



Understanding Chromosome & Gene Disorders

Grants and Funding



rarechromo.org

Grants and Funding guide

Children with rare chromosome and gene disorders often have additional needs and require specialist items of equipment or services, to help them live more fulfilling lives and to make life that little bit easier for those caring for them. The specialist nature of these items means that they can sometimes be very expensive and outside of the budgets of many families caring for a disabled child. Costs are often not borne by one of the statutory services meaning that families have little choice but to raise the funds themselves to pay for the equipment they need.

Parents of Unique children often approach the team at Unique to ask for information and guidance on how they might raise the funds they need. Having talked to lots of different parents and carers about what they need, we have decided to write this guide to show the types of funding that are available and to signpost carers to potential sources of grants and other funding. It is intended as a resource to help locate possible funders, something which can be very time-consuming and hard work, particularly when you are caring for a child with disabilities and their siblings. We have included the details of some of the grant providers/funders in the UK, who offer assistance to families caring for disabled children. You will need to read the guidelines for each organisation carefully before making an application, as they will often have different eligibility criteria (some, for example will

undertake means testing). Often funders are registered charities and receive lots of different applications, so they may well have quite long waiting lists. You could wait some time for a decision about funding of an item, so if it is urgent.... speak to them!



Help can be for everyday items

This guide is a dynamic resource and the details included are correct at the time of publication. However, if you should find any new sources of funding that we haven't included, please contact Unique to tell us about them. We are always pleased to receive new information that we can pass on to carers of children with rare chromosome or gene disorders.



Therapies take many different forms

Where to Begin

It's time to do some research!

Once you have identified a need for a piece of specialist equipment or a service that you believe will help your child, you will need to compile a list of potential funders. Be careful to only include those organisations you are eligible to apply to, as otherwise you'll just be wasting your time and theirs on an application that probably won't be successful. Remember that many funders are oversubscribed – they receive more requests for help than they can fulfil – so you need to make sure you only apply to those organisations likely to support you.

This guide is a starting point and includes details of various funders you might want to consider applying to but it isn't an exhaustive list. If you have internet access, begin with a thorough search, using terms like 'grants for disabled children' and you will be able to find a variety of different funding organisations. You can also contact your local council, Citizen's Advice Bureau and charities like Carers UK, Contact and Unique. It's amazing the amount of information you can access through simple searches on Google, Bing and other search engines. Other parents and carers are always a good source of information too, so consider joining one of our Unique Facebook groups to connect with others and ask about grants that they may have received. We often find they are a mine of information.... you just have to ask!

It's also worth visiting your local library reference section. Here you might find a good source of information in a book called **'A Guide to Grants for Individuals in Need'** (2022/23 edition) by Jessica Threlfall from the Directory of Social Change (ISBN: 9781784820824). It contains addresses of UK National and local charities that are able to fund different items, such as buggies, electric wheelchairs, tricycles, computers as well as day-to-day items of equipment. Usually you won't be able to take the book away from the library, but if you take a pen and notepad, you can ask the library where to find the book and sit and write down useful addresses that you can contact for help.

You can get a brief overview of what it contains by visiting their website: <https://www.dsc.org.uk/publication/grants-individuals-need-2022-23/>

■ Disability grants

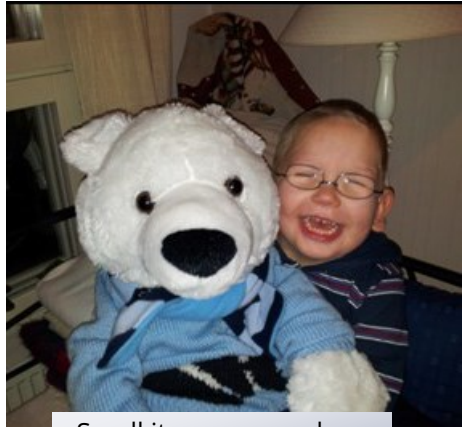
website: <https://www.disability-grants.org/>



Writing about your child's rare chromosome disorder

When you have found a potential source of funding for a specialist item (referred to here as a 'funder'), you will usually need to fill out an application form, usually online. This will involve writing in detail about your child's rare chromosome or gene disorder and the different ways it affects their daily life and yours. Remember, lots of people won't ever have heard about rare chromosome or gene disorders and it is possible that your child's diagnosis will be a series of letters and numbers. This is why you need to explain carefully the different ways in which it affects your child and you as their carer. Just writing 'chromosome disorder', 'deletion' or 'duplication' for example probably won't mean very much to someone who is reading your application form, with little or no medical or genetics knowledge.

Completing an application form like this can sometimes be quite difficult because it can mean writing about all the things your child can't do, when your instinct as a parent/carer is to celebrate what they can do! Keep in mind though that you need to try to paint a picture of your child's life so that the funder can really understand how difficult it can sometimes be to do things most people take for granted. Explain how the equipment you are requesting will help them or you, how their funding would make a real difference to your lives. What will you or they be able to do that can't be done now? They will have many applications to read so it is important to include lots of details to help them visualise and understand the challenges your child (and you as their carer) face. It is advisable to gather as much information as you can about your child's medical, behavioural and other relevant issues. Check the Unique website to see if we have an information guide to your child's condition and go through your past medical reports, school reports and your child's Education and Health Care Plan (EHP) if they have one. Some funders will ask for



Small items can make a big difference!

additional information such as this, so it's good to have it to hand before you start. If you don't have it, talk to your child's school, your GP and/or Community Paediatrician and see if anyone is able to write a supporting statement that can help to add weight to your application. Always read each funder's guidelines through as they sometimes stipulate exactly what they do and don't want to receive from you.

In this guide we have responded to feedback from our members who tell us that specialist equipment is often very expensive (beyond their means) and that searching for information about potential sources of funding takes lots of time - time that is very precious when you are caring for a disabled person. It is always worth remembering that although your request for funding might be unsuccessful at first, all these organisations exist to give away money. That's their reason for being - they want to help disabled children, adults and their carers to live more fulfilling lives.

Sources of Funding

Statutory Funding

Before looking for a charity or other funding organisation to possibly fund the item your child needs, it is worth double checking to make sure there are no statutory (government) sources available. Talk to your social worker if you have one, or contact your local Social Services/Disabled Children's Team or local council. The Citizen's Advice Bureau may also be able to help.

Sources of funding include **Disabled Facilities Grants** which could pay to make changes to your home, such as the bathroom, widening of doors and adapted lighting or heating controls. These are means tested for disabled adults, but not families with a disabled child.

A Disabled Facilities Grant won't affect any benefits you get.

How much you get depends on your:

- Household income
- Household savings over £6,000

Country

Grant

- | | |
|--------------------|----------------------------------------------|
| ■ England | Up to £30,000 |
| ■ Wales | Up to £36,000 |
| ■ Northern Ireland | Up to £25,000 |
| ■ Scotland | Disabled Facilities Grants are not available |

find out about support for equipment and adaptations at website:

<https://www.gov.scot/policies/independent-living/housing-adaptations/>

Depending on your income, you may need to pay towards the cost of the work to the property. Disabled children under 18 can get a grant without their parents' income being taken into account.

Contact your local council for more information. You might not get a grant if you start work on your property before the council approves your application.

For further details visit

Website: <https://www.gov.uk/disabled-facilities-grants>

■ Sullivans Heroes

Website: <https://www.sullivansheroes.org/>

Contact: [via the website](#)

They offer financial grants towards home adaptations for your disabled child.

Charities & Other Funding Organisations

Here are some of the many different organisations offering grants to carers of disabled children. Again, it's important to realise that this is not a list of all funders, it is just intended to help you to make a start. Read their criteria carefully, talk to them (if they welcome calls) and only apply to those who you know you are eligible for. The organisations listed are in alphabetical non-specific order. Inclusion in this guide does not mean we are endorsing them.



■ Able Kidz Disabled Children's Educational Trust

Website: <https://ablekidz.org/>

Telephone: 0300 365 4102

Email: info@ablekidz.org

Able Kidz aims to make a variety of learning aids accessible to children with disabilities all over the UK, both on an individual basis and for use in schools and playgroups etc.

■ Action for Kids

Website: <https://www.afkcharity.org/>

Telephone: 020 8347 8111

Text to: 07949 245 131

Email: info@afkcharity.org

Action for Kids welcome applications from or on behalf of children and young people up to their 25th birthday, who need specialist mobility equipment or a wheelchair to help them become more independent. The child or young person must be resident in the UK. They can also fund other mobility equipment for specific purposes including specialist trikes, scooters, buggies, walkers and car seats. This

list is not exhaustive and if you are unsure please telephone. They will only provide aids that are not normally available through the NHS. Wherever possible they ask Wheelchair Services to provide vouchers or part funding towards chairs.

“ I was so grateful to get funding for my sons Tricycle. It was an expensive item; one that we as a family could never have afforded. It is sad that you just can't go and buy an item like this in a shop, it makes you feel excluded from what other parents can do for their typically functioning children. ”

■ **Caudwell Children**

Website: <https://www.caudwellchildren.com/>

Telephone applications: 0345 300 1348

email: applications@caudwellchildren.com

Their seven core services include provision of equipment such as wheelchairs, specialist car seats and sensory equipment, various treatments, therapies and in-home practical and emotional support. Applicants are means tested so you will need to read their guidelines carefully to check eligibility.

■ **Cerebra**

Website: <https://cerebra.org.uk/>

Telephone: 01267 244200

Email: grants@cerebra.org.uk

Cerebra help to fund Equipment for children with Special Needs. The Cerebra Bulletin also provides support and information for parents and carers.

■ **Children's Hope Foundation**

Website: <https://www.childrenshopefoundation.org.uk/>

Telephone: 0207 700 6855

Email: info@childrenshopefoundation.org.uk

Accept applications for almost anything that will benefit a child although there are, some requests that they are unable to fund, e.g. structural alterations and/or repairs, motor vehicles, household white goods and items which have already been supplied. Application forms can be downloaded from their website.

■ **Children Today Charitable Trust**

Website: <https://www.childrentoday.org.uk/>

Telephone: 01244 335 622

Email: info@childrentoday.org.uk

Children Today helps disabled children and young people up to the age of 25 enjoy a better quality of life by providing them with the specialised equipment they need.

■ **Elifar Foundation**

Website: <https://www.elifarfoundation.org.uk/>

Email: enquiries@elifarfoundation.org.uk

The Elifar Foundation aims to help improve the care, facilities and equipment available to disabled children and young adults, whether living at home or in residential care. They will also consider applications from children and adults with any form of physical or learning disability. They fund the purchase not only of specialised equipment, but also therapies, adaptations and much more besides, in fact almost anything which will greatly improve the quality of life of the severely disabled and more often than not, their carers as well.

■ Family Fund

Website: <https://www.familyfund.org.uk/>

Telephone: 01904 550055

The Family Fund helps low income families raising disabled and seriously ill children (up to age 17) by providing grants for essential items to help parents and carers with their day-to-day lives. Children and young people must have a severe disability with additional complex needs, or have a serious or life-threatening illness. Grants provided might be for furniture, clothing, bedding, kitchen appliances, sensory toys, computers or tablets, a family break, etc. (This information applies to families living in England).

■ The Marian Elizabeth Trust

Website:

<https://www.familyfund.org.uk/grants/schemes/marian-elizabeth-trust/> is working with Family Fund to provide further grant funding for families caring for children and young adults with multiple complex significant learning and physical support needs living in Liverpool, Wirral, and the Midlands up to the age of 21.

“ I applied to Family Fund for a grant for A's tricycle, a lovely gentleman came to interview us and asked why we wanted the fund, I explained A. couldn't ride a standard pedal cycle due to his mobility/balance problems. We wanted A. to have the freedom to be able to ride a tricycle after seeing them at a recent ability day provided by the local council, the local inclusive sports guy had arranged for a company who provide cycles for children and adults with disabilities to participate, when I contact them they were quoting in excess of £600, so this is why I initially contacted Family Fund. After the interview Family fund awarded us £350 so I did a little digging and found Jorvik cycle's in York who quoted us £350 so we wouldn't need to put anything towards it. Family Fund also sent A's brother, as a gesture, a voucher of £50 towards something he may like (they called it siblings matter too), how amazing was that? ”

“ I am so grateful that we were able to get funding from the Family Fund. It allowed us to have our first family holiday following diagnosis, and we also got help with funding for bedding and a washing machine and tumble dryer, they were a Godsend to us in those early days of diagnosis.”

■ Family Action

Website: www.family-action.org.uk/what-we-do/grants/

Telephone: 020 725 46251

Email: info@family-action.org.uk

Family Action's grant programmes help families find solutions to problems.

■ Hospital Saturday Fund Charitable Trust

Website: <https://hospitalsaturdayfund.org/apply-for-a-grant/>

Applications must be made online. One-off grants are made towards medical equipment and appliances, dietary needs, disability aids and furniture, help in the home and hospital travel. Grants are not made to anyone without a medical connection. Eligibility criteria: individuals who live in the UK, Channel Islands, Isle of Man and the republic of Ireland who are ill, disabled or receiving medical care. The maximum amount that can be applied for is £2,000.

■ Lifeline 4 Kids

Website: <http://www.lifeline4kids.org/>

They only consider applications for equipment. The age group of children they support is from birth to 18 years old.

■ Newlife Foundation for Disabled Children

Website: <https://newlifecharity.co.uk/>

Telephone: 0800 902 0095

Email: nurse@newlifecharity.co.uk

Newlife provides funding for essential community equipment, such as beds, buggies, wheelchairs, seating systems, and much more. An application form can be downloaded from their website.



■ **React**

Website: <https://reactcharity.org/applications>

Telephone: 020 8940 2575

Email: react@reactcharity.org

React stands for **R**apid **E**ffective **A**ssistance for **C**hildren with potentially **T**erminal illness. The organisation provides funding in situations where none is available elsewhere. An application form can be downloaded from their website.

■ **Roald Dahl's Marvellous Children's Charity**

Website: <https://www.roalddahlcharity.org/>

Telephone: 01494 890465

Email: enquiries@roalddahlcharity.org

Roald Dahl's Marvellous Children's Charity helps to make life better for seriously ill children in the UK. Grants of up to £500 are available. They are only able to accept applications completed via a healthcare professional, social services, health visitors, or grant co-ordinators within a charitable organisation. Ideally, this should be someone who knows your family and your history and would be happy to complete an application on your behalf (the Applicant Officer).

■ **Smile for Life**

Website:

<https://www.smileforlife.org.uk/>

Telephone: 0191 284 4166

Email: info@smileforlife.org.uk

Dedicated to enhancing the lives of disadvantaged children, their mission is to assist children who are unable to get all the funding they require from the larger national charities and other organisations.



■ **Strongbones Children's Charitable Trust**

Website: <http://strongbones.org.uk>

Telephone: 01708 750599

Email: Trustees@strongbones.org.uk

A national registered charity set up to help families who have children suffering from brittle bone disease, bone cancer, scoliosis, arthritis, and all other serious conditions of the bone. To be eligible the child must be under 21 years of age, and suffer from one of these ailments. Applications are means tested.

Improved quality of life:
Grants are often for items
that increase mobility/
independence.

■ **The Daisy Garland**

Website: <https://www.thedaisygarland.org.uk/>

Telephone: 01803 847999

Can supply epilepsy monitors for children with drug-resistant epilepsy.

■ **The Tree of Hope Children's Charity**

Website: <https://www.treeofhope.org.uk/>

Telephone: 01892 535525

Email: info@treeofhope.org.uk

Tree of Hope children's charity helps children and young people with a disability or illness by supporting their families to raise the funds that they need to pay for specialist care that is not freely available through the UK healthcare system via secure crowdfunding.

■ **Variety**

Website: <https://www.variety.org.uk/>

Telephone: 020 74288100

The Variety club provide mobility and specialist equipment grants to children in the UK who have to cope with sickness, disability or disadvantage.

■ **Wellchild Charity Helping Hands project**

Website: <https://www.wellchild.org.uk/>

Telephone: 01242 530007

Email: info@wellchild.org.uk

WellChild Helping Hands is a home improvement programme which, with volunteers from local companies, transforms gardens and bedrooms for children and young people with exceptional health needs across the UK. Applications via an online form.

■ **Whizz-Kidz**

Website: www.whizz-kidz.org.uk

Telephone: 0800 151 3350

Email: kidzservices@whizz-kidz.org.uk

Whizz-Kidz provide essential mobility equipment to give young disabled people the independence to enjoy a more active childhood. Whizz-Kidz provides powered wheelchairs, manual wheelchairs, sports wheelchairs, trikes and buggies to give young people with a disability independence. Applications must be submitted before the child's 18th birthday. You can download the application form from their website, or can apply via a paper copy.



Grants can be for garden play Equipment.

Wish Granters

The next group of potential funders are charities who exist to 'grant the wishes' of children (and often adults) who are terminally or seriously ill, disabled or life-limited. These can often be for things like holidays of a lifetime (for example to Disneyland, Florida) or meeting a pop star which ordinarily would be beyond the wildest dreams of the children. These charities also often have strict eligibility criteria, which you will need to read before considering whether to make an application. Once again, this is not intended to be an exhaustive list, just a starting point to give you some ideas for where to look for funding of this type.

■ Children's Wish Foundation International

Website: <https://childrenswish.org/>

UK Office 0186 548 7373

USA office: 770-393-9474

Email: info@childrenswish.org

The Children's Wish Foundation is an International organisation and registered charity dedicated to fulfilling wishes for children under the age of 18, suffering from a life threatening or terminal illness.



■ Dreams Come True

Website:

<https://www.dreamscometrue.uk.com/>

Telephone: 01428 762330

Email: info@dreamscometrue.uk.com

They only accept referrals from professionals known to the child, including medical, healthcare, educational, or social care professionals. You can apply online or download an application form from their website.

Please note: Due to the continuing demand for long haul holidays, including Florida, the waiting time to start work on holiday dreams outside of Europe is currently over a year. It would be a minimum of 6 months after that before you could travel at the earliest, so please bear that in mind if requesting this type of dream.



■ Dream Flight

Website: <https://www.dreamflight.org/>
Telephone: 01494 722733
Email: office@dreamflight.org



Each year the charity sends many seriously ill children on their 'Holiday of a Lifetime' to Orlando, Florida. The children go without their parents, but are accompanied by a team of medical carers.

■ Dream Makers

Website: <https://dreammakerschildrenscharity.com/>
Telephone: 01564 778121
Email: dreammakers21@outlook.com

Dream Makers Children's Charity grants the wishes and dreams of ill and disabled children. The wishes could be a holiday at Disney World, Lapland, or swimming with the dolphins. They also provide funding for therapy, wheelchairs and other equipment including special outdoor play areas in the child's home. For children who are too ill to travel long distances the charity have several eight berth mobile holiday homes in Torbay, Devon.

■ Make a Wish foundation UK

Website: <https://www.make-a-wish.org.uk/>
Telephone: 01276 40 50 70
Email: referrals@makeawish.org.uk

Make a Wish accept wish referrals from parents or guardians, medical professionals – or even the children themselves. Application forms can be downloaded from their website.

■ Rays of Sunshine

Website: <https://raysofsunshine.org.uk/>
Telephone: 0208 782 1171
Email: info@raysofsunshine.org.uk

Rays of Sunshine is a national charity that brightens the lives of seriously ill young people and their families by granting wishes and providing ongoing support in hospital and within the community. The charity grants wishes to children aged 3-18 years living with serious or life-threatening conditions. There is a medical criteria divided into four categories. Different types of wishes such as special holidays to Lapland or Disneyland, a UK holiday or a special day out are offered for each medical category.



■ Round Table Children's Wish

Website: <https://www.rtcw.org/>

Telephone: 01202 514515

Email: info@rtcw.org

Grants wishes for children and young people aged 4 to 17 years who are suffering from life-threatening illnesses. The child must not have received a wish from another wish granting charity or organisation before. Past wishes have included a trip to Disneyland Paris, an iPad, a garden playhouse, a trip to the theatre and swimming with dolphins. It is the child's wish and the child's choice - not what someone else has chosen.

Applications can be made online.

■ Starlight Foundation

Website: <https://www.starlight.org.uk/>

Telephone: 020 7262 2881

Email: talktous@starlight.org.uk

Starlight supports seriously and terminally ill children aged 4-18 years, across the UK by granting wishes-of-a-lifetime and by providing a variety of entertainment and distraction in and out of hospitals and hospices.

Applications can be made online.

■ The Dream Factory

Website: <https://www.yourdreamfactory.org/>

Telephone: 020 8501 1234

Email: info@yourdreamfactory.org

The Dream Factory has been set up to brighten the lives and encourage hope for children and young adults aged 3-25 years, who have either life limiting or life-threatening conditions, or who suffer from severe disabilities. They do this by making their wishes come true!

■ When You Wish Upon A Star

Website: [https://](https://www.whenyouwishuponastar.org.uk/)

www.whenyouwishuponastar.org.uk/

Telephone: 0115 9791 720

Email: head.office@whenyouwish.org.uk

When You Wish Upon A Star aim to grant the wishes of children between 2-16 living with a terminal illness who have not previously had a wish granted by another charity.



Grants for Adults

Many of the organisations we have listed in this guide focus on funding items for children and in some cases young adults, but there are others who work with adults in need, not as many, but there are some. You might also consider approaching your local Rotary, Lions Club or Round Table, as they support people locally (telephone numbers should be in your local telephone directory or online), or contact your local library for information. To search for grants for adults (or children) in your local area, please visit:

■ **Turn2US** Website: www.turn2us.org.uk/Find-Benefits-Grants

■ **Florence Nightingale Aid in Sickness Trust**

Website:

<https://home.fnaist.org.uk/how-we-can-help/>

Telephone: 020 7998 8817

Email: lisa.hungerford@fnaist.org.uk

They consider all requests for funding for people of all ages who are sick, in poor health or disabled and require medical items and services to improve their quality of life.

■ **R.L. Glasspool Charitable Trust**

Website: <https://www.glasspool.org.uk/>

Telephone: 0208 5204354

Email: grants@glasspool.org.uk

They provide timely, small, one-off grants to individuals and families in need of financial support for everyday items to help them set up or remain in their home; improve their well-being and in some cases providing grants to support training to enable applicants to take up an offer of employment. GrantsPlus is their online application system. To use the system you will need to register at this website: www.grantsplus.org.uk



■ **Skidders Company Charities**

Website: <https://www.skidders.org.uk/charities/>

Telephone: 020 7236 5629

These charities consist of a number of small trusts, each of which has different eligibility criteria. Applicants should be in receipt of a state pension or, be an adult with a disability and receiving relevant benefits.

■ **The Willow Foundation**

Website: <https://www.willowfoundation.org.uk/>

Telephone: 01707 259 777

Email info@willowfoundation.org.uk

A charity providing special days for 16 to 40 year olds. Special days aim to provide young adults living with life-threatening conditions a chance to escape the pressures of their daily routine and share quality time with family and/or friends.

Inform Network Support



Understanding Chromosome & Gene Disorders

Rare Chromosome Disorder Support Group
The Stables, Station Road West, Oxted, Surrey RH8 9EE, United Kingdom
Tel: +44(0)1883 723356
info@rarechromo.org | www.rarechromo.org

Join Unique for family links, information and support. Unique is a charity without government funding, existing entirely on donations and grants. If you can, please make a donation via our website at www.rarechromo.org Please help us to help you!

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