



SUMMARY REPORT

THE FIRST INTERNATIONAL CONFERENCE ON BIRTH DEFECTS AND DISABILITIES IN THE DEVELOPING WORLD

Johannesburg (South Africa)

6 - 10 August 2001

www.publichealth.uct.ac.za/bd1.htm

The South African Department of Health hosted the First international Conference on Birth Defects and Disabilities in the Developing World from 6 - 10 August 2001 in Johannesburg, South Africa.

Partners were - World Health Organization (WHO); UNICEF; World Alliance of Organizations for the Prevention of Birth Defects (WAOPBD); and the March of Dimes. Support was also obtained from the Centers for Disease Control and Prevention (CDC) as well as New Zealand Aid.

More than nineteen countries from six continents were represented at this first international conference on birth defects and disabilities in the developing world.

This conference was conceptualized at a workshop of the World Alliance of Organizations for the Prevention of Birth Defects” (WAOPBD) held during the 24th annual meeting of the International Clearinghouse for Birth Defects Monitoring Systems (ICBDMS) in Cape Town, South Africa in November 1997. A WAOPBD declaration on the importance of birth defects in the developing world was drafted at that workshop.

Web reference: www.publichealth.uct.ac.za/waopbd.pdf

Follow-up workshops were held by WHO – one in January 1999 in the Hague, where experts involved in the delivery of genetic services in the developing world compiled a document on “Services for the prevention and management of genetic disorders and birth defects in developing countries” (WHO/HGN/GL/WAOPBD/99.1), and a second workshop held later in 1999 in Cairo where a document was produced entitled “Primary health care approaches for the prevention and control of congenital and genetic disorders” (WHO/HGN/WG/00.1).

The Minister of Health, South Africa, launched the first policy guidelines on genetic disorders and birth defects in South Africa during the opening ceremony of the conference. She indicated that minimum estimates for the birth prevalence of infants with serious congenital disorders are at least 7.3 million. In Sub-Saharan Africa alone, it is estimated that there are about 1.4 million children born with serious birth defects annually. Because of lack of services and facilities in the developing world, the proportion of children with chronic disabilities and birth defects that die early in life is great. The Minister emphasized the need for the developing world to embark on programs for the primary prevention of birth defects. She also stated that the management and prevention of birth defects did not belong to any one discipline nor was it exclusively a medical issue. She also encouraged conference participants to learn from each other about what models of care have been successful in various parts of the world and to consolidate this for the benefit of those with birth defects and disabilities.

Web reference: <http://www.info.gov.za/speeches/2001/010807945a1001.htm>

The South African Human Genetics policy guidelines outline the services that should be offered prior to conception; during pregnancy; at birth; in infancy and childhood; as well as in adolescence and adulthood. It also provides a guide as to how genetic services can be integrated into primary health care.

Reference: *Human Genetics policy Guidelines for the management and prevention of genetic disorders, birth defects and disabilities. Department of Health, Pretoria, South Africa, 2001*

Web reference: <http://www.doh.gov.za/docs/policy/humangenetics.pdf>

The conference program consisted of several major themes:

- Birth defect surveillance – methods from different countries as well as South African programs
- Medical genetics services – local needs and global strategies
See detailed discussion report by Prof. A Christianson
Web reference: www.publichealth.uct.ac.za/bd1genetics.pdf
- Ethics and human rights
- Community issues – including community visits
- Specialized sessions – Fetal Alcohol Syndrome, Neural Tube Defects

Some of the important outcomes from the first International Conference on Birth Defects and Disabilities in the Developing World were the following:

There is a need to know

- The extent of the problem of birth defects in developing countries
- Have locally relevant data for appropriate interventions
- Develop generic training material for developing countries which can then be adapted by countries according to their needs
- Genetic counseling be available even if resources for other services are limited
- Governments to set norms and standards for genetic services
- Involve communities in the planning, implementation and evaluation of genetic services as well as the allocation of resources

Full program: First International Conference on Birth Defects and Disabilities in the Developing World, 2001, Johannesburg South Africa

Web reference: www.publichealth.uct.ac.za/bd1program.pdf

Abstracts: First International Conference on Birth Defects and Disabilities in the Developing World, 2001, Johannesburg South Africa

Web reference: www.publichealth.uct.ac.za/bd1abstracts.pdf