

# *FINRRAGE*

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*Feminist International Network of Resistance to  
Reproductive and Genetic Engineering*



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## LOCAL NEWS

### ***MEDIA UPDATE***

#### **FERTILITY DRUGS PARALYSE WOMAN**

A Perth woman has been paralysed on her right side, rendering her without speech after a stroke (Sunday Times, Western Australia, 8 April, 1990. p.1). Doctors say she developed a severe case of ovarian stimulation syndrome which can have life-threatening effects including blood clotting. The woman had been given the hormonal drugs, not at an IVF clinic but at the Reproductive Medicine Institute at Queen Elizabeth Medical Centre. Ultrasound examinations at King Edward Memorial Hospital (KEMH) revealed more than 20 follicles containing eggs. The woman was referred to Concept private IVF Clinic at KEMH, where her follicles were punctured and three replaced for fertilization via the GIFT technique on March 18. Five days later her stomach swelled the next day she was admitted to hospital. On March 25 the woman experienced a brain thrombosis. She was transferred to the Charles Gardiner Hospital where she spent five days in intensive care. Sandy Webb, Health Department co-ordinator on Reproductive Technology, in response to this tragedy commented that that people are concerned about the use of superovulation drugs more broadly than in IVF clinics. She said that within IVF clinics the use of these drugs is usually closely monitored but this isn't necessarily the case when they are used for infertility treatment which doesn't involve IVF. Reverend Colin Honey, bioethicist, said "It sounds as though things people have been saying about not harvesting so many eggs and not hyperstimulating women are coming home to roost." He also expressed concern regarding "the drive for pregnancy at any price." Canberra bioethicist Nicholas Tonti-Fillippini is quoted saying, "There's always that sort of risk with the fertility drugs, they are well known to drug companies. When you get something as dramatic as this, it highlights the risks. Women need to be told that hormone treatments have these risks."

\*Two Perth women have died in recent years subsequent to procedures performed at Concept Clinic. An inquest into the death of the second woman returned a finding of "therapeutic misadventure", due to an accident with anaesthetic equipment.

was first reported in the 1988 report on IVF issued by the West Australian Department of Health. According to Sandy Webb, co-ordinator of Reproductive Technology for the WA Department of Health, WA is the only state in which legislation does not prohibit the sale of human tissue. Nick Tonti-Fillipini, bioethicist and former director of the Bioethics Centre at St. Vincent's Hospital in Melbourne said: "Women who want to be sterilized are advanced up the list if they are willing to donate eggs. Such women must go on superovulation drugs prior to their sterilization." Dr. Stephen Steigard, council member for the Fertility Society of Australia (FSA) said that the practice of discounting \$50 for each ovum donated was against the ethical guidelines of the National Health and Medical Research Council. PIVET's scientific director, Dr. Jim Cummins, said that such discounting was occurring at PIVET and they were unconcerned by the new WA legislation. However, prior to the publication of the April edition of the Medical Observer, Dr. Cummins wished to retract his statement and claimed that PIVET no longer practised discounting for ovum donation.

#### **RADIOGRAPHER ACQUITTED ON RAPE CHARGES.**

In the March 1990 issue of this newsletter we reported that a Melbourne radiographer, Vincenzo Mobilio was given a suspended sentence last February for raping three women with an ultrasound probe. It was alleged that Mobilio had raped eight women with an ultrasound probe which is normally used for external examinations of the pelvis. Following an appeal in the Full Supreme Court, Mobilio has been acquitted of the charges (R. West, The Age, 8/6/90). The appeal court judges said that the women had consented to the insertion of the probe into their vaginas. The consent was valid according to the judges, regardless of whether it was done for Mobilio's sexual gratification and of whether the women believed it was done for a medical diagnostic purpose. Two of the three women whose treatment led to the original conviction said that the probe had been inserted and withdrawn on more than one occasion, and

## NATIONAL BIOETHICS CONSULTATIVE COMMITTEE RELEASES FINAL REPORT ON SURROGACY.

The National Bioethics Consultative Committee (NBCC) released its final report on surrogacy in June this year. As reported in the March 1990 issue of the *FINRRAGE* (Australia) newsletter, the draft report was issued in September 1989 and was then open to submissions from the public. The recommendations of the final report are essentially the same as those put forward in the draft report, i.e., that surrogacy should not be prohibited and that its practice should be controlled by uniform legislation. The NBCC discussed surrogacy as a legitimate means of alleviating infertility, and based its discussion on the principle of qualified personal autonomy, i.e., that any person should be free to make their own life decisions as long as it does not involve harm to others, and therefore a "surrogate" mother has the right to freely make decisions about the use of her own body, and that couples have the right to seek a child through a surrogacy arrangement, as long as "surrogate" mothers and children born through surrogacy arrangements are not used merely for the ends or purposes of others. As *FINRRAGE* stressed in its response to the NBCC draft report, surrogacy arrangements are inherently exploitative of women and children, and the ill-considered recommendations of the NBCC legitimizes and potentially institutionalizes this exploitation.

Notably, the final report had strong dissenting statements from two of the 13-member NBCC. Sister Regis Dunne, director of the provincial bioethics centre for the Queensland Catholic dioceses, said that she was unable to endorse the report because of the treatment of women and children as commodities in surrogacy arrangements, the impact of legalized surrogacy arrangements on public policy, and the application of the principle of personal autonomy (The Sunday Age, 24/6/90). The principle she wrote "pays small regard to common interest, is unevenly applied to the woman who bears the child and mainly supports the case of the commissioning couple." She also pointed out that there was no reason why IVF-assisted surrogacy arrangements would have a higher success rate than the current overall success rate of 10%. "If surrogacy is acknowledged, tolerated and legally established in Australia, we provide yet another means of exploiting the poor." She perceives "surrogacy as a further movement towards the commodification of life and towards treating people, and parts of people - organs, sperm, eggs, embryos, as commodities in a consumer

mother-child bond "Knowing you were conceived deliberately to be given away could be ..... a painful reality for the child born," Ms Dietrich said. The surrogate mother could not know before she conceived and bore a child how she would feel about relinquishing it. She also commented (The Age 27/6/90) that the pain of infertility should not be dismissed. "All of us would probably be tempted (to consider surrogacy) if we couldn't have a child. You'd want to close your eyes a bit. The aim should be not to criticize these people who are tempted but to criticize the doctors and public policy that should have a broader perspective."

Astoundingly, of the 142 submissions received to the draft report, 58% disagreed with the preferred option of the NBCC that surrogacy be allowed but controlled. Only one submission supported uncontrolled surrogacy (The Sunday Age, 24/6/90). However, this sway of community opinion did not influence the NBCC in its final deliberations. Why bother then to canvas community opinion? *FINRRAGE* has also noted that the NBCC was divided between options 3 and 4 listed in the final report, which are ethically diametrically opposed. Option 3 said that there was 'nothing inherently immoral or anti-social in surrogacy arrangements, whereas option 4 said that surrogacy is undesirable in that there is real risk that harm will be caused as a result of such arrangements. In fact, the NBCC only reached consensus on appropriate and necessary uniform legislation, not on the social desirability of surrogacy. There have been nine other reports on surrogacy published thus far in Australia, and none, except the NBCC's report, has encouraged surrogacy.

*FINRRAGE* also received comment (The Age 27/6/90) on the invoking of the principle of qualified personal autonomy, at best being an ideal. "In reality, our society does not grant women equal status, power or personal autonomy.....This principle ignores the power imbalance inherent in any surrogacy arrangement." Robyn Rowland commented "Mothering has always been experienced by women in terms of relationships, whether that be in terms of that be in terms of gestation and birth, or social motherhood (The Sunday Age 24/6/90). She argued that there was no such thing as "genetic motherhood" because motherhood is a relationship rather than a status position. Dr. Rowland also said "I am surprised that no account of the public costs has been incorporated into this draft report, but

was no evidence that the breaking of the bond between mother and child caused psychological scarring.

Marie Meggitt, of the Association of Relinquishing Mothers (ARMS) argued that surrogacy should be prohibited in the interests of the child and the relinquishing mother (The Sunday Age, "Surrogacy Diminishes All of Us", 24/6/90). She said that the use of medical technology to facilitate surrogacy arrangements compartmentalizes motherhood and essentially diminishes it. "Now we will have a genetic mother, a gestational mother and a social mother.....The proponents of IVF/surrogacy would relegate birth mothers to the status of incubator. Compartmentalizing motherhood makes it much more difficult for women to claim the status of mother. It enables the medical profession to dismiss the experiences of any one of these mothers, by suggesting that she was not the 'real' mother anyway. Ms Meggitt quoted the comments of Lori Jean, an American woman who bore a child for her sister: "The baby I promised was theoretical: the baby I gave birth to was real. I thought I could give my sister her very own baby, but I gave her my very own baby."

## LOBBY BY IVF DOCTOR TO APPROVE IVF/SURROGACY IN VICTORIA.

Melbourne IVF doctor Prof. John Leeton has presented a submission to the Victorian Standing Review and Advisory Committee on Infertility (SRACI) to approve IVF/surrogacy arrangements for seven women who want to bear children for their sisters or best friends (Sunday Herald, 17/6/90). He claims that his submission hinges on the lack of any definition of infertility in the Victorian (Medical Procedures) Infertility Act. If potential "surrogate" mothers can be defined as infertile, then they would be eligible to participate in the IVF procedure. Most of the seven women say they are prepared to undergo voluntary sterilization if it would help their sister or friend to have a child. Professor Leeton claims that the risk of the birth mother bonding to the child would be minimised in cases of IVF/surrogacy arrangements where the pregnant woman is carrying a child that is genetically unrelated to her (Sunday Age, 1/7/90). Leeton advocates that the existing Victorian legislation be changed "to allow infertile couples the only chance of conceiving their own child."

## MEDICARE CHANGES TO IVF AND GIFT PROCEDURES.

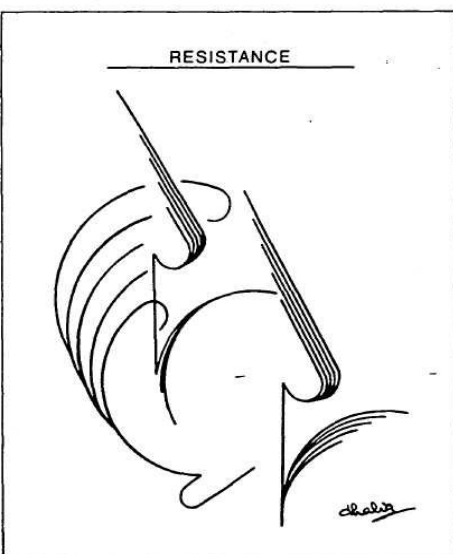
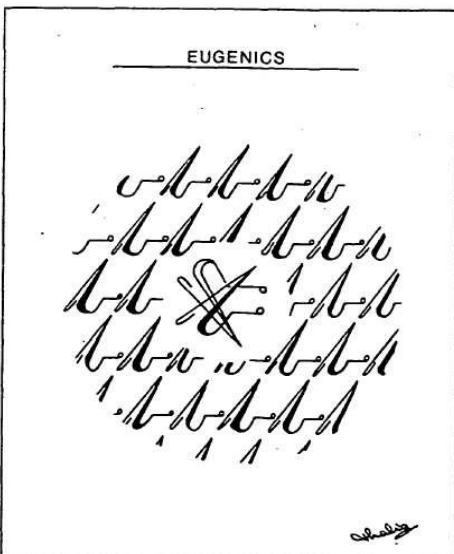
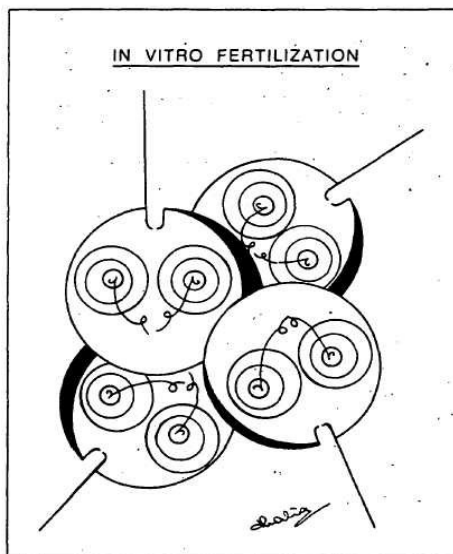
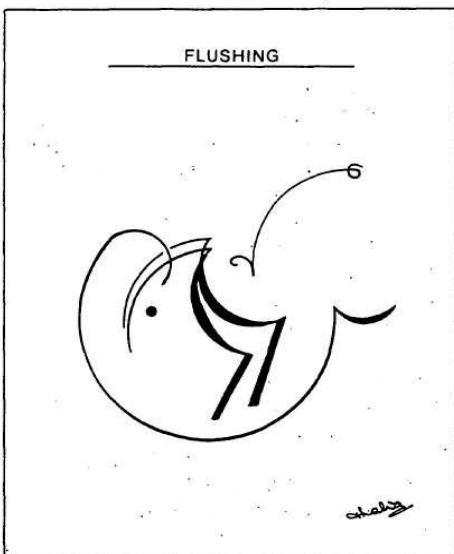
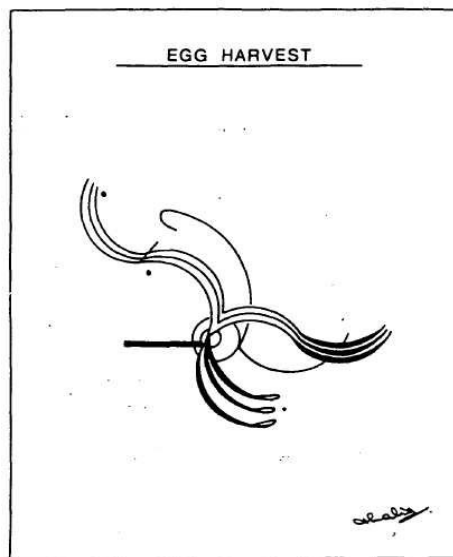
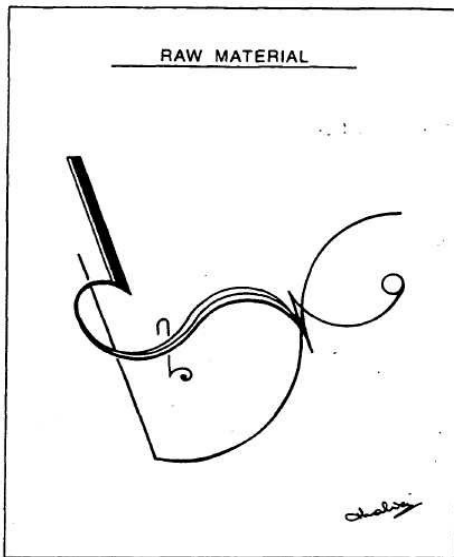
It was announced in the Federal Budget that new comprehensive Medicare benefits will be provided for reproductive technologies such as IVF, GIFT (gamete intrafallopian transfer) and similar procedures. A news release from the Minister for Community Services and Health, Mr Brian Howe said "Under the new arrangements, different kinds of treatment cycles will be covered by Medicare items. Each of these items will include a number of services required during the treatment cycle, for example, pathology and ultrasound. Benefits will also be provided for embryology services and treatment counselling, which were not previously covered." Benefits for treatment cycles involving hormone stimulation and monitoring will be limited to six times during a patient's lifetime. Mr Howe said, "This takes into account evidence that about 90 per cent of women who become pregnant through IVF do so in four cycles or less. Couples won't be prevented from having more treatment involving hormone stimulation, but they won't get a rebate after six cycles." There would be no such limitations on other new items, e.g., IVF or GIFT

acknowledge that while these technologies are still developing, they are no longer purely experimental but are accepted medical procedures for the alleviation of infertility," Mr Howe said. The Commonwealth government will spend \$6 million in the next full year on the new benefits.

Note: Community Services and Health issued a report in 1988 "IVF Funding in Australia" which estimated the average live birth rate at 8.8% per treatment cycle. The unproblematic birth rate was put at 4.8%. In that report, it was suggested that IVF was an experimental procedure which should, not necessarily attract Medicare rebates, and that the whole question of success rates in relation to IVF was confused and obscure. For example, pregnancy rates do not mean birth rates. Concern was also expressed about the lack of information about the long-term safety of some of the drugs and hormones used in IVF. The 1990 Federal Budget announcement appears to reflect a change in government policy, since it is now said that IVF is an accepted part of the treatment of infertility. Success rates are still modest to say the least. The latest

million, and the subtotal cost of this through Medicare was \$17 million. It must be assumed that the \$6 million is an extra sum, possibly making the

amount spent on IVF through Medicare around \$25 million (given that the 1987 figure would have risen).



Postcards available from FINRRAGE \$1-20 each or \$6-00 per set

# ARTICLES

## ISSUES (IN)FERTILITY - A SELF-HELP GROUP

ISSUES (IN) FERTILITY<sup>1</sup> is a self-experience group for women with fertility problems who are seeking alternatives to reproductive technology programs. The Perth-based group was set up in September 1989 when eight women, who had decided not to go on (or continue with) IVF<sup>2</sup> came together to share experiences, information and options. Founding member Geraldine Stevens talks about the group, how and why it was established, and the positive changes experienced in the lives of the women involved.

Until Issues (In) Fertility, there was nowhere to go and no support for women like myself who said no to reproductive technology programs. IVF consumer groups and an independent support group for infertile couples were mainly interested in supporting women on the IVF program and, as such, were not open to exploring the issues or alternatives. The argument was: If you want a child badly enough, you'll do anything - otherwise, you can't really be serious. But I was not prepared to have a child at any cost. More than anything else, I wanted to restore my health and well-being.

I was also angry that "advances" in reproductive technology and genetic engineering were occurring in the name of "desperate infertile couples", yet nobody had asked what our needs were. Slick public relations and the euphoric media surrounding IVF claimed "Women want it". I felt there must be others who did not want dangerous experimentation on women or genetic manipulations, so I decided to ask women exactly what they did want.

Notices were sent to The Family Planning Association, women's health and information centres and existing support groups and I was interviewed on radio and by the print media. Interested women were asked to take part in a study which aimed to:

1. Look at the process by which women come to make active choices to resist or not use particular technologies.
2. Identify the problems and needs of women for whom IVF is not an option.
3. Bring interested participants together for a

area. However, most were in favour of a 24 hour, toll free telephone information and counselling service. Those concerned with the well-being of women with fertility problems should make this a priority in their work.

Mostly, the women who eventually came together to form Issues (In) Fertility came by word of mouth. Many were involved at some level in the healing professions, conventional or natural therapies. From the outset they were opposed to high-technology, drug-based medicine and in favour of holistic healing. Because of this, the group has a strong focus on women's healing and spirituality.

The three major findings of this study and all the discussions which followed (confirming the earlier works of FINRRAGE) are:

1. The multiplicity of women's experiences with fertility problems, the diversity of women's lives and the need for a broad range of options.
2. The medical abuse of expertise including coercive pressures for women to go on IVF, often as a first and only option.
3. The institutionalisation of motherhood is so strong that women are not being listened to. Their needs and desires are of no consequence and the women themselves receive little care or respect.

For women in this group, the unmet desire for a child or a fertility problem is experienced as a process deeply intergrated with, and shaped by, the whole of our life as a woman. Issues (In) Fertility is therefore interested in the personal, bodily, emotional, psychic and spiritual dimensions of this experience which intermesh with our relationships and with wider social processes.

The medical focus on infertility as a biological state, "solved" (at any cost) by a pregnancy, is rejected. Not only because the focus is too narrow and unable to deal with the complexity of issues involved but because it does nothing to address the needs of, for example: girls and adolescents with fertility problems; women who don't want a/another child or who are ambivalent about children; menopausal women experiencing fertility loss; women with religious, spiritual or other

interested in empowering women to take control and make active choices about their lives and their treatment as part of the healing and resolution process. When women are no longer “passive victims” of medical “experts”, (in)fertility becomes a positive learning experience.

An important aim of the group is to support women in coming to terms with their unmet desire for a child/fertility problem and to resolve other ways of living happily. This involves the opportunity to examine, in a supportive environment, what it means personally to be a woman without children in our society.

This is not something that can happen over night, but it is part of an on-going process that requires support. But once the process of resolution begins, the often-desperate compulsion/coercion some women experience to try every avenue available to them can be alleviated. In so doing, a woman will then be more open to exploring the alternatives. For members of ISSUES these include: other ways of having children in one's life - including various options for social parenting; other ways of living happily - including options for career, study, being creative, joyful and attached to the world in ways which do not involve children; and alternative treatments - including natural therapies, counselling and spiritual healing and/or conception.

It is important for women to realize that saying no to IVF does not mean giving up or being childless. There are many ways of making children a part of your life as well as being positively child-free. To illustrate these points the following anecdotes provide examples of some of the ways women have chosen to live their lives differently.

Michelle had suffered from severe endometriosis affecting her uterus, fallopian tubes, bowel and bladder and was in constant and debilitating pain when she contacted Issues (In) Fertility. Her gynaecologist had booked her for a hysterectomy after all else had failed. We were able to provide her with details of a homeopath reputed to have had success in treating this type of problem. Michelle visited the homeopath in desperation and with little hope. One month later she telephoned to say she was experiencing her first day free of drugs and pain in years. She expected a total cure within three months and hoped to conceive within the year. Now that she was free of pain and fatigue, she had the time and energy to explore other options and

hormonal pump. Jane did not want biological children, but wanted to recover her health and then do social parenting. In the group we asked Jane what had happened five years ago. A man with whom she had wanted a child did not want to have children. The relationship broke down and Jane had a breakdown. A few weeks after this session Jane began to menstruate. (A few women have noticed increases in mucous and menstrual flow since the group began meeting.) Jane is now a foster parent.

Dhenu found that her experience of living in a household with children only increased her desire for a child of her own and has since decided to re-channel her energy for nurturing a child into nurturing women. She is now involved with a group of “women healing women” who promote conscious conception. Amongst other things, the women are interested in exploring the psychic and emotion connections and the barriers to conception. For example: unresolved grief over a past abortion, miscarriage, relationship or other loss; psychological factors from birth trauma or early childhood; unfocused anger, or the way in which rape and incest survivors, in particular, experience invasive reproductive technologies as a violation or sexual assault.

Lauren, with the help of the group, realised that her desire to have another child was not as strong as her desire to please her husband and daughter and that if she didn't have another child all of them could cope. She is now exploring other ways of being creative and nurturing and wants to give some of that energy to women. Women, she says, are always giving so much to everybody else. Lauren has recently decided to speak out publicly about her experiences on IVF, to warn other women about the dangers and the risks.

Punya used positive visualisation and lots of meditation to heal her blocked fallopian tube. She had some success with a partial healing of the tube, but warns that women contemplating this method should do so under expert guidance and use contraception during the healing phase as the risk of ectopic pregnancy is increased during this time. Punya has since come to terms with her fertility loss and recently began fostering a baby on a long-term arrangement.

After discussions with a network of supporting mothers, I became involved in shared community



IVF. But the group is not for everybody. Some have found that coming to meetings raises too many negative feelings - they just want to get on with their lives. But knowing that we are there and that they are not alone is helpful. Ideally, we would like to expand our services beyond self-help to provide information, resources, counselling and advocacy for women.

Until now, we have deliberately kept a low profile as we supported one another. Now we are ready to open the group to others and to share the skills information and benefits we have gained.

In January, we were given a grant by the West Australian Government's Women's Trust and have used the money to fund a self-experience workshop for women with fertility problems in June. Participants explored alternatives to reproductive technology after hearing other women's stories. They experienced the benefits of sharing in a self-help/experience group and learned how to set up their own support group. Emphasis was given to empowering women.

Giving the women the opportunity to share their experiences with others in the same situation, to express their feelings and examine their own desires for a child; most importantly, just listening to women may be the biggest contribution and catalyst we can make to the well-being of women with fertility problems.

**For information, contact Issues (In) Fertility, Multicultural Women's Health Centre, 114 South Street, Freemantle, 6160, WA; or telephone W.J.S.H. (Western Institute of Self Help) on (09) 383 3188.**

1. Lindsay Napier first used the term (in) fertility to overcome the division of women into "fertile" and "infertile" in "Infertility: Women Speak Out About their Experiences of Reproductive Technology", ed. R. Klein, Pandora, London 1989, pp 188-197.

2. IVF will be used to represent the entire range of new reproductive technologies including in vitro fertilization (IVF), embryo transfer (ET) and tubal transfers such as gamete intrafallopian tube transfer (GIFT), etc..

## IVF BABIES - PAY ON DELIVERY.

On May 11, 1990, CONCEPT FERTILITY CENTRE, formerly the AVRO IVF Unit in Perth, announced its decision to, "break with tradition and offer IVF and related treatments on the basis of a fee being charged *only upon a successful outcome i.e. your baby being born.*" Unfortunately this economic inducement also breaks with medical ethics and proposed legislative prohibitions contained within the Reproductive Technology Bill, to go before the Western Australian Parliament later this year. Under the Act, no economic inducements for clients to undergo treatments or experimental research will be permitted.

Prospective participants will have the option of free treatment cycles and payment of \$400 - only in the event of a baby being born, or, paying the usual \$1200 - \$1400 per treatment cycle. To be eligible clients must have had two or more treatment cycles or one treatment cycle more than eighteen months ago. In other words, the offer only applies to women who have already dropped out of IVF treatment, or those about to. It is not available to women just commencing or considering IVF and related treatments for the first time.

Moreover the \$1200 - \$1400 saving on each unsuccessful treatment cycle refers only to out-of-pocket expenses after all government and health insurance rebates. Our enquiries revealed that uninsured clients would still be paying about \$700 for each treatment cycle, in addition to the \$4000 due in the event of 'success'. (In Perth private insurance companies will only pay out on IVF and related treatments after a five year qualifying period.)

Concept claims that each treatment has a 1 in 7 chance of success, but stresses: "Your best opportunity for a successful outcome depends upon your acceptance that you need a number of attempts." When we telephoned the clinic we were told that you really need about five attempts to optimise the probability of success. After the fifth attempt Dr. Swann said, the statistics showed the success rate dropped off markedly. He also offered the information that most women included in the success rates had conceived before - either by assisted or non-assisted conception.



uninsured) for a baby. The reality is that those who do have children will be paying for those who don't. In purely economic terms, the uninsured would have to undergo seven treatment cycles (not including the treatments prior to the new scheme) before making a saving on one treatment cycle, in the event of 'success'. Those with health insurance would need **four** extra treatment cycles, before realising any monetary benefits.

This 'opportunity' is a highly polished marketing exercise which will increase coercive pressures on women to undergo "treatments", by offering an economic incentive. No-where are the other costs to the women (i.e. the dangers of the technique, the effects of the drugs on themselves and any children born, the risks of anaesthesia and surgery, the emotional and psychic stresses) considered.

Already a support group in Perth has been involved in counselling a woman seriously disturbed by this offer, just as she was coming to terms with her decision to discontinue IVF. Many other women must be experiencing similar emotional upheaval after receiving their letter from CONCEPT.

Once again practitioners of reproductive technology have shown themselves to be more interested in sophisticated and misleading sales pitches, than in the interests of those whom they are supposedly helping.

*Geraldine Stevens, Western Australia.*

## 12th National Homebirth Conference

**Melbourne, July 12th-15th 1991**

### "Homebirth Reborn"

#### **CALL FOR PAPERS**

All those interested in presenting papers or workshops particularly focussing on:

New initiatives in homebirth  
Promoting change in community attitudes  
Making homebirth accessible

please send topic outlines to:

## SEMINAR REPORT

On April 2nd, 1990 Monash Medical Centre held a public seminar on IVF (\$15 per person). Speakers included Prof. Carl Wood, IVF counsellor Louise Bowen, Dr. Gabor Kovacs, Jeremy Osborn and Dr. Alan Trounson. The future innovations and directions of IVF were discussed as follows:

1. Simplify techniques to reduce patient commitment and stress and increase their awareness of the choice of technologies.
2. Reduce cost.
3. Increase effectiveness to reduce the need for repeated treatment cycles and multiple embryo replacement.
4. Allow a greater variety of choice to patients to suit their needs. This would include offering GIFT, PROST, TEST, the "natural" IVF cycle that does not use fertility drugs, and the use of GnRH analogues instead of convention\*-ovulation induction (use of these analogues . require less monitoring).

Changes presently being made to procedures are: reducing the number of embryos placed in the woman's uterus from 4 to 3 (and sometimes 2), increase in the use of cryopreservation, increase in the use of "simpler" techniques such as GIFT, ultrasonic egg collection with local anaesthesia or mild sedation, development of ultrasonic GIFT techniques to avoid laparoscopy and general anaesthesia.

Future developments in IVF and GIFT include the following:

1. Collection of numerous eggs without the use of fertility drugs, using cryopreservation of immature eggs instead of embryos, and maturation of one or two immature eggs for replacement in a natural cycle.
2. Development of sperm microinjection for treatment of male infertility.
3. Identification of chromosomally abnormal embryos using embryo biopsy, so that these embryos will not be used for transfer to a woman's uterus.

## ETHICS IN IVF

June 1990 saw the commemoration of Candice Reed's tenth birthday in both the Melbourne press and on national radio and television. Her birth on June 23rd 1980 had been extraordinary - she was the first baby in Australia to be born after an IVF conception.

In the decade since, the research and development of IVF technology has continued to attract a lot of public debate. This in turn led to State and Commonwealth governments setting up long and expensive enquiries into reproductive technologies - ten in all. At present, the Victorian and South Australian governments have laws to regulate what IVF researchers can do, and many scientists see these laws as an unreasonable interference in what they have called "their most precious possession - the right to choose their own subject of research."

A lot of public, parliamentary and academic debate has been about the ethics of the IVF procedure itself. For example, some church leaders have said that removing a woman's egg from her body, fertilizing it in a laboratory with sperm from her male partner who has masturbated, is unnatural and therefore immoral. The Right to Life Association objects to the research because it has meant destroying human embryos. And many feminists consider IVF unethical because it exposes women to potential harm, and encourages the development of other dangerous technologies like genetic manipulation of embryos, sex selection and eugenic selection.

On the other hand, little attention has been paid to the ethics of the research process itself. When I first started thinking about IVF in 1986, it intrigued me to see how one scientist's decision to pick an interesting research topic could have all these social, legal and ethical ramifications. So I decided to try and trace the decision-making process used to develop IVF, and then see what could be learned from that experience by public policy makers who are concerned with medical and health research.

First, I studied the Annual Research Reports and minutes of Monash University's Council meetings since 1970. That was the year in which Carl Wood, Professor in Obstetrics and Gynaecology at Monash University, began his pioneering IVF research. My

standard on which, as an outsider and a non-medical person, I could evaluate the ethics of IVF research.

My findings were unexpected on several counts. First, I found that IVF research failed to meet the NH & MRC standards in three ways. I was surprised by this because previously Carl Wood and his colleague William Walters had publicly emphasised that IVF work had always been vetted by ethics committees. I discovered that the Monash ethics committee did not examine research protocols individually. The Queen Victoria Memorial Hospital ethics committee, although established in 1975, did not establish its formal guidelines for IVF work until 1981. This was after the media attention to IVF had started to encourage the demand for IVF.

A second guideline which IVF work didn't conform to adequately was ensuring that informed consent was obtained from the research subjects. Some of the researcher's own publications, and interviews they did with others including myself, show that some women were not fully informed of the risks involved, particularly those to do with superovulation drugs.

Thirdly, and I think most importantly, a standard which wasn't met was that which required long-term care and follow-up of volunteers involved in new therapeutic or experimental procedures. It is recognised internationally that Australia has one of the best national statistical registers on IVF, which greatly assists in long-term evaluation of the procedure. But there has been no follow-up of the physical and mental health of individual women who have gone through IVF procedures. My evidence for this includes the NH & MRC's audit of IVF centres done during 1985/86.

Another unexpected finding came from my analysis of NH & MRC guidelines themselves. They focus mainly on the process or conduct of the research - for example, how to obtain informed consent, or having adequate laboratory facilities. Otherwise, the guidelines focussed on outputs or outcomes of the research, such as monitoring the research so that it can be stopped or changed if harmful outcomes are noticed.

But a full evaluation also needs to look at the inputs

that both the guidelines and the researchers didn't recognise that.

I have asked myself the question that all researchers should ask: "So what?" about these findings. They are only guidelines, without the backing of the law. Does it matter that researchers didn't conduct their research ethically? I think it does, for at least three reasons.

Firstly, the NH & MRC statement follows the pattern of the judgement of the Nuremberg and Helsinki Declaration - the prime motivation of which was to ensure that medical researchers followed the physician's Hippocratic duties of doing good and not doing harm to patients. So far, the results of the research and practice of IVF haven't been good enough to reassure the Australian community that no harm is being done to women who go through the procedure, particularly to the 90% or so of women who do not achieve their goal of a live child, at the end of a mostly long and traumatic process. Some IVF researchers have now publicly acknowledged the harmful results of the drug administration that was first made a standard part of the IVF procedure in Australia.

Secondly, failure to do long-term follow-up also means that external evaluators and third-party funding bodies can't determine the full costs of the program, or judge whether the money allocated to IVF is well-spent. No one can say then, whether or not the funds could have been better deployed on other more effective and safer alternative therapies, or if the money would have been better spent on primary prevention of infertility.

Thirdly, a year ago three of Australia's Law Reform Commissions recommended that the NH & MRC should formulate specific guidelines on informed consent for patients, and said that laws should be passed so that those guidelines will be admissible in evidence in any action for professional negligence. If those recommendations are adopted, it would strengthen the NH & MRC's power to ensure that its guidelines are followed in future.

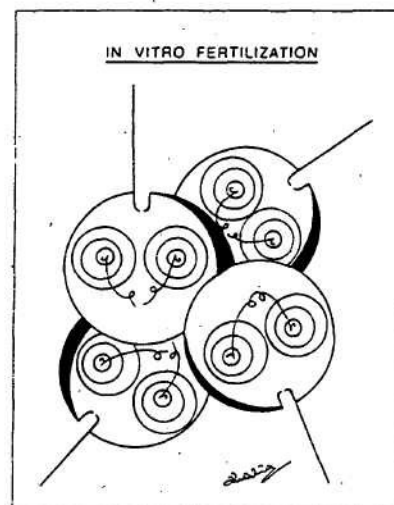
What if NH & MRC guidelines are silent about the ethical choice of a research topic? That issue has become more important since the Australian Health Minister's Conference in 1988 decided to adopt a goal of reducing inequities in health funding. If our health system is to be guided by such a goal, then it is crucial that the earliest decisions made on

eminist critiques of traditional moral philosophy or ethics, suggest that valuing of the skills and knowledges produced by women can assist in ensuring more ethical and effective scientific practices. This was unexpected by me because because it was through feminist critiques of IVF that I first came across this rich and exciting literature.

These are only a few of the lessons I have drawn from this ethical evaluation of IVF research and development in Australia, but I think they are applicable to the ethical regulation of medical research in general.

**Romaine Rutnam,  
Holder, ACT. 2611.**

*Note: This is an expanded version of an interview given on the ABC Radio National Program, the Health Report, on June 25th, 1990. It is based on research undertaken towards a PhD at the Department of Government and Public Administration, University of Sydney, Australia.*



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## INTERNATIONAL NEWS

### THE LITTLE SHOCK THAT'S TOO MUCH FOR A SPERM.

A contraceptive device which works by electrocuting sperm is being developed in the United States. The device, similar to a tiny heart pacemaker consists of a lithium/iodide battery, which is about the thickness of a cotton bud and has two electrodes. The plastic cylindrical battery is placed in the cervix of a woman and is anchored in place by two plastic lugs. The 2.8 volt battery generates a constant electrical current of 50 microamps. The current is conducted across the cervix by cervical mucus or seminal fluid, immobilising sperm in three to four minutes, according to researchers at the Women's Medical Pavilion in New York. So far, the device has been tested in *in vitro* studies which have shown that 100% of sperm are stopped in their tracks by this level of current. The device has also been tested in baboons where similar findings have been observed. Steven Kaali, medical director of the Women's Pavilion says human trials lasting years would be necessary before the device could be used. He says however, "Everyone believes in their own invention - I think this is the best thing ever to happen to women." He believes that the device has few side effects: there have been no reports of burns or chemical changes in people who wear pacemakers. An electrical current may also kill bacteria and fungi. Dr Kaali believes it would cut down the risks of sexually transmitted diseases.

Reported by Susan Hulme. "New Scientist" May 12, 1990.

### GROWTH HORMONE LINKED TO CANCER.

Human growth hormone is secreted by the pituitary gland throughout life and in smaller quantities after the age of 30. Dwarfism and other growth abnormalities result from a lack of it and these conditions have been treated with growth hormone. Recently, growth hormone has been produced from genetically engineered micro-organisms. Tests recently concluded in the US show that the hormone given to men between the ages of 61 and 81 was able to reverse some of the outward signs of ageing. However, the growth hormone has been linked with leukaemia. In Japan, there was a

order births including stillbirths as a result of the use of fertility drugs and the new reproductive technologies, such as IVF and GIFT (gamete intrafallopian transfer). From 1982 to 1989, the number rose from 12.2 to 28.6 sets per 100,000 deliveries in England and Wales. In 1989, 183 sets of triplets, 11 sets of quads and one set of quintuplets were born. These figures are an underestimate, since foetal deaths before 28 weeks are not officially registered as stillbirths.

More triplets and quads now survive than was the case in the 1970's. However, they tend to be premature and suffer from crowding in the uterus. Infants delivered at a multiple birth are at an increased risk of cerebral palsy.

Things often go wrong as doctors incorrectly diagnose the multiple pregnancy or fail to explain adequately what they see on the ultrasound scan. In 6% of triplets and 16% of quadruplet births, the correct number of babies became clear only on delivery. Quins were born to a mother who was asked by the radiographer; "Are you good at knitting?" She had been told the scan showed "a lot of arms and legs, two babies, possibly three."

More than half of the quads and a quarter of the triplets weighed less than 1500 grams at birth. About half of the quadruplet and higher births occurred before 32 weeks gestation. Almost three quarters of the quadruplets were caesarian births, as were almost two thirds of the triplets. In the study, 28% of all-live born triplets and 62% of all live born quads spent a month or more in intensive care.

A third of women with triplets and half of women with quadruplets had complications with their pregnancies. Almost all the women had at least one stay in hospital before the birth. Several mothers spoke of feeling institutionalized after many weeks in hospital. About two thirds of the parents said that no plans had been made to help them when they came home from hospital with their babies.

Typically, women who were given fertility drugs were made aware of the possibility of twins - but nothing more. Those who sought IVF were told that a pregnancy was more likely if several embryos

performed each year. The legal status of selective reduction in Britain has been uncertain, but the amended Human Fertilization and Embryology Bill proposes to bring it under the Abortion Act.

Frances Price. New Scientist. August 18. 1990.

## **US CONGRESS TO CONSIDER GENETIC PRIVACY LAW.**

An attempt to codify a person's right to genetic privacy has been initiated by a US congressman, scientists and activist Jeremy Rifkin. Efforts in the 1970's to quantify the sickle-cell anaemia trait, found almost exclusively in blacks, led to widespread discrimination against people with the trait. If passed, the proposed Human Genome Privacy Act would bar government researchers (and universities receiving government funds) from disclosing genetic information about a person without his or her written permission. The bill's promoters say the measure is aimed at insurance companies and employers who might seek such information on patients or prospective employees.

Susan Watts. New Scientist. September 22. 1990.

## **FIRST GENE THERAPY TRIAL**

The world's first course of gene therapy commenced in Maryland USA in September. Doctors infused whitew blood cells back into a four-year-old girl, after genetically altering them to correct a fata, illness. Dr. W. French Anderson has spent more than three years preparing the experiment which seeks to treat a rare and fatal disease called adenosine deaminase (ADA) deficiency. People who have the condition cannot resist common infections, and sometimes must live in plastic "bubbles", with their own purified air supply. Some scientist and opponents of genetic engineering have questioned the value of genetic therapy because a new treatment for the condition is available. It involves injecting the enzyme that is missing in children with ADA deficiency.

Christopher Joyce, New Scientist. September 22. 1990.

## **MONSANTO TRIALS WITH BOVINE GROWTH HORMONE**

The Monsanto Company in the USA is placing a billion dollar bet on biotechnology. Their laboratories

production. In farm trials, milk yields have increased by 10% to 25%. But the Governor of Wisconsin signed into law in June a one-year ban on the commercial use of BGH in that state, following an outcry from the very market that Monsanto had hoped to tap - the dairy farmers.

Some small farmers fear that the use of the hormone would cause an oversupply of milk, forcing milk prices down. Groups against the use of BGH are setting up campaigns elsewhere. Federal Drug Administration (FDA) officials say the milk from BGH-treated cows is safe and has approved the sale of milk produced. But opponents may press for laws that would require milk from treated cows to be labelled as such. That could alarm consumers who are increasingly concerned about food safety. Some supermarket chains have refused to sell the milk, saying that they are trying to evaluate consumer attitudes.

Richard Koenig. The Wall Street Journal. May 18. 1990.

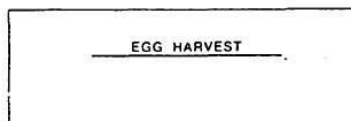
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..... Seminar Report cont'd

growth to a minimum, or remove the need for either.

IVF scientists believe that the use of the natural cycle in IVF and ultrasonic GIFT procedures will become simple additions to gynaecological services. In future, they hope to have three options of using eggs: (i) natural cycle with immature eggs and freezing, (ii) natural cycle with one mature egg, and (iii) use of fertility drugs with the option of freezing.

The return to the natural cycle is especially interesting in the light of comments made by Professor Wood. Even though Dr. Steptoe in England thought IVF had been successful because women were in their own natural cycle, use of the natural cycle didn't suit doctors here in Australia, particularly because the time of ovulation was not precise. Wood also referred to "wastage of sperm" in the female reproductive tract. Dr. Gabor Kovacs, in referring to GIFT'S higher success rate, remarked that the human female body might be a better incubator for early development of the embryo.



**WEEKEND SEMINAR  
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Women who have fertility problems or an unmet desire for a child are invited to attend this two-day seminar, to meet and discuss their experiences in a supportive and confidential environment.

Geraldine Stevens, founding member of the Western Australian self-help group, Issues (In) Fertility will share the experiences and insights of the WA group. She will also facilitate workshops and small group discussions.

The seminar will be of interest if you are a woman who has a diagnosed or unexplained fertility problem, if you have a male partner who has a diagnosed or unexplained fertility problem, if you are on or discontinuing with reproductive technology programmes and want to consider alternatives, if you have been excluded from reproductive technology programmes, if you are at risk of complications with pregnancy, if you have a partner who does not want children, and if you want to come to terms with your fertility problems or childlessness with other women who are in similar circumstances.

The focus of the seminar will be on small discussion groups. Workshops will also be held on infertility counselling, alternative therapies for the treatment of some fertility problems, social parenting options, and how to establish self-help groups. The sponsors hope that interested women who attend the seminar may wish to establish their own self-help groups or support networks.

For more information and registration details, contact Christine Ewing or Shannon Keebaugh on (03) 489 7748. The seminar is free. Child care is available on request. The YWCA building is wheelchair accessible.

**Sponsored by:**

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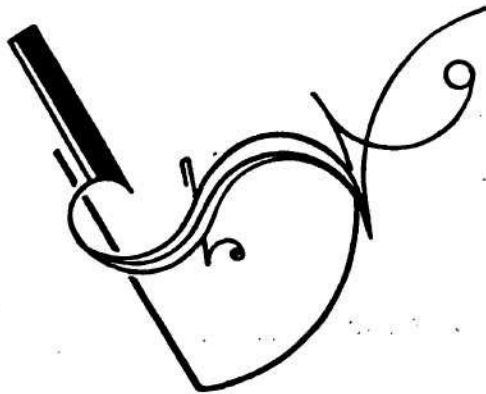
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DrRenateKlein



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*"IVF meant only pain and disappointment."*

*"I felt like a baby machine; no one was interested in me as a person. I was just a chook with growing eggs inside..."*

*"I felt very unspedal, like a laboratory rat..."*

Renate D. Klein is widely published in the area of reproductive technology and is currently a Research Fellow at Deakin University.

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