



Genetic Support Council of WA Inc

Gene Advocate

Issue 64

West Australian Register of Developmental Anomalies

After several decades as successful voluntary notification registers, the WA Birth Defects Registry and the WA Cerebral Palsy Register have combined and are now to be known as the Western Australian Register of Developmental Anomalies (WARDA).



The two Registers have produced a significant body of well regarded and internationally recognised research. The combination of the two provides WA with a comprehensive Register that will continue to support research into causes and prevention of developmental anomalies.

The name reflects the conditions on which information is collected, as, although some anomalies are diagnosed before birth, not all anomalies are obvious at birth and many may not be diagnosed until several years after birth.

WARDA is a statutory register as the *Health (Western Australian Register of Developmental Anomalies) Regulations 2010* came into effect on January 7, 2011.

These regulations can be found on the WARDA website.

The decision to become statutory was reached by consensus, after consultation with health professionals, consumers and the community, and brings the Register in line with other important health information collections in WA, such as the WA Midwives Notification of Birth System and the WA Cancer Registry.

What does this mean?

As a statutory register, it is mandatory for developmental anomalies to be reported. This means that the medical practitioner making the diagnosis or caring for the patient diagnosed and/or the chief executive officer of the hospital in which the diagnosis of a developmental anomaly is made are responsible for making the notification. This is required within six months of the diagnosis.

Defining a Developmental Anomaly

For the purposes of these regulations, a developmental anomaly means:

- ♦ Cerebral palsy or
- ♦ Anomalies that affect structure or function, which are present before birth and are diagnosed by six years of age.

Structural means how the body is built and functional means how the body works. Structural developmental anomalies include conditions such as spina bifida, congenital dislocation of the

hip and congenital heart defects.

Functional anomalies include conditions such as cystic fibrosis and haemophilia. Fetal alcohol syndrome and Down syndrome are also developmental anomalies.

Minor anomalies are not usually included unless they need treatment, eg some birthmarks, extra finger or toe.

The Regulations use the term child to refer to both a developing fetus and a child.

What information is collected?

The Register collects a range of information on the child and his/her mother and father, including:

Child: Name, address, date of birth, gender, Aboriginality/non-Aboriginality, birth measurements and diagnostic information for each developmental anomaly (up to a total of 10 anomalies and the age at which each anomaly was diagnosed. Information is collected on all diagnoses up until the age of 6 years.

Mother (and father where appropriate): Name, address, date of birth

Information is also collected on pregnancy termination or stillbirth, and, if the baby has died, the date of death.

Information on names and dates of birth are needed so each child is only counted once. Information on the register will be linked with other information collected by law on births and deaths in Western Australia

Privacy Issues

We take privacy seriously and all information held by the Register is maintained securely. Register staff abide by the WA Health Code of Conduct which highlights confidentiality as an important part of Responsible Care.

Reports released from the Register are in statistical form, without identification of individuals, doctors or hospitals. It is unusual for named data to be provided, and those who request this information must go through several rigorous steps before gaining access. Families who do not want to be contacted for research purposes can tell the Register this.

Informing Parents

We believe that it is important for parents to be informed that the details of their child are being placed on the Register. Medical practitioners have been advised of this and have been provided with a phraseology to help them. Additionally, the WARDA website provides parents and the general public with extensive information about the Register. WARDA has also developed a brochure that can be given to parents at the time of diagnosis. This handout can be found on our webpage.

The Regulations include a section on the right of persons (or, in the case of children, their parents) to know if information about them is included on the Register and, if so, to have a copy of that information. There is also provision for identifying information to be removed, once it has been kept on the Register for at least six years (non-identifying information will be retained). Requests in relation to these two sections must be made in writing. Forms are available on the website or you can obtain a copy by contacting the WARDA offices.

If you have any queries regarding WARDA, the notification process or would like further information, please visit our website or do not hesitate to contact us.

Source:

WARDA

King Edward Memorial Hospital

PO Box 134 Subiaco 6904

Western Australia

Phone (08) 9340 2735

Fax (08) 9340 2636

http://www.kemh.health.wa.gov.au/services/register_developmental_anomalies/