

List of registries and time periods

Registries	Years
Argentina	1993-1998
Australia	1993-1997
Austria, Styria	1993-1998
Belgium, Antwerp	1993-1998
Belgium, Hainaut	1993-1998
Bolivia	1993-1998
Brazil	1993-1998
Bulgaria, Sofia	1996-1997
Canada, Alberta	1993-1998
Canada, British Columbia	1993-1998
Canada, National	1993-1997
Chile	1993-1998
China, Beijing	1997-1998
China, CBDMN	1997-1998
Colombia	1993-1994
Croatia, Zagreb	1993-1997
Cuba	1993-1998
Czech Republic	1993-1998
Denmark, Odense	1993-1998
Ecuador	1993-1998
England and Wales	1993-1998
England, Mersey	1998
England, North Thames West	1997-1998
Finland	1993-1998

France, Central East	1993-1998
France, Paris	1993-1998
France, Strasbourg	1993-1998
Germany, Saxony-Anhalt	1993-1998
Hungary	1993-1998
Ireland, Dublin	1993-1998
Israel, IBDMS	1993-1998
Italy, BDRCAM	1993-1998
Italy, IMER	1993-1998
Italy, ISMAC	1993-1998
Italy, North East	1993-1998
Italy, Tuscany	1993-1998
Japan, JAOG	1993-1998
Malta	1993-1998
Mexico, RYVEMCE	1993-1998
New Zealand	1993-1998
Northern Netherlands	1993-1998
Norway	1993-1998
Paraguay	1993-1998
Russian Federation, Tomsk	1993-1998
Scotland, Glasgow	1997-1998
South Africa, SABDSS	1993-1997
Southern Portugal	1993-1998
Spain, Asturias	1993-1998
Spain, Barcelona	1993-1998
Spain, Basque Country	1993-1997
Spain, ECEMC	1993-1998
Spain, El Valles	1993-1997

Switzerland, Zurich	1993-1998
United Arab Emirates	1996-1998
Uruguay	1993-1998
USA, Atlanta	1993-1998
Venezuela	1993-1998

Registry Descriptions

Australia

Australian Congenital Malformation Monitoring System

History: National monitoring of malformations began in 1981, but not all States and Territories were collecting data at that stage. Subsequently, perinatal data systems have been introduced in all States and Territories. The programme became a member of the ICBDMs in 1982.

Size and coverage: All births in Australia are included, now more than 250,000 births annually. Coverage increased from about 50% in 1981 to 100% in 1986. Stillbirths of 20 weeks or more are registered. Data for Tasmania (about 6,000 births) were excluded from this report.

Legislation and funding: State and Territory health departments, and birth defect registers in New South Wales, Victoria, South Australia and Western Australia, report data to the national monitoring system, which is funded by a grant from the Australian Institute of Health and Welfare, an independent health and welfare statistics agency in the Commonwealth Department of Health and Aged Care.

Sources of ascertainment: Reports are obtained from birth notifications, death certificates, cytogenetic laboratories, autopsy reports, children's hospitals, and notifications of terminations of pregnancy.

Background information: Data on births are obtained from State and Territory perinatal data collections and from birth and perinatal death registrations compiled by the Australian Bureau of Statistics.

Exposure information: Except in South Australia, exposure information is not routinely recorded but has to be obtained ad hoc.

Address for further information:

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Austria, Styria

Styrian Malformation Registry

History: The registry was set up as a regional population-based registry in 1986 following the Chernobyl disaster. It registers embryos/fetuses/babies with congenital anomalies (CA) born after January 1st 1985. The registry joined EUROCAT in 1995.

Size and coverage: A total of 192,530 live and stillbirths were surveyed between 1985 and 1999. The annual number of births covered is at present approximately 11,000. Embryos/fetuses/babies with anomalies are registered if diagnosed before birth, at birth or during the first year of life. There is no lower limit of gestational age for registration. Terminations of pregnancy are included as well. The maternal residency is recorded and can be used for evaluating the regional pattern of birth defects.

Legislation and funding: The programme is a research programme with voluntary participation of hospitals and funded by research grants provided by the Styrian government.

Sources of ascertainment: The SMR is based on information actively gathered from 49 sources. These consist of 34 minor or major obstetric hospitals, 1 cytogenetic laboratory, 2 pathology services, 11 child health services, including specialised departments for diagnosis and treatment, and free practicing midwives. 48 % of cases are reported by more than one source, which allows checking for reliability of data in these cases. In 52 % of cases only one source provided data.

Exposure information: not available

Prenatal diagnosis information: Data about techniques of prenatal screening (ultrasound, serum markers) and prenatal diagnosis are not systematically collected.

Background information: Information on all births is available from birth certificates, gathered by Statistics Austria

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Prof. Andrea BERGHOLD, PhD, Institute for Medical Informatics, Statistics and Documentation, Karl-Franzens University, Graz, Engalgasse 13, A-8010 Graz
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Belgium, Antwerp

Eurocat registry of congenital anomalies

History: The registry was initialized with a pilot study in 1989. In 1990 the registry really started in a region in Antwerp. Since 1997 the whole province of Antwerp is covered. The registry is developed in collaboration with the provincial government and the university of Antwerp. The registry joined EUROCAT in 1990.

Size and coverage: The registry covers about 18000 births, these are all births in the province of Antwerp (about 15% of the births in Belgium). It includes livebirths, stillbirths (20 weeks or more) and terminations of pregnancy after prenatal diagnosis. There are 23 participating hospitals.

Legislation and funding: Reporting by hospitals and health workers is voluntary. Privacy legislation in Belgium deals with rules for information to the public. Individuals can refuse registration. The program is funded by the provincial government of Antwerp.

Sources and ascertainment: Reports are actively collected from maternities and paediatric and neonatologic units. Notification also by gynaecologists, paediatricians, GP's, child welfare nurses.

Exposure information: includes: maternal drug use maternal smoking and alcohol ab(use), maternal and paternal diseases and family history, parental occupation

Background information: Background data on births are retrieved from the population databases of the communities and from the study center for perinatal epidemiology in the Flanders region.

Address for further information:

Dr. Vera Nelen, Provinciaal Instituut voor Hygiëne, Kronenburgstraat 45, 2000 Antwerpen, Belgium

Phone: 32-3-259-12-70. Fax: 32-3-259-12-01. E-mail: vera.nelen@pih.provant.be.

Belgium, Hainaut

Registry of Hainaut-Namur

History : The registry of Hainaut-Namur was initiated in 1978 and it started in 1979. Since the beginning it is a member of Eurocat. From 1979 to 1990, it was located at the School of Public Health of the Catholic University of Louvain (Brussels). Since 1990, it was integrated into the Centre of Human Genetics of the Institute of Pathology and Genetics (Loverval – Belgium). The registry joined EUROCAT in 1979.

Size and coverage : The registry annually covers 12,500 births in East Hainaut and the whole province of Namur, which represents about 10.5 % of all births in Belgium. The registry includes livebirths, stillbirths and terminations. The coverage rate of congenital anomalies is estimated at around 100 %.

Legislation and funding: As a part of the Institute of Pathology and Genetics of Loverval, it is supported by an annual grant from the Institute of Research in Pathology and Genetics of Loverval. From 2001 it is also partly supported by the Ministry of Public Health of Wallonia.

Sources of ascertainment: Delivery units, neonatal and paediatric departments divided into 13 hospitals. All cytogenetic, genetic and pathological data including the examination of aborted fetuses are regionally concentrated in the Institute of Pathology and Genetics of Loverval.

Exposure information: All that concerns information of maternal diseases during pregnancy, maternal drugs, occupations and genetic data is available.

Background information: Background data on births are available from national and regional institutes of statistics. It is also based on our own statistics in collaboration with the ONE (Office de la Naissance et de l'Enfance)

Adress for further information:

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Bulgaria, Sofia

Sofia Registry of Congenital Anomalies (SORCA)

History: The registry started in 1996. The registry joined EUROCAT in 1996.

Size and coverage: The registry is population-based and covers approximately 10,000 births annually in the region of Sofia. The registry covers livebirths up to 1-year life, stillbirths and terminations of pregnancy.

Legislation and funding: The registry is organised by the Bulgarian Society of Human Genetics and Sofia Municipality, and was supported by the State and private sponsors. The registry is currently not funded.

Sources and ascertainment: Cases are notified by obstetricians, neonatologists, paediatricians, and pathologists.

Exposure information: Information about maternal drug use, maternal diseases, maternal occupation, and obstetrical history is available for cases.

Background information: Denominators are available from the Statistics Unit of the regional health centre of Sofia municipality, the Ministry of Health and the statistics units of Sofia maternity clinics.

Address for further information:

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Canada, Alberta

Alberta Congenital Anomalies Surveillance System

History: This programme began in 1966 as a general Registry for Handicapped Children. This was disbanded in 1980 and continued as a surveillance programme for live and stillborn infants with congenital anomalies who were born in the Province of Alberta. The programme became a member of the ICBDMs in 1996.

Size and coverage: All live and stillbirths in the province are covered which at present comprises about 40,000 births per year. The definition of stillbirth is 20 weeks or more or 500 grams or more. The vast majority of births occur in hospital (approximately 97%). In 1997 a special fetal congenital anomalies surveillance system was started to include those fetuses with congenital anomalies who were either spontaneously lost prior to 20 weeks or where there was termination as a result of prenatal diagnosis.

Legislation and funding: Reporting is voluntary. The system is run by members of the Department of Medical Genetics, Alberta Children's Hospital/University of Calgary reporting to Alberta Vital Statistics and Alberta Health. Funding is from Alberta Ministry of Health.

Sources of ascertainment: Reports are obtained from physician's notice of birth, live birth and stillbirth registrations, death registrations and a special congenital anomalies reporting form (CARF) from hospitals. This is based on discharge diagnosis, including readmissions for any reason up to one year of age. Additional sources are speciality clinics, such as medical genetics and cytogenetics laboratories.

Exposure information: None is routinely collected.

Background information: Linkage studies are possible with other statistical data from Alberta Health.

Address for further information:

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Canada, British Columbia

British Columbia Health Status Registry (BCHSR) Congenital Anomalies Surveillance Program

History: The programme was established in 1952 as the *Crippled Children's Registry*. Until 1959 the programme had an age limit of 21, but this was removed in 1960 and the name was change to the *Registry for Handicapped Children and Adults* and included all familial conditions and congenital malformations. In 1975, the Registry's name was changed to the *Health Surveillance Registry* as risk registers for amniocentesis, rubella, hyaline membrane disease, and fetal alcohol syndrome were added. In 1991, the Royal Commission Report on Health Care and Costs contained a recommendation that Vital Statistics should develop and maintain a registry of individuals with disabilities to assist in the development of long-range plans and to monitor the changing needs of the population. Subsequently, in September 1992, amendments to the Health Act established the legislative mandate and responsibilities for the HSR. The Registry's current name, *Health Status Registry*, was acquired in 1992. In order to refocus the Registry's emphasis on children, the criteria for registration of individuals with long-term physical, mental and/or emotional problems was restricted to persons under the age of 20 years old, however registration of persons with genetic conditions was not age limited. By 2000 there were approximately 215,000 records in the Registry.

Size and Coverage : The registry covers all births in the province approximately 45,000 births annually including stillbirths with at least 20 weeks gestation or birth weight 500 grams or more.

Legislation and Funding: In 1992, amendments to the Health Act established the legislative mandate and responsibilities for the BC HSR. Funding comes from the British Columbia Vital Statistics Agency.

Sources of Ascertainment: Sources include: Notice of Live and Stillbirth, Death registrations, Hospital Admission/Discharge Abstracts, Children's Hospital, Sunnyhill Hospital, UBC and Victoria General Medical Genetics Clinics,

Child Development Centres, Health Regions, the Asante Centre for Fetal Alcohol Syndrome.

Exposure Information: Information on complications of pregnancy, labour or delivery is available on Vital Statistics birth registrations and environmental/occupational and drug/alcohol/smoking lifestyle related information can be obtained from

the death registrations for the deceased.

Web site: <http://www.vs.gov.bc.ca/stats/hsr/index.html>

Background Information: The registry data are regularly matched to Vital Statistics birth registrations to obtain birth particulars of the registrants and maternal/paternal information, and also matched to death registrations to get the date of death and causes of death if the registered person was deceased. The registry is also working on the collection of the medically terminated pregnancies due to congenital anomalies.

Addresses for further information:

Programme Director to British Columbia Health Status Registry :
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Canada, V8W 1H8
Phone : 250-952-2567. Fax : 250-952-2587
E-Mail: SooHong.Uh@gems6.gov.bc.ca

Canada, National

History: The program was started in 1966. The program was a full member until 1987, when it became an associate member. The program was discontinued a member of the ICBDMs in the early 1990s, and reinstated its associate member status in 1996.

Size and coverage: The system presently monitors about 280,000 births annually, which represents about 70% of all births in Canada. Stillbirths of at least 20 weeks of gestation are included.

Legislation and funding: Reporting is based on an agreement between the Canadian Institute for Health Information, a non-profit organization which collects and disseminates data on hospital admission/separation in Canada, and the central registry, which is run and funded by Health Canada. Alberta Congenital Anomalies Surveillance System and Manitoba provincial government also provide the two Canadian provinces' data.

Sources of ascertainment: Cases are ascertained from hospital admission/separation summary records collected by the Canadian Institute for Health Information, or by Alberta Congenital Anomalies Surveillance System and Manitoba provincial government. Follow-up continues to one year of age.

Exposure information: No exposure information is routinely collected in the central registry.

Background information: Background information is based on hospital admission/separation summary records from the Canadian Institute for Health Information, or provided by Alberta Congenital Anomalies Surveillance System and Manitoba provincial government.

Address for further information:

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China, Beijing

Birth Defect Surveillance System in Thirty Counties of Four Provinces, People's Republic of China (BDSS - China)

History: The programme began in 1992. It became a member of the ICBDMs in 1997.

Size and coverage: This is a population based monitoring system. Reports were obtained from all hospitals and village health stations, which together cover all geographically defined population. Total number of population in these areas is around 17 millions and total number of births per year is around 150,000.

Legislation and funding: Funding is from China Ministry of Health and local health authorities.

Sources of ascertainment: Reports are obtained from delivery units, paediatric clinics, ultrasound departments, pathology departments and perinatal health care departments of different level hospitals, MCH institutes and village health stations in the participating counties and cities.

Exposure information: Exposure information is obtained from the perinatal health care surveillance system (PHCSS) in the same areas for all women and their babies from pre-marital examination till six weeks after birth. BDSS data is linked with PHCSS data by using an ID number assigned to each woman.

Background information: Background information is also obtained from PHCSS data.

Address for further information:

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China, CBDMN

Chinese Birth Defects Program of Sichuan Province, China (until 1994)
Chinese Birth Defects Monitoring Network

History: The programme began in 1984. It became a member of the ICBDMNS in 1985.

Size and coverage: In 1984, reports were obtained from 100 hospitals but participation has increased. In 1985, 205 hospitals participated. At present, the programme covers approximately 260,000 births annually in 31 provinces.

Legislation and funding: Participation is voluntary. Funding is mainly from local health authorities.

Sources of ascertainment: Reports are obtained from delivery units, paediatric clinics, and pathology departments of the participating hospitals.

Exposure information: Exposure information is obtained by interviews of mothers of the reported malformed infants. No information is available on exposures in controls.

Background information: Total number of births from each participating hospital is known.

Address for further information:

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Phone: 86-28-5501363. Fax: 86-28-5501363. E-mail: lzh@public.bta.net.cn

Croatia, Zagreb

History: The project started as a pilot investigation in 1982. The registry joined EUROCAT in 1983.

Size and coverage: The registry is population based and covers approximately 7,500 births per year, up to 12 % of births in Croatia (cities Rijeka, Varazdin, Koprivnica and region Pula). During the covered period 1983-1999 we have monitored 103,265 pregnancies. The average prevalence rate of congenital anomalies during the monitored period was 17.0 per 1,000 births.

Legislation and funding: Till the end of 2000 we did not have any local funding, collection and transmission of data were on voluntary basis. From the year 2000 we receive the funding from Ministry of Science and Technology and as a public health project we are in process of applying for funding from the Ministry of Health.

Sources and ascertainment: Data are actively collected from four Delivery Units in the cities of Rijeka, Varazdin, Koprivnica and region Pula by neonatologists and gynecologists.

Exposure information: information on maternal drug use, maternal and paternal diseases and occupations, outcome of previous pregnancies is available for almost all malformed cases.

Background information: Information on all births is available from the birth certificates.

Address for further information:

Dr Ingeborg Barisic, MD, Ph.D., Registry Leader and Medical Geneticist, Children's University Hospital Zagreb, Department of Paediatrics, Division of Clinical Genetics, Klaićeva 16, 10 000 Zagreb, Croatia

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Czech Republic

Congenital Malformations Monitoring Programme of the Czech Republic

History: A registration of congenital malformation began in 1961 and regular monitoring started in 1975. The programme was a founding member of the ICBDMs.

Size and coverage: All births in the Czech Republic (Bohemia, Moravia and Silesia regions) are covered, at present comprising approximately 90,000 annual births. Stillbirths weighting at least 1,000g are included.

Legislation and funding: Reporting is compulsory. The registration is financed and run by the government in the Institute of Health Information and Statistics of the Czech Republic. Analysis of data is supported by Grant projects (NJ 6214-3, 6224-3 and NJ/5764-3) of Grant Agency Ministry of Health of the Czech Republic in the Institute for Care of Mother and Child.

Sources of ascertainment: Reports are obtained from delivery units, neonatal, pediatric, child surgery, pathology departments and cytogenetic laboratories. Reporting to the central registry occurs via Regional Department of Institute of Health Information and Statistics.

Exposure information: Some exposure information is available on malformed infants, at present none on controls.

Background information: Information's on all births are available in the Institute of Health Information and Statistics of the Czech Republic.

Address for further information:

Antonin Sipek, Department of Population Teratology, Institute for Care of Mother and Child, Podolske nabrezi 157, 147 10, Prague 4, Czech Republic.
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Cuba

Cuban Register of Congenital Malformations (RECUMAC)

History: The program started in 1985 in Havana City, and was extended to the other hospitals in 1987 .

Size and coverage: Reports are obtained from hospitals distributed all over Cuba. The number of participating hospital has grown 4 in 1986 to 36 at the present time. The annual number of birth is approximately 60,000, representing almost 50 % of all births.

Legislation and funding: Reporting is voluntary. The registry is associated with the National Center of Medical Genetics.

Sources and ascertainment: Reports are obtained from delivery units and paediatric departments of the participating hospitals. Mothers are also interviewed directly to gather information and fill in the RECUMAC standard protocols.

Exposure information: The mother of each reported infant and the mother of a control infant, the next non malformed infant born at that hospital with the same sex as the proband are interviewed on various exposures, including drug usage and parental occupation.

Background information: Total number of birth by sex and number of twin pairs in each participating hospital are known. Other background information is obtained partly from summarizing tables of births in each participating hospitals, partly from the control material.

Address for further information:

Maria Emilia Ferrero Oteiza and Luis Herebero, Recumac. Centro Nacional De Genetica Medica. ISCM-Habana. Victoria de Girón, C.P. 16000 Ciudad de la Habana. Cuba.

Denmark, Odense

Registry of Funen County

History: The registry joined EUROCAT in 1979.

Size and coverage: The registry covers Funen County (island of Funen with surrounding small islands) situated in the middle of Denmark. The total number of births per year in Funen County is around 6000.

The registry includes information about induced abortions after prenatal diagnosis of malformations, fetal deaths with GA \geq 20 weeks and livebirths. For livebirths late diagnosed cases are included up to the age of seven years.

Legislation: In Denmark induced abortion is allowed for any reason with gestational age \leq 12 weeks. After 12 weeks of gestation induced abortion can be performed after permission from a local committee. Usual upper limit for induced abortion is 24 weeks. Stillbirths include fetal deaths with gestational age \geq 28 weeks.

The registry is approved by the "Data Tilsynet" as a private registry for research.

Sources and ascertainment: The registry is based on active case finding. Data for the registry includes hospital records from obstetric and paediatric departments, birth notifications, deaths certificates, post-mortem examinations and data from the cytogenetic laboratory.

Exposure information: Parental occupation. Maternal smoking and medication during first trimester. Maternal illness before and during pregnancy

Background information: Data on births per year and maternal age distribution covering Funen county is available from National Danish Statistics.

Address for further information:

Ester Garne, Eurocat Registry of Congenital malformations, Epidemiology – Institute of Public Health, University of Southern Denmark, Sdr Boulevard 23A, DK – 5000 Odense C
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England and Wales

The National Congenital Anomaly System

History: The monitoring programme was started in 1964. It was a founding member of the ICBDMs.

Size and coverage: All births in England and Wales are covered, at present approximately 610,000 annually. Stillbirths of 24 weeks or more gestation are registered.

Legislation and funding: Reporting is voluntary. The system is financed by the governmental Office for National Statistics.

Sources of ascertainment: Reports are mainly based on notifications of births prepared by attendants at birth, either physicians or midwives, supplemented by other reports from neonatal intensive care units, special care baby units etc. Reporting via the Wales regional congenital anomaly register began in 1998, and in 1999 from the Trent Region. In 2000 reporting has started from the Merseyside and Cheshire register and the North Thames West register. These four registers together use several sources for ascertainment and cover 27% of the births in England and Wales

Exposure information: Parents' occupation is known. No other information on other exposures is available but can be retrieved ad hoc from general practitioners.

Background information: Information on all births is available from birth certificates.

Address for further information:

Beverley J Botting, Office for National Statistics, B6/08, 1 Drummond Gate, London SW1V 2QQ, UK
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England, Mersey

Mersey Congenital Anomaly Survey

History

In 1992 a fetal anomaly survey was initiated in the former Mersey region. Its aim was to assess the effectiveness of antenatal diagnosis. However, this survey proved difficult to establish and anomalies were under reported. The registry joined EUROCAT in 1995.

In 1995 the survey linked to CESDI, (Confidential Enquiry into Stillbirths and Deaths in Infancy) and became the responsibility of the CESDI Regional Coordinator. A great deal of time and effort has been concentrated on the Survey, which was relaunched as the Congenital Anomalies Survey.

Size and Coverage

The Survey presently covers Merseyside and Cheshire that has over 28,000 births per year. The survey records all anomalies which:

- a) are first detected antenatally, at birth or termination of pregnancy, or during the first year of life.
- b) Involve a structural, metabolic, endocrine or genetic defect in the child/fetus.

Legislation and funding: Funding is obtained from various sources and is bid for annually. Reporting is voluntary.

Sources of Ascertainment: The survey relies on multi source ascertainment and has developed an extensive network of health professionals, obstetricians, paediatricians, midwives, neonatal nurses, pathologists and ultrasonographers. There is also close collaboration with CESDI, cytogenetics, cleft lip and palate unit, Royal Liverpool Children's Hospital and district health authorities. This network has ensured our local ascertainment is better than national statistics.

Exposure Information: No information on exposure is collected other than self reported information on smoking, alcohol and drug intake during pregnancy.

Address for further information:

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England, North Thames West

North Thames (West) Congenital Malformation Register

History: We began registering cases on 1 January 1990. We began reporting to EUROCAT in 1996. We began transmitting data to ONS (the Office for National Statistics) on 1 January 2000.

We are active members of BINOCAR (British Isles Network of Congenital Anomaly Registers) and FOCAL (Follow-up of Congenital Anomalies Long Term). Our data continue to be used in many collaborative research projects as well as for local audit of prenatal screening and diagnostic programmes. The registry joined EUROCAT in 1996.

Size and coverage: We cover 15 obstetric units, which together have about 46,000 births

per year. We register fetuses with prenatally diagnosed anomalies, affected fetuses spontaneously lost from 16 weeks gestation, and babies diagnosed before their first birthday in the case of structural anomalies and at any time in the case of chromosome anomalies. We use the EUROCAT exclusion list, but we also exclude babies in whom the main diagnosis is hypospadias, polydactyly, syndactyly, talipes, or soft markers on ultrasound. We now have more than 9,000 cases on the register.

Legislation and funding: Reporting is voluntary. We are funded by our regional Genetics Commissioning Group

Sources and ascertainment: We have multi-source reporting. Sources include:

- Delivery suite staff
- Ultrasound Staff
- Post natal ward staff
- Paediatric Intensive Care unit staff
- Fetal Medicine Unit staff
- Paediatricians
- Post mortem reports
- Cytogenetic reports
- Computerised obstetric records
- CESDI (Confidential Enquiry on Still births & deaths in Infancy)
- Regional Genetic Service Notes
- Serum Screening for Down Syndrome Programme
- Notifications to Office for National Statistics
- Paediatric Cardiology Referral Centre

Exposure information: Chronic illness in mother, pregnancy induced condition in mother, acute maternal illness during pregnancy, therapeutic and recreational drugs taken around conception and during pregnancy, details of assisted conception, invasive tests in pregnancy, smoking habits, alcohol abuse. Post code of residence.

Prenatal screening and diagnosis information: We collect information on how and when anomalies were diagnosed and the indication for any invasive tests that were done. We also collect information about why prenatal karyotyping was not done.

Denominator Data: As numerator is hospital based, we use as a denominator the births and TOPs in the contributing hospitals. There is a computerised database which stores information on all births similar to that which we have on the births on our register.

Address for further information:

Lenore Abramsky, CMR Co-ordinator, North Thames Perinatal Public Health Department,
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3UJ, England

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Finland

History: The registry was established in 1963 and regular monitoring started in 1977. It was a founding member of the ICBDMs. The registry joined EUROCAT in 1998.

Size and coverage: The registry is national and population based. All births in Finland are covered, at present approximately 57.000 annually. Stillbirths of 22 weeks / 500 g or more are registered. As a research project selective terminations for fetal reasons and spontaneous abortions with malformations have also been included since 1993.

Legislation and funding: Reporting is compulsory. The registry is run and financed by STAKES, the governmental National Research and Development Centre for Welfare and Health (under the Ministry of Social Affairs and Health).

Sources and ascertainment: Reports are obtained from delivery units, neonatal, pediatric and pathology departments, death certificates and cytogenetic laboratories. Case information is also received from the national Medical Birth Register, Abortion Register and Hospital Discharge Register.

Exposure information: Until 1986, extensive exposure information was obtained from maternity health centers and by personal interview for selected malformations and their controls. In 1987-1992 only parental occupation was reported. Exposure information, like maternal occupation, medication, X-rays and diseases, etc., has been obtained since 1993. Some exposure information on all births is also available in the Medical Birth Register since 1987.

Background information: Epidemiological background data are available on all births in the Medical Birth Register and in the Statistics Finland.

Address for further information:

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France, Central East

Central-East France Register of Congenital Malformations

History: The registry began in 1973 within the Rhone-Alps area -the Auvergne region was added in 1983, the Jura area in 1985, the Côte d'Or & Nièvre in 1989 and Saône-et-Loire in 1990. The programme was a founding member of the ICBDMs. In 1998 the registry was split up and the Auvergne region, became financially independent, under the responsibility of Christine Francannet. The collaboration between Auvergne and the rest of the FCE-registry is maintained and common results are published. The registry joined EUROCAT in 1999.

Size and coverage : The registry covers all births in the area approximately 100,000 births annually, which represents about 13% of all births in France. Stillbirths of 22 weeks or more gestation are included.

Legislation and funding: Reporting is voluntary. The system is run by a privately funded research organisation. It is now officially recognised by the French Ministry of Health and partially supported by an annual grant from the National Committee of Registries.

Sources of ascertainment: Reports are received from delivery units, pediatric and child surgery clinics, pathology departments, and cytogenetic laboratories. Infants up to the age of one are registered, as well as fetuses delivered after medical abortion.

Exposure information: Information on maternal and paternal occupation, drug use, diseases, etc. is collected by interviews of the mothers of the malformed infants. No controls are interviewed.

Background information: Some background information is available from the general population statistics.

Address for further information:

Elisabeth Robert, Institut Européen des Génomutations, 86 Rue Edmond Locard, F-69005 Lyon, France.

Phone: 33-478-258210. Fax: 33-478-366182 . E-mail: elisabeth.robert@ieg.asso.fr

Contact for the Auvergne registry: Christine Francannet, CEMC Auvergne, e-mail : CEMC-Auvergne@wanadoo.fr

France, Paris

History: The programme was initiated in 1975, but the registry really started in 1981. It became a member of the ICBDMs in 1982. The registry joined EUROCAT in 1982.

Size and coverage: The registry covers 38.000 annual births (about 5% of all births in France), that is all births (live and still births of 22 weeks or more) and terminations of pregnancy in the population of Greater Paris delivering in Paris maternity units. The estimation of the coverage of the registry is around 95%.

Legislation and funding: Reporting is voluntary. The registry is part of a research unit of INSERM (National Institute of Health and Medical Research). The registry has been officially recognized by the French National Comity of Registries, and is renewed for four years (2001-2004) and supported by an annual grant from INSERM and Institut de la Veille Sanitaire (Institute for Health Surveillance).

Sources of ascertainment: Reports are actively collected from delivery units, pediatric departments, cytogenetic laboratories, pathology departments. Terminations of pregnancy are included. Case information is also received from the health certificates of the first week.

Exposure information: Information on maternal drug use, maternal and paternal diseases and occupations, outcome of previous pregnancies, is available for the malformed cases.

Prenatal diagnosis information: Data about techniques of prenatal screening (ultrasound, serum markers) and prenatal diagnosis are systematically collected.

Background information: Background data on births are available from the National Institute of Statistics (INSEE)

Address for further information:

Catherine De Vigan, INSERM U149, 16 av P Vaillant-Couturier, 94807 Villejuif Cedex, France.
Phone: 33-1-45 59 50 09. Fax: 33-1-45 59 50 89. E-mail: devigan@vjf.inserm.fr

France, Strasbourg

Strasbourg Prospective Study of Congenital Malformations

History: The registry was started in 1979. The programme became a member of the ICBDMs in 1982. The registry joined EUROCAT in 1982.

Size and coverage: All births in an area including and around Strasbourg and the Bas-Rhin are covered –13,000 to 13,500 annually, or 1.8% of all births in France.

Legislation and funding: The programme is a research program, recognized by the local health authorities and funded by Social Security, Ministry of Health and INSERM.

Sources of ascertainment: Reports are obtained from pediatricians examining the newborn infants. A control infant is selected for each malformed one : the next infant of the same sex as the proband born at that hospital.

Exposure information: Detailed information on various exposures is obtained by interview of the mothers of the malformed infants and their controls. The children are followed to the age of one year.

Background information: General demographic information is obtained from the National Institute of Statistics. Further information is obtained from Social Security Records and Health Sheets.

Address for further information:

Claude Stoll, Service de Génétique Médicale, Hôpital de Hautepierre, Avenue Molière, 67098 Strasbourg Cedex, France.

Phone : 33-3.88.12.81.20. Fax : 33-3.88.12.81.25. E-mail : Claude.Stoll@chru-strasbourg.fr

Germany, Saxony-Anhalt

Malformation Monitoring Saxony-Anhalt

History: Since 1980 in the city of Magdeburg all live- and stillbirths, abortions after the 16th week of gestation (spontaneous and induced abortions according to medical evidence based on prenatal diagnoses of congenital defects), and postnatal anomalies or congenital defects have been recorded up to the first week of life. After the reunification of Germany and the creation of the federal state of Saxony-Anhalt, the survey of congenital defects included approximately two-thirds of all births with postnatal anomalies and congenital defects in the same federal state. Since 1 January 2000 the survey region includes the entire state of Saxony-Anhalt. Saxony-Anhalt has 2.7 million inhabitants and annual births at a rate of about 19,000 children. The survey system is multi-centric and based on population. The registry joined EUROCAT in 1992.

Legislation and funding:

1980 to 1989 Ministry of Health of the former German Democratic Republic

1990 to 1992 Academy of Medicine, Magdeburg

1993 to 1995 Ministry of Health, Federal Republic of Germany

since 1995 Ministry of Labour, Women, Health and Social Security of the Federal State of Saxony-Anhalt

The Malformation Monitoring is working in order of Ministry of Labour, Women, Health and Social Security of the Federal State of Saxony-Anhalt.

Sources:

The co-operation partner are:

32 obstetrics departments;
29 children hospitals;
10 institutions of prenatal diagnostic;
6 departments of pathology

Exposure information:

maternal and paternal occupation (in groups);
occupation risk;
drugs in pregnancy (ATC-code);
alcohol, nicotine, drug abuse.

Background:

population based registry (Federal State Saxony-Anhalt);
written informed consent of the mother (parents);
name and address don't registered;
two healthy "controls" per one malformed child;
inclusion of terminations of pregnancy, spontaneous abortions after 16th week of gestation, live and stillborn babies;
definition of stillbirth: < 500 grams;
maximum age to include diagnoses: 1 year, almost 1st week of life;
annual reports (in German)

Web site:

<http://www.med.uni-magdeburg.de/fme/zkh/mz/>

Address for further information:

Prof. Dr. Volker Steinbicker, Program Director (Paediatrician, Geneticist), Malformation Monitoring Saxony-Anhalt, Faculty of Medicine, Otto-von-Guericke University, Leipziger Straße 44, Haus 56, D-39120 Magdeburg, Germany.
Telephone: +49-(0)391- 6714174. Fax: +49-(0)391-6714176.
Email: volker.steinbicker@medizin.uni-magdeburg.de

Hungary

Hungarian Congenital Abnormality Registry

History: Centralized registration of congenital abnormalities began in Hungary in 1962, and became under our co-ordination in 1970. Monitoring began in 1973. The programme was a founding member of the ICBDMs.

Size and coverage: The registry covers all births in Hungary, approximately 120,000 annually. Criteria to define stillbirth was changed in 1998. At present, stillbirths of at least 24 weeks gestation or 500 grams are registered. Prenatally diagnosed and terminated fetuses are also registered.

Legislation and funding: Reporting is compulsory. The registry is run and financed by the governmental National Center for Epidemiology (formerly the National Institute of Public Health).

Sources of ascertainment: Reports are obtained from delivery units, neonatal and pediatric surgery, pathology, and prenatal diagnostic centers. Abnormalities detected before the age of one are reported. Variations in figures (especially in the 1990s) compared with data from previous years may reflect incomplete notification. In most instances, decreases can be noticed in the rates of birth defects.

Exposure information: Exposure information has been available since 1980, when a case-control system was initiated. Mothers of selected malformed infants and controls are interviewed by community nurses to collect information.

Background information: General background information on all births is available from central statistics.

Address for further information:

Csaba Siffel/Julia Metneki, Department of Human Genetics and Teratology, National Center for Epidemiology, Gyali ut 2-6., H-1966 Budapest, Pf. 64., Hungary.
Phone/fax: 36-1-4761129. E-mail: siffel@antsz-oth.hu

Ireland, Dublin

Dublin EUROCAT Registry

History: Register began in September 1979. Joined the ICBDMs in 1997. The registry joined EUROCAT in 1980.

Size and coverage: The Registry is population-based and situated in the East of Ireland covering the counties of Dublin, Wicklow and Kildare. About one third (20,000 births) of all births in Ireland occur in this area.

Legislation and funding: The Registry is located within the Public Health Department of the Eastern Regional Health Authority. Staffing includes a full time nurse/researcher and a part time secretary plus a part-time public health specialist and a part-time epidemiologist. Funding is provided by the Department of Health through the Eastern Regional Health Authority. There is a Steering Committee comprising specialists from each of Maternity and Paediatric Hospitals in the catchment plus a representative from the Department of Health.

Exposure information : For each malformed infant reported, limited information is given on certain exposures. No information is available on controls.

Sources of ascertainment: All live and still births are covered. Abortion is illegal in Ireland.

Address for further information:

Robert Mc Donnell, Department of Public Health, Eastern Regional Health Authority, Dr. Steeven's Hospital, Dublin 8, Ireland.
Phone: 353-1-6352750. Fax: 353-1-6352745. E-mail: bob.mcdonnell@erha.ie

Israel, IBDMS

Israel Birth Defects Monitoring System

History: The programme started in one hospital in 1966 and was a founding member of the ICBDMs.

Size and coverage: Reports are now obtained from three hospitals located in the central region of the country, with more than 20,000 annual births (more than 15% of all births in Israel). Stillbirths of 20 weeks gestation or more and 500 gm or more are included. The registry of termination of pregnancy began in 1995.

Legislation and funding: The programme is a research programme supported by research grants without any governmental support.

Sources of ascertainment: Reporting is voluntary. Reports are obtained from delivery units and neonatal departments in the participating hospitals. The three included hospitals are: Rabin Medical Center, Beilinson Campus' Petah Tikva; Kaplan Hospital, Rehovot (Dr. Kohan Dr. Shinwell) and Lis Medical Center, Tel Aviv (Prof. Mimouni, Dr. Dolberg). These hospitals are affiliated to Sackler School of Medicine, Tel-Aviv University.

Exposure information: Complete anamneses are obtained by interviews of mothers of all malformed infants. All the other women with normal newborns complete a similar form at discharge.

Background information: Epidemiological information on all births occurring in the participating hospitals is available.

Address for further information:

Paul Merlob, Department of Neonatology, Rabin Medical Center, Beilinson Campus, 49100 Petah Tikva, Israel: IBDMS.
Phone: 972-3-9377473/2/4. Fax: 972-3-9220068. E-mail: merlob@post.tau.ac.il

Italy, BDRCam

Birth Defects Registry of Campania

History: The registry started in 1991. The registry joined EUROCAT in 1997.

Size and coverage: The programme is based on reporting from hospitals distributed in Campania, a southern Italy region. Naples is main city. Initially 38 hospitals reported and the annual number of births was 38.000. At the present time, 60 hospitals participate, covering approximately 50.000 annual births or approximately 80% of all births. Stillbirths and induced abortions are included

The programme became a full member of the ICBDMs in 1996.

Legislation and funding: The programme is a surveillance programme supported by grants from Regional Health Authorities. Participation was voluntary up to 1995. From 1996 participation is mandatory.

Sources of ascertainment: Reports are obtained from delivery units and pediatric clinics at the participating hospitals. For selected malformations multiple sources are used with follow-up to one year using specific records from pediatric specialties department dealing with malformed infants.

Exposure information: For each malformed infant reported, information is given on certain exposures, including maternal drug usage and parental occupation. Up to now no information on induced abortions and controls is available.

Background information: Up to now little background information is given on certain exposures, including maternal drug usage and parental occupation. Up to now no information on controls is available.

Address for further information:

Gioacchino Scarano, Registro Campano Difetti Congeniti, Azienda Ospedaliera "G. Rummo", Via dell'Angelo 1 , 82100 Benevento, Italy
Phone +39 0823 57374. Fax +39 0824 57495. e-mail : giorecam@tin.it

and

Osservatorio Epidemiologico Regionale, Assessorato alla Sanità, Regione Campania, Centro Direzionale isola C3, Naples, Italy.
Fax +39 081 7969347

Italy, IMER

Emilia-Romagna Registry of Congenital of Malformations

History: The registry started in 1978 in a few hospitals and has increased in size to now include 44 delivery units. The programme joined the ICBDMs in 1985. The registry joined EUROCAT in 1980.

Size and coverage: The programme is population-based (about 95% of all births in the Emilia-Romagna region) and covers approximately 28,000 annual births. Stillbirths of 28 weeks or more gestation are included.

Legislation and funding: The programme is recognised and financed by the health authorities, the National Research Council, and the Regional Health Council. Hospital participation is voluntary.

Sources of ascertainment: Reporting is made by neonatologists and pediatricians during the first week of the infant's life. Selected malformations are followed up.

Exposure information: Detailed exposure information is obtained by interviews of the mothers of malformed infants. For each malformed infant, a control is chosen (the baby born before or after the malformed case in the same hospital) and its mother is interviewed in a similar way.

Background information: Some general demographic information is known for all births in the area. For each participating hospital, the number of livebirths and stillbirths are known.

Address for further information:

Guido Cocchi, Istituto Clinico di Pediatria Preventiva e Neonatologia, Università di Bologna, Via Massarenti, 11, 40138 Bologna, Italy.

Phone: 39-051-342754 / 6363654. Fax: 39-051-342754. E-mail: cocchi@med.unibo.it

Italy, ISMAC

Sicilian Registry of Congenital Malformations

History: The Registry started in 1991 and became an ICBDMMS member in 1996. Sicilian Registry collaborates with other Italian Registries under supervision of Italian National Institute of Health – Rome. The registry joined EUROCAT in 1997.

Size and coverage: It is hospital based and actually collaborates with four south-east provinces of the nine Sicilian provinces, (with a covering rate higher than 75%) and with more than 19000 controlled newborns for year.

Legislation and funding: The programme is on a voluntary basis, supported at local level by A.S.MA.C, Sicilian association for congenital malformations prevention.

Sources of ascertainment: Reports are obtained from delivery units, pediatric units and other specialist departments.

Exposure information: For each malformed reported (livebirth, stillbirth and voluntary abortion), information is given on certain exposures, including maternal drug usage and parental occupation. Up to now no information on controls is available.

Address for further informations:

Sebastiano Bianca, Dipartimento di Pediatria, via S. Sofia, 78 – 95123 Catania, Italy.
Fax: 39-095-222532. E-mail: sebastiano.bianca@tiscalinet.it

Italy, North East

North East Italy registry of Congenital Malformations

History: The Registry was established in 1981 to include Veneto and Friuli Venezia Giulia regions. Trentino Alto Adige region was added in 1990. The registry joined EUROCAT in 1985, and became a member of the ICBDMs in 1997.

Size and coverage: Reports are obtained from 73 participating hospitals, with a total of approximately 49,500 annual births; the actual coverage is estimated at 99%.

Legislation and funding: Reporting is voluntary. The programme is partly run by Regional Health Authorities.

Sources of ascertainment: Reports are obtained on specific forms from delivery units, induced abortion units, pediatric, cardiology, ophthalmology and pathology departments, regional induced abortion database and cytogenetic laboratories. 32 selected malformations are recorded within 7 days from birth (within 3 years of age for cardiovascular and ophthalmological anomalies only). In terminated fetuses all anomalies are recorded. From 1st January 2000 we are now registering all congenital anomalies adopting the Eurocat list of exclusions (revised 1985).

Exposure information: Detailed information on various exposures, including maternal or paternal occupation, diseases and drug use is obtained by interview of the mothers at the birth of the malformed infants and their controls.

Background information: Some epidemiological background data of all births are available. For each participating hospital the number of livebirths and stillbirths by sex and number of twin pairs are known.

Address for further information:

Romano Tenconi MD, Clinical and Epidemiological Genetic Service, Pediatric Department, via Giustiniani 3, 35128 Padova, Italy.

Phone: 0039-049-8213513. Fax: 0039-049-8211425. E-mail: romano.tenconi@unipd.it

Web: www.genetica.pedi.unipd.it

Italy, Tuscany

Tuscany Registry of Congenital Defects

History: The registry started in 1979 in the province of Florence and from 1992 in the whole Tuscany region. The programme became a member of the ICBMDS in 1998. The registry joined EUROCAT in 1979.

Size and coverage: The programme is population based, involves all the regional hospitals and the coverage is around 95% of all births in the Tuscany region (approximately 3.5 millions inhabitants and 25,000 births/year). Stillbirths of 20 weeks or more gestation and induced abortions after prenatal diagnosis of birth defects are systematically included. Malformed babies diagnosed within the first year of life are also registered.

Legislation and funding: The Registry is a surveillance programme included in the Regional Statistics System; it is formally recognised and supported by the Tuscany Region Health Authority.

Sources and ascertainment: Multiple sources are used to ascertain malformed infants; records are obtained from all obstetrical and maternity units, pediatric departments, neonatal and pediatric surgery units, prenatal diagnostic centers and pathology services. Mothers are interviewed by using a standardized questionnaire.

Exposure information: Exposure information on maternal and paternal occupation, life-style, and socio-economical characteristics are obtained by interviews of mothers of malformed infants.

Background information: Vital statistics and other epidemiological information are obtained by the birth medical records collected by the Regional Bureau of Statistics. Selected information is obtained from the control material collected.

Address for further information:

Fabrizio Bianchi, Sezione di Epidemiologia e Biostatistica, Istituto di Fisiologia Clinica del Consiglio Nazionale delle Ricerche, Area della Ricerca di S. Cataldo, Via Moruzzi, 1, 56127 Pisa, Italy.

Phone: 39 050 3152100. Fax: 39 050 3152095. E-mail: fabrizio.bianchi@ifc.cnr.it

Japan, JAOG

Japan Association of Obstetricians and Gynecologists

History: The programme started in 1972 and became a full member of the ICBDMs in 1988.

Size and coverage: The programme is based on reports from 330 hospitals throughout Japan. At present, approximately 110,000 births are covered, representing about 9 % of all Japanese births. Stillbirths of 22 weeks or more gestation are included.

Legislation and funding: The programme is a research programme acknowledged by the Ministry of Welfare and Health and supported by JAOG and Ogyaa-Donation.

Sources of ascertainment: Reports are obtained from delivery units and pediatric clinics of participating hospitals.

Exposure information: Detailed information on various exposures including maternal or paternal occupation, chronic diseases and drug use, X-ray and viral infections are available.

Background information: Basic epidemiological information on all births is available from each participating hospital.

Address for further information:

Yoshio Sumiyoshi, JAOG, Yokohama City University, Urafune Hospital, 4-57 , Urafune-cho, Minami-ku, Yokohama, 232-0024, Japan.

Phone: 81-45-2533668. Fax: 81-45-2533668. E-mail: fuhira@hamakko.or.jp

Malta

Malta Congenital Anomalies Register

History: The register started in 1985 as a research project of the University of Malta. It started as a hospital based register collecting data regarding congenital anomalies diagnosed in babies born at the main general hospital. The registry joined EUROCAT in 1986. Funding for the research project was stopped in 1995 and in 1997 the Department of Health Information resumed the functions of the registry increasing coverage to all hospitals on the islands making it a population based register. Several new sources of data were included at this stage. The Register was accepted as an associate member of the International Clearinghouse in 2000.

Size and Coverage: The registry is population based and presently covers about 4500 births per year. Stillbirths of 20 weeks gestation or more are registered. Termination of pregnancy is illegal in Malta.

Legislation and Funding: Reporting is voluntary. The registry is run and funded by the government Department of Health Information.

Sources of ascertainment: The registry employs active data collection from multiple sources including: labour, postnatal and nursery wards, cardiac lab records, genetics clinic records, National Mortality Register, National Obstetric Systems database, Hospital Activity Analysis database, National Cancer Register and the hypothyroid screening programme. Voluntary reporting by doctors is also available. These sources cover the whole population of the Maltese Islands.

Exposure information: Information regarding maternal disease and exposure to medicinal drugs, smoking, alcohol and drug abuse as well as parental occupation are collected for all malformed infants.

Background information:

Epidemiological background data on all births are available from the National Obstetric Information Systems database and the National Statistics Office (NSO).

Address for further information:

Miriam Gatt, Malta Congenital Anomalies Registry, Department of Health Information, 95, Guardamangia Hill, Guardamangia MSD 08, Malta.
Phone: (+356) 21234915. Fax: (+356) 21235910. E-mail: miriam.gatt@magnet.mt

Mexico, RYVEMCE

Mexican Registry and Epidemiological Surveillance of External Congenital Malformations

History: The programme was started in 1978. The programme became a member of the ICBDMs in 1980.

Size and coverage: Reports are obtained from 15 hospitals in 11 cities in Mexico. Participation is voluntary. The annual number of births is approximately 40.000, about 3.5% of all births in Mexico. Stillbirths of 20 weeks or more gestation and/or at least 500g birthweight are included.

Legislation and funding: The programme is a research programme and is funded by research grants.

Sources of ascertainment: Reports are obtained from the delivery units and pediatric departments of the participating hospitals.

Exposure information: The mother of each reported infant and the mother of a control infant-the next non-malformed infant born at that hospital with the same sex as the proband - are interviewed on various exposures, including drug usage and parental occupation.

Background information: The total number of births in the hospitals is known.

Address for further information:

Oswaldo Mutchinick, Departamento de Genetica, Instituto Nacional de Nutricion, Salvador Zubiran, Vasco de Quiroga 15, Tlalpan, 14000 Mexico, D.F., Mexico.

Phone: 52-5-5731200/ 52-5-5730611, 52-5-5737333 (ext 2426, 2425). Fax: 52-5-6556138.

E-mail: osvaldo@servidor.unam.mx

New Zealand

New Zealand Birth Defects Monitoring Programme

History: The program began in 1975 and became a full member of the ICBDMs in 1979. **Size and coverage:** The programme covers all livebirths (approximately 56,000 per year) delivered or treated in a New Zealand publicly funded hospital. Only these data are included in the quarterly and annual reports to the ICBDMs. Data on stillbirths are retrospectively added to the database together with additional cases derived from the national perinatal and mortality databases. In late 1995 the definition of stillbirth was changed from 28 weeks completed gestation to 20 weeks or more gestation and/or 400g birthweight.

Legislation and funding: The programme is run and funded by Public Health Intelligence, Ministry of Health.

Exposure information: No exposure data are currently available, but attempts are being made to obtain such data.

Background information: General epidemiological characteristics for all births are available.

Address for further information:

Dr Barry Borman, Public Health Intelligence, Public Health Directorate, Ministry of Health, PO Box 5013 Wellington, New Zealand.

Phone: 64-4-495-4379. Fax: 64-4-495-4401. E-mail: barry_borman@moh.govt.nz

Northern Netherlands

EUROCAT registration Northern Netherlands

History: The programme started in 1981, and became a ICBDMs member in 1993. The registry joined EUROCAT in 1981.

Size and coverage: In the beginning the programme covered 7,500 births annually. Coverage was gradually increased to 19,000 births annually in the provinces Groningen, Friesland and Drenthe from 1989 onwards. Home deliveries (30% of births) are included.

Legislation and funding: The programme is funded by the Dutch Ministry of Public Health, Welfare and Sports. The registry is carried out in the Department of Medical Genetics of the University of Groningen.

Sources of ascertainment: Obstetricians, paediatricians, clinical geneticists, surgeons, general practitioners, midwives, well-baby clinics, pathologists and the national obstetric registry send information to the registry on a voluntary basis. Informed consent of the parents is needed. Registry personnel is actively involved in data collection. No age limits are applied.

Exposure information: Since 1997 parents are asked to fill out a questionnaire including questions on occupational activities and drug use. Besides, data from community pharmacies are used to collect maternal drug exposure data.

Background information: General statistics are available from the Dutch Central Bureau of Statistics (CBS).

Address for further information:

Hermien de Walle, Department of Medical Genetics, Ant. Deusinglaan 4, 9713 AW Groningen, The Netherlands.

Phone: 31-50- 3633193/3632952. Fax: 31-50-3187268.

E-mail: H.E.K.de.Walle@medgen.azg.nl

Norway

Medical Birth Registry of Norway

History: The programme was started in 1967. The programme was a founding member of the ICBDMs. The registry joined EUROCAT in 1979.

Size and coverage: The programme covers all births in Norway, approximately 60,000 annual births. Stillbirths of 16 weeks or more gestation are included.

Legislation and funding: The programme is run and funded by the governmental Norwegian Institute of Public Health. Reporting is compulsory.

Sources of ascertainment: The registry is based on the notification of births from the delivery units and since 1999 also from the neonatal units.

Exposure information: Some basic information, such as maternal disease and since 1999: smoking and occupation, is collected on all infants, malformed or not.

Background information: All information available for the reported malformed infants is also available for the total population of births.

Address for further information:

Lorentz M. Irgens, Medical Birth Registry of Norway, Armauer Hansen Bldg, Haukeland Hospital, N-5021 Bergen, Norway.
Phone: 47-5-5974667. Fax: 47-55-974998. E-mail: lorentz.irgens@mfr.uib.no

Russian Federation, Tomsk

Tomsk Birth Defects Monitoring Programme – Tomsk Genetics Registry

History: The registration of malformations in Tomsk begin in 1984 but actual The Tomsk Birth Defects Monitoring Programme started in 1990. It became an associate member of the CBDMS in 1996.

Size and coverage: The Tomsk Birth Defects Monitoring Program are population based surveillance system. At present, the program covers approximately 10.000 birth annually in the Tomsk, or about 100% all births in the Tomsk, or about 50% of all births in the province-less Tomsk. Stillbirths of 28 weeks or more gestation are registered. The prevalence estimates for all diagnostic categories are on data.

Legislation and Funding: The programme is funded by Institute of Medical Genetics Tomsk Scientific Center Russian Academy of Medical Sciences.

Sources of ascertainment: Reports are obtained from all maternity hospitals, pediatric clinics, and pathology departments of the participating hospitals of Tomsk.

Exposure information: Exposure information is obtained by interviews of mothers of the reported malformed infants. No exposure information is routinely available.

Background information: Total number of births from each participating hospital is known.

Address for further information:

Ludmila P. Nazarenko, Nataly I. Krikunova, Programme Director, Institute of Medical Genetics Tomsk Scientific Center of Russian Academy of Medical Sciences hereditary pathology laboratory, Ushaika embankment, 10, Tomsk, 634050, Russian Federation.
Phone: (3822)515339. Fax: (3822)513744. E-mail: Lnaz@img.tsu.ru.
E-mail: krikunova@img.tsu.ru

Scotland, Glasgow

*Greater Glasgow NHS Board (formerly Greater Glasgow Health Board)
Congenital Anomalies Register*

History: The programme was started in 1972. The registry joined EUROCAT in 1978, the first full year for which standardised notifications were made being 1979.

Size and coverage: The reference population is defined as all births to women resident in the Greater Glasgow NHS Board area, around 12,000 annually, irrespective of the place of birth. Live births, stillbirths of 24 weeks or more, spontaneous and induced abortions are included.

Legislation and funding: Reporting is voluntary. The Register is funded by Greater Glasgow NHS Board.

Sources of ascertainment: Hospital discharge data, Child Health Surveillance Programme, Health Visitor Immunisation Consent Forms, Death/Stillbirth Registration, Medical Genetics and Pathology Departments, Inborn Errors of Metabolism Screening Programme.

Exposure information: Information on maternal drug use, maternal habitual and unusual exposures, maternal and paternal diseases and occupations is available.

Prenatal diagnosis information: Data about techniques of prenatal screening and prenatal diagnosis are collected.

Background information: Data on births is available from the Registrar General for Scotland.

Address for further information:

Dr David H. Stone, Paediatric Epidemiology and Community Health (PEACH) Unit, University of Glasgow, Royal Hospital for Sick Children, Yorkhill, Glasgow G3 8SJ, Scotland, UK.
Tel 44 141 201 0178/0171. Fax 44 141 201 0837. Email: d.h.stone@clinmed.gla.ac.uk

Hilary Jordan, Information Services Unit, Greater Glasgow NHS Board, Dalian House, PO Box 15328, 350 St Vincent Street, Glasgow G3 8YY, Scotland, UK.
Tel 44 141 201 4563 Fax 44 141 201 4539. Email: hilary.jordan@gghb.scot.nhs.uk

South Africa, SABDSS

South African Birth Defects Surveillance Systems

History: The programme started in 1988 and became a full member of the ICBDMs in 1992.

Size and coverage: The programme is hospital based covering 11 sentinel sites over the country with approximately 75,000 annual or 5% of all births in South Africa.

Legislation and Funding: The programme is funded by the Department of National Health. Participation in the programme is voluntary.

Sources of ascertainment: Notifications are obtained from delivery units and paediatric units of the participating hospitals.

Exposure information: No exposure information is routinely available.

Background information: Total births for some participating hospitals are not accurately known.

Address for further information:

David Bourne-Rauf Sayed, Programme Director, Dept. of Public Health and Primary Health Care, University of Cape Town-Medical School, Observatory 7925, Cape Town, South Africa
Phone: 27-21-4066482. Fax: 27-21-4066163.
E-mail: db@cormack.uct.ac.za E-mail: rauf@cormack.uct.ac.za

South America, ECLAMC

Latin American Collaborative Study of Congenital Malformations

History: The programme started in 1967 and has grown in size and coverage. The programme became a full member of the International Clearinghouse in 1977.

Size and coverage: The number of participating hospitals has grown from 20 in 1977 to 70 at the present time, distributed over most South American countries. The annual number of births covered is at present approximately 150,000, less than 1% of all births. Stillbirths of at least 500g birthweight have been included since 1978.

Legislation and funding: The programme is a research programme with voluntary participation of hospitals and funded by research grants provided from several sources, mainly the national research councils of Argentina and Brazil..

Sources of ascertainment: Reporting is made by collaborating pediatricians at the delivery units of participating hospitals.

Exposure information: The mother of each reported infant and the mother of a control infant - the next non-malformed infant born at that hospital with the same sex as the proband - are interviewed on various exposures, including drug usage and parental occupation.

Background information: Background information is obtained partly from summarising tables of births in each participating hospital, partly from the matched control newborns.

Address for further information:

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Southern Portugal

History: The registry started in 1990 and the registry joined EUROCAT in 1989.

Size and coverage: The registry is population-based and covers approximately 15,000 births annually in the Health Region Algarve, Health Region Alentejo, and District of Setúbal. The registry covers livebirths up to the first month of life, stillbirths and terminations of pregnancy.

Legislation and funding: The registry is funded by the National Institute of Health.

Sources and ascertainment: Cases are notified by paediatricians and obstetricians responsible for registration in each region. Data are validated in the registry in Lisbon.

Exposure information: Information about maternal drug use, maternal diseases, maternal occupation, and obstetrical history is available for cases.

Background information: Denominators are available from the National Statistics.

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Spain, Asturias

History: The registry started in 1990. The registry joined EUROCAT in 1992. The registry is situated in the Epidemiology Unit of the Regional Public Health Department.

Size and coverage: The registry covers approximately 7,000 births annually in the Asturias region. The registry covers livebirths up to the first week of life, stillbirths and terminations of pregnancy.

Sources and ascertainment: Case forms are collected from pathology units, biochemical and cytogenic laboratories, neonatology and paediatric units, obstetricians, geneticists, death certificates and hospital discharge forms.

Exposure information: Information about maternal drug use, maternal diseases, and obstetrical history is available for cases.

Background information: Denominators are available from the Asturias Natural Population Movement Statistics.

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Spain, Barcelona

Barcelona Birth Defects Registry (Registro de Defectos Congénitos de Barcelona: REDCB)

History: The programme was initiated in 1990 and reached a population based status by 1992. The registry joined EUROCAT in 1992.

Size and coverage: The registry covers all livebirths and stillbirths of 22 weeks or more (about 12,500 annually) and terminations of pregnancy following prenatal detection of anomalies, in the population of Barcelona city. The coverage of the registry is estimated around 98%.

Legislation and funding: The registry is part of the Health Information Service in the Municipal Institute of Public Health of Barcelona. It is partially funded by national research grants.

Sources of ascertainment: General information on cases and controls as well as clinical information on cases is collected using questionnaires specifically made for the registry. An interview with the mother is the main source of general information. Delivery units, pediatric departments, cytogenetic laboratories, pathology departments, prenatal diagnosis units, etc. are the sources of clinical information.

Exposure information: Information on maternal drug use, maternal and paternal diseases and occupations, is available for cases and controls.

Prenatal diagnosis information: Data about techniques of prenatal screening and diagnosis are systematically collected.

Background information: Background data on births are available from birth certificates and the Barcelona perinatal mortality registry.

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Spain, Basque Country

Registry of Congenital Anomalies of the Basque Country (RACAV)

History: Registration of congenital anomalies in the Basque Country started on January 1st 1990. The registry joined EUROCAT in 1990.

Size and coverage: The registry is located in the Basque Country region, in northern Spain, with a total extension of 7,260 Km², and a population of 2,250,000 inhabitants. It is a population-based registry that covers 16,000 to 17,000 annual births.

Legislation and funding: Reporting is voluntary. The registry is financially supported by the Health Department of the Basque Government.

Sources of ascertainment: There is an active research for cases (livebirths, stillbirths and induced abortions) through multiples sources of information: Neonatal Units, Specialist Paediatrics Departments, Cytogenetics and Pathology labs, Hospital discharge records and private maternities. Data about techniques of prenatal screening and diagnosis are systematically collected.

Exposure information: Information on maternal drug use, maternal and paternal diseases, outcome of previous pregnancies and assisted conception is available.

Background information: Statistics are provided by the Basque Statistics Institute (EUSTAT).

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Spain, ECEMC

Spanish Collaborative Study of Congenital Malformations

History: The programme started in 1976 as a hospital-based case-control study and surveillance system. It became a member of the ICBDMs in 1979. The registry joined EUROCAT in 1979.

Size and coverage: Reports are obtained from hospitals (83 at present) distributed all over Spain. The annual number of births surpasses 100,000, representing more than 27% of all Spanish births. Stillbirths of at least 24 weeks or 500 g. have been included since 1980.

Legislation and funding: It is a research programme with voluntary participation of hospitals, and is financed mainly by the Spanish Administration and, partially, by non-governmental organisations.

Sources of ascertainment: The detection period is the first 3 days of life, including major and/or minor/mild defects. Reports come from delivery units and paediatric departments of the participating hospitals. Mothers are interviewed directly to fill in the ECEMC standard protocols, which include more than 300 data for each child (family history, demographic and obstetrical data, prenatal exposures, etc), whether case or control. Controls are defined as the next non-malformed infant born at the same hospital that the case with the same sex as the malformed infant. In many instances, photographs, imaging studies, high resolution bands karyotypes and molecular analysis when needed, and other complementary studies are available.

Exposure information: The mother of each reported infant (case or control) is interviewed on various exposures (parental occupation, maternal acute or chronic diseases, drug usage, exposure to other chemical or physical factors) within the first three days after delivery.

Background information: Total number of births by sex and number of twin pairs in each participating hospital are gathered. Other background information is obtained from the control material.

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Spain, El Vallès

History: The registry started in April of 1991. The registry joined EUROCAT in 1993.

Size and coverage: The registry covers approximately 9,000 births. It includes livebirths, stillbirths and terminations of pregnancy. Cases are collected from the prenatal period until 3-4 days after birth. The coverage of registry is around 90%.

Legislation and funding: Until 2000 the registry was financed by grants. Currently, the registry has no financial support.

Sources and ascertainment: Case forms are collected from obstetrics, pediatric and pathology units. Terminations of pregnancy are collected from Department of Health (Catalonian Government).

Exposure information: Information about maternal drug use, maternal diseases, maternal and paternal occupations, and obstetrical history is available for cases.

Background information: Denominators are available from Department of Statistics (Catalonian Government).

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Switzerland

Registry of Switzerland

History: the registry of Switzerland was set up in 1988. The registry joined EUROCAT in 1988; different cantonal registries send their data to the central registry in Lausanne.

Size and coverage: the aim at the beginning was to cover the whole country (80,000 births/year). In the first years of activity, 30% - 81% of births were surveyed. For financial reasons, many cantons had to stop this activity and since 1993, the Swiss registry covers 50% of all births in Switzerland. Since 1998, the following cantons are included in the program : Zurich, Fribourg, Argovie, Tessin, Vaud, Valais, Neuchâtel, Jura. The registry covers congenital anomalies in live and still births of 20 weeks or more and in induced abortions following prenatal diagnosis.

Legislation and finding: reporting is voluntary. The registry is localized in the Division of Medical Genetics of the University hospital in Lausanne. The registry has formerly been elaborated with members from the Swiss Academy of Medical Sciences and from the Swiss Society of Paediatrics. The system is financed by the Swiss Federal Agency for Statistics for the central registry and by cantonal health departments for some cantonal registries.

Sources of ascertainment: active case-finding and multiple source of information are used: delivery units; paediatric departments; cytogenetic and genetic counselling; pathology unit. Data about different methods of prenatal diagnosis are collected (ultrasound, serum markers, cytogenetic and molecular).

Background information: background data on births are available from the Swiss Federal Agency for Statistics.

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Web site EUROCAT Switzerland : www.hospvd.ch/public/chuv/genmol/eurocat/euro-home.htm

United Arab Emirates

Congenital Abnormality Study Group

History: Although started 1992, the program started continuous monitoring only in 1994. It is now a Member of the ICBDMs.

Size and coverage: The program covers about 8000 births a year occurring in three major hospitals of the Al Ain Medical District, situated in the eastern part of the Abu Dhabi Emirate. It has a population of about 270,000. Still births with a weight of only more than 500 gm are included.

Legislation and funding: The program is funded by the Faculty of Medicine and Health Sciences of the UAE University.

Sources of ascertainment: In each hospital, there is a neonatologist who examines, identifies abnormalities and records at birth in a form provided. The diagnosis is further assisted by a clinical geneticist/dysmorphologist and pediatricians.

Exposure information: Some basic information on exposure such as maternal disease is collected in all cases.

Background information: General epidemiological data for all births are available.

Address for further information:

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USA, Atlanta

Metropolitan Atlanta Congenital Defects Program

History: The program started in 1967 and was a founding member of the ICBDMs.

Size and coverage: The program covers all births within a five county area in metropolitan Atlanta, Georgia. The annual number of births in this area is approximately 47,000. Stillbirths and terminations of at least 20 weeks gestations (or a birth weight of at least 500 grams) are included. Terminations less than 20 weeks are included for selected defects.

Legislation and funding: In 1994 the Georgia Department of Human Resources (GDHR) added birth defects to the list of legally reportable conditions in Georgia. In 1997 the GDHR authorized the Birth Defects Branch at the Centers for Disease Control and Prevention (CDC) to act with and on its behalf to collect health information on children with birth defects. The program is funded by the Centers for Disease Control and Prevention.

Sources of ascertainment: Multiple sources, such as delivery units, pediatric departments, laboratories, prenatal diagnostic centers and other specialties, are used to ascertain malformed infants born in the defined area with a follow-up to age six years.

Exposure information: Exposure information is obtained by interview for mothers of reported malformed infants who participate in various research projects.

Background information: Number of live births and demographic information on the five counties are obtained from vital statistics.

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