



**QUEEN'S
UNIVERSITY
BELFAST**

Northern Ireland Cerebral Palsy Register
Information Leaflet



Funded by the Public Health Agency, Northern Ireland *Revised August 2010*



**Health and
Social Care**

What is the Northern Ireland Cerebral Palsy Register?

The Register is a confidential record of children born or living in Northern Ireland with cerebral palsy. It is important to know about every child with the condition, even those with mild forms, particularly when researching the causes of cerebral palsy and trends over time.

Why a Register?

- To provide accurate and complete information about the number and the needs of children and young people with cerebral palsy for planning services.
- To monitor changes in the condition over time particularly to see if cerebral palsy is becoming more common or more severe and how any changes compare with other areas and countries.
- To support research involving children and young people including health services research, functional abilities, quality of life and causes of cerebral palsy.

What information is collected?

- Child's name, address of residence and date of birth
- Type and severity of movement problems including walking ability and use of arms
- Presence of any other problems related to seizures, learning, speech and language, vision and hearing
- Birthweight, gestation, if the child was a singleton or multiple birth (e.g. twin, triplet) and postcode at birth
- Schools attended
- Professionals seen
- Child's G.P.

How is the information collected?

Professionals involved in the care of children with cerebral palsy inform the Register on a monthly basis about any newly diagnosed or newly referred children with cerebral palsy. Sometimes parents contact the Register directly to notify their child. This contact with parents and people with cerebral palsy is particularly welcome.

Taking part in the Register is voluntary. **If you DO NOT wish to take part please inform your child's doctor or physiotherapist.** Refusing to take part will not affect any services your child receives now or in the future. You can also request to have your child removed from the Register at any time. Under the Data Protection Act (1998) you are entitled to know what information is kept about your child. Please ask your child's doctor if you would like a copy of this information.

The information on the Register is used to form reports, published papers in scientific journals, scientific presentations and to generate local information. Individuals are not identified or identifiable in any reports, publications or presentations produced.

The Register has been approved by the Queen's University Ethics Committee. The Register also has an Advisory Committee to guide and advise on its management and its future direction and includes a parent representative. The Register is funded by the Public Health Agency for Northern Ireland.



Contact and further information

If you have any further queries or if you would like more information or to notify a child to the Register please contact us.

**Northern Ireland Cerebral Palsy Register
Room 1.36
Mulhouse Building
Queen's University Belfast
Institute of Clinical Science
Grosvenor Road, Belfast BT12 6BJ
Telephone: 028 9097 1616**

Or look up our website:
www.qub.ac.uk/research-centres/nicpr

Frequently Asked Questions

What is cerebral palsy?

The term cerebral palsy describes a wide range of conditions affecting a child's ability to move or control their movement. The child's movement can be affected by increased tone or stiffness in their muscles (**spasticity**); or by short and jerky movements (**ataxia**); or by poor control of slow and writhing movements (**dyskinesia**).

Other terms commonly used to describe types of cerebral palsy include **hemiplegia** (one side of the body is more affected than the other); **diplegia** (the legs are more affected than the arms); and **quadriplegia** (all four limbs are affected).

What have we found out so far?

- About 50 children are newly diagnosed with cerebral palsy every year in Northern Ireland
- Most children with cerebral palsy have mild forms of the condition
- 8-12 year old children with cerebral palsy report the same quality of life as their peers who do not have cerebral palsy
- While children with cerebral palsy are at higher risk of having emotional and behavioural problems most are kind and considerate to other children
- Functional abilities can change over time although most ambulant children reach their peak around 11-12 years of age

Still, very little is known about the causes of cerebral palsy and so possibilities for prevention remain limited until more research is undertaken. It is also important to find out more about how services could be improved. Read more about our research at our website

What if I do not want to take part in the Register?

Please tell your child's doctor or physiotherapist that you do not wish to include your child on the Cerebral Palsy Register. It is also possible to change your mind and either include your child or remove your child from the Register at a later date.