EB118.R1   Thalassaemia and other haemoglobinopathies[1]

The Executive Board,

Having considered the report on thalassaemia and other haemoglobinopathies;[2]

Recalling resolution WHA57.13 on genomics and world health, resolution EB117.R3 on sickle-cell anaemia, and the recognition by the Executive Board at its 116th session of the role of genetic services in improving health globally and in reducing the global health divide;[3]

Concerned at the impact of genetic diseases, and of haemoglobinopathies (thalassaemia and sickle-cell anaemia) in particular, on global mortality and morbidity, especially in developing countries, and by the suffering of patients and families affected by the disease;

Recognizing that the prevalence of thalassaemia varies between communities, and that insufficient epidemiological data may hamper effective and equitable management;

Deeply concerned that thalassaemia and other haemoglobinopathies are not recognized as priorities in public health;

Deploring the current worldwide lack of access to safe and appropriate genetic services;

Aware that effective programmes for thalassaemia must be sensitive to cultural practices and appropriate for the given social context;

Recognizing that the management of haemoglobinopathies, particularly prenatal screening, raises specific ethical, legal and social issues that require appropriate consideration,

1.   URGES Member States:

(1)   to design, implement and reinforce in a systematic, equitable and effective manner, comprehensive national, integrated programmes for prevention and management of thalassaemia and other haemoglobinopathies, including surveillance, dissemination of information, awareness-raising and screening, such programmes being tailored to specific socioeconomic and cultural contexts and aimed at reducing the incidence, morbidity and mortality associated with these diseases;

(2)   to develop their capacity to monitor thalassaemia and other haemoglobinopathies and to evaluate the impact of national programmes;

(3)   to intensify the training of all health professionals in high-prevalence areas;

(4)   to develop and strengthen medical services, within existing primary health-care systems, in partnership with parent or patient organizations;

---

[1] See Annex 2 for the administrative and financial implications for the Secretariat of this resolution.

[2] Document EB118/5.

[3] See document EB116/2005/REC/1, summary record of the first meeting, section 4.

(5)   to promote relevant community education, including health counselling and ethical, legal and social issues associated with haemoglobinopathies;

(6)   to promote international cooperation in combating haemoglobinopathies;

(7)   to provide support for basic and applied research on thalassaemia, in collaboration with international organizations;

2.   REQUESTS the Director-General:

(1)   to raise awareness of the international community of the global burden of thalassaemia and other haemoglobinopathies, and to promote equitable access to health services and medicines for prevention and management of these diseases;

(2)   to provide technical support and advice to Member States in framing of national policies and strategies for prevention and management of thalassaemia and other haemoglobinopathies;

(3)   to promote intercountry collaboration in order to expand the training and expertise of personnel, and to provide support for the further transfer of affordable technologies and expertise to developing countries;

(4)   to continue WHO's normative functions by drafting guidelines on prevention and management of thalassaemia and other haemoglobinopathies;

(5)   to promote research on thalassaemia and other haemoglobinopathies in order to improve the duration and quality of life of those affected by such disorders;

(6)   to consider setting the theme of haemoglobinopathy diseases such as thalassaemia and sickle-cell anaemia for a World Health Day in the near future.

(Second meeting, 29 May 2006)