الفحص الطبي للمقبلين على الزواج من الجنسين، فقد تم فحص كل من:

NAME الاســـم

الرقم الشخصي C.P.R

NAME الاســـم

الرقم الشخصي C.P.R

This was done upon their request and according to the regulations issued by the Ministry of Health.

The results were discussed in the presence of both parties, and they were advised accordingly. The decision to get married is solely their own.

This certificate was given to them on their request for the formalities of marriage.

وذلك بناء على طلبهما وحسب ما تقتضيه الإجراءات المتبعة لمثل هذا الفحص، وبناء عليه فقد تم مناقشة نتائج الفحص مع كلا الطرفين مجتمعين، وتم تقديم النصائح الضرورية واللازمة حسب ما تقتضيه حالتهما، وقرار الارتباط يعود إلى الطرفين.

وقد أعطيت لهما هذه الشهادة بناء على طلبهما لإتمام إجراءات عقد النكاح.

ختـم جهـة الفحـص Examining Facility	ختـــم وتوقيـــع الطبيـــب Doctor's signature & stamp	التاريخ Date

ختم وزارة الصحة

Distribution:
- White copy: Ministry of Justice
- Blue copy: Husband
- Pink copy: Wife
- Yellow copy: Examining facility

للتوزيع:
- النسخة البيضاء: وزارة العدل
- النسخة الزرقاء: الزوج
- النسخة الوردية: الزوجة
- النسخة الصفراء: جهة الفحص

STOCK NO. G 45500115 - 2005

Premarital Counseling is provided at :

-Genetic department at SMC

-All health centers at the Primary Healthcare facilities

- other private health facilities

- It has to be certified by the Ministry of health.

- This service is provided by physicia supported by trained health nurses

- **- Objectives**
- To reduce other hereditary disorders by identifying problems followed by counseling.
- Counseling regarding high-risk behaviors, including those related to HIV, Hepatitis B, and other infectious diseases.
- Early detection and treatment of some sexually transmitted diseases.
- To promote awareness regarding reproductive health, family planning, and healthy lifestyles.
- To provide couples with medical, social, and psychological support.
- To provide immunizations as required

-Premarital Counseling will identify couples at high risk.

-by subjecting all couples intending to marry to screening by history taking,

-physical examination and laboratory investigations.

-Accordingly, advice is provided in the form of further investigation if needed, treatment advise, health education ,promotion of healthy lifestyle , and counseling regarding their health status.

- Medical/Surgical/Psychological History
  - Significant systemic illness such as: Hypertension, Diabetes mellitus, Heart problems, Epilepsy etc.
  - Previous surgical history
  - History of mental illness
  - History of sexually transmitted disease (STI) such as:
- Syphilis
- Gonorrhea
- Hepatitis B
- Genital warts and ulcer
- Urethral/vaginal discharge, burning micturation

- **VII. When to Refer to Genetic Department**
- **Couples at High Risk**
- Both partners are carrier of o sickle cell disease (sickle cell trait).
- Both partners are carrier of B-thalassemia
- One partners has sickle cell trait and the other has B-thal trait.
- One Partners has sickle cell trait while the other has Abnormal HB, HBD Punjab, HBE, HBC, HBO

- 5. One partner is carrier for B-thalassemia (B-thal trait) and other partner is carrier for HBE or HbO .Arab.
- 6. Blood results need clarification.
- 7. Family history of other genetic diseases.
- 8. Family history of congenital or chromosomal abnormalities.
- **Couples Who May Be at Risk**
- One partner has cell trait or B-thal trait and the other partner has hypochromia microcytosis and/or HBA2 between 3.4-3.7


البرنامج الوطني للكشف المبكر
على حديثي الولادة
إحمي طفلك بالفحص المبكر
يداً بيد نحو مستقبلاً أفضل لأولادنا
مع تحيات
اللجنة الوطنية لمكافحة الأمراض الوراثية في البحرين

3- The national Newborn screening for Hemoglobinopathies.

-It started in May 2007.

-It is on the national budget.

-All neonates delivered in the MOH maternity hospitals are included

The neonatal screening in 1984 –1985 covered:-

10000 newborns, birth prevalence of **sickle cell disease (SCD)** was **2.1%** of **sickle cell trait 11%**

A pilot study on hempglobinopathies ,2002 covered:- 2000 newborns ,

sickle cell disease incidence **1%**

with a decline of **50%**

A pilot study on metabolic disorders 1995 showed high incidence.

Another study reported the incidence of **1/1000**

A pilot study on **hempglobinopathies , 2002 covered 2000 newborns** ,

sickle cell disease incidence 0.9% with a decline of 60%

NBS form:

-A specific form is filled with the demographic information about: the baby, mother and father, the relationship between father and mother.

-Blood Sample:

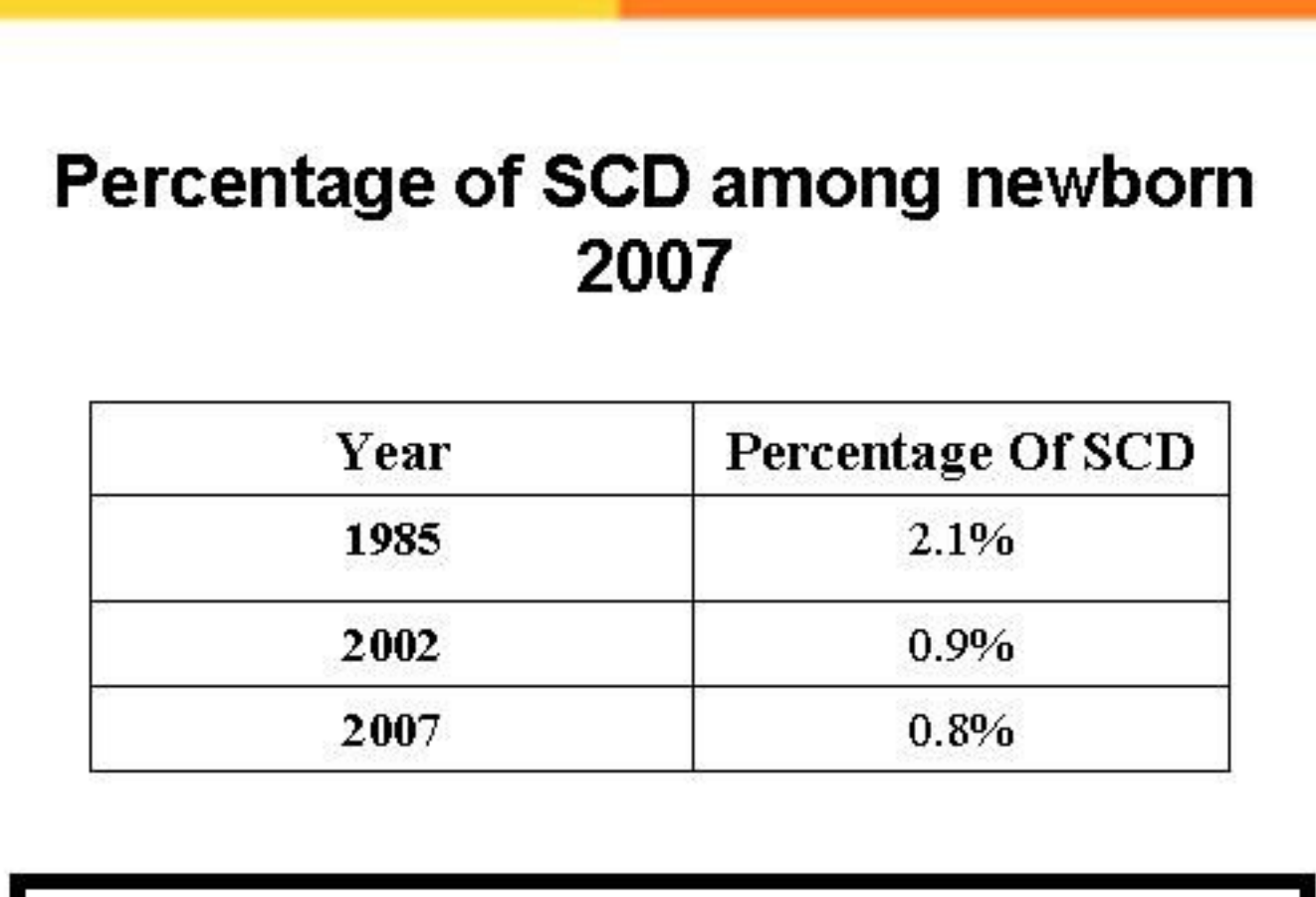
-Cord blood sample is collected at birth, and sent to the neonatal screening laboratory within 24 hrs of collection.

For the Newborn screening service:

Educational and awareness leaflets are provided during pregnancy, the parents have the right to opt the screening, privacy is secured and genetic counseling given.

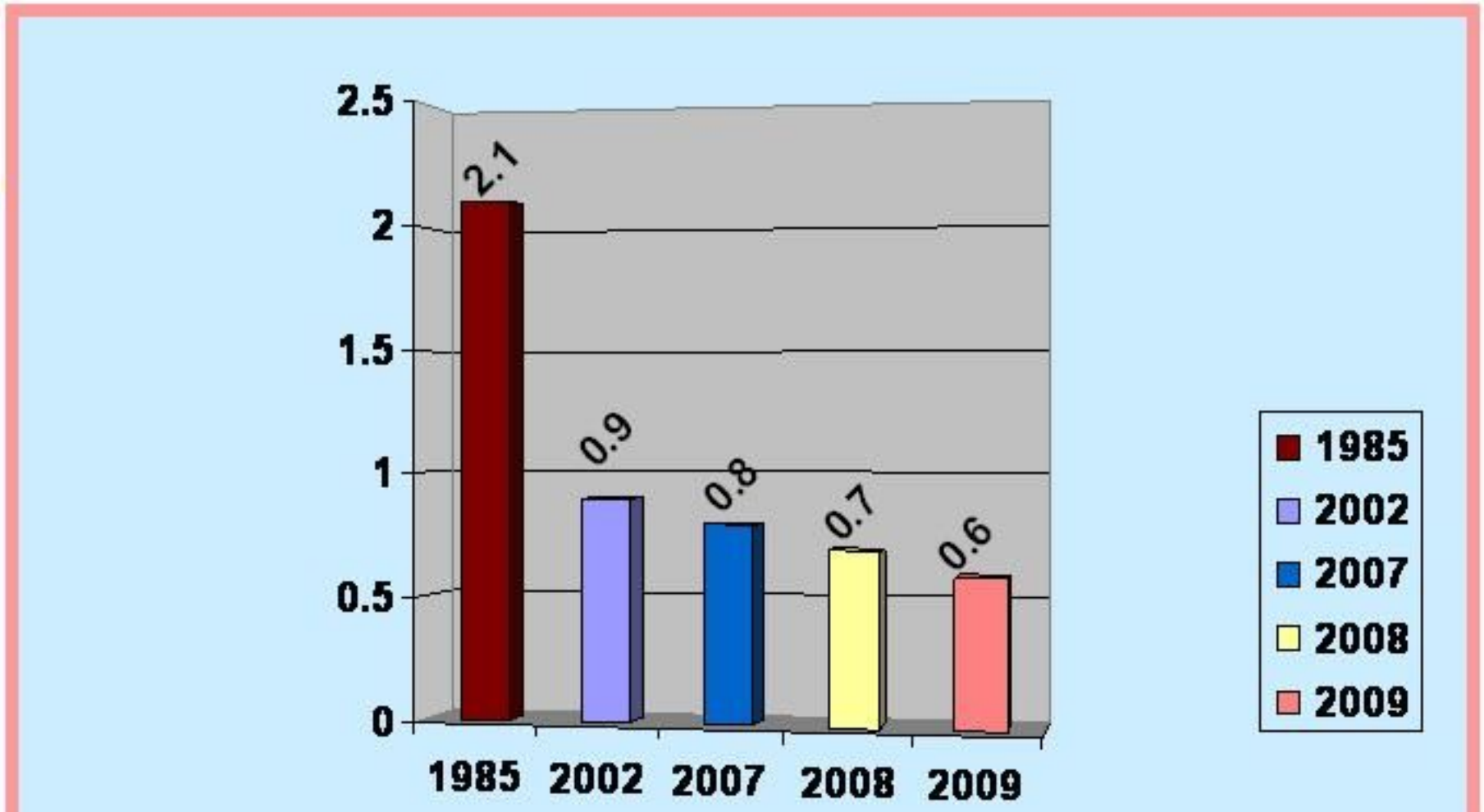
Percentage of SCD among newborn 2007

Year	Percentage Of SCD
1985	2.1%
2002	0.9%
2007	0.8%

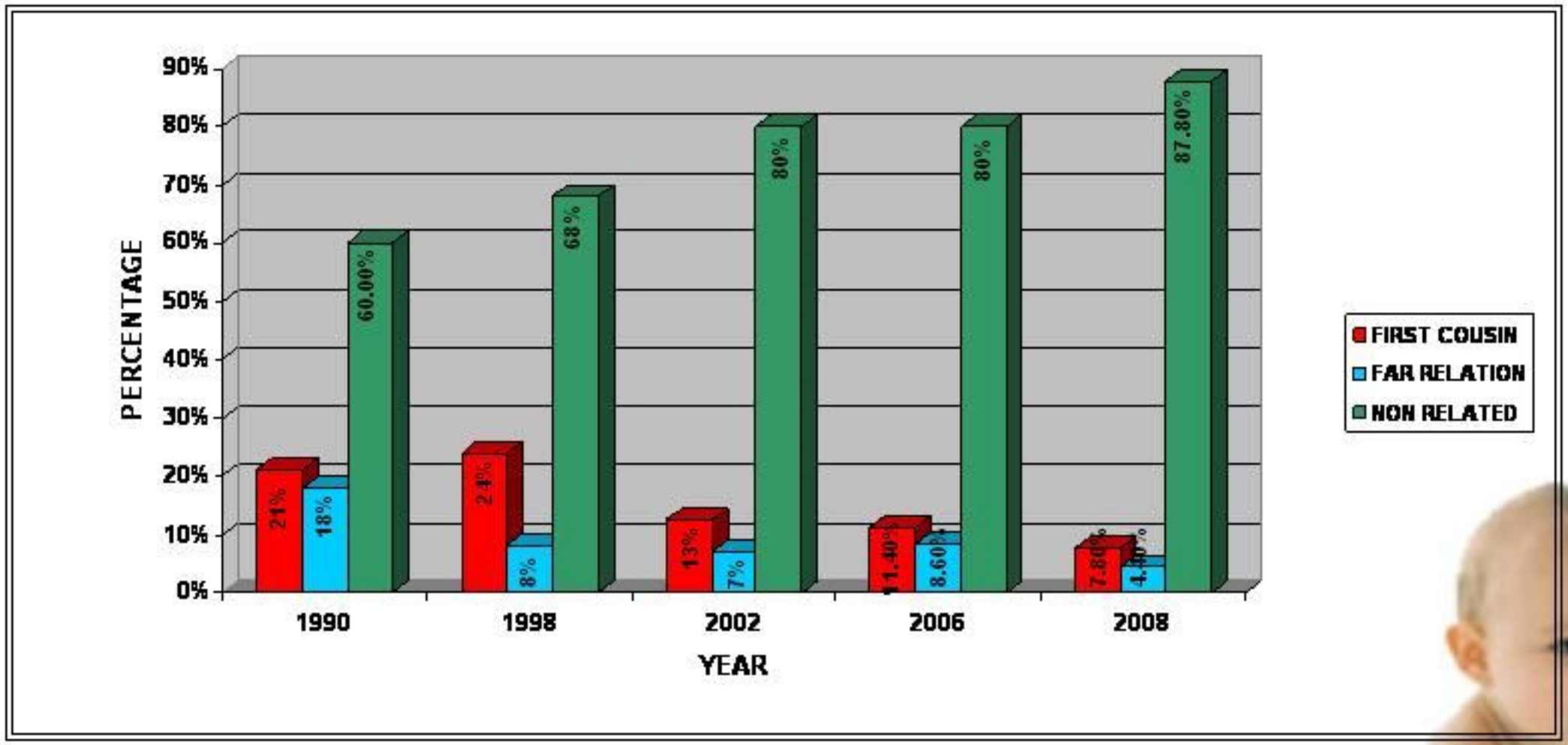


Percentage of SCD among newborn

YEAR	1985	2002	2007	2008	2009
PERCENTAGE OF SCD	2.1%	0.9%	0.8%	0.7%	0.6%



Consanguinity rate in Bahrain 1999-2008



Conclusion:

- For the first time, Bahrain has recorded 0.6% of newborns with SCD.
- This is a success story for both the Ministry of Health in Bahrain, the Bahrain Hereditary Anemia Society and all those involved in this campaign.

Conclusion:

The ethical legal social issues have been implemented during the campaign to control GDB in Bahrain.

The campaign gets support of the community and the policy makers, and was successful in reducing the rate GBD in the country.

More efforts are needed to reduce the rate of other genetic diseases, and to improve services for patients taken in consideration all the ELSI.

شكرا

Thank You