

Protocol
for the prevention of blindness programme in
the west Bank and Gaza Strip

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INTRODUCTION

Following my preliminary recommendations (21.4.1987) for a Programme for the Prevention of Childhood Blindness in the West Bank and Gaza Strip, I have endeavoured to set out in more detail the aspects that would need to be covered by such a programme.

It must be re-emphasised that this prevention programme is aimed at combating childhood blindness in the population of the West Bank and Gaza Strip. The main cause of this blindness is basically genetic in origin and specific to the areas defined because of the immobility of the population and social customs inherent in the society. It is a very different situation from that found in populations where the blindness is basically acquired (ie trachoma, river blindness, vitamin A deficiency etc). As such a prevention programme cannot feasibly be undertaken as a short term project (e.g by such means as a drug campaign) it will only be achieved by commencing the programme from several different approaches and gradually building on these over a period of time and with the aid of continual reassessment to achieve the final goal.

APPROACHES

There would be four principle approaches involved in the Programme and these will be as follows:-

- A) Patients Follow Up
- B) Educational campaign
- C) Genetic screening
- D) Associated Aspects

Whilst it is planned that all four areas of work will be commenced simultaneously, it will obviously require a much longer period of time to assess the success of the Educational Campaign. This success will be measured by a study of the origin of marriage partners after a specific period of time and whether there has been a significant decline in the rate of consanguineous marriages and a consequent decline in the number of children affected by blindness of genetic origin. This aspect of the prevention programme is, however, essential as a means of eradicating childhood blindness and, therefore, the visual well-being of the future generations in this population. It is intended that the work will commence on a selected number of families and patients and be expanded when more finances become available.

A) PATIENTS FOLLOW UP

This would involve a combined effort between ophthalmologists, paediatricians, ophthalmic/paediatric hospitals, social workers/health visitors etc. and the Programme can be commenced as soon as the appropriate staff (e.g social worker/health visitors) has been appointed.

In addition to those cases already referred from my research, also included would be new cases referred by the ophthalmologist with conditions where neglect could lead to blindness such as congenital cataract and glaucoma together with cases referred by the paediatricians and other institutions (e.g blind schools).

The practical application of this would be as follows:-

- 1) The doctor or the hospital would initially contact the Programme secretary to give details of the patient.
- 2) The patient would be provided with a standardised letter or card which contained full details including instruction and advice on treatment, glasses or any other requirement.
- 3) The Programme will then send a health visitor to visit the patient and the family for the purpose of follow up, education and detailed family information and genealogy trees on new referrals (these already exist for my patients).
- 4) Where necessary, the Programme will provide financial help to the family for the purchase of glasses, contact lenses (and their replacement), medications etc. where the family cannot afford the cost.
- 5) The Programme will keep the ophthalmologist informed on the patient's progress and on such matters as the wearing of glasses.
- 6) The Programme will keep full records on patients and pedigrees and these will be used for the periodic assessment of the Programme with pedigrees being continually updated in terms of changing marriage/social patterns. These changing patterns would include marriage partners being taken from a wider geographical area and from outside the family; a lowering or raising of the marriage age; numbers of children being conceived and number of live births. This last factor is of importance as there are very few statistics at present giving accurate information about neonatal mortality. This is especially so in the poorer families and rural areas where very often women are not admitted to hospital following miscarriages.
- 7) In respect of those cases which are genetic in origin, the programme will arrange for the appropriate genetic screening to be performed in the nearest participating laboratory centre.

The health visitor would ensure that:-

- 1) Treatment is being received by the child as indicated.
- 2) Glasses are worn as instructed and instruction is given to the family in how to handle contact lenses.

- 3) Where families cannot afford the medication and glasses, financial assistance is arranged.
- 4) Instruct parents in how to use the medications prescribed, and carry out other aspects of education such as the dangers of consanguineous marriage.
- 5) In cases when special diet is required, the health visitor should check on this and approach the appropriate person who can oversee it and, if necessary financial help may be required.
- 6) Any other aspects or additional requirements could be reassessed and added as and when the need arises.
- 7) It is also anticipated that the social worker will participate in performing some of the above duties as her timetable allows.

B) EDUCATIONAL CAMPAIGN

This would be one of the major elements of the prevention programme which effects would be long-term and would be measured through the marriage pattern of the continually updated family records of those registered on the Programme.

The principal of this aspect is to raise the level of social awareness in respect of the effects of consanguineous and single village based marriages.

The programme would be divided into:-

a) Mass Education

1. Families (individual and extended i.e Hamoula).
2. Society at large.

b) Specialist Education

1. Paramedics Training.
2. Medical Personnel.

a) Mass Education:-

Educational programme needs the co-operation and services of the widest range of personnel and facilities. It is also hoped that other organisations would follow our example and cover a wider range of topics on other avoidable handicaps. The educational topics should cover the following areas;

Instruction and advice on:-

- 1) Consanguinity and its harmful effects.
- 2) The invisible consanguinity from marrying from within the same village and immobile community which in effect creates a large pool of heterozygous genes.
- 3) Causes leading to the high incidence of unilateral blindness caused by trauma and accidents in children.
- 4) General instructions regarding eye care etc.
- 5) Genetic counselling would be required to explain the risks involved in consanguineous and village based marriages. Such counselling would include:-
 - a) In the affected family - The risks involved in producing other children affected by the same condition and the detection of carriers and their risks of producing affected children.
 - b) The risks of spreading the pathologic genes within the society.

This aspect would be effected by:-

- 1) Visiting the families with the affected members (as above). This would be carried out by the social worker in co-operation with the health visitor.
- 2) Lectures in the villages by the health visitor and the social worker and any other suitably qualified volunteers. Other organisations working in similar fields who already have established educational programmes could also be asked to participate by including our educational material in their lectures. It is hoped that a full time health educator appointment could be made if the Programme expands.
- 3) Approaching prominent people in the communities heavily affected with congenital problems to explain the magnitude of the problem, such as the Mukhtar (village heads), the village councils.
- 4) Approaching religious leaders to propagate the inherent problems of the immobile society affecting all religious sects and communities, and the problems of consanguineous marriage.
- 5) Media such as the newspapers, radio and television.
- 6) Posters and leaflets explaining the various problems such as blindness and retardation.
- 7) Approaching the education authorities to encourage the new generations to rethink the old social and family traditions.

b) Specialist Education

i) Paramedics Training:-

Paramedics and field social workers should similarly be trained by a series of lectures and attachments to the appropriate centres such as eye and paediatric hospitals, laboratories etc.

ii) Medical Personnel:-

Medical personnel would need to be alerted to the dangers and incidence of genetic problems in the society. This could be achieved by means of lectures by specialist personnel, and reprints and circulars from local and international research projects on similar subjects. The Programme should arrange to keep such material at their headquarters and circulate reports on the progress of the Programme to medical personnel.

Educational Material

Lectures on selected topics are to be prepared jointly and in consultation with the Ophthalmic Advisor and should be presented in an audio-visual form. Also leaflets, posters etc. for distribution are to be prepared jointly and to use comparative photographic methods i.e normal and abnormal to give maximum impact.

C) GENETIC SCREENING

This element of the Programme is reliant upon referrals of new patients to the Programme from a variety of sources and their investigation and follow up by the appropriate bodies. This will require the continuous liaison and co-operation of several bodies between the Programme and individuals and the bodies involved. This will be the responsibility of the project Director.

Those involved will include:-

1) Source of referrals -

Ophthalmologists, paediatricians, hospitals and clinics throughout the country who will refer patients for screening.

2) Centres for study -

Geneticists, laboratory specialists, hospitals, and universities (for genetic expertise and laboratory facilities), and in some instances in co-operation with medical societies and associations for support.

3) Associated Bodies -

a) Social Services Departments to assist in providing social workers to

help the programme who in turn will feed back the information to help them in assisting these communities and families in their problems.

- b) University for volunteers for the educational element and questionnaires as part of their practical courses and also during their vacations together with computer analyses.
- c) It is also intended that approaches be made to bodies such as United Nations and charitable organisations, especially those working with children, for additional support.

Principles of genetic work:

As mentioned in the previous section, multicentre co-operation is essential if the principles of the programme are to be achieved. The following is an outline of the basis of the genetic screening programme:-

- 1) Screening for associated biochemical findings and the heterozygous states in the individual families and the society at large. (To be done by regional hospital laboratories and some universities).
- 2) Specific genetic analysis such as gene probing. (To be done in the future by Najah University who are willing to finance a member of their staff for a period of training in the UK). At the present time selected blood samples will be sent to the Medical Research Council Trials in Edinburgh.
- 3) Genealogy trees of affected families to assess the pattern of inheritance (this part is completed by my work on the causes of visual impairment), but new cases should be assessed using the same protocol. This will be the responsibility of the Programme's social worker and when necessary with the help of the health visitor.
- 4) Genetic counselling for affected families. This will be arranged by the Project Manager.

D) ASSOCIATED ASPECTS

- 1) The Programme will be responsible for providing, free of charge, visual aids and medications for the children affected to those families in hardship.
- 2) Other genetic problems encountered during the screening e.g deaf mutism, mental retardation and any other handicap, will be referred to the appropriate body.

- 3) The Programme should be responsible for enlightening the authorities into the causes of the high incidence of unilateral blindness.
 - a) This should include cases that caused by trauma and due to children playing in filthy streets amid dangerous rubbish. This basically is due to the absence of supervised playing areas, nurseries and kindergarten. Municipalities, village councils and societies should be encouraged to build such facilities and make sure they will not end up as dumping places for rubbish, empty cans and broken bottles and glass.
 - b) In addition parents and chemists should be advised about the dangers of using medications and traditional substances not medically prescribed. At the present time it is common practise for chemists to "prescribe" a course of treatment.

GEOGRAPHICAL ORGANISATION

In order to facilitate the efficiency of the Programme it is planned that the work be divided between four geographical regions. It is intended that these regions will, with time, be self sufficient in being able to carry out the basic elements of the Programme. That is, they should each have their own social workers, health visitors, educational programme and screening service for the common screening tests. The more specialised work will be performed in a specific centre where more sophisticated facilities are available.

The regional centres will be:-

- 1) Northern Region: Nablus, Jenin and Tulkarem,
- 2) Central Region: Jerusalem, Ramalla, Jerico and Bethlehem
- 3) Southern Region: Hebron.
- 4) Gaza Strip.

It is intended that representatives from each of the regions will serve on the Programme Committee.

PROGRESS ACHIEVED SO FAR

- 1) The Programme will be provided with the relevant information on 350 pedigrees and the names of 550 patients.
- 1) Makasid Hospital- Jerusalem has been approached and they have agreed to the use of their laboratory facilities for the chemical analyses and electrophoresis. In addition, they currently have one technician being trained abroad and he will be prepared for the type of work we require.
- 3) Najah University- Nablus has expressed an interest in the Programme and is willing to take the responsibility for the biochemical screening and

the advanced genetic work required. They have agreed to send the Head of the Biology Department (who already has a postgraduate degree in genetics) to the UK for further practical training on gene probing.

- 4) The Computer Department at Bethlehem University and the Department of Biological Anthropology at Oxford University, have offered the use of their computer facilities for programming and data analysis and have already started work on one of the major families. (This should not preclude the necessity of the Programme purchasing its own computer). The Department of biology and Human Anatomy at King College, London (Dr A.Bittles) have also offered their assistance in respect of advice on genetic screening.

FUTURE PLANNING AND RECOMMENDATIONS

- 1) As mentioned previously, it is hoped that each region should have its own team when funds allow.
- 2) Given the amount of information anticipated, it would be advisable for the data to be stored on computers. I am in the process of arranging a genetic computer programme that will be ideal for the situation. It is strongly recommended that the Programme should have its own computer as a matter of urgency.
- 3) It is hoped that the Programme should continue to function side by side with the other medical and ophthalmic services. Results of this work should be published periodically as and when they are accumulated. This academic part of the work would provide continuous evaluation of the Programme's achievements and would demonstrate any fall in the incidence of genetic disorders in the population. The family history and pedigree charts would also give valuable information on changing social patterns.
- 4) As many of these families are spread into the East Bank and there are similar factors which would suggest the presence of a comparable problem there, it is hoped that this programme may extend to the East Bank and preferably be preceded by a screening programme on the blinding conditions of childhood.

IN CONCLUSION

This protocol sets out the steps that are required to accomplish the Prevention Programme. Practically, we intend to commence within the limits of the funds and staff available. In time we hope to gather more expertise and funds to expand the Programme in a scientific and well planned manner that will maximise the impact of the Programme upon this population.

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