Ukraine

History and funding
Population based birth defects surveillance began in 2000 in the framework of the Ukrainian-American Birth Defects Program (UABDP) funded by the United States Agency for International Development (USAID). The program became an associate member of ICBDSR in 2001. In 2005 the USAID component was completed and the program was assumed by OMNI-Net, a not-for-profit international organization incorporated in Ukraine, and is continued as OMNI-Net Ukraine Birth Defects Program. OMNI-Net represents five resource OMNI-Centers all of which provide care for children with birth defects, promote prevention programs, participate in parental organizations and engage in collaborative programs with national and international partners.

Program objectives include universal folic acid flour fortification, methods to reduce alcohol impact on child development in collaboration with partners and promoting international partnerships.

OMNI-Net personnel are financed from regional budgets. The legislation and rules by the Ministry of Health mandates the reporting of birth defects. BD data is reported by Oblast Vital Statistics Centrum who aggregates, formats and forwards the data to the Ministry of Health.

Population Coverage
BD surveillance annually covers about 28000 births in two oblasts (provinces) of Western Ukraine – Rivne and Khmelnytsky, representing approximately 6% of births in Ukraine. The population is relatively homogeneous and stable (data is pooled from these two oblasts). The Registry is of Type III (all mothers delivering in the defined geographic area excluding non-residents of that area).

Sources of Ascertainment
Relevant hospital admission/discharge summaries are systematically reviewed. Qualified Registry specialists also routinely review all medical records of regional paediatric cardiology centres and obtain ascertainment of diagnostic details. Data from specialty clinics, laboratories (including cytogenetic one) and other services are explored. Our cytogenetic laboratories are the only ones in the region and they provide us with study reports. Pregnancy, obstetrics, delivery, neonatal and pediatrics records are reviewed. The information is substantial regarding service providers located in regional centres, but limited regarding service providers in rural environments.

Maximum Age at Diagnosis
Up to 1 year of age.

Termination of Pregnancy for Fetal Anomaly
Termination of pregnancy is legal and performed by a physician when: 1) a pregnancy poses danger to health or life of a pregnant woman; 2) prenatal diagnosis or other medical evidence indicates high probability of serious and irreversible damage to a fetus or it is an untreated life-threatening disease; 3) there is a plausible suspicion the pregnancy has arisen from a prohibited act.

Up until 31 December 2005, the upper gestational age limit for termination of pregnancy in Ukraine was 28 weeks AND/OR 1000 g.
From 1 January 2006, Ukraine redefined the definition and the current upper gestational age limit for termination of pregnancy is 22 weeks AND/OR 500 g.

Stillbirth Definition and Early Fetal Deaths
The stillbirth definition is as follows: fetal death (stillbirth) is a death prior to the complete expulsion or extraction of a product of conception. Till January,1, 2006 for statistical purposes we include all fetuses weighing 1000g or more at the moment of birth or/and gestational age above 28 weeks; Spontaneous abortions include fetuses weighing less than 1000g and gestational age less than 28 weeks.
From January 1, 2006, Ukraine redefined stillbirth definition as all fetuses weighing 500g or more at the moment of birth or/and gestational age above 22 weeks.
In Ukraine Certificates of Neonatal Death are NOT medical documents, they are issued by civil authorities.
Exposure Data Availability
Routine information collection is limited except when ad hoc circumstances are noted. An expansion of exposure data collection is in progress.

Denominators and Controls Information
Information on all births (live and stillbirths) is available from birth certificates, gathered by the Regional Vital Statistics. There are 2 control cases for each BD case.

Background information
The northern counties (rayons) of one of the two oblasts are contaminated from Chornobyl disaster. Data regarding ionizing radiation pollution in contaminated rayons is available by special agreements. Data from a population based neonatal registry is also available by special agreements.

Ethics & Consent
Registration of birth defects and follow-up is an integral part of health care protocols.
The registry does not require ethics committee approval in order to collect and store data.
National legislation does not require informed consent in order to register a baby with a congenital anomaly.

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