REPORT OF THE SPECIAL ADVISORY COMMISSION ON MANDATED HEALTH INSURANCE BENEFITS

HOUSE BILL 1348 MANDATED COVERAGE FOR ALPHA-1 ANTITRYPSIN DEFICIENCY

TO THE GOVERNOR AND THE GENERAL ASSEMBLY OF VIRGINIA

COMMONWEALTH OF VIRGINIA RICHMOND 2003

January 10, 2003

To: The Honorable Mark R. Warner
Governor of Virginia
and
The General Assembly of Virginia

The report contained herein has been prepared pursuant to §§ 2.2-2504 and 2.2-2505 of the Code of Virginia.

This report documents a study conducted by the Special Advisory Commission on Mandated Health Insurance Benefits to assess the social and financial impact and the medical efficacy of House Bill 1348 regarding a proposed mandate of coverage for Alpha-1 Antitrypsin Deficiency.

Respectfully submitted,

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INTRODUCTION

The House Committee on Commerce and Labor referred House Bill 1348 to the Special Advisory Commission on Mandated Health Insurance Benefits (Advisory Commission) in 2002. House Bill 1348 was introduced by Delegate John S. Reid.

The Advisory Commission held a public hearing on October 10, 2002 in Richmond to receive comments on House Bill 1348. In addition to the bill's chief patron, one physician with experience treating Alpha-1 patients, one representative of the national Alpha-1 Foundation, and one representative from the American Lung Association (ALA) spoke in favor of the proposed bill. A representative of the Virginia Association of Health Plans (VAHP) spoke in opposition to the proposed legislation.

A representative from the Alpha-1 Foundation, who spoke in favor of the bill at the public hearing, provided written statements that contained a cost analysis of treatments for Alpha-1. The Virginia Chamber of Commerce, the Health Insurance Association of America (HIAA), and VAHP provided written comments that were in opposition to House Bill 1348.

SUMMARY OF PROPOSED LEGISLATION

House Bill 1348 amends and reenacts § 38.2-4319 and adds § 38.2-3418.14 to the Code of Virginia to require each insurer proposing to issue individual or group accident and sickness insurance policies providing hospital, medical and surgical, or major medical coverage on an expense-incurred basis; each corporation providing individual or group accident and sickness subscription contracts; and each health maintenance organization providing a health care plan for health care services to provide coverage, as provided in the bill, for Alpha-1 Antitrypsin Deficiency.

The coverage shall include expenses incurred in connection with the treatment of Alpha-1 Antitrypsin Deficiency. The bill also states that no insurer, corporation, or health maintenance organization shall impose upon any person receiving benefits pursuant to this section any copayment, fee or condition that is not equally imposed upon all individuals in the same benefit category, nor shall any insurer, corporation, or health maintenance organization impose any policy-year or calendar-year dollar or durational benefit limitations or maximums for benefits provided under this section.

ALPHA-1 ANTITRYPSIN DEFICIENCY

The ALA explains that Alpha-1 related emphysema or Alpha-1 deficiency, "is caused by an inherited lack of a protective protein called Alpha-1 antitrypsin

(AAT or Alpha-1). In normal and healthy individuals, Alpha-1 protects the lungs from a natural enzyme (called neutrophil elastase) that helps fight bacteria and cleans up dead lung tissue. However, this enzyme can also eventually damage lung tissue if not neutralized by Alpha-1." If allowed to progress, this form of emphysema can become chronic, and lung tissue will continue to be destroyed; eventually, the conditions become fatal if the progress is not slowed down or halted. (See Appendix A for "How do normal lungs work?)

The Alpha 1 Association explains that "Alpha-1 is a blood protein of small size that diffuses into tissue spaces and protects the tissues from being digested by enzymes released from inflammatory cells. When Alpha-1 is deficient or absent, infection or inflammation can destroy tissue cells. This is seen most commonly in the lungs, which are always exposed to the environment (especially to cigarette smoke), and emphysema develops as the lung septae are eaten away."

"Alpha-1 is produced in the liver and is normally released into the blood. A gene mutation sometimes produces an abnormal form of this protein, which gets caught up in the liver and can enter the blood stream. This form (called the Z variant, or PiZ (protease inhibitor Z)) is the most common cause of Alpha-1."

How Alpha-1 Is Acquired

Alpha-1 Antitrypsin is an inherited genetic disorder passed down from parents. The National Institutes of Health explains that Alpha-1 is received from defective genes from a person's parents. "Everyone receives one gene for Alpha-1 antitrypsin from each parent. The M gene is the most common type of gene, and it is normal. The person who inherits an M gene from each parent has normal levels of Alpha-1 antitrypsin."

"The Z gene is the most common defect that causes the disorder. If a person inherits one M gene and one Z gene, that person is a carrier of the disorder. While such a person may not have normal levels of Alpha-1 antitrypsin, there should be enough to protect the lungs. The person who inherits the Z gene from each parent is called "type ZZ." This person has very low Alpha-1 antitrypsin levels, allowing elastase to damage the lungs."

"In rare cases, a person's body may not produce any Alpha-1 antitrypsin. This condition is also inherited, and it is called "null-null type." Another type is called "dysfunctional." In this case, the Alpha-1 antitrypsin level is normal but it does not work the way it should. This type of the disorder is very uncommon." (See Appendix B)

CURRENT INDUSTRY PRACTICES

The State Corporation Commission's Bureau of Insurance surveyed sixty of the top writers of accident and sickness insurance in Virginia in March 2002, regarding the bills to be reviewed by the Advisory Commission in 2002. Fifty companies responded by the deadline. Fourteen companies indicated that they have little to no applicable health insurance business in force in Virginia. Of the remaining 36 companies, 26 companies reported that they provided the coverage required by House Bill 1348 under their standard benefit package. Ten companies responded that they did not provide the coverage under their standard benefit package.

Fifteen respondents to the Bureau of Insurance survey provided cost figures of between \$.02 and \$1.12 per month per standard individual policy. Cost figures were between \$.01 and \$5.53 per month per standard group certificate, to provide the coverage required by House Bill 1348. Insurers providing cost figures for coverage on an optional basis gave figures that ranged from \$.03 to \$5.58 per month per individual policy, and between \$.03 to \$3.98 per month per group certificate.

Two companies provided cost figures as percentages of annual premiums. Cost figures were estimated at .75 % per month, per standard individual policy and between .7% and 1.5% per month, per standard group policy. To provide the coverage on an optional basis, cost figures were 1.5% per individual policy and between .7% and 1.5% per group certificate.

An additional survey was developed to gather more data regarding coverage of Alpha-1 Antitrypsin Deficiency. The survey was sent to the 26 companies that responded that their company already covered treatment for Alpha-1 in its standard benefit package. Eighteen companies responded by the deadline. One company returned the survey and stated the questions were too broad in nature. The survey contained six questions but some respondents were unable to answer all of the questions.

Question one asked if coverage for Alpha-1 Antitrypsin Deficiency was subject to any inside limits, such as classification as replacement therapy or prescription drugs, etc. Sixteen companies responded that their coverage of Alpha-1 was not subject any limits such as replacement therapy or prescription drug coverage. One company said there was an inside limit on replacement therapy.

Question two asked what the amount of copayments for Alpha-1 treatments are? Ten companies responded that copayments were dependent upon the benefit plan selected. Three companies said that copayments for treatment of Alpha-1 were the same as those covered for any illness under the standard medical benefits. Two companies provided cost figures between \$7

and \$35, and \$25 and \$45 for the amount of copayments for treatment of Alpha-1. One company reported that there was no copayment for this treatment.

Question three asked the amount of the deductible for Alpha-1 treatment. Ten companies responded that deductibles were dependent upon the benefit plan selected. Four companies responded that deductibles for treatment of Alpha-1 were the same as those for any covered illness under the standard medical benefits. One company responded that there was no deductible for treatment of Alpha-1.

Question four asked if there were any caps on the treatment coverage, such as limits on the number of visits, the dollar amount per visit, a lifetime maximum amount, etc. Twelve companies reported that they had no caps on the coverage of treatment. Two companies said it was dependent upon the benefit plan selected. One company responded that all their plans have a lifetime maximum.

Question five asked if claims had been submitted for other treatments for Alpha-1 Antitrypsin Deficiency that have been denied because they are considered experimental. Ten companies responded that no claims were denied for Alpha-1 based on treatment considered to be experimental.

Question six asked how much the insurance company pays for replacement therapy. Nine companies responded that they pay the same as any other sickness, based on usual and customary charges. Four companies estimated that Prolastin treatment could require them to pay between \$2,000 and \$8,000 per month. One company indicated that payment would be based on the contracted pharmacy rates, and another company reported that it had no claims on this medication in 2001.

SOCIAL IMPACT

Since the Alpha-1 deficiency is an inherited disease, the population most at risk are those who have relatives with Alpha-1 deficiency. The ALA estimates that there about 100,000 Americans alive today (approximately one in 2,500 people) who were born with Alpha-1 deficiency. The ALA further reports that most of those afflicted are of Northern European descent, and that emphysema could afflict a majority of these 100,000 people. The ALA also notes that often times, Alpha-1 deficiency is under diagnosed or misdiagnosed, leading to the possibility of more people being affected by Alpha-1 deficiency. Further, as many as 3% of individuals who have chronic obstructive lung disease (COPD), may also have undiagnosed Alpha-1 deficiency.

The Alpha-1 Association believes that there is evidence that 80,000 to 100,000 Americans have severe Alpha-1 deficiency, which is approximately 1 in 3,000 individuals. The Alpha-1 Association also reports that many in the medical

community perceive Alpha-1 to be rare, but suggests that "95% of those estimated to have Alpha-1 have not been identified."

FINANCIAL IMPACT

The Alpha-1 Foundation provided financial data about the cost of diagnosis and treatment of Alpha-1 Antitrypsin Deficiency. The clinical diagnostic laboratory costs ranged from \$25 to \$35. The clinical diagnostic laboratory phenotype/genotype cost is approximately \$200.

The cost for someone with lung disease receiving augmentation therapy is estimated at approximately \$54,000 annually. This is based on a formula where augmentation therapy is \$2.09 for 10 milligrams (mg) of product. The amount of mg per person is based upon weight. The average person receives 5,000 mg intravenously on a weekly basis.

If the severity of Alpha-1 has progressed enough to require a lung transplant, the transplant cost is estimated between \$180,000-\$260,000. Post transplant medications cost approximately \$12,800 annually. If the severity of Alpha-1 has progressed enough to require a liver transplant, the cost is estimated between \$190,000-\$270,000.

MEDICAL EFFICACY

As previously mentioned, Alpha-1 antitrypsin is a protein that is made in the liver. The liver releases the protein into the bloodstream. The protein is used to protect the lungs so that they can work normally. Without enough of the Alpha-1 protein, the lungs may become damaged and cause breathing to be difficult.

The reason the lungs may become damaged is because there is not enough Alpha-1 protein to fight neutrophil elastase, which can destroy the lungs. This will actually cause the lungs to lose their ability to expand and contract and may lead to emphysema.

The Alpha-1 Association explains that emphysema is a lung disease caused by the destruction of the delicate walls of small air sacs called alveoli. With the destruction of the small sacs, elasticity is lost, and larger inefficient sacs are formed that cannot properly exchange oxygen and carbon dioxide with the bloodstream. This makes it harder to breathe since each drawn breath inflates the lungs, but the lungs do not return to normal with the exhaled breath.

The Alpha-1 Association suggests that early identification of Alpha-1 Antitrypsin Deficiency is of "paramount importance." It suggests that someone known to have Alpha-1 should avoid smoking. In fact, the Association states that avoiding smoking is the single most important thing a person can do if they have

the deficiency. The Alpha-1 Association notes that smoking and excessive alcohol consumption may "hasten lung and liver damage." Smoking can advance the progression of emphysema. It was also noted that someone with Alpha-1 must view environmental pollution as a hazard.

The Alpha-1 Association reports that Alpha-1 Antitrypsin Deficiency is treated by medicine. The only medicinal treatment available is replacement therapy. The first use of replacement therapy (also called augmentation therapy) was in December of 1987. The replacement therapy uses Prolastin, a "purified alpha-1 antitrypsin which is derived and isolated from pooled human blood plasma." The therapy is given to the Alpha-1 patient by intravenous infusion, and is usually recommended weekly.

The Alpha-1 Association reports that some patients may take Prolastin biweekly or on a monthly basis. The American Lung Association adds that this treatment must be taken for the remainder of the patient's life for its protective effect to work. If a patient were to stop therapy, the individual's lungs would return to the prior damaged state caused by non-protection of neutrophil elastase.

The amount of Prolastin that a patient receives is based on the individual's weight. The current formula of Prolastin is 60mg per kilogram or 2.2 pounds. The results of studies performed on this drug suggest that those who have damage to the lungs, caused by neutrophil elastase, can return to normal lung decline like those who do not have Alpha-1. Patients are also usually immunized against hepatitis B in a series of three shots before Prolastin is given.

Treatments for those with Alpha-1 emphysema are usually the same as those given to asthma patients. This is because there is no medical treatment for the emphysema that Alpha-1 can cause, and emphysema is incurable. The Alpha-1 Association reports, that because many Alpha-1 patients have an "asthma component" to their Alpha-1, it is essential to keep their airways open and free of inflammation. Some of the common medications are anti-inflammatory steroids.

SIMILAR LEGISLATION IN OTHER STATES

Information was obtained from other insurance departments, the National Association of Insurance Commissioners, the National Insurance Law Service, and other sources to determine if requirements are imposed in other states that are similar to House Bill 1348. No state had requirements similar to House Bill 1348. One source representing the Alpha-1 Association indicated that no state mandates coverage for Alpha-1, nor were there any states in the process of mandating coverage for the deficiency.

REVIEW CRITERIA

SOCIAL IMPACT

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

The ALA estimates that there are approximately 100,000 Americans alive today (approximately one in 2,500), who were born with Alpha-1 deficiency. The ALA reports that most of those afflicted with Alpha-1 are of Northern European descent.

The Alpha-1 Association believes that there is evidence that 80,000 to 100,000 Americans have severe Alpha-1 deficiency, which is approximately 1 in 3,000 individuals. The Alpha-1 Association reports that many in the medical community perceive Alpha-1 to be rare, but also suggests that "95% of those estimated to have Alpha-1 have not been identified."

A physician who works with Alpha-1 patients estimated that there are probably 1,500 people in Virginia who may have the severe form of Alpha-1 Antitrypsin Deficiency.

b. The extent to which insurance coverage for the treatment or service is already available.

Of the 36 companies that responded to the Bureau's survey, 26 companies reported that they provided the coverage required by House Bill 1348 under their standard benefit package. Ten companies responded that they did not provide the coverage under their standard benefit package.

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

Representatives from the VAHP provided information from a survey of their member companies regarding coverage of Alpha-1 Antitrypsin Deficiency. VAHP has 13 member companies that operate 26 health plans. Out of 13 companies, 9 responded to their survey. All 9 companies responded that they provide coverage for infusion therapy, transplants, and other treatment conditions related to Alpha-1 Antitrypsin Deficiency.

A physician who works with Alpha-1 patients explained that 50% of the patients he has worked with experience some types of insurance coverage problems. The coverage problems have been with dollar or durational limits in

relation to treatments. The physician testified that the lack of insurance coverage for treatments left the patient with a huge financial void to fill.

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

There would be a considerable amount of financial hardship on those unable to access care because of the cost of treatment. Financial cost data from the Alpha-1 foundation explains the costs. The clinical diagnostic laboratory costs ranged from \$25 to \$35. The clinical diagnostic laboratory phenotype/genotype cost is approximately \$200.

The cost of someone with lung disease receiving augmentation therapy is estimated at approximately \$54,000 annually. This is based on a formula where augmentation therapy is \$2.09 for a 10 milligrams (mg) of product. The amount of mg per person is based upon weight and the average person receives 5,000 mg intravenously on a weekly basis.

If the severity of Alpha-1 has progressed enough to require a lung transplant, the transplant cost is estimated between \$180,000-\$260,000. Post transplant medications cost approximately \$12,800 annually. If the severity of Alpha-1 has progressed enough to require a liver transplant, the cost is estimated between \$190,000-\$270,000.

e. The level of public demand for the treatment or service.

Since Alpha-1 Antitrypsin Deficiency is an inherited disease, the persons most at risk are those who have relatives with Alpha-1 Antitrypsin Deficiency. The American Lung Association estimates that there about 100,000 Americans alive today (approximately one in 2,500), who were born with Alpha-1 Antitrypsin Deficiency. The American Lung Association reports that most of those afflicted are of Northern European descent. The American Lung Association says that emphysema could afflict a majority of these 100,000 people. The American Lung Association also notes that often times, Alpha-1 Antitrypsin Deficiency is under diagnosed or misdiagnosed, leading to the possibility of more people being affected by Alpha-1 Antitrypsin Deficiency. Further, as many as 3% of individuals who have chronic obstructive lung disease (COPD), may also have undiagnosed Alpha-1 deficiency.

The Alpha-1 Association believes that there is evidence that 80,000 to 100,000 Americans have severe Alpha-1 deficiency, which is approximately 1 in 3,000 individuals. The Alpha-1 Association reports that many in the medical community perceive Alpha-1 to be rare, but also suggests that "95% of those estimated to have Alpha-1 have not been identified."

f. The level of public demand and the level of demand from providers for individual and group insurance coverage of the treatment or service.

One physician who works extensively with Alpha-1 patients spoke in support of House Bill 1348. He discussed the complexity of diagnosing the disease and how the treatments can stall the progression of the disease rather than cure Alpha-1. He described that the majority, about 80%, of his patients have responded positively to replacement therapy. He also stated that at least half the patients he has cared for have had problems with their insurer covering Alpha-1 treatments, due to dollar or durational limits on the benefit.

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

No information was received from collective bargaining organizations addressing potential interest in negotiating privately for inclusion of this coverage in group contracts.

h. Any relevant findings of the state health planning agency or the appropriate health system agency relating to the social impact of the mandated benefit.

No information or relevant findings of the state health planning agency or the appropriate health system agency relating to the social impact of this mandated benefit was presented during this review.

FINANCIAL IMPACT

a. The extent to which the proposed insurance coverage would increase or decrease the cost of treatment or service over the next five years.

Fifteen respondents to the Bureau of Insurance survey provided cost figures of between \$.02 and \$1.12 per month per standard individual policy. Cost figures were between \$.01 and \$5.53 per month per standard group certificate, to provide the coverage required by House Bill 1348. Insurers providing cost figures for coverage on an optional basis gave figures that ranged from \$.03 to \$5.58 per month per individual policy, and between \$.03 to \$3.98 per month per group certificate.

Two companies provided cost figures as percentages of annual premiums. Cost figures were estimated at .75 % per month, per standard individual policy and between .7% and 1.5% per month, per standard group policy. To provide the coverage on an optional basis, cost figures were 1.5% per individual policy and between .7% and 1.5% per group certificate.

b. The extent to which the proposed insurance coverage might increase the appropriate or inappropriate use of the treatment or service.

One health care provider who works extensively with Alpha-1 patients spoke at the public hearing. He explained that the diagnosis for Alpha-1 has been a difficult issue and that many physicians do not have experience with treating the disease. The provider explained that the only therapy for Alpha-1 is replacement therapy. He maintained that the therapy only halts progression of the disease at best, and does not cure or correct the cause of the disease. The physician told the Advisory Commission that before 1988, when replacement therapy was first used, Alpha-1 was only treated palliatively.

It is not expected that the mandate of coverage would increase inappropriate use of the treatment.

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

There is no alternative treatment for Alpha-1 Antitrypsin Deficiency. The only proven treatment is replacement therapy. The replacement therapy uses Prolastin, a "purified alpha-1 antitrypsin which is derived and isolated from pooled human blood plasma." The therapy is given to the Alpha-1 patient by intravenous infusion, and usually recommended weekly. The patient must take the treatment for the rest of his or her life for its protective effect to work. If a patient were to stop therapy, the individual's lungs would return to the prior damaged state caused by non-protection of neutrophil elastase.

d. The extent to which the insurance coverage may affect the number and types of providers of the mandated treatment or service over the next five years.

Since Alpha-1 is a rare and unknown disease, there is no reason that it would increase the number or types of providers. Also, since Alpha-1 is a disease associated with the lungs, it would probably be treated by a pulmonologist.

e. The extent to which insurance coverage might be expected to increase or decrease the administrative expenses of insurance companies and the premium and administrative expenses of policyholders.

Fifteen respondents to the Bureau of Insurance survey provided cost figures of between \$.02 and \$1.12 per month per standard individual policy. Cost figures were between \$.01 and \$5.53 per month per standard group certificate, to provide the coverage required by House Bill 1348. Insurers providing cost figures for coverage on an optional basis gave figures that ranged from \$.03 to

\$5.58 per month per individual policy, and between \$.03 to \$3.98 per month per group certificate.

Two companies provided cost figures as percentages of annual premiums. Cost figures were estimated at .75 % per month, per standard individual policy and between .7% and 1.5% per month, per standard group policy. To provide the coverage on an optional basis, cost figures were 1.5% per individual policy and between .7% and 1.5% per group certificate.

Representatives from the VAHP provided testimony in opposition to House Bill 1348 at the public hearing. They indicated that coverage of Alpha-1, as indicated in the language of House Bill 1348, would increase insurance costs. The reason is because of the wide range of coverage that is within the language of House Bill 1348. The bill does allow limit dollar or durational limits on coverage of Alpha-1 treatments. Also, VAHP testified that under the current language in the bill, all expenses in relation to treatment of Alpha-1 would be covered. VAHP argued that this could be interpreted to include travel costs, lodging, meals, and other expenses that are not usually covered by health insurance.

f. The impact of coverage on the total cost of health care.

VAHP representatives commented on the effect of this mandate on the total cost of health care. They included general remarks that mandates cause more people to be unable to afford health insurance. This is due to the fact that mandates cause insurance premiums to rise to a level that employers cannot afford to provide coverage for employees, and others cannot afford to pay for insurance for themselves.

A proponent representing the Alpha-1 Foundation argued that coverage of Alpha-1, including testing for diagnosis and treatment, would lead to decreased hospitalization and transplants. This bill would therefore be a preventive health measure, which will ultimately reduce the cost of the illness and health care.

MEDICAL EFFICACY

a. The contribution of the benefit to the quality of patient care and the health status of the population, including the results of any research demonstrating the medical efficacy of the treatment or service compared to alternatives or not providing the treatment or service.

One health care provider who works extensively with Alpha-1 patients spoke at the public hearing. He estimated that most patients, about 80%, respond to replacement therapy treatment in that the progression of the patient's disease has slowed.

There is no alternative treatment for Alpha-1 Antitrypsin Deficiency. The only proven treatment is through replacement therapy. The replacement therapy uses Prolastin, a "purified alpha-1 antitrypsin which is derived and isolated from pooled human blood plasma." This therapy is given to the Alpha-1 patient by intravenous infusion, and usually recommended weekly. The patient must take the treatment for the rest of his or her life for its protective effect to work. If a patient were to stop therapy, the individual's lungs would return to the prior damaged state caused by non-protection of neutrophil elastase.

- b. If the legislation seeks to mandate coverage of an additional class of practitioners:
 - The results of any professionally acceptable research demonstrating the medical results achieved by the additional class of practitioners relative to those already covered.

Not applicable.

2) The methods of the appropriate professional organization that assure clinical proficiency.

Not applicable.

<u>EFFECTS OF BALANCING THE SOCIAL, FINANCIAL AND MEDICAL</u> EFFICACY CONSIDERATIONS

a. The extent to which the benefit addresses a medical or a broader social need and whether it is consistent with the role of health insurance.

Proponents suggest that House Bill 1348, mandating coverage for Alpha-1 Antitrypsin Deficiency, addresses both a medical and broad social need. They assert that coverage for treatment is generally covered, but dollar or durational limits place a burden upon patients who need the service, causing the patients to lack continuing coverage of treatments. Proponents believe that with mandated coverage, patients will not only have access to care, but also to all the necessary treatments to improve their prognosis. They believe access to treatment will not cure Alpha-1, but will slow the progression of the disease, which will reduce more serious health problems and improve the quality of life for those with the disease.

Opponents contend that insurance companies are already providing coverage of treatment. The VAHP spoke about a survey of its member companies regarding coverage of Alpha-1. VAHP has 13 member companies that operate 26 health plans. Out of 13 companies, 9 responded that they provide coverage for infusion therapy, transplants, and other treatment conditions related to Alpha-1 Antitrypsin Deficiency. VAHP also commented that it believes

the language of House Bill 1348 mandates coverage for a diagnosis, rather than for a medical treatment.

b. The extent to which the need for coverage outweighs the costs of mandating the benefit for all policyholders.

Fifteen respondents to the Bureau of Insurance survey provided cost figures of between \$.02 and \$1.12 per month per standard individual policy. Cost figures were between \$.01 and \$5.53 per month per standard group certificate, to provide the coverage required by House Bill 1348. Insurers providing cost figures for coverage on an optional basis gave figures that ranged from \$.03 to \$5.58 per month per individual policy, and between \$.03 to \$3.98 per month per group certificate.

Two companies provided cost figures as percentages of annual premiums. Cost figures were estimated at .75 % per month, per standard individual policy and between .7% and 1.5% per month, per standard group policy. To provide the coverage on an optional basis, cost figures were 1.5% per individual policy and between .7% and 1.5% per group certificate.

Proponents argue that coverage of Alpha-1 is cost-effective. They argued that coverage of Alpha-1, including testing for diagnosis and treatment, would lead to decreased hospitalization and transplants. This therefore will be a preventive health measure, which will ultimately reduce the cost of the illness and health care.

Opponents contend that coverage of Alpha-1, as indicated in the language of House Bill 1348, would increase insurance costs. Their reasoning is based on the wide range of coverage that is within the language of House Bill 1348. The bill does not allow dollar or durational limits upon the benefit of Alpha-1 coverage. Also, VAHP testified that under the current language, all expenses in relation to treatment of Alpha-1 would be covered. VAHP argued that this could be interpreted to include travel costs, lodging, meals, and other expenses that are not usually covered by health insurance.

c. The extent to which the need for coverage may be solved by mandating the availability of the coverage as an option for policyholders.

In the case of group coverage, the decision whether to select the optional coverage or not would lie with the master contract holder and not the individual insureds.

RECOMMENDATION

The Advisory Commission voted 9 to 1 to recommend against the enactment of House Bill 1348.

CONCLUSION

The Advisory Commission concluded its review of House Bill 1348 on November 12, 2002. The Advisory Commission agrees with the importance of diagnosing the disease at an early stage to create a better quality of life for the patient. The Advisory Commission believes that, based on information it reviewed, some coverage for treatments for Alpha-1 Antitrypsin Deficiency are available. The Advisory Commission believes there is no need to mandate coverage for treatment at the present time.