

AUTUMN 2020



DONOR FAMILY NETWORK

CONNEXIONS

Registered charity
1098781



Thank you for sharing your photographs of loved ones as we were unable to have our candle ceremony this year at the National Arboretum. The response was amazing!



RIGHT NOW TAKE A MOMENT, CLOSE YOUR EYES

Double lung recipient Vicky Pettersen shares her transplant journey with us

"I'm currently on my 5 month count down to my 50th birthday. Unlike most woman my age this is a celebration I am so looking forward to, a milestone I never dreamt that I would survive to see.

Since my transplant over 21 years ago we have celebrated so many fantastic milestones as a family together. It's hard to put into words how fortunate I feel as a CF woman, who was born at the beginning of the 70's and was not expected to survive beyond my teens, to still be alive to celebrate my 50th Birthday with my family by my side.



My medical story started when I was diagnosed with Cystic Fibrosis at the age of 3. I failed to thrive as a young child but became much stronger by the time I was 11.

I started jogging for my physio and became really strong and athletic and a good cross-country runner. I was so good in fact that I represented my school in the cross-country county championships when I was 15.

By the time I was 18 my health had started deteriorating and I could no longer run by age 19 when I got married.

I was on the transplant list at 21. I was diagnosed with CFRD (Cystic fibrosis related diabetes) at 22 and soon after that I transferred to Leeds regional CF unit under the care of Dr Conway and his team. I became so well again that Newcastle took me off the transplant list.

I went on to have my son at the age of 23.

Unfortunately, I developed CF Arthritis after the pregnancy.

By the time I was 28 I was sent back up for transplant assessment and went onto the list for a double lung transplant.

Our son Antony was 5 when I received my transplant at Freeman Hospital, Newcastle.

I have now celebrated beyond my 21st transplant anniversary.

We never believed 21 extra years was possible.

Our hope was that we would get a few extra years together as a family so that Antony would have significant memories of me.



Erik and I are truly blessed as a family for me to have survived to see Antony become an adult and graduate from Uni and go onto work as a Music teacher and live his life in Leeds with his girlfriend Emily.

I love my life and spend my spare time crafting, gardening, doing zumba and walking with my husband in one of our happy places - 'The Lake District' or by the beach where we live.

I also try to promote organ donation whenever possible.

Erik and I celebrated our Pearl Wedding Anniversary in the lakes together in March 2020.



Going home day—19 days post transplant

AND REMEMBER THE SMILE OF THE LOVED ONES

We feel very fortunate to have achieved these milestones and will be forever grateful to my donor and donor family who said YES when it mattered and gave me life.

Through my previous involvement as the Adult Freeman Transplant Team Manager and on the Transplant Sport Committee I have had a lot of involvement with the Transplant Games.

To me the highlight of every games are the times when the Donor Families are remembered. Without them there is no story, no future, no life to remember.

In the parade where all the teams come in with their flags there is the greatest cheer when the donor families walk in.

Nothing stirs your emotions and makes you cry good tears more. It fills you with a sense of gratitude, humility and thanks to see and meet a donor family. It makes me cry time every time during the parade and literally makes my heart skip a beat. This is a common emotion in most recipients at the games.



It is so wonderful to have the donor families there.



It's the same now when they do the donor run, a similar sense of pride and gratitude which again stirs the emotions and remind you why you are alive. Through doing an interview for channel 5 and spending a few hours with Lorraine Furfie and hearing about Lorraine and her boys donating her husband Paul's organs we started a very special friendship.

On the year anniversary of my transplant I wrote to my donor family to thank them for their gift of life to myself and my family.

I gave it to my transplant co-ordinator but never heard anything back .

It was a very hard letter to write , as how do you thank someone for a new life, but it felt important to write and something I wanted to do so regardless.



Thanks again to all Donors and Donor Families.

You are all our heroes.

We are forever grateful .

Myself and my family are forever grateful.

Thanks can never be enough, but thanks from Vicky, Erik and Antony Pettersen .

You didn't just save me , you saved my family and made our extended story possible."

(Our thanks go to Vicky for sharing her story and thoughts with us. We wish her many healthy years to come.)

BEYOND GRIEF THERE IS HOPE

The **British Transplant Games**, due to have been held in Coventry during the Summer of 2020, may have been cancelled due to the pandemic but it didn't stop the organisers wanting to include the athletes and supporters in other ways:

Westfield Health organised some **Virtual Games**, encouraging the sharing of past experiences from different parts of previous Games, allowing athletes and supporters to reminisce on events such as the Opening Ceremony and the Donor Run.



On 30th July, DFN Trustee Audrey Wheeler attended a short flame lighting ceremony of the Donor Flame, an important part of the Opening Ceremony.

Nigel Burton, Chairman of the DFN, was asked to introduce what would have been day 4 of the games, a full day of athletics, which would have been held on 2nd August.

Recipients took part in many events, playing games outside, inside, in their gardens or in the park, posting pictures and videos on Facebook and YouTube. Social media became very important this year as old friends met up this way.

The MLS team of golfers used DFN golf balls, others played volleyball, table tennis, badminton or cycled.



Not to be outdone, the **Donor Family Network** were keen to take part in something which would remind us of the usual Games. So, on Saturday 1st August, some of our members and Trustees took part in our own version of the Donor Run, wearing the butterfly wings previously worn at the Donor Run at the Newport Games. Many paid the fee which would usually have been charged to take part, to raise funds for Transplant Sport at this difficult time.



Once again, pictures were shared on social media:

Donor mum Rebecca Patel and her friend Sal Salter led a group in a run around Roberttown, Leeds. On the same day two of their friends ran 5 km in the South of France, two more ran in the Yorkshire Dales and one in St Albans.



Lorraine Morgan-Brinkhurst says, "As a Patron for the Donor Family Network Charity I was delighted to take part and I did my charity walk this morning in Victoria Park, Bath, with my dear friend Jane".



WE WILL NEVER FORGET THEM



DFN Trustees Jim Fallow, Andrea Fallow and Emma Thirlwell joined Patron Justin Grace and others for a socially distanced walk at Wigg Island.

A face book message posted in response to these pictures said,

"You are amazing. Without you guys we wouldn't be here. I wouldn't have had 19 yrs of love and happiness and watched my daughter give birth, marry and met both my grandson who is 6 and socially distant granddaughter who is 3days old. You are amazing THANK YOU ALL".



Andrea Fallow and Lorraine Furie

Other Donor Family Network Members who took part in the Donor Run, sporting their butterfly wings included:



Mick and Natalie Hawkridge



Liz Phillips



Babs and Brenda Bryson

WE MAY NOT HAVE YOUR PHYSICAL PRESENCE



(Right): This picture was posted on our face book page, with the message, " After a 3k run tonight for our donors, from a little girl and her family with forever grateful hearts x".



(Above): Tom's mum and Keira's mum walked to the top of Codden Hill, the highest point in North Devon in memory of their children. Local TV and Radio coverage helped awareness of this year's virtual donor run.

(Right):

This message was also posted on our Facebook page from a grateful recipient, "Not a day goes by that I don't think of my donor and his family, and every one of those days starts with a 5K dog walk alongside my bouncy 10 month old Labrador Bailey.

However, today's walk was special. My 5K today was in honour, recognition and remembrance of all donors and their families. The difference you have made to many of our lives is immeasurable. Thank you is never enough".



Transplant Sport

developed a face book page called "**Magic Moments**" and asked their followers to share their most cherished memories from previous Games. There were so many wonderful photos and comments, so we would like to share a few with Donor Family Network members:

"I always find it inspirational when the Donor Families are received at the British Transplant Games. I wear the Butterfly Badge with much pride. We have to remember that no matter what legislation is in place, to them falls the ultimate decision to save another life, whilst in grief thinking of others. That is what makes them special Human Beings and I salute them." (Patron- Transplant Sport)

"At the Opening Ceremony everyone stood to honour the donor families. I was humbly moved as without them none of us would be able to do what we do. I wanted to make my donor proud. I am, and always will be, in awe of every one I have ever met at the Games. All the unique stories I have had the privilege of hearing and the courage and resilience that shines through, bringing an unseen unity." (Recipient)

BUT YOU ARE WITH US IN EVERYTHING WE DO

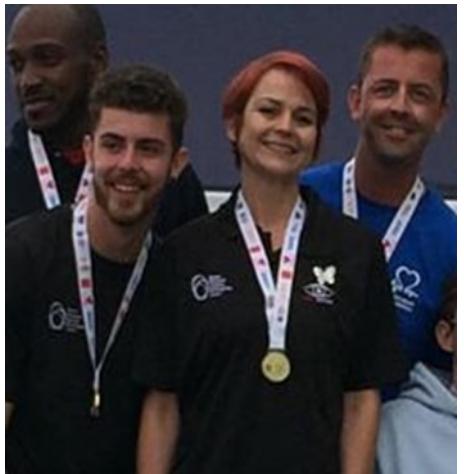
(Right): My first Games in Liverpool as part of the Donor Family Network. I ran the donor run in memory of my husband Rick." (DFN member Liz)



(Below): "Being on the winning team for Birmingham Adults in 2010 in Bath. So very grateful to my donor." (Recipient Martin)



(Right): "My first Games in Birmingham in 2016. Just 12 months post transplant. Asking me to join meant the world to me, it was the point I believed I could." (Recipient Sue)



(Left): "This was last year at my first games as part of the Donor Family Network, after my dad donated his organs in 2003. I am forever grateful to see all the recipients who remind us of our loved one's. Looking forward to my next Games already." (Sophie- DFN member)

(Right): "My Magic Moment was presenting Tom's Baton with my daughter Pippa to Transplant Sport and lighting the Donor Family Network flame to declare the Games open. To do this on behalf of my organ donor son Tom and all Donor Families was an incredible honour." (Lisa- DFN member)



"The Games are an annual highlight and source of strength for our families." (Recipient)

"So many emotions, new friends made, becoming part of a team and a member of the Transplant Family." (Recipient)

"Showing my donor I'm still here and spending time with my transplant family." (Recipient)

WE MISS YOU EVERY DAY

More "Magic Moments" :

"I love to see the little one's run after their unbelievable journey. Families chatting, having fun, siblings making friends. The Games bring so much happiness to so many."

(Children's Team Manager)

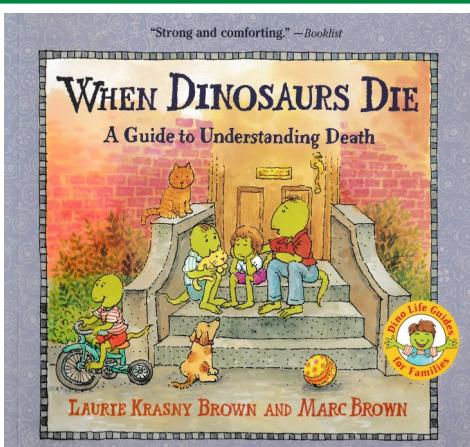
"To me the highlight of every Games are the times when the Donor Families are remembered. Without them there is no story, no future. In the parade where all the teams come in with their flags, there is the greatest cheer when the Donor Families walk in. Nothing stirs your emotions more. It fills you with a sense of gratitude, humility and thanks to see and meet a donor family. This is the emotion felt by most recipients at the games. It is so wonderful to have them there. Thanks again to all donors and Donor Families. We are forever grateful." (Vicky—Recipient)



"The Magic Moments confirm for me what the Westfield Health British Transplant Games mean to so many participants and their joy should encourage us to publicise the benefits. I am so proud to be Patron." (Graham Moore)

TS Kids is a project funded by BBC Children in Need for children and young people who have received a transplant, their siblings and children of parents who have had a transplant. Simon, TS Kids organiser, works with the hospital Team Managers to hold regional events and activities and kids and family weekends, encouraging children to keep healthy, support each other and be proud of their achievement.

This year, due to the cancellation of the British Transplant Games, Simon organised family fun sessions of light exercise which could be done at home. Over the British Transplant Games weekend Simon organised a "sports weekend in the garden", with coverage on YouTube.



This book addresses children's fears and curiosity head on.

Along with many others it can be borrowed at no charge from the **Donor Family Network Bereavement Library**.

Please see our website or contact us for details



Follow us on Facebook and Twitter

@DonorFamilyNetw



YOU ARE ONLY EVER A HEARTBEAT AWAY



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

Patrick Gallagher

Keith Astbury

Darren Cox

J Fletcher

A Heron

SJ Hall

Albert Massingham

Roger Quick

Hilary Sidwell

Ed Keeble

Philip Cairnduff

Judith Coutinho

Eric Scoones

Alicia Young

Caroline White

Mr & Mrs Heywood

Mrs Nash

Wadsworth WI

Otley Townswomen's Guild—following a talk about the work of the DFN

by Trustee Karen Piotr

Horsford Lodge of Freemasons—following a further talk given by Trustee Karen Piotr

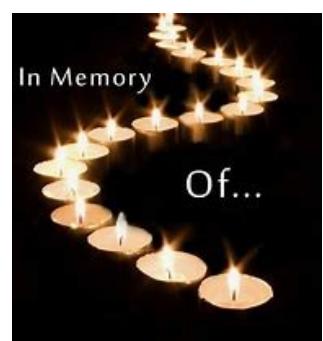
Step by Step Dancing - monies raised though regular raffles at their social dances allowed us to purchase a new printer for the DFN.

NHSBT Eye and Tissue Services

Funds raised in memory of Jane Reynolds

Funds raised in memory of Peter Ford

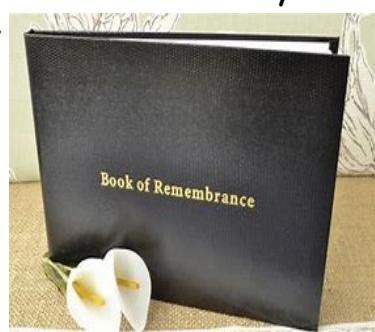
Funds raised in memory of Gary Walklett



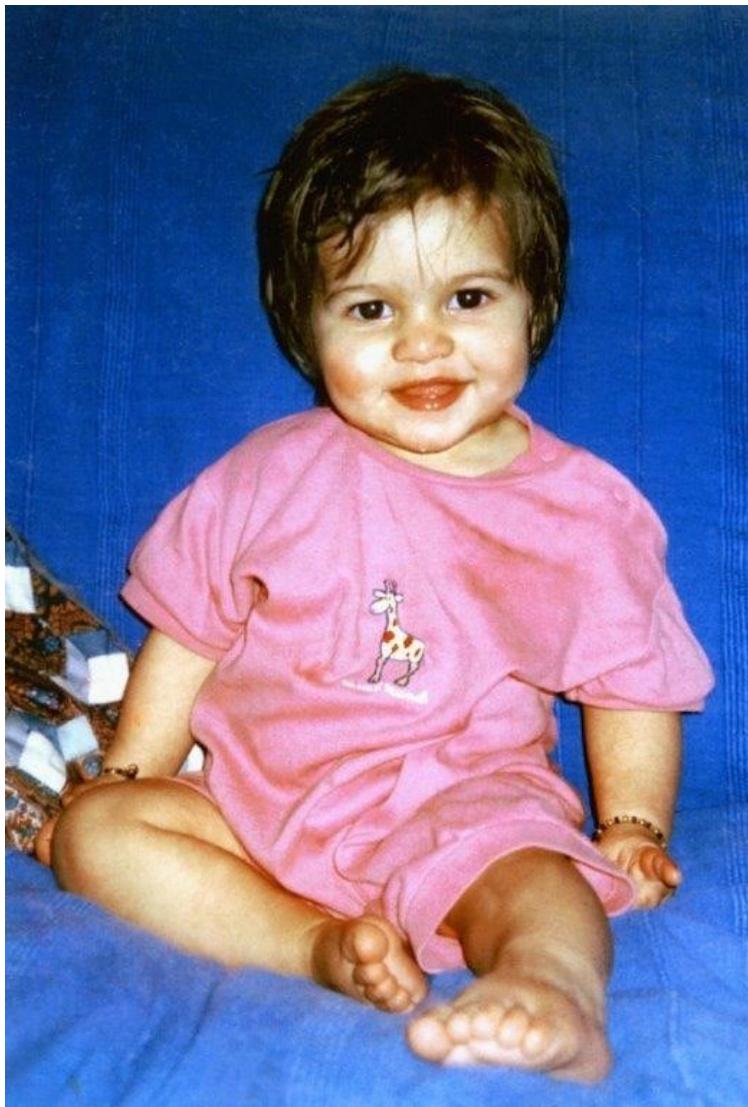
Donor Family Network on-line BOOK OF REMEMBRANCE

To add your tribute to a loved one who has donated, or a tribute to your donor, please complete the on-line form on our website and your entry will be added to the relevant month. This is another way in which we remember those who gave the Gift of Life.

You are welcome to include a photograph of your loved one in your entry to the Book of Remembrance.



BUTTERFLIES HOVER AND FEATHERS APPEAR



This gorgeous little girl is Zara. Mum Rebecca tells her story:

"Zara was our second daughter, a happy playful toddler, very easy going, only seemed to have a temperature when she had a new tooth coming through. One Thursday in June 2002, aged 14 months, she had yet another temperature, we just thought it was another tooth, and tried to control the temperature with Calpol.

The following day, Friday, she was the same, an extremely high temperature, but oddly no runny nose. I called the GP who suggested we carry on giving her alternate Calpol and Nurofen.

On Saturday, Zara was unrousable. Her eyes were open but she wasn't there. As we live quite close to our local hospital, Northwick Park Hospital, we took her straight there, I was immediately taken to the resus area, they asked all the usual questions about her health including, 'Where's the rash?' At this point I thought, "they think it's meningitis".

Zara was intubated and transferred to Great Ormond Street Hospital where she was admitted to intensive care. She

had further tests which came back clear, they said they would wake her up. Late that afternoon she had another brain scan, following which the doctors invited us to a room. They told us that they suspected that Zara had meningitis and that they believed she was braindead. I only remember asking the question 'Are you saying my baby's dead?'

The doctors said they believed so, but would wait until the morning to confirm by performing the tests. It was around 10.30 pm on Saturday night. My husband went home to look after Sophie, our older daughter who was almost 3 years old.

I am not sure how the subject of organ donation came up, whether it was me who suggested it or the clinical team. I was in favour, and rang home to my husband who also agreed. We had never discussed it before, but I knew I did not want another mum to go through what we were going through. We watched the brain stem tests which confirmed there was no brain activity, after that the doctors said they had to confirm the diagnosis before organ donation could go ahead. They performed a lumbar puncture during which I was allowed to hold her in position. It confirmed Zara had had Pneumococcal Meningitis.

We were given books to help Sophie understand what had happened, we said our goodbyes not knowing if organ donation would happen and what organs would be used.

WHENEVER LOST LOVED ONES AND ANGELS ARE NEAR

The following day the transplant coordinator let us know that Zara's heart had been donated to a little girl who would have died that night, and one lobe of her liver was transplanted into a baby girl who had never left hospital. Hearing the news that Zara had saved two lives was amazing. (I don't remember this but apparently I was very keen for her heart to be donated). Staff also gave us hand and footprints and a lock of her hair.

I have received cards, letters, and even pictures of the little girl who received her heart. That little girl is now 18 and at university! She still has hospital appointments, and obviously they are all virtual at the moment, but she is keeping very well.

For me promoting organ donation keeps Zara's memory alive. I work at our local hospital and sit on their Organ Donation Committee. I am also the chair of the Organ Donation Committee at Great Ormond Street.

Last year my best friend and I attended the Transplant Games in Newport. An unbelievable experience, meeting transplant recipients and their families. I was hoping to bring Sophie (21) and George (17) this year, instead, due to COVID-19, the three of us took part in a virtual 5k with our friends".

Thank you so much Rebecca for sharing your story with us. May your memories of Zara stay with you forever, together with pride for the gift she gave.

(We hope that it helps members to read stories from families who have faced the same heartache and decisions. Please contact us if you would like to share your experiences in a future edition of our newsletter).



Anthony Clarkson, director and chief nurse of organ and tissue donation and transplantation at NHS Blood and Transplant was recognised at the Royal College of Nursing (RCN) Awards in July 2020. He was made a Fellow of the RCN, which is the highest accolade the College bestows. Anthony has represented the UK on several organ donation and transplantation forums across the globe and in 2016 was appointed to the position of group leader of the prestigious organ donation global leadership symposium.

In 2019 his contribution to saving lives through organ donation was further recognised when he was elected as the European representative on the council of the International Society for Organ Donation and Procurement.

He said, "I believe being awarded the RCN Fellowship is the greatest honour any nurse can receive. When I was informed of my award I was humbled by my nomination for, and acceptance to, the fellowship and proud to be recognised by our profession in this way. I have dedicated my career to striving to provide the best possible care for organ and tissue donors, their families and ultimately the patients who require an organ or tissue transplant and have been fortunate to learn from and work with incredible colleagues along the way".



IN OUR HEARTS YOU WILL ALWAYS STAY

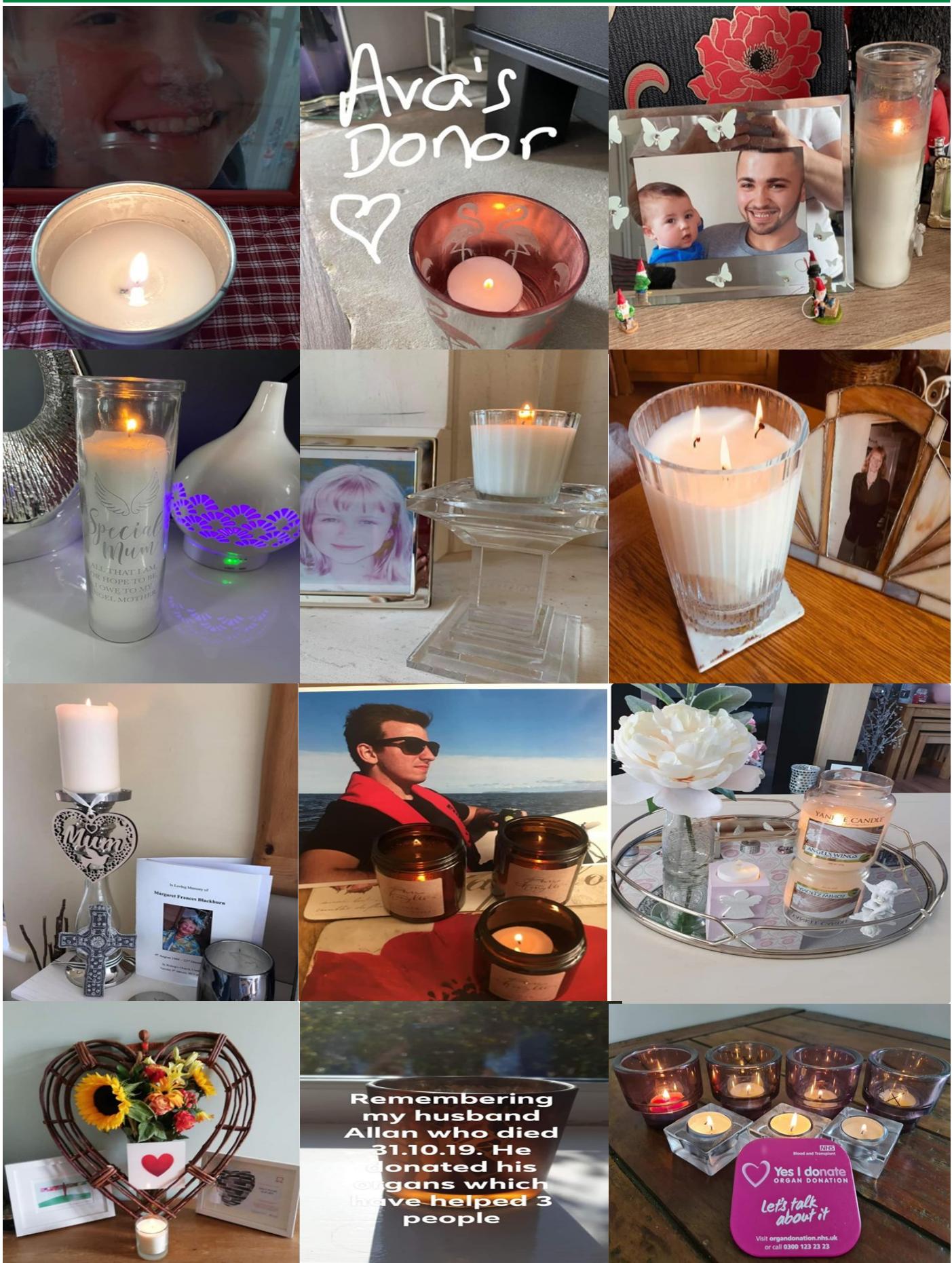
More lovely photos of your loved ones.

What fabulous tributes.

We hope to see you at our Family Event in September 2021 !



LOVED AND REMEMBERED EVERY DAY



THANKYOU FOR THE LOVELY MEMORIES

Keith Astbury shares his daughter Pippa's donation story :

"On the evening of 14th November 2018 I was at home when the telephone rang. It was a paramedic telling me they were with my daughter Pippa who had rung them just before she collapsed at home. They told me she was very poorly and they were taking her to the local A&E and advised us to get there ASAP. We arrived there about one hour later to be told that Pippa was in ICU and being ventilated as she was not breathing by herself. It appeared to be very chaotic with lots of medics around. We were then informed that Pippa was to be transferred to Preston Royal Hospital. We arrived there shortly after and were met there by a family liaison nurse and a consultant who were very caring and told us that Pippa had suffered a 'catastrophic instant brain haemorrhage'.

About an hour later two more Consultants spoke to us and informed us that there was very little hope of Pippa surviving but they would be doing a 'brain stem' test to confirm or otherwise any signs of life. We were asked if we wanted to attend the tests but we declined as we thought the procedure was intrusive and we were in 'some sort of trance' and couldn't comprehend what was going on. A short while after one Consultant returned along with a couple of other nurses (a CLOD/Clinical Lead Organ Donation and a SNOD/Specialist Nurse Organ Donation). The Consultant confirmed that there was no sign of Pippa's brain activity and expressed his condolences, then he left the small private room we were in. At this point we were devastated with shock and grief.

The specialist nurses supported us with care and compassion when they informed us that Pippa had registered on three separate occasions to be an 'organ donor' and asked us what our thoughts were on that. Myself, my wife and other daughter had a short discussion over a cup of tea with added tears from us. It soon became apparent that we should honour Pippa's wishes and give our consent. We were informed as to what would happen next and were given paperwork and information leaflets etc. The specialist nurse's gave us as much time as we needed to say our heart breaking 'good byes' to Pippa (I am beginning to well up again writing this twenty one months later).

A few hours later (I think) as we were still in the 'time warp' of disbelief and shock we left the hospital and went home to our utter devastation and endless tears. However, throughout our grief we gained some comfort in knowing that we had honoured Pippa's wishes and made the correct decision. About a week later we received a letter from the NHS family care donation service informing us that Pippa had donated both her lungs in a life saving transplant to a lady who is a mother and kidneys to two gentlemen. Pippa also donated her corneas and various tissues for future use.

A few months later we were invited to Preston for a formal ceremony of 'The Order of St John' in recognition of Pippa's 'gift of life' to others. A couple of months after that we received a very heart-warming letter from the recipient of Pippa's lungs.



WHICH NO AMOUNT OF MONEY CAN EVER BUY

I realise how difficult that letter was for her to write but we very much appreciate the letter knowing that we made the correct decision. Since then we have exchanged letters each way. We recently received an update from The Family Donor Care Centre informing us that all Pippa's recipients were doing well at the time of writing to us. Since then I have become a voluntary NHS 'Organ & Tissue Donation Ambassador' promoting Organ and Tissue donation.

Supporting Pippa's decision to donate her organs and help others has brought me great comfort. She will be so missed but her legacy will live on through her son John Aaron and the recipients of her organs and tissue. She was able to help three people through her donation".

(Thank you so much Keith for telling us all about your beloved Pippa!)



A Brief History of Organ Donation

Solid organ transplantation is one of the most remarkable advances in medicine, progressing from what was a clinical experiment to routine and reliable practice which has proven to be clinically successful, life saving and cost effective.

Christian Barnard, a South African Surgeon performed the world's first human to human heart transplant on 3rd December 1967. Although his patient only survived for 18 days, it proved this type of transplant was possible.

1962 saw the first kidney transplant from a deceased donor, 1963 the first lung transplant, 1967 the first liver transplant and 1981 the first heart and lung transplant.

The Organ Donor Card was first introduced in 1971 and the Corneal Transplant Service in 1994. The Organ Donation Register started in 1994 and by 2004 there were 15 million people registered. By 2018 this had risen to 25 million (around 38%).

Statistics:

Figures from previous years (1st April—31st March) show that there has generally been a steady increase in the number of donors:

2010 /2011	-	1010	2015/2016	-	1364
2011 /2012	-	1088	2016/2017	-	1413
2012 /2013	-	1212	2017/ 2018	-	1574
2013 /2014	-	1320	2018 /2019	-	1600
2014 /2015	-	1282	2019 /2020	-	1584

With the recent change in the law from May 2020 it is hoped and expected that this will continue to increase year on year. The donation of tissue, such as bone, skin, heart valves and corneas also continues to increase.



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LEND ME YOUR HOPE

Lend me your hope for a while.
I seem to have mislaid mine.
Lost and hopeless feelings accompany me daily.
Pain and confusion are my companions.
I know not where to turn.

Lend me your hope for a while.
I seem to have mislaid mine.
Hold my hand and hug me.
Listen to all my ramblings, recovery seems so far distant.
The road to healing seems like a long and lonely one.

Lend me your hope for a while.
I seem to have mislaid mine.
Stand by me, offer me your presence, your heart and your love.
Acknowledge my pain, it is so real and ever present.
I am overwhelmed by sad and conflicting thoughts.

Lend me your hope for a while.
A time will come when I will heal.
And I will share my renewal, hope and love
with others.

(Please do not hesitate to contact us if we
can offer you any support at any time)

