

Fertility, a Human Right

According to Catherine Garner, author of "Principles of Infertility Nursing", "Infertility is the inability to conceive a child after a year or more of unprotected intercourse or the inability to carry a pregnancy to live birth (recurrent miscarriage)." Today 1 in 5 couples struggle with infertility. Of these 50 - 60% will conceive, while the others will spend thousands of dollars and years of unsuccessful treatments to come to a negative end. How does this happen? Is infertility a new diagnosis? Why didn't past generations have this problem? The answers are complicated, the solutions expensive. Factors involved are: delayed childbearing. In past generations, women were educated to a minimum. Girls were taught how to keep a house and take care of a baby. School wasn't really a necessity. After all they would get married and their husband would take care of all the complicated things. Money matters, including savings, investing, retirement would all be taken care of by the husband. Women didn't need to worry. Just stay home and clean the house and have the babies, the men would take care of all the complicated stuff. Women today don't look at education in the same way. Most women today go to college and start a career before there is any interest in getting married or having a baby. Women want to have security and not a husband to take care of them. So while the past generations were having babies in their teens, in the 1990's it's not unusual for a woman to be between the ages of 30-34 when they have their first baby. The bad news is peak fertility for a woman is between the ages of 13 - 24 years of age. Fertility rates dramatically fall after the age of 35. At this age there is an increase in ovulation disorders. Women tend to have more sexual partners and are at greater risk of sexually transmitted diseases. Once women make the decision to have children then there are may be cultural or family pressures to hurry and have the children. When fertility doesn't come easy, couples experience loss of self esteem, loss of a dream for a family, and at times the relationship between husband and wife becomes strained. With all this pressure on board, when the couple seeks medical treatment, to their dismay, they find fertility is considered an elective service and most insurance companies will not pay for their treatments. There are currently seven states that have infertility covered in their mandated care laws. In the rest of the states, this diagnosis is a self pay item. Infertility, as a diagnosis, needs to be considered for Federal Mandatory Health Care Coverage because reproduction is a basic human right, it can be costly for the couple, and permanent emotional scars may result if the issue is left unresolved.

The authors of "Fertility and Reproductive Medicine", Kempers, Cohen, Haney, and Younger state in their textbook, "One of the basic human rights is that of a woman to be able to decide when and how to conceive." There are laws that protect women from unwanted sterilization. The ACLU (American Civil Liberties Union) has a reproductive project. They conduct litigation and public education on these issues. Since 1960 this organization has been fighting to protect women's right for access to birth control, the right to have a child and the right to not have a child. In 1977 this organization litigated Walker vs Pierce. Because of that trial we now have federal regulations that prohibit recipients of Medicare from sterilization without consent. In 1985, Virginia was forced to inform 8000 women from a state mental institution, that they had been involuntarily sterilized. The state was forced to give the women counseling and treatment..Also women who receive Medicare cannot be sterilized before the age of 21. It is believed that young women, over-stressed with children at an early age need a chance to mature before making such a permanent decision. The stressors of early childbirth, single parenthood, high divorce rates may cloud the decision making process in young women. This litigation established reproductive freedom for women to have the right to have a baby. It is a fundamental constitutional right as shown in the First, Fifth, Ninth, and

Fourteenth Amendments of the Constitution. So what do we do with women who are unable to get pregnant through the “normal” process? What if having a glass of wine and just not thinking about “it” doesn’t work? Are we violating their right by not mandating insurance companies to pay or at least help out with the cost of treatment. There are laws against sterilization , what if you are sterile and don’t know why?

There are laws to protect women if they don’t want to have a baby. In 1973 Roe vs Wade paved the way for women to get out of the back alley clinics and go to clean, sterile clinics to have abortions if they chose not to have a baby. This right is protected because it is well known an unwanted pregnancy can cause negative physical, mental, and social side effects on a woman. An abortion by definition is a termination of a pregnancy. In the United States it is law for a women to have an abortion up to her sixth month. The procedure is done by a Doctor, under sterile conditions, using local anesthesia. Women can return to normal activity with in 24 hours. The physical effects are not well tolerated by a woman who is forced to carry on with an unwanted pregnancy. These women tend not to follow their Doctors instructions, if they even bother to go to a Doctor. Proper nutrition is a problem . Both the mother and child can be hurt by this. These women do not do well with the labor process. Excess medications can lengthen an already agonizing process. The woman’s mental state is also affected. These women do not bond well with these babies and child abuse may become an issue. A woman’s social life may be affected by an unwanted pregnancy. She may lose her job because of lost work time. It may affect her current, existing family. Money is a big issue. Can she afford another baby? It’s a nice fantasy to think the father of her baby will help to support her, but many social situations prove this not to be the case. We may not agree with some of these social problems. It’s very easy to hide our head and say this isn’t my problem. My sister, my daughter would never allow herself to get into a situation like this. But unfortunately many sisters and daughter fall into this unfortunate place. The law helps to try and help these women, it tries to avoid the additional problems that will happen if this pregnancy goes through. Most important it tries to protect girls and women from an unwanted pregnancy. It protects these women from the horrors that await them in the back alley clinics. Our sisters and daughter should never have to face those deadly clinic ever again. Never again should a girl or woman be sterilized or killed by one of these doctors, never, never again.

There are currently laws and guidelines that are on the book for infertility. How good those laws are depend on where you live in the world. A law according to “Fertility and Reproductive Medicine” is “regulations governing the centers and members of the team and there are sanctions in case of non-application.” A guideline “centers may not respect rules and will not be sanctioned”. However a suit can be filed for complications or violation of guidelines laws. So, laws protect the potential consumer. Guidelines should be followed or the clinic can be sued.

In 1978 the European Convention made it law that even lesbians and single women had the right to bear children. During the early years of ART (Assisted Reproductive Technology), there were no laws regulating what the clinics could do. There were great advancements made, the first baby, Louise Brown was born. The clinic developed protocols for embryo freezing, hatching, and safe treatment cycles. But the politicians thought the doctors were acting to much like God so now the people making the laws know nothing about the medical practice of ART or any other medical procedure for that matter. They wish to please their electorate. In countries such as Germany and Hungary, access to Art services is reserved for married couples only. Austria and Denmark require cohabitation proof of 2 years or more to be eligible for services. In Canada and the U.S. we do not have restrictions on the marital status, but each clinic can set up its own guidelines. There are some

clinic that will not accept single or lesbian women. There are strict laws in Europe which direct how many embryos are to be put back into the woman. Denmark Sweden and the U.K. restrict this number to 2 embryos per try, four in Brazil and the Czech Republic. Currently there are no laws in the U.S. restricting the numbers of embryos used in each cycle, that is still a private matter between the doctor and the patient. Currently there are 35 states that have laws regulating donor insemination. There are 5 with egg donor laws on the book and 4 that regulate embryo donation. According to Susan Crockin, Esq., from "Fertility and Sterility", she wrote to the Editor's Corner and stated, "The Assisted Reproductive Technologies (ART) and collaborative reproduction have brought the unparalleled joy of parenthood to thousands." Today's laws and technology do have a wide gap. The politicians love to make headlines of the litigations that occur with complicated outcomes of ART and social issues and outdated laws. The lawyers are quick to point the finger at the medical community and place blame there. Do they look at their antiquated laws? Do they easily alter laws in complicated social issues? Just look at Children & Youth Services. How many children die each year even though they are under the protection of this service. Now this same government wants to make decisions on the unborn, the potentially born. Susan Crockin also states, "As my law practice keeps providing to me, infertility programs no longer practice medicine. Instead they regularly face decisions about parental rights, marital obligations, physical and psychological fitness, privacy and disclosure concerns, and other interdisciplinary issues. These issues invite, if not demand, closer collaboration with other professional disciplines." With who, the lawyers, the politicians. Professional who have no idea what it means to practice medicine. Every day in medicine these issues are considered in all kinds of medical treatment. Parental rights and marital obligations are considered when treating a pediatric patient. Physical and psychological fitness is considered when prescribing medication. Privacy and disclosure concerns are now an issue even when filing insurance claims. Unfortunately these are the people who will regulate the monies needed by the infertile. The politicians know nothing about medical practice. They wish to please only their constituents. Their concerns are centered with the cost and how can they reduce them, to make themselves look good. The people making these decisions are more concerned with power in the government and it shows the wishes of the people they wish to impress.

What choices do couples have? What do they have to endure just to have a baby? When a couple has been trying for more than a year (6 months if the woman is age 35 or more) with no contraception and no success, their first step is to see a Reproductive Endocrinologist. This is usually a MD with a back-round in OB/GYN who has specialized in reproductive medicine. In order to call themselves RE, he/she will have successfully completed written and oral exams. Fifty % of the OB/GYN's do not successfully complete the exam. Obviously you have to be extremely knowledgeable to be able to call yourself this title. It is wise to select out the specialist when the couple decides to seek treatment. If the woman goes to the local OB/GYN he will only be able to do some basic test and treatments, if unsuccessful he will then refer her to the specialist. At the specialist they may need to repeat some of the test, some are painful, and they may have wasted precious time. If the woman is over the age of 35, this unfortunately is called advanced maternal age, she don't have time to waste. If the woman is over the age of 40 she should run to her local RE's office. The first thing the couple needs to consider is the natural conception rate. For a couple having "timed" intercourse, if they are between the ages of 13 - 24, the chances of natural conception, per month, is 25%. On the negative side, if you are paying a bill trying to conceive, you have a 75% chance of not being successful. If you are just at home having intercourse, you always have next month. After the age of 24, the stats start to fall. At the age of 35, the patient has less than 19% per

month. At the age of 40, the change of pregnancy will drop to less than 10 %. When the couple decides to go to the MD's office, he/ she will initially conduct an interview. This interview is quite graphic. He needs information on menstrual status, intercourse frequency, lubricants, and past reproductive history. For some patients this interview is very difficult. Most couples are not prepared to discuss the most intimate details of their love life. Next comes the exam and scheduled tests. The MD will run some tests to look for obvious problems. This will include post coital test, hysterosalpingogram, endometrial biopsy, hormonal blood tests, and for the man, the dreaded semen analysis. This is considered the basic work-up. If the patient has no insurance, the cost may be up to \$2000.

If a problem is found, the MD will recommend treatment and proceed from there. Sixty percent of the patients going through this work-up will have all normal results from the testing. Next step is then ovulation induction. Depending of the patients age, the MD will probably recommend Clomid therapy. This is a pill taken for 5 days at the beginning of the month to help the woman ovulate. Cost \$60/month. Clomid is usually tried for 4 - 6 months if no success then on to the next step. That step may include a laparoscopy. To check inside the woman's pelvis to determine scarring or endometriosis, a disease process that may impede pregnancy. Most insurance companies will cover this procedure. If you have no insurance, cost \$5000 and up. Next, we move on to more aggressive therapy, Gonadotropin and artificial insemination. This therapy includes daily injection. The patient takes these injections for 7 - 10 days per month. She is taught how to give the injections to herself or the husband can also be taught. This medication works on the ovary to make more than one egg in a cycle. The thought is to give the sperm more opportunities for fertilization and pregnancy hopefully will occur. Side effects: multiple births or canceled cycles to prevent possible multiple births. Artificial insemination (IUI) can be included to help increase the chances of success. IUI is a process when the man will provide the andrology lab with a sperm sample. The lab processes the sample to remove just the live sperm. The processed sample is placed in the woman's uterus, a procedure no more uncomfortable than a pap test. This hopefully will also increase the pregnancy chances. Cost: \$2000/month. About half the insurance companies either limit coverage or will not pay for this treatment.

After 8 -10 months of trying these therapies is no pregnancy has occurred the MD may recommend Advanced Reproductive Technologies (ART). This can also be looked as additional diagnostic measures. This therapy involves the use of Lupron, a medication that will help to control the ovulation process, high dose gonadotropin therapy. And an in & out surgical procedure called IVF (In vitro Fertilization). During the surgery the MD removes the eggs from the ovaries and sends them to the andrology lab for evaluation and fertilization. The woman is given conscience sedation for pain relief and is able to be discharged 2 hours after the procedure. The lab collects a sperm sample and inseminates the eggs that were harvested. The embryologist can determine egg quality or detect egg defects under microscopic examination. Sperm abnormalities can also be determined at this time. If there is a low sperm count. ICSI (Intracytoplasmic sperm injection) can be done at the time of insemination. The embryologist actually will inject the egg with a sperm to increase fertilization rates. from 0% -20% fertilization. Twenty four hours later the couple will have embryos. The embryos will be returned to the woman's uterus 2 - 5 days after fertilization. Typically 3 embryo are returned to help increase the odds of pregnancy. The odds of getting pregnant, with a single baby, if the patient is under the age of 34, ranges from 30 - 60% depending on the statistics the clinic has reported to the federal government. By the way, it is law for all IVF clinics to report yearly stats of their clinic. A form is filled out reporting details of the cycle, if pregnancy occurred, multiple

pregnancy, and pregnancy outcomes. If the woman is age 35 - 40 pregnancy rates are 20%. Dismal results occur if the couple waits until after 40 years of age, less than 10% with a 50% miscarriage rate. After the age of 40 the MD will probably recommend donor egg, which will increase the pregnancy rate to 30 - 60 %. Multiple births occur in about 20% of the pregnancies, mostly twins. About 3 % will conceive triplets. Less than 1% conceive more than triplets because very few clinics will put back more than 3 embryos. Imagine these clinics can produce pregnancies better than mother nature! However the insurance companies consider these procedures experiential even though the first child born from this is 20 years old. Very few insurance companies will help couples pay for this. Cost \$10000/cycle.

According to "Fertility and Sterility", Dr. D. Stovall MD and his colleagues "Infertility healthcare costs are difficult to calculate and are often overestimated." So these Doctors did research at their university using data from a self insured, fee for service health care plan. Their results showed that most couples do not need the high tech, high cost IVF procedures . Most patients got pregnant in the first 6 months using the low tech, low cost procedures. The study was very complex because of the complexities of the diagnoses and the fact that patients under going basic treatment either through their OB/GYN or their RE is not reportable like IVF is. A study done at the University of Iowa Hospital and Clinics did show that by adding infertility, including IVF to the health coverage it would cost an additional \$2.79/member/year. This study used the data collected from the clinic and calculated a cost per member/month based on the total number of lives insured.

The study was performed on the employees of the university from 1993 - 1995. The employees could seek infertility treatments without any out of pocket payment. Services included basic diagnostics, ovulation induction, IUI, donor egg or sperm services, IVF, embryo cryopreservation, and frozen embryo transfers. Patients who had undergone previous sterilization could also participate (Most insurance companies will not cover any services if you have the preexisting condition of permanent sterilization. This applies to both male and/or female in the couple.) Women over the age of 42 were not permitted to do IVF with their own eggs, based on the dismal statistics for that age group (0%). These women were offered donor egg. However at the age of 50 all services were terminated. Women with FSH (Follicle Stimulating Hormone) levels greater than 20 were not permitted to use their own eggs and again donor eggs were an option. In the end the statistics showed: Patients of all ages, (accepted parameters) got pregnant on basic infertility treatment, Clomid/Gonadotropin/IUI therapy, 10 -11%/month. With IVF/FET the patients got pregnant 30 - 34%/month. Multiple birth rates ranged from 5 - 36%. This study in the end shows that there is only minimal cost to adding infertility coverage to the policies. It is truly a myth that this coverage will "sky rocket" the cost to the consumer. Everyone is paying for maternity benefits. This part of the population will never get to use those benefits if treatment is out of site. How many people are paying for maternity benefits that have past their reproductive time or decided the time has past no matter what their age? You are paying for maternity care, male or female consumer, right now.

For couples suffering from infertility this is truly a life crisis. They feel isolated from family and friends. The treatments seem to go on and on with no ending in sight. Other people don't seem to understand and many are insensitive. How do you avoid the families questions? How do you not hear the excitement in the grandparents voices when they talk about their future grandchildren? What about the social stressors: the daily news report of abused and abandoned children, the unwed, pregnant neighbor who already has four kids, your cousin's baby shower, or Christmas, truly a child's time of year. It is very difficult to balance stress, grief and hope and continue with your daily life. As time goes by words are inadequate, both from the partners themselves and the medical

professionals. Feelings of failure start to surface. Am I really a man/woman if I cannot bear children? What about the money? No new car this year. Maybe next year we will start to save for the new house. No vacation this year or last, we will be at the clinic. How much stress can a marriage take before it starts to crumble? Will this build a stronger relationship? Maybe or maybe not. Unfortunately divorce rates are high for infertile couples. The subject gets old when it's the main topic of conversation forever with never a conclusion. Sex becomes an ordeal instead of marital bliss. Months of having sex on demand may make a man feel like a sex object, which by the way is an interesting twist on fate. At first a man may be able to grin and say "do it to me" but after a year or two or three it's not a game any more. It's a test of performance and men don't like to fail. Men can become humiliated and impotent. Grief may now set in. According to "In Pursuit of Fertility" by Robert Franklin and Dorothy Brockman, "Ranging from unhappiness to deep, intense sorrow, grief is a cluster of emotions, felt when we either anticipate or experience a loss." In infertility the loss is of a dream, the dream of having a beautiful new baby. A baby that you and your husband created together. A perfect baby. Maybe he/she will look like you or me. Maybe he/she will have blond hair like my Dad or blue eyes like your mom had before she died... Gone.

Anger can set in next. Patients feel misunderstood. The body and the mind feel abused by the endless tests and treatments, the constant failures, the unfairness of it all. Anger then becomes directed to the partner, the family, the medical community, and the world. Sometimes patients wonder if God is punishing them for some past evil they may have done. Patients may feel abandoned by their own God. Anger toward the spouse is the most damaging. Arguments arise from nowhere over the smallest incident. There is intolerance towards normal daily activities, normal daily routine. This is where the marriage gets in danger. The longer the anger remains unresolved the more chance this marriage will not survive. Patients can actually become self-abusive. They continually think about what if.. If only... Why hadn't I known? If only I would have seen the Doctor 2 years ago, 5 years ago. Hopeless desperation can set in. After receiving so many negative results, after getting her period again, they feel there is no hope. No future for them. At times for some patients this feeling may be overwhelming. Some patients need to seek professional counseling. Many patients have a problem finding their identity. They know they were married and are now a wife. But what happens next? Isn't motherhood a natural progression? Society in general puts pressure on the couple. Even at work people start to ask "After 10 years of marriage when are you going to start that family? The clock is ticking you know." Form that you fill out, income tax returns, DEPENDANTS? I just filled out a form to register my new computer, the question asked, "How many children will be using the computer?" "What are their ages?" Well that may seem like a benign question but if you are suffering from infertility this is another reminder of what a failure you are in fulfilling your marriage obligations. Where are the children? Didn't you make a vow to have children on your wedding day? Wasn't that assumed? Men usually deal with this issue differently. They usually are not consumed by these emotions. However they also do not have constant monthly, physical reminders of their failures. Men will usually deal with it in a more physical way. Maybe he will become compulsive about his work patterns. Work harder or longer. Take on a new job. Develop new hobbies, golf or woodworking. Start to drink. Alcohol seems to help the pain, at the time. Contrary to popular understanding, Men hurt! Men cry! A man can feel emasculated if he cannot impregnate a woman. He has nowhere to go for comfort. Most men don't know how to seek support. Some men will even try to prove they are masculine by pursuing other women. Depending on which road he chooses this will also affect the outcome of this marriage. Men need to change the way they were taught to handle emotions. They need to know it's all right to cry. It's all right to talk

to your partner . It's all right to be sad.. Unresolved feeling can emerge at any time. A previous abortion may haunt an infertile woman forever. Some of these women may need therapy to help the realize their current situation is not a punishment. For some patients this is not easily resolved. Sometimes it is difficult to get through this process without therapy. Couples do have a difficult time getting though daily life and being infertile. According to Barbara Eck Menning, "Infertility: Diagnosis and Management" "Society has elaborate rituals to comfort the bereaved in death. Infertility is different. There is no funeral. No flowers. Family and friends may never know. The infertile couple often grieves alone."

Where are the insurance companies in helping these this rather large population of people? After all 1 in 5 couples suffer from infertility, in doing the math that's 20% of the population! Depending on which study you wish to quote, infertility treatments are effective in about 60% of the couples who can afford to pursue their dream of having a baby, of being a real family. Studies show it will only cost about \$2.00/year to make this a mandatory coverage item. For most insurance policy holders this is less than the normal yearly increase we have come to expect each year any way. We already are required to pay for maternity benefits. When you buy that single person or family plan its in there whether you plan to have children or not. In the state of Pennsylvania there is no mandatory coverage for infertility. Some insurance companies will give partial payments but coverage is denied once you start doing ART or "experimental treatments." A good example is the company I work for, their coverage is very typical. I work for a major medical center, infertility coverage is limited to diagnostic tests and laboratory tests. There is a \$5000/year cap on fertility medications. The prescription plan is based on an 80/20 payment plan. There is also a \$25000/lifetime cap on fertility medications. No coverage starts with IUI and IVF. If you wish to pursue these treatments the patient is expected to pay for their services the day of the procedure, in full. No payment plans are offered or accepted. If you have any outstanding bills in the hospital system payment is due prior to any elective services, such as infertility. If you or your husband have ever been sterilized there is no infertility coverage, not even the day of consultation! We are actually lucky, there are some insurance carriers that will pay \$0 for any infertility treatments. It is all out of pocket and all expected the day of service. The insurance companies are not even expected to pay for same day treatment. They pay when the forms are received and fill out to their satisfaction. Some hospital bills are not being payed for a year or more with no penalties to any insurance companies. It has been more than eight years since any state enacted legislation regarding infertility. More than 72000 babies have been born, through treatment, since ART was introduced in the US in 1980. Interestingly the drug Viagra is covered by insurance. I wonder if this were a drug for women's sexual problems would the men in the board rooms been so quick to give it coverage. Contraceptives are still a non-covered item! Some people are suing their employers for denying them infertility coverage and they are winning. After all, in 1998 the Supreme Court ruled that reproduction is a "major life activity"and people are suing on the grounds of discrimination. Infertility is a disease. By law sufferers of infertility should have mandatory insurance coverage, otherwise permanent damage may occur to this couple's marriage, financial status, and mental stability.

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