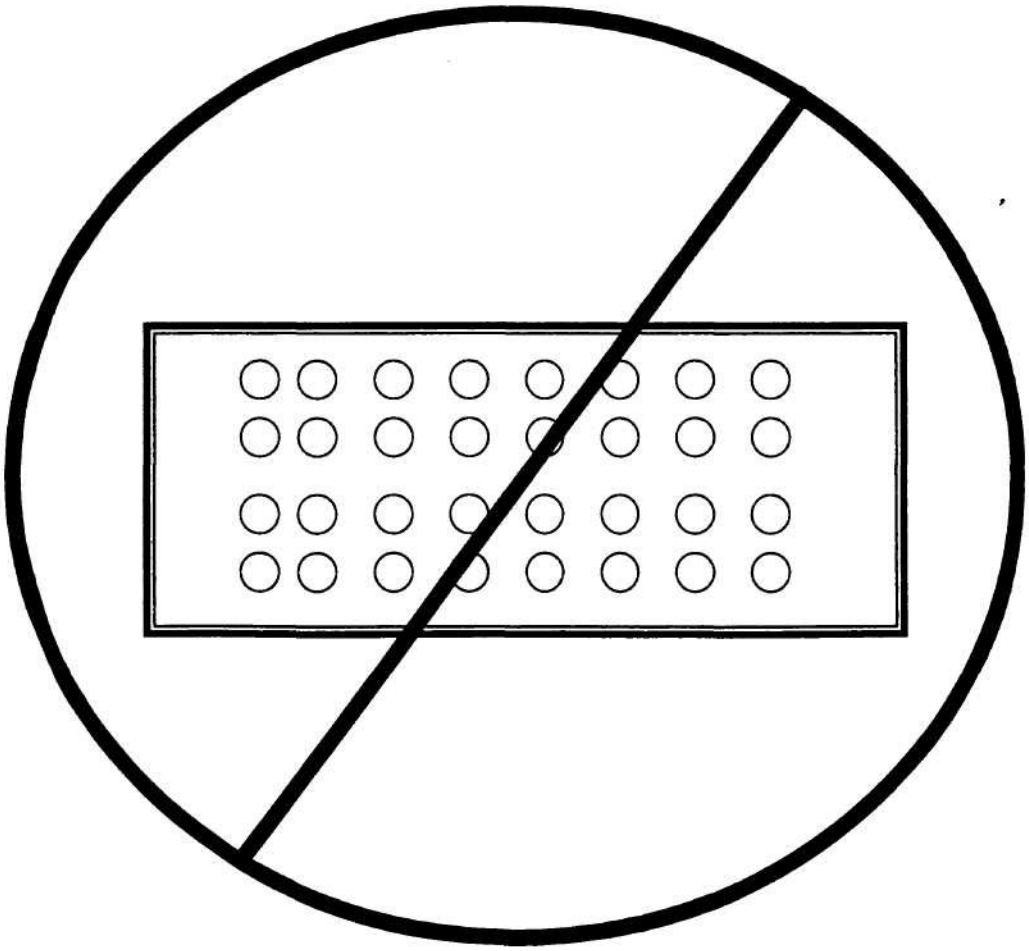
July 1999

FINRRAGE

Feminist International Network of Resistance to Reproductive and Genetic Engineering

Sandra Coney (1999) asks "My question is: who is accountable for these deaths? Is it the drug companies, who bullied to the extent of threatening legal action against the Ministry when it planned to issue warnings when the risks of these pills were first known?"



CONTENTS

COVER ART: Renee Beggs and Laurel Guymer © 1999

LAYOUT: Laurel Guymer and Renee Beggs

ISSN 1328-5955
FINRRAGE (Australia is indexed in APAIS (Australian Public Affairs Information Service)

Editorial

Dear Readers,

Welcome to the very delayed first issue of FINRRAGE for 1999. We hope you enjoyed the last issue of FINRRAGE (Australia) in July, 1998. Due to a hectic year the promised four issues of FINRRAGE (Australia) never made it into press in 1998. Nevertheless, we sincerely hope that you, our subscribers, will continue your support. The Journal depends on many factors: adequate financial support, your submissions, and heaps of time and energy from the co-ordinators. All these elements have contributed to this edition and so far seem to be in motion for the next one too.

We are pleased to announce a renewed group of FINRRAGERS interested in resistance to reproductive and genetic engineering. If you would like to become an active member of FINRRAGE (Australia) please contact the co-ordinators on the details below.

Again, thanks to all those who renewed your subscriptions in the last twleve months. This issue has articles ranging from contraceptive technologies to unethical medical trials.

FINRRAGE (Australia) continues to support the international campaign to stop anti-pregnancy vaccines. T-shirts are still available which display a woman stamping out the vaccine shown on a previous edition of the FINRRAGE (Australia) Newsletter.

If you would like to contribute to FINRRAGE (Australia) with articles, conference reports, announcements and news, and views nationally and internationally, write to the co-ordinators at the following address. Preference is for copy to be submitted in Word on Macintosh discs (we can convert IBM too!!) and email is also fine.

We hope you enjoy this issue of FINRRAGE (Australia) and continue to support us be renewing your subscription. All going to plan, the next issue will appear by October and we look forward to your contributions and comments.

Laurel Guymer and Renate Klein
Co-ordinators FINRRAGE (Australia)

c/o Australian Women's Research Centre (AWORC)
Faculty of Arts
Deakin University,
Geelong, 3217
capri@deakin.edu.au
http://arts.deakin.edu.au/guvmer/aworc/finrrage.html

Natural Family Planning: an avenue viable for self control of fertility.

George W. Heath

Abstract

Feminists, especially radical feminists, posit that male oppression of the female as the most basic oppression. This includes the most personal and intimate relationships between male and female as well social conventions. Answers provided by the male dominated medical/ industrial complex of technological based artificial contraception do not change this domination. Modern Natural Family Planning changes the basic paradigm of the intimate male/female relationship. The fertility remains a part of the individual with care as the basic orientation instead of it being a problem to be solved. The decisions of the use of fertility are between the couple without any need of outside assistance or consultation. The self awareness, freedom from drugs, naturalness and effectiveness are the main reasons cited by users of NFP for satisfaction. NFP offers a viable avenue to those who wish to control their fertility and freedom from oppression in both intimate and social relationships.

Introduction

The specter of control of fertility by governments still haunts women even after a near half century after the sixties sexual revolution. A recent international conference that featured Mrs Hilary Clinton in February of this year had this subject as a theme. Even with a freedom from governmental control, there is also the control of western medical practice by white male. This control has only been accentuated by the shifting of health care to a more market capitalism orientation in a creation of a medical/industrial complex (Relman, 1970).

Radical feminists see the oppressive nature of the control within the structure of the male/female relationship. This has not changed by the introduction of artificial methods but may have enhanced them. To escape this birdcage of culture, an alternative would have to change the orientation of the basic male/female relationship, where male gratification dominates.

Natural Family Planning is the method presented in this paper that opens a counter-cultural path. The efficiency of NFP is comparable to the artificial methods with no side effects. A presentation of radical feminists views will be made followed by the history, philosophy, and scientific basis for one method of NFP, the ovulation method. I chose one method for-purposes of discussion but I recognize that there are several other viable methods. There will be a case study that indicates the cross cultural potential of NFP, the potential to use with those that are less educated, the ability to be used despite severe disabilities, and holistic nature of the practice of NFP. Throughout the paper there will be reference to nursing literature since that is my professional orientation.

Feminism: Radical Feminism

For most radical feminists, the oppression of women is the first, most widespread, and the deepest form of human oppression (Tong, 1989). With liberation from this oppression, women will be able "to discover the richness and diversity of the female body" (Tong, 1989, p. 72). Tong (1989) states radical feminists have directed attention to the ways in which men control women's bodies including contraception and sterilization. Gena Corea in Tong (1989, p.83) asks, "Why are men focusing all this technology on a woman's generative organs– the source of her procreative power?"

Adrienne Rich expresses the present situation by saying that it is men (medical doctors, medical suppliers) who say when and how to be pregnant, but this conflicts with the lived experience of women (Tong, 1989). Robyn Rowland in Tong (1989) sees women's reproductive powers are anything but oppressive. With my score of years in

nursing, I can agree with Rowland that if women's power over life is the paradigm for anything, it is for one person's or group's ability to connect with another (Tong, 1989). This paradigm is forever being negated by men in any form possible. Tong (1989) summarizes Mary Daly's comments in Gyn/Ecology concerning negation by patriarchy,

> Not only are men out to oppress women's minds, they are out to oppress women's bodies through such practices as Hindu suite, Chinese foot binding, African female circumcision, European witch burning, and Western gynecology.

The strongest statement I have ever read directly concerning contraception comes from Gena Corea (1977) in her book *The hidden malpractice: How American medicine treats women as patients and professionals:*

> Almost any kind (of contraception) that prevented births were acceptable, the regard given to its safety varying with the color and economic status of the women that would use it. A primary purpose of contraception became the control of population rather than the well being of individual women. An examination of the development of modern female contraceptives reveals that too often devices and drugs have been inadequately researched before being widely sold and that, once available, many women have used them without informed consent (Corea, 1977, p. 137).

It is interesting to note that I began my career in nursing in 1977 and Evelyn and John Billings work on the ovulation method was coming to fruition. There are reasons that Ms Corea (1977) would not know of NFP but I wonder if she would be inclined to endorse such a method in light of a statement later in the same text.

> Originally, many women wanted a contraceptive they could use themselves so that they did not have to depend for protection on the goodwill of their partners. But women's expectations have risen; she thinks her regular sexual partner should share the birth-control responsibility, (ibid. p. 158)

Andrea Dworkin (Tong, 1980) conjectures a bi-model paradigm for the traditional relationships between men and women, the farm model and the brothel model. The farm model is the women as only a procreative receptacle for men. The brothel model is women as mere sources of sexual pleasure. While Dworkin does not explore the Western medical model question, one can question if present artificial contraceptive technology only allows a single woman to be switched between the two poles of farm and brothel at will. Instead of oppression in categories of groups under one model or the other, there is oppression by each woman under both models.

Indications of radicalism in nursing literature

There is a reflection of this distrust of the present medical paradigms discussed in nursing literature. Murray & Zenner (1993) is most strong questioning the willingness of present research and practice to bombard the womb chemicals or bayoneted with foreign objects to be rid of the problem of pregnancy. Miller (1995) claims that this follows the male medical model that considers pregnancy to be a pathology to be cured as opposed to the nursing/feminist model that is holistic and caring in approach.

Natural Family Planning: Ovulation Method

History

The ovulation method was developed by a couple living in Australia. It was in response to the emphasis on the protection of life by the Catholic Church and the inaccuracy of the calendar method (Guy, 1980). Evelyn and John Billings, physicians, used findings, concerning cervical mucus that changes dramatically with ovulation, as a basis for prediction the fertile time of the menstrual cycle (Billings, Billings, Brown, & Burger, 1972). When the studies of the method done over 20 years, without the slant of pregnancy as pathological, the method is as good, too within 1% of the best artificial

methods and better than some artificial methods, without any side effects (Wilson, 1993). The greatest difficulty has been the acceptance of this method by mainstream physicians due to the impetus of its development being religious and the admission on the part of the physician that it calls for the life style of the couple be considered in its prescription (Lee, 1993).

Philosophy

There is a concern for the environment that has increased over the years. This movement has extended to the environment of the person with the increase concern for the type of foods and water that one ingests. This is evident within almost any class at Ca. State University, Northridge by the ubiquitous bottles of "Natural" waters and the packages of "organic" foods. Yet there is a willingness to bombard the womb with chemicals or bayoneting the same with foreign objects to be rid of the problem of pregnancy (Murray & Zenner, 1993). Natural Family Planning falls into the holistic view where the treatment is seen in the context of the whole (Kavangh, 1991). Natural Family Planning falls well within the Orem Theory of Nursing as it turns the control of the health of the couple to them. A "self care agency" is created with the instruction of the method to the couple by definition (Orem, 1991). The need for-repeated visits to the primary medical care giver is minimized. In fact, the changes in cervical mucous can be used as an early warning sign of gynecological disorders (Billings, Billings, & Catarinich, 1980). Natural Family Planning can be used to maximize the chances for pregnancy as well as prevention (Hilgers, Daly, Prebil, & Hilgers 1992). Artificial methods allow for sex relations to be engaged in the masculine character of anywhere at any time. Natural Family Planning, with its days of abstinence, works, as Martha Rogers would say, with the dynamic energy fields of the couple (Lutjens, 1991). A search of the literature shows that Natural Family Planning is slowly increasing in interest and has cross cultural appeal (Stanford, Lamaire, & Fox, 1994; Billings, 1993). The Billings' express themselves best with this quote, (Billings, 1980)

> The use of a natural family planning method also implies a basic respect for the biological processes of human reproduction, respect for the creative power of the sexual union, and a recognition that the act of intercourse finds its true meaning only when it gives physical expression to a permanent commitment of one man and one woman to each other, two people who have demonstrated the union of their lives by a contract of marriage. (P.l)

Scientific Basis

The ovulation method depends on the awareness of the fertile time of the menstrual cycle via the observation of the cervical mucus at the mouth of the vagina. (Hilgers & Prebil, 1979) The cervical mucus that enhances pregnancy is for a short time, usually 3 - 4 days, of the cycle (Billings et. al, 1980). This "fertility mucus" is different that the mucus seen during the infertile periods or discharge from the vagina that is due to some abnormality (Flynn & Lynch, 1976). The correlation between the changes in the hormones that produce ovulation and changes in the type of secretion is a very high positive correlation (Billings et. al., 1980). The effective teaching tools developed by John and Evelyn Billings, using a chart and different colored stamps, brought this theoretical basis into an easily accessible visual measurement of fertility (Foxwell, 1994). At the vulva there are two basic sensations: dryness or slipperiness. Fertility depends upon: a good ovum, a good sperm cell, and good mucus, to reach the ovum (Billings et. al.,1980). The duration of the fertile phase of the cycle depends on: the life of the ovum and the life of the sperm cell, with the sperm cell requiring good mucus to protect and nourish it (Winikoff & Wynlenberger, 1992). Ovulation occurs on only one day in the cycle (e.g. ibid, 1992). Ovulation is followed by two weeks later by menstruation, in the absence of pregnancy (Billings, et. al., 1980). It is necessary for the woman, if she wishes to avoid pregnancy, to recognize the commencement of the phase of fertility. She then needs to

follow the mucus pattern until she knows that she has ovulated.

The cervical mucus which occurs close to ovulation is characterized by greater transparency, lower viscosity, pronounced thread ability or stringiness and a low percentage of solid material (Odeblad, 1973). The mucus that occurs after ovulation has an increased cellularity and viscosity that form a meshwork which obstructs sperm migration (e.g. ibid, 1973). The mucus at the time of ovulation is called E mucus while the non-fertility mucus is called G mucus. (Odeblad, 1978). The other type of mucus found in the vaginal discharge usually relates to some gynecological disturbance. It has a milky or watery character (Billings, et. al., 1980). Recent studies confirm the earlier ones of the efficiency of the Ovulation Method being 98% to 99% in avoiding pregnancy (Billings, et. al., 1980; Perez-Sanchez, 1980; Fehring, Lawernce, & Philpot, 1994; Foxwell, 1994; Xu, Yan, Fan, & Zhang, 1994; Guida, et. al., 1997; Trent & Clark, 1977; Pypes, 1997; Vekemans, 1997; Fehring & Gaskin, 1998).

One article documents that the unplanned pregnancy rates are declining with natural family planning (France, 1994). The development of simple home use tests of fertility markers, such as a PG/53 protein in the saliva, will make the difference between natural family planning and the best artificial methods minimal (probably less than 1%) except surgical sterilization (Barbato, Pandolfi, & Guida, 1993; Cavero, 1995; Fehring, 1996). Again it must be noted, that by the criterion of the definition for side-effects, there are no side-effects from Natural Family Planning. A recent article not only confirms that Natural Family Planning can be used to ensure pregnancy but to reduce the risk of spontaneous abortion in women that have a history of such (Gray, Simpson, Kambic, Queenan, Mena, Perez, & Barbate, 1995).

Case Study

The case study that I am going to use sounds a little extreme but is true since it is the experience of my wife and myself in using the Ovulation Method. What makes this whole scenario less than credible is the fact that my wife, the one that has to do most of the observation, is a quadriplegic and legally blind secondary to spastic cerebral palsy. Only my wife and I took the training to learn the method. From the first, I had to understand the significance of my wife's vaginal secretions. In my absence, my wife had to depend upon the help of the aides that she hired to assist her with her needs. These aides were usually of Latino origin and did not speak English. They had an education that was not even beyond the elementary level. Despite these obvious disadvantages, we were able to avoid pregnancy until we wanted our last child two years later. My wife does have a degree from Ca. State University, Northridge in Spanish Language and Literature but it did tax her ingenuity to explain what to look for as they gave her personal care. In a manner reflecting the experience of the promoters of the method, we found that it was easier to teach those women who were less educated and closer connection to agrarian life style. The most difficult problem we had was with a Caucasian female that had a high school degree. An advantage, which occurred to my wife immediately, was the cessation of repeated urinary tract infections. The oral hormonal, that we had been using, places the woman's body in a pseudo-pregnant state. One of the facets of this state is dilated ureters. These dilated ureters made my wife, who is sedentary, even more prone to an invasion from bacteria.

On my part, I found the periods of abstinence to be less burdensome then conjectured. The motive to pay attention to my wife's other needs was increased. A natural rhythm created was a semi-courtship followed by exciting fulfillment. This was aided, I speculate, by the storing of sexual energy for a few days before release. Also, from strands of thoughts from many different articles on human pheromones, I suspect there is a biochemical component that is adulterated when one is using artificial methods.

Difficulties with NFP

NFP does have the disadvantage of needing a couple in a committed relationship. It does take the cooperation of the male for the method to be feasible. One that is engaged with multiple partners or concerned with only satisfying sexual desires or just procreation will not find NFP convenient. It may be the case that couples who are centered on career over personal growth would find NFP bothersome. The plethora of advertisements of deodorants and other methods to rid oneself of bodily secretions is an indication of societal dislike for the facts of life, especially in the female. NFP focuses on just such secretions. NFP is best if discussions of bodily fluids between partners. NFP cannot be mass produced or mass marketed. It is taught, usually, in several sessions between an instructor, who does not need to be professional, and a couple or, as one pro-NFP organization is entitled, "couple to couple." NFP does not lend itself to profit creation. It does not interact with a culture of acquisition and satisfaction but will create joy and happiness. These cultural points are among the reasons that NFP is practiced by only 4% of couples in the United States (Stanford, Lamaire, & Thurman, 1998). In the truest sense, NFP is countercultural.

Conclusion

The feminists featured in the first part of the article are keenly aware of the domination of male over female in every aspect of the relationship. They promote liberation on every level, form personal to global. Some feminists demand an alteration of gender presentation even to its physical characteristics with the help of technology. Another alternative is creation of women only societies with a promotion of lesbianism. Apparently, both of those answers are problematic since most of the world does not have access to the advance technology and women only societies are prejudicial to of the population by definition. NFP goes further than the domination of government on fertility. Reproductive decisions, with NFP, are limited to a discussion between the two people involved the reproduction. There are implications for third world and non-white societies for freedom from the white industrialized world. A woman's culture can be created since the method can and has been passed from mother to daughter.

Since I am part of a female oriented sub-culture, nursing, and the usual paradigm of female being a caregiver for the male is reversed for my intimate relationship, I can attest, with some authority, of how NFP can draw a male into more caring behaviors. Instead of being aware of my own physical needs, the male can become aware, as no other method of family planning can, of the partners cycles. Not only does permanent disability, as in the case of my wife and me, require a man to know his partner's fertility but temporary disfunction, as in alcoholic intoxication, require that the male be able to know her signs of fertility before the Biblical knowing.

Instead of trying to use "The Master's Tools" to "Dismantle the Master's House," NFP can be a way to change the male of orientation of society toward ethics of justice to the feminine ethics of caring not in a mass marketed manner of the individual subsumed into the group but in the manner of personalism (Lorde, 1984; Gilligan, 1982; Jay, 1997). Of those who use NFP, over ninety percent give it a rating of highly satisfied (France, France, & Townsend, 1997). The reasons given by the participants for there satisfaction appears to answer the concerns of the feminists in artificial contraception. In order, they are self awareness, freedom from drugs and devices, naturalness, and effectiveness (France, France, & Townsend, 1997). A survey done by the Couple to Couple League of their members and users of NFP finds a preliminary result of 5% percent divorce rate as an upper limit (Kipley, 1994). While there are reasons one could find flaws and explanations extraneous to NFP for the low divorce rate, it is remarkable statistic in a the background of the American scene where the divorce rate is 50%. Since there has been no other work done on this subject, acceptance can be based prima facie. In any case, for NFP users, it appears to be a peace in the war between the sexes. Peace, I hope, is the ultimate goal for the feminist and non-

feminist alike.

For the feminist that wishes to be involved with men, especially a personal long-term relationship with a man, NFP offers an avenue to freedom from sources outside the relationship. As a positive benefit, the fertility awareness not only changes the parameters of the basic male female relationship but increase gynecological health awareness (Cachan & Marshall, 1997). If one does not commit the logical fallacy of the poison well to the motivation to the development of NFP, Catholicism, NFP, on its own merits, offers more to women than technology has delivered.

References

Barbato, M., Pandolfi, A., & Guida,M.(l993) *A new diagnostic aid for natural family planning. Advances in Contraception* 9(4), 335-340

Billings, J. J. (1993). 'Natural family planning: Natural methods have cross cultural appeal.' in *British Medical Journal* 307(6915), 1357

Billings, E. L., Billings, J. J., Brown, J. B., & Burger, H. G. (1972). *Symptoms and hormonal changes accompanying ovulation.* Lancet 1,. 282

Billings, E. L., Billings, J. J., & Catarinich, M. (1980). *Atlas of the Ovulation Mehtod* (4th. Ed.) Chicago, II., Fransican Herald Press

Cachan J. & Marshall (1997; 'Implementing reproductive health awareness: Progress to date. *Advances in Contraception* 13 (2-3), 363-71

Cavero, C. (1995) 'Using an ovarian monitor as an adjunct to natural family planning.' in *Journal of Nurse Midwifery* 40(3). 269-276

Chica, M. D. & Barranco, E. (1994) 'Fertility control by natural methods. Analysis of 218 cycles.' in *Advances in Contraception* 10(1). 33-36

Corea, G. (1977). *The hidden malpractice: How American medicine treats women as patients and professionals* New York, William Morrow and Company

Fehring R. J. (1996), 'A comparision of ovulation method with the CUE ovulation predictor in determing the fertile period,' in *Journal of the American Acadamey of Nurse Practioners* 8(10), 461-6

Fehring, R.J., Lawrence, D., & Philpot, C. (1994), 'Use effectiveness of the Creighton model ovulation method of natural family planning' in *Journal of Obstetrical, Gynecological, and Neonatal Nursing,* 23(4). 303-309

Fehring, R. J. & Gaska, N., (1998), 'Evaluation of the Lady Free tester in determining the fertile period,' in *Contraception* 57, (5), 325 - 8

Flynn, A. M., & Lynch, S. S. (1976). 'Cervical mucus and identification of the fertile phase of the menstrual cycle,' in *British Journal of Obstetrics and Gynecology,* 83, 656

Foxwell, J. (1994) *Natural family planning. Modern Midwife,* 4(3), 21-24

France, J. (1994). 'Natural family planning: Unplanned pregnancy rates are declining,' in *British Medical Journal,* 307(6915), 1357

France, M, France J., & Townsend, K (1997) 'Natural Family Planning in New Zealand: A study of continuation rates and characteristics of users,' in *Advances in Contracpetion,* 13 (2-3), 191-8

Gilligan, C. (1982) *In a different voice: Psychological theory and women's development,* Cambridge, Harvard University Press, p174

Gray, R. H., Simpson, J. L., Kambic, R. T., Queenan, J. T., Mena, P., Perez, A., & Barbato, M. (1995) 'Timing of conception and the risk of spontaneous abortion among pregnancies occuring during the use of natural family planning.' in *American Journal of Obstetrics and Gynecololgy* 172(5) 1567-1572

Guida, M., Tommaselli, G. A., Pellicano, M.,

Palomba S., & Napdi C. (1997), 'An overview of the effectivenss of Natural Family Planning.' in *Gynecology and Endocrinolgy,* 17 (3), 203-19

Hilgers, T. W., and Prebil, A. M. (1979). 'The ovulation method: Vulvar observations as an index of fertility/infertility.' in *Obstetrics and Gynecology* 53,(1), 12

Hilgers, T. W., Daly, K. D., Prebil, S. K., & Hilgers, S. K. (1992) 'Culmative pregnancy rates in patients with apparently normal fertility and fertility-focused intercourse.' in *Journal of Reproductive Medicine,* 37(10), 864-866

Jay, M. (1973), 'Aesthetic theory and the critique of mass culture', in *The dialectical imagination: A history of the Frankfurt School and the Institute of Social Research,* Los Angeles, University of California Press, 173-218

Kavanagh, K. H. (1991). 'Values and beliefs,' in Cresia, J. L. & Parker, B. (eds), *Conceptual foundations of professional nursing practice,* (p202) St. Louis, Mo., Mosby Year Book

Kippley, J. & Kippley, S. (1996) 'Your marriage and Natural Family Planning,' in *The art of natural family planning, Cincinatti,* Ohio, Couple to Couple League, pp 243 -251

Lee, J. (1993). 'Natural family planning: Advocates and detractors have different sexual philosophies,' in *British Medical Journal* 307 (6915), 1360

Lorde A. (1984) 'The master's tools will never dismantle the master's house,' in *Sister Outsider.* Freedom, Ca., The Crossing Press, pp 110 - 117

Miller, C. A. (1995). *Nursing care of adults: Theory and Practice.* (2cd. Ed., p.42) Philadelphia, Pa. J. P. Lippincott Co.

Murray, B. R. & Zenner, J. P. (1993). *Nursing assement and health promotion: Strategies through the life span* (5th. Ed., pp 404-405) Norwalk, Ca., Appleton and Lange

Odeblad, E. (1973). 'Biophysical techniques of assessing cervical mucus and microstructure of cervical epithelium,' in *Cervical Mucus in Human Reproduction.* WHO Colloquim, Geneva, 1972, pp58-74

Odeblad, E. (1978) 'Cervical factors,' in *Contraception, Gynecology, & Obstetrics,* 4 132-142

Orem, D.E. (1991). *Nursing: Concepts and practice* (4th. Ed., pp 148-154) St. Louis, Mo., Mosby Year Book

Perez- Sanchez, A. (1980) 'Use-effectivness of the ovulation method initieated after childbirth, preliminary report,' in Zimmerman, A., Guy F., & Tettamanzi, D. (Eds.), *Natural Family Planning: Nature's Way - God's Way* (pp90-94) Milwaukee, Wi., De Ranee, Inc.

Pypes, CM., (1997) 'Fertility awareness and natural family planning,' in *European Journal on Contraception and Reproductive Health Care* 2,(2), 131-46

Stanford, J. B., Lemaire, J. C, & Fox, A. (1994) 'Interest in natural family planning among female family practice patients', in *Family Practice Research Journal* 14(3), 237-249

Stanford, J. B., Lamaire, J. C, & Thurman, P. B. (1998) 'Women's interest in natural family planning,' in *Journal of Family Practice,* 46, (1), 65-71

Tong, R. (1989). *Feminist thought: A comprhensive introduction* (pp 71-134 & pp 195-233), Boulder, Colorado. Westview Press

Trent, A. J. & Clark, K.(1997) 'What nurses should know about natural family planning,' in *Journal of Obstetrics, Gynecological, & Neonatal Nursing,* 26 (6), 643-8

Vekemans, M., (1997) 'Postpartum contraception: The lactational amenorrhea method,' in *European Journal of Contraception and Reproducive Health Care,* 2, (2), 105 - 11

Wilson, M. B. (1993). 'Natural family planning: Cheap, effective, and free of side effects,' in *British Medical Journal* 307 (6915) 1357-1358

Winikoff, B., & Wynelberger, S. (1992). *The contraceptive handbook,* Yonkers, N. Y., Consumers Report Book

Xu, J. X., Yan, J. H., Fan, D. Z., & Zhang, D. W. (1994), 'Billings natural family planning in Shanhai, China,' in *Advances in Contraception,* 10(3), 194-204

B. A. in Philosophy 1999
gheath@email.csun.edu

More deaths following Third Generation Oral Contraceptives.

Sandra Coney

Buried in the New Zealand Ministry of Health's Prescriber Update publication (December 1998), was the news that six young women had recently died as a result of blood clots while taking Third Generation oral contraceptives. The women were aged between 19 and 32. They were healthy young women, responsibly using contraceptives to prevent unwanted pregnancies. Most had few symptoms of the impending calamity. A pain in the leg in two women, a recent knee injury causing immobilisation in another.

My question is: who is accountable for these deaths? Is it the drug companies, who bullied to the extent of threatening legal action against the Ministry when it planned to issue warnings when the risks of these pills were first known? Is it the medical groups who pressured the Ministry by saying they would disassociate themselves from the advice? Or is it the various officials of the Ministry of Health who caved in under the pressure, selling New Zealand women down the river?

The Ministry of Health first knew about the increased risk of potentially fatal blood clots in users of Third Generation OCs in October 1995. The brand names of the products are Femodene, Marvelon, Mercilon and Minulet. What differentiated these from 'older OCs was that they contained progestogens called desogestrel or gestodene. The news was that Third Generation Pills had double the risk of blood clots compared to older OCs.

The drug companies had done such a good job selling these brands to New Zealand doctors that around 175,000 young women were using them, an astounding 75-80% of all women on OCs. This is the highest rate in the world, which tells us something about the too cosy relationship between doctors and drug companies in New Zealand. In Australia, only 5% of OC users were on the suspect pills.

The scale of the problem was embarrassing and probably explains the foot dragging that followed, but it also meant that this was no minor health scare, but a major public health problem. Blood clots are rare in young women, but at this rate you could expect about 35 cases of blood clots in users of Third Generation OCs each year, about 12% of which were expected to be fatal.

In October 1995 I was asked to sit on a Ministry working party to discuss what to do. I should have seen the writing on the wall when I saw seven drug company bosses lined up around the table, including marketing managers. I was the sole consumer rep. 'Adverse Reactions Committee (MARC), gave its advice. It unanimously decided that doctors should review their prescribing practices and 'preferentially prescribe' brands of OCs other than those containing desogestrel and gestodene. MARC said this advice to doctors was urgent. All hell broke loose. The drug companies bombarded GPs with dossiers contradicting the studies that had shown the risk. Legal action against the Ministry was threatened. Then the Royal New Zealand College of Obstetricians and Gynaecologists proclaimed that it would publicly disassociate itself from the advice. Family Planning went about saying that the studies on which MARC's advice was based were affected by biases so that the results couldn't be trusted.

Professor David Skegg, a member of MARC and a WHO expert on hormonal contraception, complained to the Director(c)General of Health about the delay and 'the extent of to which the pharmaceutical industry is able to influence key decisions in New Zealand'. Through all this ran claims that unless the whole thing was damped down, the media would blow it up into a 'pill scare', resulting in unplanned pregnancies among young women. Professor Skegg commented on the 'exaggerated fear of the news media', noting that women would act with commonsense as long as they were given adequate information.'

Nevertheless, the Ministry bowed to the pressure. The MARC communication to doctors was pulled back from the printers and shredded. In the revised version the information was watered down. Instead of advising doctors to prescribe other brands in the first instance, the advice was now only to 'consider prescribing' other brands. The leaflet that was produced for women was so bland and reassuring that it would not have rung any alarm bells. Thus women were left unable to act to protect themselves, to the extent that they were not even informed by the Ministry of what the symptoms of blood clots were.

In mid 1996 when this advice appeared, the Ministry predicted that there would be one death every 1.5 to 2.5 years of New Zealand women on these Pills. Now it is known that four women died in the 18 months from January 1997 to June 1998. (Another two died earlier.) An 'unexpectedly high number', says the Ministry. There may well be even more than four, as the Ministry says it is unlikely all cases have been reported. The reason for the high number is unclear. Monitoring the impact of its actions in 1996, it was unable to tell me whether there had been a fall in usage of Third Generation OCs. Fortunately I was able to learn this from elsewhere. The government's drug agency, Pharmac, was able to tell me that the decrease in use of these pills in 1996, the year the Ministry gave its advice, was only 19%, followed by a tiny 3% decline the following year. Third generation OCs still make up 65% of the total OC market.

This means that the Ministry's low key approach has resulted in an exceptionally high number of women still using Third Generation OCs. Are they warned of the risks? Do they know that they could reduce their risk by using older forms of OCs, or even eliminate it by using another method? Have their doctors explained to them the symptoms of blood clots? Do they know they are at additional risk if they are immobilised because of injury, illness, surgery, or a long plane flight? Finally, did the young women who died make an informed choice to take the risk that ultimately cost them their lives? Will anyone be held to account for their deaths? Somehow, I doubt it.

Postscript:

After this column appeared in the Sunday Star Times 'in January 1999, I did a great number of media interviews. As well, I was contacted by hundreds of women wanting information, and women and families reporting cases of blood clots, including deaths. Women's Health Action, the women's advocacy group of which I am director, is sending packs of information to women, many of whom report that they have had their concerns brushed aside by their doctors.

Deaths from third generation oral contraceptives in New Zealand. At least six young New Zealand women who were taking third generation oral contraceptives (OCs) containing desogestrel or gestodene died of pulmonary embolism between January 1993 and June 1998. This is a much higher number than was predicted by the Ministry of Health when it issued prescribing advice about the increased risk of venous thromboembolism (VTE) in users of third generation pills in July 1996. Four of the deaths occurred in an 18 month period between January 1997 to June 1998. In 1996 the ministry said that with a case fatality rate of l(c)2%, one death would be expected every 1.5 to 2.5 years.

The government's Medicines Adverse Reactions Committee (MARC) warned the Ministry, in early 1996, that the increase in prevalence of VTE attributable to these pills 'can be expected to be significant' in the New Zealand context. Third generation Pills had quickly gained a large market share in New Zealand where women are historically high users of oral contraception. By 1996 some 150,000 women 80% of users of oral contraceptives were using third generation pills. New Zealand had (and still has) the highest usage of such pills in the world. Nevertheless, the Ministry says the number of deaths is 'unexpectedly high' and because New Zealand has a voluntary adverse events reporting system, the actual number is believed to be higher. The ministry can give

no explanation for the numbers, although it points out that the reporting system is 'subject to natural fluctuation and reporting bias'.

In 1996 the Ministry of Health did not follow the initial advice of MARC to advise doctors to preferentially prescribe' older forms of OCs. After the Family Planning Association and the Royal College of Obstetricians and Gynaecologists said they opposed the advice, the wording was modified to 'consider prescribing'. The Ministry said this was to avoid 'confusion and noncompliance that would result from these bodies publicly disassociating themselves from the advice'. Pharmaceutical companies were clearly unhappy about the Ministry's intentions and one went so far as to threaten legal action. Professor David Skegg, a member of MARC, complained to the Director General of Health about the involvement of industry members in the process and the 'extent to which the pharmaceutical industry is able to influence key decisions in New Zealand.'

The Ministry feared a 'Pill scare' following the experience in Britain when the news hit the media. However, the outcome of the mild advice was that the use of third generation pills in New Zealand fell by only 19% in the first year and 3% in the following year. The women whose deaths have recently been made public were aged between 19 and 32 and only one was contraindicated for oral contraceptives. Most of the women had no warning symptoms. In two of the women there had been symptoms of recent thromboembolic ' activity, in the form of pain in the leg or legs. In two women recent injury may have played a part, one woman having been immobilised due to a knee injury and the other having injured her knee five months previously.

The Ministry has now reiterated its advice from 1996, but sees no need to change it. Coroners' reports are being studied by researchers at the Otago School of Medicine to try to ascertain the full picture and the ministry says MARC will be reviewing significant new data at it first meeting of 1999.

Sandra Coney has been involved in women's issues for many years. She is especially interested in issues concerning women's health.

Time for Australia to Act on Pill warnings

Melinda Tankard Reist

Another New Zealand woman dead - killed by the contraceptive pill - and still Australian authorities take no action to improve patient information leaflets in pill packaging to adequately warn women of known risks associated with pill use.

The latest death, reported in New Zealand last month, adds to the blood-clot deaths of six NZ women revealed in January. In addition, recent news reports have revealed another woman left severely brain damaged after taking the pill.

While the UK Committee on Safety of Medicines issued a health alert in October 1995 and suggested women change brands after serious risks involved in the use of third-generation pills such as Marvelon, Femodene became known, in New Zealand the Ministry of Health watered down its advice to doctors. In Australia nothing has been done at an official level to inform women of the latest known risks associated with these pill types.

The words "safe" and "effective" and few side-effects" continue to dominate the public discourses on the contraceptive pill. Family planning spokes people rush to press to "assure" women the pills are safe and instruct them not to stop taking them.

Dr James Wright in an article, "Better ways to plan the family" in *The Sunday Telegraph,* March 7, writes: "Regular media scares about the risks of contraceptives are invariably followed by more and more unwanted pregnancies."

The mentality seems to be better a dead woman than an unplanned pregnancy. Unplanned pregnancy is considered a fate worse than death. Dr Wright continues: "Nevertheless, systems now available, especially the "third-generation" oral pill, are safe and highly acceptable."

The latest deaths in New Zealand seem to have escaped him. Or perhaps the words "safe" and "dead" are not contradictory?

"The deaths are unfortunate and tragic, but with the third generation pills deaths are expected..." said NZ senior medical adviser, Dr Stewart Jessamine *(Sunday Star-Times,* February 28, 1999)

Do women using these pills know "deaths are expected"?

The issue of informed consent and the need for accurate information to be provided to consumers of the pill has not been given due attention by health officials in Australia.

It is clear that product information and patient information leaflets concerning various brands of the contraceptive pill in use in Australia do not properly reflect vital research findings on the pill and health risks, reported in the medical literature.

More than 20 studies carried out in the last 10 years all indicate an increased relative risk of breast cancer for pill users. Since 1988, at least 14 papers have reported on the increased incidence of cervical cancer in pill-users. The pill has also been implicated in haematological and cardiovascular risks.

The product information and patient insert leaflets of Schering and Wyeth products ie., Triquilar ED®, Triphasil 28®, Microgynon ED®, Nordette 28® and Biphasil 28® do not reflect the research findings in regard to cervical and breast cancer and DVT. Searle products ie., Brevinor®, have recently updated their product information leaflet to more accurately reflect the research literature in regard to blood clotting, however is equivocal regarding breast cancer and says nothing on cervical cancer.

These leaflets therefore give the misleading impression that there is minimal, or no risk of breast or cervical cancer, or DVT associated with the use of the pill. Unfortunately, the accuracy of the information provided with the pill depends on the individual brand and the date the information was last reviewed by the relevant authorities (for example, the

Australian Drug Evaluation Committee approved leaflet for most Wyeth and Schering products is about seven years out of date).
Women receive conflicting information depending on the particular brand in use. In Britain, legal action is being taken for failure to inform of pill risks.

The British Department of Health has noted 50 pill-related deaths in three years up to December 1997. A total of 170 women have sued pill manufacturers "over deaths and serious illness" (A Gordon "Victims and families sue over 'danger' Pill". *The Mail on Sunday,* February 15, 1998, p. 13). One of the victims was 15 – she had been put on the pill at 14 by a family planning clinic without her parent's knowledge, suffered a stroke at 15 and died 11 months later. Another woman had only been using the pill for five weeks before her death.

The 50 pill related deaths were compiled by the Adverse Drug Reaction On-Line Information Tracking (ADROIT) data base for deaths associated with oral contraceptives. The 50 fatalities reported were associated with the pills: Binovum (1), Cilest (6), Femodene (10), Loestrin (2), Logynon (3), Marvelon (8), Mercilon (2), Microgynon (11), Micronot (1), Minulet (4), Noriday (1) and with Norplant (4).

Her Majesty's Coroner, Sir Montague Levine, has recommended that the exterior of pill packets carry a warning about the pill's potential complications.

Women users of the pill are being given a false sense of security. How can they make informed decisions about their health if relevant information is minimised or not disclosed at all? The Department of Health, including the Australian Drug Evaluation Committee, needs to be pressured to review product information and packet insert leaflets to bring them into line with the latest findings on pill risks.

The Ministry of Health in NZ has been accused of failing to issue proper warnings. Our own Department of Health also stands accused.

Women in Experiments: recent case studies

Melinda Tankard Reist

Introduction

The history of unethical research gives us a context for understanding the need for ethical practices in clinical research. Because of their lower status, the vulnerable - most often women, children, ethnic groups, prisoners, and the disabled, for example, are more at risk of exploitative medical practices. In Australia, public confidence in experimental programs is at an all time low in the wake of revelations in recent times about questionable experiments on orphanage babies, psychiatric patients, the elderly, "tall girls" and other vulnerable groups.

Women have always been used as test sights for experimental treatments - and have often borne the brunt of unrestrained and unethical medical experiments. Witness for example, the history of DES, thalidomide, the Dalkon Shield, and the current debacle over leaking silicone breast implants. There exists a substantial body of research devoted to gaining control over women's reproductive abilities. This is due to the concentration by many in the medical profession on women's reproductive role: gaining supremacy over women's reproductive abilities. Much of the experimentation involving women has been directed at controlling the gamut of reproduction: whether preventing pregnancy, medicating women when pregnant or trying to create pregnancy- and women have in many instances paid a heavy price.

The use of women's bodies to test out contraceptive/abortifacient drugs and devices has led to injured women seeking legal redress against the manufacturers of the Dalkon Shield and, more recently, Norplant.

Injury has resulted from drugs prescribed in pregnancy (DES, thalidomide). Assisted Reproductive Technology (ART) procedures have also caused documented harm. I contend that ART, though presented as therapy, is one big experiment on women - and, indirectly, on the children born through these procedures. Not enough attention is given to the health risks to women and to the children born as a result of these technologies. There is little acknowledgment of the reality of ART as experimental, potentially very dangerous and so far not all that successful. Some feminist critics have gone so far as to describe much of technological reproduction as violence against women - in the words of Janice Raymond, "brutality with a therapeutic face."

NRT have been criticised for their medicalisation of women's reproductive capacity - making infertility into a disease that needs to be cured or at least fixed-up. Again, the woman is not treated as a whole person but is depersonalised as the raw material for science. The language of IVF researchers justifies this contention: women are "endocrinological environments", "therapeutic modalities", "egg crops" and "alternative reproductive vehicles." Dr Renate Klein quotes a French doctor: "The aim of the treatment is to reimpose a normal rhythm over a disordered one, to recover virgin soil.' Women are sometimes spoken of on a par with animals. "The human female is capable of having substantial litters." wrote Drs John McBain and Allan Trounson some years ago.

Feminists activists have also drawn attention to the broader ramifications of these practices - the development of more dangerous technologies such as genetic engineering, sex selection and eugenics, along with population control technologies. There are a number of Austraian case studies I could go into as part of my topic today. But I have chosen two: one designed to ending pregnancy, the other to making pregnancy happen: an abortion drug and an infertility treatment.

The inadequate system of ethical evaluation and trial monitoring in Australia, the unacceptable means by which hazardous drugs are allowed to be trialed on Australian subjects and the inadequacy of the functioning and membership of

Institutional Ethics Committees have been highlighted in a number of clinical trials in the past few years involving women research subjects, the most controversial being RU-486.

RU486

In March 1994, an unidentified official with the Therapeutic Goods Administration authorised the import of the previously banned abortion drug RU-486. That action set in train a series of events culminating in the halting of a Victorian trial of the drug and four separate department investigations into the trials. RU-486 (also known as Mifepristone and sold in France as Mifegyne) is a synthetic steroid which blocks the positive effects of the hormone progesterone, which is necessary to sustain the rich, nutrient lining of the womb during pregnancy. When the function of progesterone is inhibited by RU-486, the womb's lining is broken down and the embryo is destroyed in the process. This is RU-486's most common function. If administered after fertilisation but prior to implantation RU-486 is intended to make the womb unreceptive to the fertilised egg, because the lining is inadequate for it to attach. However RU-486 has a significant "failure" rate when used alone. To make it more effective, the three RU-486 tablets taken by the pregnant women are followed several days later by a prostaglandin injection or suppository. This causes powerful uterine contractions to expel the embryo.

Clinical trials of the experimental chemical abortion drug RU-486 were carried out on 300 women in Australia by the Sydney Centre for Reproductive Health and by Monash University Department of Obstetrics and Gynaecology at the Family Planning Association of Victoria. The trials were part of worldwide trials by The Special Program of Research Development and Research Training in Human Reproduction, (HRP) of which the World Health Organisation is the executing agency. HRP is involved in research to perfect existing abortion methods and to develop new abortion drugs. One trial in Victoria and the trial in Sydney were described as trials of RU-486 for "emergency postcoital contraception" - or morning after pill trials. The other Victorian trial was for "termination of early pregnancy" and involved two combination regimens of RU-486 and misoprostol (prostaglandin). It was this latter trial that was stopped.

As an abortifacient, RU-486 was a prohibited imported unless exempted by the Department of Human Services and Health pursuant to the Customs (Prohibited Imports) Regulations. A policy had been adopted that no such exemption would be given unless the Minister was consulted. Neither the Minister for Human Services and Health nor the Minister for Family Services (Senator Crowley was the Minister responsible for the TGA at the time) were consulted prior to the exemption by the Departmental delegate. The then Health Minister Graham Richardson acknowledged that the official assurances were "breached" and said the Government would see whether it could rectify the situation. He resigned and it wasn't until other procedural breaches were uncovered that the Government and relevant departments became involved.

When concerns about the trials were first raised, the officials responsible tried to assure those concerned that all was in order. But there was obvious confusion. According to the NSW Health Department: "...there is a rigid process, through which every proposal for the clinical trial of a drug must pass, before any research is allowed to proceed. This procedure is in place to ensure adherence to strict ethical, legal and scientific standards. ... This research can not proceed unless approval is obtained, after rigorous scrutiny of the legal and ethical implications of the trial, by the relevant Institutional Ethics Committee and the Therapeutic Goods Administration (TGA)"
However during a Senate hearing, Dr Malcolm Wright, head of the drug evaluation Branch of the TGA demonstrated that this was not correct. "We do not evaluate and if you look in the document it says that TGA has not carried out an assessment to the quality, safety and efficiency of this product in connection with

this notification. That is up front..."

The NSW Health Departments line about "rigorous scrutiny of the legal and ethical implications of the trial, by the relevant Institutional Ethics Committee and the Therapeutic Goods Administration (TGA)" was shown to be incorrect, when Wright, in response to a question at the hearing, stated: "The TGA is not required to and it certainly is not required to approve it because the approval is by the Ethics Committee. That is what the notification tells us." The TGA's only responsibility was to send out a receipt for the application fee for the trial to proceed once approval was granted by the relevant IEC - in essence merely acting as a "postbox, receipt operation."

The Government knows nothing of the trials it clears - it trusts the IEC's. Should those concerned that the highest standards are applied in examining the legal and ethical implications of drug trials have faith in the ability of Institutional Ethics Committees to carry out this grave responsibility? The conduct of the IEC's involved in approving the RU-486 trials do not give us much confidence.

The approving committee in Melbourne was the Victorian Family Planning Ethics Committee and in Sydney, the NSW Family Planning Association Ethics Committee. The membership of the NSW Family Planning Ethics Committee includes Dr. Edith Weisberg, who is the Medical Director of the NSW FPA and State Manager of the Sydney Centre for Reproductive Health - which is conducting the Sydney trials. Should those approving the trials be running the trials?

The attitude of these committees and the researchers involved in the trials, when asked for information about the trials and the process whereby approval was given, illustrated the contempt in which they held public accountability and freedom of information. They complained to the NHMRC that parliament's demands for trial details and consent forms were a threat to academic freedom. There was doubt that the trials were consistent with the NHMRC Statement of Human Experimentation: Supplementary Note 5. In an earlier opinion on the possibility of trials of abortifacient drugs, Dr Robert Jansen, an advocate for human embryo experimentation and former member of the Medical Research Ethics Committee of the NHMRC, stated: "...the NH&MRC's current statement and supplementary notes on human experimentation do not obviously permit such trials." Questions were also raised about the legality of the trials. The Department admitted it did not seek legal advice on the legality of the trials.

There were other factors which led to the halting of the RU-486 prostaglandin trial in Melbourne. Probably the most important safeguard for the protection of subjects in research trials is informed consent. The consent form used in these trials was far from adequate. They did not give full information on the short and long term health risks. They contained no information on the side effects of prostaglandins, no mention of the medical evidence that RU 486 crosses the blood-follicle barrier and therefore can harm woman's ovaries and egg follicles (which raises another question, how can the patient "withdraw from the trials" when the drug is already in her system?). There was nothing in the consent forms about cardiovascular risks not that if the drugs did not work, gross defects could result and a surgical abortion was required.

Perhaps the authors of the informed consent forms hadn't heard of Rogers v Whitaker? The consent forms did not make it clear that a woman must agree to undergo a surgical abortion if the pills fail. Dumble and Klein challenged the attitude of other feminists who hailed RU-486 as a welcome new choice on the contraception/abortion buffet, and who said it didn't really matter that official undertakings had been breached or that the committee was not properly constituted at the time the decision was made. It was also revealed that the mandatory religious member of the Victorian Family Planning Ethics Committee had no involvement with the approval process. He had resigned and a replacement has not been found. Some "pro choice" women said who

cares if the religious member wasn't involved, but as Margo Kingston pointed out in The Canberra Times "What if in such a trial a woman was appointed who never attended and something went wrong? The cries of patriarchal double-speak and betrayal would be deafening." Not only had the mandatory religious member of the Victorian Family Planning Ethics Committee had no involvement with the approval process, the Department of Health was forced to admit that there was no need for any of the people compulsorily on the board to actually do anything or even turn up.

There were more contradictions when health department deputy secretary Ian Lindenmayer, told The Canberra Times the department was completely happy with the patient consent form. The forms "provide the information we believe they (the women) responsibly can be given, given the need to ensure the information is relayed in a straightforward and intelligible way." But Carmen Lawrence disagreed: "Obviously the (department advice) is that it falls short of what's desirable and that's why they (FPV) were asked to do it again."

The tests were suspended August 16 after Minister Lawrence threatened to ban them in the public interest for failing to properly inform women of the drugs health risks and side effects. The debate over RU-486 goes beyond the pro and anti-abortion polarities. It also concerns issues of public accountability, parliamentary scrutiny, issues of ethics, legality, monitoring procedures, in short, weighty matters which need to be given due and proper treatment and consideration to ensure the protection of the lives and health of human subjects of experimental trials in this country. Similar criticisms were made about trials in Sydney last year of the anti-ulcer drug Misoprostol in chemical termination of pregnancy. A prostaglandin, Misoprostol causes the uterus to contract and expel the foetus.

While not manufactured as an abortion inducing agent, Misoprostol was, nevertheless, used off-label in Australia to terminate pregnancies. It was trialed in Sydney by Australian Birth Control Services and the Sydney Centre for Reproduction Research (the research division of the Family Planning Association of NSW) as part of an international trial coordinated by the New York Population Council. The aim of the trial was to determine the effectiveness of Misoprostol in aborting pregnancies between 9 and 12 weeks. The drug was given twice a day for two days or until the abortion took place. Patients were advised they may bleed for up to two weeks and that if they were between 10 and 12 weeks they may pass "obvious products of conception". They had to agree to a surgical termination if the drug failed to expel the foetus -which was the case for 39 percent of the women in the trial.

Some women's health activists feared the risks of abortifacients like Misoprostol were downplayed in the rush to find a replacement for RU486. Dr Renate Klein criticised the patient information sheet as "hopelessly inadequate" in providing full and accurate information of the health risks. The drug has also been linked with congenital or neurological disabilities where pregnancies have been continued after the drug being administered.

At the Family Planning Association's Biological Sciences Conference meeting in May 1997, Dr Geoff Brodie of the Abortion Providers Federation, gave some results of the Sydney trials of Misoprostol. These results showed that:

- Drug failed to induce abortion in 39 percent of cases
- Long lag time between administration of drug and expulsion of foetus
- One woman expelled the foetus in McDonalds
- Sixteen percent of women experienced a drop in haemoglobin levels greater than 20 percent.
- Some women lost 40 ipercent of their blood volume
-Four required emergency D&C, one a blood transfusion and one collapsed at home due to heavy bleeding. Another witnessed the foetus after expelling pregnancy at home.

These results have not been widely disseminated.

CJD

This year, an Australian Senate Committee heard evidence of breaches of proper procedure in the processing of pituitary hormones used in infertility and growth treatments and linked with the rare fatal brain disorder Creutzfeldt-Jacob Disease (CJD). It was alleged Government bodies failed in their responsibility to ensure the highest standards in the regulation and manufacture of biological products.

Women seeking help for infertility, and men and women of short stature were guinea pigs in an unlawful experiment which has so far taken the lives of four Australian women and one man. A South Australian woman is dying from CJD. Recipients of human pituitary hormones live with the knowledge that they could be incubators of the human equivalent of mad cow disease. A form of bovine spongiform encephalopathy (BSE) or mad cow disease CJD causes spongy formations in the brain. Symptoms include loss of balance and coordinator, decline of mental faculties sometimes leading to dementia, jerking movements and rigidity prior to death.

The Senate Community Affairs References Committee was appointed to examine the Federal Government's treatment of recipients of human pituitary hormones, whether the Government's response to the 1994 Allars inquiry into the pituitary hormone program was fair and adequate, whether documents related to the inquiry were withheld and why legal aid was denied to "APQ", a claimant, in a land-mark test case for compensation. The inquiry also examined whether the Commonwealth Serum Laboratory (CSL) or CSL Ltd, the National Health and Medical Research Council, the Department of Health and Family Services or any other Commonwealth department, agency or employee failed to adequately protect public safety in relation to the Human Pituitary Hormone Program.

The test case seeking compensation for nervous shock involving 132 recipients of hormones manufactured by CSL and distributed at the direction of the Department of Health from 1967-1985 was settled in April on the eve of what was to be a 15-week jury trial. The case was hampered by denial of legal aid by the Commonwealth and problems securing necessary documents. An out-of-court settlement involved no immediate money and no admission of liability on the part of the Commonwealth.

Australia was the only country providing a government sponsored program using hPG. It was banned in the US. CSL collected, manufactured and distributed the glands which were derived from dead bodies. A total of 171 091 pituitary glands were collected with removal carried out mainly by mortuary staff who were paid fifty cents for each gland collected. Relatives had not given their consent. Dr P Schiff of CSL's representative on the Human Pituitary Hormone Advisory Committee (HPAC) and responsible to the Minister for Health in overseeing the program, advised gland collectors that "unless the body is badly decomposed it is never too late to take the gland." In other words, decomposing body parts could be removed and processed for use in living humans.

There was enough information in 1966 to indicate that the program should not have been allowed to proceed. However it continued until May 1985 when two US recipients died of CJD. There was no evidence that the hormones prepared from human cadavers had ever been tested for safety. There could have been any of a number of pathogenic viruses e.g. hepatitis, herpes, polio, rubella, measles etc. While examination of the method of preparation showed that viruses would not have been excluded. Thorough testing would have used up much of the hormone available. Tests for CJD were not available but already CJD had been transmitted to monkeys.

The Senate Committee heard damning evidence against CSL. CSL did not follow world's best practice in the pooling and

homogenising of glands, had failed to comply with the Code of Good Manufacturing Practice and told pathologists to ignore the exclusion criteria about possible Hepatitis infected glands. CSL had also failed to utilise a simple technique to destroy the infectivity of enveloped viruses such as Hepatitis B in pituitary hormones. The Department had not taken steps to monitor the health of recipients during and after treatment to determine whether the virus had been transmitted, nor sought to find out if recipients suffered hepatitis or liver problems. Less harmful techniques for ovarian stimulation such as the use of gonadotrophin from menopausal urine, a standardised product with lesser side effects including fewer multiple births and the preferred treatment in almost all other countries, were not used (even though CSL described human pituitary gonadotrophin (hPG) as a treatment of "last resort").

The Committee also heard that in addition to the 2000 hormone recipients on the official program, possibly another 500-600 unofficial recipients were treated with "leftover" product and in other experimental programs. Disturbing evidence was given by reproductive physiologist, Dr Wes Whitten, former assistant director, National Biological Standards Laboratory (now known as the Therapeutic Goods Administration Authority) that batches of pituitary hormones were 99.9 percent impure, i.e only one tenth of one percent pure. "It was a shocking product, I can't believe this had ever been marketed" he said.

Dr Frank Peters, former assistant and acting director, NBSL, told the committee "... it is my opinion that not one batch of fertility hormone met all the regulatory standards and many did not even meet CSL's own rudimentary standards."

Hormone recipients believed the hormones were safe and "natural". They did not know they were guinea pigs in an unlawful, experimental program using hormones processed from glands taken from corpses in morgues. As author of Cannibals, Cows and the CJD Catastrophe Jennifer Cooke puts it: "It is a horror story which begins and ends in morgues." Recipients did not know that hPG had not been evaluated for clinical use before the program started. They were not informed of a risk per treatment cycle of ovarian hyperstimulation of 30 percent. The first guidelines for selecting women for the program was that they should not be ovulating. However ovulating women were given hPG.

It has only come to light recently that some hormone batches were contaminated with Hepatitis B, others were unsterile and that there is the possibility of mother to child transmission of CJD as extrapolated from animal studies. Conflicts of interest were also alleged. Convenor of the CJD support group and a recipient, Sue Byrne told the hearing:

Four people who were intimately involved with the program are actually controlling the program. The regulation of product is being conducted by somebody who works for the organisation who is controlling the products and who invented the process. There were no checks and balances. There was no independent review. There was no scope of expertise. It was a very narrow, a very self-interested group, who were running the ... Program.

Geraldine Brodrick gave birth to nontuplets in 1971. The six babies born alive died within two days. She told the committee, "All who conspired to force this terrible legacy on hPG and hGH [human growth hormone] recipients are now being protected by a government and its officers who would rather see innocent recipients denied justice than admit to the ineptitude and negligence of those involved in producing these treatments and administering this program." The Government accepted the majority of the recommendations of the committee report. It announced that an amount of "up to a further $3million will be allocated to the Pituitary Hormones Trust Accourt to "allow for payments to be made to recipients who can demonstrate that, prior to 1 January 1998, the have, or have suffered, a recognised psychiatric injury due to the recipient having

been informed that they are at a greater risk of contracting Creutzfeldt-Jakob Disease." However the Government would not extend payments to recipients who have suffered "psychological stress or significant life disturbance" at the committee recommended. The Government also decided against extending the eligibility guidelines for legal aid which would have ensured that cases involving issues of public interest be eligible to receive legal aid in the future. The Government acknowledged that there were deficiencies in the operation of the program.

The CJD episode and the bungling over RU486 provide windows into the lax processes and cover-ups by those responsible for regulating human experimentation. It is hoped these and other case examples will lead to a serious tightening of the rules governing human experimentation in Australia.

I'd like to end with a quote from Dr David Howes, former chief virologist and head of biologicals branch, NBSL which doesn't only apply to women but to everyone: "It is the consumers who will pay the heaviest price...when the duty of care plays second fiddle to other imperatives..."

Reference:

This paper was originally given at the Experimentation on Humans: Dilemmas for medical research and practice at St John Fisher College University of Tasmania on Saturday 19 September, 1998

Melinda is a Canberra based writer with a special interest in women's health, bioethics and the abuse of women in coercive population control programs.

Indian women's groups question contraceptive vaccine research

Ganapati Mudur, New Delhi

Women's health groups in India have called on scientists to abandon research into contraceptive vaccines. Activists staged a protest outside the opening of the 10th international congress of immunology in New Delhi last week, describing immunological routes to contraception as "scientifically unsound and inherently unsafe." On the eve of the congress, the non-governmental Saheli Women's Resource Centre released a report that accused scientists of pursuing trials of contraceptive vaccines on humans without conclusively establishing their safety.

The report says that the efficacy levels shown for contraceptive vaccines are unacceptable. Six contraceptive vaccines, all aimed at eliciting antibodies against reproductive hormones, have reached phase I clinical trials in different countries. Only one vaccine--developed at India's National Institute of Immunology in New Delhi - which is directed against the human chorionic gonadotrophin hormone has passed through phase II clinical trials, which were carried out in the late 1980s. Only 80% of the women who received the vaccine raised antibody titres above the threshold of 50 ng/ml which is required to prevent pregnancy.

"We've established the scientific feasibility of preventing pregnancy by immunisation," asserted Gursaran Talwar, who developed the Indian vaccine. However, he conceded that the uncertainty of achieving an adequate immune response in every recipient was an inherent problem. The Indian government has not approved phase III clinical trials of the vaccine but continues to fund research on contraceptive vaccines.

The Saheli report also claimed that Indian researchers followed up children born to women during or after the trials for only four years. Dr Talwar, however, reported that long term studies of the progeny of primates tested with the vaccine have shown that it is "completely safe."

Delegates at the congress suggested that opposition to basic research was "premature and unscientific." "The goal is to widen the contraceptive options available for women," said

Satish Gupta, from India's National Institute of Immunology.

Unethical medical trials lead to reproductive health problems for women

Janet Cregan and Tricia Gardner

Below is a letter recounting an unethical drug trail on girls in Australia, which has led to them suffering a variety of reproductive and infertility problems as they get older. South Asia is particularly vulnerable to these sort of drug trails where the subjects are not informed that they are participating in an experimental trail, as evidenced in the Quinacrine sterilisation trails in India and elsewhere.

E-drug: Stilboestrol adverse effects

Dear Sir/Madam,

Approximately 17 months ago a group of women in Australia discovered they had been part of an experimental trial using the following drugs diethylstilboestrol (DES), ethinyloestradiol, norethisterone. The trial was conducted on organically healthy girls who were very tall, in an effort to 'stunt their height'. This trial was conducted between 1959-1975 using heroic doses of the drugs mentioned. The children were approximately 10 years of age (although some as young as 8 years of age) and were subjected to the experiment for up to 4 years duration.

The parents were not informed that this was an experimental trial. They were lead to believe that this was a bonafide treatment without any long term side effects or ill effects. If reassurance was not sufficient that the 'treatment' was extremely safe and had been used with 'safety' for years, other inducements were used. For example, parents were told that their daughters would have to have pieces of bone removed from their long bones to correct the 'predicted' extreme height that would 'inevitably' happen.

The women's discovery of the trials was made possible by the research of two investigative newspaper journalists: Gary Hughes, 'The Age' in Melbourne, and Gerard Ryle also at 'The Age' at the time, but now at 'The Sydney Morning Herald'. They appeared to be interested in postwar experimentation and unearthed the research papers. As the women came forward we developed into a group called Tall Girls Inc, as that is what the media and research papers dubbed us. A documentary was made by another Investigative journalist - Belinda Hawkins at network SBS in Melbourne, Australia.

The women are now suffering a variety of reproductive and infertility problems. Most of us never made any connection between the 'treatment' we received and DES. As we were either too young to understand the drug name which was labeled 'stilboestrol' and later to make any connection to the term DES and the effects on DES daughters. Enquiries to gynaecologists led to very little further information. We are a distinct group of people who are suffering similar reproductive problems like the DES daughters without the structural defects of the reproductive system that they have suffered. The Tall Girls group has developed a database of 135 women and the following statistics have been developed from phone testimony or questionnaires returned to us. These histories are far from complete or definitive, but certain trends are apparent. Of the 135 - 1 in 3 have experienced ovarian cysts; 1 in 3 have had problems with fertility; 1 in 5 have endometriosis; 1 in 10 fibroids; 1 in 10 have had an hysterectomy and 1 in 6 a miscarriage.

We believe that these figures are a reason for concern.

The endocrinologist who instituted this trial brought back the foundations of it from Boston, America. We have had contact with two American women similarly treated as children, who have the same reproductive and health problems as their counterparts in Australia - they have found us. It concerns our group that there are also a large contingent of women in America and Europe who are at risk and probably wondering why they are having many reproductive and

health problems. They are also at double risk if their mothers were give DES.

I have read an article recently sent by a 'Tall Girl' in America written by 'The Boston Sunday Globe', dated March 5th, 1967 (page 1 and 14), it mentions that the 'treatment' was thought about in the 1940's but 'treatment' was put off for fear it might interfere with fertility. The article then states....'The work at the Children's service of the M.G.H., headed by Dr Nathan Talbot, and in other leading centres from Boston to Melbourne, Australia indicate the therapy is safe. Unfortunately, the trial was still at too early a stage to convey this comforting information. It also did not have any real significance in reducing height.

There is a lot more to this story that I cannot convey to you about the mechanics and spread of this 'treatment'. At this time though, it is paramount that the women concerned are notified of the research and its possible repercussions. We have thought about relaying this information and the effects emotionally it may have. If our experience, in Australia, is anything to go by, that is, meeting up with women who have been similarly affected - it has been an answer to the puzzling reproductive and health problems we have had. To not feel so incredibly alone with 'it'.

We look for support from you to disseminate this information. To discuss it with fellow scientists, or the medical fraternity, to research and discuss, whatever your capacity. I hope to develop open channels to communicate our discovery and for you to discover what you can about our experience (and your countries experience), reproductive biology, endocrine disruption or similar, with others. Any help you can give, we will be very grateful to have. If you want copies of the research papers we have - please correspond with us.

Thank you
Tricia Gardner

©Tricia Gardner
24 Murray Street
YARRAVILLE VICTORIA, 3013,
AUSTRALIA
0011 61 3 96872844 (PHONE)
0011 61 3 98185421 (FAX)
datr@bigpond.com.au
www.users.bigpond.com/datr/index.html
OR
Tall Girls Inc.
PO BOX 7
CARNEGIE VICTORIA 3163, AUSTRALIA
21 SEPTEMBER 1998

Who Says You Can't Win Then All

Carmell Flavell

In December, 1990, after fourteen years of marriage, my husband and I separated. As I had three children and was not working, and had just found out I was pregnant again, I decided that in order to secure a future for my family, I needed to find work. My ex husband suggested I abort the expected baby, however I refused and decided to go ahead with the pregnancy. I decided not to undergo any prenatal diagnostic testing. It was explained to me that testing may reveal any abnormalities with my expected child, however, aborting my child because of disability was not an option for me. I decided to proceed with the pregnancy.

At 28 weeks into the pregnancy, I undertook a secretarial refresher course of six weeks full time study. I booked my youngest child and expected child into care. The pregnancy was uneventful, however, when my son, Michael was born, the attending midwife said to me: "He looks strange, he looks like he has Down Syndrome to me. Do all your children look like that?" As Michael was only seconds' old and I certainly had not had time to get my thoughts together after just giving birth, I felt emotionally and physically destroyed. She was right, however. He would not feed, and all he was doing was sleeping. After being transferred to the maternity ward, I reported my concerns regarding Michael's lack of interest in feeding to the sister on duty. She told me that I was probably not feeding him properly, and proceeded to take the bottle from me to demonstrate how it was done. She too, was unsuccessful in feeding him.

As a result the paediatrician examined Michael and confirmed Hirschsprung's Disease, a lack of nerve cells in the bowel, preventing bowel evacuation and requiring three separate stages of surgery. He was three days old when he was baptised at hospital and transferred to a Sydney hospital for the first stage, a transverse colostomy. Down Syndrome was also confirmed, and a paediatric cardiologist confirmed congenital cardiac failure. Michael had a Patent Ductus Arteriosis and a Ventricular Septal Defect This meant he had two holes in his heart. The P.D.A closed, but the V.S.D. never will. The consulting paediatricians raised concerns about the dangers of surgery, but the cardiologist said without surgery, he would die. So surgery was performed and was successful. Michael had a colostomy which he would later rip out with the enthusiasm and speed of Mario Andretti, chew on it, and wave in the air with great excitement.

Before his surgery, however, the head neonatologist said to me "Well, he has congenital cardiac failure, and Hirschsprung's Disease, do you realise he will be mentally retarded as well'?"

Again I was floored by the insensitivity of such a prominent person. The fact that my son had Down Syndrome, and had an intellectual disability did not phase me at that particular moment, I just wanted him to live.

After three weeks of confinement in hospital, Michael was finally discharged. As I had no money, I asked the social worker at the hospital if she could help me obtain a car seat for my son. She told me that she could not help me and did not refer me to anyone who could help me. At that time I had no knowledge of charitable organisations that existed for this purpose and of course since discovered that I could have been referred to organisations such as Lifeline, the Sydney City Mission, or other existing organisations. I was referred, however to the Down Syndrome Association, but I felt that I was not ready at the time to be confronted with Michael's disability as a reality, I was too involved with his survival.

A significant person in my son's survival was his general paediatrician. He was able to appropriately discuss my son's disability with me, and answered every question regarding the concerns I had about Michael's future without hesitation. He lessened the stress of my son's medical needs to a major

degree. I knew Michael was in the best care while this doctor was his paediatrician In addition, Michael's community nurse from the Developmental Disability Team saved my sanity on many occasions. She was one of only a few people who would find someone who could help if she could not. For a while, Michael's Occupational Therapist visited us at home and gave me further confidence to do all sorts of things with Michael, even though he had a colostomy bag.

It was apparent to me, however, that Michael's needs would be paramount for some time to come, so my plans for working were temporarily shelved. The day I brought him home from the hospital I was told to watch for two things and they weren't nappy rash and colic. I had to watch his tongue and his stoma for signs of going blue. If the tongue went blue it meant heart trouble. If the stoma went blue, which was the part of the bowel protruding on the surface of his abdomen, it meant bowel strangulation. I was also told to watch that the stoma did not pop out, but it did, about twenty times per day, every time he moved, coughed or cried. I had to manipulate it back in time and time again. I ended up taping it in over the bag to prevent it from prolapsing. The same day I brought Michael home, my second oldest daughter broke her arm at school, so I had to go back to the hospital that day with the rest of the family for her treatment. Her broken arm meant many more visits to the orthopedic specialist.

Michael's needs required much paediatric intervention: the general paediatrician, surgical paediatrician, paediatric cardiologist, and when available, physiotherapist, speech therapist, occupational therapist, the stomal therapist for his colostomy, the ear, nose and throat specialist, the endocrinologist, speech clinic for his apnoea, the podiatrist and the ophthalmic specialist. I was frequently travelling all over town for specialists. On one occasion, Michael had a surgical and cardiology visit in the one day. My daughter's orthopedic specialist insisted that she be seen on the same day in the afternoon after the visits I had in town with my son's specialists. I explained to him how difficult it was, that I had to take the four children to town for Michael's two specialist appointments, but he was unmoved and said he was going on holidays so we had to take that appointment or none.

At the age of nine months the second surgical stage was performed on Michael, the Duhammel's Rectosigmoidectomy, in which the bowel tissue was fused to activate nerve cells in the rectum. He was in a gallows cot in traction for nine days. An Ikeda clamp doing the fusion in his rectum had become lodged and had to be surgically removed. The anaesthetist later told me that he thought Michael dribbled too much and should have surgery to remove taste buds from his tongue, even though he was only nine months old. I emphatically declined. I was later to discover that his appendix were removed without my knowledge or consent. Although I understood their rationale, it would have been nice if I had been asked. However, that decision was made for me.

At twenty months his colostomy was successfully closed. Soon after his sleep apnoea was attended to: he had his adenoids removed and grommets inserted.

After this he had many hospital admissions both related and unrelated to Hirschsprungs Disease. Most admissions were due to respiratory infections. On one admission, polyps were found in the bowel and the question of a malignant growth in his bowel was raised. The gastroenterologist informed me that his bowel might have to be removed. I waited for five days in absolute distress to get the results. As the pathology unit was closed for the weekend, I had to wait. The results eventually showed the polyps were benign.

Michael was admitted to hospital approximately once every two months for the first few years of his life. As nursing staff levels were dangerously low? I had to be at the hospital as much as possible, even though I was working and studying as well as caring for the family. To overcome this problem, I took my three other children with me, as well as my typewriter and set up next

to his bed. During these admissions, Michael became quite familiar with the intravenous drip. He would disconnect it repeatedly, and with poor nursing staff levels, this was a problem of major proportions. For four days in succession on one admission, he had disconnected the drip, the first day I found him in his cot with blood all over the place. The second day, after I was shown by the staff, I was able to shut off the canula and stop the blood loss, then I notified the staff. On the third day, he disconnected the drip but I was not panicked as I could control the bleeding. But on the fourth day he not only disconnected the drip, but was holding the tube in the air and drinking it. It soon became apparent that in order for the drip to stay in, it was necessary to put his arms in splints and insert the drip in his toot. He overcame this by disconnecting the drip with the big toe on the opposite foot.

Soon after these events, Michael developed asthma so a nebulizer was required. All the time I felt like Michael was a jigsaw puzzle and I had to put bits of boy back together all the time.

There have been night admissions as well, where I had to leave my other children at home to admit Michael. During all of this my other children were suffering. As a result of the difficult situation, both my older daughters needed ongoing counseling. Their school grades fell dramatically. They had to bear the situation as best as possible. They also had to cope with the separation and divorce of myself and my husband, and the fact that he was in no way supportive. One of my daughter's needs became especially acute when I discovered that she had an eating disorder. She lost a life threatening amount of weight and needed the intervention of specialists for approximately one year. Although she appears to have fully recovered, I feel I am forever having to closely monitor her health and well being.

Although I had support from my own family, it has been very difficult for myself and my children to survive. But the most difficult has been the reactions from society. He has been called "Handicapped, Mongoloid, retard, and brain damaged". When we go out as a family, people often stare at Michael. This is difficult for Michael's sisters and myself to endure as we are only too aware of the pain and sickness he has experienced without having to be a victim of social stigma.

By the time Michael had turned two I had become quite cynical about existing organisations who dismissed our needs, and about the lack of services available for families who have children with disabilities. When the original organisation called Families First was formed however, I finally received the support and nurturance I needed to continue tending to my family's demands. Although all the children in the program at Families First have a vast degree of varying disabilities, I gained the specific support I needed from staff and other parents. The friendships I made will stay with me forever.

Michael now is 7 years old and well. He still has his ventricular Septal defect and the infrequent hospital admissions. His development is delayed, however, our whole family adore him. He did not walk until he was three and a half years old. He does, however, attend school and is coping well considering his painful introduction to life.

Michael's scholastic needs have been more than adequately attended to by a school for specific purposes, whose staff has been flexible and very supportive of Michael's needs. They have helped Michael achieve skills past my wildest dreams.

The key words here are "delayed", not "stopped", and " disabled" not "unable". It is not Michael who is the problem, it is the ambivalence and negativity, the lack of knowledge and understanding and lack of networking in society that is the problem. Some say the answer to disabled children is abortion, to get rid of the imperfect child. If I had done this, I would have deprived the world of a beautiful child that has contributed to the cohesiveness of our family, something that no one else could have done so effectively. His sisters love him as their brother, his disability is

irrelevant to all of us.

While I was in hospital with Michael, I became aware of not only my family's acute needs, but of those of other families in similar situations, and the lack of support we all received, especially during the most trying time of our children's illnesses. This lack of support was a focal point for me to commence building a career. I became a volunteer Lifeline telephone counselor for four years and embarked on study as an off-campus student with Deakin University. For a time I joined volunteers with another organisation where I met a lecturer from the health faculty of University of Western Sydney, Macarthur. We became firm friends and I insisted she visit Families First as we had something in common, she had a sister with Down Syndrome. She introduced her friend, a psychologist, who became involved in the program as well, and then moved on to assist other programs within the Macarthur district. This also led to an invitation being extended to me to give a number of presentations to third year nurses at UWS Macarthur about my experiences with my son.

Soon after this I became employed with Family Support services as a casual worker, then became a permanent part time special needs worker.

The next step was to find adequate before and after child care for Michael. The first child care centre I found was an absolute disaster as they could not cope with my son's special needs. After this experience, my daughters cared for him. In the meantime, I put Michael's name on a waiting list with a family day care centre in the Macarthur region. I inquired about the special subsidy care program available for children with special needs but discovered there was at least a long waiting list. After two years of no assistance from the family day care centre, I was told that although the organisation would take him, the carers would not! It was up to me to find alternative private care which I have now done. There are, however no centres appropriate for Michael's needs at this time.

As a family unit, everyday has been a fight and struggle for us, not only financially but emotionally and socially. As a result of a child making a derogatory remark about Michael to my daughter at school which was "clap, clap for the handicapped" another parent and myself gave a successful talk to the children at the school about our experiences with disabilities in the family. The reaction was very favourable.

My experiences have shown, however, that there are major gaps in the community that need to be addressed. Serious gaps I would identify as working against our family with a special needs child are lack of referrals, lack of acknowledgement of family needs and supports, lack of education in schools regarding disabilities, lack of adequate child care facilities for disabled children and quite often lack of sensitivity and concern within some professional circles as to the specific situation of families.

Everyone can play their part to bridge these gaps. Ask families about their needs, bring information to families and allow them to make choices. Families are experiencing the consequences of gaps within disability services and have knowledge through these experiences. Services need to actively listen to families to assist in addressing inadequacies. Because parents have children with disabilities, professionals often treat parents as idiots. Past practices have left parents feeling powerless and pushed into decisions they do not want to take. Encourage them to make decisions for themselves by consulting them. If parents cannot be empowered, they cannot empower their children go become independent.

Carmel Flavell currently works with families who have a disabled member. She has been involved with developing an organisation (Families in Partnership) with

University of Western Sydney, Macarthur, Campbelltown and Macarthur Temporary District Family Care.

All correspondence should be sent to:

FINRRAGE (Australia),
c/o Australian Women's Research Centre (AWORC)
Deakin University,
Faculty of Arts,
Geelong, 3217.
ph: 613 (03) 5227 1335
fax: 613 (03) 5227 2018
mobile: 018 946 912
email: klein@deakin.edu.au or capri@deakin.edu.au

- Your donations will assist:
- Anti-Pregnancy 'Vaccine' Campaign
- FINRRAGE (Australia)

All cheques should be made out to FINRRAGE (Australia)

Check out our web page via http://arts.deakin.edu.au/guymer/aworc/finrrage.html

International FINRRAGE (Feminist International Network of Resistance to Reproductive and Genetic Engineering) is a network of feminists in over 35 countries concerned with the development of reproductive and genetic technologies and the attempt to control population quantity an quality through controlling women's reproductive capacities. Women in the developing world and poor women in the industrialised countries are increasingly faced with unsafe, harmful and coercive contraceptives. Other women are the subjects of experimental technologies, such as in-vitro fertilisation which are promoted as pro-fertility and involve the use of harmful drugs and invasive surgery.

FINRRAGE aims to monitor international developments in the area of reproductive medicine and technology; to assess their implications for the socio-economic position and well being of women in different situations, cultures and countries and the impact on the environment; to raise public awareness and extend links with women internationally; to analyse the relationship between science, technology and social relations in patriarchal societies, and the implications for the feminist movement and the development of alternatives; to work towards feminist resistance to population control policies.

Regular **FINRRAGE** information packs contain a bibliography, selected articles of special interest, network news of **FINRRAGE** activities, working groups, dates, new books etc. Theme packs on specific issues are also produced.