

SPRING
2023



DONOR FAMILY NETWORK

CONNEXIONS

Registered charity
1098781



Spring symbolises a time for new beginnings and transformations, starting afresh, hope reborn.

Spring brings with it warmth, light, an abundance of flowers, often rainbows too.

Spring is an opportunity to experience a renewal of body and soul, starting afresh and new beginnings.

For some people this happens when organs or tissues are transplanted, life can begin again.

Donor families have to start their lives without the person they loved, in the knowledge that their loss has brought new life.

New beginnings for all, the circle of life continues.

Samuel Coleridge said in his poem The Keepsake

"By rivulet, or spring, or wet road-side, That blue and bright-eyed floweret of the brook, Hope's gem, **the sweet Forget-me-not!**"



Without the organ donor, there is
no story, no hope,
no transplant.

But when there
is an organ donor,
life springs from death,
sorrow turns to hope
and a terrible loss
becomes a gift.

-UNOS



MANY THANKS TO THE FOLLOWING PEOPLE AND ORGANISATIONS WHO HAVE GENEROUSLY GIVEN

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

Thank you to our regular donors

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



Donations have been gratefully received from

Lemone McVaris
Sid & Carol Lamb
Ieuan Ellis
Bird & co Solicitors
Victor Young
Jim & Linda Fallow
Steve Lawrence
Forward Lodge of Freemasons in Birmingham
Anchorsholme Lodge of Freemasons in Lancashire
West Lakes U3A following a talk by a kidney recipient
Mr Garner on the 1st anniversary of his son's kidney & pancreas transplant

Pauline Holmes (in memory of Russell)
Alik & Penny Moore (in memory of their son David)
R & V Livingstone (in memory of their son Peter)
Stella Nash (in memory of Robert)
Carol Thompson (in memory of her sister Cathy)
Alison Wagstaff (in memory of her mum Patricia)
Martin Smith (in memory of his wife Christine)
Brigitte Lilley Fortin (in memory of Claire Lilley)



Donations in memory of Francis Jennings
Donations in memory of Barry Evans
Legacy from Jacqueline Mary Thompson

FUNDRAISING

Much loved pages have been created and funds raised for us by family and friends in loving memory of:

Martin Cumpstey
Ian Keillor
Ian McGinn
Patricia Waller



<https://www.muchloved.com>

Just Giving pages have been created by:

Abigail Whitehouse- in memory of her friend Oliver who gave a second chance of life to four people

Andrew White – who took part in the Ironman Wales, together with other swimming, cycling and running events to kindly raise funds for the Donor Family Network

Jack Amesbury- who raises funds every Christmas in memory of his son Dayle, with "Dayle's Christmas Tree Baubles"

Vanessa Pritchard- who is running the London Marathon in memory of her mum who gave the gift of life in October 2022

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



<https://www.justgiving.com>

GEMMA PICKETT'S TRANSPLANT STORY

When I was 5 years old I was diagnosed with kidney failure. I had kidney dysplasia, which meant my kidneys had stopped growing with me. They supported me just till I was 6 years old then I had to have dialysis. Dialysis for me was for 3 times a week for 3 hours each time. After dialysis I was very tired and could not do much, so my friends would be out playing and I would not be able to do this or if I did it was not for long. I also had a very limited diet to ensure less pressure on my kidneys. Also during this time I was very poorly with high blood pressure, being admitted a lot with passing out due to this.

After a year on dialysis I finally got the call for a new kidney and my parents got me to St James' in Leeds to have my transplant. After my transplant I was like a normal 7 year old and could play with my friends and play my favourite sports again. I represented my county in Tennis and also played football for Grimsby Town Ladies FC. The generous gift of organ donation from my donor and donor family gave me my life back and a mother and father their child.

From then I represented my hospital in The British Transplant Games winning numerous medals from bronze to gold, and then went on to represent my country in the Official World Transplant Games, winning gold for 100m sprint and badminton.

I have graduated from University and I now practice as a nurse. I am married with a beautiful daughter who without my transplant would not be here. So not only has my donor given me life but also my daughter too.

However it has not been all perfect and when I was 12 years old I was told my liver had been scarred. They were not sure how but felt this may have been due to a virus I had caught but fought off. My liver supported me until I was really ill and close to not being here. As nearly every week/month I was in a comatose state due to encephalopathy where the toxins from the liver build up. I was told I needed a liver transplant and was placed on the list in February 2021.

My condition was getting worse very quickly but luckily and again from the selfless act of organ donation I was given the call as in July 2021 I was asked to come to Leeds for my Liver transplant. Again without my donor and donor family I may not have been here.

The difference to how I felt was instant and waking up in ICU I felt a new woman. My mum wrote to my donor family after my transplant and I did the same for the donor family of my liver. I received a letter back and reading about my donor and how the family felt to hear about me getting such a precious gift of life was truly emotional.

I will be planning on returning to the transplant games to show what organ donation can do for people and to show my gratitude to my donors and both donor families. You are all so precious to us.

Thank you again for such a great gift.

GEMMA'S SUCCESSES

Gemma, Lexi and Andrea at
Birmingham in 2017



Gemma showing Andrea
Fallow her medal at the
Birmingham games in 2017



Gemma with her husband Carl and



Gemma with Andrea at the
Newcastle games in 2019,
having won another medal.



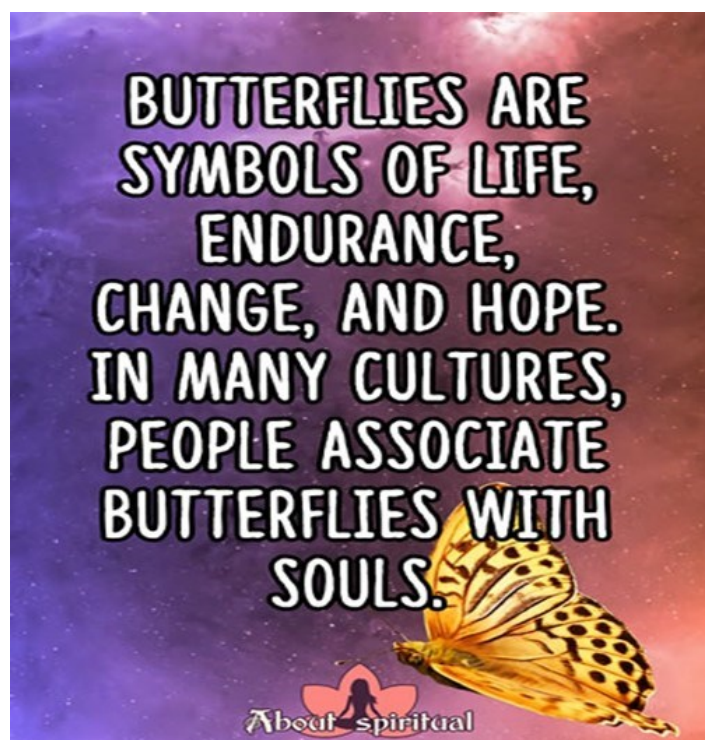
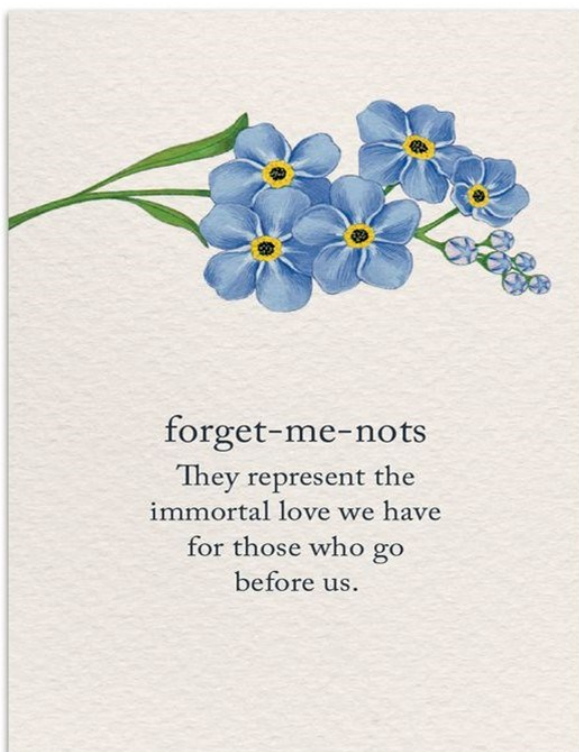
WE MAY NOT HAVE YOUR PHYSICAL PRESENCE

Precious Gift Event; A date for your diary

Last year, having set the date for this event as the Sunday at the end of Organ Donation week, we were caught out because of the funeral of our late Queen and it was actually held at the start of the rearranged week. This turned out to be very popular with many people commenting that it was appropriate because transplantation starts with the donor. As a result, we have booked the Aspects building at the National Memorial Arboretum for Sunday 17th September. As always, this will be open to all donor families, recipients, their families and anyone else who would like to attend. Please reserve your places by sending us an email, (details on back page). The event will be preceded by our Bi-annual general meeting which is for donor families only.



People sometimes ask about the pin badges depicting the butterfly and forget me not flower and ask what they represent.



BUT YOU ARE WITH US IN EVERYTHING WE DO

The gift of sight, why cornea donation is crucial.

An article in the "I" newspaper last year stated that corneas rarely feature in most people's minds when it comes to organ donation which, combined with incorrect assumptions and squeamishness, has led to a shortfall in the number needed. Many older people do not know that they can safely donate when they die, despite age and illness.

NHSBT figures for 2021-2022 up to 31st March 2022 state that 9.5% of people joining the organ donation register chose not to donate their corneas. People with poor vision can donate, as can people who have died from most types of cancer as the corneas do not contain blood vessels, eliminating the risk of transmitting the disease. It is easier to donate corneas than organs but the NHS is still facing a shortfall.

Now is the time to think about donation and talk to your family about it.

Huggas

Now that every one of the twelve regional offices have a supply of Huggas we are receiving reports of how well they are received, not only by donor families but the SNOD and ITU teams have commented that they make the treatment rooms look less stark. The feedback below is exactly the sort of reaction that we had hoped would happen:



Dear DFN Team,

I am one of the SNOD's in the South West team. We recently had Jim come and show us the 'hugga' blankets at one of our team meetings.

I just wanted to say thank you. I have placed one on an organ donor's bed and the family have taken turns having it on their laps while they have sat by the bedside. They are going to take it home and put it on the sofa so everyone can carry on having special cuddles on the sofa.

It's a wonderful thing for us to be able to offer families and all of the ITU staff commented on it. It's made a sad situation more positive for the ITU team. Huge thanks for providing these wonderful blankets. They are very special and the impact shouldn't be underestimated.

Best wishes

Rebecca

We already hold sufficient stock to see us through this year and we will continue to supply the regional offices for the foreseeable future.

LIZ PHILLIP'S STORY OF HER HUSBAND RICK'S DONATION

My husband Rick donated his organs 23 years ago in August 2000.

Rick was 38 and collapsed on a football pitch. He spent 3 days on life support but he had an aneurysm on his communicating artery.

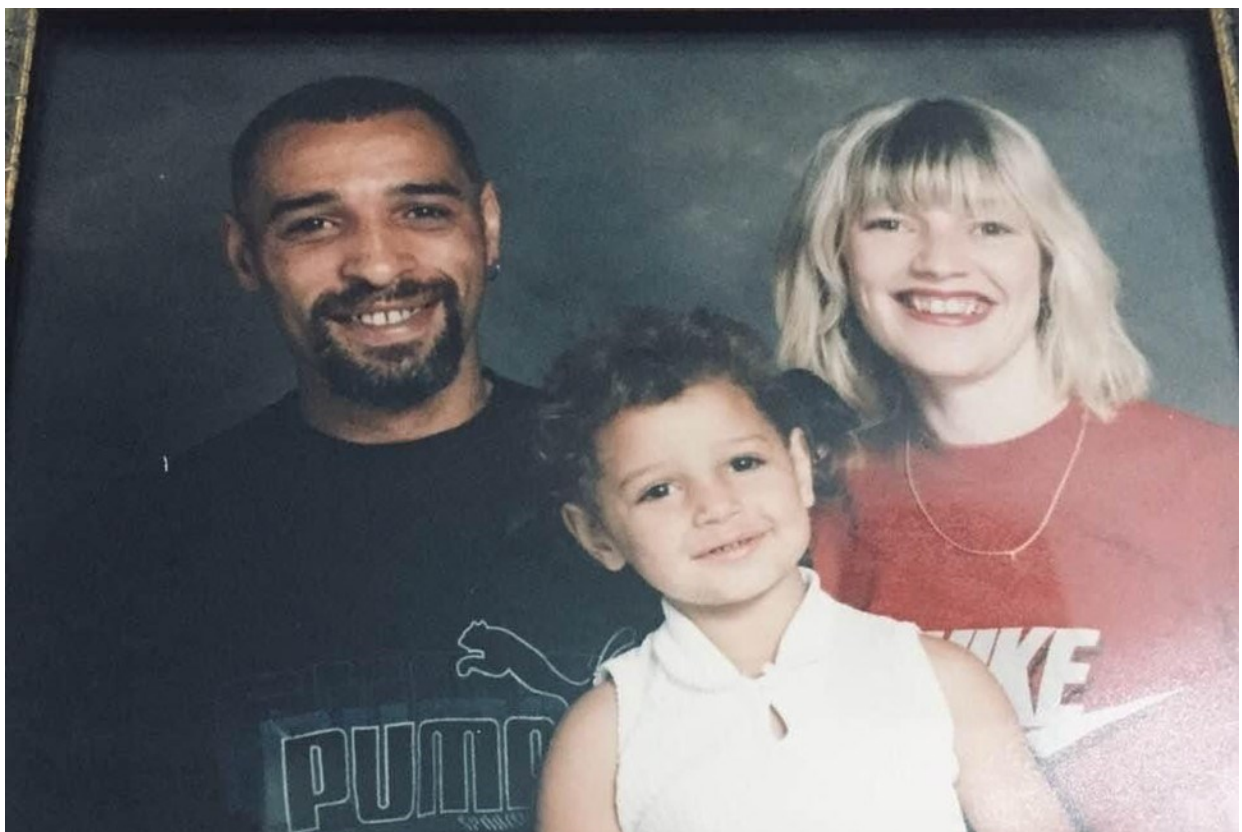
We had talked about organ donation and therefore I knew his wishes. It was still the hardest thing I had to do. I didn't want him to die. I loved him so much and so did our children.

20 years on we have had so many positive experiences through that decision. We have received letters from some of the recipients and I'm forever grateful they took the time to do that. It really is a joy to see people go on with their lives. We are members of The Donor Family Network and have made so many great friends.

We attend The British Transplant Games annually and give out medals to the recipients who take part. We take part in the Donor Family Run, which is always humbling and emotional.

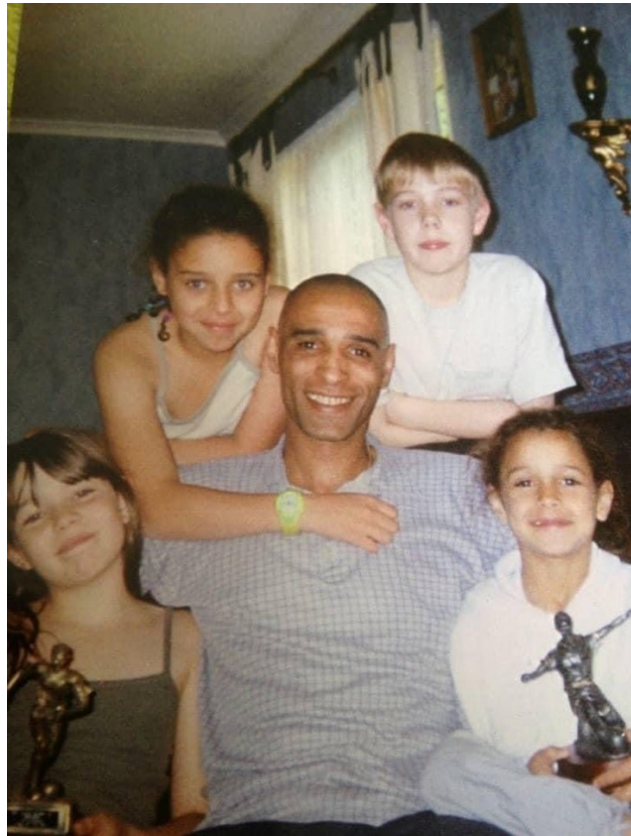
At the World Transplant Games I was very excited that Rick's Liver Recipient, Steve, won a bronze medal on the actual anniversary day 😊. I was very proud of both Steve (who did all the hard work) and of course Rick.

Our youngest daughter Jade has completed her training as an Organ Donation Ambassador. She was diagnosed with Autoimmune Liver Disease, Ulcerative Colitis and Primary Sclerosing Cholangitis aged 12 so she has had a rough ride and may eventually need a liver transplant too. This has spurred us on as a family to promote Organ Donation in any way that we can. We lost our loved one and it was the hardest time but so many years on he lives in so many ways. He won't ever be forgotten



NEVER FORGOTTEN

Rick with his family



Liz and daughter Jade

BUTTERFLIES HOVER AND FEATHERS APPEAR

Hello from Yorkshire, my name is Matt and I'm one of the newer specialist nurses for organ donation (SNOD) within the team and I'm based out of York and Scarborough Hospitals. I'm hoping that this next few paragraphs will give you a bit of an insight into my life as a SNOD both in and out of work.

My nursing career started when I was 16 when I decided to change course from schoolwork which I just didn't get on with and started a nursing apprenticeship for two years in Scarborough hospital. These two years allowed me to get practical experiences of hospital working and I gained my NVQ level 3 in care along with completion of a modern apprenticeship before going to university to undertake my nurse training, which I did at the university of York. Since qualifying as a



nurse, I made the decision to work in intensive care as I had spent a placement on an ICU. I liked how you can give gold standard care to your patient and the vast array of medical conditions making every day different. It's not the easiest environment to work in as not only are we caring and managing the sickest patients in the hospitals we are also supporting their nearest and dearest and checking in on their welfare. This is where my passion for organ donation really started, as a few years in to working on ICU I was caring for a young man who had suffered major trauma to his head, unfortunately he had sustained irreversible damage to his brain and his amazing family were supportive of him becoming an organ donor. I was then introduced to the role of the SNOD as I worked with them to support the family and donor through the significant number of questions that we ask families. When the time came to go to theatre (in the very early hours of the morning), I had asked if I was ok to follow my patient through the process which the family found very supportive knowing that I was coming in to keep an eye on their loved one as he went on to become a donor. This really did ignite the spark to become an advocate for organ donation and assist in becoming a link nurse within Scarborough ICU.



The last twelve and a half years of working on ICU have changed me as a person and I have progressed through the rankings to become deputy charge nurse and then clinical nurse educator for the intensive care nursing team along with gaining my critical care nursing degree also. Over the years of meeting some of the specialist nurses and speaking to them over the phone when making referrals it became more and more apparent that this is a job that I would really like to do and be a part of an amazingly caring and friendly team.

Eventually I felt I was ready for another challenge within my career, and I had also noted that the local SNOD job had been recently advertised. After asking questions to a few SNOD's they gave me a bit of an insight into the role, so I applied and was successfully appointed into the role starting in May 2022.

WHENEVER LOST LOVED ONES AND ANGELS ARE NEAR

But the role doesn't stop there... Despite working closely with the specialist nurses for years on ICU post donation there is still a lot of work to be done. We liaise with local and national transplant centres relaying vital microbiology reports that are reported on post donation, we check wording on letters before they are sent to the wonderful families and friends who have supported the donation process and then occasionally, we liaise with donor families when letters and cards come in from transplant recipients before they are sent on in which the messages are so heart felt.

So, although I am only just 7 months into the role I am still learning everyday and I have even had to deliver the odd presentation to a trust board of directors to share the amazing things that happen. However, I do much prefer to be at a bed space supporting the ICU staff with a potential donor than stood in front of a room full of people delivering a presentation on the role of the SNOD, albeit I always run over my time as I just can't stop talking!

However, this is only one side to my life in which I have three main aspects the other two revolve around being at home and at sea....

Outside of work I am a devoted husband and dad to three amazing kids, Elsie (my youngest) was born in November 2022 who brought her own challenges for the first couple of months of life in which my fellow colleagues within the Yorkshire team were so supportive and thoughtful despite only knowing them for the last 5 months... but life at home is great fun if not slightly chaotic having three under three and a half.

Living on the coast also allows me to be a part of another great passion of mine being out at sea. In which I am a volunteer crew member for the RNLI at Scarborough lifeboat station. On station I am a Helm for the inshore D-class lifeboat, and a mechanic/navigator for the Shannon All-weather Lifeboat (ALB for short). This again has been a big passion of mine and has helped me immensely with staying calm under pressure and being able to work in tense situations with sometimes limited resources.



In recent years this has helped no end working in critical care through covid.

Thank you for taking the time to read this little insight into me and my escapades but I am so happy and grateful for the work I get to do, the team I work with and the people I get to meet as everyone's story is so interesting and the people, we all support also deserve their stories to be told and heard too.

Matt Marks

Specialist Nurse Organ Donation

Yorkshire organ and tissue donation service team

DON'T TAKE YOUR ORGANS TO HEAVEN

Organ Donation Bereavement Follow Up Group

Emma Thirlwall, Jenny Hedingham, Yorkshire Organ Donation Services Team, North West Organ Donation Services Team, Ben Cole

In 2021, a group of Specialist Nurses Organ Donation (SNODs)/Specialist Requesters (SRs) from the North West and Yorkshire Organ Donation Services Teams, began a six-month Organ Donation Bereavement Follow Up pilot, completing follow up calls to all families/NOK who had consented to donation in both regions, regardless of the outcome.

“She was so helpful and informative, nothing was too much trouble”

These calls allowed the SNODs and SRs the opportunity of ensuring that families had all the information they required post donation, whilst exploring any feedback or questions they may have had. The calls also allowed for sign-posting the family/NOK on to further support services if necessary and giving them opportunity to address any complaints and compliments, ensuring direction of these to the correct channels.

A Management Process Document was developed to maintain consistency in the service provided and to ensure that the correct processes were in place to address potential safeguarding concerns.



A robust documentation, rota and record system were created to maintain accuracy and easy use for all involved.

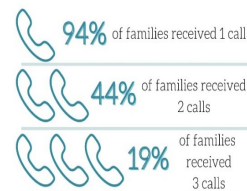
“Even after everything had kind of gone back to normal, they phoned up to check how I was. It was really lovely to know that they still cared.”

During the pilot period, 123 families/NOK agreed to receive a follow up call and as this became business as usual, from the start of the pilot period until the end of December 2022, this number grew significantly to 402.

82%

of families agreed to a follow up call

Up to 3 calls will be made to the families/NOK as needed, with most cases closed after 2.



“Each phone call reminded us that we should be proud of Tony helping to change peoples lives and making them better”

All the families/NOK have been grateful to have had further support from the Organ Donation Services Teams; anecdotal feedback

from these families has been positive; they describe feeling that they have not been forgotten and having the opportunity to raise questions has been helpful.

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DFN Award Nomination

The Trustees of the DFN were thrilled to receive notification that the charity has been nominated in the BTS/NHSBT Awards for Excellence, 2023. The awards celebrate excellence in all areas of transplantation and we are proud to be included in the category -“Volunteer”. Many of our members sent congratulations on our Facebook page stating the nomination was well deserved. Graham Moore, Chair of Westfield Health, sponsor of the British Transplant Games and supporter of the DFN, said “congratulations to the bravest of the brave”.



2023 UK Awards for Excellence in Organ and Tissue Donation and Transplantation

Donor Family Network

Nominated for
Exceptional Volunteer



Blood and Transplant



HEAVEN KNOWS WE NEED THEM HERE

TRANSPLANT SPORT

After a very successful British Transplant Games in Leeds last year there are a number of events this year.

In April the Great Britain and Northern Ireland athletes will be competing in Perth, Australia – the first time that the World Games have been held since the ones in Newcastle and Gateshead in 2019. Unfortunately, the games planned for Houston, Texas, had to be cancelled in 2021. If the team this year performs as well as it has at previous games, the athletes will return at the top of the medal table. We are sure that all the Donor Families will wish them well during their trip down under.

BRITISH TRANSPLANT GAMES

Registration for the British Transplant Games, to be held in Coventry from Thursday 27th July to Sunday 30th has now opened. It's a 4 day event and everyone who attends really seem to enjoy themselves, whether competitor, spectator or volunteer. Already many members have registered, several of them for the first time. They will, of course, be welcomed by the regular attendees and, hopefully, they will experience a memorable time. The opening will take place in the centre of the city with the muster point being the original cathedral which was destroyed in a bombing raid during the Second World War. The teams will then parade to Broadgate for what is a very impressive and emotional ceremony. The donor run will take place on the Saturday at the War Memorial Park which is between the city centre and the University of Warwick campus.

Accommodation has been booked at the Radcliffe Hotel on the University of Warwick campus where many of the events will take place. If you want to stay with us in the hotel, please email at info@donorfamilynetwork.co.uk and our team manager will contact you for details. The onsite venues are all within about five – ten minutes walk from the hotel. If you wish to join us, please go to www.britishtransplantgames.co.uk, click on 'register now' and complete the form.

For more information please go to the BTG website <https://fal.cn/3wOnQ>

If you want any help with completing it, please contact us by email.

Prior to the games there will be a satellite event, TRANSPLANT SPORTive, at which members will be very welcome. This will be held on Sunday 11th June at the Skelton Lakes Extra motorway services which is at junction 45 of the M1 near Leeds and involves either a 35 mile or 60 mile bike ride. Further details can be found on the Transplant Sport website under 'events'. Although this seems an odd venue, there are several RSPB sites located nearby with easy access by foot or bike. Non-competitors are welcome to join us.

RIDDLES AND QUESTIONS

1. What has a tail and head but no body?
 2. What never goes up but only comes down?
 3. What is coming but never arrives?
 4. What cannot eat, even though it has teeth?
 5. Who invented the word VOMIT?
 6. How many sides are there in a circle?
 7. Where can we find an ocean, lake or river without water?
 8. What can run but never walk?
 9. What is Google's motto?
 10. What never grows larger the older we get?
 11. Where is your purlicue?
 12. The more you make of me, the more you leave behind, I am?
 13. I have a face, but no eyes, hands but no arms, what am I?
 14. I eat, I breathe, I live. I live, I drink, I die. What am I?
 15. What was the first fruit eaten on the moon?
 16. What has 13 hearts, but no other organs?
 17. How many people boarded Noah's Ark?
 18. Which metal is heavier, Gold or Silver?
 19. What is the only thing you can lose and never get back?
 20. What is Kopi Luwak?
 21. Where would you find an ISBN number?
 22. What goes up but never comes down?
 23. Which language has the most words?
 24. What is the national animal of Scotland?
 25. How many noses does a slug have?
 26. Which 2 cities represent letters in the phonetic alphabet?
 27. What is a Interrobang?
 28. What food is a Twinkie?
 29. Can you name a sport where the winner moves backwards?
 30. I am the type of room you cannot enter or leave. What am I?
 31. I have a neck but no head, arms but no hands, what am I?
 32. What is a group of Unicorns called?
 33. Which company's motto is Grace, Space and Pace?
 34. What kills most fruit flies?
 35. Which animal can't stick it's tongue out?
-

CHOCOLATE AND SWEET QUIZ ANSWERS

1. High class thoroughfare	QUALITY STREET
2. Money making royalty	MINT IMPERIALS
3. Dark occult	BLACK MAGIC
4. Clever folk	SMARTIES
5. Alcohol and frozen water	LIQUERICE
6. Gardener's delight	ROSES
7. Feline equipment	KIT KAT
8. Assorted girls	DOLLY MIXTURES
9. Dating agencies	MATCHMAKERS
10. Edible fasteners	CHOCOLATE BUTTONS
11. Wobbly infants	JELLY BABIES
12. Talk quietly	WISPA
13. Big bus	DOUBLE DECKER
14. Gem orchard	OPAL FRUITS
15. 100% Au	ALL GOLD
16. Bowled over	SKITTLES
17. Ottoman joy	TURKISH DELIGHT
18. Plentiful	BOUNTY
19. Sport for Princes	POLO
20. Noisy insect	HUMBUG
21. H2S04 spillage	ACID DROPS
22. Chardonnay glues	WINE GUMS
23. U S monetary exclusion	DIME BAR
24. Race course signals	TIC TACS
25. Tartan granite	EDINBURGH ROCK
26. Sweet tooth cleaner	CANDY FLOSS
27. Outside meal	PICNIC
28. Cork for mouths	GOB STOPPER
29. 9, 10, 11	AFTER EIGHT
30. Lots of parties	CELEBRATIONS
31. A galaxy	MILKY WAY
32. Fallen fruits	PEAR DROPS
33. Sly giggles	SNICKERS
34. Good, twice in succession, in France	BON BON
35. One who wanders	DRIFTER
36. Mothers local	MARS BAR



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DON'T FORGET TO FOLLOW US ON FACEBOOK!

This short poem was read at the funeral of a cancer patient who was very keen to donate. Unfortunately as he died of active cancer he was only able to donate his corneas.

Grateful thanks to Andrew Fallow's family. RIP Andrew.

JUST A LITTLE HUG BY ROY HORNBY

A HUG CAN SAY I'LL MISS YOU
OR EVEN I'LL BE THERE
IT CAN SAY YOU'RE SOMEONE SPECIAL
OR BEST OF ALL I CARE.
IT CAN SOOTHE A HURT
OR CALM A FEAR
OR CHEER US UP WHEN WE ARE BLUE
IT ALMOST SEEMS A MIRACLE
ALL THE THINGS A HUG CAN DO.
SO IF YOU'RE FINDING IT HARD TO COPE
WHEN YOU'RE SEEING MORE RAIN CLOUDS THAN STARS
AND YOU FEEL LIKE GIVING UP HOPE
THAT'S THE TIME SOMEONE COMES ALONG WITH A WARM HUG
AND SAYS THAT IT'S OKAY
TOMORROW IS COMING, BRIGHTER TIMES ARE ON THEIR WAY.

This was part of a poem written by an ex alcoholic, homeless man. His life changed for the better after the sudden, unexpected death of his brother. Sometimes when you hit rock bottom a simple gesture, like a hug, can make such a difference.

We now have 509 members of the Donor Network Family

131 Friends of the DFN

Facebook followers 3213

Twitter followers 2965

Please encourage your friends and family to follow us, they can contact us via the information at the top of the page.
