

contact a family
for families with disabled children

in contact



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

ADVICE

INFORMATION

LINKING

Winter Newsletter Issue No 16

With thanks to the Children's Fund

Contact a Family Road Shows for BME and Traveller Families in the SHSSB Area

Thanks to the Southern Health and Social Services Board, Contact a Family will be holding a series of Information/Road Show events for BME and Traveller families. We will take this opportunity to show case the information and support that Contact a Family can offer families.

Contact a Family is the only UK-wide charity providing advice, information and support to the parents of all disabled children – no matter what their disability or health condition. We also enable parents to get in contact with other families, both on a local and national basis. Each year we reach at least 275,000 families.

Our telephone Helpline offers an interpreted service covering 150 different languages via Language Line. You just need to call us on 0808 808 3555 and give us your phone number and preferred language and we will call you back via an interpreter, usually within a few minutes.

Two of our parent advisers are registered with the Office of the Immigration Service Commissioner to give basic immigration advice. All our advice and information services are free of charge to parents.

We also have a web based linking service <http://www.makingcontact.org>, whereby you can register to be contacted by other families across the world affected by a particular condition by e-mail. This service is also available in a number of different languages.

We will use the feedback from these events to organise specific workshops on welfare benefits, education, tax credits, accessing services and a range of other topics. If you are interested please phone us to the office on 028 92 627552 or email fidelma.mccoy@cafamily.org.uk, please let us know what area is most accessible to you and if you need translation. **But hurry as there are limited places available!**

Inside this edition

Find out more about Sibs, the Siblings Organisation, profile on Changing Faces, Contact a Family news, holidaying in Scotland and more.....

Contact Family Helpline 0808 808 3555

Information Groups and Resources

Parents can you help?

RehabCare is the Health and Social Care division of the Rehab Group. They are currently carrying out research into rare disorders on the island of Ireland. The research is an investigation of the support needs of families affected by rare disorders with the aim to make recommendations for the development of an all-Ireland support service. We have chosen eight rare disorders to study as follows but we are also interested in other more rare disorders:

- Prader Willi Syndrome
- Cornelia de Lange
- Rett Syndrome
- Williams Syndrome
- Cri du Chat
- Fragile X
- Neurofibromatosis
- Sotos Syndrome

Participation in the research is highly confidential and only the researcher will have access to the names and contact details of the participants. If you or you're family have had experiences with rare disorders and wish to take part in the research please contact Frances Murphy at Contact a Family on 028 9262 7552 or Bernadette McGarvey, Research Assistant with RehabCare in Dublin for further details T +353 (1) 2057224 or email bernadetteemcgarvey@rehabcare.ie.

Wheelchair Services Review

The Regional Reform Project of Wheelchair Services has been set up to examine how the Wheelchair Services can become more person-centred, responsive and accessible to wheelchair users.

For further information and/or comments, please contact the Project Manager, on or before the end of February at Tel. No. 078 25 146511 or E Mail lockhart@btinternet.com

Siblings of Disabled Children

Growing up with a brother or sister with a disability or chronic illness creates challenges and opportunities. Sibs is the UK organisation for siblings. Our aim is to enhance their lives by providing them with information and support, and by influencing service provision for siblings throughout the UK. Our long term vision is that each local authority in the UK will have a dedicated sibling service, providing sibling groups and one to one support for children who are siblings.

We provide:

Information and support to siblings and their families through our helpline, website, literature, workshops, e-mailings (including a weekly parent tip), and database of services for siblings.

Training and support for professionals in order to increase their skill and knowledge in supporting siblings. We run workshops, training days for sibling group leaders, and an annual sibling group leader conference. Influencing service providers to deliver sibling support through raising awareness of siblings' needs, via presentations and the media, and working with service providers to develop appropriate local and national services for siblings.

Contact Sibs on 0114 230 2548 or chris@sibs.org.uk or visit the website on www.sibs.org.uk

Dystonia Society

The Dystonia Society currently has over 3,500 members and is dedicated to supporting all those affected by dystonia in helping them and their families cope with the everyday challenges this neurological condition can bring. It is thought that there are more than 40,000 people with dystonia in the UK.

We are dedicated to providing the most up to date information about all aspects of dystonia and where possible will endeavour to fund or be involved in research into anything that may have a positive outcome for our members. We will also assist those who are experiencing difficulty with access to services and benefits, by raising awareness of dystonia with health and social care providers.

Many people affected by dystonia gain a great deal of support from talking to others that suffer from this condition or who have family members or friends with dystonia.

We are always keen to increase our membership and provide our members with the opportunity to:

- become involved with a local branch and gain support from other people who also suffer from dystonia
- attend annual general meetings and help decide on policy
- benefit from our volunteer development programmes

The Society's helpline is available from Monday until Friday between 10am and 4pm and provides an opportunity for people to discuss their concerns in confidence and find out more about Dystonia. For more information please contact:

The Dystonia Society, 1st Floor, Camelford House, 89 Albert Embankment, London SE1 7TP

FPLD Fathers Survey

The Foundation for People with Learning Disabilities (FPLD) is conducting a survey in Northern Ireland, as part of a national campaign, to gain insights into and views of fathers who have a carer role for a child with a disability.

They are asking any father in this position to fill in a survey either by going to their website, www.learningdisabilities.org.uk, or a paper survey can be obtained by phoning 0207 803 1100.

**Contact Family Helpline 0808 808 3555
10am-4pm, Monday to Friday and 5.30-7.30pm, Monday**

Christine Towers from FPLD has found that the survey has actually helped some fathers to realise their role in the family as a carer, and that it has made them feel more valued and proud of what they do. Fathers often feel helpless or that they don't do enough in the home when they are part of a disabled child household.

Contact a Family also recognises this – we have a support leaflet, *Fathers*, which can be requested free of charge as well as web support, *Dads' Zone*, on our website.

Benefits Update

Important Changes to Your Rights

The earnings limit for Carers' Allowance has been increased from £87 to £95 net from 1st October, 2007 – this is the amount you can earn without losing your entitlement to this benefit.

Also from 1st October, the statutory paid holiday entitlement rises from 4 weeks per year to 4.8 weeks. Therefore, a full-time worker would receive 24 days now instead of the previous 20 days. Part-time entitlement is on a pro-rata basis.

1st October also sees the National Minimum Wage increasing to £5.52 per hour for workers aged 22 and over. For 18-21 year olds this rises to £4.60, and 16-17 year olds will receive £3.40 per hour.

The Blue Badge Scheme regulations change from 15th October. Children under the age of 2 may be eligible if they have a medical condition which requires them to be near a vehicle for emergency treatment, or that they be accompanied by bulky medical equipment. Further information on the changes can be obtained by phoning the Blue Badge Helpline on 0207 944 2914.

Carers Rights

Carers Rights Day was Friday 7th December. The value of unpaid support that carers provide has now reached GBP87 billion a year according to a new report by Carers UK – more than the annual total spend on the NHS, which stood at GBP82 billion in the year 2006-7.

The new figures, calculated by the University of Leeds for Carers UK, are more than 50 per cent higher than previous estimates of how much carers save the UK, with the 'average carer' saving the nation over GBP15,260 a year.

The new figures are also more than four times the amount spent on social care services for adults and children by local authorities each year – GBP19.3 billion in the year 2005-2006.

Carers UK wants the government to recognise the huge contribution made by carers. The report, *Valuing Carers – calculating the value of unpaid care*, is published by Carers UK and is available at Web: <http://www.carersuk.org>

Transition

Mencap's Employment Service recently launched the Transition Project in Lisburn. This aims to help prepare young people with a learning disability in the 16 – 19 age group as they make the transition from education to the world of work by:

- Identifying and matching suitable work placements
- Developing the employability skills of those using the service to a suitable standard
- Increasing social and leisure opportunities



Scott McCready (below), from Lisburn has taken part in the project. Scott now volunteers part time at both the Lagan Valley Hospital and T.K. Maxx. Scott says:

“Mencap has got me 3 jobs in the last 2 months and I am still working in 2 of them. It has helped my social abilities as in these jobs I meet a lot of different people which I really enjoy.”

This Transition Project is just one of Mencap's many employment services that operate throughout Northern Ireland. Sadly 9 out of 10 people with a learning disability of working age are unemployed despite the fact that many would like this opportunity. Mencap firmly believes that people with a learning disability should have all of the exciting challenges and benefits that employment can bring.

Anyone of working age who has a learning disability can use Mencap's Employment service. For information on services in your area please contact Mencap on Tel: 0845 7636227, Email: mencapni@mencap.org.uk or visit our website: www.mencap.org.uk.

Making Contact

We have been contacted by a father in USA asking to contact families with children labelled with Plantar Lipomatosis, Unusual Facial Phenotype and Developmental Delay or as it was recognized in 2005: Pierpont Syndrome. His daughter has been recently diagnosed with Pierpont Syndrome and he would like to be contacted by any parents, anywhere, of children with this or similar syndromes. His contact details are: Clyde Bryant, Ogallala, NE. USA. clydegbryant151@hotmail.com

Parents – could you share your story?

Contact a Family is always looking for volunteers to talk in the media, to help us explain what life is like for families with disabled children. Illustrating the issues families face in their day-to-day lives through real life stories, helps us to push for change and campaign for better services.

We need people from all backgrounds with a variety of stories to tell and you don't have to be a polished media performer. If you would like to be one of our media-friendly families visit Web: <http://www.cafamily.org.uk/beinthemedia.html> .

Changing Faces

Don't look away now ...

Disfigurement and its effects on the lives of individuals and their families and friends is not something we often discuss or are indeed are particularly aware of in Northern Ireland – until it touches us personally. Although accurate up to date official statistics are difficult to obtain, it is estimated that there are at least 11,000 children, young people and adults in Northern Ireland with a disfigurement to their face, hands or body [Source: UK Disability Survey 1988]. Common causes include congenital conditions (e.g. birthmarks, cleft lip and palate), through to 'acquired' conditions such as traumas as a result of accidents, disease (e.g. skin cancer or head and neck cancer), facial paralysis and skin conditions (e.g. acne, vitiligo or psoriasis). Every one of these individuals, as well as their families and friends, not only have to come to terms with their appearance but learn how to get on with the rest of their lives.



Living successfully with a disfigurement isn't easy. Other people's reactions such as being stared at, avoided or ignored, or asked curious questions, name-called, and refused or given inadequate services are difficult to cope with: if these encounters go badly, a person's confidence and self esteem can be so negatively affected that s/he may become withdrawn, reclusive and isolated. Left unresolved, psycho-social problems such as these can also lead to social phobia/anxiety, depression and, in extreme instances, suicide.

Changing Faces is committed to ensuring that this doesn't happen. With 15 years experience of working with individuals and families to build strong social support networks, robust social interaction skills, access to accurate and high quality information about treatment options, and intensive support to develop positive beliefs about the future, the charity is now seeking to ensure that its services and campaigns are relevant and appropriate to people with disfigurements in Northern Ireland. The appointment of a locally based officer [Jan Wright] is regarded as critical in this respect as the charity places great significance on individuals and families having access to a local person who understands how things work 'on the ground' in their area.

If you are interested in finding out more about Changing Faces Northern Ireland or are looking for help and advice, please contact Jan Wright on 0845 4500 732 any Monday or Tuesday, between 8am to 6pm, or email Jan at nireland@changingfaces.org.uk. The postal address is c/o PO Box 1080, Belfast BT19EN.

Disfigurement in the Media

Researchers at Cardiff University are looking for volunteers to take part in a project which aims to explore how disfigurement is represented on TV. The research is funded by the Healing Foundation, a charity which helps people living with disfigurement. If you have experience of any kind of

disfigurement, such as scars, burns, birth marks, limb-loss, psoriasis, vitiligo or any kind of 'visible difference', and would like to take part in a focus group to have your views included in the project, please contact Joana Barron on 029 2087 0744, or e-mail barronja@cardiff.ac.uk. Joana will be in Belfast conducting focus groups and interviews during the week commencing 11th Feb, and she would like to hear from as many people as possible. To find out more about the project, have a look at the website at <http://www.cardiff.ac.uk/jomec/en/projects/22/324> , and to find out about the Healing Foundation and the work they do, have go to www.thehealingfoundation.org . Volunteers will be paid a £15 thank you fee, plus travel and child-care expenses, and focus groups will take between an hour and half and two hours.

Alternatively log on to www.changingfaces.org.uk for more general information about the work of Changing Faces. Christmas cards are also available at this address.

Contact a Family News and Updates

New Publications

- **Working** – This explains schemes and help for returning to work, including information on employment rights, childcare and financial help if you do return to paid employment.
- **When your Child has Additional Needs** – this updated version of our existing leaflets is full of information, from benefits to respite care to education.
- **Holidays, Play and Leisure** – this publication covers all aspects of play and leisure from days out, to longer breaks away, to wish granting and travel insurance.
- **Winter Guide: Help with fuel bills and keeping warm** – This new Contact a Family winter guide gives information about keeping fuel bills low, sources of financial help to pay bills and some practical suggestions around keeping warm in winter.

How About a Holiday in Sunny Scotland?

This is a rare chance to hire a private holiday caravan at Sundrum Castle, Ayrshire, Scotland.

The caravan is sited at a Parkdean Holiday Park within easy reach to excellent facilities that offer sport, leisure and entertainment for all the family.

Our 2 year old, 8 berth caravan has gas central heating and double glazing to ensure a comfortable and relaxing holiday. There are 3 double bedrooms and a $3/4$ size lounge bed with easy access for wheelchairs which is ideal for children or adults with disability.

If you would like further information please contact Mrs C Rennie on 01294 270890 or 07828211361 or email walterrennie@aol.com

A Bill of Rights – Public Asked to ‘Make it Right’

A third of children living in poverty, 600 older people die of cold here every year, 1700 sectarian attacks across the country last year and people with disabilities are twice as likely to be out of work in Northern Ireland. That’s why we need a Bill of Rights, according to the Human Right’s Consortium’s new ad campaign, launched today, called “Make it right.”

Speaking at the launch of the campaign in Belfast, Fiona McCausland, Chairperson of the Consortium says:

“At a very basic level, a Bill of Rights is a contract between the government and the people. It means the government will be more accountable and responsible, so that the things we lobby and campaign for today, will be our right in the future.

A Bill of Rights will protect everyone in society equally, meaning we all have access to strong human rights protections.

The Bill of Rights is for everyone – young and old, Catholic and Protestant, rich and poor. We are a society looking forward, moving away from conflict and we need the basic building blocks to make sure this happens. The government needs to know that there’s a set of rules out there which they are socially answerable to.

More children in Northern Ireland live in poverty than any other part of the UK. At a basic level, this means that countless children here have no winter coat to wear to school or have no breakfast in the mornings because their parents can’t afford it. It is issues like these, where a strong Bill of Rights could really help vulnerable and marginalised groups, by providing them with protections and acting as a basic safety net.

We need a strong Bill of Rights, but it will only be inclusive and representative if the people of Northern Ireland get behind it. It’s up to every individual to make sure that this Bill represents them. We want people to have their voices heard. The Human Rights Consortium’s new website – www.billofrightsni.org – allows people to lobby easily online.



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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 Freephone Helpline: 0808 808 3555

E-mail: nireland.office@cafamily.org.uk Web: www.cafamily.org.uk/nireland

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