Infertility Network

THINGS TO CONSIDER WHEN CHOOSING A CLINIC

FREQUENTLY ASKED QUESTIONS

“Can you please recommend a doctor or a clinic?”
As a registered charity, we cannot recommend a specific doctor or clinic. Please see the list of Clinics on our website. Depending on where you live, we may be able to give you the names of specialists who might meet your needs.

“Should I go to a doctor or a clinic?”
Most infertility treatment in Canada takes place in clinics, although some of the “lower tech” treatments (e.g. ovulation induction, donor insemination) is still done in individual doctors’ practices.

“How long will I have to wait for an appointment?”
3-8 months is not uncommon. You may be able to reduce this by asking to be put on a cancellation list and calling in regularly. For women over 35, be sure to mention this when making your appointment since your fertility is declining rapidly and you should be seen as soon as possible. Ask to be put on the ‘cancellation list” then be sure to call the office frequently to see if any appointments have become available.

“What is my chance of success? Which doctor/clinic has the best success rate?”
In December 2008, the Canadian Fertility & Andrology Society (www.CFAS.ca) released the following statistics, submitted voluntarily by the 25 IVF centres, noting that:

- the information should be reviewed together with an appropriate health care professional
- results vary by centre; specific information can be obtained from each centre.
- a list of the participating IVF centres is available on request through the CFAS

For 2006, live birth rates for 8,278 IVF cycles (including ICSI):
- no difference in congenital anomalies compared to babies conceived naturally
- 70% singletons; 95% of multiples were twins
- overall live birth rate: 27% / cycle started
  - women < 35: 34%
  - women 35-39: 26%
  - women >39: 11%
- miscarriage rate: 15% per clinical intrauterine pregnancy in keeping with that for natural conceptions)

Live birth rates for cycles started in 2007 will be released when they become available. Preliminary 2007 results for 9,019 cycles (including ICSI) in the 25 centres:

- overall pregnancy rate: 35% / cycle started (an increase of 9% since 1999 when data collection was first performed)
  - women < 35: 43%
  - women 35-39: 33%
  - women >39: 18%
- complications: < 2% of treatment cycles
  - 68% singletons; 92% of multiples were twins
  - complications in < 2% of treatment cycles

In the USA, Congress enacted the Fertility Clinic Success Rate & Certification Act in 1992 requiring all clinics practising ARTs (i.e. IVF, GIFT, ZIFT) to report their statistics to the Centers for Disease Control. These are published annually and are available to the general public broken down on a clinic-by-clinic basis.

The 2006 CDC report, www.cdc.gov/ART/ART2006/index.htm shows a decline with increasing maternal age in the proportion of fresh, non-donor procedures leading to live births, based on 138,198 ART cycles at 483 clinics, with 41,343 live births (of 1 or more infants) & 54,656 infants.

- women < 35: 37%
- women 35-37: 28%
- women 38-40: 20%
- women 41-42: 11%
- women > 42: 4%

In Canada, there is no reporting on a clinic-by-clinic basis. However, the Assisted Human Reproduction Act, passed by Parliament in March 2004, will – eventually – require all fertility clinics to report their statistics to the Assisted Human Reproduction Agency of Canada. These will be independently verified and released to the public, as set out in regulations that have yet to be established.

Such legislation had been promised by the federal government for more than a decade and, when fully enacted, will finally bring Canada into line with all other western industrialized nations; these countries have had similar legislation in place, many of them for years, to govern reproductive and genetic technologies, along with well-established processes for consultation & review.

UNDERSTANDING SUCCESS RATES

Treatment for infertility often requires considerable time, effort, emotional energy and money, with no guarantee that it will work. Understanding your chance of taking home a baby at the end of treatment can empower decision-making. Help you actively participate with your physician in developing a treatment plan, and identify realistic goals and limits.

It’s important to consider in advance:

- What is your real goal? Pregnancy or parenthood?
- How important is the genetic link?
- How long is it reasonable to continue? How many treatment cycles? How many months or years?
- How much money are you able & willing to spend?
- Should you pursue adoption instead of treatment, either within Canada or abroad?
- Should you pursue adoption instead of treatment, either within Canada or abroad, given that for the same cost as 1-3 IVF cycles, parenthood will almost certainly be guaranteed, without any medical intervention or risk?

There can be significant differences in success rates between clinics, with the result that couples who go to clinics which have poorer rates may spend more time and money, and suffer greater heartache than necessary, and perhaps waste the woman’s fertile years in the process.

Patient reactions to success rates vary but it is not unusual to feel the following, somewhat irrational, ways:

- “The rates don’t apply to us. Our situation is different.”
- “The chances are 50-50; either it will work, or it won’t.”
- “We don’t care. We will try anyway.”

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There are also various ways to quote “success rates”. To compare rates from one clinic to another, it is essential to know exactly what is being measured. For example, consider the following hypothetical example:

- # cycles started: 100
- # embryos transferred: 80
- # pregnancies: 20
- # live births: 10

The commonly used methods of quoting “success rates” each yield a different result:

- pregnancy / cycles started: 20%
- pregnancy / embryo transfer: 25%
- live birth / cycle started: 10%

Moreover, probability is multiplicative, not additive; therefore, if the pregnancy rate is 25% per cycle, over 3 cycles your chance of conceiving in 1 of those cycles is 35%, not 75%.

Given all the risks inherent in multiple pregnancy/birth and prematurity – for both mother & babies – more and more researchers are arguing that most relevant standard of success is the delivery of a single, term gestation, live baby per cycle initiated.

Be sure to ask for written information on the clinic’s success rates that you can take home and review at your leisure. Many clinics also post statistics on their web site.

What is the size of the sample that the statistics are based on? If the number of cycles is large, the success rate is more likely to hold true for future cycles than if the sample size is small (and therefore, more subject to individual variation).

What is the time period being reported? Success rates can vary from month to month, and from year to year. Statistics that include only the best months can be misleading. The longer the period of time being reported, the greater the number of cycles that are included, and therefore the less variation there will be in cycle success rates.

What is the patient population that the statistics are based on? Does the clinic accept all patients, or only those with certain types of problems who have a good chance of conceiving? Is there an age cutoff? Clinics which accept only women under 35 with blocked fallopian tubes who are trying IVF for the first time will likely have higher success rates than those which accept a broader range of patients, or patients who have been unsuccessful on previous cycles.

How many embryos does the clinic transfer? Clinics that transfer > 2 embryos may have a higher pregnancy rate but they will also have higher rates of miscarriage and multiple births, with all the accompanying risks and long term implications for both mother and child(ren). European countries, as well as Australia/New Zealand typically impose a limit of 1-2 embryos except under very unusual circumstances, while USA clinics typically transfer 3-5+ embryos; Canadian clinics fall somewhere in between.

Similarly, clinics that use a lot of drugs to stimulate the woman’s ovaries will have a higher pregnancy rate, but also a higher risk of ovarian hyperstimulation (which is serious and can be life-threatening) and a higher rate of multiples and miscarriage. Clinics that carry out a relatively high proportion of unstimulated (natural) cycles will have lower success rates than those which do not.

Some clinics cancel patients who respond poorly to stimulation; if these cancelled cycles are excluded, their success rates will look better than they really are. Cancellation rates can vary widely; a high cancellation rate tends to lower the live birth / cycle rate, but may increase the live birth / retrieval or live birth / transfer rates.

How is “pregnancy” defined? Clinics that measure pregnancy by an elevated HCG level in the blood on day 18 may have a higher pregnancy rate but some of these pregnancies will be non-viable and short-lived. It is more accurate to wait until day 40 and count only those pregnancies which have an embryo sac or a fetal heart beat.

A change in personnel, especially the embryologist, can affect success rates, for better or worse. It is absolutely essential that training and equipment be kept up to date.

Be sure to ask your doctor / clinic for specific details about their practice:

1. What are their qualifications? Any OB/GYN can call themselves a “fertility specialist,“ but is the doctor trained in the field? Reproductive endocrinology is a recognized subspecialty in OB/GYN with a 3 year training requirement following residency at an approved fellowship program. Membership in a professional medical association (e.g. the Canadian Fertility and Andrology Society, the American Society of Reproductive Medicine) does not necessarily mean they’ve had training in the field of reproductive medicine.

2. How experienced are the doctors, embryologist and lab staff? As with any field, experience counts. Has the program been around for some time and does it have a good reputation? Be wary of a new clinic claiming excellent results with less than ideal numbers of cases treated. There is a balance between experience and longevity in the field. If someone has been practicing for 30 years, this does not necessarily mean they are good at their work, but it does mean that they have extensive experience and a reputation behind them as opposed to those who may be new on the block (and unproven), but who may be more up-to-date on the latest developments & methodologies.

3. Reproductive medicine is constantly changing; in order to stay up-to-date, professionals need to continuously evaluate their methods and techniques. Do the physicians and the lab director publish in medical journals? Present abstracts at scientific meetings? Lecture to colleagues? Ask about this and also look for their work on the internet.

4. What action will they take to (further) investigate the cause of your infertility?

5. What is their treatment plan for you? How many cycles will they do before moving on to the next step? What will the next step be? What will all this cost?

6. How many cycles of this treatment do they do each year? (Usually, the more the better, because it gives the staff more experience.)

7. What is their take-home-baby rate for a couple in your situation?
   - based on the female partner’s age?
   - your medical problems as a couple?

8. How many cases do they treat a year which are similar to yours?

9. What is their rate for multiple pregnancies: for twins? for triplets? for quadruplets or more? A multiple pregnancy (even twins) is a high risk in terms of:
   - the health of the mother and babies.
   - the chance of carrying the pregnancy to term and the babies surviving.
   - the incidence of respiratory, visual and learning problems in the children.

10. What is the clinic’s miscarriage rate?

11. If considering IVF/ICSI, ask:
   a) what genetic testing do they offer to ensure serious genetic mutations are detected so they are not passed on to offspring. Cystic Fibrosis (CF) is the most...
common genetic disorder in North America; it can lead to debilitating and fatal lung problems. Although infertile couples run a 1/100 risk of having a child with CF, routine genetic screening tests detect only the most common mutations of the 800+ associated with CF. 80% of men with missing tubes and 33% of those with blocked tubes have at least one mutation; some even turn out to have mild forms of CF. Female partners of infertile men should also be tested since there is a much lower risk of a child developing severe CF if only one of the parents passes on a mutation.

b) When did they start doing any recently developed procedures? How many cycles do they do a year? (Experience is critical to success.)

c) What is their fertilization rate? Pregnancy rate? Take-home-baby rate?

d) How long has their embryologist been with the clinic? Doing IVF/ICSI?

e) Does their embryologist have a PhD?

13. Does the clinic address the emotional needs of their patients? Studies have shown that the stress associated with infertility can be enormous, akin to that associated with the diagnosis of cancer, and also that reducing this stress can increase pregnancy rates. A clinic should have access to well-trained social workers or psychologists, and also to stress reduction programs (e.g. a mind-body fertility program) to help patients deal with the anxiety that often accompanies infertility.

14. Does the clinic focus on quality? A clinic must be well-run and continually improve. Clinics around the world are adopting ‘Quality Management Systems’ to assure that systems and procedures are developed and followed so that the patient needs are met; one such standard is the International Standards Organization (ISO).

After you do this, contact other clinics and ask them the same questions.

IVF requires an integrated team of scientists, physicians, ultrasound technicians, nurses and administration. It needs to be a well-managed team to work well. Fertility clinics should continually survey their patients to see if their needs are being met, but this doesn’t always happen.

Try to network with other patients to find out their experience with doctors/clinics you are considering. A good way to make contact is to attend an infertility support group &/or to post questions on the various online bulletin boards, e.g.:

- IVFconnections.com
- IVF.ca

You can also ask to speak to other patients of the clinic. But try not to get caught up in ‘war stories’ – for every patient whose treatment is successful, there are many more who fail, so not everyone will be successful and not everyone will be satisfied. Moreover, everyone’s story is a little different and may not be applicable to your situation or relevant to your case.

Finally, there is the question of a “fit” between doctor/clinic and patient. Look – and keep looking until you find it – for a doctor/clinic with whom you feel comfortable, who treats you with respect, who takes time and makes the effort to answer your questions. If you don’t feel comfortable, seek a second opinion. This is your life, your hopes and dreams. Take charge. Be proactive!

N.B. The decision to use Assisted Reproductive Technology (ART) involves many factors in addition to success rates. Going through repeated ART cycles requires substantial commitments of time, effort, money and emotional energy. Therefore, patients should carefully examine all related financial, psychological and medical issues before beginning treatment. Also, consider the location of the clinic, the counselling and support services available, and the rapport that staff have with their patients.

“What can I do if I believe my medical treatment was inappropriate, inadequate or mismanaged?”

Write a letter detailing your experience & concerns to:

- the College of Physicians & Surgeons for the province in which you were treated. In Ontario, contact: College of Physicians & Surgeons 80 College St., Toronto, ON, M5G 2N9 416-961-3330, www.cpso.on.ca
- Elinor Wilson, President, Assisted Human Reproduction Agency Canada 2nd Floor, 301 Elgin St, Ottawa, ON, K2P 2N9 elinor_wilson@hc-sc.gc.ca
- Francine Manseau Senior Strategic Policy Advisor AHR Implementation Office 200 Place du Portage, 2e étage, AL 7002A Gatineau, QC, K1A 0K9 819-953-3856, francine_maneau@hc-sc.gc.ca

Cost of Infertility Treatment

Costs vary by clinic. Fertility drugs cost an extra ($3,000-$7,000) on top of clinic fees and may be covered under private health insurance through your employer. Be sure to get in writing a detailed list of all the costs before you start treatment.

Although public awareness of infertility has increased in recent years, provincial and private health insurance, as well as employers, have been slow to recognize infertility as a legitimate medical problem. As a result, patients must often bear significant costs in order to access treatment.

Some doctors charge only for what provincial health insurance does not cover (e.g. sperm wash, donor sperm), while others add a “monitoring” or “administration” fee. Some clinics:

- allow you to pay by credit card, which lets you spread the payments out over time (albeit, with interest) and perhaps earn “points” with the credit card company which can then be redeemed for merchandise or travel.
- arrange easy bank loans.
- offer reduced fees to patients unable to pay.
- offer “egg sharing” which enables you to have some/all of your eggs to another patient. (NB. The Canadian Assisted Human Reproduction Act, passed in March/04, bans this practice, along with payment or the exchange of goods/services for egg, sperm & embryos although genuine expenses which meet regulated guidelines are still be allowed. Moreover, egg-sharing decreases the number of embryos you will have left available for freezing and future transfer(s), and hence your own chance of conceiving. There are also ethical concerns as to whether a woman who can only access treatment by giving up some of her eggs is really in a position to freely give consent to the procedure. Sharing eggs is acceptable to some people but not to others because they fear it is a decision they may come to regret; if they are unable to conceive, they may wonder whether someone else is raising (what is, after all) their biological child, while if they do get pregnant, they then have to deal with the fact that they may have other children (conceived from those donated eggs and born into other families) whom they and the child(ren) they are raising will likely never know.

3
Out-of-pocket expenses for infertility treatment & drugs can be claimed on your income tax return as a medical expense.

The pharmaceutical manufacturers have “compassionate plans” which may enable you to get some/all of your fertility drugs for free or at a reduced cost for 1 or more cycles; ask your doctor.

There can be significant variations in the prices charged for fertility medications. Some pharmacies will ship to your home/place of business, and even out-of-province. The following pharmacies (which will ship anywhere in Canada) typically offer lower prices than those charged by clinics or other pharmacies:

- Glen Shields Pharmacy, 905-669-6851, www.GlenShieldsPharmacy.com (NB. Until January 14, 2008, this program was run out of Wexford Pharmacy.)

There are serious legal and medical risks to be considered before importing drugs from abroad, or buying them from other patients or over the Internet. Please see the ‘Fertility Drugs’ section on our website, www.infertilitynetwork.org/fertility_drugs

**Insurance coverage for IVF**

*Note.* If the cause of your infertility is blocked fallopian tubes, mild endometriosis or unexplained infertility, there may be other simpler, less invasive and cheaper alternatives to IVF. Ask your doctor.

**Ontario**

(The only province in Canada which funds any IVF treatment)

In 1994, the Ontario Health Insurance Plan (OHIP) fee schedule was changed to cover IVF only for 3 cycles (through to embryo transfer), for women whose fallopian tubes are both blocked/missing, residents of Ontario, and who are Canadian citizens, landed immigrants or refugees.

This decision marked the end of a long, exhausting battle waged by our organization to maintain full funding which included meetings with politicians and policy makers, petitions, an intensive letter-writing campaign, countless media interviews, formal briefs to the government panel on de-listing, etc..

In the end, we managed to keep IVF at least for the one instance validated by the Royal Commission on the New Reproductive Technologies (based on out-of-date data that failed to recognize its success in treating other causes of infertility, e.g. endometriosis, male factor, unexplained). Without our aggressive campaign, it seems likely IVF would have been totally dropped from the OHIP fee schedule.

The effort to mount this campaign drained our limited financial resources; we simply do not have the money or staff necessary to pursue this issue further at the present time.

The current OHIP fee schedule is unfair in that it discriminates on the basis of the cause of the infertility and essentially says one type of infertility (female blocked tubes) is worthy of IVF treatment, while others are not. And it sets limits (3 cycles) not imposed for other medical treatments.

However, this situation seems unlikely to change for the better in the foreseeable future, given the current problems with the economy, and the ever-increasing, quite overwhelming demands on our healthcare system which consume more than 45% of each province’s total annual budget and are growing at a clearly unsustainable rate.

Some people have appealed to the Health Services Review Board and male factor couples have appealed to the Human Rights Commission on the grounds of sexual discrimination; so far, appeals have been rejected because of concerns over the safety of ICSI on the children conceived using this procedure. One Nova Scotia couple appealed their province’s refusal to fund any IVF all the way to the Supreme Court of Canada without success.

Over the years, many patients have tried meeting with their MP and/or MPP, and some have also started petitions to secure more funding under medicare. So far, there has been no significant change in the level to which infertility treatment is funded in Canada.

**Quebec**

Some private insurance plans cover the cost of IVF treatment; coverage ranges from 1 attempt/life-time to a pre-established amount applicable to the treatment &/or medication. There is also a 50% tax credit.

**British Columbia**

The University of British Columbia (UBC) Centre for Reproductive Health and the Vancouver General Hospital & UBC Hospital Foundation have established the Hope Fertility Fund, www.ubcfertility.com/hopefund.php to assist BC residents who can’t afford treatment.

List of clinics: www.infertilitynetwork.org/fertility_clinics

NB. Some American clinics offer telephone consultations for a fairly reasonable fee. This can be helpful (for more info & another perspective) even if you plan to continue your treatment in Canada. For names of clinics, contact:

- The American Fertility Association, www.theAFA.org
- INCIID, www.inciid.org