How government-funded IVF is turning into a baby lottery

The first publicly funded treatments of in-vitro fertilization are expected to start next week, but patients and doctors are still struggling with the question of who goes first.

Last month, Allison Boyes set up consultations with 12 fertility specialists across Greater Toronto. "We're going to try to put as many tickets — quote, unquote — into this lottery as we can," Boyes, 33, says.

By: Diana Zlomislic  News reporter, Published on Wed Dec 16 2015

Ontario’s $50-million a year infertility program was supposed to be a solution for people struggling to make a child. Instead, would-be parents are finding themselves bumped from oversubscribed waiting lists, weeded out entirely, or competing in a high-stakes baby lottery.

The first publicly funded treatments of in-vitro fertilization are expected to start next week, the Star has learned, but patients and doctors are still struggling with the question of who goes first.

With potentially 20,000 people vying for 5,000 coveted spots of funded treatment, and virtually no centralized criteria from the health ministry to help clinics whittle their waitlists, some sites will hold raffles, turning the program into a game of luck where the jackpot is a live baby. Others will create triage systems to prioritize urgent cases; a medically sound but ethically fraught approach as the definition of urgent will vary from clinic to clinic. Bioethicists involved in the debate say a first-come, first-served plan seems the simplest way forward but even it is complicated by the unpredictability of menstrual cycles; a woman's body may simply not be ready when her name is called.

“This program is actually going to generate an enormous amount of frustration and anger . . . and potentially harm if we can't treat everybody fairly,” says Dr. Rahi Victory.
a fertility specialist who practises in Windsor and Greater Toronto. "And there is no way to treat everybody fairly in this program.

"How do you decide if it’s the 41-year-old whose time is running out or the 33-year-old whose endometriosis is getting worse?" he asks. "They’re both running out of time. But what makes one choice better? There is no answer for that."

Dr. Rahi Victory, of Victory Reproductive Care a medical clinic specializing in Obstetrics, Gynaecology, and the comprehensive evaluation and treatment of Infertility, in Windsor, Ont.

Quebec introduced Canada to publicly funded IVF in 2010 but ended its $72-million program this year over criticisms it was a pricey “open bar” though it met its goal of reducing the multiple pregnancy rate to the lowest in North America. Quebec’s program had no health or age restrictions.

Last month, Allison Boyes set up consultations with 12 fertility specialists across Greater Toronto after the specialist she’d been seeing for more than a year leveled with her and her husband about the likelihood of them getting picked for funded IVF. She said her doctor told them he’s expecting eight patients for every funded slot available and that a lottery seems the most “dispassionately fair” way to decide who gets picked. They were told to register with multiple clinics to improve their odds.

"We’re going to try to put as many tickets — quote, unquote — into this lottery as we can," Boyes, 33, says. "We haven’t won the fertility lottery yet so I feel the odds in this aren’t really with us. It really frightens me thinking that again, it could be left to chance."

While the health ministry pledged to cover treatment for people under 43 of any gender or sexual orientation, the triage process means some clinics will need to create their own discriminating criteria. They could decide, for example, to exclude any woman over 35, the age at which eggs become statistically less likely to fertilize. Quebec data show vanishingly small success rates for women over 40. Only nine per cent of the IVF cycles in women aged 40 to 44 resulted in a live birth.

"Assuming the goal of triage is live birth, healthy outcome, then, in fact, you would probably move away from age," says Kerry Bowman, a University of Toronto bioethicist. “The goal, generally, of fertility clinics is healthy offspring.”

Choosing the healthiest patients over those who have struggled for years to conceive could boost the program’s image during its crucial first year, statistically speaking. Ontario taxpayers and high-profile critics who dismissed the funding as a wasteful election ploy could potentially be quieted by a bump in the birth rate.

At Create, a fertility centre in downtown Toronto known for taking on complex cases, each doctor will manage their own patient lists for funded treatments, Dr. Prati Sharma told the Star.

In the past few weeks, several of her patients have already “aged-out” of the program.
before it has started. Sharma says the province will allow them to begin registering patients starting Monday, Dec. 21. She plans to prioritize the rest of her 42-year-olds in the first few weeks.

“It’s do or die for them,” she says.

The ministry has yet to release a public list indicating which clinics are authorized to provide publicly funded treatments. Government money will be distributed directly to each site based on the volume of treatments it has agreed to provide. Many patients are still in the dark about how this will impact their care.

“I know there’s a lot of confusion about this,” says Shea Greenfield, spokesman for Ontario Health Minister Eric Hoskins. “I know that some clinics aren’t necessarily being clear with their patients but we will be providing more details about this very soon.”

Dr. Tom Hannam doubled the size of his practice last year when he took over the 15th floor of an office space that overlooks Summerhill and Rosedale. Even with twice as many doctors on staff and a state-of-the-art laboratory, he says his clinic can’t come close to accommodating the number of patients seeking funded treatments.

“There’s a lot of pent-up demand,” Hannam says. “People have been waiting years for this opportunity.”

He’s been open with patients about the possibility of a lottery. By Friday, his clinic will settle on a selection strategy.

“What I like about a lottery is its objective fairness,” he says. “What I like about triage (is) everyone in medicine understands the value of that. Providing limited resources to individuals with the greatest need — however you define that.”

Victory takes the credit and the blame for the lottery idea, which he says he raised during a webinar with colleagues and government officials. He estimates that every four months, the system will generate a one-year waiting list at his practice: “so when I see someone in 2017, I can offer them IVF in 2021.”

Victory wants the province to provide additional criteria or more money to help clinics manage patient overload.

“We either have to have centralized limitations that narrow the number of people eligible for IVF to something that approximates the number the government is allowing us, or we need to have unrestricted access where we can say everyone is eligible for one cycle of IVF.”

One cycle has rich, diagnostic value, says Jan Silverman, one of Canada’s longest-standing infertility counselors. She’s been at it for 24 years and was a founding member of Ontario’s first expert panel on infertility and adoption.
Sperm is stored in liquid nitrogen tanks like this one at the Hannam Fertility clinic in Toronto.

With IVF, fertility-stimulating hormones are typically injected into the body to produce a high number of eggs that are retrieved and then fertilized by sperm outside of the body. The most-promising-looking single embryo is then transferred to the uterus for implantation. Remaining embryos will be frozen and can be transferred back to the uterus one by one until the reserve is empty or the patient decides to quit trying. That whole process constitutes one cycle, the ministry says. Drugs required for the treatment will not be covered.

For some, the procedure can help define the root cause of infertility. It’s not always about having a baby, Silverman says, but having the information to know when to quit.

“It can stop people from staying on a futile treadmill,” she says.

Silverman runs a support group for infertile people. At their last meeting, stress and confusion overtook the room. Women who had viewed one another as allies are now seeing rivals.

“When the funding notice came out, they had the understanding they would all be entitled to a covered cycle of IVF,” Silverman says. “There’s been a perceived lack of transparency. I’m hearing women who feel a little duped.”

Meet the families vying for IVF treatments

Family wants a sibling for their daughter

Mari-Beth and Kyle Davis have spent nearly $70,000 trying to create their family.

They have an 8-year-old “miracle” named Ella, who was born using a frozen embryo from an IVF cycle.

Over the years, through six in vitro fertilization treatments, they've lost three children — “and more embryos than I care to think about,” says Mari-Beth, who works in the alumni office at the University of Waterloo.
“We've had a couple weeks where we've been pregnant but we knew we were going to lose the pregnancy. Yet you continue going to work. And you continue pretending like life is normal. And then you finally have to take some medication and help the pregnancy pass. It's heartbreaking. It's hard to keep picking yourself up.”

In 2012, she had surgery to remove an inverted, triangular-shaped piece of tissue that divided part of her uterus in two.

While devastating, her last miscarriage, in 2013, brought some hope that her body may still respond positively to a pregnancy. She's 40 now and would love one last opportunity, unless her doctor rules it out at their appointment this week.

“I think couples really struggle to know, when is enough, enough?” Mari-Beth says. “It's been tough for Kyle to watch me go through all these procedures. You're kind of a little out of it when they do the (egg) retrieval, but I know he's standing there and this great big needle comes out that they're going to retrieve the eggs with.

“I think sometimes he wants to say, 'I don't want to put you through this any more,' and I'm the one who reminds him, it's short-term pain for long-term benefit.”

The couple has worked with two clinics. No one has been able to pinpoint the root of their infertility, but their current doctor suggests Mari-Beth's immune system could be a factor. She's undergone costly drug therapies and a blood platelet transfusion. The hope is these treatments will help her body accept another pregnancy.

Family and friends have struggled to understand why they've stayed the course.

“People see us and say, ‘You have a daughter, why don't you call it a day?’” Davis says. “Knowing what a great kid she is and seeing our characteristics in her is what drives us. We want to give her the opportunity to have a sibling. I don't want her to be alone when we're old. I want to make sure we've exhausted all our options so I can say to her, ‘Trust me, we did everything we could.’”

Mari-Beth says she's speaking publicly about her condition to increase awareness about infertility as an illness.

“People's tax dollars are going to fund this and they think: ‘Why should I?’” she says.

“If someone's kidneys are not functioning properly, there is care to help them,” she says. “This is the same kind of situation. If there was another way for us to have a child, believe me, IVF would not be the way.”
Dr. Tom Hannam doubled the size of his practice last year when he took over the 15th floor of an office space that overlooks Summerhill and Rosedale. Even with twice as many doctors on staff
On the 15th floor of a commercial tower at the corner of Bloor and Church Streets, the elevator doors open on a Christmas scene.

“What happened to the leaves on the trees?” a boy asks as he walks through a long hallway with his mom, pointing at a series of life-sized photographs lining the walls. The floor-to-ceiling images depict a white wonderland; birch and alder trees covered in snow.

“The pictures change with the seasons,” a young woman in grey and navy scrubs answers. “It’s winter now.”

It’s another reminder of how much time passes for the boy’s mother and the women in the waiting rooms at the end of the hall. Some are with partners, a few are with children but most have come alone, sitting on cushioned benches waiting for their name to be called.

They’re here for “cycle monitoring” — step one on the road to pregnancy. For five to 15 days a month, this is their morning routine. From the waiting room, they move to private cubicles where technicians draw blood to assess critical hormone levels. In a larger exam room, they undress for a trans-vaginal ultrasound where a condom-covered wand sends out sound waves, creating a picture on a nearby monitor of the woman’s uterus and ovaries. A technician moves the wand left and right to count antral follicles growing in the ovaries. These follicles represent the reserve of eggs in a woman’s ovaries and her odds of getting pregnant.

Doctors use this daily information to pinpoint a patient’s best time of the month to try either natural conception or a procedure such as IVF.

Eighty to 100 women will pass through Hannam Fertility Centre on a busy day.

And lately, every day is a busy one.

Hannam is one of the few fertility specialists in the province who has kept in regular contact with patients through blogs and newsletter updates about the status of Ontario’s funded fertility treatments.

The ministry had promised it would begin funded treatments in December but that’s logistically impossible for Hannam’s clinic, spokeswoman Jennifer Foster told the Star.

Just last week, clinics received funding contracts from the health ministry, which were to be finalized early this week. Each site approved for funding will receive money to perform a limited number of treatments.

“We just received the news and need to understand key details (exactly how registration occurs; what consents need to be signed),” Hannam wrote in a letter to patients.

By Friday, his team will have figured out how the clinic will select patients for funded treatments, which will start in the new year.

Because the definition of “greatest need” will vary clinic to clinic, Hannam has advised his patients to register with multiple sites.

“Should a patient visit five different fertility clinics? Yeah, actually, they totally should,” he says. “They’re incented to go to many locations to get the advantages of every location depending on how that clinic handles it.”
Dr. Clifford Librach has added a second operating room, more staff and patient recovery areas to prepare for the spike in volume at his downtown clinic, Create.

His clinic has “hundreds of patients” on its wait list — both new and returning.

Librach says it’s still too early to say how many of them will be treated with public funds in the next 12 months.

“We can all complain that it’s not a perfect system,” he says. “But the good news is they’re providing something that wasn’t there before. Whether there is enough money to provide for everyone who wants to do it is ultimately going to be the question.”

Dr. Michael Hartman completed his fellowship in Gynecologic Reproductive Endocrinology and Infertility at McGill University in June, which at the time was one of the busiest IVF clinics and largest university-based reproductive centres in Canada. He worked alongside physicians performing 2,500 IVF cycles a year, which is half of what will be funded in all of Ontario.

Hartman joined Trio — a recent merger between TCart Fertility Partners and Lifequest Centre for Reproductive Medicine — in November and is one of two doctors on staff with Quebec experience, which he says should give the clinic an edge.

“We both learned about some of the administrative hassles of dealing with larger patient load,” Hartman says. “Typically, when there are more cycles, you always worry that people are going to get lost in the shuffle. There could be administrative mistakes. You worry the patient may be rushed through things or they may not necessarily comprehend things as well as they should. You always worry whether they take the medications at the wrong times or they don’t take medications. We did see a lot of that in Quebec.”

The trickle of funding details from the health ministry isn’t helping the situation in Ontario, he says. “I don’t want to disparage the government because they’ve been generous by starting this but we are left guessing a lot,” says Hartman. “We really don’t have a lot of time to prepare.”

**Infertility and IVF**

**By the numbers**

**CANADA**

- 16%

**PREGNANCY**

- 91%
<table>
<thead>
<tr>
<th>Category</th>
<th>Percentage</th>
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<tbody>
<tr>
<td>Couples experiencing fertility problems.*</td>
<td>16%</td>
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<tr>
<td>Women who can get pregnant at age 30</td>
<td>91%</td>
</tr>
<tr>
<td>Women who can get pregnant by age 35</td>
<td>77%</td>
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<tr>
<td>Women who can get pregnant by age 40</td>
<td>53%</td>
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<tr>
<td>Average clinical pregnancy success rate per IVF cycle</td>
<td>25%</td>
</tr>
<tr>
<td>Fertility clinics providing IVF services: 16 are privately owned and 2 are hospital clinics</td>
<td>18</td>
</tr>
<tr>
<td>Multiple births that occur naturally</td>
<td>2%</td>
</tr>
<tr>
<td>Multiple births born through IVF due to multiple embryo transfers*</td>
<td>30%</td>
</tr>
<tr>
<td>Costs for insured IVF treatment</td>
<td>$0 to $7,500</td>
</tr>
<tr>
<td>Cost for uninsured IVF treatment. There may be extra fees of up to $5,000 for drugs and services</td>
<td>$7,000 to $11,000</td>
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<tr>
<td>Canada</td>
<td>16%</td>
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<td>Canada</td>
<td>91%</td>
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Couples experiencing fertility problems.* It has doubled since the 1980s.

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<thead>
<tr>
<th>PREGNANCY</th>
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- 77% women who can get pregnant by age 35
- 53% women who can get pregnant by age 40

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<th>SUCCESS</th>
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- 25% average clinical pregnancy success rate per IVF cycle
- 2% multiple births that occur naturally

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<td>30%</td>
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- 18 fertility clinics providing IVF services. 16 are privately owned and 2 are hospital clinics
- 30% multiple births born through IVF due to multiple embryo transfers*

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- Costs for insured IVF treatment
- Cost for uninsured IVF treatment. There may be extra

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