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Dear Secretary Sebelius

Oct. 13, 2011

The Honorable Kathleen Sebelius Secretary U.S. Department of Health and **Human Services**

Hubert Humphrey Building 200 Independence Avenue S.W. Washington, D.C. 20201

Dear Secretary Sebelius:

On behalf of an ad hoc work group comprised of members of the Society of Actuaries' (SOA) Long-Term Section Council and the American Academy of Actuaries'2 (Academy) Federal Long-Term Care Task Force, we offer the following analysis of the key actuarial considerations associated with respect to the potential application of the Genetic Information Nondiscrimination Act of 2008 (GINA) to long-term care (LTC) insurance. As you know, the Department of Health and Human Services (HHS) has proposed extending GINA's prohibition against using genetic information for underwriting purposes to LTC insurance.3 We ask that you consider this analysis of the effect of GINA on the cost and availability of LTC insurance as you finalize the regulations.

Barring LTC insurers from obtaining test results already known to such applicants could result in a significant imbalance of information between LTC insurers and applicants. Such asymmetric information could result in adverse selection that would have a direct and significant impact on LTC insurance-premium and insurance coverage rates.

GINA did not affect life insurance and LTC insurance when it was signed into law. That exclusion was not arbitrary; these insurance products are fundamentally different from medical coverage. Both life insurance and LTC insurance have substantially longer terms than medical insurance, with premium rates intended to remain stable or fixed for long periods of time. Neither product is seen by consumers as a practical necessity to ensure access to health care. Both life insurance and LTC insurance depend on insurers having access to similar information as the applicant so that insurers can charge appropriate premiums and protect their risk pools from adverse selection. If applicants were to adversely select against the insurer, premium rates would be significantly higher (and less stable in the case of LTC insurance), fewer carriers would offer such coverage, and significantly fewer individuals would elect to purchase it.

In the 2009 proposed regulations for implementing GINA, HHS indicated its intent to apply the law to LTC insurance. Because the final regulations have not been released yet, we want to take this opportunity to point out that LTC insurance is more akin to life insurance than to medical insurance—both with respect to both the use of genetic information in underwriting and the voluntary nature of the purchasing decision. As such, the adverse effect on consumers if GINA were applied to LTC would be greater than the relatively modest effect on medical insurance. We believe, therefore, that GINA should not apply to LTC insurance.

Like whole life insurance, LTC insurance premium rates are designed to remain level for the life of the policy, and the pricing period is measured in multiple years, rather than in months as is true for medical insurance. Also like whole life insurance, the decision to purchase LTC insurance is entirely voluntary and premiums rarely are subsidized; only about 10 percent of eligible Americans have LTC insurance coverage.4 In contrast, with approximately 85 percent of Americans currently having

- The Society of Actuaries (SOA) is the largest professional organization dedicated to serving 20,000 actuarial members and the public in the United States and Canada. The SOA's vision is for actuaries to be the leading professionals in the measurement and management of financial risk. To learn more, visit www.soa.org.
- The American Academy of Actuaries is a 17,000-member professional association whose mission is to serve the public and the U.S. actuarial profession. The Academy assists public policymakers on all levels by providing leadership, objective expertise, and actuarial advice on risk and financial security issues. The Academy also sets qualification, practice, and professionalism standards for actuaries in the United States.
- Federal Register 74(193):51698-51710 (Oct. 7, 2009)
- A.M. Best Company. U.S.—Long-Term Care. March 29, 2010

medical insurance coverage,5 the purchase of medical insurance will become mandatory in 2014 and the premiums for such coverage will continue to be subsidized for large proportions of the population.

The economic impact of applying GINA to LTC insurance would be significant (using the \$100 million "significance" threshold in Executive Order 12866 as cited by HHS in its 2009 notice in the Federal Register).6 Indeed, the potential effect for the LTC insurance industry of having no genetic information available to them, when the LTC insurance applicants have such information, eventually could be significantly in excess of \$100 million per year based on the following considerations:

- New sales of individual LTC insurance in 2010 generated \$525 million in new annual premium.⁷
- If, for example, apolipoprotein E (APOE) genetic information—one gene associated with a higher risk of developing Alzheimer's Disease—were to become readily available to potential applicants, but not to the insurers, the adverse selection eventually could result in an increase in premiums by an amount in excess of 30 percent.8 This would be based solely on currently available genetic testing for the disease.
- The final amount likely would be much greater due to continuing advances in genetic testing.

An ad hoc work group was convened to quantify the potential impact of the proposed regulations on the LTC insurance marketplace. To quantify the effect on consumers, the work group conducted a morbidity analysis using Alzheimer's Disease, which provided the basis for estimating the substantial negative economic impact this extension of the GINA regulations would have on the LTC insurance marketplace. Based on this analysis, we believe that GINA should not apply to LTC insurance. The remainder of this letter presents the work group's findings and our conclusions.

EXECUTIVE SUMMARY

Voluntary insurance mechanisms function properly if rates charged to individuals reflect actuarial risks that are based on known characteristics of the insured. Each insured is assigned to a homogenous risk pool, a pool of multiple insureds with similar risks. If an applicant for LTC insurance has mate-

rial knowledge that he or she is likely to require LTC services but the insurance company is not allowed to obtain and factor in that information, the homogenous risk pool mechanism will break down. Applicants who understand that their risk is substantially higher than the risk of other applicants likely would use that information to buy insurance coverage that effectively pools their higher risk and cost with lower-risk insureds. For a voluntary product, like LTC insurance, with fairly low sales penetration, higher-risk applicants have a significantly greater effect on the overall risk pool than for mandatory or other insurance products with significantly high participation rates, such as the current medical insurance marketplace.

Higher-risk insureds initially are not charged a premium commensurate with the risk they bring to their pool. As time progresses and the higher-risk insureds produce more claims, it then becomes apparent that the risk pool needs a premium rate increase. In other words, the initial premium rate is too low to cover the unexpected claims presented by the higher representation of higher-risk individuals in the pool. When premium rates are increased, lower-risk individuals paying a higher premium rate than the risk they represent are more likely to terminate their coverage. This behavior could be exaggerated by insureds who find through genetic tests that they are not at as great a risk as other insureds. As these insureds opt out of the insurance pool, the average cost for the remaining insureds increases again. This creates a rate spiral in which the increased cost causes lower-risk individuals to forgo insurance, further driving up the cost for those remaining in the pool. The cycle continues its spiral until only the higher-risk individuals remain in the pool.

If LTC insurers do not have access to the health information that individual applicants possess. this rate spiral is inevitable. Underwriting known

- U.S. Census Bureau. Statistical Abstract of the United States: 2011, Table 151, 2011.
- Federal Register 74(193):51698-51710 (Oct. 7, 2009).
- Fisherkeller, Karen, U.S. Individual LTC Insurance—Annual Review 2010 (powerpoint). LIMRA. http://marketing.cpsinsurance.com/visionscape/2011/April/pdf/LIMRA-%20US%20 Individual%20LTC%20Insurance-%20Annual%20Review%20
- The body of this report shows how this amount was derived.

morbidity risk and assigning to homogenous risk pools is vital to pricing LTC insurance properly. The result will be a shrinking private LTC insurance market and an increase in the number of individuals who will have to rely on programs such as Medicaid. This appears to us to contradict other public and private efforts that have been designed to encourage individuals to plan for their long-term care needs and help alleviate the growing costs of Medicaid programs.

It should be emphasized here that it is not enough to permit LTC insurers to use genetic information for underwriting if the individual provides written permission. Insurers need to be able to decline applicants who have had genetic testing but do not provide permission to use the results. Genetic tests that indicate an elevated risk level likely would not provide such permission unless it was a requirement to get the coverage.

As an example of a potential effect should GINA regulations be extended to LTC coverage, the work group evaluated a single genetic test. Since Alzheimer's Disease is a leading and costly LTC insurance claim, the work group decided to focus on a gene that has been shown to be associated with a higher risk of developing the disease. This gene is the apolipoprotein E (APOE) gene, and the specific subtype that carries increased risk for developing Alzheimer's Disease is the APOE ε4 allele.

The total LTC claim costs (including Alzheimer's Disease and all other causes) for an individual with two APOE \(\epsilon\) alleles is 5 times as great as for an individual with no APOE ε4. The total claim costs for an individual with one APOE ε4 allele is 1.55 times as great as for an individual with no APOE ε4 alleles (from the data contained in Table 5). Although APOE testing is not commonly performed, if it were to become prevalent, the cost of LTC insurance would increase by as much as 32 percent (see Tables 6 and 7).

As new genetic research finds even better predictors for Alzheimer's Disease (or other debilitating conditions), the risk of adverse selection would be greater. If GINA were to be applied to LTC insurance, this risk could result in fewer carriers being willing or able to write this business, leading to further strain on public programs.

If insurers were to price for the anti-selection due to the applicants' enhanced knowledge that the insurer cannot obtain, individuals who are average risks could be priced out of the LTC insurance market. They likely would recognize that they are paying more than their expected future costs without insurance. This would increase the volatility of LTC insurance rates and add another risk factor (more effective testing or more widespread use of testing) that could increase the likelihood of future in-force rate increases.

Details of Analysis

Aggregate claim costs were developed using an SOA intercompany experience study for long-term care insureds.9 We divided those claim costs between Alzheimer's and other conditions. Then we determined the total claim costs for insureds with 0, 1, or 2 APOE \(\alpha \) alleles along with their relative risk compared to the aggregate insured population. We applied Appendix D2-A and Appendix E3 to represent incidence by attained age and average length of stay (ALOS) in days by age at claim. 10 We geometrically interpolated figures for missing ages. We multiplied the incidence rates and ALOS values to arrive at claim costs per dollar of daily benefit. Sample age results are provided in Table 1.

Table 1: Derivation of Aggregate Claim Costs Unisex				
Attained Age	Incidence	ALOS	Aggregate Claim Costs*	
42	0.0002278	820.90	0.187	
45	0.0002787	820.90	0.229	
47	0.0003183	820.90	0.261	
52	0.0004435	820.90	0.364	
55	0.0005411	820.90	0.444	
57	0.0006502	820.90	0.534	
60	0.0008564	820.90	0.703	
62	0.0010290	808.83	0.832	
67	0.0020280	779.43	1.581	
70	0.0035078	762.30	2.674	
72	0.0050545	758.82	3.835	
77	0.0124027	750.20	9.304	
80	0.0199636	745.07	14.874	
82	0.0274192	722.70	19.816	
87	0.0516468	669.68	34.587	
92	0.0783281	539.75	42.277	

*Aggregate claim costs are equal to incidence times ALOS (e.g., 0.187 = 0.0002278 x 820.90); ALOS assumed constant under age 60.

- Society of Actuaries (SOA). Long-Term Care Experience Committee Intercompany Study: 1984-2004. (November 2007).
- 10 Society of Actuaries (SOA). Long-Term Care Experience Committee Intercompany Study: 1984—2004. (November 2007), Appendix D2-A is a pivot table that provides incidence by issue age, duration and other characteristics. Appendix E shows continuance by elimination period, region, diagnosis, and other demographic characteristics

Using Appendix G5 of the SOA intercompany study, the aggregate incidence and length of stay were then adjusted to derive Alzheimer's and non-Alzheimer's claim costs.11

Table 2: Incidence Distribution and Severity Relativities by Alzheimer's and Non-Alzheimer's Claims						
Attained	Incidence Distribution		Severity Relativities			
Age	Alzheimer's	Non-Alz	Total	Alzheimer's	Non-Alz	Total
0-64	7%	93%	100%	2.83	0.86	1.00
65-69	14%	86%	100%	2.43	0.76	1.00
70-74	18%	82%	100%	2.02	0.77	1.00
75-79	21%	79%	100%	1.74	0.81	1.00
80-84	21%	79%	100%	1.61	0.83	1.00
85-89	21%	79%	100%	1.43	0.89	1.00
90+	18%	82%	100%	1.39	0.91	1.00
Total	20%	80%	100%	1.71	0.83	1.00

Table 3: Claim Costs by Alzheimer's and Non-Alzheimer's Unisex					
Attained Age	Alzheimer's*	Non-Alzheimer's**	Aggregate Claim Costs***		
42	0.037	0.150	0.187		
45	0.045	0.183	0.229		
47	0.052	0.209	0.261		
52	0.072	0.292	0.364		
55	0.088	0.356	0.444		
57	0.106	0.428	0.534		
60	0.140	0.563	0.703		
62	0.165	0.667	0.832		
67	0.542	1.038	1.581		
70	0.958	1.715	2.674		
72	1.414	2.421	3.835		
77	3.328	5.977	9.304		
80	5.205	9.668	14.874		
82	6.833	12.983	19.816		
87	10.335	24.252	34.587		
92	10.499	31.778	42.277		

 $Alzheimer's \ claim \ costs \ are \ equal \ to \ Table \ 1 \ aggregate \ claim \ cost \ times \ Table \ 2 \ Alzheimer's \ incidence \ distribution$ times Table 2 Alzheimer's severity relativity factor (e.g., 0.037 = 0.187 x 7% x 2.83).

FOOTNOTES

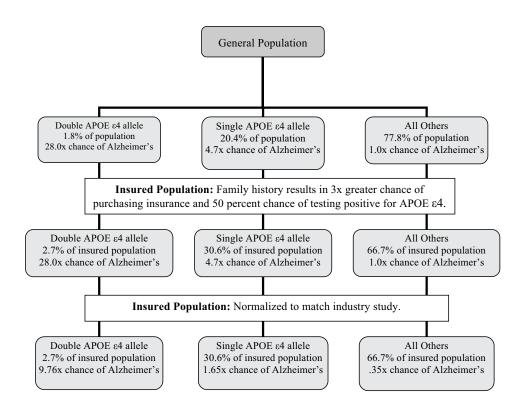
11 Society of Actuaries (SOA). Long-Term Care Experience Committee Intercompany Study: 1984-2004. (November 2007). Appendix G describes how claims were mapped into diagnosis categories.

Non-Alzheimer's claim costs are equal to Table 1 aggregate claim cost times Table 2 non-Alzheimer's incidence distribution times Table 2 non-Alzheimer's severity relativity factor (e.g., 0.150 = 0.187 x 93% x 0.86).

^{***} Aggregate claim costs are equal to Table 1. They may not equal the Alzheimer's plus non-Alzheimer's claim costs due to rounding.

We know the underlying insured population consisted of a mix of APOE ε4 positive and negative insureds. Based on a study published in the Journal of Clinical Psychiatry, ¹² 20.4 percent of the control population tested positive for the presence of one APOE & allele, indicating they have a 4.7 times greater likelihood of developing Alzheimer's Disease than those without APOE ε4. Of the control population, 1.8 percent tested positive for the presence of two APOE ε4 alleles, which corresponds to a 28.0 times greater likelihood of developing the disease. In addition, the Risk Evaluation and Education for Alzheimer's Disease (REVEAL) study, conducted between 2000 and 2003, indicated that individuals with a family history of the disease were 3 times as likely to purchase LTC insurance.¹³ In addition, the presence of a family history of Alzheimer's was associated with a 50 percent chance of testing positive for APOE ε4. 13 Data from elderly controls in the Swedish Kungsholmen Project indicated that the probability of a family history of dementia-related symptoms was approximately 18.6 percent (46/247).¹⁴

Using the above research results, we estimated that 2.7 percent of the LTC insured population would test positive for two APOE ε4 alleles and that 30.6 percent of the LTC insured population would test positive for one APOE ε 4 allele.15



- 12 Coon, Keith D., et al. "A High Density Whole-Genome Association Study Reveals That APOE is the Major Susceptibility Gene for Sporadic Late-Onset Alzheimer's Disease." Journal of Clinical Psychiatry (April 2007; 68:4, pp. 613-618).
- 13 Zick, Cathleen D., et al. "Genetic Testing for Alzheimer's Disease and its Impact on Insurance Purchasing Behavior." Health Affairs (March/April 2005; 24:2, pp. 483-490)
- 14 Fratiglioni, Laura. "Risk Factors for Late-Onset Alzheimer's Disease: A Population-Based, Case-Control Study." Annals of Neurology (March 1993; 33:3, pp. 258-266).
- 15 The 2.7 percent estimate represents the conditional probability of having two APOE &4 alleles, given that the person actually purchased LTC insurance; the 30.6 percent estimate represents the conditional probability of having one APOE £4 allele, given that the person actually purchased LTC insurance. In making these estimates, we reduced the 18.6 percent family-history estimate from Sweden to 16.6 percent for the U.S. to reflect, in part, reports that APOE £4 allele frequencies are lower at mid-latitudes than at high latitudes (such as in Sweden); see Eisenberg et al. "Worldwide Allele Frequencies of the Human Apolipoprotein E Gene: Climate, Local Adaptations, and Evolutionary History. American Journal of Physical Anthropology (2010; 143, pp. 100-111).

Combining these distributions resulted in the following claims projections:

- Those insureds who are positive for two APOE ε4 alleles will have a claim cost 9.76 times that of the aggregate Alzheimer's claim cost (9.76 is equal to $28.0 / (2.7\% \times 28 + 30.6\% \times 4.7 + 66.7\% \times 28 + 30.6\% \times 4.7 + 66.7\% \times 4.$ 1)—values are rounded).
- Those insureds who are positive for a single APOE ε4 allele will have a claim cost 1.65 times that of the aggregate Alzheimer's claim cost (1.65 is equal to $4.7 / (2.7\% \times 28 + 30.6\% \times 4.7 + 66.7\% \times$ 1)—values are rounded).
- In contrast, those insureds who are negative for the APOE ε4 allele will have a claim cost 0.35 times that of the aggregate Alzheimer's claim cost (0.35 is equal to $1/(2.7\% \times 28 + 30.6\% \times 4.7 + 66.7\%)$ x 1)—values are rounded).

The following table applies the above assumptions and calculates Alzheimer's claim costs as well as the non-Alzheimer's claim costs and shows the total based on the presence or absence of APOE ε4.

Table 4: APOE ε4 Specific Claim Costs Unisex				
Attained Age	Double APOE ε4 Positive*	Single APOE ε4 Positive**	APOE &4 Negative***	Aggregate Claim Costs****
42	0.512	0.211	0.163	0.187
45	0.627	0.258	0.199	0.229
47	0.716	0.295	0.228	0.261
52	0.997	0.411	0.317	0.364
55	1.217	0.501	0.387	0.444
57	1.462	0.602	0.465	0.534
60	1.925	0.793	0.612	0.703
62	2.279	0.939	0.725	0.832
67	6.333	1.931	1.228	1.581
70	11.066	3.292	2.049	2.674
72	16.226	4.749	2.915	3.835
77	38.455	11.454	7.138	9.304
80	60.464	18.236	11.485	14.874
82	79.674	24.231	15.367	19.816
87	125.122	41.264	27.858	34.587
92	134.248	49.061	35.442	42.277

Double APOE £4 positive claim cost is equal to Table 3 Alzheimer's claim cost times 9.8 plus Table 3 non-Alzheimer's claim cost (e.g., $0.512 = 0.037 \times 9.8 + 0.150$). Number may differ slightly due to rounding.

Single APOE &4 positive claim cost is equal to Table 3 Alzheimer's claim cost times 1.6 plus Table 3 non-Alzheimer's claim cost (e.g., 0.211 = 0.037 x 1.6 + 0.150). Number may differ slightly due to rounding.

APOE £4 negative claim cost is equal to Table 3 Alzheimer's claim cost times 0.35 plus Table 3 non-Alzheimer's claim cost (e.g., $0.163 = 0.037 \times 0.35 + 0.150$). Number may differ slightly due to rounding.

Aggregate claim cost remains equal to Table 1. It is the sum of the three APOE ε4 statuses with each weighted by the portion of the insured pool that each status represents.

From Table 4, double APOE £4 positive claim costs are 274 to 423 percent of the aggregate claim costs, and single APOE ε4 positive claim costs are 113 to 124 percent of the aggregate claim costs. As has been noted, this history can be priced for in current premium rates. If LTC insurance is purchased by 10 percent of the population, and if we have a population of 1,000, the required premium (using claim costs as a proxy) could be viewed in the following manner:

Table 5: Claim Cost Relativities by APOE ε4 Presence				
	Number of Policies	Relativity to Aggregate*		
Double APOE ε4 Positive	2.7	3.904		
Single APOE ε4 Positive	30.6	1.214		
APOE ε4 Negative	66.7**	0.784		
Aggregate	100.0	1.000		

- * Relativity to aggregate equals the sum of the relativities by age from the data in Table 4 multiplied by the weight of the number of claims at each age to the total number of claims in the 2004 Intercompany Study.
- ** Balancing item equals aggregate (10 percent of 1,000 population) minus 2.7 percent of insured population testing double APOE £4 positive minus 30.6 percent of insured population testing single APOE £4 positive.

If genetic testing were to become widely available without insurers having access to the same information, the risk pool will worsen by 28 percent from the APOE test alone. This would occur with the likelihood that the remainder of the APOE & positive lives will buy insurance but the penetration rate of APOE & negative lives will remain unchanged.

Table 6: Claim Cost Relativities by APOE ε4 Presence 100% Purchase by APOE ε4 Positive Population				
	Number of Policies Relativity			
Double APOE ε4 Positive	18*	3.904		
Single APOE £4 Positive	204**	1.214		
APOE ε4 Negative	67	0.784		
Aggregate	289	1.283		

^{18 = 1.8%} of 1,000 population

According to a Forbes Consulting report, "a 20-25% increase in premiums is associated with a 30% decline in sales." 16 Those who have tested positive for the APOE ε4 allele, however, are not likely to change their

FOOTNOTES

16 Price Elasticity and Optimization. Forbes Consulting (2004).

^{** 204 = 20.4%} of 1,000 population

purchasing behavior, causing further deterioration in the purchasing pool to be 32 percent worse than today.

Table 7: Claim Cost Relativities by APOE ϵ 4 Presence 100% Purchase by APOE ϵ 4 Positive Population, 30% Reduction in APOE ϵ 4 Negative				
	Number of Policies	Relativity		
Double APOE ε4 Positive	18	3.904		
Single APOE ε4 Positive	204	1.214		
APOE £4 Negative	47*	0.784		
Aggregate	269	1.320		

^{*67} x 70% (30% reduction in APOE £4 negative purchasers)

As testing improves and becomes more readily available, those who purchase LTC insurance will become more heavily weighted toward the 3.9 cost relativity. As the lower-risk population determines that it no longer is willing to bear this price and leaves the insured pool, the required premium rates will continue to increase. As such, only the very highest-risk individuals would purchase LTC insurance, which would shrink the market drastically, causing more individuals to rely on public programs such as Medicaid.

CONCLUSIONS

The analysis performed by this work group serves to emphasize some of the actuarial implications of extending GINA regulations to the LTC insurance market. GINA would prevent an LTC carrier from being able to underwrite its potential risk appropriately. It would promote anti-selection as more high-risk individuals would apply for coverage at the same time low-risk individuals potentially would leave the market due to increasing premiums. This likely would lead to rate spirals and a significant contraction of the LTC market. It would threaten the financial stability of LTC market, potentially resulting in carriers' inability to pay their customers' claims. One important result would be more pressure on the already strained public programs such as Medicaid.

We urge you to carefully consider the actuarial considerations outlined above. Extending GINA to LTC insurance has the potential to disrupt the financial stability of an insurance market of vital importance by preventing proper assignment of risks to homogenous premium rate pools.

We would welcome the opportunity to speak with you in person about our concerns. If you have any questions or would like to discuss these comments further, please contact Heather Jerbi, the Academy's senior health policy analyst (202.785.7869; Jerbi@actuary.org).

Sincerely,

David R. Plumb, MAAA, FSA Member, Long-Term Section Council Society of Actuaries

P.J. Eric Stallard, MAAA, ASA, FCA Chairperson, Federal Long-Term Care Task Force American Academy of Actuaries