FERTILITY associates | a better understanding

The IVF Experience

How to help your patients survive fertility problems

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Fertility Associates

Journey to a Baby

Our aim today is to…

- Share a little about what some patients face to give you a better understanding
- Arm you with information that might help patients survive their journey
- Give you or point you to some resources that might assist

Infertility brings with it intense emotional pain

- “Give me children or else I die” Genesis Chapter 30 Verse 1
- “Grief fills the room up of my empty child, lies in his bed, walks up and down with me, puts on his pretty looks, repeats words” William Shakespeare 1564-1616

Infertility involves a series of losses

- Dreams and schemes
- Plans, goals, expectations *
- Privacy, dignity - “Only viewed from one end”
- Choice - “Drafted” don’t want to be here
- Control
- Trust and Confidence
- Femininity-fertility
- Masculinity-virility

Infertility involves a series of losses

- Assumptions
- Romance
- Spontaneous sexual relationship
  - baby making / love making
- Life on hold
- Connectedness
  - Partner
  - Friend
  - Women
  - “Pumpkin Patch men”

Infertility involves a series of losses

- Genetic relationship with past and future
- Direction, purpose
  - rite of passage
- Accomplishment
  - *'Achieve' a pregnancy*
- Feeling Understood

Effects of the losses?

Grief is the reaction to all these losses

Complex grief

- Ambiguous loss
- No ‘maps’
- No tangi or funerals
- No flowers
- Misunderstood
- Crisis

Grief is the reaction to loss

- People experiencing infertility are more inclined to be anxious and depressed,have lower self esteem, feel sadness, frustration, moodiness, disorganisation, fatigue, betrayal, hostility,guilt and be unpredictable

  (Attwood & Dobkin, 1992; Daniluk, 1997)

- Many reactions consistent with the grief of death

Grief is Normal

Important Message

Infertility causes the grief not
the other way round!

Gender differences

Woman

- Talking
- Weeping
- Shopping
- Cafes!

Man

- Silent
- Action
- Work / Sport
- Sheds!

Generalisations

- Infertility is a unique experience
  - Eldest child
  - Only child
  - Only daughter/only son
  - Big Family
  - Ethnicity

What might exacerbate the grief?

- Past experiences
  - TOP, adoption, sexual abuse,
- Age
- Limited resources
- Festivals / Media
- Duration
  - Chronic sorrow
- Lack of understanding

The dance of grief

- Two to tango
- Out of step / tune

What alleviates the grief?

- Access to accurate information - dispel the myths
- Resources
- Empathy - no reframing
- Moving at own pace – Gen Y
- Self-help organisations - Fertility New Zealand
- Support Groups for some people
- Counselling – referral to specialist
- Taken seriously – referral to specialist

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The role of the Fertility Nurse

Fertility nurses coordinate care

PATIENT

Fertility Nurse

Fertility Specialist

Embryologist

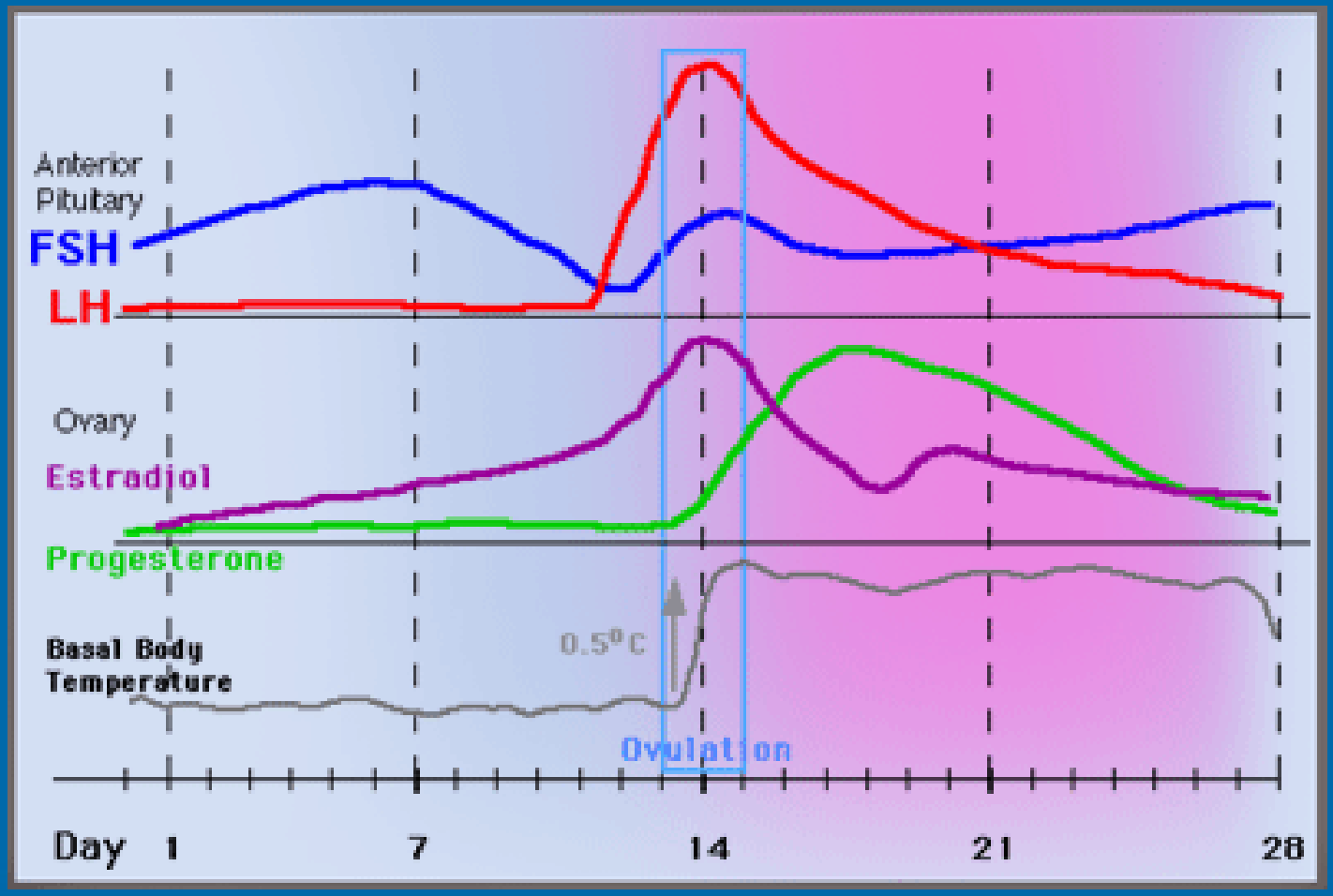
Fertility Counsellor

Fertility nurses provide Education & Support

- Advice to optimise chance of pregnancy
- Advice throughout fertility treatment journey

What patients need to know… (how you can help us)

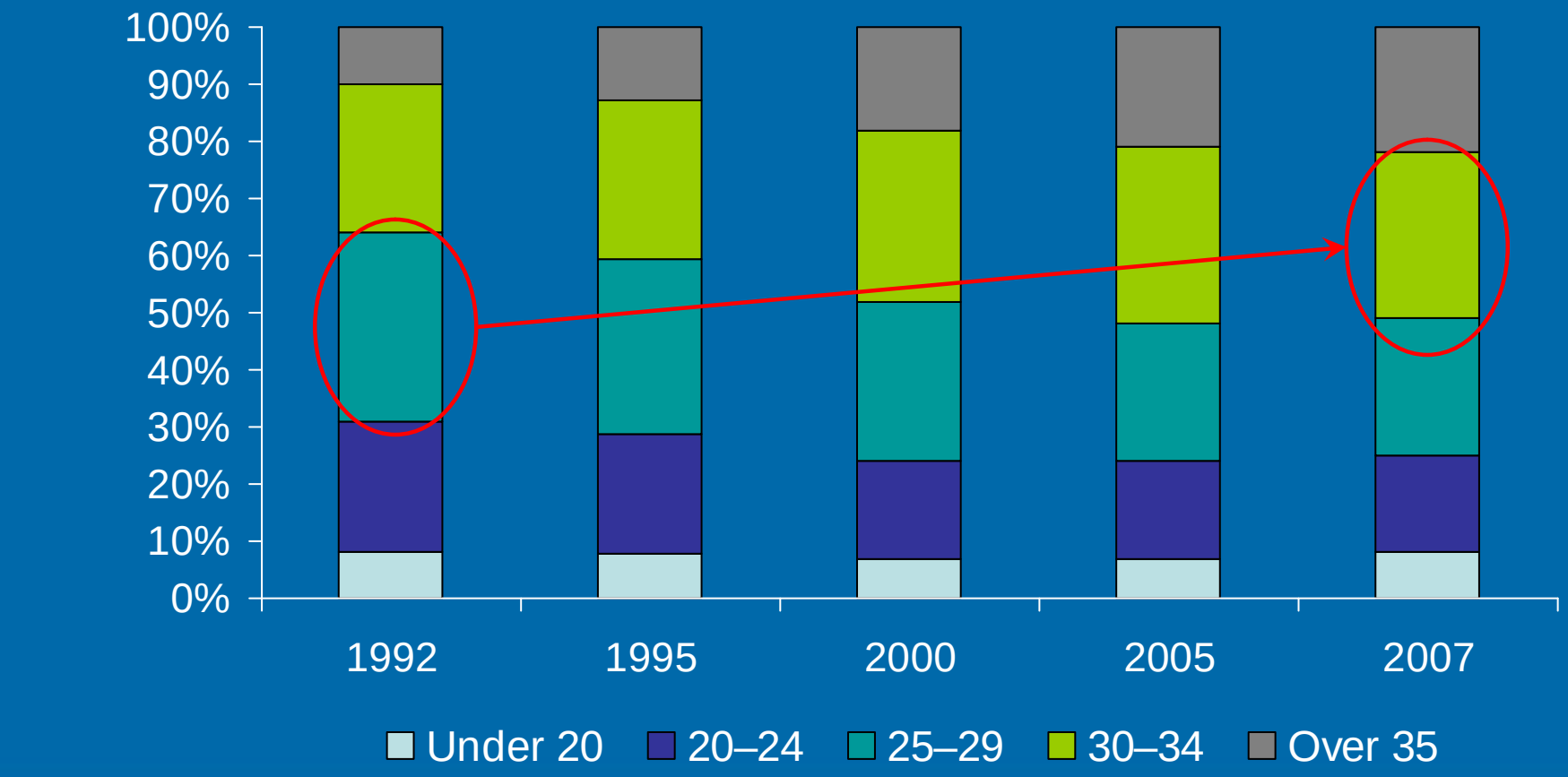
Monthly Cycle



Egg Timer

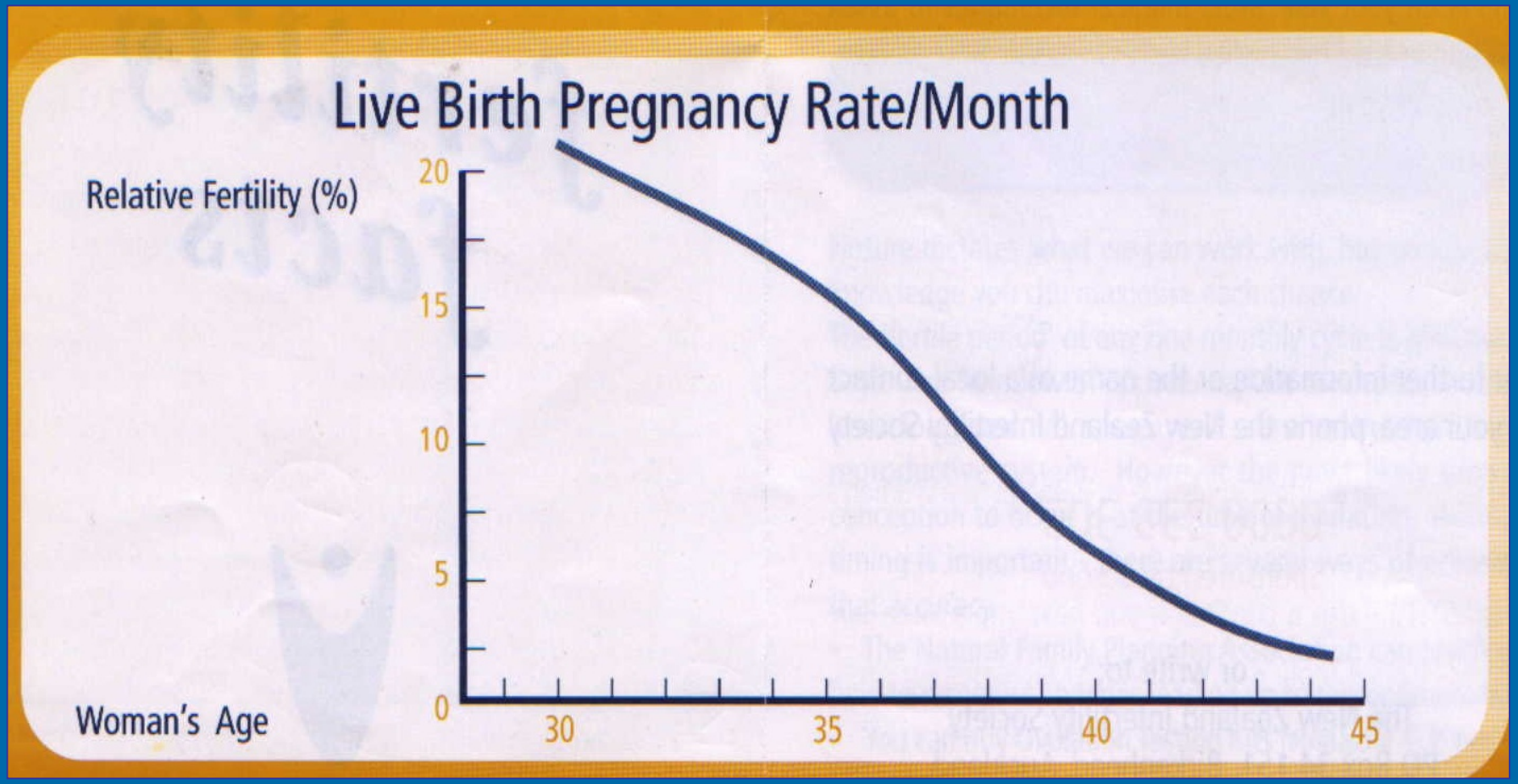
- Eggs present few weeks after conception
- 6 months gestation– 7 million eggs
- Birth – 2 million
- Puberty – few hundred thousand
- Late 30’s – 20,000
- Mid 40’s – few hundred

NZ Mothers are Aging



Source: Statistics NZ

When is it getting too late?



Causes of Infertility

Male	40%
Female	40%
Combined/unknown	20%

Causes of Infertility – Male

- Genetic
- Developmental
- High body temperature
- Physical injury
- Chemicals / hormones
- Medical
- Lifestyle factors

Causes of Infertility - Female

- Failure to ovulate
  - Age
  - Eating disorders
  - Cancer treatment
- Tubal damage
  - STD / PID
  - Previous surgery
- Endometriosis

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The journey to a Fertility Specialist

Where do patients initially look for info about their fertility problem?

Internet – 'Dr Google'	39%
GP / Specialist	37%
Friend / Family	18%

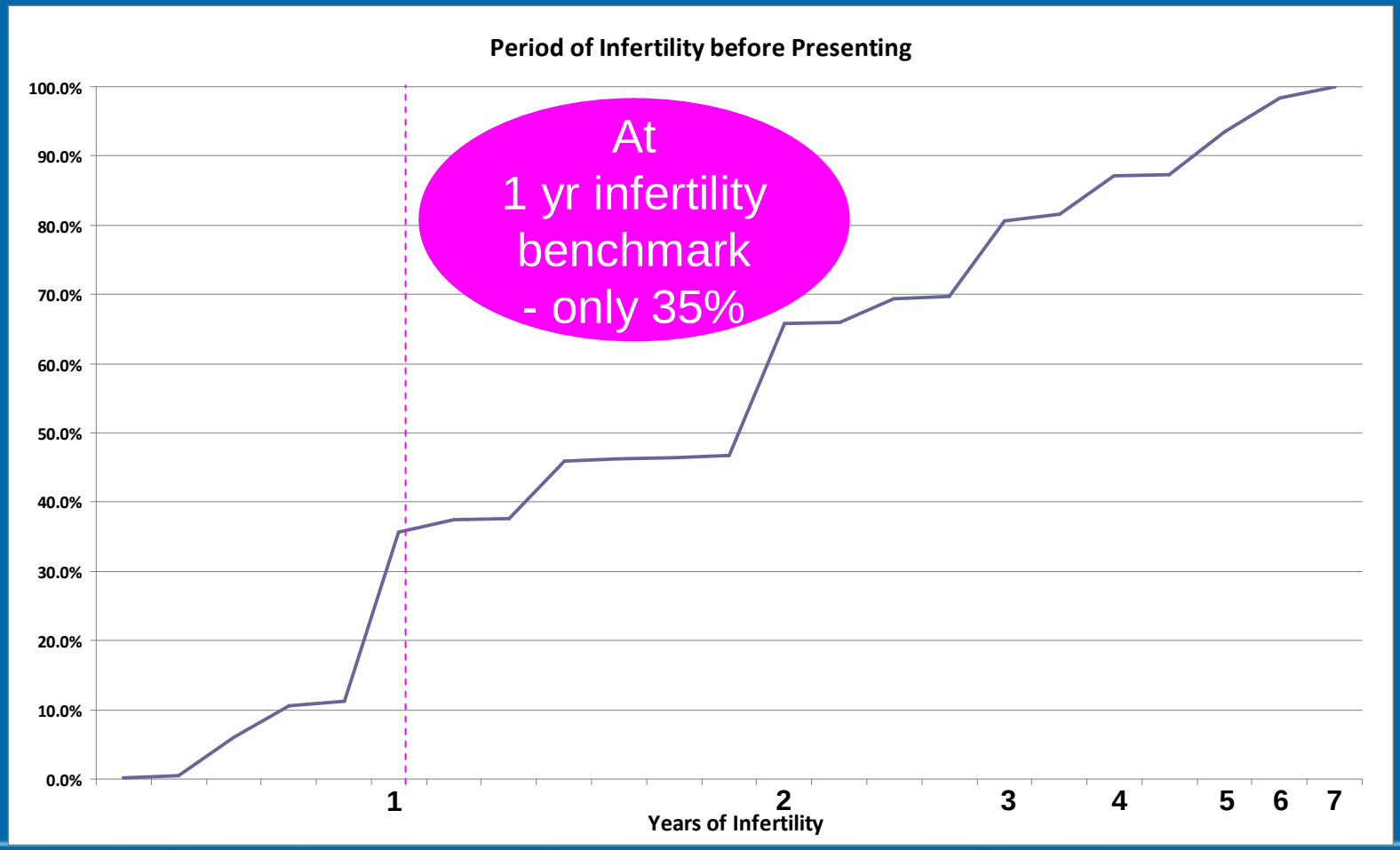
Source: Fertility Associates 2009

How are patients referred to us?

GP-referred	51%
Self-referred	34%
Specialist-referred	15%

Source: Fertility Associates 2009

How long does it take for patients to get to us?



Source: Fertility Associates 2009

When to refer?

- 1 year benchmark
  - 84% of general population will conceive in 1 year
  - 92% in 2 years
  - about half of those who don't conceive in 1 year will not do so after another year
  - Can go on public funding wait list after 1 year
- Earlier for women >35 yrs
- Earlier for women and men with known issues
- Earlier for patients with extreme anxiety

Source: National Institute for Clinical Excellence

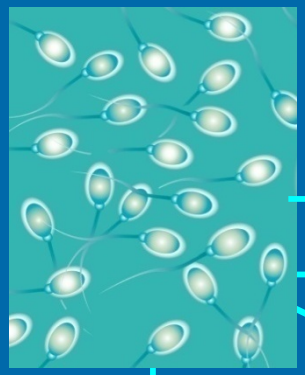
Available Tests

- AMH – Anti-Mullerian Hormone (<40 yrs)
- FSH – Follicle Stimulating Hormone (>40 yrs)
- Other hormone tests such as P4
- Semen Analysis
- Ultrasound

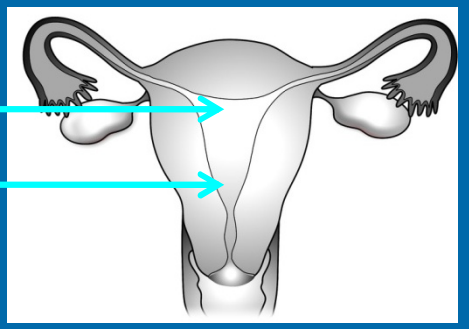
Available Treatments

- Ovulation induction - Clomiphene, FSH
- IUI - intrauterine insemination
- IVF - in vitro fertilisation
- ICSI - sperm injection
- PGD - preimplantation genetic diagnosis
- Fertility preservation – freeze eggs, sperm, tissue
- Microsurgery
- DO - donor egg
- DI - donor sperm
- DE - donor embryo
- Surrogacy

Number of sperm to fertilise an egg

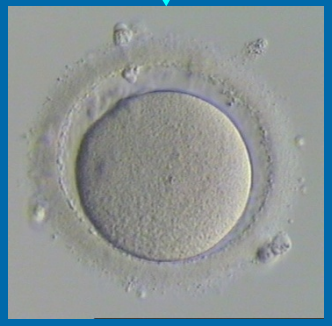


20,000,000 - Intercourse



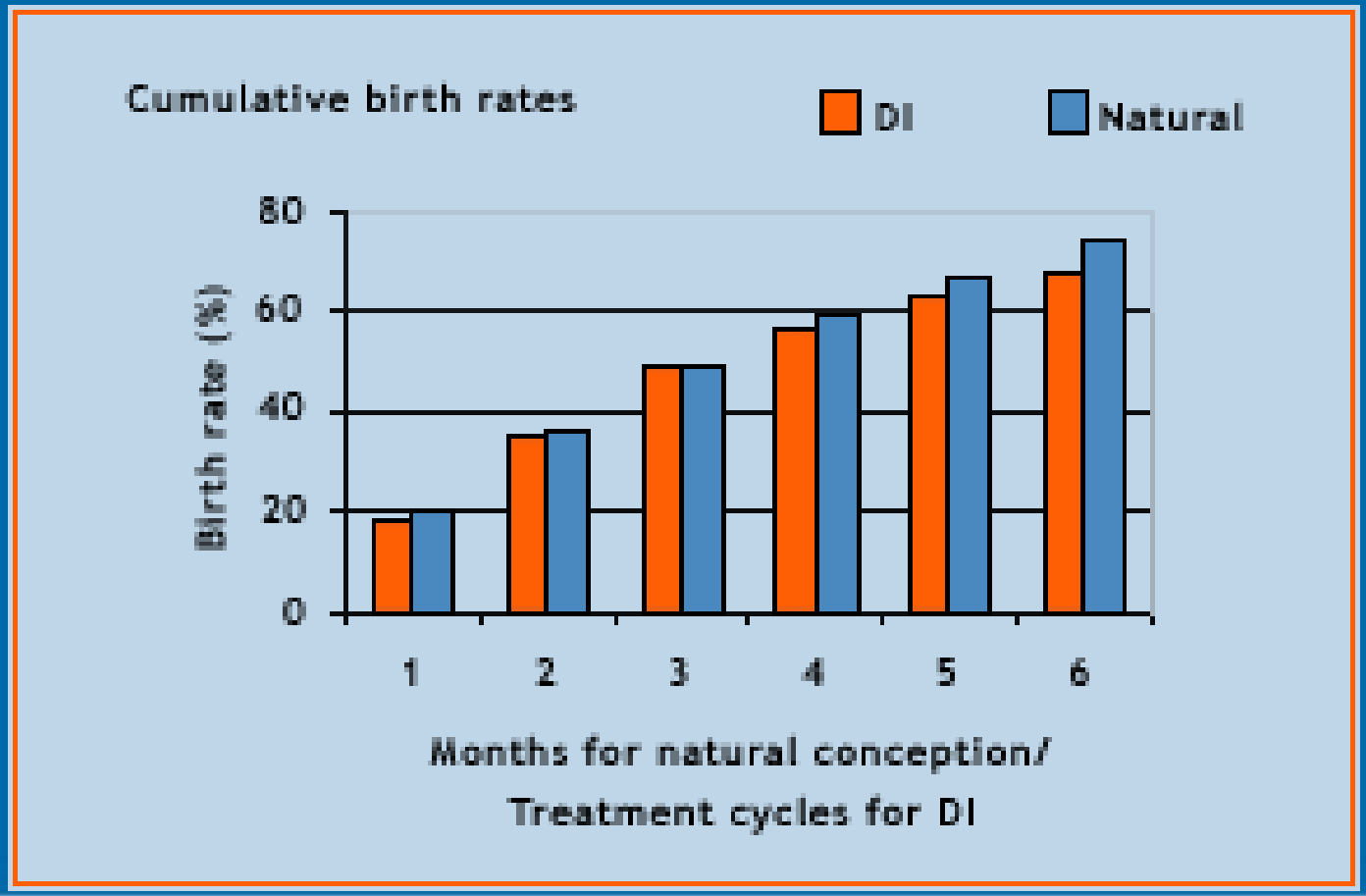
1,000,000 - IUI & DI

ICSI - 1



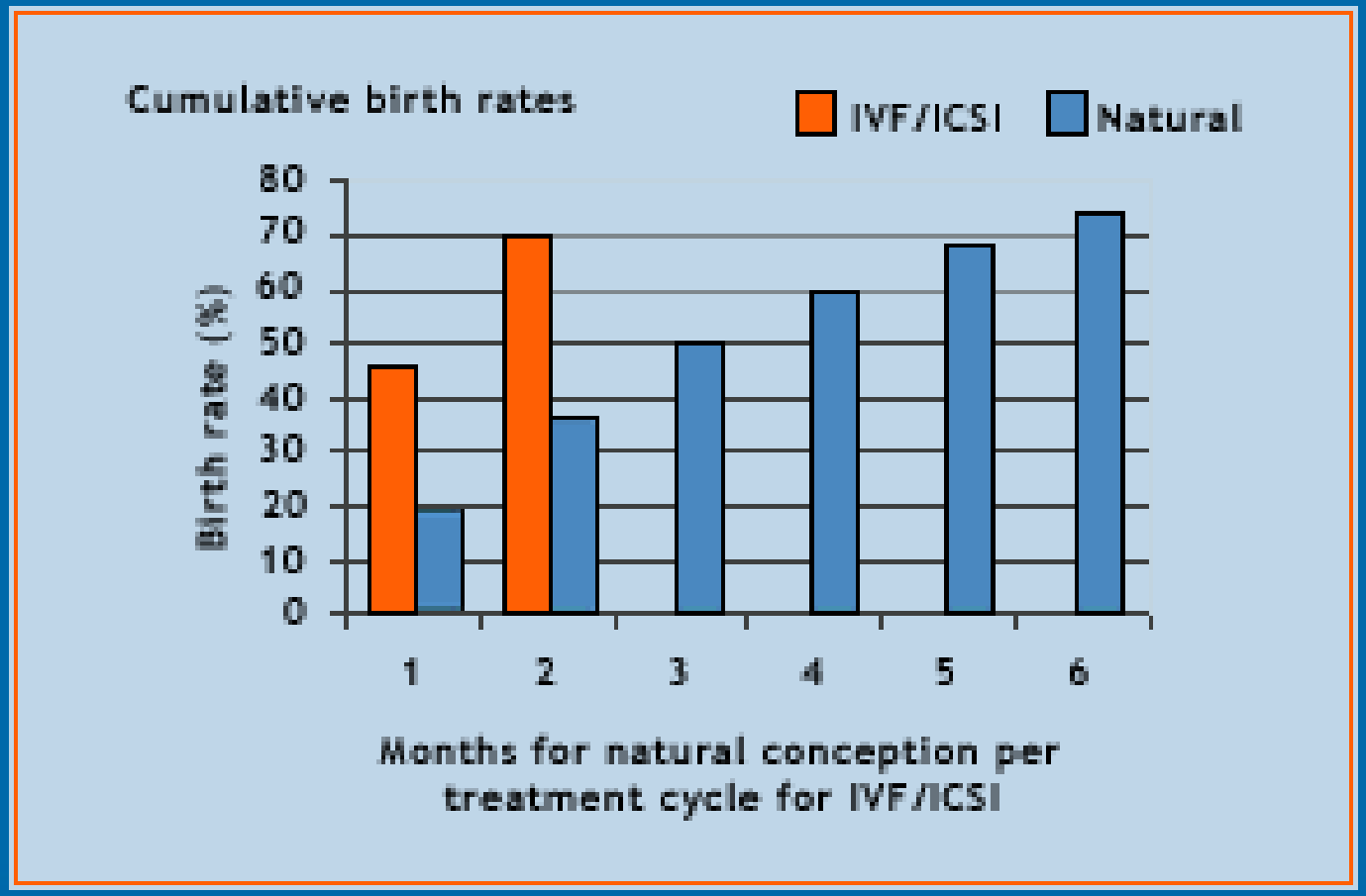
50,000 - IVF

DI success for women <37 yrs



Source: Fertility Associates

IVF/ICSI success for women <37 yrs



Source: Fertility Associates

Funding

Public Consultation
- Need GP referral
- Must meet criteria
- $0
- 2 months wait

Private Consultation
- GP or self-referral
- $175 - $240
- approx 2 weeks wait

Scoring for Public Treatment
- Female
  - under 40 yrs
  - BMI under 32
  - Non-smoker
- NZ residents
- + CPAC score

Public Treatment
- $0
- 1 month wait (IUI)
- 10 – 24 month wait (IVF + ICSI)

While waiting

Private Treatment
- approx $ 825 (IUI)
- approx $ 9545 (IVF)
- approx $11,500 (ICSI)
- approx 1 month wait

Understanding laws and regulations

Variety of laws apply

- Adoption Act 1955
- Status of Children Act
- HART Act
- Laws and regulations in other countries

HART ACT

- Part 1
  - Purpose & principles of the Act
- Part 2
  - Prohibited & restricted activities
- Part 4
  - Enforcement
- Part 3
  - Linking families & donors

PART 1: Purpose

- To control ART procedures and research to protect all individuals, particularly women and children
- To secure the benefits of defined, *established* ART procedures
- To prohibit certain procedures
- To establish an information-keeping system for informing and linking families and donors

PART 2: Prohibited activities

- The Act lists a number of prohibited activities including importing &/or possessing & use in treatment of:
  - A cloned embryo
  - A human / animal hybrid embryo
  - An embryo formed from a gamete(s) derived from a foetus
  - Genetically modified embryos or gametes
- Penalties: up to 5 years in prison &/or $200 000 fine

PART 2: Restricted activities

- **Freezing and Storage**
  - Gametes and embryos may be stored for up to 10 years
  - The Ethics Committee may give prior approval for longer storage.
  - Penalties: up to $20 000 fine

- **Commercial Supply of Gametes / Embryos / Uterus**
  - Prohibited, i.e. payment or *valuable consideration* is not allowed
  - Re-imbursement of travel expenses is OK
  - Penalties: up to 1 year in prison &/or up to $100 000 fine

PART 2: Restricted activities

- **Obtaining Gametes from Minors**
  - Donors may not be obtained from people < 16 yrs
  - Penalties: up to 1 year in prison &/or up to $100 000 fine

- **Gender Selection**
  - Gender selection is not allowed
  - However, it is a defence if it was performed to prevent or treat a genetic disease or disorder
  - Increasing the chance that an embryo will be of a particular sex is not allowed. (This includes providing patients with treatment or information with that intention.)
  - Penalties: up to 1 year in prison &/or up to $100 000 fine

PART 2: Restricted activities

- **Surrogacy**
  - Altruistic surrogacy is not illegal, but not enforceable
  - No payment or valuable consideration may be involved in surrogacy arrangements
  - ECART approval on a case-by-case basis for surrogacy involving ART
  - Penalties: up to 1 year in prison &/or up to $100 000 fine

- **Advertising not allowed for:**
  - Prohibited activities
  - *Commercial* supply of gametes or embryos
  - *Commercial* surrogacy arrangements
  - Penalties: up to 3 months in prison &/or up to $2 500 fine

Within Family Donations

- Some proposals for donation between certain family members require individual ECART approval

- Only able to do within family donation if:
  - √ Sister for sister
  - √ Brother for brother
  - √ Cousin for cousin

Prohibited

- Donor eggs may not be combined with donor sperm
  - However a female may donate eggs to her female partner
- PGD is allowed but not for sex selection

PART 3: Donors

- Provision in the Act to ensure that information and identity of donors is available to people who have been conceived with donor gametes or embryos
- If donations occurred after August 2005
- Access by parents until child 18 years old
- 18 year olds and over can access information
- Some meetings occur between donors and recipients

Voluntary Register

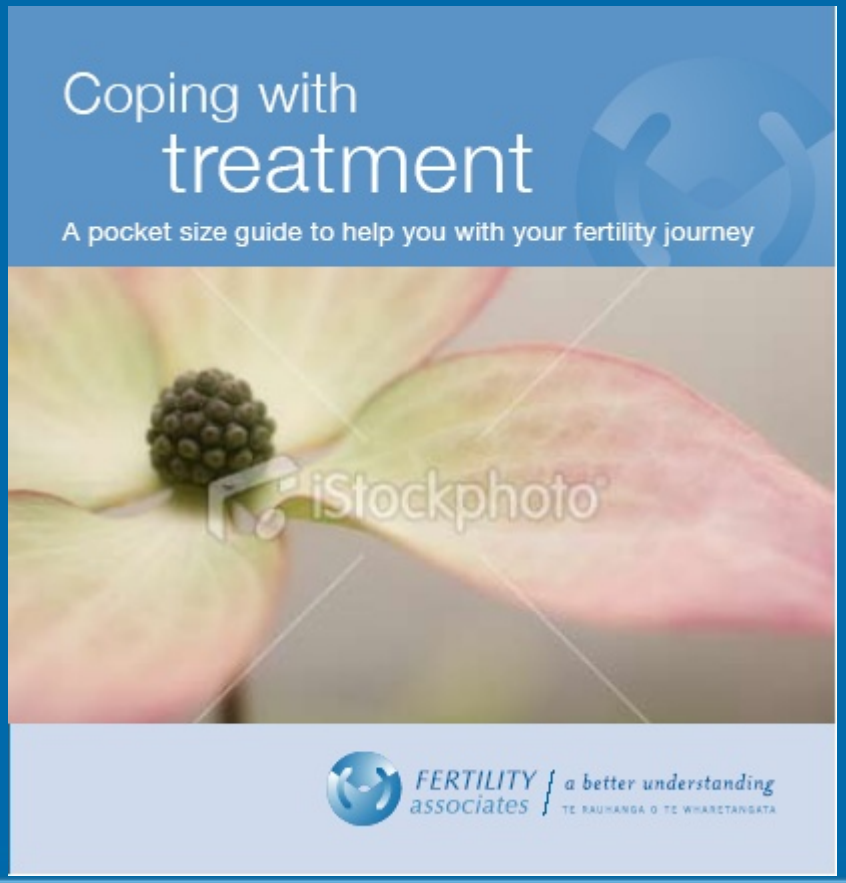
- Available for donors and PCDGs conceived from gametes donated prior to 22 August 2005
- Maintained by the Registrar-General (not by clinics)

Surrogacy

- The person giving birth is the legal parent
- Intending parents (genetic parents) must adopt child
- Individual approval from ECART

Resources

Emotional Support
Coping with Treatment brochure



available here

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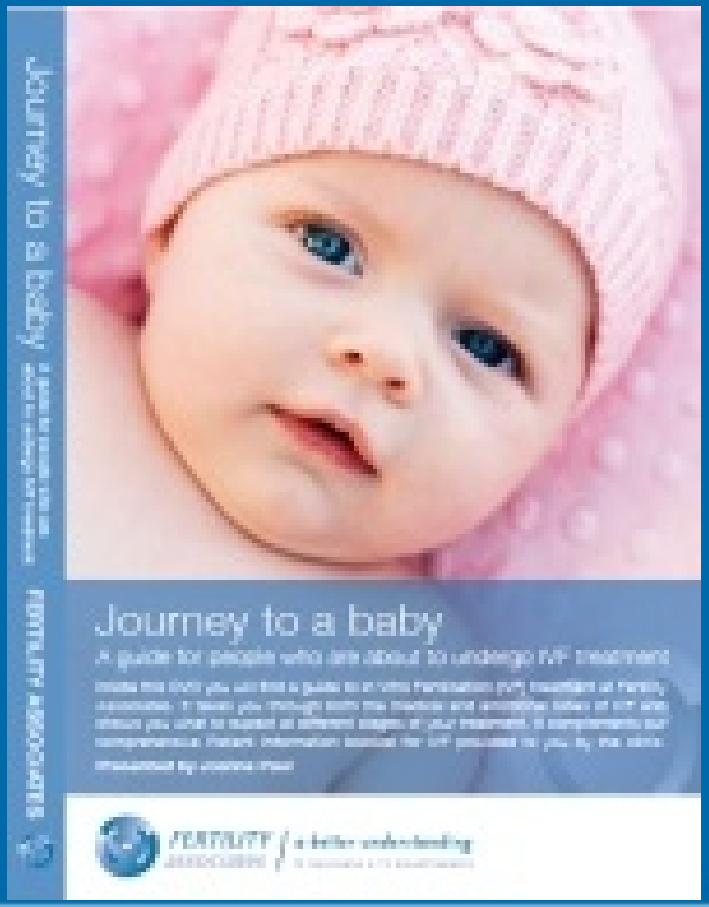
Treatment Information
Journey to a Baby DVD

available here



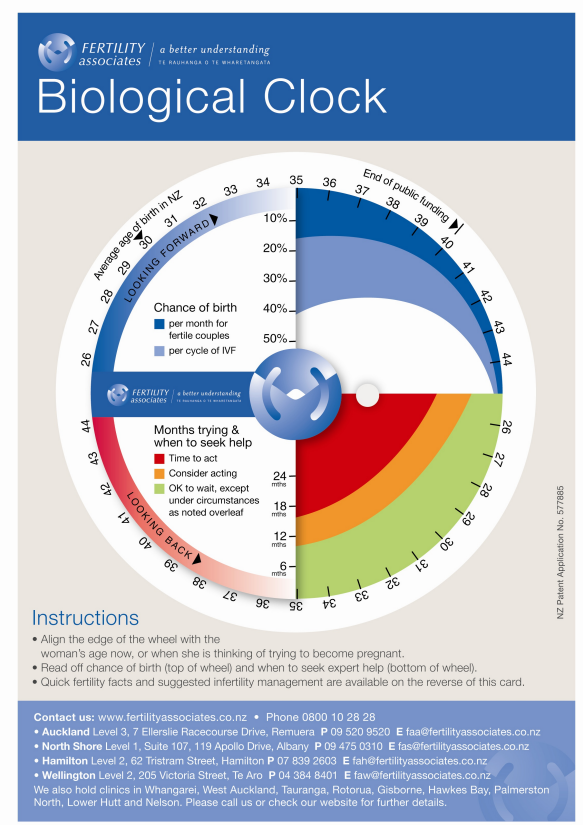
Support Organisation
Fertility New Zealand

www.fertilitynz.org.nz

available here

When to refer?
Biological Clock

from
Stand 38



www.fertilityassociates.co.nz

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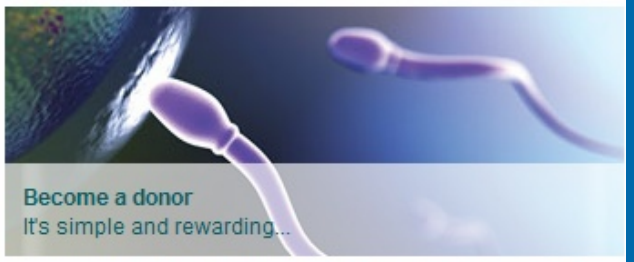
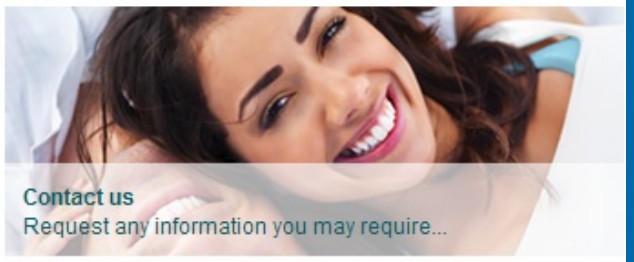




Information for GPs

Email to a Friend Print

At least 20% of people will experience some degree of difficulty in trying to conceive. That is 1 in 5 couples of reproductive age. While strictly speaking infertility is defined as the failure to conceive one after one year of regular, unprotected sex, people need advice from whenever they begin to fear something may be wrong.

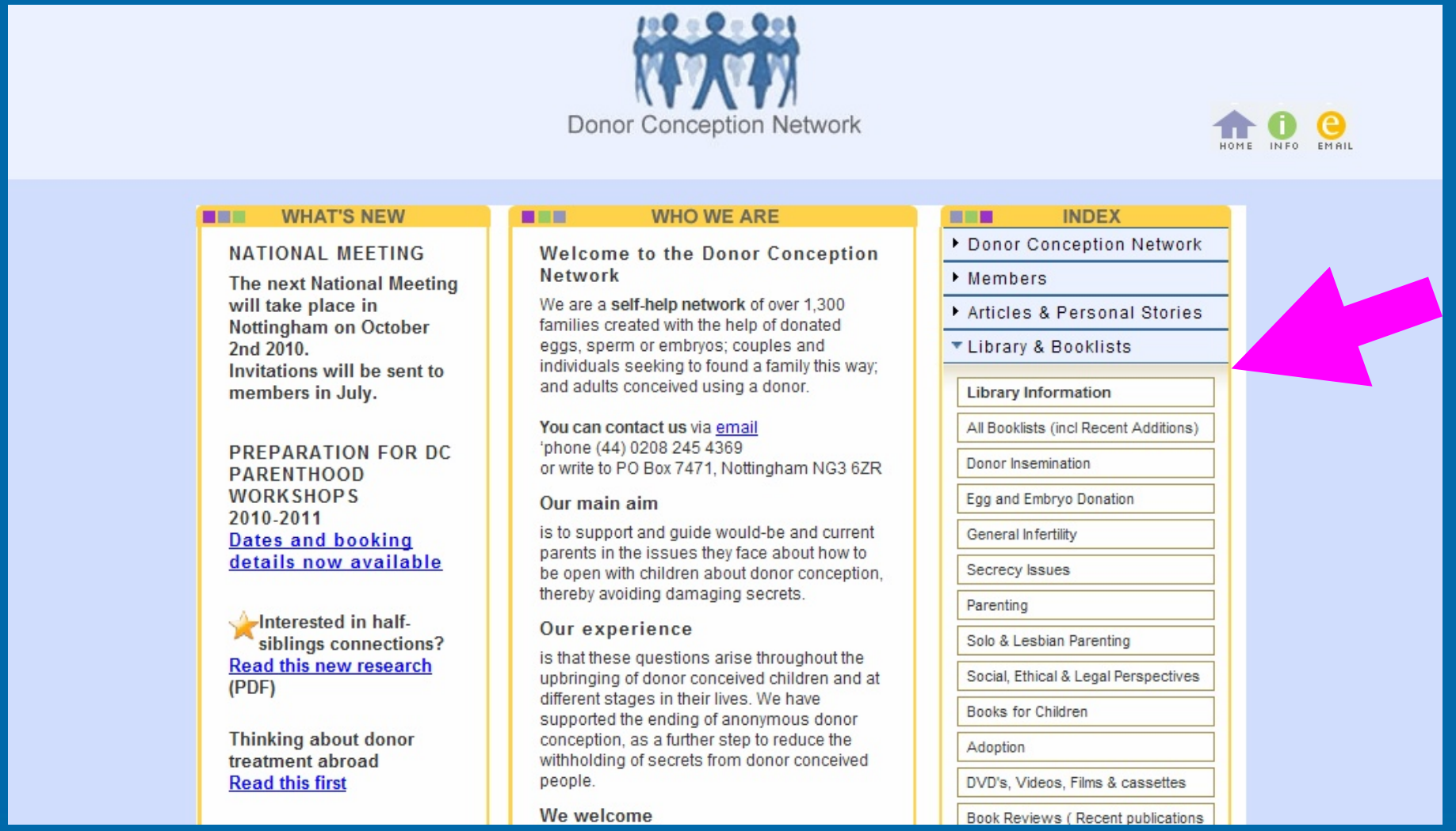
This part of the website includes summary material from our 'Quick fertility facts' and 'Suggested fertility management' checklists for GPs.

Related Links »

- Understanding your fertility
- Fertility treatments
- Fertility preservation & cancer
- Boosting your fertility

LEADERS IN FERTILITY

www.donor-conception-network.org



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www.ivf-lings.co.nz

IVF-lings

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Welcome to IVF-lings

This is an exciting new place dedicated to kiwi IVF-lings. It will explain and help you to understand how you came to be and what IVF is all about.

This is a place for you to openly ask questions and find answers to everything and anything that has ever crossed your mind about IVF. What's even better is

Why is a child born from IVF called an IVF-ling?
For more information click here...

LEADERS IN FERTILITY

How can you contribute patients' Journey to a Baby?

- Community education regarding fertility and age
- Lifestyle modification – smoking, alcohol, weight
- Information regarding ART and fertility preservation
- Information regarding public funding
- Early referral to specialist doctors
- Initial work up
- Early referral to specialist counsellors
- Management of complications (OHSS, early pregnancy issues)
- Provide ongoing support and referral for families

Thanks