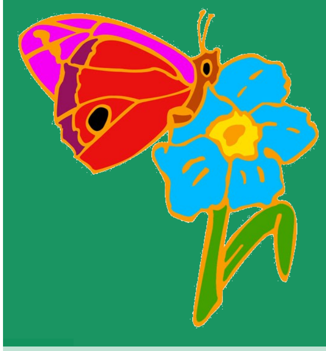
SUMMER

2021



DONOR FAMILY NETWORK

Registered charity
1098781

The Gift of Life Memorial

The Donor Family Network provides support for the families of those who have died and donated organs and tissue for transplant. The Network also works to promote awareness of organ and tissue donation. This newsletter is written for families of those special people, offering practical and emotional support via e-mail,

Welcome to the summer edition of your newsletter. So much has changed in the past few months with Covid restrictions ruling our lives. Some opportunities have been lost, The Transplant games for instance. However people have come up with innovative ideas to keep in contact and further into this newsletter are future events and dates for the coming months. Whether you are a new reader, or have received the newsletter before, please do not hesitate to contact the DFN if you wish to talk about your situation. There is always someone to listen, someone who can empathise and understand what you are going through. Be proud of the donation your family member made, through them another family has the privilege of seeing their loved one's life prolonged.

THANK YOU TO THESE SPECIAL PEOPLE

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

J Fletcher
Keith Astbury
Darren Cox
Roger Quick
A Heron
Patrick Gallagher
Pauline McDonnell
S J Hall
Judy Coutinho
Jim Birrough
Karen Rockell
Joyce Currie
Elizabeth Foster
Terri Leahy
Shibden WI
Gavin Shorrock
Nicholas McCrickard
Roche & District Young Farmers
Poundbury Women's Institute
Holystone Women's Institute
Fundraisers:
Linda Fallon (she is Mum to heart recipient) – she is part of a fitness group called Lesley Marshall Fitness & they held a raffle for DFN
Just Giving page – in memory of Ina Shorrock
Nicki Detko – has a Just Giving page in favour of DFN so you can find a bit more out about her there. She received a liver 16 years ago and is doing 16 talks about organ donation
Kelsey Hewitt- she has a JG page & has raised a lot of money for DFN in memory of her Dad.
Limestone Rock Lodge (Freemasons) – monies to be used to purchase some more Huggas to be given to donor families.

One person saves all his small coins in a jar, emptying his pockets daily. He empties the jar every year. This is an excellent way to save money, which you don't really miss at the time.

Would you consider doing this to help raise funds?

IN FOR A PENNY, IN FOR A POUND. REMEMBER THAT AT THE END OF YOUR LIFE YOU CANNOT TAKE A PENNY WITH YOU.

DFN Trustees.

Over the years I have been asked many times "what do you have to do as a DFN Trustee?" As with all charity Trustees we have to ensure the correct operation and function of the charity. We are there to make sure that the charity is run in accordance with all the rules and regulations of the Charity Commission and that the finances of the charity are conducted in a correct and prudent fashion. The DFN always operates to all GPDR guidance ensuring the safety of our member's data.

All Trustees of any charity have certain similar roles and responsibilities. Trustees of the DFN attend four meetings over a year where we discuss and organise what the charity is doing over the next few months and plan for any future events. The DFN holds an annual memorial event at the end of Organ Donation Week for all people affected by organ transplantation. The Trustees will plan, organise and run this event, usually held at the National Memorial Arboretum near Alrewas in Staffordshire. Transplant Sport are responsible for running the British Transplant Games. Over the years the DFN have been actively involved in the games. The DFN help to organise medal presentations to the athletes, and present medals during the games, as the competitors feel it is a great honour to have their medal presented by a donor family. We run a stall to help raise funds for the charity and use this as an opportunity to make contact and talk to the people attending the games; we act as a link between donor families and recipients and gain valuable information from these talks.

The DFN also works very closely with NHS Blood and Transplant and the research community on committees and meetings to put forward donor family views to ensure that any future donor families are given the best treatment and any potential donor is given the very best care.

There are individual roles within the charity which Trustees take on. There is the management of the committee which is a role for the Chairman and Vice Chairman. Dealing with correspondence and registration of the charity Trustees is done by the Secretary. The charities' finances are controlled by the Treasurer. Additional roles include: anniversary cards, Facebook and Twitter, website management, web sales, control of the telephones, writing of this newsletter. Any Trustee is also prepared to talk to any donor family who has a need to talk to a person who will understand what they are going through. We are not a counselling service but we will be there to support and give advice where we can. We will also liaise with the NHS to resolve any problems which we become aware of.

The role of a DFN Trustee is varied. We provide a very valuable service to future and present Donor Families. At present there are 9 Trustees on the Committee. We will advertise any vacancies on the Board of Trustees in our newsletter, Facebook and Twitter.

Treasurer of the Donor Family Network

My position as Treasurer is a busy one, with responsibilities I take very seriously. I am grateful for the trust given to me by the Trustees and members of the charity.

My main role is to ensure that the bank statements are regularly reconciled. Whilst doing this I note all donations received, in order that the donor or fund raiser can be thanked in our newsletters. We are very fortunate to have a number of regular donors, both donor families and recipients.

Alongside the regular updating of spreadsheets noting the income and expenditure of the Charity I am the administrator of the various fund-raising platforms used by our amazing fund raisers – Just Giving, Virgin Money Giving, Charities Aid Foundation and Charities Trust being the main ones. I collate the necessary reports from all of these in readiness for our annual audit and to ensure that all fund raisers are thanked. When a new page is developed, I contact the person concerned, not only to thank them for raising funds for the DFN but also to ask why they chose the DFN and request photos and details of their events so we can share this with you all.

I monitor the finances of the charity carefully, ensuring that all action is in accordance with the rules of the Charity Commission and check that we always have regard to the guidance issued by the Charity Commission on public benefit. I report to the Board of Trustees at our meetings and to our members at our bi annual AGM.

I ensure that all necessary expenses are paid, including the renewal of our PO Box, our telephone line, website management and Public Liability Insurance premium.

I am also responsible for ensuring that any funds received as restricted funds are recorded as such as they cannot be used for any other purpose other than that specified by the donor.

Where possible we try to claim Gift Aid on donations, so annually I submit a Gift Aid Declaration to the HMRC, detailing monies due to us.

The DFN aims to ensure that we have at least two years running costs available to us at all times. We are very fortunate that we are able to do this due to the fantastic support we get. Any surplus funds are placed into a savings account, allowing us to earn a little interest. It is my role to ensure that we get the highest percentage of interest we can.

One of my responsibilities is to prepare our accounts at the end of the financial year, in readiness for our accountants to audit. This involves ensuring that all reports are ready and all receipts available. I compile our Trustees Annual Report to go with the accounts. This details our organisational structure, together with the objectives, activities and achievements of the charity. When our accounts have been signed off by the accountants, I then upload them to the Charity Commission.

Sue Burton

THANK YOU THANK YOU THANK YOU THANK YOU THANK YOU

Grateful thanks are given to Sue Burton who has been the Editor of this newsletter for the past 9 or 10 years. Nigel has apparently tweaked the wording, and layout, so many thanks to you too!

I have been asked to take over but Sue and Nigel will be a hard act to follow. My name is Linda Spakouskas, sister of Jim Fallow, auntie to Andrea Fallow, both trustees. Jim's son Iain died and donated 20 years ago.

Please may I ask readers to continue contributing to the newsletter in the usual way by sending articles of interest to the website at:-

www.donorfamilynetwork.co.uk

E-mail:- info@donorfamilynetwork.co.uk or

Phone:- 0845 6801954/0333 0129025


When someone you *love* becomes a memory...that memory becomes a *treasure*

How many words can you make from the word **TREASURE**?

Each word should be 3 or more letters long, no plurals or foreign words and must contain the letter T. Good luck.

HOLLY MORIARTY'S STORY; AS TOLD BY HER MUM HARLIA GIVENS


by Anthony Higginson

Holly was my first born. I was so excited as I had always wanted a little girl and for her to become the smart, beautiful, caring, striving lady she became was the biggest gift. Throughout her life she faced struggles that would usually set people back but her determination to reach her goals out weighed them all.

Becoming a diabetic at just 5 years old she had to grow up pretty quickly but she adapted well and was giving herself her own injection by the age of 7yrs old, both our lives changed and we adapted to the "new normal" which often threw some obstacles ....like her school would ring to say she had a funny turn and I needed to collect her. So her school week became 1/2 a day, then 3 days a week and so on.

At home she would often read her books and learn about all things. One of her favourite things were dinosaurs and could name all of them by age of 3yrs. When she was in high school she was a school prefect and also counselor. Along with her high grades she found her love of rugby and played for LSH rugby union and North West of England at a high level.

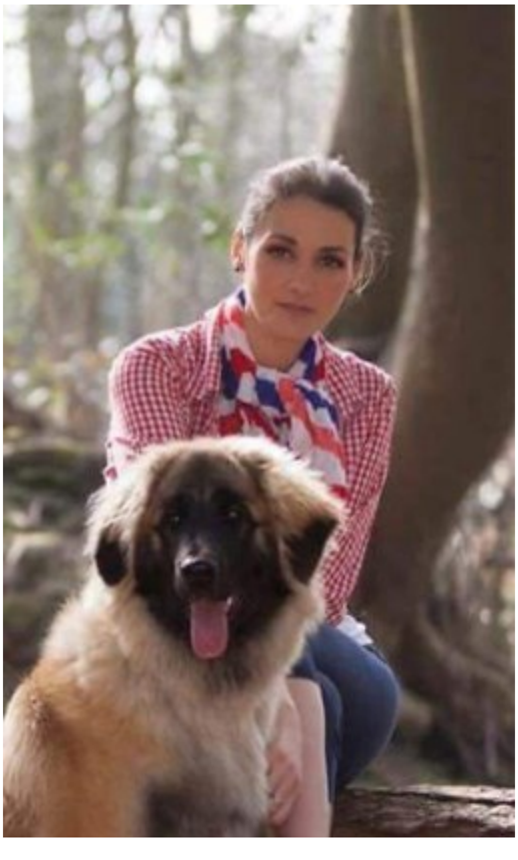
With her diabetes came neuropathy which caused her a lot of pain. When her time to go to university arrived she was still reading her books and studying and became a corporate lawyer for a top firm in Manchester, where she met Kristian. Throughout her life she worked hard, in her spare time becoming a part time model, enjoying fast cars, and her unlimited shoe collection, but the one thing she always wanted to be was a mother. Holly and Kristian then gave me the best news ever. I was going to be a Nanna! On the 14/04/2016 Jensen was born! Holly's world was complete.

I know Holly had a gut feeling, with some health conditions she would always say Momma I'm not going to live a long life... as she always told me this and I know in her 33 years she packed in every goal and experience she ever wanted; and really did live for every moment. Sadly she suffered low blood pressure after having Jensen, and she was on medication for it. Just 8 months after the birth of her son she had a fall and ended up breaking her leg. She called her neighbour, after which Holly pulled herself into the living room, to Jensen. She was taken via ambulance to Blackburn hospital. She had her operation and had called us all to say it all went well. I had collected Jensen to look after him whilst Holly was in hospital.

Later that night I got the call that every mother dreads, "you need to come to the hospital, Holly isn't going to make it". I raced up the motorway to a place I hadn't been to before thinking she won't die, I've just spoken to her. I was told she had suffered a cardiac arrest and the hospital didn't know how long she had arrested for. They had put her into an induced coma and when they tried to wake her up, she did not respond; they performed a brain scan and called us all to the family room and told us that Holly was brain dead, my body went into shock I didn't take in what they had said. “I thought no! they are wrong, she will prove them all wrong”.

Unfortunately they said, “It’s time to turn her life support machine off”. I was allowed to lie with her in the bed when they turned it off; it was day 4. I hadn't been home nor changed my clothes, I was on automatic. They also told me that Holly was on the Donor list and did I agree with her wishes, she hadn't ever told me this, but I said of course, take what you want but not her eyes; I need her to look down on her beautiful son. The Donor nurse was so compassionate and understanding, she told me what was happening every step of the way. When they found recipients, the surgeons were ready and then it was time for Holly to go to the theatre. I walked her to the door I told her how very proud I was and that I will always love her. Holly donated her lungs, liver, kidneys and skin tissue. She went on to save 4 women's lives, and one of them Sinead, I have met a few times, she calls herself “Holly and I”. I now say Holly is still alive in others, but I just can't see her...

A mother's love never dies.. ☐



SINEAD ANDERSON'S STORY OF HER LIFE SAVING SURGERY

One of Holly's recipients was a lady called Sinead. She had a life limiting genetic condition called Cystic Fibrosis, which destroys the lungs with sticky mucus. Sinead was taking 58 tablets daily, using nebulisers and inhalers to keep her condition under control. Sinead thought prior to the transplant that she may only have two years to live. Her health deteriorated to such a point that her life expectancy was greatly reduced

Sinead became a recipient after suffering from serious life limiting diseases that affected her lungs and pancreatic system. Not only did she have Cystic Fibrosis but was an insulin dependent diabetic, two chronic disabling illnesses.

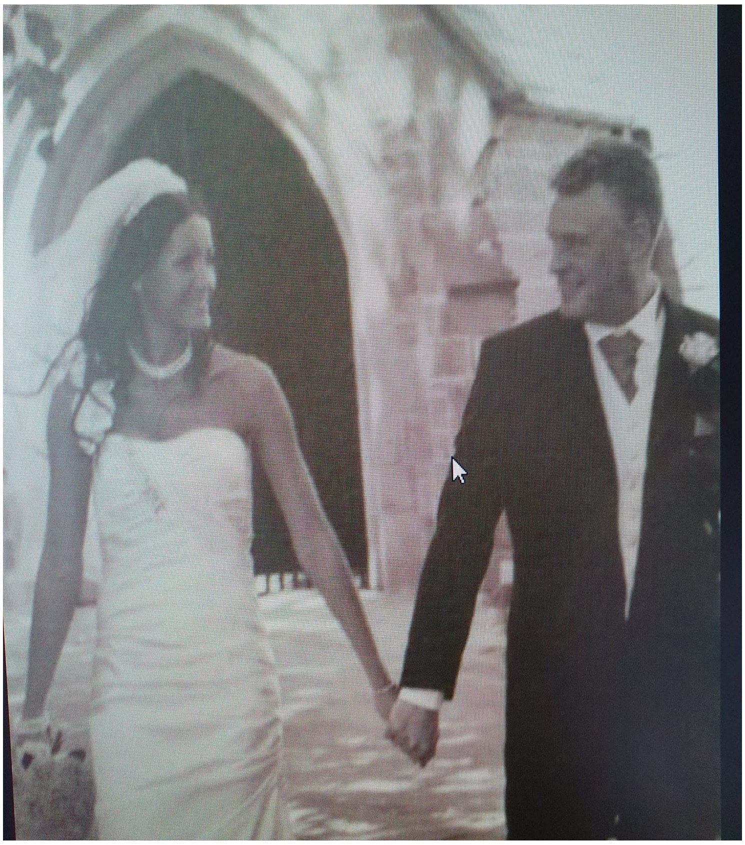
Former primary school teacher Sinead lived with her husband Lee and thought she would only live to reach 40, if she was lucky. She just hoped that she would be well enough to receive a transplant once a suitable donor was found.

On five occasions Sinead was prepped for theatre, only for the operation to be called off.

On each occasion she was transported to the transplant center at the Royal Papworth Hospital in Cambridge– only to be told she would be unable to have surgery. In December 2016 she was called again and told there was a match. Holly's lungs were transplanted after an operation that lasted 14 hours.

Sinead wrote to Harlia to say thank you but no names were involved.

Then Harlia saw a video where Sinead thanked the NHS as they celebrated their 70th anniversary.



She sent a letter to Sinead wishing her a long, healthy and happy life, from your donor's Mum.

The next day Harlia received a request on Facebook from Sinead's husband Lee, and later spoke on the phone. Sinead had been trying to contact her donor's family for a while.

The two ladies arranged to meet, both were very nervous. It was a very emotional meeting, Sinead met face to face the woman whose daughter's lungs had saved her life. Sinead was told that both Holly and her had similar traits, both strong women who had gone through so much. It was a surreal experience and it has helped both women. Harlia told Sinead if Holly could have picked anyone to have her lungs, it would have been her. They plan to keep in touch.

Jade Carr, transplant recipient story

I was born with Dilated Cardiomyopathy, a congenital heart condition that had unknowingly been passed on to me from my mum. This diagnosis led me to needing and subsequently receiving a heart transplant at the age of 3 in 1997.

After my transplant, hospital staff suggested we came along to the British Transplant Games which is an event organised annually for transplant recipients of all ages. We were able to socialise with other transplant families, have fun and I met other children who had had transplants like me. We first attended when I was only 4 months post-transplant and I've taken part in the Games every year since!

At the age of 13 I was selected to represent Great Britain & NI in the World Transplant Games because of my performances in athletics, badminton and table tennis, where I had won medals in each event. I continued to represent GB for a further 3 years in European and World Games getting to travel all over the world.

Having my heart transplant has brought many wonderful opportunities not only competing in the sports I love but it has enabled me to finish school getting through my GCSE's, my prom, I learnt to ski at something called TACKERS (a ski camp for children and teenagers who have had transplants) and also in 2012 I was an Olympic Torchbearer.

While at college and beginning to pursue my dreams in sports coaching, as well as about to represent GB & NI for the fifth time, I was diagnosed with kidney failure at the age of 17. This came as a huge blow and in time meant I had to give up all of my sporting commitments one by one. I luckily finished college but the hospital didn't allow me to move away for university so I stayed on at college to start a sports degree and at the same time I had to start peritoneal dialysis.

I started with CAPD, carrying out fluid exchanges through a tube in my stomach 4 times a day, for 3 months to get used to the routine as I would progress to APD, where I would connect my tube to a machine and fluid would exchange through several bags overnight while I slept. Peritoneal dialysis gave me my life back and I was still able to do some sports, compete at the Games the following year and go skiing again! I used PD for 3 and a half years but it began to fail in 2016 and I became extremely unwell. I was too ill for education, became housebound, in a wheelchair and at deaths door a few too many times, spending more of my time in hospital than at home that year.

Plans were made for a fistula to be created in my arm for haemodialysis access but this only uncovered more problems. My veins were poor and I backed up with fluid, discovering I had narrowing's in my chest from my pacing wires as I had a pacemaker. I then got sepsis making things worse. My fistula got tied off after ten weeks and my only option left was a line in my leg.

I was transferred onto haemodialysis during one of my extended hospital stays and had to d o four, four hour sessions every week at the hospital for a long, complicated nine months.

Altogether I spent five years on and off the transplant waiting list because my health was so unpredictable.

My mum was a match for me but she was rejected because of her heart condition and my dad wasn't a match, we had been in the paired pooling scheme but didn't have any luck.

In the summer of 2017, I was lucky enough to be allowed back onto the list after keeping well for a few months. To my amazement a week later while on dialysis I got a visit from a very excited transplant coordinator with the news I had been waiting for, saying a match had been found for me. Unexpectedly, my kidney would be coming from a live altruistic donor, which still shocks me to this day!

Since my kidney transplant I have been able to return to the British Transplant Games and I was selected to represent Great Britain & NI once again for our home World Transplant Games in Newcastle in 2019. I travelled to New York with my boyfriend Aaron, who proposed to me there and now engaged we have moved into our first home together which would never have been possible without my donors.
I was also able to start work coaching children table tennis in schools and I became an Organ Donation Ambassador in 2019.

With the ongoing pandemic, life is currently on hold. I was due to compete at last year's transplant games which had to be cancelled and I have been unable to continue coaching as I have had to shield, however just being here today is a success. I aim to make the most of every single day and live life to the fullest in the hope that I do my two donors proud.

RYAN BRETT’S LEJOG FROM LAND’S END TO JOHN O’GROATS

Ryan, a transplant recipient had his kidney transplant in 2015, and has fulfilled a dream this year.

On the 30th May, he embarked on his biggest adventure yet - attempting to become the 1st “transplant athlete” to complete LEJOG and of course HE DID IT!!!!

(LEJOG is the abbreviation of Land's end – Cornwall, the most south western point of the UK, to John O'Groats, Scotland, the most north eastern point.)

Ryan’s aim was to complete the walk in 17 days, averaging 50 miles, very day. He was self supporting, without a support team to help him, so he carried his bag and belongings. He had dreamed of doing this challenge for some time, and had originally planned to do it in 2020, to coincide with the change in law, and to raise awareness of organ donation; but like many things in 2020, covid-19 put a stop to his plans! This made him more determined than ever this year. His two main reasons for doing this were to inspire his son & other children to push themselves to achieve the unachievable and to believe they can do, or be anything. The other reason was to test himself both physically & mentally to see what he could do, after he was given a second chance at life; and in his words “my God I'm not going to waste it”.

Ryan was supported by lots of people throughout his journey, from people tooting the car horn as they passed, some followed him for a number of miles, school children cheered as he passed in Perth, joining him for a short walk, running a few miles with him, to running a marathon with him. Lucia,his wonderful partner was fielding lots of messages from people trying to find him; (Ryan didn't bother with a tracker, as he didn't think anyone would be bothered following his journey, how wrong he was!!)–

Ryan was so grateful for all the support. Some of the Donor Family Network managed to meet Ryan on his journey; we even managed to get him one of our baseball caps to wear for a photo; because he was carrying everything himself, this was sent to his partner, and she took it to John O'Groats for the final photo He says he could not have done it without all the support he had received. It was the hardest thing he had ever done, both physically and mentally, but using the gift of life given to him, it got him through many dark and hard times.

Ryan wanted to raise awareness for organ donation and using sport as a way to improve health and wellbeing for post transplant patients. He has been fundraising for Transport Sport Kids and teens, because all children have been hit hard this last year, especially ones that have had to shield, so all the money will go towards setting up family events for them and other ways to support them. Ryan's mantra is Believe & Achieve.

Some statistics from his adventure:-

17 days 3 hours 46 minutes

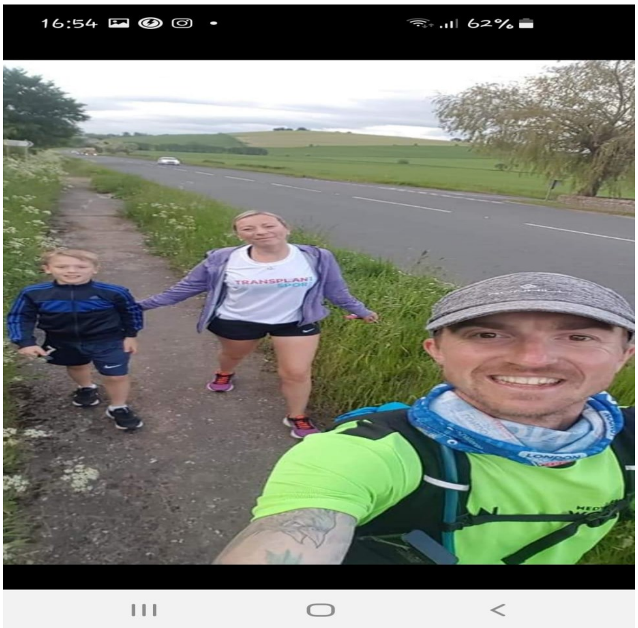
847.67 miles

Total average pace 12.51 min/mile

Moving time 182 hours 42 minutes

Elevation 49,676 foot

Calories approximately 105,086



BRITISH TRANSPLANT GAMES

Unfortunately, the Transplant Games planned for this year in Leeds have had to be cancelled. However, they have been rescheduled to next year, still in Leeds, from Thursday 28th to Sunday 31st July so please put those dates in your diary. It will be great to see you all again. There will also be a number of satellite events this year, starting with a cycling sportive in Leeds on Sunday 8th August. This will be followed by a golf tournament on Tuesday 28th September in Birmingham and a football competition with dates and details still to be confirmed. Further details will be on Facebook, Twitter and our website, wwwdonorfamilynetwork.co.uk

As we did last year, we are hoping that as many people as possible will do the Donor Run (or walk!) on Saturday 7th August. This year we are hoping to arrange a route in Leeds, similar to the one we would have done had the games gone ahead. Bearing in mind the current restrictions, full details have yet to be finalised but will be publicised as above. For those who can't get to Leeds we hope that you will run / walk a 3K or 5K route wherever you are and post details on Facebook. Again, as last year, we would like everybody to donate at least the £6.50 that would have been charged by Transplant Sport to the DFN (Account details below) and, where possible, add gift aid. Last year over £1100 was transferred to Transplant Sport. This was a tremendous figure much appreciated by Transplant Sport. Please send pictures and comments to our Facebook page.

Account details:
Bank : Lloyds
Account name: Donor Family Network
Account number: 03566388
Sort code: 30 99 06
Reference : Please use your name and Donor Run.
If you can also send an email to let Sue, our Treasurer, know it will help her keep track of the money.

SMILE AMAZON

With all the problems during lockdown there are probably very few of us who have not placed at least one order with Amazon. Do you know that, when you place an order, you can also support the DFN financially? Using their Smile Amazon page you can nominate the DFN as your chosen charity and we will receive money from them. Normally it is 0.5% which is a relatively small amount but, over the last couple of years, the charity has received £15.00 annually. Sometimes there will be a promotion from Amazon when the rate increases considerably so please consider nominating us as your chosen charity.

PRECIOUS GIFT EVENT AT THE NATIONAL ARBORETUM

Plans are being put in place for our (normally) annual Precious Gift Event at the National Memorial Arboretum, Alrewas. DE13 7AR. Unless there are further restrictions relating to Covid, the event will be held at the end of Organ Donation Week on Sunday 26th September. The event will commence at 2.00 pm in the Aspects Building and will be followed by a tea and cakes reception. There will be candles for all who would like one. Please let us know the name of the person you want to remember and we will ensure that it is on the holder ready for you on arrival.

There will be a rolling screen with pictures of our loved ones. If you would like to have a picture included, please send it, together with brief details, to our email address. You can also request a Certificate of Appreciation, which will be presented to you during the ceremony. Just request this with your attendance details.

This event is open to anybody with an interest in organ donation, not just donor families. Recipients and their families, NHS staff and friends are all welcome but please, let us know via our email address (info@donorfamilynetwork.co.uk) how many will be in your party so that we don't run out of cake! As well as the number in your party we need to know how many candles you would like and the names that you would like on them by no later than 5th September please.

Preceding the Precious Gift Event will be our bi-annual general meeting for members only. This will take place at 1.00pm in the Aspects building and the agenda is:-
Welcome by the Chairman
Chairman's report
Accounts
Election of Trustees and Officers.
Close

All the current Trustees are happy to continue in their roles

ORGAN DONATION WEEK LIGHTING OF THE BRIDGE

This year Organ Donation Week will be from Monday 20th September to Sunday 26th when we will be holding our Precious Gift Event. Once again, one of our members, Lorraine Furfie, has arranged for the Mersey Gateway Bridge between Runcorn and Widnes to be lit up in pink on Monday 20th. Members, friends and others with an interest in organ donation who live in the north are invited to join us in the car park at Wigg Island country park at 7.30 pm to watch the switch on.

To be certain of the time please check the website before you leave, www.donorfamilynetwork.co.uk. There is no formality, just a chance to meet up and talk.

There will be other events during the week, so please look at our Facebook page.

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DON’T FORGET TO FOLLOW US ON FACEBOOK!

JEALOUS OF THE ANGELS

A beautiful song written by Jenn Bostic following the death of her father.

Katherine Jenkins sings it beautifully.

I didn't know today would be our last
Or that I'd have to say goodbye to you so fast
I'm so numb, I can't feel anymore
Prayin' you'd just walk back through that door
And tell me that I was only dreamin'
You're not really gone as long as I believe

There will be another angel
Around the throne tonight
Your love lives on inside of me,
And I will hold on tight
It's not my place to question,
Only God knows why
I'm just jealous of the angels
Around the throne tonight

You always made my troubles feel so small
And you were always there to catch me when I'd fall
In a world where heroes come and go
Well God just took the only one I know
So I'll hold you as close as I can
Longing for the day, when I see your face again
But until then
God must need another angel
Around the throne tonight
Your love lives on inside of me
And I will hold on tight
It's not my place to question
Only God knows why
I'm just jealous of the angels
Around the throne tonight
Singin' hallelujah
Hallelujah
Hallelujah