

contact a family
for families with disabled children

in contact



The newsletter of Contact a Family Northern Ireland
www.cafamily.org.uk/nireland

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EDCM Campaign

Some of you will have heard about the Every Disabled Child Matters campaign (EDCM) which was launched in England last year. Initially the campaign focussed on Westminster but has quickly gathered support from all four nations of the UK.

The campaigns aim is to promote new rights for disabled children and their families to access services and support, to establish models of good practice.

The situation regarding funding for disability services in Northern Ireland is that £11.5 million has been allocated but it is administered through the Barnett formula which means that the funding for disability is not ringfenced so there is no legal requirement for it to be used solely for disability. Currently Contact a Family is campaigning along with other organisations in Northern Ireland to get our local Ministers to agree to ringfence the monies allocated for services for disabled children. Watch this space for further news.

Contact Family Helpline 0808 808 3555

Staff News – Family Support Officers

Contact a Family created two new posts for Family Support Officers for Northern Ireland which are funded by the Big Lottery Fund NI. Karen and Patricia have been in place since September 2006, and their function is to assist parents and families caring for their disabled child/children. This can include practical issues like;

- accessing local services such as support groups
- providing information on the child's condition
- assistance with benefits, grants
- acting on parents behalf on issues like education or health services
- providing emotional support and a listening ear

They also visit families either in their own home or elsewhere if it is more suitable and at a time that is convenient for them. Here is some information about them.



My name is Karen Patterson, I began my post as Family Support Officer with Contact a Family in September 06. My background is that of paediatric nurse for 25 years. I have worked in both hospital and community settings which have provided me with invaluable experience. I devoted a lot of my time to families of children with severe disabilities, rare medical conditions and life limiting and life threatening conditions. This experience has enabled me to fulfil my role as FSO with CAF.

I currently cover Co Antrim, Down and Armagh.

To date I have found my job very rewarding and fulfilling. I know that the service is appreciated by many families and professionals.

Hi Everyone, my name is Patricia McAroe and I recently joined Contact a Family NI as Family Support Officer. I cover the west of NI bringing the service to the Counties of Tyrone, Fermanagh and Derry/Londonderry.

My background is in childcare and education. I have held a range of posts including childminding, nursery assistant in daycare, playgroup leader and Lifestart Family Visitor delivering a child development programme to families with children aged 0-5 years.

I recently graduated from Queens University Belfast with a degree in Early Childhood Studies. My academic and working knowledge has given me many opportunities to learn about children with disabilities, working in partnership with parents and home visiting which has provided a good base for my work as Family Support Officer.

Welcome home to Dylan Dicks

Dylan Dicks was diagnosed on 23rd January 2007 with Tay Sachs Disease. His parents Carrie and Gary were obviously distressed at the diagnosis and found it difficult to accept that there was no treatment for this fatal disease.

Tay Sachs disease is a genetic disorder caused by a missing enzyme which causes the accumulation of a fatty substance in the nervous system resulting in disability, deterioration of motor and developmental skills. It eventually leads to the inability to swallow and breathe and paralysis as the disease progresses.



Dylan's parents researched the condition in great depth and discovered Tübingen Hospital in Germany which offered them some hope. On 16th March, Dylan had a consultation in Tübingen where he was seen by a neurologist, Professor Hardgretinger and Dr Mueller who specialises in metabolic diseases. It was subsequently agreed that Dylan was fit for a bone marrow transplant. Carrie and Gary were given a full explanation of the procedure and also that there were no guarantees that the treatment could halt the progression of the disease but were given some hope that it could be successful.

Dylan, Carrie and Gary travelled to Germany on 1st April where they stayed for three and a half months. Initially Dylan had a series of tests and investigations and had a catheter fitted through which he would receive the treatment. His father Gary donated his bone marrow and Dylan had his bone marrow transplant on the 3rd May after ten days of chemotherapy. During the treatment Dylan received 24 million stem cells. He came out of hospital on 1st June but had to remain in Germany to attend the day clinic for regular blood tests. On 12th July, he had his catheter removed and the family travelled back to Belfast on 14th July.

Dylan has to return to Germany on 22nd August for an MRI scan which will show if there is any deterioration in his condition. Carrie and Gary have received a lot of support from their respective families and friends who visited them in Germany.

Contact a Family sends Dylan and his family our best wishes for the future and hope that Dylan continues to make progress. Karen Patterson, our Family Support Officer will continue her involvement with the family.

Respite Care

We have had a number of people calling the office complaining about the lack of respite care. This is an important service that should be available to families to enable them to have a break from caring, to 'recharge their batteries' and in the long run it will cost the government less in care facilities as there would be less stress on carers in the long run. Let us know your views and experiences on this issue.

Launch of Changing Faces in NI

Contact a Family NI would like to extend a warm welcome to the Northern Ireland branch of the charity Changing Faces which was launched here in June. The NI Support Officer is Jan Wright. Contact details are 0845 4500 732 or email janw@changingfaces.org.uk. Website address www.changingfaces.org.uk It will be a much appreciated support service for people with a disfigurement and we wish Jan well!

NI Benefits checklist

The new Northern Ireland benefits checklist has proved a great success with statutory and voluntary agencies and individuals alike. If you would like to receive a copy, contact the office on 028 92627552 or email nireland.office@cafamily.org.uk

New Autism Support Group

P2P Autism is a recently formed support group for parents in the Belfast region. They are conducting a study into services for children with ASD in the West Belfast and surrounding area and would like parents to contact them. They are working to develop an after school autism specific play group and will be hosting a lecture by Australian author Donna Williams, a prolific writer on autism. Donna will be speaking in Belfast on Tuesday 18 September 2007 from 1:00-3:00pm at the Medical Biology Centre (97 Lisburn Road, Belfast). Contact details are: Chair Karen Buchanan 028 9060 0172 or email p2pautism@yahoo.com

William Keown Personal Achievement

On 12th June 2007 the William Keown Personal Achievement awards were presented in the Europa Hotel, Belfast. Among the many recipients for the Young Carers award was Amy Johnston aged 10 from Belfast. Amy was nominated in recognition of the devotion and care she gives to her siblings Nathan and Katie.

Nathan is 10 years old and is Amy's twin, both were born prematurely. Nathan has cerebral palsy and uses a wheelchair. Katie is 9 years old and suffers from hydroencephaly and has severe learning disabilities. Amy is very attentive to her siblings and devotes a lot of her time to assist in caring for them.

The award ceremony was an emotive experience and emphasised the need to recognise and acknowledge carers of all ages.



Amy (centre) with Nathan and Katie on a well deserved holiday in Spain last year.

Recent publications

Siblings
Benefits, Tax Credits and other financial help
Tax Credits Guide
Tax Credits – Polish – Web only
Child Tax Credit and families on Income Support – Web only
Grandparents
How Contact a Family might help – General leaflet

New publications this year

Checklist for Parents Northern Ireland
Potty/Toilet Training
Sleep Problems
Family Support Service leaflet
A Tax Credits Guide for self employed parents – Web only
A Guide to claiming Disability Living Allowance for children
Resources for local and national support groups

Translating your medical details

The Doctor Babel website allows the creation of a simple medical record online that can be translated into many languages. For someone with a medical condition who happens to be on holiday in Spain, Turkey or Greece, for example, trying to explain their condition and needs to a medical professional who may not be fluent in English can present difficulties.

The website allows people to record their condition along with their medications and other medical details. It can then be translated into any number of languages by selecting the relevant language and clicking on 'translate'. The normal cost of registration is GBP20 for individuals. Visit Web: <http://www.doctorbabel.com> .

Parenting a deaf child with additional needs

The National Deaf Children's Society has produced a series of publications on parenting a deaf child. 'Parenting a deaf child with additional needs' is a practical guide full of tips from other parents. The contents include: developing communication; safety; your child's emotions; independence; time for yourself and support from others.

All of their publications are free to parents and professionals and can be ordered online at Web: <http://www.nds.org.uk>, via e-mail: <mailto:helpline@ndcs.org.uk> or by calling their freephone helpline on 0808 800 8880 (voice and text).

Have Your Say

'Have Your Say' on support for parents in Northern Ireland.

mallni, a broadband web development team has been commissioned by government to develop a resource that will help people understand how government policies and procedures work, so they can play an active part in deciding what happens in their community.

NICVA and other organisations have been involved in the steering group for this project. The site is for you, about you, and to help you deal with issues that affect you and your community.

One issue that mallni will be looking at is 'What is there to support parents in NI?' For this website to be useful, you need to be a part of it – so if you are a parent or guardian, please take a few moments to complete the online survey at www.ictconsortiumni.org/nicvasurvey/index.php?sid=71229.

Child poverty: A new report by Barnardo's

A report published by Barnardo's looks at how the government can meet its pledge to eradicate child poverty within a generation and to halve it by 2010.

The charity says spending GBP3.8 billion would be enough to halve child poverty in the present decade. That is less than half the predicted GBP9 billion cost of hosting the Olympics, and equates to just one fifth of one per cent of this year's public spending. Also, the report – *It Doesn't Happen Here* – describes life for many of the poorest families in Britain today, including the working poor.

Barnardo's is calling on the government to:

- keep their pledge to halve child poverty by 2010;
- establish a UK commission on ending child poverty which would deliver a road map setting out the investment and policies needed to hit the 2020 target to tackle fuel poverty by working with the private sector;
- compensate families whose children get free school meals for the additional spending on food during school holidays.

For more information see Web: <http://tinyurl.com/3dt5ua> .

Trustee for Contact a Family Northern Ireland

Join the Board of this dynamic charity for families with disabled children. This is a particularly exciting time for Contact a Family both in Northern Ireland and across the UK as it balances consolidation of recent growth and the rising public profile of the needs of disabled children and their families.

We require a new Trustee specifically from Northern Ireland to strengthen our existing UK Board and help us formulate and deliver our strategy. The person appointed will also help ensure that the Board is up to date and aware of Contact a Family's work in Northern Ireland.

The Trustee will also take a leading role with Contact a Family's Northern Ireland Council.

We are looking for a range of expertise and particularly welcome applications from parents of disabled children and/or experience in policy work, HR, finance and fundraising, and the health and social care sectors.

Further details can be downloaded from the Contact a Family website at: <http://www.cafamily.org.uk/jobs.html>

If you are interested in this post please send your CV along with a covering letter to: **Dean Casswell, Contact a Family, 209-211 City Road, London EC1V 1JN**

Stating why you are interested in joining the Board of Contact a Family.

Closing date for applications is Friday, 21 September 2007.

Interviews will be held in London in Early October.

Contact a Family is an equal opportunity employer and welcomes applications from all sections of the community.

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I would like to be added to your mailing list and receive the Contact a Family Northern Ireland Newsletter (free of charge).

OR

Please remove me from your mailing list

Name.....

Organisation.....

Address.....

..... Postcode.....

Tel:.....Email:.....

I am a parent/carer voluntary org health professional

other.....

Please detach and return this form to:

Contact a Family Northern Ireland
1 Wallace Avenue
Lisburn
BT27 4AA

Tel: 028 9262 7552
E-mail: nireland.office@cafamily.org.uk
Web: www.cafamily.org.uk/nireland
Freephone Helpline: 0808 808 3555

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