



JANE NIX

It is with great sadness that we share the news that Jane Nix, co-founder of the Donor Family Network, sadly passed away on 5th September.

Jane was an amazing lady who offered support to so many over the years and touched the lives of innumerable people.

She was instrumental in setting up the charity with husband David, following the tragic death of Rebecca, their daughter. Jane started up a local support group in 1997 which reached registered charity status in 2003. Over the years Jane was Secretary, wrote the newsletter, made anniversary cards and arranged the annual memorial service.

Jane worked tirelessly as a Trustee and has helped us become the successful organisation we are today.

Jane and David have received a well-deserved Special Recognition Award from the Order of St John and a Points of Light Award for their voluntary work.

We are sure that you will all join the Chairman and Trustees in sending our deepest condolences to Jane's husband David and their son Stuart.





Our grateful thanks go to all those who have donated to the charity and supported others in their fund raising activities.

We thank everyone who has kindly raised funds or made a donation to the Donor Family Network recently:

Thank you to our regular donors

Roger Quick
Patrick Gallagher
Darren Cox
Keith Astbury
Pauline McDonnell
A Heron
J Fletcher
S Hall

Donations have been gratefully received from

Paul White
Virginia Marsh
Bird & Co
A Platts
Shibden Women's Institute
Liam Barnett

In memory of Richard Whitehouse
In memory of Jane Nix
In memory of Bethan Phillips
In memory of Caitlin Sharp
In memory of Michael Coulson
In memory of Gus Riddell

Phillip Russell – who ran the Belfast Marathon in memory of Debbie White
Hollie Alexander who held a fund raiser in memory of her brother Adam
Sarah Hickman and family who held their annual fundraiser in memory of Georgi

Just Giving pages have been created by

Lisa Dominy who is doing the Hyrox Birmingham in October 2023 in memory of her mum who donated in October 2022



Zara Gillespie says: "To celebrate three decades of Conor McTeague I will be walking three kilometres a day from the 19th of September till Conor's birthday, the 19th of October. My aim is to raise money for a charity called the Donor Family Network.

This is in honour of Granda Stevie, Conor's daddy and our girls Granda, who donated three organs in 2016 following his untimely passing. Stevie gave the gift of life to three others through organ donation.

The Donor Family Network works along side the organ donation team in SWAH by providing families with keep sakes while they're in hospital with their loved ones prior to donation. The Donor Family Network is run by donor families for donor families offering support when needed. The charity is entirely funded by donations.

Most of my walks will be completed with our three girls, Alía, Eden and the dog Kayos. On days when the weather isn't on our side it will just be Kayos and I." Thank you Zara.



DO IT FOR JO

Friends of Jo Binks are raising funds for the Donor Family Network via Just Giving.

On their page they say, "Her life was suddenly cut short after a brief but intense fight with Strep A & Influenza, culminating in a heart attack at the age of 33, on 3rd January 2023.

Jo was woman full of life and vitality, whose intensity of life and passion knew few bounds.

She was such a bright star, always running at 110% and the energy she brought to everything she did will be sorely missed by many.

A newlywed, PhD in Infectious Disease, MSc in Cancer Research, ex-GB team freestyle kayaker and overall lover of the outdoors, she leaves behind a long shadow in the lives of those she expedited with, worked with, and loved.

Amongst Jo's many accomplishments, she completed the Slateman triathlon in May 2019. Post-pandemic she had her sights set on the legendary Sandman triathlon on Anglesey, in September of this year.

Her widower Sam, sister Steph, and friends Rosie, Lucy, Jonny, Rich, Leo, Andy, & Jeff are finishing the race Jo was unable to start.

It was abundantly clear that Jo wanted to donate; so much so that she signed up on 5 separate occasions over the past 7 years!"



ORDER OF ST JOHN AWARD

On 15th September a celebration of the 10th Anniversary of the Order of St John Award (awarded posthumously to organ donors) was held in the Order of St John Museum in London. Invites were sent to all regions who selected representatives to attend the event. Two of our Trustees, Karen and Eunice attended on behalf of their local Organ Donation Committees. The Donor Family Network was offered two places and Trustees Nigel and Jim represented the charity. Donor families and staff from NHS Blood and Transplant from across the UK were in attendance, allowing for plenty of networking.

The Duke of Gloucester unveiled a memorial stone in honour of all donors for their precious gift, to be installed in the Cloister Garden at the museum, where anyone will be able to visit it.



Jim, Eunice, Karen and Nigel in London.



The Duke of Gloucester unveiling the memorial stone.

On Wednesday 20th September a similar celebration was held in Glasgow, this time presided over by the Duchess of Argyll, the Grand Prior of the Order in Scotland. Trustee Jim and his wife Linda were invited to represent the charity. The event was held in the magnificent City Hall and 51 donors were honoured with the award after which over two hundred family members enjoyed an afternoon tea and the chance to mingle and talk about their loved ones.

National Memorials

Apart from our Gift of Life memorial at the National Memorial Arboretum in Alrewas there are many others around the country, mainly in hospitals. We have recently been in contact with Hospital Art Studios who have produced many of them and we now have pictures of several on the website. They can be found at the 'hospital donor memorials' section under "*information*". Although they are shown in black and white, if you hover the cursor over them, they will appear in colour. A click will bring them up as full size versions. If you know of any other memorials, please send high quality photographs to our email address, see back page, and we will add them to the gallery.

On Saturday 23rd September Linda and Jim again represented the DFN charity at a memorial service held at the National Botanic Garden of Wales near Carmarthen. This was a beautiful service attended by over one hundred people in the theatre and then in the great glass house for refreshments where entertainment was provided by the 2wish choir. This is a choir which has been set up to support those affected by sudden death in young people. Following this, Linda and Jim enjoyed the chance to wander through some of the extensive gardens and viewed the memorial to donor families which is pictured here.



The Welsh Memorial at the National Botanical Gardens of Wales near Carmarthen

Artificial intelligence tool – Kidney transplantation

A new Clinical Decision Support Tool (CDST) has been developed to find out if the use of Artificial Intelligence (AI) software will help clinicians to make better decisions around kidneys offered for donation. There are currently 5,000 on the waiting list for kidney transplants, but only half this number will receive a transplant each year. When a kidney is offered for donation the transplant team have limited time and information to decide whether to accept the offer. The CDST has 20 years of transplant data to predict patient health outcomes following acceptance or refusal of an offer. It gives the doctor clear information about why the prediction has been made and will allow the patient to understand how the doctor made their choice. A clinical trial will provide evidence that the tool can help decision making and is safe to use. Each kidney offered will be placed at random into one of two groups. In the second group the doctor will use their clinical expertise, together with information from the CDST. The trial will take place at two UK transplant centres. Patients will be asked to provide feedback as to how useful they found using the tool. If the study shows that the AI tool helps decision making, a larger UK wide study can be planned.

Organ Donation Week 2023

Sandi Sund from NHSBT sent an update on activity during Organ Donation Week. "If someone asked me what was my highlight of this year's Organ Donation Week (ODW) I don't think I could pinpoint one thing, from our stands to our webinars, they were all a success, and the sheer number of activities was astonishing. Our campaign "The Best Thing You'll Do Today" was targeted for our Quiet and Caring audience.

"What's the best things you did today? Well, what if you could do something even better? Something that takes only 2 minutes and could save up to 9 lives. Because being an organ donor is just that.

Confirm your decision to be an organ donor, it's the best thing you'll do today!

Our aim was to Inspire, Explain and Act, to Drive awareness of the need to register your decision, to Drive urgency and to take action, to Direct people to the Organ Donor Register, and to achieve 25,000 opt-ins.

Well, how did we do???

NHSBT created over 230 new assets for this very special week and our team of amazing Organ Donation Ambassadors certainly played a massive part in the success of ODW 2023.

There were..... (see picture below)

47 - ODW Stands & Speaking opportunities

8 - Webinars

3 - Podcasts & Blogs

6 - Radio Opportunities

4 - Newspaper articles

2 - TV interviews

2 - Organ Donation Memorials

2 - PSHE Assembly Presentations – ks3/4 school presentations

An ambassador record total of 74 activities during ODW 2023 and a 230% increase from ODW 2022. No pressure for 2024!

This does not include the endless number of social posts, which were simply too impossible to capture!

So an amazing ODW 2023!!!

None of this would have been possible without everyone's contributions, our amazing charities & partners, our amazing Donor Families and our outstanding Organ Donation Ambassadors!!

You are all so special and on behalf of NHS Blood and Transplant, our sincere and humble thanks to you all".



Never forget the difference you make!

PRECIOUS GIFT EVENT

On Sunday 17th September we held our annual Thanksgiving and Remembrance Event. Almost 200 people joined us on the day at the beautiful National Memorial Arboretum. We hope that many of you had the time to go and see the Gift of Life Memorial in the grounds.

Guests enjoyed music and poetry and the opportunity to light a candle in memory of their loved one or donor. Andrew Dorrian spoke about his transplant journey which has led to success in the British and World Transplant Games. Dr Dan Harvey gave us a very interesting insight into the Signet trial, where research is being undertaken to improve outcomes in heart transplants. Trustee Audrey Wheeler and her daughter Sophie stole the show, telling their story of Ian, Audrey's husband and Sophie's dad, who gave the gift of life. Sophie was very young when Ian passed away but as a teenager she wrote a poem, "Daddy, are you proud of me?". There wasn't a dry eye in the room!

Tea and cake was enjoyed after the event as was the time allowed for families to speak to each other, share stories and offer support to those who have recently started their transplantation journey as donor family or recipient.

This event is held annually in September. We hope to see you in 2024.

CONVERSATIONS FOLLOWING THE PRECIOUS GIFT EVENT

During the Precious Gift event, conversations with recipients and donor family members took place. One lady was visibly upset and she said that she was a recipient from many years ago. The reason that she was upset was that she felt she had let her donor family down as she had never had 100% good health since the transplant. She said the problem with the newsletter was that all the stories were of successful transplants, and she couldn't relate to this. Her comment was food for thought.

Organ transplants are a very successful therapy, and most people who receive them can live relatively normal lives. There may still be hiccups in the road to recovery, but for some people these hiccups can be hard to handle.

Receiving an organ is a life changing experience and the relief of receiving the transplant is often paired with the heartbreak of knowing that someone they have never met has died.

While being grateful for the gift of life, this may cause feelings of joy and guilt. Prior to the operation thoughts are mostly about the illness, the procedure and the healing. The recipient is less likely to focus on the emotional and mental impact that occurs afterwards.

As time passes survivor guilt is a common reaction, thinking about the

donor and their family.

This guilt can be especially strong for people who became very sick whilst waiting and praying for an organ to become available. Some have the thought that they are wishing someone would die. It is important to remember that unfortunately someone did die but not to save their life, however they were the lucky recipient.

Sometimes these feelings can become so severe that they impact on the recipient's ability to function, mental wellbeing and their quality of life.

Guilty feelings can also be felt by recipients who do not regain 100% good health following the operation. They may feel they have let their donor family down and the organ transplanted should have been given to another sick person, who may have fared better. It takes time to recover and get back to normal, not being prepared for reality can cause disappointment and lead to depression.

This guilt can prevent them feeling truly happy, or may make them feel worse after enjoying simple pleasures.

Anyone who's undergone organ transplantation needs to take drugs to suppress their own immune system and reduce the risks of the organ being rejected by the body. These drugs may also cause mood swings, depression, and insomnia, but are vital.

Many people find support groups can make a big difference. In everyday life you don't meet many people who have had a transplant. By joining a group of people experiencing the same worries and talking together can make them feel more positive about life.

Talking with a counsellor, social worker, faith leader or psychologist about these feelings and being offered coping strategies can help people cope with their guilt.

Talking to a member of the Donor Family Network or the Samaritans may also help. Phone number for the Donor Family is **0845 6801954**, Samaritans have over 200 branches throughout the country and phone calls are free.

A quote from a recipient who said "Every morning I rise, I remember and am thankful for my donor, his family, and all donors. I know I did not cause his death, so I try to think positively about the life his given organ has given me. It is a struggle to move forward at times."

Transplantation is an amazing journey that tests the limits of human strength and courage. It requires commitment and faith as well as mental, emotional and physical endurance. If you can handle transplantation, you can conquer anything you set your mind to. It is one of life's greatest challenges, and among the rewards is LIFE itself.

AVA TAYLOR'S TRANSPLANT STORY

Fifteen-year-old Ava was diagnosed with OTC deficiency at eight months old.

OTC, also known as Ornithine Transcarbamylase Deficiency is a rare inherited metabolic condition named for the enzyme that people with OTC are missing. The lack of this enzyme stops her liver breaking down protein. Unused protein first gets converted into a toxic chemical called ammonia. This chemical can cause damage to the body and brain if it's not removed and is allowed to build up. This build up of ammonia means some babies can become ill in the first few days of life, whilst some may be diagnosed later as children. For both, the effects of high ammonia, known as hyperammonaemia, can quickly become life-threatening if untreated.

OTC is estimated to occur between 1 in 56,500 to 1 in 77,000 people.

Just two months after being diagnosed and after multiple hospital admissions, Ava had a gastrostomy feeding tube fitted. Despite her diet and nutrition being calculated by a metabolic dietician, Ava still regularly needed an emergency regime to keep her ammonia levels from rising.

At the age of five Ava was deemed too unstable and received a liver transplant in 2013. She faced 18 difficult months of severe rejection before she very slowly began to improve.

As she had never learnt to eat, conventional food made her ill and it took more than 4 years for her to start her transition to a normal diet. Mum said anything with a high amount of protein in it would make her feel ill.

Slowly with the help of counselling, Ava started to learn to eat; something which she had never done before. Four years later her gastrostomy was removed. Ava has always loved swimming, but her condition and gastrostomy made it difficult. With the removal of her gastrostomy and slowly building up her strength and stamina after her transplant, Ava can now fully enjoy swimming. Not only does she swim regularly with her local club, but she has also competed at the British Transplant Games and represented Great Britain at the World Transplant Games!

At her first World Transplant Games in 2019 she won five gold medals and set four world records in her age category! Ava and her family flew to Perth this April to compete in the 2023 World Transplant Games, where she won another five gold medals, set a new world record, and two silver medals.

Ava already has her sights on Germany 2025 World Transplant Games.

Caroline, Ava's Mum said, "I am so proud of Ava. Despite everything she has been through she always has a smile on her face and never ever complained at missing out on the normal childhood events growing up. Even when she was well, she still often had to miss out on activities due to the risk of getting childhood illnesses that could have had serious consequences for Ava. Being part of the Leeds Transplant team and now Great Britain has helped build Ava's confidence, allowed her to make life long friends and not feel different".



The British Transplant Games 2023 – Coventry

This year NHSBT attended the British Transplant Games. The stand was managed and coordinated by Sandi Sund with NHSBT staff, including the Donor Family Care Service.

Included was information on research projects led by Katie Barrowclough from Donor Family Care Service and Transplant Recipient Organ Donation Ambassadors.

The photographs below shows Competitors, Organ Donor Ambassadors, NHSBT staff, Donor Family members, and an altruistic kidney donor. A great time was had by all at the games.

Congratulations to everyone who took part, whoever you were.



Over the past few years at the British Transplant Games there has been interest in letter writing following transplant. The Donor Family members were asking attendees if they have written to their donor family, and the replies have mostly been of a negative response, or many people had written but received no reply and there appeared to be no co-ordinated method to address this.

Sandi Sund wrote, "Last year, NHSBT launched the pilot of a special stand at the Leeds Games, our *"Letter Writing Stand"*, the success of this stand gave us scope to plan for Coventry 2023. The NHSBT stand provided an opportunity for individuals from any side of donation and transplantation to drop by and learn a bit more about the process.

The idea of writing a letter to a loved one's recipient, donor family, or even living donor, is very complex, sensitive, and emotional, so this was an opportunity for those who are interested to learn more about the process, receive support, as well as hear from some people who have lived experiences. This was not going to be a place for people to write letters, but rather to talk to others about the idea, share questions or concerns and perhaps get some reassurance, support, and learn about how the process works.

As well as sharing the letter writing resources, I was joined by various colleagues from NHSBT, Katie Barrowclough from our Patient & Public involvement & engagement team, Kay Sybenga, Lisa Greenslade, Nicola Fagan, Hayley Forster from our Donor Family Care Service, Jonathan Robinson and Karen Healy from our Social Media and Case Studies team, as well as various Organ Donation Ambassadors.

NHSBT's presence and participation was appreciated by those attending and competing in the games, and on a personal note I would like to thank the Donor Family Network, Ambassadors, and wider teams at NHSBT for their contributions.

Collectively, our stand was a success, so to everyone involved, thank you for being so amazing and making a difference to each person you spoke to. The success of all our events are only possible by the team participating, and you were all an integral part of this success and your presence was greatly appreciated.

A date for your diaries, 1st – 4th August 2024, Nottingham, all will be hosted by Nottingham Trent University and further details will follow later in the year”.

If you would like to listen to Doroti's beautiful poem, which was heard at the opening ceremony, please follow this link: <https://www.bbc.co.uk/sounds/play/p0q3wrbp>. More information on the letter writing resources (LWR), which launched in autumn 2021, can be found on the Donor Family Care Service website.



NAME THE MEALS

The following are all popular meals or dishes, the clues are given as the initial letter together with the number of letters in the word. For example:- **S5&K6 P3** would be **Steak and Kidney Pie**

1	B5 & E4		
2	F4 & C5		
3	T4 I2 T3 H4		
4	R5 B4 & Y9 P7		
5	I5 S4		
6	W5 R7		
7	C7 P3		
8	L5 & B5		
9	B5 B5 O2 T5		
10	S7 D4 & C7		
11	B7 & M4		
12	S9 B10		
13	C6 C3 C5		
14	B5 &B6 P7		
15	C3 A2 V3		
16	C6 B4 H4		
17	T5 & O6		
18	L5 M8 P3		
19	F7 &M5 P4		
20	C7 T5 M6		
21	K8		
22	C6 & B8		
23	S9 P3		
24	J3 R4 P4		
25	C7 C4 M4		
		TOTAL	

SPORTS AND ACTIVITIES NOT FOUND AT THE BRITISH TRANSPLANT GAMES

1.	Where is Tin Bath racing held?	Isle of Man
2.	When does Bog Snorkelling take place?	August Bank Holiday
3.	Where is the Cheese Rolling event held in England?	Coppers Hill, Gloucester
4.	What type of tree is the Scottish caber usually made from?	Larch
5.	What is a Dorset Knob, used in an annual throwing event?	A hard, dry savoury biscuit
6.	Where is Hurling played?	Ireland
7.	Face Gurning is held at the Egremont Crab Fair, on what date?	3 rd Saturday in September
8.	What is Zorbing?	Running around inside a large transparent ball
9.	Where is the annual world Poohsticks competition held?	Day Dock, River Thames
10.	What annual event is held in Knaresborough, North Yorkshire?	Bed Racing
11.	Wife carrying competition is held annually in Finland. What is the prize?	The wife's weight in beer
12.	When did Shin Kicking start as a sport in England?	17 th Century
13.	Competitive Worm Charming started where in Britain?	1980 at Willaston, Cheshire
14.	Which sport has a player known as a "tosser"?	Tossing the caber
15.	Pillow Fighting is a sport played by whom?	Women only
16.	Which sport is played with an iron puck?	Underwater hockey
17.	Which game has teams known as the Up'Ards and Down'Ards?	Royal Shrovetide Football Club
18.	Which country would you normally find Broom-ball played?	Canada and USA
19.	Which sport is a hybrid form of American Football and Australian rules football?	Austus
20.	What is Pottermus?	A mascot for Stoke City Football Club
21.	Which sport is considered to be the oldest in the world?	Either running or wrestling
22.	What date is Haxey Hood game played?	12 th night, 6 th January
23.	What has replaced elephants in a version of Polo in Sri Lanka?	Tuk tuks
24.	Where do they play the game Pétanque?	France
25.	Which sport do men have to have written permission from their partners to play?	Ferret legging



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Some people wait all day for 5pm,
All week for Friday,
All year for the holidays,
All their lives for happiness.
Don't be one of them.
Don't wait until your life is almost over
To realise how good it has been.
The good life begins right now,
When you stop waiting for a better one.
One day you will wake up and
There won't be any more time to do
The things you've always wanted.
DO IT NOW !

