SPRING 2024







Welcome to the latest edition of our newsletter.

This Easter, we extend our gratitude and warmest wishes to the donor families who have shared the gift of life and we celebrate the connections that bind us together with recipients. Your compassion and selflessness has created hope and renewal in countless lives.

Happy Easter to our extraordinary donor family and friends of the network!

In these pages we bring inspiring stories, heartfelt narratives, share the impact of generosity, and honour the memory of our loved ones as we celebrate the gift of life.

We would like to wish all the incredible participants at the British Transplant Games the very best of luck!

May your strength, determination, and sportsmanship shine as you compete and celebrate life. Your journey and resilience inspire us all. Go out there, give it your all, and may the spirit of competition and camaraderie bring joy to each moment. Good luck!

Have fun with our puzzle, see how many you know WITHOUT resorting to the internet!

A big thank you to everybody who has contributed to this newsletter. If you have a story, fundraising or sporting event you would like to share, please contact us using the details on page 16.

CONNEXIONS

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Registered charity





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Our grateful thanks go to all those who have kindly donated to the Charity or raised funds for us:

Thank you to our regular donors

Patrick Gallagher

Darren Cox

Keith Astbury

Pauline McDonnell

A Heron

J Fletcher

S Hall

Roger Quick

Paul White

Donations have been gratefully received from:

Bird & co Solicitors

Stephen Hancock

J Peterson

Sue Evans

Sid & Carol Lamb

Brenda Shave

James Burrough

Jo Shafer

Karli Pepper

Carly Craddock

Brigg Women's Institute

Fundraising

Andrew Smith in memory of his son Aaron James
Teresa & Alan Wilkins in memory of their daughter Claire
Rob Hudson in memory of his wife Elaine
G Heywood in memory of his son Phillip
Gavin & Tracy Atkins in memory of their son Joshua Patrick
Kirsty Gudgin in memory of her husband Robert Christopher
Paul Calloway
Ashley Snelson

Donations in memory of Jane Nix Donations in memory of Jane Seymour Donations in memory of Richard Saville

Just Giving

Jack Amesbury in memory of his son Dayle
Recipient Nikki Detko
Abigail Whitehouse – in memory of Oliver Amess who gave the Gift of
Live in January 2022

Transplant Sport fund raising

Alison Bridge from MLSGB, the company that organises the games, and Daley Cross, one of the Trustees of Transplant Sport, will be taking part in a fund raising event to raise money for the British Transplant Games. Alison will be taking part in the London Landmarks half marathon on Sunday 7th April and Daley will be doing the London marathon on Sunday 21st April.

If you would like to sponsor either or both of them, please use the links below:

Alison's Half Marathon:

https://www.justgiving.com/page/alison-bridge-1701954709750

Daley's Marathon:

https://www.justgiving.com/page/daley-cross-1706712340112

Lisa Dominy

Lisa has set up a Just Giving page in memory of her Mum.



She says, "Our Mum passed away suddenly and organ donation was no question for us. Our Mum had donated over 50 units of blood and was on the organ donation list twice!

Taking part in the Hyrox competition with my lovely friend Vikki and the @BFunctional team was a fitting way to celebrate Mum's giving of life. Mum loved to keep active and walked (very quickly) most places! It was a huge challenge but knowing we were doing it in memory of her made it all worthwhile!"

Thankyou ladies for the funds you raised for the DFN.

Grahame Green

Grahame's daughter Hannah kindly set up a Much Loved page in his memory, in favour of the Donor Family Network, which says:



"This site is a tribute to our Grahame, a, devoted Husband and Dad, cherished Son, loving Brother, Brother In-Law, Uncle, and the most wonderful friend, coach, mentor, and Teacher. Dad passed away unexpectedly but peacefully on Thursday 5th October, at 68 years young.

He lived a (too short, but) very full life predominantly devoted to my Mum, whom he was married to for 45 loving years. He spent most of his time supporting, helping, and teaching, that extended to not only his students, but his friends, neighbours, family, and extended family and friends. He is and always will be much loved and will always stay in our hearts."

British Transplant Games, Nottingham

1st to 4th August 2024

Over the weekend of 9th and 10th February the managers from the 59 teams that will be competing at this year's games gathered, in person and virtually, to find out about them. On the Friday evening there was a review of the very successful Coventry games (see below for some impressive stats.), information about Transplant Sport governance and forthcoming changes and separate meetings for the adults and children's teams to discuss their specific events. At the evening meal Tim Reddish, the Chair of the local organising committee and a former medal winner at three paralympic games, spoke passionately about this year's games in Nottingham.

On Saturday individual meetings were held to organise accommodation before the final session with all the information about the games, venues, opening and closing ceremonies. The delegates then boarded a double-decker bus for a tour of the venues.

The main venue will be the Harvey Hadden Sports Village, which will host sports every day; the David Ross Centre with events on Thursday and Friday and the Clifton Sports hub with most of the children's events on the Saturday. Other venues will host a single sport. One big plus this year is that both the cycling and swimming will be held at the main venue, Harvey Hadden, so travelling will be reduced and, hopefully, there will be larger crowds of spectators.

The opening ceremony will take place at Nottingham Castle while the closing ceremony will be at Nottingham Trent University Student's Union, the Level. This year there will not be a food offering so that teams can arrange their own meals before the party!

Registration is now open and will close on 26th May. Those who attended last year should have received an email to reactivate their registration. If you are a donor family and would like to attend, please drop an email to info@donorfamilynetwork.co.uk and Jim, out team manager, will send you details of how to register.

Needless to say, the organisers hope that this year will be better than any other but, more importantly, that all the competitors and supporters have a wonderful and memorable time.

Coventry 2023 in numbers



- * 270 child competitors * 80 technical officials * 190 volunteers
- * 2000 took part in the Donor Run, the biggest number ever
- * 599 adult competitors * £2.4million economic impact.

<u>Transplant Sport Satellite Event – Pétanque</u> <u>Saturday 13th April 2024</u>

Following a successful event at both the European Transplant and Dialysis Games in Oxford in 2022 and the World Games in Perth, Australia, last year, pétangue will be included in the British Transplant Games this year.

At both of these games, with little training, the GB & NI team won several medals. To try and improve skill levels and to introduce new players, a taster day has been arranged at the Rochdale Pétanque Club based at Milnrow Cricket Club. The cost will be £10 or, if you want to take part in the Rochdale Cup on the Sunday as well, it will be £20.

If you would like to attend and compete or just to watch, please contact Daymon Johnstone at daymon11396@hotmail.co.uk

Trentham Gardens, Stoke on Trent

In March 2022 a sculpture 'In thanks and honour of the Gift of Life given by donors and their families through organ donation' was unveiled in Trentham Gardens. This is known as 'Beyond Ithaka' and was created by Robin Wright who has produced many other sculptures that are to be found in the grounds.

Following a request from the local Specialist Nurses, any donor family who has received the gold heart from NHSBT, (after saying they would also accept our Bronze GOLM Brooch, the trustees have now informed us that this will now not be accepted), will be able to visit free of charge. The DFN will continue to talk to the gardens to see if we can get this decision changed. Not only is this a beautiful sculpture and memorial celebrating organ donation, the gardens are extensive and a wonderful place to visit for a relaxing day out.



Thinking of joining us in Nottingham this year?

Not sure what to expect? Here are some words from Donor Families who experienced their first Transplant Games in Coventry last year, lets see if this helps you decide!

"Words do not describe the feeling of love and inclusivity I felt when I attended the transplant games in Coventry. It was days that were filled with pride, emotion, compassion, love, determination. This was my first games, certainly will not be my last and have already booked the time off in work ready for next year's games in Nottingham. If you have not attended before then I can strongly recommend you do. X" (Helen)

"The Coventry games was our first games as part of a team. Walking in with the DFN, as the last 'team' in the opening ceremony, gave me goosebumps. We were greeted by recipients & their families loudly applauding, many with tears in their eyes. Throughout the weekend I was surprised at how many recipients' families would stop & say 'Thank you' for saying yes to organ donation.

The highlight for me was on the final day when I got to present a medal to Ollie, a 7 year old who is one of Miriam's recipients - an emotional moment for us & his family.

It was great to see the camaraderie between competitors, see the joy that a transplant has brought, as well as having opportunities to speak to other donor families." (Nicola & David)

"This is the first time we attended the British Transplant Games because of past commitments, and would, without a doubt, like to be involved with the games in future .

It was so lovely to be included in the circle of friends with all whom we met within the membership of the DFN. Thank you so much.

At the heart of the event, were the participants of the games, each living because of an organ transplant and so grateful for the gift of life.

I was drawn to the many I spoke to and look forward to meeting them again next year.

The highlight of the Donor walk was a little boy who couldn't have been more than 3. He looked like our son Alan and as we turned the last corner, I saw him looking up at the butterflies with bright eyes and a stretched arm and opened hand hoping for a response to his 'high five '.

I was at the back and as I got to him, I bent down and said, hello, as I gave him a high five in return. He was so happy and gave a shout of joy as he rushed to his mum.

I cannot get that picture out of my mind. It was amazing!" (Norma & Errol)

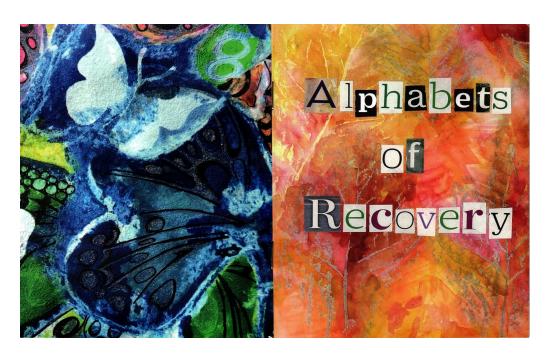
With this newsletter you will receive a book written by Helen, a member of the Donor Family Network. Helen hopes that you will find the book of interest and helpful. Creating this book has helped her cope with her grief. Her message below is self explanatory.

Many thanks Helen for your thoughtful gift.

Hello, my name is Helen.

My daughter Alice became an organ donor when she passed away at Christmas five years ago. Art, design and craft have always been my mainstay of happiness and what started out as collages and doodles in my sketchbook slowly developed into the little book that you have received. I didn't want to read books that described to me how I should or shouldn't be feeling and found the adult books I tried to read were very dry, and referenced other people's case studies. I wanted to have a book that would mould itself around how I was feeling and that would resonate in some way to each different person who might read it; a book where you could choose your own favourite pages or images, a book that encourages your own thoughts. I wanted to create a happy and positive book that gives quick messages rather than having to read endless pages when you are not really in the mood to be searching for answers. Also, I wanted to create a small sized book that could be easily carried around in your pocket or bag. I love colour and pictures and these are almost totally absent in adult literature about grief. Children's books are amazingly illustrated, so why can't adults have their own colourful picture books too? The Donor Family Network has helped me through many dark times. This little book goes some way to repay the love and kindness that they have given me.

I hope that in some way my book helps you too!



SIR ROY CALNE

It is with sadness that the death of Sir Roy Calne has been announced. Sir Roy Calne was a British surgeon and pioneer in the field of organ transplantation. Born on February 6, 1930, Calne played a crucial role in the development of organ transplantation, particularly liver transplantation.

He studied medicine at Cambridge and St. Thomas' Hospital in London. He later pursued a career in surgery and transplantation. He was renowned for his significant contributions to the field of organ transplantation. In 1968, he performed one of the world's first successful liver transplants at Addenbrooke's Hospital in Cambridge, United Kingdom.

Sir Roy also helped carry out the world's first triple liver, lung and heart transplant in 1986 and in 1994 led a six organ transplant of liver, kidney, stomach, duodenum, small intestine and pancreas.

His work also involved the development of immunosuppressive drugs to prevent the rejection of transplanted organs. He played a key role in the development of cyclosporine, an immunosuppressive medication widely used in organ transplantation.

In recognition of his groundbreaking contributions to medicine and transplantation, Calne received numerous honours and awards. He was knighted in 1986.

Sir Roy Calne's work has had a profound impact on the field of



transplantation, and his contributions continue to influence medical practices related to organ transplantation.

In 2021 Addenbrooke's Hospital named it's transplant unit, one of Britain's largest, after Sir Roy Calne. There are many people alive today who are deeply grateful for his work.

Born 30th December 1930

Died 6th January 2024

ALTRUISTIC KIDNEY DONATION

Altruistic kidney donation is a selfless act that can save a life of someone in need of a kidney transplant. By donating a kidney to a stranger, individuals can make a significant impact on a recipient's quality of life and overall well-being. This act of kindness not only helps the recipient but also has positive effects on a donor's emotional well-being and sense of fulfilment.

Altruistic kidney donation also promotes awareness about organ donation and encourages others to consider becoming donors, thereby potentially saving more lives. This selfless act can create a ripple effect of compassion and generosity within communities. Additionally, altruistic kidney donation can lead to advancements in medical research and technology, ultimately benefitting society as a whole. Overall, the benefits extend beyond the immediate impact on the recipient, fostering a culture of empathy and altruism.

NHS have announced that they are delighted to share the recent milestone that more than 1,000 people in the UK have donated a kidney anonymously to a stranger on the transplant waiting list since the law was changed to allow this in 2006.

Thanks to these 1,000 donors, countless lives have been changed for the better. Meet Neil Cheetham from Devon! He was the 1,000th nondirected living kidney donor in the UK.



He said: "I had a close friend who needed a kidney transplant. Ultimately, sadly, he was unable to receive a kidney, but it made me realise that there are many people whose life could be transformed by living donation.

"I met a local man who had already donated a kidney to a stranger many years ago and he helped to guide me to through the process. I have no regrets at all. I'm as healthy as ever, regularly cycling walking and climbing. "Just six months after the donation I visited Norway to climb there.

It feels good to have been able to help someone in need."

MUM DONATES KIDNEY TO SON

Dad-of-four Simon Fellows was diagnosed with IgA nephropathy, a type of kidney disease, back in 2019. Simon already had ulcerative colitis and at one of his bi-annual reviews, a standard blood test highlighted a change in his kidney function. Prior to this, the 39-year-old had been feeling unwell but had put this down to pushing himself too hard in the gym and having early morning starts.

Upon being diagnosed, Simon was advised that kidney failure was likely and was told this normally happens five to 10 years after diagnosis. By 2022, Simon's kidney function had dropped below 15 per cent of normal, meaning he had kidney failure.

This meant he had to start dialysis.

In the months leading up to this, Simon had started to experience extreme fatigue, dizziness, headaches, and nausea.

He and his family had gone on holiday to Greece and by the time they got home, Simon had to go straight to A&E where consultants arranged for him to have an emergency neckline fitted in order to start dialysis a few days later.

Simon attended the dialysis unit at Warrington Hospital for three afternoons a week to receive treatment that was keeping him alive. During this time, his consultants had started the conversation around a transplant and had begun discussing options available to him.

He was fortunate enough to have the option of a live donor with his Mum Marion and his sister Rachael – as well as close friends and colleagues of his, offering to come forward for match testing. It was confirmed that Marion, 67, was the perfect match and so early that year, the mum and son received the news that the transplant could go

ahead.



Marion said she underwent tests from September 2022 and was told she could be a donor around January 2023. She said it was an easy decision to make to donate her kidney to Simon. Once she knew she was a match, she did not hesitate to undergo the operation. Simon's partner was due to have a baby in April so the decision was to have the operation soon after the baby was born. Simon and Marion counted the days off before the due date.

The transplant took place on 15th May 2023 at the new Liverpool Royal Hospital and was a 'huge success' but there were hiccoughs along the way for Simon.

Marion was discharged home after 5 days, Simon however stayed in hospital until 11 days after the operation. During this time he had



to drink 10 litres of fluids every day, very different from a restricted intake of 800mls prior to the operation!

He had several problems, including a kink in his urinary catheter, several emergency scans and being told he was facing possible kidney rejection. He spent 24 hours thinking he might not survive this only to be told it meant altering his drug regime.

Once discharged he had another setback when his wound failed to heal following removal of the staples. He had to attend hospital daily for his wound to be packed before being resutured a week later.

Simon has to take immunosuppressant drugs and over the winter months has had several infections, including Covid and Pneumonia, which have left him feeling tired. Despite these setbacks the duo are both doing very well with their recovery. Simon feels incredible now and enjoys spending time with his family and is back at work as a performance manager at AutoTrader. He is now free from dialysis which previously took around 15 hours a week. Once he has fully recovered from the operation, which can take around six to 12 months, he will be able to lead a 'relatively normal lifestyle'.

The dad-of-four will always have chronic kidney disease and will need to be reviewed by consultants, but for now, things are 'much more positive' for Simon. And he will always be grateful to his Mum for 'doing such a selfless thing and undergoing a major operation to essentially save his life'.

On a positive note, Simon is very keen to attend the British Transplant Games, not as a spectator but as a competitor. Watch this space!!

NAME THE MEAL ANSWERS

1	B5 & E4	BACON AND EGGS	
2	F4 & C5	FISH AND CHIPS	
3	T4 I2 T3 H4	TOAD IN THE HOLE	
4	R5 B4 & Y9 P7	ROAST BEEF AND YORKSHIRE PUDDING	
5	I5 S4	IRISH STEW	
6	W5 R7	WELSH RAREBIT	
7	C7 P3	CHICKEN OR COTTAGE PIE	
8	L5 & B5	LIVER AND BACON	
9	B5 B5 O2 T5	BAKED BEANS ON TOAST	
10	S7 D4 & C7	SPOTTED DICK AND CUSTARD	
11	B7 & M4	BANGERS AND MASH	
12	S9 B9	SPAGHETTI BOLOGNESE	
13	C6 C3 C5	CHILLI CON CARNE	
14	B5 &B6 P7	BREAD AND BUTTER PUDDING	
15	C3 A2 V3	COQ AU VIN	
16	C6 B4 H4	CORNED BEEF HASH	
17	T5 & O6	TRIPE AND ONIONS	
18	L5 M8 P3	LEMON MERINGUE PIE	
19	F7 &M5 P4	FAGGOTS AND MUSHY PEAS	
20	C7 T5 M6	CHICKEN TIKKA MASALA	
21	K8	KEDGEREE	
22	C6 & B8	CHEESE AND BISCUITS	
23	S9 P3	SHEPHERDS PIE	
24	J3 R4 P4	JAM ROLY POLY	
25	C7 C4 M4	CHICKEN CHOW MEIN	
		TOTAL	

BABY ANIMALS

1	What is a baby Fox called?		
2	What is the name of a baby Owl?		
3	Baby Hedgehogs are called what?		
4	Jellyfish offspring are known as ?		
5	A baby Penguin is called?		
6	What are baby Bats called?		
7	Sloth babies are called?		
8	Butterfly young are ?		
9	Snail offspring are called ?		
10	Peacock babies when hatched are ?		
11	What are baby Armadillo know as?		
12	Seahorse young are called?		
13	The name for Alpaca babies is?		
14	Pangolin young are ?		
15	The common name for Cockroach young is?		
16	What are the young of an Axolotl known as?		
17	Young Guinea Pigs are called?		
18	Baby Dik Dik are called?		
19	Yak young are known as?		
20	What is a baby Cuttlefish called?		
21	Young Slug babies are ?		
22	Tarantula young are ?		
23	Baby Turkeys are known as?		
24	What are baby Platypus known as?		
25	Koala young are ?		



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The Donor Family Network

THE PRECIOUS GIFT EVENT 2024

An Event of Hope, Thanksgiving and Remembrance

Donor and recipient families, professionals and anyone interested in organ and tissue donation welcome

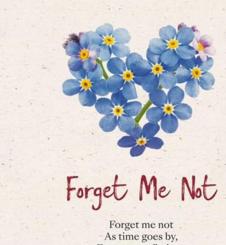
SUNDAY 22nd SEPTEMBER 2024 at 1PM

National Memorial Arboretum Croxall Road, Alrewas, Burton-on-Trent DE13 7AR

Please e-mail the charity is you plan to attend so we can cater for the numbers attending. Please attach a photo of your loved one if you wish this to be displayed.

www.donorfamilynetwork.co.uk

Email:info@donorfamilynetwork.co.uk



For you can find me In the sky.

Forget me not Though we're apart, For you carry me Within your heart.

Forget me not Although I've gone, For my memory Will always live on.

Instead, remember me In every special way, Keep me close to your heart We'll meet again, one day.