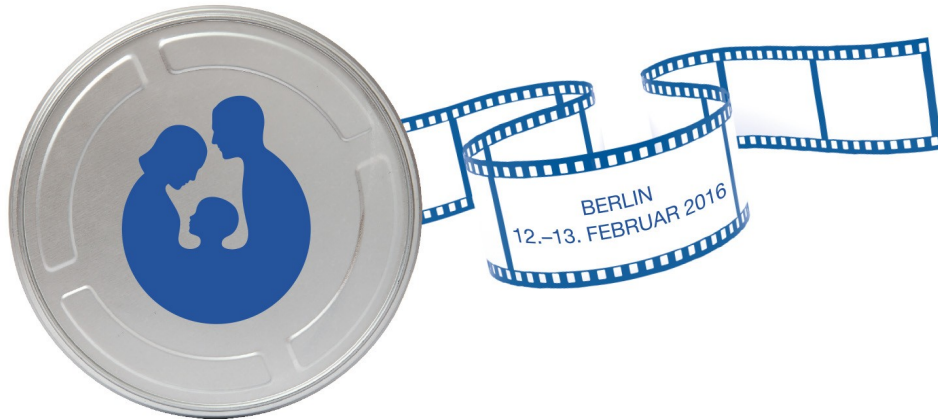


# Donor conception families: how do they fare best?

Walter Merricks, Donor Conception  
Network, London



# A little UK history

- DI practised openly in the UK from 1940's
- Drs Mary Barton, Berthold Wiesner, publish BMJ article Jan 1945
- c.1,500 births, 2 donors, 18 adult half-siblings who know
- 1950's – 1970's concern over DI practice
- 1978 Louise Brown born





# UK law and regulation

- Since 1991 all donor treatment clinics licensed by HFEA
- They must send treatment data to HFEA
- HFEA national register of all IVF and donor treatments, patients, donors, and births since 1991
- HFEA Code of Practice includes detailed requirements and guidance for clinicians



# UK policies

- Both sperm and oocyte donation continue to be permitted, only in HFEA licensed clinics
- Donors not to be legal parents; recipients to be legal parents
- No restriction on recipient marital status, purpose of treatment (single women, unmarried couples, lesbian couples), or knowledge of donor
- Counselling for patients/donors mandatory



# Moves to end anonymous donation

- 2005: donor identity to be available to adult offspring – treatments from 1/4/2005 can only be from donors who have consented to identity release
- Government stresses rights of children
- Despite predictions, sperm donor numbers did not fall: donors are willing to be identified



# 2008 Act

- Clinics must tell patients that it is in their child's best interest to tell about origins at an early age
- Donors entitled to know number, year of birth and sex of resulting children
- HFEA to facilitate contact between willing donor conceived adult half-siblings



# From secrecy to openness

- 1993 Donor Conception Network is founded with 60 member families, all committed to telling children and family
- Children's story books, films, materials for parents on "telling and talking", conferences, local groups
- 2016: Network now has 2,000 member families, a director, 5 staff and a London office





## Since 1993, DCN has

- held 2 national meetings a year, in total around 5,500 people attending: I have met them all
- handled some 20,000 support calls/emails from families or those planning
- all these families have told or will be telling their children and are open with their friends and family
- I have not heard of bad outcomes as a result of telling; if there had been I would know.
- nor is there any such research evidence



# Research on donor conceived children/adults

- Many qualitative studies, researchers talking to hundreds of donor family parents, children, grandparents in different family types
- In 2012 Blyth et al reviewed 13 peer reviewed studies; in total 1,266 participants
- No studies identified telling as problematic per se
- Conclusion: evidence supports promotion of openness policies

Blyth E, Crawshaw M, Frith L, and Jones C, *Donor conceived people's views and experiences of their genetic origins: A critical analysis of the research evidence*: (2012) 19 JLM 769



# Donor conceived families fare best when...

- children are brought up by parents who are confident about what they've done and why,
- and can explain it to their children, and to friends and family, without embarrassment
- preferably at an early age (3/4) – so that children can never remember exactly when they learned; they always knew; there was never a revelation moment
- telling is a process, not a one-off event

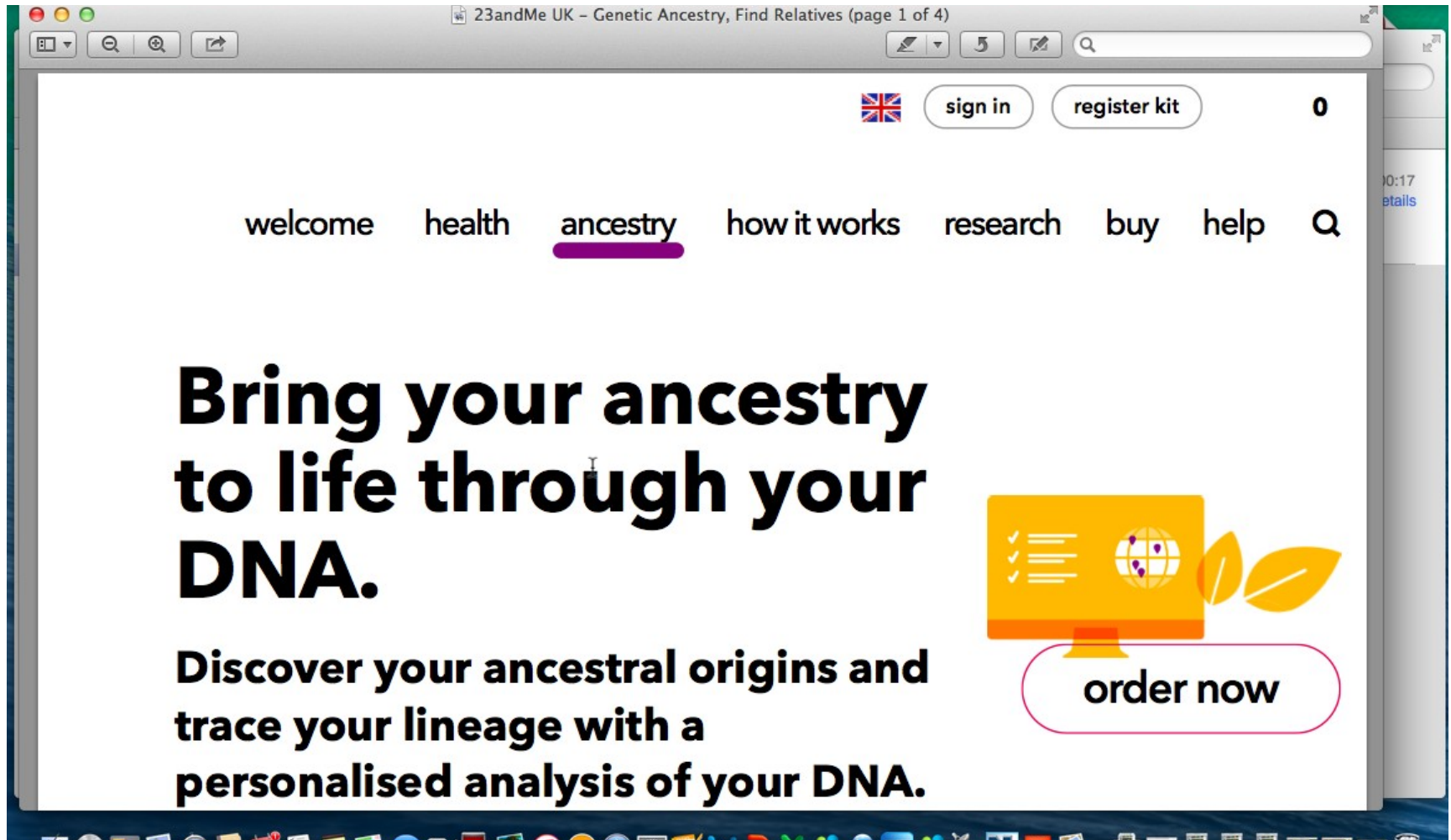


# Honesty is the best policy

- Misleading your own children is not good for family relationships
- Anxiety heightens as time passes and possibilities for the secret to be blown
- Children often sense something is wrong, and blame themselves
- When the secret comes out, they can be angry: “It’s not the **con**ception, it’s the **de**ception that hurts”
- Children born today will grow up in a new world



# 23 and me



# Donor Sibling Registry



The screenshot shows the Donor Sibling Registry website in a web browser window. The browser's address bar displays "https://www.donorsiblingregistry.com". The website's header includes a navigation menu with links: Home, FAQs, Site Help, DSR Blog, HuffPo Blog, and Contact. Below this, there are three prominent orange buttons: "Interactive Map", "Join Now", and "Sign In". A secondary navigation bar contains links: About DSR, Search the Registry, Browse by Clinic, DSR Library, DSR Support & Info, Success Stories, and News & Events. The main content area features a large blue banner with the text "EDUCATING CONNECTING & SUPPORTING DONOR FAMILIES". Below this text, it states: "The DSR has helped to connect more than 12872 half-siblings (and/or donors) with each other." and "The total number of registrants, including donors, parents and donor conceived people, is 48792." There are two orange buttons: "Search Database" and "Join Now". To the right of the text is a photograph of three young children sitting together and smiling. Below the banner, there are three distinct sections: a Facebook link with the text "Join the DSR's 'secret' Facebook group: Email Wendy for your invite!"; a "NEED HELP?" section with a life preserver icon and text "Confused? First-time user? Click here to learn how to use the Donor Sibling Registry."; and a "MEMBER LOGIN." section with fields for "username" and "password", and "Login" and "Login Help?" buttons. The browser's taskbar at the bottom shows various application icons.

Donor Sibling Registry

Home | FAQs | Site Help | DSR Blog | HuffPo Blog | Contact

Interactive Map | Join Now | Sign In

About DSR | Search the Registry | Browse by Clinic | DSR Library | DSR Support & Info | Success Stories | News & Events

**EDUCATING  
CONNECTING &  
SUPPORTING  
DONOR FAMILIES**

The DSR has helped to connect more than **12872** half-siblings (and/or donors) with each other.

The total number of registrants, including donors, parents and donor conceived people, is **48792**.

Search Database | Join Now

**facebook** Join the DSR's "secret" Facebook group: Email Wendy for your invite!

**NEED HELP?**  
Confused? First-time user?  
Click [here](#) to learn how to use the Donor Sibling Registry.

**MEMBER LOGIN.**  
username   
password   
Login | Login Help?



# Some estimated numbers

- 110,000 donor conceived children/adults living in Germany
- 1,000 sperm donation children born in Germany each year
- 2,000 German patients travel abroad for oocyte donation each year @ 35% success= 700 children
- 50,000 donor conceived living in UK
- 2,000 donor children born in UK annually
- In rest of Europe? World wide?



# Preparation: what can clinicians do to help?

- Don't rush: patients who've learned of infertility need time to adjust before moving on
- “the use of donated gametes should be a family-building process rather than just a treatment pathway”
- Encourage openness, the modern approach is telling – it's in their children's best interests – and their family's
- Offer access to professional counselling





# Family networking

- People feel isolated, unable to talk to others
- Talking to other families who have “been there, done it”, to people who understand is hugely valuable
- DCN and our sister organisation DI-NETZ
- Connecting families and patients, counselling (personal, at phone, email, internetfora) before, during and after treatment, preparation workshops, several local groups and one national group with weekend meetings





WIR SIND DI-NETZ

COMMUNITY

WIR SIND AKTIV

KONTAKT

MITGLIED WERDEN / FAQ

SPENDEN

## Wir sind DI-Netz

Search

## Hallo! – Willkommen beim DI-Netz.

DI-Netz e.V. ist die deutsche Vereinigung von Familien nach Samenspende.

In unserem Netzwerk sind Familien von verheirateten und unverheirateten Paaren vertreten, sowie Familien von lesbischen und Solo-Müttern. Ebenso sind wir für Paare und Personen da

### AKTUELLES

[Samenspende für uns?](#)

[Vorbereitungsseminare von DI-Netz –](#)

[Weitere Termine für 2016](#)

16. 01. 2016

[Mitgliederversammlung 2015 mit Vorträ](#)



# The donor's role

- The paradox that genetics are both really important (the non-genetic connection to be acknowledged) and not important at all (in the quality of family relationships)
- Ancestry is undeniable and carries legal rights
- Donors too need preparation for their responsibilities, and information about outcomes
- What will the impact be on their family life if and when the children who have resulted from their donations make contact?



# Donor information

- Many (not all) donor conceived young people and adults are curious about their identity
- They may want non-identifying or identifying information about their donor and half-siblings
- Without a central register, what can clinics do to facilitate and preserve access to this information?



# Confidence is the key

- Patients can draw confidence from supportive clinicians, counsellors, and mutual help organisations (like DI-Netz)
- Well prepared patients make parents confident about openness – who make resilient children and families
- These children may be curious about their origins: it's part of their family story for them to explore and decide how they feel



# Will Germany catch up?

- The recent decision of the Federal Court of Justice is opening the way to the end of anonymity
- Policy-makers now have to consider what the legal and practical framework should be to implement the rights of the donor conceived
- How details of donors and recipients should be preserved securely and made accessible
- How the rights and obligations of donors should be set out and respected in practice
- What should be the rights and duties of clinicians



# Clinicians' responsibilities

- To patients, to donors, to children who are conceived as a result
- As the new world of openness, information, transparency and connection develops, clinicians should expect more contact
- and will want parents, donors and children to regard the role of the clinician with respect, understanding and gratitude



# And oocyte donation?

- Will Germany follow Austria, UK and others and end the oocyte donation ban ?
- Embryo donation is not a good place to start law reform, but it has opened up the question
- This ban has not stopped German women going semi-illegally to Spain, Czech Republic, etc where donors are all anonymous
- Would it not be better for German women lawfully to receive oocytes donated by identifiable German women? And better for their children?





# Our adult children



# Now let us watch a real film!

<http://www.di-netz.de/kurzfilm-des-donor-conception-network/>

