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#### AHR in Canada: The times they are a changin'

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## A brief moment in time

- 1989 Royal Commission on New Reproductive Technologies
- 1993 RCNRT Final Report Proceed with Care
  - "some practices are harmful to the interests of children born through the use of various technologies, such as the lack of records kept on their origins." p. xxxi
  - "Canadians were concerned about record keeping and the needs of DI recipients and their children with respect to genetic, medical, and other information about donors." p. 428

VERS

## **Royal Commission**

• "The Commission therefore proposes a system whereby information (standard non-identifying genetic, social and medical information) about a donor would be available at any time to DI parents and children. Such information would be stored by the National Reproductive Technologies Commission for 100 years after the birth of the last child from the donor's sperm. Identifying information would also be stored for the same length of time, under conditions of strict security. Only in very rare cases would this information be revéaled ..." p. 446.

VERS

## A brief moment in time

- *1996* Bill C-47 (prohibited activities); Bill died on the Order Paper
- *2002* Bill C-56 (prohibited and controlled activities); Bill died on the Order Paper
- Bill C-56 reintroduced as Bill C-13; Bill C-13 died on the Order Paper in *2003*

#### A brief moment in time

- 29 March 2004: Bill C-6 An Act Respecting Assisted Human Reproduction and Related Research (formerly Bill C-13) receives Royal Assent
- 22 April 2004: Many of the key provisions of the AHR Act come into force (but a number of discrete provisions are not in force)

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#### **AHR Act**

- Disclosure to recipients of reproductive material
- 18. (3) The Agency shall, on request, disclose health reporting information relating to a donor of human reproductive material or of an in vitro embryo to a person undergoing an assisted reproduction procedure using that human reproductive material or embryo, to a person conceived by means of such a procedure and to descendants of a person so conceived, but the identity of the donor or information that can reasonably be expected to be used in the identification of the donor shall not be disclosed without the donor's written consent.

ERS

## **Constitutional challenge**

- *4 December 2004*: Government of Quebec launches constitutional challenge (modified and expanded 14 February 2006)
  - Les articles 8 à 12 de la Loi sur la procréation assistée, L.C. 2004, ch.2, excèdent-ils, en tout ou en partie, la compétence du Parlement du Canada en vertu de la Loi constitutionelle de 1867?
  - Les articles 8 à 19, 40 à 53, 60, 61 et 68 de la Loi sur la procréation assistée, L.C. 2004, ch.2, excèdent-ils, en tout ou en partie, la compétence du Parlement du Canada en vertu de la Loi constitutionelle de 1867?

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## **Constitutional challenge**

- June 2008, the Quebec Court of Appeal found in favour of the Attorney General of Quebec
- December 2010, the Supreme Court of Canada issued its ruling: Reference re Assisted Human Reproduction Act
  - Sections 10, 11, 13, 14 to 18, 40(2), (3), (3.1), (4) and (5) and ss. 44(2) and (3) were struck down by the court (and repealed in 2012)

VERS

# Information to be collected by licensees

 14. (1) A licensee shall not accept the donation of human reproductive material or an in vitro embryo from any person for the purpose of a controlled activity, and shall not perform a controlled activity on any person, unless the licensee has obtained from that person the health reporting information required to be collected under the regulations

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#### Information to persons undergoing procedures

• **15.** (4) Before performing an assisted reproduction procedure that makes use of human reproductive material or an in vitro embryo, a licensee shall disclose to the person undergoing the procedure the health reporting information in its possession respecting the donor, but the identity of the donor — or information that can reasonably be expected to be used in the identification of the donor shall not be disclosed without the donor's written consent.

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#### **Destruction of information**

• **16.** (2) A licensee or any other person that has control of the health reporting information provided by a donor of human reproductive material or an in vitro embryo, by a person who has undergone an assisted reproduction procedure or by a person who was conceived by means of such a procedure shall, at the request of the donor or that person, as the case may be, destroy that information in the circumstances and *to the extent provided by the regulations*, and shall inform the donor or that person that the destruction has occurred.

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#### Personal health information registry

 17. The Agency shall maintain a personal health information registry containing health reporting information about donors of human reproductive material and in vitro embryos, persons who undergo assisted reproduction procedures and persons conceived by means of those procedures.

#### **Consent to disclosure**

• **18.** (2) Notwithstanding section 8 of the *Privacy* Act but subject to subsections (3) to (8), health reporting information under the control of the Agency relating to a donor of human reproductive material or an in vitro embryo, a person who has undergone an assisted reproduction procedure or a person who was conceived by means of such a procedure is confidential and shall be disclosed only with the written consent of the donor or that person, as the case may be.

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#### Meanwhile ...

- <u>Pratten v. British Columbia (Attorney General)</u>, 2010 BCSC 1444 (CanLII) — 2010-10-15 Supreme Court of British Columbia — British Columbia
- <u>Pratten v. British Columbia (Attorney General)</u>, 2011 BCSC 656 (CanLII) — 2011-05-19 Supreme Court of British Columbia — British Columbia
- <u>Pratten v. British Columbia (Attorney General)</u>, 2012 BCCA 480 (CanLII) 2012-11-27 Court of Appeal British Columbia
- <u>Olivia Pratten v. Attorney General of British Columbia, et al.</u>, 2013
  CanLII 30404 (SCC) 2013-05-30 Supreme Court of Canada -Applications for Leave — Canada (Federal)

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## Judgment

 The application for leave to appeal from the judgment of the Court of Appeal for British Columbia (Vancouver), Number CA039124, 2012 BCCA 480, dated November 27, 2012, is dismissed without costs.

#### The future

- Continued use of anonymously donated sperm (no personal information available to donor-conceived person)
- Voluntary use of "known donors" or "open identity donors" (increasing preference for use of known or open-i.d. donors)

# What is in the best interests of children?

- From whose perspective?
- Based on what data?
- Is the real issue the value of "secrecy" or the risk(s) to parentage?

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