further exacerbated the crisis. Western journalists provided reports of the seriousness of the situation in Ukraine, and the few non-Soviet visitors who were permitted to visit Ukraine confirmed the seriousness of this tragedy.

Demographers who have carefully studied this era have concluded that seven to ten million people died as a consequence of this government-induced famine and the terror and repression carried out against peasants in Ukraine. When Members of Congress wrote to the Soviet government at that time, the Soviet Foreign Minister responded by calling reports of the famine 'lies circulated by counterrevolutionary organizations abroad.''

Mr. Speaker, it is most appropriate that we commemorate—in sorrow and in regret—this tragic episode in the history of Ukraine. It is important that in remembering this period, we commit ourselves to take action to prevent similar atrocities in the future in Ukraine or in any other nation.

This is also an occasion, Mr. Speaker, for us to rejoice that the people of Ukraine are now in the position to determine their own destiny. As a free and independent nation, the fate of the people of Ukraine now lies in their own hands. It is important for the people of Ukraine to know that we in the United States welcome their independence and that we are committed to their success as they seek to move toward a free and open and democratic society and toward a prosperous and free market economy.

Mr. Speaker, I join in marking this tragic era in the history of Ukraine, and I extend my best wishes to the people of Ukraine as they work to assure that such a catastrophe never befalls their country.

LIHEAP PROGRAM

SPEECH OF

HON. LUCILLE ROYBAL-ALLARD

OF CALIFORNIA

IN THE HOUSE OF REPRESENTATIVES

Thursday, October 8, 1998

Ms. ROYBAL-ALLARD. Mr. Speaker, I am outraged that the Labor, Health and Human Services Appropriations bill has eliminated all funding for LIHEAP, the Low Income Home Energy Assistance Program.

This critical program provides energy assistance to over 170,000 households in my home state of California and over 4 million needy families nationwide. Many of these families have young children and over half include elderly or handicapped persons.

By eliminating LIHEAP, Congress is causing unnecessary suffering and forcing poor families to choose between heating their homes and buying food for their children. When winter temperatures fall below zero, children can freeze to death.

When heat waves soar above 90 degrees, the elderly and handicapped are at high risk of heat stroke and other grave health complications. The heat wave in Texas this past summer killed over 100 people, many of whom were elderly. Clearly, air conditioning is a life and death matter.

This vital program can be fully funded for the modest sum of 1.1 billion dollars. It is unconscionable that we would even consider eliminating this inexpensive and compassionate program.

I urge my colleagues to restore full funding for the LIHEAP program in the omnibus appropriations bill.

MANAGED CARE MANAGES NOT TO CARE ABOUT MEDICAL PRIVACY

HON. EDWARD J. MARKEY

OF MASSACHUSETTS

IN THE HOUSE OF REPRESENTATIVES

Tuesday, October 13, 1998

Mr. MARKEY. Mr. Speaker, on September 27, The Washington Post chronicled a shocking violation of patient privacy and the aggressive tactics of Pharmacy Benefits Managers. This article shines a light on efforts by PBMs, often owned by drug manufacturers to accumulate extremely sensitive and private medical data on individuals which they claim is being used to manage their health plans more economically. The article describes the experience of a woman whose prescription purchases were tracked by a pharmacy benefits manager, which in turn, used the information to inform her doctor that she would be enrolled in a ''depression program'', to monitor her prescriptions for anti-depression medication and to target her for ''educational'' material on depression. Even more alarming is that her employer had free access to all this sensitive information.

As it turns out, this woman was not suffering from any depression-related illness. Her doctor prescribed the medication to help her sleep. She had no idea that by signing up for her managed care plan, she was signing up for an invasion of her privacy. By using her prescription-drug-card, the privacy she had every right to expect between patient, doctor and pharmacist was breached and abused

This story serves to underscore my concern that laws protecting the privacy of personal information are woefully inadequate. In this electronic age, we must strengthen our privacy rights in proportion to the supersonic speed at which privacy can now be stripped from unsuspecting patients. I urge my colleagues to reflect on this situation and to work to address it in the next Congress.

[From the Washington Post, Sept. 27, 1998]

PLANS' ACCESS TO PHARMACY DATA RAISES PRIVACY ISSUE—BENEFIT FIRMS DELVE INTO PATIENT RECORDS

By Robert O'Harrow Jr.

Joan Kelly knew she would save money at her pharmacy when she used her prescription-drug card to buy an antidepressant her doctor prescribed to help her sleep. Instead of paying $17 for a month's supply of trazodone, she paid just $8.

But Kelly didn't know that when she filled her prescription last fall at a drugstore in Austin, Tex., she would also be swept up in a technology-driven revolution to control medical costs, a new kind of managed care that trampled on her notions of privacy.

Sensitive information about her prescription was flashed to PCS Health Systems, a company in Scottsdale, Ariz., that administers her pharmacy benefit on behalf of her health insurance plan. Computers instantly matched her information with other data previously collected about medications she had been taking, and the new data was stored for review by PCS administrators.

A few months later, PCS sent Kelly's doctor a letter. At the request of Kelly's employer, it said, the company had peered into one of its databases of more than 500 million prescriptions, pinpointed her as someone who used antidepressants and enrolled her in a ''depression program.'' Kelly's prescriptions would not be monitored, it said, and the doctor would be notified of any lapses. Kelly also would be sent educational material on depression.

The aim of the company, the letter noted, was to ''optimize pharmaceutical care.''

When Kelly's doctor told her about the letter, Kelly began to fret about being watched. She wondered if her bosses at Motorola Inc., which runs its own health insurance plan, would mistakenly think she was mentally ill.

''I feel it's an invasion of privacy,'' said Kelly, 50, who has worked at Motorola for 20 years as an engineering assistant. ''I feel that if I go looking for a job or a promotion, they'll say, 'She's on antidepressants.'''

A Motorola spokesman said the company chooses not to receive information about specific employee prescriptions, but there are no laws preventing it from doing so. Indeed, there are few federal rules governing the use of personal information by companies such as PCS.

They are called pharmacy benefit managers. Not long ago, such companies primarily determined if individuals' prescriptions were covered by a health plan. Today, they are technology-savvy giants that stand at the heart of a dramatic change in how medicine is being practiced under managed care.

Using powerful computers, these firms have muscled their way into what was once a close and closed relationship between patients and their doctors and pharmacists. They have established electronic links to just about every pharmacy in the United States. And they now gather detailed prescription information on the 150 million Americans who use prescription cards. PCS, which administers the benefit of 56 million people, adds about 35 prescriptions a second to a storehouse of 1.5 billion records.

PCS and other benefit managers said prescription cards should be considered an unprecedented opportunity to improve medical care and save health plans money.

Working on behalf of health plans, the benefit managers said, they use the data to pinpoint dangerous overlaps in medications that shouldn't be taken together, or to suggest generic drugs that might be just as effective at a fraction of the cost. They also reach out directly to patients and advise them on when and how to take their medication, a practice they say saves money by improving individuals' health. Industry officials estimate that their companies have saved health plans billions of dollars in recent years.

''They're the patient's caretaker,'' said Delbert Konnor, president of the Pharmaceutical Care Management Association, an industry group that represents some of the nation's largest benefit managers. ''They're monitoring the physician. They're monitoring the patient. They're also monitoring the costs.

''The whole health care industry is in a state of strategic flux,'' Konnor added. ''It's the information that really is the valuable portion of what's going on.''

But a growing number of patients, doctors and pharmacists complain that they never gave explicit approval for personal information to be collected and analyzed. Some doctors contend that the benefit managers have overstepped their roles as administrators, and they worry that new programs touted as improving care mask efforts to market drugs.

Critics say the top three benefit managers sometimes highlight medications made by their parent companies—drug manufacturers

Eli Lilly and Co., which owns PCS; SmithKline Beecham, which owns Diversified Pharmaceutical Services; and Merck & Co., which owns Merck-Medco Managed Care. At the same time, drug companies often pay for benefit managers to send in-house specialists to visit doctors in attempts to modify patient care—sometimes without asking patients' permission.

''Right now people live with this myth that the doctor-patient confidentiality is sacrosanct. We know that's not true,'' said Janlori Goldman, director of the Health Privacy Project at Georgetown University.

''Once they file a claim, once they fill a prescription, the personal, sensitive information they shared with their doctor is fair game,'' she said. ''The information about them essentially becomes a commodity.''

Some specialists fear that patients anxious about giving up their privacy may ultimately lose trust in the medical profession.

''There's a fundamental realignment of the players here,'' said Daniel Wikler, a professor of medical ethics at the University of Wisconsin. ''The question is: Who is the patient supposed to look to?''

Regulators in Nevada, Ohio and elsewhere have begun examining possible violations of state confidentiality laws or regulations protecting medical records. Legislators in Virginia, New York and elsewhere also have begun considering laws that would give their states more control over pharmacy benefit managers.

''By what authority do these companies believe they have a right to collect this information?'' asked Charles Young, executive director of the Massachusetts Board of Registration in Pharmacy. ''And once they get it, how are they using it? Is it in the best interest of the patients? Or is it in the best interest of the company?''

Pharmacy benefit managers have been in business for more than two decades. They began playing a more central and controversial role in health care just a few years ago.

That's when drug manufacturers and pharmacy chains—including CVS, Rite Aid and others—began spending billions of dollars to acquire such companies as part of the race to capture a larger share of the fast-growing market for prescription drugs.

Improvements in computer technology also made it vastly easier to gather, store and track information about patients. This technology has become widespread in recent years, in part because of the plummeting cost of data storage and steady increases in computer processing speeds.

New benefit management companies popped up everywhere. Now more than 150 pharmacy benefit managers manage 1.8 billion prescriptions every year, and the number of people who use prescription cards has more than doubled since 1990 to more than 150 million, according to the industry association. At the same time, the proportion of prescriptions covered at least in part by managed care has soared from about one in four to almost two of every three, according to IMS Health Inc., a health care information company.

The market for prescription drugs is worth more than $81 billion annually, more than twice the amount at the beginning of the decade. Officials at the benefit management companies say that figure would be significantly higher without them. Studies by the General Accounting Office, the Congressional Budget Office and other researchers tend to support that contention.

A GAO report said that three plans in the Federal Employees Health Benefits Program estimated benefit managers saved up to $600 million in overall spending in 1995 ''by obtaining manufacturer and pharmacy discounts and managing drug utilization.'' The report also found a ''high degree of satisfaction'' among Federal employees with pharmacy benefit management services.

A more recent analysis by the Congressional Budget Office concluded that pharmacy benefit managers have helped to slow the rising cost of prescription drugs. The authors suggested in July that the benefit managers accomplished this by directing doctors and pharmacists to use certain lower-cost drugs.

''We're achieving the dual objective of ensuring appropriate care for patients, while at the same time reducing pharmaceutical costs for health plans,'' said Blair Jackson, spokesman for PCS Health Systems.

To assess the impact of the benefit management revolution on personal privacy, it is necessary to understand how the system works. But that's not easy. Even many regulators and doctors have only recently begun to sort out how these companies gather, use and resell patient information.

To many consumers, the process is almost invisible, even though in most cases they have given their consent by signing up for a health plan, industry officials say.

It starts when someone uses a prescription card to get medication. Their information is electronically messaged to their health plan's benefit manager, a transaction that in most instances takes seconds. A computer checks to see if the medication is covered and whether the drug is safe for a particular patient, in many cases as the patient waits for the prescription to be filled.

The computers also match the prescription against a formulary, a list of medications the benefit managers have arranged for health plans to buy at a lower cost or that have been determined to be more effective. Health plans often get the discounts by pledging to use certain drugs exclusively. Sometimes the pharmaceutical companies give rebates as their drugs are dispensed, industry officials said.

These formularies are the cornerstone of efforts to control drug costs. They also are a contentious issue. Critics, including some federal and state regulators, contend that benefit managers appear to have shown a bias toward the products of their parent companies.

A study two years ago by the office of the public advocate for the city of New York, for example, found that benefit managers steered doctors and patients toward their parent companies' drugs, an allegation that the benefit managers deny. Public Advocate Mark Green said the companies should not have such sweeping access to patient records.

They ''are using medical histories of millions of unsuspecting patients. This is as little known as it is wrong,'' Green said. ''It would be hopelessly naive to trust the voluntary virtue of these PBMs.''

If the benefit manager's computer approves a transaction, an affirmative message is sent back to the pharmacist. But if it determines that a less expensive drug can be safely switched, that suggestion is sometimes flashed back. PCS offers pharmacists up to $12 to secure approval from a patient and the patient's doctor for a ''therapeutic interchange'' of certain drugs. A change can't be made without such approval, PCS officials said.

Meanwhile, a patient's information is stored in various computers, including data warehouses operated by the benefit managers. The technology allows the benefit managers to keep close track of individuals. In some cases, they remind patients to refill prescriptions and take their medicine at appropriate intervals, Medical officials say that up to half of all patients with some conditions—such as hypertension or high cholesterol—fail to take their medicine as prescribed.

The benefit managers also can track people with chronic illnesses and offer suggestions about their care. These increasingly common efforts are known as ''disease management'' programs. One of the problems with these programs is the risk of misidentifying a person's ailment. Medical specialists say that's because certain drugs can be used to treat different problems.

Kelly, the Texas woman, said she was mistakenly enrolled in a program called ''Journeys: Paths Through Depression.'' She took antidepressant medicine because she was having trouble sleeping because of menopause, she said, not because she was mentally ill. Karen Hill, the physician who was treating Kelly at the time, confirmed Kelly's account.

In the letter, the company acknowledged the possibility of making an incorrect assumption about a patient's ailment and said those who have questions should consult their doctor.

Kelly said she had no idea when she enrolled in her health plan that it would open the way to close scrutiny of her prescriptions.

''Mainly, what you're looking at is what you get and what you pay. I wasn't even thinking about personal information going out,'' Kelly said. ''With managed care, I know it's getting more convoluted. But this never occurred to me.''

Motorola officials said there was no reason for such anxiety. They described the PCS effort as a ''stigma-free mental health'' program that provides employees with help and educational material about depression. So far, 167 of the 5,721 employees enrolled in the program have opted out.Connie Giere, a benefit official at Motorola, said information about patients is protected. ''Obviously, we own that data,'' she said. ''But we have chosen not to receive that data because it's counter to our philosophy of confidentiality.'' Motorola officials said the company chooses only to receive general reports about trends, not the names of employees or other personal information.

Pharmacy benefit managers also routinely urge doctors to change a patient's medicine to a brand or generic drug that the companies believe is less expensive or more effective. The benefit managers contact patients and doctors through letters, telephone calls and faxes. Some benefit managers also send messages to pharmacists as patients wait for their prescription.

Bernard Steverding of Fairfax County received a letter several months ago that said the prescription he was taking to lower his cholesterol had been changed by a pharmacy benefit manager to another drug. The letter he received was typical, but it made him furious.

The letter, from a company now called Express Scripts/ValueRx, said: ''When we find a medicine that we believe to be better for a particular patient, we review the patient's medication profile and then confirm with the prescribing physician that a change of medication is appropriate. We know that the only way to help control prescription drug costs is in partnership with you and your doctor.''

Steverding and his wife said the letter arrived after the new prescription was filled and the change was made without his consent. Souzana Steverding said her husband wasn't sure if he should take the new drug concurrently with the remaining pills he had under the old prescription. ''We got this new prescription and didn't even know what it was for,'' she said. ''Nobody told us you can't take these two together.''

Dan Cordes, a vice president at Express Scripts/ValueRx, said Steverding had given

his consent to the program by signing up with his health insurance plan, which authorized the collection of his prescription information. Cordes said Steverding's doctor approved the switch. ''It's a totally voluntary program,'' Cordes said.

Officials at benefit managers say they take great care with the information they collect and understand its sensitivity. At PCS, for example, employees must sign a pledge that they will respect the confidentiality of personal records. Patient information also is encrypted or depersonalized whenever PCS transmits it.

''We clearly recognize that by being a part of the health care system we have to abide by this type of ethics,'' said Nick Schulze-Solce, a vice president for health management services at PCS.

But given the limited oversight by state and federal authorities, there's no way to guarantee information will be used appropriately. In Las Vegas last year, patients who shopped at three independent drug stores later received $5 coupons and promotional fliers in the mail from a pharmacy chain, American Drug Stores. Among them was Mary Grear, a pharmacist and owner of the independent stores.

Grear wondered why she and so many of her customers received the same flier. By looking in her own computers, she discovered they all had the same pharmacy benefit manager, a company owned by American Drug Stores. She complained to state authorities, who confirmed this spring that a pharmacy benefit manager owned by American Drug Stores had passed along the names and other information from confidential prescription records.

Grear said she was outraged, both as a patient and a pharmacist.

''I mean, it's medical information. That's how it should be used. It isn't for marketing,'' Grear said. ''I believe it's between me and my health professional.''

State authorities also were unsettled.

''Something like this has never happened before,'' said Larry L. Pinson, president of the Nevada State Board of Pharmacy, who described the prescription records involved as ''very, very private medical histories.''

In response, regulatory officials in Nevada recently sent out a stern letter to 275 pharmacy benefit managers and other administrators, warning that many of the companies' activities may be illegal. ''You are now on notice,'' the letter said, ''and the board hopes that these illegal practices will now stop.''

Dan Zvonek, a spokesman for American Drug Stores, said the sharing of patient records by the companies was a mistake that would not happen again.

He acknowledged that pharmacy benefit companies are struggling with privacy issues, trying to determine what's appropriate as financial matters take an ever larger role in decision making.

''You run this risk of stepping over those boundaries of confidentiality. But no one knows where those boundaries are,'' Zvonek said. ''You running a risk of ignoring the health care aspect and focusing on profit.''

One source of profit for the benefit managers is the resale of aggregations of patient data. Although benefit managers remove patient names and other personally identifying information from the records, such data has become increasingly valuable for drug companies and health researchers.

During companies mine the data, for example, to track how much a health plan spends on each specific drug and to try to document whether treatment resulted in the desired outcome. They also use the information to measure the success of direct marketing campaigns and to focus sales forces on doctors who prescribe certain medicines.

Raymond Gilmartin, chief executive of Merck & Co., the giant pharmaceutical company that owns Merck-Medco, said that by monitoring how diabetics take their medication, the firm can save health plans $260 a year per diabetic by keeping them well—and out of the hospital.

''This is exiting stuff,'' Gilmartin said. ''This is the information everyone is looking for and that everyone wants.''

Among the many unresolved questions posed by benefit mangers is who has the final say on how personal date is used and maintained. In most cases, according to Schulze-Solce, the health plan that has contracted with a benefit manager to gather the information owns the information.

In many cases that owner is an employer that provides it own health insurance.

''That of course is something that needs to be recognized,'' said Schulze-Solce. ''For society, it is important to get their arms around that because that is a potential source of leak. . . . In theory, [privacy] is depending on the self-discipline of those companies.''

In any case, officials at pharmacy benefit managers said patients, doctors and the rest of the medical community might as well get used to them. Not only are they increasingly important to the health care system, but they're not going away anytime soon.

As medical professionals come to rely on a person's genetic history to recommend treatments, even more detailed data will be needed to provide proper care. Schulze-Solce said pharmacy benefit managers will be expected to help fill that need.

He likened the development of pharmacy benefit managers to the evolution of nuclear bombs: ''In the case of nuclear weapons, you try to contain the risk,'' he said. ''Trying to go back is moot.''

MULTIPLE CHEMICAL SENSITIVITY

HON. BERNARD SANDERS

OF VERMONT

IN THE HOUSE OF REPRESENTATIVES

Tuesday, October 13, 1998

Mr. SANDERS. Mr. Speaker, I rise today to discuss the issue of Multiple Chemical Sensitivity as it relates to both our civilian population and our Gulf War veterans. I continue the submission for the RECORD the latest ''Recognition of Multiple Chemical Sensitivity'' newsletter which lists the U.S. federal, state and local government authorities, U.S. federal and state courts, U.S. workers' compensation boards, and independent organizations that have adopted policies, made statements, and/or published documents recognizing Multiple Chemical Sensitivity disorders for the benefit of my colleagues.

U.S. DEPARTMENT OF HOUSING AND URBAN DEVELOPMENT

In a letter from HUD Assistant Secretary Timothy Coyle to Senator Frank Lautenberg, confirming HUD recognition of ''MCS as a disability entitling those with chemical sensitivities to reasonable accommodation under Section 504 of the Rehabilitation Act of 1973'' and also ''under Title VIII of the Fair Housing Amendments Act of 1988'' [26 October 1990, 2 pages, R–13]. This was followed by a formal guidance memorandum from HUD Deputy General Counsel G.L. Weidenfeller to all regional counsel, detailing HUD's position that MCS and environmental illness ''can be handicaps'' within the meaning of section 802(h) of the Fair Housing Act and its implementing regulations [1992, 20 pages, R–14]. Also recognized in a HUD Section 811 grant of $837,000 to develop an EI/MCS-accessible housing complex known as ''Ecology House'' in San Rafael, CA, consisting of eleven one-bedroom apartments in a two-story complex. This grant was pledged in 1991 and paid in 1993. [2 pages, R–15] (See also Recognition of MCS by Federal Courts, Fair Housing Act, below.)

U.S. DEPARTMENT OF THE INTERIOR, NATIONAL PARK SERVICE

In response to a disability rights complaint filed against the Baltimore County Parks and Recreation Department (BCPRD) by Marian Arminger on behalf of her three children, which the National Park Service (NPS) accepted for review pursuant to both Section 504 of the Rehabilitation Act and Title II of the Americans with Disabilities Act. The Acting Equal Opportunity Program Manager of the NPS ruled that ''the BCPRD must accept the determination of disability by the Baltimore County Public Schools [BCPS, see US Department of Education, above] regarding the children and their disability of MCSS [MCS Syndrome]. This will eliminate possible retaliation with a different conclusion by the same public entity.'' [Case #P4217(2652), 1996, 4 pages, R–102]. The NPS further ruled that ''With the determination that these children are individuals with a disability (MCSS), it is necessary to make reasonable modifications to program facilities. It appears that discontinuing, temporarily or permanently, the use of outside or inside pesticide application and toxic cleaning chemicals is the basic reasonable modification necessary in this case. . . . Therefore we believe that steps should be taken by the BCPRD to provide the necessary communication with other affected agencies such as the BCPS and develop, in consultation with the parents and others deemed appropriate, a plan for the reasonable modification of the program environment for these children.''

U.S. DEPARTMENT OF JUSTICE

In its enforcement of the Americans with Disabilities Act of 1990, under the terms of which MCS may be considered as a disability on a case-by-case basis, depending—as with most other medical conditions—on whether the impairment substantially limits one or more major life activities. The Office of the Attorney General specifically cites ''environmental illness (also known as multiple chemical sensitivity)'' in its Final Rules on ''Non-Discrimination on the Basis of Disability in State and Local Government Services'' (28CFR35) and ''Non-Discrimination on the Basis of Disability by Public Accommodations and in Commercial Facilities'' (28CFR36), as published in the *Federal Register*, Vol. 56, No. 144, pages 35699 and 35549 respectively [26 July 1991, 2 pages, R–16]. ''Environmental illness,'' also is discussed in the *ADA Handbook*, EEOC–BK–19, 1991, p. III–21 [14 page excerpt, R–17], jointly published by the Department and the U.S. Equal Employment Opportunity Commission. The *ADA Handbook* describes environmental illness as ''sensitivity to environmental elements'' and, although it ''declines to state categorically that these types of allergies or sensitivities are disabilities,'' it specifically asserts that they may be: ''Sometimes respiratory or neurological functioning is so severely affected that an individual will satisfy the requirements to be disabled under the regulations. Such an individual would be entitled to all the protections afforded by the Act.''

U.S. DEPARTMENT OF VETERANS AFFAIRS

In recognizing MCS as a medical diagnosis (although not as a ''disability'') in the case of at least one Persian Gulf War veteran [Gary Zuspann, October 1992, 3 pages, R–18].