

contact a family

for families with disabled children

In Touch June 2010

Contact a Family - Northern Ireland Bi Monthly newsletter

Our latest Regional newsletter has just been posted out. If you are not on our mailing list for your FREE copy please send us your postal address and tell us if your are a parent, carer, professional or work for another voluntary or community group. Please enter NEWSLETTER in the subject box of your e mail.

In Touch is issued every two months and aims to bring you up to date news, details of training courses, group information and new resources available from within Contact a Family and from other organisations. We hope the information is useful and helps you and your family. We value your feedback on this and all our services and publications. Please forward you comments to the e mail address below.

For right up to date information on events, consultations, local groups our most recent Newsletter and more see our webpage at www.cafamily.org.uk/inyourarea/nireland.html bookmark this page and then you can access it quickly!

We are available to help with any issues that affect the disabled child or young person, parents, families and professionals.

Contact us at 028 92627552 or e mail nireland.office@cafamily.org.uk

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NEW! The 2010 edition of the Directory is hot off the press!

The essential guide to medical conditions, disabilities and support

Price each: £ 40.00



The Contact a Family Directory is the UK's leading guide to disabilities and health conditions, including rare disorders. If you work with children or adults affected by disability or additional needs, this is a vital resource for you and your colleagues.

The Contact a Family Directory has:

- * More than 430 entries (including three new entries this year)
- * More than 1,200 conditions described
- * More than 400 UK family support groups listed
- * Details of groups helping with specific issues like aids and equipment, caring and bereavement.

Each entry contains a medical description of the condition together with details of inheritance patterns and prenatal diagnosis, and details of related support networks and groups, where available.

Available to order online at <http://www.cafamily.org.uk/publications.html?scat=6>

Contact a Family - Local Parent Support Group Network Scheme Becoming a member

Contact a Family is an organisation founded on the principle of mutual support between parents and families caring for disabled children. We endeavour to offer a flexible, relevant and inclusive service to parent groups offering support and information to families in their local area. This is achieved through the Contact a Family Local Parent Support Group Network Scheme.

What are the benefits of joining the Contact a Family Local Support Group Network?

As a member of the Network your group will be entitled to the following, all free of charge:



Our quarterly magazine, "Connected".

Advice and support from Contact a Family development staff on any matter relating to the setting up and/or management of your support group.

Referral of families or individuals who may wish to become members, or use the services, of your group.

The choice of being consulted on both:

- a. Contact a Family policy and;
- b. Matters arising as a result of our work relating to the support of families and the welfare of disabled children.

The option of receiving the Contact a Family Local Parent Support Group Network quarterly bulletin which enables groups to share ideas, information and expertise.

Permission to state that your group is part of the Contact a Family Local Parent Support Group Network on all group literature.

What does Contact a Family expect from members of the Network?

In joining the Contact a Family Local Support Group Network, all we ask is that you:

Run your group in a non-discriminatory way.

Manage any funds your group has in an accountable way.

Wherever possible, inform Contact a Family of any changes to your group which affects the information we hold on our database.

Return an update form on an annual basis.

Comply with the law of the land.

If you would like your group to be a member of the Contact a Family Local Parent Support Group Network, please contact the N Ireland office for a membership form at nireland.office@cafamily.org.uk or tel: 028 9262 7552

Contact a Family – call for new Nation Council Members

Are you a parent that could get involved in our organisation in N Ireland?

Help to advise and support the team in their roles and offer assistance, as able, to other parents or for events, training, or focus groups.

If you think this is something you could do we would love to hear from you. We have vacancies for several new parent members. For more information or a chat please contact Frances Murphy at 028 9262 7552 or e mail nireland.office@cafamily.org.uk and put NATION COUNCIL in the subject box and we can send you more details.

Unique - Information Guides to Specific Disorders

No other organisation has the range of accessible, understandable guides to specific rare chromosome disorders that Unique provide. Covering vital subjects about each condition, such as health, behaviour and development, these are compiled using information provided by Unique members.

All Unique's information guides are available completely FREE to download from the website at www.rarechromo.org

Recently published guides include a ground-breaking guide to array CGH, a new test used to diagnose rare chromosome disorders. It contains everything you need to know if someone you know or care for is having an array CGH test. Other guides include Duplications of 6q, Triple X and 2q24.3 microdeletions.

For help or information, contact Unique by email at info@rarechromo.org at any time or by calling +44 (0)1883-330766.

Gingerbread - NI Holidays 2010 guide

This useful self help guide contains practical information and contacts for organisations, which may be able to assist with the organisation and financial costs of holidays for One Parent families. To get a copy of this guide contact Gingerbread NI on 08088088090 or e-mail advice@gingerbreadni.org.

Mencap - Launch of the Getting it Right campaign in Northern Ireland

Many people with a learning disability are being denied their basic human rights. They are all too often on the receiving end of poor treatment and their health can suffer as a result.

During Learning Disability Week (21-27 June) Mencap will be asking healthcare authorities and hospitals to sign up to a charter that will show their support for bringing about changes in care and treatment of people with a learning disability.

Its time for the NHS to get it right.

People with a learning disability are not getting equal access to healthcare.

Poor communication, assumptions about quality of life and a dangerous lack of understanding by healthcare professionals means that patients with a learning disability are getting poorer standards of care - **and even dying**.

Mencap's 'Death by Indifference' campaign highlighted the untimely deaths of six people with a learning disability while in NHS care. Unfortunately, several years on from this report, we are still hearing of patients with a learning disability receiving poor treatment.

As the work of 'Death by indifference' continues, our 'Getting it right' campaign aims to support local campaigners, health professionals, GP surgeries, hospitals and healthcare authorities to work together to make improvements.

Mencap believes that:

- healthcare professionals need support, encouragement and guidance to make reasonable adjustments for patients with a learning disability
- members of the public should be given the tools to persuade health professionals and healthcare authorities to make adjustments and treat people with a learning disability equally

Mencap has worked with healthcare professionals and Royal Colleges to develop the **Getting it right charter**. The charter spells out the nine key activities that all healthcare professionals should make to ensure that there is equal access to health.

Mencap is asking healthcare professionals to pledge to:

- Make sure that hospital passports are available and used
- Make sure that all of our staff understand and apply the principles of mental capacity laws
- Appoint a learning disability liaison nurse in our hospital/s
- Make sure every eligible person with a learning disability can have an annual health check
- Provide ongoing learning disability awareness training for all staff
- Listen to, respect and involve families and carers
- Provide practical support and information to families and carers
- Provide information that is accessible for people with a learning disability
- Display the Getting it right principles for everyone to see

To sign up to the campaign follow the link below. Takes 2 mins at most!

<http://e-activist.com/ea-campaign/clientcampaign.do?ea.client.id=78&ea.campaign.id=6882&ea.param.extras=source:ACTION>

MONEY - £20 million from Child Trust Funds for disabled children to be redirected to short breaks

The new coalition government has announced that Child Trust Funds would be scrapped and £20 million would be redirected to fund "additional respite breaks" for families with disabled children.

Contact a Family welcomes the focus on families with disabled children from the new government. We believe that the £20 million announced is additional to funding already allocated for short breaks next year.

Srabani Sen, Chief Executive of Contact a Family, said: "It is important that in yesterday's announcement the government has recognised the pressures that families with disabled children face and any additional funding for respite care is welcome. To live ordinary lives, families with disabled children need a range of services and financial support. We look forward to seeing the detail about yesterday's announcement and how this relates to the coalition government's overall plans for families with disabled children."

Family Fund changes income criteria to help working families on lowest incomes

The Family Fund, the largest charitable grant-maker for families with disabled children, has changed the way it looks at income to help more families on the lowest of incomes.

From 1 April 2010, the Family Fund will consider a grant application where a family's total income from all sources, including net income and benefits £27,000 in Northern Ireland.

Previously a limit was imposed on working families, as families in receipt of benefits were automatically eligible. These new income limits have been agreed so the Family Fund can help more working families on a low income.

ARK : Mental and emotional health of 16-year olds Research Update

The Young Life and Times (YLT) survey has monitored the mental and emotional health of 16-year olds in Northern Ireland since 2004. In 2009, ARK was contracted by the Patient and Client Council (PCC) to ask 16-year olds a range of questions on their emotional and mental health and their attitudes towards, and experiences of, mental health services for young people. Follow this link to find out more http://www.ark.ac.uk/ylt/2009/Mental_Health_and_Self-harm/index.html

Launch of new project to support blind and partially sighted people in Lisburn

RNIB and Guide Dogs for the Blind launch "Lisburn in Focus" a 5 year project funded by The Big Lottery aimed at improving the quality of life of blind and partially sighted people in the Lisburn Council area. The launch which took place in the Linen Centre, Lisburn, on the 20th April outlined the main goals of this innovative project; to make blind and partially sighted people feel secure in their homes, to provide safe and clear public spaces and a mobility guidance system in the city of Lisburn, to ensure all written information in Lisburn is accessible and to provide training to services and businesses on visual awareness.

If you'd like to learn more or to offer to be amongst the first beneficiaries, please email lisburninfocus@rnib.org.uk or telephone 028 9260 0388.

NEW! Citizens Advice have launched its first ever set of BSL films

These are dedicated to helping over 250,000 BSL users find an alternative and convenient way of accessing Citizens Advice services.

The films are accessible through the Citizens Advice website www.adviceguide.org.uk or on You Tube.

Citizens Advice in Northern Ireland have produced a wide range of publications dealing with issues connected with being in debt. These help you understand how to construct a debt letter, a jargon buster factsheet and what happens if you are taken to court for debt. They are available through your local CAB office or by contacting

Citizens Advice, 46 Donegall Pass, Belfast, BT7 1BS.

Tel : 028 9023 1120 or Fax: 028 9023 6522,

email: info@citizensadvice.co.uk or visit the website at www.citizensadvice.co.uk

Law Centre (NI)

A not for profit agency working to advance social welfare rights in Northern Ireland.

The Law Centre promotes social justice and provides specialist legal support to advice giving organisations and disadvantaged individuals.

They deliver legal services to members in community care, employment, immigration, social security and mental health. We support the work of advice agencies through advice, casework, training, information, publications and policy development.

They aim to work closely with our membership of independent advice giving agencies and associate members including social services and probation offices, solicitors' practices, trade unions and community based organisations.

The Law Centre NI seek to promote the work of local, regional and specialist independent advice in partnership with Advice NI and Citizens Advice.

Their work is guided by their core values: professionalism, independence, accountability, responsiveness, and a commitment to social justice and equality

Services

Casework: advice and representation on referral from our membership, including strategic court work and representation before the social security commissioners, industrial tribunals, immigration appellate authorities, social security tribunals and Mental Health Review Tribunals.

Policy: informed comment on public policy and legislation, lobbying and campaigning for legal reform and positive change to law and policy.

Training: courses aimed primarily at advisers, both new and experienced.

Publications: briefings, bulletins and other publications to assist advice agencies in their operation.

Fora: Quarterly practitioner meetings in social security, community care and immigration to bring together advisers to discuss legal, policy and practitioner developments.

Casework Areas of Work

Social Security: most social security benefits, representation before the social security commissioner and/or at social security appeal tribunals that raise complex/technical legal issues or points of public importance.

Community Care: legal issues surrounding provision of services, facilities or accommodation, carers' rights and other legal issues.

Employment: advice on employees' rights and representation at Industrial Tribunals.

Immigration: asylum and other complex applications to the Home Office, representation before the AIT.

Mental Health: advice and representation at the Mental Health Review Tribunal.

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Western Area Office

9 Clarendon Street
Derry BT48 7EP
Telephone: 028 7126 2433
Fax: 028 7126 2343

Moyle Children and Young People's Locality Group

Are organising a Family Fair and Fun Day on **Saturday 26th June from 12-2pm at The Parochial Centre in Cushendall** . The aim of this event is to reach families in The Glens and raise awareness of the services which are available in the area.

You are invited to come along to this event and display information about your service and what you can do to support these families.

Can you please RSVP your attendance to Selena Ramsey, Children's Services Planning Locality Development Officer on 02825636608 or selena.ramsey@northerntrust.hscni

Positive Attitudes and Action for Inclusion

A conference entitled Positive Attitudes and Action for Inclusion is to be held in Dublin, Ireland, on Thursday 7th October 2010 in D4 Hotel (formerly Jury's). The organisers of this event plan to show for the very first time in public in Ireland a documentary called Including Samuel. This is an award winning documentary that has played on PBS (Public Service Broadcasting USA) and has, and continues to garner, worldwide acclaim. Professional Photojournalist Dan Habib, tells the story of his son, Samuel, diagnosed with cerebral palsy and several other families of children with special needs. Dan Habib will fly over from Boston to attend and speak at this conference. A large audience has been invited and it is expected that between 500 and 1000 people will attend the event. This is to include a Government Minister, many Irish Assembly delegates and Senators, representatives from Government Departments, Special Needs Service Providers, Parents, Special Needs Schools, Primary Schools, Secondary Schools, Third Level Education providers and a whole host of voluntary and professional associations. Admission to the Conference is FREE. So book your place quickly before they are all gone! For more information please visit www.myspecialneeds.ie.

Have a great summer and the next edition of "In Touch" will be with you at the end of August!

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