

Supporters' Update

August 2005

contact a family
for families with disabled children
incorporating
The Lady Hoare Trust

New Face to Face Service For Families

Following the recent merger with the Lady Hoare Trust, Contact a Family has gained a team of experienced social workers who, from the beginning of July, will be piloting the brand new "face to face" Family Work Service.

The service, for families who have a child with a diagnosed or undiagnosed disability or long term health condition, aims to help them with issues that arise in caring for their child that no-one else is helping with. Together, the family and a Family Worker will decide how best the Family Worker can help in their situation such as providing information on local services; negotiating with other agencies - like schools or social services; helping the family access benefits; or by providing emotional support through a crisis or time of stress - such as receiving a diagnosis or moving to a new school.

Here, the Family Worker for South Yorkshire, gives an overview of how she's helping one family.

"I'm working with the family of Sarah (not her real name), a teenage girl who has early osteoporosis, a long-term health condition which affects her bones. She needs daily medication, special transport to school, and has to attend the nearest paediatric unit for two days every month to have a transfusion which helps to strengthen her bones.

She is a bright girl with loads of potential, living in an isolated community with two much older, disabled family members. Her mother, who is in her early 40s, has a severe learning disability and cannot be left alone. Sarah's grandmother, who is aged over 70 and has arthritis and breathing difficulties, looks after both her and her disabled mother.

The family do not have their own transport and live in a community that has about 47% unemployment and a huge drug culture.

I have supported the family getting to hospital for treatment, and have visited Sarah whilst in hospital. I support grandma in claiming all the benefits she's entitled to, and also give her some time to off-load all her concerns about Sarah's future. I also support Sarah's learning disabled mother, in a simple befriending role, as she receives a hostile response from the local community.

My main work though is with Sarah herself, also in a befriending role, enabling her to see the bigger picture, liaising with school and various charities to make sure she gets all the aids and adaptations she needs. But most of all, trying to make sure she has the confidence to try and achieve her dream, which is to become a veterinary nurse."

"One of Life's Musts"

That's the verdict from Graham Jackson, one of Contact a Family's 2005 London Marathon team.



Some members of the Contact a Family marathon team. From left: Mark Clawson, John, Alexi and Nick Laws

Graham was one of our nine-strong team of runners, some pictured opposite, who ran the gruelling 26 mile course in this year's Flora London Marathon on 17 April for Contact a Family and have so far raised an amazing £12,000!

We met some of the team at our 'Pasta Party' where they were treated to a carbohydrate loaded meal in preparation for the following day's exertions and were able get to know their fellow team mates.

"Thank you for giving me an opportunity to do one of life's musts...a memory that I will remember for the rest of my life...a truly fantastic experience." Graham Jackson

The team included Mark Clawson who lost over 4 stone in weight whilst training for the marathon. He finished the course in 5hrs 4mins.

We have places available for the 2006 London Marathon. If you're interested in running for Contact a Family, contact Maggie on 020 7608 8734.

"It was a great day...I'm still in a fair bit of pain - but it was worth it!" Nick Laws

Roger Rabbit-aka Dean Casswell, Contact a Family's Director of Finance and Fundraising - proves a big hit at the **Sherborne Castle Country Fair**. See back page for more photos.



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NSF Conference

60 parents from around England came together in Leeds in May for a free conference organised by Contact a Family. The day explored some of the ways parents can make use of the children's National Service Framework (NSF) to improve services for disabled children.

The government's National Service Framework for Children sets out national standards for the health and social care of children in England. Contact a Family played a key role in developing those standards in the Framework relating to disabled children's services.

"After many years looking after a disabled family I felt tired and thought "What's the point?" The conference left me feeling motivated and ready for a new challenge. It has been invigorating and given me new hope. Thank you." Mother, South Yorkshire

The conference was attended by parents, representatives from Parents' Forums and Parent Carer Councils who heard from a variety of speakers in the morning on what the NSF means for families with disabled children. In the afternoon workshops gave practical advice on aspects of parent participation, including how to start a parents' forum.

Following the success of the conference, Contact a Family is hoping to hold a similar event in the south in the Autumn.



Opposite: Contact a Family's Chief Executive, Francine Bates, introduces one of the day's speakers, Virginia Bovell from PACE

Dealing with Debt

Recent research carried out by Contact a Family and the Family Fund found that families looking after a child with a disability are more likely to be in debt and face debt problems. It is also estimated that it costs, on average, three times as much to bring up a child with a disability. So it is no surprise that many families with disabled children struggle financially.

To help families cope, Contact a Family Scotland is running two free workshops for parents on managing debt in early September in Glasgow. A new factsheet on debt management is also being produced.

Another Successful Night Of Comedy!

Contact a Family's third fundraising Comedy Night took place on 18th July, and has been hailed as another success!

The night was once again compered by Radio 4 stalwart Arthur Smith, brother of Contact a Family Patron Dr Richard Smith. He was joined on stage by some top stand-up comics including Heart Radio's Drivetime presenter, Greg Burns and Brian Higgins, whose own son has a rare syndrome (pictured below).



Our thanks go to all the artists who gave their time for free and to all the companies who kindly donated prizes worth over £650 for the evening's raffle. The night raised £2,400.

Fundraising Explained

Why are there so many charities? Why do charities send out pens? Why do charities need to spend money on fundraising and administration? How does street fundraising work?

The answers to these and many more questions can be found on a new independent website www.charityfacts.org. The site, an initiative from Bristol Business School, is designed to address concerns about how charities operate and how fundraising actually works - what techniques are used, what they cost and what they deliver. Specific sections cover what to expect



from various forms of fundraising and FAQ's dispel common fundraising misconceptions.

"Contact a Family relies on fundraising and donations from the public to continue our work supporting families with disabled children," said Jon Anscombe, Fundraising Manager. "Yet many people don't fully understand how or why it costs money to raise money - charityfacts.org gives people a clear and objective explanation."

A new independent report examining the needs of disabled children and their families has highlighted Contact a Family amongst its recommended charities to support.

Ordinary lives from **New Philanthropy Capital (NPC)** discusses the issues facing these families in the UK and provides information and analysis to guide donors and funders interested in supporting this area.

The report focuses on:

- The needs of disabled children and their families and the attitudes of society;
- Activities of government and charities in response to these needs;
- Results of these activities;
- Priorities for funders.



The research illustrates a range of ways private funders can support vital work at different levels, from supporting charities directly helping the disabled child and their family, to charities driving change amongst policy-makers, professionals and society's attitude in general.

Throughout the report, examples are given of organisations, including Contact a Family, that NPC believe warrant support, allowing donors to target resources more efficiently and to maximise impact.

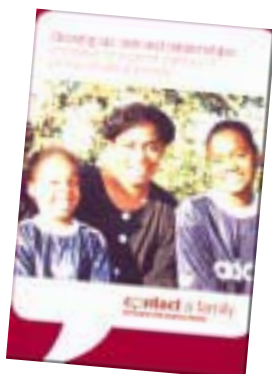
"The organisation [Contact a Family] has an excellent track record of providing high quality support to parents," said the report.

Growing Up As A Disabled Young Person

Growing up is a difficult time for all young people and parents often feel uncomfortable talking to their child about growing up, puberty and sex. This can be even more difficult if their child has a disability.

Contact a Family, together with other charities including the Council for Disabled Children, have tackled some of the difficult issues around sexuality and growing up in **Growing Up, Sexuality and the Young Disabled Person**, a series of three new booklets offering guidance on what support is available to young people as they start to form intimate relationships.

Each of the three booklets has been written for a different audience; one for young disabled people, one for parents and one for teachers.



Finding Medical Information on the Internet

How do you tell whether medical information you find on the internet is good quality and reliable?



Contact a Family's new leaflet, **Finding medical information on the internet**, has been produced as part of the **Parents and Paediatricians Together** project in response to concerns from paediatricians and support groups who found that some parents were getting the wrong information from the web or were spending large sums of money on unnecessary treatment.

The leaflet contains a checklist of questions you should ask when reading medical websites, including who produced the website, who is it for, and how recent is the information provided. Asking questions like this will help direct parents to websites produced by respected organisations, and rule out those containing unreliable information.

Congratulations to MARK GARRATT who took part in the **British 10k London** in July for Contact a Family. He finished in an hour and raised £450.

Good luck to JENNIE PARSONS (pictured) who's running this year's **Great North Run** for Contact a Family on September 18th. You can help Jennie reach her target sponsorship of £300 by making a pledge or donation on her web page www.justgiving.com/jenniep



DAVID PARKER will be undertaking a challenge of a lifetime when he treks the Ecuadorian Andes in January 2006 for Contact a Family. The **Andean Volcanoes Challenge**, organised by fundraising expedition specialists Charity Challenge, also takes in Cotopaxi, the world's highest active volcano. For details of other expeditions you can participate in, see their website www.charitychallenge.com



Injury may have forced MARGO TITMUSS (pictured) to pull out of the Contact a Family London Marathon team but it didn't stop her running in the **Edinburgh Marathon** instead! Margo raised £6,000 but said afterwards she'd never do it again!

Don't forget if you have secured your own place in an event and would like to raise sponsorship for Contact a Family, contact us on 020 7608 8731.

Supporters' Update

All the Fun Of The Fair

Glorious sunshine and rocketing temperatures made for a scorching 10th Anniversary of the Sherborne Castle Country Fair.

And thanks to free tickets kindly provided by the organisers, we were able to invite along a number of disabled children and their families too for a great day out.

The Fair, which previously supported the Lady Hoare Trust and local children's charities, will this year donate part of the proceeds from the fair to Contact a Family.

"We had a great day... and unusually for us, we stayed right to the end!"



Left: 'Roger Rabbit' and Contact a Family staff keep children amused with the "Find a Carrot" game at Contact a Family's stand. From left: Maggie Mooge, Appeals Manager, Rachel Goodkin, Finance Officer and Francine Bates, Chief Executive.

Right: Contact a Family's volunteer Parent Representative, Chris Faulder and her family at the Fair with 'Roger'.



Will you leave the world a better place?

67% of people support charities during their lifetime but only 4.3% include a charity in their will.

Remember A Charity is the combined effort of over 130 UK charities who have joined forces to raise awareness about leaving money to charity and to make it the norm rather than the exception.

Almost 7 out of 10 people in the UK support charities, but fewer than 1 in 20 remember a charity in their will. The Remember a Charity campaign aims to show that leaving a gift to charity in your will via a legacy is a very easy way to give whilst still ensuring that your dependants, family and friends are adequately provided for.

"Everyone can leave the world a better place," said campaign director Jonathan Parris. "At the moment people wonder *whether* to include a charitable donation in their will - instead we want them to think *which* charity to include." In the latest stage of the campaign, respected TV journalist and broadcaster Michael Buerk appears in a TV ad asking, "I will. Will you?"

"For its size, a relatively small proportion of Contact a Family's income is from legacies," said Jon Anscombe, Fundraising Manager. "However, legacies are the most valuable source of income as we are able to use the money where the need for funding is greatest."

For further details about leaving a legacy to Contact a Family, contact Maggie on 020 7608 8734 or maggie.mooge@cafamily.org.uk

PERU TREK: 22 Sept - 1 Oct 2005

Experience the challenge of a lifetime and raise money for Contact a Family

Immerse yourself in ancient Peruvian culture and trek along one of the world's most stunning trails.

Experience diverse scenery from tropical Andean rainforests to the snow-capped mountain ranges of the Andes and of course Machu Picchu, one of the world's most important archaeological finds. For those with a love of landscape, a passion for history and a sense of adventure, an unforgettable experience awaits you.

For more information about taking part in this, or our Vietnam Cycle later in the year to raise money for Contact a Family, contact 020 7608 8731.



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