MANDATED BENEFIT REVIEW OF HOUSE BILLS 988, 1036, 1050, 1116, & SENATE BILL 563 SUBMITTED TO THE 191ST GENERAL COURT:

AN ACT RELATIVE TO ENSURING TREATMENT FOR GENETIC CRANIOFACIAL CONDITIONS

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CHIA.

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1.1 History of the Bill

The Committee on Financial Services referred House Bills (H.B.s) 988, 1036, 1050, 1116, and Senate Bill (S.B.) 563, all entitled "An Act relative to ensuring treatment for genetic craniofacial conditions,"[1] to the Center for Health Information and Analysis (CHIA) for review. Massachusetts General Laws (MGL) Chapter 3 §38C requires CHIA to review the medical efficacy of treatments or services included in each mandated benefit bill referred to the agency by a legislative committee, should it become law. CHIA must also estimate each bill's fiscal impact, including changes to premiums and administrative expenses.

This report is not intended to determine whether H.B.s 988, 1036, 1050, 1116, and S.B. 563 would constitute a health insurance benefit mandate for purposes of state defrayal under the Affordable Care Act, nor is it intended to assist with state defrayal calculations if it is determined to be a health insurance benefit mandate requiring state defrayal. The language in each bill is the same; for the remainder of the report, "the bill" will collectively refer to H.B.s 988, 1036, 1050, 1116, and S.B. 563.

1.2 What Does the Bill Propose?

As submitted in the 191st General Court of the Commonwealth of Massachusetts (Commonwealth), the bill requires carriers to provide coverage for medically necessary functional repair or restoration of craniofacial disorders (CFDs) to improve the function of, or approximate the normal appearance of, any abnormal structures caused by congenital[i,2] disease or anomaly except for coverage for cleft lip and cleft palate, which is prescribed elsewhere in MGL.[ii] The coverage shall include the necessary care and treatment of medically diagnosed congenital disease or anomaly, including, but not limited to, ectodermal dysplasia (ED), dentinogenesis imperfecta (DI), and amelogenesis imperfecta (AI). As set forth in the bill, coverage shall not include cosmetic surgery or dental or orthodontic treatment unrelated to the congenital disease or anomaly. Further, the benefits "shall not be subject to any greater deductible, coinsurance, copayments, or out-of-pocket limits than any other benefit provided by an insurer."

Upon receiving the bill, CHIA and its consultants submitted an inquiry to the sponsoring legislators and staff to clarify the bill's intent. The sponsors clarified the following. The bill's intent is to:

- Provide coverage for three specific genetic CFDs: ED, DI, and AI.
- Require coverage for all ages.

[i] Congenital conditions are those present at birth and can be caused by a genetic mutation, an unfavorable environment in the uterus, or a combination of both factors.

[ii] M.G.L. c.175 §47BB, c.176A §8EE, c.176G §4W, and c.32 §17J.

- Require all services, including medical, surgical, and dental, to be covered as medical benefits of a health plan.

1.3 Medical Efficacy of the Bill

A CFD refers to an abnormality of the face and/or the head and might include disfigurement brought about by birth defect, disease, or trauma.[3] When the cause of the CFD is congenital, abnormalities are typically referred to as craniofacial anomalies (CFAs). Representing a diverse group of deformities in the growth of the head and facial bones, some CFAs are mild, while some are severe and require surgery.[4] CFAs might also be associated with anomalies elsewhere in the body, which can be serious.[5,6] CFAs other than cleft lip and palate occur in 1 in every 1,600 newborns in the United States; they include jaw deformities, malformed or missing teeth, defects in the ossification of facial or cranial bones, and facial asymmetries.[7] CFA's impact on speech, hearing, appearance, and cognition can have a prolonged and adverse influence on health and social integration.[8] The bill would require coverage for medically necessary, functional repair or restoration of CFAs to improve the function of, or approximate the normal appearance of, any abnormal structures caused by ED, DI, and AI. The bill also requires that coverage include the necessary care and treatment of medically diagnosed ED, DI, and AI. While there are thousands of CFAs, each with a different etiology,[9] this report is limited to the review of CFAs caused by ED, DI, and AI.

The goal of treating CFAs is to help restore the jaw and facial structures, leading to normal function and appearance while also taking into consideration nutrition, speech, and hearing as well as emotional and psychological development.[10] Surgical and dental procedures to treat CFAs are often required throughout life and are performed not for aesthetics, but for reconstructive purposes.[11,12] Allowing patients to grow and function normally, a multistage correctional approach often involving the jaw as well as the teeth can significantly improve a patient's quality of life.[13,14] Although ED, DI, and AI are all associated with dental problems, the symptoms are not limited to dental problems and might include the following:

- ED often requires treatment to address its impact on skin, sweat glands, hair, teeth, and nails.[15]
- Patients with DI might also have osteogenesis imperfecta (OI), a genetic condition in which bones are brittle, causing them to break easily and requiring treatment.[16]
- AI might also be associated with morphologic and biochemical changes elsewhere in the body.[17,18]

1.4 Current Coverage

The Commonwealth currently mandates coverage for newly born infants and adoptive children for the necessary care and treatment of medically diagnosed congenital defects and birth abnormalities.[iii] BerryDunn surveyed 10 insurance carriers in the Commonwealth, and 7 responded. All respondent carriers currently cover surgical and medical treatment for genetic craniofacial conditions, including oral surgery. One carrier indicated that oral surgery is not covered in the large group market. None of the carriers cover preventive and restorative dentistry needed to support orthodontic and prosthetic therapy related to the three specific conditions in the proposed mandate. One carrier

[iii] MGL c 175, § 47C; MGL c 176A, § 8B; and MGL c 176B, § 4C.

indicated its qualified health plan (QHP) products include coverage for pediatric dental services, which includes restorative and orthodontic services for the conditions specific to the proposed mandate.

1.5 Cost of Implementing the Bill

Requiring coverage for this benefit by fully insured health plans would result in an average annual increase, over five years, to the typical member's monthly health insurance premium of between $0.10 and $0.28 per member per month (PMPM), or between 0.017% and 0.045% of premium. The impact on premiums is driven by the cost of adding coverage for the extensive dentistry services needed for treatment of CFAs.

1.6 Plans Affected by the Proposed Benefit Mandate

The bill applies to commercial, fully insured health insurance plans, hospital service corporations, medical service corporations, HMOs, and to both fully and self-insured plans operated by the Group Insurance Commission (GIC) for the benefit of public employees. The proposed mandate as drafted affects Medicaid/MassHealth; however, CHIA's analysis does not estimate the potential effect of the mandate on Medicaid expenditures.

1.7 Plans Not Affected by the Proposed Benefit Mandate

Self-insured plans (i.e., where the employer or policyholder retains the risk for medical expenses and uses a third-party administrator or insurer to provide only administrative functions), except for those provided by the GIC, are not subject to state-level health insurance mandates. State mandates do not apply to Medicare and Medicare Advantage plans or other federally funded plans, including TRICARE (covering military personnel and dependents), the Veterans Administration, and the Federal Employees Health Benefit Plan, the benefits for which are determined by or under rules set by the federal government.

2.0 Medical Efficacy Assessment

The bill, as submitted in the 191st General Court, would require fully insured plans to provide coverage for medically necessary functional repair or restoration of CFDs to improve the function of, or approximate the normal appearance of, any abnormal structures caused by congenital disease or anomaly.[19]

MGL Chapter 3 §38C charges the Commonwealth's CHIA with reviewing the medical efficacy of proposed mandated health insurance benefits. Medical efficacy reviews summarize current literature on the effectiveness and use of the mandated treatment or service and describe the potential impact of a mandated benefit on the quality of patient care and health status of the population.

The report proceeds in the following sections:

- Section 2: Medical Efficacy Assessment
  - Section 2.1 describes the genetic conditons causing CFAs
  - Section 2.1.1 provides the incidence and prevalence of ED, DI, and AI
  - Section 2.2 details medically necessary treatment
  - Section 2.2.1 decribes the dental treatment
  - Section 2.2.2 discusses other treatment that might be required
  - Section 2.2.3 describes treatment efficacy

2.1 Genetic Conditions causing CFAs

CFAs are caused by many genetic conditions, including, but not limited to: Antley-Bixler Syndrome, Carpenter syndrome, Coffin-Lowry syndrome, Crouzon syndrome, and Treacher Collins syndrome.[20] Research on the genetic basis of CFAs has increased dramatically over the past decade, resulting in genes being either mapped to a chromosome location or actively isolated in over 50 syndromes causing CFAs.[21] The genetic conditions considered by the proposed mandate are ectodermal dysplasia (ED), dentinogenesis imperfecta (DI), and amelogenesis imperfecta (AI), which might occur alone or in combination with other genetic conditions.

The term ED refers to the abnormal development (dysplasia) of structures derived from one of the germ cell layers in the embryo (ectoderm).[22] ED is a **genetic disorder** with anomalies in a minimum of two of the structures derived from the embryonic ectoderm with at least one involving the skin appendages (hair, nails, and sweat glands) or teeth.[23] For patients with ED, other parts of the body, such as the eyes or throat, might also be affected.[24] Because more than 180 different types of EDs exist, early diagnosis allows for identification of which symptoms might manifest, even though many ED types share common symptoms ranging from mild to severe.[25] This combination of physical features and the method by which a disorder is inherited determines if it is an ED; and if so, which type.[26] Hypohidrotic ectodermal dysplasia (HED), for instance, affects the hair, teeth, and sweat glands, while Clouston syndrome affects the hair and nails.[27] Patients with HED, the most common form of ED, have several missing teeth or teeth that are malformed, such as those erupting from the gums later than usual or being small and pointy.[28]

DI is a tooth development disorder that causes teeth to be discolored.[29,30] The teeth in patients with DI are also weaker than normal, which makes them prone to rapid wear, breakage, and loss. These problems affect both primary (baby) teeth and permanent teeth.[31] There are three types of DI with similar dental abnormalities as described by researchers. Type I occurs in people who have **OI**,[32] a genetic condition in which bones are brittle and easily broken, while type II and type III usually occur in people without other inherited disorders.

AI is a disorder of tooth development causing **teeth to be unusually small**, discolored, pitted or grooved, and prone to rapid wear and breakage.[33,34] In patients with AI, other dental abnormalities are also possible and these defects, which vary among affected individuals, can affect both primary (baby) teeth and permanent (adult) teeth.[35] Researchers have described at least 14 forms of AI with the types distinguished by their specific dental abnormalities and by their pattern of inheritance.[36] Although AI is a disorder primarily associated with dental problems with treatments limited to the jaw and teeth, it might also be associated with morphologic and biochemical changes elsewhere in the body.[37,38]

2.1.1 Incidence and Prevalence of ED, DI, and AI

As a highly diverse group of complex congenital anomalies, CFAs collectively affect a significant portion of the global population, with the prevalence of individual conditions varying considerably across geographic areas and ethnic groupings.[39] However, this bill only requires coverage of ED, DI, and AI, which are extremely rare disorders with low prevalence. According to the National Foundation for Ectodermal Dysplasias (NFED), an estimated 3.5 in 10,000 people are affected by ED. It is difficult to know the prevalence with certainty because ED is considered a rare disorder, impacting fewer than 200,000 people in the United States.[40] This rarity makes conducting a study to determine exact numbers of impacted individuals challenging and expensive.[41] As the most common form of ED, HED is estimated to occur in 1 in 20,000 newborns worldwide.[42] Overall, DI affects an estimated 1 in 6,000 to 8,000 people.[43] The exact incidence of AI is uncertain with estimates varying widely, from 1 in 700 people in northern Sweden to 1 in 14,000 people in the United States.[44,45] Given the rarity of these disorders, our literature review found no state-level prevalence data for ED, DI, and AI.

2.2 Treatment of ED, DI, and AI

Treatment of CFAs depends on the type of problem and might involve plastic and reconstructive surgery, dental-related procedures such as orthodontia and dental implants, or other medical interventions to treat other affected parts of the body.[46,47,48] As a result, care for patients with CFAs is mostly treated by an interdisciplinary team beginning in early childhood.[49] Early diagnosis is crucial for the effective treatment of functional and developmental aspects of these syndromes. Unfortunately, treatment is often complicated by delayed diagnosis, especially in the absence of known family history.[50]

2.2.1 Dental Treatment

Early detection of the syndrome affecting the craniofacial structures improves long-range treatment planning.[51] ED, DI, and AI affect the teeth, albeit differently. Thus, the timing and types of treatment for these CFAs thus vary by condition and across patients. Prompt initiation of dental treatment for children with a CFA improves outcomes, especially for those without teeth.[52,53,54] Patients with ED, DI, or AI might only have dental abnormalities, while others

have no teeth or malocclusions[iv] that could impact jaw growth. A wide range of treatment modalities might thus be provided depending on the individual presentation for each of these genetic conditions. The different types of dental specialties involved in the treatment of ED, DI, and AI are:

- Prosthodontics – the replacement of missing parts of teeth, bone, gums, or facial structures, which might be fixed (crowns and bridges) or removable (dentures) [55]
- Orthodontics – the prevention and correction of misaligned teeth in jaws as well as the proper position of the jaws in the face[56]
- Dental Implants – the replacement of missing teeth[57]
- Orthognathic surgery – the correction of dentofacial deformities and malocclusions[58]

In patients with ED, the teeth are markedly reduced in number and often develop abnormally in shape; as a result, the incisors often appear tapered, conical, or pointed in shape, and molars are reduced in size.[59] The dental treatment modalities for ED vary depending on clinical manifestations and might include prosthodontics, orthodontics, and dental implants.[60] Because hypodontia[v] of the primary and permanent dentition is the most common oral presentation in ED, affected patients need dental prosthetic treatments to replace the teeth during their developmental years.[61] For children with no teeth, as commonly occurs with ED, or very soft teeth, dentures are often recommended by the time a child starts school, but children as young as 2 ½ years old can successfully wear dentures, as they provide the following benefits:[62]

- Improve nutrition by allowing for a wide variety of foods
- Improve smiles
- Create an age-appropriate facial appearance
- Improve speech
- Stimulate tooth eruptions when tooth buds are present
- Positively affect psychological and emotional well-being

Management of the different clinical manifestations associated with ED presents a unique clinical challenge for prosthodontists, and the long-term success of treatment depends on regular appointments and maintenance of oral and prosthetic hygiene.[63]

For patients with DI, the primary goals for treatment are to remove sources of infection or pain, restore aesthetics, and protect the posterior teeth from wear.[64,65,66] Treatment varies according to the patient's age, case severity, and presenting complaint.[67] Because the patient's type of DI impacts the level of bone fragility, dentists must be cautious when performing surgical procedures on patients prone to fracture.[68] Some patients present with severe tooth wear in permanent dentition; as in the primary dentition, one option is over-dentures.[69] Treatment options include **amalgams** as dental fillings, veneers to fix the discoloration of teeth, **crowns**, caps, and

[iv] Malocclusion means the teeth are not aligned properly.

[v] Hypodontia is the developmental absence of one or more teeth excluding the third molars.

bridges.[70] **Dentures** or dental implants might be necessary if the patient has lost the majority of his or her teeth. Some dentists might also recommend **resin restorations** and teeth bleaching.[71] Oral health management, including oral hygiene introduction (regular brushing and flossing to avoid tooth chipping and potential fracture during dental procedures), and crown restoration should be applied to prevent caries and periodontitis, and to optimize aesthetics.[72]

AI treatment depends on the specific type of AI and the character of the affected enamel, which ranges from preventive care using sealants and bonding for aesthetics to extensive removable and fixed prosthetic reconstruction.[73] Given the diverse dental and skeletal manifestations resulting from the different types of AI, treatments can require intervention from various dental disciplines. Treatments might include: dentures that cap the teeth (full crown restorations); orthodontic treatment; surgical interventions for malocclusions; bonding; and special toothpaste for the tooth sensitivity.[74,75] The problems of socialization, function, and discomfort for patients with AI may be managed with early and vigorous interventions, both preventive and restorative, with treatment continued throughout childhood and into adult life.[76]

2.2.2 Other Treatment

Beyond the treatments necessary to address the CFAs associated with ED, DI, and AI set forth in the bill, the coverage shall include the necessary care and treatment of medically diagnosed congenital disease or anomaly. Patients with CFAs might need treatments for other parts of the body.

There are many options for treatment for patients with ED to address symptoms that might involve the skin, hair, nails, sweat glands, eyes, ears, nose, throat, respiratory system, gastrointestinal issues, and growth and nutrition.[77] These treatments are no different than those that would be offered to patients with similar symptoms without a diagnosis of ED. Up to 50% of patients with ED, especially HED, have atopic dermatitis,[78] which can often be treated with over-the-counter medications, but might require the consultation of a physician.[79] For the symptoms affecting the hair, which is often brittle, there are no treatments that can change the structure of the hair. As a result, care is directed toward preventing damage to the hair shafts.[80] Patients with ED are not good candidates for hair transplants because of the lack of donor hair; however, some hair growth products might be of benefit, and wigs can improve a patient's self-image.[81] Treating the nail problems can be difficult, as there are very limited therapies available, and medications will treat secondary infections but will not correct the inborn nail defects.[82] Preventive measures might be necessary to address frequent nosebleeds.[83] In most patients with ED, the eye and vision problems are not different than those in the general population and would require the same treatments.[84]

Patients with DI might also have OI. OI is a genetic disorder that mainly affects the bones but it might also result in hearing loss, respiratory problems, blue sclera of the eyes, and joint deformities.[85] OI treatment is directed toward specific symptoms and might include: exercise and physical therapy programs; placing metal rods in the long bones to prevent fractures; surgery for severely malformed bones; and assessment of hearing impairment.[86]

The provision of these treatments should be currently covered pursuant to MGL Chapter 175, § 47C; MGL Chapter 176A, § 8B; and MGL Chapter 176B, § 4C, which provides coverage for newly born infants and adoptive children, including the necessary care and treatment of medically diagnosed congenital defects and birth abnormalities. However, some treatments might be considered cosmetic, such as a wig to address the hair symptoms in ED.

2.2.3 Treatment Efficacy

The outcomes for patients with ED, DI, and AI largely depend upon the age at which the diagnosis was given, as well as the speed and quality of treatment provided.[87,88,89] When diagnosis and treatment occur early in life and treatment follows, good aesthetics and function can be obtained, thereby minimizing nutritional deficits and psychological stress.[90] Patients with AI have been known to cover their teeth with pieces of paper, chewing gum or other material in order to mimic an ordinary appearance; and adolescents in particular have been known to become withdrawn.[91] Surgical and orthodontic treatment can significantly improve self-perceptions of dental-facial appearance and some aspects of self-image, which is especially important in adolescence--an important time in social development.[92,93] Before and after images of the teeth in patients with ED, DI, and AI resulting from the treatments described above are set forth in Appendix A. [94]

Addressing the other symptoms that may be present in patients with ED, DI, and AI, besides those associated with the CFAs, might involve multidisciplinary management.[95,96] For patients with OI, treatment can stabilize joints and prevent progressive deformities.[97] Further non-dental treatment is not only important for minimizing symptoms, but it also impacts symptoms affecting appearance.

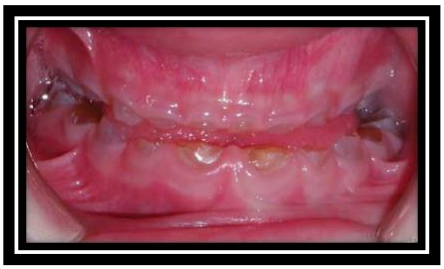
Unusual facial features exacerbate the social challenges of meeting new people, and research has shown that self-esteem in children and adolescents is highly determined by assessment of one's own physical appearance, in addition to comparisons with attractiveness, ability, intellectual skills, and social acceptance of other people.[98]

3.0 Conclusion

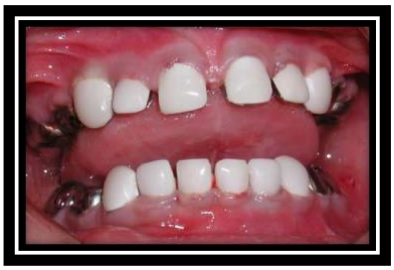
Although the incidence of CFAs associated with ED, DI, and AI is extremely low, their presence can have a significant impact on patients' quality of life. Early identification of these genetic conditions and provision of treatment early in life is critical for helping to ensure the normal development of the jaw and restoring teeth that are present, as well as addressing issues related to nutrition, speech, and differences in physical appearance. The current mandate requires the provision of services for the necessary care and treatment of medically diagnosed congenital defects and birth abnormalities;[99] however, services involving dental or orthodontic procedures are frequently not covered or are determined to be cosmetic by insurance. As a result, many patients do not receive the requisite dental treatments to help ensure the best functional and restorative outcomes. This bill would require coverage of dental services currently not covered in the Commonwealth. Some cumulative research suggests that many children with craniofacial conditions develop in a typical manner and do not experience psychological problems.[100] Despite this, a significant number of children (30% to 40% in most studies) experience difficulties with internalizing and/or externalizing problems, learning disorders, and social competence.[101] Given the impact on dental development and facial growth, early detection of the genetic conditions affecting craniofacial and dental structures is crucial for the effective treatment to improve function and aesthetics for these patients.[102]

Appendix A

Dentinogenesis Imperfecta:[103]

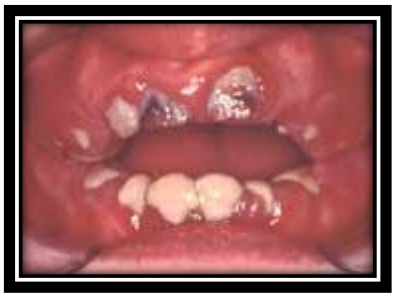


Before



After

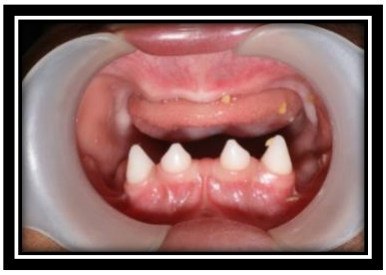
Amelogenesis Imperfecta:[104]



Before

After

Ectodermal Dysplasia:[105]



Before

After

Endnotes

1 The 191st General Court of the Commonwealth of Massachusetts, House Bills 988, 1036, 1050, 1116 and Senate Bill 563, "An Act relative to ensuring treatment for genetic craniofacial conditions." Accessed 15 September 2020: **https://malegislature.gov/Bills/191/H988; https://malegislature.gov/Bills/191/H1036; https://malegislature.gov/Bills/191/H1050; https://malegislature.gov/Bills/191/H1116;** and **https://malegislature.gov/Bills/191/S563**.

[2] National Institutes of Health (NIH), National Human Genome Research Institute. Congenital. Accessed 17 September 2020: **https://www.genome.gov/genetics-glossary/Congenital.**

[3] Children's Craniofacial Association. What is a craniofacial disorder? Accessed 13 July 2020: **https://ccakids.org/syndromes.html**.

[4] University of Rochester Medical Center. Overview of Craniofacial Anomalies. Accessed 1 October 2020: **https://www.urmc.rochester.edu/encyclopedia/content.aspx?contenttypeid=90&contentid=p01830**.

[5] *Op. Cit.* University of Rochester Medical Center. Overview of Craniofacial Anomalies.

[6] Craniofacial Anomalies. White Paper. American Association of Oral and Maxillofacial Surgeons. Reaffirmed January 2020. **Accessed 9 July 2020: https://www.aaoms.org/docs/govt_affairs/advocacy_white_papers/craniofacial_anomalies.pdf**.

[7] Global registry and database on craniofacial anomalies. Craniofacial anomalies and associated birth defects. Report of a World Health Organization Registry Meeting on Craniofacial Anomalies 2001 Dec. Chapter 2. **https://www.who.int/genomics/anomalies/en/Chapter00.pdf.**

[8] Global Strategies to reduce the health-care burden of craniofacial anomalies: Report of WHO meetings on International Collaborative Research on Craniofacial Anomalies. Geneva, Switzerland 5-8 November 2000; Park City, Utah, USA, 24-26 May 2001. Accessed 23 September 2020: **https://www.paho.org/hq/dmdocuments/2009/OH_top_craniofac.pdf**.

[9] Saal HM. Genetic Evaluation for Craniofacial Conditions. Facial Plast Surg Clin North Am. 2016 Nov;24(4):405-425. Accessed 21 October 2020: **https://pubmed.ncbi.nlm.nih.gov/27712809/.**

[10] *Op. Cit.* Craniofacial Anomalies. White Paper. American Association of Oral and Maxillofacial Surgeons.

[11] *Op. Cit.* Craniofacial Anomalies. White Paper. American Association of Oral and Maxillofacial Surgeons.

[12] American Association of Oral and Maxillofacial Surgeons. Craniofacial Anomalies. Accessed 1 October 2020: **https://www.aaoms.org/docs/govt_affairs/talking_points/116-2_craniofacial_anomalies.pdf**.

[13] *Op. Cit.* Craniofacial Anomalies. White Paper. American Association of Oral and Maxillofacial Surgeons.

[14] *Op. Cit.* American Association of Oral and Maxillofacial Surgeons. Craniofacial Anomalies.

[15] NIH. National Center for Advancing Translational Services. Genetic and Rare Diseases Information Center (GARD). Ectodermal dysplasia. Last updated 17 July 2017. Accessed 21 September 2020: **https://rarediseases.info.nih.gov/diseases/6317/ectodermal-dysplasia**.

[16] NIH. National Center for Advancing Translational Services. GARD. Dentinogenesis imperfecta. Last updated 17 March 2017. Accessed 21 September 2020. **https://rarediseases.info.nih.gov/diseases/6258/dentinogenesis-imperfecta-**.

[17] NIH. National Center for Advancing Translational Services. Genetic and Rare Diseases Information Center (GARD). Amelogenesis imperfecta. Last updated 11 June 2018. Accessed 21 September 2020: **https://rarediseases.info.nih.gov/diseases/5791/amelogenesis-imperfecta**.

[18] Amelogenesis Imperfecta. Crawford, P.J., Aldred, M. & Bloch-Zupan, A. Amelogenesis imperfecta. *Orphanet J Rare Dis* **2,** 17 (2007). Accessed 1 October 2020: **https://ojrd.biomedcentral.com/articles/10.1186/1750-1172-2-17**.

[19] *Op. Cit.* The191st General Court of the Commonwealth of Massachusetts, House Bills 988, 1036, 1050, 1116 and Senate Bill.

[20] *Op. cit.* Children's Craniofacial Association. What is a craniofacial disorder?

[21] *Op. cit.* Global Strategies to reduce the health-care burden of craniofacial anomalies: Report of WHO meetings on International Collaborative Research on Craniofacial Anomalies.

[22] Shiel M. Medical Definition of Ectodermal Dysplasia. Reviewed 11 December 2018. Accessed 1 October 2020: **https://www.medicinenet.com/script/main/art.asp?articlekey=20848**.

[23] National Organization of Rare Diseases (NORD). Ectodermal Dysplasias. Accessed 1 October 2020: **https://rarediseases.org/rare-diseases/ectodermal-dysplasias/**.

[24] National Foundation for Ectodermal Dysplasias (NFED). Learn. Accessed 23 September 2020: **https://www.nfed.org/learn/.**

[25] *Op. cit.* NFED. Learn.

[26] *Op. cit.* NFED. Learn.

[27] *Op. cit.* NFED. Learn.

[28] NIH. U.S. National Library of Medicine. MedlinePlus. Hypohidrotic ectodermal dysplasia. Last reviewed 1 November 2018. Accessed 1 October 2020: **https://ghr.nlm.nih.gov/condition/hypohidrotic-ectodermal dysplasia**.

[29] *Op. Cit.* NIH. National Center for Advancing Translational Services. GARD. Dentinogenesis imperfecta.

[30] Barron MJ, McDonnell ST, Mackie I, Dixon MJ. Hereditary dentine disorders: dentinogenesis imperfecta and dentine dysplasia. Orphanet J Rare Dis. 2008 Nov 20;3:31. Accessed 23 September 2020: **https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2600777/**.

[31] NIH. U.S. National Library of Medicine. MedlinePlus. Dentinogensis imperfecta. Description. Last reviewed 1 June 2017. Accessed 21 September 2020: **https://ghr.nlm.nih.gov/condition/dentinogenesis-imperfecta**.

[32] *Op. Cit.* NIH. U.S. National Library of Medicine. MedlinePlus. Dentinogensis imperfecta.

[33] NIH. U.S. National Library of Medicine. MedlinePlus. Amelogenesis imperfecta. Last reviewed 1 May 2015. Accessed 1 October 2020: **https://ghr.nlm.nih.gov/condition/amelogenesis-imperfecta**.

[34] https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1853073/.

[35] *Op. Cit.* NIH. U.S. National Library of Medicine. MedlinePlus. Amelogenesis imperfecta.

[36] *Op. Cit.* NIH. U.S. National Library of Medicine. MedlinePlus. Amelogenesis imperfecta.

[37] *Op. cit.* NIH. National Center for Advancing Translational Services. Genetic and Rare Diseases Information Center (GARD). Amelogenesis imperfecta.

[38] Crawford PJ, Aldred M, Bloch-Zupan A. Amelogenesis imperfecta. Orphanet J Rare Dis. 2007 Apr 4;2:17. Accessed 23 September 2020: **https://ojrd.biomedcentral.com/articles/10.1186/1750-1172-2-17**.

[39] *Op. cit.* Global Strategies to reduce the health-care burden of craniofacial anomalies: Report of WHO meetings on International Collaborative Research on Craniofacial Anomalies.

[40] NFED. FAQS. How many people are affected by ectodermal dysplasia? Accessed 30 September 2020: **https://www.nfed.org/learn/faqs/**.

[41] *Op. cit*. NFED. FAQS. How many people are affected by ectodermal dysplasia?

[42] *Op. cit.* NIH. U.S. National Library of Medicine. MedlinePlus. Hypohidrotic ectodermal dysplasia.

[43] *Op. Cit.* NIH. U.S. National Library of Medicine. MedlinePlus. Dentinogensis imperfecta.

[44] *Op. cit*. NIH. U.S. National Library of Medicine. MedlinePlus. Amelogenesis imperfecta.

[45] *Op. cit*. Crawford PJ, Aldred M, Bloch-Zupan A. Amelogenesis imperfecta.

[46] NIH. U.S. National Library of Medicine. MedlinePlus. Craniofacial Anomalies. Last reviewed 27 July 2016. Accessed 1 October 2020: **https://medlineplus.gov/craniofacialabnormalities.html**.

[47] *Op. cit*. American Association of Oral and Maxillofacial Surgeons. Craniofacial Anomalies.

[48] NFED. Medical Treatment Options. Accessed 1 October 2020: **https://www.nfed.org/treat/medical-treatment-options/**.

[49] Bartzela TN, Carels C, Maltha JC. Update on 13 Syndromes Affecting Craniofacial and Dental Structures. Front Physiol. 2017 Dec 14; 8:1038. Accessed 23 September 2020: **https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5735950/**.

[50] *Op. cit*. Bartzela TN, Carels C, Maltha JC. Update on 13 Syndromes Affecting Craniofacial and Dental Structures.

[51] *Op. cit*. Bartzela TN, Carels C, Maltha JC. Update on 13 Syndromes Affecting Craniofacial and Dental Structures.

[52] *Op. cit*. NFED. Medical Treatment Options.

[53] *Op. cit*. Crawford PJ, Aldred M, Bloch-Zupan A. Amelogenesis imperfecta.

[54] *Op. cit*. Barron MJ, McDonnell ST, Mackie I, Dixon MJ. Hereditary dentine disorders: dentinogenesis imperfecta and dentine dysplasia.

[55] Science Direct. Prosthodontics. Advanced Ceramics for Dentistry, 2014. Accessed 1 October 2020: **https://www.sciencedirect.com/topics/medicine-and-dentistry/prosthodontics**.

[56] Science Direct. Orthodontics. A Consumer's Guide to Dentistry (Second Edition), 2002. Accessed 1 October 2020: **https://www.sciencedirect.com/topics/medicine-and-dentistry/orthodontics**.

[57] Science Direct. Dental Implant. Advanced Ceramics for Dentistry, 2014. Accessed 1 October 2020: **https://www.sciencedirect.com/topics/medicine-and-dentistry/dental-implant**.

[58] The American Society of Maxillofacial Surgeons. Dentofacial Anomalies. Accessed 23 September 2020: **https://maxface.org/conditions-and-treatments/dentofacial-anomalies-treatment.cgi**.

[59] Hekmatfar S, Jafari K, Meshki R, Badakhsh S. Dental management of ectodermal dysplasia: two clinical case reports. J Dent Res Dent Clin Dent Prospects. 2012 Summer; 6(3):108-12. Accessed 24 September 2020: **https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3442425/**.

[60] Murdock S, Lee JY, Guckes A, et al. A cost analysis of dental treatment for ectodermal dysplasia. J Amer Dent Assoc. 2005 Sep;136(9):1276-1276. Accessed 1 October 2020: **https://www.sciencedirect.com/science/article/abs/pii/S000281771463110X**.

[61] *Op. cit*. Hekmatfar S, Jafari K, Meshki R, Badakhsh S. Dental management of ectodermal dysplasia: two clinical case reports.

[62] NFED. Dental Treatment Options. Accessed 1 October 2020: **https://www.nfed.org/treat/dental-treatment-options/**.

[63] *Op. cit*. Hekmatfar S, Jafari K, Meshki R, Badakhsh S. Dental management of ectodermal dysplasia: two clinical case reports.

[64] *Op. cit*. Barron MJ, McDonnell ST, Mackie I, Dixon MJ. Hereditary dentine disorders: dentinogenesis imperfecta and dentine dysplasia.

[65] NIH. National Center for Advancing Translational Services. GARD. Dentinogenesis imperfecta.

[66] *Op. cit*. Barron MJ, McDonnell ST, Mackie I, Dixon MJ. Hereditary dentine disorders: dentinogenesis imperfecta and dentine dysplasia.

[67] *Op. cit*. NIH. National Center for Advancing Translational Services. GARD. Dentinogenesis imperfecta.

[68] University of North Carolina, Adams School of Dentistry. Dentinogenesis Imperfecta. Accessed 24 September 2020: **https://www.dentistry.unc.edu/dentalprofessionals/resources/defects/di/**.

[69] *Op. cit*. Barron MJ, McDonnell ST, Mackie I, Dixon MJ. Hereditary dentine disorders: dentinogenesis imperfecta and dentine dysplasia.

[70] *Op. cit*. NIH. National Center for Advancing Translational Services. GARD. Dentinogenesis imperfecta.

[71] *Op. cit*. NIH. National Center for Advancing Translational Services. GARD. Dentinogenesis imperfecta.

[72] Luo, E., Liu, H., Zhao, Q. *et al.* Dental-craniofacial manifestation and treatment of rare diseases. *Int J Oral Sci* 11, 9 (2019). Accessed 1 October 2020: **https://www.nature.com/articles/s41368-018-0041-y**.

[73] University of North Carolina, Adams School of Dentistry. Amelogenesis Imperfecta. Accessed 24 September 2020: **https://www.dentistry.unc.edu/dentalprofessionals/resources/defects/ai/**.

[74] *Op. cit*. NIH. National Center for Advancing Translational Services. Genetic and Rare Diseases Information Center (GARD). Amelogenesis imperfecta.

[75] *Op. cit*. University of North Carolina, Adams School of Dentistry. Amelogenesis Imperfecta.

[76] *Op. cit*. Crawford PJ, Aldred M, Bloch-Zupan A. Amelogenesis imperfecta.

[77] *Op. cit*. NFED. Medical Treatment Options.

[78] NFED. Itching to know more about eczema and ectodermal dysplasia. Accessed 1 October 2020: **https://www.nfed.org/learn/library/eczema-ectodermal-dysplasia/**.

[79] NFED. Treatment Guide for Skin Issues in Ectodermal Dysplasias. Accessed 1 October 2020: **https://juyhw1n8m4a3a6yng24eww91-wpengine.netdna-ssl.com/wp-content/uploads/2016/06/Guide-to-Treating-Skin-Issues-in-Ectodermal-Dysplasias.pdf**.

[80] NFED. Treating Hair Problems in Ectodermal Dysplasias. Accessed 1 October 2020: **https://juyhw1n8m4a3a6yng24eww91-wpengine.netdna-ssl.com/wp-content/uploads/2016/06/Treating-Hair-Problems-in-Ectodermal-Dysplasias.pdf**.

[81] *Op. cit*. NFED. Treating Hair Problems in Ectodermal Dysplasias.

[82] NFED. Guide to Treating Nails in Ectodermal Dysplasias. Accessed 1 October 2020: **https://juyhw1n8m4a3a6yng24eww91-wpengine.netdna-ssl.com/wp-content/uploads/2016/06/Nail-Treatment-Guide-1.pdf**.

[83] NFED. Treating Nasal Problems in Ectodermal Dysplasias. Accessed 1 October 2020: **https://juyhw1n8m4a3a6yng24eww91-wpengine.netdna-ssl.com/wp-content/uploads/2016/06/Treating-Nasal-Problems-in-Ectodermal-Dysplasias-1.pdf**.

[84] NFED. How Ectodermal Dysplasias Affects Eyes and How to Treat. Accessed 1 October 2020: **https://juyhw1n8m4a3a6yng24eww91-wpengine.netdna-ssl.com/wp-content/uploads/2016/06/Eye-Problems-in-Ectodermal-Dysplasias-2.pdf**.

[85] NIH. U.S. National Library of Medicine. MedlinePlus. Osteogenesis imperfecta. Last reviewed 1 July 2020. Accessed 1 October 2020: **https://ghr.nlm.nih.gov/condition/osteogenesis-imperfecta**.

[86] NORD. Osteogenesis Imperfecta. **https://rarediseases.org/rare-diseases/osteogenesis-imperfecta/**.

[87] *Op. cit*. Barron MJ, McDonnell ST, Mackie I, Dixon MJ. Hereditary dentine disorders: dentinogenesis imperfecta and dentine dysplasia.

[88] American College of Prosthodontists. Position Statement. Dental Management of Persons with Ectodermal Dysplasia. Accessed 1 October 2020: **https://www.prosthodontics.org/assets/1/7/Dental_Management_of_Persons_with_Ectodermal_Dysplasia.pdf**.

[89] *Op. cit*. Crawford PJ, Aldred M, Bloch-Zupan A. Amelogenesis imperfecta.

[90] *Op. cit*. Barron MJ, McDonnell ST, Mackie I, Dixon MJ. Hereditary dentine disorders: dentinogenesis imperfecta and dentine dysplasia.

[91] *Op. cit*. Crawford PJ, Aldred M, Bloch-Zupan A. Amelogenesis imperfecta.

[92] Judith E. Albino, Ph.D., Thomas R. Alley, Ph.D., Lisa A. Tedesco, Ph.D., Joyce A. Tobiasen, Ph.D., H. Asuman Kiyak, Ph.D., Sandra D. Lawrence, M.A., Esthetic Issues in Behavioral Dentistry, *Annals of Behavioral Medicine*, Volume 12, Issue 4, January 1990, Pages 148–155. Accessed 24 September 2020: **https://academic.oup.com/abm/article-abstract/12/4/148/4616926**.

[93] *Op. cit*. Crawford PJ, Aldred M, Bloch-Zupan A. Amelogenesis imperfect.

[94] *Op. cit*. Barron, M.J., McDonnell, S.T., MacKie, I. *et al.* Hereditary dentine disorders: dentinogenesis imperfecta and dentine dysplasia.

[95] Medscape. Osteogenesis Imperfecta. Practice Essentials. Accessed 1 October 2020: **https://emedicine.medscape.com/article/1256726-overview**.

[96] *Op. cit*. NORD. Ectodermal Dysplasias.

[97] *Op. cit*. Medscape. Osteogenesis Imperfecta. Practice Essentials.

[98] Deshmukh S, Prashanth S. Ectodermal dysplasia: a genetic review. Int J Clin Pediatr Dent. 2012 Sep;5(3):197-202. doi: Accessed 29 September 2020: **https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4155886/**.

[99] MGL c 175, § 47C; MGL c 176A, § 8B; and MGL c 176B, § 4C.

[100] Endriga MC, Kapp-Simon KA. Psychological issues in craniofacial care: state of the art. Cleft Palate Craniofac J. 1999 Jan;36(1):3-11. Accessed 24 September 2020: **https://pubmed.ncbi.nlm.nih.gov/10067755/**.

[101] *Op. cit*. Endriga MC, Kapp-Simon KA. Psychological issues in craniofacial care: state of the art.

[102] *Op. cit*. Bartzela TN, Carels C, Maltha JC. Update on 13 Syndromes Affecting Craniofacial and Dental Structures.

[103] *Op. cit*. University of North Carolina, Adams School of Dentistry. Dentinogenesis Imperfecta.

[104] *Op. cit*. University of North Carolina, Adams School of Dentistry. Amelogenesis Imperfecta.

[105] *Op. cit*. Hekmatfar S, Jafari K, Meshki R, Badakhsh S. Dental management of ectodermal dysplasia: two clinical case reports.

AN ACT RELATIVE TO ENSURING TREATMENT FOR GENETIC CRANIOFACIAL CONDITIONS

COST REPORT

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1.0 Executive Summary

Massachusetts House Bills (H.B.s) 988, 1036, 1050, 1116, and Senate Bill (S.B.) 563, as submitted in the 191st General Court of the Commonwealth of Massachusetts (Commonwealth), require carriers to provide coverage for medically necessary functional repair or restoration of craniofacial disorders to improve the function of, or approximate the normal appearance of, any abnormal structures caused by congenital[i,1] disease or anomaly.[ii] The required coverage includes necessary care and treatment related to medically diagnosed congenital disease or anomalies, including, but not limited to:

1. Ectodermal dysplasia (ED): A diverse group of genetic disorders involving hair, nails, teeth, skin, and gland defects[2]
2. Dentinogenesis imperfecta (DI): A genetic disorder associated with brittle bones and discoloration or weaker than normal teeth[3]
3. Amelogenesis imperfecta (AI): A group of inherited disorders characterized by abnormal tooth enamel development[4]

The bills require coverage similar to other carrier benefits and provide that the benefits may not be subject to any greater deductible, coinsurance, copayments, or out-of-pocket limits than any other benefit provided by an insurer. The language in each bill is the same; and for the remainder of the report, "the bill" will collectively refer to H.B.s 988, 1036, 1050, 1116 and S.B. 563.

Subsequent to referral of the bill to the Massachusetts Center for Health Information and Analysis (CHIA) for review, CHIA and its consultants submitted an inquiry to the legislative sponsors and staff to clarify the bill's intent. The bill's intent is to:

1. Provide coverage for three specific genetic conditions: ED, DI, and AI.
2. Require coverage for all ages.
3. Require all services, including medical, surgical, and dental, to be covered as medical benefits of a health plan.

Massachusetts General Laws (MGL) Chapter 3 §38C charges CHIA with, among other duties, reviewing the potential impact of proposed mandated healthcare insurance benefits on the premiums paid by businesses and consumers. CHIA has engaged BerryDunn to provide an actuarial estimate of the effect enactment of the bill would have on the cost of health insurance in the Commonwealth. The report is required to include the proposed mandate's impact on healthcare costs, including premium and administrative expenses.

This report is not intended to determine whether the bill would constitute a health insurance benefit mandate for purposes of state defrayal under the Affordable Care Act (ACA), nor is it intended to assist with state defrayal calculations if it is determined to be a health insurance benefit mandate requiring state defrayal.

[i] Congenital conditions are those present at birth and can be caused by a genetic mutation, an unfavorable environment in the uterus, or a combination of both factors.

[ii] The bill provides an exception for coverage for cleft lip and cleft palate services because these services are mandated elsewhere in the Massachusetts General Laws: M.G.L. c.175 §47BB, c.176A §8EE, c.176G §4W, and c.32 §17J.

1.1 Current Insurance Coverage

Carriers currently cover surgical and medical treatment for genetic craniofacial anomalies (CFAs), with most covering oral surgery. However, they do not cover preventive and restorative dentistry services needed to address extensive dental issues experienced by members with ED, DI, and AI (e.g., teeth that are extremely brittle or missing). Although dental services are typically covered under dental plans, many individuals with medical coverage lack dental coverage, and EHBs do not include non-pediatric dental services.[iii] Approximately 45% of individuals in the Commonwealth with fully insured medical coverage have dental coverage.[5] Furthermore, even for the individuals with dental coverage, the services required to treat ED, DI, and AI are extensive and not fully covered under standard dental plans. Therefore, the bill requires dental services (e.g., dentures, implants, bridges) related to these conditions be covered under a medical plan. No state or federal laws currently require coverage of these dental services.

1.2 Analysis

The three CFAs specified in the bill are extremely rare genetic conditions and affect approximately 860 individuals in the Commonwealth's fully insured commercial population. ED is the most common, affecting almost 500 individuals. Because of the rarity of these conditions, and resulting difficulty finding applicable cost estimates, BerryDunn used multiple sources for determining estimated lifetime costs for each of the three conditions, including data from the Massachusetts All Payer Claim Database (APCD), publicly available data, and clinical experts. ED is the most expensive of the three conditions, with necessary services costing up to three times more per affected member than DI and AI. BerryDunn estimated the lifetime costs of currently uncovered dental services for ED to range from $173,000 to $514,000 per member. For DI and AI, the estimated lifetime costs are estimated to range from $125,000 to $185,000. Converting lifetime costs into average annual costs, multiplying by the number of individuals, and accounting for carrier retention results in a baseline estimate of the proposed mandate's incremental effect of less than 0.05% of premium. The impact on premium costs is projected over the five years following the assumed January 1, 2022, implementation date of the proposed law.

1.3 Summary Results

Based on the prevalence rate and estimated lifetime costs of currently uncovered dental services, BerryDunn found the total premium cost across all two million commercially insured members to be between approximately $2.5 million and $6.6 million per year. This translates to an increase of between 0.017% and 0.045% of premium, or $0.10 to $0.28 per-member per-month (PMPM). Table ES-1 summarizes low, medium, and high scenarios of the bill's estimated effect on premiums for fully insured plans over five years (2022 – 2026).

[iii] The MA Benchmark Plan, HMO Blue New England $2000 Deductible Plan, is supplemented with the Commonwealth's CHIP plan for pediatric dental benefits. See Mass.gov. Essential Health Benefit Benchmark Plan. Accessed 26 February 2021: **https://www.mass.gov/service-details/essential-health-benefit-benchmark-plan**.

Table ES-1: Summary Results

	2022	2023	2024	2025	2026	WEIGHTED AVERAGE	FIVE-YEAR TOTAL
Members (000s)	2,014	2,010	2,007	2,003	2,000		
Medical Expense Low ($000s)	$1,385	$2,010	$2,100	$2,189	$2,276	$2,110	$9,959
Medical Expense Mid ($000s)	$2,191	$3,179	$3,322	$3,463	$3,601	$3,338	$15,757
Medical Expense High ($000s)	$3,702	$5,373	$5,616	$5,854	$6,085	$5,642	$26,630
Premium Low ($000s)	$1,628	$2,361	$2,467	$2,572	$2,674	$2,479	$11,702
Premium Mid ($000s)	$2,574	$3,736	$3,904	$4,069	$4,231	$3,922	$18,514
Premium High ($000s)	$4,350	$6,314	$6,599	$6,878	$7,150	$6,629	$31,291
PMPM Low	$0.09	$0.10	$0.10	$0.11	$0.11	$0.10	$0.10
PMPM Mid	$0.15	$0.15	$0.16	$0.17	$0.18	$0.16	$0.16
PMPM High	$0.25	$0.26	$0.27	$0.29	$0.30	$0.28	$0.28
Estimated Monthly Premium	$565	$590	$617	$645	$674	$618	$618
Premium % Rise Low	0.017%	0.017%	0.017%	0.017%	0.017%	0.017%	0.017%
Premium % Rise Mid	0.026%	0.026%	0.026%	0.026%	0.026%	0.026%	0.026%
Premium % Rise High	0.044%	0.044%	0.044%	0.044%	0.044%	0.045%	0.045%

Executive Summary Endnotes

[1] National Institutes of Health (NIH), National Human Genome Research Institute. Congenital. Accessed 17 September 2020: **https://www.genome.gov/genetics-glossary/Congenital**.

[2] National Foundation for Ectodermal Dysplasias. Accessed 2021 February 2: **https://www.nfed.org/learn/**.

[3] NIH U.S. National Library of Medicine. MedlinePlus. Dentinogenesis imperfect. Accessed 2021 February 2: **https://medlineplus.gov/genetics/condition/dentinogenesis-imperfecta/**.

[4] NORD National Organization of Rare Disorders. Amelogenesis Imperfecta. Accessed 2010 February 2: **https://rarediseases.org/rare-diseases/amelogenesis-imperfecta/**.

[5] Massachusetts All Payer Claims Data Base (APCD), 2018.

2.0 Introduction

The Committee on Financial Services referred House Bills (H.B.s) 988, 1036, 1050, 1116, and Senate Bill (S.B.) 563, all entitled "An Act relative to ensuring treatment for genetic craniofacial conditions,"[1] to CHIA for review. Massachusetts General Laws (MGL), Chapter 3, §38C, requires CHIA to review and evaluate the potential fiscal impact of each mandated benefit bill referred to the agency by a legislative committee. The report is required to include the effects on the cost of healthcare, including the premium and administrative expenses, of the proposed mandate. The language in each bill is the same; and for the remainder of the report, "the bill" will collectively refer to H.B.s 988, 1036, 1050, 1116 and S.B. 563.

Assessing the impact of the proposed mandate on premiums entails analyzing its incremental effect on spending by insurance plans. This, in turn, requires comparing spending under the provisions of the bill to spending under current statutes and current benefit plans for the relevant services.

This report is not intended to determine whether the bill would constitute a health insurance benefit mandate for purposes of state defrayal under the ACA, nor is it intended to assist with state defrayal calculations if it is determined to be a health insurance benefit mandate requiring state defrayal.

Section 3.0 of this analysis outlines the provisions and interpretations of the bill. Section 4.0 summarizes the methodology used for the estimate. Section 5.0 discusses important considerations in translating the bill's language into estimates of its incremental impact on healthcare costs and steps through the calculations. Section 6.0 discusses the results.

2.1 Background

The bill, as submitted in the 191st General Court of the Commonwealth of Massachusetts (Commonwealth), requires carriers to provide coverage for medically necessary functional repair or restoration of craniofacial disorders to improve the function of, or approximate the normal appearance of, any abnormal structures caused by congenital[iv,2] disease or anomaly.[v] The coverage shall include the necessary care and treatment of medically diagnosed congenital disease or anomaly, including, but not limited to, ED, DI, and AI. As set forth in the bill, coverage shall not include cosmetic surgery or for dental or orthodontic treatment unrelated to the congenital disease or anomaly. Further, the benefits shall not be subject to any greater deductible, coinsurance, copayments, or out-of-pocket limits than any other benefit provided by an insurer.

Subsequent to referral of the bill to CHIA for review, CHIA and its consultants submitted an inquiry to the legislative sponsors and staff to clarify the bill's intent. The sponsors clarified the following:

1. Provide coverage for three specific genetic conditions: ED, DI, and AI.
2. Require coverage for all ages.

[iv] Congenital conditions are those present at birth and can be caused by a genetic mutation, an unfavorable environment in the uterus, or a combination of both factors.

[v] The bill provides an exception for coverage for cleft lip and cleft palate services because these services are mandated elsewhere in the Massachusetts General Laws: M.G.L. c.175 §47BB, c.176A §8EE, c.176G §4W, and c.32 §17J.

3. Require all services, including medical, surgical, and dental, to be covered as medical benefits of a health plan.

3.0 Interpretation of the Bill

No Massachusetts state or federal law requires coverage for the dental services necessary for the functional repair and restoration of craniofacial disorders in patients with AI, DI, and ED. The federal ACA does not directly require insurance carriers to cover craniofacial disorders. However, because coverage for cleft palate was mandated in Massachusetts prior to 2012, it is considered an essential health benefit (EHB) for which carriers must provide coverage. Massachusetts state law requires insurance carriers to provide coverage for "congenital malformations" for newborn infants and newly adopted children under most health plans, but it does not require coverage of the dentistry-related services needed by members with CFAs.[3,4,5]

This report examines the cost impact of requiring coverage for medically necessary functional repair or restoration of craniofacial disorders to improve the function of, or approximate the normal appearance of, any abnormal structures caused by the following congenital diseases: AI, DI, and ED. As proposed in the bill, extensive dental services (e.g., implants) would be covered under a member's medical plan, instead of a dental plan. Many individuals are not covered by dental plans, and EHBs do not include non-pediatric dental services.[vi] About 50% of adults in New England who have medical coverage have dental insurance[6] and a review of the APCD indicates that in 2018 approximately 45% of members with fully insured medical coverage had dental coverage. Even if individuals are covered, dental plans typically limit annual benefits to a relatively low annual limit (e.g. $2,000). These limits are significantly lower than the cost required for some of the extensive dental services required by members with AI, DI, and ED such as dental implants, which can cost $100,000 or more. Health insurers may have provider contracts in place to provide some dental-related services (e.g. cleft palate services, pediatric oral care), however, if enacted, the bill would likely present some additional operational and/or contracting modifications by health insurers.

3.1 Plans Affected by the Proposed Mandate

The bill as drafted amends statutes that regulate healthcare carriers in the Commonwealth. The bill includes the following sections, each of which addresses statutes dealing with a particular type of health insurance policy:

- Section 1: Chapter 32A – Plans Operated by the Group Insurance Commission (GIC) for the Benefit of Public Employees
- Section 2: Chapter 175 – Commercial Health Insurance Company Plans
- Section 3: Chapter 176A – Hospital Service Corporation Plans
- Section 4: Chapter 176B – Medical Service Corporation Plans
- Section 5: Chapter 176G – Health Maintenance Organization (HMO) Plans

[vi] The MA Benchmark Plan, HMO Blue New England $2000 Deductible Plan, is supplemented with the Commonwealth's CHIP plan for pediatric dental benefits. See Mass.gov. Essential Health Benefit Benchmark Plan. Accessed 26 February 2021: **https://www.mass.gov/service-details/essential-health-benefit-benchmark-plan**.

Self-insured plans, except for those managed by the GIC, are not subject to state-level health insurance benefit mandates. State mandates do not apply to Medicare or Medicare Advantage plans, the benefits of which are qualified by Medicare; this analysis excludes members of fully insured commercial plans over 64 years of age and does not address any potential effect on Medicare supplement plans, even to the extent they are regulated by state law. This analysis does not apply to MassHealth.

3.2 Covered Services

BerryDunn surveyed 10 insurance carriers in the Commonwealth, and seven responded. All respondent carriers currently cover surgical and medical treatment for genetic craniofacial conditions, including oral surgery. One carrier indicated oral surgery is not covered in the large group market. Respondent carriers do not cover preventative and restorative dentistry needed to support orthodontic and prosthetic therapy related to the three specific conditions in the proposed mandate. One carrier indicated its qualified health plans (QHP) product(s) include coverage for pediatric dental services, which includes restorative and orthodontic services for the conditions specific to the proposed mandate.

3.3 Existing Laws Affecting the Cost of the Bill

Although Massachusetts state law[7] provides for coverage of necessary care and treatment of medically diagnosed congenital defects and birth abnormalities for newly born infants and adoptive children, many of the procedures required to treat AI, DI, and ED occur later in childhood, are considered dental and/or cosmetic, and are not covered. The bill requires coverage in addition to the current required state-mandated coverage and is not in conflict with any existing state or federal mandates.

4.0 Methodology

4.1 Overview

Estimating the impact of the bill on premiums requires assessing the incremental cost due to the requirement that insurers cover the medically necessary functional repair or restoration of craniofacial disorders for three conditions: ED, DI, and AI.

The incremental cost of the provision is estimated using claims data from the APCD, publicly available information, and interviews with two Massachusetts craniofacial clinical experts to calculate the average lifetime cost to treat these services. The number of people expected to receive these services is estimated using academic literature. Combining the two components, and accounting for carrier retention, results in a baseline estimate of the proposed mandate's incremental effect on premiums, which is projected over the five years following the assumed January 1, 2022, implementation date of the proposed law.

4.2 Data Sources

The primary data sources used in the analysis are:

- Information about the intended effect of the bill, gathered from legislative sponsors
- Information, including descriptions of current coverage, from responses to a survey of commercial health insurance carriers in the Commonwealth

- The Massachusetts APCD
- Academic literature, published reports, and population data, cited as appropriate
- Discussion with clinical experts and providers

4.3 Analytic Steps

To implement the analysis, BerryDunn performed the steps summarized in this section.

1. Estimated the cost to insurers for treating genetic craniofacial conditions.

To estimate the cost impact of treating each of the three genetic craniofacial conditions, BerryDunn:

A. Used the APCD, input from clinical experts, and publicly available data to estimate the average cost per person for dental treatment not currently covered. The average cost was determined for the initial treatment years for ages 4 through 18, and for maintenance treatment years for ages 19 to 64.

B. Divided the estimated cost for each age cohort in Step A by the number of treatment years to obtain the average annual cost of treatment.

C. Used input from clinical experts and publicly available literature to find the prevalence rate of each of the three craniofacial conditions.

D. Multiplied the prevalence rate obtained in Step C by the total number of members in the commercial fully insured population to estimate the number of members who will be treated.

E. Multiplied the estimated number of members who require treatment from Step D by the annual treatment cost in Step B to determine the incremental cost of treating genetic craniofacial conditions.

F. Divided the incremental cost by the total corresponding membership to determine the incremental PMPM.

G. Projected the baseline cost forward over the five-year analysis period using an estimated increase in dental services over the period.

2. Calculated the impact of the projected claim costs on insurance premiums.

To calculate the impact on health insurance premiums to the estimated claims costs, BerryDunn:

A. Summed the estimated incremental PMPM costs for the three genetic craniofacial conditions.

B. Estimated the fully insured Commonwealth population under age 65, projected for the next five years (2022 – 2026).

C. Multiplied the estimated aggregate incremental PMPM cost of the mandate by the projected population estimate to calculate the total estimated marginal claims cost of the bill.

D. Estimated insurer retention (administrative costs, taxes, and profit), and applied the estimate to the final incremental claims cost calculated in Step C.

4.4 Limitations

Carriers in Massachusetts do not currently provide coverage for dental treatment for craniofacial conditions, and the cost and utilization could not be calculated from APCD claims. Each of the conditions are very rare, which makes studies on prevalence rates extremely difficult and cost prohibitive. BerryDunn thus found limited publicly available prevalence literature for these conditions.

COVID-19 has impacted the number of commercial, fully insured members in 2020. Fully insured membership declined due to decreased enrollment in employer-sponsored insurance (ESI). The impact that COVID-19 will have on unemployment in the 2022 – 2026 projection period is uncertain.

BerryDunn addresses these limitations further in the following section through a detailed, step-by-step description of the estimation process.

5.0 Analysis

This section describes the calculations outlined in the section 4.3 in more detail. The analysis includes development of a best-estimate middle-cost scenario, as well as a low-cost scenario using assumptions that produced a lower estimate, and a high-cost scenario using more conservative assumptions that produced a higher estimated cost impact.

Section 5.1 describes the steps used to calculate the average annual lifetime cost to treat each of the three craniofacial conditions. Section 5.2 describes the steps used to calculate the number of members and PMPM expenses associated with treatment of ED. Section 5.3 describes the steps used to calculate the number of members and PMPM expenses associated with treatment of DI. Section 5.4 describes the steps used to calculate the number of members and PMPM expenses associated with treatment of AI. Section 5.5 describes the steps used to aggregate the marginal PMPM costs. Section 5.6 describes the steps used to project the fully insured population age 0 – 64 in the Commonwealth over the 2022 – 2026 analysis period. Section 5.7 describes the steps used to calculate the total estimated marginal cost of the bill, and Section 5.8 describes the steps used to adjust these projections for carrier retention to arrive at an estimate of the bill's effect on premiums for fully insured plans.

5.1 Estimated Lifetime Treatment Costs

Estimated lifetime treatment costs of each of the three craniofacial conditions.

Treatment of CFAs depends on the type of condition and associated impact on the teeth; it might involve plastic and reconstructive surgery or dental-related procedures, such as orthodontia and dental implants. Care for patients with CFAs is often treated by an interdisciplinary team beginning in early childhood. ED, DI, and AI affect teeth differently, so the timing and types of treatment for these CFAs vary by condition and across patients. A wide range of treatment modalities might thus be provided depending on the individual presentation for each of these genetic conditions. Treatment modalities are summarized in Table 1.

Table 1: Dental Treatment Modalities of CFAs

TREATMENT MODALITY	ED	DI	AI
Prosthodontic Treatment	X		X
Orthodontic Treatment	X		X
Dentures	X	X	X
Implants	X	X	
Veneers		X	
Crowns		X	
Bridges		X	
Preventive Care Using Sealants and Bonding			X
Bonding			X
Toothpaste for Tooth Sensitivity			X

BerryDunn used a combination of publicly available information, claims data from the APCD, and interviews with four Massachusetts craniofacial clinical experts, two with specific expertise in the provision of the necessary dental care, to calculate the average lifetime cost to treat these conditions. Unit costs for each of the treatment modalities were provided by both clinical experts and were based upon prices at two Massachusetts dental schools. The clinical experts used 2020 claims cost as the basis to derive the unit costs. Unit costs were verified and adjusted as necessary using a publicly available dental cost estimator[8] and available claims data from the APCD.

Dental treatment modalities for ED vary depending on clinical manifestations and might include prosthodontics, orthodontics, and dental implants. For children with no teeth, as commonly occurs with ED, or very soft teeth, dentures are recommended by the time a child starts school. According to the clinical experts, typically children about four years old start to successfully wear dentures. Because of growth, dentures are replaced, on average, every six months. Factored into the lifetime treatment costs for children for dentures is an average treatment cost between $4,000 and $6,000. A full set of dental implants costs between $70,000 and $110,000 per treatment and is used after growth has stopped. Implants might need to be replaced every 20 years, or they could last a lifetime, depending upon the patient's compliance with proper care. These cost ranges are factored into the average lifetime costs for ED. Using available unit cost information, and input from clinical experts regarding the use and frequency of available treatment modalities, BerryDunn estimated the average lifetime cost of dental and orthodontic services for two age cohorts. The first cohort includes children between the ages of 4 and 18 when the initial treatments occur. The second cohort includes adults between the ages of 19 and 64 when maintenance treatments occur. BerryDunn added the total costs for the two age cohort ranges, and results are presented in Table 2.

According to the National Foundation for Ectodermal Dysplasias (NFED) a person can expect to spend more than $150,000 in their lifetime on dental costs needed to treat ED.[9] This is based on input from families that the NFED serves and is near the mid cost estimate for the child age cohort (as informed by the clinical experts). Cost information supplied to NFED from families likely excluded long-term maintenance costs encountered by adults.

Table 2: ED Lifetime Treatment Costs by Modality (in thousands)

TREATMENT MODALITY	LOW	MID	HIGH
Prosthodontic Treatment	$5	$8	$10
Orthodontic Treatment	$2	$4	$6
Dentures	$96	$140	$168
Implants	$70	$135	$330
Total	**$173**	**$287**	**$514**

DI and AI are less prevalent than ED and have a wider range of treatment modalities. For patients with DI, treatment varies according to the patient's age, case severity, and presenting complaints. Treatment options include dental fillings, veneers to fix the discoloration of teeth, and crowns. Dentures or dental implants might be necessary if the patient has lost the majority of his or her teeth. According to clinical experts, the total initial treatment cost for children between the ages of 4 and 18 is approximately $65,000. BerryDunn assumed $55,000 in the low scenario and $75,000 in the high scenario. For adults between the ages of 19 and 64, the average treatment cost ranges between $70,000 and $110,000.

AI treatment depends on the specific type of AI and the character of the affected enamel, which ranges from preventive care using sealants and bonding for aesthetics to extensive removable and fixed prosthetic reconstruction. Given the diverse dental and skeletal manifestations resulting from the different types of AI, treatments can require intervention from various dental disciplines. Treatments might include dentures that cap the teeth (full crown restorations); orthodontic treatment; surgical interventions for malocclusions; bonding; and special toothpaste for tooth sensitivity. According to both clinical experts, the average lifetime treatment costs of AI are similar to DI.

BerryDunn presents a summary of lifetime treatment costs for ED, DI, and AI by age cohort in Table 3.

Table 3: Estimated Lifetime Cost for Treatment of Craniofacial Conditions (in thousands)

	CHILDREN			ADULTS			TOTAL		
	ED	DI	AI	ED	DI	AI	ED	DI	AI
Low Scenario	$101	$55	$55	$72	$70	$70	$173	$125	$125
Mid Scenario	$148	$65	$65	$139	$90	$90	$287	$155	$155
High Scenario	$289	$75	$75	$225	$110	$110	$514	$185	$185

The average annual cost of treatment is necessary for estimating the cost impact to commercial insurance. Based on input from clinical experts, initial treatment occurs for children between the ages of 4 and 18, or over a period of 15 years. Maintenance treatment for adults occurs between the ages of 19 and 64 or over a period of 46 years. In order to estimate the average annual cost, BerryDunn divided the estimated lifetime cost for children by 15 treatment years and the estimated lifetime cost for adults by 46 treatment years. Results are shown in Table 4.

Table 4: Estimated Annual Cost for Dental Treatment of Craniofacial Conditions

	CHILDREN			ADULTS			TOTAL		
	ED	DI	AI	ED	DI	AI	ED	DI	AI
Low Scenario	$6,733	$3,667	$3,667	$1,565	$1,522	$1,522	$8,299	$5,188	$5,188
Mid Scenario	$9,867	$4,333	$4,333	$3,022	$1,957	$1,957	$12,888	$6,290	$6,290
High Scenario	$19,267	$5,000	$5,000	$4,891	$2,391	$2,391	$24,158	$7,391	$7,391

In the following sections, BerryDunn presents the methodology for estimating the number of commercial fully insured members with ED, DI, and AI, as well as the total annual dental costs to treat people with these conditions.

5.2 Ectodermal Dysplasia (ED)

Estimated marginal costs to insurers to cover dental and orthodontic services for ED

The bill requires insurers to cover dental and orthodontic services for treatment of ED. According to the NFED, an estimated 3.5 in 10,000 people are affected by ED. It is difficult to know the prevalence with certainty because ED is considered a rare disorder, impacting less than 200,000 people in the United States.[10] This rarity makes conducting a study to determine exact numbers of impacted individuals challenging and expensive.[11]

According to the NFED, 73% to 74% of its registered ED patients have missing teeth and dental problems. BerryDunn used 73% in the low and mid scenarios and to be more conservative used 74% in the high scenario. Using the ED prevalence rates and these percentages, BerryDunn calculated that between 0.0256% and 0.0259% of the population require dental treatment for ED. BerryDunn used these in the low and high scenarios, respectively, and assumed a 0.0256% in the mid scenario.

Based on a population estimate, there are a total of 271,172 fully insured children between the ages of 4 and 18, and 1,636,984 fully insured adults between the ages of 19 and 64 in the Commonwealth. BerryDunn multiplied the number of fully insured children and adults by their estimated prevalence rates to project the number of members impacted by ED. Results are displayed in Table 5.

Table 5: 2020 Estimated Members with ED

SCENARIO	PREVALENCE RATE	TOTAL CHILDREN WITH ED	TOTAL ADULTS WITH ED	TOTAL MEMBERS WITH ED
Low	0.0256%	69	418	488
Mid	0.0256%	69	418	488
High	0.0259%	70	424	494

BerryDunn multiplied the estimated number of members with ED by the annual treatment cost from Table 4 to determine the incremental cost of treating ED. The results by age group are presented in Table 6.

Table 6: Estimated Annual Cost to Treat ED

	MEMBERS WITH ED	AVERAGE ANNUAL COST	ANNUAL MARGINAL COST	MEMBERS WITH ED	AVERAGE ANNUAL COST	ANNUAL MARGINAL COST	TOTAL MARGINAL COST
	Children			Adults			Total
Low Scenario	69	$6,733	$466,515	418	$1,565	$654,651	$1,121,167
Mid Scenario	69	$9,867	$683,607	418	$3,022	$1,263,841	$1,947,447
High Scenario	70	$19,267	$1,353,166	424	$4,891	$2,073,810	$3,426,976

BerryDunn divided the annual incremental cost by the corresponding membership to estimate the incremental PMPM amount. This analysis used the long-term average national projection for cost increases to dental services over the study period.[12] BerryDunn multiplied the incremental PMPM amounts by the projected cost increase to project the PMPM impact of requiring coverage for ED. Table 7 displays the results.

Table 7: Estimated PMPM Marginal Annual Cost of ED

	2020	2022	2023	2024	2025	2026
Low Scenario	$0.05	$0.05	$0.05	$0.06	$0.06	$0.06
Mid Scenario	$0.08	$0.09	$0.09	$0.10	$0.10	$0.10
High Scenario	$0.14	$0.15	$0.16	$0.17	$0.18	$0.18

BerryDunn multiplied the annual incremental PMPM cost by the corresponding membership to estimate the total incremental amount. This analysis projected fully insured membership in the Commonwealth over the study period, which is further discussed in Section 5.5 of this report. Table 8 displays the results.

Table 8: Estimated Total Marginal Cost of ED

	2020	2022	2023	2024	2025	2026
Low Scenario	$1,121,167	$1,218,488	$1,279,413	$1,340,824	$1,399,821	$1,455,814
Mid Scenario	$1,947,447	$2,116,493	$2,222,318	$2,328,989	$2,431,465	$2,528,723
High Scenario	$3,426,976	$3,724,451	$3,910,674	$4,098,386	$4,278,715	$4,449,864

5.3 Dentinogenesis Imperfecta (DI)

Estimated marginal costs to insurers to cover dental and orthodontic services for DI

The bill also requires insurers to cover dental and orthodontic services for treatment of DI. According to research indicated in the U.S. National Library of Medicine, DI affects an estimated 1 in 6,000 to 8,000 people.[13] One of the clinical experts cited 1 in 8,000 as the right prevalence rate. BerryDunn thus used 1 in 8,000 for the low and mid scenarios and to be more conservative used 1 in 6,000 for the high scenario. Based on a population estimate, there are a total of 271,172 fully insured children between the ages of 4 and 18, and 1,636,984 fully insured adults between

the ages of 19 and 64 in the Commonwealth. BerryDunn multiplied the number of fully insured children and adults by the prevalence rates to estimate the number of children impacted by DI. Results are displayed in Table 9.

Table 9: 2020 Estimated Members with DI

SCENARIO	PREVALENCE RATE	TOTAL CHILDREN WITH DI	TOTAL ADULTS WITH DI	TOTAL MEMBERS WITH DI
Low	0.0125%	34	205	239
Mid	0.0125%	34	205	239
High	0.0167%	45	273	318

BerryDunn multiplied the estimated number of members with DI by the annual treatment cost from Table 4 to determine the incremental cost of treating DI. Table 10 displays the results by age group.

Table 10: Estimated Annual Cost to Treat DI

	MEMBERS WITH DI	AVERAGE ANNUAL COST	ANNUAL MARGINAL COST	MEMBERS WITH DI	AVERAGE ANNUAL COST	ANNUAL MARGINAL COST	TOTAL MARGINAL COST
	Children			Adults			Total
Low Scenario	34	$3,667	$124,287	205	$1,522	$311,383	$435,670
Mid Scenario	34	$4,333	$146,885	205	$1,957	$400,349	$547,234
High Scenario	45	$5,000	$225,977	273	$2,391	$652,421	$878,398

BerryDunn divided the annual incremental cost by the corresponding membership to estimate the incremental PMPM amount. This analysis used the long-term average national projection for cost increases to dental services over the study period.[14] BerryDunn multiplied the incremental PMPM amounts by the trend factor to project the PMPM impact of requiring coverage for DI. Table 11 displays the results.

Table 11: Estimated Marginal PMPM Cost of Treatment of DI

	2020	2022	2023	2024	2025	2026
Low Scenario	$0.02	$0.02	$0.02	$0.02	$0.02	$0.02
Mid Scenario	$0.02	$0.02	$0.03	$0.03	$0.03	$0.03
High Scenario	$0.04	$0.04	$0.04	$0.04	$0.04	$0.05

BerryDunn multiplied the annual incremental PMPM cost by the corresponding membership to estimate the total incremental amount. Table 12 displays the results.

Table 12: Estimated Annual Cost of DI

	2020	2022	2023	2024	2025	2026
Low Scenario	$435,670	$475,307	$496,459	$518,551	$541,626	$565,729
Mid Scenario	$547,234	$597,022	$623,589	$651,339	$680,323	$710,598
High Scenario	$878,398	$958,315	$1,000,960	$1,045,502	$1,092,027	$1,140,622

5.4 Amelogenesis Imperfecta (AI)

Estimated marginal costs to insurers to cover dental and orthodontic services for AI

The bill requires insurers also cover dental and orthodontic services for treatment of AI.

The exact prevalence of AI is uncertain; one estimate indicated a frequency of 1 in 14,000 people in the United States.[15,16] BerryDunn's research found no recent study available. One of our clinical experts suggested that 1 in 14,000 from the U.S. study was the most reliable prevalence rate. BerryDunn therefore assumed 1 in 14,000 in the mid scenario; 1 in 12,000 in the high scenario; and 1 in 16,000 in the low scenario. Based on a population estimate, estimate, there are a total of 271,172 fully insured children between the ages of 4 and 18, and 1,636,984 fully insured adults between the ages of 19 and 64 in the Commonwealth. BerryDunn multiplied the number of fully insured children and adults by the estimated prevalence rates to estimate the number of children and adults impacted by AI. Results are displayed in Table 13.

Table 13: 2020 Estimated Members with AI

SCENARIO	PREVALENCE RATE	TOTAL CHILDREN WITH AI	TOTAL ADULTS WITH AI	TOTAL MEMBERS WITH AI
Low	0.0063%	17	102	119
Mid	0.0071%	19	117	136
High	0.0083%	23	136	159

BerryDunn multiplied the estimated number of members with AI by the annual treatment cost from Table 4 to determine the incremental cost of treating AI. Table 14 displays the results.

Table 14: Estimated Annual Cost to Treat AI

	MEMBERS WITH AI	AVERAGE ANNUAL COST	ANNUAL MARGINAL COST	MEMBERS WITH AI	AVERAGE ANNUAL COST	ANNUAL MARGINAL COST	TOTAL MARGINAL COST
	Children			Adults			Total
Low Scenario	17	$3,667	$62,144	102	$1,522	$155,691	$217,835
Mid Scenario	19	$4,333	$83,934	117	$1,957	$228,771	$312,705
High Scenario	23	$5,000	$112,988	136	$2,391	$326,211	$439,199

BerryDunn divided the annual incremental cost by the corresponding membership to estimate the incremental PMPM amount. This analysis used the long-term average national projection for cost increases to dental services over the study period.[17] BerryDunn multiplied the incremental PMPM amounts by the trend factor to project the PMPM impact of requiring coverage for AI. Table 15 displays the results.

Table 15: Estimated Marginal PMPM Cost of Treatment of AI

	2020	2022	2023	2024	2025	2026
Low Scenario	$0.01	$0.01	$0.01	$0.01	$0.01	$0.01
Mid Scenario	$0.01	$0.01	$0.01	$0.02	$0.02	$0.02
High Scenario	$0.02	$0.02	$0.02	$0.02	$0.02	$0.02

BerryDunn multiplied the annual incremental PMPM cost by the corresponding membership to estimate the total incremental amount. Table 16 displays the results.

Table 16: Estimated Annual Cost of AI

	2020	2022	2023	2024	2025	2026
Low Scenario	$217,835	$237,654	$248,229	$259,275	$270,813	$282,864
Mid Scenario	$312,705	$341,155	$356,337	$372,194	$388,756	$406,056
High Scenario	$439,199	$479,157	$500,480	$522,751	$546,014	$570,311

5.5 Marginal Cost PMPM

Adding together the estimated PMPM costs associated with the three craniofacial conditions (from Tables 7, 11, and 15) yields the total PMPM marginal cost, shown in Table 17.

Table 17: Estimated Marginal PMPM Cost of Craniofacial Mandate

	2022	2023	2024	2025	2026
Low Scenario	$0.08	$0.08	$0.09	$0.09	$0.09
Mid Scenario	$0.13	$0.13	$0.14	$0.14	$0.15
High Scenario	$0.21	$0.22	$0.23	$0.24	$0.25

5.6 Projected Fully Insured Population in the Commonwealth

Table 18 presents the projected fully insured population in the Commonwealth, ages 0 to 64, from 2022 through 2026. Appendix A describes the sources and the methodology used to develop these values.

Table 18: Projected Commercial Fully-Insured Population, Ages 0 – 64

2022	2023	2024	2025	2026
2,014,007	2,010,132	2,006,510	2,003,142	1,999,776

5.7 Total Marginal Medical Expense

Multiplying the total estimated PMPM cost by the projected fully insured membership over the analysis period results in the total cost (medical expense) associated with the proposed requirement (Table 19). This analysis assumes the bill, if enacted, would be effective January 1, 2022.[vii]

Table 19: Estimated Marginal Cost of Treatment of Craniofacial Conditions

	2022	2023	2024	2025	2026
Low Scenario	$1,385,260	$2,009,594	$2,099,676	$2,188,767	$2,276,104
Mid Scenario	$2,190,848	$3,179,293	$3,322,497	$3,463,370	$3,600,604
High Scenario	$3,702,196	$5,373,324	$5,615,889	$5,853,923	$6,085,130

[vii] The analysis assumes the mandate would be effective for policies issued and renewed on or after January 1, 2022. Based on an assumed renewal distribution by month, by market segment, and by the Commonwealth market segment composition, 72.1% of the member months exposed in 2022 will have the proposed mandate coverage in effect during calendar year 2022. The annual dollar impact of the mandate in 2022 was estimated using the estimated PMPM and applying it to 72.1% of the member months exposed.

5.8 Carrier Retention and Premium Increase

Carriers include their retention expenses in fully insured premiums. Retention expense includes general administration, commissions, taxes, fees, and contribution to surplus or profit. Assuming an average retention rate of 14.9% based on CHIA's analysis of fully insured premium retention in the Commonwealth,[18] the increase in medical expense was adjusted upward to approximate the total impact on premiums. Table 20 shows the result.

Table 20: Estimate of Increase in Carrier Premium Expense

	2022	2023	2024	2025	2026
Low Scenario	$1,627,677	$2,361,269	$2,467,116	$2,571,798	$2,674,418
Mid Scenario	$2,574,242	$3,735,663	$3,903,927	$4,069,454	$4,230,704
High Scenario	$4,350,073	$6,313,646	$6,598,660	$6,878,349	$7,150,017

6.0 Results

The estimated impact of the proposed requirement on medical expense and premiums is explained in Section 6.1 and summarized in Table 21. The analysis includes development of a best estimate "mid-level" scenario, a "low-level" scenario using assumptions that produced a lower estimate, as well as a "high-level" scenario using more conservative assumptions that produced a higher estimated impact.

The impact on premiums is driven by provisions in the bill that require carriers to cover treatment of dental services for craniofacial conditions. Variation between scenarios is attributable to uncertainty surrounding the ED, DI, and AI prevalence rates, along with the average lifetime cost for treatment of these conditions by carriers.

6.1 Five-Year Estimated Impact

For each year in the five-year analysis period, Table 21 displays the bill's projected net impact on medical expense and premiums using an estimate of Commonwealth fully insured membership. The low scenario impact is $2.5 million per year on average and is based on the assumption that prevalence rates are 0.0256%, 0.0125%, and 0.0063% for ED, DI, and AI, respectively. This scenario assumes that, on average, the lifetime cost to treat ED, DI, and AI are $173,000, $125,000, and $125,000, respectively. The high scenario impact is $6.6 million per year, on average, and is based on the assumption that prevalence rates are 0.0259%, 0.0167%, and 0.0083% for ED, DI, and AI, respectively. This scenario assumes that, on average, the lifetime costs to treat ED, DI, and AI are $514,000, $185,000, and $185,000, respectively. The middle scenario assumes that prevalence rates are 0.0256%, 0.0125%, and 0.0071% for ED, DI, and AI, respectively. This scenario assumes that, on average, the lifetime costs to treat ED, DI, and AI are $287,000, $155,000, and $155,000, respectively. The middle scenario has average annual costs of $3.9 million, or an average of 0.026% of fully insured premiums paid by carriers in the Commonwealth.

Finally, the bill's impact on any one individual, employer group, or carrier may vary from the overall results, depending on the current level of benefits each receives or provides, and on how benefits might change under the proposed language.

Table 21: Summary Results

	2022	2023	2024	2025	2026	WEIGHTED AVERAGE	FIVE-YEAR TOTAL
Members (000s)	2,014	2,010	2,007	2,003	2,000		
Medical Expense Low ($000s)	$1,385	$2,010	$2,100	$2,189	$2,276	$2,110	$9,959
Medical Expense Mid ($000s)	$2,191	$3,179	$3,322	$3,463	$3,601	$3,338	$15,757
Medical Expense High ($000s)	$3,702	$5,373	$5,616	$5,854	$6,085	$5,642	$26,630
Premium Low ($000s)	$1,628	$2,361	$2,467	$2,572	$2,674	$2,479	$11,702
Premium Mid ($000s)	$2,574	$3,736	$3,904	$4,069	$4,231	$3,922	$18,514
Premium High ($000s)	$4,350	$6,314	$6,599	$6,878	$7,150	$6,629	$31,291
PMPM Low	$0.09	$0.10	$0.10	$0.11	$0.11	$0.10	$0.10
PMPM Mid	$0.15	$0.15	$0.16	$0.17	$0.18	$0.16	$0.16
PMPM High	$0.25	$0.26	$0.27	$0.29	$0.30	$0.28	$0.28
Estimated Monthly Premium	$565	$590	$617	$645	$674	$618	$618
Premium % Rise Low	0.017%	0.017%	0.017%	0.017%	0.017%	0.017%	0.017%
Premium % Rise Mid	0.026%	0.026%	0.026%	0.026%	0.026%	0.026%	0.026%
Premium % Rise High	0.044%	0.044%	0.044%	0.044%	0.044%	0.045%	0.045%

6.2 Impact on the GIC

Findings from BerryDunn's carrier surveys indicate that benefit offerings for GIC and other commercial plans in the Commonwealth are similar. For this reason, the bill's estimated impact on GIC's incremental PMPM medical expense is assumed the same as other fully insured plans in the Commonwealth. To separately estimate the total medical expense for the GIC, BerryDunn applied the PMPM medical expense to the GIC membership.

BerryDunn assumed the proposed legislative change will apply to self-insured plans that the GIC operates for state and local employees, with an effective date of July 1, 2022. Because of the July effective date the results in 2022 are approximately one-half of an annual value. Table 22 breaks out the GIC's self-insured membership, as well as the corresponding incremental medical expense.

Table 22: GIC Summary Results

	2022	2023	2024	2025	2026	WEIGHTED AVERAGE	FIVE-YEAR TOTAL
GIC Self-Insured							
Members (000s)	314	313	312	312	311		
Medical Expense Low ($000s)	$150	$313	$327	$341	$354	$330	$1,484
Medical Expense Mid ($000s)	$237	$495	$517	$539	$560	$522	$2,348
Medical Expense High ($000s)	$400	$837	$874	$911	$947	$882	$3,969

Endnotes

[1] The 191st General Court of the Commonwealth of Massachusetts, House Bills 988, 1036, 1050, 1116 and Senate Bill 563, "An Act relative to ensuring treatment for genetic craniofacial conditions." Accessed 15 September 2020: **https://malegislature.gov/Bills/191/H988**; **https://malegislature.gov/Bills/191/H1036**; **https://malegislature.gov/Bills/191/H1050; https://malegislature.gov/Bills/191/H1116**; and **https://malegislature.gov/Bills/191/S563**.

[2] National Institutes of Health (NIH), National Human Genome Research Institute. Congenital. Accessed 17 September 2020: **https://www.genome.gov/genetics-glossary/Congenital**.

[3] MGL Chapter 175, § 47C; MGL Chapter 176A, § 8B; and MGL Chapter 176B, § 4C.

[4] Centers for Medicare and Medicaid Services (CMS), Center for Consumer Information and Insurance Oversight, Information on Essential Health Benefits (EHB) Benchmark Plans. Accessed 11 November 2020: **https://www.cms.gov/cciio/resources/data-resources/ehb.html**.

[5] CMS. Massachusetts State Required Benefits. Cleft palate: M.G.L. Chapter 175 § 47Y; M.G.L. Chapter 176A, § 8CC; M.G.L. Chapter 176B, § 4CC; M.G.L. Chapter 176G, § 4U. Accessed 11 November 2020: **https://downloads.cms.gov/cciio/State Required Benefits_MA.PDF**

[6] Centers for Disease Control and Prevention, Regional Variation in Private Dental Coverage and Care Among Dentate Adults Aged 18-64 in the United States, 2014-2017. Accessed 2021 February 26: **https://www.cdc.gov/nchs/products/databriefs/db336.htm**.

[7] MGL Chapter 175, § 47C; MGL Chapter 176A, § 8B; and MGL Chapter 176B, § 4C.

[8] Delta Dental. Cost Maters, Accessed 18 January 2021: **https://www.deltadental.com/us/en/member/cost-estimator.html**.

[9] National Foundation Ectodermal Dysplasia (NFED). Funding Treatment, Accessed 30 October 2020: **https://www.nfed.org/treat/**.

[10] National Foundation Ectodermal Dysplasia (NFED). FAQS. How many people are affected by ectodermal dysplasia? Accessed 30 October 2020: **https://www.nfed.org/learn/faqs/**.

[11] *Op. cit*. NFED. FAQS. How many people are affected by ectodermal dysplasia?

[12] U.S. Centers for Medicare and Medicaid Services (CMS), Office of the Actuary. National Health Expenditure Projections. Table 7, Physician and Clinical Services Expenditures; Aggregate and per Capita Amounts, Percent Distribution and Annual Percent Change by Source of Funds: Calendar Years 2010-2026; Private Insurance. Accessed 4 November 2020: **https://www.cms.gov/Research-Statistics-Data-and-Systems/Statistics-Trends-and-Reports/NationalHealthExpendData/NationalHealthAccountsProjected.html**.

[13] U.S. National Library of Medicine. MedlinePlus. Dentinogenesis imperfecta. Description. Last reviewed 1 June 2017. Accessed 30 October 2020: **https://medlineplus.gov/genetics/condition/dentinogenesis-imperfecta/#frequency**.

[14] U.S. Centers for Medicare and Medicaid Services (CMS), Office of the Actuary. National Health Expenditure Projections. Table 7, Physician and Clinical Services Expenditures; Aggregate and per Capita Amounts, Percent Distribution and Annual Percent Change by Source of Funds: Calendar Years 2010-2026; Private Insurance. Accessed 4 November 2020: **https://www.cms.gov/Research-Statistics-Data-and-Systems/Statistics-Trends-and-Reports/NationalHealthExpendData/NationalHealthAccountsProjected.html**.

[15] NIH. U.S. National Library of Medicine. MedlinePlus. Amelogenesis imperfecta. Last reviewed 1 May 2015. Accessed 15 October 2020: **https://ghr.nlm.nih.gov/condition/amelogenesis-imperfecta**.

[16] Amelogenesis Imperfecta. Crawford, P.J., Aldred, M. & Bloch-Zupan, A. Amelogenesis imperfecta. *Orphanet J Rare Dis* 2**,** 17 (2007). Accessed 15 October 2020: **https://ojrd.biomedcentral.com/articles/10.1186/1750-1172-2-17**.

[17] U.S. Centers for Medicare and Medicaid Services (CMS), Office of the Actuary. National Health Expenditure Projections. Table 7, Physician and Clinical Services Expenditures; Aggregate and per Capita Amounts, Percent Distribution and Annual Percent Change by Source of Funds: Calendar Years 2010-2026; Private Insurance. Accessed 4 November 2020: **https://www.cms.gov/Research-Statistics-Data-and-Systems/Statistics-Trends-and-Reports/NationalHealthExpendData/NationalHealthAccountsProjected.html**.

[18] Massachusetts Center for Health Information and Analysis. Annual Report on the Massachusetts Health Care System, September 2019. Accessed 05 November 2020: **http://www.chiamass.gov/annual-report**.

Appendix A: Membership Affected by the Proposed Language

Membership potentially affected by proposed mandated change criteria include Commonwealth residents with fully insured, employer-sponsored health insurance issued by a Commonwealth-licensed company (including through the GIC); nonresidents with fully insured, employer-sponsored insurance issued in the Commonwealth; Commonwealth residents with individual (direct) health insurance coverage; and lives covered by GIC self-insured coverage.

Please note these are unprecedented economic circumstances, due to COVID-19, which makes the estimation of membership extremely challenging. The membership projections are used to determine the total dollar impact of the proposed mandate in question; however, variations in the membership forecast will not affect the general magnitude of the dollar estimates. As such, given the uncertainty, BerryDunn took a simplified approach to the membership projections as described below. These membership projections are not intended to be used for any other purpose than producing the total dollar range in this study. Further, to assess how recent volatility in commercial enrollment levels might affect these cost estimates, please note that the PMPM and percent of premium estimates are unaffected because they are per-person estimates, and the total dollar estimates will vary by the same percentage as any percentage change in enrollment levels.

The 2018 Massachusetts APCD formed the base for the projections. The Massachusetts APCD provided fully insured membership by insurance carrier. The Massachusetts APCD was also used to estimate the number of nonresidents covered by a Commonwealth policy. These are typically cases in which a nonresident works for a Commonwealth employer that offers employer-sponsored coverage. Adjustments were made to the data for membership not in the Massachusetts APCD, based on published membership reports available from CHIA and the Massachusetts Department of Insurance (DOI).

CHIA publishes monthly enrollment summaries in addition to its biannual enrollment trends report and supporting databook (enrollment-trends-March-2020-databook[1] and Monthly Enrollment Summary – August 2020[2]), which provides enrollment data for Commonwealth residents by insurance carrier for most carriers (some small carriers are excluded). CHIA uses supplemental information beyond the data in the Massachusetts APCD to develop its enrollment trends report. The supplemental data was used to adjust the resident totals from the Massachusetts APCD. In 2020, commercial, fully insured membership is 2.9% less than in 2019 with a shift to both uninsured and MassHealth coverage. The impact of COVID-19 on fully insured employers over the five-year projected period is uncertain. BerryDunn took a high-level conservative approach and assumed that membership would revert to 2019 levels by January 1, 2022. Given this approach, the 2021 assumption is dependent upon emerging 2020 fully insured membership levels.

The DOI published reports titled Quarterly Report of HMO Membership in Closed Network Health Plans as of December 31, 2018[3] and Massachusetts Division of Insurance Annual Report Membership in MEDICAL Insured Preferred Provider Plans by County as of December 31, 2018.[4] These reports provide fully insured covered members for licensed Commonwealth insurers where the member's primary residence is in the Commonwealth. The DOI reporting includes all insurance carriers and was used to supplement the Massachusetts APCD membership for small carriers not in the Massachusetts APCD.

The distribution of members by age and gender was estimated using Massachusetts APCD population distribution ratios, and was checked for reasonableness and validated against U.S. Census Bureau data.[5] Membership was

projected from 2020–2026 using Massachusetts Department of Transportation population growth rate estimates by age and gender.[6]

Projections for the GIC self-insured lives were developed using the GIC base data for 2018, and 2019 received directly from the GIC as well as the same projected growth rates from the Census Bureau that were used for the Commonwealth population. Breakdowns of the GIC self-insured lives by gender and age were based on the Census Bureau distributions.

Appendix A Endnotes

[1] Center for Health Information and Analysis. Estimates of fully insured and self-insured membership by insurance carrier. Accessed 15 November 2020. **www.chiamass.gov/enrollment-in-health-insurance/** .

[2] Center for Health Information and Analysis. Estimates of fully insured and self-insured membership by insurance carrier. Accessed 15 November 2020. **www.chiamass.gov/enrollment-in-health-insurance/**.

[3] Massachusetts Department of Insurance. HMO Group Membership and HMO Individual Membership Accessed 12 November 2020 https://www.mass.gov/doc/group-members/download **https://www.mass.gov/doc/individual-members/download**.

[4] Massachusetts Department of Insurance. Membership 2018. Accessed 12 November 2020 **https://www.mass.gov/doc/2018-ippp-medical-plans/download**.

[5] U.S. Census Bureau. Annual Estimates of the Population for the United States, Regions, States, and Puerto Rico: April 1, 2010 to July 1, 2018. Accessed 12 November 2020: **https://factfinder.census.gov/faces/tableservices/jsf/pages/productview.xhtml?src=bkmk**.

[6] Massachusetts Department of Transportation. Socio-Economic Projections for 2020 Regional Transportation Plans. Accessed 12 November 2020: **https://www.mass.gov/lists/socio-economic-projections-for-2020-regional-transportation-plans.**

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