OUR BODIES OURSELVES
information inspires action

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Katherine Ceroalo
New York State Department of Health
Bureau of Program Counsel, Regulatory Affairs Unit
Corning Tower Building, Rm. 2438
Albany, New York 12237

Dear Ms. Ceroalo:

Our Bodies Ourselves (OBOS) has for decades provided evidence-based information to the public on pregnancy, birth, and infertility, advocated for LGBTQ rights, and been actively engaged in emerging issues in assisted reproduction, genetics, and public health. We have paid particular attention to possible risks to women's health arising with assisted reproductive technologies and related contractual arrangements, as well as their potential impact on future generations of children.

As advocates of women's health and reproductive rights for 50 years, we are writing to express our deep concern with a number of problematic issues in the Department of Health's recently posted guidelines on gestational surrogacy in New York State. The New York Department of Health's guidelines are similarly problematic to the Child-Parent Security Act, which Governor Cuomo passed without discussion last spring when the attention of policy makers, women's health advocates, and the general public was dominated by the global Covid pandemic. Rather than passing a law that could have been a model for the country, the Governor's undemocratic process left New York State with legislation that puts at risk the health of gestational surrogates, egg providers, and children born through surrogacy.

As protector of the public health, it is incumbent on the Department of Health (DOH) to address flaws and omissions in the law by providing information that will serve to safeguard the health and rights of all parties in surrogacy arrangements. At present, the DOH guidelines fall short in the ways outlined below.

The health and rights of gestational surrogates
The guidelines do not adequately convey risks to gestational surrogates and mislead by stating that "there are health risks to the surrogate as with any pregnancy." In fact, particular practices common in surrogacy result in health risks to surrogates that are greater than in "any pregnancy," and for this reason informed consent must be particularly rigorous. Further, the DOH guidelines should present full and evidence-based information on best health practices. Instead:

- The Surrogates' Bill of Rights allows surrogates to accede to medically unnecessary cesarean section and multiple embryo transfer, going against ACOG recommendations for best practice. Like prospective mothers in general, gestational mothers should be able to benefit from best practices, and because many are not aware of them, information on this should be made abundantly clear in the guidelines.

- There is no specific recommendation that all health-related decisions be made in consultation with the surrogate's independent physician. This should be made explicit so that the surrogate has the benefit of expert opinion on best practice in all health matters.
- While surrogates can make decisions about particular "health and welfare" issues, there is no broader allowance for her agency in behavior, freedom of movement, or daily activities (e.g., diet, exercise, travel). Because staying physically active, emotionally/socially engaged, and individually empowered are the hallmarks of a healthy pregnancy, this agency is essential and should receive explicit mention. If it does not, surrogates' movements and behavior are open to excessive control by others.
- The recommended age range for surrogates (21 – 45 years) does not take into consideration ACOG's definition of advanced maternal age. If surrogates are over 35, these women need to be explicitly informed about the risks of pregnancy at advanced material age, especially alongside the additional risks of gestational surrogacy.

The health and rights of egg providers

Though often under-protected in surrogacy legislation, egg providers are key participants in gestational surrogacy arrangements. Given the known and unknown risks in the process of egg retrieval, these healthy young women deserve to know what they are signing up for and to give informed consent – to the extent it is possible. And given that the surrogacy law includes no Egg Provider Bill of Rights (comparable to the Surrogates' Bill of Rights) and no provision for medical coverage for complications resulting from the procedure, the DOH has an added responsibility to provide full and transparent information to egg providers on these risks. Unfortunately, the egg provider section of the DOH guidelines is insufficient in this regard, as it is missing numerous essential elements outlined below.

- The DOH guidance does not include a list of short and long term risks associated with egg donation, including the fact that there is, at present, scarce research data on long-term impact. This is exacerbated by an inadequate description of the informed consent process itself, which should include a full discussion of known and unknown risks to current and future health.
- There is no list of recommendations for best practices in egg retrieval, including limits on the number of eggs retrieved, the number of cycles a donor may undergo, and use of a low-stimulation protocol.
- No special attention is given to the common risk of ovarian hyperstimulation syndrome (OHSS). The guidelines should include a recommendation for controlling the levels of hormonal stimulation to avoid the risk of OHSS, possibly including a cap on the dosage of gonadotropins administered.
- There is no mention of medical contraindications for egg donation, including prior history of ovarian hyperstimulation syndrome, polycystic ovarian syndrome, endometriosis, or family history of reproductive cancers.
- There is no mention of the possibility that unused eggs might be used for research purposes – something egg providers need to know when they agree to provide their eggs.
- The NY DOH website provides a document titled *The Guidelines for Assisted Reproductive Technology Service Providers*, which says that the tissue bank "must mitigate risks to the eventual recipient(s)" of the donated egg. Disturbingly, both this document and the DOH website fall short by not mentioning mitigating risks to the egg provider herself.

- There is no recommendation that egg providers should retain separate legal counsel to negotiate their contract and that costs for this counsel should be covered by the intended parents. Like gestational surrogates, egg providers should have this legal protection while they consider and participate in surrogacy arrangements.

The health and rights of future children born through surrogacy

The best practices discussed above for gestational surrogates will clearly also be essential in ensuring the health of future children born through surrogacy. Unfortunately, as previously mentioned, the DOH guidelines should, but do not, include recommendations for using single embryo transfer and for utilizing cesarean section *only* when medically necessary. This puts future offspring at considerable health risk.

In addition, the Child-Parent Security Act (CPSA) has shortchanged the rights of children born through surrogacy:

- There is no provision for them to access their original birth certificate, even upon reaching the age of majority, which is in direct contradiction with NY State adoption law; and
- They cannot access information from the ART Registry regarding the health and medical conditions of their conception, gestation, and birth.

Although little is known about the impact of contractual surrogacy on children regarding their origins and identity, lessons from other fields may help forge a path forward. Advocates of adoption reform, for example, have addressed the importance of access to medical information, birth records and birth stories. The Donor Sibling Registry, founded in 2000 to support donor-conceived children, now includes more than 62,000 members. The organization assists individuals born as a result of sperm, egg, or embryo donation who are seeking to make mutually desired contact with others with whom they share genetic ties. New York State law and public health guidelines should strive to stay current with this growing and vital sector of the public voice.

Proscription of heritable human genome editing

On a more far-reaching issue, the DOH guidelines provide an important opportunity – albeit a missed one – to educate and reinforce the bright line proscribing heritable genome editing (or human germline modification). The Child-Parent Security Act does include in its definition of “gamete” a proscription on nuclear DNA that has been deliberately altered, as well as a proscription on combining nuclear DNA from one human with the cytoplasmic DNA of another human (3-person IVF). Given that use of these emerging and very controversial technologies would impact all subsequent generations, they require a robust public debate and taking every opportunity to begin this discourse is critically important.

Concerns with the ART Registry

Our Bodies Ourselves has for a long time worked to help establish a mandatory registry to collect safety data and allow for long term follow up of egg providers and surrogates. While we welcome the establishment of a registry in New State through the CPSA, the proposed model lacks several components that would give it teeth, as follows:

- The proposed registry is essentially a voluntary SART-type database that will include anonymous cycle-specific information. This level of information should be mandatory, as should collection of surrogates’ and egg donors’ prior health histories, as compiled during the screening process.

- The registry should include a full reporting of all complications encountered during the surrogacy/donation process, including ovarian hyperstimulation syndrome and adverse pregnancy outcomes.
- Surrogates and egg donors should be offered the option to update their health information, including health outcomes that may relate to the procedures they underwent or that may be relevant to the future offspring they may produce.
- Surrogates and egg donors should be offered the option to make their identities known to future offspring when they reach the age of majority.
- Surrogates and egg donors should be offered the option to provide information so that they may be contacted for future research.
- Offspring born from surrogacy and egg donation arrangements should have access to their surrogate's/donor's registry data when they reach the age of majority.

In conclusion, the Child-Parent Security Act has many unfortunate and problematic provisions. It missed an historic opportunity to correct unsound practices in an insufficiently regulated field, put in place protections for the health and rights of *all* participants to surrogacy arrangements, and develop a national (and perhaps global) model in still uncharted legal waters. Because of flaws in the New York law, the Department of Health has a special obligation to inform and safeguard all participants in surrogacy arrangements with full, clear information and best practice recommendations.

Our Bodies Ourselves calls on the DOH to help ensure expanded options for family formation for everyone, protect the rights of intended parents pursuing these options, and *simultaneously*, to safeguard the health and rights of the women who make family formation through surrogacy possible – gestational mothers and egg providers. It goes without saying that the health and well-being of future children born of these arrangements is a primary concern for all involved and we all need to step up and do right by them.

Sincerely,

Judy Norsigian

Gloria Steinem

Judy Norsigian, Board Chair

Gloria Steinem, Advisory Board member and New York Resident