

CARIS

Congenital Anomaly Register and Information Service for Wales



GIG
CYMRU
NHS
WALES

Iechyd Cyhoeddus
Cymru
Public Health
Wales

CARIS – the story

1957 – Thalidomide sold in Germany for morning sickness

1958 – Licensed in UK

1961 – Taken off the market

1964 – National Congenital Anomaly Monitoring system – SD56 form

1988 – Nant y Gwyddon landfill site opens

1996 – OPCS aware that reporting could be improved

1996 – Welsh Office – invitation to tender

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2010 – EUROMEDICAT research, SD56 stops

2015 – Public Health England transforms regional registers

2017 – CARIS takes on Rare Disease register

THE NATIONAL GUARDIAN, 1990

* "Others" is defined as pregnancies that ended in other than a registrable live or stillbirth.



Living in the shadow of a landfill

Nantygwyddon landfill site has come under fire from residents

Harriet Medlicott was born six years ago with a deformed windpipe and she has had to undergo three major operations. She suffers from pneumonia and needs regular medication and constant care from her family.

Her mother Natalie, from Gelli, Rhondda, south Wales, she had been told at the time of Harriet's birth that she had been born with a rare defect.



***Assessment of impact on health of
residents living near the Nant-y-
Gwyddon landfill site: retrospective
analysis - Fielder et al***

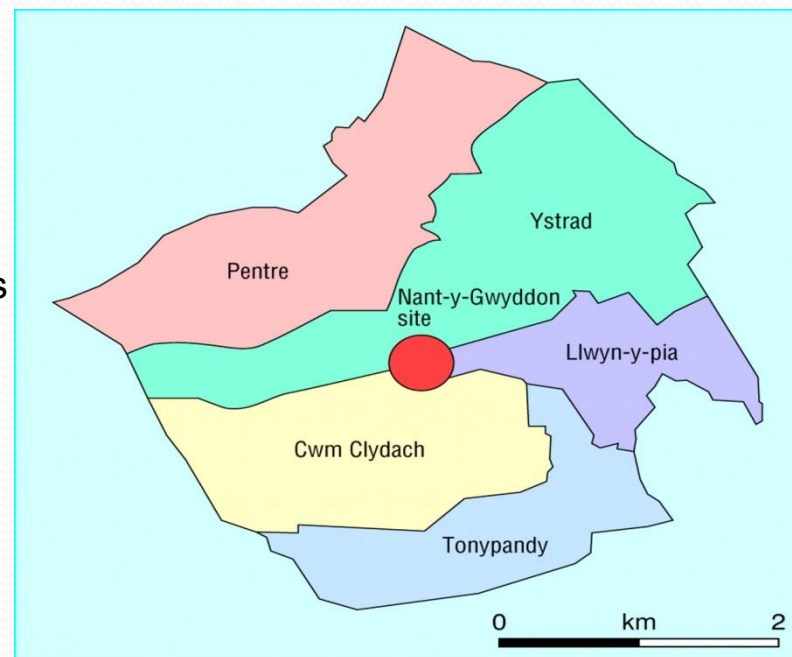
BMJ 2000; 320 doi:

<https://doi.org/10.1136/bmj.320.7226.19>

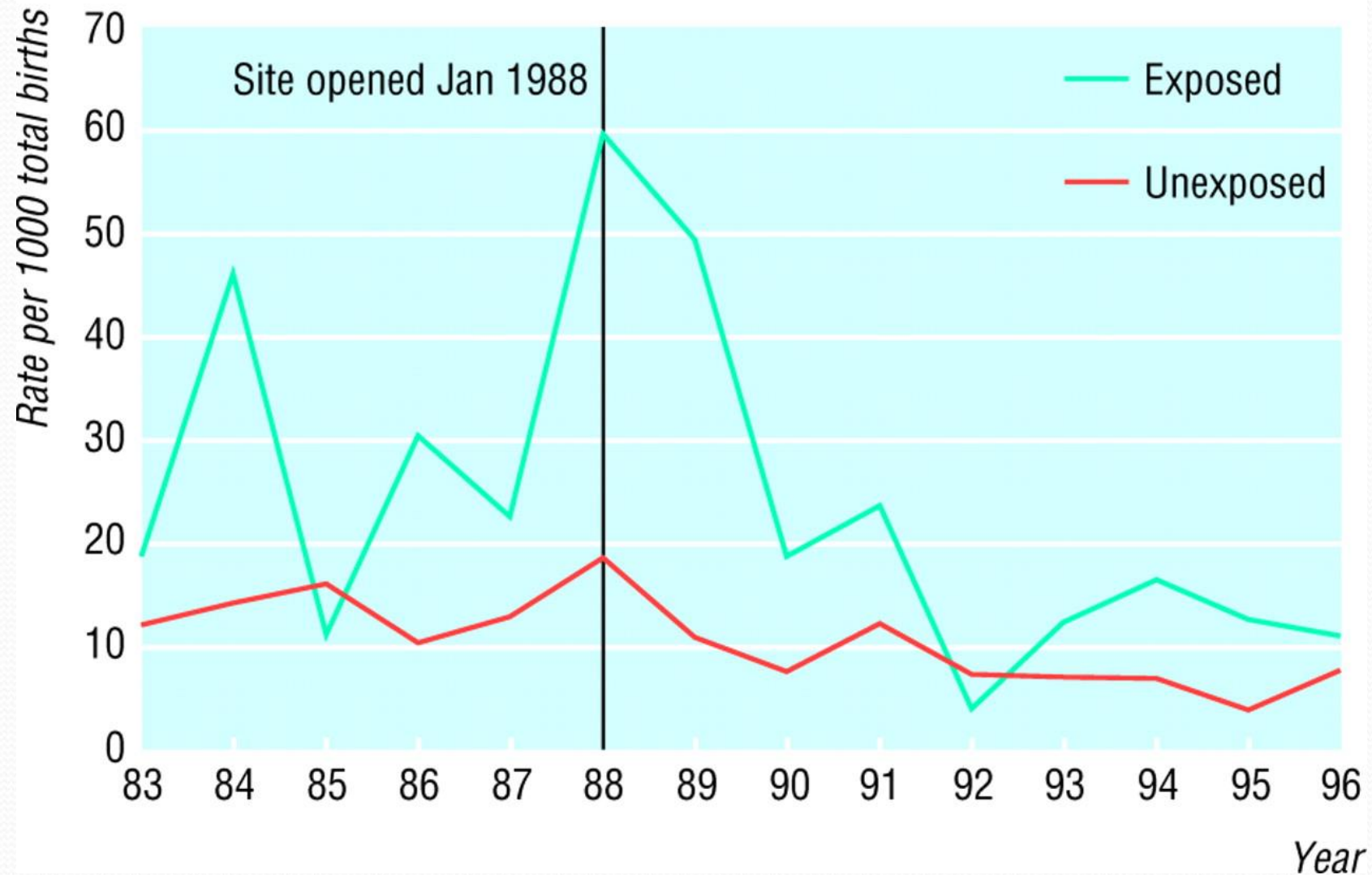
(Published 01 January 2000) Cite this as:

BMJ 2000;320:19

‘Although the Office for National Statistics recognises that the data on congenital malformations are not always accurate or complete, we have no reason to suppose that the data for the five exposed wards are any different in quality to those for the 22 unexposed wards....’



Congenital Anomalies in relation to Nant y Gwyddon landfill



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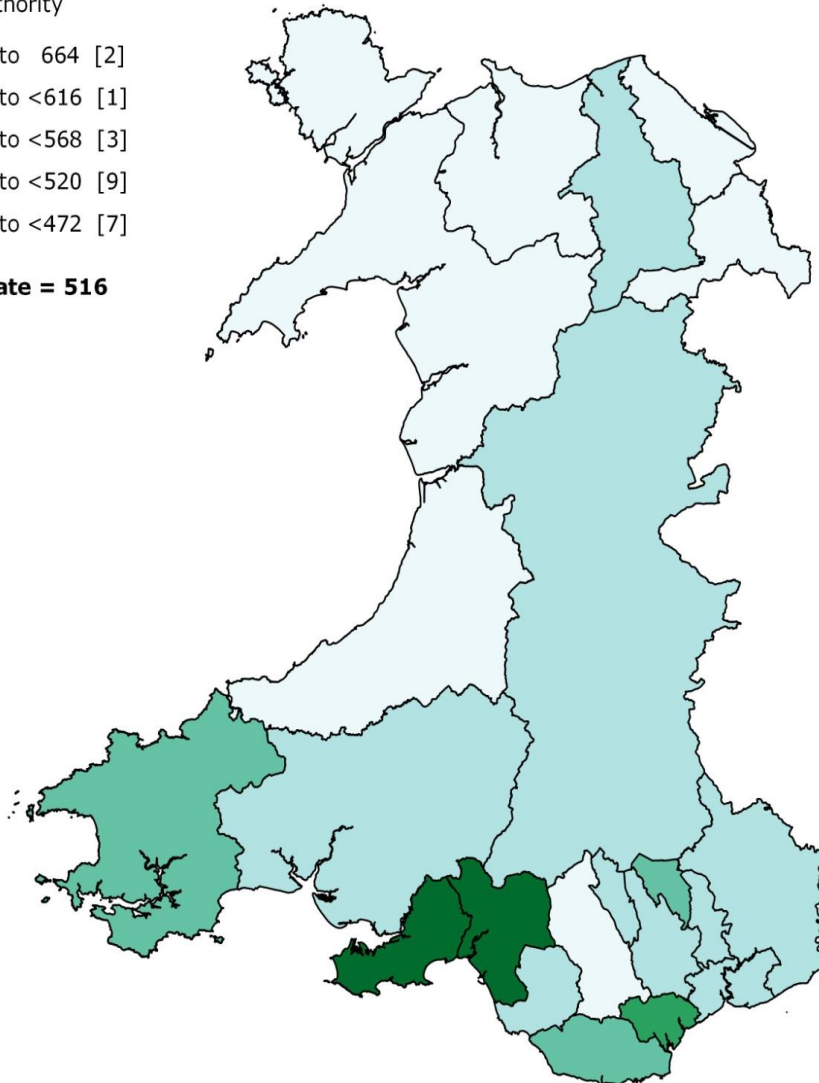


Rate of CARIS cases per 10,000 births, 1998-2015

Local Authority



Wales rate = 516



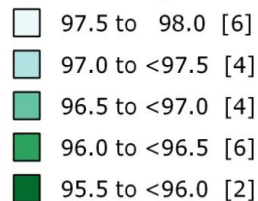
Congenital anomaly rates across Wales – 1998 to 2015

CARIS – headlines 1998 to 2015

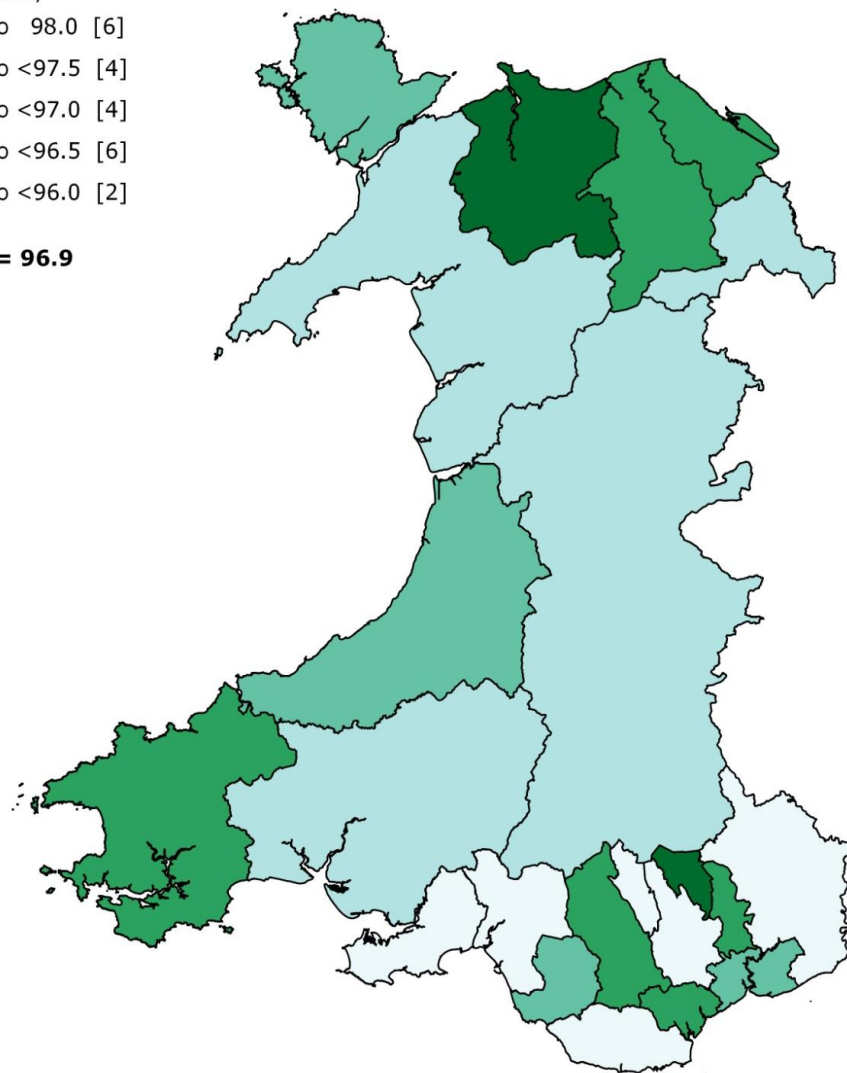
- 31,123 cases recorded in CARIS
- Gross rate of 5.2%
- 86.2% live born of whom 96.9% survived to one year
- More males than females – 58% to 40%
- Most (59.9%) with a single anomaly

Percentage of CARIS cases surviving to one year of age, 1998-2015

Local Authority



Wales % = 96.9



Survival to the age of one year

The impact of more complete data from Wales on the National Congenital Anomaly System

Boy Botting,
ONS

BACKGROUND

The National Congenital Anomaly System began in 1964 after the thalidomide epidemic. Its primary purpose was surveillance, to quickly detect any similar increase in notifications. At that time people were aware of the importance of monitoring anomalies, so notification was never made statutory – instead, notification was voluntary and provided by the local health area. Data are currently provided by NHS trusts on a standard CNS notification form (known as form SD55). Research estimates of the completeness of notification to the national system vary by type of anomaly, with those which are easily visible at birth being more completely notified than internal and chromosomal defects.

A review of the National System in 1993 recommended that 'where good congenital malformation registers exist outside GPCS (now CNS), information should be exchanged with them to improve the completeness and validity of both local and national data'. A number of local registers exist, but there had never been any formal contact between these registers and CNS. The local registers have the advantage that those working in it have local knowledge, and are therefore more able to obtain data. They are also more visible to local clinicians. As a result, the local registers hold more complete data. Nevertheless, the national system still provides the best estimate of national prevalence and allows comparisons across Health Authorities.

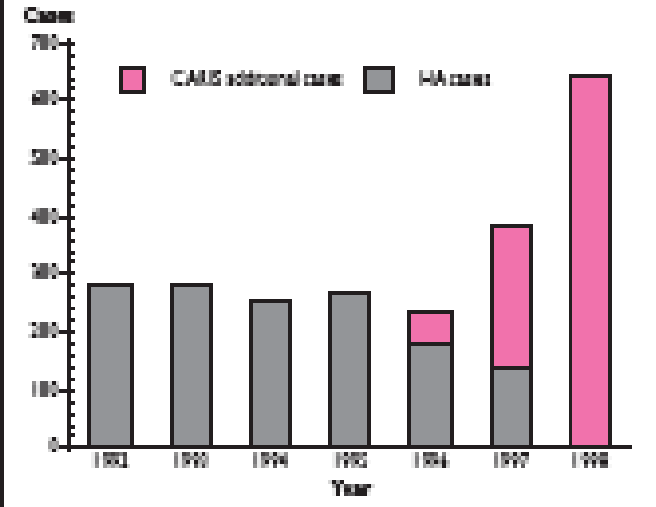
In 1998 ONS, in collaboration with Dr David Stone from the Glasgow Register of Congenital Anomalies, began the creation and co-ordination of BINOCAAR (the British Isles Network Of Congenital Anomaly Registers). Two new registers had recently obtained funding, and they were keen to work with CNS – indeed a condition of the Wales register (CARIS) funded by the Welsh Office was that they were to take over the notification to CNS of congenital anomalies for all of Wales. The

It has long been known that notifications to the National Congenital Anomaly System is incomplete. A review of the system recommended that CNS should explore data exchange with local regional registers. In 1994 ONS began data exchange with a local register (known as CARIS) which covers children in Wales and collects data from several different sources. This paper reports on the impact on monitoring a step change in ascertainment using multiple source notification from the Wales register. Following data exchange with the CARIS register there appears to be a real increase in the completeness of notification between 1997 and 1998. The number of respiratory anomalies notified in 1998 was four times higher than in 1997. The number of notifications of several other anomalies doubled between these two years. These levels of notifications from Wales are close to the levels expected based on previous research from ad hoc surveys.

Office for National Statistics

Figure 1

Cases reported to the Office for National Statistics 1992-98 - comparison of number reported by Health Authorities and CARIS



Evaluation of the National Congenital Anomaly System in England and Wales



Figure 2 Coverage of the local congenital anomaly registers in England and Wales in 2003.

Evaluation of the National Congenital Anomaly System in England and Wales

T Misra, N Dattani, A Majeed

Arch Dis Child Fetal Neonatal Ed 2005;90:F368-F373. doi: 10.1136/adc.2004.052936

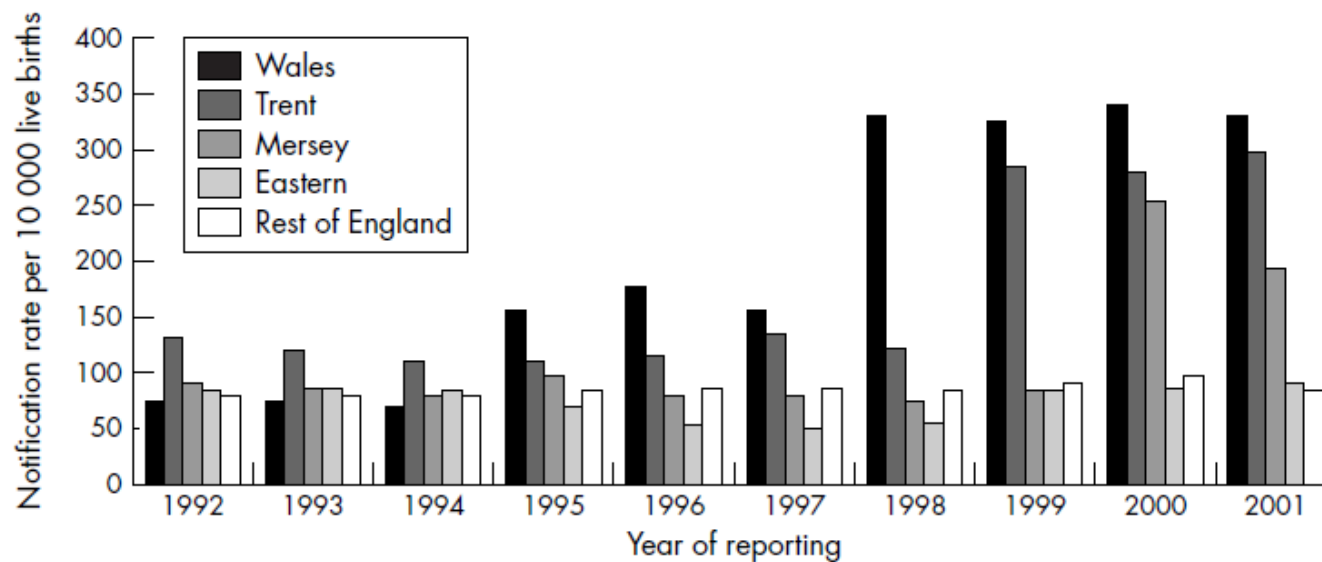


Figure 1 Notification rates from three registers compared with the Eastern region and the rest of England.



The CARIS team. We are (left to right) Helen Jenkins, David Tucker, Margery Morgan, Judith Greenacre and Val Vye.

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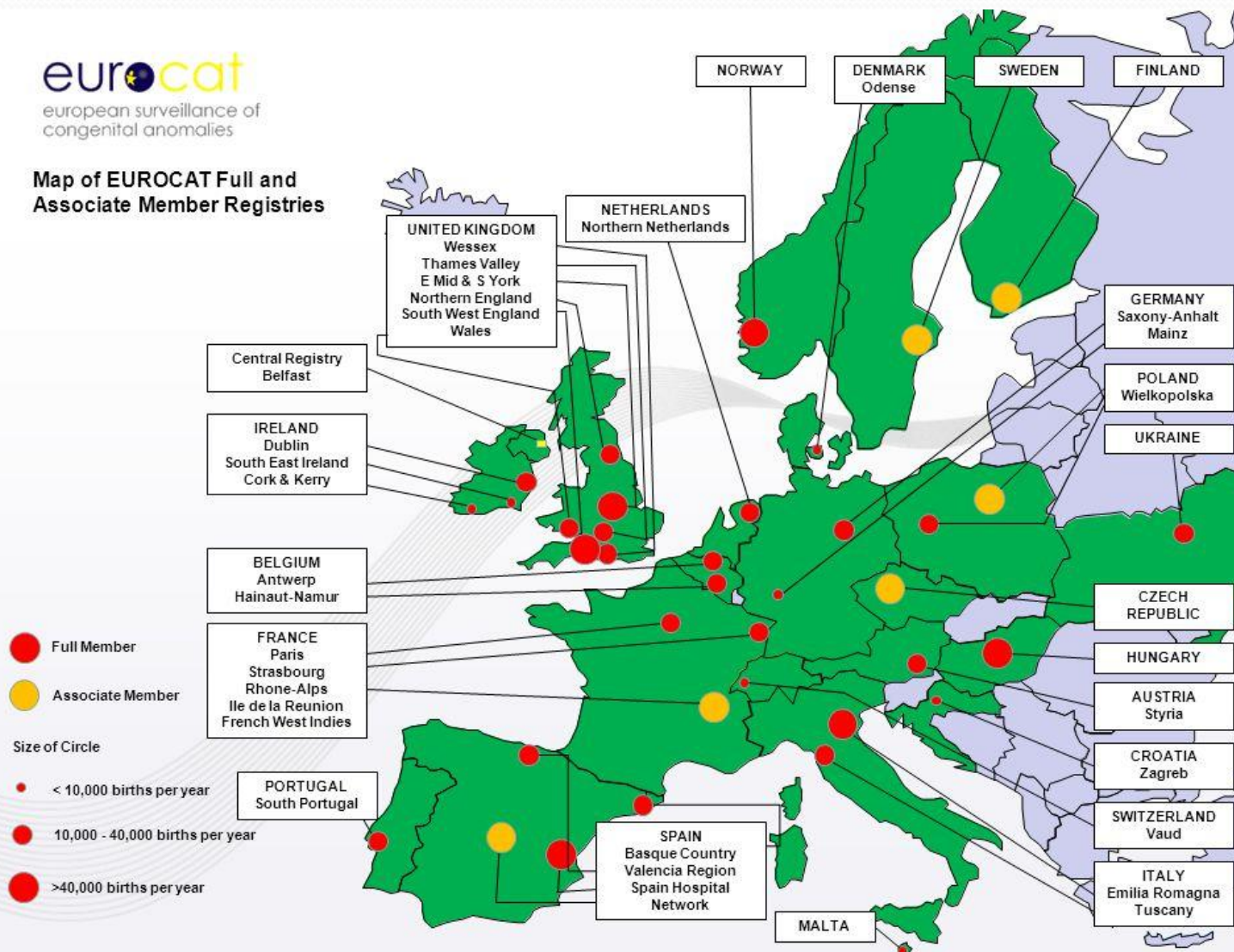
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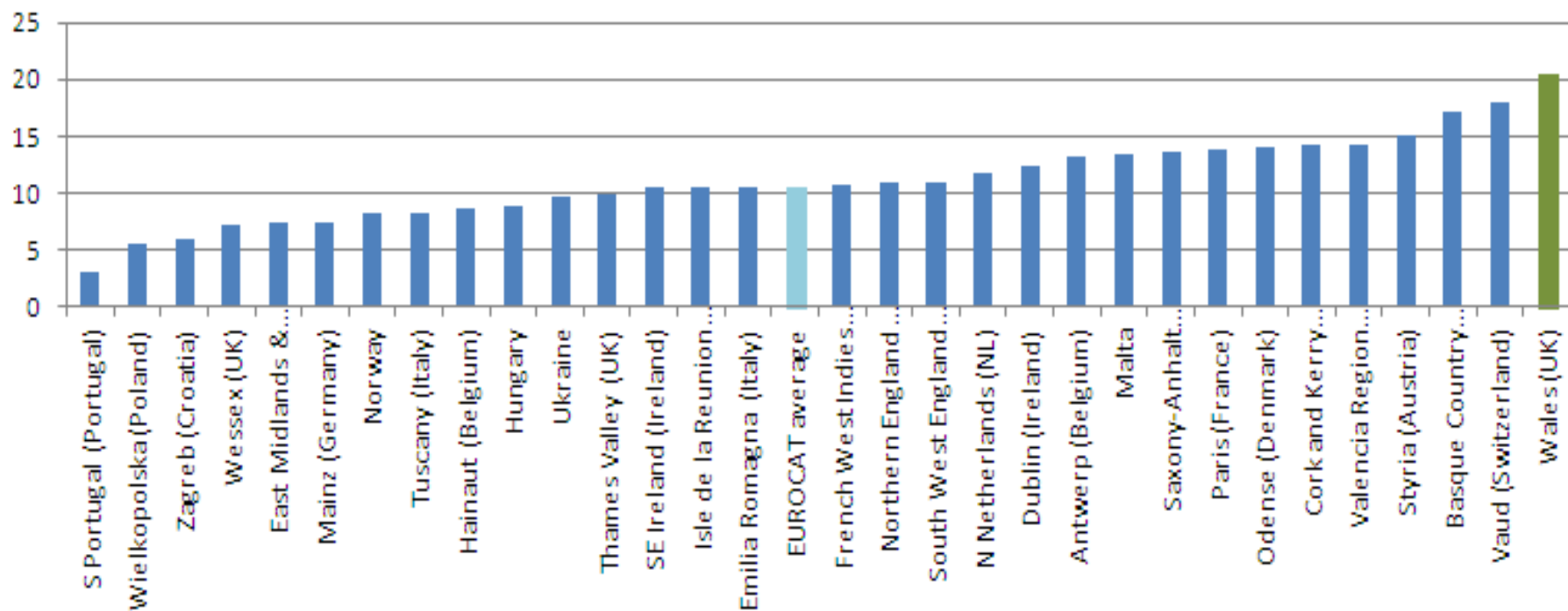
Map of EUROCAT Full and Associate Member Registries

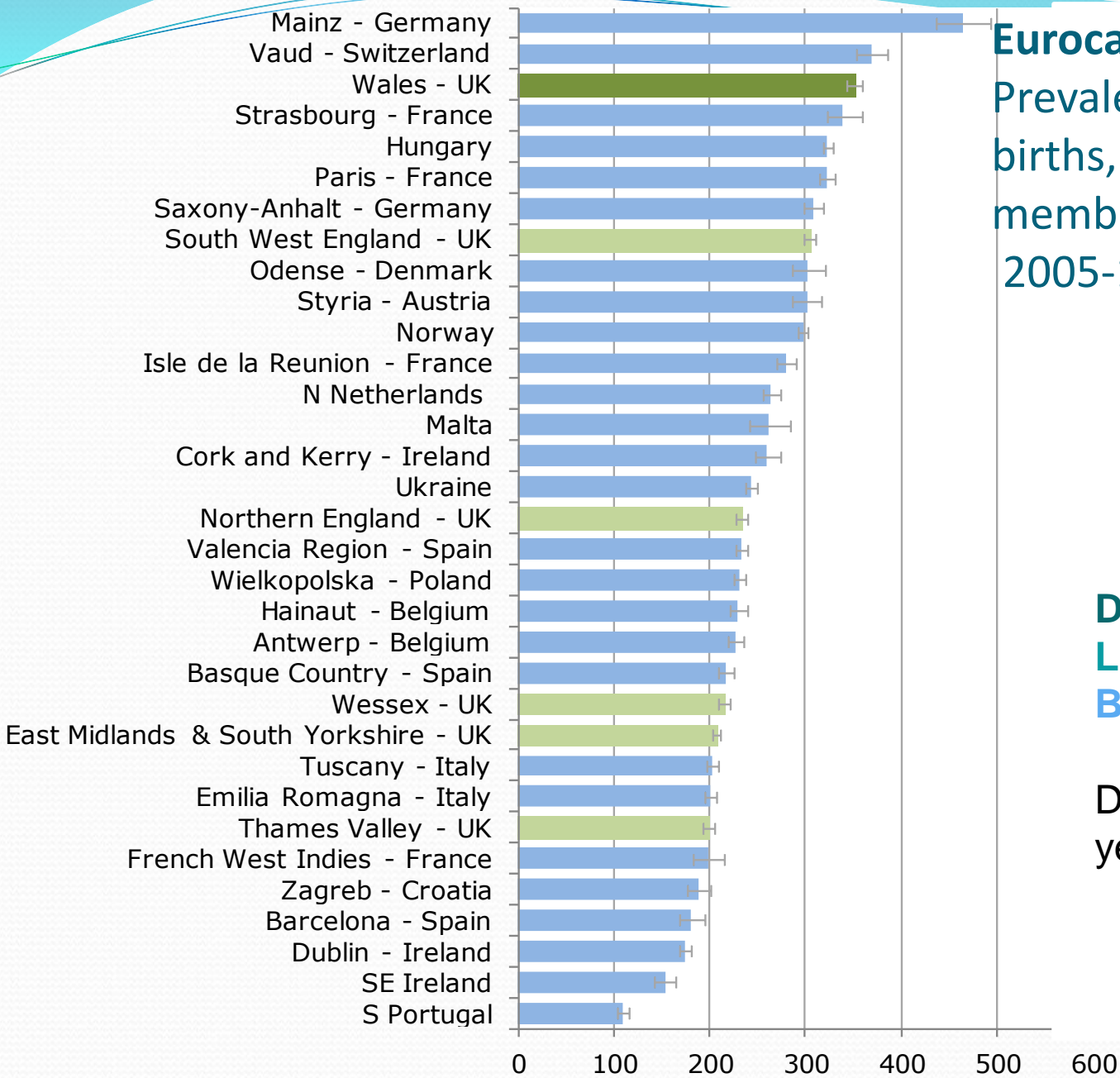


Data quality indicators

2007-2011

Prevalence of selected postnatal diagnosis





Eurocat

Prevalence per 10,000
births, all anomalies, full
member registries,
2005-11

Dark green: Wales
Light green: other UK
Blue: other Eurocat

Data not available for all
years for all registries

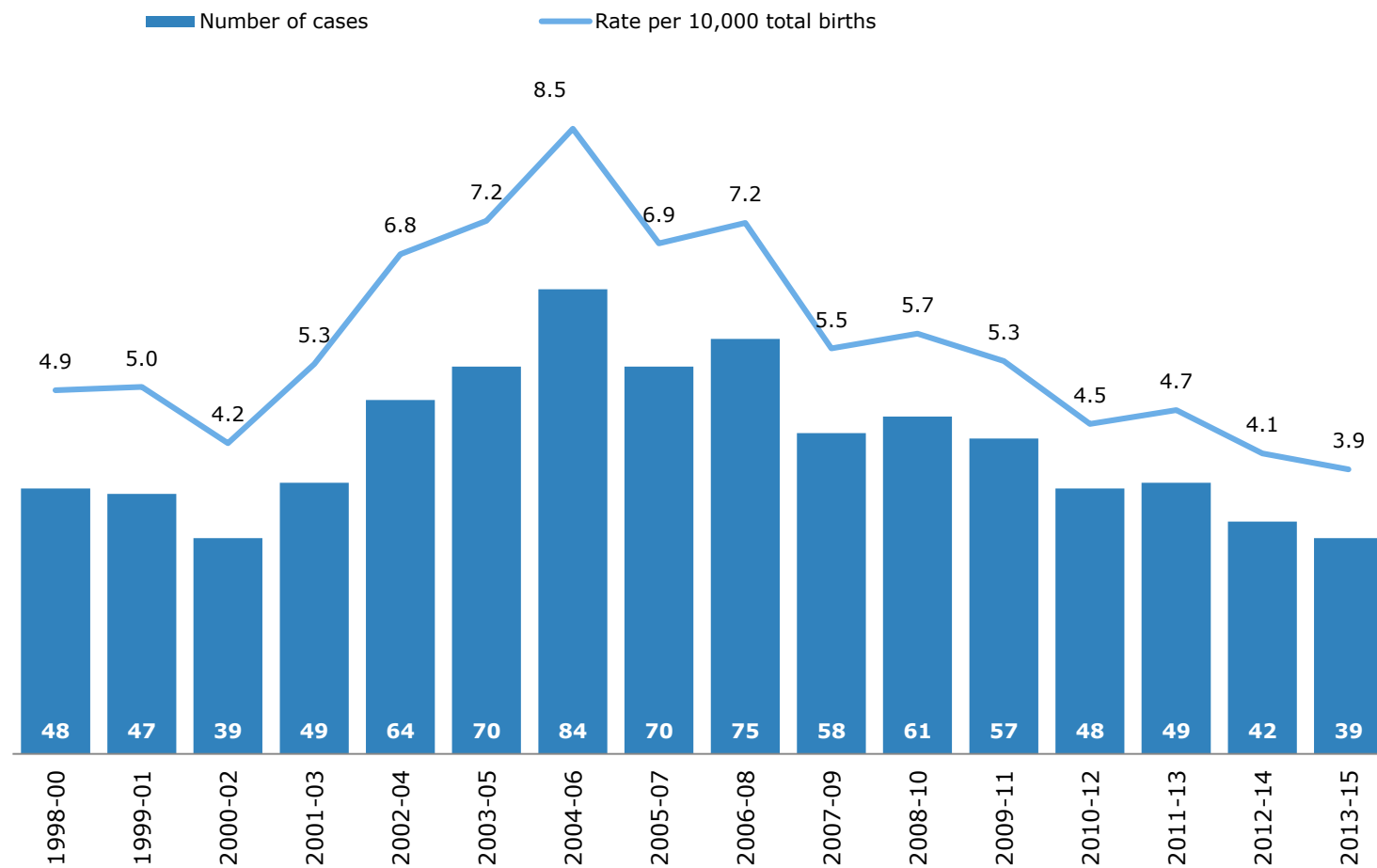
Gastroschisis





Prevalence of gastroschisis, 1998-00 to 2013-15 (three-year rolling counts and rates)

Produced by Public Health Wales Observatory, using CARIS (Public Health Wales) & PHB (ONS)





2016 – Members of the International Clearinghouse for Birth Defects Surveillance and Research (ICBDSR)

**42 Surveillance Programs, 4 ml births per year
36 Countries**





Alessandra Lisi Prize

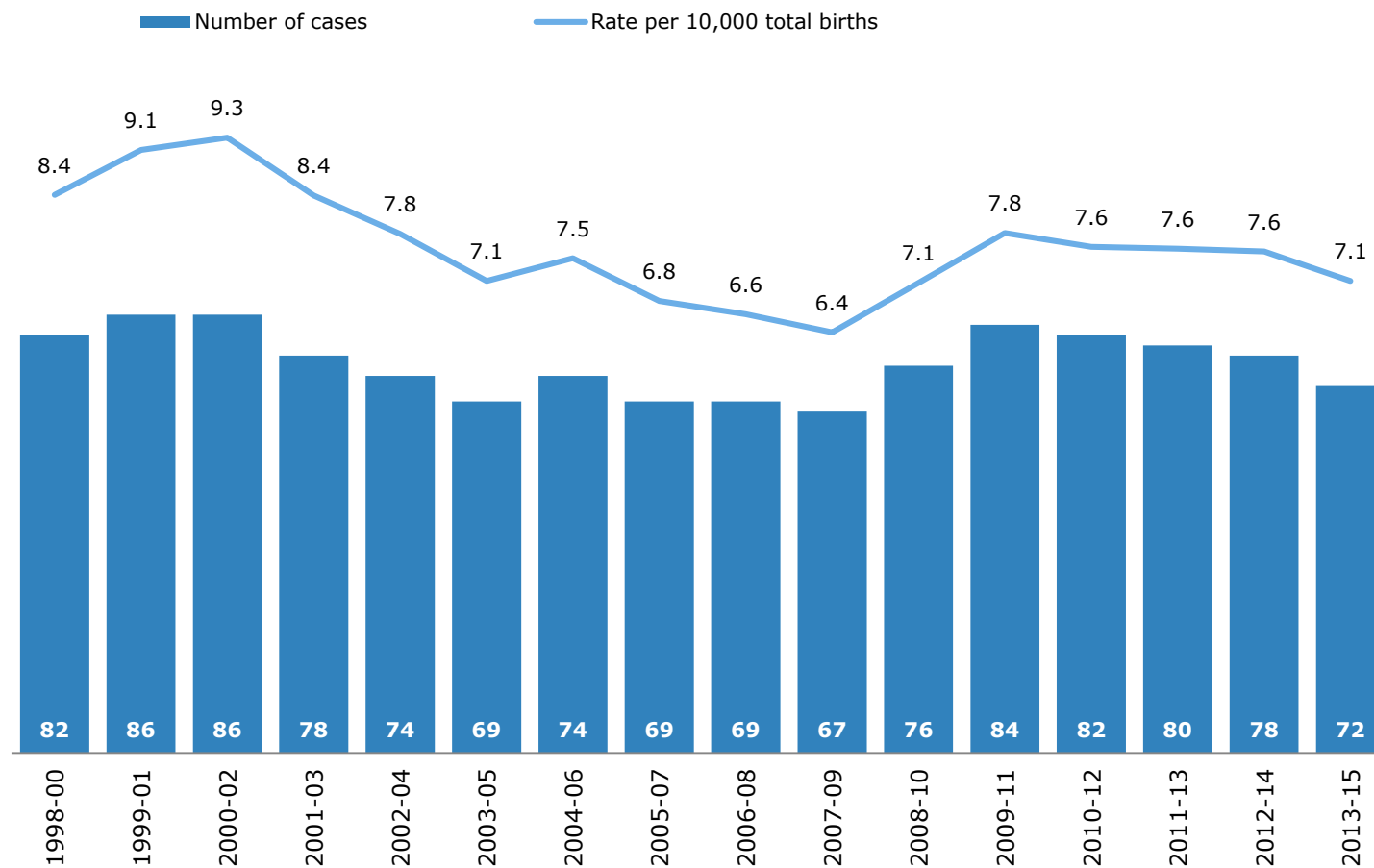
Outcome of fetuses with Turner syndrome:
a 10 year congenital anomaly register based study”

Journal of Maternal-Fetal and Neonatal Medicine, 2011

Iyer NP, Tucker FD, Roberts SH, Moselhi M, Morgan M, Matthes JWA

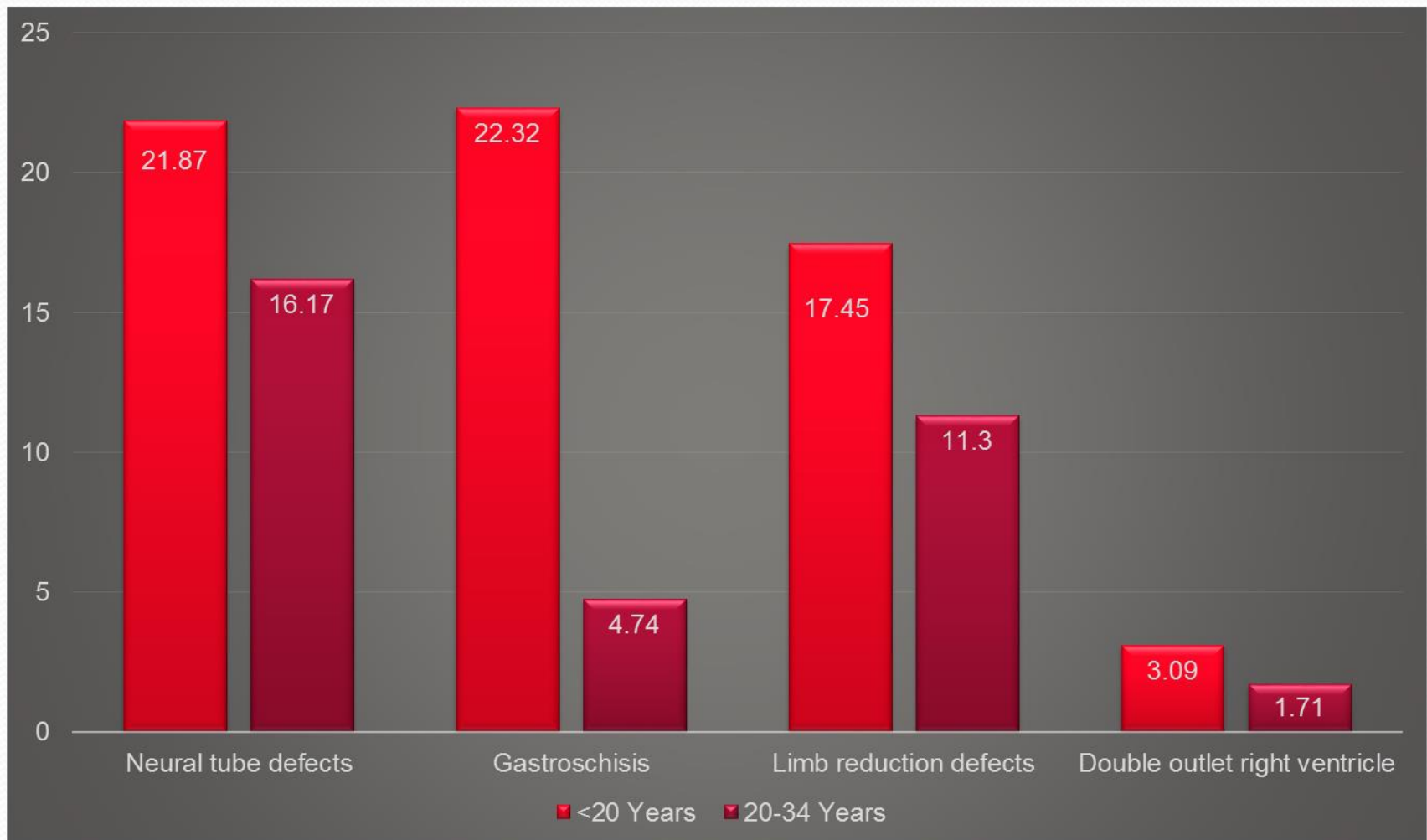
Prevalence of spina bifida, 1998-00 to 2013-15 (three-year rolling counts and rates)

Produced by Public Health Wales Observatory, using CARIS (Public Health Wales) & PHB (ONS)



Rates of Anomalies per 10,000 Births by Maternal Age

F Hodge, D Tucker, M Morgan 2015



Thinking about a baby?

Trying to conceive?
...be baby
SAFER!

@babysafer

Do you **Smoke**?
Do you take **Alcohol** or drugs?
Are you taking **Folic acid**?
Do you eat well & **Exercise**?
Have you had two **MMR** jabs?

www.nhs.uk/planningyourpregnancy



© Margery Morgan, Singleton Hospital, Swansea



Get yourself fit for pregnancy and improve the chances of success! Check out the free **babySAFER** information card and pick one up where you see this poster...



If you take prescription drugs or have a medical/genetic problem like diabetes or epilepsy discuss this with your GP first.

@babysafer

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Do you take **A**lcohol or drugs?

Are you taking **F**olic acid?

Do you eat well & **E**xercise?

Have you had two MMR **R**jabs?

www.nhs.uk (planning your pregnancy)



© Margery Morgan,
Singleton Hospital, Swansea



Smoking can delay conception and cause problems with pregnancy. Quit with stopsmokingwales.com, 0800 085 2219

Alcohol increases risk of miscarriage and can cause problems for baby. It's safest not to drink but if you do, only one to two units, once or twice a week. Never get drunk. Drugs like cannabis, cocaine and heroin cause problems as well. Contact dan247.org.uk freephone 0808 808 2234 for help to give up.

Folic acid is important for baby's spine. Take 0.4mg daily as soon as you stop contraception until you are 12 weeks pregnant. Some women (diabetics, epileptics, overweight) need a higher dose of 5mg daily.

Eat 5 portions of fruit and vegetables a day. Being under or overweight can complicate pregnancy. Keep your Body Mass Index between 19 and 25. Caffeine can delay conception so limit to 200 mg a day (2 cups coffee or 4 cups tea).

Exercise 30 minutes a day, 5 days a week. Do pelvic floor squeezes 30 times a day for better sex, an easier birth and less risk of wetting yourself.

Rubella (German measles) can cause serious problems in early pregnancy. Make sure your MMR (measles, mumps, rubella) vaccination is up to date. Your GP will know.

If you take prescription drugs or have a medical/genetic problem like diabetes or epilepsy discuss this with your GP first.

Public Health Wales has four statutory functions: established 2009

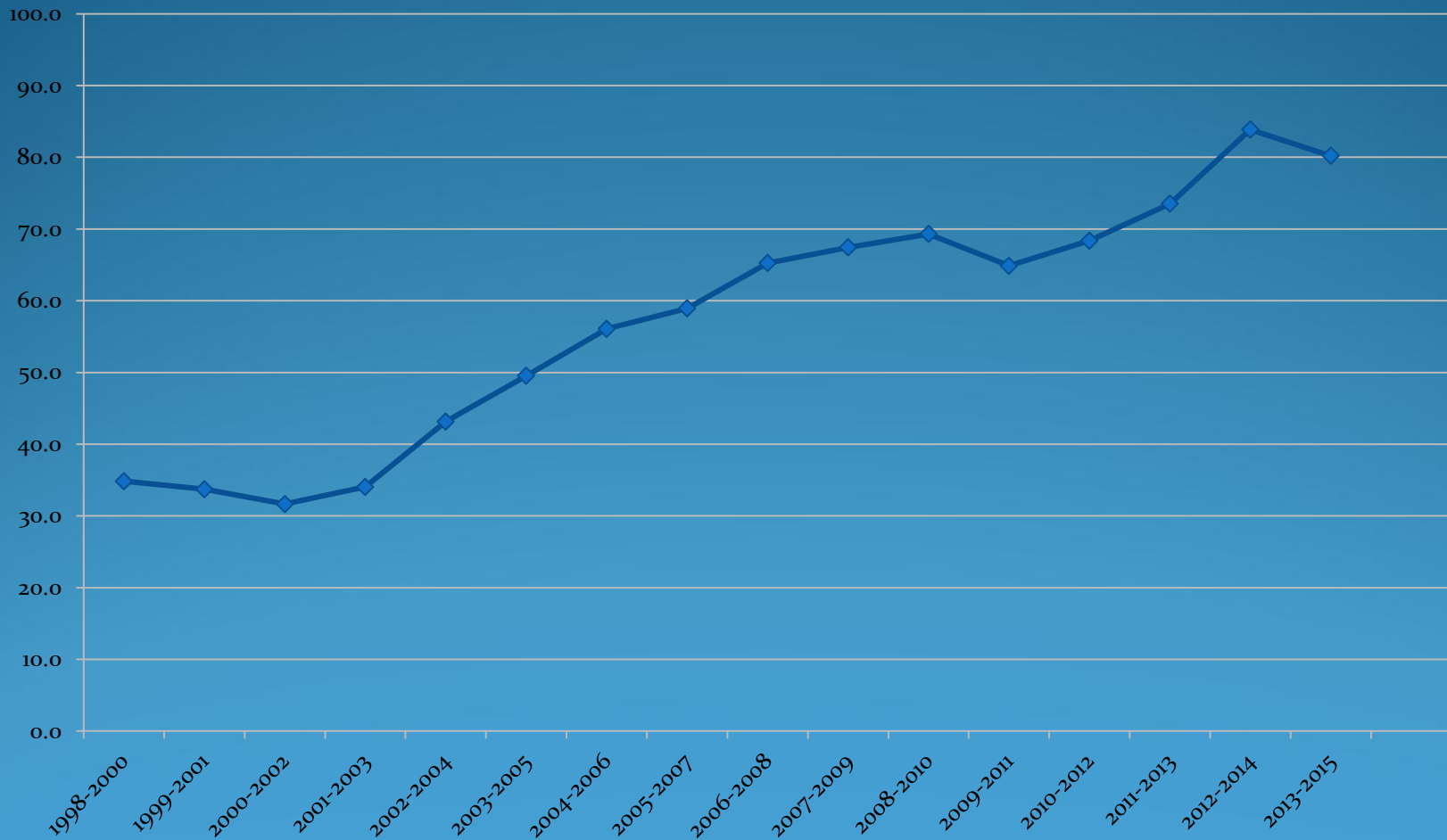
- To provide and manage a range of public health, health protection, healthcare improvement, health advisory, child protection and microbiological laboratory services and services relating to the surveillance, prevention and control of communicable diseases;
- To develop and maintain arrangements for making information about matters related to the protection and improvement of health in Wales available to the public; to undertake and commission research into such matters and to contribute to the provision and development of training in such matters;
- To undertake the systematic collection, analysis and dissemination of information about the health of the people of Wales in particular including cancer incidence, mortality and survival **and prevalence of congenital anomalies; (official statistics)**
- To provide, manage, monitor, evaluate and conduct research into screening of health conditions and screening of health related matters.



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Cleft lip: Antenatal detection rate based on 18-20 week anomaly scan, 1998 - 2015



euromedicat

EUROmedICAT

Safety of Medication Use in Pregnancy



EUROmediCAT

euromedicat.eu

Prescribing of Antidiabetic Medicines before, during and after Pregnancy: A Study in Seven European Regions (PLOS ONE 18.5.16)

*(wide variation in treatment for gestational diabetes, increased use of insulin analogues
no increased risk of congenital anomaly with insulin analogues)*

Asthma medication prescribing before, during and after pregnancy:
a Study in Seven European regions (BMJ 6.9.16)

Risk of congenital anomalies after exposure to asthma medication in the first trimester of pregnancy – a cohort linkage study (BJOG 12.5.16)

(small excess risk of major congenital anomaly)

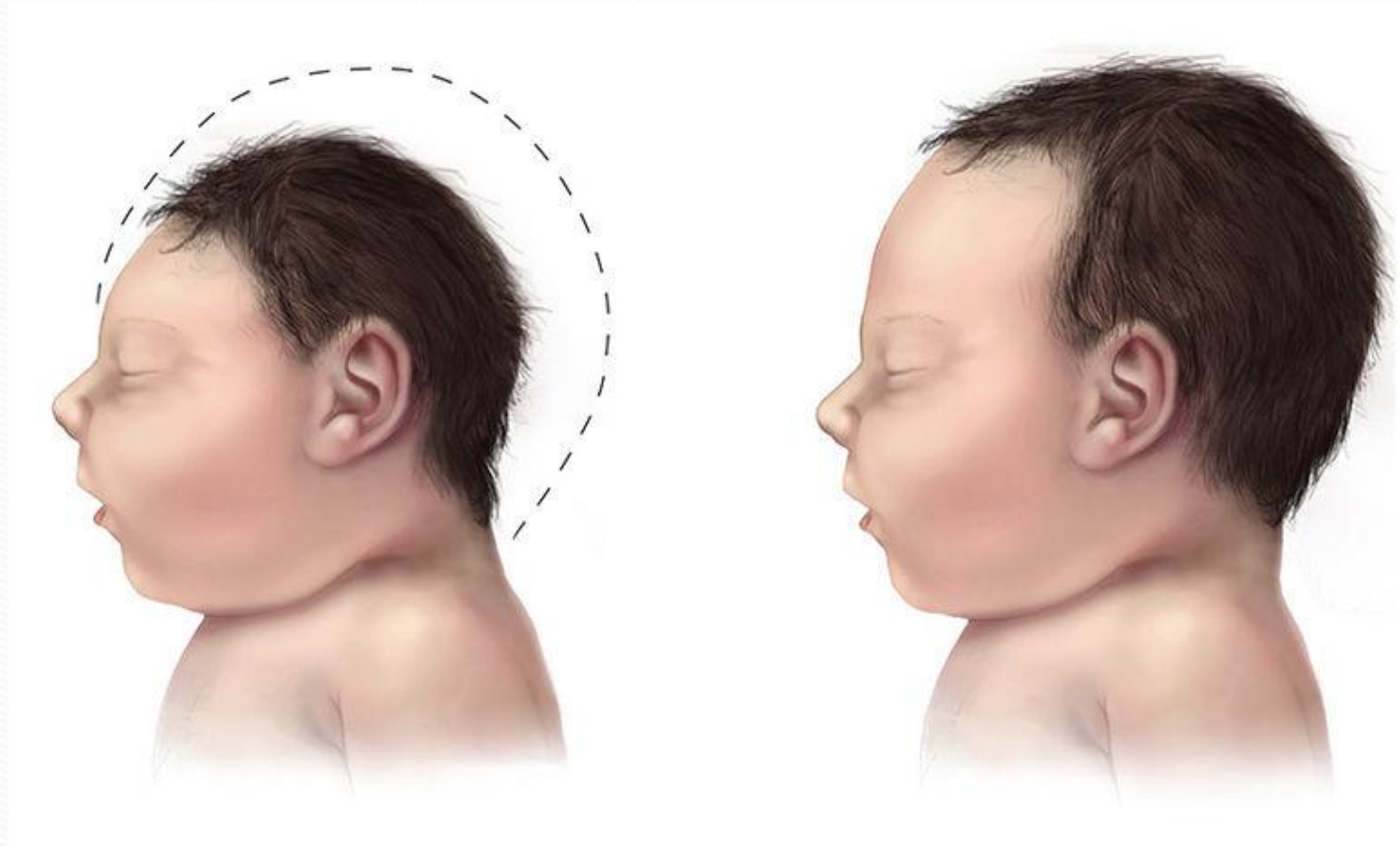
Selective serotonin reuptake inhibitor antidepressant use in first trimester pregnancy and risk of specific congenital anomalies:

a European register-based study (EUR J Epidemiol 7.7.15)

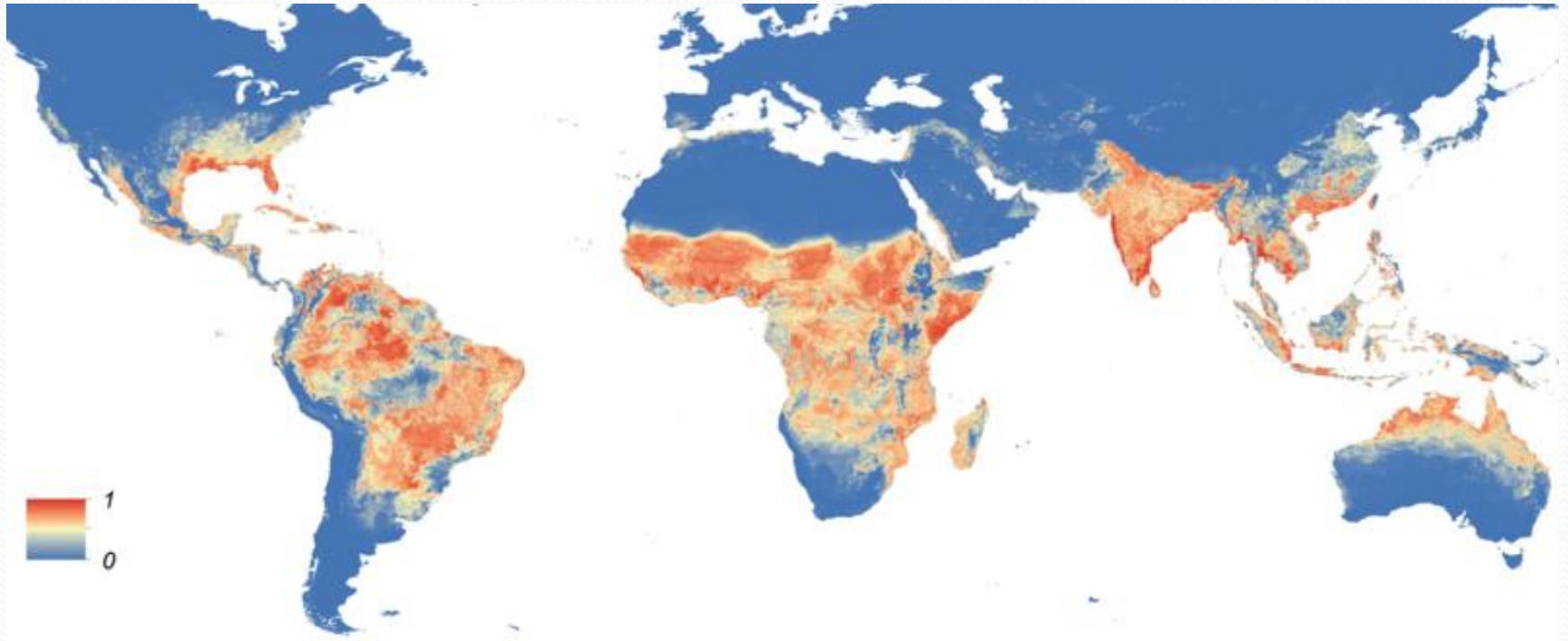
(increased usage since 2004, much higher in UK, raised risk of heart defects but no overall excess of major anomalies)

Aedes mosquito





Predicted distribution of Zika virus



world
birth
defects
day



march 3



1 in 33

1 in every 33 babies is
born with a birth defect.

We want to help you reduce that risk.

January is Birth Defects Prevention Month.

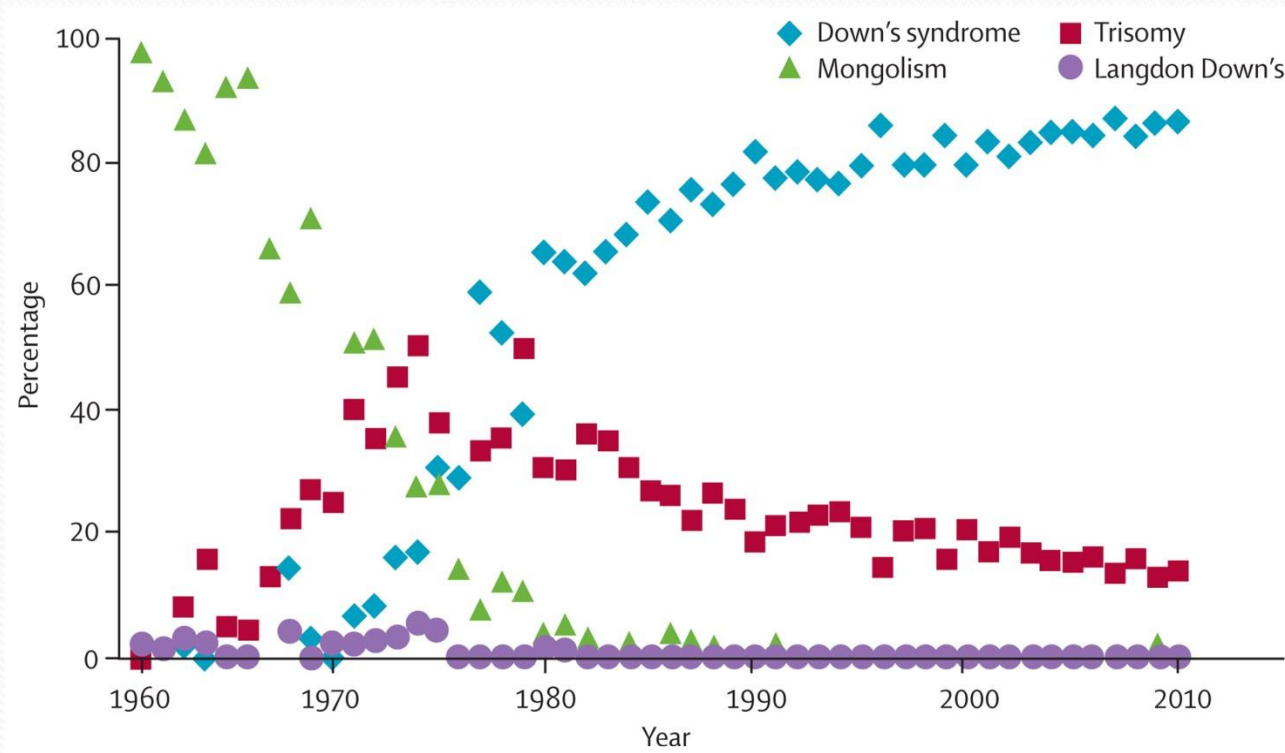
Learn more about prevention, detection, treatment and living with
birth defects at www.cdc.gov/birthdefects and www.nbdpn.org.

National Center on Birth Defects and Developmental Disabilities
Division of Birth Defects and Developmental Disabilities

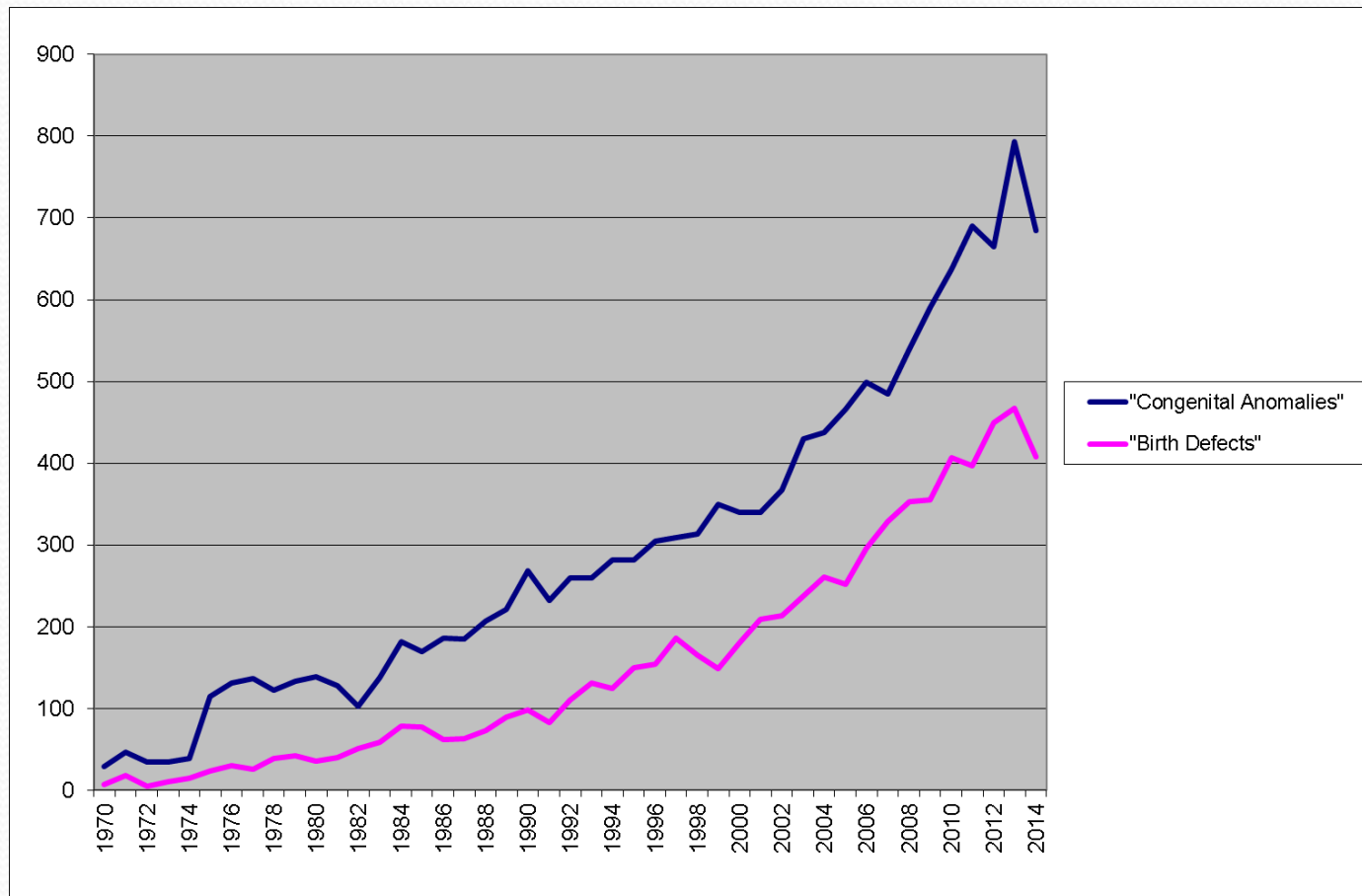


This flyer was developed in partnership with the National Birth Defects Prevention Network (NBDPN). The NBDPN is a national network of birth defects programs and individuals working at local, state, and national levels in birth defects surveillance, research, and prevention.

Evolution of the use of the terms mongolism, Down's syndrome, trisomy 21 and Langdon Down's syndrome in publication titles listed in PubMed (1961-2010)



Usage of terms in Pubmed 1970 – 2014



Rare diseases

- >6,000 recognised rare diseases
- 80% in infants & under 5 years
 - mostly congenital / genetic
- Orphanet
 - portal on rare diseases sponsored by EU
- EU directive on rare diseases for each country to have a plan of action
- Wales published its plan in Feb 2015
- CARIS now records Rare diseases



CARIS meetings 2017

cardiac anomalies

27.11.17 afternoon Dylan Thomas theatre, Swansea
Dr Orhan Uzun, Dr Helen Wallis



30.11.17 morning Postgrad centre, Ysbyty Gwynedd, Bangor
Dr Joyce Lim, Dr Sarah Vause



