AUTUMN
2022

CONNEXIONS

DONOR FAMILY NETWORK

Registered charity
1098781

The
Gift of Life
Memorial

SEASONS GREETINGS

Welcome to the winter edition of the newsletter. We have had a very busy few months, and have had the opportunity to meet up with families at various events. Although Covid still lurks in the background we have had the chance to celebrate the achievements of those people competing in the British Transplant and European games. Everyone who takes part is a hero, they have overcome so many obstacles just to live a normal life but to compete in the games is a wonderful achievement, even if you don't win a medal! New friendships are made and renewed each year, a true family feeling.

The annual Gift of Life ceremony, held at the National Arboretum, was attended by many families, with some new faces this year. It is always an emotional day but there is support for everyone and friendships are made or renewed.

If you wish to talk about your situation please contact a Trustee via the contact details at back of this newsletter.

THANK YOU TO THESE SPECIAL PEOPLE

Regular donors
Patrick Gallagher
Keith Astbury
Pauline McDonnell
Darren Cox
R Quick
A Heron
S Hall
J Fletcher

Donations Received From:
Sue Michener
Enid Ashkenazi
C Perkins
S Clark
Deborah Shinett
Caroline Lewis
John Saffer
Dr James Neuberger
Rachel Stoker
Lemone McVarish
Sutton on Sea Barn Dancing Easter Bonnet Parade.
Donations in memory of Linda Meeks.
Donations in memory of Hannah Netley.
Ameshia Williams- opened her gardens to the public to raise funds for the DFN.
Cheshire Wheatsheaves Womens Institute.
Soroptimist International of St Helens.
Sarah Hickman, family and friends raised funds in memory of Georgi.
K Durkan, in memory of a friend’s daughter who was an organ donor.
Bev Kirmond, in memory of her son Jack (funds raised by friends and family and Sharlston Rovers Rugby Club).

Just Giving:
Abigail Whitehouse, in memory of Oliver Amesbury.
Andy Smith who took part in the Aberdovey Bike Ride.
Andrew Dorrian, to help the DFN ensure that the “heroes” are remembered and their legacy lives on.
Rebecca Patel continues to raise funds to allow us to send huggas to new donor families.

WHBTG Leeds 2022 – Tom's Story

Grandfather Gordon, lifted Tom's Baton above his head with Fatima and everybody cheered. What a special moment for me – Tom's Mum, Lisa.

My son Tom was accidentally hit on the back of the head by a hockey stick at training, and tragically died, aged 22 in December 2015. In the Intensive Care Unit at the Royal London Hospital, Whitechapel, it was my husband Graham who said, 'Lisa, there isn't anything anyone can do for Tom now, but there is something Tom can do for others, organ donation'. If my stomach hadn't turned a thousand times that night, it turned again, but I knew he was right. We asked to see an organ donation nurse who came back with the news Tom had signed the organ donor register as a fresher at University. How proud I was of him. On hearing this news, we gave permission for the organ donation to commence. Tom's organ and tissue donation went on to apparently help save and improve the lives of up to 50 people.

However, tragedy struck again, two months later, when Graham suddenly died. My daughter Pippa and I, in our grief, wrote to Tom's recipients and imagine our joy when we heard back from a little girl called Fatima Mirza, who received part of Tom's liver, and Gordon Paw who received Tom's heart. We continued corresponding and then had the wonderful opportunity to meet separately.

Following Tom's accident, the Tom Wilson Memorial Fund,

(http://tomwilsonmemorialfund.co.uk) was set up and in 2019 donated Tom's Baton, a beautiful art work, to Transplant Sport, to be presented every year at the opening ceremony of the Westfield Health British Transplant Games. Imagine my excitement when Fatima and Gordon were asked to do the honours at BTG Leeds 2022!

The day before the event Fatima, her Mum Lubna, and I were asked to appear on the ITV Lorraine show. We proudly told Tom's story, informed viewers about the WHBTG Leeds coming up over the next few days and how Fatima was looking forward to competing in the swimming and Gordon in the table tennis event. Plus, of course, meeting Gordon for the first time!

Then the big moment came. For me, at the WHBTG opening ceremony, the chance to stand next to the closest I could be to Tom on this earth. His heart and his liver. Being with Gordon and Fatima, two recipients at the same time was amazing. An incredibly emotional experience. Gordon and Fatima were given the baton on stage, and then when Gordon raised it above his head a huge cheer went up from the many spectators in the crowd. I thought immediately of how proud Tom and my late husband Graham would have been. An unforgettable moment.

Organ donation – it truly is the gift of life.

In memory of Thomas Wilson (1993-2015).

Tom playing hockey

A happy family photograph before tragedy struck.
Graham, Pippa, Lisa and Tom.

Fatima Mirza, Lisa and Gordon Paw at the opening of the British Transplant Games in August 2022, with Tom's baton.

Fatima was a participant in the swimming race, whilst Gordon took part in the table tennis

Lisa appeared on the TV show Lorraine with Fatima, Lubna, Fatima's mother on 27th July.

HELEN WILSON’S PERSONAL STORY OF TWO TRANSPLANTS

My journey started 22 years ago when a routine urine test showed blood in my urine and this resulted in me being sent for an ultrasound scan on my stomach.

I’m not normally one to ask questions however on this occasion I decided to, and soon wish I hadn’t. The lady said in response to me “oh, so many cysts. I will write a report to your Dr in the hope that they can find someone with a more favourable outcome”. That was back in 2000 and her words have stayed with me ever since.

The result of this was diagnosis of polycystic kidney disease which I had never heard of back then and although I was on the organ donation register, organ donation was not something that I knew anything much about.

I was referred to our local hospital and regular check-ups and blood tests were started and for five years I continued to be well and the only sign that anything was going on was the fact that my stomach was getting bigger and bigger as the cysts in my kidneys grew.

In December 2005 I was told I was in end stage renal failure and needed to start thinking of who I could ask for a kidney. It was December and I remember thinking, well I’ll just put it on my Christmas list then. I was in total shock when I came out of the appointment and was struggling to make sense of what I had just been told. I also decided asking this question of anyone was not something that I would be able to do.

I spoke to my husband Chris when I got home and then had to break the news to my parents although I still wasn’t totally sure what was going on.

I was referred from our local hospital to St Hellier’s and as my kidneys had got so big, the decision was taken to remove them both so there was room if I was ever going to get a kidney transplant. Chris and I went on an information day to talk about dialysis which would be needed once my kidneys were taken out and I don’t think either of us really understood what we were told.

In May 2006 I had a double nephrectomy which resulted in me going on to haemodialysis. I was plugged into a machine for 5-hour stints on a Tuesday, Thursday and Saturday evening and strict food and fluid restrictions were introduced. This brought a massive change to our lives.

Haemodialysis was fine for a while but then stopped working very well so we switched to peritoneal dialysis which I did at home overnight. Again, this was fine for a while but then also stopped doing what it was supposed to. Things started to look really grim. That was until my amazing brother Steve rang me up one day and said he wanted to be a donor for me. I remember the call really well as it was such an incredible thing he was offering to do for me.

Months of tests followed for us both and then the transplant took place at St George’s in February 2007. The next day two of the transplant coordinators came to see me and asked if I had looked in the mirror. I worriedly replied no and they said “but you look so much better”. Sydney, as I affectionately refer to my new kidney, had kicked in straight away and was doing his job brilliantly. No more dialysis. No more food restrictions. No more fluid restrictions. And importantly, Steve was fine after the operation and has been ever since, as have I.

Things were great for about three years and then my stomach started to grow again and it was discovered that I also had a polycystic liver. We couldn’t help but think, here we go again.

I once again became incredibly ill. My body was full of fluid and I couldn't walk far, struggled to dress myself, had to sleep sitting up on the sofa as I couldn't breathe if I laid down and my husband had to sell his beloved car as it was quite low and I couldn't bend down to get in or out of it.

I had bandages on my legs as they were so swollen and were leaking fluid all the time and my mum had to crawl round on our kitchen floor to change the bandages for me. Horrendous is the word that comes to mind when I think back to these times.

Then in June 2013 Sydney's consultant referred me to Kings Liver Unit and I was called in for an appointment. The lovely Professor I saw there asked me if I was worried about anything and my reply was to walk out of there, but with him saying there was nothing that he could do for me. His answer still makes my eyes well up when I think about it as he said that I needed to be put on the list for a transplant.

So many mixed emotions were going round in my head, and the same went for Chris, my family and friends as we knew what would need to happen in order for me to be given a new liver.

I continued on, existing not living, and in the August went into Kings for a series of tests to check that I would cope with another big operation. Thankfully all went well and I was put on the list. There was a concern about my heart at one point and I was taken off the list and the feeling of utter despair was unbelievable. A scan resolved that issue and thankfully I was put back on.

I was extremely poorly by this stage but was also extremely lucky in that we got the call in December 2013 that we had been waiting for and an ambulance came and took me into Kings. The transplant went ahead and in December 2013 I received another chance at life from an amazing donor family who gave me a new liver, affectionately called Lionel.

I spent January 2014 in an induced coma in the ICU unit due to complications and rejection, however, I finally made it onto a ward in February 2014. Things were still not settled and I remember that three chaplains came to visit me as I don't think I was expected to make it home.

However, I can be pretty stubborn when I want to be and the enormity of the chance that I had once again been given at life started really sinking in.

I weighed 18.5 stone when I went in to Kings and weighed just under 10 stone when I came out. It was when I couldn't even walk or sit myself up in bed that I was told about the Westfield Health British Transplant Games so I didn't really pay much attention. However, it obviously stuck with me as I travelled to Bolton in 2014 to go and watch and was immediately hooked.

Since then, I have competed in 100m, 200m, long jump, archery, shot put, discus and javelin and these are all sports that I hadn't done before my transplants. I have trained hard and have been lucky enough to medal. I was part of Team GB&NI in 2019 when the World Transplant Games came to Newcastle and I came away with a silver in discus and a bronze in shot.

The feeling of pride when standing on the podium with Team GB&NI kit on and a Union Jack round my shoulders was immense. What an honour to represent my incredible donors, my hospitals, my country and everyone who has helped me along the way over the years and to show what is possible having been so unwell.

And the story doesn't stop there.

At the Westfield Health British Transplant Games in July this year, I won bronze in archery and gold in discus, shot and javelin. I then went on to compete at the European Transplant and Dialysis Games in Oxford in August. I was really pleased to be fourth in javelin with a season's best and came away with gold in discus and shot which makes me a double European Champion. How surreal is that! And I have recently been contacted to say that I have been selected to represent Team GB&NI again in athletics at the World Transplant Games in Australia in April 2023. What a further fantastic opportunity to represent Steve, my donor family and my hospitals again. To make sure I do the best I can, I have already started training for this so I know I will be fully prepared and can then savour and enjoy the experience whilst, hopefully, putting all my training to good use.

When I think of all the opportunities that I have been given since my second transplant I know how lucky I have been and I know how important it is to make the most of every day and to live life to the full. I have met the most inspirational people at the Games, be that fellow recipients, donor family members or the organisers and officials who make it all possible.

The other important aspects of this for me are about raising awareness of organ donation and of the Transplant Games and showing gratitude.

In regard to raising awareness, our local paper has run a number of articles for me over the years and I have spoken at events and been invited to do local radio interviews. My aim is to ensure that as many people as possible can be given a second, or third, chance at life through organ donation and I hope that sharing my story, and talking about how lucky I have been, will help to make this possible.

In regard to gratitude and my brother, Steve knows that he saved my life and that I will never forget what he did for me. In regard to gratitude and my donor family, I write twice a year to let them know what I have been up to and how I am doing. It's so important to me, and my family, that I do this and I hope I am showing them that I am making the most of the incredible and generous gift that they have allowed me to have.

Without these acts of selflessness, I simply would not be here. Forever grateful.

My brother Steve and me after completing the London Bridge Walk for Kidney Research

How I looked after my liver transplant

Shot at the recent European Games

Celebrating!

Above-The Mersey Gateway Bridge lit up for Organ Donor Week. Thanks to Lorraine Furfie for organising this.

Below– A few members of the Donor Family Network and friends raising awareness for Organ Donor Week.

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.

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 SNODs 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 in 2021 and arrangements were made for 100 to be delivered to both Jim Fallow and Karen Piotr for onward delivery to NHSBT at Speke and to Leeds hospital. To ensure compliance with hygiene rules they had to be individually bagged which delayed their despatch 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 was delivered to Speke and gratefully received by Emma and her colleagues.

At a Trustees meeting later that year it was agreed that, following the trial in the Northwest and Leeds area, the idea and fleece were what we wanted so it was agreed to roll it out across the country. When we tried to order more we were told that there was at least a six month lead time and that they only expected to have one delivery per year! Eventually they arrived and were sent to be embroidered with a delivery of 900 arriving in late July.

The next stage was to get them out to the twelve regional offices including Falkirk, Belfast and Cardiff. This has now been completed with Trustees delivering them at team meetings round the country when we had the opportunity to meet many of the Specialist Nurses, Team Managers and office teams.

The name HUGGA was chosen as it is an Old Norse word meaning 'comfort' and we hope it will give comfort to families at a very dark time.

The Order of St John Award for Organ Donation

Following an enforced break because of covid, a number of presentation events were held around the country during September and October. This award was launched in 2013 jointly by the Order of St John and NHSBT to honour organ donors. It is awarded, posthumously, to donors and received on their behalf by a relative. An indication of how highly this award is recognised is shown by the fact that Lords Lieutenant (or their deputies) and Lord Mayors are regular attendees together with senior members of the Order and NHSBT. Donor family members and NHSBT Ambassadors are also asked to be there in support. The ceremonies are often held in prestigious venues such as Town and City halls and other high profile venues. The relative of each donor receives a pin badge, as shown above, and a certificate followed by refreshments and the opportunity to talk to other donor families.

In 2019 an equivalent award for tissue donation was launched but, again because of covid, the formal launch was delayed until October 2021.

At the launch in the Priory Church of St John in London our founders, David and Jane Nix, were honoured with a special recognition award for their work in setting up the charity and continually promoting organ and tissue donation.

Although the award was set up in 2013, if your loved one donated prior to this date you can still request that they are honoured.

To receive an award, please contact your Specialist Nurse or email-info@orderofstjohn.org.

Thank you to David Nix

This year marks 25 years since our founders David & Jane first set up a local support group after their daughter Rebecca died whilst in America, and donated tissue. Over the years, that local support group has grown momentum, became a registered charity and we are where we are today because of them.

To mark this special occasion, David organised (with a little help), another of his famous fundraising charity balls. What a great night was had by all those there!

Lovely food, Irish bingo, table raffle, a silent auction, 'Nifty's lucky dip', live music and a singer, followed by lots of dancing.

We couldn't let the occasion pass without a cake for David!!

He said its his final ball, but we will see!

Transplant Games

After a break since Newport in 2019, the British Transplant Games were held in Leeds from Thursday 28th July until Sunday 31st July. Despite a natural wariness because of covid, over 850 athletes, together with over 1700 family and team supporters, competed over the four days. Everybody who attended was so grateful to be meeting again in person and the atmosphere was superb.

An innovation promoted by the Leeds SNOD team was a daily workshop about writing letters from grateful recipients to their donor families and replies in return. This proved so popular that the two hour time slot was exceeded every day. The feedback about this workshop was so positive that it is planned to run similar schemes in the future.

The following month the European Transplant and Dialysis Games were held in the UK for the first time. Oxford was the host city with the main venues being Radley College and Blenheim Palace. Following the opening ceremony in the Sheldonian Theatre attendees enjoyed a boat trip down the Thames on a glorious summers evening to Radley College boat house where transport took them to the College itself for an opening dinner. After a week of competition, frequently with stunning backdrops, and several excellent social events, the closing ceremony was held in the theatre at the college followed by a dinner in the formal dining hall. This was followed by various forms of entertainment including dodgem cars, a casino and live bands. Needless to say, the dodgems proved extremely popular!

Looking forward, the World Transplant will be held in Perth, Australia, from April 15th to 21st next year. Team selection, based on performances at Leeds and Oxford, has seen invitations sent to many of our recipients and they are now raising funds of approximately £4000 each for this amazing opportunity. Hopefully, they will all manage to reach their targets and honour their donors by representing the country in Australia.

Coventry had been selected to host the games in 2020 but, with the country in lockdown, they had to be cancelled. However, as things are returning to normal, the city will be the host next year from Thursday 27th July to Sunday 30th so please put the dates in your diary. More details will be available early next year.

> “Winning is something, but participation is everything.”
>
> ***Debasish Mridha***

Quiz Answers For Summer 2022 Newsletter

1. Jubilee
2. Coronation
3. Sovereign
4. Knighthood
5. Princess
6. Throne
7. Commonwealth
8. Aristocracy
9. Sceptre
10. Royal Seal
11. Royal Garden Party
12. Succession
13. Consort
14. Palace
15. Crowning
16. Monarchy
17. Royal Family
18. Queen
19. Sandringham
20. Royal Wedding
21. Majesty
22. Castle
23. Royalty
24. Nobility

Congratulations to Max

Heart transplant champion receives national honour.

A selfless schoolboy has been honoured for helping save lives. Crusading heart transplant champion Max Johnson is only alive today thanks to organ donor Keira Ball. The 9 year old girl tragically lost her life in a car crash but her heart has continued to beat inside 14 year old Max. After receiving the priceless gift, Max has been campaigning to raise awareness of organ donation. Max spearheaded the new legislation known as Max and Keira's law. Under these new rules, introduced in 2020, consent for organ donation will now be presumed, unless people opt out. Max has helped raise more than £500,000 and after sharing his story in a BBC documentary has helped increase organ donor registrations by 500%. Max was among 25 young people from across the UK who received the British Citizen Youth Award for his achievement and commitment.

Max was only 8 years old when he suddenly fell ill and was diagnosed with dilated cardiomyopathy, until then he was a healthy child. He spent many months in hospital awaiting a heart transplant. His parents were told he could have died at any time and if Keira's heart hadn't been donated, Max would not be here today. Since his transplant operation Max has been determined to make the most of his life, keeping fit and active. He is deeply indebted to Keira's family, the British Heart Foundation and the NHS and spends time talking to the local community about his incredible journey, encouraging people to make their wishes regarding organ donation known to their families.

CHOCOLATES AND SWEETS QUIZ

1. High class thoroughfare
2. Money making royalty
3. Dark occult
4. Clever folk
5. Alcohol and frozen water
6. Gardener's delight
7. Feline equipment
8. Assorted girls
9. Dating agencies
10. Edible fasteners
11. Wobbly infants
12. Talk quietly
13. Big bus
14. Gem orchard
15. 100% Au
16. Bowled over
17. Ottoman joy
18. Plentiful
19. Sport for Princes
20. Noisy insect
21. H2S04 spillage
22. Chardonnay glues
23. U S monetary exclusion
24. Race course signals
25. Tartan granite
26. Sweet tooth cleaner
27. Outside meal
28. Cork for mouths
29. 9, 10, 11
30. Lots of parties
31. A galaxy
32. Fallen fruits
33. Sly giggles
34. Good, twice in succession, in France
35. One who wanders
36. Mothers local

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DON'T FORGET TO FOLLOW US ON FACEBOOK!

HAVE YOU HEARD ELLIE GOULDING'S SONG? HOW WILL I LOVE YOU?

How long will I love you?
As long as stars are above you
And longer if I can
How long will I need you?
As long as the seasons need to
Follow their plan
How long will I be with you?
As long as the sea is bound to
Wash up on the sand
How long will I want you?
As long as you want me to
And longer by far
How long will I hold you?
As long as your father told you
As long as you can
How long will I give you?
As long as I live through you
However long you say
How long will I love you?
As long as the stars are above you
And longer if I may
How long will I love you?
As long as stars are above you