COMMONWEALTH OF MASSACHUSETTS

MANDATED BENEFIT REVIEW

REVIEW AND EVALUATION OF PROPOSED LEGISLATION TO MANDATE COVERAGE FOR SCALP HAIR PROSTHESES:

S. 916/ H. 3180

PROVIDED FOR:
THE JOINT COMMITTEE ON INSURANCE

DIVISION OF HEALTH CARE FINANCE AND POLICY
COMMONWEALTH OF MASSACHUSETTS
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EXECUTIVE SUMMARY

This report was prepared by the Division of Health Care Finance and Policy (DHCFP) pursuant to the provisions of M.G.L. c. 3, § 38C. This section requires the Division to evaluate the impact of a mandated benefit bill referred by legislative committee for review and to report to the referring committee within 90 days. The Division was requested to evaluate two bills pertaining to health insurance coverage for scalp prostheses.

Proposed H. 3180 and S. 916 would require "all health insurers" (except MassHealth, supplemental policies providing coverage for only specific diseases and Medicare supplemental coverage) to cover the cost of "scalp hair prosthesis" not exceeding an amount of $3,000 per enrollee within a three-year period for people with alopecia areata, alopecia totalis, non-classical 21-hydroxylase deficiency, or permanent hair loss that is due to injury. Massachusetts insurers currently provide coverage, under an existing mandate, of up to $350 per year for scalp prosthesis for cancer patients. In addition, several insurers in Massachusetts already provide coverage to people suffering from hair loss attributed to conditions covered under the proposed mandates. Since the incidence rates of the diseases in the proposed mandate are low, newly diagnosed people would become eligible for scalp prostheses should one of these mandates pass. However, some people who are already eligible but have chosen not to buy a scalp prosthesis may add to the numbers slightly.

DHCFP contracted with Compass Health Analytics Inc. (Compass) to estimate the expected change in health care costs in the event H. 3180/S916 becomes law. The change in annual premium cost from the proposed benefit will result in a three-year cycle in which the first year of the new benefit will be higher than the two following years. Compass estimated the additional premiums in 2005 to be one-fifth of a cent per member per month which amounts to $68,000 in Massachusetts. This estimate is higher than projected costs in each of the two years immediately following 2005 for two reasons: 1) pent-up or "dormant" demand for high quality scalp prostheses will be highest in the first year of the benefit, and 2) people who use all or most of the $3,000 benefit in year one will not become eligible for the benefit again until 2008.

Compass estimated that the additional annual costs in the second year (2006) to be $38,000. In 2008, the first year of the next three-year cycle, costs would increase to $48,000 and decrease again in 2009, to $39,000 or one-tenth of a cent per member per month (see Appendix 1).

Table of Contents

Section **Page**

Introduction ………………..……………………………………………...4

Overview of Proposed Legislation ……………………………….....4

Background of Issue……………………………………………….5

Medical Efficacy ……………………………………..……………6

Current Coverage and Costs …………………………….…….8

Financial Impact of Mandate ……………………………...….12

Legislative Activity in Other States ………………………..…...14

Endnotes…………………………………………………………...14

Appendices:

Appendix 1: Compass Analytics Report (actuarial assessment)……………………………………………………17-34

Appendix 2: Testimony Submitted..……………………………….35

Appendix 3: Glossary…………………………………………….37

INTRODUCTION

The Joint Committee on Insurance referred proposed H. 3180 and S. 916, entitled "*An Act Providing Health Insurance Coverage for Scalp Prosthesis,"* to the Division of Health Care Finance and Policy (DHCFP) for a review and evaluation.

OVERVIEW OF PROPOSED LEGISLATION

H. 3180 and S. 916 propose mandating coverage of scalp prosthesis for people with alopecia areata, alopecia totalis, non-classical 21-hydroxylase deficiency, or permanent loss of scalp hair due to injury, provided that the alopecia is not part of natural or premature aging process. The benefit, as proposed, is $3,000 every three years.

Three of four health insurance carriers that responded to a DHCFP survey reported that they already provide scalp prosthesis coverage for at least some of the conditions covered by the proposed mandates, and these three carriers insure the majority of commercially insured people in Massachusetts. Of enrollees of a plan that already offered the broader prosthesis coverage, i.e., for non-cancerous as well as cancerous conditions, fewer than 3% of claims were for non-cancerous diagnoses in 2003. Therefore, we would expect relatively few additional enrollees to use the benefit proposed in H. 3180 and S. 916.

The average paid claims for scalp prostheses by the four health insurance carriers that responded to a DHCFP survey ranged from $304 to $380. Most of the claims paid (even for insurers that provided coverage of scalp prostheses for alopecia areata, alopecia totalis, and injury) were for cancer patients. The new legislation proposes a higher benefit for a small population of enrollees who also need hair replacement and for a longer time-span than do cancer patients whose hair usually grows back when treatment is over.

BACKGROUND

Hair is an important facet of human appearance that is commonly used for recognition and is one determinant for physical attractiveness.[1] Studies have shown that loss of hair can have a negative impact on social perceptions and behavior, as physical appearances convey immediate information about a person, and reliably influence social perceptions in various contexts.[2]

Heredity and aging are not the only causes of hair loss (also known as alopecia). Diseases such as alopecia areata, alopecia totalis, non-classical 21-hydroxylase enzyme deficiency, and injury can cause hair loss.

Alopecia Areata:

Alopecia areata is defined by the National Alopecia Areata Foundation as being “a highly unpredictable autoimmune skin disease that results in the loss of hair on the scalp and elsewhere on the body. In alopecia areata, the affected hair follicles are mistakenly attacked by a person’s own immune system, resulting in the arrest of the hair growth stage.” While some cases result in a few bare patches, more severe cases can result in the loss of 50 to 100 percent (alopecia totalis) of scalp hair.

Alopecia areata appears equally in males and females, although children and adolescents are more commonly affected. Safavi et al[3] in their study concluded that the lifetime risk of alopecia areata was estimated to be 1.7 percent, suggesting that the disorder was fairly common although spontaneous resolution is expected in most patients. Approximately 7 percent of patients experience severe or chronic hair loss. A more recent study, Madani et al[4], concludes that one percent of the individuals suffering from alopecia areata will develop alopecia totalis.

Non-Classical Congenital Adrenal Hyperplasia:

The most common cause of congenital adrenal hyperplasia (CAH) is a deficiency in the 21-hydroxylase enzyme caused by a genetic disorder affecting the adrenal gland. The deficiency in this enzyme may be inherited in either a severe or a mild form, and affects males and females in equal numbers. The milder form of this disease, often referred to as non-classical congenital adrenal hyperplasia (NCAH) may develop at any time from infancy to adulthood. In females, symptoms may include baldness, especially at the temples (as with male pattern baldness) after the onset of menses. This mandate concerns only this latter milder form of the disease, which often results in hair loss. The severe form, often referred to as Classical CAH, is usually detected in the newborn period or in early childhood but is not associated with hair loss.

The results of epidemiological studies on the prevalence of NCAH are inconclusive. Published studies estimate that NCAH affects between 1 in 100 to 1 in 1,000 persons.

Injuries:

In addition to providing coverage to those with alopecia and NCAH, the proposed bill also provides coverage to individuals suffering permanent hair loss that was due to an injury. Hair regrowth treatments, such as drugs and transplants, may not work for people who have suffered hair loss that was due to burns or other scalp injuries. The only alternative for such individuals is a scalp prosthesis. The Centers of Disease Control (CDC) does not record statistics concerning permanent hair loss that result from injuries. Hence, it is not possible to estimate the number of individuals who need a scalp prosthesis because of an injury.

Screening for the diseases:

Hair loss may occur for many reasons including aging, diet, stress, plucking, use of toxic and strong chemicals or certain kinds of medications, male pattern baldness, or fungal infections. Someone suspected of having hair loss might be referred to a dermatologist or an endocrinologist (in cases of enzyme or hormone deficiency related hair loss) to determine the cause of their hair loss if a disease is suspected.

To determine if the hair loss is due to alopecia, a clinical examination may be performed. This examination includes the scalp condition, pattern of hair loss, and length and diameter of hair fibers. Additional examinations may include a scalp or skin biopsy.[5]

The diagnosis of 21-hydroxylase deficiency is established by testing the serum concentration of a steroid 17-hydroxyprogesterone (17-OHP).[6] To be diagnosed with NCAH, a 17-OHP level between 2,000 and 15,000 ng/dl is considered the benchmark.[7]

Further, to determine whether hair loss that was due to an injury would be permanent, a dermatologist's opinion would be necessary.

MEDICAL EFFICACY

DHCFP is charged with reporting: 1) the expected impact of the benefit on the quality of patient care and the health status of the population, and 2) 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 service.

Impact of the benefit on quality of life:

Studies show somewhat conflicting results regarding the impact of hair loss on individuals. Some studies suggest that hair loss has a negative impact on quality of life,[8] and some studies suggest otherwise.[9] However, most studies suggest a significant impact on psychological well-being when the onset of hair loss is sudden, severe, or accompanied by a life-threatening illness.[10] The impact on the psychological well-being is greater for women and children than for men.[11,12]

Table 3 (below) presents the conclusions of some of the published studies. Few studies measured the impact of hair loss attributable to alopecia areata and totalis, NCAH, or scalp injuries. Much of the research is limited to understanding the effects of hair loss in general, known as male pattern baldness, also called androgenetic alopecia (AGA). AGA is mostly seen in men but occurs in women as well. Unlike alopecia areata or totalis, AGA occurs gradually at any age after puberty.[13]

We include these studies and their conclusions while cautioning that the effect of hair loss on an individual stemming from a disease (rather than "natural" balding) may be different than for the populations described.

Although most research findings demonstrate the importance of scalp prostheses among women and men of all ages, the importance is especially strong in women and men younger than age 26[14,15] and in children. Alopecia areata is more common in 'children and young adults[16,17] who are more likely to suffer the psychological impact than adults.

Table 3: Summary Conclusions on the Health Status of Patients Suffering from Hair Loss

Study	Year and Place	Summary Conclusions
Güleç et al[18]	2004, Turkey	"Alopecia areata seems to have a partly negative impact on the health-related quality of life."
Rajkumar et al[19]	1979	"Alopecia areata seems to have a negative impact on the quality of life."
Bull[20],Cash[21] and Jackson[22]	1988, 1990, 1992 respectively New York	"Appearance stereotyping can shape how others treat people; it is possible that bald or balding men may be disadvantaged in initial interactions, which may affect their social experiences and quality of life."
Vander Donk[23, 24]	1991, Dutch study	No psychological impairment was found among AGA men. However, women seeking treatment for AGA experienced more psychosocial problems than did female controls and male alopecia patients
Cash[25]- (Various levels of alopecia in men compared)	1992, U.S.A	"The presence or absence of AGA was not associated with difference in self-esteem, social anxiety, sexual confidence or locus of control. Balding men reported increased stress, but impact was seen on body image rather than on other facets of psychosocial functioning."
European Survey[26]	1997, Europe	"Hair loss increased body image distress. However, hair loss was unrelated to global measures of physical and mental health"
Wells et al[27]	1995, U.K.	"Greater hair loss among men was correlated with poorer self-esteem and body image and with greater depression, introversion and neuroticism"
Cash TF[28]	1993, U.S.A	"52% of women vs. 27% of men related their emotional distress was due to AGA. Women also reported needing

		more effort to cope than men, in addition to a negative body image, more social anxiety, powerlessness, poorer psychological well-being and life satisfaction."

Alternative treatments:

There are several alternatives available to treat hair loss. The treatments vary according to the severity of alopecia (ranging from mild patches to complete hair loss) and the age of the patient. For individuals in whom the hair loss is less than 50%, the suggested treatment options are corticosteroid injections, topical minoxidil, and anthralin cream or ointment.[29] For individuals in whom the severity of the disease is much greater, resulting in the loss of more than 50% of hair, the suggested treatment options are cortisone pills, topical minoxidil, or topical immunotherapy.[30]

CURRENT COVERAGE AND COSTS

The existing mandate for hair prostheses is limited to hair loss suffered as a result of cancer treatments with a minimum benefit of $350 per member per year. However, several Massachusetts insurers already cover scalp prostheses for individuals suffering from alopecia areata, alopecia totalis, and permanent loss of scalp hair that was due to an injury, when it is determined to be "medically necessary" (see Table 1). Some insurers also pay more than the mandated minimum of $350 for a scalp prosthesis.

Proposed H. 3180/S. 916, if enacted, would be preempted by the federal Employee Retirement Income Security Act (ERISA), which precludes state laws from regulating self-insured benefit plans and their members. The 2001 DHCFP Massachusetts Employer Health Insurance Survey found that approximately 27% of Massachusetts employees were enrolled in self-funded, employer-sponsored health plans, and would therefore not technically be covered by this legislation. However, many self-insured employers adopt state mandates voluntarily. Nevertheless, all actuarial projections are calculated as if only fully insured individuals in Massachusetts would be affected.

Coverage of scalp prostheses for all age groups:

The DHCFP surveyed the Massachusetts Association of Health Plans (MAHP) and Blue Cross Blue Shield[31] regarding current coverage of scalp prostheses. DHCFP received completed surveys from four Massachusetts insurers regarding coverage being offered at the time. Three of the four plans already covered at least some of the conditions mandated by H. 3180 and S. 916. None of the plans explicitly covered NCAH. Table 1 (below) summarizes the plans' policies. The survey results were anonymous.

Table 1: Current Scalp Prosthesis Coverage

Questions:	Plan 1	Plan 2	Plan 3	Plan 4
Do you cover scalp prosthesis for non-cancer diagnoses?	Yes	Yes	No	Yes
What non-cancer benefits are covered?	Alopecia areata, alopecia totalis, or permanent hair loss that was due to injury	Alopecia areata, alopecia totalis, or permanent hair loss that was due to injury	N/A	Infections, burns, traumatic injury, congenital baldness, and medical conditions resulting in alopecia areata or totalis (capitus).
Dollar limit for non-cancer benefit?	$350 per year	Applied to member's annual DME benefit[a]	N/A	$500 per year
Average dollar on claims?	$360	$304	$318.62	$380
How many claims were received for non-cancer patients?	Did not distinguish between cancer and other; but received claims for non-cancer dx	5 claims[b]	No claims received[c]	Did not distinguish between cancer and non-cancer claims, but received claims for variety of conditions covered
Any coverage appeals received from members on scalp prosthesis in 2003?	Yes, 4 appeals	No	No	Yes, 5 appeals

[a] DME benefit may cover up to a maximum of $5000.
[b] The remaining 144 claims were received from cancer patients.
[c] All claims were received from cancer patients.

Cost of scalp prostheses:

The price range of hair prostheses, based on a survey of internet suppliers, is approximately $100 to $5,000. Table 2 provides a price range based on the types of scalp prosthesis available.

Types of scalp prostheses:

An internet survey of the various retailers offering this product yielded the following information summarizing the types of hair prostheses available, advantages, disadvantages, and associated costs.[32] A world-wide company that is based in California reported that 52% of the wigs that it sells to alopecia patients are vacuum wigs.

Table 2: Types of Scalp Prostheses

Types	Advantages	Disadvantages	Costs
Machine produced (synthetic) with an adjustable back	Easy care; fast delivery 3-4 days; many styles available	Stiffer hair than most others, looks unnatural, uncomfortable in warm weather, lasts for about a year	From $39 to $300
Hand-tied ready made (Available in synthetic or processed human hair)	More natural looking than machine made; individualized styling possible	If using human hair heat is not a problem; lasts for about a year	From $400 to $800
Custom shaped net base and hand-tied (common with alopecia areata patients)	Fit to client's head and more natural look; can be worn through hair loss and re-growth patterns	4-6 weeks for delivery; lasts for about a year	From $1,200 to $1,800
Custom made vacuum wigs (usually used for permanent or total hair loss)	Most precise fit; worn without adhesive; most secure and natural looking; life expectancy 2-3 years	Used only for permanent and total hair loss; uncomfortable in summer months or warm climates; require 4-6 months to be made	From $2,000 to $5,000 and beyond

Efficacy of scalp prostheses compared to alternative treatments:

Although there are several treatments available for hair loss, individuals would need treatment until they were free from the condition causing hair loss, as treatments stimulate hair growth but do not prevent new bare patches from developing.[33]

Generally, cortisone pills can be tolerated only by healthy young adults. Although the pills produce hair growth, they are used in relatively few patients suffering from alopecia areata owing to possible health risks with prolonged use.[34]

The costs of alternative treatments range from $351 to $3,915. However, alternative treatments do not guarantee hair growth and are less effective for individuals who have

hair loss greater than 50 percent (see Table 5). A study by Price (1999)[35] concluded that treatment with Minoxidil produced acceptable results in 40 percent of the patients who had lost 25 percent to 99 percent of their hair. Fiedler-Weiss[36] concluded that treatment with anthralin produced acceptable results 25 percent of the time within a six-month period.

Table 4: Treatment Options and Results

Type of Treatment	Usage	Average Costs (For 3 years)	Side Effects	Effectiveness
Minoxidil 5% (stronger dose than 2%)	Twice daily	2% dose: $360-$1,080 5% dose: $1,664	• May cause severe itch, redness, excessive flakes, and crust.	• Not effective in treating 100% hair loss • Must be taken continually to show effective results
Anthralin ointment	Once daily	$1,440-1,800	• May cause skin irritation. • For children; use and dose should be dictated by a doctor	Hair growth seen 0-80% of the time Not effective for more than 50% hair loss
Cortisone Injections or Pills	Used once every 3-4 weeks for less than 50% hair loss	$1,305 to $3,915	Small amounts of cortisone when injected may produce minor side effects[37]	Pills are not recommended, although they produce hair growth, because prolonged use increases health risk
Topical immunotherapy with diphencyprone (DCP)	Weekly treatments applied to the whole head	$351	Could result in itchy rash during hot weather	• "Hair growth seen in 40 to 60% of patient with 50 to 99 percent hair loss • Hair growth seen in 25% of patients with total hair loss"[38] • Only a small proportion of children with more than 50 % hair loss obtain consistent benefit[39]
Propecia® (Finasteride) for men only	Administered orally, 1mg per day	1mg- $1,752 5mg- $1,800-$2,160	• Clinical significance of prolonged use unknown. • Not indicated for use by women and children	Must be taken continually to show results of hair growth

FINANCIAL IMPACT OF MANDATE:

Compass Health Analytics performed an actuarial analysis to determine whether and by how much health insurance premiums would increase because of this proposed mandate. See Appendix _ for Compass Health Analytics' entire report.

DHCFP is required by Section 3 of Chapter 300 of the Acts of 2002 to answer the following questions:

1. *To what extent would the proposed insurance coverage increase or decrease the cost of the treatment or service over the next 5 years*?

   No information was available to estimate the effect of the bill (which could create additional demand for hair prostheses that are worth up to $3,000) on the supply or pricing of hair prostheses. It is unlikely, however, that the small amount of increased demand would have an effect on the cost of hair prostheses.

2. *To what extent might the proposed coverage increase the appropriate or inappropriate use of the treatment or service over the next 5 years*?

   Studies show that hair loss that is due to illness could result in psychosocial impairment and the use of mental health services that stems from that. The proposed coverage would benefit those patients seeking relief from medical symptoms that are not currently covered by a mandated benefit.

   The bill does not specify the extent of the disease necessary for coverage under this mandate, thus people suffering from relatively milder cases of hair loss, (thinning of the hair or patches of hair loss) might apply for the prosthesis benefit.

3. *To what extent might the insurance coverage affect the number and types of providers of the mandated treatment or service over the next 5 years*?

   This mandate should have no impact on the number of scalp prostheses vendors or manufacturers due to the small numbers of people who would be afforded access to this treatment through these bills.

4. *To what extent might the mandated treatment or service serve as an alternative for more expensive or less expensive treatments or services?*

   Alternatives to scalp prostheses are presented in Table 4. These alternatives are generally less expensive, but their results are more variable and they are not without side effects. While a scalp prosthesis might be more expensive than most alternatives, it is regarded as a better option for individuals with total hair loss. There are affordable options available on the market and it is possible that the

$3,000 benefit will encourage people to seek more expensive prostheses than necessary.

5. *What are the effects of the mandated benefit on the cost of health care, particularly the premium, administrative expenses, and indirect costs of large and small employers, employees and non-group purchasers?*

   Compass Health Analytics, Inc. developed an actuarial assessment of the likely increased health care costs resulting from the proposed mandate. These costs, which included the increased value of the benefit and resulting increase in administrative costs, were estimated to range from $38,000 and $68,000 per year from 2005 to 2009 (see answer to question 9).

6. *What are the potential benefits and savings to large and small employers, employees and non-group purchasers?*

   A small number of people whose insurance does not provide coverage for a scalp prosthesis for members other than cancer patients will become eligible. People who are eligible will have access to higher quality scalp prostheses. We were not able to quantify the savings from possible improved psychological well-being.

7. *What is the effect of the proposed mandate on cost-shifting between private and public payers of health care coverage?*

   No effect.

8. *What will be the cost to health care consumers of not mandating the benefit in terms of out-of-pocket costs for treatment or delayed treatment?*

   A small number of people, whose insurance provides scalp hair prostheses for cancer patients only, will continue to have to pay for scalp hair prostheses out of pocket. The vast majority of people who are already eligible will be limited to the maximum benefit for Durable Medical Equipment, or if they want a more expensive prosthesis, they will have to pay out of pocket..

9. *What is the effect on the overall cost of the health care delivery system in the Commonwealth?*

The mid-range estimates (below) represent the expected costs of S. 916/H. 3180. Costs are presented as the change in annual premium (per insured person) and the annual increase in costs to the Commonwealth.

Exhibit E1
Summary of Cost Impact Scenarios for Scalp Prosthesis Mandate

	2005	2006	2007	2008	2009
Low Scenario					
Change in Annual Premium	$ 0.01	$ 0.00	$ 0.00	$ 0.00	$ 0.00
Annual Dollar Impact (000s)	$ 22	$ 12	$ 13	$ 16	$ 13
Mid-Range Scenario					
Change in Annual Premium	$ 0.02	$ 0.01	$ 0.01	$ 0.01	$ 0.01
Annual Dollar Impact (000s)	$ 68	$ 38	$ 39	$ 48	$ 39
High Scenario					
Change in Annual Premium	$ 0.04	$ 0.02	$ 0.02	$ 0.03	$ 0.02
Annual Dollar Impact (000s)	$ 130	$ 73	$ 75	$ 92	$ 75

*source: Compass Health Analytics, Portland, ME

LEGISLATIVE ACTIVITY IN OTHER STATES

As of July 2004, the National Conference of State Legislatures reported that three states require insurance coverage of scalp prostheses. Montana currently mandates scalp prostheses coverage for children up to age 18 when diagnosed with alopecia areata or alopecia totalis. New Hampshire currently mandates coverage of scalp prostheses for individuals diagnosed with alopecia areata, alopecia totalis, alopecia medicamentosa and hair loss suffered as a result of permanent injury. Minnesota currently mandates coverage for scalp prosthesis for individuals diagnosed with alopecia areata only.

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