

SPRING
2022



Welcome to the Spring newsletter. After more gloomy days with the pandemic ruling our lives, restrictions have been lifted and life appears to be resuming its normal pattern. There are several events happening in the next few months to enable us to meet up, details are inside the newsletter.

DONOR FAMILY NETWORK

CONNEXIONS

Registered charity
1098781



You can shed tears because they are gone,
Or you can smile because they lived.
You can close your eyes and pray they will come back,
or you can open your eyes and see all that they left for you.
Your heart can be empty because you can't see them,
Or you can be full of the love you shared.
You can turn your back on tomorrow and live yesterday,
Or you can be happy for tomorrow, because of yesterday.
You can remember only that they are gone,
Or you can cherish their memory and let it live on.
You can cry and close your mind and feel empty,
Or you could do what they would want.
Smile, open your heart, love... and go on.



The
Gift of Life
Memorial

Organ donation is not a tragedy



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

Regular donors:

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

Other donations received:

Bird & co
Sid Lamb, Scalm Park
St Joseph's Pantomime
Renzo Giovannini in memory of his son Luca
Derek & Alan Walsh in memory of Luca
Sue Evans
Paul Waggott
S Mitchener
Patricia Turner
Alicia Young
Simon Steward
Bassingham WI
Erin Burt in memory of her mum
British Association for tissue bank following the dissolution of the organisation
P Holmes in memory of son Russell
Keith Shuttleworth in memory of his wife Carol
Rob Hudson in memory of his wife Elaine
Alik & Penny Moore in memory of son David
Rosemary & Vivienne Livingstone in memory of Peter
Janet Neville in memory of daughter Debbie
Martyn Smith in memory of Christine
Olde Laira Lodge in memory of Wendy Black, partner of a member
Mr & Mrs Chew
Trish Robinson, in memory of Craig. DFN Huggas to be given to families in the Newcastle area



but it can be a beautiful light in the midst of one.

JUST GIVING PAGE

Jack Amesbury, in memory of son Dayle

Helen Holloway, in memory of her nephew Shane

Abigail Whitehouse, in memory of Oliver Amess

Rebecca Patel, in memory of her daughter Zara, who would have been 21 this year.

FUND RAISING EVENTS

- * Rebecca Patel and 9 family members are each raising funds to purchase 21 Huggas to be given to donor families in the London area.
- * David Nix is organising another of his renowned fundraising balls at the Tally Ho centre in Birmingham on 24th September. The final details have yet to be confirmed but tickets will be about £60.00. Places for this popular event have been snapped up but at the time of writing, there are still about 20 available.

UPCOMING EVENTS

- * This year's British Transplant Games will be held in and around Leeds. The dates are Thursday 28th July until Sunday 31st.

After 2 years of not being held we are hoping for a great turnout of competitors, families, supporters and healthcare professionals.

If you wish to sign up as a competitor or supporter, you can register via the following e-mail,

<https://www.britishtransplantgames.co.uk/post/registration-2022>

- * The European Transplant and Dialysis Games will be held around Oxford, mainly at Radley College and Blenheim Palace from Sunday 21st August until Sunday 28th.

If you are keen to join, further details will be available on our website but, if you would like to attend any or all of the events, please contact us via our e-mail address, info@donorfamilynetwork.co.uk and we will contact you directly with all the information.

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.

ONE OF THE BEST FEELINGS IN THE WORLD IS KNOWING THAT

Organ Donation Memorial, East Lancashire Hospital NHS Trust

The Organ Donation Memorial honours the organ and tissue donors from East Lancashire Hospital NHS Trust who have through their gifts changed the lives of the recipients and their families.

The original Organ Donation Memorial was designed by four year 8 students from Witton Park Academy in 2016. Angela Ditchfield the Specialist Nurse for Organ Donation at the time engaged with the students and asked them to design some artwork. The winning design was selected by the CEO Kevin Magee.



YOUR PRESENCE AND ABSENCE BOTH MEAN SOMETHING TO SOMEONE



Deborah Vernon, Specialist Nurse Organ Donation says, "I took over as the Specialist Nurse in 2017 and worked with Lisa Grendall to find the best way to display the student's artwork for a memorial. A plaque was chosen and this was placed outside the W H Smith in the main entrance. An opening ceremony took place on the 6th September 2018 during Organ Donation week, some donor families from ELHT attended alongside the students.

During the last 2 years it was noticed that unfortunately due to other signage the Plaque had become obscured and we asked if this could be moved to another wall in Hospital Street. Working with Ryan Chappell and his team the plaque was moved to a bigger area, which allowed us to add to the original design which would make the memorial more visible to those who walked past. Sarah Hicks was chosen as a local artist whose beautiful work was already displayed in the trust. The Organ Donation Committee would like to give thanks to the Donor Family Network whose logo we have used for the design. The forget-me-nots as we will never forget the donors and their families and the butterflies to signify the new life given to the recipients and their families. A quote was chosen by the committee to enhance the artwork and give thanks to the donors and the impact of their generosity. We are grateful to Sarah, the artwork is stunning and has definitely made an impact with a number of people commenting that they have noticed this as walking past.

Organ and tissue Donation are amazing gifts and ELHT are proud of all our donors and their families".

WE MAY NOT HAVE YOUR PHYSICAL PRESENCE

CORNEAL TRANSPLANTS, MYTHS AND FACTS

Many people are agreeable to donate organs and tissues but somewhat reluctant to donate eyes. Apparently 1 in 10 people decline to donate eyes when completing donation forms.

People often view eyes with more emotion and see them as more symbolic than other parts of the body.

Some reasons for this reluctance include family wishes, fear that the body will be disfigured, especially if the mourners view the deceased, and eyes are thought to be the windows to the soul.

Lack of understanding is also a key issue when it comes to not wanting to donate.

When people are made aware of the current deficit and life changing potential of a corneal donation, over half change their minds and say they would consider donating.

In 2020 it was estimated that there were over 285 million people worldwide living with sight loss. 39 million were blind and 246 million were partially sighted.

In the UK it is estimated that there are as many as 2 million people suffering from some or total sight loss.

Since 1961 more than 1 million people have had sight restored.

There are many myths surrounding corneal transplants which include:-

- The whole eye is transplanted.

Fact:- The whole eye is never transplanted, only the cornea. The cornea is the clear outer layer at the front of the eye that helps focus light. The sclera, which is the white part of the eye, can also be donated to help people.

- Having poor eyesight means corneas cannot be donated.

Fact:- People with poor eyesight can still donate their corneas, even some blind people.

- Having cancer means the cornea cannot be used.

Fact:- People with most types of cancer can still donate their corneas. The corneas do not contain blood vessels, eliminating the risk of transmitting most types of cancer. There are however a few malignancies such as Melanoma and Haematological cancers that prohibit donation.

- Donation might delay a funeral or affect how the donor looks.

Fact:- After donation the specialist team ensure the donor maintains a natural appearance. Corneal donation does not delay a funeral.

BUT YOU ARE WITH US IN EVERYTHING WE DO

- Timings for organ and tissue retrieval are as soon as possible after death has been confirmed.

Fact:- Unlike organ donation, corneas can be donated up to 24/48 hours after death and retrieval can take place in hospital, hospices, home or funeral parlours. Corneas can be stored up to 10 years.

The cornea is a transparent dome of tissue that forms the front protective coat of the eye. It is responsible for the majority of the focusing power of the eye. Any condition that reduces transparency of the cornea will result in loss of vision.

Reasons why people need a corneal transplant:-

- Disease or injury that has made the cornea cloudy or distorted, causing vision loss.
- Scarring of the cornea after infections such as a corneal ulcer.
- Keratoconus (thinning of the cornea that causes a cone-like bulge to develop), usually in young people.
- Age or inherited conditions that lead to cloudiness in older people.
- Scarring caused by Herpes, the cold sore virus.

Eye donation does not include donating your iris (the coloured part of the eye)

There are some exclusions:-

- Over 96 years of age (over 85 with eye problems)
- Transmissible viral infections, such as HIV and Hepatitis
- Neurodegenerative conditions, (Dementia, Parkinson's and MS)
- Some malignancies such as Melanoma, Haematological cancers
- Covid 19

As a result of the pandemic NHSBT tissue banks are receiving 20% fewer donations than pre pandemic.

Corneas and globes can also be used to support research or training.

Last year the number of corneal transplants decreased to 2,412 due to Covid 19.

140 corneas are needed each week to keep up with the transplant list requirement of 560 per month.

WE MISS YOU EVERY DAY

Can you be a cornea donor?

If you want to donate your eyes after you die it is very important to discuss this with your family and friends. It is necessary that they understand and support your decision because your family's support is needed for the donation to go ahead, even though there have been recent changes to the laws regarding donation.

If you are receiving a cornea the operation is quite straightforward.

Corneal transplant can be performed under general anaesthetic (where you are asleep) or local anaesthetic, where the area is numbed and you're awake.

The surgery usually takes less than an hour and depending on your circumstances, you either leave hospital the same day or have an overnight stay.

Corneal grafts are some of the most successful of all tissue transplants, often over 90% success rate, and lasting at least 10 years.

After an initial transplant it is possible that corneal transplant can be repeated with good results, although overall rejection rates are slightly higher.

Donating sight means there can be light after darkness. When people are made aware of the current deficit and life changing potential of corneal donation over half change their minds and say they would consider donating.

Sight loss affects every aspect of your life, whatever degree of sight loss you have.

Bharat Patel, an Organ Donor Ambassador, recently had a corneal transplant. He has been very impressed with the result after suffering with an eye condition Keratoconus for over 45 years. Keratoconus is a progressive eye condition that can lead to partial or significant visual impairment. He has made a quick recovery and is already benefitting from the transplant.

Another person who has had the benefit of several years sight following a corneal transplant is John Davies, married to Loraine Morgan Davies, a Patron of the Donor Family Network. John had an eye condition which meant he would be blind within a few years. The corneal graft has saved John losing his sight.

For further advice check the RNIB website.

You can transform the life of someone suffering from corneal blindness; register to be an eye, organ and tissue donor, and let someone see life through your eyes.

YOU ARE ONLY EVER A HEARTBEAT AWAY

Answers to the last newsletter quiz.

- | | | | |
|-----------|----------|---------|----------|
| 1. HEART | 6.FACE | 11.HEAD | 16.LEG |
| 2. FINGER | 7.BACK | 12.FOOT | 17.NECK |
| 3. HAND | 8.BREAST | 13.NOSE | 18.BELLY |
| 4. EYE | 9.TOOTH | 14.HAIR | 19.MOUTH |
| 5. TOE | 10.ARM | 15.LIP | 20.BONE |

Did you spot the mistake? Number 19 should have read WASH not WATCH, SORRY!

BEGINNING AND END

Each answer starts and finishes with the same letter, but different letters for each word.

1. Physical exertion done for fitness(8)
 2. Relating to the heart.....(7)
 3. Common lung condition causing breathing difficulties.....(6)
 4. Cholesterol lowering drugs.....(7)
 5. Protective clothing used in theatres.....(6)
 6. Pain relief.....(9)
 7. Region under the shoulder joint.....(6)
 8. Infection of the nail.....(7)
 9. Patchy baldness.....(8)
 10. Pulling a grotesque face.....(7)
 11. Itchy skin condition caused by a mite.....(7)
 12. A gland that secretes tears.....(8)
 13. A device used when taking blood tests.....(10)
 14. 6 babies in a single pregnancy.....(10)
 15. Lacking fluids.....(10)
 16. The muscle that raises the arm in different directions.....(7)
 17. A disinfectant type of soap.....(8)
 18. Involuntary spasm of the diaphragm and lungs.....(8)
 19. First faeces passed by a baby.....(8)
 20. A doctor who is junior to a Consultant.....(9)
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BUTTERFLIES HOVER AND FEATHERS APPEAR

HOLLY'S STORY, as told by her Mother, Natalie Wilson

"Holly was born 3 weeks early at Pinderfields Hospital by emergency Caesarean section. On day 2 Holly was being bathed by a midwife, who noticed her legs were swollen, she was rushed straight to the Neonatal Unit. Doctors were unsure as to what was wrong as she had no liver functions, was hyperthermic, had no platelets and no kidney function. Eventually Holly was diagnosed with congenital nephrotic syndrome, a very rare genetic kidney disease. We were devastated. We were eventually transferred to Leeds General Infirmary where Holly's new team were awaiting her.

Holly started albumin infusions to replace lost protein and a high dose of diuretic to make her wee. At 4 months old Holly had a Broviac line (used to administer long term antibiotics) inserted into her chest as the infusions were getting more frequent. She was attending hospital 3-4 times a week for treatment, that could last between 4 to 10 hours.

At around age 2 years Holly entered what is known as "the honeymoon" phase. This is where the kidneys slow down (renal failure) so she held onto her protein, meaning no infusions. We had 18 months of normality, no treatment, just medication and regular check ups. In this time we had normal family holidays.



What a Kidney Does

WATER. Ensures that there's not too much or too little water in the body.

BLOOD PRESSURE. Makes sure that pressure isn't too high or too low.

WASTES. Gets rid of urea, uric acid, toxins, and other wastes via urine.

BONES. Activates vitamin D, which helps the body absorb calcium.



ACID-BASE BALANCE. Makes sure that the body isn't too acidic or too alkaline.

HEART. Maintains a balance of electrolytes (like potassium, sodium, and calcium), which is critical for heart rhythm.

BLOOD. Releases erythropoietin, which tells bone marrow to make red blood cells.

WHENEVER LOST LOVED ONES AND ANGELS ARE NEAR

By the age of 3 1/2 years Holly's bloods started to show signs transplant wouldn't be far away and she started to become poorly on a regular basis with minor illnesses such as colds, sore throat etc. Each time it resulted in admission to the renal unit. At this stage we as parents were tested to see about being a live donor. After numerous tests I (Mum) was chosen and signed off to become Holly's donor.



In February 2015 we're given the date of March 23rd for a bilateral nephrectomy (to remove both kidneys). This was just 3 days after Holly's 4th birthday. From this day Holly was dialysis dependent. She was fluid restricted to 300mls a day and her diet was also restricted. Dialysis happened every other day for around 5 hours.



On Friday 8th May I was taken to theatre at St James Hospital to donate my kidney to Holly, who was waiting at Leeds General Infirmary. Both operations were a success and Holly recovered really well. Holly came home after 10 days on numerous medications. After nearly 7 years she still takes 11 tablets a day and has a fluid target of 3 litres. She is absolutely thriving and enjoying life.

Holly became a member of Leeds Children's Transplant Team and has won numerous gold, silver and bronze medals but more importantly she has made life long friends. Holly has also recently become Head Girl at school, another great achievement".

The Donor Family Network are very proud of you Holly, and your achievements.



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This poem was written by Janet Neville for her daughter Debbie and read at her funeral.

“There was a feather as light as light could be
It floated all the way out over the sea
It floated high above the clouds way up high
Until it was invisible to the eye.
A rainbow it did meet and gave it a magical touch
It shimmered and shone and floated merrily on
Higher and higher it went, until there was only one place left to go
Through the gates of Heaven where everyone said hello.
I have magic properties whispered the feather
Touch my friends and you will see
The joy I can give to thee.
A queue was formed and one by one
The magic had begun
Fronds were touched by spirits anew
And feathers were formed in front of their eyes
A few whispered words from spiritual thoughts
And a new journey began.
Down floats the feather and searches and finds
The loved ones who have been left behind
I am here, I am near, no need to shed a tear
My lightness and brightness is here to lessen your fear
That I am gone forever, you are here, I am there
But our love will always share”



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