



PLENARY 2B

**BIRTH DEFECTS FROM SURVEILLANCE TO PREVENTION:
CHALLENGES AND OPPORTUNITIES**

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KEY ISSUES TO HAVE A GOOD BIRTH DEFECTS SURVEILLANCE AND RESEARCH PROGRAM IN EARLY 2000S.

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Birth Defects Surveillance was born in part as a public health response to an international tragedy, the thalidomide epidemic of the late 1950s. Within a few years a number of programs for birth defects were created in Europe, the Americas and elsewhere in the world. Descriptive epidemiology and “monitoring” activities were the prevalent aims of these programs in the early years.

In last decades some of these programs have expanded their aims, including other research and public health functions: identifying causes, evaluating policies and services, assessing disease impact on morbidity and mortality. These aims should be pursued by all Birth Defects Programs.

At the beginning of the third millennium more and more Birth Defects Surveillance Programs should have the necessary resources to provide valid data; collect the complete set of information on risk factors; and perform a suitable follow-up of affected children. Moreover the registered cases should not be limited to “structural” birth defects but should include metabolic and functional congenital (or partly congenital) diseases (e.g.: congenital deafness, cerebral palsy, autism, cognitive impairment).

A new paradigm is highly needed to reach these aims, as well as radical changes and more investments in the Birth Defects Surveillance and Research Programs, in order to implement at least the following tools: (a) active registration of any kind of birth defects from multiple sources of ascertainment (including services where termination of pregnancies after a prenatal diagnosis of a birth defect are performed and services for diagnosis and treatment of children up to, at least, 7 years of life); (b) clinical genetic review of cases to be registered, in order to obtain the correct etiopathogenetic diagnosis and not a simple crude (and often vague) description of the defect(s); (c) collection of reliable prenatal information and blood samples from cases, as well as from healthy controls, for etiologic studies (mainly environment-genetic interaction studies using SNPs); (d) follow-up of infants with birth defects to evaluate their needs, their quality of life and the services answers.



A POPULATION HEALTH PERSPECTIVE ON BIRTH DEFECTS RESEARCH AND PREVENTION

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Efforts to prevent birth defects include medical and risk prevention interventions targeting individual women of childbearing age, as well as programs and policies designed to affect whole populations. Generally, goals of population health are to improve services and outcomes for whole populations, reduce health disparities within a population, and involve many sectors of society to accomplish these ends. Population health is not a new concept; it has been applied to health issues in a number of countries including many in Europe. However, it deserves more attention because of its promise for broad impact. This presentation will focus on population-level approaches to intervention programs to prevent birth defects, reviewing the work of international scientists and authors. It will review definitions of population health relevant for preconception care. Drawing on international examples, the presentation will review preconception care initiatives that target populations, including cross-national collaborations, cross-sector approaches within a population, legislative approaches, integrated care services, and national policies. The talk will also emphasize the need for new or alternative research and analytical methods for the study of population-level interventions for preconception care. Methodological challenges to be discussed include the development of measures appropriate for assessing interventions across whole populations, measurement of health disparities and other social determinants of health that influence intervention outcomes, standardization of measures across a population, and use of designs that can reveal the impact of population-level initiatives. The presentation will also cover ideas on initiating population health programs, the limitations of a population health approach, and the need to combine individual- and population-level interventions to reduce birth defects. Audience discussion will be encouraged.



PUBLIC HEALTH CHALLENGES IN CENTRAL AND EASTERN EUROPE

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Although the health status of the population in the Central and Eastern European Countries improved in the last decade, it still unfavorable compared to Western Europe and worse than expected based on their economical development. Premature mortality (i.e. before age 65 years) is still very high, it affects the economical competitiveness of these countries.

High premature mortality is related to the high burden of non-communicable diseases. The excess mortality and morbidity is mostly explained by environmental factors and the unfavorable lifestyle of the population, including cigarette smoking, unhealthy diet, lack of physical exercise and alcohol abuse.

Maternal and child health has been traditionally high on the health agenda in most of the countries in the region (e.g. vaccination coverage is very high). Since the 80s reduction of infant mortality has been in the focus by developing prenatal and neonatal health services. The programs were successful; in Hungary for example infant mortality was reduced from 35.89‰ (1970) to 6.23‰ (2005). Nevertheless, just like for other health indicators this country level indicator hides high health disparities within a population. Infant mortality rate varied between 3.6 and 9.7‰ in 2005 by counties.

Besides genetic counselling, preconceptive health is more or less a neglected area in Hungary. The high rate of abortion (463/1000 live births in 2006) shows that many pregnancies are unintended. The health of women of childbearing age is generally not a concern, (e.g. the very unfavourable trend of increasing smoking prevalence). The rate of all types of congenital anomalies monitored in Hungary is relatively high in the region (ca. 5500/1000000 live births in 2005), the occurrence of neural tube defects did not decrease in the last 10 years.

The positive trends in the health of the populations in the region of recent years are mostly explained by the social and economical development. It is a major challenge for public health professionals to find partners and together with them to put the health of the population higher on the political agenda and to get the necessary long term political and financial support to run effective public health programs that would speed up the slow positive developments.