



Cerebral Palsy Register *for* Scotland

A joint project between Napier University and NHS Scotland

Issue 3

Funded by Cerebra

December 2004

The CPRS would like to wish you all:

Seasons Greetings



and

A very prosperous New Year!

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Welcome to the 3rd edition of the CPRS newsletter. Since we last spoke things have been progressing well for the register. We have registered over 100 more children, with many coming from the more rural areas of Scotland.

In this issue we've included updates on our collection and work, along with some more organisations we thought you might find interesting.

We hope that early in the new year we will be representing the whole of Scotland, and can welcome more families to the CPRS.

Please feel free to send in any comments, or questions, you may have about the newsletter or register. We're always interested to hear your views.

We hope you and your family enjoy the festive season, and I look forward to keeping you updated in 2005!

Abbi Green
Health Services Researcher

Please send comments to:

cprs@napier.ac.uk

or

CPRS,
Merchiston Campus,
Napier University,
Edinburgh, EH10 5DT.

What we've been up to..

Presentations:

We dedicate most of our time at the CPRS to working with health boards and promoting the register.

Recently we have had a poster presentation at the annual European Academy of Childhood Disabilities conference, which was held in Edinburgh. There were a number of people attending from throughout Scotland, and also several hundred from all over Europe. There was a lot of interest in how we set up the register and the work we are doing. This conference also gave us the opportunity to meet people working directly with children with cerebral palsy and for them to share their experiences with us.



Leaflet:

We have been collaborating with Capability Scotland to produce an information leaflet about cerebral palsy. Capability Scotland is one of the organisations that have been supporting the register since we launched in 2003. The leaflet will be a condensed version of some of the material Capability Scotland has available, and will act as a starting point for parents and carers to find out more about cerebral palsy, and what information and support Capability Scotland can provide them with.

Once the leaflet is complete copies will be available online, or from the CPRS office.



Future work:

An important point of setting up the CPRS was to identify areas and issues within cerebral palsy that might need further investigation.

Through receiving your Lifestyle Assessment Questionnaires (green questionnaires) we have noticed that many of you are not reporting receiving services that we thought you would be.

(Continues on page 3)

Future work continued:

Also many of you have made some interesting points in the comments section at the end of the questionnaire. Some of these points have been positive, and are praising the work of certain services you are receiving, whilst others are negative and are pointing out the problems with various services.

This leads us to believe that it would be interesting to explore service use amongst families with children with cerebral palsy.

We are applying for some funding so we can investigate this area in more detail. In particular we want to know;



- What services families are using?
- What services are useful to families?
- What services do families want?

We hope that we are successful so that we can answer the above questions. If we are we will produce a report on our findings, and make it available to you and the people involved in planning services. We hope that this can then aid future decision making.

We will keep you informed of our progress!

Birth Records

When the CPRS asked for your consent to join the register we also asked if we could access your child's birth records. We ask this because we are very fortunate in Scotland that we have some of the most complete national health records in the world.

In Scotland all births are recorded on a SMR2 form (Scottish Morbidity Record-2). Birth records have been kept since 1969, changes were made to the information collected in 1975, and this is the basis of the information we collect today.

The record contains information on both the pregnancy and birth, and information about the baby, such as their gestational age (number of weeks in the womb), and birth weight, as well as information of any complications with the delivery.

This information is mainly used for the planning of future services, but is also useful to research, such as ours into cerebral palsy.

Some research has suggested that a low birth weight for gestational age can be a risk factor to cerebral palsy. Looking into this issue can be difficult because few medical records record gestational age; luckily we do in Scotland, which makes this research more straightforward here.

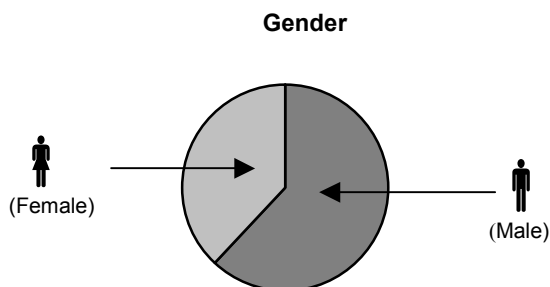
One example of how these routine birth records can be used to investigate cerebral palsy is in a study carried out by Dr Sandra Bonellie, a member of the CPRS team. Dr Bonellie and colleagues used the SMR-2 data, along with data from the previous cerebral palsy register to look into risk factors of cerebral palsy for twins and singleton births. This research has been accepted for publication, and copies are available from our website (www.napier.ac.uk/cprs/research).

Bonellie S., Currie D., & Chalmers J., (In Press) "Comparison of risk factors for cerebral palsy in twins and singletons" *Developmental Medicine and Child Neurology*.

Update

About the children

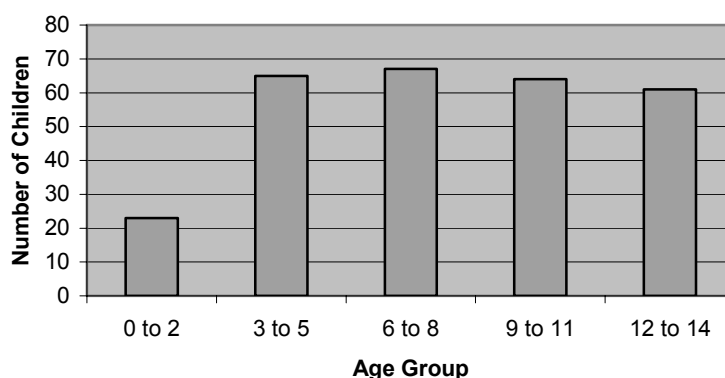
Currently there are 302 children on the register and the information below tells you a little more about them.



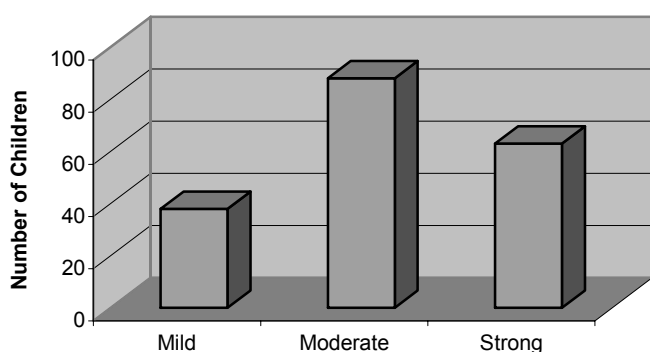
The pie chart opposite shows the number of male and female children on the register. As you can see about 60% of the children on the register are male. As we've reported before, cerebral palsy is more common in males, and so we would expect to have more of them registered with us.

Bar chart 1 shows the age range of the children on the register. This graph shows us that we have roughly the same number of children in each of the age groups, apart from the youngest group. We would expect to have fewer children in this group because for some children it is difficult to make a diagnosis of cerebral palsy before the age of 3 or 4 years old. This is due to some of the cerebral palsy symptoms being difficult to spot in some children before this age.

Bar Chart 1: Age



Bar Chart 2: Severity



As we've reported before (newsletter 2, available on line at www.napier.ac.uk/cprs/research), we can use the information from the Lifestyle Assessment Questionnaires that you fill in; to work out how each child's cerebral palsy is affecting their daily life at that time. From bar chart 2 we can see that at the moment most of the children on the register seem to be moderately affected by their cerebral palsy. We have fewer children in the mild group, and we think this is because we haven't yet managed to contact as many of these children.

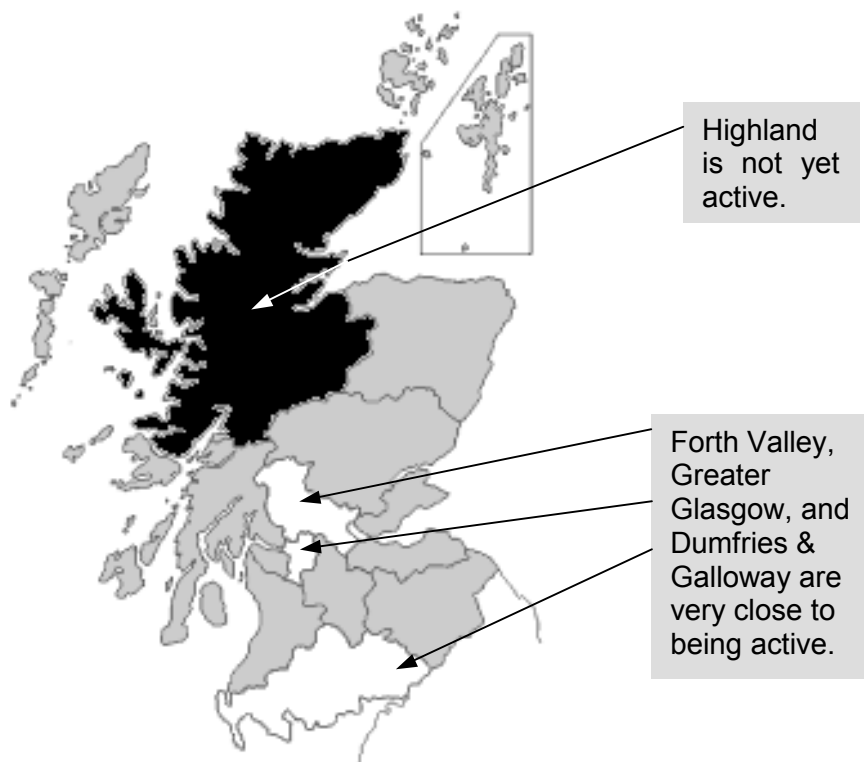
How to interpret these graphs

Pie charts: The whole circle represents all the children on the register. For each different group (males and females in this case) a part of the circle is shaded in to show how many of the children are in this group. The bigger the section, the more children there are in that group.

Bar graphs: Different groups are set out across the bottom of the graph (age groups, or severity groups here). Each child is then put into one of the groups. The more the bar rises, the more children from the register there are in that group.

CPRS Coverage

Information about the CPRS is now being handed out in most of the health boards across Scotland. These areas are shaded in grey on the map.



Receiving Information

Many of you would have first heard about the register through a visit to your paediatrician, or a NHS staff member. However we do contact families in other ways, such as through the website, special schools and charities for example. If you know of anyone wanting to register their child, please let them know that they don't have to wait to receive information from their paediatrician. Having children register with us before the health board is actively providing the information is very helpful for us to show that we have support for our work, and that you as parents and carers want this work to be carried out.

Confidentiality

Regardless of whether you received information on the register from your health board, GP, or any other route, all information you provide us with will be kept confidential, and the only people who will see it are members of the CPRS team.

CPRS and GPs

In the Islands of Scotland we have contacted families through their local GP. This is because there are no paediatricians based in these areas, and although we are aware that many of these children may visit hospitals in other health board areas, we thought it was important that these families were able to register based on where they live. This allows us to work out the number of children with cerebral palsy living within each area, which may be useful for future work.

Organisations



Contact details:

Fabb Scotland, Norton Park, 57 Albion Road, Edinburgh, EH7 5QY

Phone: 01314752313

E-Mail: info@fabb.org.uk Web: www.fabb.org.uk

Fabb (Facilitating Access Breaking Barriers) is an organisation which empowers disabled people to actively engage in the social, leisure, educational, and vocational activities of their choice. There are 18 clubs across Scotland who meet generally about once a week to promote inclusion for individuals with all kinds of disability.

Fabb Clubs:

Ayrshire & Arran

Archaway Fabb Club, Kilmarnock
Ayr Fabb Club
Bonnie Doon Fabb Club, Dalmelington
Contact Fabb Club, Kilmarnock
Fabb R Us, Cumnock

Forth Valley

Grangemouth Fabb Club

Grampian

Aberdeen North Fabb Club, Middlefield
Aberdeen Woodside Fabb Club, Ruthreston
Buckie Fabb Club

Highland

Inverness Fabb Club

Lanarkshire

Hamilton District Fabb Club

Lothian

Bathgate Fabb Club
Lasswade Fabb Club, Bonnyrigg
Yellow Teapot Fabb Club, Uphall

Orkney

Caven Fabb Club, Kirkwall

Tayside

Dundee Disabled Children's Association
Dundee Fabb Club

Western Isles

Stornoway Fabb Club

Please contact the Fabb main office for further information.



CAPABILITY SCOTLAND

TURNING DISABILITY INTO ABILITY

Advice Service Capability Scotland (ASCS)

11 Ellersly Road

Edinburgh, EH12 6HY

Tel: 0131 313 5510

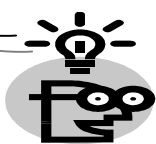
Textphone: 0131 346 2529

Fax: 0131 346 1681

ascs@capability-scotland.org.uk

www.capability-scotland.org.uk/

Don't forget that Capability Scotland can give specialised advice on cerebral palsy, and have a number of resources available to families.



Their commitment is to ensure that:

- ↪ people with profound and multiple learning disabilities are valued both as individuals and in the contribution they make to the community
- ↪ they should receive all the support needed to realise their full potential
- ↪ their right to a full life shaped by personal choice, abilities and needs underlies all provision and policy affecting their lives
- ↪ the knowledge and experience of family carers is recognised, and that their views are fully taken into account in service development

To achieve this, PAMIS offers families:

- ↪ practical help, advice, training and information
- ↪ individual support, and contact with other families
- ↪ assistance with achieving better access to community resources, whether mainstream or specialist
- ↪ the opportunity to influence policy and services significantly, both at local and national levels

Contact PAMIS:

PAMIS Head Office,
 Springfield House, 15/16 Springfield,
 University of Dundee,
 Dundee, DD1 4JE.

Tel: 01382 345 154 **Fax:** 01382 227 464

www.dundee.ac.uk/pamis
pamis@dundee.ac.uk

chip+ Children in the Highlands Information Point+

Chip + provides information, advice, and support, for families all over the Highlands who have a child with special needs. They produce a free quarterly newsletter with all the latest special needs news, and also produce a parent information pack. The pack is free and contains information on issues such as benefits, education, therapy, and family issues.

CHIP + also provides information regarding local groups and services throughout the Highlands that families with a child with cerebral palsy may find useful.

Chip+ can provide information on:

- Child minders
- Parent Support Groups
- Play Schemes
- Sibling Groups

Contact details:

CHIP+,
 Birnie Child Development Centre,
 Raigmore Hospital
 Inverness
 IV2 3UJ

01463 711189

chip.birnie@ukgateway.net
www.chip.childreninthehighlands.com

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