

**contact** a family

for families with disabled children  
dèan ceanglaichean le teaghlaichean

incorporating  
**The Lady Hoare Trust**

**in contact**



**The newsletter of Contact a Family Scotland**

[www.cafamily.org.uk/scotland](http://www.cafamily.org.uk/scotland)



**For Scotland's Disabled Children - issues facing families in Scotland are kept high on the political agenda - page 4**

[Clockwise from left: Shirley Young; Adam Ingram, Minister for Children and Early Years; Alex Salmond, First Minister; Faye Gatenby, Capability Scotland; Brett Millett, Parent; Ellenor Anwyl, Contact a Family; Dorothy McDonald, Parent; Frances Teckkam, Contact a Family Voluntary Parent Representative with Lewis Teckkam and Nina McDonald.]

## **Inside**

Music-making with Drake Music, Royal Hospital for Sick Children Edinburgh - reprovision project, Direct payments workshops, and more...

**Spring 2008**

## Contact a Family Scotland

Craigmillar Social Enterprise & Arts Centre  
11/9 Harewood Road  
Edinburgh EH16 4NT  
tel 0131 659 2930

email [scotland.office@cafamily.org.uk](mailto:scotland.office@cafamily.org.uk)

web [www.cafamily.org.uk/scotland](http://www.cafamily.org.uk/scotland)

### Freephone Helpline

**0808 808 3555**

### Textphone 0808 808 3556

Monday-Friday 10am-4pm, Monday 5.30-7.30pm  
The Language Line interpretation service is available  
for those whose first language is not English.

### Ellenor Anwyl

*Manager*

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### Cathering Loutit

*Family Worker - Highland & Moray*

[catherine.loutit@cafamily.org.uk](mailto:catherine.loutit@cafamily.org.uk)

01463 831 506

## Volunteer Parent Representatives

Our Volunteer Parent Representatives are all parents of disabled children who offer information and support to other parents in their area.

### Aberdeenshire Carol McBride

Tel: 01651 891 468

e-mail: [carol.mcbride@cafamily.org.uk](mailto:carol.mcbride@cafamily.org.uk)

### Borders Frances Teckkam

Tel: 01450 379 081

e-mail: [frances.teckkam@cafamily.org.uk](mailto:frances.teckkam@cafamily.org.uk)

### Dumfries & Galloway Jacqui Law

Tel: 01387 263 563

e-mail: [jacqui.law@cafamily.org.uk](mailto:jacqui.law@cafamily.org.uk)

### Inverclyde Nicola Reid

Tel: 01475 635 022

### North Lanarkshire Elaine Glynn

Tel: 0131 659 2930

(Contact through Edinburgh office)

### Orkney Trudy Marwick

Tel: 01856 761 835

e-mail: [trudy.marwick@cafamily](mailto:trudy.marwick@cafamily)

### South Lanarkshire Elaine McKelvie

Tel: 0131 659 2930

(Contact through Edinburgh office)

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**Welcome** to the spring 2008 edition  
of *In Contact*.

**Contact a Family News**

So far 2008 has been a very busy year but one of the highlights in January has been a key meeting between For Scotland's Disabled Children (FSDC) and Alex Salmond, First Minister and Adam Ingram, Minister for Children and Early Years - a full update is included on page 4.

As promised, we will be rolling out a series of Direct Payments workshops from May onwards - see page 3 for details. Finally, as spring is just around the corner - we hope! - we have included information on outdoor facilities and events for families in Scotland and will continue to keep you posted throughout the year on events and days out, across Scotland, to keep you and your children active.

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*The views and suggestions in this newsletter are those of individual contributors and are not necessarily supported by Contact a Family. Contact a Family cannot accept responsibility for any goods or services mentioned in or enclosed with this newsletter.*

# Contact a Family News

## Caroline Hamilton

We are sad to announce the untimely death of Caroline Hamilton our Parent Representative on the Contact a Family National Council for Scotland. Caroline died tragically on 18 December.

An extraordinary, kind and thoughtful individual. Caroline's input to the work of Contact a family was both intelligent and insightful as a parent. We are very grateful for her contribution over the last 2 years and she will be much missed by us. Our heartfelt condolences go to Caroline's family and friends in Lochaber.

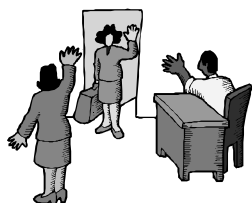
## Contact a Family's Directory - New Edition

The new edition of Contact a Family's Directory - the UK's leading guide to disabilities and rare disorders - is out next month. The Contact a Family Directory 2008 is an essential resource for parents of children with a disability or rare condition and those professionals working with them.

Available online or in print, the latest edition has information on almost 450 rare conditions and disabilities, with details of related family support groups. If you buy two printed paperback copies or two online subscriptions before April 30th you get a 3rd free of charge. All orders received before the end of April come with a free wall chart detailing benefits, practical help and support for families of disabled children.

Visit Web: <http://store.securehosting.com/stores/sh201819/shophome.php> to order your copy or download our flyer for it at Web: <http://www.cafamily.org.uk/dirsubs.html>.

## Hazel Weir Parent Volunteer Representative for Fife



Hazel has decided to stand down from her role as Parent Rep for Fife due to family circumstances. We will certainly miss her lively and intelligent input, both as an organisation and a contact for parents in her area. We would like to say a big thank you to Hazel for all she has done in her two years with Contact a Family and wish her well in all her future endeavours.

The position is funded by the kind generosity of the Appletree Trust so we are re-appointing in Fife. If you are interested in becoming a volunteer rep in this area please get in touch with Jacqui Law Tel: 01387 263 563.

## Direct Payments Information Workshops

Direct payments are a way of having more say about the care services your child gets. Instead of organising services for you, social work give you the money to buy in care yourself. Direct payments are a great idea if you want more control in how your child's needs are met. However a lot of parents are unsure about what direct payments are and how they work in practice.

Contact a Family Scotland will be holding a series of free events this year on direct payments for families with disabled children. The first three of these will be held in Glasgow, Dundee and Inverness during May and June.

If you are keen to learn more about direct payments please complete the form on the back page of this issue.

# For Scotland's Disabled Children

## UPDATE ON FOR SCOTLAND'S DISABLED CHILDREN

*.....from good intentions to better lives*

**For Scotland's Disabled Children (FSDC)** is led by the Task Group comprising major organisations working with disabled children and their families in Scotland – Capability Scotland, Care Co-ordination Network UK (CCNUK), Contact a Family, The Family Fund and the Scottish Society for Autism – and supported by many more. Ellenor Anwyl, Manager for Contact a Family Scotland chairs the Task Group.

As a result of the HM Treasury announcement of an additional £340 million awarded to begin transforming the services that disabled children and their families receive in England, under the Barnett Formula Scotland has received £34 million.

We want to see the new money used to:

- improve provision of, and access to, quality short breaks
- increase and improve provision for periods of transition, when young people move through different phases in their lives, for example from children's to adult services so that young disabled people have access to further education, training and appropriate services to help them move towards more independence
- improve access to better quality, affordable and appropriate childcare provision to enable families to return to work
- review of the Education (Additional Support for Learning) (Scotland) Act 2004 to ensure that it meets the particular needs of disabled children and young people, and supports them to achieve their potential

### **What has been achieved to date:**

Many MPs and cross-party Scottish Members of Parliament have received a briefing on the campaign and several have responded requesting meetings to discuss how they can lend their support to ensure that there is an improvement and extension of services in Scotland. On 4 January a meeting took place with the First Minister for Scotland, Mr Alex Salmond and the Minister for Children and Early Years, Adam Ingram, and the FSDC, who were represented by Shirley Young, Disability Consultant, Faye Gatenby, Capability Scotland, Frances Teckkam, Contact a Family Volunteer Parent Representative for The Borders and her sixteen year old son Lewis, Dorothy Macdonald, a parent from the Isle of Bute and her daughter Nina, Brett Millett, parent from Glasgow and Ellenor Anwyl, Manager Contact a Family Scotland.

The meeting lasted two hours and a number of further actions were agreed. In a follow-up letter from Alex Salmond, First Minister, to Ellenor Anwyl, Manager Contact a Family Scotland he states:

**“As you'll recall, at the meeting we agreed a number of further actions. These recognise the key role the coalition (FSDC) can play in influencing the delivery of services for disabled children at local level, and focus on three key issues forming the agenda for a follow-up meeting to be chaired by the Minister for Children and Early Years, drawing in other ministerial colleagues as appropriate:**

- **The role of the coalition (FSDC) in monitoring issues around both national and local outcome agreements**
- **Review of the ASL Act**
- **Transitions issues**

**...I am sure that going forward we can work together to better support families with disabled children in Scotland.”**

Following this a further meeting took place with Wendy Alexander (Labour), Leader of the Opposition in Scotland and further meetings with the Conservative and Green parties are in train.

A meeting with Adam Ingram (Minister for Children and Early Years) is taking place on 20 March to discuss how we take the actions forward. FSDC is determined to continue to seek cross party support and to ensure the issues facing families in Scotland are kept high on the political agenda.

# Having your say - parent participation

## Royal Hospital for Sick Children Edinburgh Reprovision Project

### Children, Young People and Families Advisory Board supporting families when their child dies

Plans are now underway to build a new hospital for children and teenagers in Edinburgh. In order to provide the best service we can for children, young people and their families, we need your help. We would like to hear your views on the services and facilities you think the new hospital should have to support children and young people at the end of their lives, and to support bereaved families.

To help us gather information that represents as many views and experiences as possible we have put together a short questionnaire.

We recognise that for many people it may be difficult to talk about these things, so we want to be as flexible as we can. You can respond in any of the following ways:

- In writing
- A telephone conversation
- Meeting in person with Carrie (see below for details)

If you would like to get involved please contact Carrie Upton by 30<sup>th</sup> June 2008. Carrie will talk with you to find out the way that is best for you to tell us your views and ideas about this service at the new hospital.

Thank you for taking time to respond concerning an important part of the care we provide to children, young people and their families at RHSCE.

Carrie Upton, Hospital Chaplain and member of Children, Young People & Families Advisory Board  
Royal Hospital for Sick Children, Sciennes Road, Edinburgh, EH9 1LF

Tel: 0131 536 0144 (Direct line) 0131 536 0000 (switchboard) Email: [carrie.upton@luht.scot.nhs.uk](mailto:carrie.upton@luht.scot.nhs.uk)

### Action for Sick Children - New Booklets

Action for Sick Children is a charity specially formed to ensure that sick children always receive the highest standard of care possible. Their recently produced booklets are specifically designed to help children and young people in hospital whether it be their first visit or if they have been in hospital before.

*Teenagers in Hospital* - is a step-by step guide for teenagers staying in hospital which covers areas such as consenting to treatment, having an operation and privacy.

*Helping Children Cope with Pain* is an easy to read factsheet helping you help your child cope with pain.

*Helping Children Cope with Needles* covers ideas for preparing your child and details special techniques to distract your child.

Please contact Action for Sick Children for your free copy. Tel: 0131 553 6553 or E-mail [enquiries@ascscotland.org.uk](mailto:enquiries@ascscotland.org.uk)

# Information, groups and resources

## Lochaber Community Care Forum

Lochaber Community Care forum aims to enable clients and carers in Lochaber who use community care and health services to have their voice heard and to be involved in the development of services. Representing various groups throughout Lochaber we can make representation on behalf of older people, those with disabilities, and carers including parents of children with special needs.

Finding it difficult to access public transport? - our **Car Scheme** is aimed at people who have difficulty accessing public transport. There are over 250 registered clients who benefit from this service which is supported by 74 volunteers.

We operate the **Lochaber Handyperson Service**

which aims to support clients to remain in their homes by providing a small repair service.

Our **Volunteer Visiting Service** is aimed at providing activity based support to isolated or vulnerable members of the community with a one to one volunteer or group based activity.

If you are based in the Lochaber area and would like to benefit from any of these schemes please contact Mervyn James.

Or if you are interested in volunteering to support this service - which can be for as little as one hour a week - please phone Mervyn James at the Forum Development Tel 01397 700311.

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## Highland Bikes 'n' Trikes Day

Organised by Highland Disability Sports and NHS Highland Children's Services Therapists

1st April 2008, Inverness Leisure, Bught Park - Inverness

10.00-12.00 'Come and Try Session'

13.00 - 15.00 'Fun event on your own bike'

Come along and try out bikes and trikes (which will cater for most abilities) - ranging from children through to young adults. In the morning there will be opportunities to try out the different bikes and trikes available. The afternoon session will be aimed at those who already have bikes so bring them along.

For further information contact your physio or phone Laura Cheadle at the Birnie Child Development Centre on 01463 704419.



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## Lochore Meadows Country Park, Fife - facilities for disabled people

Not just a great place for all the family, Lochore Meadows is a great place for disabled people. As well as having a network of paths, any of which are suitable for mobility scooters or power chairs, the Country Park has a range of specialist equipment for disabled people. These include a play area designed for disabled children, a wheely boat for disabled anglers, tandems and adapted cycles suitable for a range of abilities and sailing dinghies and canoes suitable for disabled people.

The park covers 1200 acres and includes a loch with a beach, picnic areas, BBQs, a 9-hole golf course, riding stables, ponds, wildflower meadows, fields and woodlands. The nature reserve ponds have a wheelchair-accessible bird hide, and there is always wildlife to be seen. For further information contact the Education Department Tel: 01592 583388.

# Information, groups and resources



## Discover the fun of music-making for free (!) at Drake Music Scotland



Drake Music Scotland is delighted to be providing **free taster sessions**, funded by the Scottish Arts Council, to individuals and groups interested in interacting with music technology and discovering the enjoyment of music-making.

Drake Music Scotland is the nation's leading organisation creating opportunities for people with disabilities to access music making and music education, working across Central Scotland with the education, health and community sectors, providing opportunities for people of all ages and with a wide range of disabilities to play, learn and compose music independently.

The Drake studio, where taster sessions take place, is situated within SPACE, Craigmillar Social Enterprise & Arts Centre and is fully accessible. The music technology includes *Soundbeam*, a fantastic, fully adaptable musical sensor, played by moving any part of the body within the beam. An enormous variety of instrumental sounds is available, including violin, piano, electric guitar, saxophone or even Chinese Guzheng Zither! Switches can be used to trigger all kinds of sounds and provide special effects.

At Drake Music Scotland we believe everyone has the ability to participate in music making. We run a series of projects both small and large scale that see participants composing and performing their own music. Projects often involve the recording and production of an original CD or putting on a public performance. Taster sessions are an excellent introduction to some of the elements of our wider programme.

To find out more please contact Bethany Whiteside, Administrator on 0131 659 4766 or email [bethanywhiteside@drakemusicscotland.org](mailto:bethanywhiteside@drakemusicscotland.org) [www.drakemusicscotland.org](http://www.drakemusicscotland.org)

## Motability promotes new year bargains.

Drive away a new car with no advance payment!

Motability, the car scheme for disabled people, has launched a promotional campaign to highlight the biggest savings available on new cars this year. Featuring models that are now available at no advance payment, the new prices apply to cars ordered by 31st March 2008. Anyone who claims the higher rate mobility component of Disability Living Allowance or the War Pensioners' mobility supplement, is eligible for the scheme and can exchange this allowance for a brand new car.

Visit Web: <http://www.motability.co.uk/main.cfm> .

# Contact a Family Factsheets and Workshops

## Grandparents



## Siblings



## Relationships



New Factsheet

Remember - these are just some of our factsheets which are available, free of charge and can be down loaded on-line from our website [www.cafamily.org.uk/factsheets.html](http://www.cafamily.org.uk/factsheets.html) or by calling our Edinburgh office Tel: 0131 659 2930.

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## Workshops 2008

If you would like more information about any of our Direct Payments workshops planned for your area, please tick this box and add your details below. We will then send you a booking form.



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Please remove me from your mailing list

Name: .....

Organisation (if applicable) .....

Address .....

..... Postcode .....

Tel: .....

Email: .....

I am

a parent / carer

a parents' group contact

a professional

Please detach and return this form to:  
Contact a Family Scotland, Craigmillar Social Enterprise  
& Arts Centre, 11 Harewood Road, Edinburgh EH16 4NT