

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

Dreams can come true... for one little boy and his family, a wish to meet Santa in snowy Lapland finally came true, *see page 4.*



Inside

Transition - Henrietta Forman tells us what transition has meant for her family, For Scotland's Disabled Children Campaign announces appointment of Policy Manager, and the Genetic Interests Group seeks to create a Virtual Panel of Patients in Scotland.

Spring 2009

Contact a Family Scotland

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Volunteer Parent Representatives

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

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Welcome to the spring 2009 edition of *In Contact*.

Contact a Family News

At last, signs of Spring are appearing and with it we welcome the appointment of Kate Higgins as FSDC Liaison Project Policy Manager - see page 5. 'Having to Learn the Hard Way' (page 6) tells us what transition has meant to one Edinburgh mother and her family and the Family Fund has more good news this month as they announce that they will now be able to accept grant applications from families with disabled young people up to their 18th birthday - see page 9.

Finally, don't forget to tweet us using twitter - see page 3 to find out how!

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



30 years of
strengthening
families with
disabled children

Celebrating 30 years of Contact a Family

Contact a Family celebrates its 30th anniversary in 2009 and our work continues to be as vital now as it was 30 years ago. To mark this milestone in Scotland we will be holding events to promote our work as the leading organisation supporting and strengthening families with disabled children regardless of disability. Watch this space for further details.

New Podcasts & Twitter

Take part in one of our Podcasts

Contact a Family is looking for families to take part in our podcast series on what it is like for families affected by rare disorders.

Families whose children have very rare disorders often don't have a support group to turn to or access to other parents to share their experiences, so hearing the stories of other families can be a great source of support.

We would like to interview families or affected adults about their experiences of a disorder or having a child or children with a rare disorder. We are interested in hearing about any rare condition, or from any family whose condition is in our Directory.

For more information, contact Sasha Henriques, Information Officer (Rare Disorders), Tel: 020 7608 8714, <mailto:sasha.henriques@cafamily.org.uk>

To listen to the podcasts visit
Web: http://www.cafamily.org.uk/news_podcasts.html

Send us a Tweet using Twitter!

Twitter is an increasingly popular online messaging service that allows you to send out short messages (known as 'tweets') to a group of people.

Contact a Family is using Twitter to keep communities updated on what we are doing, in addition to using it as a way for parents to 'tweet' us any concerns or queries they may have.

You can send us a message - whether it's a request for information, a rant after a stressful day or just to say hi - and we'll be happy to tweet back.

If you're new to Twitter visit Web: <http://twitter.com> to sign up for free and you can follow Contact a Family on Twitter at Web: <http://twitter.com/contactafamily>

Electronic Newsletter

We are planning to cut down on our postal mailing list to save on postage costs and paper. In doing so we would like to encourage our readers to receive *In Contact* electronically. This will have no effect on the information that you currently receive.

To register for this service please send an email from your chosen address entitled "EMAIL NEWSLETTER" to lesley.gray@cafamily.org.uk

In your email, please state your **name**, **postal address** and the **region** you live in.

Volunteer Parent Representatives - News



Elaine with Jamie, Zara and Karla having fun in the snow

Magical Lapland

Hi, my name is Elaine, my husband Tom and I are parents to 3 children Jamie 6, Zara 6, and Karla 4. Jamie and Zara are 2 surviving children of triplets. They were born 13 weeks prematurely, and both have cerebral palsy as a consequence.

This is a short story of how a charity called 'Starlight' made my son Jamie's wish come true. Jamie made a wish to Starlight to visit Santa. So on the 12th December all 5 of us were heading off to Lapland for 4 days. There were 14 other families going along too, who also had their wish granted by Starlight.

From the minute we met at the airport it was wonderful, staff were dressed as Santas helpers handing out little treats to the children, but that did not compare to what was to come.

As we landed in Lapland it looked like a Christmas card, it was so beautiful all fir trees and snow. We arrived at the hotel and were kitted out in our snowsuits, boots and all the equipment we needed to keep us warm throughout our trip.

Our first trip was out on the sleigh being pulled by the Huskies, we also went a ride through the forest on sleighs being pulled by Santas reindeers. We enjoyed a trip on Snowmobiles and visited The Ice Hotel to name just a few of the fantastic things we did.

The highlight of the trip for our family was the private family visit to see Santa in his cottage. It was so amazing that Jamie and Karla fell out of the toboggan when Santa waved out of his window to us. When we entered Santas cottage it was wonderful, a big roaring fire and Santa sitting in his big chair with the letter Jamie had written and posted to Santa in the North Pole over a month previously. Jamie and Santa read Jamie's letter, we took lots of photos and all 3 children were asked to draw a picture in Santa's Big Book.

Starlight is a charity that grant wishes for children with terminal illness and lifelong conditions. The people who work for Starlight are fantastic. They made sure every detail was perfect for our family, which is not an easy task when travelling with 2 children with disabilities, as there is access, medication, wheelchairs, insurance and so on to think of.

Our family had the time of our life and can't thank Starlight enough for this wonderful experience. We hope other families reading this article can have their wish come true by this amazing charity.

To help grant other seriously ill children's wishes, please make a donation. Or to refer a sick child to Starlight for a wish please contact Tel; 0207 2622 881 or visit <http://www.starlight.org.uk>.

For Scotland's Disabled Children Campaign (FSDC)

New Appointment to Improve Lives of Scotland's Disabled Children

For Scotland's Disabled Children (FSDC), the campaign to secure rights and justice for disabled children, young people and their families in Scotland, has appointed a policy manager.

We are delighted to welcome Kate Higgins to the FSDC team. Kate has extensive experience of working in the disability sector and campaigning for better lives for disabled children.

Kate will work with the FSDC Steering Group for the Liaison Project that will seek to address four key issues impacting on disabled children's lives. A key part of her role will be to monitor the impact of Scottish Government action on these issues through its policy priorities and to map and evaluate local services to ensure they are working effectively.

Ellenor Anwyl, Chair of FSDC and Director of Contact a Family Scotland, said: "FSDC recognises there has been positive policy progress in Scotland in recent years but seeks to encourage politicians and policy-makers to make good the commitment to get it right for every child. Services for disabled children and their families have been under-funded for far too long."

Kate worked at Capability Scotland from 2000 to 2006 where she established a range of innovative ways to engage the views of disabled people and led the campaigns to improve the lives of disabled children. Most recently she was the Scotland and Northern Ireland Manager of the Fundraising Standards Board.

Kate will be making regular contact with parents through newsletters, special mailings and consultations.



A Hectic Start!

Kate Higgins launches into her new role as FSDC Liaison Project Policy Manager

I didn't expect a leisurely start to my new role but nor did I expect it to be quite this hectic! But actually that's fine – FSDC's Liaison Project is funded for 3 years and that's a fairly short time in which to get going and make a real difference to the lives of disabled children and young people and their families in Scotland.

The Liaison Project is focused on four objectives that were identified by the current members of FSDC:

- improve the 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
- improve access to better quality, affordable and appropriate childcare provision
- review the Education (Additional Support for Learning) (Scotland) Act 2004 to ensure that it meets the particular needs of disabled children and young people

And because the way the Scottish Government has changed how it funds and supports local authorities, we will also be involved in working out what money is being spent locally and whether money is being spent as initially intended.

For Scotland's Disabled Children Campaign (FSDC)

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Already we have been busy – MSPs are now in no doubt that we are here and we mean business! We briefed them on the issues affecting carers of disabled children and young people for a recent debate and are also working with other organisations and coalitions to influence the bill currently going through Parliament to amend the Education (Additional Support for Learning) (Scotland) Act. We are about to conduct research with parents and children on their experiences of “life under ASL”.

The immediate priorities are to get a website established so people can find us, and more importantly join the campaign. We also want to do a big push on recruitment of members – all parents, disabled children, young people, organisations and interested professionals welcome! Every Disabled Child Matters, our sister campaign in England, has an astonishing 30,000 individual supporters: it would be good to get at least 3000 supporting FSDC and because this campaign is about disabled children and young people, it is vital that they feel part of it, and indeed feel that it belongs to them. So we are looking at ways to engage disabled children and young people in the coalition and in campaigning activities.

Ultimately, this campaign is about you, the estimated 70,000 families with a disabled child or young person in Scotland. It is all about translating politicians' good intentions into better lives for you and your son or daughter. We cannot do that without your help and support. So don't wait for the website or the invitation to join – sign up now. You can call me on 0131 659 2938 or email at kate.higgins@cafamily.org.uk. I look forward to hearing from you and welcoming you to the FSDC campaign.



Finola and Henrietta

Transition - Having to Learn the Hard Way

Finola Forman wants to go to college, yet because she has cerebral palsy and is in a wheelchair, a postcode lottery and mammoth costs stand in her way. Here Finolas' mother, Henrietta, tells us what transition has meant to her family.

My daughter Finola is a bright sociable happy 16year old girl who lives in Edinburgh and has complex needs, but we have always ensured that Finolas' condition has never stopped us from living life to the full. However, other parents advised me, as a single full time working parent, that once children reach 16 years old in Scotland, services start 'dropping off'. Listening to this advice I decided to start looking at colleges when Finola was just 15yrs old. Much to our horror we learnt very quickly that there are **no** specialised residential colleges in Scotland for complex needs further education. That there are 56 specialised colleges in England & Wales and that if you lived south of the border, as long as you meet

the criteria, your funding would be met in full by Social Work, Education and Learning and Skills Council until the young person reaches 25 yrs old. If you live north of the border then the responsibility of further education for complex needs is up to each local authority. There is no ring fencing of budgets any more, each Local Authority can prioritise its own spend so there is currently a huge variation across Scotland as to whether you receive assistance or not. The cost for these children attending residential college for a 3 year (and in some cases 4 year course) can range from £70,000 - £120,000 plus per year. Portland College near Nottingham has been identified as the college that will best

For Scotland's Disabled Children Campaign (FSDC)

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Finolas's Flowers

meet Finola's complex needs. She has been assessed and has now been offered a 3 year placement to commence on 1 September 2009 at a cost of £74,488 per annum. Portland College has the capacity to take 300 students per year / 150 complex needs residential. Sadly there have only been 2 young people from the whole of Scotland attending Portland College in the last 7 years owing to the large amount of money that Scottish local authorities expect families to raise. This therefore has and is excluding the majority of young people from Scotland.

How much assistance/ funding will Finola receive from Edinburgh Local Authority? Well we are still waiting to be advised however the figure to date has been maximum £32,000 which leaves a shortfall to find of £43,000 per year for the family.

The Scottish Government/ Scottish Funding Council commissioned the Brite report '2008 Survey of Provision in Scotland's Colleges for Learners with Profound and Complex Needs' to consult with the 36 main stream colleges in Scotland that were offering courses for complex needs further education. The survey responses highlight a variety of issues – lack of funding to

provide appropriate courses/ expertise of teaching for complex needs/ learning goals being often ill-defined by referring agencies who tend to focus on social inclusion rather than educational needs/ lack of personal care provision and support/ isolation of individuals/ part time courses being offered; 1 to 2 hours per week with very limited full time courses. Full time courses then being offered with a 1 year placement only and so it goes on.

Education is not the only provision to fall away when you reach transition.

Health

Finola has scoliosis of her spine and decided against surgery last year so she has been monitored on a regular basis by Sick Kids. We learnt recently (Finola is 16 years old) that once she leaves Braidburn Special School the monitoring at Sick Kids will cease with no equivalent provision in Adult services.

Social Services

Children's respite services end when the child reaches 17 years old. Currently there is a waiting list for adult provision, that is if you can find an appropriate service. If like Finola you would prefer Direct Payments then we are currently advised that no one in Edinburgh to date has received Direct Payments for respite however this IS the way forward for Finola. We are currently awaiting the decision from Social Services Short Breaks Panel.

Transition – to what?

Henrietta Foreman

Since 2007 Finola and her family started fundraising in earnest and formed the Finola Trust Education Fund. Finola herself has been involved with all activities to date to try and highlight this inequitable situation. To learn more go to www.finolatrust.co.uk

Contact a family produces a factsheet entitled 'Preparing for adult life and transition - Scotland'. If you would like a copy please telephone the Edinburgh office on 0131 659 2930.

Information, groups and resources



The National
Autistic Society
Scotland

Advocacy for Education

There are 50,000 people in Scotland with autism – that's 1 in 100.

Many children and young people with an autism spectrum disorder experience major difficulties with education: bullying, isolation, apathy, frustration and even exclusion. Many parents struggle to get their child the education they need and can become embroiled in disagreements with their school and education authority.

The **National Autistic Society (NAS) Scotland** is part of the UK's leading charity for people affected by autism. The **NAS Scotland's Advocacy for Education Service** aims to encourage, enable and empower parents to help them get the education that their child is entitled to. The service is divided into two specialist areas and is provided by trained volunteer advisers who offer telephone-based advice and support:

The **Education Advice Line** offers advice and information on education law to ensure parents understand their rights and entitlements. Our trained volunteers can help parents compile correspondence and prepare for meetings, challenge unfair exclusions, get their child a place in a school they know will best suit their child's needs, get necessary support in place for their child and more importantly help rebuild relationships with their child's school and local authority.

The **Tribunal Support Scheme** provides telephone advice and information for parents who wish to resolve a disagreement with an education authority at Additional Support Needs Tribunal for Scotland. Volunteer caseworkers have undergone extensive training to help parents submit their reference and prepare their case statement.

We also offer information sheets and template letters on a wide range of educational issues which are available on our website www.autism.org.uk or directly from the service.

To contact the service please call **0845 070 4002**. The service is open 24 hours so parents can get in touch at any time and leave their details and a volunteer advisor will call them back as soon as possible.

Challenging Behaviour - Supporting Change

The Challenging Behaviour Foundation has produced a new DVD to help families understand challenging behaviour and support its change in children with severe learning disabilities.

The DVD features interviews with family carers highlighting the range of causes of challenging behaviour and effective strategies to encourage appropriate behaviour.

Aimed primarily at parents the DVD is free to family carers. There are clips and further information about the DVD on the Challenging Behaviour Foundation website. <http://www.thecbf.org.uk>

Support for wheelchair users

Services for people who use wheelchairs will now be closer to home and much more flexible, thanks to a newly launched wheelchair action plan. Over the next three years, £16million will be invested in a radical modernisation programme which will bring wheelchair services into the 21st century. Key improvements include a fleet of new standard wheelchairs using the latest lightweight technology; local clinics set up across the country and patient referrals to wheelchair centres will be available from a range of health professionals including registered local authority occupational therapists - without the need for approval from a medical doctor. For further details log on to <http://www.scotland.gov.uk/news/release/2009/3/03122148>

Information, groups and resources

Patient Involvement in Scotland

My name is Claire Cotterill and I work for the Genetic Interest Group (GIG) in Scotland. For those of you who have not heard of us, GIG is a national alliance of patient organisations with a membership of over 130 charities which support children, families and individuals affected by genetic disorders.

I have been funded by the Scottish Government to create a Virtual Panel of Patients in Scotland to help feed their views into policy and health debates. Anyone with experience of a genetic condition (be they a carer, relative or personally affected) is very welcome to join.

We work flexibly so that you can contribute as much or as little as you want to, and you benefit from hearing all about the relevant opportunities in Scotland to raise awareness and give your views. The virtual panel keeps in touch by email (or phone if email is not possible) and aims to be ready to respond whenever the voice of the patient needs to be heard! To date members of the virtual panel have sat on committees to oversee the addition of new genetic tests to Scotland's National Newborn screening programme, contributed to the Scottish Government's consultation on a Patients' Right's bill and lobbied the Scottish Parliament for a National Plan for Rare Disease.

So the reason I am writing this article, is to say "get in touch!" My colleague and I work to raise awareness of the needs of patients to key professionals in NHS Scotland and in the Scottish Government, and we know that there are many rare genetic conditions that are not currently represented by us. A large strand of my work over the coming year will be to develop a draft National Plan for Rare Disease that will help improve diagnosis, treatment and care for people affected by rare genetic conditions as well as stimulate research.

To find out more have a look at our website www.gig.org.uk/scotland or contact Claire at claire@gig.org.uk or by phone on 0131 624 0015.



Claire and Dr Ian McKee MSP celebrating Rare Disease Day at the Scottish Parliament

Family Fund Eligibility goes up to 18 years



From 1st April the Family Fund will be able to accept grant applications from families with disabled young people up to their 18th birthday. This is an exciting increase in our age eligibility because along with our more familiar family based grants we hope to try and help young people themselves at this important transition in their lives with things that will help in the move to College, training or employment. Some of the things might include computers or help with driving lessons for example. Additionally, we have been able to confirm that our family earned income upper limit for eligibility will be £25,000 per annum.

To find out more please visit <http://www.familyfund.org.uk>

Carers...the UK's secret service Carers Week 8 - 14 June 2009

Carers are the UK's secret service: six million people provide unpaid care to a relative, friend or child who is ill, frail or disabled. Carers week will be highlighting and celebrating the incredible contribution that carers make to society. To keep up to date with news and events log on to

<http://www.carersweek.org> or call 0845 241 2582.

Information, groups and resources

Improving the Quality of Life for Children and Young People Affected by Neurological Conditions.

Cerebra is a charity set up to help improve the lives of children with brain related conditions through researching, educating and directly supporting children and their carers. Their grant scheme offers direct and practical assistance. If your child is aged 16 or under and the equipment or resource that would benefit your child is not available from statutory agencies, such as social services or the NHS, then contact their Grants Co-ordinator, Debbie Godsave on Tel: 01267 244 216 or <mailto:debbieg@cerebra.org.uk>

They will also be running the speech and language therapy (SALT) voucher scheme again to help children who need therapy but are not getting it. The voucher is worth up to £500 of speech and language therapy.

After a successful scheme in 2007, Cerebra will continue the wills and trust voucher scheme in 2009. The voucher is worth up to £350 towards the cost of a solicitor or professional will writing service to prepare a will and discretionary trust to make provision for your child's future. For an application or more information on the voucher scheme or the wills and trusts scheme, contact Alex Elsaesser on Tel: 0800 328 1159 or <mailto:alex@cerebra.org.uk>

The Adamson Trust

The Adamson Trust is a long established Perthshire charity based in Crieff. The Adamson Trust is able to give financial help with the cost of holidays or respite breaks for young people aged 17 and under with a physical, mental or emotional disability.

Individual families can apply and in addition they accept applications on behalf of groups of children, organisations and other registered charities. For details of rules and how to apply please contact The Adamson Trust Tel: 07770 842 502 or email edward@elworthy.net

Contact a Family Scotland Exchange and Mart Column

Do you have any unused disability equipment that you or your family no longer need?

Are you looking for specialised play equipment?

Then our exchange and mart column could help. Just send an email or telephone with the details of what you wish to sell/give away/looking for and we can include it in the next edition of *In Contact*.

Just email your name and item information to lesley.gray@cafamily.com

Online Project to Bring Storytelling to Deaf Children.

ITV has launched a major web-based initiative to improve the literacy of thousands of deaf children with a free online library of signed books.

Backed by leading UK publishers and The National Literacy Trust, Signed Stories will feature the best of contemporary children's books in sign language with audio, animation and text. The £1.5 million initiative is designed to enable deaf children to access stories at a much earlier age, and share in the joy and benefit of storytelling with hearing family and friends.

It follows a report from the National Deaf Children's Society last year that found only a third of deaf children achieve five A-C GCSE grades compared with 60 per cent of hearing children.

The site will provide advice and guidance for parents and give access to the NDCS Family Curriculum so that they can learn basic BSL. It will also provide resources around which teachers can base lessons for deaf children in either special or mainstream schools.

<http://www.signedstories.com/page/index.cfm>

Information, groups and resources

Calumn's Cabin

12 year old Rothesay boy, Calum Speirs lost his fight for life little more than a year after being diagnosed with a brain tumour. Calum was diagnosed with an inoperable brain tumour only a few days after the first symptoms were noticed last January - but he's left his family with a host of happy memories from the 13 months since then.

Calum and his family had decided that they would like to keep helping others by having a Holiday Cabin in Calum's name to allow other families who are dealing with a child with cancer

to have a wonderful holiday on the Isle of Bute.

As Calum's Cabin is nearing it's completion, bookings can now be made for families who would like to use the Cabin's services. The cost of your ferry travel together with "spending money" when you arrive, will be met by Calums Cabin. The cabin is solely for use by families who have a child suffering from cancer or a cancer related disease.

For further details or to make a booking please visit <http://www.calumscabin.com> or call 07544979538.

Interested in Sport?

Scottish Disability Sport (SDS) is the co-ordinating body for sport for disabled people in Scotland. They have a role in promoting and developing disability sport, and to help with this they have co-ordinators based in different areas of the country.

If you are interested in getting involved in a sport - football, athletics, swimming, etc. - then it is worthwhile speaking to the SDS coordinator in your area first. They will have a good idea about the kinds of sports activities that are available near you.

To find the coordinator in your area, you can check Scottish Disability Sport's website: <http://www.scottishdisabilitysport.com> or you can contact the administrator at Scottish Disability Sport, Calendon House, South Gyle, Edinburgh, EH12 9DQ. Tel 0131 317 1130. Email: admin@scottishdisabilitysport.com.

For a free factsheet on some of the leisure activities across Scotland including sports and social clubs, contact Advice Service Capability Scotland Tel: 0131 313 5510.

Turner Syndrome Support Society Open Day

Sunday 17th May

To request a booking form for the open day please contact the Turner Syndrome Support Society Tel: 0141 952 8006 or to log on to www.tss.org.uk

Pamis - Conference on Invasive Procedures: Breaking barriers and achieving control for people with profound & complex disabilities

Thursday 11 June 2009 West Park Conference Centre, University of Dundee, Dundee.

A conference for family and paid carers/professionals working in the learning disability field. With professionals from the National Health Service, Local Authority Services, Education Providers, Respite Services and Advocacy Services.

For further information contact PAMIS on www.dundee.ac.uk/pamis or call 01382 385154



Disabled Parking Bay Fines become Law

A bill to impose fines on anyone parking incorrectly in a Local Authority disabled parking bay became law at the end of February.

Transport Minister Stewart Stevenson said the move was much needed as fines were the "only real deterrent" to prevent abuses. Fines will be £30, rising to £60 if not paid within 14 days.

Contact a Family Workshops

Moving On with Shirley Young Thursday 11th June 2009, Edinburgh
Adjusting and adapting to parenting your disabled young person into adulthood, and reclaiming your life!! A workshop for parents of disabled young people aged 14 and upwards.

Come along to a motivational, interactive workshop, facilitated by the parent of two disabled young men, which will give you the opportunity to be supported by other parents in the same position to consider:


- The changing roles of *all* parents, what are the ordinary feelings and experiences that all parents share? What are the additional/different issues for parents of disabled young people?
- Goals – what do you want for *yourself* as your young person grows into adulthood? How can you achieve these goals and what support will you need to reclaim time for yourself – whether or not your caring role lessens.....
- Separating –How to establish boundaries – imperative if you are to maintain a positive parenting relationship with your adult child


You will be shown, using a variety of coaching methods and tools how you can help each other to create your own 'Person Centred Plans'.

Places are limited so early booking is advisable. For further information and a booking form
Tel: 0131 659 2930 or email: scotland.office@cafamily.org.uk.

Keep an eye on the Contact a Family Scotland webpage for details of other forthcoming workshops and events for parents. Visit <http://www.cafamily.org.uk/scotland>

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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