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SCIENCE MOVING
PEOPLE
MOVING SCIENCE
Theory and practice update in
third party reproduction
Special Interest Group Psychology and Counselling
8
3 July 2011
Stockholm, Sweden

Theory and practice update in third party reproduction

Stockholm, Sweden
3 July 2011

Organised by
Special Interest Group Psychology and Counselling

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Course coordinators

Petra Thorn (Germany), Chris Verhaak (The Netherlands)

Course description

In many countries, third party reproduction has undergone changes: legislations and professional guidelines have been introduced, it has become less stigmatized and an increasing number of parents seek information on how to talk to their children about their method of conception. In the morning, this course will provide an overview of these changes, in the afternoon, participants can attend workshops focussing on clinical issues.

Target audience

Counsellors and other professionals involved in psychosocial care

Scientific programme

09.00 – 09.30	Open-identity embryo donation – experiences from New Zealand - **Joy Ellis (New Zealand)**
09.30 – 09.45	Discussion
09.45 – 10.15	Gay men using surrogacy and egg donation for family building - **Robert-Jay Green (USA)**
10.15 – 10.30	Discussion
10.30 – 11.00	Coffee Break
11.00 – 11.30	Intrafamilial gamete donation – what issues are relevant in psychosocial counselling? – **Elizabeth Grill (USA)**
11.30 – 11.45	Discussion
11.45 – 12.15	Mapping relationships in lesbian-led families built by third party reproduction – a genogram technique for use with children - **Fiona Tasker (United Kingdom)**
12.15 – 12.30	Discussion
12.30 – 13.30	Lunch
13.30 – 14.00	Information sharing with teenagers conceived by gamete donation – **Olivia Montuschi (United Kingdom)**
14.00 – 14.15	Discussion
14.15 – 14.45	Information sharing with young adults conceived by gamete donation – **Ken Daniels (New Zealand)**
14.45 – 15.00	Discussion
15.00 – 15.30	Coffee Break
15.30 – 16.00	Preparing semen donors and offspring for contact – **Marilyn Crawshaw (United Kingdom)**
16.00 – 16.15	Discussion
16.15 – 16.45	Pre- and post-treatment counseling for egg donors – what issues are relevant? – **Sheila Pike (United Kingdom)**
16.45 – 17.00	Discussion
17.00 – 17.30	Business meeting of the SIG Psychology & Counselling

ESHRE – European Society of Human Reproduction and Embryology

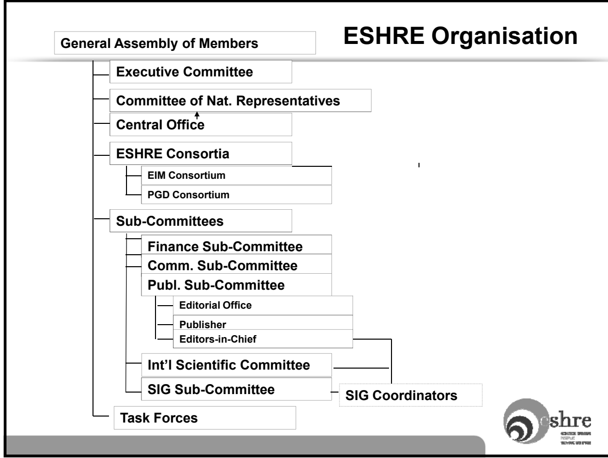
What is ESHRE?

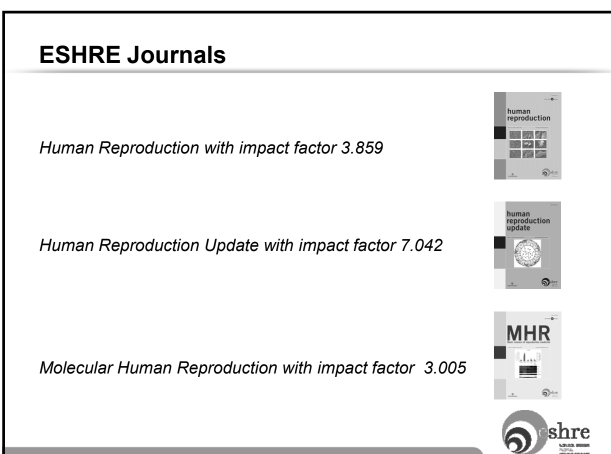
ESHRE was founded in 1985 and its **Mission Statement** is to:

- promote interest in, and understanding of, reproductive science
- facilitate research and dissemination of research findings in human reproduction and embryology to the general public, scientists, clinicians and patient associations.
- inform policy makers in Europe
- promote improvements in clinical practice through educational activities
- develop and maintain data registries
- implement methods to improve safety and quality assurance

Executive Committee 2009/2011

Chairman	• Luca Gianaroli	Italy
Chairman Elect	• Anna Veiga	Spain
Past Chairman	• Joep Geraedts	Netherlands
	• Jean François Guérin	France
	• Timur Gürgan	Turkey
	• Ursula Eichenlaub-Ritter	Germany
	• Antonis Makrigiannakis	Greece
	• Miodrag Stojkovic	Serbia
	• Anne-Maria Suikkari	Finland
	• Carlos Plancha	Portugal
	• Françoise Shenfield	United Kingdom
	• Etienne Van den Abbeel	Belgium
	• Jolieneke Schoonenberg-Pomper	Netherlands
	• Veljko Vlaisavljevic	Slovenia
	• Søren Ziebe	Denmark





Campus Activities and Data Collection

Campus / Workshops

- Meetings are organised across Europe by Special Interest Groups and Task Forces
- Visit www.eshre.eu under CALENDAR

Data collection and monitoring

- European IVF Monitoring Group data collection
- PGD Consortium data collection

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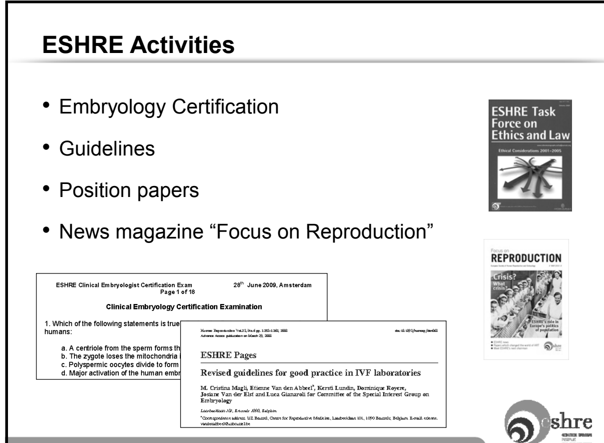
ESHRE Activities
• Embryology Certification
• Guidelines
• Position papers
• News magazine "Focus on Reproduction"
ESHRE Task Force on Ethics and Law
REPRODUCTION
ESHRE Clinical Embryologist Certification Exam
Clinical Embryology Certification Examination
ESHRE Pages
Revised guidelines for good practice in IVF laboratories
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ESHRE COMMUNITY
RSS feeds for news in reproductive medicine
facebook
Since launch 12/2009: 1,360 Fans
twitter
Since launch 12/2009: 190 followers (journalists, scientific organisations, patient societies, governmental bodies)
MHR
Retweets to MHR
You Tube
IVFPODCASTS
Find a member
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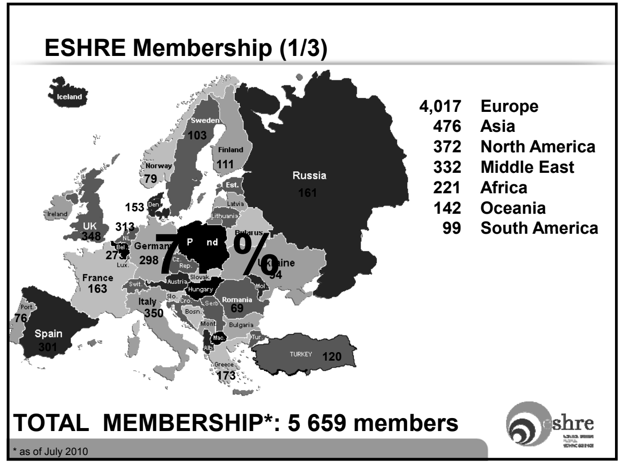
ESHRE Membership (1/3)
4,017 Europe
476 Asia
372 North America
332 Middle East
221 Africa
142 Oceania
99 South America
Iceland
Sweden 103
Finland 111
Norway 79
Russia 161
UK 348
Ireland
France 163
Germany 298
Italy 350
Spain 301
Romania 69
TURKEY 120
Greece 173
TOTAL MEMBERSHIP*: 5 659 members
* as of July 2010
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ESHRE Membership (2/3)

	1 yr	3 yrs
Ordinary Member	€ 60	€ 180
Paramedical Member*	€ 30	€ 90
Student Member**	€ 30	N.A.

*Paramedical membership applies to support personnel working in a routine environment such as nurses and lab technicians.
**Student membership applies to undergraduate, graduate and medical students, residents and post-doctoral research trainees.

ESHRE Membership – Benefits (3/3)

1) Reduced registration fees for all ESHRE activities:

Annual Meeting	Ordinary	€ 480	(€ 720)
	Students/Paramedicals	€ 240	(€ 360)
Workshops*	All members	€150	(€ 250)

2) Reduced subscription fees to all ESHRE journals – e.g. for Human Reproduction €191 (€ 573!)

3) ESHRE monthly e-newsletter

4) News Magazine “Focus on Reproduction” (3 issues p.a.)

5) Active participation in the Society’s policy-making

*workshop fees may vary

Special Interest Groups (SIGs)

The SIGs reflect the scientific interests of the Society’s membership and bring together members of the Society in sub-fields of common interest

- Andrology
- Early Pregnancy
- Embryology
- Endometriosis / Endometrium
- Ethics & Law
- Safety & Quality in ART
- Psychology & Counselling
- Reproductive Genetics
- Reproductive Surgery
- Stem Cells
- Reproductive Endocrinology

Task Forces

A task force is a unit established to work on a single defined task / activity

- Fertility Preservation in Severe Diseases
- Developing Countries and Infertility
- Cross Border Reproductive Care
- Reproduction and Society
- Basic Reproductive Science
- Fertility and Viral Diseases
- Management of Infertility Units
- PGS
- EU Tissues and Cells Directive

ESHRE – Annual Meeting

- One of the most important events in reproductive science
- Steady increase in terms of attendance and of scientific recognition

Track record:

ESHRE 2010 – Rome: 9,204 participants
ESHRE 2009 – Amsterdam: 8,055 participants
ESHRE 2008 – Barcelona: 7,559 participants

Future meetings:

ESHRE 2011 – Stockholm, 3-6 July 2011
ESHRE 2012 – Istanbul, 1-4 July 2012

ESHRE 2011, Stockholm, Sweden

When: **3 - 6 July 2011**
Where: **Stockholmsmässan,**
Mässvägen 1, Älvsjö, Sweden
www.stockholmsmassan.se

Chair of conference: **Kersti Lundin**

Hotel and Travel:
MCI - Stockholm Office
Phone: +46 (0)8 54651500
E-mail: eshre@mci-group.com

For updates visit www.eshre.eu

ESHRE 2011, Stockholm

Keynote Lectures

Aneuploidy in humans: what we know and we wish we knew – Terry Hassold (USA)

Historical Lecture

A brave new world with a brave old humankind; quo vadimus – E. Diczfalusy (SE)

MHR Symposium – The paternal genome

Sperm chromatin packaging – B. Robaire (CDN)

The human sperm epigenome – B. Cairns (USA)

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ESHRE 2011, Stockholm: Debates

This house believes that obese women should not receive treatment until they have lost weight

- **Yes: Mark Hamilton *(UK)***
- **No: Guido de Wert *(NL) - TBC***

Paramedical invited session: Should we pay donors?

- **Yes: Herman Tournaye (BE)**
- **No: Laura Witjens (UK)**

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Annual Meeting – Pre-Congress Courses

- PCC 1: The challenges of embryo transfer (Paramedical Group)
- PCC 2: The blastocyst: perpetuating life (SIG Embryology and SIG Stem Cells)
- PCC 3: From genes to gestation (SIG Early Pregnancy and SIG Reproductive Genetics)
- PCC 4: Lifestyle and male reproduction (SIG Andrology)
- PCC 5: Ovarian ageing (SIG Reproductive Endocrinology)
- PCC 6: The impact of the reproductive tract environment on implantation success (SIG Endometriosis/Endometrium)
- PCC 7: Adhesion prevention in reproductive surgery (SIG Reproductive Surgery)

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Annual Meeting – Pre-congress Courses

- PCC 8: Theory and practice update in third party reproduction
  (SIG Psychology and Counselling)
- PCC 9: Ethical aspects of non-invasive prenatal diagnosis
  (SIG Ethics & Law)
- PCC 10: Patient-centered fertility services
  (SIG SQUART)
- PCC 11: Clinical management planning for fertility preservation in female cancer patients
  (TF Basic Science and TF Preservation in Severe Disease in collaboration with the US OncoFertility Consortium)
- PCC 12: Opportunities for research in female germ cell biology
  (TF Basic Science)

Annual Meeting – Pre-congress courses

- PCC 13: Assisted reproduction in couples with HIV
  (TF Fertility and Viral Diseases)
- PCC 14: Prevention of infertility – from preconception to post-menopause
  (TF Reproduction and Society)
- PCC 15: Hot topics in male and female reproduction
  (ASRM exchange course)
- PCC 16: Academic Authorship programme
  (Associate Editors ESHRE journals)
- PCC 17: Science and the media, an introduction to effective communication with the media
  (Communications SubCommittee ESHRE)

Certificate of attendance

1/ Please fill out the evaluation form during the campus

2/ After the campus you can retrieve your certificate of attendance at www.eshre.eu

3/ You need to enter the results of the evaluation form online

4/ Once the results are entered, you can print the certificate of attendance from the ESHRE website

5/ After the campus you will receive an email from ESHRE with the instructions

6/ You will have TWO WEEKS to print your certificate of attendance

Contact

ESHRE Central Office
Tel: +32 (0)2 269 09 69
info@eshre.eu / www.eshre.eu

Open-Identity Embryo Donation - Experiences from New Zealand

Joi Ellis
ANZICA
Counsellor, Fertility Associates, New Zealand
jellis@fertilityassociates.co.nz

Objectives

Understand

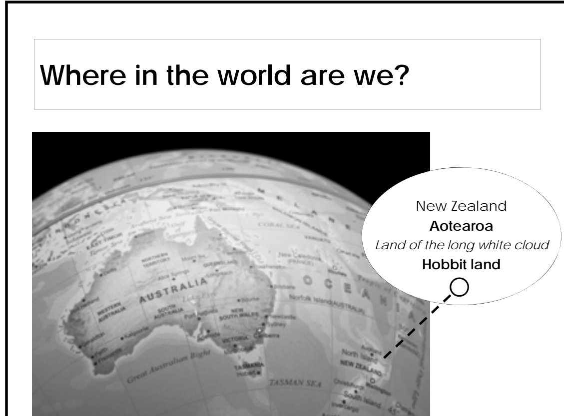
- NZ Law (HART Act 2004)
- Principles
- Influences
- Guidelines

Examine

- Challenges posed by the law, guidelines and principles

Case discussion

Where in the world are we?



New Zealand
Aotearoa
Land of the long white cloud
Hobbit land

The Law

Human Assisted Reproductive Technology Act 2004 (HART Act)

Established an:
Advisory Committee on Assisted Reproductive Technology (ACART)
Advises the Minister of health
Issues advice to the:

Ethics Committee on Assisted Reproductive Technology (ECART)

Principles of the HART Act

- Health and well-being of a resultant child should be an important consideration
- Women participating in ART are more vulnerable than men
- Health and well-being of future generations should be preserved and promoted
- individual has made an informed choice and given informed consent
- Donor offspring should be made aware of genetic origins and able to access info
- The needs, values and beliefs of Maori should be considered and treated with respect
- Different ethical, spiritual, and cultural perspectives in society should be considered and treated with respect

Why were these principles enshrined in the HART Act 2004?

Influencing factors

1. New Zealand population

- Just over 4 million people
- A third of total population live in one city
- Maori indigenous people. Approx. 15% of total
- Approx. 60,000 live births a year

Influencing factors

2. Maori culture and values

- Communal society
- Genealogy
- Whakapapa
- Land inheritance
- Children belong to the whole
- Whangai

Influencing factors

3. European adoption practice

- Adoption common in 1950 – 1980
- Adoption ACT 1955
- Due to population easier for birth mothers to have voice
- Adopted persons could more easily have their voices heard too
- Adult Adoption Information Act 1985

Influencing factors

4. Social workers experience

- Most counsellors working in ART were social workers with experience in adoption work
- Held firm view that children must have access to genetic origins
- Influenced medical staff early in NZ ART and legislators
- Self Help groups also brought on board

Influencing factors

5. Related practices
   - Identifiable donors (sperm and egg)

6.Others
   - Arguably leaders of social change
     Vote for women, Civil Union, Women holding key positions (Prime Minister, Governor General, chief Justice)
   - Quick to adopt change (EFTPOS)
   - The existing practice (law catching up)

HART Act and Donations

- No "valuable consideration" allowed
- All donors must be willing to be identifiable (Aug 2005)
- Recipients access to donor identity until resultant children 18 yrs
- Donor Conceived Person access to donor identity from 18yeasr of age (special case for 16/17yrs)
- Gametes and embryos stored only for ten years (apply for extension) (2014 looming!!!)
- Donors may change or withdraw consent

Guidelines from ACART (Handout)

Embryos from donors own IVF, own gametes, supernumerary

Full genetic siblings in no more than two families

One recipient must have medical condition

Individual case by case application for approval

Recipients have police check

Legal advice

Disposal of unused embryos discussed

Counselling for each party

Guidelines to ECART (Handout)

ECART must consider:

- Donors completed family?
- Written consent
- Counselling accessible to all parties:

Implications, joint, culturally appropriate, whanau, children

- Residency safeguards all parties
- Coercion?

Advice to ECART

ECART must consider:

If all parties have discussed and consider the implications and the counsellors professional opinion of all parties understanding of;

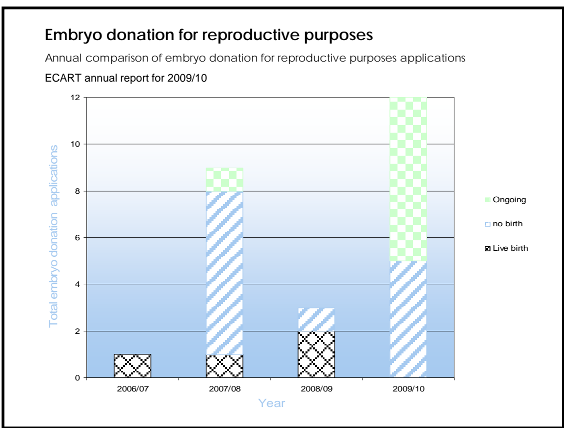
- Rights of access to information about genetic origins
- Arrangements for on going contact
- Issues which might effect well-being
- Impact of: disability, attitudes to termination, storage, use, disposal
- Donors may withdraw , embryos may not be available
- Reasons for donating and being recipients
- Feelings now and in future
- Impact on donors own children

Numbers

ECART annual report for 2009/10

Embryo donation for reproductive purposes

- ECART saw a significant increase in applications for embryo donation in 2007/08, followed by a decrease in 2008/09. This decrease may have been due in part to the introduction of new ACART guidelines for embryo donation for reproductive purposes in 2008, which included a new requirement for legal reports to be provided
- Embryo donation has resulted in one or two live births per year since guidelines were introduced in 2006/07



Challenges for Counsellors

- Who is the client?
  Ethics committee?
  Recipient/Donor?
  Unborn child?
  Clinic?
- Approval focus
- Not individual client focussed
- Allocating donors
- Cultural issues
- Imposed process
- Prescriptive reports
- Time consuming
- Not client focussed process
- Two counsellors
- Geography
- Research needed
- No maps

Challenges for clients

Donors

- May have to engage with a new counsellor, new doctor
- View counsellor as assessor
- Process insists a focus on embryos as future person
- Challenges nurture conquers all theory
- Time consuming and costs
- Forces responsibility into the future
- Confront possible future regret
- May still have remaining embryos
- Raises contradictions : conditional gift/unconditional some control/ lose control

Challenges for clients

Recipients

- View counsellor as assessor
- Means putting aside protective reserve about live birth
- Process insists on a focus on embryos as future children
- Challenges the nurture conquers all theory
- May emphasise loss of genetic connection
- Forces a relationship with donor family
- Intrusion into privacy(police check)Discrimination
- Possibly hard to feel "entitled" (attachment?)
- High anxiety levels due to process
- Time consuming and costs

Challenges for clients

Who pays for what? No Valuable consideration

Estimate of Costs to make an application

$3000-$4000 –recipients

Travel and loss of earnings

$1000- 1500- donors

Travel and loss of earnings

Challenges for clients

Resultant persons

- Unknown
- Need for research in NZ context

Possibly

- Retain connections with genetic family
- Confusions belonging/not belonging
- Confront relinquishment
- No secrets

Case illustration

Donors

Mrs C
MR C
1daughter from 1IVF cycle, 1 embryo remaining
Family complete

- Pro life concepts
- Active members of church
- Donation only possibility for embryo
- Wished to engage in relationship as if relatives
- "Met" Mrs B on line

Case illustration

Recipients

- Mrs B 30yrs & Mr B 50yrs, Married 8 years
- Mr B Previously married at 19yrs with a son and daughter)
- Dysfunctional family background
- 2 children from 3 IVF/ICSI cycles
- Fostered many children

Motivation and Attitudes

- Increase own family
- Past medical experiences
- Cost of IVF/ DE
- Genetics not important to attachment
- Active members of church
- Every embryo needs opportunity

What is the right thing to do?

- Consider implications into the future
- Consider best interests of children
- Use what we know works in similar situation

So commitment to principles even with the challenges and wait

Proceed with caution

Thank you to my colleagues and clients ESHRE and IICO

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Gay Men Using Surrogacy and Egg Donation for Family Building

Robert-Jay Green, PhD

Executive Director, Rockway Institute for LGBT Psychology
Distinguished Professor, Clinical Psychology PhD Program
California School of Professional Psychology
Alliant International University, San Francisco, CA, USA

Pre-conference Course 8, ESHRE Conference, Stockholm, 2011
(no conflicts of interest or commercial relationships)

Learning Objectives - Information

Participants will learn about:

- The psychological and social challenges in becoming gay fathers via surrogacy
- Normative changes in gay men's careers, lifestyles, couple relationships, family of origin relationships, friendship patterns, self-esteem, and self-care as a result of becoming fathers via surrogacy

Learning Objectives - Skills

Participants will learn how to:

1. Help gay male couples develop an explicitly shared psychological-emotional conception of their child and of legitimate parenthood before birth, in contrast to the implicitly shared biological conception of a child by heterosexual parents
2. Help gay fathers deal with their new minority status in the gay male community and minority status in the mostly heterosexual, female community of primary parents, including coping with marginalization in both communities

Three Central Risks & Resilience

- Stigmatization/prejudice
  Coping with discrimination from people and institutions outside the nuclear family
- Relational ambiguity
  Creating mutual legitimacy, equal roles, and boundaries to protect couple and parent status
- Fragmented social supports
  Weaving together a "family of choice" made up of gay and heterosexual components of the parents' social networks

References on Gay Fathers via Surrogacy

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Intrafamilial Gamete Donation –What Issues Are Relevant in Psychosocial Counselling?

Elizabeth Grill, PsyD
The Ronald O Perelman and Claudia Cohen Center for Reproductive Medicine
Weill Medical College of Cornell University

LEARNING OBJECTIVES

At the conclusion of this presentation, participants should be able to:

1. Identify the psychosocial issues associated with intrafamilial gamete donation.
2. Summarize the professional guidelines for intrafamilial gamete donation.
3. Describe the relevant counseling issues associated with intrafamilial gamete donation.

DISCLOSURE

Nothing to Disclose

Introduction to Intrafamilial Gamete Donation

Intrafamilial Gamete Donation

- Quantitative data about this practice are lacking or scarce.
- Recipient couples prefer non-anonymous donation where the option is available.
  - Baetens, et al., 2000; Sauer, et al., 1991; Leeton et al., 1993; Pettee and Weckstein, 1993
- Regulation in each country varies
  - In some countries, it is illegal and the relevant laws against incest and consanguinity apply
    - to protect the offspring from genetic risks
    - to avoid possible social disruptions and conflicts

Patient Preferences-Gender

- The acceptability of using a sister for oocyte donation is much greater than the acceptability of a brother as sperm donor (Sauer, 1988)
  - oocyte donation is seen in a familial, clinical and asexual context -the donor is considered to be altruistic (Haimes,1993)
  - sperm donation is regarded in an individualist unregulated context of dubious sexual connotations
  - oocyte donation is considered less of a threat to the femininity of the infertile women than semen donation is for the masculinity of the sterile male (Pettee and Weckstein, 1993)

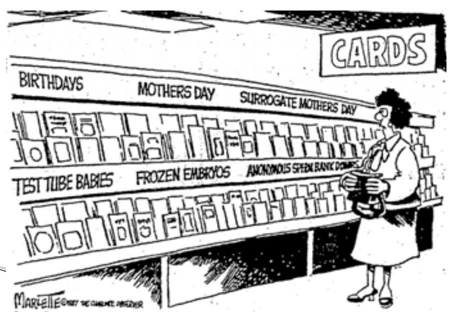
Program Preferences

- 1992 SART survey found(Braverman, 1993):
  - almost all North American ART programs accepted sister-to-sister ovum donation
  - 43.3% would allow brothers to be sperm donors
- In Oocyte Donation Programs
  - 37.5% allowed child-to-parent donation
  - 28.6% allowed parent-to child donation
- In Sperm Donation Programs
  - 26.4% allowed parent-to-child donation
  - 18.9% allowed child to-parent donation
- A 1998 survey (Stern et al., 2001) of ART clinics found
  - 60% of clinics would accept sperm from brothers
  - 90% would accept sisters

More Questions than Answers

- Can a donor closely tied to and perhaps dependent on the recipient couple make a free and fully informed decision?
- What are the consequences of the unusual resulting relationships on the donor, offspring, and rest of the family?
- What are the consequences of the creation of new genetic relationships that would be otherwise impossible?

Change Is reflected everywhere....



Defining the Terms

Intragenerational *and* Intergenerational Donation

- *Intragenerational=members of the same generation*
  - between siblings or cousins of similar ages
  - sister providing eggs for a sister
  - brother donating sperm to a brother
- *Intergenerational=* members of different generations
  - mother gestates her daughter's embryos
  - father provides sperm to his infertile son

ESHRE Task Force on Ethics and Law, 2011
The Ethics Committee of ASRM, 2004

Incest and Consanguinity

- *Incest* refers to sexual relations between two closely related individuals.
- *Consanguinity* refers to marriage and reproduction between individuals who are closely related genetically.

ESHRE Task Force on Ethics and Law, 2011
The Ethics Committee of ASRM, 2004

ASRM and ESHRE Guidelines

- Fertility practices should not assist or participate in gamete donation or surrogacy in situations in which the child would have the same genetic relationship to the participants as children would of incestuous or consanguineous unions between first-degree relatives (including adopted and stepchildren).

The Ethics Committee of ASRM, 2004

- In general, medical professionals should not offer intrafamilial medically assisted reproduction (IMAR) when this is at odds with (the spirit of) anti-incest or anti-consanguinity laws in their country.

ESHRE Task Force on Ethics and Law, 2011

Incestuous or Consanguineous Examples

- A brother may not provide sperm to a sister or a sister provide eggs to a brother.
- A father (or uncles) should not provide the sperm to replace that of his daughter's infertile husband. Nor should a mother (or aunts) provide eggs for her son's infertile wife to be inseminated by his sperm.
- A child may not provide the gametes for the infertile partner of an opposite sex parent (son-to-mother or daughter-to-father).

The Ethics Committee of ASRM, 2004

Appearance of Incestuous or Consanguineous Unions

- An adult daughter donates oocytes to her mother, whose new partner's sperm will be used to conceive the child
- A lesbian woman wants to have a child by receiving (an) IVF-embryo(s) created with sperm of her brother and oocytes of her partner (or anonymous egg donor)
- A sister provides the eggs for her brother's infertile wife who will be inseminated by a donor

ESHRE Task Force on Ethics and Law, 2011
The Ethics Committee of ASRM, 2004

Appearance of Incestuous or Consanguineous Unions

- IMAR involving the mere semblance of first- or second-degree consanguinity may still raise concerns about incest.
- Providing assistance to such arrangements may well be justified.
  - without further arguments establishing that these concerns refer to serious moral objections

ESHRE Task Force on Ethics and Law, 2011
The Ethics Committee of ASRM, 2004

The 'Yuck Factor'

- These cases 'don't feel good' or the 'yuck factor' are emotional expressions rather than moral arguments.
- A conceivable argument is that these cases may provoke negative reactions from other relatives and society, which may have adverse consequences for the welfare of the child.

Cultural Factors

- Vietnamese customs dictate that if a parent dies, the aunts and uncles take on the children as their own with no distinction between their biological and adopted children.
- In Papua New Guinea, there is no word for 'niece' or 'nephew', but rather, the children of one's sister are the same as one's own

Reitz,1988

Intrafamilial Donation Versus Anonymous Donation

Motivations for Known Donation

- Shared genetic link or heritage and continuity of the bloodline:
- Sisters share ½ of their genes
  - child shares ¼ of genes
- Cousins share 1/8 of their genes
  - child shares 1/16 of genes

"I told my parents that if grades were so important they should have paid for a smarter egg donor."

Motivations for Known Donation

- Fear of genetic material of unknown origin
- Knowledge of medical and social histories
- Trust in the personality of the donor
- Physical resemblance between donor and recipient
- Practical motives (reduced costs and wait times)
- Child's access to information about donor

Baetens, 2000

Potential Risk Factors

Potential Risks to Recipient Couple

- The recipient couple derives almost all of the benefits, while others carry most of risks
- Old patterns of sibling/family rivalry may get stirred up
- The couple needs to assess how the arrangement would influence their own relationship, as well as each partner’s relationship with the gamete donor
  - only as good as the health of the relationships between the two siblings/cousins and their respective spouses

Potential Risks to Recipient Couple

- Parents have different views from donor on how the child should be informed of its genetic origins
- Fear that their children are likely to form a stronger attachment to the family donor than to them
- Bear the emotional burden of being indirectly responsible for any physical or emotional harm done to its offspring or to other family members.

Potential Risk to Gamete Donor

- Attachment to a different primary family unit
- Donors may have difficulty detaching themselves from the children
- If conflict among family members develops, the situation could be especially painful for familial donors who may no longer be allowed to contact or visit a genetically related child

Potential Risks to Gamete Donors

- May expect special recognition from family members and others for her donation.
  - Instead, negative feelings about the arrangement may be directed at her from many sources
- If the procedures are not successful, all involved are disappointed and old family dynamics may be reenacted resulting in blame or feelings of guilt
- If the child has a genetic or birth defect or disability, the donor may blame herself or himself or feel blamed by others

Potential Risks to Gamete Donors

- Coercion or manipulation
- Differentiated power structure and undue family pressures may cause grave conflicts, guilt feelings, stress and emotional disturbances with long-lasting adverse effects (Saunders and Garner, 1996; Ahuja et al., 1997; Marshall,1998)
- Generally considered to be greater with (first-degree) intergenerational collaboration than with intragenerational collaboration

Minimal Risks to Gamete Donors

- Research has found little evidence that any of the donors felt pressured or obligated to donate oocytes.
- The likelihood of a woman becoming an altruistic donor is influenced by her personal relationship and emotional bond with the recipient couple, her motherhood status, her own experiences with parenting and the wish to help the recipient couple in a concrete way to alleviate their pain of infertility.
- Donors not willing to donate oocytes to other unknown parties who had no emotional ties with them

Baetens et al., 2000; Kalfoglou and Gittelsohn, 2000; Winter and Daniluk, 2004; Yee et. al., 2007

Potential Risk to Offspring

- Children can never consent to the circumstances of their conception
- The importance of the goal to preserve genetic linkages may be questioned when the reproductive arrangements become so extraordinary and complex.

Potential Risk to Offspring-Genetic and Social Roles

- Child may be confused about role and relationships in the unconventional familial environment created.
- The risk of identity problems of the child may increase when there is role confusion on the part of a collaborator wanting to take up part of the parental responsibilities.
- Sibling Donation
  - the rearing parent is actually the genetic aunt or uncle of the child, whereas the social aunt or uncle is the genetic parent.

Potential Risk to Offspring-Genetic and Social Roles

- In daughter-to-mother egg donation, the offspring's gestational and rearing mother is also the genetic grandmother.
  - the donor is the genetic mother but is regarded as the half-sister
  - the offspring has two maternal grandfathers, the rearing mother's father and the rearing mother's ex-husband.
- In father-to-son sperm donation, the offspring's rearing father is his genetic half-brother and the rearing grandfather is his genetic father.

Minimal Risk to Offspring?

- Initial reports of the emotional health of the families created by gamete donation, including intrafamilial cases, are reassuring (Golombok, 1995, 1996, 2005)

Potential Risks to Society

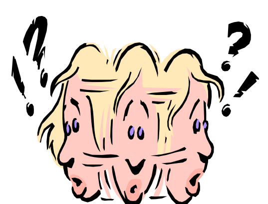
- Larger societal issues are raised because new genetic relationships are created that were not possible without the use of reproductive technologies.
- Consanguinity or incest may generate negative societal reactions.
- Families resulting from reproductive technologies such as gamete donation actually mirror our society's norms (Seibel et al., 1996)
  - complicated blended family relationships exist in American society, often products of divorce and remarriage.
  - these arrangements will add complexity to only a small number of families in a society with an increasingly complex concept of the family.

Counseling

Recipients, Collaborators, and the Group

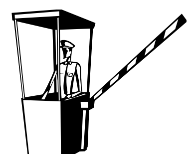
The Role of the Mental Health Professional

- Ever changing and expanding
  - Assessment
  - Treatment
  - Education
  - Consultation
  - Collaboration
  - Research
  - Gatekeeper?



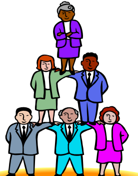
The Mental Health Professional as Gatekeeper

- International legislation, regulations, and guidelines require clinics to address the best interest of the potential child but are lacking in specifics.



Overview

- Is the reproductive plan in the best interests of all of those involved, including the potential child?



Overview

- Combined and separate counseling of recipients and collaborators to assess:
  - the voluntariness of the collaboration
  - the need for emotional support
  - the roles of the parties and their mutual expectations
  - their motivations, concerns, wants, hopes, and fears regarding the process
  - clear understanding of boundaries
  - scenarios that may challenge these arrangements in the future

ESHRE Task Force on Ethics and Law, 2011

Counseling Tasks

Gift Giving- When a debt has been incurred

- How are obligations handled in the family?
- how is gratitude shown?
- How is the debt to be repaid?
- Will the parents feel obliged to treat the child in a special way?

Lessor, 1993

Negotiating Dissimilar Treatment Experiences

- The experience of treatment by recipients and by donors differs dramatically
- The recipient, who has been actively involved in treatment steps back while her donor is suddenly thrust into treatment
- Donors move suddenly from complete inexperience with infertility treatment to intense treatment

Lessor, 1993

Donor as Patient

- None of the participants, including the donor herself, had an image of the donor as a 'patient'
- To the medical team the donor is not a patient because she has no pathological condition
- To the recipient the donor is not a patient because she has no history.
- Once treatment begins, the donor abruptly begins to see herself as a patient

Lessor, R. , 1993

Failed Cycles

- Recipient and Donor may experience the impact of a failed treatment differently.
- Recipients have already experienced prior cycle failures before moving to oocyte donation.
- Donors have no infertility or IVF history
  - may be more optimistic of the success rate
  - may face greater disappointment

Lessor, 1993

Interacting in a Triad

- Sister egg donation brings to mind the special alignment between the two sisters
- Most of the burdens of treatment are managed by the two women.
- Initially, the husband may feel excluded, and later, as dyads shift, the donor sister may feel left out
- The recipient sister is often trying hard to attend to both significant others

Lessor, 1993

Boundary Negotiation

- Must negotiate the genetic relationship and the socially defined role of the donor in relation to the resulted child
  - It is not surprising that the donor may have special feelings and perhaps even maternal bonding with the conceived child.

Saunders and Garner, 1996; Fielding et al., 1998; Winter and Daniluk, 2004.

Sister Study

- Donations are affectively intense experiences with often unanticipated emotional complications for both sisters
  - More emotionally intense than expected in either positive or negative sense or both
- High intensity positive emotions of receiving/giving
- No regrets
- For recipients, unquestionably “my child;” for donors with children, unquestionably “not my child”

Josephs, et al., 2004

Future Implications

- Future tensions between recipients and collaborator and relevant others
- Negative societal reactions, especially in cases resembling incest
- Whether, how, and when the child should be informed about the method of its conception and about the identity of the donor?

ESHRE Task Force on Ethics and Law, 2011

Counseling

For Recipients

Decision Making Psychological Implications

- Usually entails the couples' conscious decision to stop current reproductive treatment
- Must address the emotional consequences and mourn unsuccessful reproductive attempts as individuals and as couples
  - For most couples, this is a difficult and emotionally painful process
  - Raises intense feelings of loss
- The mourning phase can vary in length and intensity between both partners

Decision Process
Practical Considerations

- Should mutually agree that this is their best alternative to genetic parenthood.
- Think about the choice of an anonymous or known (sister, relative, or friend) donor
- Must think about how the addition of a third party will affect their feelings about themselves, the relationship between partners, and the parents' relationship with their potential child.

Cooper and Glazer, 1998

Sister Study– Challenges/Difficulties for Recipients

- Guilt about burdens for donor
- Continuing sense of infertility, despite motherhood
- If donor not happy in her life, recipient's indebtedness to sister can become sense of "owing," discomfort with "having more"

Josephs, et al., 2004

Sister Study–Positive Experiences for Recipients

- Joy in receiving, gratitude
- Bond with sister

Josephs, et al., 2004

Counseling

For Donors

Donor Screening

- Understand the boundaries of their role
- Fully capable and free from any kind of coercion in giving informed consent
- Donors need to be screened for:
  - psychopathology
  - ability to cope with the psychological unknown and stresses in a donor cycle.
- Psychological Testing
- Drug Testing

Implications Counseling

- Targets informed consent by
  - Walking the oocyte donor through possible future scenarios arising out of the donation procedure
  - Considering all emotional and relationship ramifications

Applegarth & Kingsberg, 1999; Boivin et al., 2001

Informed Consent

- Thorough discussion of potential physical and emotional risks to all parties and to the anticipated child.
- Voluntary and free from manipulative and undue influence.
- Option of being excluded without other family members learning of their reluctance to participate.
- Financial incentives (direct and indirect payment and inheritance) should not lead the prospective donor to discount the risks

Lessor, 1993

Counseling-Intergenerational Donation

- Children donating to their parents
  - must address the imbalance of power
  - most children feel indebted to their parents and are not truly free to say no
  - inherent boundary violations that may leave the family system or the relationships vulnerable
  - must consider a son or daughter's relationship with the stepparent -no sexual overtones.
  - the nature of the relationship may be violated as children are providing for their parents while they are still competent

Sister Study-Positive Experiences for Donors (Higher to Lower Frequency)

- Honor to be asked
- Joy in giving
- "Good eggs:" pride in success of cycle
- Support /praise from other family members
- Personal growth
- Role reversal in helping/advising older sister
- Biologically help carry on family, biological connection of her own children with child

Josephs, et al., 2004

Sister Study– Challenges/Difficulties for Donors

- Surprise at physical aspects
- "Bad eggs:" feeling of failure/self-blame if negative cycle, problem in pregnancy, etc.
- Sense of exclusion/alienation with experience of feeling left out or disrespected
- Sense of alienation from own partner; donor husband potentially "odd man out"
- If no children of own, potential for boundary issues/painful sense of own voids

Josephs, et al., 2004

Post-Donation Counseling

- Donors strongly endorsed the need for providing post-donation counseling by a mental health professional as part of the routine procedures in both successful and failed donations

Yee, et. Al, 2007.

Donor's Role: A changing picture

- Role of donor in offspring's life: what is the donor's expectations and what are the recipient(s)' expectations
- What are the donor conceived persons needs? And do they change?
- Donor's children & offspring relationship?
- Roles for the rest of the family?
  - We have zero idea of how the donor's children will feel

Disclosure

Disclosure

- All parties should be in agreement regarding disclosure to others as well as to the potential child.
- Ultimately, the donor should feel comfortable allowing the recipients to make all decisions related to disclosure, the pregnancy, and the upbringing of the potential child.
- Subjects overwhelmingly indicated that mandatory psychological counselling was an important part of cycle preparation and was quite helpful to them in making the disclosure decision (Yee et al., 2007)

Secrecy and Known Donation

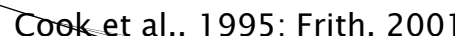
- Fathers more often than mothers are secretive with regard to the use of a donor and are more in favor of donor anonymity.

  Brewaeys et al.,1997
- Couples who opted for known donation tended to be more inclined towards secrecy
  - discomfort when they have continuous contact with the known donors.
  - donors are well connected with the recipients' family or social network.

  Baetens et al.2000

Nondisclosure

- Nondisclosure of gamete donation is a way to maintain the normal bonds between the child and the parents
  - to avoid distressing the child
  - to establish a 'normal' family



Cook et al., 1995; Frith, 2001

Sister Study-Disclosure

- Generally plan to disclose to child
- Disclosure discordance: donors wish to tell more people and/or make unplanned disclosures

Josephs, et al., 2004

Secrecy

- Limits on communication, adds pressure to those who are keeping the secrets and causes stress within the family system (Frith, 2001; Daniels, 2002)
- This system of secrecy can inadvertently promote family estrangement and create unhealthy alliances between those who know and those who do not know
- May undermine the trust that is vital to a healthy parent-child relationship

Right of Child

- Child has the right to know her/his origin for ethical and medical reasons
- Nondisclosure violates the child's rights to autonomy
- Nondisclosure may create family tension detectable by the child
- Disclosure of the child's origin either accidentally or intentionally later in life may cause distress and challenge the family relationships

McGee et al., 2001; McWhinnie, 2001

ASRM and Disclosure

- While ultimately the choice of recipient parents, disclosure to offspring of the use of donor gametes is encouraged.

The Ethics Committee of the American Society for Reproductive Medicine & Infertility, 2004

ESHRE and Disclosure

- If other relatives are aware of familial collaboration, counselors should
  - encourage disclosure
  - discourage IMAR if applicants are not willing to opt for disclosure.
- In other situations, may accept a parental preference for secrecy
  - concerns about the risk of confusion in the child who may frequently meet the relative who was involved

ESHRE Task Force on Ethics and Law, 2011

Counseling

For Offspring

Best Interest of the Child

- The potential emotional consequences to the child should be a primary concern
- Specialized counseling may be desirable as they get older, especially for arrangements that give any impression of incest or may result in disruption of family relationships.

Conclusions

- Intergenerational gamete donation is especially challenging
- Morally acceptable practice in some situations and in some conditions.
- Both combined and separate counseling of recipients and collaborators (including partners of donors) are crucial as this may contribute to both well-considered decision making and risk reduction.

Conclusions-Denying Treatment

- IMAR should be withheld in case of undue pressures on the collaborators or a high risk of serious harm for the possible child.
- Consanguineous gamete donations from first-degree relatives are unacceptable.

Conclusions-Questioning Treatment

- First-degree intergenerational collaborations need special scrutiny in view of the increased risk of undermining autonomous choice.
- Cases of IMAR involving third-degree consanguinity, though acceptable in principle, call for additional counseling and risk-reduction.
- Cases involving only a semblance of first- or second-degree consanguinity may be acceptable.

Conclusions

- Practitioners who refuse to collaborate in demands for IMAR should refer the patients to another centre for consideration.
- More research into the psychosocial implications of IMAR is of paramount importance.
- The findings of such research may well contribute to more adequate moral guidance.

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Mapping relationships in lesbian-led families built by third party reproduction – a genogram technique for use with children

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27th Annual Meeting ESHRE Stockholm Sweden, 3-6 July 2011
SIG Psychology & Counselling: Theory & Practice in Third Party Reproduction.
No commercial relationships or potential conflict of interests are reported.

learning objectives

- To depict a diversity of family forms
- To consider different family constellations of lesbian-led family relationships
- To expand techniques for clinical and research interviews with children.

lesbian-led families built by third party reproduction

- Diversity of lesbian and gay parenting experiences
- Planned lesbian-led families through donor insemination

  Brewaeys et al. (1997).

  Gartrell et al. (1996).

  Herrmann-Green & Gehring (2007).

challenge of depicting lesbian parented families …

- How to represent a same-sex couple parenting?
- Couple separation
- New adult partnerships

... & depicting family beyond the household

Complex layers of extended family relationships

Including family of choice relationships

Weston (1991)

Is the donor included on the family map?

- Openness about donor conception
- Involvement of male figures

mapping family relationships

Traditionally family relationships mapped through genograms – pictorial description of family relationships across and within generations

Genograms developed by Monica McGoldrick & Randy Gerson

(see McGoldrick et al. 2008)

traditional (Heteronormative) Genogram Symbols

- Male Female
- relationship between indicated by a line
- features depicting dependent children

Including LGBT family members in genograms

- Gay man
- Lesbian
- Bisexual woman
- Transgender woman to man

Source: McGoldrick et al. 2008

Mapping lesbian-led family constellations

- Basham (1999) use traditional genogram notation with lesbians to describe family
- Swainson & Tasker (2005) lesbian couples constructing genograms:
  freedom to describe connections of choice

Engaging children in talking about their family

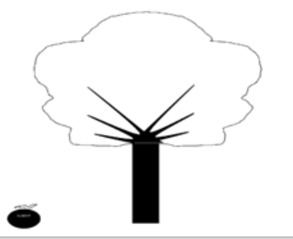
a genogram technique for children: Apple Tree Family (ATF)

- A representation free measure
- Creative yet not reliant on child's skills
- Julia Granville (Tavistock & Portman Clinic) developed ATF in clinical practice with adoption and fostering

Julia Granville M.Sc. in Family Therapy, Birkbeck University of London (UK) in collaboration with the Institute of Family Therapy, London (UK) under the supervision of Dr. F. Tasker.

Apple Tree Family Study

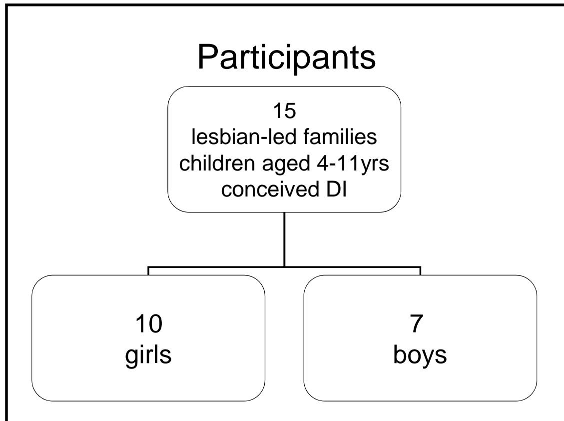
a tree to put family apples on



How do children conceived by third party reproduction in lesbian-led families define their family?

- Would children describe the same network of family relationships that adult family members did?
- Did different methods of interviewing children about family relationships vary as to who was included in the family?

Participants



Interviews with Adult Family Members

- o Demographic data
- o Who do you see as members of your child's family?
- o Relationship terms used in different contexts

Apple Tree Family (ATF)

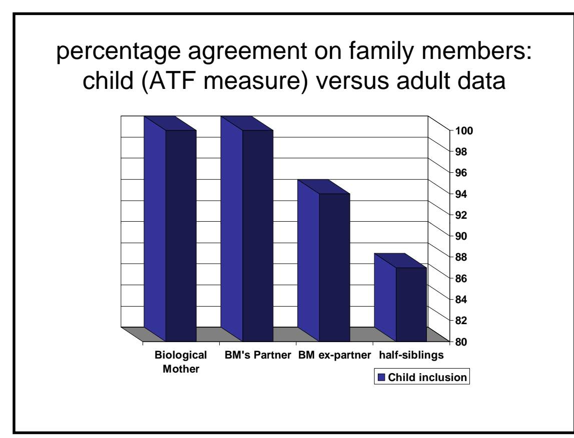
- Standard picture of a tree (A3 size paper) and a pile of red paper apples
- Put an apple on the tree for family member.
- Each apple named
- is this person always called that or sometimes do you say something different?

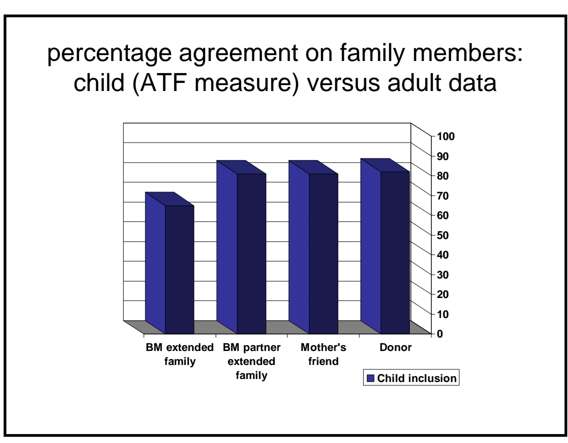
Kinetic Family Drawing Test

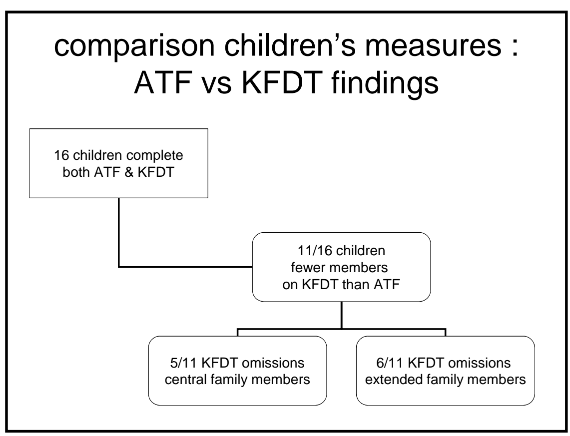
- Kinetic Family Drawing Test (Burns & Kaufman, 1971)
- “Draw everyone in your family doing something”

Kinetic Family Drawing Test (KFDT)

- widely used clinical and research measure (developed by Burns & Kaufman, 1971)
- ATF vs KFDT comparison of type and number of relationships included


percentage agreement on family members:
child (ATF measure) versus adult data
100
98
96
94
92
90
88
86
84
82
80
Biological Mother
BM's Partner
BM ex-partner
half-siblings
Child inclusion


percentage agreement on family members:
child (ATF measure) versus adult data
100
90
80
70
60
50
40
30
20
10
0
BM extended family
BM partner extended family
Mother's friend
Donor
Child inclusion


comparison children's measures :
ATF vs KFDT findings
16 children complete both ATF & KFDT
11/16 children fewer members on KFDT than ATF
5/11 KFDT omissions central family members
6/11 KFDT omissions extended family members

discussion: lesbian-led families & ATF potential

- Inclusivity of family members
- Creative but independent of children's abilities.
- Potential for further developments
  - Reliability and validity work
  - Emotional tone
  - Distances between family members

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Information sharing with teenagers conceived by gamete donation

Olivia Montuschi
Donor Conception Network

What is DC Network?

www.dcnetwork.org

- Family support network
  started in 1993 by 5 families with DI children
- Parent led, child focused
- Inclusive - single, lesbian, heterosexual
- Parents, offspring, those contemplating or having treatment
- Sperm, egg, embryo donation
- Strongly advocate openness

More about DC Network

- 1600 member families
- Increasing number of older children, teenagers and young adults because DCN now 18
- Also increase in families approaching us for information about how to tell older children

What can we offer older children and teenagers?

- Developmental context important 8+, 12+, 17+
- Whether told early, late or not yet told
- Family context – not so much structure but if parents are comfortable with their decisions, couples have similar views, how they have dealt with their situation generally.

Children of 8+

- Leap in brain development at this time
- If parents started the story early, this is when it sinks in
- Sadness about lack of 'blood connection' to much loved parent
- Parents starting to hand over ownership of 'their story'
- If 'told' at this age, needs to be straightforward information
- Children's groups for age 8-12 at national meetings

Children's Groups

- Initiative came from both parents and children
- Children only attend if *they* want to
- No more than 8 per group
- Led by psychologist and specialist children's group worker who talk with parents prior to the meeting day
- Fun, age appropriate games and activities to enable children to talk about their family and the way it was made

The children speak

- "There were 7 children in the group. S and J, the adults, were very nice. I liked that everybody could join in and even if you didn't say anything, it still counted as joining in. I made some friends. **Rachel, 8, conceived by sperm donation**
- "The people running the group were really nice and kind and funny. We did a bit of biology about half brothers and sisters and it made me understand a bit more about it. It's good for children to have the group so that they can find out more about their family and other children's families whilst having fun" **Hannah, 9, conceived by embryo donation**

Donor Conception Network

And the last child…

- "I thought it was all good but the thing I liked the most was when we were given a piece of strong and we explained to the next person what we had in common with our family. I said I was like Mummy because we both enjoy walking in the mountains in the summer. I passed the strong to the next person and they repeated what I said. We said a different thing 3 times to different children and when we had done that S cut the string and that is why we are like our family" **Duncan, 10, conceived by double donation**

Donor Conception Network

Children of 12+

- For most, pre or actual puberty preoccupies and they don't want to be different – boys in particular
- Open communicators become grumpy non-communicators who don't want to talk about DC – gender differences
- Generally not a good age to start telling…but with exceptions
- School curriculum may pose challenges
- Don't seem to want connections with others
- DCN Young Person's Network open from 13

Donor Conception Network

Two different experiences

- Linda and Daniel, both 'told' at 13 as parents were divorcing
- Linda shocked but has accommodated news
- Daniel devastated, news has affected whole of his life
- Linda has some non-identifying information but has not found donor or half sibs
- Daniel knows who the donor was and has located half-sibs
- Linda is a moderate, Daniel believes DC inevitably damaging
- What makes the difference?

What does make the difference?

- Age and era of donation?
- Parental willingness to talk?
- Temperament and personality?
- Opportunities for understanding and integration?

Young adults 17+

- Suddenly it's OK to talk again
- Starting - shock, disbelief - may be relief - grief process
- If continuing and comfortable, more mature acceptance and understanding of parental perspective
- Continuing and less comfortable, *perhaps* because of family issues – parents reluctant to talk, shame about infertility
- How parents feel and behave likely to influence how they respond - keep talking!
- Much more open to connections – social networking

Keys to getting it right for teenagers

- Parental comfort and confidence: well supported parents
- Respect for developmental stage: DC teenagers are just like any other
- Parental willingness to own authority "You're not my Dad anyway"
- Parental ability to tune in and listen to the feelings

DC Network Resources for Parents

- Story books for parents of young children in heterosexual couples, single mother and lesbian mother families
- Telling and Talking booklets for parents of 0-7, 8-11, 12-16 and 17+
- Workshops for those preparing for DC parenthood and to help with Telling and Talking

Benefits of a supportive community

- Children and parents grow up knowing each other
- Move from creche, to Children's Group to Young Person's Network
- Just knowing there are many others can be enough

INFORMATION SHARING WITH YOUNG ADULTS CONCEIVED AS A RESULT OF DONOR CONCEPTION

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No commercial interests or conflict of interest

LEARNING OBJECTIVES

To explore the advantages of a family focus to sharing the donated gamete family history with adult offspring.

To enhance the knowledge base required for working with families who wish to share the donated gamete family history with their adult offspring.

To learn intervention strategies for working with families who wish to share the donated gamete family history with their adult offspring.

INTRODUCTION

Early sharing of information advisable
Jadva et al., 2009, Mahlstedt et al.,2010, Daniels 2004

Changing culture—time warp for parents

Our family history not *your* history

Focus on facilitating parents to share information that has till now been secret

Evolving field of practice

Bring together research, clinical practice and some conceptual thinking

OUTLINE

Introduction
Parent considerations
Offspring considerations
Family consideration
Conclusions

PARENTAL CONSIDERATIONS (1 of 8)

Assuming contact because issue/reflection arisen for parents

" I am just realising that our daughter is coming up to the age of 18 and she is getting to the point where she will be leaving home and getting in to relationships and parenting in her own right" Father NZ study

PARENTAL CONSIDERATIONS (2 of 8)

Motivations for sharing:

- Moral issues-- integrity/honesty
- Health information/history
- Consanguinity

Issues

- Loss reactivated (Montuschi 2006)
- The journey to this point
- Who is the sharing of information for?

PARENTAL CONSIDERATIONS (3 of 8)

The impact of keeping a secret

PARENTAL CONSIDERATIONS (4 of 8)

Anxieties about sharing information

"will this tear us apart?"

" will they see me as less of a father?"

How will she/he react?

The importance to confidence and preparation

Daniels, Thorn and Westerbrooke (2007)

Meeting parents needs/issues first

" a good relationship will see you through"

PARENTAL CONSIDERATIONS (5 of 8)

Parent or parents sharing information?

Impact of death, separation, divorce

Partner dynamics as a factor

Shehab et al 2008: Gillett et al 1996

Who takes the lead?

An example of the sharing

PARENTAL CONSIDERATIONS (6 of 8)

Interventions:

- Telling and talking booklets 23,25,19 and 13
- Setting up—location/timing
- Having others available—support networks
- The words we use—how we became a family
- Cognitive and affective
- Focus on the offspring
- Not filling the silences—waiting for responses

PARENTAL CONSIDERATIONS (7 of 8)

Interventions—continued

- Sharing as a process
- The start of an on-going dialogue
- Role playing
- A clinical example
- The advice given to parents at treatment
- The shame/stigma of infertility

PARENTAL CONSIDERATIONS (8 of 8)

Power factors:

- The significance of power
- Adult to adult
- Power then—power now
- Parents accepting powerlessness
- Sharing power
- Who else knows?

Wished had told earlier

OFFSPRING CONSIDERAATIONS

(1 of 13)

" Once I realised exactly what was being said and that was how I was conceived a real rush of emotion overtook me. I immediately wanted to be reassured that Mum was my biological mother. I then realised that my sister might not have been conceived through the same donor and asked about that. When Mum told me she wasn't I started crying and this part of the realisation hit me really hard"

Claire 2011

OFFSPRING CONSIDERATIONS

(2 of 13)

" I don't think I even remember their words. It took them about 5 minutes to say what they wanted and at least a couple of years for it to sink in. Its such a shocking thing for the offspring to hear. I don't think there is any way to soften the shock when they have gone all their life thinking Mum met Dad, got married and had my sister , usual story—no different than other kids at school. Next thing I discover Mum had my sister before my Dad and then hear that I have no genetic connection with my Dad and grandparents. WOW!!!"

Louise 2011

OFFSPRING CONSIDERATIONS

(3 of 13)

"Mum was faced with having to tell us in a 'bombshell' type way, because once the offspring become adults, there is no slow process way of letting the truth out. It is important to set aside time when you will not be interrupted. It makes it seem like a big deal, sitting every one down, but then it is a big deal!"

Ali 2011

OFFSPRING CONSIDERATIONS
(4 of 13)

" In thinking about all the thoughts that went through my head these were the main ones:

1. *Wow I cannot believe we didn't know about this and that it has been kept a secret from us for our whole life.*
2. *Devastation that my sister is not connected to me in the way I thought she was and wanted her to be.*
3. *Wondering about who else knew and how they must have been in on the secret.*

OFFSPRING CONSDIERATIONS
(5 of 13)

4. *Mixed feelings about how this made me feel towards my Dad and what our relationship would be like now.*
5. *Knowing that this was a huge moment in my life, one which at the time I thought " I really don't want to be different in this way, why couldn't life be simple like everyone else? "*

Claire 2011

OFFSPRING CONSIDERATIONS
(6 of 13)

You will have observed the:

- shock
- the theme of genetic connectedness
- affective and its impact on cognitive
- time as a factor
- the importance of the disclosure
- secrets and their impact

We return to these later.

OFFSPRING CONSIDERATIONS
(7 of 13)

Research findings :
Turner and Coyle 2000
- First formal study of adults experiences N16
- Felt mistrust in family
- Lack of genetic continuity important
- Frustrated at lack of information about donor
- Need to talk to a significant other who understood
- Used identity process theory

OFFSPRING CONSIDERATIONS
(8 of 13)

Jadva et al. 2009
- DSR Registry 63 who were 18 or over
- Compared views of those who learnt early and those who learnt later
- Those told later reported more negative feelings, confused, angry ,shocked, upset
- Feelings to parents less clear—mixed
- Those from heterosexual families more likely to feel angry at mothers for lying than fathers

OFFSPRING CONSDIERATIONS
(9 of 13)

Jadva et al. 2010
- DSR Registry 163 (13-61) respondents who were searching for information
- 78% searching for siblings, 77% for donors and most for both
- Those finding out when over 18 more likely to be searching for medical reasons and those before 18 for curiosity
- Impact of having own family

OFFSPRING CONSIDERATIONS

(10 of 13)

Other studies of relevance

- Mahlstedt et al. 2010
- Becker et al. 2005
- Shehab et al. 2008
- Scheib et al. 2003 and 2005
- Kirkman 2003

Research findings available to parents

OFFSPRING CONSIDERATIONS

(11 of 13)

Themes that emerge from clinical and research:

- Shock at being told or finding out
  - impact at affective and cognitive
- Having time to reflect/assimilate
- Identity and self image factors Daniels and Meadows 2006. Turner and Coyle 2000.
- Loss of genetic connectedness
- Stigma—desire to be “normal”

OFFSPRING CONSIDERATIONS

(12 of 13)

- Anger over secrecy
- Who else knows
- Sharing is on-going

“ I didn’t have any pressing questions but might have liked to hear the ‘story’ again with not so shocked ears’ Louise 2011

- The need of others to share with
- Trust

OFFSPRING CONSIDERATIONS
(13 of 13)

How secret is a secret?

Findings from Turner and Coyle study

Current research –in five of seven families the parents reported that offspring had come home and asked questions about their genetic connectedness to their parents. This often included questions about being adopted.

Biology lessons at school and their impact

FAMILY CONSIDERATIONS (1 of 7)

Adopting a family focus

Our family history—how we came to be

Family issues to face arising from sharing of Information

" The assumption of consistent social and genetic parentage has been shown to be based on a false premise" Kirkman 2003

FAMILY CONSDIERATIONS (2 of 7)

Significant challenges for offspring, but these influenced by the understanding of 'my' family and family generally. These understandings may in turn impact on the nature of family relationships now and in the future and with immediate family as well as extended family.

Four areas of particular significance.

FAMILY CONSIDERATIONS (3 of 7)

1. Genetic and social understandings of family:
   - Grace and Daniels, 2007
   - Back to nature/nurture issue
   - The significance of likeness. Becker et al on resemblance talk and its impact
   - The importance of genetic history
   - The "love bond" in families
   - The importance of language
   - An example

FAMILY CONSIDERATIONS (4 of 7)

FAMILY CONSIDERATIONS (5 of 7)

2. The notion of trust within the family
   - Trust and security closely linked
   - Secrets and their relationship to trust
   - Trust has been challenged
   - Rebuilding trust—a family task
   - Understanding why secrets kept
   - Cognitive and affective

FAMILY CONSIDERATIONS (6 of 7)

3. The notion of an extended family
   - Another person is a part of this family
   - What does this mean?
   - How is the donor to be seen?
   - Who is the donor?
   - What about half siblings?
   - Seeking more information

FAMILY CONSDIERATIONS (7 of 7)

4. The identity of the offspring within this family
   - Where does my identity come from?
   - The challenge of readjustment
   - Parents know the challenge of readjustment---the experience of infertility
   - Individual identity and influence of family

CONCLUSIONS

- Need for assistance to be available
- An emerging field of practice
- Preparation for counsellors
- A family and individual focus

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Preparing semen donors and offspring for contact

Marilyn Crawshaw: mac7@york.ac.uk
UK

Some background

- Organisational context:
  - UK DonorLink (www.ukdonorlink.org.uk)
    - Pilot launched April 2004; Govt funded
    - DNA based Voluntary Register
    - Open to donor conceived adults (DCA), genetically related siblings and donors
    - 300+ on the Register
    - Approximately 30 'links' between genetically-related siblings and 2 links between DCA and donor

Political context:

- Born out of a political desire to be seen to be doing something
- What happens next? Who picks up the tab?
- The unexpected pressure group – the switch of alliances in the face of a common enemy
- Volunteers; peer support; professional – whose skills are required and who decides?

Social context

- Medical versus social model – which is dominant?
- Changing nature of family configurations
- Managing shame and stigma
- Altruism versus inducement

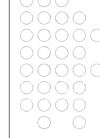
What didn't we expect?

- *Donors and donor conceived adults* – the potential for healing; the potential for grounding fantasies
- *Donor conceived adults* – the birth of a face to face social movement: painful and joyous solidarity

So what are the key practice issues?

- Uncertainty – better than nothing?
- Replacing 'knowledge' with uncertainty – a good thing?
- Managing expectations of each other – and of 'us'
- Seeking relationships or meeting identity needs – does it affect outcome?
- Managing the unexpected

Pre- and post-treatment counselling for egg donors – what issues are relevant?



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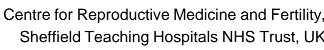


Aims

To explore

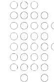
- International context of egg donation
- Different forms of and motivations for egg donation
- UK practice
- Key counselling issues pre-donation
- Meaning of post-donation counselling

International context

Widespread differences between countries in relation to:

- Legislation, including legality of egg donation, egg sharing, known donation
- Regulation
- Anonymity
- Donor records / registers
- Payment / compensation
- Assessment of donors
- Access to counselling

UK: HFEA 8th Code of Practice



Mandatory requirement: All prospective donors must be given a suitable opportunity to receive proper counselling

- If the possibility of donating gametes or embryos for the treatment of others…arises, the centre should offer counselling about the implications of donation separately from counselling about the implications of treatment before the treatment starts (3.4)
- requires centres to take all practicable steps to provide an opportunity for counselling throughout treatment, donation or storage processes and afterwards (3.5)
- The centre should offer people the opportunity to be counselled with a partner, if they have one, individually or both. Group sessions may be offered in addition to individual and couple sessions (3.6)

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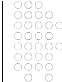
BICA Guidelines for good practice in infertility counselling (2nd ed 2007)



Process pre-donation:

- Referral to counsellor should be routinely offered…and people expected to take it up.
- A minimum of 2 counselling sessions should be made available
- The offer should also be made if donors return to centre at a later date

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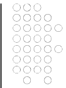
What happens in practice?



Survey questionnaire emailed to BICA membership:

- 25 respondents covering 27 UK clinics
- 3 additional responses from overseas members
- Protocols shared by 9 colleagues, including 2 from overseas

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Overview

- 52% counsellors employed by clinics; 48% self-employed
- 70% practising in private clinics; 30% in NHS managed services
- 30% attached to more than one HFEA licensed centre; 70% work for only one clinic

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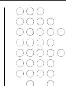
Implications counselling provision



Counselling is mandatory for

- identifiable and known donors in 92% of clinics
- egg share providers (donors) in 94% of clinics
- Counselling is supported but essentially optional for all donors in 2 clinics; one is private and one is NHS managed.

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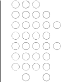
Charges for pre-donation counselling sessions



Unlimited access to pre-donation counselling free of charge is provided by

- **48%** of clinics for identifiable egg donors (71% of NHS centres, 37% of private centres)
- **44%** of clinics for known egg donors (as above)
- **50%** of clinics for egg share providers (75% of NHS, 32% of private)
- The majority of remaining clinics provide 1-2 sessions free of charge

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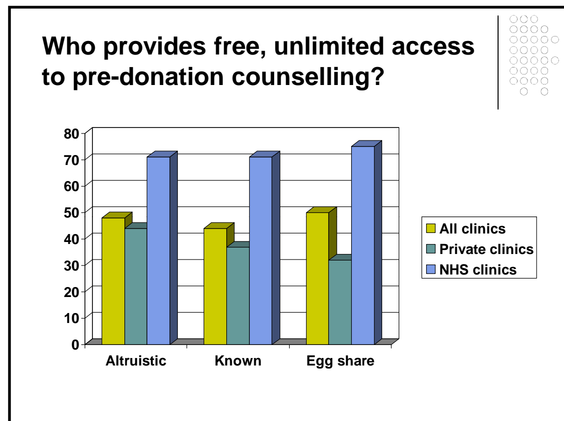
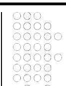
Who provides free, unlimited access to pre-donation counselling?



Who attends pre-donation counselling sessions?



- Most counsellors also routinely see egg donors' partners (84% of identifiable donors, 85% known donors, 88% egg share providers)
- Group counselling in known egg donation arrangements is provided:
- ✓ Routinely 44%
- ✓ Optional 34%
- ✓ Not provided 22%

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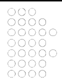
Post-donation and subsequent egg donor counselling provision



- Very few counsellors (between 1-3) routinely provide post-donation counselling although the option is available in most clinics
- However, if women donate for a second or subsequent time, further implications counselling is routinely provided in some clinics (32% identifiable donors, 33% known donors, 28% egg share providers) and optional in most other clinics.

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Later counselling provision

- Confusion over definition of 'later counselling'
- All clinics offer some provision (in line with HFEA and BICA guidance)
- 67% offer later counselling with no limitations to all egg donors and 59% offer same provision to anyone affected by their donation
- Limitations quoted include:
- ✓ Restricted number of sessions
- ✓ Time limits since donation
- ✓ Offer dependent on presenting issues

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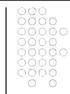

LIFE

It's all about RELATIONSHIPS!

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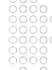

Egg donors: different types and motivations, different relationships?

Egg donors may be:

- Altruistic / anonymous (non UK)
- Altruistic / identifiable
- Commercial / anonymous (non UK)
- Commercial / identifiable (non UK)
- Known: inter-familial, intra-generational, friend, acquaintance
- Egg sharing

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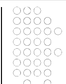
Key counselling issues Altruistic / identifiable donors (i)



- Motivation
- Understanding of process / risks / side effects / existing legislation
- Attitudes and potential feelings towards any children conceived from their donation
- Implications for partner / future partner
- Implications for own family / existing and future children – their information needs and feelings
- Attitudes and feelings of significant others in wider family and social network

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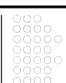
Key counselling issues Altruistic / identifiable donors (ii)



- the welfare of any resulting children
- Information needs of children who may be conceived and their parents
- Information needs of such children as adults and possibility of future contact
- Potential impact on self and own family
- Approaches to preparing for and managing contact

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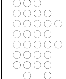
Key counselling issues Known donors (i)



- What is the primary motivation – voluntary / altruistic donation v coercion?
- What is the nature of the relationship ?

  - genetic / non genetic, familial / non familial, intra-generational, length, quality, frequency of contact
- How much has been discussed already? Tensions / reservations

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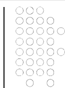
Key counselling issues Known donors (ii)



Impact on future relationship:

- Anticipated future contact
- Nature of involvement in each other's family lives / boundaries
- Possibility of relationship changing / being adversely affected
- Gender issues +/or resemblance to donor?
- Impact of donation or treatment failure / pregnancy loss or child born with abnormalities

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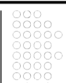
Key counselling issues Known donors (iii)



Managing information about donation:

- Agreements and disagreements
- Whether to tell, why tell, when, whom, how?
- Impact on own child/ren; nature of their relationship with donor-conceived child/ren
- Loss of control / meeting children's needs
- Impact on self / partner / significant relationships if not sharing information

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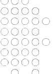
Key counselling issues for egg share providers



- Motivation – altruistic; access to treatment / financial needs; equal commitment
- Thoughts and feelings about
  - ✓ A possible pregnancy at same time as / close to recipient's pregnancy
  - ✓ Possibility of recipient's treatment resulting in a live birth whilst own treatment does not
  - ✓ Whether to find out about result of donation(s) and when

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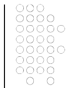
Complexities: inter-generational or intra-familial egg donation



- Younger donors without children
- Younger donors not yet sexually active
- Confused boundaries / relationships
- Pressure to donate / accept donation
- Parent storing own gametes as option for child's future use
- Balance of power

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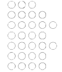
Additional issues for all donors (i)



Legal aspects of donation include:

- Donor's legal status in respect of any child that may be born
- Identifiability of donors
- Right to withdraw consent to use of donated eggs or embryos created using donated eggs
- Potential for legislation to change in the future
- Storage of donated eggs / embryos created with donated eggs

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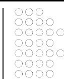
Additional issues for all donors (ii)



Understanding of HFEA Register including:

- Access to register
- Proposed framework for disclosure and possible contact
- Information to be recorded, purpose of pen portrait and good will message
- Content of pen portrait – examples / brainstorming
- Information available to donor in future (number of live births, year of birth, gender)

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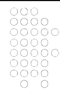
Post-donation counselling



Why?
When?
Where?
With partner?
With children?
With recipients?
Aims?

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Post-donation counselling

Donor's experience of donation –

- Donation cycle
- Emotional impact of donation on self / partner
- Impact on quality of relationship with recipient/s (known donation); tensions
- Level of confidence in decision and future feelings
- Regrets?
- Support needs – past, present and future
- Subsequent donation decisions

Post-donation / later counselling

'The centre should take all practicable steps to provide an opportunity for counselling throughout the treatment, donation or storage processes, and afterwards if requested. If a person who has previously donated gametes or embryos, or received treatment, requests further counselling at any point, the centre should take all practicable steps to help them obtain it.'

HFEA Code of Practice 8th ed (3.5)

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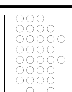
Later counselling

- Information on outcome of donation: decision-making; receiving information; exploring meaning
- Sharing information with children / new partner
- Longer term impact on existing relationships, particularly with regard to known donation
- Managing future contact
- Living with uncertainty



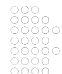
Current challenges/ Cross Border Reproductive Care

Gaining popularity with UK patients: accessibility, cost, quality of care?

BUT potentially involves lack of

- background information re donors / anonymity
- short and long term counselling support for recipients
- short and long term counselling support for donors

AND cultural differences and implications; exploitation of donors OR fairer, more transparent payment?



A generic protocol?

- 80% UK BICA members responding to the survey have implications counselling protocols for egg donation and 77% have protocols for egg sharing
- All 3 overseas respondents have protocols

What issues are common to all?

Is a generic, cross border implications counselling protocol feasible and if so, who is best placed to work on this?

Mark your calendar for the upcoming ESHRE campus workshops!

- Early pregnancy disorders: integrating clinical, immunological and epidemiological aspects
  23-26 August 2011 - Copenhagen, Denmark
- The management of infertility – training workshop for junior doctors, paramedicals and embryologists
  7-8 September 2011 - St. Petersburg, Russia
- Basic genetics for ART practitioners
  9 September 2011 - Bucharest, Romania
- The whole man
  22-23 September 2011 - Sevilla, Spain
- Accreditation of a Preimplantation Genetic Diagnosis Laboratory
  3-4 October 2011 - Athens, Greece
- Human reproductive tissues, gametes and embryos: Innovations by science-driven culture and preservation systems
  9 October 2011 - Cairns, Australia
- Comprehensive preimplantation screening: dynamics and ethics
  13-14 October 2011 - Maastricht, The Netherlands
- Endometriosis and IVF
  28-29 October 2011 - Rome, Italy
- Endoscopy in reproductive medicine
  23-25 November 2011 - Leuven, Belgium
- What you always wanted to know about polycystic ovary syndrome
  8-10 December 2011 - Sofia, Bulgaria

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(see "Calendar")

Contact us at info@eshre.eu

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