WORLD HEALTH ORGANIZATION
Regional Office for the Eastern Mediterranean
ORGANISATION MONDIALE DE LA SANTE
Bureau régional de la Méditerranée orientale

بسم الله الرحمن الرحيم

منظمة الصحة العالمية
المكتب الإقليمي لشرق المتوسط

In the Name of God, the Compassionate, the Merciful

Address by

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WHO EASTERN MEDITERRANEAN REGION

to the

THE INTERNATIONAL CONFERENCE ON SICKLE CELL DISEASE MANAGEMENT AND PREVENTION

Bahrain, 5–7 February, 2013

Your Excellency,
Distinguished speakers,
Guests and Colleagues,

It gives me great pleasure to join you today for The International Conference on Sickle cell Disease Management and Prevention under the theme “Hand in hand towards a better life for sickle cell disease patients”. Let me take the opportunity to thank the Government of Bahrain for inviting me and to congratulate you all on the great achievements in this field which have helped in building a momentum in the Region to provide quality of care to those living with the disease and their families.

Ladies and Gentlemen,

Sickle cell disease and other genetic blood disorders have significant presence in many countries of the Eastern Mediterranean Region. Several countries of the Region have a high prevalence of thalassaemia and lie in the ‘thalassemia belt’. Many of these countries also have focal areas of high sickle cell (trait or disease) prevalence. While Bahrain has achieved a decline of around 60% in the frequency of births with sickle cell disease (from 2.1% reported in 1984-85 to 0.9% in 2002), carrier rates for haemoglobinopathies in the Region vary from

2% to 7% for beta-thalassaemia, 2% to 50% for alpha-thalassaemia and 0.3% to 30% for sickle-cell disease.

Sickle cell anaemia and other haemoglobin disorders have major social and economic implications for the individuals affected, as well as their families. Recurrent sickle-cell crises interfere with the patient's life, especially with regard to education, work and psychosocial development, and lead to premature death and disability.

Despite the huge burden of these diseases in many countries in the Region, prevention and control programmes are challenged in most countries by a number of common factors. These include insufficient commitment and priority to preventive programmes. High consanguinity rates, coupled by large family size, are the trigger for the large number of haemoglobin and genetic disorders in the Region. Lack of adequate epidemiological data and research on genetic diseases, including haemoglobin disorders, together with inadequate surveillance systems and registries of haemoglobinopathies and common genetic diseases also constitute a huge challenge in most low and middle-income countries of the Region. Screening and management have received limited attention from health authorities, while those affected lack the information and proper management that would ease the burden on them.

Recognizing the huge burden of this genetically determined disorder in the Region, the Regional Office undertook a number of initiatives, working jointly with affected countries. I was involved in a number of initiatives when I was with the Regional Office in the 1990s including: the setting up of a regional task force to determine the regional situation and priorities for prevention; a consultation on community genetic services at which preventive strategies were discussed; and clear strategic directions for the prevention and control of genetic and congenital disorders in Member States in the publication "Community control of genetic and congenital disorders".

At the global level, the governing bodies of WHO adopted two resolutions in 2006 on haemoglobin disorders: a resolution on sickle-cell disease which was adopted by the 59th World Health Assembly and a resolution on thalassaemia which was adopted by the 118th WHO Executive Board. These resolutions called upon affected countries and the Secretariat of WHO to strengthen their response, focusing on increasing awareness of the community regarding the burden of these disorders; promoting equitable access to health services and promotion of and support for research to improve the quality of life of the affected individuals. In addition, a resolution on the prevention and management of birth defects,

including those due to sickle-cell disease and thalassaemia, was adopted by the 63rd World Health Assembly in May 2010.

In recent years, the Regional Office, in collaboration with other international partners like the Centers for Disease Control and Prevention (CDC), Atlanta and Member States established a task force of prominent regional experts, including from Bahrain, to review the regional situation and establish a regional framework for action.

Ladies and Gentlemen,

WHO's focus is on: scaling up community genetic services and integrating preventive measures into primary health care systems to reach all those in need with equity and quality; strengthening the surveillance programme; and encouraging collaboration among Member States in the fields of clinical and diagnostic laboratory genetics services. Such measures will ensure a substantial reduction in the number of children born with haemoglobin disorders.

Your deliberation and inputs will definitely enrich the conference and advance the agenda on prevention and control of these disorders.

I wish you a very successful conference.

Thank you.