

## Blue Badge Campaign

Two mums, whose daughters have hip disorders, have joined forces to launch a campaign to change the law on the Blue Badge disabled parking scheme.

Helen Grindrod and Kelli-Ann Rushton are not entitled to the badges due to their girls' age and type of disability. Under current legislation families whose disabled children are under two years old do not qualify. Also those who have a disability lasting less than three years are not eligible.



*Helen's daughter, Mia, in her hip cast which goes from her chest down to her ankles with a bar between her legs.*

Kelli-Ann Rushton's one-year-old daughter, Jessica, needs to wear a special heavy plaster cast to keep her legs in place as her hips heal. Her legs are extremely fragile, so Kelli-Ann has to be careful when getting Jessica in and out of the car. The car door needs to open as wide as possible, to avoid dislocating her hip again. Jessica will have to wear the casts for around 8 months.

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**"If we can claim disability allowance then surely our children are classed as having a disability?"**

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*"We were amazed when we found out that our children weren't eligible for a Blue Badge despite the fact that it was completely impossible to get them in or out of a car in a normal car parking space."*



*Helen struggles to get daughter Mia in and out of the car.*

*"Children under two do not fit the current criteria as it is argued they can be carried in much the same way as a child without special needs."*

*"Many parents with disabled children end up being housebound for months on end and this simply isn't acceptable. We believe that every child has the right to get out and about and to lead as normal a life as possible."*

The campaign, supported by Contact a Family, was recently featured on BBC's Watchdog programme.

## North East Parents Negotiate for Rights

Parents of disabled children often report that their feelings of protection toward their disabled children are of such an intensity that they struggle to control their emotions when they attend meetings with teachers, health professionals or social care staff.

They say they will often resort to manipulation, become overly complacent or verbally aggressive in order to obtain the right service for their children. We hear time and time again about parents' need to fight for their child's rights; the right to access suitable education; the right to a properly fitting wheelchair for their child; the right to appropriate respite services - the list goes on.

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**"This has given me more courage - to know that I will be okay in the meeting and not start crying and making a fool of myself. It's my right to ask for things for my son." Parent from Bishop Auckland**

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To address this, **Contact a Family North East** has set up a series of free workshops for parents across the North East region. A skilled negotiation expert facilitates the events which explore assertiveness skills; develop strategies for confidence building; review negotiation skills, and look at how parents can manage themselves in stressful meetings and challenging situations.

Parents from Berwick to the Tees are learning the subtle art of assertiveness, finding they can make their point by using simple methods, like the 'broken record technique' - quietly repeating their request until the point is made; using 'deep breathing' and 'visualisation' to steady their nerves when they feel under pressure; and by getting together with other parents and realising they are 'not alone' with their fears.

Feedback is already positive, with parents reporting that the skills they are learning at the workshops are of great benefit to them.

# Supporters' Update

## Chief Executive Collects OBE

Francine Bates, Contact a Family's Chief Executive, was awarded an OBE in the recent Queen's birthday honours list. Here she recounts the experience; Francine said:

*"No one was more shocked than I was to get a letter from 10 Downing Street, asking whether I would accept an OBE from the Queen for services to families with disabled children.*

*"Once you send back your letter saying you will accept you have to keep it top secret until the Honours List is announced - in my case two months after I got the original letter. Not easy for a talker like me!*

*"Finally the big day came on 2nd November. I took my husband Russell, mother and sister. It was a very cold but bright day and Buckingham Palace looked wonderful in the morning sunlight.*

*"Unfortunately, the Queen was unable to attend the investiture that day because she had a bad back, as you may have read about, so Princess Anne stepped in to do the honours (so to speak). It was a wonderful occasion and I met some very interesting people who were also being invested.*

*"When the honours list was announced, I was amazed and touched by how many people sent cards and emails congratulating me. Without exception, people have felt that getting the OBE was long due recognition for disabled children and their families and the work of Contact a Family - I so accepted the honour on that basis."*



Congratulations to all those who successfully made their way around Hyde Park, London in aid of Contact a Family for the **Hydro Active Women's Challenge** back in September.



The 22-strong Contact a Family team included staff member, Rosie Noble and her two daughters (pictured). The team raised an amazing £2,000.

The 2007 Hydro Active Women's Challenge will take place on Sunday 16th September.

To take part contact Gemma on 020 7608 8733 or [gemma.turner@cafamily.org.uk](mailto:gemma.turner@cafamily.org.uk)

## Every Disabled Child Matters

Every Child Matters is the Government's new UK-wide strategy for ensuring the well-being of children from birth through to the age of 19. So why aren't disabled children getting their rights?

Only 1 in 13 families get support from social services; Disabled children are 13 times more likely to be excluded from school; and 8 out of 10 families with disabled children say that they are at breaking point.

Contact a Family is a founder member of Every Disabled Child Matters, a new campaign to get rights and justice for every disabled child.



The campaign, backed by The Daily Mirror, wants all disabled children and their families to have the right to the services and support they need to lead ordinary lives. It is challenging politicians and policy-makers to make good on the Government's commitment that every child matters.

As part of its message, the campaign has been highlighting the need for regular, reliable and appropriate short breaks from caring for parents.

Short breaks are an essential service and can be provided within the family home, through accessing community facilities, or by the child staying overnight with another family or in a residential setting. The lack of short breaks was parents' biggest single cause of dissatisfaction with services.

Even for those families receiving breaks, 1 in 3 had experienced a cut in service in the past year. As a consequence 8 in 10 families caring for disabled children described themselves as at, or close to, breaking point.

## Websites Win Awards



Both Contact a Family's main website [www.cafamily.org.uk](http://www.cafamily.org.uk) and its web-based family linking service [www.makingcontact.org](http://www.makingcontact.org) were recently awarded 'Best Use of New Media' at the 2006 UK Charity Awards.



Many thanks to staff at NIG, part of the Royal Bank of Scotland, who raised over £700 through various fundraising activities. NIG then boosted that amount with a donation for another £500. Staff nominated Contact a Family to benefit from their donations as their office is located just a few doors away from our City Road office.

Bethan Thomson, NIG Communications Executive (pictured, centre) presented a cheque to Gemma Turner, Fundraising Officer and Dean Casswell, Director of Finance and Fundraising.

Contact a Family's annual comedy night fundraiser **'Stand Up For a Good Cause'** took place on 18th September and was a complete sell-out, raising over £8,000, making it the most successful to date. This year's event will take place on 17th September 2007.

## Different Dads

Fathers of disabled children can feel overlooked when so much parenting support is aimed at mothers. **Different Dads**, a new book from Contact a Family, is a collection of inspiring personal testimonies written by 21 fathers of disabled children who reflect on their own experiences and offer advice to other fathers and families on the challenges of raising a child with a disability.

They discuss the reactions of family, friends and colleagues; how to deal with the organisations and professionals that support families with a disabled child and the difficulty of being open about feelings in a culture that doesn't always expect men to have a sensitive or nurturing role.



David Cameron, MP and Conservative Party Leader is himself a father of a disabled child and wrote the foreword for the book. He said:

*"It is a great idea to draw together stories of fathers' experiences in bringing up disabled children. One of the ways parents manage to cope is to know that others have been through the same experiences. Then you learn that it isn't just about coping - there are positive stories to tell."*

## New Volunteer Parent Representatives for Scotland

Contact a Family Scotland has strengthened the support it offers to families in Scotland with the appointment of two new volunteer Parent Representatives.

Contact a Family currently has 28 volunteer Parent Representatives across the UK whose role is to help make sure that local families of disabled children can access the support and information they need.

They are all parents of disabled children, some with quite complex and rare conditions, with a great knowledge of the day-to-day issues confronting parents and access to a wide range of information on local services, voluntary organisations and useful sources of help. They volunteer their time and energies to help other parents.

Carol McBride, who has two disabled sons aged 10 and 12, became the Parent Representative for Aberdeenshire in October.



*"As many other parents have found, as my sons' disabilities became clearer and life became more stressful and difficult, I drifted away from friends who were not 'in the same boat' however understanding they were," explains Carol.*

*"Finding mutual support from other carers and sharing information became more and more important. It was frustrating to find that we were 're-inventing the wheel' so often in our attempts to get the services our families need.*

**"Becoming a parent representative has been so rewarding for me, I have learnt new skills, met new friends and feel I make a difference to the lives of the people who contact me." Current parent representative**

*"I found out about Contact a Family through a support group. When the advert appeared in their newsletter the other parents pointed to me and gave me the confidence to think that here was a way to spread the help we give each other beyond our local informal group.*

*"As a parent representative and part of the Contact a Family team, I hope to provide sources of information to parents at every stage from diagnosis onwards, because knowledge is the first step to empowerment. I also hope to be a listening ear who does understand the ups and downs of life as a parent and a carer."*

# Supporters' Update

## Parents Caught In Childcare Trap

The findings of a major new research report into the difficulties of combining paid work and care for disabled children has unveiled that barriers still persist for parents.

The report, **Caring for Sick or Disabled Children: Parents' experiences of combining work and care,**

**Too many parents of disabled children find themselves 'between a rock and a hard place' - caught between a lack of appropriate childcare and the high cost of any services that are available**

is the culmination of a four year study commissioned by Contact a Family and Carers UK. It looks in detail at parents' experiences, attitudes and aspirations around work.

*"I used to work as a radiographer in the local hospital. I really enjoyed my job but can't imagine I'll ever be able to go back. I'd never find the right childcare for my son as he has medical needs,"* said one parent.

Unsurprisingly, many parents of disabled children want to work - for their own identity as adults, and for social and intellectual opportunities - but also to help with family finances, particularly as raising a disabled child costs up to three times more than bringing up other children.

But the report found that parents with disabled children face many barriers to work including inadequate support services and a 'benefits trap' meaning that work is often not financially viable.

Contact a Family Chief Executive Francine Bates, said *"The findings of this report are depressingly familiar. Many parents desperately want to work, to support themselves and their families - and to do their bit for society; but services just aren't organised to help them."*

Chief amongst the report's recommendations are better access for disabled children to after-school and holiday care and a review of benefits for parent carers.

**"The nursery said they could look after my disabled son but after two hours they called and said they couldn't cope." Parent**

## Take The Challenge

Contact a Family has expanded its range of overseas challenges for 2007. Here's just some of the amazing experiences you could take part in to raise money for disabled children and their families:

**Kilimanjaro** : 21st September - 2nd October

**Everest Base Camp** : 12th - 29th October

**Great Wall of China** : 13th - 21st October

**India Motorcycle Challenge** : 14th - 22nd October

**Vietnam Cycle** : 27th October - 8th November

**Peruvian Inca Trail** : 10th - 19th November

These are just some of the destinations and dates available; others include Borneo, Canada, Lapland, the Grand Canyon, Iceland and South Africa. For more information contact Gemma on **020 7608 8733** or see [www.cafamily.org.uk/adventures.html](http://www.cafamily.org.uk/adventures.html)

Rosey Foster has been appointed as Chair of Contact a Family. Rosey succeeds Mike Lancaster, who has stood down after seven years.

Rosey has worked for over 30 years in the NHS in general practice management, followed by ten years with the Institute of Healthcare Management. Rosey was also previously Chair of Carers UK.

*"I want to pay tribute to Mike Lancaster who has been a passionate and committed advocate for families with disabled children."* said Rosey. *"His contribution as Chair has been vital to the continued success and growth of Contact a Family. I will do my utmost to follow his successful lead."*

**"It is a great privilege to be appointed chair of Contact a Family, an organisation I have long admired from afar."**



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