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Ms. Kerry Weems
Acting Administrator
Centers for Medicare & Medicaid Services,

Re: Response to Request for Information on the Genetic Information Nondiscrimination Act of 2008 (GINA)

Dear Ladies and Gentlemen:

This letter is submitted by MIB Group, Inc. ("MIB," which is sometimes known as "Medical Information Bureau") in response to the Request for Information published in the Federal Register on October 10, 2008. The Request for Information solicits public comments to aid the Department of the Treasury, Department of Labor, and the Department of Health and Human Services in the development of regulations regarding sections 101 through 104 of GINA. The Departments requested specific feedback on how health plans and issuers currently obtain genetic information and asked whether MIB is an information source. We are pleased to have the opportunity to describe MIB's role as an information source for life and health insurance companies in the individual insurance market and as the premier provider of fraud detection services for the life and health insurance industry in North America. Although MIB currently provides very little "genetic information" (as defined by GINA) to our Members, we are taking steps to ensure that those MIB Members that are impacted by GINA will be able to continue to use MIB without compromising their ability to comply with the law.

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¹ Request for Information Regarding Sections 101 Through 104 of the Genetic Information Nondiscrimination Act of 2008, 73 Fed. Reg.60208 (Oct. 10, 2008).

MIB is a Delaware membership corporation that has operated for over 105 years in North America. As a membership corporation, it has no stock (or shareholders) and it is owned by its 475 member life and health insurance companies ("Members"). MIB's traditional Members are life insurance companies doing business on a legal reserve basis while "Select Members" are insurance companies and health plans that provide health insurance, but are not licensed as life insurance companies. Select Members include commercial health insurers, non-profit insurers, HMOs, managed care organizations and PPOs underwriting individual health insurance policies and contracts.

MIB has long had a large footprint in the life insurance industry. MIB Members underwrite an estimated 90% of all individually underwritten life insurance. MIB's presence in the health insurance industry is far smaller and more recent (past 10 years). Moreover, MIB's role is limited to the individual (non-group) health insurance market – a market that currently provides coverage to approximately 18 million people while over 230 million Americans currently access health care coverage through their employers or through government programs such as Medicare or Medicaid. ²

MIB's Checking Service

The primary purpose of the MIB Checking Service is to detect and deter fraud in the application process for individually underwritten life, health, disability income, critical illness (specified disease) and long-term care insurance from its Members. MIB's Checking Service protects insurers from attempts to conceal, omit or misrepresent information that is significant to the sound and equitable underwriting of these types of individually underwritten insurance. Losses due to this type of insurance fraud are estimated at over \$80 billion per year. MIB's fraud detection and deterrence saves its Members, on an annual basis, an estimated \$1 billion by allowing them to avoid fraudulent insurance applications and early claims. [Source: Milliman Study 2001] These savings may be passed down to insurance buying consumers in the form of lower premiums (and higher dividends payable by mutual companies), which allow them to buy more insurance at affordable premiums. Indeed, a recent study performed by Milliman, Inc. in 2006 entitled "The Impact of the MIB Checking Service on Health Insurance Underwriting" shows that MIB Checking Service projects a reduction in the overall loss ratio by 6 %, thereby allowing health insurers to keep their premiums affordable for consumers.

MIB's business model is sometimes described as an "information exchange" because MIB Members contribute data to the MIB database that may be useful to other Members that later search the database with the authorization of the insurance applicant. Using Fair Credit Reporting Act terminology, MIB Members are both the exclusive "users" of MIB's consumer reports and "furnishers" of information to MIB for inclusion in such reports. MIB Members agree to report information to MIB using proprietary and highly confidential "codes" (a simple form of encryption) that signify different medical impairments and conditions (for example, heart attacks, diabetes, cancer), certain diagnostic test results (for example, EKG), and other

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² Guaranteeing Access to Coverage for All Americans, America's Health Insurance Plans (2008).

conditions affecting the insurability of the proposed insured such as hazardous avocations (sports) or adverse driving records, all of which are significant to the underwriting of insurance because of their impact on morbidity and mortality. MIB codes often represent broad categories of medical histories. These codes do **not** indicate what action another Member company took with respect to the application (approval, denial, approval with a substandard rating). With the exception of data from the Department of Treasury on "Specially Designated Nationals" or "blocked persons" and Canada's Office of the Superintendent of Financial Institutions (OSFI) list, MIB only receives information from its Member companies.

MIB's codes are not the same codes as the Healthcare Common Procedure Coding System (HCPCS) that is based upon on the American Medical Association's Current Procedural Terminology (CPT). The HCPCS was established in 1978 to provide a standardized coding system for describing the specific items and services provided in the delivery of healthcare. In contrast to the HCPCS system, MIB's codes were developed over 100 years ago to alert underwriters to conditions significant to underwriting life and health insurance. Also, MIB's codes should not be confused with "ICD-9"coding adopted by the World Health Organization's International Statistical Classification of Diseases and Related Health Problems (ICD).

Because MIB uses proprietary codes, it does not report the actual or complete details about a person's medical condition or impairment. The codes have been described as "brief resumes" serving simply as "red flags" that alert companies to the fact that information was obtained and then reported by a Member company on a particular medical impairment or avocation risk.³ These codes do not provide enough detail for an underwriter to make an underwriting decision and, further, MIB Member companies are expressly prohibited under the MIB General Rules from making underwriting decisions on the sole basis of a reported code.⁴ Records for individuals in the MIB "Checking Service" database do not indicate whether any policy has been issued or the amount of any coverage. In other words, MIB does not maintain any record reflecting the underwriting action taken by a Member company (whether to issue "standard," charge an additional premium, or decline the application). In contrast to credit bureaus, MIB does not use any type of scoring system.

At the time a proposed insured applies for individually underwritten life, health, disability income, critical illness or long-term care insurance with an MIB Member company, he or she is provided with an MIB Pre-Notice about MIB's role in the insurance underwriting process. The MIB Pre-Notice notifies the consumer that a report regarding the person's medical conditions and avocations may be made to MIB and further, that if he or she later applies for life or health insurance (or files a claim for benefits) with an MIB Member company, then MIB may supply such company with an MIB report. After receiving the notice, the applicant is thereafter asked to sign an authorization allowing the Member company to search the MIB database and allowing MIB to release the consumer's MIB record, if any, to the Member.

⁴ In the 17 states that have adopted the '82 NAIC Model Insurance Information and Privacy Act (AZ, CA, CT, GA, HI, IL, KS, ME, MA, MN, MT, NV, NJ, NC, OH, OR, VA), an insurance company cannot make an adverse underwriting decision on the sole basis of information received from MIB.

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³ MIB codes *prompt* underwriting investigation into certain medical conditions and impairments.

When a Member completes the underwriting of an individual's application, any conditions that have a material mortality or morbidity impact are reported to MIB under those broad categories of medical histories or conditions for which we have codes. Only information that is collected by the Member insurance company from the applicant or from healthcare providers (or other sources) with the applicant's authorization during the course of its underwriting of the consumer's application for insurance may be reported to MIB. As a practical matter, MIB codes are not reported on many individuals whose life and health insurance applications are treated by the insurers as "clean cases," meaning that they are approved as standard or preferred risks. Reportable MIB codes are currently purged after seven (7) years in order to prevent the reporting of obsolete information.

MIB's Regulatory Environment

MIB is a "nationwide specialty consumer reporting agency" subject to the Fair Credit Reporting Act (FCRA), as amended by the Fair and Accurate Credit Transactions Act of 2003 (FACTA). FCRA was enacted by Congress in 1970 to promote accuracy, fairness, and the privacy of personal information assembled by "consumer reporting agencies." The FCRA establishes a framework of consumer rights and protections, a few of which include: free annual disclosure of consumer files upon their request, the right to dispute information in consumer files and seek its correction, limitations on the use of consumer reports, requirements for notice, user participation (consent), and accountability. Because MIB Member companies are also governed by Gramm-Leach-Bliley Act (GLBA), Health Insurance Portability and Accountability Act (HIPAA) and numerous state privacy laws, including the NAIC Model Insurance Information and Privacy Act, and Canadian Members are governed by the Personal Information Protection and Electronic Documents Act ("PIPEDA") and provincial laws, MIB conducts its business in a manner that allows its Members to comply with such laws.

In addition to compliance with FCRA and applicable privacy laws, MIB and its Members operate in conformity with MIB's longstanding General Rules. MIB's General Rules ensure the confidential treatment of information, the accuracy and timeliness of reports made to MIB, and other consumer protections. MIB has been long been an advocate of protecting the confidentiality of the consumer information entrusted to it. Indeed, MIB has maintained an unblemished record in this regard for over 105 years. To that end, MIB has a comprehensive enterprise information security program.

Potential Implications of GINA for MIB and its Members

MIB plays a critical role in the underwriting of individual policies of health insurance and contracts with health plans, including traditional fee-for-service indemnity policies, direct pay contracts with Health Maintenance Organizations (HMOs and managed care organizations), policies and contracts with Preferred Provider Organizations (PPOs), policies of disability income, long-term care, and critical illness (specified disease) insurance. In certain states like New York, individual health insurance is not underwritten due to open enrollment, community

⁵ MIB consumer files are "consumer reports" under FCRA.

rating, and portability laws affecting the small group and individual marketplace. Therefore, MIB's Checking Service is not used for New York health business (other than individual long-term care, disability income and specified disease insurance, all of which are individually underwritten). Likewise, MIB's Checking Service is not used by single employer self-insured health plans or multiple employer welfare arrangements (MEWAs), or for eligible individuals under the Health Insurance Portability and Accountability Act (HIPAA) who have lost their employer sponsored group health plan coverage and apply for individual policies that must be issued on a guaranteed basis. Finally, MIB's Checking Service has no role in group health insurance with the exception of association group health insurance that is individually underwritten.

In the individual health market in which MIB plays an important role, GINA prohibits health insurance issuers from using genetic information to determine individual eligibility or premium rates, although they are allowed to use information about the manifestation of a disease or disorder to determine eligibility or premium rates for an individual. Individual market health insurance issuers are also prohibited from using genetic information in imposing a pre-existing condition exclusion, although a manifestation of a disease or disorder in an individual can be the basis for an exclusion. In the Medicare Supplement market, GINA prohibits issuers from denying or conditioning the issuance or effectiveness of a policy (including the imposition of any exclusion of benefits based on a pre-existing condition) or discriminating in the pricing of the policy based on an individual's genetic condition. However, if the Medicare Supplement policy can be underwritten as permitted by law, the issuer can still impose such limitations based on a manifested disease of an individual who is covered or would be covered under the policy.

Under GINA, health insurers are prohibited not only from using "genetic information" for underwriting, but from purchasing or collecting "genetic information." MIB does not have any codes that report "genetic test" results ("genetic tests" being defined under GINA as analyses of human DNA, RNA, chromosomes, proteins, or metabolites that detect genotypes, mutations, or chromosomal changes). However, a few of MIB's codes could meet the GINA definition of "genetic information" if it is broadly construed to mean "family history" of a hereditary disease (the manifestation of a disease or disorder in a family member, but not the individual). "Genetic information" is defined in GINA as information about an individual's genetic tests, the genetic tests of family members, and the manifestation of a disease or disorder in family members of such individual. GINA proponents have construed this definition to mean that "family history"

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⁶ See generally, Fundamentals of Underwriting in the Nongroup Health Insurance Market: Access to Coverage and Options for Reform, National Health Policy Forum (Mark Merlis, April 13, 2005).

⁷ Section 1882 of the Social Security Act

⁸ "Routine tests" such as complete blood counts, cholesterol tests, and liver-function tests are not protected under GINA.

⁹ (16) GENETIC INFORMATION-

⁽A) IN GENERAL- The term `genetic information' means, with respect to any individual, information about--

⁽i) such individual's genetic tests,

⁽ii) the genetic tests of family members of such individual, and

⁽iii) the manifestation of a disease or disorder in family members of such individual.

¹⁰ What Does GINA Mean? A Guide to the Genetic Information Nondiscrimination Act, Coalition for Genetic Fairness (2008), and the Genetic Alliance, www.geneticalliance.org.

of a manifested disease alone will constitute "genetic information." even though there has been no genetic testing for the individual or his family member. Under this interpretation, GINA will protect information about manifested disease in an individual's family members when the individual has not had any symptoms or diagnosis of the disease. However, the definition of "genetic information" could be construed more narrowly to mean the manifestation of the disease in the individual's family members when there has also been a genetic test for the individual or family member (manifestation of disease in a family member *in addition to* a genetic test). Again, if the definition of "genetic information" is broadly construed to prevent the use of family history in underwriting individual health insurance, then MIB may have to modify certain codes or suppress the reporting of them.

As the federal rulemaking process unfolds, MIB will continue to investigate solutions to the potential problem that a few of our codes may cause for those MIB Members that underwrite individual health insurance. We are confident that MIB will be able to respond to the compliance requirements imposed by GINA in a way that will ensure the ability of our Members to comply with it.

We appreciate the opportunity to comment on this important matter. If you have any questions about these comments or you would like any clarification or elaboration, please do not hesitate to contact me.

Sincerely,

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