

SUMMER
2019



Medical history was made when **Kaylee Olley**, at just 4 months old, received a new heart on 14th October 1987 at Freeman Hospital, Newcastle.



Mum Carol tells her story, "It was a very scary time. She was a healthy baby who within a matter of a few days became critically ill in intensive care fighting for her life. Agreeing to the heart transplant was the most important day of my life. We had been told that there was a real possibility that a donor would not be found and a 50/50 chance of surgery being successful as Kaylee was so tiny. I now realise that even though my baby was so desperately poorly, some one somewhere sadly would experience what I didn't want to, regardless of whether Kaylee needed a new heart or not. However, that did not stop the pain and the guilt at the time. When the call came on 13th October 1987 I cried oceans for the family whose baby had died. To this day I am still very emotional when discussing this particular issue. This will never change!

Since Kaylee's transplant I have planned and campaigned for others to have the same opportunity, to repay the gift. Our world was suddenly invaded by world wide publicity and sacks of mail arrived from around the world.



I feel very proud when other parents and recipients say that Kaylee has been an inspiration to many. The greatest accolade is when people state that they have joined the NHS Organ Donor Register after seeing Kaylee's story.

I never believed that so many years later Kaylee would have become a fit and healthy young woman, working and playing hard".

DONOR FAMILY NETWORK

CONNEXIONS

Registered charity
1098781



The
Gift of Life
Memorial

MAY YOU RECALL THAT RADIANT SMILE

Carol continues, "Transplantation creates miracle stories every day however the heroes are the donor families who selflessly give to others with no gain for themselves. Each and every day I give thanks to the family whose brave decision utterly changed my life and gave life to my child. There is no greater gift. Thankyou is such a small word and just never seems to quantify how I feel as a mum. A stranger, whom I have never met, gave the most precious gift, the gift of life, to my baby. I owe a huge debt to this family and I am forever grateful each time I look at Kaylee. On each anniversary, amongst the celebrations, my family and I spend reflective quiet time remembering the amazing family who made this possible.

Kaylee has a passion for sport. Aged 2 years old she attended her first British Transplant Games and of course won a gold medal in her chosen event "throw the welly". She has attended the British Transplant Games almost every year since then and has lifted the Union Jack above her head on a medal stadium, winning medals at the World Transplant Games in 2003, 2005, 2007 and 2013, representing the UK in athletics and badminton.



Her involvement with high level publicity is priceless for the transplant community and her promotional work is immense. She often asks, "Mum, do I make a difference?" and the answer is of course, "Yes you do!" To watch her now as a young woman, visit a newly transplanted child and speak to their parents or to watch her gently encourage a transplant child at a sports event is testament to the impact she has on others.

The joy of Kaylee being given a second chance was overwhelming. Kaylee is a living testament to the skill of the surgeons involved".



Our grateful thanks go to Carol for sharing her transplant journey with us. She is naturally very proud of Kaylee, who adds, "I live a normal, happy life and can't believe it is so many years since my transplant. I often think about my donor and can't thank them enough for the second chance I was given".

IN THE SPARKLE OF A STAR

The **British Transplantation Society and NHSBT** joined forces to run a Congress at the Harrogate Convention Centre in March 2019.

The aim of the Congress was to unite clinicians, surgeons, nurses, laboratory scientists, transplant co-ordinators and all of those interested in all aspects of organ donation and transplantation.



Two DFN Trustees were invited to attend so Jim Fallow and Eunice Booker represented the Charity at the Congress, enabling us to be included in the discussion groups and listen to specialist speakers, who, at the start of the Congress, gave an overview of organ donation and transplantation, an update on the opt out in the UK and a speech regarding the National Organ Retrieval Service. Further presentations were made including: research and collaboration; ethics, law and public policy when decision making.

Various discussion groups were held over the three days including:

Donation from black and ethnic communities

Showcasing donation education

Should we do more to support donor families and recipients meeting?

Novel technologies and research

The story of "Max and Keira's Law" was also told:

Max Johnson was 10 when he was diagnosed with a disease of the heart muscle. He spent eight difficult months in Freeman Hospital waiting for a heart transplant. Max thankfully had his transplant on 2nd August 2017 after which he made a speedy recovery. Max and his family made it their mission to raise public awareness about the desperate shortage of donor organs and tissue in order to help others. Max's family knew from personal experience that his survival was entirely dependent upon the generosity of another family agreeing to organ donation. Max campaigned extensively in the media to raise awareness and featured in a powerful documentary "A Chance to Live", which generated a huge public response. His efforts had a phenomenal impact that helped to bring about a change in legislation and the presumed consent law became known as "Max's Law". The heart of nine year old Keira Hall saved Max's life and upon Max's request the law has become "Max and Keira's Law".

Max spoke confidently before the attendees and was followed by an emotional speech by Keira's dad.

AND KNOW ITS SHINING EXTRA BRIGHT



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

Natasha Strickleton
Amanda Ranson
Paul Jasper
Dr Lisa Collins
Patrick Gallagher
J Fletcher

Jo Pool
Sarah Mitchell
Keith Astbury
Irvine Mackenzie
Glemsford WI

Karen Shorrocks who's employer HSBC matched her funding

Gavin Shorrocks - in memory of Iain Fallow

Martyn Smith in memory of his wife Christine

Caroline Brown who hosted a gathering in memory of her husband

Freemasons—Chapter of Perseverance

Donations in memory of Peter John Hubner

Donations in memory of Stuart Rexter

Donations in memory of Mervyn Brooker

Donations in memory of Toby Group

Donations in memory of Peter Livingstone



Our thoughts are with these families

TO FIND YOU FROM AFAR

Fundraising

Gavin Dixon ran the Great Grimsby 10k on behalf of the DFN.

Niall Kelly ran the Sunderland Half Marathon

Louise Tapster-Clark & Stacie Castle are continuing to raise funds in memory of Darren Andrew.

Stacie was fortunate enough to be picked from thousands and thousands of people totally at random and offered a place to run 2019's Virgin London Marathon. Stacie says, "My decision was a no brainer and there is absolutely no better cause for me than to run the 2019 London Marathon for the amazing 'Always With D' charities, St Mary's Hospital and the Donor Family Network. Darren Andrew, husband of my very lovely friend Jane and dad to 3 daughters Louise, Charlotte and Briony, was very cruelly taken from them in January 2018 after contracting bacterial meningitis.

During his illness Darren was cared for by the ICU department at St Mary's Hospital who I myself work closely with in my role in theatres and after Darren passed away he donated his organs to people in desperate need of life saving transplants".



Stacie and a group of friends also climbed the Yorkshire Three Peaks on 11th May 2019 to raise money for a number of charities, of which the DFN was one.

Our grateful thanks go to Stacie and Louise who have raised a considerable sum of money from their events.

WE MAY NOT HAVE YOUR PHYSICAL PRESENCE

Donor family member **Anna Louise Bates**, from Cardiff, has kindly shared her family story with us:

Anna's husband Stuart and seven year old son Fraser were hit by a car in December 2015 whilst walking home from a Christmas event. Stuart was killed instantly, and, despite putting up a brave fight, Fraser died several hours later, leaving mum Anna-Louise and three year old sister Elizabeth. The family agreed to organ donation and

Fraser's organs went on to save the lives of four people.

Anna Louise realised she could direct her grief in a positive way and just one week after losing half of her family unit, Anna-Louise founded a charity, "Believe", to educate people on the fabulous gift of life. Through "Believe" Anna-Louise aims to break down the taboo around organ donation and to get people talking about their wishes to their loved ones. She has also spoken regularly to students and teachers about understanding organ donation and incorporating it into the curriculum.



She has also worked with Mike Young, the animation producer behind iconic '80s children's show SuperTed, to create an animated film to help spread the charity's message. The short film, scripted by Anna-Louise and voiced by two local Cardiff schoolchildren in English and Welsh, shows an animated version of the Believe charity mascot, 'Fraser Bear' - the nickname Anna-Louise and Stuart had given to their son - explaining how his organs have gone on to save the lives of four people. "Organ donation is not an easy topic but the teddy bear provides a softer, cuddly way of approaching the subject" says Anna-Louise.

Anna-Louise concludes, "The charity has helped save our lives in many ways as we come to terms with the horrendous loss to the family. That's why I'm determined to spread the word and ensure Stuart and Fraser's untimely deaths can lead to something incredibly positive."

The film, "The Fab Gift of Life", to educate children on organ donation, was chosen as a finalist in the 2019 Charity Film Awards and recently won! It can be viewed on You Tube <https://www.youtube.com/channel/UCpWfCru1aFWxrL-cJRMbP3w>



Fraser Bear can also be followed on Facebook and Twitter

BUT YOU ARE WITH US IN EVERYTHING WE DO

Donor Town Project

TV chef and health campaigner Sally Bee has survived five major heart attacks. Sally has started a donor town project commencing in her home town Stratford-Upon Avon. She is encouraging people to sign the donor register and increase awareness of those in desperate need of organs.



The 'donor town project' will encourage a network of businesses, schools and organisations to help spread the message about becoming a life-saving donor, and promote the campaign through posters, window stickers and banners. The title of 'donor town' will be held for a year before transferring to another town. Sally said: "This is a win-win project. There is no downside, there are no losers, everyone has the potential to become a hero and save up to nine lives. Why wouldn't you? "

An official launch event was held on 24th January 2019 at Stratford Butterfly Farm and was attended by Trustees of the DFN, other donor families, recipients, surgeons and other NHSBT staff. A pack is to be sent home with school children, hoping parents will then take the information into the workplace and discuss organ donation with their friends and colleagues.

LET'S HAVE
A CONVERSATION



— Families are *twice* as likely to *allow* donation when your decision is *known*.

Let's *save* lives, let's make
STRATFORD-UPON-AVON
the *FIRST DONOR TOWN*—



@donortownproject

www.donortownproject.uk



WE MISS YOU EVERY DAY

UK Points of Light

Points of Light are outstanding individual volunteers - people who are making a change in their community. Every week day the Prime Minister recognises an inspirational volunteer with the Daily Point of Light Award.

First established by President George H. W. Bush in 1990, over 6,000 US Points of Light have been recognised in the USA. UK Points of Light was developed in partnership with the US programme and launched in the Cabinet Room at 10 Downing Street in April 2014.

Since then hundreds of people have been named Points of Light by the Prime Minister, highlighting an enormous array of innovative and inspirational volunteering across the length and breadth of Britain.

Doing everything from tackling knife crime, to supporting families of dementia patients, our UK Points of Light are fundraising, awareness raising, problem solving heroes who all had an idea they decided to make a reality. Their actions have changed lives and their stories can inspire thousands more to get involved or start their own initiatives.

DFN Founder and Life Time President **DAVID NIX MBE** and his wife **Jane** recently received the Points of Life award.

In a personal letter to Jane and David, Prime Minister Theresa May said:

"As founders of 'The Donor Family Network' you have helped to raise awareness of organ donation and have provided support to hundreds of donor families nationwide. By working in partnership with donor families, professionals and recipients you are helping to make positive changes in the transplant community. This is a truly remarkable way of honouring your daughter's memory, and you should be very proud of what you have achieved."

Jane and David said:

"We consider it a great honour to be even thought of for any award as the charity was set up to help as many donor families as possible and also to promote organ/tissue donation, not for any gain on our part. We have received great satisfaction out of assisting those who need our help and establishing the charity to continue with this work for many, many years to come".



Donor, Rebecca Nix



YOU ARE ONLY EVER A HEARTBEAT AWAY

John Denver – Perhaps Love

*Perhaps love is like a resting place
A shelter from the storm
It exists to give you comfort
It is there to keep you warm
And in those times of trouble
When you are most alone
The memory of love will bring you
home*



*Perhaps love is like a window
Perhaps an open door
It invites you to come closer
It wants to show you more
And even if you lose yourself
And don't know what to do
The memory of love will see you
through*

*Oh, Love to some is like a cloud
To some as strong as steel
For some a way of living
For some a way to feel*

*Perhaps love is like the ocean
Full of conflict, full of pain
Like a fire when it's cold outside
Or thunder when it rains
If I should live forever
And all my dreams come true
My memories of love will be of you*

*And some say love is holding on
And some say letting go
And some say love is everything
And some say they don't know*

NHS Blood and Transplant statistics:

Between 1.4.18 to 1.4.19 there were 1600 deceased donors.

3959 deceased donor transplants were carried out, which included 2409 kidneys and 181 heart transplants.

Since April 2019 there have been 367 deceased donor transplants.

There are still 6070 people on the waiting list for transplants in the UK.

BUTTERFLIES HOVER AND FEATHERS APPEAR

We are holding our annual **Family Event of Remembrance and Thanksgiving** in the Aspect Centre at the National Memorial Arboretum, Alrewas, DE13 7AR, on Sunday 8th September 2019.

Prior to the event we will hold our Bi Annual General Meeting where the Donor Family Network's Management Committee will be elected. All donor families are invited to attend this meeting which will commence in the Aspect Centre at 1.15 pm.

At 2 pm we will commence our Remembrance and Thanksgiving Event to which everyone is welcome, donor families and recipients and any family and friends who would like to come along. The event allows donor and recipient families to come together and share their experiences.

There will be a mixture of music, readings and poems, together with donor family and recipient speakers.

During the event we will be presenting our Certificates of Recognition to all donor families who wish to receive one.

There will be an opportunity for everybody to light a candle in remembrance or thanksgiving.

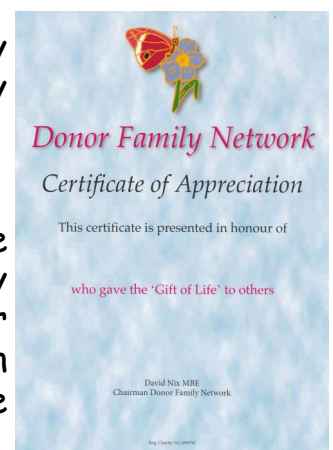
We will use a rolling scroll of photographs to honour donors. Please forward a photograph to us if you would like your loved one to be included. Please also let us know if you would like to receive a certificate of recognition for the gift of life given .

We would appreciate it if you could advise us if you are planning to attend, with approximate numbers for catering purposes, by August 20th, 2019.

You can spend part of the day wandering around the lovely grounds of the Arboretum and visit the Donor Family Network Gift of Life Memorial.



Our grateful thanks go to the family of organ donor Kelly Ashton who raised funds for the Donor Family Network in Kelly's honour, which will be used to fund this event.



WHENEVER LOST LOVED ONES AND ANGELS ARE NEAR

More Fabulous Fund Raisers

Darten Jones

On his Just Giving page Darten says, "I lost my Dad on father's Day 2017, due to a freak accident where he had fallen over and banged his head. This caused a brain haemorrhage and unfortunately he sadly passed away with his loved ones around him at 4:12am on Sunday the 18th of June. Since then if I am being totally honest I have struggled and have been drinking too much to get me through. So this is why I am taking it upon myself to have a dry January.

The Donor Family Network really helped explain the donation process and offered a really great support system which was really helpful. I also wanted to give something back and try to raise awareness of organ donation".

Hannah Jefferson

Hannah calls her Virgin Money Giving page "Swimming the Channel sort of". She explains, "over the course of three months I will be swimming 22 miles, the distance of swimming the English Channel." In the past Hannah used to swim a lot but has not been back in the pool since she was 17. She says, "combining this with working full time, being a mum and living on a small holding, it will be quite a challenge". Hannah is however very determined and the DFN is one of Hannah's chosen charities for two specific reasons as she explains, "this year my dad's transplant turns forty years old. I was only three years old so all I can remember is having a normal dad, doing everything a dad should do, as I grew up. To make this possible, forty years ago, a family lost a loved one. Not only that, they selflessly agreed to allow their loved one to become a donor. I doubt they would even imagine that this act would still be bringing benefits forty years on. We are so grateful to them.

Ten years ago we lost one of my closest friends in a motorbike accident. In death he became a donor and helped many people. It is some comfort to know that he has helped other families just as my own family has been helped. I wanted to do something to honour him this year".

Kevin Westwood

Kevin organised a Kayak Challenge and Family Fun Day on 18th May 2019, in Shrewsbury. He and a friend undertook 34 miles kayaking from the Pool Quay to The Crown Inn, where Kevin had organised live music, food, drink, games and fund raising stalls for all to enjoy. Kevin received a liver transplant in 2018 and wanted to show his gratitude by raising funds for the DFN.



RIGHT NOW, TAKE A MOMENT, CLOSE YOUR EYES

Memorials

We would like to share with you details of some more memorials from around the country which have been dedicated to organ and tissue donors.

If you visit a memorial to organ donation in your area please let us have a photograph to share in our future newsletters. If possible photographs need to be at least 1m resolution so that we can also use them on our website.



This memorial is sited at City Hospital, Birmingham, incorporating a sculpture of a heart located with a circle of benches, inside a garden, which gives both patients and visitors the chance to relax in hospital grounds.

The memorial honours the gift that families and patients make when consenting to offer organs to help save the lives of others.



This 12 foot high sculpture called the Walton Willow Tree stands in the Courtyard of the NHS Walton Centre in Liverpool. Families whose loved ones have donated after death are invited to place a stainless steel leaf bearing their name on the tree.

AND REMEMBER THE SMILE OF YOUR LOVED ONE



Families whose loved ones have donated organs now have a special place in Royal Berkshire Hospital to remember them. The hospital has unveiled a stunning memorial to organ donors in its main entrance at Craven Road which features scores of butterflies native to Berkshire. Spanning an entire wall, the eye-catching butterflies come alive with a striking 3D effect, which also promotes a powerful

message to the people who have given 'the gift of life' and will hopefully inspire others to become donors.



The first **Awards for Excellence in Organ Donation** were presented this year at the National Organ Donation Conference in Harrogate in March 2019. DFN Trustee Sue Burton was invited to join the awards panel, independently scoring all 130 nominations, with regard to individuals and teams, across all aspects of transplantation. The number of nominations was staggering and it was an extremely hard challenge for the panel to make decisions after reading details of the nominations. Trophies were presented to those who received the highest score in each category and certificates were awarded to those in second and third position. Further nominees received certificates of excellence through the post and all of those who were nominated were subsequently informed.

The awards were considered a definite success, there being an incredible number of nominations and the responses of those in receipt of awards and certificates being one of gratitude. It has been agreed that the awards will take place every two years in the future.

The categories and winners were:

Excellence in transplantation - Clinical role - Aisling Courtney & Belfast Team

Awarded for revolutionising the Live Donor Transplant Programme in Belfast, reducing the screening test time for potential donors from twelve months to one day.

THANKYOU FOR THE LOVELY MEMORIES

Excellence in deliverance of patient care within transplantation- Melinda Po Chuo Yil

Melinda has been Sister-in-charge of the Liver Transplant Theatres for 25 years at King's College Hospital, London. She was nominated for being an organised leader who has used her experience to help to set up liver transplant theatre services around the world. She works closely with a patient charity group and is well respected by all medical staff.

Exceptional Clinical Lead Organ Donation - Paul Glover An intensivist based in Belfast, Paul, despite some apprehension and objections, tirelessly worked to reform Northern Ireland's deceased donation service ensuring that organ donation is now an expected part of end of life care.

Exceptional Organ Donation Services Team (SNODS)- North west Team

This team was nominated for demonstrating flexibility, commitment, innovation and dedication. They successfully trialled the Specialist Requestor role and achieved the highest number of proceeding donors in 2017/18, going above and beyond to ensure that donation is offered to each and every family for whom it is a possibility.

Excellence in Retrieval - Papworth Team

On a day of unprecedented transplant activity, 5 transplants took place in 36 hours, requiring more than 40 staff. Theatres had to be turned around in record time so all the team involved were nominated. Papworth's Heart Transplant Programme has resulted in a 40% increase in the number of patients who have benefitted from heart transplantation. Papworth has one of the most versatile and dedicated organ retrieval teams worldwide, achieving numerous significant achievements.

Exceptional Volunteer -Jay and Sina Patel

Aari Patel donated in November 2016 at the age of 3. His parents have tirelessly shared his story on social media. They have helped to dispel faith-based myths, highlighting the acute shortage of BAME donors. A video made by the family is now part of mandatory training for staff and trainee doctors at St George's to raise awareness of the impact of donation on donor families. Jay and Sina are both Organ Donation Ambassadors and front multiple campaigns and initiatives.

Excellence in Research - Gavin Pettigrew

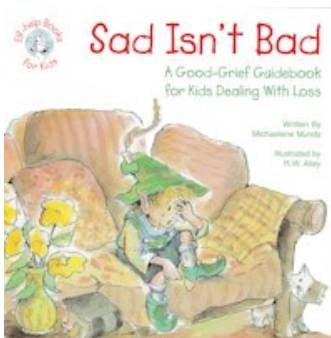
Gavin, an honorary consultant transplant surgeon from Addenbrooke's Hospital, Cambridge, has focussed his research on organ utilisation and clinical decision making with regard to higher risk organs. He is committed to challenging existing thinking.

WHICH NO AMOUNT OF MONEY CAN EVER BUY

Book Reviews

The Donor Family Network Bereavement Library consists of a selection of books related to grief and bereavement that can be borrowed free of charge from the Network. Information on all of the books can be found on our website.

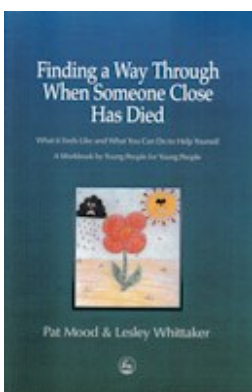
All we ask is that you post them back to us in good condition once you have finished with them. Please contact us if you would like to use this service.



A good grief handbook for children dealing with loss, this book offers a comforting, realistic look at loss- and growth.



This book contains a collection of letters sent from transplant recipients to donor families.



A workbook for young people and teenagers, this book gives guidance as to what it feels like to lose someone and what you can do to help yourself. The supportive and interactive style of this book also helps adults to understand how children and teenagers experience bereavement.



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Beyond Life

By Patricia Rose



*To shed its heavy mantel
And emerge with gossamer wings
In a golden shaft of sunlight
Where a faraway angel sings*

*In this glorious transformation
Death holds no mystery,
For the butterfly, like the spirit,
Was born to fly and be free*

*Life is like a butterfly
That spends its life earthbound,
With a caterpillar overcoat
Until the time comes around*

*It lifts its wings and flies skyward
Out of reach and out of view,
Towards a place called Heaven
Somewhere beyond the blue*

Facebook – DON'T MISS OUT , FOLLOW US NOW

You can follow us on social media to get all the latest up to date news and stories. We love to hear what you are all doing to raise awareness and interest in organ donation, so please remember to tag us and share photos.

You can send us private messages too, which we will respond to as soon as possible.

Facebook We currently have over 2400 followers— get involved and join us!!

We had a surge of new followers over Christmas after our Tatty Ted post was shared, reacted to or commented on 208,000 times.

Twitter We have over 1900 followers and get good reactions to tweets we post and engage with many recipients.

Please let us have any interesting stories or details of events that we can share with all of our friends.