

Paediatric Organ and Tissue Donation

NHS

Blood and Transplant



6th APPM Paediatric Palliative Care study day

27th November 2015, Park Crescent Conference Centre

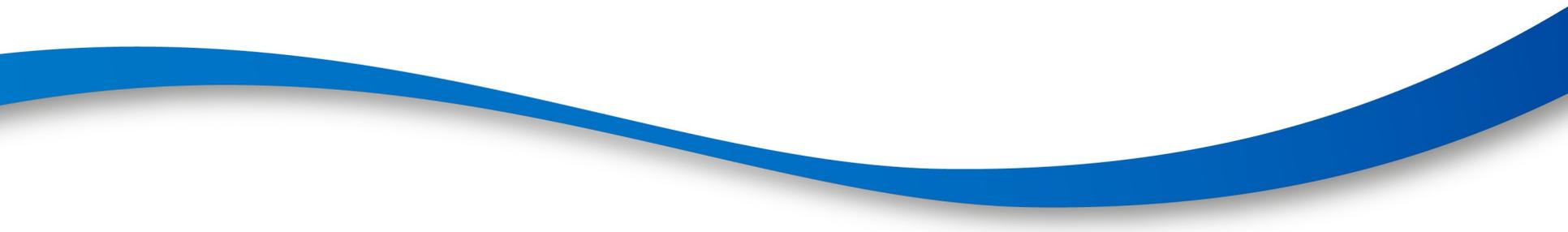
[Neil Healy, Specialist Nurse in Organ Donation](#)

[RHC Yorkhill & RHSC Edinburgh](#)

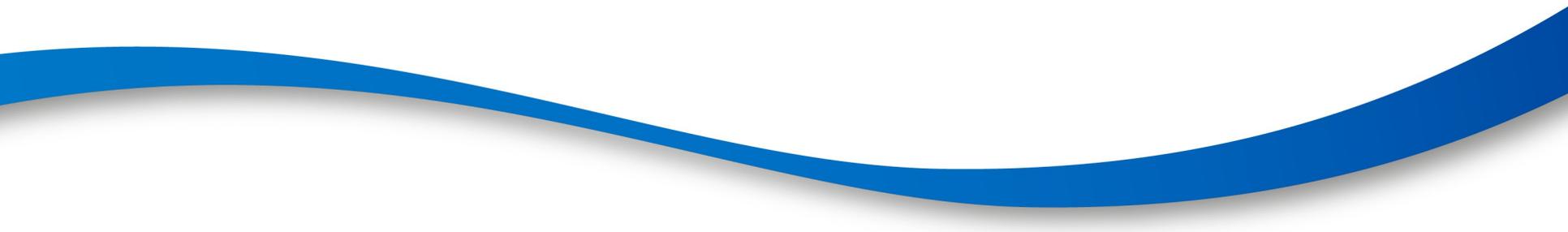


Caring Expert Quality

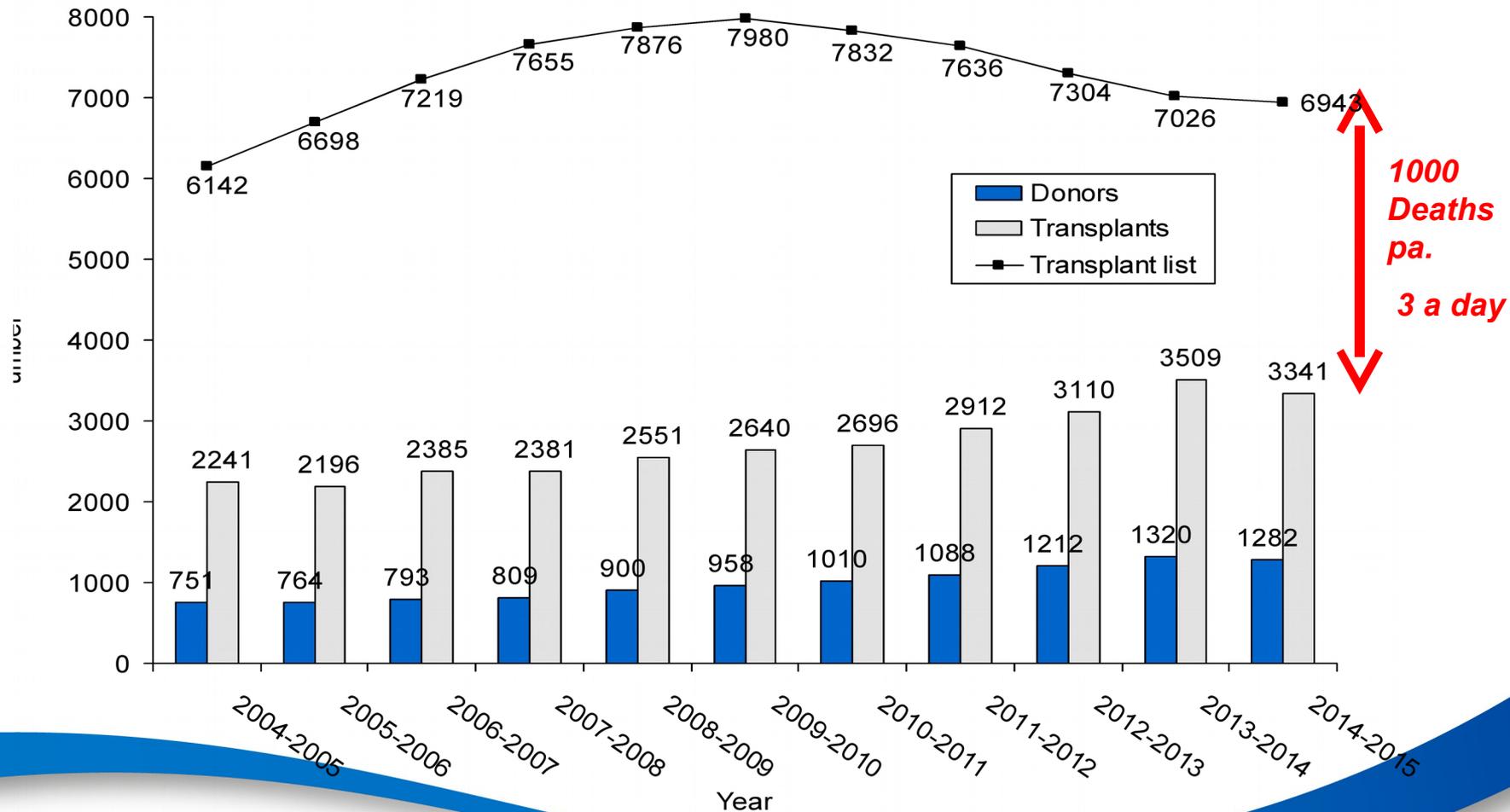
Why are you here?



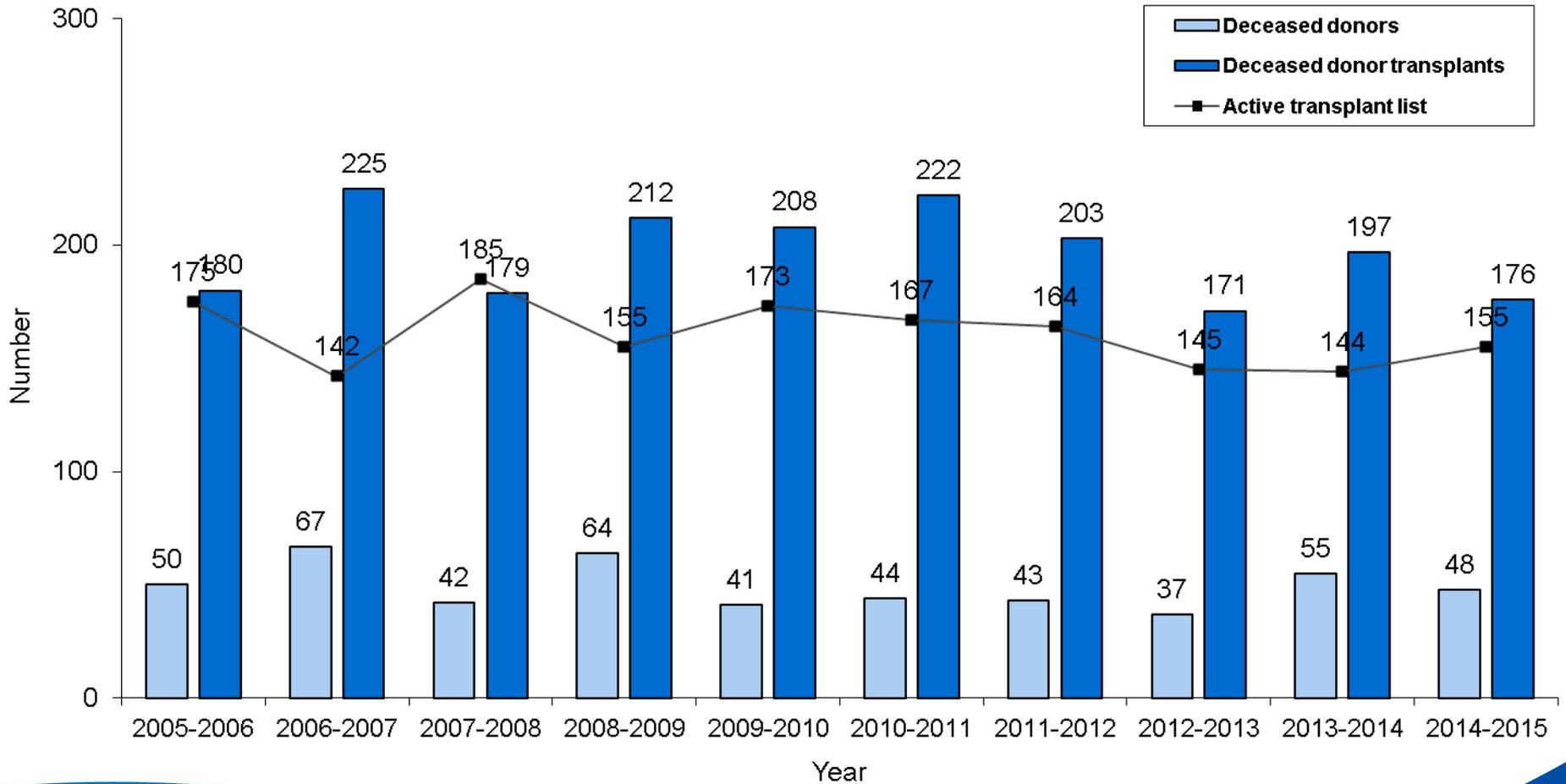
Why am I here?



Number of deceased donors and transplants in the UK, 1 April 2004 - 31 March 2015, and patients on the active transplant lists



Deceased paediatric donors, transplants and active transplant list in the UK



Waiting List under 18 at 20 November 2015

| | |
|-------------------|------------|
| Kidney | 67 |
| Pancreas | 0 |
| Kidney/Pancreas | 0 |
| Pancreas Islet | 0 |
| Heart | 39 |
| Lung | 10 |
| Heart/Lung | 1 |
| Liver | 40 |
| Other Multi organ | 9 (1 + 8) |
| Total | 166 |

Rachel aged 7 years

- 'What good are my organs to me when I am dead? If someone can get life out of them, then that's what I want'
- 'We had to approach the staff to ask them if they were going to test because we wanted to fulfil Rachel's wishes'



Cole aged 5 years

Cole Gibson proudly carried a donor card from the age of 5. Last month, he was killed in a car crash but his organs saved 4 people. Now his mum is asking Sun readers to...

SAVE A LIFE FOR COLE



• MUM'S LETTER - PAGE 7 • HOW YOU CAN HELP - PAGES 8&9

By YVONNE BOLOURI

THE grieving mother of a little boy who saved four lives after his death is calling on others to follow his inspiration — by also giving their organs.

Little Cole Gibson carried a donor card from when he was just five before losing his life in a car accident last month aged seven.

Last night his pregnant mum Hazel, below, whose partner also died in the crash, launched The Scottish Sun's For Cole campaign to find more donors.

Hazel, 29, of Lochgelly, Fife, vowed: "This will be his legacy."

DONOR BOY'S HEARTBREAK PLEA TO MUM

If I am a ghostie I won't need anything... two people dying is just silly



-COLE GIBSON AGED 5

Dear Sun readers,

SIX weeks ago the unthinkable happened — my seven-year-old son was killed in a

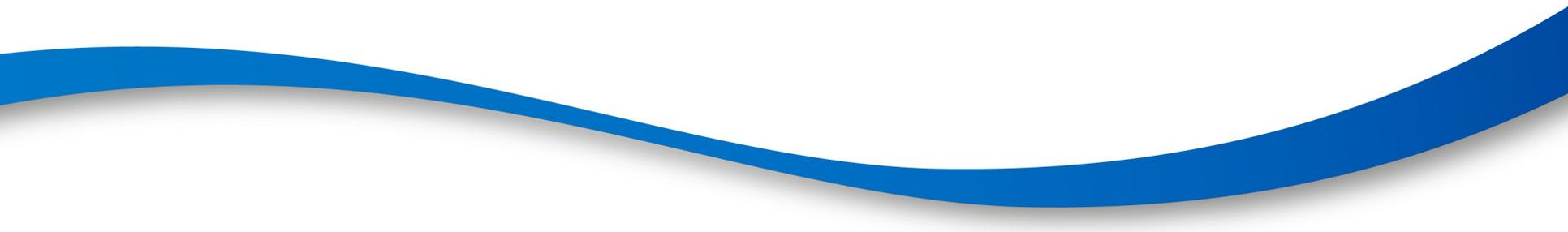
car accident.

Cole Jay Gibson was a very special little boy who won the hearts of everyone.

Words cannot begin to express how much I love him and miss him more every day.

He would have had his eighth birthday two days after Christmas. But Cole's death is even more poignant because my remarkable little boy made me promise to donate his organs if anything should happen

Why should we consider doantion?



How Does it Affect Practice?

- **GMC Para 81:** “If a patient is close to death and their views cannot be determined, you should be prepared to explore with those close to them whether they had expressed any views about organ or tissue donation, if donation is likely to be a possibility”
- **NMC:** you must respect patients and clients autonomy - their right to decide
- **Human Tissue Act 2004 / Human Tissue (Scotland) Act 2006** governs practice



ARCHIVES OF DISEASE IN CHILDHOOD

Making decisions to limit
treatment in life-limiting
and life-threatening
conditions in children:
a framework for practice

adc.bmj.com

RCPCH
The Royal College
of Paediatrics and Child Health
The Journal of the Royal College
of Paediatrics and Child Health

BMJ

Organ Donation

- 1) Should be considered in any child dying in the intensive care environment
- 2) Discussions should be separated from discussions about withholding or withdrawing life sustaining treatment
- 3) Responsibility for deciding whether the child would be a suitable donor rests with the transplant team not the treating team

Diagnosis of death by neurological criteria

Preconditions

- 1) Comatose and mechanically ventilated for apnoea
- 2) Diagnosis of structural brain damage had been established (drugs and neuromuscular blockade reversed, temp $>34^{\circ}$, no endocrine or metabolic disturbance)
- 3) *In post- asphyxiated infants or those receiving intensive care after resuscitation- Period of at least 24 hours observation*

Clinical Diagnosis

- 1) Absent brain stem reflexes
- 2) Absent motor response
- 3) No respiratory stimulus to hypercarbia.

A stronger hypercarbic stimulus should be used: rise of at least $>2.7\text{kPa}$ from a baseline of at least 5.3kPa to $>8\text{kPa}$

The diagnosis of death by neurological criteria in infants less than two months old

April 2015

Updated recommendations

Implications for practice

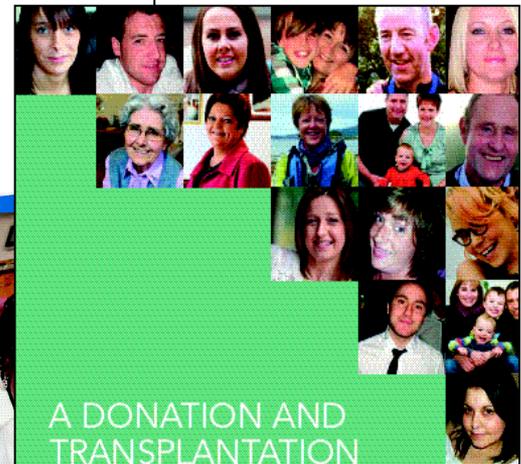


RCPCH
Royal College of
Paediatrics and Child Health
Leading the way in Children's Health

- Referral
- BSD Testing
- Donor Management
- Utilisation of Organs
- Donor recognition
- Public engagement
- Clinical knowledge

Taking Organ Transplantation to 2020

A UK strategy

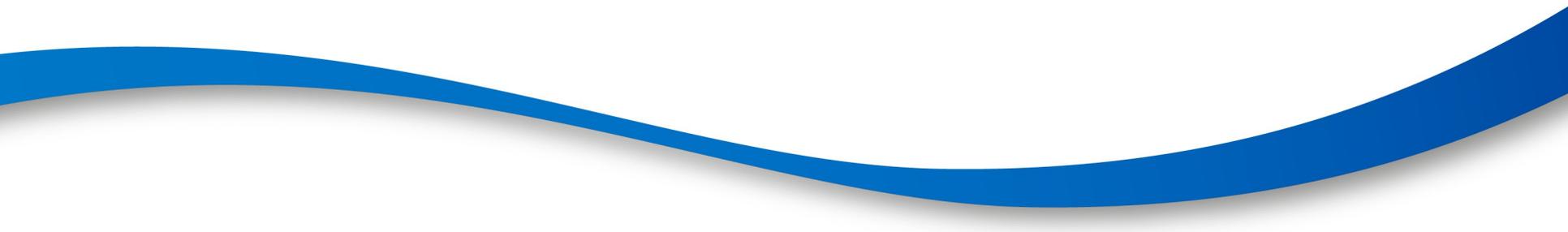


A DONATION AND TRANSPLANTATION PLAN FOR SCOTLAND 2013-2020

More donors, more transplants, more lives saved



What about the public?



Organ Donation.
Don't keep it to yourself.



organdonationscotland.org



I donate
ORGAN DONATION



Population on ODR

| | ODR | POPULATION | % |
|-------------------------|------------|-------------------|--------------|
| ENGLAND | 17,800,212 | 53,865,817 | 33.05 |
| SCOTLAND | 2,216,662 | 5,327,700 | 41.61 |
| NORTHERN IRELAND | 649,389 | 1,829,725 | 35.49 |
| WALES | 1,074,377 | 3,082,412 | 34.86 |
| TOTAL | 21,770,940 | 64,105,654 | 33.96 |

Young people on ODR

| | ODR (<18) | POPULATION (<18) | % |
|-------------------------|---------------------|----------------------------|-------------|
| ENGLAND | 398,740 | 11,506,451 | 3.47 |
| SCOTLAND | 82,001 | 1,035,394 | 7.92 |
| NORTHERN IRELAND | 9,683 | 432,015 | 2.24 |
| WALES | 23,348 | 630,211 | 3.7 |
| TOTAL | 513,772 | 13,604,071 | 3.78 |

Organ Donation

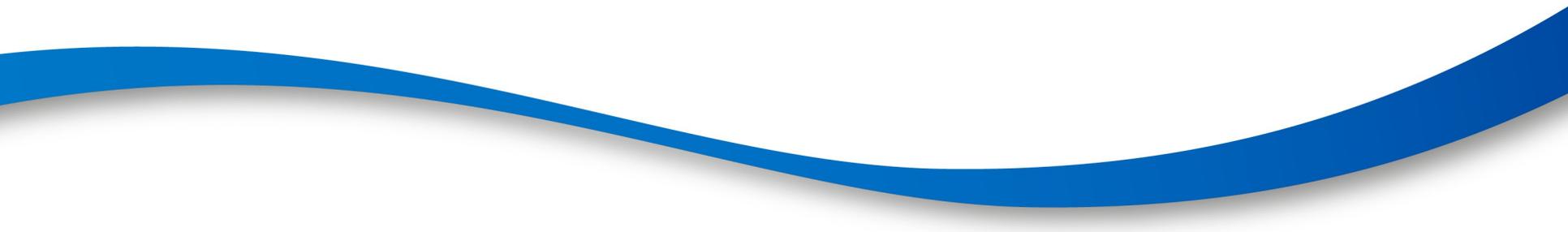
TEACHING RESOURCE PACK

A teaching resource for primary school children explaining donation that makes the difference between life and death.

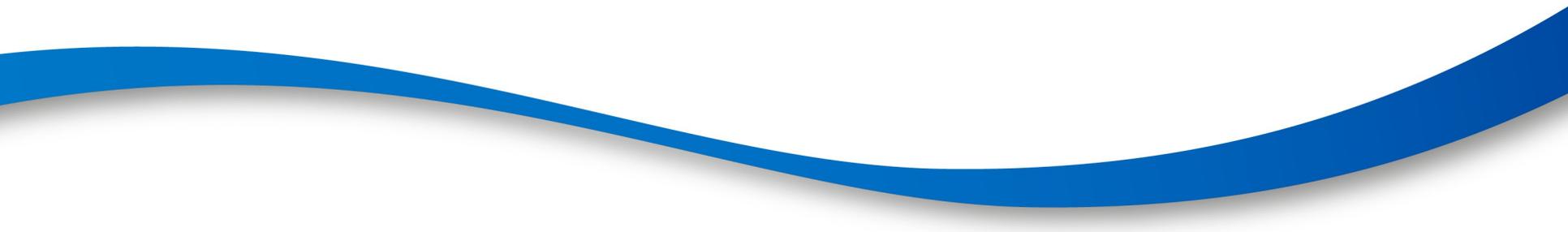


The screenshot shows the NHS Blood and Transplant website for 'Give and Let Live'. At the top, there is a navigation bar with links: HOME, BECOME A DONOR, FACTS ABOUT DONATION, REAL STORIES, QUIZZES AND GAMES, TEACHER'S ZONE, and ABOUT US. The main content area features a large red banner with the text 'What's Give and Let Live all about?' and a 'New updated Spring 2016' badge. Below this, there is a video player with a play button and the text 'Watch a short film to find out why donation is so important.' To the right of the video is the NHS Blood and Transplant logo. Below the main content, there are five interactive buttons: 'Body Bits' (Explore the interactive donor body and find out what you can donate), 'Glorious Blood' (What happens when I give blood?), 'Body Bingo' (Check out the facts behind the numbers), 'Donation Nation' (Find out how and where to donate), and 'Teacher's Zone' (Give and Let Live is an educational resource from NHS Blood and Transplant. The aim of the Teacher's Zone resource is to provide students aged 14 or over with the knowledge and understanding of key issues relating to donation. Order free teacher's pack).

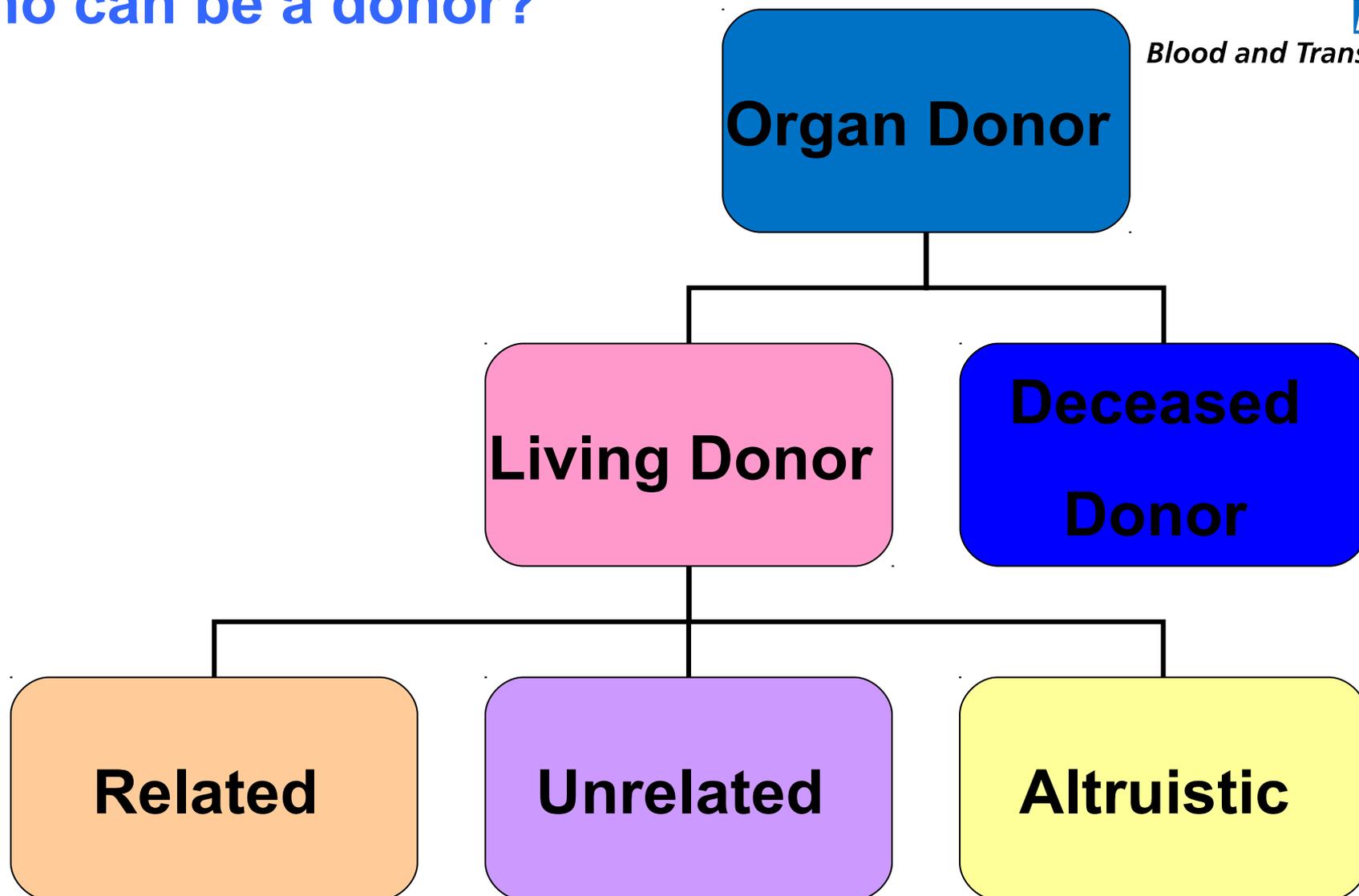
<https://www.organdonationscotland.org/sites/default/files/Organ%20donation%202.mp4>



How can one donate organs?



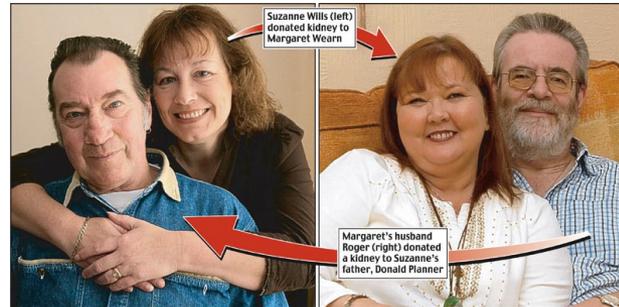
Who can be a donor?



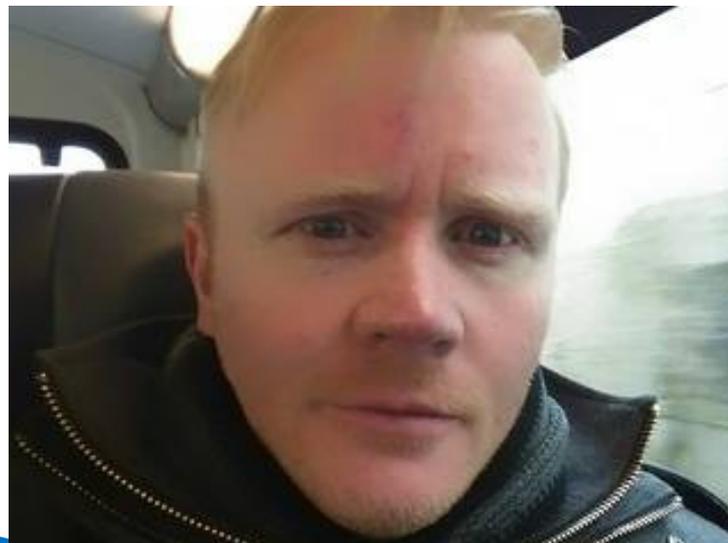
Related Donor



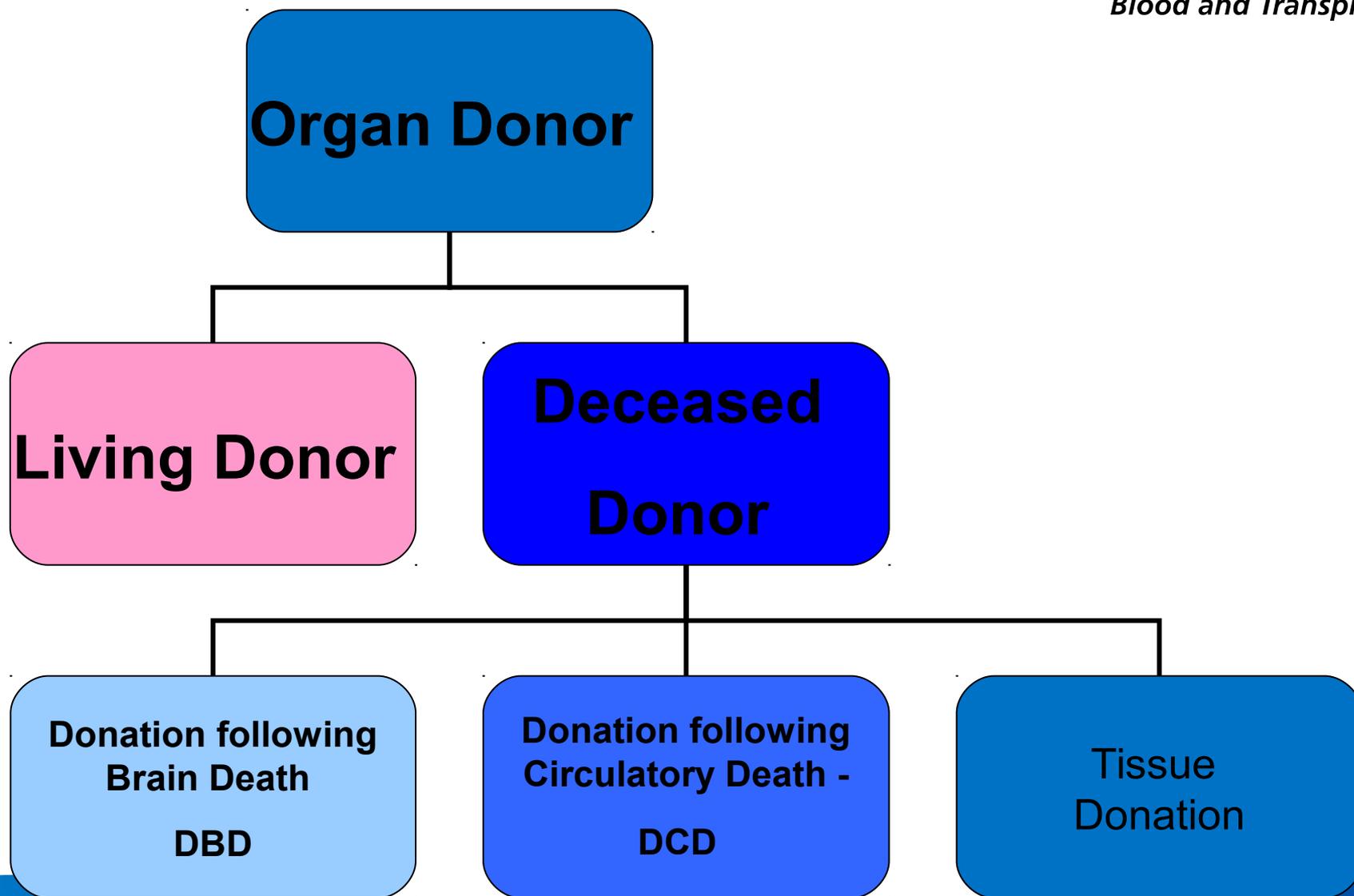
Paired Donation



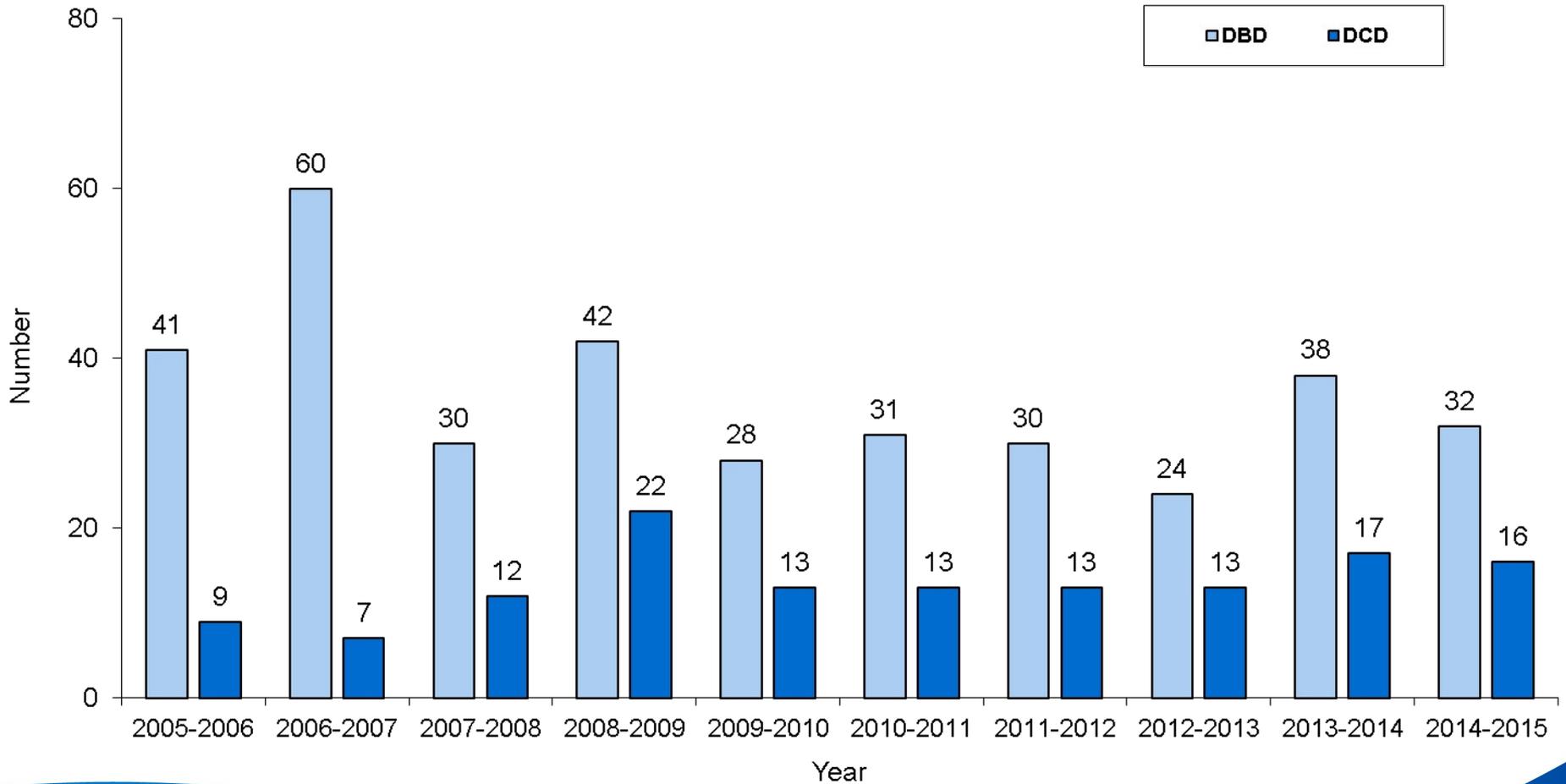
Altruistic donor



Who can be a organ donor?

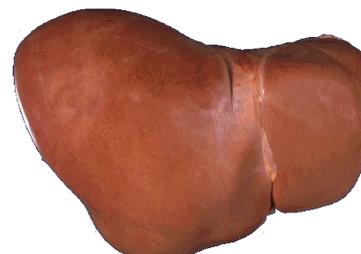
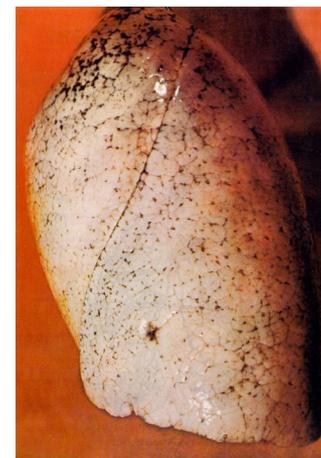
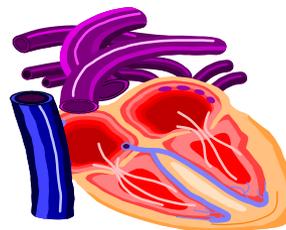


Deceased paediatric donors, by donor type



Transplantable Organs

- Heart
- Lungs(2)
- Liver (2)
- Kidneys (2)
- Pancreas
- Small bowel



Where does organ donation happen?

DBD and DCD





Baby becomes youngest organ donor in Britain after dying at five weeks as kidneys are given to 22-year-old woman

- Unnamed five-week-old child died from heart failure earlier this year
- Kidneys from baby transplanted into 22-year-old Samira Kauser by surgeons at St James's University Hospital in Leeds
- Healthcare assistant from Halifax, West Yorkshire, had kidney failure due to genetic condition
- Procedure declared a success after six months of monitoring

By BEN SPENCER

PUBLISHED: 16:46, 13 October 2013 | **UPDATED:** 01:26, 14 October 2013

Share Tweet +1 Share **16** shares

91 View comments

An infant just five weeks old became the youngest organ donor in Britain, saving a woman dying of kidney failure.

The tiny organs were transplanted into Samira Kauser after the child died of heart failure.

Miss Kauser, a 22-year-old healthcare assistant, said: "Words cannot express the gratitude I feel to the parents of this baby. My life was standing still – now I can live it."

Site Web Search





Just hours after Teddy Houlston lost his fight for life the baby saved another **#TeddysStory**
mirror.co.uk/news/real-life...



RETWEETS

20

FAVORITES

16

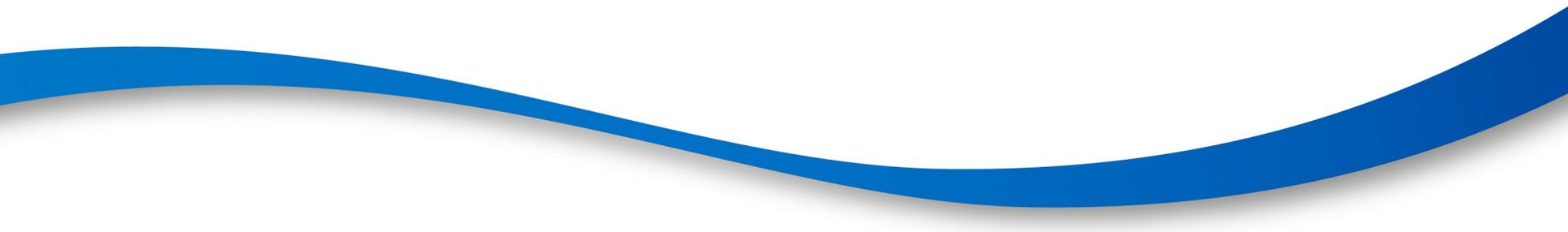


2015

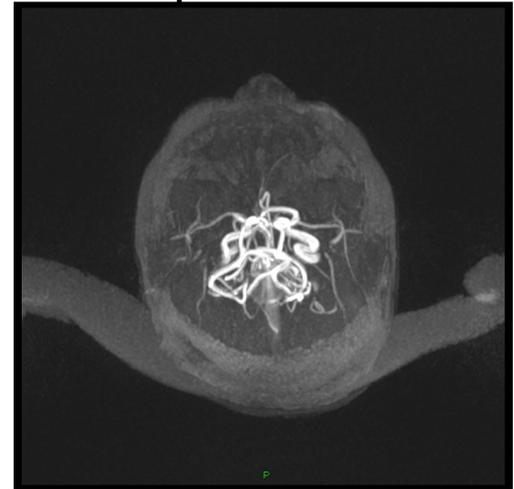
"Our baby was a hero" – parents speak one year on from their baby's death
23 April 2015

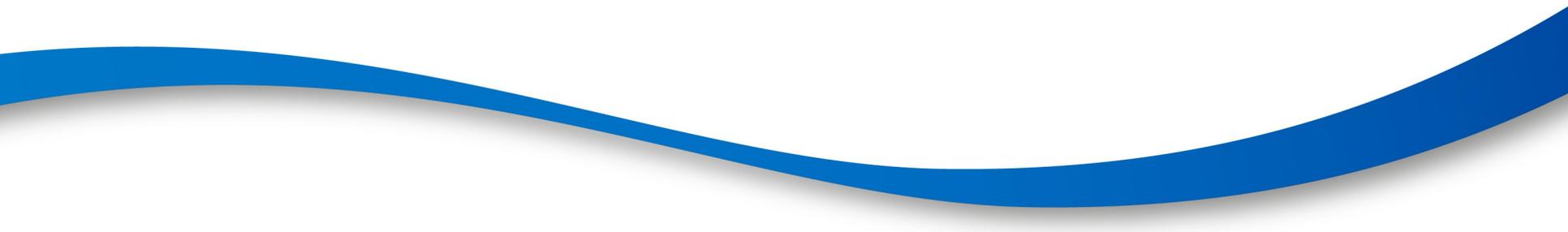


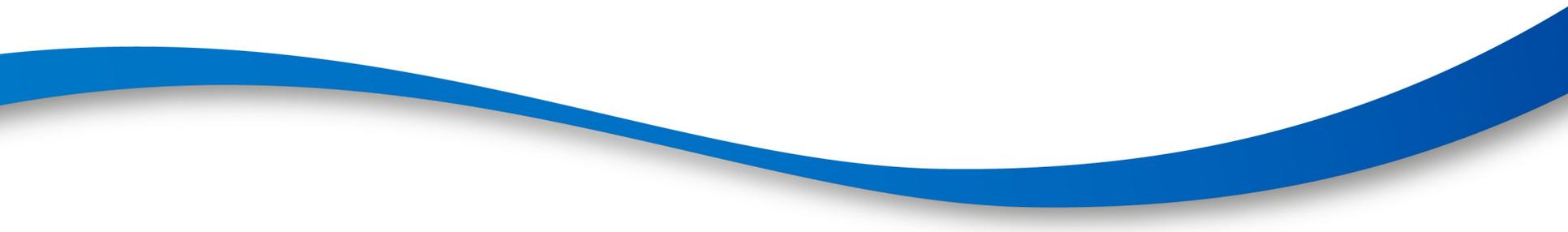
<http://www.mirror.co.uk/news/real-life-stories/teddys-story-youngest-ever-organ-5565854>



- Mason was a 4 week old baby boy (4.8kg) electively born in Glasgow with an ante natal identified Vein of Galen abnormality.
- Post corrective surgery/embolisation had sudden neurological deterioration
- CT: Intraventricular haemorrhage with no hydrocephalus, mass effect on the underlying brain and likely tonsillar herniation. The diffusion weighted imaging suggests diffuse ischaemia of cerebrum with relative preservation of the cerebellum.
- Decision made to reorientate care to palliative support
- Neonatologist approached CLOD for advice



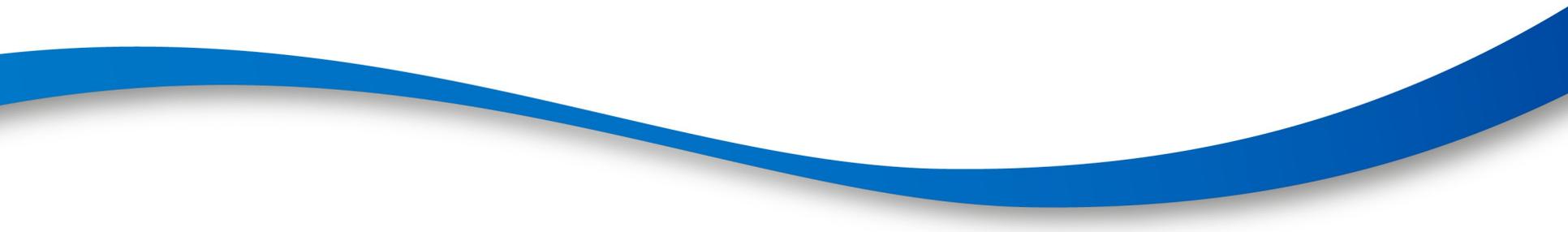
- Parents approached and after much consideration authorised donation
 - Modified screening undertaken
 - Lungs offered – No suitable recipients
 - Kidneys en-bloc - two centres interested
 - Liver – one centre interested for hepatocytes
 - Donation progressed
 - Withdrawal of supportive treatment in theatre complex and surgery within 1 hour
 - Post retrieval Mason transferred to Robin House CHAS
- 

- the recipient of both kidneys is a middle-aged lady with adult children. She is recovering very well with the kidneys beginning to work. The unit feel she will make a full recovery with no need for dialysis.
 - The liver transplant unit were able to isolate 3 sets of high quality cells; these cells have now been preserved. The cells will now be stored; they will be issued as required for up to 3 people suffering from acute liver failure.
- 

What it means



What about tissue donation?

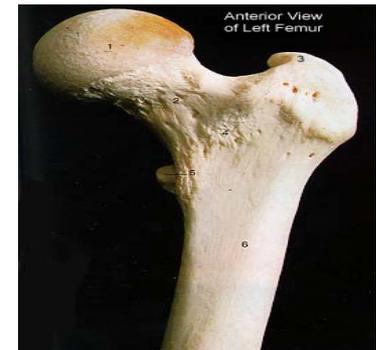
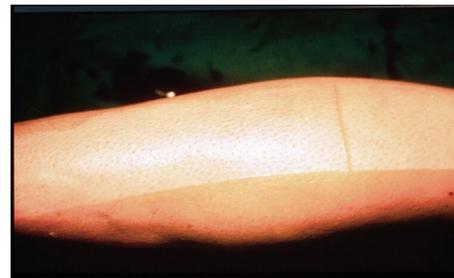
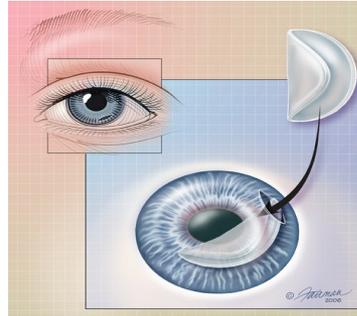


Tissue Donation

- Cornea
- Heart Valves
- Tendons

- Bone

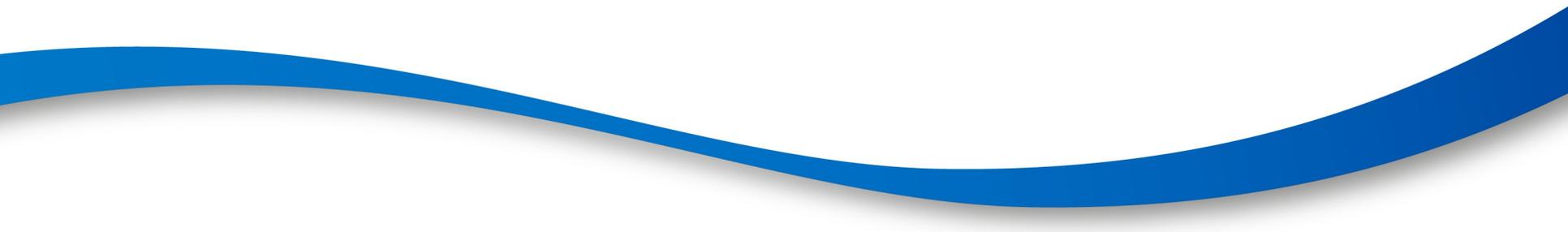
- Islet Cells
- Skin
- Limb
- Face



Age Criteria (Tissues)

- Heart Valves - 32 weeks gestation – 70 yrs
3 months to 65 yrs (Scotland)
 - Eye - Older than 2½ years

 - Tendons - 16 to 65 yrs
 - Skin - 16 to 65 yrs

 - Can be retrieved up to 24 - 48 hrs following death.
 - Often carried out in local mortuary.
 - Body must be cooled within 6 hours of death
 - Blood samples up to 7 days pre-mortem
- 

Contra-indications to Tissue donation

- Untreated systemic infection*
- HIV, Hepatitis B or C
- Any high risk factor for HIV
- Haematological cancers
- Alzheimer's disease or other diseases of unknown aetiology
- Motor neurone disease
- Creutzfeldt-Jakob disease



Tissue donation enquiries



Blood and Transplant

England, Wales & Northern Ireland

Tissues National Referral Centre

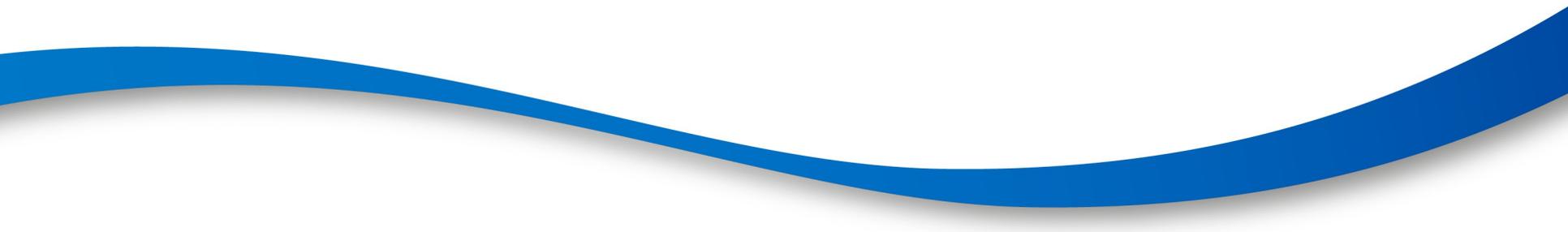
Tel: 0800 432 0559

Scotland

SNBTS Tissue Services

Tel: 0131 536 5751

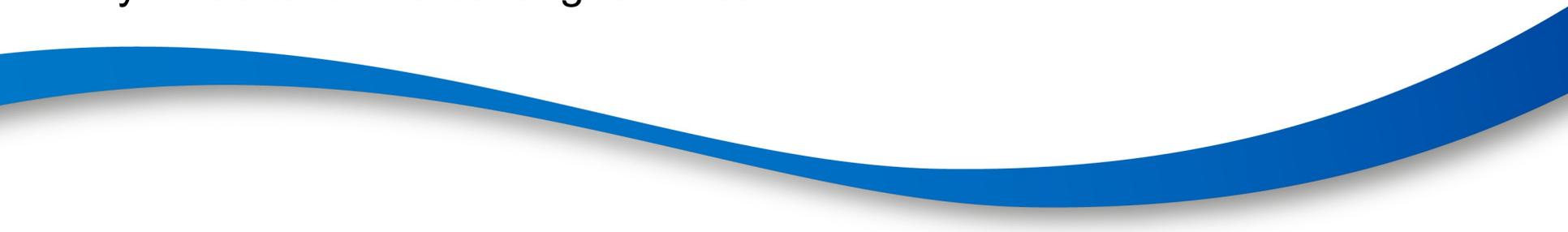
Specialist Nurse in Organ Donation through hospital switchboard



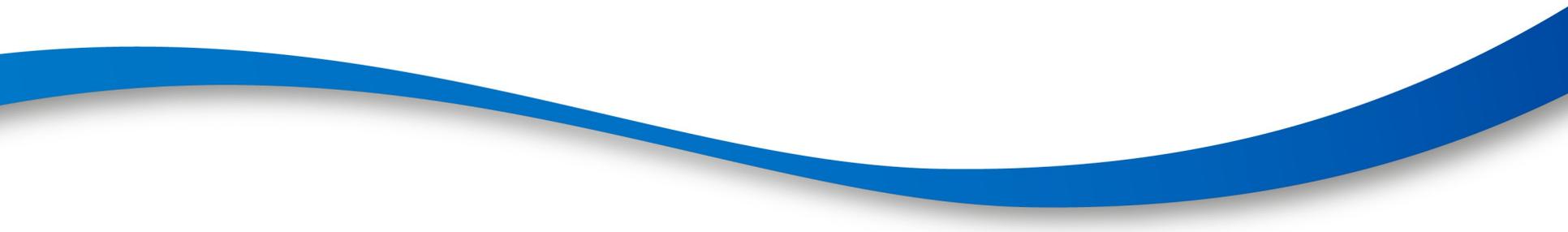
I'm sure this letter will be as difficult to read as we have found to write it. It is both painful and joyous. The reason we are writing is to thank you. The importance and immense meaning of the gift you and your family have given our daughter, truly cannot be expressed in words. Our daughter Caitlin was born with a rare heart condition which causes the main arteries from the heart to stop forming correctly in the womb.

One of the surgical options required using a donated heart valve. This was felt by the specialists looking after Caitlin to provide her with the best possible chance of surviving. At the time we were happy with the news and it was not till a few hours later that we actually realised the implication of using a donor heart valve, i.e. that it had been donated by someone else's child, and that was when we registered your loss and the generosity of your decision at what must have been a very difficult time for you.

We are very grateful that your family made the decision that you made, without your gift Caitlin would not have made it another week. Since the operation Caitlin is doing well doctors are very happy with her progress. As we said at the beginning this has been a very difficult letter to write which is why it has taken us so long to write.

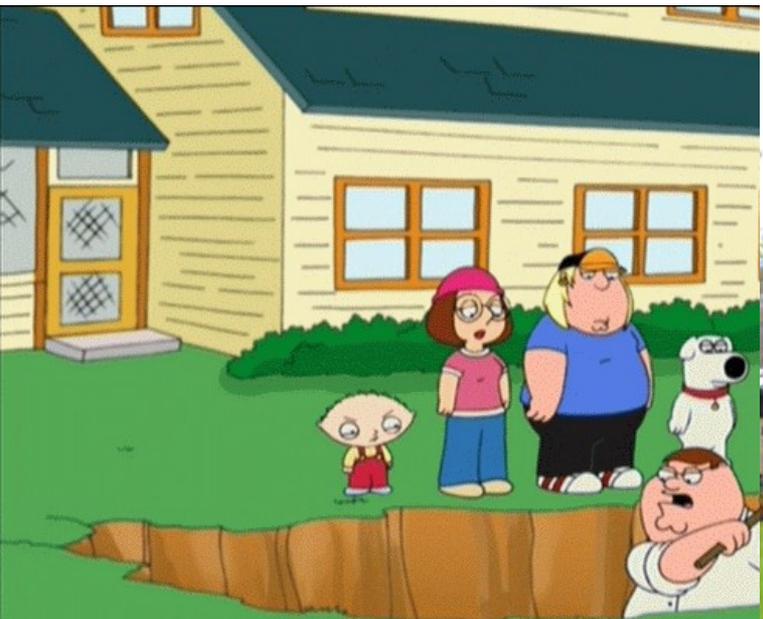


What is the single most important factor in considering organ or tissue donation?





Location,
Location,
Location



Name:

NHS/CHI Number:

Wishes around end of life care (*preferred place of care and after death care*):

Organ & Tissue Donation:

Spiritual & Cultural Wishes:

Funeral Preferences

Other wishes (*i.e. what is to happen to favourite memorabilia, toys, possessions?*)

8 month old Otahara Syndrome

Epilepsy – status

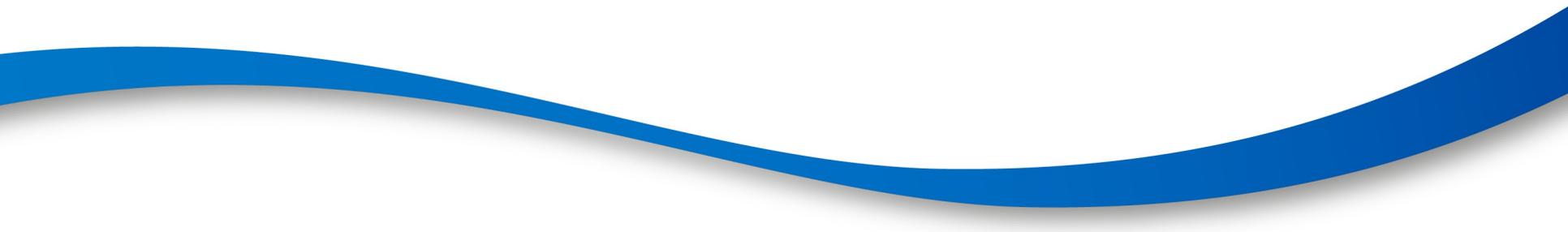
Recurrent chest infections possible aspiration

Oxygen dependant

PEG feeding

Oromorph Phenybarbitone nitazepam paraldehyde

In respite care



2½ year old child with West Syndrome

Previous Ecoli meningitis

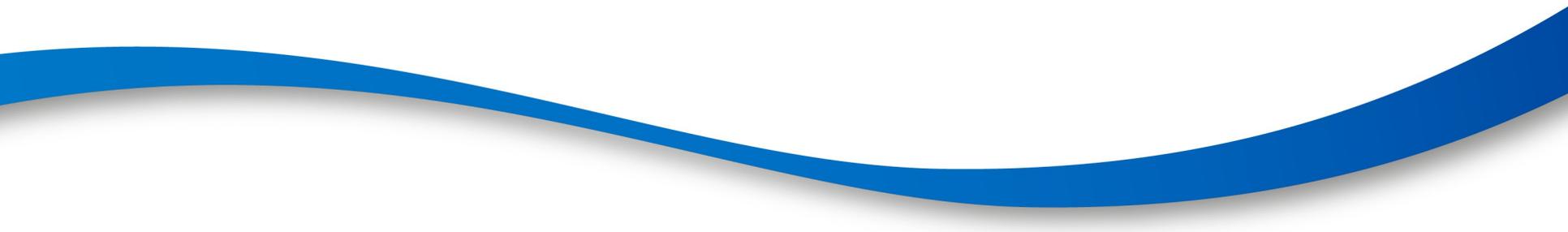
Congenital heart with ASD VSD and pulmonary stenosis

Hypogammaglobulinaemia on weekly IgG transfusions.

Cortical Eye damage registered

Prognosis 6 months.

Donation raised by family in OPD clinic

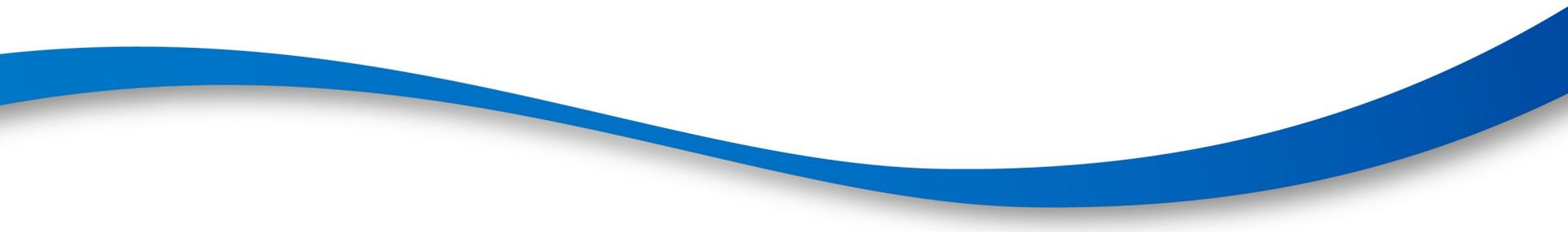


9 year old Lissenpephaly Lennox Gastout Syndrome

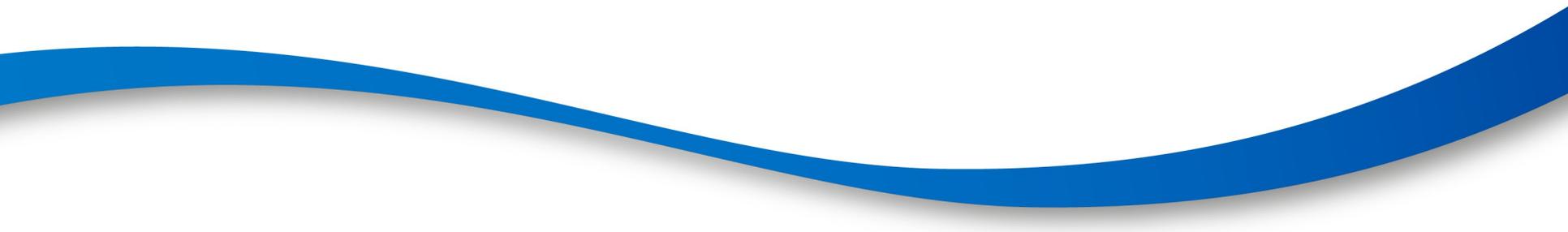
Recurrent admissions to ED / ICU

Well and at home

Family raised during ACP



What do I say?



- Contact Specialist Nurses Organ Donation through any hospital switchboard or National Tissue Referral centre
- *“It is our normal practice to consider donation as an end of life option for all children*
- *In order to respect those wishes, we have checked the Organ Donor Register and your child **was/was not** registered.*
- *If donation is something you would like to consider, I can arrange for a Specialist Nurse to speak with you and give you information about this/ the Specialist Nurse will call you and give you all the information you need to make this decision”.*

OR

- *“We have discussed your child with the specialists and donation is not an option because*”



What does it mean for our families?

“The compassion extended to us at this horrible time has helped us look back with a sense of peace, of acceptance of the situation, if this is at all possible. The same can be said for the compassion shown to us when we were approached about donating Mason's organs, we thought the way the process was explained to us was factual and presented in a way that enabled us to make the decision we did. The hospital staff were ever present and offered a sense of comfort and security when discussing our options and at no point did we feel pushed into anything”

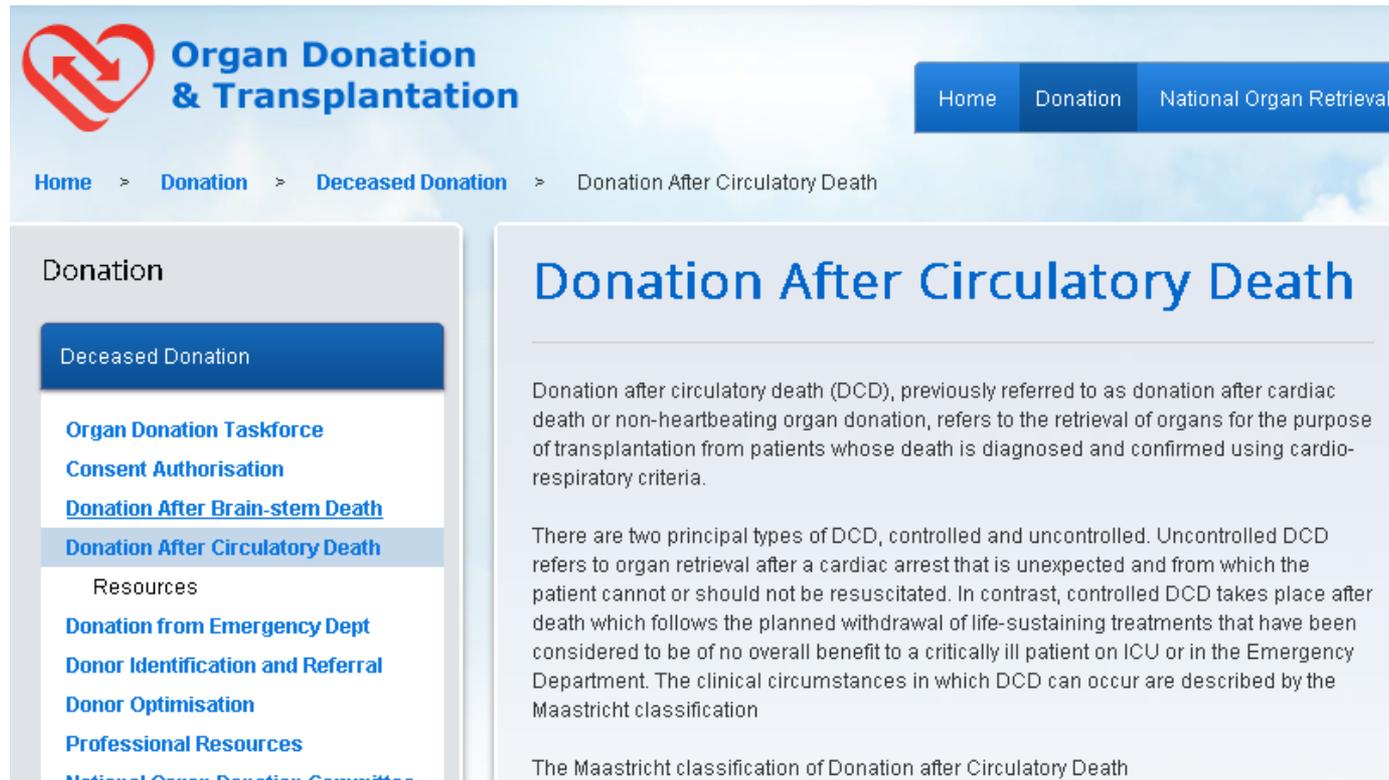
Helen & Edward

"Our baby was a hero" - parents speak one year on from their baby's death

23 April 2015



<http://www.organdonation.nhs.uk/teddysstory/>



The screenshot shows the NHS Organ Donation & Transplantation website. The main header includes the NHS logo and the text "Blood and Transplant". The website title is "Organ Donation & Transplantation". A navigation menu at the top right contains "Home", "Donation", and "National Organ Retrieval". A breadcrumb trail below the header reads "Home > Donation > Deceased Donation > Donation After Circulatory Death". On the left, a "Donation" sidebar menu lists: "Deceased Donation" (highlighted), "Organ Donation Taskforce", "Consent Authorisation", "Donation After Brain-stem Death", "Donation After Circulatory Death" (highlighted), "Resources", "Donation from Emergency Dept", "Donor Identification and Referral", "Donor Optimisation", "Professional Resources", and "National Organ Donation Committee". The main content area is titled "Donation After Circulatory Death" and contains the following text:

Donation after circulatory death (DCD), previously referred to as donation after cardiac death or non-heartbeating organ donation, refers to the retrieval of organs for the purpose of transplantation from patients whose death is diagnosed and confirmed using cardio-respiratory criteria.

There are two principal types of DCD, controlled and uncontrolled. Uncontrolled DCD refers to organ retrieval after a cardiac arrest that is unexpected and from which the patient cannot or should not be resuscitated. In contrast, controlled DCD takes place after death which follows the planned withdrawal of life-sustaining treatments that have been considered to be of no overall benefit to a critically ill patient on ICU or in the Emergency Department. The clinical circumstances in which DCD can occur are described by the Maastricht classification

The Maastricht classification of Donation after Circulatory Death



www.odt.nhs.uk



Thank you for your attention

Questions?