American Federation of Labor and Congress of Industrial Organizations

815 Sixteenth Street, N.W.
Washington, D.C 20006
(202) 637-5000

June 23, 1998

Dianne C. Sellers, Commissioner
North Carolina Industrial Commission
Dobbs Building — Sixth Floor
430 North Salisbury Street
Raleigh, NC 27611

Dear Dianne:

Enclosed is a copy of my bio and some material that you may wish to include with program conference materials that are being prepared for participants to the SAWCA Convention next month.

I haven't prepared an outline of my presentation as I am not sure how the format of the panel will proceed. Among the issues we should discuss are the Health Insurance Portability and Accountability Act of 1996, the President's Advisory Commission on Consumer Protection and Quality in the Health Care Industry, the NAIC Health Information Privacy Model Act, and proposals for federal legislation in this area that would include, but not necessarily be limited to: the Patients' Bill of Rights Act of 1998 (H.R. 3605, S. 1890); the Health Care Personal Information Nondisclosure Act of 1998 (S. 1921); and the Patient Access to Responsible Care Act of 1997 (H.R. 1415, S. 644).

With best wishes,

Sincerely,

James N. Ellenberger
Assistant Director
Occupational Safety and Health

From Washington Post
March 22, 1998

Privacy: A Moving Target

THREATS TO the privacy of medical data strike a chord with nearly everybody. In this case, not only are the chords struck likely to be different for each person—they're also, by definition, likely to be things nobody but the person in question knows about. How many variations are there on the fear that something in your medical background might leak—an embarrassing procedure in your past, a genetic predisposition that could ruin your insurance, a life-threatening illness that could threaten your job, a former addiction, a sexual preference, a personal agony? As proposals multiply on the Hill and in the states for privacy legislation, causing worry about a patchwork of contradictory rules and loopholes, it's becoming obvious that there are almost as many different threats to privacy and personal security from the release of private medical data as there are people with data to leak.

The chaos of the health care industry and its record-keeping—hospitals merging or going private, doctors entering and leaving HMOs, HMOs analyzing treatment results for cost savings, insurers sharing computerized data—has slowed efforts to devise a privacy law that would really work, as opposed to one that would merely penalize unauthorized release of data after the fact—when, for most people, the harm is done. But the nature of what's classified as medical information to begin with—the stuff in the files—is almost as much of a moving target. Things count as medical now that a decade ago would never get into the files to begin with; the familiar example is genetic predisposition to an expensive disease, which, if known, could affect insurance coverage. That fear has inspired six separate bills to prevent discrimination based on genetic information.

But genes are not the only new kind of information now flooding into the realm of diagnosis. Two unrelated news reports on a single day last week offered two more conditions apparently being pinned down to a physiological site. In one, scientists said they had found a taggable brain function linked to dyslexia, the learning disability that slows children down in school; in another, comparisons of the inner ear in lesbians and heterosexual women suggested a specific difference brought about by hormone action. Progress? A sure diagnosis of dyslexia could benefit innumerable kids by cutting through the fog that attends learning disability. Gay spokespeople are split on whether evidence that their sexual preference is truly unchosen would help the argument for equal treatment. What links them with genetic profiles and clinical histories, rather, is their existence as medical data. The more aspects of life, personality and potential a thorough checkup by your doctor can send into your file, the greater the opportunity for those files to end up in hands that are neither the doctor's nor yours.

AUTHORIZATION TO RELEASE
HEALTH CARE INFORMATION

TO WHOM IT MAY CONCERN:

PURSUANT TO MCA 50-16-526 OF THE MONTANA UNIFORM HEALTH CARE INFORMATION ACT ANY ANY OTHER LAW THAT MAY BE APPLICABLE I,_____, SSN # _____ HEREBY AUTHORIZE ALL OF MY HEALTH CARE PROVIDERS TO DISCLOSE TO AND PROVIDE COPIES TO LIBERTY COMPANIES, 607 SW HIGGINS MISSOULA, MT 59803, ALL HEALTH CARE INFORMATION IN YOUR POSSESSION, WHETHER AUTHORED BY YOU OR NOT, RELATING TO YOUR EXAMINATION, TESTING, EVALUATION OF ME INCLUDING BUT NOT LIMITED TO EXAMINATION NOTES, TEST RESULTS, X-RAYS, SUMMARIES, ADMISSION AND DISCHARGE RECORDS, OPERATION REPORTS, NURSES' NOTES, PRESCRIPTIONS, MEDICAL BILLS, HISTORIES, TREATMENT RECORDS AND NARRATIVES, PSYCHIATRIC AND/OR PSYCHOLOGICAL RECORDS, TESTS, TREATMENT, REPORTS, INTERVIEW NOTES, EVALUATIONS AND TEST RESULTS AND ANY OTHER DOCUMENTARY OR OTHER INFORMATION YOU MAY HAVE.

THIS AUTHORIZATION ALSO INCLUDES DISCLOSURE AND COPYING OF CORRESPONDENCE TO AND FROM EACH HEALTH CARE PROVIDER IN ANY WAY REGARDING ME, MY MEDICAL CARE, MEDICAL RECORDS, PSYCHIATRIC OR PSYCHOLOGICAL RECORDS.

THIS AUTHORIZATION ALSO AUTHORIZES ALL OF MY HEALTH CARE PROVIDERS TO SPEAK WITH LIBERTY COMPANIES ADUSTERS OR AGENTS ACTING ON THE BEHALF OF LIBERTY COMPANIES, AND TO ANSWER ANY QUESTIONS HE MAY ASK YOU ABOUT ANY CARE, SERVICE OR PROCEDURE YOU OR ANYONE ELSE HAS PROVIDED ME INCLUDING BUT NOT LIMITED TO MEDICAL, PSYCHIATRIC OR PSYCHOLOGICAL DIAGNOSIS, TREATMENT, EVALUATION, ADVICE OR OTHER SERVICES THAT AFFECT THE STRUCTURE OF ANY FUNCTION OF THE HUMAN BODY OR MIND.

I REQUEST YOU EXTEND YOUR FULL CO-OPERATION IN PROVIDING THE HEALTH CARE INFORMATION DESCRIBED ABOVE. A COPY OF THIS AUTHORIZATION IS AS EFFECTIVE AS THE ORIGINAL.

DATED THIS_____ DAY OF _____,199__.

CLAIMANT NAME_____.

SSN #_____

DATE OF BIRTH_____

American Federation of Labor and Congress of Industrial Organizations

815 Sixteenth Street, N.W.
Washington, D.C. 20006
(202) 637-5000

October 3, 1997

The Honorable Donna Shalala
Secretary
Department of Health and Human Services
Washington, DC 20201

Dear Madam Secretary:

The AFL-CIO applauds the efforts by the Department of Health and Human Services to provide recommendations to the Congress on federal standards for protecting the confidentiality of an individual's medical records. The confidentiality of medical records is vitally important to the consumer's trust of health plans and providers. In the workplace, where employers sponsor the health plan, additional protections are necessary. In one survey of 84 Fortune 500 companies, one-third of the human resource employees said that had used such records in the hiring, promotion and firing decisions. This abuse of confidentiality can only grow as computerized medical records and genetic testing become more common.

While we wholeheartedly support protecting personal health information through privacy legislation, we are troubled with several aspects of the recommendations you delivered to the Congress on September 11, 1997.

In our view, it is essential that medical privacy legislation apply to the coverage of all health information, including data related to any worker covered by a workers' compensation program. Workers should not be expected to surrender their rights to privacy, respect and dignity in connection with personal health information as a condition of employment. Employers and workers' compensation insurers must be bound by the same principles and requirements concerning health care information as all others. A jury in Texas recently awarded $10.6 million in damages to five garment workers for actions by their employer that involved willful and malicious discrimination against them for filing workers' compensation claims. These employer actions included publicly disclosing personal medical information about them to their fellow employees.

The current proposal does not go far enough in protecting the confidentiality rights that workers should have to prevent unauthorized and inappropriate access to their workers' compensation records. Despite existing laws (such as the Americans with Disabilities Act of 1990 and the Rehabilitation Act of 1973), it is common for workers' compensation insurers to "share" information about claimants through an information sharing exchange called the "Index System" and for state agencies to make personal workers' compensation claims records, including medical information, available to private, for-profit information-gathering firms. These firms then sell this data to employers. One prominent firm advertises that its services can help employers determine "which applicants are safe" and boasts that they "manage the largest body of workers' compensation records in the United States."[1]

Overall, the current proposal to ban employer access to individual medical records for non-health purposes does not go far enough in distinguishing claims payments from medical review. This is a particular problem with workers compensation claims, where employers play a large role in determining eligibility for coverage. It may also apply to certain conditions such as HIV/AIDS where purchasers may request small sample data to determine quality assurance.

We also see no reason to exclude from the definition of payers the broad category of "liability insurers." As you know, the term "liability insurer" covers the vast majority of insurers, including both commercial insurers and state funds, who provide workers' compensation coverage to more than 60 percent of the workforce in the United States. Privacy protection applicable to payers of health coverage should cover all insurers, both medical and general liability, who arrange, provide or pay for medical care.

We also have concerns that third-party administrators may be excluded from the definition of payers. The AFL-CIO believes that there should be no exclusion for third party administrators or for employers who self-administer their own workers' compensation program and who have access to personal health information.

Finally, the definition of research should be tightened. We strongly support the appropriate disclosure and use of personal health information for the care of the individual, public health purposes, research, and oversight of particular public health activities. However, the current practice, particularly in workers' compensation, of employers and insurers using an individual's personal health information for their own "research" purposes must, in the future, be limited to those situations where proper authorization is obtained from the individuals who are the subjects of such research.

In summary, the AFL-CIO believes that employer restrictions on access to individual employee information should be further strenghthened and should apply uniformly to insurers and employers who operate workers compensation programs. State workers' compensation laws merit no special exclusion or treatment in the application of a future Federal privacy law.

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[1] Sales brochure from AVERT, "TSB 96.03"

We look forward in the coming months to the opportunity of working with the Administration as they draft their bill and as you continue your review on the need for federal medical privacy standards for workers compensation.

Sincerely,

John J. Sweeney
President

American Federation of Labor and Congress of Industrial Organizations

815 Sixteenth Street, N.W.
Washington, D.C 20006
(202) 637-5000

February 5, 1998

John Conniff
Deputy Commissioner
Washington Office of the Insurance Commissioner
14th and Water Streets
P.O. Box 40255
Olympia, WA 98504-0255

Via Fax to: 360-586-3535

Dear Commissioner Conniff:

Thank you for the opportunity to submit comments on the work of the Health Information and Privacy Working Group that you chair for the National Association of Insurance Commissioners.

The Health Information Privacy Model Act that your working group is considering is an important part of various efforts to insure that every individual's private health care information is properly used and protected. As you know, the United States Congress has mandated that the Department of Health and Human Services make recommendations for federal legislation to provide for safeguards in the protection of an individual's personal health information. Additionally, the President's Advisory Commission on Consumer Protection and Quality in the Health Care Industry recently adopted a statement emphasizing that:

> Consumers have the right to communicate with health care providers in confidence and to have the confidentiality of their individually identifiable health care information protected. Consumers also have the right to review and copy their own medical records and request amendments to their records.

The AFL-CIO is fully cognizant of the critically important responsibility of state insurance commissioners as regulators over the operations of insurers in their jurisdictions. We congratulate the NAIC for its leadership in attempting to provide state policy makers with important recommendations on a variety of issues, including the regulation of insurance carriers on issues concerning the privacy of an individual's personal health information.

In this regard, the AFL-CIO urges the NAIC, in the context of its work on a "Health Information Privacy Act," to carefully avoid creating exceptions for different types of insurers in recommending standards to protect the unauthorized collection, use and disclosure of an individual's health information.

We are particularly concerned with the unreasonably broad exception contained in **Section 11 (C)**, "Special Rules for Workers' Compensation Insurance Carriers." It is our firm position, as outlined in the attached letter of October 3, 1997 from AFL-CIO President John J. Sweeney to HHS Secretary Donna Shalala, that workers should not be expected to surrender their rights to privacy, respect and dignity in connection with personal health information as a condition of employment.

The language contained in the NAIC draft of 1/30/98 would grant workers' compensation carriers unrestricted rights to collect, use and disclose protected health information for whatever they claim is "incidental" to their obligations under any workers' compensation or related law or contract.

The plain meaning of "incidental" is "occurring merely by chance or without intention or calculation." Such language, in our view, would give workers' compensation carriers absolute freedom to ignore every aspect of the NAIC's well-intentioned effort to ensure confidentiality and privacy that individuals would otherwise have.

What does "related" law mean? Would this enable a workers' compensation carrier to ignore the privacy laws or regulations of state A due to what they claim would be their obligation under a "related" law in state B?

Do you really mean to offer an exclusion for workers' compensation carriers to divulge an individual's private health information to employers or others with whom they have a "contract?" What if their "contract" is with AVERT, a firm that advertises that it helps employers determine which job "applicants are safe" and claims that they manage the largest body of workers' compensation records in the United States? Does the NAIC want to abide or encourage such efforts?

Unfortunately, workers who lose their jobs or who are otherwise discriminated against due to disclosure or misuse of personal health information would have no protection and no recourse under present version of the model act that your working group has produced.

It is our firm belief, based on years of experience that workers have had with abuse of private health information by workers' compensation insurers, that privacy standards, laws and regulations must apply equally to those carriers as with all other insurers.

Section 9, Section 10 and Section 11, **without subsection C**, would permit workers' compensation carriers to perform their obligations under workers' compensation law but, more importantly would afford workers the same rights, dignity and respect over access to and use of their private medical information as all other citizens would have.

The AFL-CIO believes that restrictions on collection, access, use and disclosure of private health information, including private health information of workers, should be strengthened and should apply uniformly to all insurers, including those who underwrite workers' compensation. Workers' compensation insurers merit no special exclusion or treatment in the standards or models adopted by the NAIC.

Sincerely,

James N. Ellenberger

James N. Ellenberger
Assistant Director
Department of Occupational Safety and Health