Donor conception and the search for information

- APPROACHES TO INFORMATION RELEASE AROUND THE GLOBE
- 2016
DONOR CONCEPTION: A LONG HISTORY OF SECRECY

‘...the historical origins of assisted conception are clearly tainted by doubts about the morality of the acts involved [including masturbation and instrumental substitution for sexual intercourse] and their legitimacy as medical treatment.’

Simone Bateman Noveaus
DONOR CONCEPTION: A LONG HISTORY OF SECRECY

- 1884: donor insemination by Professor William Pancoast (reported 25 years later)

- 1890s: Dr Robert L. Dickson (research reported 40 years later)
Donor Conception: Preserving Donor Anonymity

- Adultery?
- Illegitimacy?
- Paternity?
- Inheritance of the child from the donor and/or husband?

- 1960 UK interdepartmental committee, chaired by Lord Feversham:
  - DI ‘undesirable’ and should not be practiced...
  - donation ‘is an activity which might be expected to attract more than the usual proportion of ‘.”
DONOR CONCEPTION: PRESERVING DONOR ANONYMITY

Who/what is the focus of secrecy?
- Donors; doctors; recipient parents...
- Religion? (Against natural law)
- Morality? (Adultery; Masturbation)
- Shame? (Infertility)
- Fears regarding parentage?
- Fears regarding rights & responsibilities?
- Fear of interference with family sphere (emotional/physical)
- Commercialisation? (Supply and demand)
DONOR CONCEPTION: A SHIFT TO OPENNESS

In some countries the focus shifted to the child. There was and continues to be discussion of:

- Identity formation
- Medical history
- Consanguineous relationships
- Human rights (identity; genetic heritage; private and family life)
- Interests
- Equality
- Genetic relatives (i.e. siblings)
- Truth/Openness/Honesty

Shift also in who accesses donor gametes
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<tr>
<th>Jurisdiction</th>
<th>Legislation</th>
<th>Date of implementation</th>
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<td></td>
<td>Infertility Treatment Regulations 1997; Assisted Reproductive Treatment Act 2008</td>
<td>(respectively)</td>
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<td>Prospective; Retrospective</td>
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<td>Sweden</td>
<td>Lag om insemination (Law on Insemination) 1984 (replaced by Genetic Integrity Act 2006)</td>
<td>18 March 1985</td>
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<td>Prospective</td>
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<tr>
<td>Austria</td>
<td>Fortpflanzungsmedizingesetz. 275 Bundesgesetz.</td>
<td>1 July 1992</td>
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<td>Prospective</td>
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<td>III, 197 (LPMA)</td>
<td>Prospective; Retrospective</td>
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<tr>
<td>Western Australia</td>
<td>Human Reproductive Technology Act 1991 (WA)</td>
<td>2004</td>
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<td>New Zealand</td>
<td>Human Assisted Reproductive Technology Act</td>
<td>2004</td>
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<td>Norway</td>
<td>Act on Biotechnology 2003</td>
<td>1 January 2005</td>
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<tr>
<td>UK</td>
<td>Human Fertilisation and Embryology Authority (Disclosure of Donor Information) Regulations 2004</td>
<td>1 April 2005</td>
</tr>
<tr>
<td>Finland</td>
<td>The Act on Assisted Fertility Treatments (1237/2006)</td>
<td>September 2007</td>
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<td>Legislation</td>
<td>Date of implementation</td>
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<tr>
<td><strong>New South Wales (Australia)</strong></td>
<td>Assisted Reproductive Technology Act 2007</td>
<td>Prospective (retrospective with consent recommended, but pending) (register based)</td>
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<tr>
<td></td>
<td>1 January 2010</td>
<td></td>
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<td><strong>South Australia</strong></td>
<td>Assisted Reproductive Treatment Act 1988 (SA);</td>
<td>Prospective (clinic based)</td>
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<td>Assisted Reproductive Treatment Regulations 2010 (SA).</td>
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<td>1 July 2010</td>
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<td>July 2011</td>
<td>NB. Subject to veto by donor</td>
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<tr>
<td>Croatia</td>
<td>ZAKON O MEDICINSKI POMOGNUTOJ OPLODNJI (Law on Medically Assisted Reproduction, 12 July 2012) (Croatia), No: 71-05-03 / 1-12-2</td>
<td>12 July 2012 Prospective (Register Based)</td>
</tr>
<tr>
<td>Argentina</td>
<td>Código civil y comercial de la nación (Civil and Commercial Code of the Nation), Title V, Ch2, approved by Law 26,994.</td>
<td>1st of October 2014 Prospective (Birth registration, and medical records)</td>
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<td>Ireland</td>
<td>Children and Family Relationships Act 2015 Act No. 9 of 2015</td>
<td>6 April 2015 Prospective (Register)</td>
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GERMANY

28 January, 2015, the German Supreme Court (Bundesgerichtshof) held that all children have a right of access information, regardless of age, and that that rights trumps any right the donor has to privacy. BGH, Urteil vom 28. January 2015 - XII ZR 201/13.

October 2016 – Hanover Court reaffirms that a ‘child's’ right to know about where they come from weighed more significantly than a sperm donor's right to determine how their personal information is shared. (Nb. Plaintiff 21 yr old female).
DUAL TRACK

- Not statute or court based
- Donors choose whether to be ‘anonymous’ or ‘open-identity’
- Recipients choose whether to use anonymous or ‘open identity’ donor

Places that allow for ‘anonymous’ or ‘open-identity’ donations: Canada, Denmark, Iceland, Hungary and the United States.

But NOTE – where the emphasis lies…
Approaches to information Release

- **Mandatory Register (with/without notification)**
  - Held at birth records office (Victoria – notification since 2010) (management to be transferred to VARTA in 2017)
  - Held at Health Department (NSW, Netherlands, Switzerland (govt. dept), Croatia – notification (parents), Ireland – notification B/C, WA)
  - Run by Stand-alone body (UK, Finland)
Approaches to information Release

- **Clinic based**
  - Compulsory (Austria, Sweden, Switzerland (retrospective), Washington State*, Germany)
  - Determined by clinic (incl. open identity v anonymous)

- **Court Application**
  - Uruguay, Argentina – notification B/C,
Approaches to information Release

**Voluntary Registers**
(with/without DNA testing)

- United Kingdom
  - Voluntary DNA register pre 1991 donations/conceptions
  - Voluntary donor sibling registry run by HFEA
- Australia (NSW, Victoria (potential for DNA testing with new laws), Western Australia )
- Netherlands (DNA register)
- New Zealand (may voluntarily place information on HART register)
Retrospective?

- **Australia**
  - Victoria (laws passed 23 February 2016, commence March 2017)
  - South Australia (current inquiry)
  - Tasmania (current inquiry)

- **Switzerland**

With or without support services?

Information Release

- Notification?
- Counselling/support regarding access to information?

Contact:

- Intermediary services for example:
  - liaise b/w donor and donor-conceived person regarding optional contact – (letters, meeting?)
  - Expectation counselling/support
Thank you....

Want to know more?

Contact:

drsoniaallan@gmail.com