United States Senate

WASHINGTON, DC 20510

September 19, 2022

Jor-El Godsey President Heartbeat International 8405 Pulsar Place Columbus, OH 43240

Dear Mr. Godsey:

We write to express our concerns about the sensitive health information Heartbeat International and its affiliate crisis pregnancy centers (CPCs) collect from women who misleadingly believe they can seek legitimate abortion and reproductive health care services at more than 2,000 affiliate CPC facilities in the United States. After luring pregnant people – many in desperate situations – to affiliate CPC facilities by using a variety of false and misleading tactics, Heartbeat International then collects a significant amount of their personal health care information, which in many cases does not appear to be protected by the *Health Insurance Portability and Accountability Act* (HIPAA). We fear that, in the wake of the Supreme Court's *Dobbs v. Jackson Women's Health Organization* decision that stripped women of their right to an abortion, this information may be used to put women's health and freedom to choose in jeopardy, and to put them and their health care providers at risk of criminal penalties.

Heartbeat International explicitly states that its vision "is to make abortion unwanted today and unthinkable for future generations." To accomplish that goal, it invested in data collection and in 2017 created a database called the "Next Level Content Management Solution" (Next Level CMS)³ to keep track of people that contact Heartbeat International or any affiliate CPCs. Next Level CMS' website states that it "harnesses the power of big data" to "[make] sure that no client ever falls through the cracks from the moment you say 'Hello."

Often, when people contact or visit a CPC, they share personal information, including their name, address, and phone number, and more private information such as "sexual and reproductive histories, test results, [and] ultrasound photos." Next Level CMS is a one-stop shop for storing that data, and you promote services such as a Client Risk Tracker, which "keep[s]

¹ Over 3,000 affiliated pregnancy help locations worldwide and over 971 affiliate locations outside of the United States; Heartbeat International, "Heartbeat International," https://www.heartbeatservices.org/services-home; Heartbeat International, "International Affiliates," https://www.heartbeatinternational.org/international.

² Heartbeat International, "Heartbeat International," https://www.heartbeatinternational.org/.

³ Privacy International, "How anti-abortion activism is exploiting data," July 22, 2019, https://privacyinternational.org/long-read/3096/how-anti-abortion-activism-exploiting-data; Pregnancy Help News, "How Every Pregnancy Center Can Make the Most of 'Big Data," Heartbeat International, April 23, 2017, https://pregnancyhelpnews.com/next-level.

⁴ Next Level Center Management Solution, "About Us," https://www.nextlevelcms.com/about-us.

⁵ Time, "Anti-Abortion Pregnancy Centers Are Collecting Troves of Data That Could Be Weaponized Against Women," Abigail Abrams and Vera Bergengruen, June 22, 2022, https://time.com/6189528/anti-abortion-pregnancy-centers-collect-data-investigation/.

[CPCs] up to speed on each individual woman's anticipated risk level" for obtaining an abortion. In addition to Next Level CMS, you have also marketed a 24/7 hotline, Option Line, which has fielded calls – and collected data – from more than five million women. It is deeply troubling that your organization has provided limited clarity, or no clarity whatsoever, about "how the data [it collects] is used [and] stored, and for how long."8

Patient data privacy has become a significant concern in the aftermath of the Supreme Court's decision in Dobbs v. Jackson Women's Health Organization, with advocates worried that, in states that have banned or severely restricted abortion, "the CPC industry is now functioning as surveillance infrastructure for the anti-abortion movement, amassing data that could be used in pregnancy- and abortion-related prosecutions post-Roe." Because your organization and its affiliate CPCs are not legitimate medical providers, they are not subject to federal health data privacy laws like HIPAA, which protects "sensitive patient health information from being disclosed without the patient's consent or knowledge." Heartbeat International – which is explicitly opposed to abortion rights – appears to be in a position to collect a significant amount of personal information from women about their pregnancies and potential plans for managing their care, but it is not under any legal obligation to maintain the confidentiality of this information, or keep it out of the hands of abortion bounty hunters.

While your organization and many of its affiliate CPCs claim to adhere to HIPAA to protect patients' health information, 11 it does not disclose how it is using the data it collects, whether it is keeping personal information secure, and whether it intends to do so in the future. Heartbeat International promotes websites that have inaccurate claims, including that CPCs "use intake forms as a type of confidentiality agreement, which grants the woman confidentiality protections like she would receive under HIPAA. In other words, they 'resemble' HIPAA forms because they act like HIPAA forms." ¹² But these forms do not offer the same protections as HIPAA. ¹³ This is deeply concerning, especially as recent reports by privacy experts have highlighted the threats posed by abortion bounty hunter laws and emphasized that "pregnant people's digital

⁶ Next Level Center Management Solution, "CMS Overview," <u>https://www.nextlevelcms.com/overview</u>.

⁷ Heartbeat International, "Option Line," https://www.heartbeatinternational.org/our-work/option-line.

⁸ Privacy International, "How anti-abortion activism is exploiting data," July 22, 2019, https://privacyinternational.org/long-read/3096/how-anti-abortion-activism-exploiting-data.

⁹ The Alliance, "The CPC Industry as a Surveillance Tool of the Post-*Roe* State," February 2022, https://alliancestateadvocates.org/wp-content/uploads/sites/107/Alliance CPC Report Feb2022 UrgentBrief2-10-22.pdf.

¹⁰ Time, "Anti-Abortion Pregnancy Centers Are Collecting Troves of Data That Could Be Weaponized Against Women," Abigail Abrams and Vera Bergengruen, June 22, 2022, https://time.com/6189528/anti-abortionpregnancy-centers-collect-data-investigation/; CDC, "Health Information & Privacy: FERPA and HIPAA," https://www.cdc.gov/phlp/publications/topic/healthinformationprivacy.html.

¹¹ Next Level Center Management Solution, "Frequently Asked Questions," https://www.nextlevelcms.com/fag; Pregnancy Center Truth, "THE TRUTH ABOUT PREGNANCY CENTERS," https://pregnancycentertruth.com/the-truth/pregnancy-centers.

¹² Tweet by Heartbeat Int'l on June 28, 2022, https://twitter.com/HeartbeatIntl/status/1542183824779517952? s=20&t=JAD2T5UQDJWUS4-8arLyAQ; Pregnancy Center Truth, "THE TRUTH ABOUT PREGNANCY CENTERS," https://pregnancycentertruth.com/the-truth/pregnancy-centers.

¹³ AMA Journal of Ethics, "Why Crisis Pregnancy Centers Are Legal but Unethical," Amy G. Bryant and Jonas J. Swartz, March 2018, https://journalofethics.ama-assn.org/article/why-crisis-pregnancy-centers-are-legal-unethical/ <u>2018-03</u>.

lives will be under the microscope."¹⁴ There have already been alarming cases where digital trails were used as evidence by prosecutors, ¹⁵ and we are concerned that the lack of transparency and lack of protection will allow the data Heartbeat International and its affiliates collect to "be used in pregnancy- and abortion-related prosecutions."¹⁶

Given our concerns about Heartbeat International's misleading practices, the information the organization and affiliates collect on pregnant people and those seeking information about abortions, and the lack of legal protections for this data, we request that you provide answers to the following questions no later than October 3, 2022:

- 1. What categories of information are collected for individuals that contact or visit Heartbeat International or affiliate CPCs, including through Option Line?
 - a. Do you obtain information on individuals' sexual histories?
 - b. Do you obtain information on individuals' pregnancy status?
 - c. Do you obtain information on whether these individuals may be considering abortions or seeking abortions?
- 2. Is any of the information Heartbeat International collects subject to HIPAA or other medical privacy laws?
- 3. Please describe Heartbeat International's guidelines for handling people's personal information or sensitive reproductive health data and provide a written copy of these guidelines.
 - a. How does Heartbeat International use the personal information it collects?
 - b. How long does Heartbeat International, or platforms it runs (including Next Level CMS), hold on to people's data?
 - c. How does Heartbeat International ensure these data are safe and secure?
 - d. Does Heartbeat International share people's data with anyone? If yes, with whom?
 - i. Has Heartbeat International ever shared people's data with law enforcement? If so, under what circumstances?
 - ii. Has Heartbeat International ever provided this information to any private citizen or other third party entity?
 - iii. Has Heartbeat International ever made this information public?
 - iv. Has Heartbeat International ever sold these data to any entity? If so, which entity, and under what circumstances were the data sold?
- 4. Have law enforcement officials ever required your organization (including Option Line, Extend Web Services, and Next Level CMS) to turn over an individual's data, including information on reproductive health care, pursuant to a subpoena, court order, or other methods of compulsory process?
 - a. If yes, please provide a list of the times and circumstances in which your

¹⁴ Surveillance Technology Oversight Project, "Pregnancy Panopticon: Abortion Surveillance After *Roe*," Albert Fox Cahn and Eleni Manis, May 24, 2022, https://www.stopspying.org/pregnancy-panopticon.

¹⁵ The Markup, "After Dobbs, Advocates Fear School Surveillance Tools Could Put Teens at Risk," Todd Feathers, July 8, 2022, https://themarkup.org/privacy/2022/07/08/after-dobbs-advocates-fear-school-surveillance-tools-could-put-teens-at-risk.

¹⁶ The Alliance, "The CPC Industry as a Surveillance Tool of the Post-*Roe* State," February 2022, https://alliancestateadvocates.org/wp-content/uploads/sites/107/Alliance_CPC_Report_Feb2022_UrgentBrief2-10-22.pdf.

organization has provided such information to law enforcement officials.

Sincerely,

Elizabeth Warren

United States Senator

Mazie K. Hirono United States Senator

Cory A. Booker

United States Senator

Bernard Sanders

United States Senator

Ron Wyden

United States Senator

Edward J. Markey

United States Senator

Richard Blumenthal

United States Senator