

Evaluation of HF1041-1E

Report to the Minnesota Legislature pursuant to Minn. Stat. §62J.26

01/24/2022

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Introduction and Policy Context

Pursuant to Minn. Stat. § 62J.26, subd. 3, the Minnesota Department of Commerce has been requested to perform an evaluation of HF1041-1E from 2019. The purpose of the evaluation is to provide the legislature with a detailed analysis of the potential impacts of any mandated health benefit proposal. House File 1041-1E was first introduced during the 2019 legislative session and meets the definition of a mandated health benefit proposal under Minn. Stat. §62J.26, which indicates the following criteria:

A mandated health benefit proposal" or "proposal" means a proposal that would statutorily require a health plan company to do the following:

- (i) provide coverage or increase the amount of coverage for the treatment of a particular disease, condition, or other health care need;
- (ii) provide coverage or increase the amount of coverage of a particular type of health care treatment or service or of equipment, supplies, or drugs used in connection with a health care treatment or service;
- (iii) provide coverage for care delivered by a specific type of provider;
- (iv) require a particular benefit design or impose conditions on cost-sharing for:
 - (A) the treatment of a particular disease, condition, or other health care need;
 - (B) a particular type of health care treatment or service; or
 - (C) the provision of medical equipment, supplies, or a prescription drug used in connection with treating a particular disease, condition, or other health care need; or
- (v) impose limits or conditions on a contract between a health plan company and a health care provider.

"Mandated health benefit proposal" does not include health benefit proposals amending the scope of practice of a licensed health care professional.

A detailed evaluation must be performed by the Department in consultation with the Department Health (MDH) and the Minnesota Management and Budget Office (MMB). Evaluations must focus on the following areas:

- Scientific and medical information regarding the proposal, including potential for benefit and harm
- Overall public health and economic impact
- Background on the extent to which services/items in the proposal are utilized by the population
- Information on the extent to which service/items in the proposal are already covered by health plans, and to which health plans the proposal would impact
- Cost considerations regarding the potential of the proposal to increase cost of care, as well as its potential to increase enrollee premiums in impacted health plans
- The cost to the State if the proposal is determined to be a mandated benefit under the Affordable Care Act (ACA)

Bill Requirements and Impact

If enacted, HF1041-1E would require regulated health plans in Minnesota to provide coverage for services related to ectodermal dysplasia. House File 1041-1E specifically amends Minn. Stat. §62A.25 to expand coverage for reconstructive breast surgery following a mastectomy for patients diagnosed with ectodermal dysplasia. The bill also identifies that scalp hair prostheses (wigs) must be covered for patients with alopecia areata or ectodermal dysplasia. The bill also establishes coverage requirements specific to dental treatment related to ectodermal dysplasia, including, but not limited to:

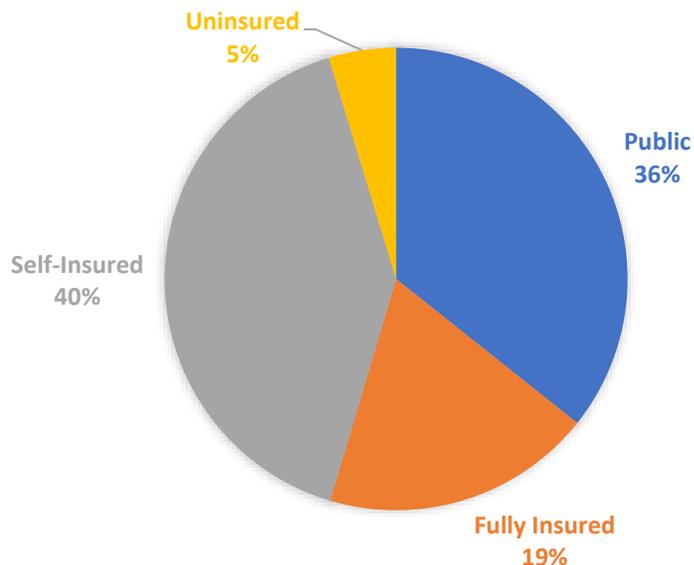
- Bone grafts
- Dental implants
- Orthodontia
- Dental prosthodontics
- Dental maintenance

The full text of the bill is available in the Appendix of this document.

Requirements under House File 1041-1E would apply to all fully insured commercial health plans regulated in Minnesota, as well as the State Employee Group Insurance Program (SEGIP). The bill also includes additions to existing statute stipulating that managed care fee for service Medical Assistance (MA) and MinnesotaCare plans must cover treatment related to ectodermal dysplasia consistent with its amending language to Minn. Stats. §§ [62A.25](#) and [62A.28](#). House File 1041-1E also indicates that these plans need to provide coverage consistent with its proposed new statute at Minn. Stat. §62A.2096.

Requirements in the bill would not apply to self-insured employer plans, grandfathered plans, and Medicare and Medicare supplemental policies. Figure 1 shows a breakdown of health insurance coverage in Minnesota by type (including uninsured).

Figure1. Minnesota Insurance Coverage 2019



Source: Minnesota Department of Health. Chartbook Section 2. Trends and Variations in Health Insurance Coverage. Accessed at <https://www.health.state.mn.us/data/economics/chartbook/docs/section2.pdf>.

State and Federal Law

This evaluation considers the interaction between state and federal law—specifically as it pertains to the potential for the bill to be considered a state benefit mandate understood under Section 1311(d)(3) of the ACA ([45 CFR § 155.170](#)), which indicates that new mandates related to specific care, treatment, or services not offered under the general essential health benefits (EHB) package in the state prior to January 1, 2012 must have associated costs defrayed by the state. The state is only required to defray associated costs that would not have been provided by the health carrier without the requirements of the new mandate.

Per the EHB final rule¹, costs associated with benefit mandates passed prior to or on December 31, 2011 do not need to be defrayed by the state.

Evaluation of Mandated Health Benefit Proposal

The Department’s evaluation of HF1041-1E includes the following elements in order to meet criteria under Minn. Stat. §62J.26:

- Solicitation of feedback from potential stakeholders by publishing a request for information notice in the State Register
- Scoping review of available literature in PubMed
- Hybrid umbrella/systematic literature review of available resources
- Consultation with the Department of Health and MMB
- Solicitation of comments from health plans, including request for actuarial analysis

Additional information regarding the Department’s literature review protocol may be found in the Appendix.

In the Department’s evaluation, HF1041-1E does constitute a benefit mandate requiring state defrayal of associated costs, as understood under the ACA². Some of the requirements are related to specific care, treatment or services that are not covered by the benchmark plan. The benchmark plan provides coverage for some of the medical/dental services identified in HF1041-1E, but not all that are noted in the proposed bill. The bill is also open-ended on treatment that is required to be covered, which is likely to include services not covered by health plans currently. Ectodermal dysplasia is mentioned in the state’s benchmark plan medical

¹ 45 CFR Parts 147, 155, and 156 Patient Protection and Affordable Care Act; Standards Related to Essential Health Benefits, Actuarial Value, and Accreditation; Final Rule. Accessed at <https://www.govinfo.gov/content/pkg/FR-2013-02-25/pdf/2013-04084.pdf>.

² 45 CFR § 155.70. Additional required benefits. Accessed at: <https://www.law.cornell.edu/cfr/text/45/155.170>

coverage criteria, noting that requests for coverage of breast surgery associated with this diagnosis will be evaluated on a case-by-case basis.³

In analyzing the benchmark plan coverage criteria, Commerce concludes that services related to ectodermal dysplasia would be covered for potentially two-thirds of the categories of coverage requirements established under the bill. Breast surgery/reconstruction appears to be the only explicitly indicated service in HF1041-1E that has both a medical coverage policy associated with the benchmark plan, and indication of potential coverage upon review.

The state's benchmark plan includes coverage for orthodontia, oral surgery, anesthesia and ambulatory hospitalization when considered to be medically necessary.^{4, 5, 6} Most consistently, these policies limit coverage to services that treat an underlying medical condition. Based on the medical necessity requirements contained in the criteria, it is reasonable to assume that HF1041-1E is at least a partial state benefit mandate, requiring defrayal of cost under the ACA.

Commerce's analysis in this report is consistent with previous analyses of potential state mandated benefits in previous legislative sessions. While a mandated health benefit proposal may contain language that is related to care and treatment of a specific health condition, it is necessary to consider if the mandated benefits in a given bill are already covered under state's benchmark plan. If services/items are not currently covered or have not been covered by the benchmark plan previously, then the proposal is a new state mandated benefit requiring defrayal of cost from the state.

This approach is consistent with the Department's analysis of HF306⁷ passed during the 2019-2020 legislative session requiring health plans to provide treatment related to pediatric autoimmune neuropsychiatric disorders associated with streptococcal infections (PANDAS) and pediatric acute-onset neuropsychiatric syndrome (PANS). House File 306 mandated coverage for PANDAS/PANS treatment, including outpatient mental health services, prescription drugs, and intravenous immunoglobulin services. While some services were covered by the benchmark plan, intravenous immunoglobulin services were not; Commerce's analysis considered this to be a new benefit mandate, given its previous lack of coverage.

³ Breast surgery. HealthPartners medical coverage criteria. Accessed at https://www.healthpartners.com/public/coverage-criteria/policy.html?contentid=AENTRY_045829.

⁴ Dental services – orthodontia. HealthPartners medical coverage criteria. Accessed at https://www.healthpartners.com/public/coverage-criteria/policy.html?contentid=AENTRY_046067

⁵ Dental services – ambulatory hospitalization and anesthesia for dental care. HealthPartners medical coverage criteria. Accessed at https://www.healthpartners.com/public/coverage-criteria/policy.html?contentid=AENTRY_045878

⁶ Dental services – medically necessary outpatient. HealthPartners medical coverage criteria. Accessed at https://www.healthpartners.com/public/coverage-criteria/policy.html?contentid=AENTRY_045880

⁷ Minnesota Statutes, 2019, §62A.3097. Full text available at: <https://www.revisor.mn.gov/statutes/2019/cite/62A.3097>

Scientific and Medical Analysis

Scientific and Medical Background

Ectodermal dysplasia includes a group of over 100 inherited genetic disorders that are characterized by anomalies in at least two structures of the embryonic ectoderm (the outermost layer of cells in embryonic development). The ectodermal layer forms skin, sweat glands, hair, teeth, and nails.

Symptoms of ectodermal dysplasia can include abnormalities in the areas described above, including skin and teeth problems, sparse or lack of hair, or inability to perspire (hypohidrosis). Different types of EDs are caused by mutations in different genes and can be inherited in a variety of ways.

Variants of ectodermal dysplasia include the following:

- Hypohidrotic ectodermal dysplasia
- Hypohidrotic ectodermal dysplasia with immune deficiency
- Hidrotic ectodermal dysplasia

No cure currently exists for ectodermal dysplasia or any variant, and treatments focus on individual presentation of symptoms relative to the variants listed above.

Potential for Harm or Benefit

The potential for harm resulting from the passage of HF1041-1E would be extremely low. The bill expands and adds coverage requirements for a number of treatments primarily related to dental services not typically covered by health plans. As a result of the expansion of coverage, the potential for benefit is high for those impacted.

Public Health, Economic, and Fiscal Impact

The following definitions apply for this and subsequent sections:

Public Health: The science and practice of protecting and improving the health and wellbeing of people and their communities. The field of public health includes many disciplines, including medicine, public policy, biology, sociology, psychology and behavioral sciences, and economics and business.

Economic Impact: The general financial impact of a drug, service, or item on the population prescribing or utilizing a particular drug, service or item for a particular health condition.

Fiscal Impact: The quantifiable dollar amount associated with the implementation of the mandated health benefit proposal. The areas of potential fiscal impact that the Department reviews for are the cost of defrayal of benefit mandates as understood under the ACA, the cost to SEGIP, and the cost to other state public programs. The fiscal impact is expressed in number of dollars required for the state to implement a proposal.

The impact of HF1041-1E on public health generally, as well as its overall economic and fiscal impact, is contingent on understanding the prevalence of the conditions and the projected utilization of associated services. The Department did not receive public comment regarding HF1041-1E that provided additional

information on potential public health impact. The Department did, however, receive comments regarding potential economic and fiscal impact of the bill.

Public Health

While increased access to coverage would help individuals with ectodermal dysplasia and would likely lead to improved health outcomes, the impact of HF1041-1E on overall public health in Minnesota would need to be considered based on the number of individuals impacted by ectodermal dysplasia and the subsequent need for treatment of related symptoms inherent to the condition. Several treatment options are available for secondary issues related to ectodermal dysplasia. Dental care and appearance-related interventions would very likely have a positive impact on individuals with any variant of ectodermal dysplasia. The expansion or solidification of coverage through legislation under HF1041-1E would likely allow for more impacted individuals to address secondary symptoms related to ectodermal dysplasia—resulting in potentially higher quality of life.

The Department did not receive any additional information regarding the potential public health impact of HF1041-1E.

Economic

Coverage requirements under HF1041-1E specifically includes scalp hair prostheses, dental and orthodontia services, as well as medical/surgical services to address related symptoms. The language in the bill specifies that these and other services must be covered with a qualifier of, “included but not limited to,” leaving the possibility of potential mandated coverage for services not currently specified in the bill.

The overall economic impact of HF1041-1E is difficult to determine with full accuracy due to the variability of services that could be utilized in addressing symptoms of ectodermal dysplasia. Increased utilization would be expected following passage of HF1041-1E, but the extent to which that would impact the overall cost of treatments related to the services in the bill is unclear. Treatment for ectodermal dysplasia is complex, individualized based on symptom presentation, and multidisciplinary.

Fiscal

Some services indicated under House File 1041-1E are not likely to be covered by the benchmark plan. Specifically, the dental treatments identified in the bill would not be covered under any health plan normally, as the required services do not specifically treat the actual underlying medical condition.

HF1041-1E does include language that acknowledges that dental plans should be the primary payer in instances where its specified coverage requirements are already a covered benefit under a dental plan. The benchmark plan does provide coverage for certain medical-dental services currently, but with limitations surrounding medical necessity.

Generally, health plans only cover dental services for enrollees when there is a specific medical issue being addressed. None of the dental treatments listed in HF1041-1E directly treat ectodermal dysplasia, and, as a result, would not be covered by a health plan. This does not preclude the possibility that some of the services

specifically identified under HF1041-1E may be covered by some plans, but they are not expressly available to policyholders who need dental services stemming from ectodermal dysplasia.

Additional interventions that are not explicitly listed in HF1041-1E would need to be assessed relative to current benchmark plan coverage to determine if they would constitute a new state mandated benefit requiring defrayal of associated costs.

Given the likelihood that most, if not all the dental interventions in HF1041-1E constitute new state mandated benefits, the Department must consider the cost of defraying these services.

Analysis from MMB assessed prevalence of the condition in membership of health plans that administer SEGIP, potential increases in utilization, and the potential for future high-cost cases. Their analysis projected a per-member-per-month (PMPM) increase ranging from \$0.00 to \$0.13 PMPM. The overall fiscal impact of HF1041-1E in subsequent fiscal years is estimated in the following table.

Fiscal Year	2022	2023	2024	2025	2026
SEGIP fiscal impact ⁸	\$0	\$33,995	\$71,388	\$74,958	\$78,705

The text of HF1041-1E indicates that Medical Assistance and MinnesotaCare cover services for treatment of ectodermal dysplasia, but specifies that coverage must comply with amending language to Minn. Stats. §§ 62A.25, 62A.28, and 62A.3096, which explicitly list ectodermal dysplasia as a diagnosis eligible for existing coverage.

Thus, HF1041-1E will have a fiscal impact on the state based on increased utilization projected under SEGIP and also based on the bill being considered a benefit mandate under the ACA.

Current Utilization

Current utilization of treatment for individuals with ectodermal dysplasia is difficult to fully quantify. As mentioned, treatment focuses on symptoms related to the condition, so there are many interventions and specialties potentially involved.

Interventions may be related to the following secondary conditions:

- Hypodontia, or abnormal teeth
- Hypotrichosis
- Dry skin
- Abnormal respiratory mucous

⁸ Figures in this table represent the cost to the state from SEGIP impact. The total cost impact to the SEGIP plan—specifically, adding in the employee share of the overall premium—will be higher.

- Hearing impairment
- Dry eyes

These conditions are not necessarily managed by any one medical specialty, and it is not known with available resources the extent to which impacted individuals may need to utilize one or all types of services associated. Interventions could additionally include dermatological consultation, orthodontia, additional primary care services, pulmonary specialist intervention, ophthalmology, and pharmacist consultation.

Current Health Insurance Coverage

Health plans offering EHBs must provide coverage substantially equal to that of the state's benchmark plan. The HealthPartners Open Access Choice Small Employer health plan from 2017 remains Minnesota's benchmark plan. This plan contains no exclusions for ectodermal dysplasia treatment, and it does contain coverage for medical/dental treatment, as well as scalp hair prostheses. Medical/dental treatment under the benchmark plan is currently subject to utilization review for medical necessity. Reconstructive surgery is also a covered benefit under the plan, but with no specific provision related to ectodermal dysplasia. Scalp hair prostheses are covered under the benchmark plan, but only with the diagnosis of alopecia areata, consistent with Minn. Stat. §62A.28.

Impact on Insurance Benefits

Requirements under House File 1041-1E apply to all fully insured health plans, including individual health plans, group health plans, health carriers, health maintenance organizations (HMOs) and health service plan corporations defined under [Minn. Stat. §62A.011](#). The requirements also apply to health plan companies defined under [Minn. Stat. §62Q.01](#), as well as to SEGIP. House File 1041-1E also extends its specific requirements to Medical Assistance and MinnesotaCare plans, which are noted to provide coverage for ectodermal dysplasia treatment generally.

House File 1041-1E requirements do not apply to self-insured employer plans, Medicare, or Medicare supplemental policies.

All listed interventions in HF1041-1E have some basis in coverage under the benchmark plan, which currently covers scalp hair prostheses, surgical interventions, and some dental services. House File 1041-1E adds the requirement that these, and potentially additional services, must be covered for the diagnosis of ectodermal dysplasia. Many services included under the bill are likely to be subject to utilization review requirements. Given the low prevalence of the condition, the addition of coverage for associated treatments would be unlikely to cause a significant change to costs.

Impact on Health Insurance Premiums

The Department consulted with MMB regarding potential impact on health plan premiums and has concluded there would be a negligible increase to health plan premiums in any regulated market. The estimated increase by MMB to per member per month (PMPM) premiums was estimated to be \$0.05.

Commerce placed a request for information in the November 22, 2021 publication of the State Register, soliciting comments regarding all mandated health benefit proposals, including HF1041-1E. The Department received feedback from health plans generally. No specific comment from a stakeholder or advocacy group was submitted for this bill.

Public Comments Summary

The Department placed a request for information in the November 22, 2021 publication of the [State Register](#), requesting comments regarding all mandated health benefit proposals, including HF1041-1E. The Department received feedback from health plans, generally. No specific comment from other stakeholder or advocacy groups was submitted for this bill.

In summary, the comments received from health plans affirmed the Department's analysis regarding the overall economic impact of HF1041-1E and the potential for it to increase enrollee premiums by a very small degree. According to their comments, there is extremely low prevalence associated with the condition and it would be unlikely that HF1041-1E would increase enrollee premiums in a substantial amount. Health plans generally mirrored the difficulty of determining precise impact associated with all available interventions for ectodermal dysplasias.

ACA Benefit Mandate Impact and Analysis

The services required under HF1041-1E may be covered by the benchmark plan in Minnesota and therefore also by most other plans offering EHBs. The ACA requires states to defray the cost of benefit mandates passed after December 31, 2011. According to the ACA, a benefit mandate is one passed by the state that imposes requirements of health plans to cover new services or items related to specific care or treatment. Under the ACA, a state may enact requirements unrelated to specific care, treatment, or services and not be responsible for defraying the cost, generally falling into the following:

1. **Provider Types.** Mandates that require a covered service to be covered by additional health care provider types.
2. **Cost-Sharing.** Mandates that require or change cost-sharing amounts for covered services, including deductibles, copayments, and coinsurance.
3. **Delivery Methods.** Mandates that require health carriers to cover new methods of delivering covered services (telehealth for example).
4. **Reimbursement Methods.** Mandates that require health carriers to reimburse health care providers for covered services provided in new ways.
5. **Dependent-Coverage.** Mandates that require health carriers to define dependents in a certain way or to cover dependents under specific circumstances.
6. **ACA Conforming Coverage.** Mandates required to comply with ACA requirements.

The requirements of HF1041-1E expand coverage that is partially offered under the benchmark plan. All three categories of services—reconstructive surgery, scalp hair prostheses, and dental services—have some form of coverage under the benchmark plan. It remains difficult to fully ascertain what other treatments may be included as a result of passing HF1041-1E. The additional treatments would be expected to be considered a state benefit mandate.

Appendix

Bill Text

1.1 A bill for an act

1.2 relating to health insurance; requiring coverage for treatments related to ectodermal

1.3 dysplasias;amending Minnesota Statutes 2018, sections 62A.25, subdivision 2;

1.4 62A.28, subdivision 2; 256B.0625, by adding a subdivision; proposing coding for

1.5 new law in Minnesota Statutes, chapter 62A.

1.6 BE IT ENACTED BY THE LEGISLATURE OF THE STATE OF MINNESOTA:

1.7 Section 1. Minnesota Statutes 2018, section 62A.25, subdivision 2, is amended to read:

1.8 Subd. 2.Required coverage. (a) Every policy, plan, certificate or contract to which this

1.9 section applies shall provide benefits for reconstructive surgery when such service is

1.10 incidental to or follows surgery resulting from injury, sickness or other diseases of the

1.11 involved part or when such service is performed on a covered dependent child because of

1.12 congenital disease or anomaly which has resulted in a functional defect as determined by

1.13 the attending physician.

1.14 (b) The coverage limitations on reconstructive surgery in paragraph (a) do not apply to

1.15 reconstructive breast surgery: (1) following mastectomies; or (2) if the patient has been

1.16 diagnosed with ectodermal dysplasia and has congenitally absent breast tissue or nipples.

1.17 In these cases, Coverage for reconstructive surgery must be provided if the mastectomy is

1.18 medically necessary as determined by the attending physician.

1.19 (c) Reconstructive surgery benefits include all stages of reconstruction of the breast on

1.20 which the mastectomy has been performed, including surgery and reconstruction of the

1.21 other breast to produce a symmetrical appearance, and prosthesis and physical complications

1.22 at all stages of a mastectomy, including lymphedemas, in a manner determined in consultation

1.23 with the attending physician and patient. Coverage may be subject to annual deductible,

2.1 co-payment, and coinsurance provisions as may be deemed appropriate and as are consistent

2.2 with those established for other benefits under the plan or coverage. Coverage may not:

2.3 (1) deny to a patient eligibility, or continued eligibility, to enroll or to renew coverage

2.4 under the terms of the plan, solely for the purpose of avoiding the requirements of this

2.5 section; and

2.6 (2) penalize or otherwise reduce or limit the reimbursement of an attending provider, or

2.7 provide monetary or other incentives to an attending provider to induce the provider to

2.8 provide care to an individual participant or beneficiary in a manner inconsistent with this

2.9 section.

2.10 Written notice of the availability of the coverage must be delivered to the participant upon

2.11 enrollment and annually thereafter.

2.12 EFFECTIVE DATE. This section is effective January 1, 2020, and applies to health

2.13 plans offered, issued, or sold on or after that date.

2.14 Sec. 2. Minnesota Statutes 2018, section 62A.28, subdivision 2, is amended to read:

2.15 Subd. 2.Required coverage. Every policy, plan, certificate, or contract referred to in
2.16 subdivision 1 issued or renewed after August 1, 1987, must provide coverage for scalp hair
2.17 prostheses worn for hair loss suffered as a result of alopecia areata or ectodermal dysplasias.
2.18 The coverage required by this section is subject to the co-payment, coinsurance,
2.19 deductible, and other enrollee cost-sharing requirements that apply to similar types of items
2.20 under the policy, plan, certificate, or contract and may be limited to one prosthesis per
2.21 benefit year.

2.22 EFFECTIVE DATE. This section is effective January 1, 2020, and applies to health
2.23 plans offered, issued, or sold on or after that date.

2.24 Sec. 3. [62A.3096] COVERAGE FOR ECTODERMAL DYSPLASIAS.

2.25 Subdivision 1.Definition. For purposes of this chapter, "ectodermal dysplasias" means
2.26 a genetic disorder involving the absence or deficiency of tissues and structures derived from
2.27 the embryonic ectoderm.

2.28 Subd. 2.Coverage. A health plan must provide coverage for the treatment of ectodermal
2.29 dysplasias.

3.1 Subd. 3.Dental coverage. (a) A health plan must provide coverage for dental treatments
3.2 related to ectodermal dysplasias. Covered dental treatments must include but are not limited
3.3 to bone grafts, dental implants, orthodontia, dental prosthodontics, and dental maintenance.
3.4 (b) If a dental treatment is eligible for coverage under a dental insurance plan or other
3.5 health plan, the coverage under this subdivision is secondary.

3.6 EFFECTIVE DATE. This section is effective January 1, 2020, and applies to health
3.7 plans offered, issued, or sold on or after that date.

3.8 Sec. 4. Minnesota Statutes 2018, section 256B.0625, is amended by adding a subdivision
3.9 to read:

3.10 Subd. 66.Ectodermal dysplasias. Medical assistance and MinnesotaCare cover
treatment

3.11 for ectodermal dysplasias. Coverage must meet the requirements of sections 62A.25, 62A.28,
3.12 and 62A.3096. This subdivision applies to services delivered under fee-for-service or by a
3.13 managed care plan under section 256B.69, a county-based purchasing plan under section
3.14 256B.692, or an integrated health partnership under section 256B.0755.

3.15 EFFECTIVE DATE. This section is effective January 1, 2020.

Associated Codes

Diagnosis (ICD-10) Code(s):

Q82.4 – Ectodermal dysplasia

Q82.8 Other specified congenital malformations of skin

CPT Code(s):

N/A*

HCPCS Code(s):

N/A

NDC Code(s):

N/A

*The number of codes possible to add here would be extremely large and is continuing to be researched. A separate document may be needed for the

Description of Review

The Department performed an umbrella review of available information related to ectodermal dysplasia. An umbrella review is similar to a systematic literature review, but with a focus on reviewing relevant information or studies that are essentially other systematic reviews and/or meta-analyses. This approach allows for gathering of significant high-level, but pertinent, information regarding the topic being researched.

The Department searched PubMed utilizing combinations of the terms “ectodermal dysplasia(s),” “treatment,” “standard of care,” “experimental,” “investigative,” and “alternative treatment.” The search limited these terms to peer-reviewed articles published in the last 20 years.

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