SENATE JUDICIARY COMMITTEE
Senator Thomas Umberg, Chair
2025-2026 Regular Session

AB 1129 (Celeste Rodriguez)
Version: June 30, 2025
Hearing Date: July 15, 2025
Fiscal: No
Urgency: No
AWM

SUBJECT

Birth defects monitoring

DIGEST

This bill authorizes a county to establish a birth defects monitoring program under largely the same terms as the California Birth Defects Monitoring Program (CBDMP), and permits the CBDMP or a county monitoring program to collect data related to conditions that manifest within the first year after birth, as defined.

EXECUTIVE SUMMARY

Current law establishes the CBDMP within the California Department of Public Health (CDPH). The CBDMP currently operates within ten counties to collect information relating to babies born with birth defects, stillbirths, and miscarriages, for purposes of determining the causes of these issues, assisting research to prevent them, and connecting the families of babies born with birth defects to services. The CBDMP is subject to strict privacy controls, including provisions making all information collected under the program confidential, not subject to subpoena, and not admissible at trial.

This bill, sponsored by the County of Los Angeles and the March of Dimes, is intended to allow counties to develop their own countywide birth defects monitoring programs. The bill also permits the CBDMP or a county monitoring program to collect data relating to "conditions," which are defined as conditions affecting a person's health that occur during the first year after the person's birth. A county monitoring program developed under this bill would be limited to collecting information relating to births within the county, and would be subject to more stringent privacy restrictions than the CBDMP. The author has agreed to minor amendments to clarify the scope of a county program and the definition of "condition."

This bill is sponsored by the County of Los Angeles and the March of Dimes, and is supported by the American Academy of Pediatrics, California; Children Now; the

First 5 Association of California; and the Health Officers Association of California. The Committee has not received timely opposition to this bill. The Senate Health Committee passed this bill with a vote of 11-0.

PROPOSED CHANGES TO THE LAW

Existing law:

1) Establishes the State Birth Defects Monitoring Program (CBDMP). (Health & Saf. Code, div. 102, pt. 2, ch. 1, §§ 103825 et seq.)

2) States that the Legislature finds and declares the following:
    a) That birth defects, stillbirths, and miscarriages represent problems of public health importance about which too little is known.
    b) That these conditions lead to severe mental anguish on the part of parents and relatives and frequently to high medical care costs.
    c) That a system to obtain more information about these conditions could result in development of preventive measures to decrease their incidence in the future. (Health & Saf. Code, § 103825.)

3) States that it the intent of the Legislature, in enacting the CBDMP, to accomplish all of the following:
    a) To maintain an ongoing program of birth defects monitoring statewide; "birth defect" is defined as any medical problem of organ structure, function, or chemistry of possible genetic or prenatal origin.
    b) To provide information on the incidence, prevalence, and trends of birth defects, stillbirths, and miscarriages.
    c) To provide information to determine whether environmental hazards are associated with birth defects, stillbirths, and miscarriages.
    d) To provide information as to other possible causes of birth defects, stillbirths, and miscarriages.
    e) To develop prevention strategies for reducing the incidence of birth defects, stillbirths, and miscarriages.
    f) To conduct interview studies about the causes of birth defects.
    g) To affirm the authority of the CDPH to contract with a qualified entity to operate the birth defects monitoring program statewide. (Health & Saf. Code, § 103825.)

4) Requires the Director of the CDPH (Director) to maintain a system for the collection of information necessary to accomplish the purposes of the CBDMP, including requiring health facilities, with 15 days' notice, to make available to authorized program staff the medical records of children suspected or diagnosed as having birth defects, including the medical records of their mothers, and the medical records of mothers suspected or diagnosed with stillbirths or miscarriages, and

other records of persons who may serve as controls for interview studies about the causes of birth defects. (Health & Saf. Code, § 103830.)

5) Provides that the CBDMP shall operate statewide, and that it is the intent of the Legislature that the adequacy of program resources shall be assessed annually, with the assessment including a consideration of at least all of the following factors:
    a) The number of births in the state.
    b) The scope of program activities.
    c) Any urgent situation requiring extraordinary commitment of present or planned program staff or resources. (Health & Saf. Code, § 103835.)

6) Requires the Director to use the information collected pursuant to 4), and information available from other reporting systems and health providers, to conduct studies to investigate the causes of birth defects, stillbirths, and miscarriages and to determine and evaluate measures designed to prevent their occurrence; the CDPH's investigation of poor reproductive outcomes shall not be limited to geographic, temporal, or occupational associations, but may include investigation of past exposures. (Health & Saf. Code, § 103840.)

7) Requires the Director to appoint an advisory committee to advise on the implementation of the CBDMP; each of the disciplines of epidemiology, hospital administration, biostatistics, maternal and child health, and public health shall be represented on the committee, and at least one member shall be a representative of the manufacturing industry. (Health & Saf. Code, § 103845.)

8) Provides that all information collected pursuant to the CBDMP shall be confidential and used solely for the purposes of the program, as follows:
    a) Information collected is referred to as "confidential information."
    b) Access to confidential information is limited to authorized program staff, and persons with a valid scientific interest, who meet qualifications as determined by the Director, who are engaged in demographic, epidemiological, or other similar studies related to health, and who agree, in writing, to maintain confidentiality.
    c) The CDPH shall maintain an accurate record of all persons given access to confidential information, containing specified information; the record of access shall be open to public inspection during normal operating hours of the CDPH.
    d) Requires all research proposed to be conducted by persons other than program staff, using confidential information, shall first be reviewed and approved by the Director and the State Committee for the Protection of Human Subjects; a project that satisfies the Director's requirements permits the researcher to review the records collected pursuant to 4) and to contact case subjects and controls.

   e) Before confidential information is disclosed, the requesting entity shall demonstrate that the entity has established the procedures and ability to maintain the confidentiality of the information.
   f) Notwithstanding any other law, any authorized disclosure shall include only the information necessary for the stated purpose of the requested disclosure.
   g) The furnishing of confidential information to the CDPH or its authorized representative shall not expose any person, agency, or entity furnishing the information to liability, and shall not be considered a waiver of any privilege or a violation of a confidential relationship.
   h) Whenever the CBDMP, pursuing program objectives, deems it necessary to contact case subjects and controls, program staff shall submit a protocol describing the research to the Director and the State Committee for the Protection of Human Subjects; once the protocol is approved, program staff are entitled to contact case subjects and controls without securing additional approvals or waivers from any entity.
   i) Notwithstanding any other provision of law, no part of the confidential information shall be available for subpoena, nor shall it be disclosed, discoverable, or compelled to be produced in any civil, criminal, or administrative, or other proceeding, nor shall the information be deemed admissible in any proceeding for any reason.
   j) The CDPH may publish reports and statistical compilations relating to birth defects, stillbirth, or miscarriage that do not in any way identify individual cases or individual sources of information. (Health & Saf. Code, § 103850(a)-(g).)

9) Provides that any person who violates a written confidentiality agreement, discloses any information provided pursuant to 8), or who uses information provided pursuant to 8) other than as approved may be denied further access to confidential information maintained by the CDPH and shall be subject to a civil penalty of $500; this penalty does not restrict any other remedy, provisional or otherwise, provided by law for the benefit of the CDPH or any person. (Health & Saf. Code, § 103850(h).)

10) Provides that a person to whom confidential information pertains has access to their own information pursuant to the Information Practices Act of 1977 (Civ. Code, div. 3, pt. 4, tit. 1.8, ch. 1, §§ 1798 et seq.). (Health & Saf. Code, § 103850(i).)

11) Permits the CDPH to enter into a contract for the establishment and implementation of the CBDMP, pursuant to the following:
   a) The contract shall include provisions requiring full compliance with all the requirements of the CBDMP.
   b) The terms of the contract may be in excess of one year, but no longer than three years.
   c) Funds for the contract shall be allocated in accordance with the state Budget Act. (Health & Saf. Code, § 103855.)

12) Provides that the only funds from the Genetic Disease Testing Fund that may be used for the purpose of supporting the pregnancy blood sample storage, testing, and research activities of the CBDMP are those prenatal screening fees assessed and collected prior to the creation of the CBDMP specifically to support the program's activities. (Health & Saf. Code, § 124977.)

13) Requires the CBDMP to collect and store any umbilical cord blood samples it receives from hospitals for storage and research, which shall be funded with fees collected from researchers who have been approved by CDPH to conduct specified types of research. (Health & Saf. Code, § 124991.)

14) Provides that the CBDMP is part of the Maternal, Child, and Adolescent Health program (Health & Saf. Code, div. 106, pt. 2, ch. 1, art. 1, §§ 123225 et seq.). (Health & Saf. Code, § 125002.)

This bill:

1) Adds, to the scope of the CBDMP and the definition of "birth defect," "conditions," defined as conditions or disorders affecting an individual that occur during the 12-month period after an individual's birth or are later diagnosed to have occurred during the 12-month period after the individual's birth, in conformity with one or more of the following:
    a) The list of Birth Defect Descriptions for National Birth Defects Prevention Network Core, Recommended, and Extended Conditions issued by the federal Centers for Disease Control and Prevention (CDC).
    b) Medical eligibility for the California Children's Services Program or its High-Risk Infant Follow-Up (HRIF) Program.
    c) As dictated by the needs of, and response to, a public health or environmental emergency.

2) Defines, within the CBDMO, "reporting institutions" as health facilities, providers, and laboratories that regularly provide services for the diagnosis or treatment of birth defects or conditions, genetic counseling, or prenatal or general diagnostic services.

3) Adds, to the statement of intent relating to the CBDMP, a statement that it is the intent of the Legislature to affirm the authority of local health officers to monitor the prevalence and incidence of birth defects and conditions in their local health jurisdictions in order to supplement state efforts or in the absence of state efforts in their jurisdiction.

4) Permits a local health officer (LHO) to maintain a system for the collection of information necessary to accomplish the purposes of the CBDMP, subject to adequate funding.

5) Provides that information about birth defects and conditions may be reported using either of the following systems at the discretion of the Director or the LHO:
    a) A system that requires reporting institutions to make their records available for review and information collection by designated staff of the local program to monitor birth defects and conditions.
    b) A system that requires reporting institutions, including, but not limited to, providers and laboratories, to transmit specified data manually or electronically to the LHO.

6) Permits an LHO to require reporting through one of the methods under 5) or a hybrid of those systems; an LHO may not impede or contradict activities of the CBDMP in the LHO's jurisdiction, but may supplement the activities for local uses and purposes.

7) Provides that the birth defects and conditions to be reported in a local health jurisdiction shall be at the direction and the discretion of the LHO, subject to adequate funding; jurisdictions shall consider implementing the same reporting requirements and workflows currently used by reporting institutions and shall consider less-costly alternative methods if current reporting requirements and workflows would impose additional costs in comparison to alternative methods.

8) Provides that an LHO may collect information as described in 4)-7) only if it is unique demographic, diagnostic, or health data directly related to a birth defect or condition, unless the patient or their parent or guardian gives consent to the LHO for the collection of data; collected data shall be used consistently with existing purposes for the CBDMP or for the purpose of facilitating access to care for an individual with a birth defect or condition.

9) Permits an LHO to require reporting institution participation in reporting of birth defects and conditions, as needed, to address the needs of the local health jurisdiction, to supplement the CBDMP in jurisdictions where it is conducted, if needed, or for reporting of birth defects or conditions where there are no state birth defects monitoring activities.

10) Provides that an LHO may use reported information for similar purposes as the Director's authorized uses, and that the LHO's investigation of poor reproductive outcomes shall not be limited to geographic, temporal, or occupational associations, but may include investigation or past exposures.

11) Permits an LHO to use resources, subject to their availability, from their local health program representing the disciplines that must be represented in the CBDMP's advisory committee, to formulate sound policy and health orders for information collected regarding birth defects and conditions.

12) Applies the CBDMP's privacy requirements to an LHO engaging in a birth defects or conditioning monitoring program.

13) Provides that, notwithstanding any other law, an LHO may enter into contracts for the implementation of programs to monitor birth defects or conditions and to collect information regarding those defects or conditions in their jurisdiction.

14) Provides that funds from the Genetic Disease Testing Fund shall not be used to support information collection or research of birth defects or conditions in a local health jurisdiction initiated by the LHO.

15) Provides that the statute placing the CBDMP in the Maternal, Child, and Adolescent Health program does not apply to umbilical cord blood samples under the supervision of an LHO in a local health jurisdiction for the purpose of monitoring birth defects or conditions or for other purposes.

COMMENTS

1. Author's comment

According to the author:

> Achieving healthy communities is a multifaceted approach. Public health professionals and medical professionals play a vital role in making sure our communities are healthy, protected, and have access to care. Whenever possible, we must expand resources to support their roles in achieving healthy communities. Making improvements to healthcare needs and ensuring our communities are safe from environmental hazards entails evaluating the health data we collect and making sure we identify needs or gaps. One way The California Department of Public Health (CDPH) is doing so is by monitoring birth defects in the state through the California Birth Defects Monitoring Program (CBDMP). However, this program is restricted to just ten counties.
>
> AB 1129 expands on this program. Specifically, it gives local health jurisdictions the ability to implement a local birth defects and conditions reporting program should they choose to do so. This allows local health jurisdiction to collect their own data and improve services for families facing healthcare challenges. It builds upon the work that CDPH is doing and allows all counties to have the option to do monitoring

2. Background on the CBDMP

As explained by the Senate Health Committee's analysis of this bill:

> According to the Centers for Disease Control and Prevention (CDC) website, every 4.5 minutes a baby is born with a condition that affects the structure or function of their body, affecting one in every 33 babies born in the United States each year. They are also the leading cause of infant deaths, accounting for one in five (20%) of all infant deaths. Birth defects can occur during any stage of pregnancy with most occurring in the first three months of pregnancy, when the organs of the baby are forming. However, some birth defects do occur later in pregnancy as tissues and organs continue to develop. While medical advancements have greatly improved health and survival, many of these conditions are lifelong and require lifelong care. Birth defects can vary from mild to severe, and health outcomes and life expectancy depend on which body part is involved and how it is affected

The CBDMP was established to learn more about, and help prevent, birth defects. According to the CDPH:

> In 1982, California established a groundbreaking program for birth defects monitoring. CBDMP has since become a model for surveillance in other states and a worldwide leader in providing data for birth defects research. CBDMP's Registry database has information amassed from surveillance of over 25 years and 6.25 million births. We strive to gather data on a core group of conditions in a large representative sample of births.[1]

While the CBDMP is intended to be statewide, the program currently monitors ten counties—Fresno, Kern, Kings, Madera, Merced, Orange, San Diego, San Joaquin, Stanislaus, and Tulare[2]—which have approximately 30 percent of the births in California.[3] The CBDMP tracks birth defects with genetic and environmental causes,[4] and provides pregnancy outcome data for the pregnancy blood samples included in the California Biobank Program.[5]

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[1] CDPH, California Birth Defects Monitoring Program: About Us (Dec. 23, 2024) https://www.cdph.ca.gov/Programs/CFH/DGDS/Pages/cbdmp/about.aspx. All links in this analysis are current as of July 10, 2025.

[2] CDPH, California Birth Defects Monitoring Program Birth Defects Report Summary (Aug 29, 2024) https://www.cdph.ca.gov/Programs/CFH/DGDS/Pages/cbdmp/Birth-Defects-Report.aspx.

[3] CDPH, California Birth Defects Monitoring Program (Jun. 24, 2024) https://www.cdph.ca.gov/Programs/CFH/DGDS/Pages/cbdmp/default.aspx.

[4] CDPH: California Birth Defects Monitoring Program: Genetic and Environmental Factors (Nov. 17, 2021) https://www.cdph.ca.gov/Programs/CFH/DGDS/Pages/cbdmp/geneenvironmentinteraction.aspx.

[5] CDPH, California Birth Defects Monitoring Program (Jun. 24, 2024) https://www.cdph.ca.gov/Programs/CFH/DGDS/Pages/cbdmp/default.aspx.

3. The CBDMP's data collection and usage

Under the CBDMP, the Director of CDPH can require health facilities—which includes general acute care hospitals and physician-owned or operated clinics that regularly provide services for the diagnosis and treatment of birth defects, genetic counseling, or prenatal diagnostic services—to make health records available to CBDMP staff with 15 days' notice.[6] The specific records available to CBDMP staff include the medical records of children suspected or diagnosed as having a birth defect; the medical records of those children's mothers; the medical records of mothers suspected or diagnosed with stillbirths or miscarriages; and other records of persons who may serve as controls for interview studies about the causes of birth defects.[7]

The Director is required to use this information, as well as information available from other reporting systems and health providers, "to conduct studies to investigate the causes of birth defects, stillbirths, and miscarriages and to determine and evaluate measures designed to prevent their occurrence."[8] Additionally, the Director, in concert with the State Committee for the Protection of Human Subjects, may approve information collected by the CBDMP to be shared with persons conducting scientific research.[9] Any person or entity wishing to gain access to information collected by the CBDMP must agree to keep the information confidential, to use it only for the approved purpose, and to not disclose it further.[10]

Outside of these designated purposes, information collected by the CBDMP cannot be disclosed for any other purpose. CBDMP information is even exempted from disclosure pursuant to a subpoena, and is inadmissible as evidence in any civil, criminal, administrative, or other proceeding.[11] These provisions make the CBDMP an exception to California's Right to Truth-in-Evidence provision, which was put into place by the voters in 1982 and modified by the voters in 2008.[12] The Right to Truth-in-Evidence provision states that relevant evidence shall not be excluded in any criminal proceeding, except as provided by statute enacted by a two-thirds vote of the Legislature.[13]

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[6] Health & Saf. Code, § 103830.

[7] *Ibid.* The statute, which has not been amended since its 1995 enactment date, refers specifically to "mothers"; presumably it is interpreted to apply to any birthing parent. (*See ibid.*)

[8] *Id.*, § 103840.

[9] *Id.*, § 103850.

[10] *Id.*, § 103850(d).

[11] *Id.*, § 103850(g).

[12] *See* Cal. Const., art. I, § 28, added by Prop. 8, as approved by voters, Primary Elec. (Jun. 8, 1982) and amended by Prop. 9, as approved by voters, Gen Elec. (Nov. 4, 2008).

[13] Cal. Const., art. I, § 28(f)(2).

4. This bill authorizes a county health officer to conduct a countywide birth defects monitoring program and expands the types of conditions that may be monitored by the CBDMP or a county

This bill, sponsored by the County of Los Angeles and the March of Dimes, is intended to allow counties to develop their own countywide birth defects monitoring programs. The bill also permits the CBDMP or a county monitoring program to collect data relating to "conditions," as defined.

a. County birth defect monitoring programs

As noted above, 48 of California's 58 counties are not currently covered by the CBDMP. This bill would enable those excluded counties—as well as the covered 10, if they so choose—to collect data about birth defects in their own counties, including data relating to region-specific issues that may be caused by region-specific natural disasters or other emergencies. If a county local health official elects to establish such a program, the county can obtain health records from hospitals and other medical facilities within its jurisdiction under largely, but not identically, the same terms as the CBDMP. The author has agreed to minor amendments to clarify that a county program can access only those records generated within the county.

The bill's authorization for county programs is slightly more restrictive than the CBDMP's authorization. The distinctions include:

- If a local health officer wants to collect information about a patient with a birth defect or condition, but the information is not directly related to the birth defect or condition, the local health officer must obtain the consent of the patient or their parent or guardian.
- A local health officer establishing a county program need not establish an advisory committee to advise on the implementation of its monitoring program, but may use resources to work with persons in relevant disciplines to formulate sound policy and health orders for the information collected.
- A county program cannot contact individuals whose information was collected for research purposes.

Information collected by a county monitoring program, like information collected by the CBDMP, would not be producible pursuant to a subpoena and would not be admissible in court. Because this bill exempts information from the Right to Truth-in-Evidence provision, it requires a two-thirds vote.[14]

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[14] *See* Cal. Const., art. I, § 28.

b. Monitoring for "conditions"

This bill permits the CBDMP or a county monitoring program to monitor—in addition to birth defects, stillbirths, and miscarriage—"conditions," which is defined to include conditions or disorders affecting an individual that occur during the 12-month period after an individual's birth or are later diagnosed to have occurred during the 12-month period after the individual's birth, in conformity with one of the following:

- The list of Birth Defects Descriptions for National Birth Defects Prevention Network (NBDPN) Core, Recommended, and Extended Conditions issued by the CDC.
- Medical eligibility for the California Children's Services Program (CCSP) or its High-Risk Infant Follow-Up (HRIF) program.
- As dictated by the needs of, and response to, a public health or environmental emergency.

The current version of the NBDPN list of conditions includes conditions in nine categories: central nervous system, eye, ear, cardiovascular, orofacial, gastrointestinal, genitourinary, musculoskeletal, and chromosomal.[15] Medical eligibility for the CCSP and HRIF programs includes a number of types of diseases, disorders, and congenital anomalies.[16] According to information provided by the author, the birth defects listed in the NBDPN, CCSP, and HRIF have significant overlap. As currently in print, coverage for conditions arising from a public health or environmental emergency could encompass any event, whether or not declared; the author has agreed to amend the bill to clarify that the public health or environmental emergency must be an officially declared emergency by county officials.

According to the County of Los Angeles, one of the sponsors of the bill, this expanded definition is essential to help them track the full range of conditions that its population may face, including those arising from increasingly frequent environmental disasters:

> For instance, if this authority were currently available in Los Angeles County, we could utilize it to monitor the effects of the recent Los Angeles fires on births in the coming years to identify possible impacts of exposure to after-fire toxicity in air, water, or soil. Likewise, we could track birth-related incidents of cerebral palsy, an area of particular concern to our Board of Supervisors. Finally, we could monitor the incidence of Sickle Cell Disease (SCD) to ensure that families of infants diagnosed with SCD are enrolling in appropriate specialty care.

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[15] NBDPN, Birth Defects Descriptions (updated Mar. 21, 2021) pp. i-ii, *available at* https://nbdpn.org/wp-content/uploads/2024/07/Appendix_3_1_BirthDefectsDescriptions_2021MAR12_Rev.pdf.

[16] *See* Cal. Code Regs., tit. 22, §§ 41515.1-41515.9.

5. Privacy questions

This bill permits a county to collect the private health data of a child and the birthing parent. As with the CBDMP, there is no opt-out right that would allow a parent to decline to allow their information to be collected and stored by the county.

In the past, this Committee has taken a broadly favorable stance in favor of provisions that allow the collection of health data for public health purposes. In light of current events at the national level, however—including the federal government's data collection activities and the federal Secretary of Health and Human Service's eugenics-adjacent rhetoric— the collection of information related to birth defects merits extra scrutiny.

To be clear, there is no question that the sponsors have anything but the best intentions. Moreover, the bill imposes more privacy protections on a county birth defects monitoring program than are in place for the CBDMP. The parties involved are also further constrained under federal and state privacy laws. Accordingly, on balance, it appears that the benefit to the community from added data collection and research outweighs the risk posed by the chance that the federal government could use this information for unintended purposes.

6. Amendments

As noted above, the author has agreed to minor amendments to clarify the scope of a county birth defects monitoring project and the nature of conditions that may be monitored. The amendments are set forth below, subject to any nonsubstantive changes the Office of Legislative Counsel may make.

Amendment 1

On page 4, in line 12, insert "local" after "a"

Amendment 2

On page 4, in line 13, after "emergency" insert "declared by the county"

Amendment 3

On page 4, in line 24, after "information" insert "within the local health jurisdiction"

Amendment 4

On page 4, in line 29, after "institutions" insert "within the local health jurisdiction"

Amendment 5

On page 4, in line 33, after “institutions” insert “within the local health jurisdiction”

Amendment 6

On page 5, in lines 36-37, delete “institution participation” and insert “institutions within the local health jurisdiction to participate”

6. Arguments in support

According to the California Health Officers Association of California:

> This bill would allow, but not require, local health officers (LHOs) to make birth anomalies reportable in their jurisdictions and to monitor those conditions. While protecting patient privacy, assuring access to these data when appropriate would improve our awareness of these conditions and allow early intervention in the factors that contribute to birth anomalies. These data could also be used to inform policy to deliver equitable maternal and child health care statewide.

SUPPORT

County of Los Angeles (sponsor)
March of Dimes (sponsor)
American Academy of Pediatrics, California
Children Now
First 5 Association of California
Health Officers Association of California

OPPOSITION

None received

RELATED LEGISLATION

Pending legislation:

AB 1063 (Dixon, 2025) authorizes the CDPH to release a physical blood test taken from a newborn to law enforcement in response to a search warrant only if the objective of the warrant is to obtain the DNA of a missing person suspected to be the victim of a homicide, child abuse resulting in death, or manslaughter in order to compare the DNA to other samples in the Department of Justice Missing Persons DNA Database and to upload the sample for future identification of that person. AB 1063 is pending before the Assembly Health Committee.

AB 242 (Boerner, 2025) requires the CDPH to expand statewide screening of newborns to include screening for Duchenne muscular dystrophy no later than January 1, 2027. AB 242 is pending before the Assembly Appropriations Committee.

Prior legislation:

SB 1099 (Nguyen, Ch. 598, Stats. 2024) required the CDPH, beginning July 1, 2026, to provide five annual reports to the Legislature on its research activities, including the number of research projects utilizing residual screening samples from the CBDMP and the number of inheritable conditions identified by the original screening tests during the previous calendar year.

SB 625 (Nguyen, 2023) would have required the CDPH to provide information about its genetic disease testing program and to permit a parent or legal guardian to opt out of the retention or use of the newborn child's blood sample for medical research or to request the destruction of a residual screening specimen. SB 625 died in the Senate Appropriations Committee.

SB 883 (Roth, Ch. 604, Stats. 2022) extended the Umbilical Cord Blood Collection Program until January 1, 2027.

SB 41 (Umberg, Ch. 596, Stats. 2021) established the Genetic Information Privacy Act, providing additional protections for genetic data by regulating the collection, use, maintenance, and disclosure of such data.

PRIOR VOTES:

Senate Health Committee (Ayes 11, Noes 0)
Assembly Floor (Ayes 77, Noes 0)
Assembly Appropriations Committee (Ayes 12, Noes 0)
Assembly Health Committee (Ayes 13, Noes 0)

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