

## What do you think is most important to research in ADPKD?

### ATMIN gene may be the key to ARPKD

PKD Charity-funded researchers at the University of Wolverhampton are exploring how a newly identified gene called ATMIN is involved in autosomal recessive polycystic kidney disease (ARPKD).

Research by Dr Evi Goggolidou's research group into the ATMIN gene could be key to finding ways to slow down kidney damage caused by the disease. This gene plays a role in the development of our kidneys when we are in the womb.

PhD student Taylor Richards has recently discovered that changes in the gene may affect the age at which young children with ARPKD get kidney failure. He is now looking at how ATMIN interacts with other proteins found in kidney cells, including a protein called fibrocystin. This knowledge could help researchers to design new treatments for ARPKD. This is important because no treatments are currently available to slow down the kidney damage caused by the disease.

The research has been funded by a £48,000 joint research grant from the PKD Charity and the Arran Brown Rainbow Foundation..



We're glad to see the latest research that might help PKD patients, such as new medicines being tested and artificial kidneys, but we want more!

Now is your chance to tell researchers what matters to you and what we want them to focus their efforts on.

Help us identify the top ten most important things to research in ADPKD - autosomal dominant polycystic kidney disease.

We've collected a range of ideas from patients, carers and healthcare professionals to find those that remain unanswered - such as how to stop cysts growing, how to slow progression, what's the best diet, how can PKD care be better organised.

Now we want you to pick the research ideas that are most important to YOU.

You can select your Top 10 research ideas in this online survey:

[adpkd-psp-survey.questionpro.com](https://adpkd-psp-survey.questionpro.com).

Or just complete the paper version of the survey enclosed with this newsletter and return in the reply-paid envelope.

It doesn't matter if you are a patient directly affected by ADPKD, a family member or carer, or healthcare professional. We just want to know what's most important to YOU!

The survey should only take a few minutes but your voice will influence ADPKD research for years to come.

If you need more copies of the survey, please contact Tess at the PKD Charity.



PKD Charity won a National Lottery grant. See page 3

## Research Updates

### Pioneering study of blood pressure in children and young people



Professor Paul Winyard and colleagues have received a grant from Kidney Research UK to study blood pressure in children and young people at risk of ADPKD (autosomal dominant polycystic kidney disease).

ADPKD is the commonest genetic cause of chronic kidney disease but most people don't get symptoms until adulthood. It was thought that there was no need to screen children and young people (C&YP) until they were old enough to understand and agree to testing. Also, current ultrasound criteria only cover adults.

However, there have been recent reports of unexpected high blood pressure (hypertension) in C&YP with ADPKD, affecting up to a third by late

teens. Screening policy may need to change because early treatment of hypertension may reduce risk of cardiovascular events long-term. But doctors don't know if current data overestimates hypertension - the evidence is from specialist centres who manage earlier diagnosed cases.

This study has three objectives:

- Measure how many C&YP at risk of ADPKD in the general population have hypertension.
- Assess the use of kidney MRI scans for rapid ADPKD diagnosis.
- Identify family ADPKD genetic mutation.

The research team will recruit 200

undiagnosed C&YP with a parent or sibling with ADPKD. They will be invited with their parents/guardians for a blood pressure test, kidney MRI and heart scan in clinics in Birmingham, Cambridge, London, Manchester, Newcastle or Nottingham. The family genetic mutation will be identified in affected relatives and checked in the C&YP. Visits will take around half a day and the results will be discussed with families. They will be asked if they wish to know whether a positive diagnosis has been made but there will be no obligation to know. However, if hypertension is found, doctors will tell the families.

This study will determine if all C&YP should be screened for high blood pressure and if including MRI and genetic testing is helpful.

The PKD Charity is a 'co-investigator' in this study, assisting Prof Winyard and the team with publicity and recruitment. We are very grateful to the individuals and families who contributed to the design of the study by providing their views and experiences.

#### Research team members

Professor Paul Winyard, Dr Manish Sinha, Professor Fiona Karet, Dr Richard Sandford, Dr Larissa Kerecuk, Dr Martin Christian, Dr Matko Marlais, Dr Mohan Shenoy, Dr Yincen Tse.

## RaDaR

At 1 January, 2020, nearly 7,000 adults and children with ADPKD and over 200 adults and children with ARPKD had registered on the RaDaR national registry of rare kidney diseases. Patient registries like RaDaR have the potential to improve health and care, and they can help drive research. We are confident that this unique registry will deliver change in how PKD patients are looked after and the development of future treatments.

RaDaR is part of the UK Renal Registry, which gathers data from all the renal units on a daily basis

about the status of kidney patients on dialysis and transplant. RaDaR collects data on patients at earlier stages of PKD and this is combined with the Renal Registry data. The data is held very securely on an NHS database server and reports are prepared from 'anonymous' extracts of the data. They can only be accessed by a small number of approved doctors and Renal Registry staff.

Follow the link to see the type of reports the Renal Registry produces [https://www.renalreg.org/reports/data\\_to\\_end\\_2017/](https://www.renalreg.org/reports/data_to_end_2017/). Soon we hope to see similar reports from RaDaR. Importantly, the RaDaR reports

will show PKD progression by eGFR and other things such as age of diagnosis, kidney volumes, people with PLD and infection rates.

Last year, RaDaR sent letters to everyone registered on the database asking them to 're-consent' to their data being used. If you haven't signed and returned your form, please do so because this will help future researchers. If you have lost the form, please email Kate Whittingham for a new one. [Kate.Whittingham@renalregistry.nhs.uk](mailto:Kate.Whittingham@renalregistry.nhs.uk)

Thank you for supporting this hugely important project!

# PKD Charity Support Services

## Meetups

Our volunteer-led meetups continue to grow in popularity, giving PKD patients and loved ones the chance to connect, chat and discuss issues with others over a cuppa in a relaxed, informal environment. There's no pressure of course. Whether you're a social butterfly or more reserved, simply being in the company of people who can relate to how you feel, can bring great comfort.

Held on a Saturday or Sunday, a typical meetup lasts 2 hours but you can choose to either stay until the very end or just pop in for a quick chat.



*"I always think PKD Charity Meetups are like the 'Love is...' cartoons, as in never having to explain, just being understood!"*

**Nicki, London**

*"I went to my first meetup in South Tyneside at a beautiful, homely coffee shop. I learned about people's experiences, from dialysis to transplant and even bilateral nephrectomy.*

*What lovely people! Really helped me put into perspective what lies ahead"*

**Sharon, South Shields**

### Meetups

**Falkirk** - Sunday 15th March, 13.00 - 15.00, Callendar House Team Room, Callendar Park, Falkirk

**London** - Saturday 28th March, 11.00 - 13.00, Concrete Cafe, Queen Elizabeth Hall, Southbank, London

**Biggleswade** - Saturday 28th March, 13.00 - 15.00, Riverside Café, Jordan Mill, Southill Road, Broom, Biggleswade.

**Taunton** - Sunday 29th March, 13.00 - 15.00, Pitcher & Piano, Corporation Street, Taunton

**Totnes** - Sunday 29th March, 11.00 - 13.00, Seven Stars, The Plains, Totnes

**Southend-on-Sea** - Saturday 4th April 11.00 - 13.00, Molo Lounge, 195-197 High St, Southend-on-Sea SS1 1LL

**Livingston** - Sunday 26th April, 13.00 - 15.00, The Coffee Shop, Williamsons Garden Centre, Uphall by Livingston

Regular meetups also held in Reading, Southend-on-Sea, Norwich and Manchester.

If you are interested in attending a meetup or you want to start one in your local area please email Susan Muirhead at [susan.muirhead@pkdcharity.org.uk](mailto:susan.muirhead@pkdcharity.org.uk) or call her on 07739 632836.

## National Lottery Grant Awarded

We have secured funding from the National Lottery Community Fund for our PKD Positive Peers Programme - a 5-year programme of vital support activities to help patients and families to deal with the traumatic and often devastating effects of polycystic kidney disease (PKD).

Community Fund award of £280,845 will enable us to build and expand our existing support services in England:

- Information & Support Days for adults and families
- Volunteer-led meetups
- Peer-support from trained volunteers with lived experience of PKD
- Facilitated group phone calls
- Webinars
- Moderated online communities
- Reliable health information, written by medical experts

We estimate that up to 70,000 adults and children, plus their families, are affected in the UK.

Our PKD Positive Peers Programme enables anyone who contacts the PKD Charity to receive the information, practical advice and emotional support they need, at the time they need it.



# Raising awareness

## World Kidney Day 2020



Thursday 12 March 2020 marks the 15th World Kidney Day, an opportunity for people around the world to shine a light on kidney disease.

For the 7th year running, the Kidney Charities Together Group, a collaboration of the major UK kidney charities - PKD Charity, Kidney Care UK, Kidney Research UK, the National Kidney Federation, the British Renal Society and the Renal Association – join as one; this year by investing in a campaign designed to make a big impact!

Together we're raising awareness of what kidneys do, what can happen when they go wrong, and how to better manage progression of inherited diseases such as PKD.

Our focus in the UK for 2020 is 'Kidneys Matter', 'The BIG topic everyone

is ignoring'. The hero of the campaign is a big yellow kidney, which is not only hard to ignore but also helps to highlight the enlarged kidneys many with PKD face. The yellow kidney, along with kidney facts, statistics and preventative health tips will be available through social media channels and the World Kidney Day website, in digital and print formats.

We're asking those who're living with PKD to share your experiences of why #KidneysMatter on social media, with friends, family and colleagues and to run local awareness events.

These free World Kidney Day materials are available to order and download now from

[www.worldkidneyday.co.uk](http://www.worldkidneyday.co.uk) or call Jane Pugh on 07866 490985



ARPKD toddler Hazel, and PKD mum and wife Kay helping to make a BIG difference in raising awareness of kidney disease

# Raising awareness

## Andy Taylor



One of my major recovery goals during the tough days on dialysis and recuperating from a combined kidney/liver transplant was to compete in the British Transplant Games.

What an honour and a privilege it was. I represented King's College Hospital where I had my transplant and met some truly inspirational people. The cheers, tears and standing ovation at the Opening Ceremony for the relatives and families of deceased donors was a wonderful outpouring of love, awe and admiration. It was incredibly emotional to have the opportunity to let them know how much they and their relatives mean to us.

I met amazing, inspiring, normal people with incredible stories of strength and resilience. Most of them wouldn't have been there or in many cases alive, and certainly not as healthy but for an organ donor. I played table tennis with double lung, heart, kidney and combined liver and kidney recipients.

The British Transplant Games will be in Coventry in 2020. See you there? Maybe make it one of your goals?



# Raising awareness

## Transplant Games



*The unstoppable Helen Wilson (liver and kidney transplant) took gold for javelin and discus before going on to win more medals at the World Transplant Games!*

Running for over 40 years, the British Transplant Games are a celebration of life. Taking place in different host cities every Summer, the games see teams and individuals from across the UK come together to compete in a medley of sports. The event attracts around 1000 transplant athletes and more than 1500 supporters.

Transplant survivors including children as young as five can compete in more than 25 sports and indeed, many athletes also go on to compete at the World Transplant Games.

Its aim is to raise awareness of the need for organ donation, encourage transplant recipients to lead active lifestyles and show appreciation



*Maurice Slapak CBE, founder of Transplant Games and Jane Pugh*

for, and remember, donors and their families.

Newport hosted the games last year, and in 2020 it's Coventry's turn.

PKD Charity takes its place amongst the other exhibiting kidney charities and organisations representing organ donor families. It's a wonderful opportunity for us to meet our supporters, share information and of course cheer on our ADPKD and ARPKD superstars competing in the games.

Some are taking part of the first time, whilst others are experienced transplant athletes. Either way, it's impossible not to feel anything other than immense admiration as you watch them fight hard for a medallist place. For some of course, just having the good fortune to take part is all

that matters, win or lose.

Not only is it an inspiring and uplifting event, it's also a fun day out for all the family. As well as the sports, there are interactive games, food stalls and memorabilia on offer too. If you've thought about attending but never had the opportunity before, now's your chance. Do come along; it's a day you'll never forget! And be sure to come and say hello to the PKD team on our stand.

For those who are competing in this year's games, please remember to get in touch for your free PKD t-shirt. Email [jane.pugh@pkdcharity.org.uk](mailto:jane.pugh@pkdcharity.org.uk).

[www.britishtransplantgames.co.uk](http://www.britishtransplantgames.co.uk)  
30 July - 2 August 2020.

## Introducing Jane

I'm Jane Pugh, Community Engagement Manager. I'm new to the charity sector, but an old 'friend' of PKD. Diagnosed as a teenager, I've run the gamut of all things PKD, from aneurysm surgery to a transplant in 2017. I can't say it's been plain sailing, but it has led to interesting challenges and

the opportunity to create positive change in my life. In particular, after a long career working with major global brands, I'm thrilled to be able to bring my experience in brand management, marketing communications, media and events to continue and develop the fantastic work of the PKD Charity. I joined in June 2019, and it's been non-stop since! My role

involves planning and coordinating information days, forging new and building on existing relationships with the medical and scientific communities, social media, as well as identifying new ways of bringing PKD to the attention of the UK media and public. It's an honour to be part of it. I look forward to hearing your stories and getting to know you all better.

## A spotlight on events

### Are you up for a challenge?



**Diane Stroud** asked on the PKD Facebook page if anyone wanted to do a sponsored walk 'up North'.

The result was that on Sunday 18th August 2019 a small team from age 8 to 81, walked across the Humber Bridge... and back!... to raise money and awareness for PKD Charity.

*So, with five of us with varying degrees of PKD, one of us on dialysis, one as a 10-year kidney donor and two potential kidney donors, various family members and friends, we set off. The weather was kind to us that day; it was dry but very windy, especially being up so high and exposed! It was a total distance of 5.28 miles and on the walk back across the Bridge, both Sophie and Chloe managed the whole distance walking backwards!*

*At the end of the walk, with no blisters between us but lots of tiredness, we retired gracefully (or rather, crawled!) to the local pub for a Sunday lunch together and a good catch up. And lots of water!*

*Together, we've raised £2,723 for the PKD charity, so while we all enjoyed ourselves immensely, we also helped to support our wonderful charity. Thanks to everyone who sponsored us and Kelly and Madeleine for your wonderful support.*

Diane Stroud

For the past 7 months **Ella-May Patey-Round** and her loved ones have been taking part in multiple fitness challenges up and down the Midlands in memory of Ella's Dad, Chris Patey-Round and have so far raised an amazing £1,295! Next year she has plans to complete four Wolf Runs and a marathon (hopefully)! Ella-May welcomes anyone to come and do a challenge with her – get in touch to find out more.

Thank you so much for raising vital funds and awareness Ella-May and all your wonderful co-challengers - Guy, Josh, Freddie and Rachel. You're all an inspiration and we're so grateful for your incredible support in memory of Chris.



These 3D origami swans were created by a talented prisoner. His daughter had kidney failure and he wanted to raise some money. He had taught himself to make origami some years ago. He filled the swans with chocolate treats and raffled them to prisoners and staff – raising over £800.



Registered with  
**FUNDRAISING  
REGULATOR**

Who wants to do something amazing this year and take on a challenge for Team PKD 2020?! With charity places in the walks, cycles and treks; 5ks to marathons - there's something for everyone to get involved with this year! And when you take part for Team PKD you'll be raising vital funds and awareness to support anyone affected by PKD and fund life-changing research into finding treatments and a cure.

## Introducing Mads

Since joining PKD Charity as Fundraising Manager in August it's been wonderful working with an organisation with such inspiring values and supporters – we may be a small charity, but our ambitions are very big!

Having worked in the charity sector as a fundraiser for over a decade I love building great relationships with fundraisers and supporting them to reach (and exceed!) their goals.

Since I joined the PKD team I've already met and supported so many amazing fundraisers and it's been a real privilege to celebrate all their incredible achievements!

If anyone is thinking about organising or taking part in an event do get in touch as I'd love to hear from you – whether it's holding a coffee morning or jumping out of a plane, every penny really will make a difference and I'll be there to support you every step of the way.

Email [fundraise@pkdcharity.org.uk](mailto:fundraise@pkdcharity.org.uk) or call **07715 664 687**



# Support our work

## Fundraising ideas

The PKD Charity is almost entirely funded by donations from people and families affected by PKD, and we are very grateful to everyone who has raised funds or given their time.

There are many ways to help us continue our work.



### Donations

Single or regular donations can be made online via our website. If you are a

UK taxpayer, we can also reclaim Gift Aid on your donations:

[pkdcharity.org.uk/fundraising/donate-to-pkd](http://pkdcharity.org.uk/fundraising/donate-to-pkd)

Payroll or Workplace Giving is a simple and cost-effective way to donate. We are registered with CAF, the UK's biggest scheme:

[www.cafonline.org/my-personal-giving/plan-your-giving/caf-give-as-you-earn](http://www.cafonline.org/my-personal-giving/plan-your-giving/caf-give-as-you-earn)

Leaving a gift in your will to the PKD Charity can help us continue our long-term research activity - such as funding the PKD bio-bank used by many researchers in the quest for new therapies.

You can donate in memory of a loved one online or set up a tribute fundraising page on one of the third party platforms we use:

[pkdcharity.org.uk/fundraising/justgiving-virgin-money-gofundme](http://pkdcharity.org.uk/fundraising/justgiving-virgin-money-gofundme)

If you are arranging a funeral collection, we can send you printed envelopes to make the collection easier. Just email [fundraise@pkdcharity.org.uk](mailto:fundraise@pkdcharity.org.uk) letting us know how many you need.



### Facebook Fundraisers

Facebook has made it super easy to raise money - to celebrate

your birthday or a special anniversary. Visit the PKD Charity Facebook Page [www.facebook.com/pg/pkdcharity/fundraisers](http://www.facebook.com/pg/pkdcharity/fundraisers) to start a fundraiser and share the link with family and friends.



### Take part in an event

You can read all about the places we have in challenge events on

the previous page, or visit [pkdcharity.org.uk/fundraising/pkd-fundraising-events](http://pkdcharity.org.uk/fundraising/pkd-fundraising-events)

'Your fundraising, your way' is a great way to involve your family, friends or work colleagues in raising money for our cause. Baking, knitting, making crafts are all popular with our supporters. Email

[fundraise@pkdcharity.org.uk](mailto:fundraise@pkdcharity.org.uk) for an ideas pack.

When you're doing a fundraising event, ask your employer if they have a **Matched Giving Scheme** where they will match the amount you fundraise up to a certain level.



### Online shopping

An easy - and free - way to raise money by shopping is to use online shopping portals.

Easyfundraising and Give as you Live® pay commission every time you shop online at over 4,200 stores. Sign up at [www.easyfundraising.org.uk/causes/pkd/?u=96OIY1](http://www.easyfundraising.org.uk/causes/pkd/?u=96OIY1) or [www.giveasyoulive.com/join/pkdcharity](http://www.giveasyoulive.com/join/pkdcharity)

Amazon has a new charity shopping scheme called Smile.

Visit [smile.amazon.co.uk](http://smile.amazon.co.uk) and login with your usual Amazon account.

Need help with fundraising? Email [fundraise@pkdcharity.org.uk](mailto:fundraise@pkdcharity.org.uk) or call 07715 664687.



### Donate your car

Do you have a car to dispose of? Giveacar is a UK based fundraising organisation that

organises car donation for good causes in the UK.

[giveacar.co.uk/charities/polycystic-kidney-disease](http://giveacar.co.uk/charities/polycystic-kidney-disease)

## Choose a challenge

Email [fundraise@pkdcharity.org.uk](mailto:fundraise@pkdcharity.org.uk) to sign up today!

### PKD Runners

- 29 Mar London Landmarks Half Marathon
- 23/24 May Edinburgh Marathon Festival
- 24 May Great Manchester Run 10k & Half Marathon
- 20 Sep Scottish Half Marathon & 10k
- 3/4 Oct Run Bournemouth Festival
- 11 Oct Great Birmingham Run
- 19 Oct Great South Run

### PKD Cyclists

- Jun & Jul Nightrider Cycle London, Bristol, Liverpool
- 13 Sep London to Brighton Cycle

### PKD Fun Runners / Trekkers

- Jun - Oct Big Fun Run 5k & Dog Jog Series - 12 venues from Falkirk to Southampton!
- Apr - Sep 12 epic Ultra Challenges 25k, 50k or 100k treks from Isle of Wight to the Lake District!

### PKD Kiltwalk walkers

Take on the mighty stride, big stroll or wee wander in Glasgow, Aberdeen, Dundee or Edinburgh and help support anyone affected by PKD - all with Hunter Foundation topping up your fundraising by 50%!



**Join the PKD Charity Genetic Lottery® and win up to £25,000!**

It's so easy to play. Visit [pkdcharity.org.uk/fundraising/pkd-genetic-lottery](http://pkdcharity.org.uk/fundraising/pkd-genetic-lottery).

Good luck and ..... you're helping support the PKD Charity's work!

# Our support services

## Helping you cope with PKD



### In person/face-to-face support

#### Meetups

We help organise regular social meetups for adults living with PKD, their family members or friends. An informal way to share experiences, offer friendship and signposting to other sources of support and information. Check our website for details.

[pkdcharity.org.uk/support/pkd-meetups](http://pkdcharity.org.uk/support/pkd-meetups)

#### ADPKD information and support days

Hosted by leading PKD renal consultants in venues around the UK. Providing an opportunity to find out more about ADPKD, treatments, ask questions, meet with others and share experiences.

#### ARPKD information and support days

For parents, carers, family members and adult patients affected by ARPKD, followed by informal social event for children and other family members.

Check our website for the next event.  
[pkdcharity.org.uk/support/pkd-information-support-days](http://pkdcharity.org.uk/support/pkd-information-support-days)



### Telephone support

0300 111 1234  
Helpline

Confidential personal support from an experienced PKD volunteer. Available from 9:30am to 5:00pm Monday to Friday.

#### Telephone peer support service

Our trained volunteers are people living with PKD. They have a range of experiences, so whether you are wondering about dialysis or transplant, or worrying about what to say to your children, our volunteers can help. Call **07739 632836** to find out more and be matched with

someone who understands what you are going through.

#### Topic based teleconference

Monthly conference call on a specific topic for up to 10 people. Hosted by a professional and a volunteer with experience of PKD. An opportunity to dial in, ask questions and listen to others' experience, from the comfort of your home.



### Online support

#### Facebook groups

We moderate dedicated PKD Charity, UK-only private

groups on Facebook. Ask questions and share your experiences with others diagnosed with PKD, their families, and loved ones. There's always someone who knows what you are going through and can give you mutual support.

For everyone affected by PKD

[www.facebook.com/groups/pkdcharityUK](http://www.facebook.com/groups/pkdcharityUK)

For Parents of Children affected by PKD

[www.facebook.com/groups/parentsofchildrenwithpkd](http://www.facebook.com/groups/parentsofchildrenwithpkd)

For everyone affected by ARPKD

[www.facebook.com/groups/arpkdUK](http://www.facebook.com/groups/arpkdUK)

#### Topic based webinars

For people who can't attend Information and Support Days. Webinars are led by a medical expert, are easy to access from a PC or smartphone or can be viewed later.

The topics will include PKD in children, tolvaptan, genetics, pain, diet and lifestyle.

Visit our **Events page** for details of upcoming webinars, information days, meetups and support group calls:  
[pkdcharity.org.uk/news-events/events](http://pkdcharity.org.uk/news-events/events)

## PKD Charity Health Information

We have adopted The NHS Information Standard - a quality standard that supports the production of health and care information which meets the needs of all patients, carers and families.

All our factsheets are written by medical experts and checked by our lay reading panel of people affected by PKD.

Key factsheets include:

**Just Diagnosed with ADPKD**  
[pkdcharity.org.uk/about-adpkd/just-diagnosed](http://pkdcharity.org.uk/about-adpkd/just-diagnosed)

**Symptoms of ADPKD**  
[pkdcharity.org.uk/about-adpkd/symptoms-of-adpkd](http://pkdcharity.org.uk/about-adpkd/symptoms-of-adpkd)

**Living with ADPKD**  
[pkdcharity.org.uk/about-adpkd/living-with-adpkd](http://pkdcharity.org.uk/about-adpkd/living-with-adpkd)

**About ARPKD**  
[pkdcharity.org.uk/about-arpkd](http://pkdcharity.org.uk/about-arpkd)

If you do not use the internet, ring our Support Line **0300 111 1234** and ask for printed copies.

## Links to Other Sources of Help

Links to other sources of help:

Kidney Care UK - individual grants  
[www.kidneycareuk.org](http://www.kidneycareuk.org)

Turn2us – broad range of advice on welfare benefits and grants  
[www.turn2us.org.uk](http://www.turn2us.org.uk)

Family Fund – grants for seriously ill or disabled children  
[www.familyfund.org.uk](http://www.familyfund.org.uk)

UK Government Benefits Info  
[www.gov.uk/browse/benefits](http://www.gov.uk/browse/benefits)

Children's Liver Disease Foundation  
[childliverdisease.org](http://childliverdisease.org)

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