

ADPKD Chronic Pain Study

Two in three people with ADPKD have chronic, often disabling pain, caused mostly by visceral pain from their polycystic kidneys. ADVANTAGE is a major new research study looking deeper into the causes of chronic visceral pain with the aim of finding better pain relief treatment.

Please help by taking this short survey about your experience of chronic visceral pain - you'll not only be able to 'rate' your pain but mark-up exactly where pain is felt with an easy-to-use virtual body map. Find out more and take the survey.

You can also answer questions on other types of visceral pain you have, for example, from the gut, uterus, and bladder.



Scan me

<https://redcap.link/mbw53y9a>

Coping with rising costs

Could you be entitled to financial support? Kidney Care UK's online Benefits Calculator will help you identify any payments you might be missing out on. The calculator is free to use, and the details you provide are anonymous.

<https://bit.ly/BenCalc>

For Adults and Children undertaking dialysis at home, you can get the utility costs reimbursed. Discuss this with your doctor, local dialysis unit or see here for more information:

<https://bit.ly/HomeDialcost>

PKD research projects that could deliver big results

Following a two-year programme to identify the top research priorities for PKD and an investment of over half a million pounds, three exciting new research projects are now underway.

Jointly funded by PKD Charity and Kidney Research UK, the projects mark the next big step in our shared commitment to accelerate PKD research, bringing hope to the thousands of individuals and generations of families in the UK affected by ADPKD and ARPKD.

Teams led by **Professor Albert Ong** at the University of Sheffield and **Professor Colin Johnson** at the University of Leeds will investigate treatments that can slow or prevent the progression of ADPKD. **Dr Joe Cockburn** also of Leeds University will study the genetics of ARPKD, the rare form of PKD.

Albert and his team are on a mission to better understand PKD cysts, which replace healthy kidney tissue over time causing kidney function decline. By studying ADPKD kidney cells that become cystic and those that don't, they hope to develop drugs that prevent cysts from forming in the first place; potentially a major step to finding a cure.

In searching for drugs to slow kidney function decline without nasty side effects, Colin's team have identified two existing drugs that could be repurposed to treat ADPKD (faster and cheaper than developing a totally new drug). They will test these on kidney organoids, mini kidneys developed in the lab using stem cells that 'mimic' an ADPKD kidney.



Joe will study the genetics of ARPKD to determine what exactly causes the condition. This could lead to improved genetic counselling for families affected by ARPKD, development of new treatments, and inform parents and would-be parents about their child's clinical course.

The teams will carry out their research over the next three years with the two academic institutions working closely together to share their findings and maximise potential positive outcomes.

For more information visit:

<https://bit.ly/PResNews>

Information and support

Living well with PKD

Protect yourself this winter



An autumn booster to top up the immunity of those most vulnerable to Covid-19 is now being rolled out.

This will be a 6th dose for people who are immunosuppressed and most likely a 4th dose for those with late kidney disease or on dialysis, and is intended to boost protection, which may wane over time.

The Kidney Charities Together Group strongly encourages everyone who is eligible to have the autumn booster as soon as possible. Winter is typically the time of greatest threat from respiratory infections, such as Covid-19 and flu, not only to the vulnerable but also to hospitals and other health care services, which are likely to face increasing pressure.

Whilst no vaccine is completely effective, and some people may still get Covid-19 despite having a vaccination, it remains an important defence against becoming severely ill from Covid-19; proven to be safe, effective and life saving for many people.

See the full Kidney Charities Together guide: <https://bit.ly/Aut22boost>

Who	Eligibility	Autumn Booster	When & How
Adults aged 50 years and over	All	✓	From 3 months after last Covid vaccination, starting 12 September 2022, with priority for the oldest and most vulnerable
Adults/children aged 16-49	<ul style="list-style-type: none">Chronic kidney disease (CKD) stages 3, 4, 5, or nephrotic syndromeDialysis patientsTransplant patientsImmunosuppressed individualsHousehold contacts of an immunosuppressed personCarers (receiving carer's allowance or primary carer of an elderly or disabled clinically vulnerable person)	✓	ENGLAND – book online or phone 119. Priority for booking for older age groups and for those at higher risk, such as immunosuppressed people. WALES – wait to be invited by your Local Health Board
Children aged 12-15	<ul style="list-style-type: none">With a chronic kidney conditionImmunosuppressed individualsHousehold contacts of an immunosuppressed person	✓	SCOTLAND – wait to be invited by letter NORTHERN IRELAND – details to be announced
Children aged 5-11	<ul style="list-style-type: none">With a chronic kidney conditionImmunosuppressed individualsHousehold contacts of an immunosuppressed person	✓ Paediatric dose	



It's good to talk

Our volunteer-led support groups continue "meeting" online and some are meeting in person.

Groups give PKD patients and loved ones the chance to connect, chat and discuss issues in a relaxed, informal environment.

Current groups:

Bedfordshire, Edinburgh and Midlothian, Forth Valley, London, Essex, Newcastle, Norfolk, North Scotland and Highlands, Wales.

"It was good to chat to others in the group - these meetings always make me feel like I am not alone. I really would encourage people to join. They are always so informative but relaxed. Lovely to be able to talk to other people who understand our experiences."

Denise, September 2022.

If you are interested in joining a group, visit: <https://bit.ly/pkdc-events>

To start a group, please contact Susan: susan.muirhead@pkdcharity.org.uk 07739 632836 (call or text).

Help at your fingertips!

For people who are newly diagnosed or at the early stages of PKD, our new self-help App is due to be launched in December 2022!

Developed by a range of experts including people with PKD, carers, clinical specialists and user experience professionals, this free App will:

- Provide credible information and health advice - all in one easily accessible place
- Offer practical tips for everyday life
- Give links to trusted further information and available support



If you'd like to be one of the first to try the App once it's available, please register your interest here: <https://bit.ly/APP-form>

GSK has supported the printing and production costs of this Newsletter and have had no editorial input in the contents.

Information and support

Living well with PKD



Tolvaptan FAQs

Many ADPKD patients in the UK take tolvaptan. Here are some FAQs from Prof Daniel Gale, Consultant Nephrologist at the Royal Free Hospital.

- Tolvaptan is only prescribed by a hospital kidney doctor, not a GP. If you live in England or Wales with kidney function from 90 to 30 eGFR, you may be eligible for tolvaptan. In Scotland, you may be eligible with more than 90 eGFR.
- You can usually take tolvaptan until you need either a transplant or dialysis.
- The two main side effects of tolvaptan are frequent urination and raised liver enzymes. There may be other minor side effects, such as itching or rash, common with many drugs.
- The amount you drink and pee will vary. Eg, with very good kidney function you might drink between 8-11 litres of water a day because your kidneys will produce lots more urine. Most people do tolerate the extra drinking and peeing without much disruption to their lives.
- Drinking squash or fizzy drinks is OK but avoid those with sugar to prevent tooth rot or diabetes. Fruit juices contain lots of sugar, so don't drink litres of those.
- Excessive urination from tolvaptan

isn't harmful. Kidneys are highly specialised, urine-producing organs. You won't wash out the 'good things' like electrolytes when you pee.

- You can skip a dose or take a break. Eg, taking a long flight or having surgery or attending a special event. But don't do this regularly because that will counteract the benefit of tolvaptan.
- No need to avoid alcohol or coffee. Alcohol harms the liver but isn't toxic to the kidneys. But if you drink a lot, you will get dehydrated which can harm kidneys. There's no evidence coffee is harmful in PKD but too much coffee causes dehydration.
- Tolvaptan doesn't affect liver cysts positively or negatively. Some people get raised liver enzymes when taking tolvaptan, but this is not associated with the cysts.
- If you've had a liver transplant for polycystic liver disease (PLD) you may still be eligible for tolvaptan if your kidney function is good enough.
- There's no evidence that drinking lots of water is as effective as tolvaptan.
- There are no alternative drugs to tolvaptan. Regarding future therapies, there's new drugs in the pipeline which give us hope.

View Prof Gale's talk.

<https://bit.ly/3CoQkZy>

What's On...

ARPKD Family Day

26 November 2022 - Birmingham

Families with ARPKD and adult ARPKD patients, join us at Birmingham Children's Hospital Rare Disease Centre - Creche and entertainment for children while adults hear from the experts, and chat with other families.

Register:

<https://bit.ly/ARPKD2022>

ADPKD Information Day

19 November 2022 - Sheffield

Hosted by ADPKD experts Professor Albert Ong and Dr Roslyn Simms, this full day event will give patients, family members, carers and healthcare professionals the chance to learn more about PKD, treatments available and what the future holds.

Register: <https://bit.ly/ADPSh22>

PKD Family Planning & Pregnancy Q&A

16 November 2022 - Online

Join Dr Kate Bramham, Consultant Nephrologist and Katherine Clark, Renal Midwife, to discuss the whole journey, from pregnancy planning to fertility issues, assisted conception and pre-implantation genetic testing through to pregnancy care.

Register: <https://bit.ly/FPF-2022>

Polycystic Liver Disease (PLD) Q&A

24 November 2022 - Online

Liver cysts are an under-recognised and extremely painful burden for some people. Put your questions to the expert, Consultant Hepatologist, Dr Ahmed Elsharkaway.

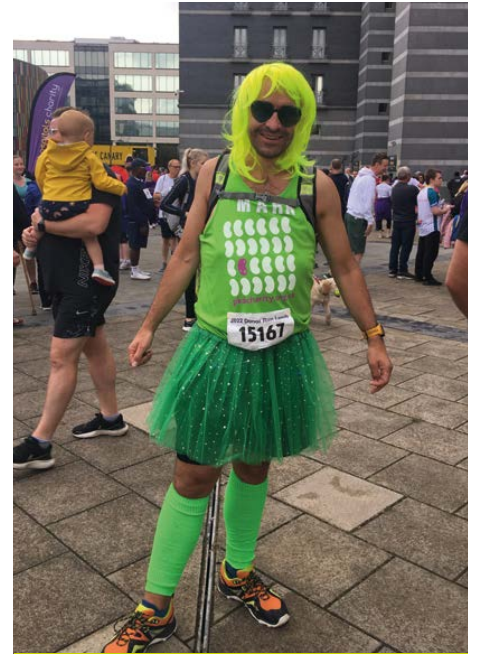
Register: <https://bit.ly/PLD-2022>

Raising awareness

PKD Voices



PKD Charity's Lewis, Jane and Tess with supporter Matt Thomas



Mark, primed for the Donor Run

On your marks, get set, go!

After a 2-year pause due to the pandemic, the British Transplant Games made a welcome return in July, this time in Yorkshire's largest city, Leeds.

First held in 1978, the Games are a celebration of life. They aim to pay tribute to donors, raise awareness of organ donation, and encourage families to discuss their wishes at a time when more than 7,000 people in the UK are waiting for a transplant.

The eagerly anticipated event saw hundreds of people competing in a variety of sports at venues across the city over 4 excitement-filled days, starting with the official opening ceremony on 28 July. Participants range in age from just 3 to 83, with everyone from beginners to experts getting the chance to go for sporting glory.

Many of those taking part are transplant recipients, although family members, living donors and the loved ones of deceased donors also line up for events.

The kidney community is very well represented - around 60% of competitors have either had a kidney transplant or are on dialysis.

The PKD team was excited to get together in person again with friends, old and new, some of whom we've only met across a Zoom screen!

It was a joy to cheer on our PKD superstars competing in the Games, not least 12-year-old Harrison who has Autosomal Recessive Polycystic Kidney Disease (ARPKD), the rare form of PKD. Since his combined kidney and liver transplant in 2015 he's been determined to make the most of life by competing in the Games. It's a great accomplishment for him, who, as dad Michael explains "couldn't walk after his transplant".



Harrison and dad Michael

Alongside others in the PKD family, including Games 'veteran' Mark, Tess and Jane (both transplant recipients) and Lewis our Fundraising Manager were grateful to take part in the Donor Run (or fast walk in their case!).

Competing for the first time, Tess also bagged a gold for archery, though she modestly puts it down to beginner's luck! She's seen here with fellow gold medalist, Khalid, who is almost 8 years post-transplant.

We look forward to the 2023 Games in Coventry!



Tess and Khalid

Raising awareness

PKD Voices

I'm not Pregnant. I've got PKD.

For Awareness Week in September, 48-year-old Katie Banks from Swansea took the brave step to share the naked truth about PKD.

Katie's belly is now so distended that she is frequently asked, "Boy or girl?" or "When's it due?" by people who innocently assume that she's pregnant. In fact, it happens so often she sometimes finds it easier to 'pretend to be pregnant'.

"I've become so weary of explaining myself, to save people's embarrassment and not wanting to hit them with the terrible news that I have an incurable disease, I just go along with it and let them go on their way" she says.

Sadly, her story is an all too familiar one.

PKD causes the growth of cysts, primarily in the kidneys, which enlarge and change shape, often resulting in what's known as a 'PKD belly'. A healthy kidney is usually about the size of a fist, whilst PKD kidneys can grow to the size of a rugby ball - the largest and heaviest reported PKD kidneys are those of Windsor dad, Warren Higgs, whose kidneys weighed a record-breaking 35kg (77lb).

Consequently, many women and even men with a PKD belly are often thought of as 'pregnant'. Not only is this psychologically distressing, but huge polycystic kidneys like Katie's often cause chronic pain and compression of internal organs, leading to digestive and breathing problems. Even simple tasks like tying shoelaces or painting toenails can cause excruciating pain.

Over time, PKD cysts slowly replace much of the kidneys, reducing kidney function and typically leading to kidney failure by middle age. Katie now has only 9% kidney function, with dialysis or a transplant the only treatment option available to her.

Husband Richard, who isn't a direct match, hopes to donate a kidney



through the National Living Donor Kidney Sharing, which offers a chance to swap or exchange donor kidneys with another donor-recipient pair in the same situation. The couple met 18 years ago in her native Estonia where Welshman Richard was on a friend's stag night. After a 12-month, long distance romance Katie left her family, friends and job to move to Swansea; a bold move for the 31-year-old who barely spoke English at the time.

Katie and Richard have now been entered into the Living Donor Kidney Matching Run, which is performed 4 times a year.

For now, Katie is in limbo, often feeling lonely and frustrated. Her PKD belly is an unavoidable daily reminder of the disease, and cause of great discomfort and embarrassment.

Yet despite her worries, she strives to have a positive attitude. "I think life is like a coin. What kind of life you have depends which side of the coin you want to see. There's nothing I can do to change the fact that I have PKD, but I can be grateful for the good things in my life, and maybe play a part in helping others," she says.

In sharing her story, she hopes to raise awareness of this distressing and misunderstood effect of PKD and raise funds for research, which is critical to improving the lives of patients and their families.

In the UK, less than 1% of all health research funding goes to kidney research, and a fraction of that amount goes towards PKD research specifically. Katie and her family want to do all they can to change that.



Richard fundraising for PKD

2023 Fundraising Event Calendar



We wouldn't be able to continue to provide support to people affected by polycystic kidney disease without our wonderful fundraisers.

If you are looking to challenge yourself in 2023, here are just some of the events you can get involved with to support PKD Charity.

March – Spring into March 2023

Over £6,000 was raised by our awesome Spring into March fundraisers in 2022 and we are bringing the event back for 2023.

Kick start a more active lifestyle and walk, run, swim, cycle, dance or stretch for just 31 minutes for the 31 days of March. Boost your energy, lift your mood and make everyday activities easier whilst helping to boost funds for PKD research.

2nd April – London Landmarks Half Marathon

This closed road, central London run is the only half marathon to go through both the City of London and City of Westminster, passing the capital's many iconic landmarks along the way.

You can be part of the action by signing up for a place with us. But be quick! We have just 1 place left!

23rd April – London Marathon

Our places in the next year's event have now sold out but if you would like to be added to our waiting list for a place or are interested in taking part in the event in 2024, please get in touch.

Or if you have been lucky enough to secure your own place in the event through the public ballot, we'd love to have you running as part of Team PKD.

10th September – Great North Run

Our amazing team of runners who took part in this event this year raised over £5,000 to help support people affected by PKD, and fund vital research,

If you would like to take part in the world's biggest half marathon in 2023, get in touch to register your interest.

Various dates – The Ultra Series

With 100km, 50 km & 25 km distances to choose from and stunning locations including routes in the Lake District, Peak District, Thames Path and Jurassic Coast – the Ultra Series has something from everyone.

With 14 events to choose from, you can walk, jog or run. Visit ultrachallenge.com to find out more about all the routes on offer, and to sign up!

All year round – Skydive

If you have ever wanted to do a parachute jump - here is your chance. You can skydive at locations all over the UK and can choose a date that suits you. In return for raising a minimum sponsorship target for PKD Charity, you can do all of this for FREE.

Take on a challenge anywhere, anytime

It could be your local 10K or a mammoth cycle from Lands End to John O'Groats, whatever you decide to do, we'll be here to support you with your fundraising. If you'd like to chat about taking on a challenge to fundraise for us, get in touch. Email fundraise@pkdcharity.org.uk or call 07715 664687

Christmas Catalogue



Product	Size	Qty	Unit Price	Total Amount
1. Christmas Café x 10	100 x 152 mm		£4.25	£
2. Skating Together x 10	128 x 128 mm		£4.25	£
3. Christmas Tweetings x 10	128 x 128 mm		£4.25	£
4. Fireside Snuggles x 10	128 x 128 mm		£4.25	£
5. Frosty Berries Robin x 10	128 x 128 mm		£4.25	£
6. Love, Peace and Joy x 10	128 x 128 mm		£4.25	£
7. Season's Greetings x 10	128 x 128 mm		£4.25	£
8. Peace, Angel and Robin x 10	128 x 128 mm		£4.25	£
9. Ornate Christmas Tree x 10	128 x 128 mm		£4.25	£
10. Snowman's Stocking x 10	128 x 128 mm		£4.25	£
11. Sparkly Forest Tree x 10	128 x 128 mm		£4.25	£
12. Waiting for Santa x 10	100 x 152 mm		£4.25	£
13. Kidney Pendant and 18" Chain - sterling silver			£19.00	£
14. Kidney Earrings - sterling silver			£11.95	£
15. PKD Charity Buff			£7.50	£
16. PKD Pin Badge			£2.00	£
17. PKD Wristband (black kidney)			£3.50	£
18. PKD Wristband (white kidney)			£3.50	£
19. PKD Pen			£1.00	£
Subtotal				£
Post & Packaging: £2 for one item, £4 for more than one item				£
I would like to make an additional voluntary donation to the PKD Charity*				£
Total				£

* If you are a UK taxpayer, we can claim Gift Aid on every £1 on any additional voluntary donation that you give. This is at no extra cost to you. Just tick the box at the declaration on next page.

Fundraising

Get involved

Walk for PKD 2022 raises over £14,000

Earlier this year we launched a brand-new fundraising challenge, Walk for PKD.

We asked our wonderful supporters to play their part in helping to raise awareness of PKD by organising their own sponsored walk and raise money to fund vital research into finding a cure for PKD. Kidney research is critically underfunded - in the UK, less than 1% of all health research funding goes to kidney research, and a fraction of that amount goes towards PKD research specifically.



We wanted as many people as possible to get involved in Walk for PKD and left it up to participants to choose a distance and location, a challenge that suited their fitness level. We had walks and challenges happening all over the country and we are delighted to have smashed our fundraising target and raised over £14,000.

Just some of the great fundraising that took place around the country in September included:

- Caitlin Seale and her Mum set themselves the challenge of walking 1 million steps in the month of September and have raised over £1,000 in memory of Caitlin's Gran and her Uncle Brian.
- Rebecca Parker, whose husband has PKD, climbed Mount Snowdon with her friends Jess, Lucy and Ellie, and raised over £500.
- Laura Gough challenged herself to walk 300,000 in the month and has raised over £350. She wanted to push herself because before being diagnosed with PKD in 2017 she struggled with her weight but since being diagnosed she has been trying to lose weight and has nearly lost 3 stone, which has allowed her to be more active.
- Sally Humphries walked 150 miles in September and raised over £540. She was diagnosed with PKD



as a young girl and sadly her Mum passed away aged 54 due to post surgery complications from having a kidney transplant.

- The Flemming family; Chris, Karen, Andrew and Jonathan raised an incredible £5,600 in memory of wife and Mum, Sandra. The family set themselves their own personal challenge related to their own fitness levels and have walked or ran hundreds of miles in September.
- Kerry Young has PKD and her Specialist's ongoing research work at Sheffield Hospital is being funded by the charity so to show her support, Kerry organised a walk from Filey to Scarborough with a group of friends and raised a fantastic £1,300.

Thank you so much to everyone for all the hard work and effort they put in to their challenge. You've helped raise an incredible amount of money that will help to support people affected by PKD and fund vital research.

In Memory of Mark Edwards

Mark Edwards was part of the account team at UBU, a longtime corporate partner of PKD Charity, until he celebrated his retirement in 2018.

Mark was a great supporter of the Charity and attended all of UBU's fundraising events along with his wife Mary. Mark sadly passed away

in August this year and leaves behind his wife of 42 years along with his sons David and Robert and his grandchildren.

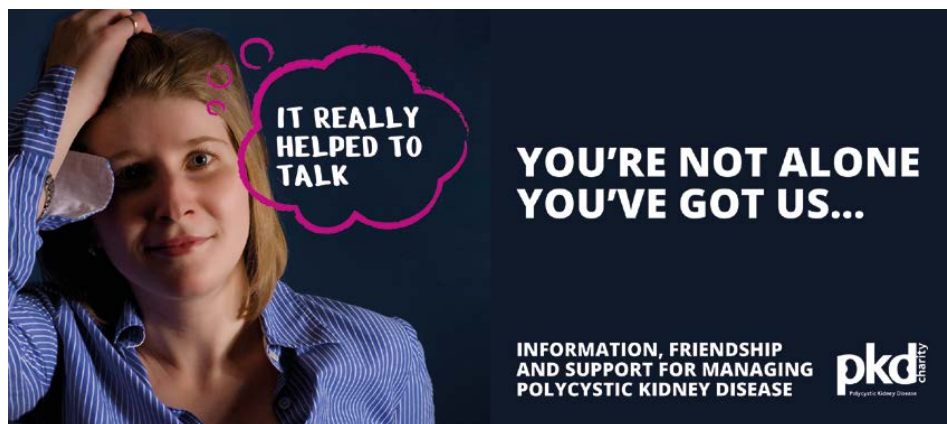
The funeral was a celebration of Marks two passions, his family and his football team, Bolton Wanderers. The family kindly asked for donations to the PKD charity in lieu of flowers and this is a testament to the family's generosity and lasting memory of Mark Edwards who will always be a part of the UBU and PKD family.



Our support services

Helping you cope with PKD

Whether you're looking for PKD information, practical advice or just someone to talk to, we're here to help you.



Ring our Helpline

If you need a friendly person to talk with about your worries or are just looking for information,

ring **0300 111 1234**, our confidential helpline. Available from 9:30am to 5:00pm Mon – Fri.

"You'll never know how much I valued speaking to you."



Find a PKD Support Group

For understanding and companionship, join one of our PKD Support Groups. Hosted by trained

volunteers with lived experience of PKD. Everyone is welcome – patients, family members and friends.

"It's great to meet others in a similar situation."



Join a Facebook Group

For a friendly and private place to connect and share with others like you, join one of our three UK-only

private Facebook groups. There's a group for everyone affected by PKD.

For ADPKD (autosomal dominant polycystic kidney disease)

- PKD Support (PKD Charity UK)
- Parents of children with PKD (PKD Charity UK)

For ARPKD (autosomal recessive polycystic kidney disease)

- ARPKD Support (PKD Charity UK)

"I found the group on Facebook and was immediately immersed into a very friendly and welcoming environment."



Take part in a workshop

Share your experiences and discover new coping strategies in a confidential online space with others

who understand the difficulties of life with PKD. Run by a renal psychologist and psychiatrist.

"To be able to share experiences helped me realise I am not the only one out there feeling the way I do."



Learn more about PKD at an educational event

Want to find out more about PKD, worried for your future, or baffled by the medical jargon? Ask the experts at one of our free educational events.

"Fantastic sessions...a very informative and interesting day."

Visit our website for more information

How to get support, visit bit.ly/pkdc-support

Upcoming events, visit bit.ly/pkdc-events

PKD Health Information

If you need reliable information about all aspects of PKD, visit our website for a range of accredited factsheets written by medical experts and checked by our lay reading panel of people affected by PKD.

Key factsheets include:

ADPKD Basics

bit.ly/adpkd-basics

Polycystic Liver Disease

bit.ly/adpkd-pld

Diet and Lifestyle in ADPKD

bit.ly/adpkd-diet-lifestyle

ARPKD Basics

bit.ly/arpkd-basics

If you don't use the internet, we can send you printed copies. Just ring our helpline: **0300 111 1234**.

Links to other sources of help

We recommend:

UK Government Benefits Info www.gov.uk/browse/benefits

Kidney Care UK - individual grants www.kidneycareuk.org

Turn2us – broad range of advice on welfare benefits and grants www.turn2us.org.uk

Family Fund – grants for seriously ill or disabled children www.familyfund.org.uk

Contact - for families with disabled children contact.org.uk

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