

# Infertility treatment: lack of consensus plagues an unregulated field

Megan Easton

## In brief

EACH YEAR, IN AN ATTEMPT TO STIMULATE JOURNALISM STUDENTS' INTEREST in medical writing, *CMAJ* sponsors the Amy Chouinard Memorial Essay Prize. The \$750 award is in memory of Amy Chouinard, a longtime and valued contributor to *CMAJ* and the *Canadian Journal of Surgery*. Students from any recognized journalism program at a Canadian college or university are eligible to enter, and the deadline for 1998 entries is June 1. The 1997 winner, Megan Easton, presents a well-written and thorough account of the issues surrounding infertility treatment. Interest in the topic came naturally enough — her father, Dr. William Easton, is a urogynecologist in private practice in Scarborough, Ont.

## En bref

CHAQUE ANNÉE, AFIN D'INTÉRESSER LES ÉTUDIANTS EN JOURNALISME à la rédaction médicale, le *JAMC* parraine le prix commémoratif Amy Chouinard de rédaction. Ce prix de 750 \$ rend hommage à la mémoire d'Amy Chouinard, qui a apporté pendant longtemps une contribution précieuse au *JAMC* et au *Journal canadien de chirurgie*. Les étudiants de tout programme reconnu de journalisme d'un collège ou d'une université du Canada peuvent s'inscrire au concours. En 1998, ils doivent présenter leur texte avant le 1<sup>er</sup> juin. La lauréate de 1997, Megan Easton, présente un excellent compte rendu sur les enjeux du traitement de l'infécondité. L'intérêt qu'elle porte à cette question est bien naturel chez elle — son père, le D<sup>r</sup> William Easton, est un uro-gynécologue exerçant en pratique privée à Scarborough (Ont.).

**W**hile the idea of tinkering with human life in a laboratory often evokes some apprehension, for people who are infertile the fusion of science and reproduction can be a salvation. Yet as the technology accelerates and the possibilities expand, even proponents of assisted reproduction want limits set on how far science should go. The current conundrum, however, is just where to draw the line.

When the federal government's reproductive technologies legislation passed through its final stages before being stalled by last year's election call, the groups that had a stake in the law tried to make their voices heard. But their message lacked unity because their voices were a cacophony, not a chorus.

This issue involves the infertile woman desperate to conceive, the scientist researching new techniques to help her, the doctor providing these treatments, the donor or surrogate supplying the requisite assistance, the advocate who offers support throughout the ordeal and, at the end, the child. They all may be part of a common process but they are from groups that often have disparate interests and different priorities.

In a recent newsletter from the Toronto Infertility Network, executive director Diane Allen expressed her unease about the divergent views that exist. "I find this schism uncomfortable and somewhat frightening in its potential to create divisions among us."



## Features

## Chroniques

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## No consensus

This lack of consensus complicates what is already a perilous process: legislating ethics. The medical, social and legal considerations inherent in human reproductive technology already assure that no legislation will satisfy everyone involved. However, there is unanimity on a few basic issues: some kind of law is needed, and science-fiction-type horrors such as animal-human hybrids are universally unacceptable. But apart from these vague assertions, there is little agreement.

Beyond their internal differences, several members of the "infertile community" share a grievance with the people behind Bill C-47, the federal Act Respecting Human Reproductive Technologies and Commercial Transactions Relating to Human Reproduction. It died on the House of Commons' order paper because of last year's election. Apart from being invited to submit responses to that proposed legislation after the fact, some organizations and professional bodies feel they were not adequately involved in the law-making process.

"While the government has not consulted with us, we have consulted with them on numerous occasions and made our concerns known over the years about such legislation," says Trish Maynard, executive director of the Infertility Awareness Association of Canada (IAAC).

Last year Bill C-47 passed second reading in the Commons before dying with the election call. A year later the Liberal government is still considering introducing new legislation. Maynard's experience makes her sceptical about how much influence groups like the IAAC will have on the final legislative product. Her group and many others submitted briefs on Bill C-47, but that experience left her jaded. "Our indication is that they are not really listening."

Carole Craig, manager of the IVF Canada clinic in Toronto, also feels shut out. She says the 1997 legislation was based largely on outdated data contained in the 1993 report of the Royal Commission on Reproductive Technologies. "So far as the information the commission reported on, we're way ahead [of them]. It's unfortunate that the people involved in these technologies were not consulted at all [since then]."

In its formal response to Bill C-47, the Canadian Fertility and Andrology Society (CFAS) indicated its disappointment with the government's decision not to ask any society members to review the bill before it was tabled.

These different groups say this alleged lack of consultation and cooperation gave the legislation a patronising

tone. Craig says her patients and colleagues resented the phrase used to justify the law, the need "to protect the health and safety of Canadians, especially women and children." She objects to the assumption that infertile women need protection. "They are not uneducated. They are not uninformed. They do know how to make choices for themselves."

Maynard says the 1997 legislation takes "a sort of daddy role" and that this political paternalism insults the intelligence of infertile Canadians. "Maybe they think infertile people think with their uteruses rather than their brains."

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Many of Canada's major medical bodies also responded negatively to Bill C-47 and argued that the legislation is insensitive to the needs of the infertile.

The CMA, for instance, said there was too much emphasis on prohibition and too little on promoting the benefits of reproductive technology, while the CFAS criticized the bill's "aura of abuse, distrust and profiteering." One of the reasons for the negative responses, says the Society of Obstetricians and Gynaecologists of Canada (SOGC), is that bizarre genetic technologies are lumped with mainstream infertility treatments and this "paints the latter with the same brush."

Despite disillusionment with the overall tenor of the legislation, most groups agree that the government's basic intent was sound. The cornerstone of the plan was a national agency that would operate at arm's length from government to monitor infertility treatment and research, issue licences to doctors and clinics, and maintain information registries. Since the field has always operated without legislated standards, most doctors and patients would welcome formal regulation.

Craig says regulations are long overdue. "It's unfair to the infertile couple, who is at the mercy of physicians, to not have the comfort of knowing that each of these facilities is functioning at a certain standard."

Jean Haase, a social worker at the reproductive medicine clinic at University Hospital in London, Ont., says patients have no way of knowing the quality of Canada's many private clinics. "People are very vulnerable and they will go anywhere where they are promised better statistics or more chance of success."

The IAAC also favoured the regulatory proposals, and Maynard says the best part of the whole package was the plan for greater openness surrounding donor insemination. The proposed donor-offspring registry would give children access to the medical records of their birth fathers.



Sherry Franz, an infertility counsellor who gave birth to 2 children following infertility treatment and a member of the Gamete Donation Advocacy and Support Group, championed this part of the planned regulations. She says patients cannot make informed decisions without knowing all the facts. "There's no [record]-keeping in any kind of organized way now," she says.

Children should be able to know their genetic origins if they choose, Franz adds. "You don't know how important that's going to be to a person when you make the decision to use an anonymous donor," she says. "That's a big decision to make on behalf of someone else."

Physicians acknowledge the need for countrywide coordination but are wary of total government control. The CFAS, SOGC and CMA say existing regulatory structures should be incorporated within any new framework. They recommend that traditional self-regulating bodies like the provincial medical colleges and research councils develop standards.

The CMA thinks this approach would prevent the "bureaucratization of ethics," avoid the set-up and operating costs of new agencies, and preserve doctors' and patients' autonomy.

Physicians are also worried that stringent regulations contained in federal legislation might inhibit research. For instance, Bill C-47 proscribed the maturation of ova outside the body for scientific investigation. As the national body responsible for much of the research, the CFAS rejects this outright prohibition.

## Bones of contention

Maynard says the proposed restrictions would have been regressive. "We won't learn more about reproductive health, and we'll certainly be at a standstill." Craig says little embryologic research is being done in Canada, but it is vital if treatments like in-vitro fertilization are to improve.

Another contentious clause in the 1997 law prohibited any commercial exchange involving sperm, egg and embryo donations. Some physicians argue that, without reimbursement, the number of donors would seriously decline. Craig says this ban would force couples to go to the US to buy gametes.

Others are not alarmed by a ban on compensation.

Haase's clinic, like most others, uses a commercial sperm bank to recruit, screen and test donors. She is not entirely opposed to a system of altruistic donation, however, since she has seen evidence that it works in some other countries. But she says egg donation, a complex process involving costly drug therapy, is a different issue: "It's an awful [procedure] to go through."

Franz is similarly ambivalent about the money issue, but notes that there is conflicting evidence on the impact of switching to altruistic donations.

"If it were easy, we wouldn't be having this debate right now." She does not think people should profit from their donations, yet is unsure about whether donors should be compensated for their expenses.

Women who need these donors now, or who might need them in the future, are more likely to fear the new system. Even though no law is yet in place, Haase says some of her clients are anticipating worst-case scenarios. "Some patients are getting really anxious and are saying, 'We've got to do this now because we've read about this legislation and maybe there won't be any sperm donors in the future.'"

Maynard says accessibility is the main concern of infertile Canadians. She predicts that tough legislation would mean that women who can afford it would go abroad for treatment, and others would resort to risky self-help procedures. "We're going to end up with people doing what they used to do a long time ago, which is to find friends and fresh sperm," she says. "We're talking about a major safety problem."

Under the regulations proposed in 1997, anyone breaking the ban on commercial transactions involving reproductive material or any other section of the law would have faced fines of up to \$500 000 and prison terms of up to 10 years. The CMA, like other medical bodies, thinks criminalization is an extreme measure and should be used only as a last resort.

## Moving underground?

Maynard says the penalties were excessive and would instil fear within the field. "Clearly, if they impose the criminal penalties no physician will practise in this area and so there will be no access to infertility services." This would force the process underground.

Craig says infertile couples are resilient and will find a way around whatever legal hurdles the government puts in their way. "People will get what they want one way or the other," she says. "It's been going on for centuries."



She thinks the government would be naïve to think blanket controls on infertility treatment would work. “People are not going to stop their attempt to become parents just because the government has decided arbitrarily that this isn’t acceptable to Canadian society,” she says. “The government has not recognized the crisis these couples are in.”

Franz and Haase help patients cope with the psychological impact of infertility and they have an intimate knowledge of this crisis. “Infertility is loss of control personified,” says Franz. “People are looking at this legislation as another area where they sense control is being taken away from them.”

She does support legislation that will address the neglected emotional side of reproductive technology. “Generally the whole counselling, psychosocial [issue] has been totally left out of the equation. And it’s important.” If the system becomes too “medicalized,” the process ignores the inevitable effects on patients’ personal lives.

Haase is one of only a few social workers in Canada who

works full time at an infertility clinic and she thinks counselling, or at least that option, should be the norm. “There are just so many issues that people need advice and help with,” she says, “and it really is part of informed consent.”

Last year she ensured that all of her patients had a through knowledge of the legislation. Despite its flaws, she encouraged her clients to think positively about it.

Like Haase, most doctors, patients and advisers said that the proposed law was imperfect but an amended law is needed. The federal government has yet to say if or when this will happen, but in the end it is infertile Canadians who will be left to contend with the new rules at the most private level.

Diane, a mother of 2 children born because of reproductive technology and a leader of an infertility support group in London, Ont., explained the current dilemma in simple terms. “It’s hard to really understand it without going through it,” she says. “People would do anything to have a baby.” ?