



**Review and Evaluation of Proposed Legislation Entitled:  
An Act Relative to Urea Cycle Disorders  
House Bill 2058**

**Provided for  
The Joint Committee on Health Care Financing**

**May 2009**



Deval L. Patrick, Governor  
Commonwealth of Massachusetts  
Timothy P. Murray  
Lieutenant Governor

JudyAnn Bigby, Secretary  
Executive Office of Health and Human Services  
Sarah Iselin, Commissioner  
Division of Health Care Finance and Policy

## Table of Contents

Executive Summary	1
Introduction	3
Background	5
Methodological Approach	8
Summary of Findings	11
Endnotes	15
Appendix: Actuarial Review of Massachusetts House Bill 2058, An Act Relative to Urea Cycle Disorders	

## Executive Summary

This report was prepared by the Division of Health Care Finance and Policy (Division) pursuant to the provisions of M.G.L. c. 3 § 38C requiring the Division to review and evaluate the impact of a mandated benefit bill referred to the agency by a legislative committee. The Joint Committee on Health Care Financing referred House Bill 2058, “An Act Relative to Urea Cycle Disorders,” to the Division for review.

## Overview of Current Law and Proposed Mandate

If passed, House Bill 2058 (H. 2058) would require that health insurers cover the cost of “nonprescription enteral formula for home use” and “food products modified to be low in protein” for members who are diagnosed with urea cycle disorders. The Bill would accomplish this by amending current state laws that mandate coverage of these benefits for other metabolic conditions. Currently, these state laws do not explicitly require coverage for patients diagnosed with urea cycle disorders. The legislative intent of H. 2058 is to require coverage of these benefits for patients with urea cycle disorders that is consistent with coverage for patients with similar metabolic disorders, the treatment of which also includes “nonprescription enteral formula for home use” and “food products modified to be low in protein.”

These benefits are mandated for patients covered under an insurance policy through the Group Insurance Commission (GIC), fully insured plans offered by commercial insurers, Health Maintenance Organizations (HMOs), and Blue Cross Blue Shield plans.

## Current Coverage Levels

In response to a survey relative to current coverage of “nonprescription enteral formula for home use” and “food products modified to be low in protein,” five of the six health plans surveyed indicated that they already include the diagnosis code for urea cycle disorders among those for which these benefits are covered. Additionally, staff from the GIC indicated the coverage under the GIC plans generally follows the standard policies of its participating health plans.

## Methodology

The Division prepared this review and evaluation of H. 2058 by conducting interviews with stakeholders, including legislative staff, insurers, and experts in the Commonwealth; reviewing the relevant literature relative to urea cycle disorders; and conducting an actuarial analysis of the fiscal impact of H. 2058.

Three different impact scenarios were developed—low, middle, and high—to present a range for the possible impact. In addition, summary-level data from Massachusetts health plans was used to assess the reasonableness of estimates developed.

## Results

*The projected five-year increase in spending that would result from H. 2058 ranges from \$58,000 to \$595,000. The per member per month (PMPM) impact in all scenarios rounds to \$0.00.*

The five-year impact results are displayed in Exhibit 1 below. In 2009, the low, middle, and high scenarios result in estimated increased total spending of \$11,000, \$29,000, and \$106,000, respectively.

The five-year impact results are displayed in Exhibit 1. The results include three sets of estimates based on low, middle, and high impact scenarios corresponding to estimated prevalence of urea cycle disorders, average costs per member of formula and food, and increases in health plan administrative expenses.

### Exhibit 1: Estimated Cost Impact of H. 2058 on Fully Insured Health Care Premiums (2009-2013)

	2009	2010	2011	2012	2013	All 5 Years
Fully Insured Enrollment	2,868,000	2,868,000	2,868,000	2,868,000	2,868,000	
<b>Low Scenario</b>						
Annual Impact Claims (000s)	\$10	\$10	\$10	\$11	\$11	\$52
Annual Impact Administration (000s)	\$1	\$1	\$2	\$1	\$1	\$6
Annual Impact Total (000s)	\$11	\$11	\$12	\$12	\$12	\$58
Premium Impact (PMPM)	\$0.00	\$0.00	\$0.00	\$0.00	\$0.00	\$0.00
<b>Middle Scenario</b>						
Annual Impact Claims (000s)	\$25	\$26	\$27	\$29	\$30	\$138
Annual Impact Administration (000s)	\$4	\$4	\$5	\$4	\$5	\$21
Annual Impact Total (000s)	\$29	\$30	\$32	\$33	\$35	\$159
Premium Impact (PMPM)	\$0.00	\$0.00	\$0.00	\$0.00	\$0.00	\$0.00
<b>High Scenario</b>						
Annual Impact Claims (000s)	\$86	\$91	\$96	\$101	\$107	\$480
Annual Impact Administration (000s)	\$20	\$21	\$23	\$24	\$25	\$115
Annual Impact Total (000s)	\$106	\$112	\$119	\$125	\$132	\$595
Premium Impact (PMPM)	\$0.00	\$0.00	\$0.00	\$0.00	\$0.00	\$0.00

## Introduction

If passed, H. 2058 would require that health insurers cover the cost of “nonprescription enteral formula for home use” and “food products modified to be low in protein” for members who are diagnosed with urea cycle disorders.<sup>1</sup> The bill would accomplish this by amending current state laws that mandate coverage of these benefits for other metabolic conditions, but do not currently explicitly require coverage for patients diagnosed with urea cycle disorders.

## Summary of Current Coverage and Law

Current Massachusetts General Laws mandate coverage of “nonprescription enteral formula for home use” and “food products modified to be low in protein” for members who are diagnosed with one of a series of listed disorders. The list of conditions for which these benefits are currently mandated is included in the language of the current law and is presented in Box 1 that follows.

These benefits are mandated for patients covered under an insurance policy through the Group Insurance Commission (GIC), fully insured plans offered by commercial insurers, Health Maintenance Organizations (HMOs), and Blue Cross Blue Shield plans. The mandates for coverage are found in the following chapters and sections of Massachusetts General Laws:

Chapter 32A, Section 17A	GIC
Chapter 175, Section 47I	Commercial Insurer
Chapter 176A, Section 8L	BCBS Hospital
Chapter 176B, Section 4K	BCBS Physician
Chapter 176G, Section 4D	HMO

These laws require the following:

- Coverage for “nonprescription enteral formulas for home use” and “food products modified to be low in protein” in the following circumstances and with the following limitations.  
Provided that a physician has written an order for its use.  
The formula is medically necessary for treatment of a defined set of conditions.
- There is no limit established for coverage for “nonprescription enteral formulas for home use.”
- Mandated coverage for “food products modified to be low in protein” is limited to \$5,000 annually per member.

Additional Notes Regarding Current Laws:

- The coverage limit for “food products modified to be low in protein” was increased from \$2,500 to \$5,000 effective October 28, 2008.

- A separate bill (H. 2094) would eliminate the need for prior authorization for coverage of nonprescription enteral formula for home use.

## Summary of Proposed Mandate

H. 2058 would mandate coverage of “nonprescription enteral formula for home use” and “food products modified to be low in protein” for members who are diagnosed with urea cycle disorders. The bill would accomplish this by amending current state laws that mandate coverage of these benefits for other metabolic conditions, but do not currently include urea cycle disorders.

Box 1 below presents a comparison of the current law and the law that would be in place if H. 2058 were enacted. The example below includes only the language related to one chapter and section, but this language is materially the same for each chapter and section that would be amended.

### Box 1: Current Versus Proposed Law

Using Chapter 175, Section 47I as an example, the text below presents the language in the current law. The language that would be added under H. 2058 is highlighted in bold. Since the language related to the mandated benefit is materially the same in each chapter/section, the Division presented the language of only one chapter/section in this Box. Only the reference to the health insurers to which the mandate applies differs in the text of each chapter/section.

#### Chapter 175. Insurance

Section 47I. Any individual policy of accident and sickness insurance issued pursuant to section one hundred and eight, and any group blanket policy of accident and sickness insurance issued pursuant to section one hundred and ten, shall provide coverage for nonprescription enteral formulas for home use for which a physician has issued a written order and which are medically necessary for the treatment of malabsorption caused by Crohn’s disease, ulcerative colitis, gastroesophageal reflux, gastrointestinal motility, chronic intestinal pseudo-obstruction, urea cycle disorders and inherited diseases of amino acids and organic acids. Coverage for urea cycle disorders, inherited diseases of amino acids and organic acids shall include food products modified to be low protein in an amount not to exceed \$5,000 annually for any insured individual.

## Background

### What Are Urea Cycle Disorders?

Urea cycle disorders are life-threatening enzyme deficiencies that prevent the body from safely processing protein. Urea cycle disorders are among a category of metabolic disorders that affect the ability of patients to digest food and metabolize nutrients. Treatment for patients with these metabolic disorders typically includes medical nutrition therapy designed to reduce the intake of proteins that lead to complications and to provide sufficient nutrition to allow for health development.

Normally the body converts excess protein components into urea that can be eliminated from the blood via urine. With urea cycle disorders, the body instead produces ammonia. The accumulation of ammonia in the blood occurs in infants shortly after birth. Without treatment, ammonia quickly accumulates in the blood, leading to seizures, nervous system damage, coma and death. In the case of partial enzyme deficiencies, illness can present later in life.

Treatment includes sharp restriction of protein intake, medications that remove ammonia from the body, and special nutritional supplements. Patients will eat a diet of foods that are naturally low in protein. However, foods that are naturally low in protein do not provide adequate nutrition and are therefore supplemented with foods that are modified to be low in protein and nonprescription enteral formula. The nutritional supports include nutrients in protein-free versions and essential amino acids that patients lack in the protein-restricted diet. Without intake of the controlled protein supplements, the body breaks down its own protein reserves and ends up increasing ammonia in the blood.<sup>2</sup>

There is no cure for urea cycle disorders.

### Survey of Health Insurers

The Division asked six health insurers in Massachusetts to respond to a set of survey questions regarding their current coverage of “nonprescription enteral formula for home use” and “food products modified to be low in protein” for patients diagnosed with urea cycle disorders. All six health insurers that were surveyed responded to the Division’s survey. The responses were then blinded prior to interpreting the results of the survey responses. Of these insurers, all but one indicated that they already include the diagnosis code for urea cycle disorders among those for which these benefits are covered.

- For those plans that offer coverage of these benefits for patients diagnosed with urea cycle disorders, the stated policies offer coverage at levels consistent with those for the other metabolic conditions covered under current mandated benefit laws.

- The one plan that does not offer coverage of these benefits for patients diagnosed with urea cycle disorders provides coverage up to the mandated levels for patients with other metabolic conditions covered under current mandated benefit laws.
- The Division also asked staff from the GIC about current coverage “nonprescription enteral formula for home use” and “food products modified to be low in protein” for patients diagnosed with urea cycle disorders. The coverage under the GIC plans generally follows the standard policies of its participating health plans.

## Federal and State Laws and Activity

The Division did not find evidence of federal laws or pending federal legislation that would mandate insurance coverage of enteral formula or food modified to be low in protein for patients diagnosed with urea cycle disorders or other similar metabolic conditions. However, numerous other state legislatures have enacted laws similar to H. 2058 that establish some form of coverage or reimbursement for medically necessary foods.

In some instances, the laws require coverage for only selected conditions, while in others, coverage is required for all related metabolic conditions. Additionally, the language in some legislation refers to only one of either enteral formula or foods modified to be low in protein, but not to both. In these instances, depending upon how the law has been interpreted and implemented, coverage may be provided for both enteral formula and foods modified to be low in protein.<sup>3</sup>

The Division identified three organizations that have developed and, in the case of two, periodically update a list of state laws related to coverage of medically necessary foods. These include the following:

### The National Conference of State Legislatures

The National Conference of State Legislatures maintains a list of state laws and legislative activity related to Coverage of Medically Necessary Foods and Formula to Treat Disorders Identified Through Newborn Screening. The list was last updated July 2008 and can be found at the following website: <http://www.ncsl.org/programs/health/lawsfoodsformula.htm> The website includes the following summary of current state laws:

“At least 37 state legislatures and the District of Columbia have enacted bills to provide some insurance coverage of medically necessary foods and formula to treat disorders identified through newborn screening. Of those states, 14 state laws specifically mention medical foods and formula in the statute. Nine states refer to formula only, and 10 states refer to food only in the text of the statute. However, states that refer to either food or formula only may be covering both depending on how the statutes are interpreted in insurance regulations. Nine of these states have statutes pertaining to access to medical foods and formula through the state. One state, Oklahoma, adopted a resolution encouraging coverage of medical foods and formula. The District of Columbia also provides treatment for disorders identified through newborn screening to eligible individuals. State requirements for coverage may have caps or age limits.”



### **National PKU News**

National PKU News is a non-profit organization that has developed and maintains a list of state laws and policies related to coverage of medical nutrition for Phenylketonuria (PKU). In this list they also indicate whether the given law or policy relates to other metabolic conditions in addition to PKU. This list was last updated October 2008.

A link to the National PKU News list can be found at the following website:

<http://www.pkunews.org/rights/lobby6.htm#3>

### **Maine Bureau of Insurance**

The Maine Bureau of Insurance prepared a report to the state legislature titled, Review and Evaluation of LD 658, An Act To Protect the Health of Infants - June 6, 2007. This report included a review of other state laws that require coverage of formulas for patients diagnosed with metabolic disorders.

A link to this report can be found at the following website:

[http://www.maine.gov/pfr/legislative/documents/ld658\\_infant\\_formula\\_report\\_final.doc](http://www.maine.gov/pfr/legislative/documents/ld658_infant_formula_report_final.doc).

## Methodological Approach

### Overview of Approach

The Division engaged three consultants for this project: the actuarial firm, Oliver Wyman Actuarial Consulting, Inc. (Oliver Wyman), and consultant James Donohue of Boston Healthcare Advisors, LLC, and consultant Tony Dreyfus. Oliver Wyman was hired to estimate the financial effect of the passage of H. 2058. James Donohue was hired to review and evaluate the legislation, including working with Oliver Wyman to provide consultation on the methodology and assumptions for estimating the financial effects of H. 2058, with support from Tony Dreyfus to research the medical efficacy. Commonwealth Enterprise Group (CEG) secured the contract with the Division under which James Donohue and Tony Dreyfus performed their work.

The following steps were taken to prepare the review and evaluation of H. 2058:

#### *1. Conducted Interviews with Stakeholders.*

The Division conducted interviews with stakeholders in the Commonwealth to ensure accurate interpretation of the proposed change in law, to understand the perceptions about how the law would be interpreted, if enacted, and to learn about the expectations of its likely impacts. The Division completed interviews with legislative staff including Michael Mullen, Staff Assistant to the bill's sponsor, Representative Christine Canavan.

#### *2. Reviewed Literature.*

A review of the literature was conducted to determine the context of the proposed mandate, including the federal and state landscape, and coverage of nonprescription enteral formula for home use and food products modified to be low in protein.

#### *3. Prepared and Collected Survey Data from the Health Plans.*

The Division asked that six health plans complete and submit their responses to a survey to determine the coverage policy and benefits of the plan relative to the proposed mandate. Responses were received from six health plans, plus additional information from the GIC, which was queried separately.

#### *4. Developed Baseline for Massachusetts.*

The Division's actuarial firm developed the baseline for Massachusetts. The baseline represents all costs already being paid by health insurers affected by the proposed mandate related to urea cycle disorders, adjusted to reflect recent changes in mandated benefits.

#### *5. Applied Assumptions and Sensitivity Analysis to Methodology.*

Model parameters were developed to estimate a range of likely cost outcomes from the proposed mandate.

## Approach for Determining Medical Efficacy

M.G.L., c. 3 § 38C (d) requires the Division to assess the medical efficacy of mandating the benefit, including the impact of the benefit to the quality of patient care, the health status of the population, and the results of any research demonstrating the medical efficacy of the treatment or service compared to alternative treatments or services, or not providing the treatment or services. To determine the medical efficacy of H. 2058, the Division conducted a literature search of the research of the medical efficacy of providing nonprescription enteral formula for home use and food modified to be low in protein to patients diagnosed with urea cycle disorders.

## Approach for Determining the Fiscal Impact of the Mandate

### Legal Requirements

M.G.L. c. 3 § 38C (d) requires the Division to assess nine different measures in estimating the fiscal impact of a mandated benefit:

1. Financial impact of mandating the benefit, including the extent to which the proposed insurance coverage would increase or decrease the cost of the treatment or the service over the next five years;
2. Extent to which the proposed coverage might increase the appropriate or inappropriate use of the treatment or service over the next five years;
3. Extent to which the mandated treatment or services might serve as an alternative to a more expensive or less expensive treatment or service;
4. Extent to which the insurance coverage may affect the number or types of providers of the mandated treatment or service over the next five years;
5. Effects of mandating the benefit on the cost of health care, particularly the premium, administrative expenses and indirect costs of large employers, small employers and non-group purchasers;
6. Potential benefits and savings to large employers, small employers, employees and non-group purchasers;
7. Effect of the proposed mandate on cost shifting between private and public payers of health care coverage;
8. Cost to health care consumers of not mandating the benefit in terms of out-of-pocket costs for treatment or delayed treatment; and
9. Effect on the overall cost of the health care delivery system in the Commonwealth.

## Estimation Process

The following steps were followed to estimate the fiscal impact of this mandate:

- Estimate the size of the affected insured population;
- Estimate the baseline claims costs for the affected benefits;
- Estimate the range of potential costs due to the impact of the mandate's required benefits; and
- Estimate the impact of administrative expenses of the relevant insurers.

Following these steps, estimates were made for a five-year timeframe (2009-2013) for a range of "low case" to "high case" scenarios. Differences between scenarios were driven by these three factors:

- Estimated prevalence of urea cycle disorders among the insured population. The low and middle estimates of prevalence were based on a review of the Massachusetts claims data on which this analysis was conducted. In these data, 0.011% of members had any claim with a primary or secondary diagnosis of a urea cycle disorder. Since this estimate was higher than other national estimates of prevalence<sup>4,5</sup>, the rate of 0.011% was used for both the low and middle scenarios. The high scenario was set at 0.013% reflecting that the prevalence has increased in recent years and could continue to increase.<sup>6</sup>
- The estimated average annual cost of formula and low protein food per member diagnosed with a urea cycle disorder that included the following: a low scenario of \$500 per year, a middle scenario of \$1,000 per year and a high scenario of \$2,300 per year as of 2006. These estimates were then trended forward to 2009.
- Estimated increases in health plan administrative expenses and contributions to surplus or profit that result from increases in benefits. The estimates were based on data and analysis conducted in Oliver Wyman's administrative expense study<sup>7</sup> that analyzed expense ratios and loss ratios of the Commonwealth's HMOs and Blue Cross Blue Shield Plans.

For more detailed information on the methodological approach used to calculate the impact of S. 2058 (including the approach to calculating administrative costs), refer to the appendix to this report.

## Summary of Findings

### Medical Efficacy

Urea cycle disorders are life-threatening enzyme deficiencies that prevent the body from safely processing protein. Normally, the body converts excess protein components into urea that can be eliminated from the blood via urine. With urea cycle disorders, the body, instead, produces ammonia. The accumulation of ammonia in the blood occurs in infants shortly after birth. Without treatment, ammonia quickly accumulates in the blood, leading to seizures, nervous system damage, coma and death.<sup>8</sup> In the case of partial enzyme deficiencies, illness can present later in life.

Treatment includes sharp restriction of protein intake, medications that remove ammonia from the body, and special nutritional supplements. The nutritional supports include nutrients in protein-free versions and essential amino acids that patients lack in the protein-restricted diet. Without intake of the controlled protein supplements, the body breaks down its own protein reserves and ends up increasing ammonia in the blood.<sup>9</sup>

Because urea cycle disorders are genetic enzyme deficiencies, they do not improve over time. But ongoing careful treatment and diet can help patients avoid dangerous ammonia buildup and intensive hospital care, including dialysis. A possible therapy in some cases is liver transplantation.<sup>10</sup>

The coverage of nutritional supplements in the case of urea cycle disorders appears strongly supported by the medical efficacy of the supplements. These supplements are an integral part of the overall treatment, not just a supportive element of care.<sup>11</sup> Without careful nutritional management, patients with urea cycle disorders face elevated ammonia in the blood, which can lead to seizure, nerve system damage, coma, and death. When dietary restrictions, drug treatment, and supplements fail to control the condition, intensive care and dialysis may be needed. The potential medical benefits or cost benefits of denying dietary supplements seem negligible because of the danger and expense of unsuccessful control of urea cycle disorders.

The Division did not see any research on the costs and benefits of not using dietary supplements. The medical literature indicates that nutritional management is an essential component of care. While efforts have been made to control the effects of urea cycle disorders through boosting alternative metabolic pathways to process excess protein safely, these efforts have not been successful enough to make dietary management unnecessary.<sup>12</sup>

Nutritional supplements play a key role in treating urea cycle disorders, which are fatal if untreated or poorly controlled. The dangers and costs of care in cases of unsuccessful management, including intensive hospital care, dialysis, and liver transplantation, are so substantial that the efficacy of not providing the nutritional supports probably deserves little consideration.

### Financial Impact of Mandate

1. *The Division is required to assess the extent to which the proposed coverage would increase or decrease the cost of the treatment or the service over the next five years.*

The Division's actuarial consultant, Oliver Wyman, estimated the fiscal impact of the bill (see appendix) relative to the effect this mandate bill would have on expanding coverage of the benefits to members diagnosed with urea cycle disorders. Estimated impacts of H. 2058 on Massachusetts health care premiums for fully insured products were calculated as follows:

- Estimated impacts of H. 2058 on Massachusetts health care premiums for fully insured products were calculated assuming that the 2009 premium for a fully insured member is \$4,800.
- The low and middle scenarios assumed a prevalence rate of 0.011% and the high scenario assumed a prevalence rate of 0.013%.
- Low, middle, and high prevalence scenarios along with the scenarios related to costs of formulas and foods per member were developed to estimate the total cost of the mandated benefits.
- Baseline costs were estimated, reflecting coverage that is already provided by the health plans. These costs were subtracted from total costs to determine the incremental impact of the mandate. Given that most of the health plans are already providing the mandated coverage levels to their members, the resulting impacts on the premium for all scenarios rounded to \$0.00 Per Member Per Month (PMPM).
- The PMPM impacts (calculated without rounding) are multiplied by the fully insured population projection for the corresponding year to arrive at estimated annual impact dollars.

The five-year impact results are displayed in Exhibit 2 below. In 2009, these scenarios result in estimated increased total spending of \$11,000, \$29,000, and \$106,000 in the low, middle, and high scenarios, respectively.

2. *The Division is required to assess the extent to which the proposed coverage might increase the appropriate or inappropriate use of the treatment or service over the next five years.*

The Division found no evidence to suggest that passage of H. 2058 would change the current treatment patterns.

3. *The Division is required to assess the extent to which the mandated treatment or services might serve as an alternative to a more expensive or less expensive treatment or service.*

The Division did not find reason to suggest that passage of H. 2058 would lead patients to receive or physicians to prescribe different treatments.

4. *The Division is required to assess the extent to which the insurance coverage may affect the number or types of providers of the mandated treatment or service over the next five years.*

It is unlikely that H. 2058 would affect the number or types of providers of the mandated service. Given that all but one of the health plans surveyed already provide coverage for the mandated formulas and foods, and the relatively small population diagnosed with urea cycle disorders, the Division would not expect to see changes in the number or types of providers.

## Exhibit 2: Estimated Cost Impact of H. 2058 on Fully Insured Health Care Premiums (2009-2013)

	2009	2010	2011	2012	2013	All 5 Years
Fully Insured Enrollment	2,868,000	2,868,000	2,868,000	2,868,000	2,868,000	
<b>Low Scenario</b>						
Annual Impact Claims (000s)	\$10	\$10	\$10	\$11	\$11	\$52
Annual Impact Administration (000s)	\$1	\$1	\$2	\$1	\$1	\$6
Annual Impact Total (000s)	\$11	\$11	\$12	\$12	\$12	\$58
Premium Impact (PMPM)	\$0.00	\$0.00	\$0.00	\$0.00	\$0.00	\$0.00
<b>Middle Scenario</b>						
Annual Impact Claims (000s)	\$25	\$26	\$27	\$29	\$30	\$138
Annual Impact Administration (000s)	\$4	\$4	\$5	\$4	\$5	\$21
Annual Impact Total (000s)	\$29	\$30	\$32	\$33	\$35	\$159
Premium Impact (PMPM)	\$0.00	\$0.00	\$0.00	\$0.00	\$0.00	\$0.00
<b>High Scenario</b>						
Annual Impact Claims (000s)	\$86	\$91	\$96	\$101	\$107	\$480
Annual Impact Administration (000s)	\$20	\$21	\$23	\$24	\$25	\$115
Annual Impact Total (000s)	\$106	\$112	\$119	\$125	\$132	\$595
Premium Impact (PMPM)	\$0.00	\$0.00	\$0.00	\$0.00	\$0.00	\$0.00

5. *The Division is required to assess the effects of mandating the benefit on the cost of health care, particularly the premium, administrative expenses, and indirect costs of large employers, small employers and non-group purchasers.*

H. 2058 is projected to result in a small increase in health plan administrative costs. Exhibit 1 above includes administrative cost estimates.

6. *The Division is required to assess the potential benefits and savings to large and small employers, employees, and non-group purchasers.*

The Division has no data to suggest that passage of H. 2058 would result in benefits and savings to large and small employers, employees and non-group purchasers.

7. *The Division is required to assess the effect of the proposed mandate on cost shifting between private and public payers of health care coverage.*

The Division has no data to suggest that passage of H. 2058 would result in cost shifting between private and public payers of health coverage. Given the relatively small size of the affected population and the current coverage levels, the Division does not have reason to suggest such a shift would occur.

8. *The Division is required to assess the cost to health care consumers of not mandating the benefit in terms of out-of-pocket costs for treatment or delayed treatment.*

The Division would expect to see a reduction in the out-of-pocket costs to consumers for purchase of “nonprescription enteral formula for home use” and “food products modified to be low in protein” for any plan that does not currently offer coverage. Based on the health plan survey, the Division is aware of one plan that does not offer coverage. It is not clear whether other carriers that were not included in the survey currently provide coverage. Data are available to support an estimation of the total current out-of-pocket expenditures. However, the range of 2009 health plan cost estimates of \$538 to \$2,625 annually per member diagnosed with a urea cycle disorder (used in the financial impact calculation) provides a sense of the potential out-of-pocket costs for patients who lack this benefit.

9. *The Division is required to assess the effects on the overall cost of the health care delivery system in the Commonwealth.*

The estimated overall impact on health insurance premiums and spending is included in Exhibit 1 above.



## Endnotes

- <sup>1</sup> H. 2058.
- <sup>2</sup> Summar ML, Tuchman M. 2005 Urea Cycle Disorders Overview, 11 August 2005 update found at <http://www.ncbi.nlm.nih.gov/bookshelf/br.fcgi?book=gene&part=ucd-overview>
- <sup>3</sup> National Conference of State Legislatures: Coverage of Medically Necessary Foods and Formula to Treat Disorders Identified Through Newborn Screening. Updated July 2008  
<http://www.ncsl.org/programs/health/lawsfoodsformula.htm>
- <sup>4</sup> According to the National Urea Cycle Disorders Foundation (<http://www.nucdf.org/ucd.htm>) , "In April 2000, research experts at the Urea Cycle Consensus Conference estimated the incidence of the disorders at 1 in 10,000 births. This represents a significant increase in case diagnosis in the last few years." This estimate represents 0.010% of members.
- <sup>5</sup> According to Marshall Summar (Summar, Marshall L., M.D., "Urea Cycle Disorders Overview", Last update: August 11, 2005), "The incidence of UCDS is estimated to be at least 1:30,000 births; partial defects may make the number much higher." This represents only 0.003% of members.
- <sup>6</sup> According to the National Urea Cycle Disorders Foundation, "In April 2000, research experts at the Urea Cycle Consensus Conference estimated the incidence of the disorders at 1 in 10,000 births. This represents a significant increase in case diagnosis in the last few years." <http://www.nucdf.org/ucd.htm>
- <sup>7</sup> Oliver Wyman, Analysis of Administrative Expenses for Health Insurance Companies in Massachusetts, September 2008.
- <sup>8</sup> Mathias RS, Kostiner D, Packman S. 2001. Hyperammonemia in urea cycle disorders: role of the nephrologist. *Am J Kidney Dis.* May;37(5):1069-80.
- <sup>9</sup> Summar ML, Tuchman M. 2005 Urea Cycle Disorders Overview, 11 August 2005 update found at <http://www.ncbi.nlm.nih.gov/bookshelf/br.fcgi?book=gene&part=ucd-overview>
- <sup>10</sup> Lee B, Goss J. 2001. Long-term correction of urea cycle disorders. *J Pediatr.* Jan;138(1 Suppl): S62-71; and Ikeda S. 2000. [Recent advances of the treatment in metabolic disorders] *Rinsho Shinkeigaku.* Dec;40(12):1264-6.
- <sup>11</sup> Singh RH. 2007. Nutritional management of patients with urea cycle disorders. *J Inherit Metab Dis.* Nov;30(6):880-7. Epub 2007 Nov 25; and Ogier de Baulny H. 2002. Management and emergency treatments of neonates with a suspicion of inborn errors of metabolism. *Semin Neonatol.* Feb;7(1):17-26.
- <sup>12</sup> Batshaw ML, MacArthur RB, Tuchman M. 2001. Alternative pathway therapy for urea cycle disorders: twenty years later. *J Pediatr.* Jan;138(1 Suppl):S46-54; discussion S54-5.

**Report Authors**

James P. Donohue, Boston Healthcare Advisors, LLC

Tony Dreyfus, Dreyfus Consulting

Dianna Welch, Oliver Wyman Actuarial Consulting, Inc.

**Division of Health Care Finance and Policy  
Executive Office of Health and Human Services**

**Contributing Staff:** Audrey Morse, Kate Nordahl, and Ellen Sandler

**Division of Health Care Finance and Policy  
Two Boylston Street  
Boston, Massachusetts 02116  
Phone: (617) 988-3100  
Fax: (617) 727-7662  
Website: [www.mass.gov/dhcfp](http://www.mass.gov/dhcfp)**

**Publication Number: 09-119-HCF-02  
Authorized by Ellen Bickelman, State Purchasing Agent**

**Printed on Recycled Paper**



# **Appendix: Actuarial Review of Massachusetts House Bill 2058, An Act Relative to Urea Cycle Disorders**

February 26, 2009

**Actuarial Review of Massachusetts House  
Bill 2058, An Act Relative to Urea Cycle  
Disorders**

Massachusetts Division of Health Care  
Finance and Policy

**OLIVER WYMAN**

Dianna K. Welch, FSA, MAAA



MARSH MERCER KROLL  
GUY CARPENTER OLIVER WYMAN

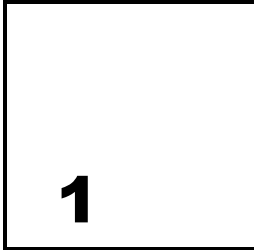
## **Contents**

1. Introduction and Executive Summary .....	1
▪ Introduction.....	1
▪ Executive Summary .....	2
2. Analysis.....	4
▪ Benefits .....	4
▪ Process .....	4
▪ Affected Population .....	4
▪ Targeted Population .....	5
▪ Cost of the Formulas and Foods .....	6
▪ Administrative Expense and Profit .....	8
▪ Marginal Costs .....	8
▪ Results.....	8
3. Five-Year Projection.....	10

### **Appendix A**

### **Appendix B**

### **Appendix C**



## **Introduction and Executive Summary**

### **Introduction**

Pursuant to M.G.L. Chapter 3, Section 38c, when reporting favorably on a mandated benefit bill, joint committees of the general court and the house and senate committees on ways and means are required to include a review and evaluation of the bill conducted by the Massachusetts Division of Health Care Finance and Policy (Division).

The Division has contracted with Oliver Wyman Actuarial Consulting, Inc. (Oliver Wyman) to perform an actuarial review of House Bill 2058, An Act Relative to Urea Cycle Disorders. The mandated benefit bill applies to the fully-insured, commercial market and the Group Insurance Commission (GIC). This market includes fully-insured plans offered by commercial insurers, Health Maintenance Organizations (HMOs), and Blue Cross and Blue Shield Plans as well as the GIC. These are the plans that are included in our analysis, consistent with the proposed mandate and the requirements of M.G.L. Chapter 3, Section 38c. It does not include Medicare Supplement or Medicare Advantage plans, Division of Medical Assistance, Commonwealth Care plans, or individual products offered prior to July 1, 2007.

We have prepared this report for the sole use of the Division for the purpose described above, and we do not authorize parties other than the Division to use the information contained herein. Any party other than the Division who chooses to use or rely on the information presented in this report does so without our authorization. This report is not intended to be a legal interpretation of the bill as written.

## Executive Summary

House Bill 2058, An Act Relative to Urea Cycle Disorders, would modify an existing mandate that requires health insurance policies to cover the cost of nonprescription enteral formulas and food products modified to be low protein. Under the existing mandate, coverage for low protein foods may be limited to \$5,000 annually. This limit was increased from \$2,500 to \$5,000 effective October 28, 2008. The existing mandate requires coverage for treatment of a list of disorders. House Bill 2058 would add urea cycle disorders to the list of disorders for which nonprescription enteral formulas and low protein foods must be covered. The full text of the bill is in Appendix A. The existing mandate that applies to commercial insurers can be found in Appendix B. The existing mandate that applies to the GIC, Blue Cross and Blue Shield plans, and HMOs contains similar language to that shown in Appendix B for commercial insurers.

We estimated the financial impact of extending the existing mandate on total and marginal costs of health insurance. The total cost estimate reflects the full cost of the nonprescription enteral formulas and low protein foods for urea cycle disorders mandated by the bill. However, there is already a baseline level of cost that is being paid by carriers. The marginal cost estimate reflects only the costs that are expected to be realized in addition to the baseline costs that are currently reimbursed for the affected population. The results of our five-year projections are included in the tables below. Exhibit 1 shows the total and marginal impacts on the fully-insured commercial market and the GIC. Exhibit 2 shows the total and marginal impacts on a per member per month (PMPM) basis. PMPM costs of \$0.00 represent costs of less than \$0.01 PMPM. They do not indicate that there is no cost associated with the mandated benefits.

We estimate the total impact on premiums of the mandated benefits for the period from 2009 through 2013 to be approximately \$1,004,000 to \$6,790,000. On a marginal basis, we estimate that the mandate would increase premiums by \$58,000 to \$595,000 for the period from 2009 through 2013. The total premium cost estimates represent an increase in premium of 0.001% to 0.009%, while the marginal cost estimates represent an increase in premium of 0.000% to 0.001%.

**Exhibit 1**

Claims and Premium due to House Bill 2058 Mandated Benefits

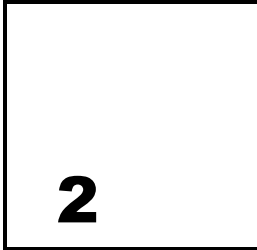
<b>Estimate of Commercially Insured Population + GIC</b>		2,868,000	2,868,000	2,868,000	2,868,000	2,868,000	
<b>Total Cost (in \$000's)</b>		<u>2009</u>	<u>2010</u>	<u>2011</u>	<u>2012</u>	<u>2013</u>	<u>2009 - 2013</u>
Claims	Low	\$168	\$174	\$181	\$187	\$194	\$904
	Middle	\$346	\$362	\$379	\$396	\$415	\$1,899
	High	\$979	\$1,033	\$1,091	\$1,152	\$1,217	\$5,472
Premium	Low	\$187	\$194	\$201	\$208	\$215	\$1,004
	Middle	\$400	\$419	\$438	\$458	\$479	\$2,195
	High	\$1,214	\$1,282	\$1,354	\$1,430	\$1,510	\$6,790
<b>Marginal Cost (in \$000's)</b>		<u>2009</u>	<u>2010</u>	<u>2011</u>	<u>2012</u>	<u>2013</u>	<u>2009 - 2013</u>
Claims	Low	\$10	\$10	\$10	\$11	\$11	\$52
	Middle	\$25	\$26	\$27	\$29	\$30	\$138
	High	\$86	\$91	\$96	\$101	\$107	\$480
Premium	Low	\$11	\$11	\$12	\$12	\$12	\$58
	Middle	\$29	\$30	\$32	\$33	\$35	\$159
	High	\$106	\$112	\$119	\$125	\$132	\$595

**Exhibit 2**

PMPM Claims and Premium due to House Bill 2058 Mandated Benefits

<b>Total Cost</b>		<u>2009</u>	<u>2010</u>	<u>2011</u>	<u>2012</u>	<u>2013</u>
Claims	Low	\$0.00	\$0.01	\$0.01	\$0.01	\$0.01
	Middle	\$0.01	\$0.01	\$0.01	\$0.01	\$0.01
	High	\$0.03	\$0.03	\$0.03	\$0.03	\$0.04
Premium	Low	\$0.01	\$0.01	\$0.01	\$0.01	\$0.01
	Middle	\$0.01	\$0.01	\$0.01	\$0.01	\$0.01
	High	\$0.04	\$0.04	\$0.04	\$0.04	\$0.04
<b>Marginal Cost</b>		<u>2009</u>	<u>2010</u>	<u>2011</u>	<u>2012</u>	<u>2013</u>
Claims	Low	\$0.00	\$0.00	\$0.00	\$0.00	\$0.00
	Middle	\$0.00	\$0.00	\$0.00	\$0.00	\$0.00
	High	\$0.00	\$0.00	\$0.00	\$0.00	\$0.00
Premium	Low	\$0.00	\$0.00	\$0.00	\$0.00	\$0.00
	Middle	\$0.00	\$0.00	\$0.00	\$0.00	\$0.00
	High	\$0.00	\$0.00	\$0.00	\$0.00	\$0.00





## **Analysis**

### **Benefits**

The benefit that this bill is intended to mandate is nonprescription enteral formula and low protein foods for persons with urea cycle disorders. Currently, there is mandated coverage for this benefit for other types of metabolic disorders, but coverage for urea cycle disorders is not required. The bill allows coverage for low protein foods to be limited to \$5,000 per year.

### **Process**

The first step we took in estimating the impact of this bill was to understand the legislative intent of the bill. We had a conference call with Michael Mullen, Administrative Assistant to Representative Christine Canavan as well as policy analysts and consultants for the Division. Through this call and subsequent communications, we were able to gain an understanding of the intent of the bill. The intent is to add urea cycle disorders to the existing mandated coverage. Our analysis estimates the impact of the intent of this bill and does not include a legal interpretation of the language of the bill.

Next we estimated the financial impact of the bill. This involved estimating the size of the affected population, the targeted population that will utilize the service, the cost of the service, and the administrative cost associated with the service. Additional detail on each of these steps is provided in the sections that follow.

### **Affected Population**

The population whose premiums will be affected by this mandate is the commercially insured population and the GIC. To estimate the size of this population we reviewed the 2007 financial statements of companies filing Health Annual Statements with commercial membership in Massachusetts. However, there are companies that insure commercial members in Massachusetts that do not file Health Annual Statements. We included an

estimate of members for companies not filing Health Annual Statements in our total membership estimate. Next we made an adjustment for the increase in coverage that has occurred since 2007 as a result of the health care reform law that was passed by Massachusetts in 2006<sup>1</sup>. In December 2008, the Division issued a press release indicating that the percentage of Massachusetts residents who remain uninsured is 2.6%<sup>2</sup>, down from previous estimates of 5-7% in 2007<sup>3,4</sup>. Using these estimates of the reduction in the percentage of residents that are uninsured, we estimated the increased number of insured residents. To estimate the number of fully-insured commercial members, we then subtracted the increased enrollment in subsidized insurance through Commonwealth Care from the total insured residents. Commonwealth Care enrollment was 162,726 as of December 2008<sup>5</sup>. Ultimately, we arrived at an estimated commercial insurance population of 2,574,000 as of the end of 2008. We estimated the size of the GIC to be 294,000<sup>6</sup>. Therefore, the estimated size of the affected population is 2,868,000.

Next we estimated the affected population as of 2009-2013 in order to perform our five-year projections. The U.S. Census Bureau has projected Massachusetts population to grow by 10.4% from 2000 to 2030<sup>7</sup>. This represents an average annual growth rate of 0.3%. However, the population age 65 or greater is projected to grow at an annual rate of 1.8%. This corresponds to essentially no growth in the under 65 age group. Because the affected population is predominantly under age 65, we are projecting no change in the affected population over the five-year projection period.

## Targeted Population

The targeted population that would utilize the benefits mandated by House Bill 2058 is individuals with a diagnosis of urea cycle disorders. For this study we obtained permission from six of the carriers that participated in the study that the Massachusetts Division of Insurance conducted, Trends in Health Claims for Fully-Insured, Health

---

<sup>1</sup> Massachusetts General Laws

<http://www.mass.gov/legis/laws/seslaw06/sl060058.htm>

<sup>2</sup> Division of Health Care Finance and Policy.

[http://www.mass.gov/?pageID=eohhs2pressrelease&L=4&L0=Home&L1=Government&L2=Departments+and+Divisions&L3=Division+of+Health+Care+Finance+%26+Policy&sid=Eeohhs2&b=pressrelease&f=081218\\_health\\_insurance&csid=Eeohhs2](http://www.mass.gov/?pageID=eohhs2pressrelease&L=4&L0=Home&L1=Government&L2=Departments+and+Divisions&L3=Division+of+Health+Care+Finance+%26+Policy&sid=Eeohhs2&b=pressrelease&f=081218_health_insurance&csid=Eeohhs2)

<sup>3</sup> U.S. Census Bureau.

[http://pubdb3.census.gov/macro/032008/health/h06\\_000.htm](http://pubdb3.census.gov/macro/032008/health/h06_000.htm)

<sup>4</sup> Kaiser Daily Health Policy Report.

[http://www.kaisernetwork.org/daily\\_reports/health2008dr.cfm?DR\\_ID=52498](http://www.kaisernetwork.org/daily_reports/health2008dr.cfm?DR_ID=52498)

<sup>5</sup> Commonwealth Connector, Connector Summary Report from Connector Board Meeting January 15, 2009.

<sup>6</sup> Commonwealth of Massachusetts Group Insurance Commission

<http://www.mass.gov/gic/> Accessed January 27, 2009.

<sup>7</sup> U.S. Census Bureau, Population Division, Interim State Population Projections, 2005.

Maintenance Organizations in Massachusetts, 2002-2006<sup>8</sup> (Trend Study) to use the data provided for that study to support this mandated benefit study. The list of the six participating carriers is in Appendix C. We reviewed these carriers' claims data from 2006 to determine the percentage of members that had any claims with a primary or secondary diagnosis of Disorders of Urea Cycle Metabolism. We found that 0.011% of members had claims with this diagnosis.

We also did a search for published prevalence data as a reasonableness check on the prevalence that we were seeing within the Massachusetts data. According to the National Urea Cycle Disorders Foundation, "In April 2000, research experts at the Urea Cycle Consensus Conference estimated the incidence of the disorders at 1 in 10,000 births. This represents a significant increase in case diagnosis in the last few years."<sup>9</sup> This estimate represents 0.010% of members. According to Marshall Summar, "The incidence of UCDs is estimated to be at least 1:30,000 births; partial defects may make the number much higher."<sup>10</sup> This represents only 0.003% of members.

We used the prevalence from the carrier data of 0.011% as the basis for our low and middle estimates. Because the 0.003% estimate was known to be understated due to the exclusion of partial defects, and the 0.011% estimate is based on actual Massachusetts insured data, we did not incorporate the lower 0.003% estimate into the projection. We used an estimate of 0.013% as our high end estimate, reflecting that the prevalence rate has increased in recent years and could continue to increase.

## Cost of the Formulas and Foods

The next step of our analysis was to estimate the annual cost of the nonprescription enteral formulas and low protein foods that would be used by a person with urea cycle disorder. We sent a survey to the six carriers shown in Appendix C to understand their existing levels of coverage for the mandated benefits. All except one indicated that they already include urea cycle disorders in the diagnoses that are eligible for the formulas and foods. We reviewed the claims data of those carriers that already cover the benefits for urea cycle disorders to estimate the costs of claims for formula and low protein foods used by those with a urea cycle diagnosis. We observed very little claims volume for these services with the urea cycle diagnosis. Reasons for this low volume could be lack of awareness of existing coverage for urea cycle diagnoses, lack of utilization among those with a urea cycle disorder, or inconsistencies in billing practices resulting in under-reporting in the data. Using this data source as the sole basis for our estimate of the impact of the mandate would have resulted in a negligible cost of the mandate. However, both the literature that we reviewed and the testimony that was provided on the bill

---

<sup>8</sup> Oliver Wyman, Report to the Health Care Access Bureau of the Massachusetts Division of Insurance, Trends in Health Claims for Fully-Insured, Health Maintenance Organizations in Massachusetts, 2002-2006

<sup>9</sup> National Urea Cycle Disorders Foundation

<http://www.nucdf.org/ucd.htm>

<sup>10</sup> Summar, Marshall L., M.D., "Urea Cycle Disorders Overview", Last update: August 11, 2005.

indicate that diagnosed prevalence of urea cycle disorders is increasing. In addition, Representative Canavan's testimony indicates that, "Metabolic disorders have changed greatly over the past few years, and urea cycle disorders are a new category of metabolic disorders for which modified formula and food are necessary." This could indicate that only recently modified formula and foods have become part of the normal treatment for urea cycle disorders which might explain the low level of claims for formula and foods in the 2006 data provided by the carriers. Therefore, instead of relying on the claims data for urea cycle disorder alone, next we examined what the utilization of the formulas and foods would be if the utilization is similar to other disorders for which formulas and foods are used.

We estimated the average annual cost of the formulas and foods per member who utilizes them. For this analysis, we did not limit the diagnosis to urea cycle disorders. We included all diagnoses in order to determine what the average cost would be if a urea cycle patient were to use a similar amount of formula as other patients. We found that those who used nonprescription enteral formulas incurred expenses for the formula that averaged approximately \$1,500 per year. Those who used low protein foods incurred expenses of approximately \$4,500 per year. The combined average amount of nonprescription enteral formulas and low protein foods used per year was approximately \$2,300. The carrier data that we used was from calendar year 2006.

Effective October 28, 2008, the existing mandate was modified to raise the annual limit on low protein foods from \$2,500 to \$5,000. Nonprescription enteral formulas do not have an annual limit. We reviewed the low protein foods data to estimate the impact of this increased benefit. However, it did not appear that a limit was being applied by the carriers in practice. The average amount of low protein foods per user was over \$4,500 during 2006 when the allowable limit was \$2,500. Therefore, we made no adjustments due to the increased benefit limit. We are also assuming that carriers will not change their practices and implement a limit as a result of this mandate.

We used the \$2,300 combined average cost per user as our high estimate. We do not have any data to suggest that those with urea cycle disorder would be more likely to utilize nonprescription enteral formulas over low protein foods, or vice versa. Therefore, we used the combined average for our estimate. We considered this a high estimate because utilization among those with urea cycle disorder in 2006 was negligible. We believe it is unlikely that those with urea cycle disorder will reach average utilization levels of other disorders during the projection period. For our middle estimate we used a cost estimate of \$1,000 per user per year, the average amount of formulas and foods used by those with urea cycle disorder who did utilize the benefit during 2006. For our low estimate, we assumed that only half of the middle estimate, or \$500, would be used. In the carrier data, we observed very little member cost sharing for these services. We believe this is in part due to many plan designs covering the benefit in full. It is also possible that these members will reach an out of pocket maximum due to other medical expenses. Therefore, no explicit adjustments have been made for member cost sharing.

Next we trended the cost of the formula from 2006 to 2009. We trended the cost per user to 2009 using an annual trend of 3.5% for our middle estimate. This trend is the average five-year cost per service trend for Other Professional services from the Trend Study, which is the category of services in which the formulas and foods are included. For our low and high estimates we used annual trends of 2.5% and 4.5%, respectively.

## Administrative Expense and Profit

Increases in benefits also result in increases in administrative expenses and contributions to surplus or profit. In 2008, Oliver Wyman performed an expense study for the Division of Insurance<sup>11</sup> (Expense Study). This was a five-year study that analyzed expense ratios and loss ratios of the Commonwealth's HMOs and Blue Cross and Blue Shield Plans. The study found that the average loss ratio in Massachusetts for 2002 through 2007 was 86.5%, meaning 13.5% of premium is available for retention items, including administrative expense and contribution to surplus. We used this 13.5% retention ratio to estimate the amount that would be included for retention in premium increases for the mandated benefits. The low and high ends of the ranges were based on the lowest and highest five-year average retention percentages of the health plans included in the analysis.

## Marginal Costs

As noted above, most of the carriers that we surveyed already provide coverage for formulas and foods for urea cycle disorders, though historical utilization levels have been low. We have estimated baseline costs in the affected population that would exist under current coverage levels assuming our projected utilization and cost per service levels. We have used projected utilization and cost levels in our baseline cost estimate instead of actual historical experience because the changes in utilization are anticipated due to changes in treatment patterns and not due to the mandated coverage. The difference between the total expected cost under the mandate and the baseline costs produce our marginal cost estimates.

## Results

The following Exhibit shows the results of our analysis. Costs shown below as \$0.00 or \$0.000 PMPM do not mean that there is no cost of the benefit. It represents costs of less than \$0.01 PMPM.

---

<sup>11</sup> Oliver Wyman, Analysis of Administrative Expenses for Health Insurance Companies in Massachusetts, September 2008.

**Exhibit 3**

Development of Total Cost and Marginal Cost Estimates of House Bill 2058

**Total Cost Estimates**

		<u>Low</u>	<u>Middle</u>	<u>High</u>
Prevalence of urea cycle disorder	(A)	0.011%	0.011%	0.013%
Annual cost of formulas and low protein food per user 2006	(B)	\$500	\$1,000	\$2,300
Annual Trend	(C)	2.5%	3.5%	4.5%
Annual cost of formulas and low protein food per user 2009	(D) = B*(1+C)^3	\$538	\$1,109	\$2,625
<b>2009 Claims cost PMPM</b>	<b>(E) = A*D/12</b>	<b>\$0.00</b>	<b>\$0.01</b>	<b>\$0.03</b>
Admin & contribution to surplus ratio	(F)	10.0%	13.5%	19.4%
<b>Premium PMPM (with Admin)</b>	<b>(G) = E/(1-F)</b>	<b>\$0.01</b>	<b>\$0.01</b>	<b>\$0.04</b>

**Baseline Costs**

<b>Baseline Claims Cost PMPM</b>	<b>(H)</b>	<b>\$0.00</b>	<b>\$0.01</b>	<b>\$0.03</b>
<b>Baseline Premium PMPM</b>	<b>(I)</b>	<b>\$0.01</b>	<b>\$0.01</b>	<b>\$0.03</b>

**Marginal Cost Estimates**

<b>Marginal Claims Cost PMPM</b>	<b>(J) = E-H</b>	<b>\$0.000</b>	<b>\$0.001</b>	<b>\$0.002</b>
<b>Marginal Premium Increase PMPM</b>	<b>(K) = G-I</b>	<b>\$0.000</b>	<b>\$0.001</b>	<b>\$0.003</b>

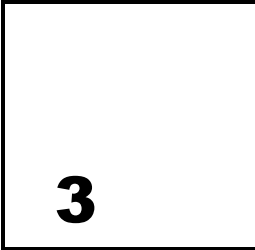
The total premium cost estimates represent an increase in premium of 0.001% to 0.009% based on an average annual premium per member of roughly \$4,800<sup>12</sup>. The marginal cost estimates represent an increase in premium of 0.000% to 0.001%.

We reviewed the cost of the existing mandated benefits as reported by the Division in 2008<sup>13</sup>. The Division estimated the claims plus administrative cost of the nonprescription enteral formulas to be \$0.02 PMPM. The estimated claims plus administrative cost of the low protein foods was \$0.01 PMPM. These estimates were based on claims data from 2004 and 2005. Our review of the Appendix to the Division's report, produced by Compass Health Analytics, Inc. showed that the urea cycle disorder diagnosis was included in the range of diagnoses that was analyzed in the study. We would expect the \$0.03 total estimate to include a negligible amount of claims volume for urea cycle diagnosis, similar to what we observed in the 2006 data. Our estimates of the costs of the mandated benefits associated with urea cycle diagnoses appear consistent with the Division's prior estimate of \$0.03 PMPM for all mandated diagnoses.

<sup>12</sup> Average commercial group premium per member is from 2007 financial statements of companies filing health statements, trended to 2009 at an annual rate of 7%.

<sup>13</sup> Division of Health Care Finance and Policy, Comprehensive Review of Mandated Benefits in Massachusetts Report to the Legislature, July 7, 2008.

[http://www.mass.gov/Eeohhs2/docs/dhcfp/r/pubs/mandates/comp\\_rev\\_mand\\_benefits.pdf](http://www.mass.gov/Eeohhs2/docs/dhcfp/r/pubs/mandates/comp_rev_mand_benefits.pdf)



### Five-Year Projection

The following two exhibits show the results of our five-year projection. Exhibit 4 shows the total and marginal impacts on the fully-insured commercial market and the GIC. Exhibit 5 shows the total and marginal impacts of the mandate on a PMPM basis. Claims and premiums associated with the covered mandated benefits are estimated to range from less than \$0.01 PMPM to \$0.04 PMPM. On a marginal basis we would expect premiums and claims to increase by less than \$0.01 PMPM.

**Exhibit 4**

Claims and Premium due to House Bill 2058 Mandated Benefits

Estimate of Commercially Insured Population + GIC		2,868,000	2,868,000	2,868,000	2,868,000	2,868,000	
<b>Total Cost (in \$000's)</b>		<u>2009</u>	<u>2010</u>	<u>2011</u>	<u>2012</u>	<u>2013</u>	<u>2009 - 2013</u>
Claims	Low	\$168	\$174	\$181	\$187	\$194	\$904
	Middle	\$346	\$362	\$379	\$396	\$415	\$1,899
	High	\$979	\$1,033	\$1,091	\$1,152	\$1,217	\$5,472
Premium	Low	\$187	\$194	\$201	\$208	\$215	\$1,004
	Middle	\$400	\$419	\$438	\$458	\$479	\$2,195
	High	\$1,214	\$1,282	\$1,354	\$1,430	\$1,510	\$6,790
<b>Marginal Cost (in \$000's)</b>		<u>2009</u>	<u>2010</u>	<u>2011</u>	<u>2012</u>	<u>2013</u>	<u>2009 - 2013</u>
Claims	Low	\$10	\$10	\$10	\$11	\$11	\$52
	Middle	\$25	\$26	\$27	\$29	\$30	\$138
	High	\$86	\$91	\$96	\$101	\$107	\$480
Premium	Low	\$11	\$11	\$12	\$12	\$12	\$58
	Middle	\$29	\$30	\$32	\$33	\$35	\$159
	High	\$106	\$112	\$119	\$125	\$132	\$595

**Exhibit 5**

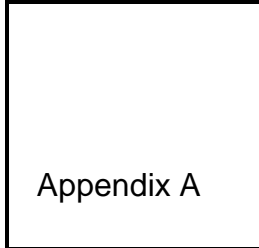
PMPM Claims and Premium due to House Bill 2058 Mandated Benefits

<b>Total Cost</b>		<u>2009</u>	<u>2010</u>	<u>2011</u>	<u>2012</u>	<u>2013</u>
Claims	Low	\$0.00	\$0.01	\$0.01	\$0.01	\$0.01
	Middle	\$0.01	\$0.01	\$0.01	\$0.01	\$0.01
	High	\$0.03	\$0.03	\$0.03	\$0.03	\$0.04
Premium	Low	\$0.01	\$0.01	\$0.01	\$0.01	\$0.01
	Middle	\$0.01	\$0.01	\$0.01	\$0.01	\$0.01
	High	\$0.04	\$0.04	\$0.04	\$0.04	\$0.04
<b>Marginal Cost</b>		<u>2009</u>	<u>2010</u>	<u>2011</u>	<u>2012</u>	<u>2013</u>
Claims	Low	\$0.00	\$0.00	\$0.00	\$0.00	\$0.00
	Middle	\$0.00	\$0.00	\$0.00	\$0.00	\$0.00
	High	\$0.00	\$0.00	\$0.00	\$0.00	\$0.00
Premium	Low	\$0.00	\$0.00	\$0.00	\$0.00	\$0.00
	Middle	\$0.00	\$0.00	\$0.00	\$0.00	\$0.00
	High	\$0.00	\$0.00	\$0.00	\$0.00	\$0.00

We trended claims and premiums forward at an annual rate of 4.6% for our middle estimate. 4.6% is the average PMPM trend reported in the Trend Study for Other Professional services. We used the total PMPM trend which includes the impact of cost per service and utilization changes, and not the cost per service trend, because of the literature that indicated that diagnosis of urea cycle disorder and utilization of formulas and low protein foods is increasing. We trended claims and premiums forward at annual rates of 3.6% and 5.6% for our low and high estimates, respectively. By using the same trend for claims and premium, we are assuming that the loss ratio remains constant. Over the five-year period covered by the Expense Study, the Massachusetts Total loss ratio fluctuated from year to year, but remained within 0.6% of the five-year average.

We estimate the total premium cost of the mandated benefits for the period 2009 through 2013 to be approximately \$1,004,000 to \$6,790,000. On a marginal basis, we estimate the premium cost of the mandate to be \$58,000 to \$595,000 for the period 2009 through 2013.





## **HOUSE..... No. 2058**

By Mrs. Canavan of Brockton, petition of Christine E. Canavan and others relative to health insurance coverage for urea cycle disorders. Public Health.

### **The Commonwealth of Massachusetts**

Christine E. Canavan Geraldine Creedon Thomas P. Kennedy Barbara A. L'Italien Linda Dorcena Forry Geoffrey D. Hall Brian P. Wallace

PETITION OF:

Martin J. Walsh Thomas J. Calter Louis L. Kafka Allen J. McCarthy Jennifer M. Callahan Walter F. Timilty

In the Year Two Thousand and Seven.

AN ACT RELATIVE TO UREA CYCLE DISORDERS.

*Be it enacted by the Senate and House of Representatives in General Court assembled, and by the authority of the same, as follows:*

SECTION 1. Section 17A of Chapter 32A of the General Laws, as appearing in the 2004 Official Edition, is hereby amended by inserting after the word "pseudo-obstruction," in line 7, the 4 following words:—urea cycle disorders.

SECTION 2. Section 17A of Chapter 32A of the General Laws, as appearing in the 2004 Official Edition, is hereby amended by inserting after the word "for", in line 8, the following words:— urea cycle disorders and.

SECTION 3. Section 47I of Chapter 175 of the General Laws, as appearing in the 2004 Official Edition, is hereby amended by inserting after the word “pseudo-obstruction,” in line 8, the following words:—urea cycle disorders.

SECTION 4. Section 47I of Chapter 175 of the General Laws, as appearing in the 2004 Official Edition, is hereby amended by inserting after the word “for”, in line 9, the following words:— urea cycle disorders and.

SECTION 5. Section 8L of Chapter 176A of the General Laws, as appearing in the 2004 Official Edition, is hereby amended by 3 inserting after the word “pseudo-obstruction,” in line 9, the 4 following words:—urea cycle disorders.

SECTION 6. Section 8L of Chapter 176A of the General Laws, as appearing in the 2004 Official Edition, is hereby amended by 3 inserting after the word “for”, in line 10, the following words:— urea 4 cycle disorders and.

SECTION 7. Section 4K of Chapter 176B of the General Laws, as appearing in the 2004 Official Edition, is hereby amended by 3 inserting after the word “pseudo-obstruction,” in line 10, the 4 following words:—urea cycle disorders.

SECTION 8. Section 4K of Chapter 176B of the General Laws, as appearing in the 2004 Official Edition, is hereby amended by 3 inserting after the word “for”, in line 11, the following words— urea 4 cycle disorders and.

SECTION 9. Section 4D of chapter 176G of the General Laws, as appearing in the 2004 Official Edition, is hereby amended by 3 inserting after the word “pseudo-obstruction,” in line 6, the 4 following words:—urea cycle disorders.

SECTION 10. Section 4D of chapter 176G of the General Laws, as appearing in the 2004 Official Edition, is hereby amended by 3 inserting after the word “for”, in line 7, the following words:—urea 4 cycle disorders and.

Appendix B

**CHAPTER 175. INSURANCE**

**PROVISIONS RESPECTING DOMESTIC COMPANIES**

**ARTICLE Organization.**

**Chapter 175: Section 47I. Nonprescription enteral formulas for home use**

*[ Text of section effective until October 28, 2008. For text effective October 28, 2008, see below.]*

Section 47I. Any individual policy of accident and sickness insurance issued pursuant to section one hundred and eight, and any group blanket policy of accident and sickness insurance issued pursuant to section one hundred and ten, shall provide coverage for nonprescription enteral formulas for home use for which a physician has issued a written order and which are medically necessary for the treatment of malabsorption caused by Crohn's disease, ulcerative colitis, gastroesophageal reflux, gastrointestinal motility, chronic intestinal pseudo-obstruction, and inherited diseases of amino acids and organic acids. Coverage for inherited diseases of amino acids and organic acids shall include food products modified to be low protein in an amount not to exceed two thousand five hundred dollars annually for any insured individual.

**Chapter 175: Section 47I. Nonprescription enteral formulas for home use**

*[ Text of section as amended by 2008, 214, Sec. 2 effective October 28, 2008. For text effective until October 28, 2008, see above.]*

Section 47I. Any individual policy of accident and sickness insurance issued pursuant to section one hundred and eight, and any group blanket policy of accident and sickness insurance issued pursuant to section one hundred and ten, shall provide coverage for nonprescription enteral formulas for home use for which a physician has issued a written order and which are medically necessary for the treatment of malabsorption caused by Crohn's disease, ulcerative colitis, gastroesophageal reflux, gastrointestinal motility, chronic intestinal pseudo-obstruction, and inherited diseases of amino acids and organic acids. Coverage for inherited diseases of amino acids and organic acids shall include food

products modified to be low protein in an amount not to exceed \$5,000 annually for any insured individual.

Appendix C

**List of Carriers That Provided Permission to Use  
Massachusetts Division of Insurance Trend Study Data and  
Provided Survey Responses**

Blue Cross and Blue Shield of Massachusetts, Inc. and Blue Cross and Blue Shield of  
Massachusetts HMO Blue, Inc.

Fallon Community Health Plan

Health New England, Inc.

Harvard Pilgrim Health Care, Inc.

Neighborhood Health Plan

Tufts Associated Health Maintenance Organization, Inc.

# OLIVER WYMAN

411 East Wisconsin Avenue, Suite 1600  
Milwaukee, WI 53202-4419  
1 414 223 7989

Oliver Wyman Actuarial Consulting, Inc.



MARSH MERCER KROLL  
GUY CARPENTER OLIVER WYMAN