

AUTUMN
2019



Let The Games Begin

The Westfield Health British Transplant Games took place recently in Newport, Cardiff. Representatives of the Trustees of the Donor Family Network attended over the four days, meeting with recipients and their families, arranging medal presentations and fund raising for the Network.



Donor families ready to take part in the Opening Ceremony

The athletes are inspirational and proof that you can live a healthy and active life following a transplant. There are lots of photos later in our Newsletter depicting the amazing and enjoyable time the transplantees have at the Games, together with some of the comments made to us during our visit to Newport. We hope these will enable you all to realise just what an amazing gift was given by your loved ones.



Prior to the Games the local council worked hard to promote organ and tissue donation, holding an Organ Donation Exhibition in the city of Newport, which was open to the public with educational games and stories of recipients and donors.

DONOR FAMILY NETWORK

CONNEXIONS

Registered charity
1098781



The
Gift of Life
Memorial

WE STAND ONE FOOT IN THE LIFE WE HAD

Thank You!

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

West Lancashire Century Lodge- Jim Fallow, DFN Vice-Chairman, received a further donation toward the cost of a trial in the Northwest where the Donor Family Network will give a "hugga" (wrap or shawl) to donor families whilst they wait for their loved one's to go to theatre for the removal of organs. (The word hugga is from Old Norse and means comfort.) Lodges and Chapters in both West and East Lancashire have donated funds to us towards this trial.



If it is successful, it is hoped that the scheme can be rolled out across the country

with support from the Freemasons nationally.

Regular donors—Keith Astbury and Patrick Gallagher

Nottingham Towns Women's Guild

Alison LaVal

A Mace

A Duckworth

J Fletcher

Barbara Hunter- whose kind donation helped to purchase a gazebo

Lesley Clarke

Gail Davies

Clitheroe & District Masonic Fellowship

Nigel and Sheila Chew —who kindly donated funds raised at their Golden Wedding Anniversary, in loving memory of their son David

QE Liver Support Group- who kindly donate annually toward our family event

Gillian Brian—in loving memory of her husband Stephen who donated in 2011

Bill Campbell—in loving memory of his wife Wendy who donated in 2016

AND ONE FOOT IN THE LIFE WE HAVE

David Mansfield, who nominated the Donor Family Network to receive the monies given by colleagues on his retirement. He requested that the monies be used to sponsor our work with the Transplant Games and was pleased that it was used to purchase the iPad which is donated annually by the DFN to be used as a prize at the Games in the children's "My Story" competition.

Donations in memory of Roy Cumberbatch

Donations in memory of Michael Power—our thoughts are with his parents Steve and Geraldine



Fundraising

We are always so very grateful to all those who fund raise for us.

The monies raised help us to continue with our work supporting donor families and raising awareness of organ and tissue donation.

You are all FABULOUS -

On 13th July **Helen and Leanne** completed the Action Challenge 50 km in the Peak District in 11 hours. They ran in memory of a good friend Jon O'Neil and once again raised funds for the DFN. Thank you ladies!!



Chris Green arranged a 24 hour gaming marathon to raise funds for the DFN in memory of Lynn Sellers, who saved the life of five others through organ donation.

Michael Mckinnon & Karen McDougall competed for us in the Gold Coast Half Marathon, along the surf beaches of Southport, Australia, in memory of their friend, heart recipient Marc McCay



Keeleigh John kindly donated to us the sponsorship funds she raised recently. Twenty year old Keeleigh received a liver and kidney transplant in 2011. She spoke to us about how normal her life is now and how active she can be. She was taking part in the British Transplant Games, competing in archery, shot put, discus and netball.

I CAN NO LONGER SEE YOU WITH MY EYES

Our thanks also go to **Suki Sharon** who ran the Birmingham 10k on behalf of the DFN

Brad Green has arranged a bike ride in memory of his much loved colleague, friend and fellow physio, Toby. Brad says, "he is greatly missed by many people, and in his memory we are going to cycle from Burnham Ramblers Football Club, where he used to play, to Tottenham Hotspur Football Club as this was the team Toby supported and was a big part of his life".

Simon Dix is arranging a Band Night to raise funds for the DFN and to raise awareness of organ donation. He is calling it "A night for Dixie", in memory of his friend Danny and it will include a Tribute Band to rock band Joy Division, one of Danny's favourites.

John Mayall has organised a fundraising concert in aid of the DFN, to be held in Cirencester on 9th November.

John tells us his story, " I had a kidney transplant on March 4th 1979 at the Churchill Hospital, Oxford. Forty years later the kidney and I are going strong! I am now 71 years of age, although the kidney is two years younger. I first became ill in my early twenties due to a viral condition that caused my immune system to attack my kidneys. My kidney function continued to deteriorate and in 1971 I was put onto artificial kidney dialysis. It was a difficult time but not all was doom and gloom as I met my future wife amongst the nurses at the Churchill and we were married in May 1973. Life was somewhat restrictive by the three dialysis treatments a week, each lasting ten hours but I was able to work and had two daughters, in June 1976 and December 1977. I was subsequently placed on the transplant waiting list and received a kidney fairly quickly in 1979. After nearly eight years on dialysis you can imagine the difference it made to our lives.

THANKSGIVING
a FUND RAISING concert giving thanks for the gift of life through organ donation with the hilarious singing men from Ashton Keynes

★ ★
THE MAGNIFICENT AK47
★ ★

www.themagnificentak47.com

SUNDIAL THEATRE GL7 1XA
7.30pm 9th November 2019

Supported by **Corinium Community Choir** ★

★
£12 (£10 conc)
from: www.ticketsource.co.uk/sundial

In aid of
Donor Family Network ★
www.donorfamilynetwork.co.uk

BUT WILL FEEL YOU IN MY HEART FOREVER

My fitness and energy levels soared, we had freedom to take family holidays and many things others would take for granted. I am indebted to the doctors and nurses but I never overlook the selflessness of the anonymous donor's family who made it all possible. In dedication to this, and to mark my 40 year milestone, I am organising a gala concert in aid of the Donor Family Network, through my involvement with a singing group of men called The Magnificent AK47. In the past, on each of the 10 year anniversaries I have raised funds for renal transplant charities. This year I want to focus on donors and their families".



Kidney recipient and joint manager of the Birmingham Transplant Team,

Martin Searle, is organising a football tournament in Solihull in March 2020. Maybe some of our recipient Friends of DFN may be interested?



Transplant Sport Football Tournament 2020

Sunday 29 March 2020, Solihull Moors FC

Take part in the Transplant Sport Football Tournament 2020 and have the chance to play on the Solihull Moors FC pitch!

The tournament is open to transplant recipients aged 16+ and will take the format of a 6-a-side tournament. Get a team together or join one yourself and have a fantastic day out playing football with other transplant recipients.



£10 per player

Sign up and find out more by contacting Martin Searle on smartmartg26@gmail.com

Queen Elizabeth Hospital Birmingham Charity

TRANSPLANT SPORT



On September 2nd, Donor Family Network member **Lorraine Furfie** arranged for the Mersey Gateway

Bridge to be lit green in honour of all organ and tissue donors. This marked the start of Organ Donation Week and attracted plenty of press interest.

Lorraine was joined on the night by donor families, recipients, those on the waiting list and others who support awareness of organ and tissue donation.

WE MAY NOT HAVE YOUR PHYSICAL PRESENCE



Our grateful thanks go to Marie Daniels who shares with us the story of her dearly beloved son Daniel:

"On February 19th 2016 my life was changed forever when I received a phone call telling me that my 20 year old son was in A&E being resuscitated following a cardio-respiratory arrest.

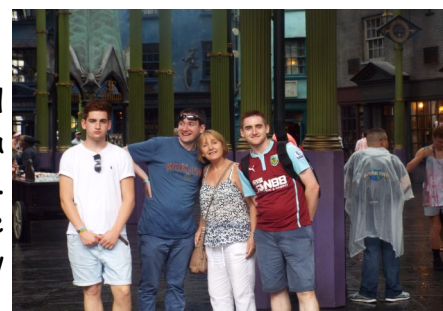


The journey to the large Manchester hospital eighty miles from the rural countryside of our Shropshire home is a blur, I think we - myself, my husband and two older sons - travelled in silence, each of us in our own personal hell. Once there, the shock of seeing my beautiful child on life support in ITU is an image that will never leave me. We sat at his bedside for three days and three nights trying in vain to make some sense where there was none. On Sunday 21st February sadly it was confirmed that he was brain dead and the following day he became a multi-organ donor, donating his heart, liver, pancreas and both kidneys.

Daniel was the youngest of my three sons. I like to remember him as a happy, sturdy toddler with beautiful red gold curls. He grew up in the Shropshire countryside and was very proud to reach the height of six foot two inches making him the tallest in our family. He had a lifelong passion for football and loved all types of music. I had of course had the usual conversations with him about the dangers of drugs, his response was always to laugh at me and tell me not to worry as he was not stupid. Like all young people he was bursting with life and no doubt felt invincible.

Daniel had started university in Manchester only five months before his death. He came home regularly and we saw no change in his appearance or behaviour. We subsequently discovered that Daniel had been using drugs with increasing frequency since his arrival at university. The inquest finally told us that Daniel had died of an accidental overdose of dihydrocodeine (a prescription only painkiller). A small amount of diazepam and amitriptyline were also present which would have increased the risk. I have no idea if he knew what he was taking - probably not. Drugs bought on a street corner do not come with a label.

Before this happened to us I was very naive about the world of street drugs. When a child dies for any reason it is a hugely traumatic event with a far-reaching ripple effect. When a child dies from taking drugs it is a taboo subject, the inference is that it is self-inflicted and therefore somehow "less" than death following illness or accident".



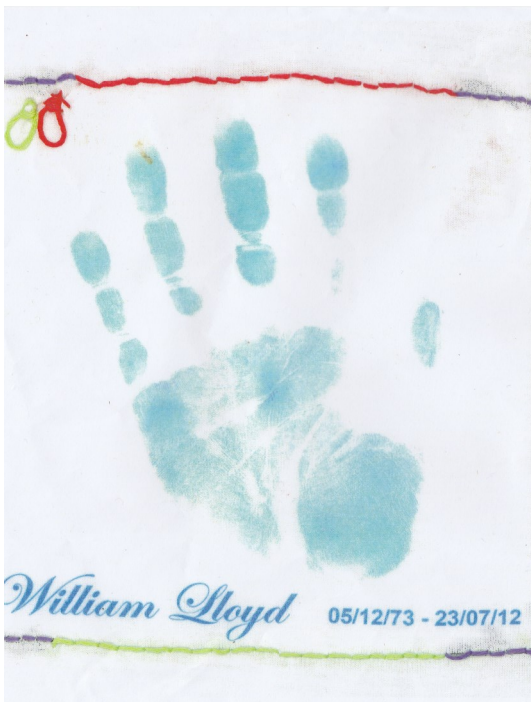
Marie is a member of the charity "Anyone's Child" - Families for safer drug control - because she wants to help prevent the senseless waste of the lives of young people. Marie says, "Daniel could have been anyone's child, but he wasn't, he was my child and I miss him everyday". Marie recently represented Anyone's Child by telling Daniel's story at the Labour Campaign for Drug Policy Reform in Liverpool. Publicly speaking in this way was a real milestone for her in the new life she is forced to live.

BUT YOU ARE WITH US IN EVERYTHING WE DO



Patches of Love I and 2

Donor mum Phyllis Lloyd made a beautiful square in memory of her son **William Lloyd**. Dad William, has requested that we share a picture of the quilt square to encourage other donor families to make a memory square, in order that we can complete the third panel of our donor quilts. If you need some inspiration, please see our website where the Patches of Love leaflets 1 and 2 show pictures of all the squares used to make the previous panels. Quilt squares should measure 7" (18.5 cms) with a border of 2" (5.6 cms). A brief explanation of the design (up to 100 words) can accompany the square. Please help to spread the message of organ donation and to remember those who gave the Gift of Life when the quilts are on show.



William has kindly agreed that we share the words written by Phyllis to accompany their sons square:

"William 5.12.73 to 23.7.12

William was our 4th child. He was a very caring person. Even after his death, donating his organs to help people live a better life. He will never be forgotten by all his family and friends. The most sadness is we will never hold his hand again. We will all love and miss him now and forever more. RIP William".

WE MISS YOU EVERY DAY

Our **Family Event of Remembrance and Thanksgiving** was recently held at the National Memorial Arboretum and attended by around two hundred donor families, recipients and friends. The list of families who have joined the Network during this last year is longer than ever before. An afternoon of music, poetry and interesting speakers, including a donor family member, a recipient and a clinician was enjoyed. An emotional candle lighting ceremony and presentation of Certificates of Recognition were appreciated.



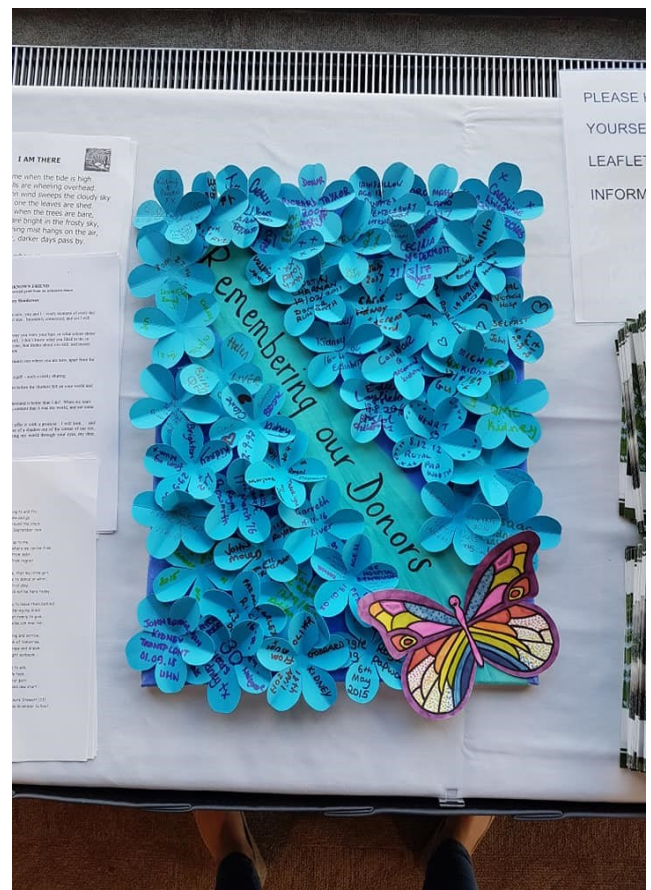
There was plenty of time to chat to other families over tea and cake after the event. Many attendees also went to visit the site of the Gift of Life Memorial.

Our event next year will be held on Sunday 9th September 2020—save the date!

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Gift of Life Memorial



Lovely messages of gratitude from recipients

YOU ARE ONLY EVER A HEARTBEAT AWAY

Donor Family Network Sales

We have some new sales items now available, all of which can be ordered from our website.



Wristband £1.00



DFN Wooden Keyring £1.50



Wristband Keyring £1.00



Ballpoint pen £1.00

Christmas is coming — why not have a look on our website at the collection of sales items and help to raise funds for the charity.

We have a good selection of clothing for adults and children, including our very popular beanie hats at £7.00 and pom pom hats at £10.00.



BUTTERFLIES HOVER AND FEATHERS APPEAR

The 42nd Westfield Heath British Transplant Games were hosted by Newport, Cardiff this year. The Games aim to demonstrate the benefits of transplantation, whilst increasing public awareness about the need for donation conversations. Celebrating life, the Games take place in different host cities and each year teams from transplant hospitals around the country come together to compete in a medley of sports. It is a four day event where over 1000 transplantees take part in over 25 sports. Competitors include children as young as three.

Newport made us very welcome for the Celebration of Life. The Opening Ceremony was amazing. The donor families walked the entire way around Newport Stadium to a continuous standing ovation, cheering and high fives! It was very emotional for all those families who attended.



Lisa Wilson, mum to Tom who donated in 2015 aged 22 years, and Tom's sister Pippa lit the Donor Flame at the Opening Ceremony in recognition of all donors. The Wilson

family also commissioned a sculptured baton, "Tom's Baton", which was handed to the host team. Tom's Baton will be a central part of the Opening and Closing ceremonies for years to come.



WHENEVER LOST LOVED ONES AND ANGELS ARE NEAR



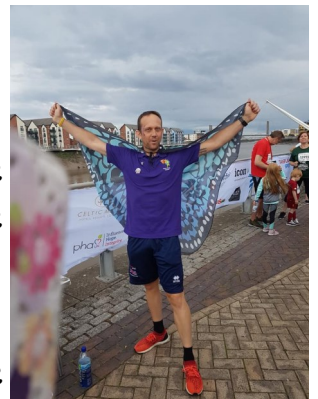
The donor run took place on the Saturday evening. All Trustees wanted to take part, although many of us walked! We had many comments about our butterfly capes.



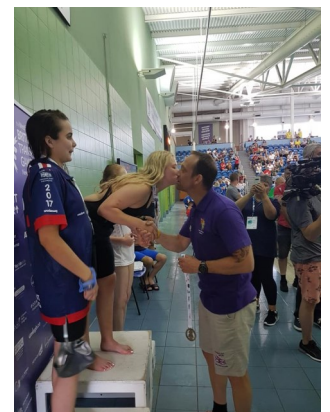
Adults and children alike keep fit and healthy so that they can compete in the Games and all love to receive their medals from donor families.



DFN Patron and recipient Justin Grace competed in the cycling and helped with promoting the DFN throughout the weekend.



This competitor had designed his tee shirt especially to show his gratitude for having received a lung transplant.



The children who compete have great fun, with enthusiastic excitement when medals are won.

The British Transplant Games 2020 will be hosted by Coventry from 30th July to 2nd August.

RIGHT NOW, TAKE MOMENT, CLOSE YOUR EYES

The following are just some of the comments left on our face book page following the Games, which we believe show you just how grateful recipients and their families are:

“A wonderful group of special people” (Kirsten)

“I just feel humbled to see these amazing people” (Pam)

“Thankyou to amazing people like you who gave people like me the opportunity to celebrate our second chance of life “ (Christine)

“As a family of a ten year old recipient the Opening Ceremony is the most emotional part of the weekend, to be able to stand and honour these incredible families “ (Claire)

“Thank you for giving us the chance to stand up and cheer you. You are amazing” (Lisa)

“It is the only way I can say thank you to the families who gave me the quality of life I have” (Karen)

“I know what a difference your families make to families like mine” (Linda)

“You are all amazing. Without you there would be no Games. You have given so much. Thank you from the bottom of my heart” (Karen)

“God bless each and every donor “ (Linda)

“I always love seeing you guys, you are so inspiring” (Paul)

“You and your loved ones are forever in our hearts” (Elizabeth)



The WTG 2019 were hosted by Newcastle Gateshead in August 2019. Thousands of athletes, aged from 6 to 84 came from 59 different countries. Team GB consisted of 330 athletes, who topped the medal table after a full week of events, taking 205 gold, 152 silver and 127 bronze.



AND REMEMBER THE SMILE OF YOUR LOVED ONE

Tom's Baton took part in a relay as a lead up to the Games, going from Whitechapel, London, touring various transplant centres and arriving in Newcastle for the commencement of the Games. British transplant cyclist Richard Caulkin, who received a life saving double lung transplant at Newcastle Freeman Hospital, cycled the last leg of the relay from Leeds to Newcastle, joined by New Zealand cyclist Jane



Donnelly to carry the Baton into Newcastle. Lisa Wilson accompanied Tom's Baton and says, "I was so excited to be travelling with Tom's Baton. It is so beautiful. Tom loved having fun in sport".

A new Baton was also presented at the World Games—the Donor Family Network World Games Baton, dedicated to all those who have given the Gift of Life. This Baton was handed over at the Closing Ceremony to the organisers of the next World Games, which will be held in Houston, Texas and in due course will be handed over to the next incumbent city.

Many donor families made the trip to Newcastle, including DFN Trustee Andrea Fallow, who says, "the atmosphere was amazing and the supporters so friendly. Lots of badge swapping went on over the week allowing us to swap our DFN badges. This led to lots of conversations about us and we received lots of hugs and thanks!



There was a beach walk for donor families from all over the world, where names of the donors were written on pebbles and laid on the beach. While doing this a rainbow appeared—our loved ones were looking down on us!

There was also a donor lunch organised, again where donor families from all over the world gathered- another lovely experience. We were also able to "gatecrash" team GB's social event and it was great to see lots of our friends from the British Transplant Games and hear how they were getting on. They were pleased to see us and welcomed us with open arms. We managed to present some medals which we love to do and this was appreciated by the recipients. Our Patron Justin was competing in the cycling, so of course we were there as his own cheering squad! We felt privileged to be a part of the amazing World Transplant Games in the UK and have fabulous memories".



THANKYOU FOR THE LOVELY MEMORIES

All four recipients of the **David Nix World Transplant Games Bursary** won medals at the Games and tell their stories to us:

Rachel Moffatt was diagnosed in 2007, aged seven, with a rare condition called restrictive cardiomyopathy.

Amazingly, on the same fateful day, **Stephen Moffat**, then aged eleven, was diagnosed with the same condition.



Both would need heart transplants.

Two weeks after being put on the transplant list in November 2007 Stephen was given a new heart. Rachel's health deteriorated rapidly and she received a new heart in August 2008. Both remained in good health for several years. But in October 2015 when Rachel was 14 she became unwell again, receiving a

second new heart in January 2016.

Throughout their trials the annual British Transplant Games have been a big part of the Moffatts life, Stephen attending for the first time in 2008.

Prior to the Games Rachel said, "this is my first World Games, my brother and I have both been selected to represent Great Britain which is a great honour to promote organ donation. Stephen's been practicing all the time because he wants a medal". Stephen added, "I'm just trying to do my best".

Despite missing many months of school Rachel is volunteering at her local hospice and hopes one day to publish her transplant story. Stephen has just completed a degree in computing.



At the World Transplant Games Rachel competed in archery and Stephen competed in 10 pin bowling, both winning medals in their events.



WHICH NO AMOUNT OF MONEY CAN EVER BUY

Fifteen year old **Saad Qayyum** has had a very successful summer, winning a total of nine medals between the British and World Games.

At the age of four, in 2008, Saad underwent a successful ground-breaking liver transplant at Birmingham Children's Hospital, his complex transplant being a world first. Since then, he has become a keen swimmer, competing this year in both Newport and Newcastle. At the British Games Saad achieved one gold, two silver and two bronze medals, despite being the youngest member of the 15-17 year group. In Newcastle, he achieved a silver medal in the 50 metre butterfly, silver in 50 metre freestyle and bronze in 50 metre backstroke. Saad was also a member of Great Britain's relay team securing bronze. Now he has his sights set on competing at the World Transplant Games in Houston, Texas in 2021. Saad's mum, Lubna, says "our thanks go to the donor family who, without a second thought, gave the gift of life. This bursary will allow Saad to show that if barriers are raised and opportunities given, children like him have the potential to compete in International Events".



Callum Turner, now aged 19, had a heart transplant at age 15 years. He says, "my health deteriorated during my early teens resulting in me being added to the super urgent list in March 2015. I received my gift of life at Great Ormand Street Hospital four weeks later from a total stranger to whom I will be forever thankful. Since the rollercoaster post-transplant world, I have completed a BTEC in Active Sports and Leisure".

Callum recalled how he first started playing table tennis at school during break times, "I just really enjoyed playing. I've always been sporty, before and after my transplant. I would tell anyone in the same position as me to go for it. Everyone's in the same boat and has similar stories. You're all in it together".

In the British Games in Newport Callum won a gold medal, not dropping a single game in any of his victories from the group stage to the final.

In the World Games Callum represented Great Britain at table tennis in singles and doubles and badminton doubles and says, "I am so pleased and honoured to represent Team GB". He was of course thrilled to win yet another medal!





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Grief

"Grief I've learned is really just love. It's all the love you want to give but cannot. All of that unspent love gathers up in the corners of your eyes, the lump in your throat and in that hollow part of your chest. Grief is just love with no place to go."

(Kathy Parker)



A Special Memory Box by Patricia Rose



It may help to put together

Symbols that will remind you

A special memory box

Of the happy times you've shared

And fill it with happy memories,

A memory you can hold in your hand

The one's that love unlocks.

To remind you how much you cared.

A precious photo or a letter

In time you will find your memory box

Or a programme from a play,

Will have grown so full of love,

A bracelet or a pebble

And that love is the greatest treasure

From a favourite holiday

On earth and in heaven above.



FOLLOW US



We are up to 2726 followers on Facebook and are going to have a push for 3000 by the end of the year— you can help!!

Some of our recent notable posts are:

BBC documentary on World Transplant Games - 9100

Member Lorraine organising the lighting of the Mersey Bridge—4200

Our service 8th September—3500

British Transplant Games Opening Ceremony—2600