



**QUEEN'S
UNIVERSITY
BELFAST**

Northern Ireland Cerebral Palsy Register

Family Information Leaflet



**Public Health
Agency**



**NORTHERN IRELAND
CEREBRAL PALSY REGISTER**

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 cerebral palsy?

The term cerebral palsy describes a wide range of conditions affecting a child's ability to move or control their movement. Cerebral palsy is the most common cause of physical disability in early childhood – there are approximately 55 new cases each year in Northern Ireland.

It is a lifelong condition and how the body is affected can change over time as the child grows and develops.

Why a Register?

- To provide accurate and complete information about the number and needs of children and young people with cerebral palsy.
- To monitor changes in the condition over time.
- To compare information from Northern Ireland with other regions and countries.
- To support research involving children and young people with cerebral palsy. Read more about our research at the following link: <http://www.qub.ac.uk/research-centres/NorthernIrelandCerebralPalsyRegister/Activities/ResearchProjects/>



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 the condition. Parents can contact the Register directly to register their child. This contact with parents and people with cerebral palsy is particularly welcome.

Who uses the information and what is it used for?

The information is used by healthcare professionals, researchers, government departments, charities and healthcare planners. The information is used for local, national and international reports, papers in scientific journals, presentations and service planning in Northern Ireland.

Individuals are not identified or identifiable in any reports, publications or presentations produced.

How is the information kept safe?

All information is held securely at Queen's University Belfast. The Register has a Privacy Notice that details why we collect personal information, what we do with it, and how we look after it. A copy of the Privacy Notice can be downloaded at: <https://www.qub.ac.uk/research-centres/NorthernIrelandCerebralPalsyRegister/Filestore/Fileupload,827896,en.pdf>

Do we have to take part?

Taking part in the Register is voluntary. If you **DO NOT** wish to take part, please inform your child's doctor, physiotherapist or occupational therapist. 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 General Data Protection Regulations (2018) 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.

Who oversees the Register?

The Register has been approved by the Office for Research Ethics Committees Northern Ireland and has Data Access Agreements with each of the Health & Social Care Trusts in Northern Ireland.

The Register has an Advisory Committee that includes a parent representative and person with cerebral palsy. A separate Register Public Involvement Group advises and monitors on public involvement and engagement activities.

The Register is funded by the Public Health Agency for Northern Ireland.



Contact us

If you have any further queries, would like more information on our work, or would like to notify a child to the Register, please get in touch.

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The Northern Ireland Cerebral Palsy Register
is funded by the Public Health Agency,
Northern Ireland.