

organizations, with 100 using email, 96 using Facebook and 66 using Twitter.

**Conclusion:** Over 97% of support organizations used online communication. Facebook was the most popular social network (82%) followed by Twitter (56%). This data has been used to justify the use of social media to facilitate a communication platform for ConnectEpeople to connect parents and researchers in discussions about shared research priorities.

#### **SOCIODEMOGRAPHIC FACTORS INFLUENCING SURVIVAL OF INFANTS WITH ISOLATED, LEFT-SIDED CONGENITAL DIAPHRAGMATIC HERNIA: A SYSTEMATIC REVIEW**

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**Background:** Congenital diaphragmatic hernia (CDH) is a malformation of the diaphragm accounting for 8% of all major congenital anomalies. While many clinical factors of survival in children with CDH have been established, there is a lack of knowledge on the role of sociodemographic factors. We aimed to systematically identify and summarise all available international literature, published from January 2000 to July 2017, evaluating specific mortality factors for children with prenatally-diagnosed, isolated, left-sided CDH.

**Methods:** Relevant papers were identified by searching four databases and the table of contents for the past five years for relevant journals. The risk factors of interest were: birth weight, gestational age (GA) at diagnosis, GA at birth, infant sex, maternal age, ethnicity, socioeconomic status and plurality. The primary outcome measure was survival. Data were extracted on study design, study quality, participant data and survival-related effect estimates.

**Results:** Seven studies fulfilled the inclusion criteria. Three were undertaken within Japan, three in USA and one in Czech Republic. GA at diagnosis and GA at birth were evaluated in six and five studies respectively, birth weight in four, infant sex in two and maternal age in one study. None of these factors showed a significant association with survival. No studies evaluated the influence of ethnicity, socioeconomic status or plurality.

**Conclusions:** Whilst the factors of interest showed no significant association with survival, more evidence is required to confirm these findings and potentially inform the development of public health interventions which can subsequently improve survival rates for CDH.

#### **KNOWLEDGE OF THE NEW GENERAL DATA PROTECTION REGULATION (2016/679) AND ITS IMPACT ON THE REGISTRATION OF CONGENITAL ANOMALIES IN EUROPE**

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**Background:** The EU regulation on data collection and processing has been recently updated (General Data Protection Regulation (2016/679) (GDPR)). One significant addition is the accountability principle, which requires the disease registries to demonstrate that it complies with the regulation principles. Our aim was to ascertain the views on the awareness and predicted impact of these changes on members of the EUROCAT network.

**Methods:** Based on a previous EUROCAT questionnaire on consent, we developed a questionnaire specifically relating to the new GDPR. The self-completion questionnaire was distributed by the EUROCAT-JRC Central Registry to 41 register leads for completion.

**Results:** A total of 23 registries (56%) replied from 16 countries. Four registries reported opt-in informed consent, seven opt-out and 12 reported mandatory registration. Thirteen registries (57% of those who responded) registered a concern with the impact of the new GDPR on their registry's consent procedures, while 16 (70%) are aware of the new accountability principle. Some concerns include: obtaining explicit individual consent will be burdensome for doctors (especially for voluntary notifications); the new regulations will result in increased incomplete data; additional subsidiary legislations will be needed for the continuing

functions of the registries; and adapting the new rules in their daily work.

**Conclusions:** EUROCAT experience has showed that informed consent is a serious threat to the operation of registries relying on clinician notification or access to medical records. There is a real concern on whether the logistical difficulties in obtaining informed consent will be further increased with the implementation of the GDPR.

#### **FREQUENCY OF “MODEL” CONGENITAL MALFORMATIONS IN CHILDREN WHOSE MOTHERS USED TO LIVE IN THE ENVIRONMENTALLY UNFAVOURABLE AREAS**

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**Background:** Congenital malformations (CM) constitute a significant part in the structure of the causes of morbidity, infant mortality and disability. Most CM have multifactorial etiology, which means the simultaneous influence of genetic predisposition and external stimuli.

**Methods:** Two groups of observations were created, depending on the geochemical disadvantages of the places of residence of the mothers of children born with “model” birth defects. The first (I) group involved 327 cases, which belonged to the CHM according to the place of residence. And the second (II) group included 162 cases in the families, referred to CC by the place of residence.

**Results:** Thus, a ten-year analysis showed that the frequency of “model” CM in Chernivtsi in general corresponds to the EUROCAT International Register indices, with the exception of multiple birth defects, which exceeded the European index by 2.4 times, hypospadias – by 6 times, and congenital hydrocephalus, the index of which was on the upper limit. A significant risk of the formation of birth defects of the heart, the central nervous system and the genitourinary system was detected in the structure of “model” congenital malformations, provided that the mothers lived in places of geochemical disadvantages.

**Conclusions:** Under the condition of mothers' living in ecologically unfavorable areas of the city, the risk of birth defects of the heart is increased RR=1.5, the central nervous system – 1.66 and the urogenital system – 1.53 in newborn babies. Congenital malformations of mandatory record regardless of the ecological characteristics of habitats develop more often in boys: in group I in 71.0%, in group II in 60.4%.

#### **IS THERE A RELATION BETWEEN ENVIRONMENTAL EXPOSURE DURING PREGNANCY AND CONGENITAL ANOMALIES IN NEWBORN? PRELIMINARY RESULTS FROM A CASE-CONTROL STUDY**

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**Background:** Maternal exposure to environmental factors has been associated with the birth of a child with specific congenital anomalies (CA). The aim of this study is to investigate the association between occupational exposure, maternal place of residence, workplace and leisure activities during pregnancy and the occurrence of CA.

**Methods:** In 2016, an observational, case control study was developed and is still in progress. Cases are live births, identified in the maternity unit, with at least one CA and controls are the two births without anomaly following each case. Residents outside the study area, stillbirths and women who decline to participate or are incapable to give consent are excluded.

**Results:** 116 live births (38 cases and 78 controls) were recruited to the study. The majority of cases reported living (68.4%) and spending leisure time (63.2%) in the industrial area. 57.7% of controls live and 46.9% spend leisure time in the same area. However, no statistical differences were detected between them ( $p=0.195$  for residency and  $p=0.175$  for place of leisure). Cases work more frequently in Lisbon (21%) and residence area (15.8%) compared to controls (17.3% and 15.4% respectively) ( $p=0.057$ ). A total of 44 CAs were detected and the most frequently reported groups were the musculoskeletal system (34.1%) followed by CA of the ear and

genital group (15.9% and 15.9% respectively).

**Conclusions:** Due to the small sample size, no statistically significant difference was found between cases and controls. This is the reason why it is necessary to continue the study and obtain the collaboration of other hospitals in the same area.

#### THE EVOLUTION OF PRENATAL DIAGNOSIS IN THE EARLY DETECTION OF CONGENITAL ANOMALIES: DATA FROM 1997 TO 2016

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**Background:** The Portuguese prenatal surveillance programme advises ultrasound screenings, in the first trimester of pregnancy in combination with the blood test, and between 20 - 22 weeks of pregnancy. Other tests are offered in pregnancies with an increased risk. The aim of this study is to assess the evolution of prenatal diagnosis in the detection of congenital anomalies (CA).

**Methods:** A cross sectional study was implemented using data collected between 1997 - 2016 by the Portuguese registry of CA (RENAC) a population base registry that follow EUROCAT guidelines. A case was defined with at least one CA potentially detectible by prenatal diagnosis. Descriptive analysis was performed using absolute and relative frequencies and bivariate analysis was conducted using chi-square statistics.

**Results:** The analysis included 13,566 cases reported with at least one CA. There was a statistically significant increase in the detection of CA through prenatal diagnosis compared to detection at birth or after birth ( $p < 0.001$ ). In addition, there was an increase of cases detected during pregnancy from 52.1% (1997-1999) to 62.9% (2009-2016) especially in cases detected before 14 weeks (7.9% to 28.9%). Comparing the same periods of time, the results also show a range of ultrasound screening from 27% to 55.8% and a decrease in invasive tests from 18.9% to 3% which was statistically significant ( $p < 0.001$ ).

**Conclusion:** The data show a positive effect on the percentage of cases with CA detected during pregnancy. These results show the importance of extending prenatal tests to the all pregnant women and not only to those with specific risk gestations.

#### EUROLINKCAT: COMMON DATA MODEL

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**Background:** Over 130,000 children are born in Europe every year with congenital anomalies which are a major cause of infant mortality, childhood morbidity and long-term disability. Twenty-two EUROCAT registries in fourteen countries are participating in the EUROlinkCAT project assessing health and educational outcomes of children up to ten years of age with a congenital anomaly, born between 1995 and 2014. Each registry records anonymised, uniformly coded data on cases of congenital anomaly registered in their local population using the EUROCAT Data Management Program (EDMP).

**Methods:** While congenital anomaly data are already standardised across Europe, information on mortality, morbidity and educational outcomes are not. Information on potential risk factors for control children in the population also requires harmonisation. Creating a common data model is challenging as there are diverse coding classification systems, languages, healthcare and educational systems in Europe. In addition, individual case data cannot be shared. This means verification and validation of all derived variables, data transformations and proxy variables must be performed locally using centrally written syntax scripts to ensure correct interpretation of local data variables.

**Discussion:** As with many administrative datasets, the common data model is based on coded data rather than the often richer "free text" information. Nevertheless, the use of administrative datasets across Europe enables pooling of data on rare outcomes and allows hypotheses on the health and education of children to be investigated. This poster will outline the necessary pathway to create a common data model and the creation of a database of standardised variables available in all registries.

#### THE ITALIAN PROJECT FOR SURVEILLANCE PREVENTION AND HEALTH CARE PLANNING OF CONGENITAL ANOMALIES INCLUDING ZIKA VIRUS

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**Background:** Registries specific for Congenital Anomalies (CA) are important tools for surveillance, prevention, research and healthcare planning for these conditions. In Italy, there are regional registries, such as IMER and RTDC and others, active since the 1970s but there is not a national surveillance system covering the whole country. In 2017, a national law on registries of several human conditions was published (DPCM 3/03/2017). This framework supports also the establishment of the National Registry for CA, with specific focus to the surveillance of microcephaly and other disorders caused by Zika virus.

**Methods:** A Coordination Team (CT), which includes scientists of the National Centre for Rare Diseases and the Department of Infectious Diseases (Istituto Superiore di Sanità), Representatives of the Ministry of Health and the Coordinators of IMER and RTDC, is committed to setting up the CA National surveillance, including the establishment of the National Registry. The Italian National Registry for CA will collect data coming from Regional Registries and it will be functionally linked to the Italian Registry for Rare Diseases. Scientific collaborations are envisaged with EUROCAT. The CT is tackling the following topics: a) definition of the data-set; b) data sources; c) epidemiological flows; d) infra-structure for data collection; e) data sharing; and f) Verification of data.

**Results and Conclusions:** We are developing a national surveillance system for CA in Italy. The National Registry will collect data from Regional CA registries so supporting Regional Health authority decision making and national surveillance. It aims to be interoperable with the National Registry for Rare Diseases and other healthcare databases.

#### THE LEVEL OF PRECONCEPTION FOLIC ACID INTAKE IN CRIMEA

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**Background:** Although the role of folic acid (FA) in the prevention of neural tube defects (NTD) is well documented in the literature, its optimal use is still low in most countries. The objective of this study was to estimate the level of preconception folic acid supplementation among pregnant women in Crimea.

**Methods:** In the cohort study, data collection was continuous and comprises all maternal hospitals in Crimea. We constructed the questionnaires, which contained items about FA usage and dosage during all studies of embryogenesis and before conception. We analysed questionnaires with multivariate logistic regression. The mothers were classified as group 1 (FA taken before pregnancy), group 2 (FA taken during pregnancy), which include subgroups according to pregnancies' trimesters, group 3 (no FA intake, who could not remember taking FA or were not sure). The study included 206 females from different region of Crimea. Our explanatory variables were bad habits, vitamin and dietary supplement consumption (especially FA), employment, place of residence, age, education and preparation for pregnancy.

**Results:** In the preconception period, only 63 (30.6%) women received folic acid. Moreover, the supplementation was more frequent in those who were prepared for pregnancy compared to women who were not prepared. The medium dose of folic acid before pregnancy was 0.1 mg. In comparison with the WHO recommendation (0, 4 mg), it was low. Moreover, 143 (69.4%) refused from FA supplementation before pregnancy. It is important to note that when FA intake began is crucial for fetus. The first subgroup (1-13 weeks) comprised 58 (28.2%) females, the second subgroup (14-27 weeks) included 26 (12.6%) women, the third subgroup (28-42 weeks) consisted of 4 (1.9%) females. Additionally, 118 (57.2%) respondents refused from FA supplementation before pregnancy. The logistic regression model