

## Critics demand change at reproductive health agency

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A federal agency created to safeguard Canadians' reproductive health is generating a firestorm of criticism after the resignation of key directors and the board's acknowledgment that it cannot fulfill its mandate.

But in a combative session of the Parliamentary Standing Committee on Health on June 14, Health Minister Leona Aglukkaq said a case before the Supreme Court of Canada is hampering Assisted Human Reproduction Canada from implementing the "full scope" of the legislation it was set up to enforce.

Although the agency was created in January 2006 and has a budget of more than \$10 million per year, it has not yet begun to enforce critical aspects of the Assisted Human Reproduction Act, such as prohibitions on the sale of human eggs and sperm or payments for surrogates.

The agency's board, headed by Dr. John Hamm, former premier of Nova Scotia, has said it cannot carry out many of its responsibilities because it is waiting for Health Canada to draft regulations to accompany the legislation.

But Health Canada says it cannot draft those regulations until the Supreme Court rules on a Quebec case challenging the constitutionality of the agency's enabling legislation on the grounds that intrudes upon provincial jurisdiction over health care.

"Out of respect for the Supreme Court of Canada, we are waiting for the decision ... before we can go on to develop the regulations," Aglukkaq told the committee.

That prompted Dr. Carolyn Bennett, once minister of state for public health under the previous Liberal government, to ask Aglukkaq to disband the board or the agency. "How can you defend \$10 million to the people of Canada when your department has not yet been able to get the regulations there that your agency is supposed to be enforcing?" asked Bennett, who also casti-



Reuters/Kim Kyung Hoon

Representatives of patient groups say that the four-year-old agency charged with oversight of assisted human reproduction in Canada has done nothing to protect the health and safety of people who access the treatment, or the children born from them.

gated Aglukkaq for spending the first hour of the meeting being briefed, instead of appearing for questioning.

"Do you have any idea of disbanding the agency until you maybe have new legislation with regulations that would actually serve the couples forming families in this country? Somehow we don't seem to be looking after the people for whom this legislation was developed," Bennett added.

Bennett also urged that the agency's budget be officially slashed, since its president, Elinor Wilson, has already voluntarily cut spending to about \$5 million per year in the absence of the regulations.

But Aglukkaq nixed those options. "Disbanding the board and the agency is not on the table at this point in time and I don't see that in the future."

In a bid to ascertain the rationale behind the resignation of three board members — Barbara Slater, a former Ontario bureaucrat; Francoise Baylis, Canada Canada Research Chair in

Bioethics and Philosophy at Dalhousie University in Halifax, Nova Scotia; and Irene Ryll, a patient advocate in Edmonton, Alberta — New Democrat MP Megan Leslie asked Wilson to table the minutes of agency board meetings. She also asked Hamm and the board to extend the scope of an ongoing audit of agency finances.

"We know that three members of the board have resigned. The minister, in questioning about this, insists they resigned for 'personal reasons'," Leslie said. "I do know that these three members are very committed to the issue, so it does raise some suspicions for me ... I am left with a lot of questions, so things don't seem to add up."

Neither Wilson nor Hamm offered explanations for the resignations to the committee, while Hamm was "unavailable" to field CMAJ inquiries.

Ryll, who runs a patient support group in Edmonton, was surprised to hear Aglukkaq tell Parliament that she resigned for "individual reasons."

In fact, Ryll says she resigned on May 30 because “I could not continue serving the Canadian public on a board I’ve lost trust in.”

Ryll adds that she’s precluded by a confidentiality agreement from revealing details about what caused her to lose that trust. But one of her concerns revolved around a response she received to a request for information she believed necessary to doing her job.

“I definitely encountered difficulties as a board member in receiving that kind of information,” she says, adding that all Canadians need assurance of the agency’s transparency, accountability and value for money.

Ryll, Slater and Baylis have indicated that they could be forthcoming about the reasons for their resignations if compelled to testify by the Commons committee.

Diane Allen, president of the patient group Infertility Awareness Association, urges that be done. “It irritates me to no end that these people are bound by government oaths of secrecy,” she says.

Allen also decries agency inaction. In addition to failing to regulate and license fertility clinics adequately, the agency has not set up information registries, such as one that could link donors to their offspring and one to track health outcomes of patients, she says, adding that if the current board can’t carry out its responsibilities, the government should appoint one that can.

“I would like to go back to the very good intent of the legislation — to protect the health and safety of people who access the treatments and the children who are born from them,” Allen says. “If this board of directors and this management can’t — or perhaps won’t —

do it, then they ought to be replaced with ones who will. Because otherwise, we’re failing those patients and their children and we’re making the law look like an ass.”

Dr. Patricia Baird, who chaired the Royal Commission on New Reproductive Technologies that paved the way for both the legislation and the agency, told a Queen’s University convocation ceremony earlier in June that she was “disappointed” that four years later, “not much has changed in practice, except that there are more clinics and more new procedures than there used to be.”

“The agency is not effective,” Baird said. “It has yet to license a single clinic, and for example, human eggs are being bought and sold in Canada.” — Laura Eggertson, Ottawa, Ont.

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