

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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The Jennifer Trust Fund



Front: Ryan Sloan
(Harmony Hill PS),
Ryan McNally (St
Colman's PS), Tom Rowan
(Malone Intergrated
College).
Back: Pat Clarke
(Grandmother) Margaret
Mateer (Parent)

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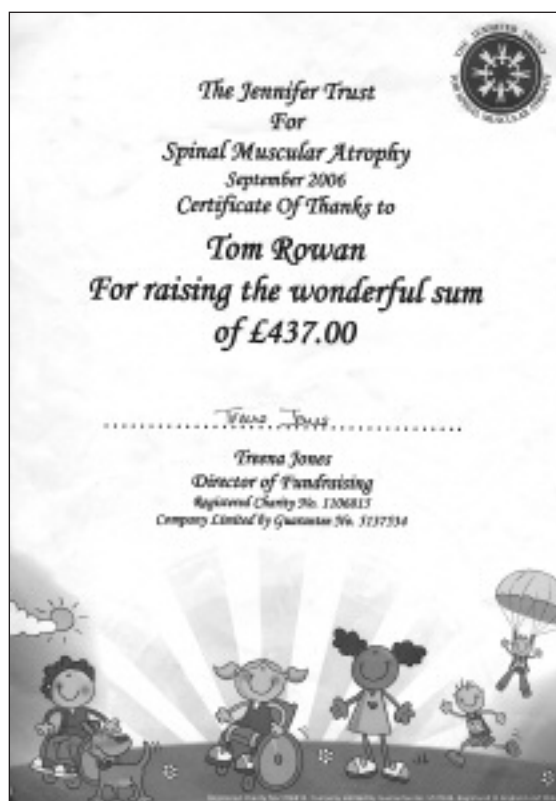
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Contact Family Helpline 0808 808 3555

A Letter From a Grandmother

“At the age of a year old my young grandchild Joshua (now aged 3) was diagnosed with Spinal Muscular Atrophy (SMA) Type II. Up until this time I had never heard of the condition. SMA is a genetic neuromuscular condition causing damage to the anterior horn cells in the spinal cord.

This damage results in generalised muscle weakness of varying severity. Children with Type II of this condition are generally able to sit but most are unable to ever walk and require a powered wheelchair for mobility. Also as a result of muscle weakness children and adults with SMA are prone to respiratory problems, for example, pneumonia.

The Jennifer Trust for Spinal Muscular Atrophy (JTSMA) is a little known charity working to support children and adults, and their families, who live with SMA by providing valuable advice and support. The charity also supports research into finding a cure for this condition.

On 29th July I organised a coffee morning to help raise much needed funds for JTSMA. A staggering £1475.00 was raised. This amount was given a great start by three young men, Tom Rowan (aged 12) and Ryan McNally (aged 11) who asked all their neighbours and friends to donate £3 (the entrance fee for the coffee morning) and Ryan Sloan (aged 10) who took part in a sponsored Fun Run. Between the three of them they raised an amazing £475.00.

I would like to take this opportunity to say a big thank you to all their friends and neighbours in Greenburn Way, Lambeg who gave so generously to my coffee morning. I would also like to thank those neighbours who paid my three young grandsons, Daniel, Michael and Patrick and their friends, to wash their cars and who raised £15 between them. And of course a big thank you also to all our friends and family who supported us at the coffee morning”.

Pat Clarke

Grandparents Factsheet

Having a disabled child has an effect on the whole family, not just parents and siblings. As a grandparent, you may find yourself in an unfamiliar and sometimes difficult situation. The child's parents, brothers and sisters and other relatives may be looking to you for information and support at a time when you are trying to come to terms with the news that your grandchild has a disability. We hope that this fact sheet will help you identify with some of the feelings and needs of other grandparents as well as highlighting a few ideas for those of you who are unsure how best to support the parents/carers of a disabled child. Call the office if you would like a free copy

Changing places – Changing lives



A new national campaign, *Changing Places* has been launched by a consortium of organisations including charities Mencap and PAMIS, and is calling for support from people across the UK.

Thousands of people with profound and multiple learning disabilities need *Changing Places* toilets. These are rooms equipped to allow people to use the toilet with assistance or have their continence pads changed. They include an adult-sized height adjustable changing bench, a hoist, a toilet with space either side for a carer, and plenty of space.

Without these facilities carers are often forced to change family members on a dirty toilet floor with little or no privacy – this is unhygienic and dangerous. However the alternative is to limit outings to a couple of hours or to not go out at all.

There are almost no public *Changing Places* toilets in the UK. The campaign is calling for *Changing Places* toilets to be installed in all big public places, including city centres, shopping malls, and arts venues. For more information visit www.changing-places.org

Parents Win Access Battle for Disabled Children

Parents who were not allowed to take their disabled child into Fulton's Fine Furnishings store in Belfast because he was in a buggy have won a legal battle in the County Court.

Justin Black, from Bangor, took a case of discrimination on behalf of his son Thomas under the goods facilities and services provisions of the Disability Discrimination Act 1995 (DDA) with the support of the Equality Commission. His complaint arose from an incident in March 2005 when the family was refused access to the Boucher Road premises unless they left the child's buggy at the entrance of the shop. Thomas, a one year old has Spina Bifida, uses a specially adapted buggy.

The court found that Fulton's refused to make an exception to their 'No Prams/Buggies' written policy, in spite of the fact that Thomas's father explained his son's disability to management. The 'No Prams/Buggies' written policy, had stated that disabled persons and wheelchair users were welcome,

however, the effect of refusing to allow the child's buggy into the premises meant that the family could not access the premises. The judge issued a declaration that this was unlawful discrimination and ordered Fulton's to pay legal costs.

If you are experiencing any situation where you feel your child may be discriminated against or victimised because of their disability please contact:

The Equality Commission Tel: 028 90 500600

Website: www.equalityni.org.uk

Remember Our Child



Remember Our Child is a project within Cruse Bereavement Care. It is a network of organisations providing support for bereaved parents following the death of a child. The Remember Our Child member groups include:

- Compassionate Friends
- The Miscarriage Association NI
- SANDS – Stillbirth and Neonatal Death Society
- SIDS – Sudden Infant Death Syndrome
- Road Trauma Support Group
- ARC – Antenatal Results & Choices

These groups offer one-to-one befriender support and provide a network of group meetings where parents share their experiences with other parents. Our role in Remember Our Child is to provide parents with information on the work of the groups and enable them to make contact with the relevant organisation.

Remember Our Child also informs healthcare professionals and the wider community of the issues of child loss. We strive to raise awareness of the profound grief experienced by parents and families following the death of a child.

An important part of our work is to give parents opportunities to acknowledge their child. Parents may record their child's name in a Book Of Remembrance – These books are kept in St Anne's Cathedral Belfast and at St.Eugene's/St Columb's Cathedrals in Londonderry.

Services of Remembrance are held annually in Belfast and Londonderry. These services are open to all bereaved parents and families.

For further information about the work of Remember Our Child, its member groups, Books of Remembrance and Remembrance Services please contact the Project Co-ordinator at:

Piney Ridge

Knockbracken Healthcare Park

Saintfield Road

Belfast BT8 8BH

Tel: 028 90797975

Email: rememberourchild@cruseni.nadsl.net

Education Maintenance Allowance

What is an Education Maintenance Allowance (EMA)

The Education Maintenance Allowance (EMA) is an allowance worth up to £30 for eligible students from low income families who stay on in education after they reach the statutory leaving age (after the end of compulsory school when students reach the age of 16).

Further bonus payments of £100 may be paid up to three times a year to a student who has met certain targets agreed with the school or college as part of the EMA agreement.

A young person will be paid the allowance for a period of three years as long as her/his household income is not more than the £30,810 per year. The allowance, is a weekly allowance that is paid fortnightly directly into the young person's bank account.

Education Maintenance Allowance may be paid in addition to other support and benefits provided by the government. EMA will not affect any child benefits, working tax credits and /or child tax credit payable to a parent or care.

The allowance will not affect any money a young person earns in a part-time job.

How to apply for Education Maintenance Allowance

Application forms are available from:

- Schools or colleges
- The careers section in Job Centres
- Job and Benefits
- Department of Education
- Department of Employment and Learning

New Publications from Contact a Family

Contact a Family, has produced two new fact sheets this summer, which are packed full of useful information for parents. One of them is an Educational Maintenance Allowance fact sheet and the other is a Finding and Paying for Childcare fact sheet

Educational Maintenance Allowance (EMA)

Explains exactly how this benefit works and who is eligible for it. Broadly speaking, EMA is for 16 to 19 year olds from lower income families in full time education, or on certain training courses, and funds some of their day to day expenses. Students are eligible for weekly payments, plus possible bonuses and should apply as soon as possible, as payments cannot always be fully backdated.

Finding and Paying for Childcare

Tells parents everything they need to know to help them arrange suitable childcare – not always easy when you have a disabled child. It runs through the childcare options for disabled children of all ages, explains how to find out what's available locally and includes a handy checklist to help parents decide if a childcare place is suitable. It also gives full details of the benefits, tax credits and grants that are available to help parents pay – as childcare for disabled children can sometimes be extremely expensive.

Training for Carers

Carers Northern Ireland are running a training session in The Human Rights Commission, North Street, Belfast for carers on Wednesday 15th November 2006 at a cost of £20.00 The session will run from 10.00am to 3.00pm and a light lunch will be provided.

The training content will include:

- What is a Carers Allowance and who would be entitled to claim it?
- What are Direct Payments and how can Carers use them to purchase services?
- What is a Carers Assessment and how would carers benefit from having an assessment carried out?
- What is the Carers Strategy?

For further information or to book your place, contact Lesley at Carers Northern Ireland 028 9043 9843

The Big Deal

The Big Deal is a new £4m programme targeted at children and young people in Northern Ireland up to 25yrs of age. The main focus of the programme is to increase children and young people's participation in ways which contribute to achievement and learning and/or enhances health and well-being.

One part of the programme is a small grants scheme for individuals and groups of children and young people offering grants of between £500 and £2,500. The scheme has three themes, which are:

- impact of conflict and tackling sectarianism;
- transition from infancy to adulthood;
- additional needs of vulnerable socially excluded and disaffected children and young people.

To find out more about The Big Deal

visit: www.thebigdealni.com

email: info@thebigdealni.com

phone (028) 9033 1880

Grants for Individuals from David West Trust

This trust was established in July 2005 in memory of David West, who was a company director of Proteus NI Ltd, with the aim of making small grants to individuals. The Trust plans to operate over a period of five to eight years, beginning in 2006.

David had a number of interests, both personal and professional, and Proteus is offering individuals the chance to apply for grants of up to £500 to assist them with personal or professional development in the following broad categories: young people, disability, cross community reconciliation, breast cancer and caring.

Grants could cover paying for a short course, a travel bursary, a study visit, a respite break or the purchase of books or a piece of equipment, for example.

Obviously, this list is not exhaustive, and the Trust will consider applications for other things, as long as the application relates to one of the above categories, and that a good case is made to support it. Applicants should be able to show that there will be some improvement to their lives from the grant, and they must let the Trust know what they did with the grant. Depending on the level of interest, there may be an interview before a final decision is made.

Visit www.proteus-ni.org or telephone 028 9037 1023 for more information. Applications should be returned by October 2006.

Alternatively, if you know someone who you feel would be deserving of an award, but might be reluctant to apply themselves, you can apply on their behalf.

The Harvest trust

The Harvest trust offers free holidays for a week to children between the ages of 8-11 during the months of April-October in Cardigan Bay.

The trust also provides free transport and the only cost to the family is food. Visit www.harvesttrust.com

Some Girls Have All The Luck



This is a picture of our very own Roma Drayne on the red carpet with Euan McGregor at the premier of Stormbreaker in Leister Square London on the 17th of July. Roma and her family were guests of The Starlight Children's Foundation.

Well done Sarah Louise



Sarah Louise King proved to be a very worthy recipient of the Children of Courage-Certificate of Merit award at the William Keown Trust Personal Achievement Awards.

The accolades were handed over in the presence of 400 guests at a prestigious function in Bangor. Mr David Hanna MBE, chairman of the Board of Directors, pointed out that the 'awards were unique in these islands' and added 'What some people can achieve in the face of severe disability is, in many cases, beyond human comprehension'.

The William Keown Trust, an independent registered charity, was set up to recognise the personal achievements of people with disabilities and create community awareness that disability does not mean inability. You can find out more by visiting their website www.wkeowntrust.org.uk

Benefit Rates

Child Benefit	Only or Eldest Child	£17.45
	Other Children	£11.70
Disability Living Allowance	Care Component	
	Higher Rate	£62.25
	Middle Rate	£41.65
	Lower Rate	£16.50
Disability Living Allowance	Mobility Component	
	Higher Rate	£43.45
	Lower Rate	£16.50
Child Tax Credit	Family Element	£545 per year
	Baby Element	£545 per year
	Child Element	£1,765.00 per year
	Disability Element	£2,350.00 per year
	Severe Disability Element	£945.00 per year
Working Tax Credit	Basic Element	£1,665.00 per year
	Couple Element	£1,640.00 per year
	Lone Parent Element	£1,640.00 per year
	Disability Element	£2,225.00 per year
	Severe Disability Element	£945.00 per year
	50-plus Element (working 16-29 hours)	£1,140.00 per year
	50-plus Element (working 30 hours or more)	£1,705.00 per year
	Childcare (one child)	Up to £175.00
	Childcare (two or more)	Up to £300.00
	Carer's Allowance	Claimant
Adult Claimant		£28.05
Earnings Limited for Claimant		£84.00



Are you getting all you are entitled too?

Contact a Family's Pound for Parents campaign is a three year campaign funded by True Colours Trust to encourage parents to claim the benefits, tax credits and concessions that they are entitled to.

We know that many families with disabled children are not claiming the benefits they are entitled to, and are missing out on vital extra income. Many parents don't know where to go for information, and find out about benefits and services from friends and family, in an ad hoc way. When parents do track down benefits information, it is often difficult to understand. In addition, the benefits system itself is complex, with eligibility for another, and parents find it difficult to navigate their way through.

The Pounds for Parents campaign funds a welfare rights specialist who is available via our freephone helpline to check families benefits and tax credits. If you would like a benefits check call our helpline on 0808 808 3555, Monday to Friday 10am to 4pm and Mondays 5.30pm to 7.30pm. It will help us if you have the details of the benefits that you currently receive to hand when you phone us. The call is free and confidential. We have access to Language Line interpreters if you would prefer to speak to us in a language other than English.

It will only take a few minutes of your time to check that you are getting all that you should be and it will cost you nothing. Whilst some of the benefits we advise on are only for those on a low income, others are payable regardless of your income and savings. It is always worth checking, so please call us.

How to invest your Child Trust Fund voucher

Every family whose child was born on or after 1st September 2002 is entitled to a Child Trust Fund voucher from the Government worth at least £250. But lots of families don't do anything with the voucher when it arrives – and lose valuable interest as a result. The Government eventually chooses an account for you at random which may not be the best one.

Contact a Family has secured some funding to pay for families to receive an hours confidential, free, independent financial advice over the telephone about which would be the right Child Trust Fund account for your family. If you haven't made a decision about what to do with your voucher, or you think you may have made the wrong decision, call the Contact a Family helpline, Tel: 0808 808 3555 to book a telephone appointment or e-mail: helpline@cafamily.org.uk

Podcasts

Several of our publications are now available to download as an audio file in MP3 format or "podcast":

- When Your Child Has Additional Needs
- Fathers factsheet
- Growing Up, Sex and Relationships: A booklet for young disabled people
- Growing Up, Sex and Relationships: A booklet to support parents of young disabled people

e-newsletters

Keep up to date with what is happening by signing up to receive one or more of our e-newsletters:

- **General** – this is a monthly newsletter about our work and news relevant to families with disabled children. Much of the information is taken from this "What's New" page.
- **Rare Disorders** – this is a bi-monthly newsletter specifically aimed at parent support groups, professional workers and anybody interested in policy issues concerning rare disorders.
- **Parent Participation** – this is a bi-monthly newsletter for anyone interested in facilitating and developing the involvement of parents of disabled children in shaping local services. It offers useful resources and news from around the UK.

Calling All SureStarts

Contact a Family England and Wales are entering in to a new and exciting phase working with SureStart Children's Centres with the aim to help all SureStarts achieve their outcomes for disabled children and families.

"Some voluntary sector organisations, such as Contact a Family (www.cafamily.org.uk) which represent families with disabled children, will often be interested in providing services from SureStart Children's Centres or can offer specialist information and guidance for planning strategies"
– **A SureStart Children's Centre for every community. Phase 2 planning guidance (2006-08)**

Contact a Family Northern Ireland would like to extend this service to all SureStarts in Northern Ireland.

We can offer you 'A Parents Starter' Pack to enable you to develop a library/information corner for parents and a 'Resource for Professionals' comprising essential information for all staff working in the children's centre.

Subscribers receive items at 50% less than their individual price.

If you would like to know more please phone Fidelma at 028 92 627552 or email ccsubs@cafamily.org.uk

Most Frequently Asked Questions about Contact a Family

What do you do?



We provide information, advice and linking to families with disabled children. The information is split between the generic topics covered by our [factsheets](#) and detailed medical information from *The Contact a Family Directory*. Advice to individual parents is provided both [locally](#) and via our freephone [Helpline](#) 0808 808 3555 or [e-mail](#). We also try to link families on either an individual basis or via a support group. For more information on our linking scheme, please download our *Making Contact* (0.3Mb) brochure. We provide [developmental advice](#) to new and existing support groups. We also influence policy at a local and national level, raise awareness and [campaign](#) for a better deal for families.

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

How did the charity start?

Our work began in the London Borough of Wandsworth in early 1974, although Contact a Family did not become a registered charity until 1979. It began due to a realisation that there was:

- hardly any provision for the whole family. Services were for the disabled child alone, leaving parents and siblings isolated.
- hardly any cross-condition support. There were separate specialist services depending on the disabled child's condition, which often meant that children had to travel further from home again leading to isolation for the families.
- no "neighbourhood" or "community" service – everything was organised on a much larger Borough or Regional basis which also led to isolation.

An archive 1984 report [Setting up for self-help](#) written by our founder, Noreen Miller, chronicles the formation and development of Contact a Family.

Why haven't I heard of "Contact a Family" before?

Although we are relatively well known in the disability and charity fields, we do not advertise in the national press or have charity shops.

How are you funded?

Most of our money comes from Government grants, from the Big Lottery Fund or from Charitable Trusts. However, nearly all this money is "restricted" – we can only legally spend it on specific items of our work. Only 18 per cent of our income is "unrestricted" giving us the ability to spend it on less glamorous, but vital, areas of work which we cannot obtain "restricted" funding for. Our liquid reserves are only enough to fund our work for 8 weeks so we are constantly in need of donations.

Is it a big charity?

In a 2004 charity survey, we were ranked 1,377th in a list of 3,000 UK charities in terms of income. However, we like to think we "punch above our weight" and this has been said to us on many occasions. For instance, this website is one of the top 40 most visited UK charity sites and is probably the most visited site in the world offering information on rare disorders.

And Finally...

Here is an example of just some of the disorders Contact a Family Northern Ireland has dealt with in the past year.

AD(H)D	Deaf Blind Rubella	
ADHD & Autism	Development Delay	
ADHD & Dyspraxia	Distal Arthrogyriposis	
Adrenleukodystrophy	Diabetes	
Agensis of the Corpus Callosum	Downs Syndrome	
Aicardi Syndrome	Downs Syndrome & Hirschsprungs	
Alternating Hemiplegia	Duane Syndrome	
Amnionic Band Syndrome	Duchenne Muscular Dystrophy	
Angleman Syndrome	Dyslexia Bardet Biedl Syndrome	Encephalitis
Benign Intercranial Hypertension	Endometriosis	
Benign Familial Macrocephaly	Epilepsy	
Biliary Atresia	Epispadias	
Bladder Extrophy		
Bone Dysplasia	Fragile X Syndrome	
Brain Injury	Fetal Alcohol Syndrome	
Brittle Bones	Freeman Sheldon Syndrome	
Apert Syndrome	Dyslexia & Asperger Syndrome	
Arthrogyriposis	Dyspraxia	Neurofibromatosis
Valporate Syndrome		
Noonan Syndrome		
Weidemann Syndrome		
Oculomotor Apraxia	Wolf Hirschorn Syndrome	
Opitz Syndrome	Wolff Parkinson White Syndrome	
Osler Rendu Weber Syndrome	Worster Drought Syndrome	
Otahara Syndrome		
Partial Trisomy 8		
Perthes Disease	Yunis Jaron	
PKU		
Poland Syndrome	Zellweger Syndrome	
Posterior Cleft Palate		
Prader Willi Syndrome		
Premature Births		
Premature Sexual Maturation		
Progressive Supranuclear Palsy		
Psuedoarthrosis		
Asperger Syndrome Dystonia		
Asthma		
Ataxia Telangiectasia		
Autism		
Friedreichs Ataxia	Fybromyalgia	
Cancer		
Cat Eye Syndrome	Global Development Delay	
Cerebellar Veris Hypoplasia	Goldenhar Syndrome	
Cerebral Palsy	Graves Disease	
Catch 22	Greig Syndrome	
CHARGE		
Childhood Cance	Hearing Impairment	
Crohns Disease	Heart Defects	
Chronic Dystemia	Hemi Hypertrophy	
Coffin Lowry Syndrome	Henoch Schonlein Purpura	
Cohen Syndrome	Hirschsprungs Disease	
Congenital Adrenal Hyperplasia	Hodgkins Disease	
Congenital Hyperthyroidism	Huntingtons Disease	
Connective Tissue Disorder	Hydatidiform Mole	
Cornelia de Lange	Hypogammaglobulinaemia	
Craniofacial Conditions	Hypomelanosis of Ito	
Cri du Chat Syndrome	Hypospadias	
Cutis Laxa Syndrome	Hypotonia	
Cyclical Vomiting	Sanfilippo Disease	
Learning Disability	Scheuermanns Disease	
Leigh Syndrome	Schinzal Giedion Syndrome	
Lennox Gastaut Syndrome	Shpritzen Goldberg Syndrome	Severe Epilepsy & Birthmarks
Marfan Syndrome		

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Are you reading someone else's **In Contact**? To receive your own copy please complete the following details and send to us at the address below. Pass it on! If you already get your own copy please pass it on to a friend once you have read it.

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
Bridge Community Centre
50 Railway Avenue
Lisburn
BT28 1XP

Tel: 028 92 627552
E-mail: nireland.office@cafamily.org.uk
Web: www.cafamily.org.uk/nireland
Freephone Helpline: 0808 808 3555

Contact a Family cannot accept responsibility for any goods or services mentioned in or enclosed with this newsletter.

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