TURNERS'S SYNDROME & FERTILITY

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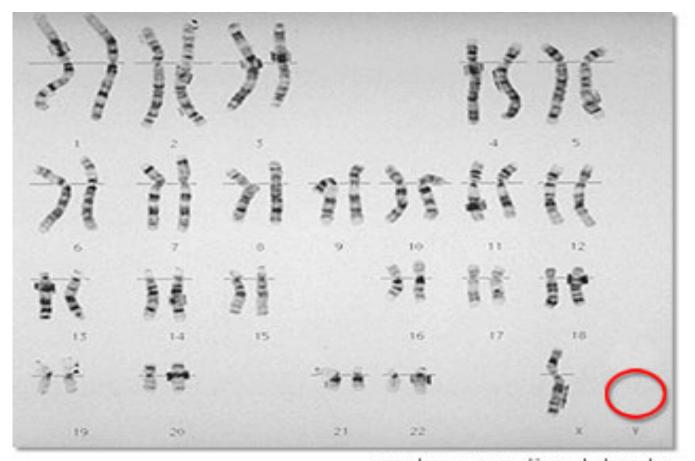
Sims IVF



Sims IVF

- OI, IUI, IVF, ICSI, IMSI
- Sperm donation
- Egg donation
- Shared care PGD & PGS, surrogacy, double & embryo donation
- Specialist fertility testing
- Immunotherapy
- Mind Body support

Genetic Profile



Dr David Walsh, 24th March 2012 genetics.utah.edu

Reproductive profile

Few or absent periods

Early change of life (POF)

Rarely fertile (mosaic only, mention gonadoblastoma)

Thyroid, diabetes, auto-immune diseases

Oocyte donation - usual fertility treatment

Single embryo transfer (uterine size)

CHD can be an issue during pregnancy

Pregnancy loss & PTL

Special obstetric care

Be prepared

- Medical treatment
- Trial simulation (womb)
- Oocyte donation (FET)
- \square SBT if < 6cm
- Specialist shared obstetric care

How to succeed

- Determined
- Emotionally resiliant
- Flexible
- "the heart & the head"

Specify a timeline

- Thus far & no further
- Your relationship
- Cumulate possibilities to make a probability
- 40% + 40% = 80% probability (that's how nature works too!)
- Anticipate & manage the risks of success as well as failure

Risk Management

- "Most women with Turner's syndrome are infertile. If you can't have a baby it can be very distressing, and donated eggs can give these women a chance of raising a family. However, this work shows that for women who have Turner's syndrome, pregnancy is a high-risk option, both for the mother and the baby. The mothers have a significantly increased risk of illness and even death by aortic dissection and eclampsia, but in addition the foetus is also at risk of problems, such as growth problems following pre-eclampsia, and stress. Only 40% of the pregnancies we studied produced an absolutely normal outcome for both mother and baby.
- "In these circumstances, we need to be very cautious indeed about recommending mothers to undergo egg donation. It is important that women with Turner's syndrome who undergo egg donation have their cardiac function monitored before, during and after pregnancy, and that they are very closely monitored by their physician throughout and after pregnancy."
- Professor Fénichel went on to state, "My group and the French oocyte donation research group will now concentrate on understanding if eclampsia is linked only to Turner's syndrome or also to egg donation itself. We will also look at ways in which better monitoring during pregnancy, delivery and the immediate post-partum period in an appropriate hospital centre might improve the outcomes of pregnancy in Turner's mothers."

(New research reveals high risks associated with egg donation to women with Turner's syndrome, 03 May 2011 <u>European Society of Endocrinology</u>)

Types of egg donor

- Known (sister/friend)
- Anonymous (eg Spain, Ukraine, Denmark)
- Identifiable (eg Denmark)
- Contactable (eg UK, Sweden)
- Involved (eg US)

Egg donation (5/6) & adoption (0/6)

Male	Female
Commissioning	Commissioning
Genetic	X
Birth	Birth

Male	Female
X	X
X	X
X	X

The ideal known donor

- Under 33
- Have a child
- Have insight regarding infertility
- Calm & balanced
- Desire to help
- Supportive
- Be prepared to go through IVF

The ideal anonymous donor

- Under 33
- Have a child
- Have insight regarding infertility
- Calm & balanced
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Absolute vs relative rights of the child

- Life
- Food
- Shelter
- Love (3rd party parenting)
- Education
- Free from exploitation
- Pursuit of happiness
- To know your genetic origins (parental dilemma)

The law of unintended consequences

- Balancing rights with their consequences
- Consequences of anonymous donation no clear evidence of harm (much loved children)
- Consequences of identifiable donation will not be known for a generation or two (for the child, their family, the genetic donor & their family)
- The duties of being a parent is to make the best decision you can for your children
- Orthodoxies change

What will I tell the child?

- Counselling will help you to know what questions to ask
- To ask yourselves these question is to start to exercise that parental responsibility
- There is no "right" answer for all circumstances you have to decide what that right answer is for you (what do Swedes do?)
- There are some wonderful books for small child –
 "Mammy needed an egg"

Useful strategies

- Be proactive
- Be informed
- Manage risk
- Make a plan
- A shared problem a shared solution
- Your relationship is most important regardless of outcome

What would I do?

- Cost Consider shared risk
- Emotion Make a timeline & support each other
- Plan to fail (but hope to succeed)
- Engage with an obstetrician before conception
- Make an obstetric plan with full support (endocrinology, cardiology, other)

Hope – Future - Family

- All you can guarantee is to do your best
- Although it is always worthwhile when it succeeds, it may not work and there are no regrets if you have moved heaven & earth and failed

The pursuit of Happiness

Dr David Walsh, 24th March 2012