

Education role of genetic centers: A Moroccan experience

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Aims and Objectives ?

to bring back the experiment of a Moroccan genetic service in
genetic counselling and information

- What we learned from moroccan families needs
- What we are currently able to offer to them
- What it would be necessary to improve healthcare of genetic diseases in our country

Who are we and What about our mission?

Public service dedicated, since 1990, to medical genetics with five
major missions:

- To provide genetic counselling and information regarding hereditary diseases
- To offer a consultation and an expertise in the field of dysmorphology
- To set up and use genetic methods to investigate hereditary diseases
- To contribute to education, Teaching and training in medical genetics
- To take part in genetics research



Our experiment enables us to appreciate the needs and requests of
the families

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Who are the persons referred to our center?

- Arabo-berber Moslem homogeneous population from different regions of Morocco
- High risk of inherited genetic diseases
 - High consanguinity rate
 - Advanced maternal and paternal age
 - Large families size
 - Low Knowledge in genetics / Well informed couples
 - Access to genetic service limited
- Low or moderate socio economical level / High level

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For which type of pathologies?

- Common genetic disorders and rare diseases which require adapted answers
- Responsible for a major proportion of severe physical and mental handicaps
- Heavy medical care with high economic cost
- Lack of public health measures (out of health system priorities)
- Diagnosis are sometimes difficult to establish: patients referred for pathologies not clearly identified and require specialized analyses often not available in Morocco

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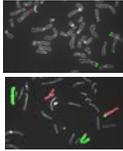
General contexte

- Largely mediatized progress in genetic research with many medical applications
- Universalization of some genetic services offered in particular by laboratories installed in developed countries

Proposals to families at genetic risk depends on:

- Progress in research and medical care
- Possibilities offered by our health system
- The means which the family can engage to finance the strategy suggested
- Our network of collaborators

46,XX,-7,+der(7)(t(6;7)(p22;q32))pat



How to improve genetic services to prevent and control genetic diseases ?

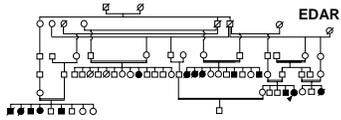
Recommendations for developing strategies for prevention of genetic diseases ?

to sensitize the policy-makers to develop a national strategy for Integrating prevention and care of genetic diseases into public health policy

To set up national programmes with preventive measures against the factors contributing to an increased frequency of genetic disorders

Consanguinity and high risk of genetic diseases

50% of couples referred to our consultation of genetics (22% of Down syndrome parents)

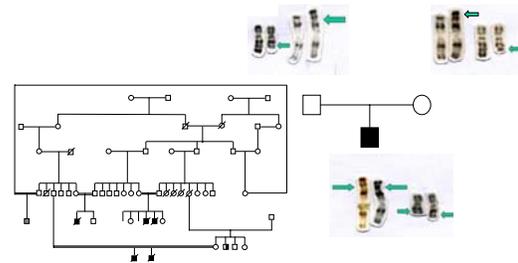


Moroccan pedigree showing high level of consanguinity and several affected children

- Account for a high prevalence of autosomal recessive diseases, some are rare or exceptional
- Education of the population should be with much of tact
- Acting firmly when families have a high risk
- Encouraging research to identify rare syndrome genes by homozygote mapping

Consanguinity and new syndromes

Large Moroccan family with autosomal recessive microcephaly syndrome co-segregating with a homozygous balanced translocation t(3;10)(p24;q22)

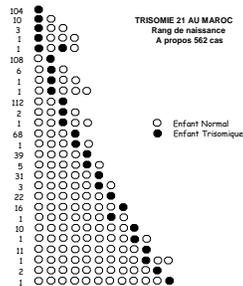


Wich strategy to prevent chromosomal disorders?

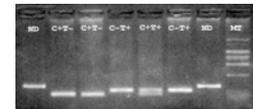
High proportion of births to older mothers

Couples got married young, family sizes were usually large with last children born at an advanced maternal age

Marriages are currently later



The development of clinical genetic services, based on easily transferable applications of DNA technology instead of conventional approaches could provide immediate benefits to health care

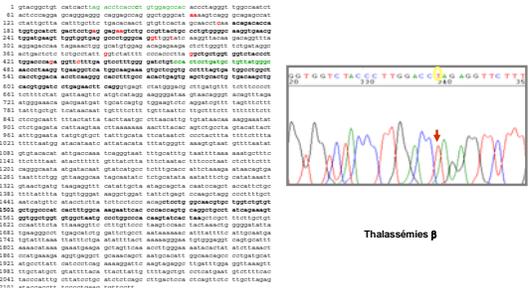


ARMS-PCR in Spinal muscular atrophy (SMN1 gene deletion)

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Education of public and a better access to updated informations

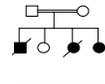
To understand the significance of genetic diseases

- Can occur with no family history
- Everyone of us carries several abnormal genes
- The concept of probability and mendelian inheritance
- Correcting the wrong ideas and perceptions

Education of public and a better access to updated informations

To reassure and avoid psychological distress when risks are not justified

to propose to couples, if possible, a prevention strategy when the genetic risk is real and high



TAR syndrome

Education of public and a better access to updated informations

To support wise decisions when couples with a high risk of inherited genetic disease in their offspring decide not to undertake a further pregnancy because they had already healthy children



Education of public and a better access to updated informations

To explain the significance of the tests performed during pregnancy

- Caryotype is not useful to detect monogenic disorders
- Maternal serum test is not diagnosis test of trisomy 21
- No test guarants the health of the future child

Infrastructures and training policy

- Strengthening the existing genetic services which require physicians well-trained in clinical, chromosomal and molecular genetics
- to improve understanding of genetic diseases among the other physicians and primary healthcare personnel
- To encourage the training by research, within international networks, on genetic diseases in the Moroccan population
- Raising the level of genetics teaching in medical schools
- Efforts should be made to increase public awareness of progress in genetics through mass media educational campaigns

Socio-cultural, ethical and religious considerations

What becomes the concept of curable diseases when the couples have no possibility to access to treatments

The femal carrier status for recessive X linked diseases must be explained to the couple with much ability and prudence

Promoting debate on prenatal diagnosis and selective termination of pregnancies: A health policy which would encourage the antenatal diagnosis should act for amending the law and allow selective termination of pregnancy for severe genetic diseases

Conclusion

Because of the time required to set up an efficient strategy for prevention of genetic diseases in Morocco

And

Because of the speed of development and discovery in genomics

it is important that this process starts with simple and low cost mesures without delay