

Stories in This Series

- [Human guinea pigs?](#)
- [Cosmetic gene therapy](#)
- [Organ transplants](#)
- [Fertility ethics: Part I](#)
- [Fertility ethics: Part II](#)
- [Engineering the unborn](#)
- [Creating flawed animals](#)

From The Post

- [Part Two: Fertility innovation or exploitation?](#)
 - Court to decide fate of [divorced couple's embryos](#)
 - Treatment helps men with [Klinefelter's syndrome](#) become fathers.
 - A 63-year-old woman gave birth with the help of [fertility treatments](#).

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Fertility Ethics

Babies in Limbo: Laws Outpaced by Fertility Advances

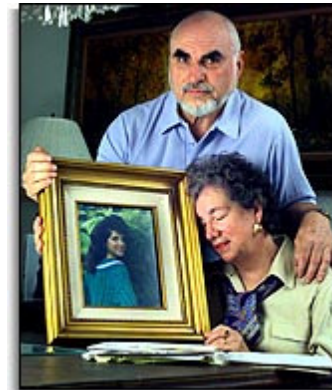
By Rick Weiss
Washington Post Staff Writer
Sunday, February 8, 1998; Page A01

Miscarriages are always tragic, but some people couldn't help privately expressing relief when Tracy Veloff's pregnancy failed in December.

Veloff was a paid surrogate mother, and the child she was carrying had been made from the egg of a woman who had been dead for a year. It was the world's first case of posthumous maternity, a precedent that many found troubling.

Lawyers were already haggling over who would be the child's parents. The biological mother, Julie Garber, was buried in December 1996 after freezing a few hastily produced embryos. Veloff, the surrogate mother, had no intention of raising the child she was paid to carry. Neither did the anonymous sperm donor who fertilized those eggs.

Even Garber's parents, who had arranged the pregnancy, did not plan to raise the child themselves. They had inherited the embryos along with their daughter's furniture and other possessions, they said -- a concept some legal authorities found disconcerting -- and it was their prerogative to grow them into grandchildren.



Howard, 68, and Jean Garber, 62, hold a framed photo of their daughter Julie who died of leukemia in December.
Kari Rene Hall/The LA Times

The Garber case is just one of an increasing number of ethical predicaments to emerge in recent years as a dizzying array of reproductive technologies has redefined the meaning of "parent" and "child" in ways wholly unfamiliar to American society and its legal system. Of

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About This Series

Biomedical research is proceeding at breathtaking speed.

Geneticists are gaining insights into how genes work. Biologists are unmasking the mysteries of how a tiny clump of cells develops into a fully formed human. Immunologists are deciphering the complexities of the body's defense systems.

The research is yielding many potential benefits. Doctors can identify people at risk for genetic diseases and fashion strategies to save their lives. Reproductive biologists can help infertile couples have children. Researchers can engineer animals with organs that may be transplanted into humans.

But as science speeds ahead, it often pushes the edges of society's readiness to cope with its consequences. Increasingly, research creates possibilities before the accompanying ethical, social and legal ramifications have been resolved. In a series of occasional articles, The Washington Post is exploring these issues.

American Society for Reproductive Medicine.

At the same time it has generated ethical, legal and social conundrums. New treatments are being rushed into use before they are fully proven to be safe or effective, potentially putting some women and children at heightened risk of physical and psychological harm. In some cases, women are not fully aware that they, their eggs

the many areas of science that today are giving rise to bioethical quandaries, this one more than any other strikes at the heart of society's most cherished institution: the family.

Today's ethical crisis in reproductive medicine is the product of converging social, economic and scientific factors. Many women in the work force have delayed childbearing to the point where technological intervention now offers their only hope of becoming biological mothers; a lack of financial support from the federal government has pushed the \$2 billion-a-year fertility industry onto an aggressively entrepreneurial track; and recent advances in egg freezing, embryo manipulation and other techniques have shattered many of the biological barriers to parenthood.

The result of this convergence has been a large, uncontrolled experiment in novel methods of family making. It has been, by some measures, a highly successful experiment -- one that has brought the joys of parenthood to thousands of women who otherwise would have remained childless. In 1995 alone, 11,315 women gave birth to children conceived by some form of assisted reproductive technology, according to the

or the resulting embryos are the subject of research, experts said.

As a result, a growing number of people are calling for new laws to regulate assisted reproductive medicine. The field today is largely free of federal or state oversight. In the continued absence of such regulation, critics say, more and more people -- particularly children -- could be harmed.

"This field is screaming for oversight, regulation and control," said Arthur Caplan, director of the Center for Bioethics at the University of Pennsylvania. "If you are going to make babies in new and novel ways, you have to be sure it's in the interest of the baby."

The ethical and legal confusion surrounding high-tech family building extends beyond the questions of embryo inheritance and parentage raised by the Garber case. Courts are also finding themselves embroiled in debates over fertility clinic record-keeping practices, which in some cases appear to have led to the loss of women's frozen embryos. And they are having to settle questions of who should bear responsibility when a woman's egg is inadvertently inseminated by diseased sperm.

In one far-reaching case, a Pennsylvania jury may soon decide the difficult question of whether fertility clinics are more than "baby marts" and have a responsibility to ensure that their clients are prepared for the challenges of child-rearing. The case came about after a 26-year-old bachelor paid a clinic \$30,000 to have a child made for him, then murdered the child within six weeks of bringing him home.

"Every so often you have to step back and say, 'What are we trying to do here?' " said Barbara Katz Rothman, a sociology professor at Baruch College in New York. "Most of us don't have a really clear sense" of how the fertility industry should be run, Rothman said. "But I'm fairly certain that we shouldn't just be turning this over to the forces of the market."

Given the lack of uniform standards and the confused state of the law, an American Bar Association panel is preparing a landmark legal analysis that it hopes will be translated into uniform legislation to be adopted by individual states. The proposal is scheduled to be unveiled this summer.

Meanwhile, some experts are saying that at a minimum, fertility doctors should provide written warnings to their clients about the legal and ethical entanglements they may face -- especially when donated eggs, sperm or embryos are involved.

"The standard of care for assisted reproductive medicine should be that you advise people not only of the medical risks but also the legal

and social risks," said R. Alta Charo, a professor of law and bioethics at the University of Wisconsin at Madison.

What Defines a Parent?

Of all the legal and social complications wrought by modern fertility techniques, perhaps the most significant are those involving embryo ownership and parentage. The courts have not been enthusiastic in their new role as arbiters of parenthood. In the words of one New York court, these "are intensely personal and essentially private matters which are appropriately resolved by the prospective parents rather than the courts."

But with baby making now being done in so many ways, with so many different participants, the question of who an embryo or child belongs to can be difficult to answer. A recent analysis by Nanette R. Elster of the Chicago-Kent College of Law found that several fertility techniques in use today allow seven or eight people to have parental claims on a single newborn. In some situations using the newest technologies, as many as 10 people could claim a piece of the parental pie.

"We've now broken up the components of parenthood into so many pieces," said Wisconsin's Charo, "we can find ourselves in a situation where nobody has presumptive parental status."

That's what happened to Jaycee Buzzanca. The infertile couple who arranged for her creation, John and Luanne Buzzanca of Orange County, Calif., hired a married woman, Pamela Snell, to carry a child to term for them -- a child made from the sperm and egg of anonymous, unrelated donors.

The situation became complicated when, in March 1995, one month before Jaycee was born, John filed for divorce -- an act he claims relieved him of parental responsibilities, including child support. According to California law, fatherhood is defined by biological parentage or by marriage to the child's birth mother. Since John Buzzanca fits neither definition, he claims he has no fatherly obligations.

Luanne Buzzanca wanted to be Jaycee's legal mother but was neither her biological mother nor her birth mother. The surrogate mother didn't qualify either, having signed a contract relinquishing her maternal rights after birth. And the egg and sperm donors, who sold their genes with no intention of becoming active parents, remain anonymous.

So it was that Orange County Superior Court Judge Robert D. Monarch ruled in September that Jaycee has no legal parents. Period.

Lawyers familiar with the case said they presume that Jaycee, now

living with Luanne, will not spend her entire life a legal orphan. Late last month, a court of appeals heard arguments in the case and is expected to assign a parent soon. But the case is emblematic of the kinds of quandaries arising as novel baby-making techniques emerge.

"The medical technologies are racing away, creating all sorts of kids," said Susan Crockin, a Massachusetts attorney specializing in reproductive technology. "Now we need the role of the law to define and protect those families."

What If a Donor Dies?

Matters become even more confusing when the most obvious parent is long dead. Julie Garber was 28 and single when she died of leukemia in December 1996. Before embarking on a course of chemotherapy and radiation that would make her infertile, she arranged with a sperm bank to have a dozen of her eggs fertilized and the resulting embryos frozen. Her hope was to have them implanted in her uterus after her recovery.

When Garber died, her parents hired a surrogate mother to bring their daughter's ungestated offspring to term -- an act they said fulfilled one of her last wishes. The plan was to give away any resulting offspring to their other daughter, Garber's sister.

After three tries, the adventure ended in December when the last of Julie Garber's embryos were rejected by the surrogate mother's body a few weeks into pregnancy.

The American Society for Reproductive Medicine recommends "caution" when posthumous reproduction is being considered, although the organization allows that the practice is not inherently wrong when the deceased has left express permission, as Julie Garber did.

Yet courts have been hostile to the idea that frozen embryos can be inherited like furniture or other property. "A man's sperm or a woman's ova or a couple's embryos are not the same as a quarter of land, a cache of cash, or a favorite limousine," a California court of appeals declared in November 1996.

Moreover, little is known about the psychological downside for a child who eventually learns that one or both parents were dead long before that child's own gestation began. Some experts have begun to complain that in the modern conception industry, the rights and privileges of potential parents -- even dead ones -- are gaining precedence over the welfare of the children being produced.

Lori Andrews, a professor of law and bioethics at Chicago-Kent College of Law, said she has been amazed at some of the things she has heard from people who support Julie Garber's right to reproduce

after death. "One surrogate who applied to carry the Garber embryos said, 'I loved [being a mother] so much, I think Julie has the right to be a mother too,' " Andrews said. "Well, I'm sorry, but Julie is dead."

In addition, Andrews said, most sperm donors probably assume that their sperm will be used to create a child with a living mother and may object to fathering a motherless child.

Similar problems arise with dead sperm donors. Not long ago, Andrews said, a man from Milwaukee deposited some of his sperm in a sperm bank before undergoing cancer therapy, with the intention of using them to have children later. The man died, and when the hospital called his mother to see what they should do with the sperm, she decided to take out advertisements offering his semen to women in need.

"She was quoted as saying she wanted to have as many grandchildren as possible," Andrews said. "Well, I'm a real big believer in consent before reproduction. I can't believe this man wanted his sperm spread all over Milwaukee. He donated thinking he would be a father to his children."

Who Takes Responsibility?

There is at least one advantage to posthumous paternity: A dead father cannot harm his child. Consider the case of young Jonathan Austin, who was killed by his 26-year-old father, James Alan Austin, three years ago last month.

The father, a Pennsylvania bank analyst, paid \$30,000 to the Infertility Center of America in Indianapolis to inseminate a woman with his sperm. Less than two months after he took his son home, he beat and shook the baby to death. Now he's serving 12 1/2 to 25 years in prison.

Child abuse is by no means a problem unique to the fertility business, but the Austin case has led some to question whether just anyone with a bank account should be allowed to order a baby.

On the one hand, said Caplan, the Pennsylvania ethicist, no one would propose placing limits on people's right to procreate naturally. "Isn't every knucklehead free to do whatever they want in the bedroom?" he asked.

At the same time, Caplan said, higher standards traditionally have applied in the baby brokering business. "Would [James Austin] have been able to adopt?" he asked. "Not without some kind of checks."

"Some clinics do psychological counseling and investigate into people's backgrounds, but this clinic did not," said Jane Lessner, a Philadelphia attorney representing Jonathan Austin's biological

mother in a civil suit against the clinic. No law requires that fertility clinics subject their clients to psychological screening for parental potential, but Lessner argues that clinics have that responsibility. "They are in the business," she said. "They are the people that should know best about potential problems and therefore have special responsibilities to the people involved."

The Indianapolis clinic has been sold, and no spokesman for the former owners could be reached for comment. The case is headed for trial in Northampton County's Court of Common Pleas.

How Is Quality Maintained?

Even if fertility clinics have no special responsibility for assuring the parental skills of their clients, generic laws regarding good business practices suggest they at least have a responsibility to keep track of and protect the eggs, sperm and embryos left in their care. Yet quality control standards for fertility clinic laboratories differ widely from lab to lab and from state to state. And the history of in vitro fertilization in this country is littered with tales of lost, damaged or misappropriated sperm, eggs and embryos.

In the most famous case, doctors at a clinic in Irvine, Calif., implanted dozens of embryos into the wrong women in the early 1990s. That clinic is now closed and Ricardo Asch, the physician who headed it, has left the country. But a stream of less well-publicized cases has followed -- each highlighting a different shortcoming in record-keeping or some other aspect of quality control.

In Rhode Island, for example, Carol and David Frisina are in the midst of a lawsuit against Women & Infants Hospital for the mysterious disappearance of six of the nine embryos they had frozen there. The Providence clinic is also defending itself against a suit brought by Vickie and Robert Lamontagne, who allege that a 1995 error led to the disappearance of three of their embryos. Doctors first informed Vickie Lamontagne of the loss while she was on her back in the hospital, ready to have the embryos implanted into her uterus.

In both cases, attorney David J. Oliveira said, incomplete records raise the discomfiting possibility that, as in the Irvine scandal, some of the embryos may have been transferred to other women.

"We really don't know what happened to them. The trail is very sparse, and that's part of the problem," Oliveira said. "We've learned from these cases and on a national basis that the [reproductive] technology has far surpassed the development of adequate record-keeping procedures. Quality assurance has been cobbled together on an ad hoc basis as problems have arisen."

Hospital officials said in a statement they could not address specific allegations. However, they said, "we affirm our adherence to accepted

standards of laboratory and clinical practice." They noted that a state health department investigation, while critical of the hospital's record-keeping, found no evidence that the embryos had been given to other women.

Record-keeping standards are also at issue in the case of Brittany Johnson, an 8-year-old Los Angeles girl who in 1995 learned she had polycystic kidney disease. Records suggest she inherited the genetic condition from a man known only as "Donor 276," whose sperm allowed Brittany's mother to become pregnant with her.

According to court documents filed by Brittany's parents, a Los Angeles sperm bank provided those sperm to them -- and to an unknown number of other infertile couples -- despite a signed statement from the donor suggesting he might have a family history of kidney disease. The sperm bank has denied negligence or blame for Brittany's kidney disease -- a condition that for now is having little effect on her life but could eventually lead to a lifetime of dialysis or the need for a kidney transplant.

Who Regulates the Field?

No single regulatory body can address the array of complications resulting from the revolution in reproduction -- least of all the federal government, which abdicated much of its responsibility over the field years ago when it slowed and then stopped all federal funding for embryo research.

In place of federal oversight, a hodgepodge of state regulations has emerged. For example, about half of all states now insist that donated sperm be tested for the human immunodeficiency virus (HIV), which causes AIDS. A similar number of states require a husband's permission before a married woman can accept donor sperm. Almost every state has laws to clarify who the legal father is when donor sperm are used. Five states have laws regulating egg donation.

Different states' laws deal differently (and some not at all) with such issues as whether embryos may be bought and sold, genetically tested or used in research. And there is enormous variation from state to state when it comes to the regulation of surrogacy arrangements. Some states ban such contracts outright. Others ban payments to intermediaries or "baby brokers." Others limit the use of surrogacy to infertile couples. At least 15 other types of limitations on surrogacy have been passed by one

Regulation of In Vitro Fertilization

Artificial Insemination

- Require written consent of father (26 states)
- Make consenting husband the legal father (34)
- Do not give legal paternity to the donor (22)

or more states.

To address that confusion, a committee of the American Bar Association has been working for more than a year to create what amounts to model legislation for states to consider. It's a difficult task.

"The field is moving so quickly, you can't easily anticipate the next twist," said Ami Jaeger, co-chairman of the ABA committee and principal at the BioLaw Group in Santa Fe, which provides legal and consulting services in genetics and assisted reproduction.

But there are several basic principles that the panel hopes the ABA will back at its annual meeting this summer: that a doctor is responsible for informing fertility patients of the potential for legal and ethical complications. That posthumous reproduction may in some circumstances be inappropriate. That only a limited number of unrelated "third party" individuals should be allowed to have a hand in creating a baby.

Overall, the aim will be to ensure that anyone seeking fertility treatment knows in advance about the possible legal pitfalls. And most important, Jaeger and others said, to assert that in all matters of assisted reproduction, the baby-to-be's interests don't get lost along the way.

"The principle I want to get in is that you must have a connection to the kid. It must be your sperm or your egg, or you're going to carry" the fetus, said Crockin, the Massachusetts attorney, who has worked with the ABA panel. "Designer embryos where you pick a sperm and you pick an egg and you pick a woman to carry the child . . . I question the ethics of providing that kind of service."

It remains unclear whether that traditional view will hold up against the tide of new reproductive technology.

- Require physician to file information with the state (15)
- Contain provisions for confidentiality (9)
- Require HIV screening on donor sperm (22)
- Make it a felony for a man to knowingly or recklessly donate sperm if he is HIV positive (6)

Egg Donation

- Give donors neither parental rights nor obligations (5 states)
- Allow "reasonable" compensation (1)
- States have differing laws regarding in vitro fertilization:

SOURCE: Lori B. Andrews and Nanette R. Elster, Chicago-Kent College of Law

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