Paediatric Organ and Tissue Donation

• 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
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

1000 Deaths pa.
3 a day
Deceased paediatric donors, transplants and active transplant list in the UK

Organ Donation & Transplantation
## Waiting List under 18 at 20 November 2015

<table>
<thead>
<tr>
<th>Organ</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Kidney</td>
<td>67</td>
</tr>
<tr>
<td>Pancreas</td>
<td>0</td>
</tr>
<tr>
<td>Kidney/Pancreas</td>
<td>0</td>
</tr>
<tr>
<td>Pancreas Islet</td>
<td>0</td>
</tr>
<tr>
<td>Heart</td>
<td>39</td>
</tr>
<tr>
<td>Lung</td>
<td>10</td>
</tr>
<tr>
<td>Heart/Lung</td>
<td>1</td>
</tr>
<tr>
<td>Liver</td>
<td>40</td>
</tr>
<tr>
<td>Other Multi organ</td>
<td>9 (1 + 8)</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>166</strong></td>
</tr>
</tbody>
</table>
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

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, 25, of Lochsilly, Fife, vowed: “This will be his legacy.”

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

Cole Jay Gibson, aged 5, was a very special little boy who won the hearts of everyone.

Weeks 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 painful.

I made a promise to donate his organs if anything should happen...
Why should we consider donation?
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
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°C, 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 >2.7kPa from a baseline of at least 5.3kPa to >8kPa
National Strategies

- Referral
- BSD Testing
- Donor Management
- Utilisation of Organs
- Donor recognition
- Public engagement
- Clinical knowledge
What about the public?
Organ Donation.
Don't keep it to yourself.
<table>
<thead>
<tr>
<th>Region</th>
<th>ODR</th>
<th>Population</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>ENGLAND</td>
<td>17,800,212</td>
<td>53,865,817</td>
<td>33.05</td>
</tr>
<tr>
<td>SCOTLAND</td>
<td>2,216,662</td>
<td>5,327,700</td>
<td>41.61</td>
</tr>
<tr>
<td>NORTHERN IRELAND</td>
<td>649,389</td>
<td>1,829,725</td>
<td>35.49</td>
</tr>
<tr>
<td>WALES</td>
<td>1,074,377</td>
<td>3,082,412</td>
<td>34.86</td>
</tr>
<tr>
<td>TOTAL</td>
<td>21,770,940</td>
<td>64,105,654</td>
<td>33.96</td>
</tr>
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</table>
## Young people on ODR

<table>
<thead>
<tr>
<th></th>
<th>ODR (&lt;18)</th>
<th>POPULATION (&lt;18)</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>ENGLAND</strong></td>
<td>398,740</td>
<td>11,506,451</td>
<td>3.47</td>
</tr>
<tr>
<td><strong>SCOTLAND</strong></td>
<td>82,001</td>
<td>1,035,394</td>
<td>7.92</td>
</tr>
<tr>
<td><strong>NORTHERN IRELAND</strong></td>
<td>9,683</td>
<td>432,015</td>
<td>2.24</td>
</tr>
<tr>
<td><strong>WALES</strong></td>
<td>23,348</td>
<td>630,211</td>
<td>3.7</td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td>513,772</td>
<td>13,604,071</td>
<td>3.78</td>
</tr>
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What’s Give and Let Live all about?

Quite simply, it’s about how you can save lives by donating parts of your body.

Take a look around and you’ll find many fascinating facts and real-life stories showing why donation is so important, as well as some fun activities!

A Welsh Version of Give and Let Live is also available.

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

Teacher’s Zone
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
How can one donate organs?
Who can be a donor?

- **Organ Donor**
  - **Living Donor**
    - Related
    - Unrelated
  - **Deceased Donor**
    - Altruistic
Live Donation

**Related Donor**

**Paired Donation**

**Altruistic donor**
Who can be a organ donor?

- **Organ Donor**
  - **Living Donor**
  - **Deceased Donor**
    - Donation following Brain Death - DBD
    - Donation following Circulatory Death - DCD
    - Tissue Donation
Deceased paediatric donors, by donor type

<table>
<thead>
<tr>
<th>Year</th>
<th>DBD</th>
<th>DCD</th>
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<tbody>
<tr>
<td>2005-2006</td>
<td>41</td>
<td>9</td>
</tr>
<tr>
<td>2006-2007</td>
<td>60</td>
<td>7</td>
</tr>
<tr>
<td>2007-2008</td>
<td>30</td>
<td>12</td>
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<td>2008-2009</td>
<td>42</td>
<td>22</td>
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<td>2009-2010</td>
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<td>2010-2011</td>
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<td>2011-2012</td>
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<td>2012-2013</td>
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<td>13</td>
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<td>2013-2014</td>
<td>38</td>
<td>17</td>
</tr>
<tr>
<td>2014-2015</td>
<td>32</td>
<td>16</td>
</tr>
</tbody>
</table>
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: 18:45, 13 October 2013 | UPDATED: 01:26, 14 October 2013

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."
"Our baby was a hero" – parents speak one year on from their baby’s death
23 April 2015
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
Neonatal referral

• 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
Outcomes

• 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

**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
Wishes around end of life care

<table>
<thead>
<tr>
<th>Name:</th>
<th>NHS/CHI Number:</th>
</tr>
</thead>
</table>

**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?)*
Case study

8 month old Otahara Syndrome
Epilepsy – status
Recurrent chest infections possible aspiration
Oxygen dependant
PEG feeding

Oromorph Phenybarbitone nitazepam paraldehyde

In respite care
Case study

2½ year old child with West Syndrome
Previous Ecoli meningitis
Congenital heart with ASD VSD and pulmonary stenosis
Hypogabbuglominaemia 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?
Conversation with families/young person

- **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 looked 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/
Donation After Circulatory Death

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
Thank you for your attention

Questions?