

Autumn

2021



DONOR FAMILY NETWORK

CONNEXIONS

Registered charity
1098781



**WELCOME TO THE CHRISTMAS EDITION
OF THE NEWSLETTER.**

SEASON'S GREETINGS TO YOU ALL

Christmas is coming and a brand New Year.

Hopefully the pandemic will be easing and life can return to a more normal pace. That being the case we hope to meet up with as many of you as possible at the various events being held next year.

Please let us know if there are any that you wish us to be aware of or to be involved with.

Several times during the year we have been able to meet, for example at the National Arboretum for the Precious Gift of Life event. This day was well attended despite difficulties obtaining fuel to get there! It was heart warming to meet up with old friends and make new ones. The ceremony, especially the candle lighting, is always very emotional and love was definitely in the air.

Those we love
don't go away, they
walk beside us
every day.

Unseen, unheard
but always near,
still loved, still
missed and very
dear.



A BIG THANK YOU TO THE FOLLOWING PEOPLE AND ORGANISATIONS

We wish to thank everyone who has made a donation or has raised funds for the Donor Family Network, their contributions are very welcome.

Regular donors:

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

Other donations.

Memory of Russell Holmes
Memory of Richard Irving
Memory of Alan Blanche
Memory of Peter Livingstone
Memory of Alex Newlove
Memory of Pauline Hulme
Memory of Mary Tyman
Memory of Gerald Hemingway

Howell WI
Brain WI
Bree on Hill WI
East End WI
Meltham WI

Keltruck
Howard Saffer
Gillian Lowe
Samantha Marsh
Jake Mills
Joyce Rudall
Anthony Ryan
Annette Mellor
Felicity Gove
Clare Copesake
Alicia Young
Lauren Stone
Chelsea Lynsky
Anne Goldie
Jeeves Worth

North Yorks East Federation of WI



Just Giving pages:

Nicki Detko who received a liver in 2005– 16 talks over 1 year to raise awareness of organ donation
Caroline White, who also received a liver-running 2021 marathon in honour of her donor

Order of St John Award for Tissue Donation

On Thursday 14th October the Order of St John Award for Tissue Donation was launched at the Priory Church in London. This complements the award for Organ Donation that has been presented to families for some years and is a pin badge of the Order's emblem – the Maltese Cross.

The afternoon started with a welcome from Surgeon Rear Admiral Lionel Jarvis, CBE KStJ DL, the Prior of the Priory of England and the Islands of the Order of St John, in the beautiful Priory Church which was consecrated in 1185. Anthony Clarkson, Director of Organ Donation and Transplantation, then gave a short address about the award. Marion Jones, Hospital Development Nurse, gave a reading before His Royal Highness The Duke of Gloucester, KG GCVO GCStJ, the Grand Prior of the Order, addressed those present. Following this, The Duke of Gloucester presented the award to seven families who had been invited to the launch.

From our point of view, the most significant part of the day was the presentation to David Nix of a Special Recognition Award for the work that he and Jane have done over so many years. Needless to say, David did not enjoy being the centre of attention but everybody present agreed that the award was extremely well deserved.

The Network was represented by David Nix and his son Stuart, Nigel Burton, Eunice Booker and Jim and Linda Fallow.

If you have not received this award but would like to, please contact

Lynne.Woolcocks@nhsbt.nhs.uk

Rachel.Stoddard-Murden@nhsbt.nhs.uk



Millie Stobie Platts

Twenty years ago this summer, when she was just nine months old, Millie Stobie Platts, who was born with the rare and incurable condition, Alagilles syndrome, received a life-saving liver transplant.

At only nine months old Millie had a liver transplant due to her genetic condition which could have caused liver failure, portal hypertension, and growth problems.

Weighing only 5.5lbs, when she was born, meant that doctors had to keep an eye on her progress and at her six-week check the family GP flagged up a slight heart murmur. A "very clever" cardiologist referred Millie to gastroenterology where she was diagnosed.

For Mum Alison Platte it was a terrifying time. "it was pretty awful to hear and a lot to take in but you have to place your trust in these people".

At one of her monthly check-ups when she was six months old, Alison and husband Bill Stobie were told that their baby's liver had started to fail.



Alison said: "You could tell she wasn't a well girl but she would sit up and play. She had yellow eyes and a swollen tummy." After a three-week spell at the Sick Kids, Millie underwent the transplant in Birmingham where the family stayed for three months – leaving older brother Sean in Edinburgh with his grandparents. Millie did get better and she even represented Great Britain in the World Transplant Games in Malaga where she competed in table tennis, athletics and volleyball.

Twenty-year-old Millie, a psychology student at University, had previously won track medals at the British and World Transplant Games. Despite having visual and hearing impairments she is healthy, 20 years since her transplant.

Millie also brought home a gold, silver and bronze medal to her proud parents.

For Millie, the fact that she was able to part take illustrates well the benefits of organ donation:

"I was very lucky to receive a donated liver when I was a baby," says Millie. "It's really important to 'have the conversation' so your family know your wishes regarding organ donation, and others like me get that chance at life. I wouldn't be here without my transplant, and without my donor and their family who had that conversation. I am so grateful to them."

"It truly is the kindness of strangers," says Alison. "We can't thank Millie's donor and family enough. Organ donation decisions are made in such difficult circumstances, but they mean the world to families like ours."

Alison and Millie took on the Great North Run. What a wonderful way to commemorate the anniversary of Millie's transplant and how inspiring for other families affected by childhood liver disease to see them take on this challenge.

Millie was one of five inspirational young people chosen to cycle across the UK as part of the BBC's Rickshaw Challenge, featuring as part of the annual Children in Need fundraising appeal.

This year, 2021, the team cycled over 140 miles between them, with Matt Baker travelling through four different cities before meeting Millie in Scotland and finishing in Edinburgh, Millie's birthplace.

"I hope that people who watched the "Rickshaw Ride" will see my life's journey and the situation my family and I were in 20 years ago and realise that there is light at the end of the tunnel and that there is life beyond a transplant."



While Millie admits that her 30-mile cycle was difficult at times, mostly due to Scotland's hills and climbs, her love for sport helped her push through. Over the years she has competed in 12 British Transplant Games and two World Transplant Games, and is also a member of the University's Women's Volleyball Team.

"The challenge was hard, really hard," said Millie. "But it was also the best thing ever. It's quite important for me to keep fit and active but part of it is just my love for sport. It gives me the motivation to keep active and getting involved in sports is just generally fun."

Congratulations Millie, the Donor Family Network are proud of you and what you have achieved following your liver transplant. You are a great example of what can be achieved if you put your mind to it!

DFN Huggas

Many months ago, Emma Thirlwall (one of our Trustees and a Team Manager for the Northwest SNODs) asked if we knew anybody who could knit or crochet shawls. The idea was that these could be given out to donor families as they waited with their loved ones in ITU. After some discussion it was decided that, to provide a sufficient supply of shawls, a large team of knitters and crocheters would be needed. Consequently, a search commenced for a suitable alternative.

For some years we have sold beautiful pashminas, decorated with butterflies and in a range of colours, at the Transplant games and online so we thought that these might suffice. Unfortunately it was felt that, lovely though they are, they were not quite right.

Eventually samples of fleecy wraps were obtained and one was unanimously chosen by the Trustees. An order was placed for 200 and they were sent to the company that supplies all our badged clothing so that the charity's logo could be embroidered on one corner. Progress was being made! Then along came Covid 19 and everything stopped. Although some transplant operations were carried out the numbers were dramatically reduced and many of the SN-ODs were redeployed into ITU centres. All storage space was taken up with the dreaded PPE so the wraps stayed with the embroiderers.

Things started to look brighter early this year and arrangements were made for 100 to be delivered to both Jim Fallow and Karen Piotr for onward delivery to NHS Blood and Transplant at Speke and to Leeds hospital. To ensure compliance with hygiene rules they had to be individually bagged which delayed their dispatch and, just as they arrived with our Trustees, along came another lockdown. Karen managed to get some sent to Leeds but the delivery to Speke had to be cancelled.

Eventually, the first batch were delivered to Speke and gratefully received by Emma Thirlwall and her colleagues. They will now be available for SN-ODs to hand out where appropriate. Karen attended a meeting for the Leeds team and delivered a further batch.

They have been called HUGGA'S and the explanation of this term is on a postcard (see below) that will accompany the wrap. So far, all the finance for these Huggas has come from Freemasons in East and West Lancashire with a recent donation from two Lodges in Leeds. It is hoped that this source of funding will continue and that we can extend the use across the country. Hopefully, in the coming months, we will have some feedback from the SNODs about how they have been received and an increase in applications from families to become members.



Please accept this "Hugga" from the Donor Family Network to give you a metaphorical hug during your difficult time. The word hugga is from Old Norse and means to comfort. We hope it does that for you. The Donor Family Network will be there to support you in any way it can whenever you need us.

This gift has been funded by:
The Freemasons of Lancashire.

The Gift of Life memorial designed by Julia Hennessy Priest, a gift from the Donor Family Network, at the National Herpetarium, Aintree, D013 7AR.
www.donorfamilynetwork.co.uk www.dfnema.org.uk www.juliahennessypriest.co.uk

Sarah Jane Robinson's personal story

1993, A few months before my 21st birthday I was diagnosed with Type 1 Diabetes. Nobody in the family had Diabetes and I was in complete shock, finding it difficult to comprehend that I would need a lifetime of Insulin injections, amongst other things, to keep me alive. My shock that day was nothing compared to what lay ahead!

Sadly, in the space of thirty three months, not only had I been diagnosed with this condition but my 2 year old daughter and my 10 month old baby were also diagnosed as having Type 1. Constant blood glucose testing, injections, strict diet, hospital appointments, trying to take in information about complications that could occur and trying to keep all three of us healthy meant life was certainly a challenge!

Fast forward exactly twenty years later to February 2013. I'd not long turned the big 40 and started to feel really unwell but stupidly put the symptoms down to the menopause. I thought I was still shaking off the winter flu so did nothing about it. I became so ill I couldn't ignore it any longer and went to the walk in centre. I was diagnosed with a kidney infection but the doctor was very concerned about my blood pressure and urine sample, saying I needed to see my own GP first thing the next morning. I did and the doctor said I needed bloods taking, I thought that was that but later the GP rang and asked me to come in to see her at 8.30am the next morning. I knew the minute I saw my GP's face that it wasn't good news. What she said next absolutely devastated me to the core. "I'm really sorry Sarah but your kidneys have failed, I've rung the Royal Liverpool Hospital and they are expecting you".

Surrounded by consultants they were talking Kidney function, kidney biopsy, medication and transplant, I was completely numb and totally convinced they'd got it wrong. They were not wrong, this was my fate and it meant dialysis and transplant or I'd die by the age of 45! I'd brought up my girls on my own since my youngest daughter Aimee was born and she was only 18. I kept thinking Kayleigh is only 20, this cannot be happening. I'm their Mum, I'm all they have and they need me, I cannot die. And so began the fight to survive. It may sound dramatic but that's the truth, you literally fight every single minute of every single day to stay alive.



By the 1st September 2015 I was placed on the transplant list for a simultaneous pancreas kidney transplant and a month later I started peritoneal dialysis four times a day, seven days a week. I sank deeper into depression and honestly had no life, I merely existed. This existence on dialysis and waiting for "the call" to say a donor had been found was definitely the hardest battle of my life, one I wouldn't wish upon anyone. I'm one of the very lucky few because the call did come at 4.23am one Monday morning in July. "We've found a donor pancreas and kidney, please make your way to Manchester".

Just writing this part makes me cry because all I could think of as I lay there waiting to go to the theatre was my girls.

I loved them more than anyone or anything in this world, I had to get through this for them. I must wake up and I must be brave but then my thoughts suddenly turned to the fact that there was a family somewhere immersed in a deep grief at the loss of their loved one, and I can tell you I have never felt so guilty and so selfish in all my life. I wanted to live yet a life had only just been lost. Every intricate detail and thought of that surreal day will stay with me forever.

Nearly eleven hours later I looked through very blurry, drug induced eyes and could just make out Aimee's face. I kept repeating "I'm alive Aimee, I'm alive Aimee". Yes you're alive Mum, you're talking to me and it all went well. I knew I wasn't dreaming this and in that moment it was like I'd been surrounded by a warmth, this weight I had carried had been lifted and someone or something had taken away years of illness.

I was very poorly after my transplant but after 12 days in Intensive Care I was moved to the Transplant Unit and 10 days later was discharged home. My new journey, my new life with a kidney that worked and a pancreas that produced insulin had begun.

Over the past 4 years since having my transplant, my pancreas and kidney have both functioned beautifully. This precious life that has been gifted to me, has not just given me my life back but my daughters their life back too. I've been able to travel and my proudest moment has been working alongside NHS Blood and Transplant as an organ donor ambassador. I've met so many extraordinary donor families during this time and I'm truly humbled and in awe by their courage and selflessness.

There are not enough words on this earth to describe just how grateful I am to my beautiful precious donor and her family. Their selfless, compassionate and loving deed has not only just saved my life but it has given 2 young women their life and Mum back too, for which I am eternally grateful.





Sarah Jane with Paul Dixon



Sarah Jane with her two daughters Kayleigh and Aimee



Paul Dixon's story

I'm a pensioner, 73 years of age, married with two grown up sons and two grandchildren. I worked for over 40 years for Ford Motor Co, then Jaguar/Landrover in Halewood Merseyside. Early in the 70's I started donating blood, the blood transfusion service used to come into the factory twice a year, just about everyone used to donate because you got time off the job, and sandwiches, tea and biscuits were provided! It was at one of these sessions that I picked up a card that stated in the event of my death I wished to be an organ donor.

Prior to 2012 I must admit I knew absolutely nothing about living donation, I had never known or met anyone with kidney failure, kidney disease or receiving dialysis treatment. I have always considered myself very lucky, as I've never been ill, been in hospital, have any health issues or take any medication, in fact my health has been, and still is, exceptional.

Fast forward to February 2012, when I happened to catch the last couple of minutes of a programme my wife Shirley was watching, in which a gentleman called Richard Pitman, the quite famous now retired jockey, was telling how he had recently donated one of his kidneys to a complete stranger. WOW! My first thought was 'I didn't know you could do that' My second thought was 'Maybe I could do that' Later on that day I found the number for the Royal Liverpool Hospital and left a message with the living donor co-ordinator to say I had seen this programme on tv and was interested in finding out more about being a living donor. I received a call back, we had a brief chat and was then sent a DVD and leaflets through the post explaining more about the procedures.

The following week I had an appointment at the Royal with the co-ordinator, and was taken through the many technical, medical and surgical tests and examinations I would have to successfully go through to ensure I would be healthy enough to donate.

It was explained to me that with any operation there is a risk. Kidney donation is comparable to the removal of an appendix. (1 in 3000 risk of death) also, as this is an operation that I didn't need, and would have no benefit whatsoever to me, I would go into the operating theatre fit and well, and come out slightly less so.

During my assessment the paired/pooled scheme was explained to me. This is a scheme that enables kidneys from living donors throughout the UK to be 'swapped' for the benefit of patients waiting for a transplant. I had a choice of donating directly to a person on the national transplant waiting list, or joining the paired scheme. I decided to join the paired scheme as then two people get a kidney, one directly and one indirectly.

It took the best part of a year to get through all the many blood tests, X-rays, CT and MRI scans etc, there was nothing embarrassing or invasive about them, but did feel a bit of a fraud going to all the various clinics and sitting with patients who had serious health problems, and here's me fit and well. The NHS staff were fantastic, it was an absolute privilege to be prodded, poked and be examined by them! I also had to have a psychological assessment with a psychiatrist, and a meeting with an independent assessor on behalf of the Human Tissue Authority. I would like to make clear that once you start the process, you can change your mind at any time, I was actually asked for the last time in the operating theatre.

The law had to be changed to enable a living donor to donate to a stranger, prior to 2006 I would have been probably considered mad!

It's amazing how a small amount of inconvenience on my part can make a huge difference to someone else, for me it was three nights in hospital and I couldn't put my left sock on for a few days, for my recipient it would mean some sort of normality.

I was given 6 weeks notice of my operation, the date chosen was my 65th birthday, just a coincidence, and I went to theatre about 7.30am and was back on the ward mid day. I didn't suffer any pain, although it was promised, and the following day had a visit from the co-ordinator with the news that my recipients operation was successful and that the kidney was working well.

I was discharged from the hospital 48 hours later, and had a very swift recovery, back swimming 14 days later.

I received a lovely thank you card from my recipient a few months later. She explained that she now had the vitality she had 10 years ago, and because of my wonderful gift, her husbands life and hers had changed 'Immeasurably'.

I started volunteering at the Royal Liverpool Hospital and Wirral University Teaching Hospital in January 2015, and promoted the Organ Donor Register one day each week at both hospitals and in 5 years I've signed over 14,000 to the register. I'm also involved with the organ donation committees at both hospitals, and I'm an Organ Donation Ambassador for the North West for NHSBT.

Donating a kidney is definitely the best thing I have ever done.

Paul and Sarah Jane are both Organ Donor Ambassadors, explaining to the public about the changes brought about by Max and Keira's law.

Please [#ShareYourWishes](#) with your loved ones about your organ donation decision and [#LeaveThemCertain](#).

As part of Organ Donation week, 20th to 26th September Paul organised a short walk on 25th around Sefton Park in Liverpool.

It was attended by other Organ Donor Ambassadors, friends and dogs! It was approximately 3 kilometres long, and was kidney shaped!



Paul with Jade Carr, recipient of a heart and a live altruistic kidney donation. Jade's story was shown in the summer edition.



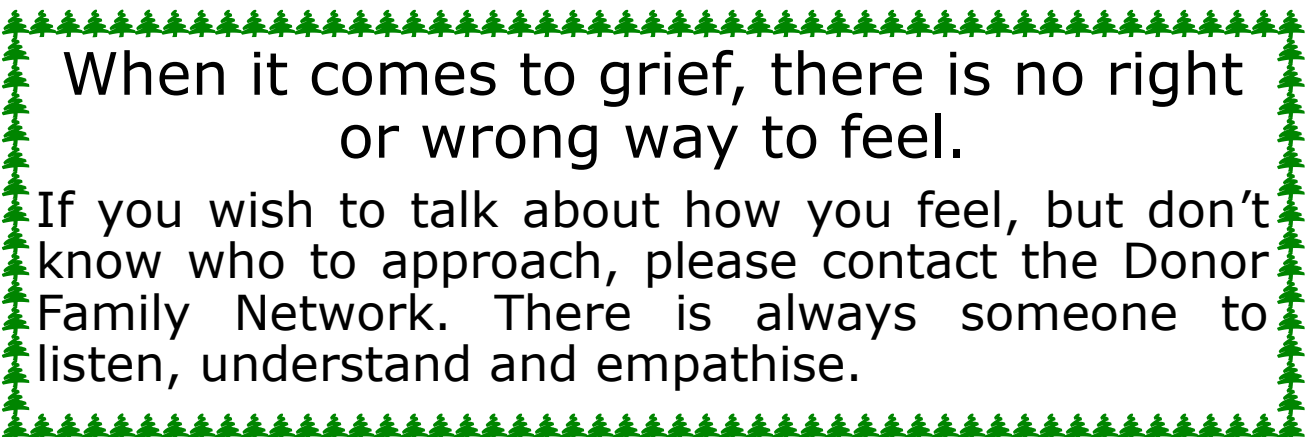
Paul said, I'm often asked 'Have you got a card' when I'm speaking to people, so came up with the idea to have a tattoo of an organ donor card using the exact dimensions of a real card on my left arm to raise awareness of ODR. People have noticed it and it starts a conversation. This is totally out of character for me. I've never had a tattoo before but organ donation means a lot to me so I thought I'd get the organ donor card on my arm.

Missing link puzzle

The answer to each clue is a word that links all 3 given words. The answer could either be before or after the given word. For example the word STONE will go before WALL but after HAIL and LIME.

1. Burn Ache Throb_____
2. Print Nail Tip_____
3. Writing Crafted Back_____
4. Witness Ball Birds_____
5. Tip Hold Caps_____
6. Cloth Shame Lift_____
7. Stabbings Benchers Quarter_____
8. Feeding Plate Red_____
9. Paste Fairy Milk_____
10. Under Chair Pits_____
11. Ache Quarters Mistress_____
12. Bridge Ball Colts_____
13. Bleed Dive Gay_____
14. Stylist Brush Bands_____
15. Reading Hare Upper_____
16. Room Dog Less_____
17. Bottle Lace Tie_____
18. Pot Ache Under_____
19. Watch Big Piece_____
20. Herring Idle Breast_____

Answers will be in the next issue. Good luck!

When it comes to grief, there is no right or wrong way to feel.
If you wish to talk about how you feel, but don't know who to approach, please contact the Donor Family Network. There is always someone to listen, understand and empathise.

Some people reading this newsletter will be "Friends" of the Donor Family Network. The form below is the one completed by people other than donor families to read about organ donations, real life stories and receive up to date information about what the Donor Family Network is about. Please encourage your friends to spend £5 for a one off subscription. This entitles them to a newsletter three times a year. To download the form please go to the Donor Family Network website at info@donorfamilynetwork.co.uk



Friends of the Donor Family Network Membership Form



Please fill in your details below:

Your Name/s

Address

.....

..... Postcode

Telephone Number Mobile

E-mail address

Are you:

Transplant recipient:

When did you receive your transplant:

Which organ / tissue:

Living donor / family member of living donor:

Date of donation:

Details of donation:

Other supporter – thank you for supporting the DFN

Your details will be added to our mailing list.

All information provided is protected by our Privacy Policy pursuant to the Data Protection Regulations. Please sign below to confirm your agreement to us holding your personal information for membership purposes:

Signature/s.....

The £5.00 fee for joining Friends of the DFN can be paid via PayPal or by bank transfer to:
Lloyds Bank

Sort code: 30-99-06

Account number: 0356 6388 Or alternatively by cheque payable to Donor Family Network sent to the address below.

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DON'T FORGET TO FOLLOW US ON FACEBOOK

To Remember Me

Robert Noel Test (1926-1994)

To Remember Me

At a certain moment a doctor will determine that my brain has ceased to function and that, for all intents and purposes, my life has stopped.

When that happens, do not attempt to instill artificial life into my body by the use of a machine. And don't call this my "deathbed." Call it my "bed of life," and let my body be taken from it to help others lead fuller lives.

Give my sight to a man who has never seen a sunrise, a baby's face or love in the eyes of a woman.

Give my heart to a person whose own heart has caused nothing but endless days of pain.

Give my blood to the teenager who has been pulled from the wreckage of his car, so that he might live to see his grandchildren play.

Give my kidneys to one who depends on a machine to exist from week to week.

Take my bones, every muscle, every fibre and nerve in my body and find a way to make a crippled child walk.

Explore every corner of my brain. Take my cells, if necessary, and let them grow so that someday a speechless boy will shout at the crack of a bat and a deaf girl will hear the sound of rain against her windows.

Burn what is left of me and scatter the ashes to the winds to help the flowers grow.

If you must bury something, let it be my faults, my weaknesses and all my prejudice against my fellow man.

Give my sins to the devil. Give my soul to God. If, by chance, you wish to remember me, do it with a kind deed or word to someone who needs you. If you do all I have asked, I will live forever.

It's a gift that keeps on giving.