
A BILL FOR AN ACT

RELATING TO RARE DISEASES.

BE IT ENACTED BY THE LEGISLATURE OF THE STATE OF HAWAII:

1 SECTION 1. A rare disease, sometimes called an orphan
2 disease, is defined as a disease that affects fewer than two
3 hundred thousand people in the United States. There are more
4 than ten thousand known rare diseases affecting approximately
5 thirty million Americans, more than half of which are children.
6 Eight out of ten rare diseases have a genetic cause. In a 2019
7 paper, researchers found that seventy-two per cent of rare
8 diseases analyzed had a genetic origin and can also be
9 classified as genetic disorders. People with rare diseases face
10 many obstacles, including delays in obtaining an accurate
11 diagnosis, finding a health care provider with expertise in
12 their condition, and a lack of affordable access to therapies
13 and medication used to treat rare diseases which may result in
14 significant physical, mental, and financial challenges.

15 Furthermore, the legislature finds that velocardiofacial
16 syndrome (also known as 22q11 deletion syndrome or DiGeorge
17 syndrome) is a rare genetic disorder which affects feeding,



1 speech, and learning. Its characteristic features include a
2 cleft palate, heart defects, and distinct facial appearances.
3 Velocardiofacial syndrome is the most common syndrome associated
4 with a cleft palate. This syndrome affects the body by
5 targeting immune, endocrine, and neurological systems. It is
6 estimated that one in two thousand to five thousand children per
7 year are born with this condition. Children who suffer from
8 this syndrome need a multidisciplinary approach to solve their
9 medical problems.

10 The legislature finds a state-based advisory council
11 composed of qualified professionals and persons living with rare
12 diseases and their caregivers could educate or advise medical
13 professionals, government agencies, legislators, and the public
14 about rare diseases as an important public health issue, and
15 encourage research or support the development of new and better
16 policies to diagnose and treat rare diseases.

17 Twenty-nine states have established a Rare Disease Advisory
18 Council (RDAC). RDACs address the needs of rare patients and
19 families by giving stakeholders an opportunity to make
20 recommendations to state leaders on critical issues including



the need for increased awareness, diagnostic tools and access to affordable treatments and cures.

Accordingly, the purpose of this Act is to:

- (1) Establish a Rare Disease Advisory Council to increase awareness and effective medical intervention for rare diseases;
- (2) Establish the rare disease advisory council special fund;
- (3) Require the department of health and the department of education to incorporate the importance of annual physical examinations for children in programs and literature; and
- (4) Amend the insurance code to include coverage for individuals who are affected with velocardiofacial syndrome to provide better overall health outcomes.

SECTION 2. Chapter 321, Hawaii Revised Statutes, is amended by adding a new part to be appropriately designated and to read as follows:

"PART . RARE DISEASE ADVISORY COUNCIL

§321-A Rare disease advisory council; established. (a)

There is established within the department of health, a rare



1 disease advisory council to provide guidance and recommendations
2 to educate the public, the legislature and other government
3 agencies and departments, as appropriate, on the needs of
4 individuals with rare diseases living in Hawaii.

5 **§321-B Duties.** (a) The rare disease advisory council
6 shall conduct the following activities to benefit those impacted
7 by rare diseases in Hawaii:

8 (1) Convene public hearings, make inquiries, and solicit
9 comments from the general public in Hawaii to assist
10 the council with a first-year landscape or survey of
11 the needs of rare disease patients, caregivers, and
12 providers in the state.

13 (2) Consult with experts on rare diseases to develop
14 policy recommendations to improve patient access to,
15 and quality of, rare disease specialists, affordable
16 and comprehensive health care coverage, relevant
17 diagnostics, timely treatment, and other needed
18 services.

19 (3) Evaluate and make recommendations to improve Medicaid
20 and state regulated private health insurance coverage
21 of drugs for rare disease patients, including



1 engagement with the state pharmacy and therapeutics
2 committee, to improve coverage of diagnostics, and
3 facilitate access to necessary healthcare providers
4 with expertise in the treatment of rare diseases.

5 (4) Identify areas of unmet need for research and
6 opportunities for collaboration across stakeholders,
7 and other state rare disease advisory councils that
8 can inform future studies and work done by the
9 council.

10 (5) Identify and distribute educational resources for
11 health care providers to foster recognition and
12 optimize treatment of rare diseases in Hawaii.

13 (6) Research and identify best practices to reduce health
14 disparities and achieve health equity in the research,
15 diagnosis and treatment of rare disease in Hawaii.

16 **§321-C Chairperson; members.** (a) The rare disease
17 advisory council's appointment process shall be conducted in a
18 transparent manner to provide interested individuals an
19 opportunity to apply for membership on the council. All members
20 of the council shall be full-time residents of Hawaii as
21 practicable. Membership shall include a diverse set of



1 stakeholders representative of the geographic and population
2 diversity of the state. All four counties in Hawaii should have
3 at least one representative on the council.

4 (b) The governor shall appoint the chairperson of the
5 council within thirty days of enactment. The chairperson shall
6 not hold any position within the government of Hawaii.

7 (c) The chairperson shall appoint no fewer than sixteen
8 members, with priority given to including the following members:

9 (1) One representative from University of Hawaii systems
10 that receives any grant funding for rare disease
11 research;

12 (2) One representative from the department of health
13 office of health equity;

14 (3) One representative from the department of health and
15 human services Med-Quest division;

16 (4) One representative from the department of commerce and
17 consumer advocacy insurance division;

18 (5) One registered nurse or advanced practice registered
19 nurse licensed and practicing in Hawaii with
20 experience treating rare diseases;



- 1 (6) One physician practicing in Hawaii with experience
- 2 treating rare diseases;
- 3 (7) One geneticist or genetic counselor;
- 4 (8) One hospital administrator, or their designee, from a
- 5 hospital in Hawaii that provide care to persons
- 6 diagnosed with a rare disease;
- 7 (9) At least two patients who have a rare disease;
- 8 (10) At least one caregiver of a person with a rare
- 9 disease;
- 10 (11) One representative of a rare disease patient
- 11 organization that operates in Hawaii;
- 12 (12) A pharmacist with experience dispensing drugs used to
- 13 treat rare diseases;
- 14 (13) A representative of the biopharma industry;
- 15 (14) A representative of a health plan company;
- 16 (15) A member of the scientific community who is engaged in
- 17 rare disease research, including, but not limited to,
- 18 a medical researcher with experience conducting
- 19 research on rare diseases; and
- 20 (16) One mental health provider with experience treating
- 21 rare disease patients in Hawaii.



(d) The governor shall appoint the chairperson for an initial term of three years. At the end of the chairperson's initial three-year term, and every two years thereafter, members of the council shall appoint, by a majority vote, a new chairperson. Members shall serve no longer than three years, except that, to facilitate a staggered rotation of members to retain continuity and knowledge transfer, during the initial five years after the establishment of the council, members may serve up to a four-year term. If a vacancy occurs, the council, by a majority vote, shall fill such a vacancy in a timely manner and in compliance with requirements set forth in this section.

(e) The members of the authority shall serve without compensation and shall be allowed their actual and necessary expenses incurred in the performance of their duties.

§321-D Meetings. (a) The rare disease advisory council shall conduct an initial meeting within the first ninety days after enactment. During, the first twelve months after enactment, the council shall meet no less than one time per month for a time period determined by the chairperson in person or via online meeting platform. Thereafter, the council will



1 meet no less than one time per quarter in person or via online
2 meeting platform as determined by the chairperson.

3 (b) The rare disease advisory council shall:

4 (1) Provide opportunities for the public to hear updates
5 and provide input into their work; and

6 (2) Create and maintain a public website where meeting
7 minutes, notices of upcoming meetings, and public
8 comments can be submitted.

9 **§321-E Funding; Rare disease advisory council special**

10 **fund.** (a) In addition to the appropriation included in this
11 Act, the rare disease advisory council shall seek alternative
12 funding through grants and other sources. The council shall
13 report funding sources in the annual report outlined in section
14 321-F.

15 (b) There is established a rare disease advisory council
16 special fund into which shall be deposited the following moneys:

17 (1) Appropriations included in this Act;

18 (2) Funding acquired through grants and other outside
19 sources; and

20 (3) All interest earned or accrued on moneys deposited
21 into the rare disease advisory council special fund.



1 **§321-F Annual report.** (a) The rare disease advisory
2 council shall submit a report of its findings and
3 recommendations, including any proposed legislation, to the
4 legislature no later than twenty days prior to the convening of
5 the regular session of 2026, and each year thereafter."

6 SECTION 3. Section 321-1, Hawaii Revised Statutes, is
7 amended to read as follows:

8 **"PART I. GENERAL AND ADMINISTRATIVE PROVISIONS**

9 **§321-1 General powers and duties of the department.** (a)
10 The department of health shall have general charge, oversight,
11 and care of the health and lives of the people of the State, and
12 shall pursue as a goal, the achievement of health equity. The
13 department shall consider social determinants of health in the
14 assessment of state needs for health.

15 (b) The department may conduct epidemiologic
16 investigations of diseases and injuries that threaten or are
17 deemed by the department to threaten the public health and
18 safety.

19 (c) The department shall have authority in matters of
20 quarantine and other health matters and may declare and enforce



1 quarantine when none exists and modify or release quarantine
2 when it is established.

3 (d) When it is determined that there is imminent danger of
4 epidemic or serious outbreak of communicable disease, the
5 department may refuse, modify, or limit attendance at any school
6 in the State.

7 (e) When in the judgment of the director, there is deemed
8 to be a potential health hazard, the department may take
9 precautionary measures to protect the public through the
10 imposition of an embargo, the detention of products regulated by
11 the department, the removal of products regulated by the
12 department from the market, the declaration of quarantine, or by
13 sequestering items suspected to be contaminated by toxic or
14 infectious substances; provided that the director shall find
15 evidence of a health hazard within seven days of the action
16 taken or rescind the action. The director shall make public the
17 findings.

18 (f) All county health authorities, sheriffs, police
19 officers, and all other officers and employees of the State, and
20 every county thereof, shall enforce the rules of the department.
21 All such powers in health matters as have been or may be



1 conferred upon any county shall be concurrent with those of the
2 department.

3 (g) The department may establish charges and collect fees
4 for any of its services; provided that the department shall not
5 refuse to provide services to any person due to the person's
6 inability to pay the fee for the service. The department,
7 through the director, shall make an annual report to the
8 governor, showing in detail all its expenditures and
9 transactions, and such other information regarding the public
10 health as the department may deem of special interest.

11 (h) The department, during the prevalence of any severe
12 pestilence or epidemic, shall publish a weekly report of the
13 public health.

14 (i) The department shall establish and administer
15 programs, and adopt rules as deemed necessary, for the
16 prevention of domestic and sexual violence and the protection
17 and treatment of victims of domestic and sexual violence.

18 (j) The department shall include in appropriate public
19 health programs and activities information concerning the
20 importance of an annual physical examination by a provider of
21 health care for children.



1 [~~(j)~~] (k) As used in this section:

2 "Health equity" means assuring equal opportunity for all
3 people in the State to attain their full health potential.

4 "Social determinants of health" means the complex,
5 integrated, and overlapping social structures and economic
6 systems that contribute to health inequities. These social
7 structures and economic systems include the social environment,
8 physical environment, health services, and structural and
9 societal factors. "

10 SECTION 4. Section 302A-1159, Hawaii Revised Statutes, is
11 amended to read as follows:

12 **"§302A-1159 Physical examination required.** (a) No child
13 shall attend any school for the first time in the State unless
14 the child presents to the appropriate school official a report
15 from a licensed physician, physician assistant, or advanced
16 practice registered nurse of the results of a physical
17 examination performed within twelve months before the date of
18 attendance at school. A child may attend school provisionally
19 upon submitting written documentation from a licensed physician,
20 physician assistant, advanced practice registered nurse, or
21 other authorized representative of the department of health



1 stating that the child is in the process of undergoing a
2 physical examination. Further documentation showing that the
3 required physical examination has been completed shall be
4 submitted to the appropriate school official no later than three
5 months after the child first attends the school.

6 (b) Beginning with the 2017-2018 school year, every child
7 entering seventh grade shall present to the appropriate school
8 official written documentation from a licensed physician,
9 physician assistant, or advanced practice registered nurse
10 showing completion of a physical examination performed within
11 twelve months before the date of attendance. The department
12 shall send notification of the physical examination requirement
13 to the child's parents or guardians, upon the child's entrance
14 into sixth grade, and post the requirement on the department's
15 website. By December 31 of each year, the department shall
16 provide to the department of health a list of students attending
17 seventh grade who have not submitted appropriate written
18 documentation, along with directory information as allowed under
19 the federal Family Educational Rights and Privacy Act.

20 (c) The department shall include in any written
21 communication with the child's parents or guardians related to



1 the health of children information concerning the importance of
2 an annual physical examination by a provider of health care for
3 children."

4 SECTION 5. Section 431:10A-132, Hawaii Revised Statutes,
5 is amended to read as follows:

6 **"§431:10A-132 Orthodontic services for orofacial**
7 **anomalies; benefits and coverage; notice.** (a) Each individual
8 and group accident and health or sickness insurance policy,
9 contract, plan, or agreement issued or renewed in this State
10 after December 31, 2015, shall provide to the policyholder and
11 individuals under twenty-six years of age covered under the
12 policy, contract, plan, or agreement, coverage of medically
13 necessary orthodontic services for the treatment of orofacial
14 anomalies and velocardiofacial anomalies resulting from birth
15 defects or birth defect syndromes. Coverage required by this
16 section shall be paid for by medical insurance.

17 (b) Every insurer shall provide written notice to its
18 policyholders regarding the coverage required by this section.
19 The notice shall be in writing and prominently positioned in any
20 literature or correspondence sent to policyholders and shall be
21 transmitted to policyholders within calendar year 2016 when



1 annual information is made available to members or in any other
2 mailing to members, but in no case later than December 31, 2016.

3 (c) Orthodontic services for treatment of orofacial
4 anomalies and velocardiofacial anomalies provided under this
5 section shall be subject to a maximum benefit of \$5,500 per
6 treatment phase, but shall not be subject to limits on the
7 number of visits to an orthodontist. After December 31, 2016,
8 the insurance commissioner, on an annual basis, shall adjust the
9 maximum benefit for inflation using the medical care component
10 of the United States Department of Labor Consumer Price Index
11 for all urban consumers. The commissioner shall publish the
12 adjusted maximum benefit annually no later than April 1 of each
13 calendar year, which shall apply during the following calendar
14 year to accident and health or sickness insurance policies,
15 contracts, plans, or agreements subject to this section.
16 Payments made by an insurer on behalf of a covered individual
17 for any care, treatment, intervention, or service other than
18 orthodontic services, shall not be applied toward any maximum
19 benefit established under this subsection.

20 (d) Coverage under this section may not be subject to
21 copayment, deductible, and coinsurance provisions of an accident



1 and health or sickness insurance policy, contract, or plan[, ~~or~~
2 ~~agreement that are no less favorable than the copayment,~~
3 ~~deductible, and coinsurance provisions for other medical~~
4 ~~services covered by the policy, contract, plan, or agreement].~~

5 (e) This section shall not be construed as limiting
6 benefits that are otherwise available to an individual under an
7 accident and health or sickness insurance policy, contract,
8 plan, or agreement.

9 (f) Coverage for treatment under this section shall not be
10 denied on the basis that the treatment is habilitative or non-
11 restorative in nature.

12 (g) This section shall not apply to limited benefit health
13 insurance as provided pursuant to section 431:10A-607.

14 (h) As used in this section, unless the context clearly
15 requires otherwise:

16 "Orofacial anomalies" means cleft lip or cleft palate and
17 other birth defects of the mouth and face affecting functions
18 such as eating, chewing, speech, and respiration.

19 "Velocardiofacial anomalies" means cleft lip and cleft
20 palate and other birth defects of the mouth and face affecting
21 functions such as eating, chewing, speech, and respiration



1 relating to velocardiofacial syndrome, resulting from 22q11
2 deletion syndrome or DiGeorge Syndrome.

3 "Orthodontic services" mean direct or consultative services
4 provided by a licensed dentist with a certification in
5 orthodontics by the American Board of Orthodontics.

6 "Treatment of orofacial anomalies and velocardiofacial
7 anomalies" includes the care prescribed, provided, or ordered
8 for an individual diagnosed with an orofacial or
9 velocardiofacial anomaly by a craniofacial team that includes a
10 licensed dentist, orthodontist, oral surgeon, and physician, and
11 is coordinated between specialists and providers."

12 SECTION 6. In codifying the new part added by section 2
13 and 3 of this Act, the revisor of statutes shall substitute
14 appropriate section numbers for the letters used in designating
15 the new sections in this Act.

16 SECTION 7. There is appropriated out of the general
17 revenues of the State of Hawaii the sum of \$50,000 or so much
18 thereof as may be necessary for fiscal year 2025-2026 and the
19 same sum or so much thereof as may be necessary for fiscal year
20 2026-2027 for the establishment and operation of the rare
21 disease advisory council.

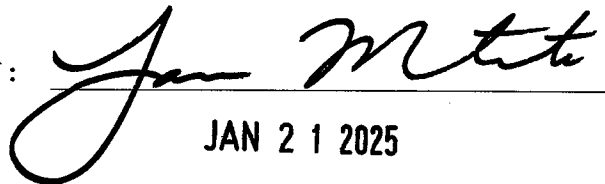


1 The sums appropriated shall be expended by the department
2 of health for the purposes of this Act.

3 SECTION 8. Statutory material to be repealed is bracketed
4 and stricken. New statutory material is underscored.

5 SECTION 9. This Act shall take effect upon its approval;
6 provided that section 7 of this Act shall take effect on January
7 1, 2026, and shall apply to all plans, policies, contracts, and
8 agreements of health insurance issued or renewed by a health
9 insurer, mutual benefit society, or health maintenance
10 organization on or after January 1, 2026.

11
12
INTRODUCED BY:


JAN 21 2025



H.B. NO. 910

Report Title:

Rare Diseases; Genetic Disorders; Advisory Council; Insurance

Description:

Establishes the rare disease advisory council to increase awareness and effective medical intervention for rare diseases. Establishes the rare disease advisory council special fund. Requires DOH and DOE to incorporate the importance of annual physical examinations for children in programs and literature. Amends the insurance code to include coverage for individuals with velocardiofacial syndrome and other genetic disorders. Exempts from cost sharing. Appropriates funds.

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