

ETHICAL CONSIDERATIONS OF FETAL ALCOHOL SPECTRUM DISORDER:
TRUTHS AND CONSEQUENCES

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ABSTRACT

Alcohol use during pregnancy has long been known to cause negative effects on the newborn. It has been and is acknowledged that prenatal alcohol usage presents babies that are smaller in size. This, however, is assumed to be corrected by adequate nutrition, time, and nurturing. It also was and is held that any problem of Fetal Alcohol Syndrome would be evidenced on the face with certain anomalies. Fetal Alcohol Syndrome is only the “tip of the iceberg” regarding what alcohol use during pregnancy can do to the unborn fetus. Those infants not showing any evident physical abnormalities can have just as many detrimental life outcomes as those who do have the anomalies. It is lesser known, but true, that prenatal alcohol causes behavioral and educational deficits due to permanent structural brain damage of the individual affected. It is estimated that 50,000 infants each year are affected. This paper will address the whole realm of prenatal alcohol effects known as Fetal Alcohol Spectrum Disorder. Ethical considerations will be correlated along with issues connected to Fetal Alcohol Spectrum Disorder.

Ethical issues to be regarded with Fetal Alcohol Spectrum Disorder focus on various aspects. What are individual and autonomous rights? What is termed abuse? What is the end result of alcohol use during pregnancy? How is this information to be effectively and compassionately used? Ethics involves what is right and what is wrong in human behavior. There are “oughts” and “ought nots” in action. Ethics also involves dilemmas and what, if any, actions are an individual’s or society’s duties in rectifying these dilemmas? How can the intent of goodwill be used? What obligation does the

scientific community or educational institutions have to educate or inform the public? Do ethical values translate into legislation?

The approach of this paper includes facts, interpretation of facts, consequences, obligations, rights, and virtues of ethics in conjunction with various aspects of Fetal Alcohol Spectrum Disorder. The ethics pertain to those who perpetuate this disorder; those who are affected by it; the preponderance of the disorder in adopted children; and the effect on society as a whole. The fact that this is a 100% preventable disorder is of relevance and makes ethical approaches viable and worthwhile.

Overall, the design of the paper is to make all of us philosophers by virtue of examining an important issue, using our own reasoning abilities, and subsequently acting or not on this information. It is a look at defining the injustice of Fetal Alcohol Spectrum Disorder and the possible compassionate, beneficial application of ethical principles for the betterment of all mankind.

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The inspiration for this final project was given to me through Dr. Jenny Yates. She helps her students "find their voice" in parleying information. The knowledge Dr. Yates conveys about personality types helped affirm my desire and inclination to research. Her vast wisdom is subtly relayed by her adept way of giving at the time one is ready to receive.

Pragmatic and humanitarian ethical concerns were learned from the enthusiasm of Dr. Candace Gauthier. Many thanks to her friendly yet forthright approach in addressing relevant issues of today. Much was learned not only by principles taught but also by Dr. Gauthier's own societal commitments in ethics.

DEDICATION

This paper is dedicated to two individuals who give enormous amounts of time and energy on behalf of the cause of Fetal Alcohol Spectrum Disorder. They do this without financial compensation but because of their dedication caused by the ramifications of this disabling disorder. One is affected by a close relatives' children and the other is implicated by her adopted children.

The first, Peggy Seo Oba is executive director of Family Information Network. Peggy works tirelessly disseminating scientific and sociological information to those who want to gain the knowledge of this disorder and to those who need information on how to best navigate the issues connected to this disorder.

The second individual, Mary Ann Lee, is the director of Fetal Alcohol Syndrome Support and Information Group in the state of Virginia. She has won a governor's award for her many contributions by speaking at seminars all over the country about the consequences of Fetal Alcohol Spectrum Disorder. I salute both of them for their endeavors. This work is dedicated in their honor.

INTRODUCTION

Ethical Thought and Theory

Ethics is one of the main fields of philosophy. Ethics is essentially the theory of right or wrong. The other three main fields of philosophy, according to some philosophers, are metaphysics, the theory of reality; epistemology, the theory of knowledge; and human nature, as Socrates said, “Know Thyself.” The whole of philosophy has to do with the search for wisdom. Philosophers are the lovers of wisdom. Philosophy, with the desire of finding wisdom, examines opinions, ideas, and thoughts that shape our lives. The value of logical thought has long been esteemed. Socrates said that, “The unexamined life is not worth living” (The Apology, Melchert, 1999, p. 97). Matters that form our lives must be thought about rationally and logically. The ethical concerns of philosophy deal with what is right and what is wrong. Ethics are these considerations put into action. Yet ethics is not as simple as compartmentalizing the good and the bad. Additional theory is needed. Is happiness the ultimate goal? How will an action affect others? On what basis do we judge what is good and what is bad? Are there societal duties as well as individual ones? What is virtue? How does justice play a part in our lives? These questions need to be examined in ethical considerations.

The Dali Lama feels that altruistic actions bring about happiness and actually lessen not only society’s experience of suffering but also our own. It is an ethical act, he feels, to refrain from causing harm to either other’s experience or expectation of happiness (Dali Lama, 1999). We need a two-pronged approach according to the Dali Lama. On one hand we have to cultivate any factors which are conducive to this type of happiness. In his view of happiness the Dali Lama is not addressing material gain in an

abundance of material wealth. He is discussing more of allowing the flourishing of mental and emotional health.

In regard to social issues the Dali Lama feels that “despair is never a solution. It is rather the ultimate failure” (Dali Lama, 1999, p.129). He reminds us that, as the Tibetan expression says, if the rope breaks nine times we must splice it together for the tenth time. Consistent endeavor is the way to provide solutions. Insight and clear appreciation of our potential to help others is necessary to lead the way. Collectively the Dali Lama sees society in recent years as giving more weight to the values of justice and truth.

The philosopher Soren Kierkegaard even goes further with his statement on despair. Kierkegaard states that despair is sin. Despair, according to his definition is an unwillingness to be yourself or what one makes of oneself. Ethically, to rid yourself of despair, serious choices must be made to make life meaningful (Melchert, 1999).

Ethics takes a preeminent role for many philosophers. Charles Sanders Peirce saw ethics as having two main divisions. Pure ethics deals with the ideal or ultimate aim of conduct. Practical ethics advances action to the ideal. Both are required. All conduct has as its aim the sake of an end. Pure ethics must be a theatre of discussion . . . study consists in the gradual development of a distinct recognition of a satisfactory aim, explains Peirce (Copleston VIII, 1966).

Rene Descartes implores us to use our reasoning powers. The difference between humans and other animals is that a human is rational. His cogito from the Latin “I think” states, “I think, therefore I am” (Melchert, 1999, p. 334). The fact that Descartes thinks proves his existence. He recommends guiding our mental powers so we can be capable of realizing and making sound and true judgments on various issues.

The respect for autonomy allows for individual freedom and choice. This allows for personal rule of the self while remaining free from controlling interferences. This does, however, imply that the autonomous person have the presence of critical mental capacities such as understanding, ability to proceed by intentions, and unforced decision making capacity (Beauchamp & Walters, 1999). Individuals are allowed to hold their own personal beliefs and values according to respect for autonomy. This idea is connected to the idea that persons possess intrinsic value. Individuals should be allowed to determine their own destiny. The concept also supposes the inherent dignity of all persons. Controversial problems arise with this principle when the principle of the respect for autonomy conflicts with other moral principles. That is when it must be determined which duty or duties are of the most importance. In this paper it is important to consider the relationship of the pregnant woman to the fetus she is carrying. Does the woman retain an autonomous status? Does she have a responsibility to the fetus she is carrying? These issues will be addressed.

W. D. Ross was a prominent twentieth century British philosopher. Ross' view is to find your actual duty among your *prima facie* duties, and act on your actual duty. A *prima facie* duty is always the strongest duty. It is to be acted upon unless it conflicts with a stronger duty. The *prima facie* duty is found by examining the respective weights of competing duties (Beauchamp & Walters, 1999). Ross adheres to the value of duties of fidelity (truth-telling), beneficence, justice (social fairness), and self-improvement (advancement). His defense is premised on basic moral conventions. A *prima facie* duty is right and binding unless it is outweighed by another more important *prima facie* duty.

The Two Most Common Approaches to Contemporary Western Ethics

Two of the most common contemporary approaches to present day ethics are deontological and utilitarianism. These approaches are exemplified by two eminent philosophers. The theorist Immanuel Kant (1724-1804) is best known for the deontological approach. Two notable utilitarians are John Stuart Mill (1806-1873) and Jeremy Bentham (1748-1832).

The deontological approach is best characterized by the concepts of duty and/or obligation. One must behave for the sake of duty. Duty is performed in the absence of hedonism or egoism. "Duty is the necessity of acting out of reverence for the law," (Copleston VI, 1966, qtd. 318). This law is universality. The principle of duty, never acting otherwise than according to universal law, formulates the categorical imperative. Kant's categorical imperative states, "Act only on that maxim whereby thou canst at the same time will that it should become a universal law" (Kant, p.38). The categorical imperative connotes obligation. Imperatives are expressed by an "ought."

Kant also promulgates an ethical stance of respect for humanity. This is in terms of never using persons as a means only; but always as an end. Means act as pathways for personal goals. Ends suffice as perpetuating the good or worthiness of the individual with no outside motive. Humanity is viewed as rational nature existing as an end in itself.

Kant views morality as *a priori* (independently of appeal to experience). The moral philosopher, according to him, should isolate the *a priori* elements of moral knowledge and show their origin. Practical reason is directed towards choice in accordance with moral law yet the basis of obligation is *a priori* in the concepts of pure reason (Copleston VI, 1966). He makes known explicit truth of moral knowledge as

exemplifying good will. The good will does not depend on consequences but always conveys good intentions.

The basic concept of utilitarian moral philosophy is based on John Stuart Mill's theory of consequentialism. Actions are determined to be morally acceptable or not due to their consequences. The way to determine this is by those who have knowledge of a situation. The only premise on which this knowledge is used is by the consequences that will arise. The consequences of an action posit whether an action is right or wrong. One must choose what is morally relevant since every action imparts many consequences.

Mill, as well as Bentham, claims that happiness is the particular end. Happiness is not only for the person perpetuating the act but for all concerned. Some thinkers contend that happiness varies from individual to individual. But according to Mill and Bentham happiness is alike for everyone. The principle of utility includes every action whatsoever in regard to how it augments and diminishes happiness for all parties involved (Copleston VIII, 1966). The greatest happiness principle involves the greatest happiness for the greatest number. The action to be performed offers the best pleasure/pain ration for all in deciding alternatives in actions. The utilitarian principal is impartial to all parties involved (Elliot & Stern, 1997).

Mill encourages people to develop individuality though. "Free development of individuality is one of the principle ingredients in human happiness," (qtd. Copleston VIII, 1966, p.36). Therefore, there is a need for liberty. As much liberty as possible should be conceded to the individual. This maintains social harmony. Conformity to a mold is not in the common interest. The individual's freedom should be unrestricted as long as freedom of others is not compromised. The only time one need compromise

absolute freedom is when others' rights may be diminished or by preventing harm to others. Altruism is a goal but egoism is also possible. Individuality, according to Mill, is not a "following of individual impulses but rather the harmonious integration of all one's powers" (qtd. Copleston VIII, 1966, p. 32). Mill views the individual as a social being, a member of society and that her/his happiness is an element of the whole. The fact that individuals conceive themselves as members of a social body is a powerful principle in human nature. Mill maintains that social feelings grow through education and advancing civilizations.

Utilitarians are not concerned with merely private actions. The party whose interest is in question is the community. Legislation and government should be directed for the greatest happiness of the greatest number who are members of the society to be affected. Utilitarians are active in areas of reform of law and in putting forth legislation. Legislation and acts of government fall within the moral sphere. The principle of utility is not only a moral guide but also a tool of social reform. Mill felt that by aiming at the improvement of mankind one could attain happiness along the way.

Jeremy Bentham saw that in order to calculate in detail pleasure and pain actions must be analyzed in terms of: intensity, duration, certainty/uncertainty, propinquity/remoteness, and fecundity (bringing further pleasure or pains), purity, and extent (number of persons to be affected) (Melchert, 1999). He and other utilitarians feel that morally and judicially choices in actions can approximate science. Bentham is concerned with establishing an objective criterion of morality (Copleston VIII, 1966).

Let us begin by looking at how these ethical theories, issues, and considerations can be discussed and applied to Fetal Alcohol Spectrum Disorder.

- **Fetal Alcohol Syndrome is amidst the most commonly known causes of mental retardation.**
- **How can FAS be defined? Is FASD different?**
- **How does it affect one?**
- **What can/should we do about it?**

The severity of the prenatal issue is shown by facts and figures. Researchers Jacobson and Jacobson (1999) link moderate alcohol usage during pregnancy (7-14 drinks per week) with developmental problems. Pregnant women drink despite warnings. It is not uncommon for pregnant women to drink frequently. Binge drinking is termed at drinking four or more drinks in one sitting. This type of drinking quadrupled in the early 1990's and has not changed since ("Alcohol use among women of childbearing age – United States, 2002"). The March of Dimes states that there are more than 50,000 infants born each year with at least some degree of alcohol-related effects in the United States (Tanner-Halverson).

These alcohol related effects deal with executive functioning or the management system of the brain's working memory, planning, and inhibitory control that allow for goal directed behavior. Key findings show that even one alcoholic beverage per day has effects on cognitive functioning in the offspring (Noland, Singer, Arendt, Short, & Bearer, 2003). Alcohol exposed children had more difficulty learning and following rules that conflicted with their natural response tendency. Children exposed prenatally to alcohol found it more difficult to inhibit inappropriate behaviors.

- **Distinctive facial features**
- **Growth deficiency**
- **Central nervous system dysfunction**

The above three conditions were determined by Ken Jones and colleagues as Fetal Alcohol Syndrome in 1973. In order to be diagnosed as having full Fetal Alcohol Syndrome the individual must have all three criteria. The specific pattern of facial features can involve micrognathia (small chin), indistinct philtrum (vertical lines between nose and mouth), thin upper lip, short palpebral fissures (eye openings) a flattened midface, or minor ear anomalies . Usually the children are born below the twenty-fifth percentile in height and weight. There also must be evidence of central nervous system (CNS) dysfunction. The CNS dysfunction might be physical (microencephaly: smaller head circumference) or behavioral (hyperactivity, mental retardation). The diagnosis during infancy is difficult. It seems that diagnosing this condition in young children is easier. Of societal and ethical concern is the need to; 1) document the exposure history of the mother, 2) educate about the lifelong effects, 3) know intervention techniques, and 4) care for those affected by prenatal alcohol. It is now known that the facial features indicative of Fetal Alcohol Syndrome (hereafter referred to as FAS) are only formed during a limited period during pregnancy. But the abnormal facial features are only a minor lifelong problem. **The major life long problems are experienced by those even without the facial features of Fetal Alcohol Syndrome.** The condition of being affected by prenatal alcohol without the distinctive facial features is Fetal Alcohol Effects. A newer term is now in use, since the lifetime outcomes are close to the same, as Fetal Alcohol Spectrum Disorder (FASD) (Dr. Kieran O'Malley, interview, 11 Aug. 2003).

- **Foolish, drunken, or harebrain women most often bring forth children like unto themselves.**

Aristotle in *Problemata*

- **Behold, thou shalt conceive and bear a son: And now, drink no wine or strong drink.**

Judges 13:7

A teratogen is a substance that causes birth defects. Detrimental effects of prenatal alcohol have been known for some time. Here are quotes from Aristotle and the Bible. The lithograph is titled “Gin Lane” by William Hogarth (1697-1764) (Rosett, 1984). It shows a prevalent condition in England during the first part of the 1700’s. A lifting of the tax made gin very cheap. At this period of time infant mortality increased and the incidence of epilepsy increased. Infant mortality and epilepsy decreased when the British College of Physicians encouraged the Parliament to re-impose the taxation (Lemoine, 1968).

JOHN STUART MILL'S ETHICAL THEORIES ON CONSEQUENTIALISM AND IMPARTIALITY

Only a small segment of those affected by prenatal alcohol show the identifiable facial features of FAS. The identifiable facial features are only formed during several days during pregnancy of the first trimester. Many more children are included who do not manifest physical features of FAS but have cognitive and behavioral problems. The cognitive and behavioral problems may show up even when the facial features do not. Even children with normal IQ's who have been prenatally exposed to alcohol do not live up to their potential (Streissguth, 1997). Cognitive memory problems or behavioral difficulties may keep them from doing so.

Dr. Edward Riley, Ph.D., is highly noted and well regarded in the fetal alcohol field. He is Director of Behavioral Teratology at San Diego State University. A behavioral teratogen is a substance causing birth defects that affects an individual's behavior detrimentally. This is an important aspect to note. Not all behavior can be determined or modified by the environment or sociologically. Much of behavior is determined by what occurs developmentally before birth. Dr. Riley is a researcher of FASD and publishes his findings worldwide. He also is an international presenter of his and his colleague's studies in this regard.

Sara Mattson and Edward Riley (1995) found that children, adolescents, and adults of alcoholic mothers and those diagnosed with FASD show a high level of neuropsychological problems. These problems included deficits in fine and gross motor function, attention, verbal learning and memory, visuo-spatial functioning, and language.

In another study the following maladaptive behaviors were found in more than half of those with FASD; 1) poor concentration, 2) withdrawal, 3) impulsivity, 4) dependency, 5) teases or bullies, 6) exhibits extreme anxiety, 7) is stubborn or sullen, and 8) lies, cheats, or steals.

John Stuart Mill's ethical theory of consequentialism decides which actions are right and which are wrong by the consequences of the action. This demands that we take into account what can be expected to produce the greatest balance of good and the least amount of harm. Perhaps the relaxing effect of the alcohol and/or euphoric feeling produced is a good for the pregnant woman. Perhaps one could consider the needs of a chronic alcoholic being met as a good. But according to Mill's consequentialism the consequences of an act must be examined. We thus need to rectify the greatest balance of good with the least amount of harm.

Another element of Mill's ethical theory is impartiality. The consequences affecting all parties must receive equal and impartial consideration. All parties affected by an action must be aligned by the best good and moral judgment (Beauchamp & Walters 1999). The parties affected in FASD would be; 1) the drinking mother, 2) the unborn child, 3) the person (infant, child, adolescent, adult) with FASD, 4) the caregivers (biological and adoptive parents), and 5) society itself. The egoism of one person is never considered above the consideration of all persons affected.

IMMANUEL KANT'S UNIVERSAL LAW AS THE INTENT OF GOODWILL

Individuals affected by prenatal alcohol may be marked by distinct facial features or not. These individuals can also have less apparent deformations. These can be heart defects, skeletal anomalies, altered palmar creases, and uro-genital anomalies (Streissguth 1994). Children with FASD often have smaller brains (microencephaly). There can be many structural anomalies inherent in the smaller brain.

There are a number of blood test biomarkers to detect alcohol consumption and abuse. The gamma glutamyl transferase (GGT), mean corpuscular volume (MCV), and carbohydrate-deficient transferrin (CDT) are a few to use on the pregnant mother. Even using maternal self-report screening tools such as T-ACE (tolerance, annoyed, cut down, eye opener) and TWEAK (tolerance, worried, eye opener, amnesia, cut down) can be used in a non-threatening, compassionate way to identify “at risk” infants. There has been recent research showing that the Binge Alcohol Rating Criteria (BARC) may identify mothers at risk having alcohol-affected offspring (O'Malley & Streissguth July 2000). Biomarkers in the newborns' meconium (stool sample) can confirm those babies who have been exposed to alcohol in utero.

The intention of using biomarkers for mothers and infants is defined ethically by Kant's concern of perpetuating good will. Good will, Kant conveys, should always promulgate good intentions. Having explicit knowledge creates an obligation of creating good will. Knowledge of a situation, negative or positive, can be used with good will in virtuous actions.

For example the good will measure of advocating neuro-protective agents that can mollify some of the neurotoxic effects of prenatal alcohol are is an affirmation of good will. Folic acid has the most documentation. There are ongoing studies of ASA and indomethacin which inhibit the alcohol induced high prostaglandin levels in urine and embryonic tissue. They have reduced perinatal mortality and decreased the incidence of alcohol related birth defects in animal models (O'Malley & Streissguth July 2000). Alcohol use during pregnancy reduces important nutrients which could be supplemented. The include thiamin, folate, pyridoxine, vitamin A, vitamin D, magnesium, and zinc. Zinc supplementation has been studied to be a neuro-protective agent. If the physician, nurse, or diagnostician acts ethically with the intention of goodwill the subject of concern is more likely to follow through with supplementation of neuro-protective agents and even consider a reduction or cessation of alcohol intake during pregnancy.

ETHICAL CONCERNS OF ADOPTION ISSUES

Changing Status of International Adoption

A situation that we, as a society, need to examine more fully is the current trend of adoptions. Two-thirds of international adoptees came from Korea fifteen years ago. At this time Korea was a country with a decent standard of living and good health care. New statistics of 1999 prove that 81% of international adoptions result from countries that rely on institutional care (Johnson, 2001). These infants and children have questionable nutrition and health care. The number of children adopted from abroad doubled in the past decade and is likely to grow 5-10% annually. There are two main reasons for this increase. One is the shortage of what is considered acceptable children for adoption in terms of race and age in the United States. Potential parents are also very concerned about the rights of biological parents and their possible return to claim.

Medical morbidity often occurs because biological mothers who relinquish their infants/children for the common economic reason usually receive inadequate prenatal care and have nutritionally inadequate diets. When evaluating an adoptee the health professional often views the socio-economic status of the adoptive family and assumes this family to be the rectifying agent for the “catching up” of the child. Just physical examination fails to diagnose half of the adopted children from abroad with major infectious diseases. It is recommended that prior to adoption health care professionals should: 1) help potential parents become familiar with developmental issues, 2) provide local resources for any possible rehabilitation, and 3) state the essential nature of obtaining as much information as possible about the child for adoption.

“Alcohol is a major factor in morbidity and mortality particularly in Eastern Europe and the Russian Federation” (Johnson, 2001, p. 17). Statistics show that 30% of the population may chronically abuse alcohol in the Russian Federation. An even more ominous statistic is the 48.1% increase in alcoholism among women during the past decade. For girls 15-17 years old, 80-94% drank sometimes and 17% drank frequently (Johnson, 2001).

Disclosure Laws

Extraordinary costs are incurred in raising a child with FASD. Unfortunately, this condition is currently and will become an even more prevalent occurrence in adopted populations. The costs to society include medical, educational, familial, and community assistance. Society-at-large must be educated to the life-long expensive care for this segment of our society. Specific caretaker needs are coming to the forefront. The main ones entail medical information, peer support, financial assistance, and respite care. Those affected by FASD impact various systems. The systems include; 1) health care system, 2) mental health system, 3) child welfare system, 4) vocational/rehabilitation system, 5) disability system, 6) chemical dependency, and 7) criminal justice system (Gelo & O'Malley, p. 2).

Distributive Justice

The ethical principle of distributive justice may be used to gauge the justice of health care systems. Two theories of distributive justice to be discussed are egalitarian and utilitarian. John Rawls' A Theory of Justice is an influential work on social justice using egalitarian theory. He argues that the good of all society is perpetuated by a communal effort (1999). People in a cooperative society should aim to correct or mollify unequal situations of disadvantaged members. Rawls cites that inequities of birth, historical circumstance, and natural endowment are undeserved and should be conciliated. He views this as a fundamental part of our shared conception of justice. This is a societal obligation that corrects, if possible, or compensates for various disadvantages. The egalitarian theory promotes increasing access to health care to those who are the least fortunate.

The utilitarian theory believes in an equitable social system that redistributes monies in order to improve health care needs of all citizens. The utilitarians believe that society must prevent harm to all members when feasible and we are blameworthy to do nothing at all. Justice, according to utilitarians, is the most stringent form of social obligation generated by the principle of utility. Justice involves seeking a balance. In terms of public funding for health care the following items/issues and the like must be balanced and weighed; public and private benefit, cost savings, probability of failure, and the magnitude of risks. The President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research considered issues of social responsibility, individuality, and social resources. Their report advocates the two tier system of health care where those who wish to pay for more than the social format of insurance may do so with their own funds (Beauchamp & Walters, 1999).

We must consider weighing the costs of prevention techniques versus the costs of care for the infant, child, and adult after the fact. Lifelong costs of necessary additional services needed for an FASD individual are tremendously high. Prevention techniques must prove effective and many studies need yet to be done. The Ninth Special Report to Congress (1997) advocates a multilevel approach. This type of approach would include community educational programs to increase the general awareness of the risks of drinking during pregnancy and identifying women. Our "fix it" society needs to examine what occurs before and during pregnancy.

Sociologically it may be impossible to remedy the effects of prenatal alcohol. We have been told to "ready" poor children for kindergarten. The Head Start Program is often thought one to effect this transition. Head Start, a federal program, does have many

beneficial tangential health services for poor children. But the long-term educational benefits are not produced (Olsen, 2000). This \$2.2 billion annual program, now nearing a forty year history, educationally has produced no significant impact. Initially those involved in the program show gains upon entering first grade. By the third grade, however, these gains are ameliorated. The Head Start children are at the same educational level as their counterparts who were not involved in the program. “Two years is all it takes for the educational gains to disappear” (Hood, 1993, p. 1).

One anomaly in FAS can be shrinking or agenesis of the corpus callosum. Reduction of the size of the corpus callosum usually occurs anteriorly and posteriorly but the corpus callosum can be totally agenized or missing. The corpus callosum is the major fiber connecting the two hemispheres of the brain. Often, where there are structures missing, vacuous areas filled with fluid can form.

The scientific community recognizes the vast implications that the MRI allows in diagnosing disorders of the brain. The Nobel Prize in medicine was won in October 2003 by an American and a Briton for their discoveries leading to the MRI (Magnetic Resonating Imagery). Paul Lauterbur of the University of Illinois at Urbana-Champaign and Sir Peter Mansfield of the University of Nottingham at England worked independently of one another in the 1970's. The Nobel Assembly in Stockholm, Sweden noted the breakthrough in diagnostics and research that the MRI has brought about in medicine. In the true scientific and humanitarian spirit, Dr. Lauterbur said that he thinks the work is helpful to many people. Dr. Mansfield also conveys a sense of authentic endeavor as he continues to work in research although retired (Weiss, 2003).

The MRI has allotted visible proof of permanent structural damage that is attributable to alcohol use during pregnancy. It is the evidence of truth-telling that can be noted in some cases by the malformed or reduced sized corpus callosum. The MRI uses gradient coils which vary the magnetic field strength of the image. This allows for a 3-D view. MRI scans appear to be biologically harmless.

JEREMY BENTHAM'S ETHICAL PRINCIPLE OF CERTAINTY/UNCERTAINTY

The principle of utility, being a moral guide as well as a tool of social reform, is used to calculate the good for society. Jeremy Bentham, a noted utilitarian, believes the good can be analyzed by weighing certainty versus uncertainty of events. Moral obligations in regard to probable certainty need to be put forth in legislation.

Deborah Mathieu addressed the “uncertainty principle” in an analysis of the pros and cons of state interventions of pregnant substance abusers in order to prevent harm to their unborn child. The “uncertainty principle” means that usually we cannot predict which infants will be injured by maternal substance abuse. How can we take cohesive action against a pregnant woman to prevent prenatal harm from illegal or legal drugs? That would mean punishing someone for an injury for which there is not definite certainty. What is the percentage of certainty needed to qualify as reasonably “good proof..” Autti-Ramo, et al. (1992) found that 60% of the children exposed to heavy prenatal alcohol consumption (2 to 4 standard drinks per day) met criteria for central nervous system dysfunction, 47% for growth retardation, yet only 10% for craniofacial anomalies.

Ernest Abel who has been studying FAS for twenty five years has found a much higher occurrence is in the United States (1998). He is still in agreement, though, that consumption of alcohol alone, even at high levels, does not conclusively result in a child with FAS. There is, however, a set of circumstances in which there is almost virtual certainty that a woman will give birth to a child with fetal alcohol syndrome or a child that dies at or shortly after birth. The two conditions that assure this are: 1) she already

has a child with FAS, and 2) she drinks during the subsequent pregnancy at the same or greater level. If the two conditions are met there is a 77% chance the subsequent children will have FAS. If the statistics include dead newborns, the certainty rises to over 90% (Abel, 1988). Abel believes that state action is moral and prudent in this situation. Also, when a child has FAS the child will likely experience child neglect/abuse since the mother's alcohol abuse will likely continue.

To quote Mathieu (Abel, 1998), "the pregnant alcoholic is less than fully autonomous." Madden (1996) has pointed out that it is the problems that lead to alcohol that causes the abuse. Madden believes that alcohol is a coping mechanism. We must then help alleviate the underlying problems which cause the abuse.

The father factor is considered of nominal importance by Abel. He sees that the father's use of alcohol or other drugs as instrumental to the increase in birth defects but that the risk is so low in comparison with the mother's use of the same substances. Yet he admits that this is as of yet an unexplored issue in research (NIAAA, 1997). Strickland (1996) has found that "no father has ever sired a child with fetal alcohol syndrome if that child's mother is not an alcoholic" (p. 70). He does admit that partial FAS is possible as the result of paternal alcoholism but the possibility is much lower than with maternal alcoholism. Other investigators found that paternal alcohol may have harmful effects on the fetus. Cicero found that male offspring of rat males exposed to alcohol before mating exhibited lower levels of testosterone and beta endorphin, poor spatial learning, and impaired immune function (NIAAA, 1997). Female offspring had abnormal stress-related hormones. Cicero believes that paternal effects may result in damage to the genetic material in sperm and altered chemical composition of semen. There are many

unanswered questions about the role of paternal alcoholism that can be explored through future animal studies. The accuracy of data is often tied to currency. Further studies must be noted for their new informational data.

The case for intervention is cohesive because brain damage from alcohol and drugs can occur anytime in a fetus' life (Abel, 1989). The decrease in birth weight, one of the hallmarks of FAS, only occurs during the last trimester. Quitting drinking anytime during pregnancy can have beneficial effects.

John Stuart Mill wrote in On Liberty:

Drunkenness, for example, in ordinary cases, is not a fit subject for Legislative interference; but I should deem it perfectly legitimate that a person, who had once been convicted of any act of violence to others under the influence of drink, should be placed under a special legal restriction, personal to himself; that if he were afterwards found drunk, he should be liable to a penalty, and that if and when in that state he committed another offence, the punishment to which he would be liable for that other offence should be increased in severity. (1975, p. 98)

This argument as applicable to the “uncertainty principle” states that society does not have a right to interfere with a pregnant woman's drinking. But in the case of a woman already with a child who has FAS this offence has been committed and society has a legal and moral right to protect itself from the recurrence of another offense, which we now know gives rise to another child with FAS. Society should not ignore its

obligation to protect these children. Mathieu (1995) feels that we must face reality and not pretend that pregnant women are not responsible for the harms they cause. She argues against autonomy in this situation in that she feels that anyone's rights to be free of interference are not absolute. Mathieu seeks a compromise between doing nothing and coercion. She proposes that a pregnant woman who already has a child with FAS must agree to participate in a community based outpatient treatment program. The penalty for not agreeing to do so would be confinement in a residential treatment facility. The justification for such action resides in the states' *parens patriae* power or its police powers, both of which are aimed at preventing harm to others (Mathieu, 1995).

In a study at the San Diego State University's Center for Behavioral Teratology the mean IQ's of children with Fetal Alcohol Syndrome were compared to controls and to those who were prenatally exposed to alcohol (PEA) but did not display the craniofacial anomalies and growth deficits associated with FAS. Both the FAS and PEA groups were alcohol exposed but the PEA group was not dysmorphic, microcephalic, or growth retarded (Mattson, Riley, Grambling, Delis, & Jones, 1997). Both groups had significant deficits in comparison with normal controls. The results show that high levels of alcohol exposure increase the risks for deficient intellectual functioning. PEA was used interchangeably with the term FAE (Fetal Alcohol Effects). Since intellectual deficits, behavioral deficits, and life-time outcomes are similar in both FAS and FAE (or PEA) groups the all-inclusive term Fetal Alcohol Spectrum Disorder (FASD) is now used.

SCIENTIFIC TECHNOLOGY, TRUISMS, AND RENE DESCARTES

Discourse on truisms, relativity, and ethics are often based on what is known scientifically. Scientific techniques, such as the use of Magnetic Resonance Imagery (MRI) have provided access to knowledge of the structure of the brain. Structural MRI's concern the analysis and measurement of the structures of the brain. Functional MRI's show the function of the intricate structures of the brain when provided with a stimulus.

Rene Descartes, philosopher and mathematician in the 1600's, states the knowledge of his existence by portraying not only his existence but the function of his existence: thinking. Descartes conveys that good sense is the most equally distributed of all things in men. He admits that some men travel more slowly mentally than others but may eventually make more progress than others who are more capable. He equates good sense with reason. Any variances of this, he feels, are due only to conducting our thoughts along different ways or fixing our attentions on different objects (Smith, 1970). Descartes, involved in analytic geometry, would have an additional and somewhat changed prospective if he had access to the diagnostic tools and instruments of today. He could then see the magnitude of alterations in the physical structures of the brain by measurement. Damage could be assessed by correlating this information with the now know function of each of the structures. His thoughts on the equal distribution of good sense and reason would be vastly different.

CHEMICAL CHANGES

After FAS was identified, it became important to show that the effects were the result of alcohol exposure and not due to other factors. Animal models were used not only to assess physical features of FAS but also to profile for behavioral, neuro-anatomical, and neuro-chemical changes. There is a need for animal research to identify risks factors, to find mechanisms by which alcohol damages the brain, and to find how the brain influences behavior. This potentially leads to ways to prevent or remediate damage. Genetic factors, which often deal with propensity to alcoholism, can also be studied and related with selected lines or strains (Sulik & Johnston, 1982).

Organic Changes

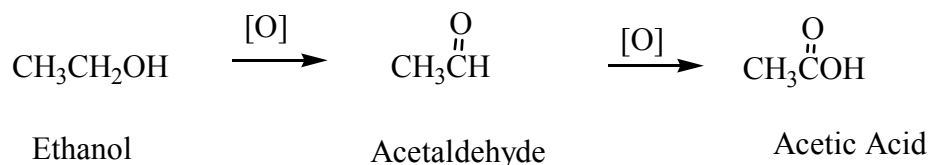
Alcohol interferes with fetal development. Alterations in brain chemistry may account for the behavioral dysfunction seen in Fetal Alcohol Spectrum Disorder. Ethanol is the most abused drug today in the United States. Studies in animals help to determine events caused by in utero ethanol exposure.

Ethanol ingestion is an assault to the fetus.

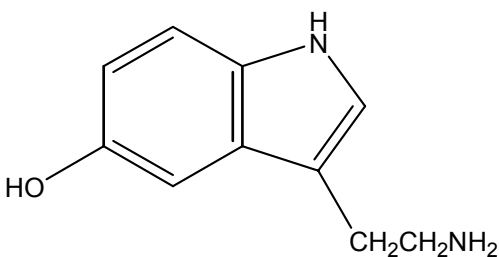


Ethanol

Enzymes such as alcohol dehydrogenase (ADH) oxidize ethanol to acetaldehyde, a substance that impairs mental and physical co-ordination. Acetaldehyde is highly toxic (Ninth Special Report to the U.S. Congress, 1997). Acetaldehyde then is oxidized to acetic acid.

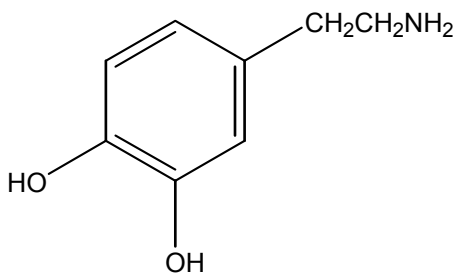


The concentration of serotonin (5-HIAA) significantly decreases in whole brain and brain regions of ethanol-exposed offspring. In utero ethanol exposure impairs development of both the cell bodies or serotonergic neurons and their projections to target areas. Ethanol impairs the synthesis, secretion, or response to astroglial nerve growth factor (NFG) secretion. NFG has chemotactic properties and an alteration in its levels due to ethanol may contribute to aberrant neuronal migration patterns.



Serotonin

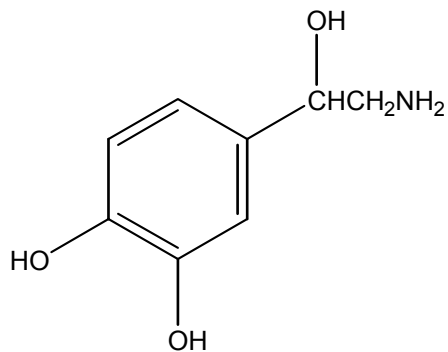
Prenatal ethanol exposure also impairs the development of the dopaminergic system (DA).



Dopamine

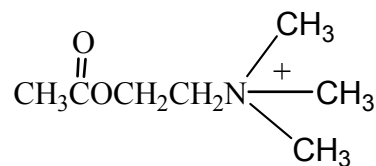
Targets of dopamine projections are the cortex, striatum, and hypothalamus. Dopamine may influence motor skills which show abnormalities in cerebellar studies. Body sway tests show motor control loss when the subject is standing. Both visual and somatic systems are challenged.

Considerable evidence shows that the noradrenergic system in the brain is markedly impaired by early ethanol exposure. Ethanol has profound effects on the maternal and fetal hypothalamic-pituitary-adrenocortical (HPA) axis (Michaelis, 1990).



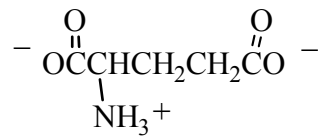
Norepinephrine (noradrenaline)

Acetylcholine concentration is significantly reduced in fetal rat brains. Ethanol exposure decreased NFG secretion from proliferating astrocytes. Astrocytes interact intimately with neurons and play crucial roles in the developing CNS.



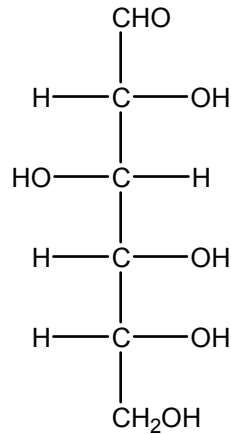
Acetylcholine

Glutamate has been associated with neurotoxicity and the generation of free radicals. The developing fetus may be particularly susceptible to the toxic effects of free radicals generated because of decreased brain levels of glutathione (GSH) (Choi, 1994). GSH is an important thiol which protects cells from damage caused by free radicals.



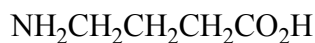
Glutamate

Ethanol significantly reduces glucose uptake in fetal neurons and retards growth, glucose metabolism, and protein synthesis. By depriving fetal tissues of essential energy sources, ethanol impairs cell proliferation, growth, and differentiation (Choi, 1994).



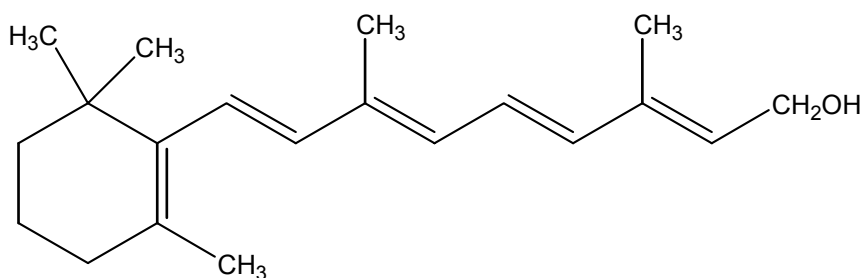
Glucose

GABA, gamma amino butyric acid, is important for glucose metabolism in the brain.



GABA, γ -aminobutyric acid

Ethanol may interfere with retinoic acid, a morphogen that regulates embryonic genes involved in limb formation and CNS patterning. The enzyme ADH possibly may convert retinol, or vitamin A, to retinoic acid. Therefore, retinoic acid is reduced at times in development when it is needed to specify spatial patterns. Some studies suggest decreased levels of retinoic acid may contribute to alcohol-related heart defects.



Retinol
(Vitamin A)

Studies are being developed to reveal how timing of ethanol exposure, dose response, and maternal drinking patterns disrupt neurotransmitter systems. Studies may provide markers of abuse. Research could potentially lead to antidotes to counteract the negative chemical effects of alcohol. Knowledge using animal subjects could lead to improved prevention and intervention strategies.

Positive Organic Interventions

The National Institute of Health published a news release in May of 2001 of findings that the long-chain alcohol 1 – octanol successfully blocks a mechanism leading to fetal alcohol spectrum disorder. It is paradoxical because the short-chain alcohol, ethanol, causes FASD. The study conducted by Drs. Chen (University of North Carolina),

Sulik (UNC), Charness (Harvard), and Wilkemeyer (Harvard) showed that ethanol inhibits cell adhesion mediated by the L1 cell adhesion molecule in selected host cells and that low concentrations of 1 – octanol can antagonize that effect. This study is due to the work with mouse whole embryo cultures and illustrates that 1 – octanol blocks alcohol teratogenesis (abnormal physical development) and associated cell death.



1 – Octanol

Further animal studies have shown the value of two peptides that prevent alcohol's disruption of the developmental process (Wilkemeyer, Menkari, Spong, Charness, 2002). Dr. Michael Charness, M.D., Associate Professor of Neurology at Harvard Medical School, and his colleagues explain that fetal cells destined to become the brain and nervous system attach to each other with the help of cell adhesion molecules, including one particular molecule called L1. Cells come together when L1 molecules on the surface of one cell link with L1 molecules on another cell surface. Ethanol (drinking alcohol) interferes with L1 adhesion and hinders cell-to-cell attachments. NAP and SAL are active peptides from two brain proteins which protect nerve cells against toxins. Extremely small amounts of NAP and SAL were found to prevent this effect of ethanol in studies with mice.

ETHICAL CONSIDERATIONS AND ANIMAL STUDIES

Between 17 and 22 million animals are used each year for research-type purposes (Penslar, 1995). Starting in 1985, experimental research with animals must receive the approval of institutional and animal care and use committees (IACUCs). IACUCs usually measure the benefits of society weighed against the suffering and loss of life of animal subjects. IACUC guidelines involve consideration of the number of animals used, the purpose of the experiment, the likelihood of achieved results, minimizing discomfort, and consideration of alternatives, undue duplication, and painless euthanasia of animals that would end in severe and chronic pain according to established regulations (Penslar, 1995).

There are different ethical approaches to animal experimentation. Each makes a different assumption about the moral status of animals. Penslar relays five main ethical approaches for consideration.

Utilitarianism

The first is the utilitarian approach which focuses on the consequences or outcomes of the actions. There are two meaningful questions in this cost/benefit analysis. One is to ask what the benefit to society would be. The other is to weigh the harm to the animals used. The benefits are recognized on the level of what they would be to humans and also what benefits would behoove animals. The research may be considered ethically justifiable if, in the predetermination, it seems that the benefits will counterbalance the harms.

According to Andrew Rowan (1997) animal research is based on a cost/benefit analysis by most people. The costs are mainly due to animal pain, distress, and death. The benefits are two-fold. They include the acquisition of new knowledge and the development of new medical therapies for humans. But there are considerable varying points of view on how to judge the amount of pain and suffering that occurs for animals. Rowan feels rather than addressing the important issue of finding ways to minimize discomfort focus is instead on addressing only the questions. Rather, if techniques were developed that could ease and eliminate animal suffering then both the public and investigators would be more at ease. The last twenty years, he feels, have been spent in debate with assertions of opinion mixed with fact. Rowan is in favor of waylaying the rhetoric to allow for the “dispassionate analysis of pain and stress reduction” (p. 79).

Deontology

The second is the deontological approach by which Kant advocates duties or obligations. The principle of whether an action is right or wrong is considered. The relative rights of animals are considered. Determination of the inherent value of animals is necessary when using this approach. Yet the derivative of what accords inherent value is not conclusive in animals. Professional codes of ethics must see some inherent value in animals because they require humane treatment.

The Code of Ethics for the American Society for Biochemistry and Molecular Biology states as their goal the quest for knowledge. Their ultimate goal is advancing human welfare. In doing so there are obligations to the public. Along with ensuring the welfare of human subjects it is stated that the comfort and humane treatment of animal

subjects be accorded. Even if the inherent value of animals cannot be known there are appropriate and kind ways to minimize pain, handle compassionately, and house humanely animal subjects. The importance of this treatment of animals is stated in their Code of Ethics along with other duties such as the reporting of research findings, using funds appropriately, and sharing propagative materials.

McGinn (1995) maintains that the Kantian view requires that a creature be a rational being to have inherent value and worth. McGinn could agree with the Kantian view if rationality means avoidance of pain and seeking beneficial stimuli. He feels that a definition of rationality as reasoning about abstract matters is too stringent. Even instinctiveness and reflexiveness are no reasons to exclude animals from moral consideration. Furthermore, innate behaviors are sensations and preferences.

Contractarian Approach

The contractarian approach views moral obligations between moral agents. A moral agent must be able to make decisions about right and wrong. Most animals therefore are not moral agents. The higher primates may be considered as such but since most studies, especially in alcohol research, use mice or rats, this approach cannot be ethically viable.

Gottlob Frege, the founder of analytic philosophy remarks on membership in the moral community. "It seems absurd to us that a pain, a mood, a wish should rove about the world without a bearer, independently" (Frege qtd. in McGinn, p. 1). Moral agents who determine rights and wrongs should not be a factor. The sentient being which has relative pains and moods is the determinate of value and worth and is cognition in and of itself. The further enhancement, if you will, of the ability to interpret morally is of no

relevance. Colin McGinn questions the ontological foundations of moral concern. He feels that if an experience occurs then, as Frege stated, it must be experienced by some being. Experiences are not free-floating. Furthermore Frege maintains that the bearer of an experience cannot be just another experience. This would lead to infinite regress because another bearer would be needed for that experience. The experience and bearer must be on different ontological levels. Frege believes that there is no requirement for the bearer to be self-reflective, only existent with experience.

McGinn mentions that the moral community is the community of selves of which animals belong as much as humans. He does, however, acknowledge different species as having differing moral weights. The heart of the argument though is that we are all subjects of experience. There is no logical gap between humans and animals as subjects being invested with moral worth. The experience is something that the subject undergoes. This rationale is based on the fact that animals exist in states that matter to them. The subject-experience connection is enough for us to be rationally caring for the animals in question.

Deni Elliott and Marilyn Brown convey Bernard Gert's thoughts of the condition of belonging to a moral community. Gert feels that moral communities construct governments (Elliott & Stern, 1997). Governments serve the purpose of managing moral protections. This is to prevent the suffering of evils by enacting laws. How could animals be protected in a community like this he asks? He maintains that animals then would have to be protected in the wild. Even further the moral community would have to protect prey from predators. Would not then certain species become extinct from not being allowed their food source of other animals?

The contractarian ethical approach should be refuted. It would exclude all infants, young children, and mentally-defective human adults. One can “experience” without sophisticated moral capacities. Even speech to convey distress is not essential. Physiological and psychological determinants of stress can be evidenced by heart rate, blood pressure, eating habits, activity levels, etc. Thus my view aligns with Frege’s and McGinn’s expression in that a moral community is ontologically similar being made up of sentient animals and humans all of which are worthy of ethical, humane treatment. I do not feel that just because animals are part of the moral community, however, they should be excluded from research.

Kinship Ethics

The fourth ethical approach for animals is rooted in kinship duties. The kinship avenue credits more worth for those closest to us. This does not imply that mishandling lower forms of animal life is appropriate. Yet it affirms a lesser status of animals and fewer requirements than those maintained in the Belmont Report for human subjects. The *Homo sapiens* species would be held in the highest regard due to kinship. Duties to human subjects therefore would be premier and paramount.

Tom Regan’s “subject-of-a-life criterion” specifies criterion most analogous to what is deemed *Homo sapiens* like.

Individuals are subjects-of-a-life if they have beliefs and desires; perception, memory, and a sense of the future, including their own future; an emotional life together with feelings of pleasure and pain; preference and welfare interests; the ability to initiate action in pursuit of their actions and goals; a psychophysical identity over time; and an individual welfare in the sense that their experiential

life fares well or ill for them, logically independently of their utility for others and logically independently of their being the object of anyone else's interests (Beauchamp & Walters, p. 489).

The above sounds like the ideal human life. Many human lives though do not function with a fraction of the welfare and independence stated. Are we logically able to operate independently of the utility and interest of others? Do we then differentiate worth and treatment within a species? Regan feels that we do not. Operating independently of utility for others does not mean that individuals are not causally related to the utility and interests of others. Even those who are enfeebled have welfare that is independent of their utility to others. Inherent value is a categorical value, of no degrees, which supposed relevant similarity is categorical. Favored abilities are thus negated.

Organic Unity

The last framework discussed by Penslar is the organic unity theory. The theory is one of compassion. It gives all of organic life as having inherent moral value. It essentially gives all animals the same status as humans. The organic unity theory looks after endangered species in particular.

Jane Goodall (2001) describes how she offered a chimpanzee in Tanzania a nut in her open palm. He looked directly at her as he took the nut and then dropped it. She relates that at the same moment he gently squeezed her hand as if to say, I don't want it but I understand your good intentions. Goodall asks us to accept that animals are sentient beings. She also asks that we change the mindset that animals are essential to medical research. She maintains that many tests can be performed on cell and tissue cultures

without using animals. Goodall also suggests the use of computer simulations. The use of alternatives to animals is compatible in support of the organic unity theory.

Albert Schweitzer's thoughts embody an interpretation also of the organic unity theory. He terms it as a "reverence for life." He formulates, "I am life which wills to live, and I exist in the midst of life which wills to live" (Beauchamp & Walters, p. 489). There is a yearning for more life and this will is called pleasure. Annihilation and injury are pain. Schweitzer believes in practicing the reverence for all life as that of his own.

Summary to Animal Ethics

There is value to all of the five theories. It is the continued concern of animals' welfare and adherence to IACUC principles that will allow for humane and compassionate animal research. We must be able to commiserate with animals in our investigations. Utilitarianism provides the overall ethical theory needed for use of research with animals for betterment of humankind. There are critical issues at hand for which there cannot be improvement or resolution without use of animals.

Animal studies are essential in addressing skepticism over the idea that maternal alcohol consumption during pregnancy could have devastating effects on offspring. In 1977 two laboratories reported that mice exposed to alcohol prenatally were smaller and had birth defects like Fetal Alcohol Syndrome (National Institute on Alcohol Abuse and Alcoholism, 1997). Using mice the investigators were able to control any other variables such as poly drug use, other health issues, and nutrition. The use of mice and rats in this field has advanced our knowledge of the biological-behavioral-cognitive connection. It also allows for an understanding of the mechanisms of prenatal alcohol exposure. Biopsy of the brain at certain stages allows for insight into the formation of the central nervous

system. The central nervous system is the longest developing system during pregnancy. The CNS begins developing in week 3 and continues throughout pregnancy. There must be allowed research to develop the understanding of critical dose and time-exposure patterns. The growth abnormalities cannot be seen manifested as congruent to human growth studies by just what can be found in a Petri dish. Animal models serve as valid and effective tools promoting the beneficence of society.

Genetic Studies and the Dalai Lama

The Dalai Lama parlays that the study of genetics must proceed with caution and humility. Motives must be examined. Only genuinely compassionate motives should be employed in genetic studies. The general principle behind genetic work is utility. Work in the fields of genetics and biotechnology should only be for developing useful techniques. The Dalai Lama sees benefit of animal experimentation but hopes that rapid advancements will be made in computer technology so less animal experimentation will be necessary. He hopes that the growing importance of human rights extends to animals. Suffering of animals is not permissible (Dalai Lama, 2000). Only for the beneficence of society can animal studies be undertaken.

Dr. Kathy Sulik, Bowles Center for Alcohol Studies at University of North Carolina, has found that by exposing pregnant mice to high doses of alcohol for a short period of time during gestation a mouse will be produced with the facial features of FAS (Sulik, 1982). The animal on the left is a control and the one on the right is alcohol exposed. The eye openings on the right model are smaller and the area under the nose is long and flat. This demonstrates that the neural crest cells are very sensitive to embryonic alcohol exposure and can lead to cranio-facial defects.

Comparison of DNA among thirteen different animals, including human beings, found that primates share common stretches of DNA with rats and mice that weren't found in carnivores such as dogs and cats or hoofed animals such as pigs and cows. Other animals studied were baboons, monkeys, chickens, zebrafish, and two species of pufferfish (Green, 2003). Since the educational and behavioral outcomes of FASD in humans affect many aspects of life which are extremely difficult to overcome it may be worthy to pursue studies with rats. Educational and behavioral outcomes do not affect the quality of life in rats as they do in humans. Kathy Sulik's work with rats and mice for over three decades has allowed much progress to be made in the diagnosis and implications of FASD.

Risk Factors

- **Quantity of alcohol**
- **Pattern of alcohol usage**
- **Timing during pregnancy**
- **Genetics variables**
- **Maternal weight, metabolism, and nutrition**
- **Reactions with other drugs**

The higher the dose of alcohol, the more damaging is done. The pattern of drinking is important also (Grant, Ernst, Streissguth, & Porter, 1997). In both animal and human studies binge drinking of large amounts of alcohol in short periods of time is more damaging to the fetus than chronic usage that produces lower blood alcohol levels. The developmental timing of exposure examines the importance of cutting down or quitting before pregnancy and stopping during pregnancy. A single exposure to high levels of ethanol can kill nerve cells. The brain develops throughout pregnancy. Some fetal alcohol effects could occur before a woman knows she's pregnant. Synaptogenesis, however, occurs from the 6th month of pregnancy to the child's second birthday. This coincides with the rat's development at birth. Synaptogenesis is when the brain cells form most of their interconnections (Ikonomidou, Olney, & Ishimaru, 2002).

The period of life in which the ovum turns into an embryo is at the beginning of the third week of pregnancy. The embryo period ends at the end of the eighth week. The period of the fetus comes thereafter to the end of pregnancy. The central nervous system

(CNS), which is the brain growth and formations, develops throughout the embryos' and fetus' life (Moore & Persaud, 1993).

AUTONOMY

There is continuous development of the fetus throughout pregnancy. We cannot and do not wait until the moment of birth to declare the fetus a human being. Therefore, the rights of the fetus and the rights of the pregnant woman need to be weighed. Some experts even feel that the fetus is a member of society-at-large so not only do the rights of the mother and fetus need to be considered but also the rights of the community in general. Is the fetus a member of the moral community with inalienable rights of life, liberty, and the pursuit of happiness? Thomas Jefferson accorded these legal rights to all men, or human beings. When is the fetus considered a human being? Would the entire duration of pregnancy, which contributes to the final outcome of the human being, be relegated to producing a healthy subject? Do we look towards the potential of becoming a person to endow it with inalienable rights (Mary Ann Warren, 1973)? One of the traits considered most central to the concept of a human being is reasoning ability. Must pregnancy then be beholden to whatever it takes to produce this complex capacity? Or need this be viewed as interference with a pregnant woman's autonomy?

John Seymour (1994) considers three different models of the maternal/fetal relationship. One view is that the fetus is part of the woman's body. Surely, the fetus is within the woman's body. But is it a body part? This first view has deficiencies. Firstly, unlike a body part, the fetus is a result of a social (sexual) relationship (Mackinnon qtd. in Seymour, 1994). Secondly, even the pregnant woman refers to the baby as something separate from herself. So this model must be rejected because it is too simplistic.

The second view is that the woman and fetus are separate entities. This view is taken by many obstetricians. It is also reinforced by all the newest technology in neuroscience. Ultrasound imaging and amniocentesis contributes to this idea. If the fetus is separate, does it have rights? To acknowledge that the fetus is a separate entity is to acknowledge its separate rights. The fetus' rights, therefore, must be protected. The health needs of the unborn fetus are one such right. Adequate health must be ensured when at all possible. In the United States this is expressed as the right "to begin life with a sound mind and body" (Smith v. Brennan qtd .in Seymour, 1994). Important aspects of this are to have prenatal care, appropriate medical treatment, assurance of a safe birth, and even intervention in a mother's behavior during pregnancy (Seymour, 1994).

What if there is a conflict of rights between a pregnant woman and the fetus? Do the rights of one then diminish the rights of another? Seymour feels that the more the rights of the fetus are recognized the less the rights of the woman may be recognized. The rights of the woman may become devalued. Control may be exercised over the woman. The best case scenario may be one in which there is equal weight to rights and responsibilities.

The third model is the indivisibly linked model. This involves the best interests of the expanding state. Ruddick and Wilson see this as a mutual dependency. (Seymour, 1994). This allows the fetus to have rights which can be protected by law, if necessary. Ramifications of legal interference may need to be addressed. Consequences by legal action may prevent women from seeking medical advice if they feel threatened. There must be ways to ensure confidentiality and ascertain lack of harm to the pregnant woman. The pregnant woman must be made to feel that it is in her and the fetus' interest to honor

her unborn child's rights. Seymour (1994) raises the question of whether a woman can be later sued by her baby that was born if a causal connection can be established of harm done. This third individually linked model opens up questions that must be examined but it is preferable to the first two models that offer only absolute approaches. This model also leads us to study and analyze the relationship between not only the woman and fetus but also the society-at-large. Hopefully pregnant women will take notice of the responsibility to their fetus by these recent legal proceedings.

In a precedent-setting decision, the United States Supreme Court decided in October of 2003 not to reverse the conviction of Regina McKnight in *South Carolina v. McKnight* who is serving 12 to 20 years in South Carolina for killing her stillborn daughter in 1999. Ms. McKnight tested positive for cocaine and acknowledged that she used crack cocaine while pregnant. Her case will be used in determining the outcome of future cases involving substance use while pregnant. Various issues center around whether a woman is autonomous during pregnancy. The South Carolina's Supreme Court decision was upheld by the U.S. Supreme Court saying that McKnight committed homicide by child abuse. The use of crack cocaine, an illegal drug, may or may not have the same legal significance as the legal drug, alcohol.

This is a monumental ruling. No court in the nation has sustained a conviction before this under a criminal statute on the premise that a woman's conduct risked or caused harm to her fetus. The subject of universal agreement is that it is public knowledge that certain substances can harm the fetus. The case of *Ferguson v. The City of Charleston*, 532 U.S. 67, 84 n. 23 (2001) was a decision where there was proven

“harm, rather than advance, the cause of prenatal health,” (*South Carolina v. McKnight*). The intention of harm was never suggested.

The recent decision by the U.S. Supreme Court was based on prior decisions that the fetus is considered a person or a child. It involves a section of a statute that states that a child must be supplied with adequate health care. Charges of homicide were also based on “the extreme indifference” to the fetus. This was considered intent (Gearan, 2003).

Those who were opposed to this decision claimed that this was a cruel and unusual punishment. They felt that McKnight was denied the right of due process because of the vagueness of the law. Competency of the mother was also an issue. The addictiveness of certain substances is another issue.

The Dalai Lama believes that every act has a universal dimension (1999). He feels that ethical discipline, wholesome conduct, and discernment are crucial in life. This can be accomplished by seeking to benefit others in preference to any narrowness of harmful self-indulgences. We must help those who are incapable of acting in this manner themselves (Dalai Lama, 1999). Perhaps free government provided health care for pregnant women would better ensure overall better outcomes for the children born.

There is very little work done in the areas of treatment and prevention. One of the side effects of Fetal Alcohol Spectrum Disorder is Attention Deficit Hyperactivity Disorder (ADHD). There are mixed reviews for use of stimulants for FASD children displaying symptoms of ADHD. Another type of treatment that may offer help to FASD individuals is early motor skills training (Kotch & Sulik, 1992). There is concern in the area of prevention that warning labels on alcoholic beverages are not reaching women.

KANT'S PRINCIPLE OF HUMANITY

Kant's Principle of Humanity encourages us to act to treat every person always as an end and never as a means only. Every person must be treated with the dignity and respect that comes with being regarded as having intrinsic value. This principle requires information and choice. Increased awareness for the general public is for overall good when considering the consequences of FASD. Information can be provided by education to the public with regard to the facts of this disorder. This may assist as a tool of social reform. There are suggestions available for educators that offer guidelines for those already affected. There are pamphlets, brochures, and magazines offered for free or a nominal charge for medical professionals and their patients. There are programs that offer help in a dignified manner. The pregnant woman and those already affected with FASD should be respected by the Principle of Humanity.

First Step is a new guide for mothers and mothers-to-be. It is developed by the First Step Campaign started in 1990. Copies can be obtained by calling 1-800-FOR-BABY. First Step's goal is to reduce North Carolina's infant mortality rate. The guides are available at no charge. Many issues are addressed in care regarding smoking, fetal alcohol syndrome, and nutritional advice. First Step offers informational articles and positive suggestions (First Step, 2002).

Wake Forest University has a newsletter called "Exposures" that is distributed quarterly. Charla Powell is the editor and writer of the newsletter that conveys articles and events from the Fetal Alcohol and Drug Program in the Department of Pediatrics of

the Section of Medical Genetics at Wake Forest University. They may be reached at 1-800-532-6302. Informational materials are available in English or Spanish (Exposures).

The Bowles Center for Alcohol Studies at University of North Carolina At Chapel Hill offers a variety of materials available to the public. They also have a quarterly newsletter that imparts the latest research one at their facility. The Bowles Center has some of the leading researchers in the country in this endeavor, such as Dr. Kathy Sulik.

THE BIRTH TO 3 PROGRAM

The P-CAP, Parent-Child Assistance Program, began in 1991 in Seattle and is ongoing (Ernst, Grant, & Streissguth, Sampson, 1999). It is an intensive program for high-risk mothers who abused alcohol and/or drugs during pregnancy. The women involved have already given birth to a child prenatally exposed to alcohol. If the woman produced a child with FASD the chance of having another one with FASD is 77-90% (Ernst, Grant, Streissguth, Sampson, 1999). The P-CAP advocacy program relies on nurturing involvement with a caseworker. The outcomes of the program have been highly successful. Fewer subsequent children are born exposed to alcohol or drugs. Benefits also include fewer foster placements and less dependency on welfare.

The Birth to 3 Program is a federally funded project. Paraprofessionals are the advocates who work with clients. A bonding process establishes trust. This program recognizes the importance of interpersonal relationships in recovery. There are three principles that characterize the advocate/client relationship. First of all, advocates understand and realize that setbacks do occur. Relapse was expected. The second principle is that relapse or non-compliance are never reasons to be asked to leave the project. This facet resulted in clients' resuming treatment by being able to overcome humiliation. Thirdly, the intervention allowed a dependent relationship to grow to a more independent and autonomous one.

Subjects came from hospital recruitment and community referral. Informed consent was obtained from all subjects. Also, a certificate of confidentiality was given by the federal government. The willingness to participate is a vital concern on any project

with human subjects. The informed consent outlined the methods and protocol of the program. Informed consent relayed the purpose of the study. The success of the project is evidenced by 67% of the most involved clients having a period of abstinence from drugs and alcohol for a year or more during the three year intervention period (Ernst, Grant, Streissguth & Sampson, 1999).

The programs aforementioned abide by Kant's Principle of Humanity. The dignity and respect with which the clients were treated in the P-Cap program was based on considering the intrinsic worth of the individuals. There was no coercion for involvement. The requirements of information and choice are met within the context of the Principle for Humanity.

PRIMA FACIE DUTY

Education via informational services is a *prima facie* duty. Truth-telling is based on this duty. The fidelity of faithfulness to newly found observations creates in us duties. The moral tenor of society may become one of non acceptance of maleficent outcomes when there are alternatives to promote beneficent outcomes. It is beneficence, weighed in the *prima facie* duty, to bring insight about rather than not acknowledge the existence of a problem to be solved. Our duties, in the *prima facie* mode, are a reflection of our moral convictions and beliefs (Beauchamp & Walters, 1999). Education is also a *prima facie* duty by virtue of self-improvement. Increasing one's knowledge creates enlightenment and awareness which can lead to furthering one's worth.

The National Institute on Alcoholism and Alcohol Abuse and the National Institute of Health have published a guide specifically designed for pediatricians, family physicians, advanced-practice nurses, and physician assistants who care for children. A request for this guide can be faxed to (202) 842-0418. This publication conveys the effectiveness of brief intervention for women problem drinkers in primary-care clinics. Brief sessions, only lasting 5-10 minutes, were found to reduce alcohol use in women by twenty to thirty percent (Fleming et al., 1997).

ETHICS OF CARE

The advocate/client relationship is also based on a supplemental ethical theory known as the ethics of care. The close personal relationships that form trust and bonding are the conceptual basis of the ethics of care. These precepts make this program effective. Sympathy and compassion are the sought after characteristics of the advocate. The traditional detachment that impartiality usually takes is now highlighted by personal attachment. There is unconditional fidelity in the ethics of care. Kindness along with sensitivity earmark interactions (Beauchamp & Walters, 1999). Better health is tied into supportive relationships. Successful prevention/intervention techniques espouse the ethics of care.

We now know that the entire spectrum disorder is a devastating disorder. The neuro-psychiatric implications can affect every aspect of daily life (O'Malley & Streissguth, 2000). The fact that it is devastating is not applicable only to the children affected but also society-at-large. This disorder overwhelms health care, educational, and judicial systems. The term "abuse alcohol" may be misleading. It is the "use" of alcohol during pregnancy that causes this developmental disorder.

By increased awareness and knowledge compassionate help can be applied. The Dalai Lama (1999) says that "knowledge is important. But much more so is the use toward which it is put" (p.181). He extols the ethical use of acquired knowledge as an obligation or duty. There is a duty of care for members of the human family who suffer the most, on one hand, and there is the duty of prevention, on the other.

LEGISLATIVE ACTION AND UNIVERSAL RESPONSIBILITY

There is universal responsibility in commitment. “Justice entails a requirement to act when we become aware of injustice,” (Dalai Lama, p. 168). Our universal responsibility begins in the political arena as well. The burdens of FASD certainly are measured in the form of pain and suffering. FASD also constitutes a considerable burden financially. First of all, the prevalence of FASD must be noted. Dr. Ann Streissguth (1998) cites a recent epidemiologic study showing the FASD occurs in nearly 1 per 100 births.

Harwood and Napolitano (1985) generated costs ranging from \$1.95 to \$9.69 billion annually in the United States. Such a wide range is due to significant differences in components of various studies (qtd. in Bloss, 1994). All of the studies included the cost of care for FAS babies with low birth weight; the cost for surgical corrections; such as cleft palates, heart defects, and audiological defects; and the cost for mild to severe retardation due to FAS. Other studies included semi-independent supervised support before and after age twenty-one. Yet other studies added costs of residential care for those over age twenty-one. Some studies included losses of the value of productivity over a lifetime (Bloss, 1994).

Abel calls for a proactive stance to prevent children born with FAS. He cites the Illinois statute that states that “proof that a minor had a medical diagnosis of Fetal Alcohol Syndrome is *prima facie* evidence of neglect’ (Abel, 1998). He also calls for the mandated reporting of all cases of FAS, as required in Florida, Illinois, Maryland, and New Jersey. Robertson (1996) sees the necessity for prevention as important enough that

he recommends financial incentives for Norplant contraceptives and the like for mothers already with an FAS child.

The Minnesota state legislature is proactive in mandating \$7 million over two years for a massive prevention/intervention plan (Streissguth, 1998). It includes a public awareness campaign, a research advocacy, a statewide promotion of maternal/child substance abuse projects, intervention and help for at-risk substance abusing women, diagnostic clinics for FAS and FAE, and Juvenile Justice Centers to provide 24 hour facilities for children offenders, or those who are victims of abuse or neglect.

Senator Tom Daschle submitted an FAS bill (S. 1875) on March 27, 1998 to Congress. The bill establishes a comprehensive program to prevent FASD. The bill sets up programs and services for children, adolescents, and adults already affected by these conditions. The bill also promotes support and help to conduct; national, state, and community-based awareness, prevention and educational programs; prevention and intervention studies and epidemiologic research; projects to initiate developmental/behavioral interventions; supportive services and models that integrate or co-ordinate such services; and a co-ordination among federal, state, and local agencies that support or conduct FASD research, programs, surveillance, prevention, and interventions. The intent of the bill was also to create a National Task Force on FASD to foster co-ordination between governmental agencies, academic bodies, and community groups. The legislation is to end after seven years after enactment. This bill did pass when attached to another bill (S. 1754, the Health Professions Education Partnerships Act of 1998).

The FASD Center for Excellence is a federally funded initiative in preventing and treating this disorder. It is operated by the Substance Abuse and Mental health Services Administration (SAMHSA). SAMHSA is part of the Department of health and Human Services. The Children’s Health Act of 2000, Section 519 D (42 USC 290bb-25d0 authorized the FASD Center to: 1) study adaptations and innovative interventions and service delivery systems for FASD individuals and families, 2) identify exemplary communities with care systems for FASD, 3) help communities without systems of care, 4) provide training for persons in service systems, 5) develop techniques for alcohol use prevention in pregnancy and child-bearing years, and 6) perform other functions as recommended by the National Task Force on FASD (“Alcohol Use Among Women of Childbearing Age – United States,” 2002).

SUMMARY

There are many ethical considerations with Fetal Alcohol Spectrum Disorder. These considerations deserve to be addressed by action. The acknowledgment of these considerations is certainly important but the implementation into action is vital. Many philosophers have notable stances on ethically transforming knowledge into action. Aristotle views action as contributing excellence to the human species. Although knowledge is a worthy goal it must be furthered by action. Immanuel Kant implores us by the categorical imperative to do what needs to be done. Kant states that the categorical imperative is an unconditional command. In essence this moral law consists of two principles. One is to find out our duty and the other is to act on that moral duty. It is our duty as a society, of which we are inherently members, to act according to our obligations. It is obligatory to minimize birth defects in all ways possible. This forms not only the duties of the pregnant woman herself but all of society. Society has the duty to inform and educate. Gynecological care for all women of child bearing age needs to emphasize the dangers of binge drinking. Gynecologists need to stress an awareness of drinking habits, and suggest extreme moderation and even abstinence for those who could become pregnant. Society must also intervene when necessary. Intervention is not interference. It should be accomplished in the way advocated by the Dalai Lama. This way is non-judgmental compassion. This is also a Kantian way of treating persons with respect.

John Stuart Mill offers that aiming at something other than happiness, such as the improvement of mankind, is the way to attain happiness along the way. He says to aim

for happiness alone is not enough. Mill advises us to be motivated by the consequences of actions and then modify our acts to tend towards beneficence. We must rectify actions that inflict society. The beneficial act of identification of pregnant alcohol users should be employed. This must be done in a non-retributive manner towards the pregnant woman. Benefits of folic acid and other nutrients need to be explained and used in order to ameliorate effects of alcohol. The ethics of Mill would have us implement legislatively the coordination of prevention/intervention plans. Bills must be passed to prevent and treat this disorder. Legally, there must be adherence to adoption disclosure laws. Medical conditions of the child need to be noted not only for the adoptive family but also for the adopted individual. Proceeding in this way leads to Mills' views of acting towards the best outcomes.

Charles Sanders Peirce, a well renowned pragmatist, defines ethics from two standpoints. Pure ethics helps us find the ultimate aim of knowledge. Practical ethics then must be employed to advance action to the ideal. Society is shaped by our knowledge and the application of ethical considerations to it. Ethical considerations implore us to act upon our knowledge. All of society needs to respond to what affects all of society. As John Donne (1664) stated, "Man is not an island, entire of itself. Every man is a piece of the continent, a part of the main," (Meditations, XVII).

RESOURCES FOR ALCOHOL AND DRUG AFFECTED INDIVIDUALS

Organizations and Agencies

Adoptive and Foster Parents of Fetal Alcohol and Drug Affected Children
PO box 626, Paramus, NJ 07653-0626 (201) 261-1450

American Medical Association
515 N. State St. Chicago, IL 60610 (312) 464-5000.
<http://www.ama-assn.org>

The Arc of the United States
500 East Border St., Suite 300, Arlington, TX 76010 (817) 261-6003

The Arc's Fetal Alcohol Syndrome Resource and Materials Guide
<http://thearc.org/misc/faslist.html>

CSAP (Center for Substance Abuse Prevention)
9302 Lee Hwy., Fairfax, VA 22031 (703) 218-5600 or (703) 218-5700

Centers for Disease Control and Prevention (CDC), FAS Prevention Section, Division of
Birth Defects and Developmental Disabilities
4770 Buford Hwy. N.E. (MS F-15), Atlanta, GA 30341-3724 (404) 488-7370
http://www.wellnessweb.com/nutri/fetal_alcohol_syndrome.htm

Fetal Alcohol and Drug Unit (FADU)
School of Medicine, University of Washington, 180 Nickerson St., Suite 309, Seattle,
WA 98109 (425) 543-7155
<http://weber.u.washington.edu/~fadu>

March of Dimes Birth Defects Foundation
1275 Mamaroneck Ave., White Plains, NY 10605 (914) 428-7100
<http://www.modimes.org>

National Clearinghouse for Alcohol and Drug Abuse Information (NCADI)
PO Box 2345, Rockville, MD 20847-2345 (800) 729-6686
<http://www.health.org>

National Organization on Fetal Alcohol Syndrome (NOFAS)
1815 H St. NW, Suite 1000, Washington, D.C. 20006 (800) 666-6327

National Women's Resource Center
515 King St., Suite 410, Alexandria, VA 22314 (800) 354-8824
<http://www.healthywomen.org>

DIAGNOSTIC CENTERS IN NORTH CAROLINA

University of North Carolina School of Medicine
Dept. of Pediatrics
CB NO. 7487, Medical Research Bldg. A
Chapel Hill, NC 27599-7487 (919) 966-3025

Geneticists: Arthur Aylsworth, MD; Cynthia Powell, MD; & Pamela Reitnauer, MD

Duke University Medical Center
Division of Medical Genetics Box 3528
Durham, NC 27710 (919) 684-2036

Geneticists: Marie McDonald, MD & Priya Kishnani, MD

East Carolina School of Medicine
Dept. of Pediatrics
Brody Bldg, 3E-140
Greenville, NC 27858-4354 (202)816-2529

Geneticist; Jean Hood, MD

Fullerton Genetics Center
14 Victoria Rd.
Asheville, NC 28801 (828) 213-0032

Geneticists; Ellen Boyd, MD & William Allen, MD

Wake Forest University School of Medicine
Dept. of Pediatrics/Medical Genetics
Medical Center Blvd.
Winston-Salem, NC 27157-1076 (336)716-2899

Geneticists: Tamison Jewell, MD; Vandana Shashi, MD; & Danette McCandless, MD

FETAL ALCOHOL SPECTRUM DISORDER RECOMMENDED READING

The Broken Cord

by Michael Dorris

The Challenge of Fetal Alcohol Syndrome: Overcoming Secondary Disabilities

by Anne Streissguth, Ph.D. & Jonathon Kanter

Diagnostic Guide for Fetal Alcohol Syndrome and Related Conditions: 4 Digit

Diagnostic Code

By Sterling Clarren, MD & Susan Astley

Fetal Alcohol Syndrome Diagnostic and Prevention Network

Children's Hospital and Medical Center

4800 Sand point Way NE

Seattle, WA 98105

Drinking During Pregnancy

Available through March of Dimes

www.modimes.org/HealthLibrary2/FactSheets/

FAS/E: A Standard of Care for Toddlers, Children, Adolescents, and Adults

Jocie Devries, Ann Waller, and Vicky McKinney

(253) 531-2878

Fetal Alcohol Syndrome: A Guide for Families and Communities

By Anne Streissguth, Ph.D.

Fetal Alcohol Syndrome/Fetal Alcohol Effects: Strategies for Professionals

By Diane Malbin

www.fascets.org

Identification and Care of Fetal Alcohol Exposed Children

Published by the Institute of Alcohol Abuse and Alcoholism

NIAAA Publication No. 99-4369

www.niaa.nih.gov/

Ninth Special Report to Congress on Alcohol and Health

From the Dept. of Health and Human Services

National Technical Information Service 1-800-553-NTIS

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BIOGRAPHICAL SKETCH

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