THE CURRENT STATE OF AFFAIRS AND BIOETHICAL ISSUES ASSOCIATED WITH GENETIC ORPHANS

A CREATIVE PROJECT 
SUBMITTED TO THE GRADUATE SCHOOL 
IN PARTIAL FULFILLMENT OF THE REQUIREMENTS FOR THE DEGREE MASTER OF ARTS 

BY 
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Tubal embryo transfer (TET). Eggs and sperm are collected and combined to ensure fertilization in the laboratory. The embryos are monitored for three to four days and then transferred by a catheter directly into the fallopian tube.

In vitro fertilization (IVF). Separately, eggs are harvested and sperm collected. They are combined in a petri dish in the laboratory and monitored for fertilization. After this is confirmed the embryos are transferred directly in the woman’s uterus via a catheter.

Frozen embryo transfer (FET). Initially, collected eggs and sperm are combined and fertilization is confirmed. A certain number of these embryos (typically one to four) are used ‘fresh’ for an IVF procedure. The remaining embryos are cryopreserved at special facilities from months to years until needed for implantation. Stored embryos can be used in a cycle by thawing, and transfer via catheter into the woman’s uterus.
Table 1. Assisted reproductive technologies (ARTs) accompanied by their requirements, procedural components, and success rates.

Table 2. Comparison of IVF Approaches using Own Eggs versus Donor Eggs per Cycle: A list of Possible IVF Procedures and the Cost Range of packaged procedures, as indicated by check marks (√), are provided. Additional information on Fertility Drug Costs for each Approach is also given.
CHAPTER ONE

Genetic Orphans

The term Genetic Orphan, in the context of this work, refers to a child, conceived of two donor individuals (usually not personally involved with the couple), who is raised by 'intended parents' who are genetically unrelated to the fetus. The initial component to be determined is the method of donor choice. Either the sperm donor and egg donor can be chosen separately, or an embryo that has been donated by another couple can be used. Regardless of the method, the result is a fetus genetically unrelated to the parents who will raise the child. The second component to be determined is the process of gestation. Again, two options exist: 1) a gestational surrogate can be used, or 2) a maternal surrogate can be used. In the former, the individual is a woman who is contracted to carry the fetus to term, but hands over the child to the intended parents after birth. In the latter, the intended mother would gestate, give birth to, and raise the child. The word surrogate is used in both these situations because in neither case is the woman genetically related to the child she is carrying.

With these distinctions in mind, there are four possible outcomes: 1) a donor egg and donor sperm fetus brought to term by a gestational surrogate, 2) a donor egg and donor sperm fetus brought to term by a maternal surrogate, 3) a donated embryo fetus brought to term by a gestational surrogate, and 4) a
donated embryo fetus brought to term by a maternal surrogate. These four categories are important only when dictating how the child was created and brought to term and hold little relevance in this paper with regards to the discussion of the ethics behind genetic orphans or any of the discussions of the psychological adjustment of the child. I mention them simply to explore all the possibilities that exist in this field. When genetic orphans are discussed throughout the rest of the paper, I make no distinction between the four aforementioned categories but rather focus on the end product: a child with no genetic link to the parents that are raising them.

The Scope of Infertility

Infertility is an increasingly prevalent concern in the world. The National Institute for Health and Clinical Excellence defines infertility as the inability to conceive after having frequent (every two to three days), unprotected sex for two years, while The Mayo Clinic cites a one year time frame. The inability to carry a fetus to term may also be considered a component of infertility. (1) Roughly 14% of couples, or one in seven, in the United Kingdom suffered from infertility as of 2008. (2) The United States, in 2009, had an infertility rate of 10-15%. (3) There are primary and secondary forms of infertility, where the former affects those couples who have never conceived and the latter involves those that have conceived at least once unassisted. (4) In contrast to common opinion that infertility is strictly a woman’s issue, male infertility is thought to be a main factor in about half of all infertility cases. (5) In 17.8% of infertility cases that received a
diagnosis as to cause, a combination of male and female factors were responsible, further showing the complexity of this issue. (6) Male and female infertility can result from physical factors, environmental stressors, and genetic conditions. Physical factors include things like failure to maintain an erection, endometriosis, and age. Environmental stressors can involve smoking, exposure to radiation, and certain medications. Possible genetic conditions contributing to infertility include men with Klinefelter syndrome and female carriers of Fragile X. (1)

According to the prior definition, infertility issues can stem from two sources: the act of conception itself or the duration of the gestational period. To begin with conception, both male and female infertility problems play a role. Male infertility problems are associated primarily with their sperm. The delivery of the sperm can be impeded by physical blockages in the male reproductive tract or failure to maintain an erection. However, even if the delivery system is functioning, the sperm themselves can have many issues that prevent fertilization. Speed and numbers of sperm are two of the main factors in male infertility. Men who have slow, sluggish, or immotile sperm, or those with low counts, fewer than 39 million sperm per ejaculation, have trouble fertilizing an egg. (7) Another consideration is the structure of the gamete. Normal, healthy sperm have an oval shaped head and a long, flagellar tail to provide motive force. A fertile male is considered to have at least 4% of his sperm fitting these criteria. (7) If functionally impaired sperm are instead produced, such as those without tails, with shortened tails, or with crooked heads, the probability of
fertilization by these gametes is significantly decreased. All of the aforementioned problems can be the result of a) physical trauma such as infection, tumors, or even prolonged bicycling; b) environmental stressors like smoking, alcohol abuse, and radiation exposure; or c) genetic conditions like Klinefelter syndrome, where the presence of an extra X chromosome renders these males infertile. (5)

Female fertility, with regards to conception, can be damaged in several ways. The female is responsible for providing the egg in order to become pregnant. Not only must a woman have eggs still available and viable but they must be released from her ovary at the proper time. After 32 years of age, a continual decline in the quantity and quality of the eggs is seen. This occurs in all women and is not necessarily subject to any particular outside force, though things like ovarian damage could accelerate the decrease. About 11% of diagnosed infertility cases are due to a diminished ovarian reserve. (6) If there are indeed eggs to be had, ovulation or the release of the egg is the next step where things can go wrong. Hormonal imbalances and extreme weight gain or loss have been noted to negatively affect women’s ovulatory cycles. In addition, ovulation disorder in infertile women is sometimes associated with the disease polycystic ovary syndrome (PCOS). (8) Ovulatory disruption is responsible for roughly 6.7% of diagnosed infertility cases. (6) Aside from ovulation, physical damage to the fallopian tubes or to the cervix can also play a role in female infertility. Much as males need to have a clear path to ejaculate sperm, females must have a clear path for the discharged egg to travel. They also must have an
uninterrupted path through the cervix to allow for the sperm to enter the uterus and, subsequently, the fallopian tubes. Finally, uterine issues can also wreak havoc. Scarring, frequently caused by previous surgeries for issues like endometriosis where uterine tissue overgrowth is removed, can prevent implantation. Polyps or tumors can also create blockages that potentially interfere with all steps of the process. As in male infertility, all of the above issues can result from many of the same physical and environmental disruptions.

The genetic causes in females can be syndromes like Fragile X, where the FMR1 gene on the X chromosome is defective causing a decrease in an essential brain protein’s production.

As stated previously, infertility trouble is not limited to conception. The second half of the reproductive process deals with making it through the duration of the gestational period. One of the most common findings in couples who are considered infertile because they cannot carry a pregnancy to term is Recurrent Spontaneous Abortion (RSA). Many know a spontaneous abortion as a ‘miscarriage’ and it is medically defined as a pregnancy loss suffered prior to the 20th week. (9) Women with RSA have had three or more consecutive losses during their reproductive years. Just as infertility has primary and secondary classifications, RSA sufferers are classified based on whether or not they have achieved a live birth before their first loss. The risk of having another spontaneous abortion continually increases in the wake of each miscarriage though the cause may not be known. Potential contributing factors derived from the female’s side include placental anomalies, environmental stressors such as
alcohol and drug abuse, and increased stress levels. In addition, one of the most cited causes is failure of the female body to properly suppress the overwhelming immune response to the pregnancy. However, males are not completely without blame as chromosomal anomalies, like balanced aberrations or trisomies, are just as likely to come from them as from their female partners. These gender neutral genetic abnormalities are thought to cause anywhere from 29-60% of all spontaneous abortions. (9)

**Assisted Reproductive Technology (ART)**

**Techniques**

The main response to the problem of infertility is the use of assisted reproductive technology (ART). The Centers for Disease Control and Prevention define ART as any procedure that handles both sperm and egg for the treatment of infertility. Despite the general definition, there are many individual forms this type of treatment can take and a variety of courses of fertility drugs are employed. The following information focuses on the biological products involved rather than the medications used. Gamete intrafallopian transfer (GIFT, see Figure 1) is when three to four of the woman’s eggs and her partner’s or donor’s sperm are combined briefly in a catheter and delivered directly into the fallopian tube of the female using diagnostic laparoscopy. The goal here is to 1) close the distance gap between the sperm and the egg, thus making it more likely they will collide, and 2) avoid any ovulatory problems as the eggs are harvested and not released solely on the body’s own schedule. (10)
Zygote intrafallopian transfer (ZIFT, see Figure 2) begins with the harvesting of a woman's eggs and the donation of sperm either from her partner or a donor, much like in GIFT. However, in ZIFT the two gamete types are introduced to one another in a laboratory setting and fertilization is confirmed. Then, within one day, one to four zygotes are transferred back into the female's fallopian tubes. The zygotes then travel down the fallopian tube to the uterus just as a normal zygote would to subsequently implant itself. This way, instead of hoping the sperm and egg meet in the fallopian tubes, as in GIFT, fertilization is confirmed. (10) Another option is tubal embryo transfer (TET, see Figure 3) which is extremely similar to ZIFT, except embryos are three to four days old when transferred back into the fallopian tubes instead of one day old zygotes. (10) The aforementioned procedures are considered rather invasive because they require laparoscopy and general anesthesia.

The most common ART technique is in vitro fertilization (IVF, see Figure 4), the method this paper will reference most. This course of treatment requires the harvesting of the egg and sperm much like in GIFT, ZIFT, and TET. IVF procedure is less complicated; the fertilized product is placed into the uterus rather than the fallopian tube. (11) However, simply because the technical process is less intricate when compared to the other options, IVF does carry its own level of complexity. The embryo can either be related or unrelated to the woman whose uterus is being utilized. In the case of the former, the egg is harvested from the female to later be implanted after it is fertilized with the sperm of choice. The sperm is typically from the woman's partner, though it can be
donor sperm as well depending upon the circumstances. In the case of the implantation of an unrelated embryo, there are three possibilities: 1) a donor egg fertilized with partner sperm, 2) a donor egg fertilized with donor sperm, or 3) a donated embryo. In the case of donated embryos, these are normally the unused products of other couples’ infertility journeys.

An alternative IVF approach is the option to undergo frozen embryo transfer (FET, see Figure 5). (10) This is available to those couples who have used ART previously and now have fertilized embryos saved at a clinic or those choosing to use someone else’s ART products via embryo donation, as mentioned previously. The difference between IVF and FET comes down to the status of the embryo being implanted. Traditional IVF is done with fresh embryos created from newly harvested eggs, though sperm may be fresh or cryopreserved. When FET is performed, the embryo to be used has been fertilized, cryofrozen between days one and six of development, and then thawed prior to uterine transfer. The woman using FET must undergo a separate course of fertility drugs to prepare the body and uterus for the potential resulting pregnancy. Traditional IVF patients are already prone to pregnancy as the cocktail of drugs they were taking prior to the egg harvest also served to make ready the womb. When the body has become sensitive to implantation, the embryo is thawed and then inserted into the uterus. (11) A drawback of FET versus traditional (fresh) IVF is the lower rate of success when using embryos that have survived the cryopreservation/thawing process. (6)
Figure 1. Gamete intrafallopian transfer (GIFT). Separately, eggs are harvested and sperm collected. They are then combined in a catheter and delivered directly into the fallopian tube. *Above image digitally modified from the original, available from the Hayat Center.* (12)

Figure 2. Zygote intrafallopian transfer (ZIFT). Eggs and sperm are collected and combined in a petri dish under laboratory supervision. Fertilization is achieved and within 24 hours the zygote is delivered to the fallopian tube via a catheter. *Above image digitally modified from the original, available from the Hayat Center.* (12)
Figure 3. Tubal embryo transfer (TET). Eggs and sperm are collected and combined to ensure fertilization in the laboratory. The embryos are monitored for three to four days and then transferred by a catheter directly into the fallopian tube. *Above image digitally modified from the original, available from the Hayat Center.* (12)

Figure 4. In vitro fertilization (IVF). Separately, eggs are harvested and sperm collected. They are combined in a petri dish in the laboratory and monitored for fertilization. After this is confirmed the embryos are transferred directly in the woman’s uterus via a catheter. *Above image digitally modified from the original, available from the Hayat Center.* (12)
Figure 5. Frozen embryo transfer (FET). Initially, collected eggs and sperm are combined and fertilization is confirmed. A certain number of these embryos (typically one to four) are used ‘fresh’ for an IVF procedure. The remaining embryos are cryopreserved at special facilities from months to years until needed for implantation. Stored embryos can be used in a cycle by thawing, and transfer via catheter into the woman’s uterus. *Above image digitally modified from the original, available from the Hayat Center.* (12)

Cost and Success Rates

In light of the above information, it should be noted that all current ART techniques evaluated (see Table 1) were expensive and time consuming, some more than others (see Table 2). Five ART practices were assessed with regards to 1) which gametes they used, 2) where the products were inserted and how many, 3) the need of fertility drugs, and 4) their overall success rates, see Table 1. Note, fertility drugs were used in all techniques and in the case of FET an abbreviated drug course was required because of the lack of fresh eggs and potential ability of the woman’s uterus to support a pregnancy unaided. Success
rates were found to be invariant between GIFT, ZIFT, TET, and IVF. (6) Two kinds of IVF (non-donor and donor eggs) as well as the fertility drugs required in association with those cycles were also assessed with regards to overall cost, see Table 2. Note, the type, name, and amount of drugs prescribed varied on a case-by-case basis as determined by things such as maternal age and the cause of the infertility. At the time of analysis, most courses of treatment took four to six weeks to complete and often more than one round of treatment was needed as ART success rates varied widely depending on external factors like age and health of the people involved. Treatments also involved multiple doctors’ appointments, either separately charged or bundled into a fertility package by the clinic handling the case, to track the progress being made or to collect the gametes. Other expenses included fertility drugs, such as those that stimulate follicle and mature egg production as well as ones that induce ovulation; cycle-suppression drugs, which function to allow a woman to exert finite control over when she ovulates; and pregnancy maintenance prescriptions like progesterone for continued endometrial development and suppression of the maternal immune response to the pregnancy, see Table 2. (13)

Another perceived detriment of ART, aside from being a long-term time and financial commitment, is the fairly low success rate (see Table 1). In 2008, licensed ART specialists performed 148,055 cycles. A cycle begins when a woman starts her fertility medications and ends with the transfer of either harvested gametes or embryos depending on the technique being implemented. (6) Out of these 148,055 cycles, 46,326 live births were achieved and 61,426
infants were born. The discrepancy here between the number of live births and the number of babies born is due to pregnancies carrying multiples, like twins or triplets. Hence, the success rate of ART can be quoted at roughly 36.14%, using live births per transfer. (6)

The reproductive community’s initial answer to the low success rate was to simply increase the number of embryos transferred into the female. With more embryos, or an increase in the number of gametes used in the case of GIFT, the odds were weighted in favor of at least one embryo implanting into the uterine wall and being carried to term. However, with more embryos came the more prominent possibility of multiple pregnancy, a riskier proposition than carrying a singleton. (14) The dangers of low birth weight, infant disability, and prematurity all increased when two or more embryos implanted.

To combat these dangers, selective reduction practices are used when needed and/or desired in the ART field. Selective reduction refers to a procedure where the number of fetuses is reduced to a more manageable number (usually no more than two) through the use of a drug designed to stop the fetal heart. Traditionally, this takes place no later than the first trimester. (14) The reproductive community has been trying to find a better way to achieve singleton pregnancies because of the social stigma surrounding the practice of selective reduction and its cost: physically, emotionally, and financially.

Recently, ART providers have been putting their energy behind elective single embryo transfer (eSET), which is when the couple, or the single woman, decides to receive only one embryo per cycle instead of the transfer of multiple
products. The Human Fertilisation and Embryology Authority cited a 5% reduction in multiple birth rates in the United Kingdom as more people opted to use eSET. (15) Should the embryo implant, the chance of having a healthy, uncomplicated pregnancy increases dramatically, while the probability of the implantation of the lone embryo remains unaffected. Therefore, eSET does not harm but rather maintains the overall ART success rate.

Table 1

<table>
<thead>
<tr>
<th>Technique</th>
<th>Egg Harvest</th>
<th>Sperm Harvest</th>
<th>Fallopian Insertion</th>
<th>Uterine Insertion</th>
<th>Number of Embryos Transferred</th>
<th>Success Rate</th>
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<tr>
<td>GIFT</td>
<td>√</td>
<td>√</td>
<td>√</td>
<td></td>
<td>n/a²</td>
<td>5.1-41.1%³</td>
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<tr>
<td>ZIFT</td>
<td>√</td>
<td>√</td>
<td>√</td>
<td></td>
<td>1-4</td>
<td>5.1-41.1%³</td>
</tr>
<tr>
<td>TET</td>
<td>√</td>
<td>√</td>
<td>√</td>
<td></td>
<td>1-4</td>
<td>5.1-41.1%³</td>
</tr>
<tr>
<td>IVF</td>
<td>√</td>
<td>√</td>
<td>√</td>
<td></td>
<td>1-4</td>
<td>5.1-41.1%³</td>
</tr>
<tr>
<td>FET</td>
<td></td>
<td></td>
<td>√</td>
<td></td>
<td>1-4</td>
<td>14.6-35.5%⁴</td>
</tr>
</tbody>
</table>

Note: Percentages listed in the table represent 43-44 year old females at the low end and <35 year old females at the high end. (6)

1 The number of embryos transferred depends on a number of factors such as the ART specialist's practice preference, patient desire, number of eggs retrieved, and the age of the patient as it correlates with the likelihood of conception.
2 This category is not applicable as GIFT, by definition, only transfers gametes to the fallopian tube, not fertilized embryos.
3 These percentages represent the number of cycles that resulted in live births. (6)
4 These percentages represent the number of transfers that resulted in live births. (6)
## Table 2

Comparison of IVF Approaches using Own Eggs versus Donor Eggs per Cycle:
A list of Possible IVF Procedures and the Cost Range of packaged procedures, as indicated by check marks (✓), are provided. Additional information on Fertility Drug Costs for each Approach is also given.

<table>
<thead>
<tr>
<th>Approach</th>
<th>Cost Range</th>
<th>Possible IVF Procedures</th>
<th>Cost Range</th>
<th>Approach</th>
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<tbody>
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<td>IVF with Own Eggs per Cycle</td>
<td>$11,000</td>
<td>✓ Personal ovarian stimulation monitoring ✓ Donor ovarian stimulation monitoring ✓ Anesthesia for egg retrieval ✓ Egg retrieval procedure ✓ Donor egg retrieval procedure ✓ Egg culture and fertilization ✓ Embryo transfer procedure ✓ Embryonic screening (pre-implantation genetic diagnosis - PGD) ✓ Physician fees for IVF procedure ✓ Lab/facility fees ✓ Donor match/coordination/administration fees ✓ Pre-IVF screening tests ✓ Self fertility medications ✓ Donor fertility medications ✓ Donor medical insurance ✓ Embryo cryopreservation/storage ✓ Pregnancy testing and subsequent monitoring ✓ Additional physician consultations if medically needed or requested by patient</td>
<td>$28,000</td>
<td>IVF with Donor Eggs per Cycle</td>
</tr>
</tbody>
</table>

**Fertility Drugs**

| Own IVF Cycle                        | Cost Range       | Ovarian follicular development drugs ✓ Additional ovarian follicular maturation drugs ✓ Ovulation inducing drugs (also known as "trigger drugs" given just before retrieval) ✓ Endometrial support drugs | Donor Egg IVF Cycle | $1,500-4,000          | $1,500-4,000          | $1,500-4,000          | $1,500-4,000          |

1 Based on the national average as cited by the Advanced Fertility Center of Chicago.
2 Refers to drugs prescribed for the woman who will be carrying the pregnancy.
3 Refers to the drugs prescribed for the donor of the egg.
Surrogacy

Surrogacy has become an accepted practice to assist couples suffering from infertility in having children of their own genetic makeup. A surrogate is a woman who becomes pregnant and carries a child intended for another couple. Typically medical fees and costs associated with prenatal care are covered by the intended parents who will raise the child after birth. If no other payment is offered the arrangement falls under the category of non-commercial surrogacy, classically used in circles where the surrogate is well known by the couple trying to conceive. Commercial surrogacy occurs in the event of additional monetary compensation being provided to the surrogate for carrying the child. The commercial agreements are normally struck through private surrogacy companies or international surrogacy agencies, recent additions within the medical tourism market.

In any given surrogate situation, the resultant child can be related or not to the woman carrying the pregnancy. Traditional surrogacy involves the surrogate’s own eggs (biological gestational surrogate) and donor sperm, typically from the male half of an infertile, intended parental couple of the child. Gestational surrogacy entails the infertile, intended parents donating or choosing both gametes, creating fertilized embryos in vitro and then having them transplanted into the surrogate (unrelated gestational surrogate) for the duration of the pregnancy. In both cases, the surrogate signs papers that assure the intended parents that she does not retain any parental rights to the child she is carrying. This particular practice becomes more difficult when the intended
recipients are a homosexual couple or a single parent. Finally, depending upon the state, surrogacy contracts have varying degrees of legal enforceability.

Surrogacy can be an integral part of gestating a donated embryo though it is not required. If the intended mother can herself support a pregnancy there is no medical need of a surrogate to carry the donated embryo. However, if she has uterine problems that make carrying a pregnancy to term impossible or extremely difficult, a surrogate provides an avenue for the couple to still have a child through embryo donation or dual gamete selection. When pairing embryo donation or dual gamete selection and gestational surrogacy, the resultant child technically has five adults involved in its creation: the biological mother and father who created the embryo from their own gametes in the first place, the surrogate responsible for gestating the pregnancy, and finally the two intended parents who raise the child. The first recognized case of this pentagonal relationship was that of Jaycee Buzzanca, a child born in 1995 after being conceived of anonymous sperm and egg donors, gestated by a surrogate, and abandoned by her intended parents because of a divorce. (17) The courts of Santa Ana, California, used the genetic definition of parenthood and thereby awarded legal motherhood to neither the intended mother nor the surrogate. Similarly, the intended father was not labeled as the legal father for the same reason. Three years later, this decision was overturned though it set the stage for many battles over how courts should handle legal parentage in an age where families and children can be brought about in unconventional ways. (17)
Embryo Donation

Currently in the United States, there are about 500,000 cryopreserved embryos. (18) These are the products of previous ART cycles and are being stored at the desire of the couple to whom they belong. Some choose to keep the embryos until they are sure they have a child, basically waiting out the pregnancy until a live birth results. Other couples have plans for future children and plan on using FET to add additional members to their family without having to go through the harvesting portion of the IVF cycle again. Regardless of the reasons for storage, the fact remains that eventually these embryos are no longer needed, and what to do with them becomes the next question. There are three options: 1) the embryos can be donated for research purposes such as the establishment of stem cell lines, 2) the embryos can be thawed and disposed of, or 3) the embryos can be donated to other infertile couples looking to conceive. (18)

This third option is called embryo donation, or sometimes embryo adoption. The couple with the frozen embryos, the donating couple, signs medical and legal paperwork releasing their embryos to the bank or couple of their choice thereby discharging themselves of any liability. Complete medical and genetic histories are provided in order to give the best background picture to the prospective parents looking to use the couple’s embryos. (18) The medical portions of this procedure in the United States are regulated to some extent by the Federal Food and Drug Administration. (19) Sometimes the donating couple is in charge of choosing the recipient of all or some of their embryo stock. In
other cases, the couple simply leaves their embryos at the bank’s discretion to be chosen in the future by an infertile patient. The donating couple also establishes how much and what type of contact they desire or are amenable to between the prospective parents, the future child, and themselves. (18) Finally, because most countries’ legal systems have yet to determine how to handle embryo donation, as it cannot legally be called adoption and thereby be subject to adoption law, most arrangements are handled by lawyers who draw up unique, legally binding agreements to be signed by the donating couple and the prospective parents. This paperwork ensures that the prospective parents are named on the birth certificate and that the donating parents no longer have any claims to the embryo or the subsequent child.

Couples most likely to benefit from using donated embryos are those including women who have undergone an oophorectomy (ovarian removal surgery), have diminished ovarian reserves, or are wrestling with concerns about genetic conditions in regards to their own eggs. (18) The success rate for ART using donated embryos is 33.2% using live birth rates per transfer. (6) This is comparable to the 36.14% for fresh embryos with the cryopreservation and thawing processes causing a slight decrease in success. This is still a viable option however, and is considered to be less invasive as egg harvesting, lab fertilization, and monitoring are not required. It should be noted, couples and women who often choose embryo donation are much further along in both age and their time spent using ART. This means they are, on average, less likely to
get pregnant and may require a greater number of cycles to achieve a pregnancy than a younger woman. (20)

**Donor Anonymity**

In the ART field, the ability to offer donor gametes to patients dealing with infertility is an important one as it opens up a new range of possibilities. To make this option available, gamete donation, either egg or sperm, is done in a directed or undirected manner. Directed donation implies the donor knows the person or couple who is going to use the gamete(s). The donor sample is collected for specified recipients and not stored in a general use bank. A common form of this type of donation is when a husband donates sperm for use in his wife’s IVF cycle. Undirected donation is done through a bank with no immediate, intended recipient. If all donor identifying information is kept confidential, then undirected donation can also be labeled as an anonymous donation. Children conceived through the use of anonymously donated gametes cannot obtain any donor information. However, if donor anonymity is abolished in a given country or region, children are entitled to the identifying information regarding their biological donor parent(s) after reaching the age of majority. (21) It should be noted that in this situation donors and parental recipients are not entitled to each other’s identifying information at any time. (22)

The issue of donor anonymity is a point of contention for many people in the ART community. Some believe that to deny donor anonymity is to drive the potential donors away. Sweden became the first country to establish an open
donor system in 1985. They reported a decrease in the amount of men willing to donate sperm under the new law in the first few years after it was enacted. Subsequently, fewer couples were able to use donated sperm and fewer children were born via this avenue. (23) The low quantity of available donor sperm as a result of the new law was seen as propagating the cycle of infertility instead of helping the situation and hence, is a major concern for those countries considering changing their donor anonymity laws. However, in a 1995 study, Sweden showed that the number of donors may have rebounded after an increase in the number and variety of recruitment methods. (23) The United Kingdom reported data that did not support the loss of donor fears though they do operate on a 'cost neutral' system which strives to ensure the donors neither profit nor lose as a result of donation. This incentive could have influenced the data although, on the other hand, it speaks to the power of a ‘cost neutral’ system as something to be considered by other countries and regions considering stripping anonymity. (22)

**Disclosure Issues & Decision Making**

With the advent of ART and its increasing usage throughout the infertile community, the situation arises where a child may not be genetically related to one or both of their parents. This leads to the question of whether or not to disclose the method of conception to the child so they are aware of their history and may seek out their biological contributors if they so desire and are allowed by law. This, however, is a touchy subject for most families. There are several
reasons in favor of full disclosure and just as many reasons in favor of non-disclosure. There is also the matter of to whom the parents disclose information: the child, family and friends, or both? To begin, reasons for both disclosure and non-disclosure in regards to family and friends will be discussed.

To Family and Friends

Many people see undergoing ART as a very stressful time in an infertile patient’s journey and as such familial and social support systems are highly encouraged. If family and friends are informed about the methods of conception they are then better able to support the person or couple through the ART process and their unique parental journey. Infertile patients view the decision to disclose differently. For some, non-disclosure is the best option for several reasons. First, they are afraid those who know the methods of conception will treat their child differently. For instance, a grandmother may feel that this non-genetically related child is not worthy of her time, energy, and praise as are the other grandchildren to whom she is directly related. Second, the couple or person may wish to avoid the disapproval of others in regards to their decision to use ART to conceive. A family may have religious objections that not all members share or some people in the same social circles as the mother- or father-to-be may not agree with using ART. These situations can cause additional stress on top of the ART itself and may be damaging to future relations. A third reason for favoring non-disclosure to friends and family involves the infertility itself. As there is a stigma surrounding infertility, some
people choose to keep it a secret. If this is the case, then revealing that ART was used to achieve the pregnancy would be a confession of infertility, something that may be extremely uncomfortable for the person or couple. Finally, some may simply believe that the issue of infertility and their decisions are private matters to remain between the mother- and father-to-be. (24)

In contrast, some infertility patients do disclose their predicament to family and friends. Many of the reasons directly mirror the reasons for non-disclosure. As some people believe the issue of infertility is a private matter as mentioned above, there are others who simply want to share with those close to them. These women may frequently share details of their lives that others would deem private so too the case of their infertility, either alone or as a couple is nothing to hide. Another reason that directly contradicts the previously given reason of secrecy is that some infertile people or couples see no reason not to tell. They do not perceive infertility as something to keep a secret and do not acknowledge, or do not care, about the stigma surrounding ART. The situation in which disclosure is favored can also come about when the family already knows of fertility issues. If the family is aware that there has been trouble in the past, then the individual or couple may not see a reason to keep the information about this particular pregnancy hidden. Finally, some people suffering from infertility may choose to disclose to their family and friends so that they appear to be open and forthcoming instead of having the information leaked by some outside source. Many people feel that this could lead to damaging feelings of betrayal that could corrupt important relationships. (24)
To The Children

It should be noted at this junction, disclosure to family and friends is one thing. Disclosure of the method of conception to the child is a completely different matter. Family and friends typically involve grown-ups and/or peers, people who are considered to be experienced in life and have developed coping skills and mechanisms to deal with information that may be upsetting. With children, depending on the timeline of disclosure and the extent of disclosure, this information has the potential to be difficult to assimilate, process, and incorporate into the child’s existence. (24)

In addition, there are various academic reasons which, in theory, give motive to disclose or not disclose this particular information to the child. Those proponents of disclosure say that the knowledge of the methods of conception helps the child to develop their identity, protects them from the harm of an accidental disclosure, and works to fulfill their human rights to autonomy and their personal information. Arguments for non-disclosure include the parents’ right to autonomy and privacy regarding their decision, a wish to avoid damaging their parent-child relationship, the desire to elude the social stigma associated with ART, and being secure in the knowledge that research has shown children to adjust just fine without disclosure. (24)

Having discussed those reasons that are general theoretical motivations for parents, some specific reasons follow. A very prominent reason that accounts for non-disclosure predispositions is the will to protect the child that has been so long in the making. Most parents feel incredibly attached to their
children and this feeling is said to be intensified in ART patients because of the additional stresses endured during the conception process. To a child, the information regarding the lack of a genetic link to their parent(s) may cause feelings of uncertainty about their position in the family. Also, the fact that their donor(s) is/are most likely anonymous could lead to a sense of total displacement in the world as they will never be able to know their biological, genetic parents. Another reason for non-disclosure involves safeguarding the parent-child relationship which the infertile individual or couple has fought so hard to have. Parents do not want to cause any feelings of isolation in the child. Again, this is due to the potential lack of a genetic link between the mother, father, and offspring depending on which ART was used. There are some parents who simply feel there is no need to tell. Here they believe, mothers especially, that the gestational link they share is, in effect, a trump card to be played against all the other pertinent facts. Finally, some parents may not know what to say to the child; and, therefore, choose to say nothing at all. (24)

The reasons given for non-disclosure only tell half the story, as people do indeed disclose the methods of conception to their children. The desire to avoid accidental disclosure from an outside source, such as a family member or friend who is ‘in’ on the secret, is a largely motivating factor. It is thought that this type of sensitive information is best delivered by the people directly involved and if it is introduced in another way, presumably less controlled, a fissure can develop between the child and his or her parent(s). Trust may become an issue as well. Some infertile patients or couples believe that the child has a right to know. In
this day and age where personalized genetic medicine is coming into its infancy, knowing one’s genetics could prove to be a very useful tool. A child who does not bear a genetic link to the parent or parents that raise them could be considered at a disadvantage because they would be under the impression that they knew the diseases that run in their family, when in fact their parents’ health (and, in reality, that of the entire family) does not actually pertain to them. With this in mind, disclosure of the methods of conception could help to clarify some of these questions as well as promote feelings of trustworthiness and loyalty in the parent-child relationship. Lastly, just as there are those who think there is no need to tell, some think there is no need not to tell the child. In these cases, disclosure is simply a given. It is only the time and manner of disclosure that is the key point of discussion. (24)
CHAPTER TWO

Interview Description

In this section, professional opinions are discussed pertaining to genetic orphans and the current state of affairs regarding this topic. The interview questions as well as the reasoning behind them are provided as well as highlights from the respondents’ answers. Throughout these discussions, each respondent is identified by their initials, as denoted in parentheses following each individual’s name in the subsequent paragraph. Interview questionnaires and the supplied operational definition of ‘genetic orphan’ provided to each interviewee, as well as, each interviewee’s email responses and curriculum vitae are provided in the Appendices.

The first of two rounds of interview focused on medical professionals, two genetic counselors and a Community Health Network Scientific Director/embryologist. Jenny Verbrugge (JV), MS, CGC, LGC, is a prenatal genetic counselor employed at IU Health North Hospital, Carmel, IN, in the maternal fetal medicine office. Stephanie Cohen (SC), MS, CGC, LGC, works at the St. Vincent’s Center for Cancer Care, Indianapolis, IN, as a cancer genetic counselor. Both counselors completed the same set of questions directed toward their expertise in the field of genetic counseling. Jeffrey Boldt (JB), Ph.D., the Scientific Director for Assisted Fertility Services, Indianapolis, IN, is also a
trained embryologist/andrologist employed by the Indiana University School of Medicine. He answered a slightly modified list of questions meant to highlight his experience in the field of ART. The second round interview delved into the psychological aspects of genetic orphans. June Payne (JP), Ph.D., is the Director of Counseling and Health Services at Ball State University, Muncie, IN.

**Baseline Interview Questions**

Two baseline questions were answered by all parties at the beginning of each interview. They were used to probe the professionals’ current knowledge base about genetic orphans as well as find out how, if at all, their opinion changed given my specific definition.

**Question One:** “What does the term ‘genetic orphan’ call to mind/mean to you?”

**Question Two:** “After having ‘genetic orphan’ operationally defined [as a child, conceived of two donor individuals (usually not personally involved with the couple), who is raised by ‘intended parents’ who are genetically unrelated to the fetus…which can be gestated by the intended mother or by a surrogate], what is your first impression?”

Both JV and SC expressed a lack of familiarity with the term though they put forth the same supposition: a person who does not know their genetic history. JB was much closer to the operational definition provided, stating that he believed a genetic orphan to be an ‘embryo’ created through IVF and not subsequently used by the couple at that time. It would then be cryofrozen and thereby abandoned. JP had little prior knowledge of the term genetic orphan and as such defined the
phrase as a genetic disease or illness rather than taking the stance of an individual.

These answers revealed that the term ‘genetic orphan’ is not currently used with any regularity in the medical or counseling fields, though it is capable of evoking partially correct responses. Overall, the embryologist was the most successful in understanding the technological aspects behind the creation of a genetic orphan. The genetic counselors were the most sensitive to the genetic orphans' potential lack of knowledge/access to information about their genetic origins. The psychological counselor is to be commended on her understanding of genetic basis of disease. The lack of specialized knowledge in medical genetics combined with the novelty of the term and status of ‘genetic orphans’ in society could account for some of the uncertainty of its definition and proper usage.

After reading the operational definition of a genetic orphan, the respondents then conveyed their impressions. JV thought the definition made sense, while SC had never heard of the term used in this context. Both genetic counselors commented on the strong negative connotation associated with the term ‘orphan’. JB thought his definition and the operational definition were comparable. JP did not feel that the definition clarified much but did mention that she believed it would involve the use of both donor egg and donor sperm. This is one of the main points of the genetic orphan situation and allowed for JP to further answer the remaining questions.
These responses demonstrate, on the one hand, an acceptance of the definition and, on the other hand, dissatisfaction with the term. Based on the medical professionals' responses, perhaps another word could be substituted for ‘orphan’ in the future in an attempt to avoid the negative undertones. The term ‘genetic orphan’ is only meant to convey the distancing of the child from their genetic origins. The word ‘orphan’ is not used to imply any negative connotations associated with a lack of concern about the child, an unwanted child, or an individual who is adrift or anyone having suffered the loss of parents.

**Interview of Medical Professionals:**

**Genetic Counselors & ART Scientific Director/Embryologist**

Beyond the two baseline questions, the genetic counselors were asked to answer an additional five questions and the Scientific Director/embryologist an additional seven. Of these questions, three were in common to all the medical professionals while two were unique to the genetic counselors and four were specifically posed to the Scientific Director/embryologist.

The third question was directed towards the genetic counselors due to the nature of their career. It was designed to explore what a counseling session would be like when the information about a child’s genetic origins is limited at best.

**Question Three:** “What are some counseling issues you believe would arise during a session with the parents of a ‘genetic orphan’?”
JV and SC expressed similar concerns: the child would not know their complete genetic history and would therefore be at a disadvantage when it comes to discussing potential diagnoses and recurrence risks in the event of a complicated genetic disorder later in life. SC also brought up the idea that because genetic orphans are conceived through ART that there may be, in fact, more genetic history known due to the extensive screening done in the ART field as compared to the adoption field. Should a genetic disease or disorder be identified in the child, JV mentioned the ramifications for the biological donor parents, who may or may not know that a child had been conceived using their embryos or gametes.

The next two questions were asked to obtain the ethical views of the medical professionals on this topic.

**Question Four (Question Five for JB):** “What are some ethical issues you believe to be involved with the situation of ‘genetic orphans’?”

This question evoked a similar response as to question three for both JV and SC. SC made an additional comment regarding the issue of legal parentage should a donor or a surrogate try to assert parental rights or a divorce occur between the two intended parents. This was the only additional information supplied by the genetic counselors in response to question four. JB’s response furthered elaborated on this latter issue. In Indiana, the legal mother is the birth mother, therefore, in the event of a gestational surrogate birth it is legally possible for the surrogate to choose to keep the child. Indiana law does not currently provide any
form of legal recourse or protections to the intended parents, as surrogate contracts are not legally enforceable.

The next question was meant to formally broach the topic of parental disclosure. As described in the section on disclosure and decision making, there are numerous reasons both for and against this action.

**Question Five (Question Six for JB):** “In terms of genetic history, do you think the ‘genetic orphans’ have a right to know the methods of their conception?”

JV and JB expressed their belief that it should be up to the parents to decide how, when, and if the child’s conception history is discussed. SC said that she thought genetic orphans had the right to know but she did not see the connection between knowing one’s genetic history and knowing the methods of conception. Having had the interviewees state their views on disclosure, the introduction of an extenuating circumstance was used to challenge these views.

**Question Six (Question Seven for JB):** “Medically, what proportion of congenital birth defects tend to be associated with in utero versus known genetic issues? And, as a follow up, what data is known to support this information or statistics? Subsequently, do you believe if a ‘genetic orphan’ was born with a congenital versus a genetic defect that this would change the necessity of disclosure of their methods of conception/medical histories of donor parents?”

SC felt that regardless of the presence of a congenital birth defect or a genetic defect, genetic histories should be shared. She continued to maintain her stance with regards to the disconnect between methods of conception and genetic history. JV thought that due to the medical community’s lack of known etiology
for some birth defects that such a condition would not change the need for disclosure as it may not even be helpful at this time. Again, this is consistent with her previous answer as well. She also brought up the notion that as long as donor banks have informed consent regarding the chances of birth defects, donors should not be held responsible in any way should a genetic birth defect of known or unknown etiology occur. JB commented that there is no increase in birth defects as a result of ART. He maintained his stance that genetic histories and donor information should be available to those seeking them.

Finally, the genetic counselors were given the opportunity to elaborate on how they would personally handle a session dealing with a genetic orphan situation.

**Question Seven:** “How would you deal with the prospect of advising/counseling a couple contemplating pursuing the ‘genetic orphan’ route to obtaining a child?”

JV and SC mentioned the inability to accurately predict all birth defects based solely on genetic and family histories. They also both discussed the importance of family histories. SC said that if histories were known she would do her standard risk assessment talk using the information available. JV added that addressing some of the potential risks of conceiving a child through ART would also be beneficial.

JB was asked a pair of questions to delve into his experiences while in school, during his fellowship, or whilst working at Assisted Fertility Services, Community Health Network.
Question Three for JB: “Have ever personally experienced a situation in which a ‘genetic orphan’ was conceived?”

Question Four for JB: “Do you know of any practitioners who have dealt with ‘genetic orphans’?”

He replied in the affirmative with regards to children conceived through the use of a gestational surrogate and to those created through donor embryo usage. His current position has allowed him to be involved with hundreds of cases thereby showing the relative frequency of this type of situation. Gestational surrogacy (regardless of the surrogate’s level of biological contribution) is more prevalent than embryo donation, though more and more centers are choosing to provide this newer service. In fact, in the year 2008, 67% of reporting USA ART clinics offered embryo donation to their patients. (6)

The next question posed to the ART professional was designed to probe the distinction between genetic orphans and adoptees. This subject was of interest because of the definitive legal gap between the two, as well as, to some extent the societal break.

Question Eight for JB: “Do you believe we/society should differentiate between genetics orphans and traditional adoptees?”

JB saw no reason to separate those children who are adopted and genetic orphans.
The final question asked of JB was intended to supplement the background information provided earlier on embryo donation as well as gain the view of a person in the field where the practice is becoming more common.

**Question Nine for JB:** “What do you think about the use of donated embryos?”

JB divulged that he sees this type of ART as a good way for couples to achieve their goal of having a family. This view stems from his involvement in the birth of over 50 children conceived using one or more donor embryos. He explained that many people are uncomfortable with the ideas of donating embryos for research use or discarding them. Because of this unease, they see embryo donation as the more altruistic choice. In addition, he commented that these feelings may come from the understanding of what it took for the couple to initially conceive and a wish to help others avoid a similar plight.

**Interview of Director of Counseling Psychology**

Beyond the two baseline questions, the psychological counseling professional was asked to answer a total of seven questions. Of these, two questions were in common with all the medical professionals, two questions were shared only with the genetic counselors, and three were unique to her interview.

The third question asked of JP was a question answered by the genetic counselors. The perspective of a counselor highly trained in psychology with limited medical training was necessary to see if there were any differences in the issues perceived to be involved with genetic orphans.
**Question Three:** “What are some counseling issues you believe would arise during a session with the parents of a ‘genetic orphan’?”

JP brought up six specific concerns. Among these concerns were the inadequacy feelings of the parents, as well as their future acceptance of the child throughout his or her life. She also expressed worry over the potential genetic problems of the biological parents, which was similar to the answers provided by both JV and SC, mentioned above. A follow up question was asked to see if JP had any different thoughts when dealing with the actual child versus the parents.

**Question Four:** “What are some counseling issues you believe would arise during a session with a ‘genetic orphan’?”

She answered again with a list of considerations including most of the issues she anticipated with the parents. She added concerns for the child's feelings of acceptance by their parents, the lack of genetic history, and the child’s general knowledge of their identity.

The next question was meant to probe into the notion of overinvolvement. Parents of children conceived through embryo donation demonstrated higher levels of participation and connection in their child’s life than those parents of adoptees or other ART children. (20) This was thought to potentially have a negative effect on the adjustment of the child later in life because the child would not be allowed to, or be capable of, make(ing) their own decisions and choosing their own path in life.
**Question Five:** “Do you think that because of the cost of the process to obtain these children ($28,500 and above per IVF cycle), the ‘parents’ might feel they should have greater control over the child?”

JP thought the parents who were undergoing such an expensive and lengthy procedure may potentially believe they had more say or could/should exert more control over the child.

In keeping with the other three interviews, JP was asked the same ethics question as the medical professionals to query her views on the ethics associated with ‘genetic orphans’.

**Question Six:** “What are some ethical issues you believe to be involved with the situation of ‘genetic orphans’?”

JP responded that counseling for intended parents was very important. They should be well informed of all the possibilities involved with starting a family as well as all the potential complications with the embryo donation method. She also mentioned a type of “final approval to move forward” prior to the parents being allowed to go through with their plans. In addition, JP stated that the medical practitioners involved in ART procedures should be careful to act in an ethical way. She referenced the Nadya Suleman (Octomom) case where the ART specialist recently lost his medical license for implanting a dozen embryos rather than the recommended two. Finally, JP wondered what would happen to the genetic orphan if the parents no longer wanted him or her.
Next, a psychological stance on the issue of parental disclosure was desired to compliment the set of medical personnel’s beliefs on the same question.

**Question Seven:** “In terms of genetic/medical history, do you think the ‘genetic orphans’ have a right to know the methods of their conception?”

JP thought the child should certainly be told. This is an opinion shared by SC, as previously discussed. JP insisted on the importance of the medical history being obtainable by the child.

The psychological counselor was asked to elaborate on how she would personally act in a session with a couple seriously considering a ‘genetic orphan’; this same question was asked of the two genetic counselors.

**Question Eight:** “How would you deal with the prospect of advising/counseling a couple contemplating pursuing the ‘genetic orphan’ route to obtaining a child?”

JP said that she would encourage the couple to discuss their parenting philosophies and perhaps revisit why they had previously eliminated options, such as adoption. She would attempt to identify both parents’ concerns about the genetic orphan path to ensure that everything was being addressed and, lastly, look into their readiness to go ahead with the procedure.

Finally, the last question posed to JP was meant to delve into probable future issues that could arise due to the widening use of embryo donation and surrogacy.
Question Nine: “In light of the situation with women’s health issues in the US, do you think that a movement towards the creation of more ‘genetic orphan’ children could result in a secondary class of childbearing women?”

JP expressed concerns that a secondary class of woman could indeed emerge, and this class formation could possibly create other legal issues regarding parental rights and responsibilities.

Commentary

The medical professionals’ answers provided above show a desire for transparency with the child. These views were mostly based on the importance of genetic histories, especially in times of need. Still, some concern was registered by this group in regards to the availability, variability, and depth of this kind of information. Without it, a typical pre-conceptual appointment would be limited and the ability of an adult genetic orphan to fully benefit from any warnings in their genetic history would be curtailed.

Therefore, the ability to access this knowledge is necessary. In order to accommodate this wish, donor anonymity needs to be removed. This would allow for genetic orphans, and others conceived using donor gametes, to retrieve possibly vital information and potentially benefit from it. However, this desire to know about one’s genetic origins is more likely to manifest itself in the child to whom conceptual history has been disclosed. Without this piece of knowledge, the child may never question their relationship to the people who raised them and may never anticipate a gap in their genetic and medical histories. Therefore,
disclosure is a crucial step in the process of getting the child all the information necessary to be armed for the future. By contrast, some people still believe that it is the parents’ right to choose whether or not to disclose. Others feel that the child’s right to know outweighs the parents’ thoughts. Based on the responses given by the medical professionals and research done on disclosure approaches and wishes, it would be difficult to garner sufficient agreement to mandate any such disclosure. The very existence of a directive of this nature is also a matter of contention.

Another controversial subject derived from the medical professionals’ answers was the legal standing of genetic orphans. The need for an overhaul of embryo donation and surrogacy law was evident. Solutions like clarifying legal parentage and making surrogacy contracts enforceable would serve to make arrangements safer to enter into for all parties involved, both legally and emotionally. Also, due to the similarities between the situations of adoptees and genetic orphans, some answers called for equivalent legal rights for those children created using ART.

JP’s responses showed a lot of congruence with the genetic counselors’ comments discussed earlier. Due to the difference in educational paths and knowledge background, JP’s answers tended to deal more with the psychological aspects of genetic orphans while the two others centered on the genetic aspects of the situation. Both complimented each other and provided a more complete picture of what should be addressed in these circumstances. All counselors picked up on the concern over missing information and the repercussions that it
could have on the child as well as the family. JP offered a more in-depth insight into the emotional aspects of this sort of journey. She mentioned many of the same counseling concerns for both the parents wanting a child and the genetic orphan (the child), perhaps showing that the situation may be handled better as a family unit rather than as individuals. This ensures everyone’s issues are addressed with the people who are most responsible and integral to those feelings.

In terms of overinvolvement (where parents are overly present and involved in the child’s daily life), a subject not discussed by the genetic counselors, JP showed some concern. This mirrored the research done by MacCallum and Keely where the notion of overinvolvement existed though did not register as a large threat. (20) This was thought to be simply because the subjects of study, the genetic orphans, had not yet reached an age where this may manifest itself as a major issue. Along these same lines, JP also registered some worry that parents may decide they have more say in their child’s life because they worked so hard to create them.

Again resembling the medical professionals, JP made mention of legal issues surrounding genetic orphans. She expressed this in the form of a question regarding what would happen to a genetic orphan should the parents no longer want him or her. This shows a worry for the safety of a child and acknowledges the potentially precarious position in which they stand. They are not genetically related to their parents and were donated by another couple so if the intended couple changes their mind, the void which the child could fall into
has yet to be addressed. At this time, legal documents drawn up by private lawyers may indeed work to fill the void, though the enforceability of these documents is questionable, as mentioned earlier.

Overall, the interviewees were in agreement on the importance of genetic histories. They were mixed on the necessity of parental disclosure with regards to the methods of conception, though maintained that donor genetic and medical histories should be available somehow should anything happen. Donor anonymity, which, if removed, would allow children access to their donor parents’ genetic and medical histories, was therefore a noted problem. The professionals were further in agreement when expressing concerns over other legal issues, including the non-enforceability of surrogacy contracts and the plethora of rights not afforded to genetic orphans, despite the similarity to adoption cases. Abandonment of the child, such as in the case of Jaycee Buzzanca, was also a worry, as the legal system does not yet have all the proper provisions in place regarding legal parentage in ART cases. Without these safeguards, a societal shift towards a situation much like in The Handmaid’s Tale by Margaret Atwood could be on the horizon. Surrogates may fall to the level of a secondary class of childbearing women meant to service the wealthy wanting children without any of the hassle. This “slippery slope” argument is compelling and a discussion of possible solutions will be addressed in the Final Thoughts section of this paper.
CHAPTER THREE

Bioethics

The field of biology is so rife with ethical issues that it has been given its own category of ethics called bioethics. This field deals with things like global disease research funding allotments, non-governmental organizations and their participation in third world country healthcare, distributive justice with regards to hospital resources, stem cell research, and so forth. The list goes on but the bioethical issues discussed herein will primarily focus on genetic orphans, ART, and the viewpoints of interviewed professionals from the medical genetics and mental health fields. Reproductive rights and the unique situations to which ART lends itself provide the perfect arena to tackle these concerns.

The New Meaning of Motherhood

Mothers and the modern concept of motherhood are evolving concepts in today’s technologically advanced world. This section discusses what is meant by the traditional and newer definitions of ‘mother’, as well as the state of motherhood. To do this, both sides of three issues are presented: 1) the separation of gestation and being a ‘mother’; 2) the importance of the genetic versus the gestational link in regards to motherhood; and 3) the compatibility of
natural and ART/adoptive mothers, and whether one is more of a ‘mother’ than the other.

A ‘mother’ is defined as a female parent by the Merriam-Webster Dictionary. This appears to be a broad meaning at first blush though early social connotations narrowed the term to a woman who raises a genetically related child. This was a reasonable constriction of the definition in the days before the notion of adoption became widespread and assisted reproductive technologies were developed. Originally, the only way to become a mother was to conceive and give birth to a child naturally. There was no interfering with Mother Nature’s plans and if a couple had the unfortunate fate of being infertile that was the end of the matter. Then, adoption provided another avenue toward motherhood. A woman could raise a child that was genetically unrelated to her and even legally be considered a mother on paper courtesy of formal adoption laws. The term ‘social motherhood’ began here as a way of separating those who had conceived and given birth to their children and those who had started a family in a different way. ART has since blurred the line between the traditional sense of motherhood and social motherhood as it allows women to conceive and give birth to babies that are either half or wholly unrelated to them genetically. As a result, ‘gestational motherhood’ has become an important term because it refers to women who have experienced pregnancy and childbirth with a child that is not necessarily genetically related to them.

There are two ethical issues here. The first lies in the separation of the gestational link and the state of being a mother. The other comes in the form of
the debate between which is more important to being a mother: the genetic link to the child or the gestational link. Both of these issues have implications on today's definition of mother and motherhood. To address the first, many believe that motherhood is driven by the complete course from conception, through pregnancy, and the birthing process. These three things constitute the mothering triad which slowly introduces the woman to her new role in life, or perhaps refreshes her memory in the event of subsequent children. Those in this camp believe that all parts are necessary in order to be a mother. Each component plays a key part in the training thereof and without any piece, the state of motherhood is not fully complete. The opposing side believes that motherhood is a state of being and caring that any woman can enter. All she needs to do is commit to raising a child from any age, perhaps not even from birth. Here, it is the commitment that is the driving force behind 'being' a mother rather than genetics and/or gestation.

The second discussion, genetics versus gestation, takes on a very familiar form often called the "nature versus nurture" argument. If applying this form to a debate about disease, nature would be referred to as the genetic component. One could ask, 'What genes are responsible for contributing to the disease state and how did one get them?' The nurture portion would refer to the environmental factors that have played a part in bringing about the disease, such as overexposure to sunlight in the case of skin cancer or a long-term smoking habit when dealing with emphysema. Most are familiar with this type of argument, but not necessarily when it is applied to motherhood. Nature, in this case, implies
the genetic link between the mother-to-be and the fetus. It can also be extended to cover the process of pregnancy and childbirth, though the strict sharing of genetic material is most strongly represented in this discussion. Nurture refers to the raising of the child, all the work that begins at or after birth and continues throughout the life of the child. This is the social aspect. As there are two words, there are two sides: the group of people who believe that the genetic link is more important and the side that feels the gestational link is more significant.

Convinced of the importance of the gestational link, there are those who believe that nurturing the fetus with your own body helps to establish the state of motherhood. Women are in control of the nutrients they consume and the environment in which the fetus is developing. The mother-to-be and the fetus get to spend the whole pregnancy together. Nine months of important bonding time is therefore absent when women do not have a gestational link.

In favor of the genetic link, some say that this is part of the original design of parenthood and, as such, should not be overlooked. Those promoting the genetic link also believe that parents would treat a non-genetically related child worse than they would treat their own flesh and blood. This means they would view the child as somewhat distanced from themselves and therefore less important.

It should be noted that some people fall onto one side or the other of the fence, not because they prefer a certain type of link rather, because they simply are not able to partake in the opposite one. For instance, a woman who has diminished ovarian reserves is more likely to take the position that the gestational
link, which she can achieve by gestating a fetus created through the use of donor eggs or embryos, is most important because she cannot achieve a genetic link. Conversely, chances are a woman without a uterus or with uterine problems would believe the genetic link to be more desirable because she is not able to gestate a fetus.

Both of these ethical issues address mothering in a new ART world. No longer is there one route to motherhood. Adoption and ART have provided ways for women, who would not normally have become mothers due to infertility, to be mothers by any means. These new capabilities and options allow for an increase in the number of mothers and to some this can be threatening. If any woman can be a mother, regardless of fertility, is it still special? Is it still desirable? Why should one woman have to go through painful childbirth while another has her new baby delivered to her by the surrogacy agency? This leads to arguments about the status of mothers who arrive at the same place through different means.

There are those who believe that being a mother, regardless of the avenue used, is the whole point while some feel that becoming a mother using anything but the natural route is inappropriate or somehow lessens the status of the state of motherhood achieved. A mother effects change in her child’s life. She guards, protects, and raises the infant. People in favor of any path to motherhood say it does not matter if the child was adopted, created by donor egg and/or sperm, gestated in a surrogate or whatever the case may be. In the end, the important thing is that the child is being guided in the world by a caring
individual. To label that person as a mother should not threaten those mothers who have used the natural route, but rather it simply allows them to join the ranks of all the individuals out there making a difference in the lives of children everywhere.

It should be stated that ‘mothers’ is used here simply because they are the easiest means by which to address the genetic versus gestational link to the child. There is no intentional exclusion of non-traditional families, such as homosexual couples. In the case of gay male couples, the possibility for a gestational link is completely excluded biologically though the same ‘social motherhood’ arguments can be applied in the form of fatherhood. Reciprocally, in lesbian couples where one gestates the child, the status of motherhood for the other partner may be in question. Still, the point remains that the individuals doing the child-rearing, regardless of how the child came to be or was brought into the family, have a unique position and therefore warrant the title ‘mother’ or ‘father’ as the case may be.

**Embryo Donation vs. Embryo Adoption: The Line Between Person and Property**

The term embryo donation is used throughout this paper though the term embryo adoption is referenced with just as much regularity in the current literature. This is the source of some contention in the field as certain words and their connotations can mislead people who are researching the subject matter. To further explore this area, two reasons that the word adoption is contested and the ethical issue raised by this debate are presented.
One of the main issues with calling the process of using a frozen embryo produced by another couple ‘embryo adoption’ is the implication that goes along with the word adoption. In truth, there are no laws that govern the acquisition and implantation of unused embryos and to use the word adoption makes it seem as if this procedure and regular adoption (where the child is placed with a family at birth or later in life) are the same. They are not. Adoption proceedings are protected and guided by certain laws and as such, the word adoption legally refers to the post-birth placement of the child. Therefore, a couple cannot technically, in the legal sense, adopt an embryo. (25) As such, the only possible source of legal protection an infertile couple or patient could obtain against the biological parents wishing to reclaim their embryo would be custom-made legal documents between themselves and the embryo bank/provider or the donating couple. As earlier noted, however, in some states these documents may not be enforceable just as in some states surrogacy agreements are not enforceable either.

Another issue with embryo adoption also stems from the legal definition of adoption as stated above. The post-birth placement of a child may only occur after the child has been deemed an orphan, an individual with no living parents. (26) This can also occur because parental rights have been terminated by the court system or the child has been abandoned. These sentiments do not merge well with the idea of embryo donation which refers to the willful giving of an embryo to a bank or another couple for future use. (19) Here the point of contention is whether or not the embryo is being abandoned/orphaned or is being
given up freely. Some view the cryopreservation of embryos to be a form of neglect or rejection while others see it as an insurance policy against pregnancy loss. Those couples or patients who have completed their families and allow other couples to use their embryos are doing so of their own free will. They have to sign paperwork of their own accord to complete the transfer of the embryos. There is no way to forcibly remove embryos from a person’s possession and as such, embryo donation appears a better fit in this case.

These debates raise the following ethical issue: is an embryo a person or property? In the legal system, embryos are considered to be the products of sperm and egg after fertilization in the laboratory and as such, property. The owners are the legal parents, those individuals who provided the sperm and egg for the procedure. They alone are solely responsible for determining what happens to their embryos. The laboratory or bank where they were created or are currently being housed has no right or say. (19)

In contrast to the current legal opinions on the matter, some people continue to use embryo adoption. By using this phrase they confirm personhood on the embryo. With personhood comes a whole host of legal protections and such that these people see as valuable. For instance, if an embryo is a person, the disposal of any embryos, or one or more not surviving the thawing process, could be considered manslaughter. (19) Their use in research also becomes morally ambiguous. Therefore, the people on this side of issue strive to make embryo adoption the only ethically viable option for all the cryopreserved embryos that are no longer needed by an original couple. Also, considering
embryos to be people would call for prescreening couples that wish to receive embryos much as prospective adoptive parents are screened before being granted a child. People in favor of this believe this would create better, more qualified families. (19)

The personhood argument, however, at the same time, allows for the opposite camp to bring its own criticisms to light. If embryos are people, transferring embryos from couple to couple could be considered human trafficking and if any ART specialist could be brought before a court of law on manslaughter charges should an embryo fail to survive the thawing process, no ART practice could hold enough malpractice insurance to keep its doors open. (19) Additionally, as slavery was abolished by the thirteenth amendment to the United States Constitution, owning embryos which are considered to be people would be in direct violation of United States law. Hence, those that believe an embryo is not a person, push the term embryo donation to keep the embryo on the level of property, as it is seen in the legal world. In fact, the American Society for Reproductive Medicine (ASRM) has stated that they find the language of embryo adoption to be misleading and inaccurate. (27) They cite the same reasons as above: the adoption term works to confirm the status of person to the embryo, a standing the ASRM finds inappropriate and deceptive.
The Ethics of Designer Babies

The Debate

Children who are created through the selection of specific donor sperm and donor egg are often classified under the umbrella term ‘designer babies’. Up until now, the majority of the focus on genetic orphans in this paper has centered on those conceived using embryo donation. It is possible to achieve the same result using dual gamete selection thus producing a child without any genetic relation to the people doing the rearing. The following discussion about whether or not it is ethical to design children uses genetic orphans, for whom both gametes were chosen, as an illustration.

The opponents of designer babies claim that children are gifts from God. Their qualities and physical attributes should not be hand-picked but rather left up to fate. Those who select the sperm and egg donors for their future child do so based on their desires then matched to profiles available from storage banks and facilities. They are provided with physical traits of the donors such as height, hair and eye color, and ethnicity as well as various other social pieces of information like educational status, hobbies, and sometimes even past employment. After choosing their donors, they proceed with the fertilization and transfer process. According to the anti-designer group, they have essentially chosen exactly what they want their child to look like and the activities or level of achievement to which they would like them to be supposedly predisposed. Scientifically, the latter portion of the previous statement is largely unsubstantiated, in part, because of the lack of evidence or reproducibility in the
studies that have claimed to link certain genes to things like athletic performance, academic ability, or environmental sensibility, to name a few.

On the other side, proponents of designer children would argue that it is unfair to call the process of picking out donors designing children. They put forth that we as a society already do the majority of the designing by simply choosing our significant other. There are a variety of psychological and biological processes and factors that assist in the choosing of a healthy and desirable mate with whom to produce children. Some of these factors include the waist-to-hip ratio on females being indicative of fertility or male-patterned aggressive behavior being used to show dominance over other males in order to win females. The true recognition of most of these signs is subconscious and goes on without our ever realizing. However, just because we are not always cognizant of these things does not mean they are not influencing our mating decisions. In this way, we are designing our children before we ever begin the mating process. Though, to be fair, designing is designing no matter how you look at it. People in this camp believe that those who disparage couples who ‘design’ their children by choosing donors should not be so quick to do so as they themselves have most likely ‘designed’ their children, albeit in a different way.

Hence, it would appear that both sides admit to some level of specific intention when it comes to choosing traits of the desired offspring. The main point of debate is, instead, not that one designs a child but that one would be so blatantly obvious about doing so. This perceived brazenness is another discussion altogether.
One of the worries for the anti-designer group is that if couples are given the opportunity to pick and choose certain traits, they will treat their offspring as a commodity instead of a child. (28) This side believes that people should be loved, children most especially, for ‘who they are’ rather than ‘what they look like’ or ‘what they are capable of’. If love was to hinge on achievement or physical beauty, then these things which are fleeting would provide an uneven system of love and caring. Such an unpredictable approach could lead to undue stress on the child and potential feelings of worthlessness. In order to avoid this, the anti-designer group believes parents should not be able to select traits because it places too high of an importance on things that are out of the child’s control.

Opponents of the anti-design philosophy would say that parents who conceive naturally already struggle with the same problems. There are plenty of children in the world who are loved based on their abilities to succeed in sports or at school rather than simply because they are a member of the family. These children were conceived and born the natural way where nothing was consciously chosen, aside from the unavoidable role of biology and the psyche as discussed earlier. And yet even though the parents did not get to pick and choose, they still expect certain things or place particular values on aesthetics and success. Again, these things are not always within the control of the child, and even if they were, they still provide an unfair basis for love and worth. With the difficulty of unconditional love in mind regardless of the methods of conception, the pro-designer camp argues that just because a couple chooses their child’s attributes does not mean that they will love them any less. Parents
of designer offspring do not hold a monopoly on the challenges associated with loving and caring for a child, and nor do the parents of traditionally conceived children.

**Pre-implantation Genetic Diagnosis (PGD)**

When considering ‘designer babies’, pre-implantation genetic diagnosis (PGD) presents an additional level of implications and depth of ethical considerations. PGD is the screening of a fertilized embryo for various conditions such as sex, where the sex chromosomes of each fertilized embryo are examined. This form of PGD is employed by patients interested in family balancing. Another kind of PGD known as aneuploidy screening is used to check embryos for any chromosomal conditions visible on a traditional prenatal karyotype, like Down syndrome or Trisomy 18. Finally, PGD can also be performed to detect certain diseases or disorders that are associated with known genetic causes. This is the rarest and consequently the most expensive form of PGD, and has been publicized most recently in news stories about savior siblings. These children are created specifically to be perfect genetic matches for their sick brothers and/or sisters. They normally provide anything from umbilical cord blood to organs to assist in their sibling’s treatment. This could be considered the epitome of and one of the earliest justifications for designer children.

Anti-designer people put forth that the use of PGD furthers the commodity argument. Not only is a person or a couple choosing physical traits, they are
selecting for an exact portion of their future child’s genetic makeup. This level of interference goes beyond psychological or biological selection that takes place subconsciously and constitutes an active meddling. As such, the anti-designer camp is quick to note that not all selections may be for the “better” as socially defined. For example, there have been cases of deaf parents wishing to select for a deaf child who would be better adapted to fit into their family and their deaf community. Many see this as a perversion of the ability to rid a child of certain diseases and as such pro-designers must be willing to swallow these cases. In response, this pro-side would say that one person’s disorder or disability is another person’s normal. As such, selection for disorders should not be considered wrong because it is simply a unique expression of the future parent(s).

Commentary

The ethical discussions associated with genetic orphans included weighty concerns. In addressing the issue of motherhood, consider what it will be like for genetic orphans who reach that stage. Several questions come to mind: How will their childhood experiences affect their view of mothers? If they have been disclosed to by their parents about the methods of conception, will this color their view of their parent-child relationship? Should the genetic orphan unfortunately suffer from infertility, will they be better adjusted to the idea of using ART? Having been born into the unique ART community, will they be proponents of non-traditional motherhood or will their experiences strengthen their desire to be
natural mothers? Similarly, will they see the genetic link or the gestational link to their future child/children as more important? It will be interesting to see what choices genetic orphans make when they reach reproductive maturity. Several ART children are currently being tracked as part of a progressive study on their psychological adjustment (20); and if they could be followed into their adult years, this may lend some insight into how their backgrounds influence their thoughts, opinions, and views of ART and their own journey into parenthood.

When discussing embryo donation versus embryo adoption, the side presented by the ASRM is a compelling one, citing that the term ‘adoption’ is misleading and can provide false hope to those researching the options available to them. By implying a level of legality that has not yet been established, this sets the system up for failure. If people think that there are legal protections when in fact there are not, the public may never call for a change in embryo donation law. This overhaul is desperately needed to safeguard the rights of intended parents and all those entering into these kinds of agreements and contracts. In addition, ART shows no signs of slowing down its progression and advancement. In this case, it will continue to outrun the legal system. One should not advance without the other to guarantee maximum protection for everyone involved. This idea will be discussed further in the Final Thoughts section.

Lastly, designing children has been a subject of contention for a long while. As the ART field has expanded and become more proficient in procedures like PGD, the possibilities for designing have become more
numerous, as have the arguments for and against. The biological, unconscious aspects of designing as mentioned earlier form a persuasive argument that humans are already fairly proficient at choosing the way their offspring will be. Those who are using ART to do the choosing may have no other choice because of their infertility circumstances and as such, should not be despised for their actions. On the other hand, those who choose to design their children through PGD could be seen as simply taking the next logical step up from letting biological and psychological instincts do their work to utilizing technological advances. If a couple loves their child and provides for him or her, should it really matter how the child came to be in the first place? Does it matter if they were designed or honed in any way? In fact, how could one even tell when meeting the child on the street? There are no markers denoting a “designer child” and, as such, successfully persecuting those families who have taken this route becomes increasingly difficult. In the end, parents cannot design for everything and genetics can only take someone only so far. People are more than their genetic makeup, thus genetics is not destiny.
Final Thoughts

The medical community has made great strides by discovering a wide variety of causes for both male and female infertility and designing ways to help alleviate these troubles. At this moment it would seem that infertility is a problem that will continue to be around for a while. Approximately 10% of infertility cases are labeled as resulting from “unknown factors” and thereby cannot benefit from targeted treatment. (6) Until these particular causes are identified and resolved, infertility cannot truly be eliminated. Hence, if people desiring children continue to be found infertile, ART will remain a large, growing industry around the world. With its use on the rise, these practices will continue to produce situations with which the public is not fully prepared to deal, i.e. genetic orphans. It is this point, I wish to drive home. We, as a community, as a nation, as a world, need to make a focused attempt to tackle the ethical, legal, and social implications of this new technology with fervor matching that of the scientists who are working to drive the field of ART forward.

Genetic orphans are the prime example of being a child without a genetic history. Unless the individual is told about their method of conception and biological donor parents, that child may never suspect that they are not related to
the parents that raised them. Think years from now, when perhaps this person ends up in the hospital with a kidney issue. When the doctor asks if there is a history of kidney disease in the family, the answer given may not be the right one. Maybe there are no renal issues in the social family with whom the child has grown up, but what if there is in fact a history of kidney infection in the biological parents’ medical histories? The genetic orphan would never know this and therefore their medical care could be compromised.

In a world where personalized genetic healthcare is supposedly just over the horizon, an inordinate amount of weight is being placed on genetics and family medical history. This trend shows no sign of stopping and because of this there is an even greater need for genetic orphans to not be left in the dust. As in the previous renal example, the genetic orphan did not intentionally lie to the doctor about his or her medical history, rather they were never disclosed to and therefore never took the time, or had the opportunity, to track down the proper biological donor medical history. This entire process could be further complicated by the legal premise of donor anonymity in many countries. Even if the genetic orphan wished to know their own medical and genetic history, they may not have legal access to the records. This again is an area where improvement is needed. Several nations have already overturned donor anonymity, and reports show that none of their centers have suffered tremendously. In fact, one could say their programs have actually become much more open and helpful to the members of the infertile community and their families. In these countries, children conceived using donor gametes are now
allowed to gather their donor’s medical records through contact with their donors. This gives them a chance to be included in, and benefit from, the personalized genetic healthcare revolution.

The above paragraphs dealt with some of the ethical issues I think need to be fervently addressed as ART continues to improve its capabilities. Legal matters are another major area for improvement. We do not have the legal jargon, know-how, precedent, or actual legislation at this time to proficiently deal with embryos, embryo donation, and the children produced. Adoption is the closest subject matter to the situation facing those wishing to use donated embryos though there are still issues regarding the actual term ‘adoption’ and what this legally means relative to children of ART. Currently, independent contracts are drafted between donors and recipients to circumvent the legal issues associated with embryo donation and its lack of legislative support. This means that everyone has a separate agreement with different wording, benefits, and level of legal binding and enforceability. These inconsistencies could cause conflicts and make reaching universal agreement on what should be included in embryo donation law increasingly difficult. However, in order to make the process easier and safer for donor couples and recipients alike, a general consensus must be reached and implemented in the legal system before much longer. Embryo donation is a rapidly growing practice. If we desire to make sure that those individuals choosing to use this method are as equally protected as those who choose other ART techniques and members of the adoptive community, then the legal system needs work.
Finally, social stigmatization surrounding infertility and those that are a product of ART must be eliminated. What it comes down to is: people are people. We are all going about our business, making our way in the world, so why should it matter how we got here? Simply because someone is a genetic orphan, a distinction you would never be able to tell from just looking, does not make one a less productive member of society. In fact, because of the home environment in which they are raised with parents who truly desire them and went to great lengths to have them, some believe genetic orphans may in fact be just as well adjusted or better adjusted than normal children.

In reference to those individuals dealing with infertility, the stigma surrounding them stems from the fact that they are having trouble performing what is perceived by many to be a basic human function, procreation. Some fail to see the use of a person who cannot produce children. Others believe that those individuals are perhaps meant for parenthood simply through another means, enter ART. Still other people see infertile individuals and couples as meant for social parenting, perhaps through adoption. Whatever the outlook, the fact that the couple or individual is infertile does not make them second class. We have come a long way from a time where, if we did not procreate, our tribe would die off and forfeit land, or not be able to defend itself. Presently, our world is dealing with an overpopulation crisis as we surpassed seven billion people. Therefore, the idea of having children no longer carries such an important life-or-death weight. With this in mind, I will say again, we are all human. We break sometimes; we are occasionally flawed. This is never cause for discrimination.
On the whole, the effort put forth and our ability to deal with the ethical, legal, and social implications of ART and the situations it creates, such as genetic orphans, is lacking. We need to bring up the rear (ethics, law, and societal awareness) before the front (technology) gets too far ahead of us. Science should not be hampered and progress is wonderful but without the safeguards of procedures in place to deal with missing medical histories, proper legal proceedings and ART law, and social adjustment education, to name just a few, progress can be dangerous. People should not suffer because they are offered, and accept the use of, a new technology that promises them a chance at a family of their own simply because the rest of the world has not quite gotten its act together. Perhaps the answer is to restrict the use of an ART that could result in a situation where there is no legal protection or too much social second-class mindset, but the problem here simply becomes where do you draw the line? In order to lift the restrictions on the use of those ARTs: when will we know enough? when will we have sufficient safeguards in place? Like all the other issues discussed in this paper, views vary and a consensus is very elusive. However, regardless of how hard it is, the benefits of improving the world’s responses to the ethical, legal, and social implications of ART are sure to outweigh the struggles we will certainly encounter along the way.
LITERATURE CITED


17. DNA or Loving Care?: Parenthood and Its Interpretations in Contemporary Biomedical Society. Frazzetto, Giovanni. 12, s.l.: European Molecular Biology Organization Reports, 2004, Vol. 5.


BIBLIOGRAPHY


## APPENDICES

### Appendix A: Operational Definition & Interview Questionnaires

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### Appendix C: Interviewees’ Curriculum Vita

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APPENDIX A-1

Operational Definition of Genetic Orphan Used During the Interview Process - Provided separately via e-mail to each interviewee.

“The term Genetic Orphan, in the context of this work, refers to a child, conceived of two donor individuals (usually not personally involved with the couple), who is raised by ‘intended parents’ who are genetically unrelated to the fetus. The child can be gestated by the intended mother or by a surrogate.”

Source: Jillian M. Carroll, Master of Arts Thesis Research (this work)
Genetic Counselor Interview Questionnaire

Targeted Respondents:
Jennifer Verbrugge, MS, CGC, LGC
Stephanie Cohen, MS, CGC, LGC

Questions:
1. What does the term ‘genetic orphan’ call to mind/mean to you?
2. After having ‘genetic orphan’ operationally defined by reading the second attached document, what is your first impression?
3. What are some counseling issues you believe would arise during a session with the parents of a ‘genetic orphan’?
4. What are some ethical issues you believe to be involved with the situation of ‘genetic orphans’?
5. In terms of genetic history, do you think the ‘genetic orphans’ have a right to know the methods of their conception?
6. Medically, what proportion of congenital birth defects tend to be associated with in utero versus known genetic issues? And, as a follow up, what data is known to support this information or statistics? Subsequently, do you believe if a ‘genetic orphan’ was born with a congenital versus a genetic defect that this would change the necessity of disclosure of their methods of conception/medical histories of donor parents?
7. How would you deal with the prospect of advising/counseling a couple contemplating pursuing the ‘genetic orphan’ route to obtaining a child?
ART Scientific Director/Embryologist Interview Questionnaire

Targeted Respondent:
Jeffrey Boldt, Ph.D.

Questions
1. What does the term ‘genetic orphan’ call to mind/mean to you?
2. After having ‘genetic orphan’ operationally defined by reading the second attached document, what is your first impression?
3. Have you ever personally experienced a situation in which a ‘genetic orphan’ was conceived?
4. Do you know of any practitioners who have dealt with ‘genetic orphans’?
5. What are some ethical issues you believe to be involved with situation of ‘genetic orphans’?
6. In terms of genetic history, do you think the ‘genetic orphans’ have a right to know the methods of their conception?
7. Medically, what proportion of congenital birth defects tend to be associated with in utero versus known genetic issues? And, as a follow up, what data is known to support this information or statistics? Subsequently, do you believe if a ‘genetic orphan’ was born with a congenital versus a genetic defect that this would change the necessity of disclosure of their methods of conception/medical histories of donor parents?
8. Do you believe we/society should differentiate between genetics orphans and traditional adoptees?
9. What do you think about the use of donated embryos?
Director of Counseling and Health Services Interview Questionnaire

Targeted Respondent:
June Payne, Ph.D.

Questions:
1. What does the term ‘genetic orphan’ call to mind/mean to you?

2. After having ‘genetic orphan’ operationally defined by opening the second document attached to the e-mail, what is your first impression?

3. What are some counseling issues you believe would arise during a session with the parents of a ‘genetic orphan’?

4. What are some counseling issues you believe would arise during a session with a ‘genetic orphan’?

5. Do you think that because of the cost of the process to obtain these children ($28,500 and above per IVF cycle), the ‘parents’ might feel they should have greater control over the child?

6. What are some ethical issues you believe to be involved with the situation of ‘genetic orphans’?

7. In terms of genetic/medical history, do you think the ‘genetic orphans’ have a right to know the methods of their conception?

8. How would you deal with the prospect of advising/counseling a couple contemplating pursuing the ‘genetic orphan’ route to obtaining a child?

9. In light of the situation with women’s health issues in the US, do you think that a movement towards the creation of more ‘genetic orphan’ children could result in a secondary class of childbearing women?
Interviewee Responses

Genetic Counselor: Jennifer Verbrugge, MS, GCG, LGC

1. What does the term 'genetic orphan' call to mind/mean to you?

I have not heard this term used in a particular context and I am therefore unsure of its meaning. My guess is that it could mean an adopted person who has no idea of their genetic family history.

2. After having ‘genetic orphan’ operationally defined by reading the second attached document, what is your first impression?

The definition makes sense but the term “orphan” socially carries a negative connotation.

3. What are some counseling issues you believe would arise during a session with the parents of a ‘genetic orphan’?

Knowledge of the detailed family history can sometimes provide additional clues on the diagnosis and recurrence risks associated with a genetic disease. This information may be missing in the case of a genetic orphan. There could be implications for the biological parents and their families if a genetic disease is diagnosed in a genetic orphan and informing the biological parents and their families may not be possible. A situation could arise that would make a genetic orphan begin to ask questions about how and why his/her parents chose to pursue ART. Maybe a couple would not wish this to be known to their child.

4. What are some ethical issues you believe to be involved with the situation of ‘genetic orphans’?

See previous answer.

5. In terms of genetic history, do you think the ‘genetic orphans’ have a right to know the methods of their conception?

I think it is the parent’s right to inform or not inform their child of this. I don’t believe there are any laws that require parents to inform their child that he/she is adopted. I don’t think a genetic orphan’s situation is any different. In addition, the parents should
be the ones to determine the optimal time to discuss these issues with a child.

6. *Medically, what proportion of congenital birth defects tend to be associated with in utero versus known genetic issues? And, as a follow up, what data is known to support this information or statistics? Subsequently, do you believe if a ‘genetic orphan’ was born with a congenital versus a genetic defect that this would change the necessity of disclosure of their methods of conception/medical histories of donor parents?*

Donors generally are and should be screened through obtaining a detailed family history. If there is a significant risk for a birth defect based on their family history, they should not be allowed to be a donor. However, most birth defects occur without a known family history, and can still be hereditary and occur without the donor’s knowledge of any increased risks. I don’t know the specific reference for this data. I am not familiar enough with the practice or guidelines in place for donor banks about notification of a problem. However, parents and donors should be counseled and informed of the risk of such a situation before participating is such a program and that information about a birth defect may not be made available to the donor or his family members. As long as there is informed consent, the donor bank should not be held responsible for such a situation as long as they can demonstrate that adequate screening of the donor was performed. They should also not be held responsible for not notifying the donor and any possible risks as long as this was disclosed as a possible risk of participating as a donor.

We don’t completely understand the specific etiology of some birth defects and their association with ART procedures so I don’t think that knowledge of how a child was conceived would be helpful or even necessary for medical reasons.

7. *How would you deal with the prospect of advising/counseling a couple contemplating pursuing the ‘genetic orphan’ route to obtaining a child?*

I would counsel a couple that any child can be born with a birth defect, despite knowledge or no knowledge of the family history. Every child has at least a 2-4% risk for being born with a birth defect. In addition, there are studies that suggest that ART procedures may carry an increased risk for birth defects (above this general population risk) and couples should be provided information about these risks/studies prior to electing to proceed with an ART procedure.
Interviewee Responses

Genetic Counselor: Stephanie Cohen, MS, CGC, LGCC

1. What does the term ‘genetic orphan’ call to mind/mean to you?

Not much in particular – I’ve heard of orphan diseases, meaning rare conditions or maybe someone who doesn’t know their family history.

2. After having ‘genetic orphan’ operationally defined by reading the second attached document, what is your first impression?

Wow – never have heard that definition used in that context. I don’t like it, because the child is not technically an orphan (meaning no parents) – seems to set up a very negative connotation. These children have parents who very much want them (maybe more than typical birth parents in a lot of cases!).

3. What are some counseling issues you believe would arise during a session with the parents of a ‘genetic orphan’?

I assume you mean adoptive parents…..the ones who are raising the child. Probably similar to issues that arise in a session where a child is adopted (worries about family hx) – although there may actually be more family history information available due to the screening that usually occurs with an adopted child. Perhaps some concerns about assumptions made in the general public regarding children looking (or not looking) like them.

4. What are some ethical issues you believe to be involved with the situation of ‘genetic orphans’?

Issues of parentage if a donor or surrogate changes their mind, situations where there is a divorce.

5. In terms of genetic history, do you think the ‘genetic orphans’ have a right to know the methods of their conception?

I think that is a personal decision that the parents who raise the child have to make – not unlike any adoptive parent. I don’t really see this as too much different. I believe they should have the right
to know their family history, but I am not certain that it is relevant how they were conceived.

6. Medically, what proportion of congenital birth defects tend to be associated with in utero versus known genetic issues? And, as a follow up, what data is known to support this information or statistics? Subsequently, do you believe if a 'genetic orphan' was born with a congenital versus a genetic defect that this would change the necessity of disclosure of their methods of conception/medical histories of donor parents?

I don’t know – does anyone?! We don’t really know the true incidence of genetic issues – what do you mean by this – including late onset conditions? Some birth defects are due to genetic issues (trisomy 18, eg). 3-5% of children are born with a birth defect. As much as 20% of us will be diagnosed with a genetic condition of some kind in our lifetime.

Method of conception – no. Medical history of donor parents – should be able to get this regardless of birth defect/genetic condition.

7. How would you deal with the prospect of advising/counseling a couple contemplating pursuing the ‘genetic orphan’ route to obtaining a child?

Just as any preconception consultation, importance of family hx information, if possible, although most birth defects and genetic conditions are not predictable based solely on family history. Discuss alternative options for adoption. If donors histories/ethnicities available, risk assessment.
ART Scientific Director/Embryologist: Jeffrey Boldt, Ph.D.

1. What does the term ‘genetic orphan’ call to mind/mean to you?

A genetic orphan would be an embryo created through IVF and frozen, which then is no longer used by the biologic couple for conception. As such, the embryo is essentially abandoned and kept frozen.

2. After having ‘genetic orphan’ operationally defined by reading the second attached document, what is your first impression?

I think my definition is essentially that of the operational definition. What you are saying is that a genetic orphan is any child either delivered by someone who has no genetic relationship (i.e. a gestational surrogate), delivered by the intended mother with no genetic link (i.e. as in a donor embryo cycle).

My problem with your definition involves use of the term "intended parents". That restricts your use of genetic orphans to only those where a surrogate arrangement is planned ahead of time. This would exclude donor embryo babies and traditional adoption.

3. Have you ever personally experienced a situation in which a ‘genetic orphan’ was conceived?

Yes. We have had several patients that have conceived using a gestational surrogate. And if your definition is expanded to include donor embryo cycles and traditional adoption cycles, I have been involved in hundreds of such cases.

4. Do you know of any practitioners who have dealt with ‘genetic orphans’?

See answer to # 4. As lab director for Assisted Fertility Services with Community Health Network I have personally been involved in such cases.

5. What are some ethical issues you believe to be involved with situation of ‘genetic orphans’?
One of the clearer ethical issues comes up with the legal definition of a mother for the State of Indiana. Indiana state law specifically indicates that a birth mother is the legal mother. Thus, if a gestational surrogate is used in Indiana the surrogate is the legal mother, and as such the intended parents must legally adopt the child. As such, if the gestational surrogate does not want to relinquish her parental rights, the intended parents are out of luck. Further clouding this issue, Indiana law clearly indicates that surrogacy contracts are not enforceable in the state. Thus, even if a contract is drawn between surrogate and couple, the couple has no legal rights if the surrogate breaks the agreement.

I don’t see any other specific ethical issues that would make the “genetic orphan” different than situations like donor embryo or traditional adoption.

6. **In terms of genetic history, do you think the ‘genetic orphans’ have a right to know the methods of their conception?**

I think this is a decision to be made by the parents. Records should be kept somewhere of whom the genetic parents were in case there would be reason for follow up testing for genetic diseases or such at a later date.

7. **Medically, what proportion of congenital birth defects tend to be associated with in utero versus known genetic issues? And, as a follow up, what data is known to support this information or statistics? Subsequently, do you believe if a ‘genetic orphan’ was born with a congenital versus a genetic defect that this would change the necessity of disclosure of their methods of conception/medical histories of donor parents?**

There are no increases in congenital abnormalities in children conceived by ART vs. the general population risk. I am in favor of maintaining records in such cases where the genetics parents can be contacted for more information if required.

8. **Do you believe we/society should differentiate between genetics orphans and traditional adoptees?**

I see no reason why these should be differentiated.

9. **What do you think about the use of donated embryos?**

We have been responsible here for the birth of over 50 children from donated embryos. It represents to me an ideal way for
couples that have undergone IVF, with excess embryos in storage, to utilize these embryos if their family is completed. Many couples are uncomfortable with the idea of donation to research with the resulting destruction of the embryo, and they view embryo adoption as a more altruistic alternative. They know what they went through to conceive and want to help another childless couple experience the same joy they have experienced.
Interviewee Responses

Director of Counseling and Health Services: June Payne, Ph.D.

1. What does the term ‘genetic orphan’ call to mind/mean to you?

   Genetic disorders or illnesses that are caused by abnormal gene development?

2. After having ‘genetic orphan’ operationally defined by opening the second document attached to the e-mail, what is your first impression?

   My first impression is that I’m still not sure I understand the operational definition but is this concept similar to having a donor egg or donor sperm? In this case it would mean having both a donor egg and donor sperm.

3. What are some counseling issues you believe would arise during a session with the parents of a ‘genetic orphan’?

   a. Concerns about genetic problems of the biological parents
   b. Concerns about psychological problems that might develop for the child because of the nature of conception; the possible unknown biological risks for the donor parents; and perceived difference because the biological parents would be unknown
   c. The intended parents’ acceptance of the child
   d. Inadequacy feelings of the intended parents
   e. Possible legal issues -- parental rights and/or unforeseen problems with the biological parents
   f. Unconditional love and acceptance of the child

4. What are some counseling issues you believe would arise during a session with a ‘genetic orphan’?

   Many counseling issues would be the same as mentioned above.
   a. Unknowns about genetic problems of biological parents
   b. General concerns about who the biological parents are and understanding for the child of exactly who he/she is
   c. Concerns about genuine love and acceptance by the intended parents
5. *Do you think that because of the cost of the process to obtain these children ($28,500 and above per IVF cycle), the 'parents' might feel they should have greater control over the child?*

This statement may be true for some; however, I suspect that most perspective parents who choose this option will be aware of the cost and inherent risks. This sounds to be one of those procedures that only the wealthy will be able to afford.

6. *What are some ethical issues you believe to be involved with the situation of 'genetic orphans'?*

Personally, I believe it is extremely important for the perspective parents to go through some type of counseling prior to entering into these types of arrangements. They should be made aware of all possible risks and complications – including the possibility of raising a child who has multiple physical complications. Ethically, I think these parents should be presented with all possible options before receiving a final approval to move forward.

Medically, I think the physicians who work in this field are responsible for how they apply their science. Just like it became an ethical issue for the physician who implanted eight fertilized eggs in Nadia Suleman (sp. The Octa-Mom) it seems important for the physician to understand his/her motives in performing these procedures. If for whatever reason the parent/child bond is not a good one, what happens to the child? Who takes care of the child? Does the child subsequently become a ward of the State?

7. *In terms of genetic/medical history, do you think the ‘genetic orphans’ have a right to know the methods of their conception?*

Yes. In my estimation, this should be explained fully to the children when they reach a certain point of maturity. I also believe that the medical history of the donor parents should be taken and provided for the child.

8. *How would you deal with the prospect of advising/counseling a couple contemplating pursuing the ‘genetic orphan’ route to obtaining a child?*

I would start by trying to identify each perspective parent’s concerns about pursuing the genetic orphan route. I would also encourage them to explore their family backgrounds and values as well as their philosophies about parenting. I think the couple should review their past history with trying to conceive and the options they
dismissed such as adoptions. I think these questions should be explored in the context of how they arrived at their decision and their readiness to proceed.

9. In light of the situation with women’s health issues in the US, do you think that a movement towards the creation of more ‘genetic orphan’ children could result in a secondary class of childbearing women?

This is an interesting concept and possibility. Yes, I believe that there is a distinct possibility that a secondary class of childbearing women could be the result of creating more genetic orphans. This also potentially creates other ethical issues in terms of parental rights and responsibilities.
Jennifer L. Verbrugge, MS, GCG, LGC

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jverbrug@iuhealth.org

EDUCATION

Master of Science - Genetic Counseling 1998
Indiana University, Indianapolis, IN

Bachelor of Science - Microbiology 1989
Indiana University, Bloomington, IN

PROFESSIONAL EXPERIENCE

Genetic Counselor, Indiana University Health North Hospital, Maternal Fetal Medicine, Perinatal Consultants, December 2005 to present

Clinical Review Coordinator, Kate Cares Stillbirth Assessment Program, May 2007 to present

Genetic Counselor, Indiana University Hospital, Department of OB/GYN, Prenatal Diagnosis Clinic, Indiana University Medical Center, September 1998 to December 2005

Supervisor of the Cytogenetic Leukocyte Laboratory, Indiana University Medical Center, July 1993 to April 1997

Cytogenetic Technologist, Cytogenetics Laboratory, Indiana University Medical Center, July 1997 to September 1998

Cytogenetic Technologist, Cancer Cytogenetics Laboratory, Indiana University Medical Center, July 1989 to July 1993

PROFESSIONAL CERTIFICATION AND LICENSURE

American Board of Genetic Counseling; Certified Genetic Counselor, 1999 to present

Licensed Genetic Counselor 2010 to present
Assisted in creating and writing Indiana Code 25-17.5, a law that requires genetic counselors in Indiana to hold a license
Testified at Indiana senate hearing in January of 2010 in support of licensure bill

PROFESSIONAL AFFILIATION

The Indiana Network of Genetic Counselors (INGC)
Vice President 2008/2009
National Society of Genetic Counselors (NSGC)
Kate Cares Stillbirth Assessment Program Advisory Group Member
Kate Cares Stillbirth Assessment Program Executive Committee Member

PRESENTATIONS AND COURSE INSTRUCTION

*Ohio Valley Regional Cytogenetics Conference, May 1993:* “The Use of FISH as a Tool for the Diagnosis of Solid Tumors”

*Ohio Valley Regional Cytogenetics Conference, May 1995:* “Possible Mosaic Prader-Willi Deletion Found Through FISH and the SNRPN Probe”


*OB/GYN Residents Training, July 1999,* “Maternal Serum Screening”

*Ohio Valley Regional Cytogenetics Conference, 2000:* “Prenatal Diagnosis of a Marker Chromosome”

*Update in Clinical Practice in Obstetrics: Implementing New Technologies in Prenatal Diagnosis and High Risk Obstetrics, March 2002:* “Utilizing First Trimester Maternal Serum Screening for Aneuploidy in Your Practice”, “Understanding and Informing Your Patients Regarding Maternal Serum Screening”, Indiana University School of Medicine

*Clarian Perinatal Conference, May 2003, October 2003,* “Genetic Counseling and Prenatal Diagnosis”, Indiana University School of Medicine


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“Ethnicity Based Carrier Screening” Indiana University School of Medicine Genetic Counseling Graduate Student Program

Supervisor of Genetic Counseling Graduate Students: Prenatal Diagnosis Practicum Q615, 1999-present; Indiana University School of Medicine Genetic Counseling Graduate Student Program

Maybe a Baby; 2009 to present: Indiana University Health North Hospital; A class for the local community of couples planning pregnancy

Care of the Antepartum Patient, June 2010, December 2010 “Genetic Counseling and Prenatal Diagnosis”, a biannual class for nurses at Indiana University Health North Hospital

An Introduction to the Kate Cares Stillbirth Assessment Program, 2010; Presented at local hospitals including Indiana University Health Bloomington Hospital, Indiana University Health Arnett Hospital, Coleman Center for Women at Indiana University Hospital

PUBLICATIONS


Stephanie A. Cohen, MS, CGC, LGC

St. Vincent Hospital Center for Cancer Care
Cancer Genetics Risk Assessment Program
8301 Harcourt Rd #100
Indianapolis, IN  46260
(317) 415-6676
sacohen@stvincent.org

EDUCATION:  University of Michigan, Ann Arbor, Michigan
MS Genetics, December 1993

Case Western Reserve University (CWRU), Cleveland, Ohio
BS Biology, May 1992
Magna cum laude with honors in Biology

HONORS:  Ohio Leadership Scholarship (’88, ’89, ’90, and ’91)
Peter Witt Scholarship for community service (’90, ’91)
CWRU Alumni Scholarship (’90, ’91)
Phi Beta Kappa

CERTIFICATION:  American Board of Genetic Counseling, 1996
Recertified in 2006

LICENSURE:  Genetic Counselor, State of Indiana (7/1/2010)

WORK EXPERIENCE:
Genetic Counselor:  St. Vincent Hospital  (5/95 to present)
Indianapolis, IN

Cancer Genetics Risk Assessment Program (6/06-present): Developed stand-alone Cancer Genetics Risk Assessment Program within the Center for Cancer Care. Provide all aspects of genetic counseling and administrative tasks associated with Cancer Genetics Risk Assessment Program, including coordinating genetic testing for hereditary cancer syndromes. Provide education to community groups, physicians and residents by giving lectures. Collaborated
with nurse practitioner to create a Breast Risk Assessment Clinic to identify women at high risk for breast cancer. Supervise genetic counseling graduate students from IUPUI in required cancer genetics rotation. Design and conduct research on professional issues in cancer genetic counseling, with a special interest in service delivery models.

*Medical Genetics (6/00-6/06):* Provided genetic counseling in Medical Genetics clinic to individuals and families with children who have a known or suspected genetic condition. Developed and implemented multi-specialty Down Syndrome Clinic; coordinated the Down Syndrome Clinic. Provided genetic counseling and coordinated genetic testing for hereditary cancer syndromes. Act as a resource on genetic topics for referring physicians, medical staff and residents.

*Maternal Fetal Medicine and Genetics (5/95 to 6/00):* Provided prenatal genetic counseling for advanced maternal age, positive triple screens, ultrasound abnormalities, family history and teratogen exposure. Developed and implemented Cancer Genetics Program, including provision of genetics counseling and coordination of genetic testing for hereditary cancer syndromes. Involved in creation of patient support group and patient brochures, education to medical staff and genetic counseling student supervision.

**Adjunct Assistant Professor:** Department of Medical and Molecular Genetics (1/1/11-present) Indiana School of Medicine

Expanded a 1 credit hour class on Cancer Genetics to 2 credit hours. Co-teach semester-long course on Cancer Genetics for genetic counseling graduated students.

**Genetic Counselor:** Consultants in Genetic Medicine (1/94-11/94) Pathology Department, The Toledo Hospital, Toledo, OH

Provided fetal pathology, prenatal, pediatric and adult genetic counseling. Involved in program development for clinical genetics services, including creating educational materials, protocols, and marketing tools. Participate in fetal evaluations by working as part of a team including pathologists, MFM specialists and geneticists to evaluate and counsel families who suffer a fetal loss.

**Genetic Counseling Assistant:** University of Michigan (9/93-12/93) Family Studies Core, Human Genome Center

Collected family history information, arranged for sample collection, data entry into Pedigree Draw, and answered inquiries about various projects. Also worked with researchers to design consent forms, provide patient information on specific research projects, and contact potential families for involvement in the project.

**Teaching Assistant:** University of Michigan (9/92-12/93) Biology Department (Biology 152, 154, 305)
Taught laboratory sections on introductory biology and discussion sections for genetics. Responsibilities included teaching course material, leading discussion and problem solving sessions, assigning lab reports and homework, writing quizzes, grading exams, holding office hours, and assigning grades.

**PUBLICATIONS:**


Cohen, SA. “Muir-Torre syndrome associated with a mutation in MSH6: multiple sebaceous carcinomas as the presenting feature” *Community Oncology* 6(9) 2009: 418-421.


**PRESENTATIONS:**
Genetic Counseling Service Delivery Models
Association of Cancer Executives: New Orleans (1/27/11)

Experience with Hughes Software
NCCCP Genetics Working Group teleconference (12/9/10)

I’m a Genetic Counselor: So what do you do?
Crispus Attucks Minority Health Professionals Development (11/3/10)

Poster: Impact of computer-assisted technology in cancer genetics
National Society of Genetic Counselors Annual Education Conference: Dallas (10/15/10)
St. Vincent Hospital Research Symposium (6/16/10)

Service Delivery Models: NSGC Task Force Report
Educational Break-out Session at the NSGC Annual Education Conference: Dallas (10/15/10)

There’s cancer in my family! Hereditary Risks for Cancer
Color Me Pink: Anderson, IN (10/5/10)

Genes, Families and Cancer
Indiana Oncology Social Workers: Indianapolis, IN (9/21/10)

Moderator and Conference organizer: Lynch Syndrome Symposium, Best Practice in Screening and Treatment
St. Vincent Hospital (8/28/10)

Incorporating Hereditary Cancer Risk Assessment into the OB/GYN Practice
St. Vincent Hospital OB/GYN Grand Rounds (4/14/10)

Nuts and Bolts: Tools for Setting up a Cancer Genetics Clinic
National Consortium of Breast Centers Pre-conference Course: Hereditary Breast and Ovarian Cancer Update: Las Vegas, NV (3/21/10)

Collaborative Model of Genetic Counseling: A new paradigm
Myriad-sponsored Genetic Counselor dinner: Denver, CO (2/3/10)

Evaluating Patient Understanding and Satisfaction of the Genetic Testing Process for Hereditary Cancer: Does Ordering Provider Make a Difference?
National Society of Genetic Counselors Pre-conference Symposium “The Changing Paradigm of Cancer Genetic Counseling”: Atlanta, GA (11/12/09)

Poster: Evaluating Patient Understanding and Satisfaction of the Genetic Testing Process for Hereditary Cancer: Does Ordering Provider Make a Difference?
National Society of Genetic Counselors Annual Education Conference: Atlanta, GA (11/13/09)

St. Vincent Hospital Research Day: Indianapolis, IN (6/10/09)

Alternate Service Delivery Models: A Shift in the Genetic Counseling Paradigm
NSGC on-line CEU course (available 7/2009)

Ethical Issues in Cancer Genetics Across the Lifespan
Ethics Day, St. Vincent OB/GYN Residency Program: Indianapolis, IN (3/4/09)

Careers in Genetics
Crispus Attacks Medical Magnet Professional Program: Indianapolis, IN (12/5/08)

Hereditary Causes of Cancer
Wellness Community: Indianapolis, IN (6/11/08)

Are You or Your Family at Risk for Cancer?
Living Vit Cancer (Jewish cancer support group): Indianapolis, IN (6/8/08)

Ethical Issues in Genetic Testing for Hereditary Breast & Ovarian Cancer
Ethics Day, St. Vincent OB/GYN Residency Program: Indianapolis, IN (4/9/08)

High Risk Breast Assessment and Screening
Komen Workshop: Everything you Want to Know, But Are Afraid to Ask, Indianapolis, IN (3/8/08)

Hereditary Causes of Cancer
Wellness Community, Indianapolis, IN (11/06)

Colorectal Cancer Genetics: An Update, Discussion and Case Studies
Myriad sponsored round-table discussion, Indianapolis, IN (3/05)

Panel: Genetic Counselors Dealing with Genetic Conditions
NSGC Annual Education Conference, Washington, DC (10/04)

Hereditary Cancer Syndromes for the OB/GYN
St. Vincent Hospital, Indianapolis (5/03)

Panel: Genetic Counselors Dealing with Genetic Conditions
NSGC Regional Meeting, Chicago, IL (4/03)

Organized and presented conference: Familial Cancer Risk Assessment: Is your patient at risk?
St. Vincent Hospital, Indianapolis, IN (4/03)

Genetic Hints and Resources
AWHONN quarterly meeting (9/01)

Careers in Genetics
Lawrence North High School (2/01)

Organized and presented panel discussion: Perspectives on Down Syndrome
St. Vincent Hospital, Indianapolis, IN (10/00)

Methotrexate Embryopathy
Tri-state Dysmorphology Meeting, Indianapolis, IN (5/00)
Moderated panel discussion at Region IV meeting in St. Louis (4/00)

Careers in Genetics
Carmel High School (2/25/00)

Genetics and Your Practice: Genetic Counseling
Anderson School of Nursing (2/18/00)

Understanding the Genetics of Cancer
Women’s Health Expo (11/13/99)

Cancer and Genetics
Indiana Cancer Registrars Annual Education Conference (11/4/99)

Genetics and Your Practice: Prenatal Genetic Counseling
V.N.A., Elwood, IN (8/2/99)

Genetics and Your Practice: Genetic Testing and Predisposition for Breast Cancer
Tipton Memorial Hospital (6/24/99)

Created and presented “Genetic Risk Assessment” Course for physicians and nurses (1997)

Poster: Use of a Family History Questionnaire as a Screening Tool in a Primary Obstetrical Setting
American Society of Human Genetics Meeting, San Francisco, CA (10/97)

Working with Families Continuing a Pregnancy with a Known Abnormality
NSGC annual education conference workshop: San Francisco, CA. (10/96)

Discussing fetal autopsy with grieving families
Prenatal Diagnosis conference: St. Vincent Hospital, Indianapolis, IN. (5/96)

Putting the Pieces together: Counseling for Ultrasound abnormalities
Ultrasound conference: St. Vincent Hospital, Indianapolis, IN. (10/95)

Panel Discussion: Update on Training Programs
Region IV conference in Columbus, OH. (4/95)

Workshop: When DNA results are not simple
Contributed case at NSGC annual education conference in Atlanta, GA. (10/93)

Bibliography and Resources for Siblings of Children with Special Needs
NSGC Region IV meeting in Minneapolis, MN. (3/93)

**PROFESSIONAL ACTIVITIES:**
Article reviewer for Journal of the American Medical Association (2010).

Appointed Chair of Service Delivery Task Force for the NSGC Genetic Access and Service Delivery Committee (11/09-present)


President, Indiana Network of Genetic Counselors (9/06-11/10)

Site-visitor, American Board of Genetic Counseling (10/05-present)

Chair, Indiana Genetic Counselors Network Licensure Committee (12/04-9/06)
State Representative for Indiana NSGC Region IV (1/04-10/06)

Chair, Publications Subcommittee (9/03-11/06)

Co-chair, 2003 NSGC Annual Education Conference

Awarded grant from the Indiana Down Syndrome Foundation for patient educational materials and supplies for the Down Syndrome Clinic (3/02).

Member, Indiana Genetics Advisory Committee (2002-present)

Member, Publications Subcommittee (2001-2006)

Co-Chair, Program Committee for the 2002 NSGC Annual Education Conference

Chair, Resource Room for 2001 Annual Education Conference

Co-Chair, Abstract Committee for 2000 NSGC Annual Education Conference

Awarded grant from the March of Dimes for a prenatal education class in Spanish (6/99).

Member, Marion County Fetal Infant Mortality Review Program (1996-1999)

Member of Workshop Committee for the 1999 NSGC Annual Education Conference in Oakland, CA

Member of Professional Issues committee of NSGC. (5/95 to 1999)
Article Reviewer for Journal of Genetic Counseling (1998)

Chair, Special Projects Fund Committee (1998)

Invited guest Editor of Perspectives in Genetic Counseling (Winter 1997/98 issue)

Member of Perspectives in Genetic Counseling staff. (3/97-1/98)

Editor of “IV Your Information”, a quarterly newsletter for NSGC Region IV. (11/96-1/98)

Member, Special Projects Fund Committee (1996-1998)

Member of Social Issues committee of NSGC. (10/93 to 1998)

Member of planning committee for NSGC Region IV meeting in Kansas City, KS. (3/96)

Member of planning committee for NSGC Annual Education Conference in Minneapolis. (10/95)

Member of planning committee for NSGC Region IV meeting in Indianapolis. (4/94)

**PROFESSIONAL MEMBERSHIPS:**

Health IT Significant Interest Group, NSGC (2011-present)

Collaborative Group of Americas on Inherited Colorectal Cancer (2010)

Familial Cancer Risk Significant Interest Group, NSGC (2004-present)

National Society of Genetic Counselors (1/93 to present)

American Society of Human Genetics (6/93 to 12/01)
Jeffrey P. Boldt, Ph.D.

Scientific Director (1998-present)
Assisted Fertility Services
Community Health Network

Clinical Associate Professor
Department of Medical and Molecular Genetics
Indiana University School of Medicine

Scientific Director
The World Egg Bank

EDUCATION

College: State University of New York at Buffalo, 1973-77
B.A. Biology (cum laude)

Graduate: State University of New York at Buffalo, 1979-1983
Ph.D Anatomy (with Distinction Honors)

Post-Doctoral Research Fellow
University of Texas Medical School at Houston, Department of OB/GYN and Reproductive Sciences

ACADEMIC APPOINTMENTS

Clinical Associate Professor, Department of Medical and Molecular Genetics, Indiana University School of Medicine, 1993-present.

Associate Professor, Departments of Obstetrics and Gynecology and Anatomy, Albany Medical College, December 1989 - April 1993

Associate Professor, Departments of Obstetrics and Gynecology and Anatomy, Medical College of Georgia, July 1989 - November 1989

Assistant Professor, Departments of Obstetrics and Gynecology and Anatomy, Medical College of Georgia, July 1984 - June 1989
CERTIFICATIONS

Board Certified Laboratory Director for Andrology and Embryology, American Board of Bioanalysis, 1994.

Certificate of Qualification from New York State Department of Health for Laboratory Director in Endocrinology, 1991

Certificate of Qualification from New York State Department of Health for Laboratory Director in Andrology, 1993

TEACHING EXPERIENCE

Courses Taught in Graduate School: Human Gross Anatomy, Histology, Embryology, Neuroanatomy, and Cell Biology

Courses Taught at Medical College of Georgia: Embryology, Histology, Endocrinology, Human Reproduction (co-course director)

Courses Taught at Albany Medical College: Human Gross Anatomy, Embryology, Cell Biology, Endocrinology, Human Reproduction

CLINICAL APPOINTMENTS

Laboratory Director, Southeastern Fertility Center, Baptist Women’s Hospital, Knoxville, TN, 2003-present

Laboratory Director, Bluegrass Fertility, Lexington KY, 2003-present

Program and Scientific Director, Assisted Fertility Services, Community Health Network, 1998-Present

Partner, Reproductive Laboratory Consultants, 1998-2000. Served as co-laboratory director at East Carolina University and Walter Reed Hospital and consulted with other fertility labs
Laboratory Director, The Center for Reproductive Medicine and Fertility, Chattanooga TN, 1999-2001

Laboratory Director, Midwest Reproductive Medicine, Indianapolis IN 1993-1997


Director, Human In Vitro Fertilization and Andrology Laboratories, Medical College of Georgia, 1984-1989.

CONSULTING/LEADERSHIP POSITIONS

FDA OB/GYN Devices Panel, 2003-present

Consultant, Cooper Surgical/SAGE Biopharma, 2003-present.


Advisory Board, Sigma Tau Pharmaceuticals, 1999 - 2002

Chair, Strategic Planning Committee, Reproductive Biology Professional Group, American Society for Reproductive Medicine, 1997-2000

Chair, Reproductive Biology Special Interest Group, American Fertility Society, 1993-1994.

Course Director, American Fertility Society Post-Graduate Course, "Controversies in Reproductive Biology and Technology", 1993.

Vice Chair, Reproductive Biology Special Interest Group, American Fertility Society, 1992-1993.

Program Chair, Reproductive Biology Special Interest Group, American Fertility Society, 1990 - 1992.

Placement Committee, American Fertility Society, 1988 - 1989

Faculty Advisor for Medical College of Georgia School of Medicine Class of 1989, 1990, 1991, and 1992
Chairman, Student Affairs Committee, Medical College of Georgia, 1988, 1989

Chairman, Dean's Student Research Committee, Medical College of Georgia, 1989

AWARDS/HONORS

Wiggers Travel Award, Albany Medical College, 1990

Chair's Distinguished Service Award, Medical College of Georgia Academic Council, 1988


SUNY at Buffalo Graduate School's Excellence in Teaching Award, 1981

SCIENTIFIC AND PROFESSIONAL SOCIETIES

American Society for Reproductive Medicine
American Association of Bioanalysis

RESEARCH GRANTS


Biomedical Research Support Grant, Medical College of Georgia. Project Title: "Culture Conditions and In Vitro Development of Mouse Embryos." $4,000 April 1, 1986 - March 31, 1987

Medical College of Georgia Research Institute, Small Grants Program Award: Project Title: "Characterization of the Mouse Egg Plasma Membrane." $7,000 July 1, 1986 - January 1, 1987

Biomedical Research Support Grant, Medical College of Georgia: Project Title: "The Mouse Egg Plasma Membrane: Isolation and Characterization of Functional Properties." $4,000 April 1985 - March 1986
PRESENTATIONS

Latest Advances in Cryopreservation of Eggs for Cancer Patients and Postponement of Reproduction, Houston IVF Center, Houston TX, October 2006

Egg Freezing and Donor Egg Banking, American Association of Tissue Banks, November 2005.

Oocyte Cryopreservation, Pacific Coast Fertility Society, May 2005.

Oocyte Cryopreservation, National Association of Genetic Counselors District IV, April 2005.


Oocyte Cryopreservation: It Really Works! American Association of Bioanalysis Regional Post-graduate course, Irvine, CA, 2004

Oocyte Cryopreservation, American Association of Bioanalysis Annual Meeting, Denver, CO, 2003

Fertility Preservation, AORN Regional Conference, Indianapolis IN 2003

Fertility Preservation (Grand Rounds), Department of Oncology, Bloomington IN, 2003

Assisted Reproductive Technology (Grand Rounds), Community Health Network, Indianapolis IN, 2001

Live Web cast of Infertility Procedures for WebMD, 1999


Update on Assisted Reproductive Technologies, University of Texas-Amarillo Department of OB/GYN, Grand Rounds, May 1997

When ART Fails, Where Should We Place The Blame?, Michigan Embryology Society, November 1996

When ART fails, who do we blame? St. Louis Reproductive Endocrine Society, June 1996
Laboratory Regulations and Their Impact on OB/GYN Practice, Medical University of South Carolina, Grand Rounds, November, 1992.


Mechanisms of Sperm-Egg Fusion in Mammals, Albany Medical College, Faculty Seminar Series, March 1991


Assisted Reproductive Technologies, Mount Holyoke College, May 1990

Mechanisms of Mammalian Sperm-Egg Fusion, Laboratories of Human Reproduction and Reproductive Biology, Harvard Medical School, April 1990

Mechanisms of Sperm-Egg Fusion in Mammals, Wadsworth Center for Laboratories and Research, March 1990

Laboratory Aspects of Infertility, Grand Rounds, Department of OB/GYN; Albany Medical College, March 1990

Sperm-Egg Recognition in Mammalian Fertilization, Department of Biochemistry, Albany Medical College, March 1990

Mechanisms of Sperm-Egg Fusion in Mice, Department of Cell and Molecular Biology, Medical College of Georgia, May 10, 1989

Mechanisms of Sperm-Egg Fusion in Mice, Department of Obstetrics and Gynecology, University of Mississippi, March 1989

Mechanisms of Sperm-Egg Fusion in Mice, Department of Physiology and Endocrinology, Medical College of Georgia, March 6, 1989

Advances in Reproductive Technologies, Sigma Xi, Augusta, GA, October 1988

Moral and Ethical Issues in New Reproductive Technologies. Grand Rounds, Department of OB/GYN, Medical College of Georgia, Augusta, GA February 1988
Of Mice and Men: Basic and Clinical Aspects of In Vitro Fertilization. SUNY at Buffalo School of Medicine, December 1987

Mechanisms of Sperm-Egg Fusion During Mammalian Fertilization. Department of OB/GYN, University of Pennsylvania School of Medicine, November 1987


Cellular Interactions During Early Embryonic Development. Department of OB/GYN, Medical College of Georgia, October 1986

Plasma Membrane Interactions During Mammalian Fertilization. Department of Gynecology, Cleveland Clinic Foundation, October 1986

Role of the Laboratory on Evaluation of the Male Factor, Clinical Review Course, Department of OB/GYN, Medical College of Georgia, September 1986

Success Rates Following Reinsemination of Human Oocytes In Vitro. Presented at the American Fertility Society Annual Meeting, Toronto, Canada, September 1986

Human In Vitro Fertilization: Methodology and Applications, Department of Endocrinology, Medical College of Georgia, May 1986

New Issues in Reproductive Technologies. Grand Rounds, Department of OB/GYN, Medical College of Georgia, 1986

Human In Vitro Fertilization: Past, Present and Future. Grand Rounds, Department of OB/GYN, Medical College of Georgia, December 1984

Fertilization Mechanisms in Man and Mouse, Department of Anatomy, Medical College of Georgia, October 1984

Neuroendocrine Control of the Menstrual Cycle, Clinical Review Course, Department of OB/GYN, Medical College of Georgia, September 1984

In Vitro Fertilization, Clinical Review Course, Department of OB/GYN, Medical College of Georgia, September 1984

Artificial Insemination and Hamster Egg Test, Clinical Review Course, Department of OB/GYN, Medical College of Georgia, September 1984
PUBLICATIONS

Abstracts


11. Padilla SL, Howe A and Boldt JP: Effects of charcoal extracted and non-extracted serum on in vitro development of mouse embryos. Published in the


PUBLICATIONS IN REFEREED JOURNALS


BOOKS AND CHAPTERS


APPENDIX C-4

June P. Payne, Ph.D.

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        Lucina Hall, Room 315
        Ball State University
        Muncie IN 47306-0895
        (765) 285-1264
        JPayne@bsu.edu

Home: 7405 N Landings Trail
       Muncie IN 47303
       (765) 289-2995

EDUCATION

1980  Ph.D., Counseling Psychology
      Ball State University; Muncie, IN

1974  M.A., Counseling
      Ball State University; Muncie, IN

1970  B.A., Sociology
      Virginia State University; Petersburg, VA

PROFESSIONAL EMPLOYMENT

2003- present  Director of Counseling & Health Services
                Ball State University; Muncie, IN

Responsible for services and programs provided by the Counseling Center, the Health Center and Health Education. Direct leadership and supervision of the Counseling Center, as well as leadership of the Health Center in collaboration and contracting with Cardinal Health Systems, Inc. Works in close collaboration with the director of PCPN in all aspects of the operation of the Student Health Center, including program planning and evaluation, personnel selection, budget planning and program evaluation. Serves as a Ball State representative in the contracting process. With respect to the Counseling Center, provides leadership in the development, implementation and evaluation of all aspects of the unit’s mission.
and goals. The program components ordinarily used in goal achievement (and supervised by the director) include individual counseling; group counseling; outreach/consultation; career counseling; testing; research and training. In charge of maintaining accreditations by the American Psychological Association and the International Association of Counseling Services and in charge of upholding the highest professional standards and ethics. Responsible for personnel recruitment, development and supervision; accountable and efficient center management; serves as the major public relations agent for the center on campus; relates to other offices, departments and individuals on campus; and responsible for maintaining a sound data base related to the center’s work. Works with a leadership team that includes the heads of medical services, health education, training, outreach/consultation and clinical counseling services.

2003-2008  **HSPP-Licensed Psychologist**
Associates in Mental Health, Inc.
Muncie, IN

Private practice with individuals and couples with specialization in treating posttraumatic stress.

1996-2003  **Associate Director for Clinical Services and Psychologist**
Counseling Center
Ball State University; Muncie, IN

Served as associate to the Director with responsibility of coordinating all clinical aspects of service delivery within the Counseling Center. Monitored intake screening and client assignment. Coordinated regular and crisis/emergency intakes. Coordinated and monitor psychiatric services. Served as the consultant and liaison of all referrals to community mental health. Monitored the clinical/psychological consultations with the Health Center. Provided individual, group, crisis/emergency, and after-hours psychological services for Ball State students. Led and conducted outreach programming in sexual assault prevention and awareness. Coordinated Sexual Assault Awareness Week. Supervised clinical work of masters and pre-doctoral interns. Provided diversity training for pre-doctoral interns.

1990-1996  **Clinical Services Director and Psychologist**
Counseling and Psychological Services Center
Ball State University; Muncie, IN
Assisted the Director with the coordination of clinical services within the counseling center for service to the broader university community. Monitored intake screening and client assignment. Chaired the case staffing committee. Coordinated regular and crisis/emergency intakes. Provided individual and group counseling. Made referrals to community mental health. Coordinated and monitored psychiatric services. Provided individual, group, crisis/emergency, and after-hours psychological services for Ball State students. Led and conducted outreach programming in sexual assault prevention and awareness. Supervised clinical work of masters and pre-doctoral interns. Provided diversity training for pre-doctoral interns.

1983-1990  **Counseling Psychologist**
Counseling and Psychological Services Center  
Ball State University; Muncie, IN

Provided individual and group counseling for students, faculty, staff and collaterals over a broad range of problems including interpersonal, career, and emotional disturbance. Treatment modalities include individual therapy, couples therapy, family therapy, group therapy, intake, crisis intervention, test interpretation, and after-hours emergency duty. Supervised M.A. and pre-doctoral interns. Taught multicultural training specialization.

1983-2003  **HSPP-Licensed Psychologist**
Professional Psychological Clinic  
Ball State University; Muncie, IN

Private practice with individuals and couples with specialization in treating posttraumatic stress.

1980-1983  **Counseling Psychologist**
Comprehensive Mental Health Services of East Central Indiana  
Delaware Counseling Services; Muncie, IN

Counseling Psychologist. Provided counseling, psychotherapy and psychological testing with an outpatient population whose problems covered a broad range of diagnostic categories. Treatment modalities included individual therapy, couples therapy, family therapy, group therapy, intake, and emergency service. Co-led Parents Group-Child Management. Participated as member of Research Team and Agoraphobia Team. Worked in conjunction with CMHS, Special Services to provide individual and family
therapy to chemically dependent outpatient population. Supervised one M.A. Intern.

1980

**Doctoral Teaching Assistantship**
Department of Counseling Psychology and Guidance Services
Ball State University; Muncie, IN

Taught Career and Life Planning.

1978-1979 **Intern**
1976-1977 Counseling and Psychological Services Center
Ball State University; Muncie, IN

Provided individual and couples counseling and psychotherapy for university college students. Received individual supervision and participated in group case conferences. Conducted intake sessions with new clients. Conducted research on the effect of pre-training clients for therapy on therapy outcome.

1976-1978 **Director of Treatment**
The Cambridge House, Inc.; Muncie, IN

Screened and evaluated applicants for admission into a residential group home for adolescent females. Supervised three masters level counselors. Developed treatment plans and program recommendations for residents. Monitored program implementation. Provided individual counseling and group therapy.

1974-1975 **Doctoral Assistantship**
Counseling Practicum Clinic and Burris Laboratory School
For Department of Counseling Psychology and Guidance Services
Ball State University; Muncie, IN

Provided individual, couples, and family therapy at the Counseling Practicum Clinic. Provided individual counseling and guidance at Burris Laboratory School.

1974-1975 **Counselor**
The Cambridge House, Inc.; Muncie, IN

Provided individual and group counseling with pre-delinquent and delinquent adolescent females who resided in a group treatment home. Developed treatment plans and recommendations for child care workers. Monitored treatment plan implementation.
1973-1974  **Counseling Practicum**  
Indiana State Women's Prison; Indianapolis, IN

Provided Individual and group counseling for female inmate population. Received individual and group supervision.

1970-1972  **Social Worker**  
Department of Public Welfare; Charlottesville, VA

Provided social casework by consulting with individuals and families who were eligible for *Aid to Families with Dependent Children*. Counseling and consulting was mainly in areas of money management, parent-child problems and employment. Other duties included child protective services and eligibility determination for *Old Age Assistance*.

**PROFESSIONAL ORGANIZATIONS**

- Board of Accreditation, International Association of Counseling Services, Inc. (IACS), Member, 2007-current
- Association of University and College Counseling Center Directors (AUCCCD), 2003-current; Member, Elements of Excellence Committee, 2008-current
- American College Health Association, current
- American Psychological Association, current
- Indiana Psychological Association, current
- Indiana Association of Black Psychologists: President-Elect, 1986-87; President, 1985; Secretary, 1984
- National Association of Black Psychologists, 1984-90
- American Personnel and Guidance Association, 1976-78

**CERTIFICATION/LICENSURE AND HONORS**

- Vivian L. Conley Award presented by National Organization for Women for Outstanding Achievement in Community Health & Welfare, 2008
- Vivian L. Conley Award presented by Indiana Women of Achievement Award for Distinction in Counseling and Health Services Leadership, State of Indiana, 2007
- Trailblazer Award, Indiana Black Expo, Muncie Chapter, 2007
- Legends Award, Black Student Association, Ball State University, 2007
- Graduate Faculty, Department of Educational Studies, Ball State University, 2006-2008
- Graduate Faculty, Department of Counseling Psychology and Guidance Services, Ball State University, 2003-2004
- Health Service Provider in Psychology, State of Indiana, 1986-present
Jack Beyerl Outstanding Professional Award in Student Affairs, 2002
Robert Q. Foster Distinguished Service Award, Office of Multicultural Affairs, Ball State University, 1996
Certificate of Appreciation, Office of Multicultural Affairs, Ball State University, 1995
Hurley Goodall Distinguished Faculty Award, Office of Multicultural Affairs, Ball State University, 1994
Certificate of Service, Office of Multicultural Affairs, Ball State University, 1991, 1992, and 1993
Listed in Who's Who Among Black Americans, 1987-present
Council for the National Register of Health Service Provider in Psychology, 1985-00
Private Practice Psychologist Certificate #09-00226-3-82, State of Indiana, issued in 1982
Basic Psychologist Certification, State of Indiana, issued in 1981

FUNDED GRANTS
Agency: Department of Justice, Office of Violence Against Women
Title of Project: Campus and Community Alliance to Support Safety and Advocacy for Victims (SAVe)
Amount Funded: $200,000
Date Approved: October 1, 2005

PUBLICATIONS AND GRANTS

RESEARCH
Intake Screening Instruments: A comparison of the OQ-45 and the Personal and Confidential Data Form, 1999-present.
Perceived Racial Prejudice of Black Graduates of Ball State University; with Joycelyn Brown, Michael Brown, and David Davis, 1987 (unpublished).
Client Satisfaction Inventory, research team member, Comprehensive Mental Health Services, 1982.

PRESENTATIONS AND WORKSHOPS (a selection)

In addition to the specific titles listed below, numerous other presentations and outreach programs on the topics of sexual assault prevention and treatment, and diversity and multiculturalism have been presented.


Payne, J. (1991). *Acquaintance Rape*. Workshop presented to Fraternities and Sororities, Ball State University, Muncie, IN.


Payne, J. (1990). *Date Rape.* Sex in the '90's, Ball State University. Muncie, IN.
Payne, J. (1988). *Date Rape.* Student Governing Board, Ball State University. Muncie, IN.
Payne, J. (1987). *Date Rape.* Alpha Phi Sorority, Ball State University, Muncie, IN.
Payne, J. (1986). *Working Mothers.* Muncie Health Fair, Muncie, IN.

**DEPARTMENTAL AND UNIVERSITY SERVICE**

Health Center Advisory Council, 2003-present
Health Center Steering Committee, 2003-present
Critical Incident Response Team, 2001-2007
Counseling and Health Services Advisory Committee, 2001-2002
Women’s Center Planning Committee, 2001-2003
Sexual Assault Prevention Outreach Team, 1989-2003
Diversity Outreach Team, 1989-2001
Minority Student Issues Discussion Group, 1990-1992
Non-Traditional Student Task Force, 1988-1990
Black History Advisory Board, 1988-1989
Minority Student Task Force, 1984-1990

**COMMUNITY AND PUBLIC SERVICE ORGANIZATIONS**

Member, Grant Policy Committee, The Community Foundation of Muncie and Delaware County, Inc., 2006-present
Member, Altrusa Club of Muncie and Altrusa International, 1998-present:
  President-Elect (2008-current); Vice President (2006-2007)
Board of Directors, Altrusa Club of Muncie, 2005-present
Member, Coalition of 100 Women, Inc. of Muncie, IN, 1998-present:
  President (2000-2002)
Board of Directors, Hospital Hospitality House, 1998-02
Member, National Association for the Advancement of Colored People (NAACP); 1970-present
Advisor, Delta Phi Chapter, Delta Sigma Theta Sorority, Inc., Ball State University, 1986-90
Member, Delta Sigma Theta, Inc., Public Service Sorority, 1967-present
Board of Directors, Wapahani Girl Scout Council, Girl Scouts of America, 1983-87
Board of Directors, Family Services of Delaware County, 1976-78

SPECIALIZED PROFESSIONAL TRAINING

Annual Conference (2008). Association of University and College Counseling Center Directors. Fort Worth, TX.
Annual Conference (2007). Student Affairs Administrators in Higher Education and Association of University and College Counseling Center Directors. Houston, TX.
Annual Conference (2007). Midwest Association of University and College Counseling Center Directors. Indianapolis, IN.
Training & Technical Assistance Institute. (2007). CALCASA Campus Institute Grants to Reduce Violent Crimes Against Women on Campus Program. Columbus, OH.
Annual Conference (2005). Association of University and College Counseling Center Directors. Vail, CO.
Annual Conference (2005). Association of University and College Counseling Center Directors. Minneapolis, MN.
Annual Conference (2004). Association of University and College Counseling Center Directors. Lake Tahoe, NV.
Staying Ethical After All These Years: Principles, Pitfalls, Prevention and Positive Prototypes (2003). Ball State University Professional Psychological Clinic. Muncie, IN.


The Ethics of Internet Therapy. (2002). Indiana Psychological Association. Indianapolis, IN.


Understanding and Applying Ethics to Clinical Practice (2002). Mary F. Zemansky, Ph.D., Karen Eggen, Ph.D., and Andrew Dixon-Reed, Ph.D. Indianapolis, IN.


Date/Acquaintance Rape Prevention. (1999). Stephen Thompson, M.S. Muncie, IN.


Psychological Approaches to Assessment & Treatment of Posttraumatic Stress. (1998). Terence M. Keane, Ph.D. Indianapolis, IN.


Childhood Trauma and Repressed Memory. (1996). Lenore Terr, M.D. Door County Summer Institute. Door County, WI.


Living & Dying, Laughing & Crying: Grief & Humor in Late Life. (1994). Center for Gerontology, Ball State University. Muncie, IN.


Minority Students in the 1990’s. (1989). Workshop presented by Brenda Green, Ball State University. Muncie, IN.


Annual Conference. (1988). National Coalition of Sex Equity in Education. Indianapolis, IN.


A Day with Carl Whitaker. (1981). Workshop, Quinco Consulting Company. Columbus, IN.


SKILLS AND SPECIAL INTERESTS
Multicultural/Diversity Issues
Parenting Skills/Child Management
Outcome
Treatment of Trauma/Sexual Abuse/Assault
Women's Issues/Therapy with Women