Eurocat Northern Netherlands

History and Funding

Eurocat Northern Netherlands (NNL) started in 1981, and was a member of the EUROCAT network since that year. The registry is funded by the Dutch Ministry of Health, Welfare and Sports and is associated with the Department of Genetics of the University Medical Centre of Groningen.

Population Coverage

The registry is population-based, including babies born to all mothers resident in the registration area. In the beginning, the program covered 7,500 births annually in the province of Groningen and the northern part of the province of Drenthe. From 1989 onwards, coverage was gradually increased to 20,000 births annually in the provinces of Groningen, Friesland and Drenthe. In recent years the number of births in the region decreased to 18.500, approximately 10% of all births in the Netherlands. Home deliveries (25% of births per year) are included and it is estimated that only a few percent of resident mothers would give birth outside the defined registry area.

Sources of Ascertainment

Children and foetuses with congenital anomalies diagnosed before or after birth are eligible for registration at the Eurocat NNL registry, if the mother lived in the region at the time of birth and the child is not older than 10 at notification. There is no lower limit for gestational age, spontaneous and induced abortions are included. Notification of children and foetuses with congenital anomalies is voluntary. Registry personnel are actively involved in case ascertainment, using multiple sources such as obstetric records, hospital administration data, pathology records, etc. Cytogenetic lab results are electronically downloaded from the Genetics department and include all abnormal karyotype reports, both from prenatal and postnatal samples. For cases reported to the registry it is verified whether any genetic tests were performed and test results are registered in the database. The only pediatric cardiology centre in the registration area, also part of the UMCG, supplies systematic case lists and diagnostic details to the registry. A number of frequently occurring mild (minor) anomalies is not registered, unless they occur in combination with other serious congenital anomalies. If new information becomes available for registered children before 10 years of age, the files are updated. We do not have birth nor death certificates as source of information. See for the procedure concerning ‘non responders’ under the heading ‘Ethics and Consent’.

Maximum Age at Diagnosis

Up to 10 years of age.

Termination of Pregnancy for Fetal Anomaly (TOPFA)

TOPFA is legal in the Netherlands. The upper age limit for termination of pregnancy (for social reasons and for fetal anomaly) is 24 weeks,. Termination of pregnancy after 24 weeks is allowed when the fetus is affected with a congenital anomaly that is considered lethal.

Prenatal Diagnosis

Since January 2007, a nationwide prenatal screening program has been implemented in the Netherlands, in which the combined test (CT) in the first trimester to determine the risk for trisomy 21 and a structural ultrasound for neural tube defects in the second trimester are offered to all pregnant women. In 2010 the CT expanded to determine also the risk for T18 and T13.More recently (April 1st 2017) the non-

invasive prenatal test (NIPT) is available for every pregnant woman in the Netherlands. For prenatal diagnosis amniocentesis or chorionic villus sampling is offered.

Stillbirth Definition and Early Fetal Deaths

A stillbirth is defined as a fetus of at least 24 weeks gestation that died in utero or during birth. There are no age or weight limits for inclusion of early fetal deaths/spontaneous abortions. Autopsy rates per year are not available and neither are stillbirth certificates.

Exposure Data Availability

Since 1997 parents have been asked to fill out a questionnaire including questions on occupational activities, assisted conception, use of folic acid, smoking habits, alcohol consumption, recreational drug use, over the counter medication use, chronic illnesses and socioeconomic status. In addition, data from community pharmacies are used to collect data on medication dispensed in the period from 3 months before and during pregnancy.

Data collection

The birth of a child with a congenital anomaly is reported to Eurocat by doctors and midwives, after informed consent from the parents. The initial information regarding type and durance of pregnancy and the anomaly is supplemented with data –as mentioned above- from the questionnaire, pharmacy records and additional information from medical records. The questionnaire for the parents covers the period before and during the pregnancy.

Denominators and Controls Information

General statistics are available from the Central Bureau of Statistics (CBS). No information on non-malformed infants is collected.

Ethics & Consent

The registry does not require ethics committee approval in order to collect and store data. The registry operates within the scope of the GDPR and the Code of Good Conduct, set up by the Dutch Federation of Biomedical Scientific Societies. National legislation requires informed consent in order to register a baby with a congenital anomaly. If parents do not respond to repeated requests to participate, they are marked as a so called 'non-responder' and only very limited data regarding diagnosis and pregnancy outcome are registered. The parents are informed about this procedure in the letter with request to participate. This procedure has been initiated since 2010, to allow a more complete registration for prevalence data. Parents are informed in writing, in compliance with applicable guidelines ('Gedragscode Gezondheidsonderzoek', Chapter 6).
Parents have to agree to the inclusion of the child on the register (opt-in). The positive response rate is 70-80%.

Address for Further Information

Hermien de Walle, registry leader
Eurocat Northern Netherlands ,Department of Genetics, University Medical Center Groningen,
PO Box 30.001, 9700 RB Groningen, The Netherlands
Tel.: +31 50 361 7115
fax: +31 50 361 7232
email: eurocat@umcg.nl
website: www.eurocat.umcg.nl
Twitter: @EurocatNL