



Cerebral Palsy Register for Scotland

A joint project between Napier University and NHS Scotland

Issue 1

Funded by Cerebra

November 2003

Welcome

Welcome to the first 6-monthly report from the Cerebral Palsy Register for Scotland (CPRS). This report is designed to keep you informed of the work we are doing, and has been written for parents, carers and organisations that have been supporting our work.

The register has been up and running since April 2003, with the aims of finding out more about children in Scotland who have Cerebral Palsy (CP). We want to look into how many children have CP in Scotland, what type of CP they have, and how it might be affecting them and their families. We are also interested in finding out what services families with a child with CP use, and what services they need. This information will be useful to those working with children with CP and will help them to improve services, if needed.

What we've been doing

Since launching in April we've been mainly raising people's awareness about the register – it is important that as many people as possible know about the register so parents and carers can contact us directly, or we can contact families through various health care professionals if the family agrees.

In order to make sure that the register reaches as many parents, carers, health professionals and other people as possible, we have been presenting information on the register at a range of meetings, written articles for various charities' newsletters, and contacted places who were willing to display information about the CPRS.

We originally launched the register throughout Lothian and the Borders and have had a really good response. We are now working on contacting families in other parts of the country. However, anyone can request to register a child with CP at any time, either through the website (www.napier.ac.uk/cprs), or by writing to us at the address on the back cover.

If you know of any organisations or groups who would be willing to support the CPRS – for example by displaying our poster, or by making our leaflets available to parents and carers – then please contact us at the address on the back cover.

About us

As this is our first issue, we thought we would introduce you to some of the people involved with the register.

The Team

The Team is made up from researchers at Napier and NHS Scotland staff, and they run the register from day to day.

We are:

- ❖ *Dr Sandra Bonellie*: A statistician, and lecturer at Napier University; Sandra has looked at the data from the previous Cerebral Palsy register. A report on some of this work is available on our website.
- ❖ *Dr Jim Chalmers*: A Consultant in Public Health Medicine, based at the Information and Statistics Division of the NHS (ISD). Jim was responsible for running the previous CP register.
- ❖ *Dr Zoë Dunhill*: A Consultant Community Paediatrician, based at the Royal Hospital for Sick Children in Edinburgh. Zoë is involved in many projects working with children with special needs.
- ❖ *Dr Paul Eunson*: A Consultant Paediatric Neurologist, based at the Royal Hospital for Sick Children in Edinburgh, Paul has previously conducted research into CP.
- ❖ *Abbi Green*: Health Services Researcher at Napier University. Abbi has research interests, and has previously worked with special needs (children and young adults).
- ❖ *Philip Mackie*: Senior Specialist in Public Health, based in Lothian Health board. Phil was previously involved in the North of England Cerebral Palsy Register.
- ❖ *Prof. Gillian Raab*: Professor of Applied Statistics at Napier University, Gillian is involved in a great deal of health related research.
- ❖ *Morag Smart*: Administrative Secretary
- ❖ *David Williams*: Head of Research at Cerebra, who are funding the project. Cerebra is a registered charity and fund research into brain injury and neurological disorders in children. They also provide information and support for parents through the PARNET network.



If you are interested in receiving information from PARNET, please see the leaflet enclosed with this newsletter, and write to them at their free post address.



The Steering group

This group offers insight, support, and guidance to the Grantholders. It is made up from representatives of various charities (such as Capability Scotland and SNIP – Special Needs Information Point), parents of children with CP, doctors from areas around Scotland, a physiotherapist, and other researchers carrying out work into CP.

Other Organisations

Many more individuals and organisations across Scotland assist us to make the register a success. NHS medical and administrative staff, charities, and groups such as local libraries have all helped in publicising the register.

What we've found

As the CPRS is a new register the number of children on the register at the moment is only a small proportion of the children in Scotland with CP. Most of the children we have registered are from areas in Lothian or the Borders, as this is where we started to collect information.

So far we have registered more boys than girls, and most of the children are aged between 9 and 13 years. This is most likely due to the fact that one of the ways we've been in touch with families is through a previous Scottish register, which most older children with CP would have been on.

Lifestyle Assessment Questionnaire for Children (LAQC)

The LAQC is the green questionnaire you will receive when your child is over 4 years old. It asks about how CP might be affecting your life and your child's life. Again information from this questionnaire isn't complete, but we've included some notes below.

If you haven't had the chance to complete your copy of the LAQC, please do when you get the opportunity. Your information and point of view is very important to us.

Some points from the LAQC (Data not complete)

- ❖ Nearly half of the children who've completed the form so far wear splints all year round.
- ❖ Most of the children whose parent or carer has completed the form go to a special school
- ❖ Nearly all the children attending school went on a daily basis.
- ❖ Most schools were 0-15 minutes away, and only a few were more than 30 minutes away

If you have mislaid your copy of the LAQC, please let us know and we will send you another one!

Frequently Asked Questions



Q. Why only register children born after January 1990?

A. The CPRS needed a clear starting point so that we could make sure we're in touch with all families that have a child with Cerebral Palsy. The register, which existed before the CPRS registered children from 1984 onwards, so many of the children born before 1990 would have been on this register. A lot of useful work has already been done on information gained from the old register, and the CPRS will continue this work.

Q. Will the CPRS be sending out a questionnaire for the children themselves to complete?

A. At the moment there isn't a questionnaire that is suitable for use with children who have CP. We do believe that it would be very interesting to hear from the children themselves, and possibly in the future, should a questionnaire be developed, this is something we might do.

Conclusion

So far we've contacted many families in Scotland, and over the next 6 months we'll be in touch with many more. If you know anyone with a child with CP please tell them about the CPRS. It is important that we make our register as complete as possible so that it can truly reflect the trends in CP throughout Scotland, and what we might be able to do in the future for children with CP, and their families.

We'll send you another newsletter in the Spring of 2004, however you can also keep up to date with developments at our website on www.napier.ac.uk/cprs.

Contact Us

Please feel free to contact us at the address alongside if you have any comments or suggestions for future reports, or about the CPRS. We would be very interested in hearing from you.

Moving? Please also contact us at this address if this is **not** your current address, or if you are moving soon, so we can stay in touch.

**Cerebral Palsy Register for Scotland
Napier University
10 Colinton Road
Edinburgh
EH10 5DT**

**0131 455 2454
cprs@napier.ac.uk**

Useful Contacts

Capability Scotland:

Provides information and services to adults and children with disabilities (www.capability-scotland.org.uk)

Contact Details:

ASCS (Advice Services Capability Scotland)
11 Ellersly Road, Edinburgh, EH12 6HY
0131 475 2608
ascs@capability-scotland.org.uk

Contact a Family:

Provides support and advice to parents and carers of children with a variety of conditions. (www.cafamily.org.uk)

Contact details:

Contact a Family
Norton Park, 57 Albion Road, Edinburgh, EH7 5QY
0131 475 2608
Scotland@cafamily.org.uk

SNIP:

SNIP stands for the 'Special Needs Information Point'; it provides information on services for parents and carers of children with special needs. (www.snipinfo.org)

Contact Details:

SNIP
14 Rillbank Terrace, Edinburgh, EH9 1LN
0131 536 0583
snip@btinternet.com

Cerebral Palsy Help-line: 0808 800 3333 (Run by Scope, open 9am-9pm weekdays, 2pm-6pm weekends and bank holidays. All calls are free and confidential)

PARNET Help-line: 0800 32 81 159 (Free-phone, run by Cerebra, open 9.30am-4.30pm Monday – Friday).