



**QUEEN'S
UNIVERSITY
BELFAST**

Northern Ireland Cerebral Palsy Register

Child Information Leaflet



**Public Health
Agency**



**NORTHERN IRELAND
CEREBRAL PALSY REGISTER**

Frequently Asked Questions

What is the Northern Ireland Cerebral Palsy Register?

The Register is a confidential record of children in Northern Ireland with cerebral palsy.

Cerebral palsy

Cerebral palsy can affect how you sit and move, but what you can do and how you feel may change as you grow up. You will have cerebral palsy for life. Each year in Northern Ireland 55 children find out they have cerebral palsy.

Why do we want to find out about you?

It is important to know about every child with cerebral palsy to:

- understand why some people have it,
- see if cerebral palsy changes over time,
- see if there are differences in cerebral palsy in other countries, and
- help with research into care and treatment.

What information do we need about you?

- Your name, address and date of birth,
- how you move,
- if you have any other conditions like epilepsy, hearing or sight problems,
- details about your birth,
- your school, and
- healthcare people who look after you.

How do we get the information about you?

The healthcare people who help look after you can send us information. You and your parent/guardian can also tell us.

Who uses the information and what is it used for?

The information can be used by people who work in healthcare, government, research and charities. They use it for reports and presentations about cerebral palsy. Health and education teams use the information to plan services.

Your name will not be used in any presentations or reports.





How do we keep your information safe?

Your information is kept on a secure computer and in a safe room at Queen's University Belfast. You can find out more about how your information is kept safe on our website.

Do we have to take part?

No – taking part is up to you. If you DO NOT want to take part, tell your parent/ guardian or doctor. You can change your mind about taking part at any time.

Who looks after the Register?

Researchers at Queen's University Belfast look after the register. The researchers are helped by a group of people that includes a person with cerebral palsy, a parent, doctors and organisations that work with people with cerebral palsy.

A separate group helps involve people with cerebral palsy in the work of the register and tells others about it.



Contact us

If you would like any more information, please look at our website: **www.qub.ac.uk/research-centres/nicpr**

You can also ask your parent/guardian to get in touch with us by email, phone or post.

Email: **nicpr@qub.ac.uk**

Telephone: **028 9097 1616**

Post: **Northern Ireland Cerebral Palsy Register
Room 1.35 Mulhouse Building
Queen's University Belfast
Institute of Clinical Science
Grosvenor Road, Belfast BT12 6BJ**



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