

# National Organ Donation and Transplantation Congress.

Warwick University- 20<sup>th</sup> & 21<sup>st</sup> September 2016.

## Opening Plenary:

Dr Paul Murphy (National Lead for Organ and Tissue Donation) opened the Congress, looking at the objectives, the successes from the last year and the challenges ahead.

Dr Murphy began with the all important statistics, including comparisons, for example in the year 2003-2004 there were 771 deceased donors whereas in the year 2015-2016 there were 1364 deceased donors, allowing 3527 transplants to take place, utilising 3932 organs. There were also 3779 corneal transplants during this period and 1075 living donor transplants. This all shows what an incredible effort is being made to continually raise awareness of organ and tissue donation and the Organ Donor Register. By 2020 the aim is to each 1770 donors enabling 5000 transplants.

Dr Murphy went on to explain the detail of the 2020 Strategy of NHS Blood & Transplant, the most important points being:

1. To raise the consent rate of those approached in relation to organ donation to 80%.
2. To ensure that systems are in place to ensure the best utilisation of potential organs as there is an obligation to the families to ensure that NHS Blood & Transplant maximise the gift of organ and tissue donation.
3. To match world class performance in organ and tissue donation.

Graphs were used to show attendees the history of organ donation consent rates. Between 1994 and 2007 numbers had stagnated. Since the publishing of the Organ Donation Taskforce there has been a steady trend upward. This has been assisted by the recommendations of the Taskforce, together with more consideration being given to organ and tissue donation at the time when end of life care is being provided and the early involvement of the Specialist nurses Organ Donation (SN-OD) when death is inevitable and donation a possibility.

## Breakout Sessions

The Congress continued with numerous breakout sessions chaired by some of the Trusts Clinical Leads in Organ Donation (CL-OD), Organ Donation Committee (ODC) Chairman and Transplant Surgeons. These sessions included:

- The Human Tissue Authority (HTA) perspective
- Organ Utilisation
- International perspectives
- Eye and Tissue donation
- Challenging the paradigms

- Cultural diversity and awareness

Short sessions also included the experiences of various Doctors including:

Dr Dan Harvey spoke about the importance of honouring the donor and donor family's wishes with regard to end of life care and organ / tissue donation. He stressed that the duty of the medical profession was to recognise the importance of end of life care following withdrawal of treatment, ensuring that families had the time, privacy and support they needed at this time. He stressed the need to explore the family's wishes regarding donation and that sometimes the use of Intensive Care Unit beds to enable this to happen was fully acceptable.

Mr David Shaw spoke about family overrule/ override when a patient is on the Organ Donation Register but the next of kin refuses consent. He explained the difficulties for the medical profession for whom challenging the family's decision is very hard and may cause distress whilst at the same time having an obligation to respect the wishes of the deceased. The things which need to be taken into account when this happens include: Ethical questions; time constraints; the best interest of the patient and family; the resources available. He stressed the importance of ensuring that sufficient information must be available to the family.

Reasons for overrule include:

- Family feeling unsure of their loved one's wishes
- Family having evidence that the deceased has changed his /her wishes
- Best interest of the patient
- The process being too long
- The family are divided over the decision
- The family feel that the patient has suffered enough
- Concerns surrounding the allocation of organs

### Reflections on Organ Donation Week

The aim of Organ Donation Week (previously referred to as Transplant Week) is to raise awareness and encourage people to join the Organ Donor Register.

Ceri Rose from NHSBT spoke about 2016's "Yes I Donate" Campaign. The aim is to increase the number of people signed on to the Organ Donor Register to 50% of the population, to present donation as a benefit to families at a time of loss and to stimulate conversation about donation in the general public. There hope is to "turn an end into a beginning".

Anthony Clarkson from NHSBT spoke about the introduction of Donation Ambassadors who will be donor families and who will follow a volunteer training programme.

### Media

Andi Ttofa led a session regarding the involvement of NHSBT's media team. She explained how they were very often placed under press scrutiny and had to deal with

difficult and complex issues which can so easily upset donor families (such things in the past have included press claims involving cash for organs, HIV transplants, cancer patient transplants and nurse shortages). It is the responsibility of the media team to minimise the effect of such stories and ensure that donor families are not judged when difficult stories emerge. They attempt to de-mystify organ / tissue donation and diffuse any difficult issues by explaining the facts behind the stories fully to the public. They often work with donor families enabling them to share their experience, pride and bravery and inspire others to consider organ / tissue donation. They work with all of the organisations involved in organ and tissue donation to ensure that all stories are dealt with sympathetically and positively.

During 2015-2016 the media team dealt with 604 media enquiries and enabled 1946 proactive stories to be told.

### Campaigns

There is a continual need for campaigns to run raising awareness of organ / tissue donation. The speaker during this session stressed the need for the following when considering campaigns:

- Delivery of the campaign
- Public engagement
- Sharing of resources
- Building trust
- Education in the community
- Working with the media and NHS communications departments
- Making information available

A few of the current campaigns were detailed at the congress:

#### 1. Eye donation

Those involved in a campaign to raise awareness of the need for eye donation pointed out that if 1% of those who died in hospital consented to eye donation this would meet the clinical demand and have a dramatic effect on lives.

#### 2. Organites

This campaign, by Livelifegivelife, uses children as change-makers and helps parents to discuss organ / tissue donation with their children.

#### 3. Be A Hero

This campaign was run by the Yorkshire Team and involved a “hero” mascot. A photo booth was erected where members of the public signing the organ donor register could immediately have their photograph taken with the “hero” mascot, together with the numerous celebrities who became involved, and then immediately share this on social media. The team were able to announce a 38% increase of people signing the register compared to the same time last year.

## Wales Opt Out

Ms Karen Morgan provided an update on the Wales system of presumed consent which was introduced on 1<sup>st</sup> December 2015. The legislation in Wales requires that a deceased person is deemed to have opted in if they have not specifically opted out and their family is then approached on this basis. She explained the criteria which needed to be met:

- Resident in Wales for at least 12 months
- Die in Wales
- Over 18 years of age
- Capacity to understand the system

The obvious question is- will the system improve the consent rate? Ms Morgan believes that it is still too early to say as there is as yet not enough data available. An annual report is to be made available for the next five years in order that the impact of the implementation of the system can be evaluated. Currently 6% of the population of Wales have opted out.

## The Waiting Game

The Congress came to a close with an inspirational talk from Dr Simon Howell who told his emotional story as he waits for a kidney transplant. He previously received a kidney from a live donor and so is aware of the enhancing effect a kidney transplant can have. However, this kidney was ultimately rejected by his body and he has now been waiting six years for a kidney to become available. He spoke about his life as a critically ill patient and the devastating effects this has on his family life. However, he was very positive in his approach to life, ensuring that memories are made with his family whenever possible. He works tirelessly to raise awareness of the need for organ donation despite his illness.