

Date of Hearing: May 18, 2022

ASSEMBLY COMMITTEE ON APPROPRIATIONS

Chris Holden, Chair

AB 1896 (Quirk) – As Amended April 21, 2022

Policy Committee: Health

Vote: 13 - 0

Urgency: No

State Mandated Local Program: No

Reimbursable: No

**SUMMARY:**

This bill requires a licensed gamete bank to provide specified information to individuals obtaining donor gametes to conceive a child, including information on 1) the risk of consanguineous relationships between half-siblings or closely related individuals that result in children, 2) genetic diseases and disease risk factors a donor-conceived child may inherit from a sperm donor, 3) how large donor-sibling groups could occur as a result of a lack of tracking or limits on sperm donation use and 4) ways to mitigate the potential genetic, psychological, and social risks faced by donor-conceived individuals. This bill requires the Department of Public Health (DPH), in consultation with stakeholders, to develop the information and guidance for gamete banks to provide to individuals obtaining donor gametes. This bill also requires a gamete bank to inform prospective gamete donors of the potential of genetic technologies to reveal the relatedness of the donor to children conceived with the donor's gametes. This bill authorizes DPH to suspend or revoke the license of a gamete bank that violates the requirements in this bill.

**FISCAL EFFECT:**

Estimated General Fund (GF) costs to DPH in the low hundreds of thousands of dollars over fiscal year (FY) 2022-23 and FY 2023-24 to convene a stakeholder group, develop the information for gamete banks to distribute and promulgate regulations. Ongoing GF costs of approximately \$100,000 annually to DPH to enforce the provisions of this bill.

**COMMENTS:**

- 1) **Purpose.** According to the author, discussions around assistive reproductive technologies have overlooked effects on those who have the least say in the matter, but are most impacted: donor-conceived people (DCP). A lack of regulation and data collection has resulted in sperm banks using donations to produce dozens of, even more than 100, children. Such large donor-sibling groups greatly increase the social, psychological and genetic harms and risks on DCP. The author cautions that an unusually large number of half-siblings who are close in socioeconomic background, age and location may lead to unwitting intimate relationships between half-siblings or closely related individuals, and children born of such relationships are at greatly elevated risk of genetic disease.
- 2) **Existing State Requirements for Gamete Banks.** Under California law, a gamete bank is defined as a tissue bank that collects, processes, stores or distributes gametes, including a facility that provides professional reproductive services, other than those facilities exempt from tissue bank licensure. Current law requires a gamete bank to collect and retain from a

gamete donor the donor's identifying information and medical information at the time of the donation. A gamete bank must also provide the donor with information about the donor's choice regarding identity disclosure, obtain a declaration from the donor regarding identity disclosure and maintain identifying information and medical information about each gamete donor. A gamete bank is also required to give a donor the choice to sign an attested declaration stating the donor either agrees to disclose the donor's identity to a child conceived using the donor's gametes, on request, once the child attains 18 years of age; or, does not agree to disclose the donor's identity to the child, but permits a withdrawal of this declaration at any time.

A gamete bank, upon request of a DCP who is at least 18 years of age, is required to provide the DCP with identifying information of the donor who provided the gametes, unless the donor signed and did not withdraw a declaration for nondisclosure. A gamete bank is required to make a good faith effort to notify the donor of their ability to withdraw a prior nondisclosure declaration and agree to release the donor's information. Additionally, a gamete bank that received gametes from another gamete bank is required to disclose the name, address, telephone number and email address of the gamete bank that provided the gametes. Upon request by a DCP who is 18 years of age, or by the guardian or parent of a donor-conceived child, a gamete bank must provide access to nonidentifying medical information provided by the donor.

**Analysis Prepared by:** Allegra Kim / APPR. / (916) 319-2081