

"(ii) further investigation is warranted."

FAIR HEALTH INFORMATION
PRACTICES ACT OF 1995

HON. GARY A. CONDIT

OF CALIFORNIA

IN THE HOUSE OF REPRESENTATIVES

Monday, January 9, 1995

Mr. CONDIT. Mr. Speaker, I have today introduced the Fair Health Information Practices Act of 1995. The purpose of this bill is to establish a uniform Federal code of fair information practices for individually identifiable health information that originates or is used in the health treatment and payment process.

In the last Congress, I introduced a similar bill (H.R. 4077) that was the subject of several days of hearings. In August 1994, that bill was reported by the Committee on Government Operations and became the confidentiality part of the overall health care reform effort. While my bill died along with the rest of health care reform, it was one of the only noncontroversial parts of health reform.

The bill that I have introduced today is identical to the version reported by the Committee on Government Operations last year. There were some changes made later in the legislative process, but I thought that the committee bill was the best starting point for now. A lengthy explanation of the bill can be found in the Government Operations Committee report, House Report 103-601, part V.

The need for uniform Federal health confidentiality legislation is clear. In a report titled "Protecting Privacy in Computerized Medical Information," the Office of Technology Assessment found that the present system of protecting health care information is based on a patchwork quilt of laws. State laws vary significantly in scope, and Federal laws are applicable only to limited kinds of information or to information maintained only by the Federal Government. Overall, OTA found that the present legal scheme does not provide consistent, comprehensive protection for privacy in health care information, whether that information exists in a paper or computerized environment. A similar finding was made by the Institute of Medicine in a report titled "Health Data in the Information Age."

A public opinion poll sponsored by Equifax and conducted by Louis Harris and Associates documents the importance of privacy to the American public. Eighty-five percent agree that protecting the confidentiality of people's medical records is absolutely essential or very important in national health care reform. The poll shows that most Americans believe protecting confidentiality is a higher priority than providing health insurance to those who do not have it today, reducing paperwork burdens, or providing better data for research. The poll also showed that 96 percent of the public agrees that it is important for an individual to have the right to obtain a copy of their own medical record.

Health information is a key asset in the health care delivery and payment system. Identifiable health information is heavily used in research and cost containment, and this usage will only grow over time. It is too early to predict what type of health reform legislation will be considered in the new Congress, but rules governing the use and disclosure of health information are certain to be a key ele-

ment. My legislation is flexible enough to fit into any health reform legislation, large or small, or to stand on its own as a separate bill. Regardless of how the health delivery and payment system is structured, there is and will continue to be a need for a code of fair information practices.

By establishing fair information practices in statute, the long-term costs of implementation will be reduced, and necessary protections will be built in from the outset. This will assure patients and medical professionals that fair treatment of health information is a fundamental element of the health care system. Uniform privacy rules will also assist in restraining costs by supporting increased automation, simplifying the use of electronic data interchange, and facilitating the portability of health coverage.

Today, few medical professionals and fewer patients know the rules that govern the use and disclosure of medical information. In a society where patients, professionals, and records routinely cross State borders, it is rarely worth anyone's time to attempt to learn the rules of any one jurisdiction, let alone several jurisdictions. One goal of my bill is to change the culture of health records so that professionals and patients alike will be able to understand the rights and responsibilities of all participants. Common rules and a common language will facilitate broader understanding and better protection. Professionals will be able to learn the rules once with the confidence that the same rules will apply wherever they practice. Patients will learn that they have the same rights in every State and in every doctor's office.

There are two basic concepts that are essential to an understanding of the new approach. First, identifiable health information that is created or used during the medical treatment or payment process becomes protected health information, or individually identifiable patient information relating to the provision of health care or payment for health care. This new terminology emphasizes the sensitivity of the information and connotes an obligation to safeguard the data. Protected health information generally remains subject to statutory restriction no matter how it is used or disclosed.

The second basic concept is that of a health information trustee. Anyone who has access to protected health information under the bill's procedures becomes a health information trustee. Trustees have different sets of responsibilities and authorities depending on their functions. The authorities and responsibilities have been carefully defined to balance legitimate societal needs for data against each patient's right to privacy and the need for confidentiality in the health treatment process. Of course, every health information trustee has an obligation to maintain adequate security for protected health information.

The term trustee was selected in order to underscore that those in possession of identifiable health information have obligations that go beyond their own needs and interests. A doctor who possesses information about a patient does not own that information. It is more accurate to say that both the record subject and the recordkeeper have rights and responsibilities with respect to the information. My legislation defines those rights and responsibilities. The concept of ownership of personal information maintained by third party record

keepers is not particularly useful in today's complex world.

A key element of this system is the specification of the rights of patients. Each patient will have a bundle of rights with respect to protected health care information about himself or herself that is maintained by a health information trustee. In general, a patient will have the right to inspect and to have a copy of that information. A patient will have the right to seek correction of information that is not timely, accurate, relevant, or complete. A patient also has a right to expect that any trustee will use and maintain information in accordance with the rules in the act. A patient will have a right to receive a notice of information practices. The bill establishes standards and procedures to make these rights meaningful and effective.

I want to emphasize that I have not proposed a pie-in-the sky privacy code. This is a realistic bill for the real world. I have borrowed ideas from others concerned about health records, including the American Health Information Management Association, the Workgroup for Electronic Data Interchange, and the National Conference of Commissioners on Uniform State Laws. Assistance provided last year by the American Health Information Management Association was especially valuable.

I believe that everyone recognizes that we do not have the luxury of elevating each patient's privacy interest above every other societal interest. Such a result would be impractical, unrealistic, and expensive. The right answer is to strike an appropriate balance that protects each patient's interests while permitting essential uses of data under controlled conditions. This should be happening today, but recordkeepers do not know their responsibilities, patient rights are not always clearly defined, and there are large gaps in legal protections for health information. My bill recognizes necessary patterns of usage and combines it with comprehensive protections for patients. There will be no loopholes in protection for information originating in the health treatment or payment process. As the data moves to other parts of the health care system and beyond, it will remain subject to the Fair Health Information Practices Act of 1995. This novel requirement may be the single most important feature of my bill.

The legislation includes a variety of remedies that will help to enforce the new standards. For those who willfully ignore the rules, there are strong criminal penalties. For patients whose rights have been ignored or violated by others, there are civil remedies. There will also be administrative sanctions and arbitration to provide alternative, less expensive, and more accessible remedies.

The Fire Health Information Practices Act of 1995 offers a complete and comprehensive plan for the protection of the interests of patients and the needs of the health care system in the complex modern world of health care. More work still needs to be done, and I am committed to working with every group and institution that will be affected by the new health information rules. I remain open to new ideas that will improve the bill.

In closing, I want to acknowledge the limits of legislation. We must recognize and accept the reality that health information is not completely confidential. It would be wonderful if we

could restore the old notion that what you tell your doctor in confidence remains secrets. In today's complex health care environment, characterized by third party payers, medical specialization, high cost care, and increasing computerization, this is simply not possible. My legislation does not and cannot promise absolute privacy. What it does offer is a code of fair information practices for health information.

The promise of that code to professionals and patients alike is that identifiable health information will be fairly treated according to a clear set of rules that protect the confidentiality interests of each patient to the greatest extent possible. While we may not realistically be able to offer any more than this, we surely can do no less for the American public.

SALUTE TO DR. JOSEPH D.
PATTERSON, SR.

HON. THOMAS M. FOGLIETTA

OF PENNSYLVANIA

IN THE HOUSE OF REPRESENTATIVES

Monday, January 9, 1995

Mr. FOGLIETTA. Mr. Speaker, I rise to salute Dr. Joseph D. Patterson as he is installed as the president of the Black Clergy of Philadelphia at Hickman Temple A.M.E. Church on January 8. Dr. Patterson takes over the presidency of the Black Clergy, one of the most influential positive social forces in the city, from Rev. Jesse Brown who has lead the organization over the past years with great dignity and ability.

Mr. Patterson is a great leader in the Philadelphia community. He is a trustee at Cheyney University, a board member of the Philadelphia Industrial Development Corp., chairman of the board of the Baltimore Avenue Redevelopment Corp., and has served over the past years as first vice president of the Black Clergy before his election to the presidency.

Dr. Patterson's commitment to the strengthening of the community is well known. He believes unflinchingly in a comprehensive approach to solving society's problems, and has been an outspoken advocate for health care improvement, the strengthening of the family, the importance of education, and the elimination of violence in our neighborhoods.

I join with Dr. Patterson's friends, family, and the entire Philadelphia community in wishing him the best of luck at his new post, and look forward to many years of his expedient leadership.

TRIBUTE TO SUPERINTENDENT
BYRON MAUZY

HON. LYNN C. WOOLSEY

OF CALIFORNIA

IN THE HOUSE OF REPRESENTATIVES

Monday, January 9, 1995

Ms. WOOLSEY. Mr. Speaker, I rise today to honor one of my district's most dedicated elected officials, Marin County Superintendent of Schools, Byron W. Mauzy. Superintendent Mauzy was elected in 1983 and has served the people of Marin County well in this capacity.

As we celebrate Byron's 41 years in public education, and his retirement as Marin County

Superintendent of Schools, I wish to recognize Superintendent Mauzy for his commitment to improving the quality of education in Marin County, and the Nation, and to thank him for his long record of public service.

Byron has been with the Marin County Office of Education since 1967 when he was director of business services. During the period between 1970 and 1982 Byron was deputy superintendent and served as interim superintendent of the Kentfield, Sausalito, and Mill Valley School Districts.

He worked as assistant superintendent of instructional and business services for the Del Norte County Unified School District in Crescent City, CA. He was also a teacher and principal at Lower Lake Elementary School in California.

Byron earned a B.A. at San Jose State College and a M.A. at Stanford University in California. He received his Ed.D from Nova University in Fort Lauderdale, FL, and has the following life credentials: general elementary, general secondary, elementary administrative, secondary administrative, and general administrative.

I was pleased to have had the opportunity to work closely with Byron over the last couple years on important education issues. We shared the same view that education must become our Nation's top priority, and Byron can be commended for his work to improve education at the local level. In fact, the outstanding work of our Marin County schools served as a model for my successful efforts to establish a coordinated services program nationally. Under Byron's leadership, Marin County schools effectively made health and social services available at or near school sites. I was also pleased to work with Byron when I brought both Secretary of Education Dick Riley and Health and Human Services Secretary Donna Shalala to the Sixth Congressional District to discuss education and other issues about youth. It was a pleasure to be working hand-in-hand with him, and I continue to be impressed by his dedication to quality education in Marin County and the Nation.

As an example of Byron's commitment to the county, he is currently on the board of directors for the Beryl Buck Institute of Education, Marin Council Boy Scouts of America, Sons of the American Revolution, Salvation Army, California Health Research Foundation, Marin Suicide Prevention, San Rafael Thrift and Loan, and Wild Care. Byron also serves on the American Heart Association's Hypertension Council: Invest in America School Advisory Committee, the Community Advisory Council at the Golden Gate Seminary, the 14th District PTA, the Elizabeth Terwilliger Foundation, the Dominican College Citizens Advisory Committee, the Human Rights Resource Center, and the Ross Hospital Advisory Committees.

In addition, Byron is a member of the Association of California School Administrators, Marin County School Administrators Association, the Marin Association of Superintendents, California Schoolmasters Club, Phi Delta Kappa, Marin Rod and Gun Club, Marin Coalition, Masonic Lodge, Elks Lodge No. 1108, Native Sons of the Golden West, Marvelous Marin Breakfast Club, Commonwealth Club of California, League of Women Voters, Marin Builders Exchange Scholarship Committee, Marin Council of Agencies, Marin Forum, Citi-

zens League of Marin, and the San Rafael Chamber of Commerce.

Mr. Speaker, it is my great pleasure to pay tribute to Superintendent Byron Mauzy. Marin County owes a great deal of gratitude for the tireless efforts of Byron Mauzy over the years. Time and time again he extended himself on behalf of so many people and for so many causes.

I regret that I am not able to join Byron and his many friends and supporters at the Embassy Suites in San Rafael as we gather to celebrate his 48 years of service in public instruction, but I extend my hearty congratulations and best wishes to Byron and his wife, Win, for continued success now, and in the years to come.

ADDRESSING THE TRANSFER OF
CUSTODY ISSUE

HON. FORTNEY PETE STARK

OF CALIFORNIA

IN THE HOUSE OF REPRESENTATIVES

Monday, January 9, 1995

Mr. STARK. Mr. Speaker, Today I am joined by Congresswoman CONSTANCE MORELLA, Congressmen ROBERT MATSUI and WILLIAM COYNE in introducing legislation that ensures that parents of emotionally disturbed and physically disabled children are not required to transfer custody of their children for the sole purpose of obtaining public services.

At this moment, in many States, parents are confronted with a Hobson's choice of either surrendering their children into the custody of the State in order to receive necessary residential services, or retaining custody and, therefore, denying their children the services they need.

These are not parents who have abused, neglected, or abandoned their children in any way, Mr. Speaker. They are simply parents who cannot afford to pay the full cost of the out-of-home treatment their child requires and have as a result, have sought the help of the State.

There are many reasons why these parents are currently required to give up custody of their children, but key among them is the simple fact that—because our country has no system designed specifically for these children—parents are forced to rely on agencies that were not designed with their needs or situations in mind. Because many of these agencies were designed to serve children being placed because of abuse or neglect, their custody transfer requirements are not appropriate to families with children who have serious emotional or physical disabilities. Also key among the reasons, Mr. Speaker, is simple misunderstanding of the requirements of current Federal law.

We believe that parents of these children should be able to keep custody of their children, continue their involvement in decision-making on their behalf, and work cooperatively with State authorities to secure needed services.

The bill we are introducing today is designed to address—to the extent possible under Federal law—the multiple causes of the practice of requiring parents to relinquish custody of their children. These include: misinterpretation or misapplication of title IV-E requirements; the application of custody transfer