



MEMORANDUM IN OPPOSITION

FOR IMMEDIATE RELEASE: JANUARY 21, 2009

Re: A.301 (Millman) AN ACT to amend the public health law and the insurance law, in relation to protocol for treatment of rare disease.

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This legislation would create a new decision standard for utilization review and external appeals determinations for individuals with rare diseases (as listed by the National Institutes of Health). The New York Health Plan Association (HPA) opposes this legislation because we are concerned about the unforeseen implications of substantially modifying the decision standard, including the potential for harm to individuals with these diseases. HPA also believes that the legislation might also interfere with an external appeal process that is now functioning smoothly.

For more than ten years, the UR and external appeals laws have provided for a balanced approach to decisions. In that time, we are aware of only one case involving a consumer with a rare disease. In that case, the consumer's situation was resolved in the context of the current law.

In the case of so called "rare diseases," the bill would lower the current standard for coverage of a treatment from "medically necessary" to an essentially subjective standard of "likely to benefit." The bill would direct the UR agent or external appeal reviewer to examine the medical and scientific evidence for a disease of higher prevalence in the same class as the rare disease. However, given the lack of medical or scientific evidence for the appropriate or best treatment of rare diseases, evidence relating to a different condition, in combination with the "likely to benefit" standard, could often result in the enrollee being given unproven treatments that may be ineffective and harmful. In addition, be mindful of the potential cost impact of this change. Such treatments could be extremely costly. Without evidence of their appropriateness or application to the rare condition, employers and consumers who pay for health insurance will be required to cover ineffective, high cost treatment. With numerous other factors already contributing to the high cost of health care, it would be inappropriate to add unproven costs to the mix.

Thus, there is no need to modify decision standard for coverage decisions. Indeed, the unforeseen consequences of potentially harmful coverage decisions should deter action on this bill.

The New York Health Plan Association represents 27 managed care health plans that provide comprehensive health care services to nearly 7 million New Yorkers.

For all these reasons and more, the New York HPA opposes the provisions of this bill, as the consequences of these measures will only increase the cost of health care for consumers, employers and health plans.

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