



# Our Impact 2023/24

**contact**  
*For families with disabled children*

# A message from our Chief Executive

Contact has a hugely important role to play in creating social change for families who need it most.

Sadly, the pressures on families with disabled children have continued to escalate. The ongoing cost of living crisis, increasing pressures on schools and the NHS, as well as a social care workforce crisis has been felt disproportionately by the families that Contact supports.

This has meant we are dealing with increasingly complex enquiries, with families experiencing multiple difficulties at one time.

## Supporting families in times of crisis

Contact has remained steadfast in its resolve to support families during times of crisis and this year, we were proud to continue that solid foundation of providing information, advice and support to families with disabled children, regardless of disability or condition.

And the figures speak for themselves. Across all our services throughout the year, 93% of families felt better informed about how to get the support they needed and 96% would recommend Contact's services to others.

## Reaching more families than ever before

We are reaching more families with disabled children than ever before through our digital services, helplines, and online and in-person programmes. And we are delighted that our fundraising efforts via our lottery and individual giving programmes continues to support families by generating income that we can put back into supporting families. Throughout the year we have not only met increased demand, we have also made strides in our second strategic ambition to build a more sustainable fundraising model.

It's been gratifying to look back over the last year and see the difference Contact has been able to make. I particularly want to thank our staff team, trustees and all of our supporters, volunteers, individual fundraisers and the many Trusts and Foundations who have enabled us to continue and to expand our work.

I've thoroughly enjoyed my first year working with the brilliant staff team and parent carers who make up the Contact family.

**Anna Bird**



# Our year in numbers



**545,947**

visitors spent time on the advice and support section of our website



We helped eligible families increase their household incomes by an average

**£5,918**

a year through our Family Finances helpline.

Our private Facebook group, a safe space and online community network for parent carers, reached

**21,500**  
members



Contact helped

**413,000**

families with disabled children with information, advice and support.



We inspired

**7,032**

parent carers to take campaign action including writing to their MPs, taking part in research and speaking out in the media



**85%**

of families felt more confident after receiving advice and support from us



# Supporting families at times of need

Samantha Tolmie and her son Lewis Jaynes, aged 20, live in Doncaster. Lewis loves giraffes and being out in the fresh air. He has Batten disease, a life-limiting condition. The family were told that Lewis wouldn't live past the age of 10.

## Every day he is here is a miracle

Samantha said: "Lewis was a healthy and completely typical baby and young toddler. The first sign we had of something wrong was a slight limp at age two. After this, the deterioration was extreme and within six months my son could not move or speak or eat. We were told he would not live past the age of 10. Every day he is here is a miracle. He requires round the clock nursing care and is reliant on electrical equipment to keep him alive.

## Making sure Lewis is happy and safe

"Through all this, he smiles, and he laughs, and he enjoys every day. Like most mums, my children are everything and I have given my life over to keeping Lewis happy and safe for as long as he chooses to be here. I am a single parent and Lewis has a terminal disease. It's not possible for me to go out and get a job as I am a carer 24/7. There is nowhere else we can get money from apart from the benefits system.



“Once Lewis turned 20 in February, he was no longer considered a child in the eyes of the benefits system. The Child Tax Credits I receive for Lewis stopped and he had to apply for Universal Credit, which is considerably less. In addition, the system is unbearably complicated for young disabled people in education transferring over to Universal Credit.

“Lewis is clearly unable to ever work and yet we have to go through processes including an interview for fitness to work. It feels cruel for families already under enormous pressure to try to work out how to claim these benefits, and to try and pull together all the information and evidence required.

## A benefits minefield for families

“Without charities like Contact, families would be left alone to navigate the benefits minefield, and it IS a minefield. I was lucky enough to come across Contact’s Facebook page and their extensive website. It was the only place I learned just how drastically the benefits system changes for children transitioning into adulthood, despite their care needs staying the same or increasing.

## Without Contact we would have been destitute

“It was only through telephone conversations with Contact’s Listening Ear service and later their Family Finances helpline that I found out what I needed to do to ensure that our financial losses are kept to a minimum. Had I relied on information from the benefits system itself, Lewis and I would have been left destitute, as all of Lewis’ childhood benefits would have stopped for a minimum of five weeks. As it is we are still going to be worse off, but not by as much as could have happened without Contact’s advice.”

*“I was proud to join Contact’s campaign and speak out in the media calling for an energy social tariff and better support via Universal Credit for disabled youngsters. They give families like ours a platform to get our voices heard so we don’t feel ignored and forgotten.”*



# We support families with trusted guidance, information and emotional support



After finding out their child is disabled families are faced with a maze of routes to support for their child and themselves. At a time of stress and emotional turmoil everything, from getting a diagnosis, receiving equipment and adaptations to the home, as well as finding a suitable place at school, can become a battle.

## Why Contact is needed

The triple whammy of the cost-of-living crisis, fallout from the pandemic and long-term underfunding of public services has made those battles even harder this year.

That's why Contact's support is more important than ever. Contact's advice and information services provide families with information that is specific to them, helping navigate those mazes. At the same time our advice team, many of whom are parent carers themselves, provide much-needed emotional support.



## Helpline and online

Gail Wagstaff has been a Parent Adviser on Contact's helpline for four years. She advises parent carers on a range of issues including financial support and benefits.

Gail said: "Just before Christmas I had a lovely email from a parent I had helped. She had just had confirmation that she would receive backdated extra payments in her Universal Credit of more than £5,000. She said it had made the family's Christmas.

"When a child gets Disability Living Allowance (DLA), and a parent gets Universal Credit (UC), the parent is entitled to an extra payment in their UC. When a child gets the higher rate of the care component of DLA that extra UC is even higher. The law says these extra payments must be backdated to the date Universal Credit started, or to when DLA started or increased.

"However, lots of parents are unaware of this until they come across the information on Contact's website or on our Facebook group for parents. In addition, officials working at the Department for Work and Pensions who administer Universal Credit often wrongly refuse to backdate too.

Our helpline responded to

**9,671**

enquiries.

We had almost

**1.3M**

visitors to our website.



## Encouraging parents to claim what they're entitled to

"We encourage parents to challenge when the DWP refuses to backdate and provide resources to help them do that. We have a template letter we can tailor for each parent's different circumstances, which they can add to their Universal Credit journal. This sets out the law about backdated payments and often does the trick.

"So far, the record backdated payment I've had feedback about from a parent was somewhere around £25,000. This was money the parent should have been receiving in her regular Universal Credit over the last few years. So it's well worth parents challenging and ensuring they get the money they are entitled to."

*"I have used the website and helpline countless times since my daughter was born 16 years ago. Thanks to the advice, we receive the benefits we are entitled to, and we have ensured that her mainstream education is accessible."*

**Parent carer**

Our Family Finance team responded to

**782** benefits enquiries and made

**332** in-depth call-backs

**99%** of families felt better informed about their rights to benefits and grants after speaking to the team

## Family Finances

Families with disabled children are disproportionately affected by financial concerns due to the difficulties of juggling work and caring, combined with the extra costs of disability.

This year our Family Finances team has been working hard to support parent carers through the managed migration process for Universal Credit (UC). More and more families are having to apply for Universal Credit as legacy benefits are phased out. It can be complicated for families, and some will lose out, so the team's advice and support has been more vital than ever.

### Financial health checks

Much of the team's work involves hour-long call-backs, where they carry out a detailed financial health check for families. This year the team also ran Facebook Q&As and webinars to reach more families.

*"Your Family Finances team helped us convince the Universal Credit office to treat my partner as a second carer and not penalise him for not looking for work. Your service is amazing. I can't thank you enough. The UC staff said it was not possible but when we showed them your email they came back to agree he could be exempt from job-seeking. I wish I had called you earlier as I would have saved myself so much stress."*

**Parent carer**

## Listening Ear

We offer hour-long telephone appointments to parents looking for a listening ear, emotional and practical support.

The Parent Advisers in our Listening Ear team are all parents of disabled children and young people and have a huge wealth of professional experience. They support parents struggling emotionally and looking for strategies to help them cope.

Our Listening Ear team supported **516** parents during **719** hour-long telephone appointments throughout the year

**93%** feel better informed about how to get the support they need and **84%** feel less isolated after speaking to a member of our Listening Ear team

*“Shona, in my daughter’s words “has changed and saved her life”. My daughter was suicidal for three years until I got in touch with Contact on Facebook and got through to your Listening Ear team. Shona has given us our family life back. Amazing, simply amazing!”*

**Parent carer**



## Fledglings

Our e-commerce venture and not-for-profit online shop Fledglings has worked hard to increase the number of products available to families whilst also reducing costs. We now deliver straight from the supplier to the customer, which has enabled us to increase the number of products we sell to 11,012. Daily average sales have increased by £760 and overall sales have increased 26% year-on-year. Having a successful business model enables us to secure donations to help provide free products either directly to families or via schools and other community groups. Fledglings is also innovating a lending library service for parents to trial products and equipment at no cost to them.





## ZAYED CENTRE FOR RESEARCH INTO RARE DISEASES IN CHILDREN

The Zayed Centre for Research is named in honour of the extraordinary philanthropic support of Her Highness Sheikhha Fatima bint Mubarak in honour of her late husband, Sheikh Zayed bin Sultan Al Nahyan, Founding Father of the United Arab Emirates.



contact

Whatever your child's additional need or health condition, we're here for you

We can help with:

- Benefits
- Education
- Practical support
- Support groups

[contact.org.uk](https://www.contact.org.uk)  
Contact's free national Helpline  
0808 808 355

*"Thanks for all the support and information you have provided. We have now been offered suitably adapted housing to enable my husband and I to continue to support our daughter. She has complex needs, is peg fed and a wheelchair user. I also didn't know our local council could offer help which I have now requested."*

**Parent carer**

## By Your Side

Since May 2023 when Covid-19 restrictions were lifted, all our teams have been back in hospitals supporting families whose child needs hospital care. This means we are in children's hospitals in London, Newcastle, Birmingham, Liverpool and Glasgow.

During the year we supported 1,731 families in hospital. We also secured increased funding to enable us to expand this much needed and valuable service next year.

Senior Parent Adviser, Ruth Stone, has been supporting families through Contact's By Your Side project for six years. She is a regular face at Great Ormond Street and Evelina Children's Hospitals in London, providing advice, information and support to families whose children need hospital care.

# 99%

**of parents said they feel better informed about how to get the support they need after help by our By Your Side team.**

## A friendly face at hospital

Ruth said: “We are here to support families during a really distressing time in their lives - when their child needs hospital care. Sometimes parents want to offload, other times they need practical help getting financial support or understanding their child’s rights to get a suitable childcare place or support in school. Families whose child is in hospital for extended periods tell me that they look forward to seeing me at the information stand, as they are often spending long periods on their own and like to see a familiar, friendly face.”

## Helping parents to get support

Ruth has supported one family whose five-year-old son has complex medical needs and a life-threatening endocrine disorder, for several years. He was admitted to Great Ormond Street Hospital when he was born and needed to stay in for some weeks. His diagnosis and medical needs meant that mum was not able to return to work, so she needed to ensure she was getting the financial support the family were entitled to. Ruth helped the family apply for Disability Living Allowance and told them about discounts for fuel bills and council tax to ease their situation.

Ruth has since helped the family with information about accessing social care. The family have been allocated a social worker and can now access direct payments and respite care, which has made a huge difference.

## A dream holiday

Ruth also helped the family understand her son’s rights to a nursery place. She referred the family to the Make-A-Wish foundation as part of a partnership with Contact and Make-A-Wish. They offered the family the opportunity of a Disney experience holiday - their first family holiday for five years.







## Workshops

Our parent workshops proved to be more popular than ever before this year. We offer the workshops online and in person providing valuable information and a chance for parents to meet others in a similar situation. It's an area of growth at Contact.

Topics include Educational Support, Understanding your Child's Behaviour, Support for your Child's Anxiety, Speech, language and communication and Managing your child's sleep. We also delivered 37 of our ever-popular Brighter Beginnings workshops targeted to parents of young children, with a total attendance of 686 parent carers.

We held  
**692**  
workshops,  
attended by  
**5,955**  
parent carers and  
**798**  
professionals



## HemiHelp

Contact run HemiHelp, the only condition-specific support group in the UK for families who care for a child with hemiplegia, a lifelong condition.

This year our HemiHelp team has developed a new animation to help explain hemiplegia and has developed a new education section that will launch soon on our HemiHelp hub.

**1,400**  
people visit our  
HemiHelp webpages  
each month.



# Supporting families around the UK

## London

We were delighted to receive three-year funding to support Lewisham families with financial advice from City Bridge Trust. This includes a three year research project to look at the experiences of London families with disabled children from black and minority ethnic backgrounds.

We continue to support Lambeth families with information advice and support, as well as hosting the parent carer forum. We secured new funding to provide a fun day for parents and we started a new one-year project in conjunction with Lambeth Family Hubs to support parents of children aged 0-2.

Our Ealing team continue to deliver a huge volume of in-depth support to some of our most vulnerable families, over 80% of whom are from ethnic minorities and some who are refugees and asylum seekers. We have increased our pool of volunteer translators and now offer support in five languages.

Our Helping Hand project, which supports families on the waiting list for a neurodevelopmental assessment in the boroughs of Ealing, Hounslow and Hammersmith & Fulham continued to provide vital support.



## Scotland

By Your Side Scotland supports families with children at Queen Elizabeth Children's Hospital Glasgow. Our parent adviser Lynn Shields has responded to 554 different enquiry issues of advice since April 2023. Often the enquiries will take many calls and research once the parent adviser has met with the parents at the stand. We work in partnership with the Office for Rare Conditions and Family Fund to ensure we have a holistic approach to our service for families.



## Wales

This was the first year of Contact Cymru's Better Together through Sport project. The project aims to provide sporting opportunities for disabled children and young people in Wales. Due to a lack of access and social stigma, those opportunities are often not there, and we want to turn the tide on that. During the year we provided eight sporting days attended by 105 disabled children and 89 parents who made new friendships and connections. Following the events, 97% of parents said they felt less isolated and 77% felt more confident to do it again. Children's feedback showed that 100% of respondents said they had fun, tried new activities, and made friends.



## Midlands and London

### Autism Peer Educator project

Contact is proud to be a pan-disability charity. But many of the families we support have autistic children and we are delighted to be part of the Autism peer education programme. Throughout the year we worked in London and the Midlands with our partner Ambitious About Autism to build knowledge and understanding of autism. We also worked to empower families and carers to advocate for autistic people they support.

Parents were supported via **5,298** enquiries and one-to-one appointments with our teams in London, the regions, nations, in hospitals and through our Listening Ear service







## Northern Ireland

Our Preparing Parents for Transition programme is in its third and final year. Working with two mainstream schools and two special schools, the team has supported 120 parents with workshops, peer support sessions and opportunity fairs highlighting new opportunities and options for their young people. In this final year we continue to support parents and are also developing new transition resources for parents as a legacy to the project that will support other parents across Northern Ireland in future.

## Yorkshire

We delivered two fun and inclusive sports events in Yorkshire where children were given the opportunity to take part in archery, volleyball, table tennis and basketball.





# We support families by bringing them together

This year we connected many families at our family events, workshops and in our online communities, helping to forge friendships and support networks.

## Reducing isolation

Parents tell us they feel isolated as they don't know anyone else with a disabled child and don't get to meet other parents at toddler groups and the school gates, like other parents do. This isolation can have a negative impact on the health and wellbeing of the whole family. This year our Better Together family fun days and safe online groups have helped to combat these feelings of being alone.



Busy mum Kirsty Shoots from Worcestershire has three daughters with SEND. Zoey is 8 and autistic and 7-year-old Zara is also autistic and a wheelchair user. Her youngest, Taylor-Jade is 5 years old and has suspected ADHD.

Kirsty told us more about her family's experience of attending two of our Better Together family events: "I learned about Contact's Better Together events from a friend who also has a child with additional needs. We are very restricted on the things we can do together as a family for all sorts of reasons so events like this are the perfect opportunity for us to enjoy something together alongside other families who understand and don't judge.

We held

**100**

family events with total attendance of

**1,424**

children and

**1,288**

parent carers



## Everyone was happy to help

"I felt very confident at both Better Together events I attended that my children were safe. All the parents were happy to help each other out and keep an eye on the children who had come along. Zara uses a wheelchair, and her mobility is limited, but she managed to climb to the top level of the Cheeky Monkey soft play venue and nobody minded that she stayed at the top of the slide for quite some time, watching her tablet which helps her feel calmer. And before going to the Better Together cinema event my youngest Taylor-Jade had never been to the cinema so that was a real treat for her. The relaxed cinema screening we attended was perfect for Zara too who was happy to watch bits of the movie and ignore other parts. If that was what she wanted to do no-one minded so I felt relaxed too!

## Online communities

We continue to run private Facebook groups for parent carers, which offer a safe space for families to network, share ideas and information. This in turn creates a sense of community and helps to reduce isolation. We moderate our online groups, which allows us to give additional support and advice where needed.

This year the Contact Facebook group grew to more than

**21,000**  
members

Our HemiHelp group has almost

**6,200**  
members

*"I'm a member of the Contact Facebook group and find the online discussions and advice really useful. It makes me feel that I'm not alone as a carer and as a volunteer for a local online group for carers I often find myself signposting Contact as a place online where information and support is trusted, helpful and understanding."*



## Rare conditions groups

Contact continued to build support for families whose children have rare conditions throughout the year. Thanks to funding from the Pears Foundation, we provided grants to parent-led rare conditions groups helping to build knowledge, skills and a network of support. In the first year, it is estimated that the grants given out impacted 41,900 people affected by rare conditions.

In addition to the grant giving, we also provided workshops, in-person events and monthly newsletters to rare condition groups. We hosted an online conference and are developing a resource toolkit to help groups build their skills and resilience to support families.

*"Thank you so much, it has all been so great - inspiring and informative."*

**Parent carer**



# We campaign side by side with families

This year we were proud to support two wonderful parent-led campaigns. This ensured we put the voices of families with seriously ill and disabled children at the forefront of our campaign work.

Despite the challenges of political uncertainty and continued austerity our policy and campaign work helped secure significant changes this year.

During the year we inspired **7,032** family carers to take action for others, including writing to their MPs, meeting government ministers and speaking out in the media

We secured more than **100** mentions in the press with an equivalent advertising value of **£1.8M** raising awareness of the issues affecting families with disabled children



## Child Trust Funds

80,000 disabled young people are at risk of being locked out of their savings. Parent Andrew Turner began a campaign after realising that his son could not access the money set aside for him in his Child Trust Fund due to his lack of mental capacity to manage his own finances.

### How we helped

Contact has been supporting and amplifying Andrew's campaign, ensuring parents in similar situations know what their options are and campaigning for a fairer process.

We were part of a new alliance to campaign on the issue alongside a legal firm and representatives from the finance industry led by Andrew.

Together we galvanised campaign supporters to take action, secured media coverage from the BBC and financial campaigner Martin Lewis to raise awareness, and securing a Westminster Hall Debate on the issue.





## Free School Meals

160,000 eligible disabled children have been missing out on their free school meal due to their disability or sensory needs.

Parent Natalie Hay recognised the discrimination that was taking place and began campaigning on the issue during lockdown. At the start of 2023 Contact joined the campaign and helped to amplify it through our networks.

### How we helped

During the year we secured media coverage on the issue and a Westminster Hall debate. Natalie Hay crowdfunded to take legal action against the government. It culminated in the government conceding that discrimination could be taking place and agreeing to update its free school meals guidance. The guidance now includes new sections making clear that most disabled children should be offered an alternative such as a supermarket voucher if they can't access a free school meal in the regular way. This will benefit many low-income families who have been missing out on the equivalent of £570 of financial help.

Contact continues to highlight the issue to our parent carer audiences, providing clear advice on how to claim their child's food vouchers and template letters. We have also provided webinars for schools.

*"I feel less isolated and alone 'in society' and positive that there is an intelligent national body supporting parents and fighting for disabled children's rights that is being respected and heard by every government and across the country -its integrity shines out!"*

**Parent carer**



## Poverty

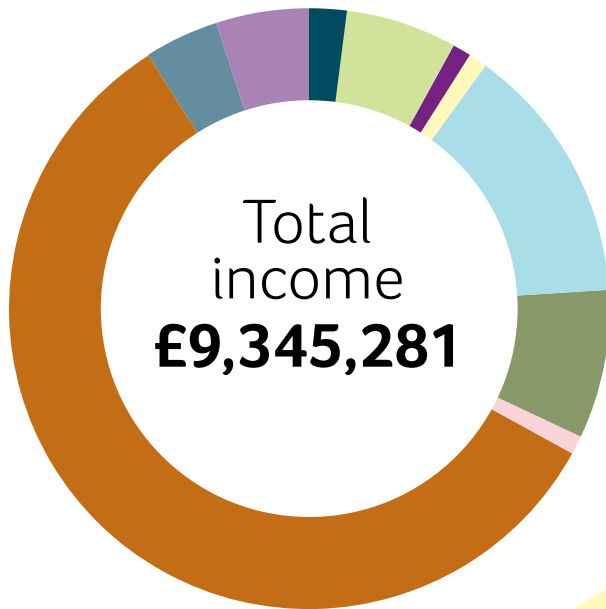
Ahead of the March budget we shone a spotlight on the continuing struggles some families are experiencing to pay their energy bills. Families of children with complex needs who require electrical equipment for their care, continue to experience sky high bills.

### How we helped

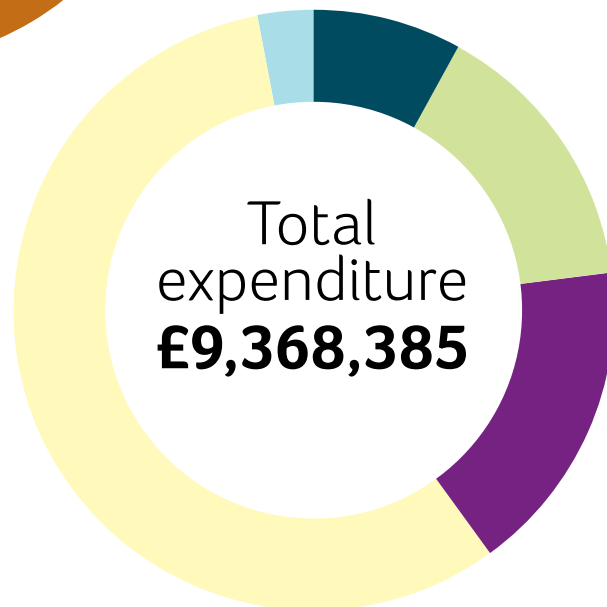
We worked with another extraordinary family – Samantha and her son Lewis – who wrote to the Chancellor of the Exchequer asking for a social tariff to help families like theirs. Samantha's letter received the support of 3,000 other families. Samantha and Lewis' story was featured in a powerful film shown on the BBC. We are determined to continue to press the government to take action on energy bills for families running hospital equipment in their home.

During the year we also highlighted the injustices of the Universal Credit system which is less generous for many families with disabled children.

# Our finances



- National Lottery Community Fund £142,427 (2%)
- Charitable trusts £602,138 (6%)
- Special events/other £62,747 (1%)
- Investment income £129,359 (1%)
- Individuals £1,412,151 (15%)
- Local government grants £790,350 (8%)
- Devolved nations government grants £90,882 (1%)
- UK government grants £5,659,987 (61%)
- Traded income £349,399 (4%)
- Property income £455,240 (5%)



- Raising Funds £713,737 (8%)
- Supporting families – central information, advice and support £1,427,539 (15%)
- Supporting families locally £1,611,766 (17%)
- Bringing families together £5,373,301 (57%)
- Helping families take action for others £242,042 (3%)

# Our awesome fundraisers

Our marathon marvels ran  
**420 miles**  
raising over  
**£43,000**



A dinosaur-sized thank  
you to all the families who  
took part in our DinoDay  
Stomp & Roar Challenge,  
raising over

**£15,000!**



Ever-popular broadcaster Jane Garvey interviewed award-winning BBC journalist Nikki Fox in an event to support Contact at the Reform Club in Pall Mall in November 2023. The entertaining evening celebrated the important work Contact does to support families with disabled children and helped engage supporters.



Huge thanks to Pamela who ran the Great North Run - her first half marathon - in the scorching sunshine, raising funds to support more families like hers.



# Our incredible funders

Grants and donations from the Department for Education, National Lottery Community Fund, NHS England, local authorities, companies, trusts and foundations and philanthropists enabled Contact to deliver our life-changing services. We are incredibly grateful to our funders and major donors for their generosity during another challenging year for families, which ensured we could continue to provide our vital support.

**A huge thank you to all the Trusts, Foundations, National Lottery Community Fund, Corporations and Major Donors who funded us this year**

Albert Gubay  
Foundation



Roald Dahl Marvellous  
Children's Charity



Basil Samuel  
Trust

London Community  
Foundation



The Eveson  
Trust



The Freemasons' Charity



Peacock Charitable  
Trust

True Colours  
Trust



The Golden  
Bottle Trust



William Leech  
Charity



Pilkington Charities  
Fund

# Get in contact

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Access to interpreters  
helpline@contact.org.uk  
contact.org.uk

Open 9.30am–5pm Monday to Friday

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We are Contact, the charity for families with disabled children.

We support families with the best possible guidance and information.

We bring families together to support each other.

We help families to campaign, volunteer and fundraise to improve life for themselves and others.