

Study of Proposed Mandatory Health Insurance for Port-Wine Stains

A Report to the Governor
and the Legislature of
the State of Hawai'i

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OFFICE OF THE AUDITOR
STATE OF HAWAII



OFFICE OF THE AUDITOR STATE OF HAWAII

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Foreword

We assessed the social and financial impacts of mandating insurance coverage for treatment of port-wine stains as proposed in House Bill No. 1705, H.D. 1, pursuant to Sections 23-51 and 23-52, Hawai'i Revised Statutes (HRS). Section 23-51, HRS, requires passage of a concurrent resolution requesting an impact assessment by the Auditor before any legislative measure mandating health insurance coverage for a specific health service, disease, or provider can be considered. The 2018 Legislature requested this assessment through Senate Concurrent Resolution No. 83, S.D. 1, H.D. 1.

We wish to express our appreciation for the cooperation and assistance extended to us by the State's health plan providers and medical professionals, as well as other organizations and individuals we contacted during the course of our audit.

Leslie H. Kondo
State Auditor



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Study of Proposed Mandatory Health Insurance for Port-Wine Stains

Introduction

PORT-WINE STAINS typically occur at birth and initially appear as flat, pink to red patches. The symptoms may initially be very subtle and could be overlooked until the port-wine stains become more pronounced over time. Port-wine stains are a common form of vascular malformation of the skin. They have also been described as a type of birthmark, but unlike a birthmark a port-wine stain will grow. Port-wine stains are most commonly found on the face and neck areas, although the trunk and extremities are also frequently affected.

Medical complications can develop from port-wine stains. Over time, port-wine stains can progress and “hypertrophy” – or thicken – and “nodules,” or lumps due to abnormal swelling, may also develop with age. The President of the Hawai‘i Dermatological Society described them as “blood blisters” which can result in bleeding with sufficient contact. The thickened lesions and nodules may also become red or purple in color and could lead to disfigurement or spontaneous bleeding.

Medical complications can develop from port-wine stains. Over time, port-wine stains can progress and “hypertrophy” – or thicken – and “nodules,” or lumps due to abnormal swelling, may also develop with age.

Port-wine stains may also result in pain, and depending on the type of malformation and location on the body, they can cause asymmetry and occasional spontaneous bleeding.

House Bill No. 1705, House Draft 1, introduced during the 2018 Legislative Session, would require insurers, hospital and medical services plans, and health maintenance organizations to provide health insurance coverage for medical procedures to eliminate or provide maximum feasible treatment of port-wine stains. Under Section 23-51, Hawai‘i Revised Statutes (HRS), before any legislative measure that mandates health insurance coverage for specific health services, specific diseases, or certain providers of health care services as part of individual or group health insurance policies can be considered, the Auditor must first assess the social and financial effects of the proposed mandated coverage. Section 23-52, HRS, lists the criteria the Auditor must address to the extent that information is available. Through Senate Concurrent Resolution No. 83, Senate Draft 1, House Draft 1, the Legislature requested the Auditor to assess the social and financial effects of the mandated coverage as proposed in House Bill No. 1705, House Draft 1.

We found there are differing positions between health insurers and members within the health care provider community as to when treatments for port-wine stains are for cosmetic purposes and when treatments are considered medically necessary. Currently, medical insurers in Hawai‘i do not provide coverage for treatment of all port-wine stains. Health care insurers who provide single and group medical coverage plans in Hawai‘i informed us that treatments for port-wine stain cases that meet the statutory standard of “medical necessity” are currently covered under their policies. However, if the treatment of a port-wine stain is for what an insurer considers to be cosmetic purposes, there is generally no “medical necessity.” In the case of port-wine stains, the majority of insurers surveyed said medical treatments are deemed necessary when a patient experiences functionality issues as previously described. However, some health care providers argue that treating port-wine stains during early childhood, before the lesions thicken and develop nodules, helps restore an individual to normal and is not for cosmetic purposes. They also argue that port-wine stains may negatively impact a person’s quality of life and have psychological impacts similar to people with other facial differences. The American Academy of Pediatrics has noted that medical treatments for other birth anomalies that can cause psychosocial issues, such as cleft lip and cranial and facial deformities, are approved by most insurance companies.¹

¹ Hassink, Sandra G., M.D., President, American Academy of Pediatrics. Letter to selected medical directors. February 25, 2015.

In response to our requests, the majority of insurers either could not provide the total number of members who received medical treatment for port-wine stains over a three-year period or said that they did not receive any claims for such treatments. However, using statistics from published medical articles and 2017 State population figures, we calculated that the number of people in Hawai‘i who may have port-wine stains ranged from several hundred to slightly more than 7,000.

The scope of coverage under House Bill No. 1705, House Draft 1, also presented some challenges to our assessment. The proposed mandate does not consider medical necessity in regard to port-wine stains and would, therefore, apply to all port-wine stain cases. The majority of insurers we surveyed said mandated coverage could cause insurance premiums to increase, but did not provide an estimate. However, we also found the State may end up paying for the cost of the proposed mandate, although it is uncertain how much of the financial burden it stands to bear. Under the Patient Protection and Affordable Care Act, also called the Affordable Care Act (ACA), any state that mandates additional benefits to qualified health plans is required to defray the cost for those added benefits unless the additional benefits are for the purpose of complying with Federal requirements. A qualified health plan provides Essential Health Benefits (EHB) which meet the ACA requirements and are certified and sold on the Health Insurance Marketplace. These and other impact assessments are reported in greater detail in this report.

Study Objective

Assess the social and financial effects of requiring insurers, hospital and medical services plans, and health maintenance organizations to provide insurance coverage for medical procedures to eliminate or provide maximum feasible treatment of port-wine stains.

Scope and Methodology

We reviewed medical articles and studies regarding port-wine stains that were published on the website of the National Center for Biotechnology Information, a division of the National Library of Medicine. Other sources used for this report included the National Center for Health Statistics, the American Academy of Pediatrics, the Sturge-Weber Foundation, the Centers for Disease Control and Prevention, the Office of Health Status Monitoring for the State of Hawai‘i Department of Health, the State of Hawai‘i Department of Commerce and Consumer Affairs, and the State of Hawai‘i Department of Business, Economic Development and Tourism.

We interviewed members of the Hawai'i health care provider community including the Executive Director of the Hawai'i Medical Association, the President of the Hawai'i Dermatological Society, the State Epidemiologist, the Chief of the Office of Planning, Policy and Program Development at the State of Hawai'i Department of Health, and practicing dermatologists in Hawai'i who have treated port-wine stain patients. We also interviewed the administrator of the Hawai'i Employer-Union Health Benefits Trust Fund (EUTF), which provides medical benefits to all eligible State of Hawai'i, City and County of Honolulu, County of Maui, County of Hawai'i, and County of Kaua'i employees and retirees and their dependents.

We surveyed Hawai'i health care insurers which accounted for more than 808,000 members enrolled in single or group health care insurance plans in 2017. That total represented more than 62 percent of the total number of people in the State who received health care coverage. The majority of insurers which provided single and group health care plans in Hawai'i participated in the survey, as well as an insurer which provided government-sponsored managed care services, primarily through Medicaid, Medicare Advantage, and Medicare Prescription Drug Plans. Three other insurers elected not to participate in our survey because they believed the proposed mandate would not affect their organizations or membership.

We conducted this study from July 2018 to October 2018 in accordance with Sections 23-51 and 23-52, HRS.

Overview of Port-Wine Stains

The location of a port-wine stain on a person's body is a factor when assessing whether it presents a potential medical risk. The most common areas where port-wine stains occur are the forehead, scalp, upper and lower eyelid areas, as well as the nose, cheeks, and upper lip. These are designated as the ophthalmic nerve division (V1) and the maxillary nerve division (V2) as shown in Exhibit 1.

When port-wine stains occur in the ophthalmic nerve division (V1), there is a higher risk that medical issues may develop in the future such as glaucoma or Sturge-Weber Syndrome.

In order to obtain information on the frequency of port-wine stains, we contacted the National Center for Health Statistics (NCHS), which is the nation's principal health statistics agency. We were informed the NCHS does not maintain any tracking data regarding port-wine stains and has no data regarding the total number of port-wine stain cases that were treated or reported on an annual basis. We also did not find

Exhibit 1

Facial Dermatomes (areas of skin supplied by nerves)

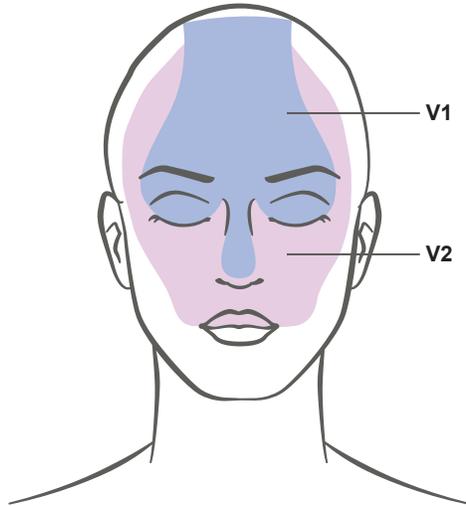


ILLUSTRATION: OFFICE OF THE AUDITOR

Sturge-Weber Syndrome

STURGE-WEBER Syndrome is a disorder that is characterized by a birthmark on the face and neurological abnormalities. Symptoms of Sturge-Weber Syndrome include eye and organ irregularities as well as developmental disabilities. A port-wine stain patient's risk of having Sturge-Weber Syndrome is only between 8 and 15 percent, but if the port-wine stain covers half or both sides of the face, respectively, the risk may increase to between 25 and 33 percent.

this information from sources recommended by the NCHS. The State of Hawai‘i Department of Health informed our office that it does not track the number of port-wine stain cases in Hawai‘i because it is not considered to be a public health priority, as opposed to, for example, tuberculosis or rat lungworm disease.

However, we found data from published studies, as well as local population figures, that enabled us to calculate an estimated number of people within the general population and the newborn population who may have port-wine stains.^{2 3 4 5} The estimated range is reported to be between 0.3 percent and 0.5 percent. One Hawai‘i insurer reported a much lower rate of 4 in every 10,000 people or 0.04 percent of the general population. Using 2017 general and newborn Hawai‘i population totals, we calculated the following estimated number of people who may have port-wine stains in the State as well as the number of infants born with port-wine stains (See Exhibit 2).

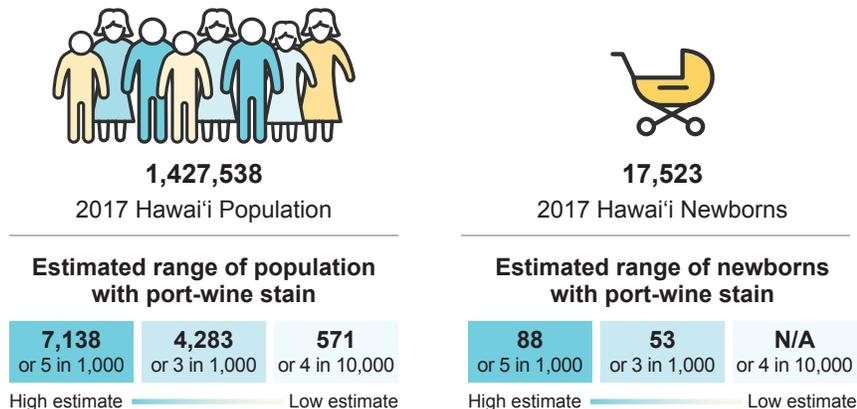
² Brightman, Lori A., et al., “Laser treatment of port-wine stains,” *Dove Medical Press Limited*. January 12, 2015. www.ncbi.nlm.nih.gov/pmc/articles/PMC4296879/.

³ Minkis, Kira, M.D., Ph.D., et al., “Port Wine Stain Progression: A Potential Consequence of Delayed and Inadequate Treatment?” *Lasers Surg. Med.*, August 2009. www.ncbi.nlm.nih.gov/pmc/articles/PMC4690461/.

⁴ Hagen, Solveig L., B.A., et al., “Quality of life in adults with facial port-wine stains.” *J. Am. Acad. Dermatol.*, Author manuscript; April 2017. HHS Public Access; available in PMC 2018 January 30.

⁵ Chen, Jennifer K., M.D., et al., “An overview of clinical and experimental treatment modalities for port wine stains.” *J. Am. Acad. Dermatol.*, Author manuscript; August 2012. Available in PMC 2012 February 3. www.ncbi.nlm.nih.gov/pmc/articles/PMC4143189/.

Exhibit 2 Estimated Port-Wine Stain Populations in Hawai‘i, 2017



Source: Population Data from State of Hawai‘i Department of Business, Economic Development and Tourism and the State of Hawai‘i Department of Health

Based on these calculations, the estimated number of people who may have port-wine stains in Hawai‘i in 2017 ranged from nearly 600 to roughly 7,100 people, while the projected number of infants born with port-wine stains that year ranged from a little more than 50 to nearly 90.

Overview of Treatment of Port-Wine Stains

In the past, the treatment for port-wine stains included skin grafting, radiation, cryosurgery, dermabrasion, and electrotherapy, all without good cosmetic outcomes. Argon lasers were the first lasers used to treat port-wine stains, but this treatment came with adverse effects including scarring. The pulsed-dye laser is currently considered the most effective and safe method of treatment. The first pulsed-dye laser revolutionized the treatment of port-wine stains when it was approved by the U.S. Food and Drug Administration in 1986. Still, there have been conflicting studies as to the effectiveness of the pulsed-dye laser treatment, with one showing a 75 percent lightening rate of the port-wine stain in more than 60 percent of patients after roughly three treatments, while other studies have not reproduced these results.⁶

⁶ Chen, Jennifer K., M.D., et al., “An overview of clinical and experimental treatment modalities for port wine stains.” *J. Am. Acad. Dermatol.*, Author manuscript; August 2012. Available in PMC 2012 February 3. www.ncbi.nlm.nih.gov/pmc/articles/PMC4143189/.

A Hawai'i dermatologist who has treated roughly five port-wine patients a year since 2015 uses a pulsed-dye laser in his practice as shown in Exhibit 3:

**Exhibit 3
Pulsed-Dye Laser**



Photo: Office of the Auditor (August 2018)

In addition to the pulsed-dye laser, there are other treatment methods such as Intense Pulsed Light, which is reported to be an effective alternative in some cases, as well as other types of lasers. A Hawai'i dermatologist who has treated an average of two port-wine stain patients a year since 2015 uses Intense Pulsed Light coupled with an “Nd: YAG laser” as shown in Exhibit 4:

**Exhibit 4
Intense Pulsed Light and Nd: YAG Laser**



560 Nanometer Intense Pulsed Light (L); Nd: YAG Laser (R)
Photos: Office of the Auditor (September 2018)

Multiple treatments are typically necessary and the effectiveness of the clearance of the port-wine stain depends on its size and location on the body. For example, Exhibit 5 and Exhibit 6 are photos of two patients in Hawai‘i who have undergone laser treatments for port-wine stains that were located on different parts of the body.

**Exhibit 5
Facial Port-Wine Stain Patient Pre- and Post-Treatment**



Before

After

A patient with a facial port-wine stain had undergone six laser treatments as of October 1, 2018. The size and number of nodules has decreased or been cleared, and the color has lightened but the port-wine stain is still clearly visible.

**Exhibit 6
Shoulder Port-Wine Stain Patient Pre- and Post-Treatment**



Before

After

Exhibit 6 are photos of a second patient with a port-wine stain on the shoulder before and after ten laser treatments as of October 1, 2018. The port-wine stain has significantly lightened and is barely visible.

The cost for each treatment varies with each health care provider. For example, a Hawai‘i dermatologist who uses the pulsed-dye laser said the charges may range between \$300 and \$1,200 per treatment. Another Hawai‘i dermatologist who uses Intense Pulsed Light treatments

combined with laser treatments said the cost may run between \$950 and \$1,200 per treatment, but both said the cost is typically based on the area of skin that is being treated. There have also been arguments from the health care provider community that treatment of port-wine stain patients is more effective during early infancy.^{7 8} If sedation or anesthesia is deemed necessary for younger port-wine stain patients, there would be an additional expense.

The American Academy of Pediatrics noted that collaborative multispecialty care involving specialists such as dermatologists, otolaryngologists, plastic surgeons, pediatric surgeons, pediatricians, and interventional radiologists is often optimal to provide appropriate treatment. The proposed mandate, as written, does not restrict the types of medical procedures that could be used to treat port-wine stains, stating that “any medical procedures” would be covered. It is reasonable to conclude that should effective treatment of port-wine stains involve multiple treatments from multiple health care providers, the overall cost would be higher.

Current State of Insurance Coverage for Port-Wine Stains

Only one of five insurers surveyed provided any data regarding the total number of medical treatments for port-wine stains that were covered between 2015 and 2017. One insurer reported about 45 port-wine stain treatments were conducted each year for an average utilization of 0.02 percent of its total membership. The remaining insurers reported either there were no claims or requests for port-wine stain treatments during that period or they could not provide a figure from its available data.

The majority of insurers surveyed responded that insurance coverage for port-wine stain treatment is already generally available. However, they unanimously said that the treatments are not generally utilized by their members and that there was little or no public demand for them. We also note that all respondents also said they had not conducted a study, poll, or survey of their memberships to assess whether there was a desire to expand health care coverage to include medical treatments for port-wine stains.

⁷ Hassink, Sandra G., M.D., President, American Academy of Pediatrics. Letter to selected medical directors. February 25, 2015.

⁸ Chapas, A.M., et al., “Efficacy of early treatment of facial port wine stains in newborns: a review of 49 cases.” *Lasers Surg. Med.*, August 2007. www.ncbi.nlm.nih.gov/pubmed/17868100.



Statutory Standards of “Medical Necessity”

UNDER SECTION 432E-1.4(a), (b), and (d), HRS, a service to treat a medical condition or to maintain or restore a person’s functional ability must be covered by health care insurers, provided it is recommended by the treating licensed health care provider and determined by the health plan’s medical director to be medically necessary. In order to determine a treatment as medically necessary, a number of criteria must be met, including whether the treatment is proven to be effective either on the basis of scientific evidence; or in the absence of scientific evidence, professional standards of care; or in the absence of both, expert opinion. The treatment must also be cost-effective compared with alternative treatments or not providing treatment at all.

The majority of insurers surveyed also said there has been no interest from collective bargaining organizations to include treatment of port-wine stains in group health insurance plans. The Hawai‘i Employer-Union Health Benefits Trust Fund – which provides health benefits to all eligible active and retired State employees and employees of the counties of Honolulu, Maui, Hawai‘i and Kaua‘i and their dependents – informed our office that providing coverage for port-wine stain treatments had not been discussed with insurers and there had been no expressed interest from affected parties to expand coverage to include these benefits.

Medical Necessity

The Executive Director of the Hawai‘i Medical Association acknowledged that “medical necessity” is a complex and often “contentious issue” between health care providers and insurers. Insurers we surveyed unanimously agreed that all treatments determined to be a “medical necessity” *are* covered and that they apply to port-wine stain cases.

The majority of insurers surveyed considered treatments for port-wine stains as medically necessary when the condition results in impaired physical function, such as bleeding or impaired vision or oral function, and the treatments are scientifically proven to be effective in improving those impairments. Two insurers added that they consider other factors when determining medical necessity such as disfigurement or discomfort or if it causes severe mental or psychological disability.

The American Academy of Pediatrics (AAP) said that port-wine stains are poorly misunderstood by insurers, who often deny treatment arguing that the procedures are for cosmetic purposes. The AAP has said treatments to improve the appearance of a patient with a birth defect of the face is a reconstructive procedure that attempts to restore a patient to normal. The President of the Hawai‘i Dermatological Society also supported the position that port-wine stains present more than a cosmetic issue, and that treatment of any condition that has a physical and psychological impact on a patient is medically necessary. Port-wine stains reportedly can profoundly influence a person’s quality of life through its impact on psychosocial development and well-being.^{9 10}

⁹ Hagen, Solveig L., B.A., et al., “Quality of life in adults with facial port-wine stains.” *J. Am. Acad. Dermatol.* Author manuscript; April 2017. HHS Public Access; available in PMC 2018 January 30.

¹⁰ Chen, Jennifer K., M.D., et al., “An overview of clinical and experimental treatment modalities for port wine stains.” *J. Am. Acad. Dermatol.*, Author manuscript; August 2012. Available in PMC 2012 February 3. www.ncbi.nlm.nih.gov/pmc/articles/PMC4143189/.

As written, the mandate proposed by House Bill No. 1705, House Draft 1, applies to *all* cases where port-wine stains are medically detected. The majority of insurers surveyed contend the mandate would expand coverage to port-wine stains that fall outside of the standard of medically necessary treatments, which would increase costs but do little to impact coverage for morbidity (illness), since treatments for port-wine stains that do involve morbidity are already covered.

However, we were unable to find any data regarding the number of port-wine stain cases involving morbidity issues, such as thickening or the development of nodules which may result in bleeding. Published medical articles and studies from as early as 1991 to as recently as 2017 found that morbidity issues could develop as early as age nine or as late as the fifth decade of life.^{11 12 13} Due to the wide age range and the absence of corroborating data, we were not able to provide any estimate as to the percentage of port-wine stain cases that may involve morbidity issues.

State and Policyholders May Share Mandated Coverage Cost

In its testimony to the House Committee on Consumer Protection and Commerce in February 2018, the State of Hawai‘i Department of the Attorney General stated the proposed coverage mandate would be viewed as an “additional benefit” to the State’s Essential Health Benefits (EHB) and would obligate the State to defray the cost. Under the Patient Protection and Affordable Care Act of 2010 (ACA) and Federal regulations, a state may require a qualified health plan to offer benefits in addition to the EHB, but the state is ultimately responsible for defraying the cost of those added benefits.^{14 15}

The Chief of the Office of Planning, Policy and Program Development at the State of Hawai‘i Department of Health said the ACA was designed to ensure a level playing field for all states and to discourage

¹¹ Geronemus, R.G. & Ashinoff, R. “The Medical Necessity of Evaluation and Treatment of Port-Wine Stains.” *J. Dermatol. Surg. Oncol.*, January 1991. www.ncbi.nlm.nih.gov/pubmed/1991884.

¹² Lee, J.W., et al., “The Natural History of Soft Tissue Hypertrophy, Bony Hypertrophy, and Nodule Formation in Patients With Untreated Head and Neck Capillary Malformations.” *Dermatol. Surg.*, November 2015. www.ncbi.nlm.nih.gov/pubmed/26506066.

¹³ Chen, Jennifer K., M.D., et al., “An overview of clinical and experimental treatment modalities for port wine stains.” *J. Am. Acad. Dermatol.*, Author manuscript; August 2012. Available in PMC 2012 February 3. www.ncbi.nlm.nih.gov/pmc/articles/PMC4143189/.

¹⁴ Patient Protection and Affordable Care Act, 42 U.S.C. 18003 (2010), Section 1311(d)(3)(B)(i), (ii).

¹⁵ 45 C.F.R. 155.170(a)(2)(3)(b).



Essential Health Benefits & Qualified Health Plans

UNDER THE Patient Protection and Affordable Care Act of 2010, each State is required to have an Essential Health Benefits package that provides coverage for at least ten categories of benefits such as ambulatory patient services, emergency services, hospitalization, and prescription drugs. Insurance plans that are certified by the Health Insurance Marketplace, provide Essential Health Benefits, and meet other ACA requirements, such as limits on deductibles and copayments, are qualified health plans which are sold to consumers by the insurers. Insurers may also include other benefits in their qualified health plans in addition to the Essential Health Benefits.



Minnesota Mandate Law Passed Before Deadline

IN ITS February 2018 testimony to the Legislature, the State of Hawai'i Department of the Attorney General said its office was not aware of any state that had faced the prospect of having to pay for a benefit in addition to the Essential Health Benefits as required under the ACA. A key lawmaker who supported the proposed mandate in House Bill No. 1705, House Draft 1, said he did not agree with the position of the Department of the Attorney General and pointed out that the State of Minnesota had passed a law mandating health insurance coverage for medical services to treat port-wine stains. Federal regulations note that, if a state takes action after December 31, 2011, requiring certain benefits to be offered in qualified health plans, those added benefits will be recognized by the Federal government as an addition to the Essential Health Benefits, in which case, the state would be responsible for the cost. In the case of Minnesota, we found that lawmakers there passed the mandate in May 1993 and it would be recognized under Federal regulations as an Essential Health Benefit since the action occurred well before 2011.

state lawmakers from mandating additional medical services for political gain by requiring states to pay for any benefits in addition to the EHB. The insurers surveyed unanimously said they believe the State would be responsible for defraying the cost of mandating insurance coverage for port-wine stain treatments under the ACA. However, several insurers noted that the State's cost obligation for the additional mandated benefits would be limited to qualified health plans – which are the individual and small group plans offered on the online market exchange. This means the State would not be responsible for the cost of the proposed mandated services for health plans that are not certified and sold on the Health Insurance Marketplace, such as large group health insurance plans.

Further, plans that are considered “grandfathered”¹⁶ or “grandmothered”¹⁷ would also not be considered qualified health plans. As a result, the burden to pay for the cost of the additional benefits, if any, would likely fall upon the individuals and employers and their employees with large group, “grandfathered,” and “grandmothered” health plans.

Federal regulations place the onus on the State to identify which mandated benefits are in addition to the EHB and place the responsibility on the insurers to calculate the cost for each additional state-mandated benefit.¹⁸ Therefore, the issue of whether the State is responsible for paying for part, all, or none of the cost for medical services to treat port-wine stains, should the proposed mandate be implemented, will likely need to be resolved between the State and the insurers.

Social and Financial Impact of House Bill No. 1705, House Draft 1

Section 23-51, HRS, requires an impact assessment by the Auditor before any legislative measure mandating health insurance coverage for a specific health service, disease, or provider can be considered. Based on the criteria provided in statute, we examined the potential social and financial effects of mandating health insurance coverage for medical procedures to treat port-wine stains as proposed in House Bill No. 1705, House Draft 1.

¹⁶ “Grandfathered” health plans under the ACA are those existing without major changes to their provisions since the enactment of the ACA in March 2010 and are not required to meet all ACA requirements.

¹⁷ “Grandmothered” health plans are also called Transitional Renewal plans which were in existence on October 1, 2013 and renewed prior to October 1, 2014 and include some but not all of the ACA features.

¹⁸ 45 C.F.R. 155.70(a)(2)-(3), (c)(1).

Social and Financial Impact

1. Social Impact

A. The extent to which the treatment or service is generally utilized by a significant portion of the population:

We did not find any government agency that tracks the total number of port-wine stain cases in Hawai‘i. However, published medical articles consistently estimated between 0.3 percent and 0.5 percent of both the general population and the newborn population may have port-wine stains. One Hawai‘i insurer estimated the number of people with port-wine stains accounted for only 0.04 percent of the general population. Using 2017 Hawai‘i population and newborn totals, we calculated the estimated number of people in the State who may have port-wine stains ranges from 571 to more than 7,100. The estimated number of newborns in Hawai‘i with port-wine stains in 2017 ranged between 53 and 88.

The insurers surveyed unanimously said that medical procedures to treat port-wine stains have not been generally utilized. We note that, when our office asked the insurers to report the number of claims for port-wine stain treatments over a three-year period, the majority said either their records showed no applicable claims or they were unable to provide any totals based on their data. Although there is a lack of utilization data, the projected population of people affected with port-wine stains is relatively modest. Therefore, it is reasonable to conclude the number of people who utilize these services will also be correspondingly low.

B. The extent to which such insurance coverage is already generally available:

All insurers surveyed responded that port-wine stain treatments *that meet the statutory standard of “medical necessity”* are currently covered. However, there appears to be differing positions between members of the health care provider community and insurers as to when a port-wine stain case merits treatment that is medically necessary. There are insurers who view port-wine stain treatments as largely cosmetic and not medically necessary. However, there are health care providers, including those in Hawai‘i, who view port-wine stain treatments as medically necessary because they are

restorative procedures and are not for cosmetic purposes. The difference in interpretation was described by Hawai‘i health care providers as “contentious.”

State law however, leaves the determination of whether a treatment is medically necessary to the health plan’s medical director. Therefore, it is the insurer which ultimately decides what treatments are medically necessary based on the information provided by the treating physician and whether the treatments are supported with sufficient evidence as required by law. Although treatment for some port-wine stains is currently covered, current coverage does not include the full range proposed under House Bill No. 1705, House Draft 1, which mandates coverage for treatments for all port-wine stains.

C. If coverage is not generally available, the extent to which the lack of coverage results in persons being unable to obtain necessary health care treatment:

Insurers surveyed unanimously said there would be little or no impact in a person’s ability to obtain necessary health care treatment for port-wine stains. They also agreed that there are medical services available in Hawai‘i to treat port-wine stains, including laser treatments. We found at least two dermatologists on O‘ahu who conduct laser treatments and/or intense pulsed light treatments for adults as well as younger children with port-wine stains.

Insurers said that medically necessary treatments are currently covered, which includes for port-wine stain cases. Coupled with the availability of medical treatment services for port-wine stains, it is reasonable to conclude that people with port-wine stains can obtain necessary health care treatment under their current health insurance plan.



Response	Number of Insurers
No Unreasonable Financial Hardship	4 (80%)
Little Financial Hardship	1 (20%)

D. If coverage is not generally available, the extent to which the lack of coverage results in unreasonable financial hardship on those persons needing treatment:

When asked this question in our survey, the insurers' responses were nearly unanimous.

Although insurers said medically necessary treatments for port-wine stains are currently covered, people whose conditions do not merit coverage but still decide to seek treatment face the prospect of undergoing multiple medical procedures that could range in price from several hundred dollars per treatment to more than a thousand dollars per treatment. However, with no definitive morbidity data, it is difficult to assess the number of people with port-wine stains with medical issues who might seek treatment.

E. The level of public demand for the treatment or service:

Insurers surveyed unanimously said there has been little or no public demand for coverage of port-wine stain treatments. In order to provide an indication of the level of demand, we asked insurers to provide the total number of members who received treatments for port-wine stains over a three-year period. The majority of respondents said either their records revealed no applicable claims or they were unable to provide any totals from their data.

One insurer and a Hawai'i dermatologist both noted that there is no medical code specifically for port-wine stain treatments which makes it difficult to easily calculate the total number of medical treatments provided each year. Instead, a "catch-all" medical code is used not only for port-wine stain treatments but for other medical procedures to treat other types of conditions.

However, the lone insurer who did provide data reported that over a three-year period, an average of about 45 port-wine stain treatments were performed each year or an average utilization rate of 0.02 percent of its total membership.

The absence of claims data from the majority of insurers hindered our ability to better assess the level of public demand for port-wine stain treatments, although the one

set of data indicates that demand may be negligible. In addition, given our estimate of the number of port-wine stain patients in Hawai‘i to be no more than about 7,100, the universe of those potentially seeking treatment is arguably limited.

F. The level of public demand for individual or group insurance coverage of the treatment or service:

The insurers we surveyed unanimously responded there has been little or no public demand for port-wine stain treatments to be covered under individual or group insurance plans. We also asked each insurer whether it had conducted a study, poll, or survey of their membership to assess whether the members wanted to expand their health coverage to include medical procedures to treat port-wine stains; all respondents said they had not.

Without documented feedback from the insurers’ membership, it is difficult to assess whether enrollees want to expand health insurance plan coverage to include port-wine stain treatments.

G. The level of interest of collective bargaining organizations in negotiating privately for inclusion of this coverage in group contracts:

Four of five insurers surveyed said there has been no interest expressed from collective bargaining organizations to include port-wine stain treatment coverage in group contracts. A fifth insurer said this issue does not apply to its organization.

EUTF is a State agency that is responsible for designing health benefit plans and contracting with insurance carriers to provide the services. EUTF provides health benefits to roughly 68,000 eligible State and county employees as well as more than 60,000 of their dependents and about 47,000 retirees plus 20,000 of their dependents. EUTF also decides the health benefits for six public labor unions: Hawai‘i Government Employees Association, United Public Workers, University of Hawai‘i Professional Assembly, Hawai‘i Firefighters Association, State of Hawai‘i Police Officers Union and Hawai‘i State Teachers Association.

EUTF said the idea of expanding health insurance

coverage to include medical procedures to treat port-wine stains had not been discussed during negotiations with insurers and there had been no expressed interest by the unions to include these treatments as part of their health coverage benefits.

H. The impact of providing coverage for the treatment or service (such as morbidity, mortality, quality of care, change in practice patterns, provider competition, or related items):

A majority of insurers surveyed said the number of medical treatments for port-wine stains would increase because the mandated coverage would encourage health care providers to perform procedures for cosmetic reasons. They did not provide any projections as to how significant an increase there might be.

A majority also agreed that morbidity and mortality rates would not be affected if coverage was mandated because treatments for port-wine stain cases that are determined to be medically necessary are currently covered. When insurers were asked to identify the factors used to determine whether a treatment for port-wine stains was medically necessary, the responses ranged from bleeding, impaired vision or oral function, disfigurement or discomfort, glaucoma, development of nodules or whether the port-wine stain is located on the face or neck areas.

Although health care providers argue that morbidity – or illness – not only includes physical functionality issues but also psychosocial morbidity issues, State law empowers the insurers to decide what treatments are determined to be medically necessary.

I. The impact of any other indirect costs upon the costs and benefits of coverage as may be directed by the Legislature or deemed necessary by the auditor in order to carry out the intent of Section 23-52, Hawai‘i Revised Statutes:

The insurers surveyed unanimously said there would be some indirect costs associated with mandated coverage. They said, if coverage expands to all port-wine stain cases that include younger patients who currently do not merit treatments that are medically necessary, they may require additional medical services which impact costs. Some of these costs include transportation and anesthesia services,

laboratory services, and increased Medicaid funding by the State. However, the insurers did not provide any estimated totals regarding indirect cost impact.

As currently written, the proposed mandate would require coverage of any medical procedure to treat port-wine stains. Typically, multiple treatments are necessary for port-wine stain cases, and effective treatment may involve procedures conducted by other medical practices which could involve additional direct and indirect costs.

2. Financial Impact

A. The extent to which insurance coverage of the kind proposed would increase or decrease the cost of the treatment or service:

The majority of insurers surveyed agreed the proposed mandate would result in an increase in the cost of port-wine stain treatments. Two insurers said there would be a “significant increase,” but none of the respondents could quantify the financial impact with a projected cost total. Cost factors cited were an increase in equipment, equipment maintenance, and the inclusion of cosmetic procedures. Some insurers noted more information would be needed, such as the potential volume of port-wine stain patients who would seek medical treatment, in order to conduct an in-depth cost analysis.

We also found that the absence of data of a definitive number of port-wine stain patients in Hawai‘i, current treatment utilization rates, and the broadness of coverage under the proposed mandate hindered our ability to assess the extent a mandate would have on treatment cost.

B. The extent to which the proposed coverage might increase the use of the treatment or service:

The majority of insurers surveyed said that expanding coverage of medical treatment for what they believe to be for cosmetic purposes will increase the volume of treatments overall, but none provided any utilization projections.

It is reasonable to conclude that port-wine stain patients whose treatments currently do not meet the standard of medical necessity will be covered under the proposed mandate which, in turn, could increase the utilization of

treatments. However, due to the lack of definitive port-wine stain population, morbidity rate, and claims data, we were unable to assess the extent a mandate would have on treatment utilization with a high level of precision.

C. The extent to which the mandated treatment or service might serve as an alternative for more expensive treatment or service:

The pulsed dye-laser treatment is considered the “gold standard” which we found is available in Hawai‘i. All five insurers surveyed said there are medical treatments available for port-wine stain cases that include laser treatments, which the majority agreed are the most expensive options currently available.

Based on responses and available data, laser treatments are the most expensive treatment for port-wine stains and are currently available in Hawai‘i.

D. The extent to which insurance coverage of the health care service or provider can be reasonably expected to increase or decrease the insurance premium and administrative expenses of policyholders:

Section 1311(d)(3)(B)(i)(ii) of the ACA enables states to mandate that qualified health plans offer benefits in addition to the Essential Health Benefits, provided the states defray the cost.

Qualified health plans are insurance plans that provide Essential Health Benefits, meet other ACA requirements, and are certified and sold on the Health Insurance Marketplace. However, certain plans are not sold on the online marketplace and are not subject to certain ACA requirements.

“Grandfathered” health plans under the ACA are those that existed without major changes since the ACA was enacted in March 2010 and are not sold on the marketplace. “Grandfathered” plans are also not required to meet a number of ACA requirements, such as the inclusion of Essential Health Benefits. There are also “grandmothered” plans which include some but not all of the ACA features and also cannot be sold on the online health exchange.

Several insurers agreed that, if the mandated coverage is implemented, the State would not be financially obligated to pay for the cost of the added benefits for these plans and that it would likely be the policyholders of affected plans who would pay for it in the form of increased premiums and administrative costs. The insurers said the State's cost obligation for the additional mandated benefits would be limited to qualified health plans, which are the individual and small group plans offered on the online market exchange. However, with no current utilization rate data or how many different types of medical treatments would be covered, we were not able to estimate what impact, if any, the proposed mandate might have on premium rates.

Federal regulations require the states to identify which state-required benefits are in addition to Essential Health Benefits and require insurers to calculate the cost attributable for each of these benefits. Therefore, the State and the insurers will likely need to agree on the interpretation of the ACA cost responsibility requirements and identify which insurance plans are affected to determine the extent of the State's financial obligation to pay for the mandated coverage and how much of the cost policyholders may be required to bear.

E. The impact of this coverage on the total cost of health care:

A majority of insurers surveyed said a mandate would increase the total cost of health care but could not provide any projections as to the extent of the impact. The remaining insurers said they had no idea regarding the impact a mandate might have on overall health care costs.

Coupled with the lack of data on specific port-wine stain patients, utilization rates, and whether the coverage extends to all medical procedures that may include multiple medical practices as a means of treatment, we are not able to provide an assessment with any reasonable certainty about the impact the coverage would have on the total cost of health care in Hawai'i.

Conclusion

Medical treatments for port-wine stains are currently covered by Hawai‘i insurers, but only if determined to be medically necessary. Although there may be differences of opinion between the local health insurance industry and members of the health provider community as to what constitutes medically necessary treatments, State law empowers the insurers to make that determination. As currently written, the proposed mandate would consider *any* medical procedure to treat port-wine stains to be covered without regard as to whether it meets the statutory standard of medical necessity. It is reasonable to conclude that the number of people whose treatments are not currently covered, i.e., not determined to be medically necessary, may pursue treatment with the knowledge that the coverage now extends to their treatments. Although there is no data available that provides a definitive picture of the population of people in Hawai‘i who have port-wine stains, we calculated the projected populace may be relatively modest.

We found that, in some cases, port-wine stains can be eliminated with treatment, but there are also cases in which there is a limit to the level of improvement treatments can provide. The bill proposes to mandate coverage for both the “elimination” and “maximum feasible treatment” of port-wine stains. In essence, it would cover both outcomes. The cost for each treatment may range from several hundred dollars to more than a thousand dollars. However, because it is typical for each port-wine stain case to undergo multiple treatments that may extend to multiple medical practices, the treatment cost may significantly grow on an individual case basis. Another factor to consider is that the frequency and number of treatments is arguably at the discretion of the treating physician. Therefore, the overall cost for each individual port-wine stain case may vary depending on several factors including the size and location of the port-wine stain, the age of the patient, and the judgment of the treating physician.

It is clear the State may be liable for paying part of the cost for the mandated coverage under the ACA, although it is not clear as to the extent of the State’s financial obligation or how much the policyholders will likely need to pay for the added benefits. Should the Legislature move forward with the proposed mandate as written, Federal regulations will require the State and the insurers to identify which State-required benefits are in addition to the Essential Health Benefits, how much these benefits will cost, and who is obligated to pay for them.

In summary, as discussed in this report, we found there will be several issues to address when considering whether to implement House Bill No. 1705, House Draft 1.

