



## Jane Stubbs

has recently joined the Network as a Trustee and we look forward to working with her in the future.

Jane is a retired Police Officer who sadly lost her father in December 2015.

Keith Buckley suffered a tragic accident when he fell off a ladder at home whilst putting up Christmas lights. He was a retired Fire Officer, aged 74. Jane's mum Joyce says "It was such a



selfless act. He spent his whole life helping and rescuing other people. It was nice to know something good came out of this tragedy and it made it more bearable for us." They had not talked about organ donation but were advised that Keith had signed up to the register when he renewed his driving licence. Clearly it was

Keith's wish to donate his organs and out of respect and love for him it was the right and only decision the family could make.

Two men received organs and ultimately the gift of life. Jane says, "You never think about this kind of thing until it happens to you. Nothing can soften the blow of bereavement but the change you can make to the lives of others is truly amazing. The gift of life to two others will always be dad's legacy. We are so proud of him."

Jane has kindly taken on the responsibility of making the lovely cards you receive on the anniversary of your loved one's donation and has represented the DFN at meetings.



**Charity Ball** We are holding another Charity Ball on Saturday 12th May 2018, at the Tally-Ho Conference Centre, Birmingham and you are all welcome. Tickets are available at £50 each, which includes a four course dinner, wine and live music. There will also be a tombola and auction. Proceeds will be split between the Donor Family Network and Transplant Sport.



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## MY HEART IS FULL OF MEMORIES

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### **Thank you to all those who have generously made donations to the Donor Family Network:**

Gwent Royal Hospital who held a cake sale.

Ruth Harvey who donated the proceeds from selling her book.

Lytham Belles Women's Institute.

Graham Moore—Westfield Health.

Steven Wonders who climbed Ben Nevis.

Renzo Giovaninni in memory of Luca.

Mr & Mrs Walsh in memory of Luca Giovaninni.

Sid and Carol Lamb who made a generous donation, following their 13th annual fund raiser in recognition of Sid's heart transplant in 2004.

Andrew Prismall whose company IPSA held a raffle for the DFN at their AGM.

Paul Jasper's sister continues to have a collection box for the DFN in her shop.

James Noon who took part in the Ironman Wales challenge in memory of his best friend Martin Burton.

Chris and Lisa Hale.

Patrick Gallaher.

Bernadette Springhall.

Ralph and Wendy Hough.

Ratcliffe Power Station held a health week and raised funds for the DFN.

Recipient Christine McCallum.

Claire Willmington.

Peter and Ann Richardson in memory of their daughter Anna Culkin.

Alick and Penny Moore in memory of their son David.

Jane Spilsby and family and friends in memory of Jane's husband.

Donations in memory of Nicola Ames.

Donations in memory of Peter Donovan.

Donations in memory of Janet Reidy.

Donations in memory of Stephen Coverdale.

Martyn Smith in memory of his wife Christine.



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Our grateful thanks go to Frank and Marjorie King of the Series 3, Land Rover Club for offering, delivering and erecting a gazebo over the Gift of Life Memorial which allowed for essential maintenance to take place.



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## WITH PRIDE I SPEAK YOUR NAME

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### Thank you to our wonderful fund raisers

**Paul Furfie** donated in January 2013. His wife Lorraine wanted to hold a special event to mark Paul's 60th birthday on 27th November 2017 and organised a fund raising event for the Donor Family Network. Lorraine collected items for a tombola with many prizes. On the evening of the event there was also a raffle to win a donated X Box. Lorraine was incredibly well supported by local businesses in relation to the items donated for auction, which included:

- \* Signed Steven Gerrard Football Shirt
- \* Football signed by Manchester United Team Members
- \* Tickets for John Bishop's Show
- \* Derry Matthews signed Boxing Glove

Lorraine had some amazing support from her friends and family, ensuring that the evening was a great success, raising over £3,000 for the DFN.

Paul and Lorraine's son recently married and gave DFN pins to all of the wedding guests, acknowledging the Network and raising awareness of organ and tissue donation on their special day.



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**Samantha Marsh** has raised funds for us throughout 2017, undertaking a year of challenges in memory of her sister Amanda, who would have been 30. Her final challenge was climbing Kilimanjaro in December 2017. Kilimanjaro stands at 19,341 feet and this challenge took 5 days to climb to the summit and 2 days to descend. Samantha says "The climb was relentless, exhausting and amazing all at the same time. We left base camp at 11.30 pm to walk through the night in temperatures of -15 to arrive at the summit in time for a beautiful sunrise on the roof of Africa—at 6.15 am on 31st December 2017!" We are very grateful to Samantha for all her efforts and for raising an amazing £3,700 for the network. Amanda would so proud of her!



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## ORGAN DONATION IS NOT A TRAGEDY

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**DFN Trustees** attend numerous meetings, allowing us to keep in touch with what is happening in the world of transplantation. Our recent involvement includes:



### **2020 Meeting**

The Donor Family Network is a member of the 2020 Stakeholder Group, the remit of which is to bring together representatives of all those with a key role in implementing the aim of matching world class performance in organ and tissue donation and transplantation by 2020 by:

- \* Advising on the development of plans to change public attitudes and actions
- \* Ensuring exceptional care for donors and families
- \* Agreeing and monitoring proposals and decisions such as: milestones for implementation; measures of progress; measures of success

The group meet twice a year.

### **NHS Blood and Transplant**

We have been working closely with NHSBT to establish good practice following donation.

DFN Chairman Nigel Burton met recently with Anthony Clarkson, Assistant Director, Organ Donation and Nursing at NHS Blood and Transplant at the Tissue Centre, Speke, Liverpool.

It has now been agreed that within 48 hours after agreeing to donation a letter is sent to the family, together with a gold heart pin, irrespective of whether or not donation takes place.

Within 10-15 days post donation the donor family will receive a letter with broad details of the recipients of their loved one's organs, together with DFN pins.

The Specialist Nurse Organ Donation teams are busy and are struggling to find time to arrange promotional events for organ and tissue donation. A new member of staff has recently been employed by NHSBT whose role will be to provide a link to transplant ambassadors who will carry out a 2 year programme to promote donation.



Getting details for donor families when they request an update on their loved one's recipients can be difficult. NHSBT are looking at ways that this can be improved.

It has been agreed that the DFN will meet with Anthony Clarkson on a six monthly basis.

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## BUT IT CAN BE A BEAUTIFUL LIGHT IN THE MIDST OF ONE

Trustees Nigel and Sue Burton recently attended a Parliamentary Event in the **Houses of Parliament** and spoke before a group of MP's. The aim of the event was to encourage MP's to consider what action they could take in their constituencies to develop awareness of organ and tissue donation.



**Wales Opt Out** A meeting was recently held in Cardiff to review the opt-out system which began on 1st December 2015. In 2016/17 there were 61 deceased donors and 135 transplants carried out. In the first two quarters of 2017/18 there were 26 donors and 67 transplants. The percentage of people in Wales who have opted-in is 38% and opted-out is 6%. Since the introduction of opt-out there have been 21 cases where families have not supported deemed consent. In the first 18 months, 28 donors have consented via deemed consent. The soft opt out system has not seen any significant changes in the number of donations made, partially due to the number of potential donors available. Difficulties still remain separating the deceased person's decision from the views of the grieving family and the Act has not helped with this dilemma.

**British Transplant Games** The British Transplant Games will be held in Birmingham from 2nd to 5th August 2018. The DFN are an integral part of the Games and attended the recent launch event for the games in Birmingham's Town Hall, together with the Chairman of Westfield Health and the Mayor of Birmingham who are currently sourcing sponsorship for what they ensure us will be an amazing event. More information will be available shortly but please do try to join us and enjoy a wonderful experience meeting donor and recipient families and presenting medals to the athletes. Please contact us if you would like further information or wish to attend the games.

**English Opt Out Consultation** The Prime Minister has announced the intention to launch a Public Consultation on increasing rates of organ donation as, in 2016-2017 470 people died whilst waiting for a transplant. The proposals will include a new opt-out system for organ donation for England. Despite reaching the highest ever rate of organ donation, there are still more people waiting for an organ than organs available. The consultation will propose an approach where every person will be deemed to have given consent unless they expressly say that they do not agree. Numerous questions will have to be considered and safeguards would be necessary. How much say should families have in their deceased relative's decision to donate their organs? When would exemptions to opt out be needed? How might a new system affect certain groups depending on age, disability, race and faith? Statistics show that more than 6,500 people in the UK need a transplant but only around 3,500 transplants are carried out annually. However, many believe that a programme designed to recruit more donors is favourable to a change in the law, believing that the opt out system is offensive and could be distressing for families and even open to abuse. The countries which have the most donors combined the introduction of their opt-out schemes with other changes, like better infrastructure and more funding for transplant programmes and took numerous years for the donor rates to rise. If successful, the new legislation is not expected to be strictly enforced since families are always consulted and have the final say.

## Campaigns



**NHS Blood and Transplant** have developed a “Promoting Donation Hub” where lots of information can be found.

They have also developed some teaching resources aimed at encouraging children to have the donation conversation with their families at home. The resources include activity sheets and videos showing real life stories.

Guidance on running a campaign and the availability to order materials / posters etc can be found here too.

**Be A Hero campaign** was organised in Leeds, involving interaction with the public.

**Share my wishes** A new online venture. In December 2017 they featured an advent calendar of 24 amazing and special stories to highlight the importance of speaking to your family and next of kin.

### Speed donating

Communications agency, Havas Lynx, recently produced an on line campaign, using video filming, aimed to encourage people to sign up to become an organ or tissue donor.

The concept centred on “speed donating”, the idea being that there are similarities between transplantation and speed dating in that people are hoping to find their match quickly and that waiting can be tiring and frustrating. The video footage starts with actors struggling to find their perfect date and then the mood shifts to donor families, stressing how proud they are of their loved one, whoever they help and to recipients, stressing how grateful they are to anyone who was kind enough to donate. A voice over says: “In the dating world everyone is waiting to find their perfect match- but they are not the only ones- people waiting for an organ donor couldn’t care who you are, just that you care enough to join the transplant list. With people dying every day waiting for transplants, speed is of the essence. Join up today”.

We are grateful to Trustee Eunice Booker and DFN member Lisa Wilson for taking part in the filming.



DFN representatives attended a

**Recycling and Waste Management Event** at the NEC in Birmingham recently. A regular supporter of ours, Andy Savery, Director of M6 Vehicle Hire, has arranged to embellish a number of his refuse vehicles with the logo “Yes, I Donate”.

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## ANOTHER FAMILY HAS BEEN GIVEN THE JOY OF LIFE AND TIME

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### Statistics

#### 1.4.16 to 31.3.17

Number of deceased donors-1413 (4% up on previous year)

Number of corneal donors - 2791 (4 % down on previous year)

Deceased donor transplants carried out -3712 (5% up on previous year)

Number on the list needing a transplant- 6389 (2% down on previous year)

(A further 875 were removed from the list as they became too ill for transplant)

Number who died whilst on the waiting list - 470

(By comparison in 2007– 2008 there were 909 deceased donors and 2384 transplants and in 2013-2014 there were 1320 deceased donors and 3508 transplants which shows that a slow rise is taking place).

#### General Statistics

Number on Organ Donation Register - 23.6 million (36% population) . This compares to 20.2 million in the year 2014-2015. The biggest increase has been by registrations through DVLA.

Of those who have registered, 88% have offered the use of any organs upon their death. Of those who have restricted their registration, 23% have refused donation of the heart and 90% have refused the corneas.

#### Audit figures show that in 2016- 2017

3,144 families were approached in relation to organ donation following brain death or circulatory death.

Of these approached, 2082 (66%) consented to donation.

Solid organ donation actually occurred in 1,413 cases (45%), allowing 3712 transplants.

The consent rate of 66% was good but of course all organs and tissue offered cannot always be used. NHS Blood and Transplant are working hard to raise the consent rate and to research the reasons for refusal.

#### Table showing figures for 2016 – 2017 (Deceased donation)

UK population	65,000,000
UK deaths	600,000
Potential donors	7,024
Eligible donors	5,681
Donation requests	3,144
Consented donors	2,082
Actual donors	1,413





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## We need your help

We are attempting to conduct a survey with regard to correspondence between donor families and recipients and would appreciate your help.

We believe that a large number of donor families would like to hear from the recipients of their loved one's donation. Although recipients are encouraged to write to their donor family we understand that this is a very difficult thing for them to do and believe that a relatively small number of donor families receive communication of any kind.

We would be interested to know your thoughts and experiences

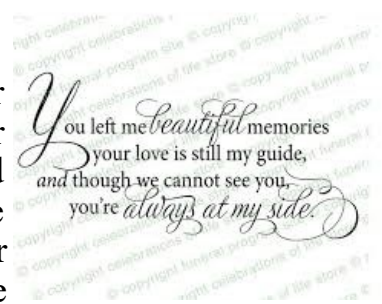
- \* Have you heard from the recipient (s)?
- \* If not, would you like to do so?
- \* If you have been in contact, how did this experience make you feel?
- \* If you have received correspondence, did you reply? (recipients tell us that they love to hear from their donor families)
- \* Have you met any of your loved one's recipients? If so, we would love to hear about your experience.



Please respond by post, e mail or phone if you have any views to share.

## Memories & Messages

Our loved ones hold a special place in our hearts carved for memories. We would like to have a section in each of our newsletters devoted to memories of, and messages to, your loved ones. Perhaps you would like to mention their birthday, the anniversary of their death or any other special date which occurs during the period between newsletters, write a short message in their memory or share a poem?



anniversary of their death or any other special date which occurs during the period between newsletters, write a short message in their memory or share a poem?

Please feel free to include a photograph.

**If you would like to include anything in our next newsletter please ensure that we receive it by the end of May 2018 to be included in our summer edition.**

**MAY YOU FIND COMFORT, HOPE AND PEACE**