Down syndrome in Africa. Our policy

In the past, it was believed that the African continent was devoid of Down syndrome babies who are normally called ‘‘imbeciles.’’ The 1958 WHO collaborative study of congenital malformations, recorded no case of Down’s syndrome in Alexandria, Egypt, or in the Cape Town coloured community in South Africa.

However, Out of 2068 consecutive deliveries studied by Simpkiss and Lowe in Uganda, only one case of Down's syndrome was recorded. Yet from the same institution, Luder and Musoke in 1955 and Leather and Leather in 1957 reported five and one cases, respectively. Hassan, working in Sudan, reported 30 cases in 1962. Studies of Down's syndrome covering a period of 9 years revealed an incidence of 1 in 865 live births in a Nigerian hospital.

So the believe that there is no Down syndrome in African has been proven wrong. Although medical practitioners in Sub-Saharan Africa may be overwhelmed with infectious diseases, the prevalence of chromosomal and other structural abnormalities is likely to be more in Africans than in any other race. This is because of the uncontrolled environmental hazards in different parts of the continent and lack of genetic counselling which should prevent the occurrence of some of those disorders.

Societal attitude toward parents of people with Down syndrome is totally negative in Sub-Saharan Africa. Society defines these babies by their outward appearance and by what they cannot do rather than what they can do. The children are stigmatised and relegated on the basis of some obscenity myth and tradition. They are sometimes killed because they are considered to be a course to their family.

Unfortunately, unlike some of the developing countries in other parts of the world, in the Sub-Saharan Africa, screening test for Down syndrome is performed sporadically only in South Africa and Kenya. Our NGO ‘‘African Women’s Health Foundation’’ therefore renders the following services with respect to Down syndrome on the African continent:

- Educational campaign about Down syndrome with particular attention to Sub-Saharan Africa. We do this by issuing information leaflets on the subject, giving lectures, referring women and parents to our website which is enriched with information about it, giving TV presentation and educating doctors and midwives on the subject.

- We offer prenatal diagnosis for Down syndrome at a subsidised rate. We also educate doctors and midwives on the need for prenatal diagnosis. The main obstacle that we face is the financial implication involved. Only few can afford to pay for the combined test (ultrasound and blood test) and the new test “cell- free DNA in maternal blood” which is not offered on the African continent. Another problem is that of cultural barrier in some African population, which prevents women from consenting to a prenatal diagnostic test. The reason they give is that even if the test is positive, their tradition does not permit them to terminate a pregnancy.

- We are in the process of introducing a new cheap and affordable screening programme that is based on ultrasound assessment alone; this removes the blood tests, which are expensive. The new screening method which has been practised in Europe in the past (please see the article under “Research and Publication” on this website) should be able to detect up to 90% of babies with Down syndrome with a false positive rate of 5 out 100 positive cases.
The African Women’s Health Foundation is in the process of collaborating with the only one Down syndrome Association in West Africa, based in Lagos, Nigeria. We will be working on the modalities of caring for babies born with Down syndrome in The Niger Delta area of the country.

We also engage in research projects in collaboration with established research institutions abroad.

On the website, under ‘research and publication’ we have uploaded some educational material on Down syndrome. Please feel free to read them.

Sources


- Nicolaides KH. Screening for fetal aneuploidies at 11 to 13 weeks. Prenat Diagn 2011; 31:7-15

- Screening and diagnostic tests for chromosomal abnormalities M. Abbey (Fellow Fetal Medicine, FMF UK; MRCOG, PhD O&G, DMAS, VRACH /MBBS.). Clinical Research Fellow, Barts Health NHS Foundation Trust
