WOLF HIRSCHHORN SYNDROME TRUST

Spring 2018 Newsletter

A Happy Easter to you all!

I trust that you all had a good festive season and New Year.

Please remember that April 16th is Wolf Hirschhorn Awareness Day. Take this as an opportunity to either raise awareness or funds for WHS and the Trust. Engage others who may be able to help us in any way however small.

This year we have signed up for the Jeans for Genes day. This is an exciting and new way for us to raise funds for genetic disorders but also WHST will get 50% of funds raised if we are a nominated charity. More details on this will be published in the next newsletter but also look on our website.

The committee is now working hard on the next national meeting in 2019. If you have any requests for speakers and subject matters please let us know as soon as possible as people do get booked up far in advance. These conferences are for your benefit so please help us to help you enjoy them. Please put a note in your diary though for the first May Bank Holiday in 2019.

The committee will hopefully be working with Napier University in the very near future on the design and implementation of a new website. This will be an improvement on our current website and more secure for our member s to use and communicate through with message boards etc. Please take the time to look at our current website and let me know how you think it could be improved. The passports are still in progress and will be an invaluable document for all when needed by our offspring. We are also looking to publish a Consensus document which will go into a lot more detail about WHS that can be used not only by our members but also health professions. More on these topics to follow in due course.

Spring 2018 Newsletter

I know that some of you have recently been asking (via Facebook) about travel insurance for our young adults. I have been given the details of an insurance company called 'Insurance With' and the information that they can provide. I have added the details to the links page on our website www.4pminus.co.uk under the heading of insurance for those with disabilities. Also is a link to Newlife Charity. This company provides grants and equipment for young people.

In this issue we have some family stories that they wish to share with us all. If you would like to share any of your family experiences with us just drop me a line and I will gladly put it in the next newsletter. We are looking to find some more regional people to replace those that have left or retired. The post is not too onerous and shouldn't take up too much of your time. See the back of this newsletter for the regions were we have vacancies.

I went to a Genetic Symposium at the beginning of the month. A lot of inspiration people were there and the presentations were exceptional. There are some developments about to happen which could have an impact on our young ones future. Watch this space.

Whilst at the Symposium I was awarded a Life Time Achievement Award for working with a Genetic Charity for a significant amount of time. That was a total shock.

One of the talks at the Symposium was about Gideon's Charter. Whilst this has been written for a young person with Prader Willi syndrome it does impact on the whole of our community. Please take the time to read this as I will be raising this at our next committee meeting to seek our backing of the worthwhile cause.

Stephen

I spoke with IMAGINE-ID at the Symposium and they again asked for our help. Below is the email I received from them:

Dear Stephen,

Thanks for speaking to us at the Genetic Disorders UK Symposium on Saturday - we discussed how you might be able to approach members with information about our project, IMAGINE-ID.

IMAGINE-ID is a research project funded by the Medical Research Council. We are studying the long term behaviour and mental health of children and young adults with intellectual disability where there is a genetic cause.

To be eligible for our study, children need to be aged 4 or over, have intellectual disability/learning difficulties/developmental delay and have a genetic diagnosis, which is thought to be the underlying cause of the learning difficulties.

This study involves parents/guardians filling in an online questionnaire (DAWBA)
about their child. Once completed the assessment we will send them a DAWBA Report. The report will summarise their child's strengths and difficulties and they may find it helpful with healthcare professionals and their child's school.

For further information, please visit our website: http://imagine-id.org/

Thank you again for your interest and help in promoting our research study.

What is IMAGINE ID?

IMAGINE ID is a research study that aims to increase understanding of children and young people with intellectual disability. It is supported by UNIQUE, the rare chromosome disorder charity. The IMAGINE ID team is very keen to learn more about the link between behaviour and rare chromosome conditions. The study, led by the University of Cambridge, University College London and Cardiff University, hopes to collect information from over 5,000 families by 2019.

To participate in IMAGINE ID your child should be aged 4 or over. The research group is based in the UK but they are interested in families worldwide. If you live outside the UK, to take part you must have access to your child's genetics reports. Taking part involves filling out secure online questionnaires about your child's development and behaviour from the comfort of your own home. If you're not comfortable with computers or do not have access to the internet, the IMAGINE ID team can go through the questionnaire with you over the telephone or in person. The questionnaires will take approximately 3 hours, but you are able to save your answers as you go and can log in an unlimited number of times to complete it.

After completing this you will receive a personalised summary report which you may find useful when your child is undergoing assessment for services, school or specialist treatment. If you wish, members of the IMAGINE ID team may also visit you at home to conduct an interview with you and puzzles with your child.

If you are interested and want to find out more about the IMAGINE ID study please contact them by telephone on +44 (0)1223 254 631 or email them at imagineID@nhs.net The team are very happy to answer any questions you have.

Gideon's Charter

What is Gideon's Charter?

Gideon's Charter is a statement of the support, respect and care that children and young people living with a Genetic Disorder such as Prader-Willi syndrome should expect, and deserve within all educational settings. We believe that everyone working with those with Genetic Disorders should respect their rights, and work towards a vision of the right support, in the right place, at the right time. Gideon has Prader-Willi syndrome (PWS), a rare, complex genetic disorder that affects both males and females from birth and throughout their lives.

PWS causes:

- Low muscle tone and strength; fine and gross motor developmental delay and disorder
- A mild to moderate learning difficulty
- Emotional and social immaturity, leading to temper tantrums and challenging behaviour
- Incomplete sexual development
- An overwhelming and insatiable chronic appetite usually develops during childhood which, without rigorous food management and exercise regimes, leads to food seeking, stealing and life threatening obesity

It is estimated that one in 25 children is affected by a genetic disorder and 30,000 babies and children are newly diagnosed in the UK each year.

Every child or young person with a diagnosis of a Genetic Disorder has the right to the support that they or their parents need 'in order to facilitate the development of the child or young person and to help him or her achieve the best possible educational and other outcomes'. (from the Children and Families Act 2014, Chapter 6, Part 3, section 19)

For those with Prader-Willi syndrome this means:

- The complex nature of Prader-Willi syndrome means that all children or young people with a diagnosis of PWS should be assessed for an Education Health and Care Plan
- Those supporting children or young people within an educational setting will need an understanding of the complex characteristics of PWS and the strategies required to support them appropriately
- The relentless and overwhelming appetite that develops in children or young people with PWS means they will need additional support at all occasions where food is available, or accessible
- The immature social and emotional development in children and young people with PWS means that even without a diagnosed Learning Difficulty they will need additional support. The degree of Learning Difficulty within PWS does not necessarily relate to the severity of challenging behaviour

Every child or young person with a Genetic Disorder has the right to access their education within a physical environment that makes provisions for the requirements of a child or young person with PWS, to enable them to take better advantage of education, benefits and services provided (from the Equality Act 2010)

For those with Prader-Willi syndrome this means:

- Children or young people with PWS have low muscle tone which affects their mobility and will require support to move around school and climb stairs safely
- Children and young people with PWS have an unsteady gait which means they will need additional support on uneven surfaces or any situation where they are likely to be exposed to pushing or jostling

- Children and young people with PWS have an unsteady gait which means they will need additional support on uneven surfaces or any situation where they are likely to be exposed to pushing or jostling
- The relentless and overwhelming appetite that develops in children or young people with PWS means they require a physical environment with high levels of food security
- A high pain threshold makes them vulnerable to hidden injury

Every child diagnosed a Genetic Disorder, as far as reasonably practical, has the right to 'engage in the activities of the school together with the children who do not have special educational needs' (from the Children and Families Act 2014 Chapter 6 Part 3, section 35)

For those with Prader-Willi syndrome this means:

- Children or young people with PWS will need additional support during School and College or other educational events and outings to ensure that high levels of food security are maintained at all times
- School and College events and outings will need to be planned factoring in the particular mobility and sensory needs of children and young people with PWS
- The immature social and emotional development in children and young people with PWS means that they will need additional support to facilitate their social development and so enable social interactions within their peer groups

Every child or young person with a Genetic Disorder has the right to expect their Local Authority to fulfil their duty to 'secure special educational provision and health care provision in accordance with EHC Plan.' (from the Children and Families Act 2014 Chapter 6 Part 3, section 42)

SAVE THE DATE

Regional Meetings:

Region 8

Regional meeting 2018:
Please contact Elizabeth McOmish for further details

Lizzie@whs4pminus.co.uk

Region 6

Regional meeting Sunday 1st July 2018:
Please contact Pauline Nixon for further details

Pauline@whs4pminus.co.uk

Simons Journey

It is now almost 7 months since Simon's transplant. His GFR (kidney function) has dropped to around 60% which is still amazing. It is probably better than mine. We are in clinic every 5 weeks now. It is a long day as we have to be at The Royal Liverpool by 8.30 am for bloods before clinic. We usually see Adham, the surgeon who performed the transplant. Simon is always pleased to see Adham. In fact he invited himself to join him for breakfast last week.

We are now in contact with the donor family. The donor was Michael. I recently wrote to them again enclosing a photo of Simon.

They wrote a reply to my initial card which arrived on Simon's birthday. Enclosed was a beautiful poem written by one of Michael's friends, which was read out at his funeral. I hope to continue to correspond with them as I would love to know more about Michael.

There have been a few hiccups in Simon's health. A recent urine infection and gout. Have to admit I panic at the slightest thing. But we have amazing GP who always fits him in the same day. I have had the support of the most amazing friends who have kept me sane.

We will be holding a fundraiser on June 30th, his first anniversary, for a kidney charity. We even have a band playing for free because the singer's wife is on dialysis. I simply cannot thank the NHS enough for our care during Simon's transplant. The staffs, nurses, doctors, surgeons, theatre nurses, physio, lab staff, cleaners and anyone who I haven't mentioned were all amazing. We simply could never find the words to thank everyone for our care. Yes the Royal Liverpool Hospital is in a bit of a state. But Simon did not get an infection. He healed very well. And we were very well cared for. A big fat YAY from us for the NHS.

A poem written by a friend of Simon's donor and read out at his funeral

Have you ever met someone who brightened each day?
Smiling and laughing. Knowing just what to say?
Would greet one and all with his infectious smile
Help everyone and go the extra mile.

Have you ever met someone so honest and kind?
Someone so special you were lucky to find
A truly loved son, brother and friend
An absolute gent, whose kindness knew no end.

Have you ever met someone so loyal and brave?
Set examples for all on how to behave
The life of the party, who was always there
He'd brighten any mood, anytime, anywhere

We've met a man who ticked every box
Fit as a fiddle and strong as an ox
A true hero to us who was taken too soon
But we like to think he is still in the room

That man's name was mike, more brother than friend
His outstanding spirit shone through till the end
The joy he could bring was unlike any other
We will never forget you, so sleep tight up there brother.

Save the Date - 25th National Meeting

FRIDAY 3rd - SUNDAY 5th MAY 2019

The next National Meeting marks the 25th year that the Wolf Hirschhorn Syndrome Trust has been hosting the event! To commemorate this landmark year, we're delighted and excited to announce the dates for 2019: Friday 3rd - Sunday 5th May, pop them in your diary and get ready to celebrate with us.

The theme of this year's event will be based on music in recognition of the love that all of our children (young and old) have for it, the connection they all have with it, the way it helps us all communicate and the way it brings us all together.

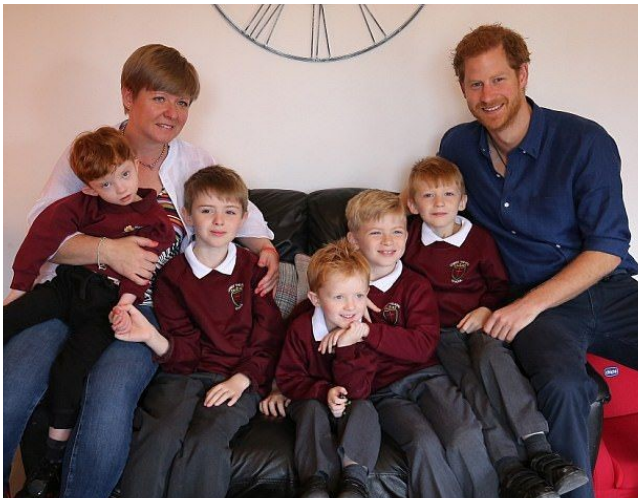
There will be opportunities to try different activities and music workshops as well as more time to listen to and discuss experiences from the other WHS families attending. Plus we have a very exciting music act for Sunday! More to follow on this and further details about the event in the invites which will be going out in September.

If we don't have your details already and you would like further information about the national meeting, and to receive an invite, please let me know on nationalmeeting@whs4pminus.co.uk.

I look forward to seeing you there!

Sarah Fleming

When Harry Met Oliver



Prince Harry met Oliver, his family and a group of volunteers who are transforming his garden into a safe play space for WellChild's 300th Helping Hands project, describing Oliver's mother Elizabeth McOmish as a 'Superwoman'.

Greetings from David, Ellen and Tanya

Dear All,

This comes with belated good wishes for the coming year. Somehow the last one went too fast and we got totally behind with everything. I guess it is old age creeping up. We thought you might like to see some pictures of Tanya.

In October Emma, the manager from her Home, rang to tell us that she and Tanya had a job - volunteering in Tilehurst at St Katherine's church hall restaurant on a Friday. Apparently the first week all went well till someone ordered an egg sandwich. As eggs are her favourite food there is no way she wanted anyone else to have that sandwich!

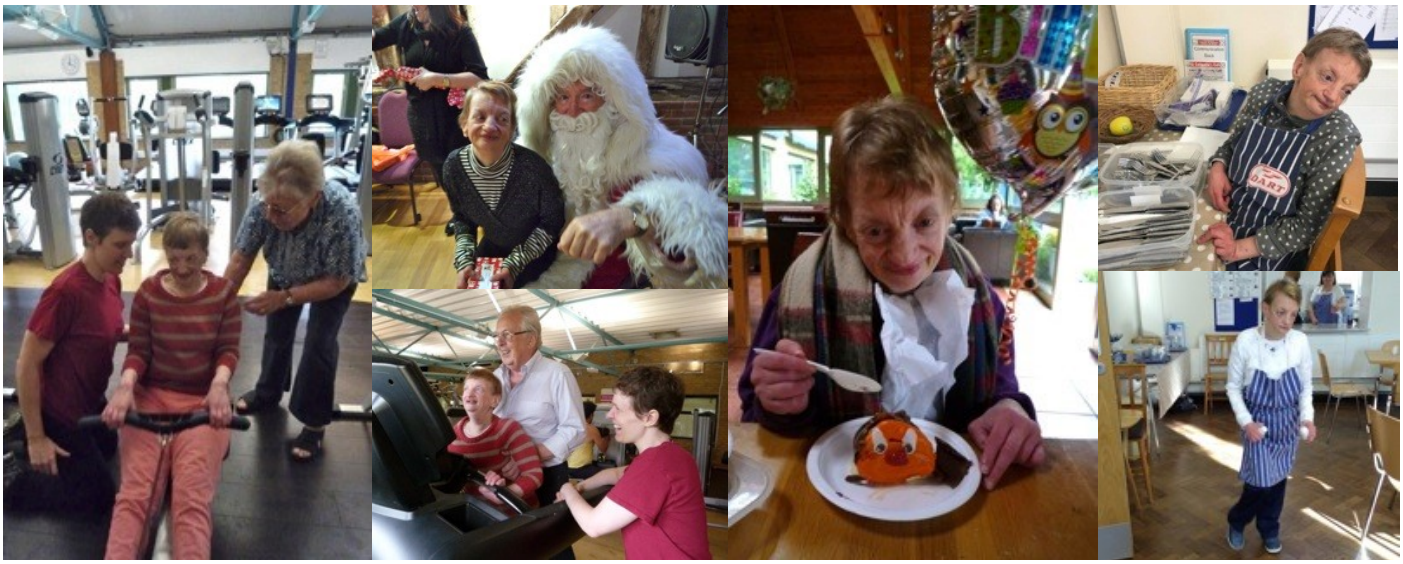
Below that a photo of her 43rd birthday celebrated at the Oxford Brooks gym's restaurant and some of her friends and volunteers, who help her, especially Jo (red tee shirt) who has organised it all for her. She herself has cerebral palsy, which has deteriorated since we first met her. But like Tanya she is a fighter and making the most of her life. David takes her to the gym most Saturdays as we want her to stay as mobile as possible.

Tanya loves all the attention she gets and cheers herself on when she feels she is doing well. As for men with beards and girls with long hair - it must be the texture she likes so much!

They had the Purley Park Christmas party in the community hall this year with most of the residents and their family there. As they had the music in the main hall this time even some of the wheelchair ones could join in with the dancing. Needless to say Tanya was up there most of the time. As always father Christmas got a tumultuous welcome.

We wish you all the very best for the year ahead,

David, Ellen and Tanya



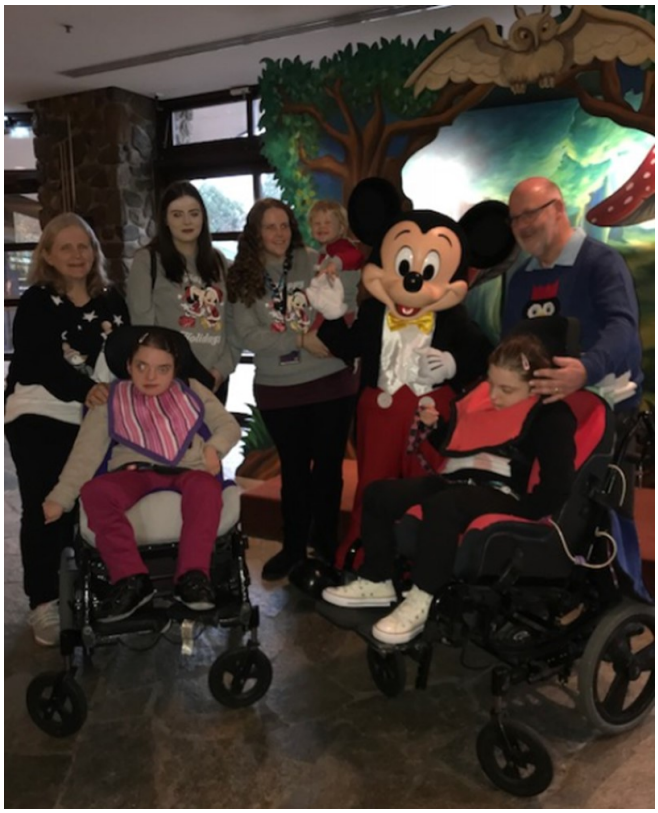
Douglas Clan in EuroDisney

In November of last year, the Douglas family of Mam and Dad, twins Una and Ailis, big sister Ciara, grandson Caleb and Ciara's friend Rebecca went on tour to Eurodisney.

We were going for 5 days but in reality it took 5 months to plan it. Memo to self: "Always be good to your children: it will pay dividends in the future!!" This worked very well for us as Ciara took on the onerous task of doing all of the booking and organising.

Una and Ailis are 22 and have WHS. They are wheelchair bound with many physical and intellectual difficulties. It was easy to book plane tickets directly from Dublin to Charles de Gaulle Airport in Paris but a bit more difficult ensuring the girls chairs would be taken on board in the hold. Thankfully Aer Lingus were very obliging. Transport from the Airport to Euro Disney was problematic to say the least. Trains were not an option as they would not accept a booking in advance for 2 wheelchairs. Buses were not a viable option either so taxis were dutifully booked. The return trip for 2 taxis each way was quoted as approximately 400 euro. It ended up as nearly 600!! Never believe a quote!! Anyway we got there!! Of course after having letters from our GP verifying medication, special food (Jevity), confirming the girls diagnosis, all of which smoothed our passage through the airport and gained us airport assistance.

We stayed in the Seqoia Lodge on a B&B basis. Services and staff there were very accommodating. However there is only one small elevator from ground floor to basement which is not adequate when so many people use wheelchairs and buggies and that's the only way out for them.
The theme parks were only a 10 or 15 minute walk away from the hotel. We got the Green Passes for the girls from the Town Hall and this gave us access to everything and priority at Meet and Greet with the Disney characters. Una and Ailis can do very little. But they love music and lights and colour and we had that in plenty! Overall we had a great time and everyone enjoyed themselves.



We were exhausted and if we were to go again we would be sure to bring someone to help us. It's amazing that when you are out of your own environment the simplest things can become more difficult! But we managed and enjoyed it all.

The Characters and Staff were all amazing and very friendly. We have lovely photos and memories of our visit.

The Douglas family returned from tour!!

A Few Tips from Nick Mcvey

Martin Lewis Money Saving Expert

If you're struggling on a low income, there's a lot more cash out there to help than you may think. Charities, the Government and even companies often have funds which are available to help, especially if you've got children.

http://www.moneysavingexpert.com/family/grants-low-income

Starlight

Starlight brightens the lives of seriously and terminally ill children by wish granting and also by providing fun, entertainment, laughter and distraction for children in every child's hospital ward and hospice throughout the United Kingdom. All Starlight's activities are aimed at distracting children from the pain, fear and isolation they can often feel as a result of their illnesses.

Starlight is there to grant a seriously or terminally ill child their greatest wish, restoring the magic and fun of childhood and creating happy memories for the whole family to share and cherish whatever the future holds.

Tel: 020 7262 2881
http://www.starlight.org.uk

Dreams Come True

Bringing joy to children and young people with serious and life-limiting conditions. We are a national UK charity that works hard to make dreams come true for children and young people with serious and life-limiting conditions aged between 2 and 21 years old.

Fulfilling a dream can help a child or young person to think beyond their illness or disability and focus on something highly positive and empowering. The experience can create amazing memories for entire families and our friendly and knowledgeable team are there to help every step of the way.

Over the years, we've arranged for thousands of children and young people to meet their heroes, enjoy amazing experiences, and visit special places and more. For some, a dream is simply to enjoy everyday activities so we're also happy to provide specialist items such as disability trikes, wheelchair swings, sensory equipment and technology.

Tel: 08000186013
www.dreamscometrue.uk.com

When you wish upon a star

This charity tries to make children's dreams come true, it is for children with life threatening illness. Epilepsy is a life threatening illness. For further information visit the website.

http://www.whenyouwishuponastar.org.uk/

Disability Rights UK

This is an organisation that gives advice on disability rights in many areas. Includes advice pages on benefit rights.

Tel: 0207 250 8181
http://www.disabilityrightsuk.org/

Cerebra

Is a charity that helps disabled children with neurological conditions. They offer grants and advice to disabled families and run events around the country. The have online articles giving advice on benefits and money matters.

Tel: 01267 24420001
www.cerebra.org.uk/help-and-information/

Children Today

Children Today was founded in 1994 to help 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.

They provide specialised equipment that has a direct and immediate impact on a child's quality

of life and independence. Equipment can include wheelchairs, walking frames, tricycles and other mobility aids, as well as, multi-sensory equipment and other information technology.

The equipment is gifted to the child concerned, it is not a loan, and it is owned by the child, not their parents or guardians. They provide ongoing support and the children can come back for further funding as their needs develop or they outgrow their equipment.

Tel: 01244 335622
http://www.childrentoday.org.uk

General Advice

When applying for government disability benefits always make sure you get expert advice from agencies such as the Carer's Centre. Many of the questions on application forms are more complex than you would ever imagine. For example you may be asked if the disabled can walk 20 metres unaided. That might seem quite straightforward, but infact it is not! The disabled person may not be able to walk without very close supervision of a responsible adult and consequently the answer would be "no". There are numerous websites and organisations that can help..

Turn2us: 0808 802 2000
https://www.turn2us.org.uk/

Benefits and Work:
https://www.benefitsandwork.co.uk/personal-independence-payment-pip/pip-points-system

Breaks for Single Parents: Care for the Family

Provide holidays for single parents with children aged 5-16. Follow the link to find out more about these holidays with a difference.

https://www.careforthefamily.org.uk/events/family-breaks/take-a-break

Family Fund

Is a government funded charity that helps families across the UK who are raising a disabled or seriously ill child or young person aged 17 or under. The Family Fund give grants for requests that relates to the needs of a disabled or seriously ill child, young person and their family. This might be furniture, clothing, bedding, kitchen appliances, sensory toys, computers or tablets, a family break, or maybe something to help with college for 16 and 17 year olds.

You can apply to Family Fund if:

- You live in England, Northern Ireland, Scotland or Wales.
- You are the parent or carer of a disabled or seriously ill child or young person aged 17 or under.
- You have permanent legal residency in the UK and have lived in the UK for the last six months.
- You have evidence of entitlement to one of the following: Universal Credit, Child Tax Credit, Working Tax Credit, Income-based Jobseeker's Allowance, Income Support, Incapacity Benefit, Employment Support Allowance, Housing Benefit and Pension Credit.

If you do not receive any of the above, you can still apply, but we will need some extra information about your household income. Depending on what money you have coming into your home we may not be able to help as we have to prioritise helping those on lower incomes. If you are not in receipt of any of the above benefits, you will need to provide additional information and evidence of your whole household income and we will contact you after you have applied. If you would like to ask any questions or discuss it before you apply please do contact us.

Tel: 01904 621115
https://www.familyfund.org.uk

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