

WHA59.20 Sickle-cell anaemia

The Fifty-ninth World Health Assembly,

Having examined the report on sickle-cell anaemia;¹

Recalling resolution WHA57.13 on genomics and world health, and the discussion of the Executive Board at its 116th session on control of genetic diseases, which recognized the role of genetic services in improving health globally and in reducing the global health divide;²

Recalling decision Assembly/AU/Dec.81 (V) of the Assembly of the African Union at its Fifth Ordinary Session;

Noting the conclusions of the 4th International African American Symposium on sickle-cell anaemia (Accra, 26-28 July 2000), and the results of the first and second international congresses of the International Organization to Combat Sickle-Cell Anaemia (respectively, Paris, 25-26 January 2002 and Cotonou, 20-23 January 2003);

Concerned at the impact of genetic diseases, and of 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 sickle-cell anaemia varies between communities, and that insufficiency of relevant epidemiological data may present a challenge to effective and equitable management;

Deeply concerned at the absence of official recognition of sickle-cell anaemia as a priority in public health;

Recognizing the current inequality of access to safe and appropriate genetic services throughout the world;

Recognizing that effective programmes for sickle-cell anaemia must be sensitive to cultural practices and appropriate for the given social context;

Recognizing that pre-natal screening for sickle-cell anaemia raises specific ethical, legal and social issues that require appropriate consideration,

1. URGES Member States in which sickle-cell anaemia is a public health problem:

(1) to design, implement and reinforce in a systematic, equitable and effective manner, comprehensive national, integrated programmes for the prevention and management of sickle-cell anaemia, including surveillance, dissemination of information, awareness-raising, counselling and screening, such programmes being tailored to specific socioeconomic, health system, and cultural contexts and aimed at reducing the incidence, morbidity and mortality associated with this genetic disease;

¹ Document A59/9.

² See document EB116/2005/REC/1, Summary record of the first meeting, section 4.

- (2) to work to ensure that adequate, appropriate and accessible emergency care is available to persons living with sickle-cell anaemia;
- (3) to develop their capacity to evaluate the situation regarding sickle-cell anaemia and the impact of national programmes;
- (4) to intensify the training of all health professionals and community volunteers in high-prevalence areas;
- (5) to develop and strengthen systematic medical-genetics services and holistic care within existing primary health care systems, in partnership with national and local government agencies and nongovernmental organizations, including parent or patient organizations;
- (6) to promote relevant community education, including health counselling and ethical, legal and social issues;
- (7) to promote effective international cooperation in combating sickle-cell anaemia;
- (8) in collaboration with international organizations, to provide support for basic and applied research on sickle-cell anaemia;

2. REQUESTS the Director-General:

- (1) to raise awareness of the international community of the global burden of sickle-cell anaemia, and to promote equitable access to health services for prevention and management of the disease;
- (2) to provide technical support and advice to Member States through the framing of national policies and strategies for prevention and management of sickle-cell anaemia;
- (3) to promote and support:
 - (a) intercountry collaboration to develop training and expertise of personnel, and the further transfer of advanced technologies and expertise to developing countries;
 - (b) the construction and equipment of referral centres for care, training and research;
- (4) to continue WHO's normative functions by drafting guidelines, including good practices and practical models, on prevention and management of sickle-cell anaemia with a view to elaborating regional plans and fostering the establishment of regional groups of experts;
- (5) to promote, support and coordinate the research needed on sickle-cell disorders in order to improve the duration and quality of life of those affected by such disorders.

(Ninth plenary meeting, 27 May 2006 –
Committee A, fourth report)