Many people have or are at risk of osteoporosis. Older white women are most likely to have osteoporosis, but younger women, men, and ethnic minority persons are also at risk. Although public awareness of osteoporosis has grown in recent years, most people are not knowledgeable about the disease.

Knowledge about osteoporosis is important because some proposed methods of prevention and treatment involve lifestyle behaviors, such as calcium intake and exercise, that require awareness and understanding for compliance. Other proposed methods of prevention and treatment involve the use of medications that may be recommended by a physician or other health care professional, but individuals must decide initially whether to contact a health care professional about osteoporosis and then whether to comply with the recommendations they receive. Public information is needed to help people make informed decisions about alternate methods of prevention and treatment.

This background paper describes the existing public information about osteoporosis and discusses problems that limit its usefulness, including problems in the dissemination and targeting of information to different types of people who have or are at risk of the disease. It also discusses problems that arise because of the way research findings are presented in the mass media and the widespread dissemination of information about medications that are available on the market but have not been approved by the FDA for osteoporosis. In 1993, Congress mandated the establishment of a national resource center on osteoporosis and related bone diseases. The analysis of problems with existing public information in this document suggests ways in which the new resource center and other organizations interested in the prevention and treatment of osteoporosis can increase public knowledge about the disease.

This background paper is one of four documents resulting from OTA’s study of policy issues in the prevention and treatment of osteoporosis. Another background paper, *Hip Fracture Outcomes in People Age 50 and Over*, is also being issued in July 1994. Two other documents, one on the costs and effectiveness of screening for osteoporosis and the other on research and training issues in osteoporosis, will be issued later this year.

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Public Information About Osteoporosis: What's Available, What's Needed?

INTRODUCTION AND OVERVIEW

Osteoporosis is a disease characterized by a decreased amount of bone and increased fragility of the remaining bone. Figure 1 illustrates the harmful effects of osteoporosis on bone. Because of their decreased amount of bone—usually referred to as low bone mass or low bone density—and increased bone fragility, people who have osteoporosis are more likely than other people to experience fractures. The fractures most often attributed to osteoporosis are fractures of the wrist, spinal vertebrae, and hip, but other fractures may also be attributable to osteoporosis.²

Many people have or are at risk of osteoporosis. Estimates of the number of people affected vary, depending on several factors, including the level of bone density defined as osteoporosis. In 1993, two international panels of osteoporosis experts defined osteoporosis as bone density more than 2.5 standard deviations below average bone density in healthy young adults. Data collected between 1988 and 1991 as part of the third National Health and Nutrition Examination Survey (NHANES III), a large-scale survey of a nationally representative sample of noninstitutionalized people of all ages, indicate that 17 to 20 percent of American

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1 The term **bone mass** means the amount of bone mineral (primarily calcium) in a particular bone. The term **bone density** means the amount of bone mineral in a unit of bone defined in terms of either area or volume.

2 The Study of Osteoporotic Fractures, a multicenter study involving more than 9,000 white women age 65 and over, found that fractures of the upper arm, collarbone, hand, rib, pelvis, leg, foot, and toe were statistically more likely to occur in women with low bone density than other women and therefore are attributable, at least in part, to osteoporosis (104).
FIGURE 1: Normal Bone and Osteoporotic Bone
women age 50 and over—approximately six to seven million women—have osteoporosis, as defined by the expert panels (55). Another 12 to 17 million women age 50 and over have low bone density, defined by the expert panels as bone density between 1 and 2.5 standard deviations below average bone density in healthy young adults (55). The comparable figures for men of all ages and women under age 50 are not yet available.

As interest and concern about osteoporosis have increased in recent years, educational materials and programs have been developed to inform the public about who is at risk of the disease and what can be done to prevent and treat it. Despite these efforts, most people are not knowledgeable about osteoporosis. Some people are simply not aware of the disease. Others are aware but not well-informed about it. Some people who are aware of osteoporosis are not worried about it. Others, who are worried about osteoporosis, are frustrated by what they perceive as a lack of information about the disease.

Each week and especially following any media report about osteoporosis, the National Osteoporosis Foundation, a private, voluntary organization, receives hundreds and sometimes thousands of calls and letters from people seeking information about the disease (95). Box 1 presents excerpts from letters that illustrate some typical questions and concerns of people who contact the National Osteoporosis Foundation for information.

In 1989, several congressional committees and individual senators and representatives requested that the Office of Technology Assessment (OTA) conduct a study of policy issues in the prevention and treatment of osteoporosis. The request letters asked about the appropriate role of public information in the prevention and treatment of osteoporosis, to whom the information should be targeted, and what the message should be. To address these questions, OTA identified and analyzed the available public information about osteoporosis. OTA also contracted for a survey of consumer magazines to learn what is being said about osteoporosis in these magazines and to whom the information is targeted (15).

OTA discovered a large quantity of public information about osteoporosis. As attention to women’s health issues has grown in the past few years, the amount of public information about osteoporosis has also grown.

The existing print information about osteoporosis consists primarily of newspaper and magazine articles and 2- to 8-page handouts, such as fact sheets, brochures, and booklets. Broadcast information consists of news reports, public service announcements, and health information features on radio and television. The bulk of this public information is produced by the following sources:

- the mass media (i.e., television, radio, newspapers, and magazines) and commercial publishers;
- private organizations (i.e., the National Osteoporosis Foundation, other voluntary associations, health care organizations, dairy industry organizations, and pharmaceutical companies); and
- federal and state government agencies.

This OTA background paper describes the public information about osteoporosis that is available from these sources. Clearly, there is a discrepancy between the large quantity of public information about osteoporosis, on the one hand, and the perceived lack of information and most people’s lack of knowledge about osteoporosis, on the other hand. OTA believes that several interrelated problems account for this discrepancy. First, the existing public information about osteoporosis is not sufficiently disseminated. As a result, the informa-

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3 OTA’s study of policy issues in the prevention and treatment of osteoporosis was requested by the Senate Special Committee on Aging, Senator Charles E. Grassley, Senator John Glenn, the former House Select Committee on Aging, Representative Olympia J. Snowe, Representative Benjamin A. Gilman, and former Representatives Brian J. Donnelly, Thomas J. Downey, and Patricia F. Saiki.
BOX 1: Excerpts from Letters to the National Osteoporosis Foundation

From Iowa

“I would like to have the latest literature you have on osteoporosis—what you can do, take, and eat that will help it from doing any more damage than it’s done already for me.”

From Nevada

“My wife’s illness has been diagnosed as osteoporosis and chronic pain. She has suffered several compression fractures in her spine. The medical center said her bones are paper-thin, and nothing could be done about her condition. If you have any information or suggestions about treatment for osteoporosis that could possibly in any way be of help to my wife or of doctors that really are the best and specialize in this area, I would truly appreciate the information.”

From Missouri

“Your address was given over TV, “Good Morning America,” to write to for information on osteoporosis. My bone scan shows osseous atrophy and fx deformations of T8 and T9. Severe pain started about Jan. 29th. Diagnosis—osteoporosis. I am under doctor’s care, I thought if you had any information that I might read to help or learn more about osteoporosis I would appreciate this material. I am 77 years old.”

From Florida

“So much is written in your bulletin about prevention and almost nothing about what the patient can do herself after she gets it. I have had, for example, 4 compression fractures. Some articles about helpful exercises, activity, as well as recommended calcium and estrogen (how much) would be appreciated. We need help too.”

From North Dakota

“Please tell me about osteoporosis prevention. What do you think of boron? Have you heard of Ethical Nutrient Bone Builder? What do you think?”

From New York

Please send information for my husband who is suffering from bone deterioration. His mother has severe arthritis and osteoporosis and is now confined to a wheelchair due to her condition. My husband (55) refuses to take calcium since his dentist claims that it can cause kidney stones. Please send research substantiating the need for 1500 mg. calcium (daily) if you think it might prevent further deterioration. Could you recommend an excellent doctor in New York City who could help him?”

SOURCE Letters provided to the Office of Technology Assessment by the National Osteoporosis Foundation, Washington, DC

Ion may not be available when people need it, and they are unlikely to know where to find it.

Second, much of the existing public information about osteoporosis is not tailored to the different needs of particular population groups. Although there are exceptions, most of the existing public information about osteoporosis focuses on prevention of bone loss and targets middle-aged and older white women. The focus on prevention of bone loss is appropriate for some people, but it does not meet the needs of other people who already have osteoporosis and need to know not only how to avoid further bone loss but also how to prevent falls and fractures and how to cope with the disability and pain that often accompany the disease.

Targeting public information about osteoporosis to middle-aged and older white women is appropriate in a sense since these women are most at risk of osteoporosis. Data from NHANES III show that in each age group, women generally have lower bone density than men, and whites
generally have lower bone density than African Americans and Mexican Americans (54). The interrelationships of age, gender, race, and ethnicity are complex, however, and bone density varies greatly among individuals of the same age, gender, race, and ethnic group. Thus, some young people have very low bone density; some men have lower bone density than some women; and some African Americans and Mexican Americans have lower bone density than some whites. Targeting public information about osteoporosis to middle-aged and older white women does not meet the needs of young people, men, and ethnic minority persons who are also at risk. In fact, this targeting probably fosters the widespread misconception that osteoporosis is a disease of middle-aged and older white women that need not concern these other groups.

Third, and most important, much of the existing public information about osteoporosis is confusing, contradictory, and incomplete. To some degree, this problem is inevitable, given the frequent publication of new research findings and the lack of definitive evidence for the efficacy of some proposed methods of prevention and treatment. As is true in many fields of medical research, new findings about osteoporosis raise questions about previously held ideas and make it difficult to determine exactly what constitutes accurate information about the disease at any given time.

The way the mass media present information about osteoporosis adds to the confusion and contradictions that are inevitable in a changing medical field. Research advances in osteoporosis prevention and treatment are frequently presented in brief news reports that do not place the findings in the context of other methods of prevention and treatment or make clear which individuals are most likely to benefit. The contraindications and side effects of new methods of prevention or treatment often are not reported. People who hear these news reports may, in fact, have the latest information but still not know whether the information applies to them or how it fits with other information they may have about the disease.

Americans are increasingly urged to become informed about and take responsibility for their own health. Reports in the mass media are one way many people obtain health information. Some, and perhaps many, people use media reports as a basis for decisions about their own health care and health-related behavior. A 1990 article in Ladies Home Journal describes the new "Take-Charge Patient" who "does not simply follow doctors' orders" but instead wants to know everything she can about her health. Understand the various options for prevention and treatment, and participate fully in decisions about her care (4). Such individuals—women and men—may go to their physician with information they have obtained from media reports and ask for particular medications or other treatments. It has been estimated that one-third of prescriptions for new medications are now written at the request of the patient (16).

The combination of these three factors-1) a changing medical field, 2) brief media reports on new research findings that may not place the findings in context or make clear which individuals are most likely to benefit from particular methods of prevention or treatment, and 3) people who depend on media reports as a primary source of health information—creates public information problems. The problems are not unique to osteoporosis, but they must be addressed by anyone who is interested in increasing public knowledge about the disease.

The growing use of the mass media to promote prescription medications adds to these public information problems. Traditionally, pharmaceutical companies have promoted prescription medications to physicians through direct mailings, personal visits by sales representatives, and advertising in medical journals. In the past decade...
ade, the companies have begun promoting various kinds of prescription medications directly to consumers, usually through the mass media (16,45). Sometimes, the companies use print or broadcast advertisements, which have been allowed by the Food and Drug Administration (FDA) since 1985. Often, however, the companies arrange and pay for press conferences or other media events at which research findings or testimonials favorable to their products (or unfavorable to competing products) are presented.

Concerns have been expressed about the latter uses of the mass media to promote prescription medications because the sponsorship of the information often is not clear, and consumers are unlikely to realize that what they see, hear, or read based on these media events is at least in part an advertisement (16,45). In the case of osteoporosis, these concerns apply equally to the use of the mass media to promote nonprescription medications—e.g., calcium supplements—and dairy calcium. For these products, as well as prescription medications, the information may be either true or false, but its sponsorship often is not clear, and consumers may not realize that the information comes from an organization whose ultimate objective is to sell a product.

Box 2 describes some of the important research findings that emerged between 1990 and 1993 about etidronate, a medication proposed for the prevention and treatment of osteoporosis. The purpose of the box is not to evaluate the efficacy of etidronate. Rather its purposes are to illustrate the important role of the media in informing the public about medications proposed for osteoporosis and to point out the kinds of problems that may arise because of the way research findings are presented, variation in media coverage of different findings, and widespread dissemination of information about medications that are available on the market but not approved by the FDA for osteoporosis.

Sodium fluoride is another medication for which similar problems have arisen. Sodium fluoride is known to increase bone density and has been prescribed by some physicians for many years for their patients with osteoporosis. Like etidronate, it is available on the market but is not approved by the FDA for the prevention or treatment of osteoporosis. In 1990, the findings of a widely publicized study showed a significant increase in bone density but no reduction in the rate of new spinal fractures and an increase in nonspinal fractures in women who took sodium fluoride compared with women who did not (100). These findings led some osteoporosis experts to conclude that sodium fluoride should not be used for osteoporosis except for research purposes (48,53).

During a 1990 osteoporosis conference at which these negative research findings were discussed, one physician asked the speaker what he should say now to the patients for whom he had been prescribing sodium fluoride. The speaker responded that the physician should not have been prescribing an unapproved medication.

In 1994, interim findings were published from a study that is using a lower dose and different form of sodium fluoride. The interim findings show a lower rate of new spinal fractures in 48 women who are receiving sodium fluoride, compared with 51 women who are not (92). These findings were widely covered by the mass media, leading some osteoporosis experts to worry that there will be a surge in the use of sodium fluoride before the interim findings are confirmed in the remaining years of the study or validated by other researchers.

Calcium is a third substance for which public information problems have arisen. Dietary calcium and calcium supplements are widely recommended for the prevention and treatment of osteoporosis, but recently published studies have had contradictory findings about the relationship

\[\text{See, for example, Leary, New York Times, Apr 15, 1994 (51) and Wall Street Journal, Apr 15, 1994 (52).}\]
Etidronate is a medication that has been considered for the prevention and treatment of osteoporosis for many years. It is known to reduce bone loss and was approved by the Food and Drug Administration (FDA) for treatment of Paget's disease in 1977 and for two other conditions in 1979 and 1987. Etidronate has not been approved by the FDA for the prevention or treatment of osteoporosis.

On May 3, 1990, the New England Journal of Medicine published the results of a three-year, randomized, double-blind, placebo-controlled study conducted in Denmark which found that spinal bone density was significantly increased in 20 postmenopausal women who took etidronate compared with 20 postmenopausal women who did not take etidronate (110). In the last two years of the study, the rate of new spinal fractures was significantly lower for the women who took etidronate, but there was no significant difference in the rate of new spinal fractures in the two groups over the full three-year period of the study. The average age of the women in the study was 68. All the women had low bone density and at least one but not more than four spinal fractures at the start of the study.

On July 12, 1990, the New England Journal of Medicine published the results of a second two-year, randomized, double-blind, placebo-controlled study conducted at seven sites in the United States which found that spinal bone density was significantly increased in 195 postmenopausal women who took etidronate compared with 183 postmenopausal women who did not take etidronate (131). In this study, however, the women who took etidronate had half as many new spinal fractures as the women who did not take etidronate (eight versus 17 new spinal fractures in the two groups, respectively). The average age of the women in the study was 65. All the women had low bone density and at least one but not more than four spinal fractures at the start of the study.

On the day the results of the second study were published, at least 400 newspapers nationwide carried stories about the study (25). In the following days and weeks, many magazines, newsletters, and other media carried stories about the efficacy of etidronate in increasing bone density and reducing spinal fractures.

Some women who read or heard these stories went to their doctor, some with a newspaper clipping in hand, to get a prescription for etidronate (62, 90). Since etidronate is approved by the FDA for the treatment of other conditions, it is on the market, and prescriptions can be filled even though it is not approved for osteoporosis.

Etidronate causes impaired bone mineralization when taken in high doses or for prolonged periods (24, 37). The recommended dose of etidronate for the treatment of Paget's disease and the other conditions for which it is approved by the FDA is higher than the dose used to treat osteoporosis in the two studies described above. Thus, some osteoporosis experts were concerned that etidronate would be prescribed in too high a dose and for too long a period and result in impaired bone mineralization and reduced bone strength (7, 90).

On March 8, 1991, in a public meeting of the FDA's Endocrinologic and Metabolic Drugs Advisory Committee, data from the U.S. study were presented, including data which showed that in the third year of the study the women who were taking etidronate had twice as many new spinal fractures as the women who were not taking etidronate (21 versus 10 new spinal fractures in the two groups, respectively) (125). Representatives of the company that produces etidronate and some osteoporosis experts argued that the third-year data should not be regarded as important because the subjects who continued in the third year of the study were self-selected, there were very few fractures overall, and the identification of spinal fractures is problematic. They argued that the increased incidence of fractures in the third year of the study in women who were taking etidronate should be regarded as an instance of spontaneous variation in fracture rates, unrelated to the use of etidronate. Nevertheless, a majority of the advisory committee voted that the data presented to them did not provide substantial evidence for the efficacy of etidronate, and the FDA did not approve the use of etidronate for the prevention or treatment of osteoporosis.
To OTA’S knowledge, information about the greater number of new spinal fractures in the third year of the study in women who were taking etidronate was not made known to the public in any way, although a transcript of the advisory committee meeting is available from the FDA. Public information about osteoporosis continues to describe etidronate as an investigational drug, implying that FDA approval has not yet been but probably will be obtained, and fails to note the FDA’s 1991 decision not to approve it or the reasons for that decision.

OTA does not know how many women are taking etidronate for osteoporosis. Sales of etidronate increased dramatically after July 1990 (1 1), and some osteoporosis experts believe that a very large number of women are taking etidronate (33,94). Some osteoporosis experts have told OTA informally that they are concerned about widespread use of etidronate, particularly for middle-aged women who do not have low bone mass or spinal fractures and are taking the drug for preventive purposes. Osteoporosis experts continue to be concerned about whether women who are taking etidronate are taking an appropriate dose, and some osteoporosis experts report seeing women in their clinical practice who have been taking too high a dose of etidronate for prolonged periods (12, 94). Since etidronate is not approved by the FDA for osteoporosis, the company that produces etidronate is prohibited by FDA regulations from disseminating prescribing information for the medication.

In December 1993, the American Journal of Medicine published the results of four years of the U S study, including the final year when the study was no longer blinded (34). The study data show that the increase in bone density that occurred in the first two years of the study for the women who were taking etidronate was maintained in the third and fourth years. The number of new spinal fractures in the third year of the study is not reported in the journal article but is said by one of the researchers to be 14 new spinal fractures in the women who were taking etidronate and 10 new spinal fractures in the women who were not taking etidronate (130). (OTA does not know why these numbers differ from the numbers presented by the company to the FDA advisory committee in 1991.) The article concludes that there was no significant difference in the rate of new spinal fractures over the three-year blinded portion of the study between the women who took etidronate and the women who did not take etidronate (34). A subgroup of women was identified retrospectively for whom etidronate resulted in a significantly lower rate of new spinal fractures these were women who had bone density below the mean for all the subjects and at least three spinal fractures at the start of the study.

In comparison with the media coverage of the July 1990 report, there was relatively little coverage of the 1993 report. As a result, the public is probably not aware of the important conclusions of the study 1) the lack of a significant difference in the rate of new spinal fractures in the study sample as a whole between the women who took etidronate for three years and the women who did not, and 2) the existence of a subgroup of women for whom etidronate did result in a significantly lower rate of new spinal fractures.  

SOURCE Office of Technology Assessment 1994 from sources cited in the text and listed in the references section.

Between calcium intake and osteoporosis. Mass media reports of these findings have resulted in confusion about the likely effects on bone density of increased calcium intake. Often, the media reports do not distinguish between different amounts of calcium intake or the effects of calcium intake on bone density in people of different ages and gender.

See, for example, Aloua et al., 1994 (3); Dawse m-Hughes et al., 1990 (19); Kanis and Passmore, 1989 (43), and Reid et al., 1993 (98).
In June 1994, the National Institutes of Health sponsored a consensus development conference to develop recommendations on optimal calcium intake for people of different ages and gender. The results of the conference will allow better targeting of public information on this issue. Since scientific research on the relationship between calcium intake and osteoporosis will continue, however, it is likely that public information problems in this area will arise again in the future.

Some of the public information problems that have arisen with respect to these three proposed methods of prevention and treatment—etidronate, sodium fluoride, and calcium—have also arisen for other methods of prevention and treatment, including estrogen and calcitonin, the only two prescription medications that are currently approved by the FDA for osteoporosis. The same kinds of problems can be expected to arise in the future for new methods of prevention and treatment.

The ongoing development and testing of methods of prevention and treatment for osteoporosis is clearly a necessary and positive process, despite the uncertainty it engenders from time to time about the efficacy of particular methods. Likewise, media coverage of new research findings and people’s desire to inform themselves about health issues are positive phenomena, despite problems they may cause. Efforts to increase public knowledge about osteoporosis must take place in the context of these phenomena, acknowledging uncertainty and devising ways to respond constructively to media coverage of new research findings and public demand for health information.

When confronted with a lack of public knowledge about a disease or condition and complaints about lack of information about the disease or condition, public policy analysts often recommend the development of more public information materials and programs. The description in this background paper of the existing public information about osteoporosis is intended to show that a large quantity of public information already exists and to direct the attention of policymakers and others to problems in the dissemination and targeting of the existing information, as well as problems that may arise because of the way research findings are often reported in the mass media, variation in media coverage of different findings, and the widespread dissemination of information about medications that have not been approved by the FDA for osteoporosis.

In 1993, legislation was enacted requiring the director of the National Institutes of Health to provide for the establishment of a resource center on osteoporosis and related bone disorders. The resource center is intended to enhance knowledge about osteoporosis among health care professionals, patients, and the public through the effective dissemination of information (P.L. 103-43). In September 1993, the National Institute of Arthritis and Musculoskeletal and Skin Diseases issued a request for applications from organizations interested in operating the resource center. The Institute received several proposals and expects to award a grant for the resource center by September 1994 (69).

A resource center is likely to improve the dissemination of information about osteoporosis. The organization selected to operate the resource center will have to develop ways of targeting information to different population groups. If the resource center is to be fully effective, the organization that operates it will also have to develop ways of responding constructively to media reports that provide incomplete or contradictory information.
about proposed methods of prevention and treatment. OTA believes, in addition, that as a publicly funded entity, the resource center should be required to state explicitly the FDA approval status of any medications mentioned in the public information it produces and to cite the reasons for FDA decisions, if any, not to approve particular medications.

Although not the immediate topic of this background paper, it is clear that federal funding for research on methods of prevention and treatment for osteoporosis is an essential component of any long-range effort to increase public knowledge about the disease. This research is needed so that definitive information about the efficacy of various methods of prevention and treatment can eventually be made available to the public.

Lastly, it should be noted that the kinds of public information materials and programs discussed in this background paper are not the only way people learn about osteoporosis. The other important source of information about osteoporosis is physicians and other health care professionals. Many health care professionals are not knowledgeable about osteoporosis. Thus, federal support for professional education and training about osteoporosis is another essential component of any long-range effort to increase public knowledge about the disease and ways to prevent and treat it.

PUBLIC KNOWLEDGE ABOUT OSTEOPOROSIS

Anecdotal evidence indicates that most people have heard of osteoporosis but are not knowledgeable about the disease. The findings of a 1991 Gallup telephone survey commissioned by the National Osteoporosis Foundation supports this conclusion. A nationally representative sample of women age 45 to 75 was interviewed. Three-fourths of the 750 women interviewed considered themselves familiar with osteoporosis: 40 percent rated themselves as very familiar, and 35 percent rated themselves as somewhat familiar (83). Nevertheless, only one-fourth of the survey respondents could identify any consequence of osteoporosis: only 17 percent knew that osteoporosis can result in curvature of the spine; only 15 percent knew that it can result in broken bones; and only 7 percent knew that it can result in height loss. Among the 40 percent who considered themselves very familiar with osteoporosis, one-fourth believed that there is no way to prevent or treat the disease.

The Gallup telephone survey identified 29 percent of the 750 survey respondents as being at high risk for osteoporosis, based on their answers to questions about family history, menopause before age 45, surgical removal of the ovaries and uterus, slender build, lack of exercise, and smoking (83). Seventy percent of women at high risk for osteoporosis reported they had never talked to their doctor about osteoporosis because they did not see the need or were not concerned about the disease.

A 1993 telephone survey conducted by Louis Harris and Associates for the Commonwealth Fund’s Commission on Women’s Health found that 73 percent of a nationally representative sample of 2,525 women age 18 and over considered themselves familiar with osteoporosis: 30 percent rated themselves as very familiar, and 43 percent rated themselves as somewhat familiar (14). Self-reported familiarity with osteoporosis varied with age: only 22 percent of the women age 18 to 45 rated themselves as very familiar with osteoporosis, compared with 39 percent of the women age 45 and over (14). Self-reported familiarity with osteoporosis also varied with educational level: only 18 percent of those with less than a high school education rated themselves as very familiar with osteoporosis, compared with 25 percent of those with a high school education and 42 percent of those with a college education (14).

OTA is not aware of any data on knowledge about osteoporosis among men. The subjects for the telephone survey conducted for the Commonwealth Fund’s Commission on Women’s Health included 1,000 men, but they were not asked any of the survey questions about osteoporosis (14). Considering the relatively small amount of public information about osteoporosis in men, it is likely
that men are less knowledgeable than women about osteoporosis.

INFORMATION ABOUT OSTEOPOROSIS CURRENTLY AVAILABLE TO THE PUBLIC
As noted earlier, the public receives information about osteoporosis from sources that include the mass media and commercial publishers; private organizations (i.e., the National Osteoporosis Foundation, other voluntary associations, health care organizations, dairy industry organizations, and pharmaceutical companies); and federal and state government agencies. The following sections describe the information typically available to the public from each of these sources.

Public Information About Osteoporosis Available from the Mass Media and Commercial Publishers
The mass media are an important source of public information about health. According to a study conducted in the late 1970s, the public ranks the mass media second only to physicians and dentists as a principal source of health information (138). The importance of the mass media as a source of health information has undoubtedly increased since then.

Commercial publishers are another source of information about health. Commercial publishers produce some of the health information disseminated by the mass media, as well as information used by hospitals, physicians, health educators, and others to inform patients and the public about health issues.

Information Available from the Mass Media
Television, radio, newspapers, and magazines provide health information. Every day, adults and children alike receive countless health messages from these sources.

The mass media often communicate health information in news reports. Some television and radio stations broadcast regular health information programs, and some carry talk shows and public service announcements that convey health information. Many newspapers have health columns or weekly health sections. Some magazines focus only or primarily on health-related topics, and many other magazines include articles on health topics.

The mass media reach far more people than other sources of health information. A single television program or newspaper or magazine article can reach millions of people. Individuals who see, hear, or read a report about a particular method of prevention or treatment may decide to pursue the method on their own, or, if a prescription is needed, they may go to their physician to ask for the prescription. As noted earlier, one source cited in Consumer Reports estimated that one-third of prescriptions for new medications are now written at the request of the patient (16).

The information about osteoporosis available to the public through the mass media often comes from other sources. The media generally adapt information they receive, however, to emphasize aspects of the information they believe will interest their respective audiences.

Scientists and health care professionals are sometimes critical of the way the mass media adapt and communicate health information. Some scientists and others complain about inaccurate or misleading coverage of research findings. On the other hand, a survey of first-listed authors of articles published in 1989 in the Journal of the American Medical Association and the New England Journal of Medicine found that 86 percent of those whose research had been reported by the media believed the coverage was accurate (133).

Some scientists, health care professionals, and others also complain about headlines that overstate or oversimplify research findings and about curiosity-peeking captions and between-program commercials intended to entice people to watch, listen, or read (71). In contrast, many journalists believe that these techniques are effective in attracting and retaining people's attention and that although some people are distracted or offended by them, the techniques are useful in conveying health information to the public (15).

As noted earlier, the mass media often present information about research advances in osteopo-
rosis in brief news reports. Because of time or space constraints, these reports often do not place the findings in context or make clear which individuals are likely to benefit from a particular method of prevention or treatment. As a result, people are unlikely to understand whether or how the information applies to them.

With respect to health information generally, some commentators have noted a bias against reporting “negative” studies, that is, studies that find no significant effect of the tested intervention. One study that compared the newspaper coverage of two articles from the same medical journal found that one article that described a positive effect was reported in many more newspapers and at greater length than another article that described the lack of an effect (50). In response to this finding, one journalist commented, “Selling a study that shows ‘no results’ to an editor who doesn’t understand science can sometimes be a tough task” (86). Another journalist commented:

To those of us in the news business, [the] finding that newspapers are biased against negative medical studies seems obvious and the reason for it quite simple. At any newspaper or magazine published for the profit of its owners, the first and foremost criterion for deciding whether to publish a story is whether it contains information that readers would like to know . . . Studies that find an effect usually are of more interest—and of more importance—to newspaper readers than studies that find no effect.

Most American newspapers strive to publish factual, accurate, and unbiased news stories, but . . . the newspaper editor who decides he has a responsibility to give his readers certain information, whether they want it or not, will see his readers turning elsewhere for news and he will soon discover he has no newspaper to be editor of(5).

Also with respect to health information generally, many commentators have noted a bias among researchers against submitting negative studies for publication (9,21,99). This bias and the media bias against reporting negative studies mean that the public is generally more likely to hear that various methods of prevention and treatment are effective than that the methods are not effective. Both biases work to the advantage of pharmaceutical companies that do not want publicity for negative findings about the efficacy of their products. Although not specific to osteoporosis, these biases are likely to influence the kinds of information the public receives about osteoporosis as well as the information it receives about other diseases and conditions.

Television

National network television reaches 98 percent of households, and cable television reaches 52 percent of households in the United States. Almost everyone watches television daily, and many people watch for many hours a day. On average, children and elderly people watch more television than other age groups; women watch more television than men; and some surveys show that minority group persons and those in lower socioeconomic groups watch more television than other persons (20,123).

National network and local television news programs sometimes report the results of osteoporosis research. These news reports are generally brief, simple statements that last less than a minute. The scripts for television news reports are usually prepared by an in-house writer, but they may be based on information from a press conference, a press release, or a commercial news service. Pharmaceutical companies also submit information directly to television news offices which may or may not use the information in a news report.

Some local television stations have aired public service announcements about osteoporosis. Each year, the National Osteoporosis Foundation prepares an educational resource kit for National Osteoporosis Prevention Week, a week in May that is designated by Congress and the President as a time to focus on osteoporosis. The educational resource kit includes sample public service announcements and suggestions on how to cent’ince
local stations to air them during Prevention Week and throughout the year. According to a National Osteoporosis Foundation official, many local television stations broadcast the public service announcements (44).

In 1991, the U.S. Administration on Aging and the National Osteoporosis Foundation cosponsored the development of public service announcements narrated by Dr. Louis Sullivan, then-secretary of the U.S. Department of Health and Human Services. The public service announcements were sent to 250 television stations across the country: 71 of the stations aired at least one of the public service announcements during the summer of 1991; nine of these stations were in the “top 20” markets. An additional 60 stations reported that they were holding the public service announcements for future use (93).

Several national network news magazine programs and talk shows have broadcast information about osteoporosis. During the 1990 National Osteoporosis Prevention Week, for example, ABC’s “Good Morning America” interviewed Dr. William Peck, then-president of the National Osteoporosis Foundation. During the interview, Dr. Peck suggested that people contact the National Osteoporosis Foundation for information about osteoporosis. As a result, the foundation received 25,000 letters from people asking for information about the disease (25).

The national television networks offer a few regular programs dedicated to health information. One such program is “Health Matters,” a 30-minute health information series that was being broadcast weekly on stations in 20 cities in 1991. The series, which was produced and distributed by a commercial publisher of health news programs, included some information about osteoporosis (103).

In comparison with the national networks, cable television has a large selection of channels, many of which specialize in specific types of programming targeted to selected audiences. Two cable television channels—the Discovery Channel and the Lifetime Channel—specialize in health information programs. Some of the programs are intended for general audiences, and others programs are intended primarily for physicians, although lay persons also watch them.

“Your Health” is a series of half-hour health information programs for general audiences that was broadcast twice a day on the Discovery Channel in 1991. The series included several segments on osteoporosis, as well as segments on menopause and estrogen therapy (103). “Your Health” was produced by a commercial publisher of health news programs.

Radio
American households have an average of eight radios, including kitchen, automobile, bedside, and portable radios (58). Nine out of 10 people say they listen regularly to the radio, for an average of two hours a day. It is unclear, however, how many people actually pay attention to radio messages since radios are frequently used as half-heard background during other activities (97).

Radio most often conveys osteoporosis information as news reports or discussions on health information programs. The news reports are generally brief. The scripts for radio news reports may be prepared by an in-house writer or a commercial news service and may be based on information from a press conference, press release, interview, or other source.

OTA is aware of several health information programs that have discussed osteoporosis. One example is a program hosted by Dr. Dean Eden and syndicated to radio stations nationwide. A second example is a program hosted by Dr. Gabe Mirkin on WWRC-AM in Washington, DC.

Newspapers
About 62 million people read one or more of the 1,600 newspapers published daily in the United States (117). Men and women over age 50 are most likely to read a newspaper regularly. Married women under age 30 with children and women over age 30 who are single parents are least likely to read a newspaper (42).

Newspapers inform their readers about osteoporosis in news reports, health columns, and weekly health sections. Newspaper reports about osteoporosis are likely to be more detailed than
those presented on television or radio, and they provide “tangible” information that can be read repeatedly.

Newspapers throughout the country published close to 1,000 news reports about osteoporosis in 1990 (115). Newspaper journalists get information about osteoporosis from press conferences, press releases, interviews, and other sources.

Big newspapers often have specialized science writers and a budget for research and investigative reporting about health issues. Small newspapers, which constitute the majority of newspapers in the United States, have few specialists and often rely on the wire services (113).

As noted earlier, on July 12, 1990, almost 400 newspapers nationwide reported that a study in the New England Journal of Medicine found etidronate effective for osteoporosis (see box 2). The newspapers used versions of the news story distributed by ten wire services. Most newspapers used one of two versions of the story written by an Associated Press science writer.

In February 1993, Ann Landers’ column, which is syndicated nationally and in Canada and Europe, discussed osteoporosis and gave the address of the National Osteoporosis Foundation. The column generated 100,000 letters to the foundation from people asking for information about the disease (96).

Magazines

Some 10,000 different magazines are published in the United States (58), and three out of 10 Americans say they read magazines daily (97). Magazines are published less frequently than newspapers, so readers do not get news as quickly. Magazines that publish health information usually take about three months to publish a news story after it has been distributed to the media (15). The longer lead time allows journalists to gather and present more detailed information, if they so choose.

To find out what is being said about osteoporosis in popular consumer magazines, OTA contracted for a survey of such magazines. From April 1990 through March 1991, OTA’s contractor reviewed the contents of 62 magazines to identify osteoporosis-related articles (15). All issues of 51 magazines, as well as some issues of 11 additional magazines, were reviewed.

Over the one-year period of the survey, 26 of the 62 magazines had no osteoporosis-related articles (15). Table A-1 in appendix A lists these magazines.

The remaining 36 magazines had one or more osteoporosis-related articles. Table A-2 in appendix A lists these magazines with the month and title of each relevant article and the category and subcategory of the article’s content. A total of 97 articles are listed. OTA’s contractor used broad criteria for identifying osteoporosis-related articles, and a few articles about vitamin D, exercise, and calcium are included even though they did not specifically mention osteoporosis (15).

OTA’s contractor regularly surveys consumer magazines for articles in the broad categories of nutrition, food, food marketing, and health policy. The 97 osteoporosis-related articles identified over the one-year period of the survey conducted for OTA constituted 3 percent of all articles identified by the contractor in this time period in these broad categories (15).

Of the 36 magazines that had one or more osteoporosis-related articles, the magazine Longevity had the largest number—17, followed by Prevention with nine osteoporosis-related articles, New Woman with six articles, In Health and Woman’s Day with five articles each, and Self with four articles. The other magazines listed in table A-2 had three or fewer osteoporosis-related articles in the one-year period of the survey (15).

Magazines are generally categorized in terms of their content and/or target audience. The 11

*News magazines were not included in the survey. These magazines have regular health columns, and OTA is aware of some osteoporosis-related articles (see, for example, Newsweek, May 14, 1990 [87]).
magazines in the health category had the most extensive coverage of osteoporosis, with a total of 47 articles or an average of 4.3 osteoporosis-related articles per magazine. Magazines that target the 20- to 45-year-old audience had an average of 1.7 osteoporosis-related articles per magazine. Magazines that target women over age 40 had an average of 1.3 osteoporosis-related articles per magazine. Relatively little attention was given to osteoporosis in magazines targeted primarily to men. African Americans, older people, parents, or teenagers. Modern Maturity, a magazine targeted to people over age 50, had no osteoporosis-related articles, even though many people in this age group have or are at risk of the disease (15).

About half of the 97 articles identified by OTA’s contractor were longer than one page. These articles are marked with an asterisk in table A-2. Longer articles usually convey more information and detail. On the other hand, journalists generally agree that shorter articles are read by more people. Thus, consumers may have read and may remember more about osteoporosis from the shorter articles (15).

Since magazine editors often weave several topics into a single article, content analysis is difficult. Clearly, however, calcium was the most popular osteoporosis-related topic in the one-year period of the survey. Twenty of the 97 osteoporosis-related articles discussed sources of calcium. In contrast to a few years earlier, the relative efficacy of dietary calcium versus calcium supplements was not a major topic. Instead, several of the articles discussed the issue of balancing one’s need for calcium against increased health risks due to the fat, cholesterol, and caloric content of dairy products (15).

Eight articles discussed factors that affect calcium absorption, including the phosphate in sodas, the oxalate in certain green leafy vegetables, and the excessive use of antacids. One article noted that absorption of calcium supplements is improved by taking a smaller dose several times a day (15).

The importance of calcium intake to achieve peak bone mass was discussed in one article targeted to college students and in a research report in Prevention. Peak bone mass was also mentioned in two of the other articles identified in the survey (15).

Exercise was the second most popular osteoporosis-related topic in the period of the study. Eleven of the 97 articles were about exercise. Four of the 11 articles focused on the negative effects of excessive exercise, i.e., amenorrhea and bone loss. Many articles about exercise that appeared in the 62 magazines during the period of the survey did not address osteoporosis (15).

Estrogen therapy was the topic of five of the 97 articles. The articles discuss the role of estrogen therapy in decreasing one’s risk of osteoporosis and heart disease, as well as its possible role in increasing the risk of certain cancers. The other medications discussed in one or more of the 97 articles were etidronate, calcitonin, sodium fluoride, progesterone, and human growth hormone (15).

Four articles discussed the use of electricity to stimulate bone healing. Two of these articles suggested that electricity may eventually be used to treat osteoporosis (15).

Osteoporosis in men was discussed in three articles. Runner’s World reported research done in Portland, Oregon, showing bone loss in 30- to 87-year-old men: it recommended regular exercise and calcium-rich foods. Two other articles discussed a study of osteoporosis in men age 21 to 79 and recommended calcium (15).

During the time of the survey, many consumer magazines published articles about the lack of research on women’s health. Osteoporosis was mentioned in two of these articles. Self published a chart showing how the National Institutes of Health budget is allocated for 10 research areas; osteoporosis was ninth on the list (15).

Very few articles gave any source for additional information about osteoporosis. Self published toll-free telephone numbers for health information, but osteoporosis was not among the diseases for which a number was given (15).

Some of the articles identified by OTA’s contractor stressed self-help, whereas other articles recommended that people see a physician before instituting a preventive or treatment strategy. Ar-
articles about calcium seldom recommended seeking advice from any health professional. Articles about exercise that included exercise instructions advised people to consult their physician before beginning the regimen. Articles about medications recommended medical supervision. Most of the articles about estrogen therapy advised women to make the decision about treatment in consultation with their physician (15).

Information Available from Commercial Publishers

Commercial publishers produce educational materials to inform health care professionals and the public about a variety of health topics, including osteoporosis. Some commercial publishers produce health and medical news programming for the mass media that has included messages about osteoporosis. Commercial publishers also produce videotapes, audiotapes, and written materials used by physicians and other health educators to inform patients and the public about osteoporosis (32,102,103).

One videotape produced by a commercial publisher features an 11-minute segment about osteoporosis that appeared on ABC Television’s “20/20” news magazine program (Churchill Films). Another videotape describes osteoporosis as a “biological time bomb set in youth to go off much later in life” and profiles a woman athlete protecting herself against risk factors for osteoporosis (Films for the Humanities & Sciences). A third videotape comes with a pamphlet that can be used to reinforce the video message or used separately (Milner-Fenwick).

Some commercial publishers produce fact sheets and brochures about osteoporosis that are distributed by health educators. Typically, these publications discuss osteoporosis risk factors, ways to reduce bone loss, and bone density testing. One brochure describes the warning signs of osteoporosis, such as loss of height, curvature of the spine, dental problems, and back pain—topics that are not addressed in many osteoporosis publications (Charming L. Bete Co., Inc.).

To ensure that the information they produce is complete and accurate, some commercial publishers have their publications reviewed before they are published. One commercial publisher, for example, contracted with two osteoporosis experts to advise its staff writers and artists who were developing a booklet about osteoporosis. The booklet was then sent to 10 osteoporosis experts for review, and their comments were incorporated into the final product. Booklets are updated periodically, and suggestions from readers are used to revise them (102).

Public Information About Osteoporosis Available from Private Organizations

Public information about osteoporosis is available from the National Osteoporosis Foundation, other voluntary associations, health care organizations, dairy industry organizations, and pharmaceutical companies. Each of these types of organizations produces and distributes printed information about osteoporosis—e.g., fact sheets, brochures, newsletters, articles, and reports. Many of these publications contain general information about osteoporosis, risk factors for the disease, and prevention strategies that focus on overall good health, a calcium-rich diet, and weight-bearing exercise. Some publications discuss the benefits and risks of various medications for osteoporosis.

Most of the organizations distribute their osteoporosis publications directly to the public. Typically, the publications are distributed free or for a nominal shipping and handling fee, but some organizations charge for some of their publications. Many of the organizations permit and encourage other organizations to use and distribute their publications.

Nearly all of the organizations not only produce publications but also conduct other types of activities to educate the public about osteoporosis. Some of the organizations have staff members who regularly answer inquiries about osteoporosis and send out osteoporosis publications. Many of the organizations conduct osteoporosis educa-
(ion programs for community groups, and some produce audiotape and videotaped public information materials as well as printed materials.

**Information Available from the National Osteoporosis Foundation**

The National Osteoporosis Foundation is a private, voluntary organization that came into existence in 1986 to advocate for osteoporosis research and services, inform the public about the disease, and conduct other activities to address the problem of osteoporosis. As of 1994, it has a mailing list of 40,000 members and donors, including scientists, health care professionals, business and community groups, patients, and their families (96). In addition to its main office in Washington, DC, the National Osteoporosis Foundation has regional offices in Atlanta and Chicago, both established in 1993, and is in the process of establishing other regional offices.

The National Osteoporosis Foundation produces and distributes public information materials about osteoporosis and functions as a national resource center for anyone seeking information about the disease. OTA’s research indicates that the National Osteoporosis Foundation is currently the primary source of public information about osteoporosis.

**National Osteoporosis Prevention Week**

A major focus of the National Osteoporosis Foundation’s public information activities is National Osteoporosis Prevention Week, usually the week in May that begins on Mother’s Day. As noted earlier, Congress and the President have designated that week as a time to focus attention on problems and solutions associated with osteoporosis. The foundation views National Osteoporosis Prevention Week as a kickoff for its year-round activities (95).

**National Osteoporosis Prevention Week: Educational Resource Kit**

The National Osteoporosis Foundation produces an educational resource kit for National Osteoporosis Prevention Week. The materials in the kit are updated annually to incorporate current scientific information about the disease and ideas from previous Prevention Week experiences. The 1990 educational resource kit contained the following materials:

- National Osteoporosis Prevention Week poster;
- suggested activities to promote awareness of osteoporosis;
- background information about osteoporosis, including a consumer information booklet, “Boning Upon Osteoporosis,” an osteoporosis risk factor questionnaire, a description of currently accepted and investigational osteoporosis therapies, and an annotated bibliography of articles about osteoporosis in men;
- "Prevention Pointers" that are targeted to specific audiences (preteens, teens, young adult women, mid-life women, older women, and men of all ages);
- sample press releases and public service announcements for use by local newspapers and broadcast media;
- guidelines on how to advocate for state and federal legislation supporting osteoporosis prevention and treatment; and
- information on managing the physical and emotional effects of osteoporosis and setting up an osteoporosis support group.

**National Osteoporosis Prevention Week: “Partners in Prevention”:** Each year, the National Osteoporosis Foundation enlists the help of government agencies, businesses, and other organizations as “Partners in Prevention” to publicize National Osteoporosis Prevention Week. In 1990, the list of "Partners in Prevention" included 120 organizations, classified as “Associate Partner,” “Contributing Partner,” “Supporting Partner” or “Sustaining Partner”. The comparable list for 1994 included 300 organizations in the same four categories (96).

Associate Partners are nonprofit, national membership associations and federal agencies. These organizations are expected to provide their affiliates at the state and local level with information about National Osteoporosis Prevention Week and to encourage their members to present osteoporosis education programs in their communities. OTA telephoned 47 Associate Partners
listed in the 1990 directory and found that the extent of their involvement in National Osteoporosis Prevention Week varied. Most of them included information about Prevention Week in their newsletters and other mailings. Some distributed National Osteoporosis Foundation educational resource kits to interested members. One displayed osteoporosis posters and pamphlets in the lobby of its office building. One participated in media interviews about osteoporosis, and one sponsored television public service announcements.

Most of the Associate Partners told OTA they generally are not sources of public information about osteoporosis and usually refer people with questions about osteoporosis to the National Osteoporosis Foundation. A few of the Associate Partners reported that they produce professional and patient education packets, and a few reported that they operate osteoporosis information clearinghouses.

Contributing, Supporting, and Sustaining Partners provide funding for the foundation educational resource kit and other materials for National Osteoporosis Prevention Week. OTA telephoned 47 Contributing Partners listed in the National Osteoporosis Foundation’s 1990 directory, including 35 health care organizations, five membership organizations, two university research centers, and five pharmaceutical or medical equipment manufacturing companies. As described later in this background paper, OTA found that the 35 health care organizations were the type of Contributing Partners most likely to conduct osteoporosis public information activities.

As part of the 1990 National Osteoporosis Prevention Week, educational programs were conducted at schools, hospitals, clinics, health fairs, shopping malls, work sites, and women’s clubs. Some of the programs were conducted only during Prevention Week, and others were also presented at other times.

The educational materials and programs developed during the 1990 National Osteoporosis Prevention Week included the following:

- a booklet with activities to encourage children to eat calcium-rich dairy foods and to educate women who care for children about osteoporosis and its risk factors, developed by the Child Care Association in Wichita, Kansas;
- a tee shirt with a logo reflecting the theme of the 1990 Prevention Week campaign, “Generations of Prevention,” designed by the Osteoporosis Awareness Resource Center in Spokane, Washington; and
- a luncheon with foods high in calcium to complement a presentation on osteoporosis and nutrition held at a local country club, organized by the Mid Michigan Regional Medical Center in Midland, Michigan.

National Resource Center

Throughout the year, the National Osteoporosis Foundation functions as a national resource center, responding to requests for information about osteoporosis from the general public, health care professionals, and community organizations. In 1990, a National Osteoporosis Foundation official estimated that the organization was receiving 200 to 300 telephone and mail inquiries a week (44). A sample of 26 letters provided to OTA by the foundation included requests for information from individuals who have osteoporosis and their families (see box 1 at the beginning of this background paper). Six requests were for general information about osteoporosis; 13 were for information about various treatments; two were for information about prevention; two sought financial assistance to pay for bone density testing or medications; one wanted to verify a diagnosis of osteoporosis; one sought psychological counseling for a family member with osteoporosis; and one sought information about starting a support group for people with osteoporosis and their families.

Since 1990, the number of requests for information received by the National Osteoporosis Foundation has increased greatly. In 1992, the organization initiated a toll-free information num-
ber. In the first two months after the toll-free number was initiated, 10,000 calls were received (95). In 1993, the foundation received 100,000 telephone and mail requests for information, in addition to the 100,000 letters received in response to the Ann Landers column mentioned earlier (96).

**Nature of the National Osteoporosis Foundation’s Osteoporosis information**

The National Osteoporosis Foundation’s publications and the information given to people who telephone the organization are general in nature and essentially unbiased. The publications typically provide an overview of osteoporosis and its risk factors and recommend regular exercise and a balanced, calcium-rich diet to prevent osteoporosis.

The National Osteoporosis Foundation does not recommend specific treatments or give medical advice. Since 1991, it has included the following statement in some of its publications:

> The National Osteoporosis Foundation does not advocate the general use of therapies not approved by the Food and Drug Administration for the prevention and treatment of osteoporosis.

Some of the National Osteoporosis Foundation’s publications are targeted to special populations. One example is the "Prevention Pointers" mentioned earlier. Another example is the "Bone-wise" osteoporosis information kit for older people produced by the foundation in 1991, with funding from the U.S. Administration on Aging. The "Bone-wise" kit includes the following brochures and fact sheets:

- "The Older Person’s Guide to Osteoporosis,” an overview of the causes, prevention, and treatment of osteoporosis;
- “Are You at Risk?” a risk assessment questionnaire;
- "Facts About Osteoporosis, Arthritis, and Osteoarthritis,” a description of each of these diseases;
- "Living with Osteoporosis,” a guide for people with osteoporosis with tips for everyday living

and advice on how to avoid fall-related fractures;
- “Testing Your Bone Health,” a description of the available tests to measure bone density; and
- a directory of state units on aging and other state sources of information about programs and services for older people.

The consumer information booklet, “Boning Up on Osteoporosis,” mentioned earlier, was developed in 1989 by the Osteoporosis Center at the University of Connecticut’s Health Center in cooperation with the National Osteoporosis Foundation (81) and revised in 1991 by the same group (82). The 60-page booklet discusses risk factors for osteoporosis, methods of detecting osteoporosis, and the role of calcium, vitamin D, exercise, estrogen, calcitonin, and several investigational medications in preventing and treating osteoporosis. It also includes exercises for people who have osteoporosis.

In addition to the public information materials already noted, the National Osteoporosis Foundation publishes a quarterly newsletter, *The Osteoporosis Report*, and produces fact sheets, charts, graphs, and videotapes and audiotapes that can be used for media presentations about osteoporosis. It has developed a booklet on medications that can cause bone loss, a pamphlet on talking with your physician about osteoporosis, and a slide show for community presentations. In May 1994, the foundation’s regional office in Chicago organized community forums on osteoporosis at six community hospitals (96).

The National Osteoporosis Foundation has co-sponsored numerous scientific conferences on osteoporosis, as well as educational workshops for physicians and other health care professionals. It also publishes a physician’s resource manual on osteoporosis.

**Information Available from Other Voluntary Associations**

Many voluntary associations other than the National Osteoporosis Foundation also inform the public about osteoporosis, although sometimes
not on a sustained basis. Most of these associations have a particular interest in women health. This section describes the public information activities of some of the associations.

The Inland Empire Council of the Girl Scouts of the U.S.A. serves girls scouts aged 5 to 17 years in Idaho and Washington State. In cooperation with the National Osteoporosis Foundation, the Washington Dairy Association, and a local support group for people with osteoporosis, the Inland Empire Council developed a “Healthy Bones” badge to teach young girls about the importance of healthy lifestyles, a calcium-rich diet, and exercise to reduce the risk of osteoporosis in later years. The educational materials compiled for the badge program include a calcium guide, an aerobic exercise fact sheet, an osteoporosis brochure and risk factor checklist, a poster on the four food groups, and the Washington State Dairy Council’s audiovisual catalogue. During the 1990 National Osteoporosis Prevention Week, a local television channel featured two girl scout troops working on the “Healthy Bones” badge.

Future Homemakers of America, Inc. is a national organization of about 300,000 young men and women who are studying or exploring career opportunities in home economics. The organization has an educational program, “Student Body,” that is intended for use by teenagers in schools and other community groups to teach their peers to eat right, be fit, and feel good about themselves. The nutrition education portion of the program, called 'Dairy Does a Body Good,” focuses on the body’s need for calcium to develop and maintain strong bones. It emphasizes dairy products as the preferred source of calcium. The program includes a videotape, a discussion guide that mentions osteoporosis, ideas for program activities, and a poster handout with calcium-rich recipe suggestions. Funding for both the videotape and supplementary materials was provided by the National Dairy Promotion and Research Board. Other corporate sponsors of the program are Frito-Lay, Inc., Kraft, Inc., and PepsiCo Foundation, Inc.

The Women’s Association of the National Rural Electric Cooperatives Association. A few years ago, in connection with National Osteoporosis Prevention Week, the Women’s Association conducted an education campaign that involved distributing National Osteoporosis Foundation materials and a videotape on osteoporosis produced by the Public Broadcasting Service to the cooperatives. The education campaign was not continued because of the cost of mailing the educational materials to the cooperatives and because, according to an association spokesperson, there have been no major changes in the information disseminated a few years ago (66).

Melpomene Institute for Women’s Health Research in St. Paul, Minnesota, is an organization of individuals professionally trained in health care, physical education, and sports for girls and women. The institute researches and distributes information on issues such as body image, athletic amenorrhea, exercise and pregnancy, and osteoporosis. The institute publishes the Melpomene Journal, which has featured two articles about osteoporosis: one article summarized current knowledge about osteoporosis, and the other described a Melpomene osteoporosis study that examined bone density, diet, activity levels, and other lifestyle characteristics of women aged 50 to 80. The institute offers an information packet containing articles about osteoporosis and a videotape on osteoporosis. The institute’s library has several hundred articles about osteoporosis and will search their database for information about a specific topic and provide callers with relevant articles for the price of copying (40).

The National Women’s Health Network in Washington, DC, publishes The Network News, a quarterly newsletter that has featured several articles about osteoporosis, including:

- “Is Osteoporosis Inevitable?” which discussed risk factors for osteoporosis and recommended self-help measures to reduce one risk (March/April 1984);
- “Major Drug Manufacturer Funds Osteoporosis Public Education Campaign,” which criticized an osteoporosis public information
campaign funded by Ayerst Laboratories—the manufacturers of an estrogen medication (May/June 1985); and

“Osteoporosis Screening: Pro and Con,” which featured opposing viewpoints about the use of bone density testing to screen people at risk of osteoporosis (January/February 1988).

The National Women’s Health Network also publishes a 40-page information packet on osteoporosis. The network maintains a bibliography on osteoporosis that is used to recommend specific articles to callers. Callers are also referred to other organizations, such as the Women’s Midlife Resource Center in San Francisco and the Older Women’s League in Washington, DC (36).

The National Women’s Health Resource Center, a nonprofit subsidiary of the Columbia Hospital for Women in Washington, DC, was founded in 1988 to increase awareness of women’s health issues through advocacy and educational programs. The center newsletter, National Women’s Health Report, provides information about a variety of women health issues. In 1990, the National Women’s Health Resource Center sponsored a two-day workshop, “Forging a Women’s Health Research Agenda,” which resulted in considerable media coverage of the participants’ concerns about lack of sufficient research on women health issues, including osteoporosis (85).

The Older Women’s League, a voluntary association in Washington, DC, with chapters nationwide, includes information about osteoporosis in its newsletter and the materials it mails to callers on request. The Older Women’s League is currently planning public information programs on osteoporosis to be held in three locations in 1994.

The American Association of Retired Persons (AARP) produces and disseminates public information about osteoporosis through several of its divisions, including its National Resource Center on Health Promotion and Aging, its Women’s Initiative, and its Women’s Activities Communications Division. AARP’s pamphlet series, Timeless Pioneers, which is produced by the Women Activities Communications Division, has, for example, included information about osteoporosis in several recent issues.

The American Running and Fitness Association is a nonprofit, educational association that educates the public about the benefits of exercise. The association publishes a newsletter that has discussed the role of exercise in reducing the risk of osteoporosis.

In 1991, the American Medical Association and the American Dental Association initiated a “Women’s Health Campaign” to inform women about 10 women’s health issues, including osteoporosis. Good Housekeeping Magazine, one of the sponsors of the campaign, featured a supplement in its January 1991 issue that included articles and editorials about each of the 10 health issues. The article on osteoporosis, entitled “Calcium: A Key to Preventing Osteoporosis,” discussed calcium, weight-bearing exercise, healthy lifestyles, and estrogen therapy as preventive therapies for osteoporosis. It recommended methods of preventing falls and fractures, discussed therapies such as etidronate and vitamin D, and referred readers to the National Osteoporosis Foundation for additional information.

Other associations of health care professionals also produce public information about osteoporosis, in addition to professional education materials and programs for their members. These professional associations include the American Academy of Orthopedic Surgeons, the American Dietetic Association, the American College of Obstetricians and Gynecologists, and the Nurses Association of the American College of Obstetricians and Gynecologists.

Lastly, the Food Marketing Institute, an association of food retailers and wholesalers, co-published with the National Institute of Arthritis and Musculoskeletal and Skin Diseases a booklet entitled “Boning Up on Osteoporosis.” A total of 20,000 copies were distributed through 1,500 grocery stores nationwide. The publication explains osteoporosis and its risk factors, discusses estrogen therapy, calcium, vitamin D, and weight-bearing exercise.
ing exercise as ways to reduce the risk, and suggests ways to prevent falls and fractures. The publication refers readers to the National Osteoporosis Foundation for additional information.

**Information Available from Individual Health Care Organizations**

Some hospitals, medical centers, and independent medical practices that provide osteoporosis diagnostic, preventive, and treatment services also conduct public information activities to increase awareness of osteoporosis and market their services. OTA contacted the 35 health care organizations that were Contributing Partners to the 1990 National Osteoporosis Prevention Week to learn what they do to educate the public about osteoporosis. OTA does not know whether these health care organizations represent many other health care organizations in the United States or whether they are relatively unique with respect to their osteoporosis public information activities.

Two of the 35 health care organizations that were Contributing Partners to the 1990 National Osteoporosis Prevention Week were independent medical practices: a private metabolism and bone health practice run by an endocrinologist and a women clinic run by four gynecologists. The endocrinologist told OTA that he does not inform the public about osteoporosis but does produce several osteoporosis fact sheets for his patients (10). A spokesperson for the women’s clinic told OTA that the clinic offers public osteoporosis seminars at least four times a year. At the seminars, the clinic presents a film, “Osteoporosis,” produced by a commercial publisher, and distributes the National Osteoporosis Foundation brochure “osteoporosis: A Woman’s Guide” and other educational materials produced by the National Institute on Aging, a pharmaceutical company, and the clinic. These publications are also displayed in the clinic lobby (106).

The remaining 33 health care organizations were hospitals or medical centers. Of these 33 facilities:

- two facilities—a women hospital and an osteopathic medical center—that had offered specialized osteoporosis services in 1990 reported that they no longer did so;
- 11 facilities diagnosed osteoporosis as one of their general services but provided no specialized osteoporosis services; and
- 20 facilities provided specialized osteoporosis services, including osteoporosis risk evaluations, information about the disease, and recommendations on how to prevent bone loss. Some of these facilities also provided bone density testing.

Spokespersons for the two facilities that no longer offered specialized osteoporosis services cited the lack of third-party reimbursement for bone density testing and the lack of demand for their services as reasons for discontinuing the services. One facility noted a preference by most people to consult their personal physician about osteoporosis, and the other facility cited a lack of public awareness of osteoporosis. Neither of the facilities had conducted public information activities (41, 70).

Of the 11 hospitals and medical centers that diagnosed osteoporosis as one of their general services, four conducted osteoporosis public information programs during the 1990 National Osteoporosis Prevention Week, and one of the four conducted osteoporosis public information programs at other times during the year. All four facilities had staff members who responded to inquiries about osteoporosis and sent osteoporosis publications to people who requested them: two used only National Osteoporosis Foundation publications (32, 137); one used a combination of National Osteoporosis Foundation and National Dairy Council publications (18); and one used an osteoporosis fact sheet produced by a commercial publisher. One of the facilities had a display of osteoporosis handouts from the National Osteoporosis Foundation and the National Dairy Council in its lobby (18), and one had a newsletter (circulation 5,000) that has included articles about osteoporosis (32).

Of the 20 facilities with specialized osteoporosis services, only one—an osteoporosis diagnostic and treatment center—did not conduct
osteoarthritis public information programs, although it had done so initially to market its bone density testing services (91). Another facility—an orthopedic clinic associated with a sports medicine hospital—conducted its first osteoporosis public information program during the 1990 National Osteoporosis Prevention Week (68). The clinic used the National Osteoporosis Foundation educational resource kit to prepare articles about osteoporosis for a local newspaper, distributed National Osteoporosis Foundation brochures and fact sheets at a local shopping mall, and presented an osteoporosis prevention program to a group of teenage girls. In addition, a foundation with which the sports medicine hospital is associated published an article about calcium and an article about osteoporosis in its quarterly magazine (circulation, 20,000) (68).

The remaining 18 centers with specialized osteoporosis services reported that they educate the public about osteoporosis throughout the year by activities such as:
- developing and distributing osteoporosis brochures and fact sheets;
- publishing osteoporosis newsletters or health promotion newsletters that include articles about osteoporosis;
- publishing information about osteoporosis in newspapers, popular magazines, professional journals, and books;
- serving as community resource centers for information, audiovisual materials, and publications about osteoporosis; and
- presenting osteoporosis information programs to community groups, such as women’s clubs, church groups, senior citizen groups, and workplace and professional groups.

Box 3 describes the public information activities that were being conducted in 1991 by one of these centers, the Osteoporosis Center at the Hospital for Special Surgery in New York City.

Seven of the 18 centers with specialized osteoporosis services reported that they operate community information and resource centers that collect journal articles and books about various health issues, including osteoporosis (8,46,49, 57,60,89, 134). One of the seven centers operates a lending library that includes osteoporosis publications and videotapes (57). All of the resource centers respond to public inquiries about osteoporosis and mail osteoporosis publications to anyone who requests them. One center maintains a list of people who have inquired about osteoporosis and regularly mails them updated osteoporosis information (89).

One of the 18 centers reported that it offers diet and exercise classes to women that include information about the importance of good diet and regular exercise in preventing osteoporosis (59). Three centers reported that they offer exercise classes to people with osteoporosis that stress muscle strengthening and behaviors to prevent falls and fractures (56,59,111). Two centers offered support groups for people with osteoporosis and their families (56, 105). One center used a mobile van to visit area neighborhoods at least twice a month to distribute osteoporosis information and provide free risk assessments (134).

In addition to the 35 health care organizations that were Contributing Partners to the 1990 National Osteoporosis Prevention Week, OTA is aware of several other health care organizations that have general health newsletters which have included information about osteoporosis. The Mayo Clinic Health Letter has printed articles on various methods of prevention and treatment for osteoporosis, including calcium, sodium fluoride, estrogen, and etidronate, and in 1984 printed a special supplement on osteoporosis (67). The Harvard Health Letter has also printed articles on methods of prevention and treatment for osteoporosis and in 1991 printed a special supplement on osteoporosis (35).

The Osteoporosis Center at the University of Connecticut’s Health Center has a newsletter, Osteoporosis Center News, that focuses entirely on osteoporosis. The newsletter includes articles about methods of prevention and treatment for osteoporosis, public information programs at the
In 1985, the Hospital for Special Surgery, a 192-bed hospital specializing in orthopedics and rheumatology, established an Osteoporosis Center in conjunction with its Metabolic Bone Disease Service. The Osteoporosis Center provides comprehensive assessments, counseling, and referrals for people who are at risk of or have been diagnosed as having osteoporosis. In 1991, the center served about 1,000 people, most of whom were women in their 40s and 50s who wanted to know about their risk for osteoporosis and methods of preventing and treating the disease (28).

In addition to patient assessments, counseling, and referrals, the Osteoporosis Center provides public information and professional education and training about osteoporosis and serves as a source of subjects for osteoporosis research projects being conducted in the hospital (27). When it was established in 1985, the center was one of the first, if not the first of its kind in the United States.

The public information activities of the Osteoporosis Center include the development and distribution of printed materials about osteoporosis, participation in community health fairs, sponsorship of public information programs about osteoporosis at the hospital, presentations about osteoporosis in community and workplace settings, and media interviews about osteoporosis. In 1991, the center was distributing a variety of printed materials about osteoporosis, including three 9- to 13-page pamphlets developed by the center, “What is Osteoporosis,” “Nutrition and Osteoporosis,” and “Exercise and Osteoporosis.” The center was also distributing printed materials produced by the National Osteoporosis Foundation and other sources.

The center staff noted the difficulty of keeping printed osteoporosis information up to date (28).

In cooperation with the hospital’s Community Education Department, the Osteoporosis Center has sponsored several public information programs on osteoporosis. One program on osteoporosis and menopause drew an audience of 250 and had to be repeated a second time for people who could not be accommodated in the first session. Another program on osteoporosis and hip fracture drew an audience of 300.

From January 1990 through July 1991, staff of the Osteoporosis Center and physicians from the hospital’s Metabolic Bone Disease Service who work with the center made a total of 27 public presentations about osteoporosis (28). Many of these presentations were to community groups, such as attendees at the Senior Citizen Center at St Patrick’s Cathedral and the JASA Westside Senior Center, both in New York.

Much of the public information produced and distributed by dairy industry organizations discusses the importance of dairy products for good health generally and does not mention osteoporosis. Some of the information mentions osteoporosis briefly, and some focuses entirely on osteoporosis.

In addition to their other public information activities, each of the dairy industry organizations has staff members who answer telephone or written questions from the public, health care professionals, and others, including questions about osteoporosis.

Information Available from Dairy Industry Organizations

Dairy industry organizations inform the public about osteoporosis primarily to promote the use of dairy calcium. The principal dairy industry organizations involved in this effort are the National Dairy Promotion and Research Board and the United Dairy Industry Association, which is composed of the American Dairy Association and the National Dairy Council.
Public Information About Osteoporosis: What's Available, What's Needed?

BOX 3 continued: Public Information Activities of the Osteoporosis Center at the Hospital for Special Surgery in New York City

City, attendees at the Austin Self-Help Senior Center in Forest Hills, New York, and members of the Stamford, Connecticut Chapter of the American Association of University Women.

Staff of the Osteoporosis Center and physicians from the Metabolic Bone Disease Service also made presentations about osteoporosis at worksites in New York City and elsewhere. Presentations were made for example, to employees at NBC, United Way, and the Hotel Worker’s Union in New York City. Some African American women came to these presentations to learn about their risk of osteoporosis. The presence of these women made the center staff painfully aware of the exclusive focus on white people in most osteoporosis information materials and the need for materials that include African American and other persons who are also at risk (28).

In 1990, Dr. Joseph Lane, medical director of the Metabolic and Bone Disease Service, was interviewed about osteoporosis on Channel 5 News in New York City. The Osteoporosis Center received 500 calls for information in the first two days following the interview (28).

The hospital’s Community Education Department has found that osteoporosis is a popular topic for public information and community presentations. When the department surveyed 75 local institutions to find out what topics they wanted information about, osteoporosis was the second most frequently identified topic, following back problems (101).

Until 1989, the hospital’s public information materials and programs were directed primarily to older people. Since then, however, efforts have been made to reach younger people, including young women who are at risk of osteoporosis because of amenorrhea caused by eating disorders and excessive exercise (101).

The Osteoporosis Center refers people to the National Osteoporosis Foundation and other organizations for further information and in turn receives referrals from these organizations. The center coordinator is aware of several other hospitals and medical centers nationwide that have osteoporosis centers and wishes she had time to visit these other centers to learn more about their public, patient, and professional education and training programs and patient assessment, counseling, and referral procedures (28).

SOURCE Office of Technology Assessment 1994, from sources cited in the text and listed in the references section.

National Dairy Promotion and Research Board

The National Dairy Promotion and Research Board is an advisory board of the U.S. Department of Agriculture. The board was established by Congress in 1983 to promote consumption of dairy products and thereby reduce milk surpluses. The board consists of 36 dairy producers appointed by the Secretary of Agriculture to represent all dairy producers in the United States. The board develops and implements research, marketing, and education projects to increase the use of dairy products. To finance its activities, the board collects fees from dairy farmers based on the amount of milk they market. In fiscal year 1990, the board’s assessment revenue and interest income totaled $77 million (79).

In fiscal year 1990, the National Dairy Promotion and Research Board spent $9.5 million—about 12 percent of its budget—for product research to develop new dairy products and improve existing products and nutrition research to examine the role of dairy nutrients—especially calcium—in human health (79). Most of the remainder of the board annual budget was spent on advertising to promote nonbrand dairy products.

The public information produced and distributed by the National Dairy Promotion and Research Board focuses on nutrition and the importance of dairy products for a balanced diet.
and good health. One television advertising campaign was produced by the board in response to a study that revealed a substantial decline in milk consumption after age 11 and a greater decline after age 17. The advertising campaign used the slogan, “Milk. It Does a Body Good,” to persuade young people that milk will help them grow up to be healthy and physically fit. Another print advertising campaign was produced by the board to convince women aged 25 to 54 that eating a variety of dairy products is the preferred way to get their recommended daily calcium allowance (80).

Some of the public information produced and distributed by the National Dairy Promotion and Research Board focuses on osteoporosis. In 1988, for example, the board and the Cooperative Extension Service of the U.S. Department of Agriculture jointly sponsored the “Calcium for the Prime of Your Life” program to inform people over age 50 about the importance of dairy calcium to maintain bone strength and reduce the risk of osteoporosis (78). A public relations firm produced and distributed the program materials to Cooperative Extension Service agencies throughout the country. The program was used by many other organizations, including AARP, the American Red Cross, senior centers, retirement centers, alumni groups, women’s clubs, garden clubs, civic clubs, adult education groups, churches, libraries, hospitals, health clubs, and corporate health programs (39).

Also in 1988, in conjunction with National Osteoporosis Prevention Week, the board sponsored a television public service announcement that identified osteoporosis as “a crippling bone disease that causes pain, disability, and in some cases may lead to death.” The announcement counseled that “... osteoporosis may be prevented with proper diet and exercise” and offered viewers a free brochure entitled, “Os-te-o-po- ro-sis.” Some versions of the announcement featured the name and address of a local congressman from whom viewers could request the osteoporosis brochure.

The board also supports professional education activities. It sponsors scientific and consensus development meetings and pays for the publication of reports from some of these meetings. For several years, the board sponsored advertisements in professional journals targeted to pediatricians, general and family practitioners, obstetricians/gynecologists, and dietitians to inform them about the nutritional benefits of dairy products. The advertisements included an order form for free patient education brochures, some of which discuss osteoporosis. The advertisements were discontinued in 1992, in part because they were perceived as having limited impact (73).

United Dairy Industry Association

The United Dairy Industry Association, established in 1971, coordinates activities and manages funds for two organizations: the American Dairy Association and the National Dairy Council. The American Dairy Association is a federation of 19 regional and state dairy farmers’ associations created in 1940 to conduct advertising campaigns for nonbrand dairy products. The association sponsors television and radio commercials to promote dairy products. These commercials often focus on the benefits of dairy calcium to build and maintain strong bones but generally do not mention osteoporosis specifically (114).

The National Dairy Council, established in 1915, produces nutrition education materials and conducts nutrition education programs for health professionals, educators, and the public. The council has a national office, 22 affiliated Dairy Council units, and 68 area offices (73).

The nutrition education materials and programs produced by the National Dairy Council target a wide range of audiences, from young children to elderly people. The council’s 1992 “Nutrition Education Catalogue” lists a variety of nutrition education materials for preschool and school-aged children, including programs to be offered by schools as part of classroom curricula or by community youth groups, such as the 4-H Club, the Boys Scouts, the Girl Scouts, and the Future Homemakers of America (77). These programs emphasize calcium’s role in bone development, growth, and maintenance throughout life.

The nutrition education materials for preschool and school-aged children that are currently offered
Public Information About Osteoporosis: What’s Available, What’s Needed?

by the National Dairy Council include the following:

- “Food . . . Early Choices,” for preschool and kindergarten students, includes a poster, booklet, puzzles, and food identification cards to teach students where and how we get our foods.
- “Food . . . Your Choice,” for elementary school students, begins with simple concepts such as “food helps me grow . . . gives me energy . . . keeps me healthy,” and progresses to detailed instruction about food groups, nutrients, calories, and the U.S. recommended daily allowance (RDA) guidelines.
- “Smart Moves,” for junior and senior high school students, includes a videotape, a poster, and a 16-page booklet that helps students record and analyze their eating and exercise habits.
- “You: A Guide to Food, Exercise, and Nutrition” for young men and women, particularly those in grades 11 and 12 (separate editions for men and women), contains information about achieving and maintaining nutritional and physical fitness.

The National Dairy Council also develops nutrition education programs for adults. One of these programs is a 15-minute videotape, “Osteoporosis and You,” that discusses the incidence and symptoms of osteoporosis; describes the effects of smoking, alcohol, and stress on bone health; and recommends calcium-rich foods and regular exercise to build and maintain strong bones.

The National Dairy Council produces an 8-page brochure, “Osteoporosis: Are You at Risk,” which is targeted to women and helps them assess whether they are at risk for osteoporosis. A Spanish version of the brochure is also available—the only Spanish-language public information about osteoporosis that OTA has seen. Other brochures produced by the National Dairy Council that discuss osteoporosis include “For Mature Eaters Only: Guidelines for Good Nutrition,” “Every Woman Guide to Health and Nutrition,” and “The All-American Guide to Calcium-Rich Foods” (77).

The National Dairy Council’s public information materials and programs are updated periodically, and some are discontinued, although older materials and programs may remain in circulation until supplies are exhausted. Many of the materials and programs have received awards from organizations such as the American Dental Association, the American Academy of Family Physicians Foundation, the National Education Association, and the American Federation of Teachers (77).

The National Dairy Council sponsors a Visiting Professor/Speakers Bureau program that provides expert spokespersons on a variety of topics, including osteoporosis. The council also produces nutrition education programs and materials for health care professionals and educators. Some of its area offices offer special nutrition education programs. In 1990, for example, the Dairy Council of Greater Metropolitan Washington, Inc. offered workshops for teachers and youth group leaders to prepare them to present the council’s programs (17).

The National Dairy Council also publishes scientific reports and summaries of scientific articles related to dairy products and calcium. A recent issue of Dairy Council Digest, the council’s newsletter that reviews nutrition research, summarized recent research on women health issues, including osteoporosis (76).

Information Available from Pharmaceutical Companies

Pharmaceutical companies inform the public about osteoporosis primarily to promote the use of medications to prevent and treat the disease. The
companies may produce and distribute public information materials and programs themselves or hire a public relations firm to conduct these activities. Some pharmaceutical companies also pay for public information materials and programs that are produced and distributed by other organizations.

By increasing the availability of public information about osteoporosis, pharmaceutical companies can generate greater public awareness and concern about the disease and thereby expand the market for their products. Other methods of expanding the market for the products are limited by FDA regulations that prohibit pharmaceutical companies from engaging in the following practices:

- promoting prescription medications that have not been approved by FDA,
- promoting unapproved indications for approved medications, and
- providing promotional information that is false, misleading, or selective (45).

FDA regulations require that promotional information about an approved medication must include a “brief summary” of its contraindications and side effects (45).

Greater public awareness and concern about osteoporosis is likely to benefit all pharmaceutical companies that have or are developing osteoporosis medications. The few companies that have approved prescription medications for osteoporosis are likely to benefit immediately. Companies that do not yet have an approved medication for osteoporosis are likely to benefit eventually from the impact of greater public awareness and concern about the disease. Companies that have a medication that has been approved for other indications but not osteoporosis may also benefit if people who are concerned about osteoporosis go to their physician and the physician happens to know about the medication and prescribe it or if people learn about the medication from the mass media or another source and ask their physician to prescribe it. These benefits are likely to occur even if the companies’ products are not mentioned specifically in public information materials.

Each year, some pharmaceutical companies provide funding for the development of educational materials for National Osteoporosis Prevention Week. In addition, many pharmaceutical companies produce or pay for other public information materials. In 1989, Wyeth-Ayerst Laboratories, which produces an estrogen medication that is approved for osteoporosis, published an educational brochure, “What You Should Know About Osteoporosis.” The brochure discusses menopause-induced estrogen deficiency as a cause of osteoporosis but does not mention any specific medication.

In 1991, Rhone-Poulenc Rorer Pharmaceuticals, Inc., which has a calcitonin medication that is approved for osteoporosis, published two educational brochures. “Postmenopausal Osteoporosis: Prevention” describes osteoporosis and its risk factors and mentions calcium, vitamin D, exercise, and estrogen therapy as ways to prevent it. “Postmenopausal Osteoporosis: Treatment” describes osteoporosis, emphasizes the seriousness of the disease, and discusses estrogen therapy and calcitonin as the two possible ways of halting its progression. Neither of the brochures mentions a specific medication.

Sandoz Pharmaceutical Corporation, which has an injectable calcitonin medication that is approved for osteoporosis and a nasal calcitonin medication that is not approved for osteoporosis, paid for the 1989 version and the 1991 revision of “Boning Up on Osteoporosis,” the informational booklet mentioned earlier that was developed by the Osteoporosis Center at the University of Connecticut’s Health Center in cooperation with the National Osteoporosis Foundation. The 1989 booklet notes that calcitonin is approved by the FDA for the treatment of osteoporosis but is only available at present by injection. It states that “nasal calcitonin is expected to be available in the future” (81). The 1991 booklet describes nasal calcitonin as an investigational treatment that has been shown to be effective over a two-year period in preventing spinal bone loss in women immediately after menopause” (82).
In 1991, Norwich Eaton Pharmaceuticals, Inc. (now Procter and Gamble Pharmaceuticals), which produces etidronate, published a brochure, “Osteoporosis: Am I at Risk.” The brochure describes osteoporosis and the role of calcium in building and maintaining strong bones but it points out the calcium is “only part of the story.” The brochure includes a risk factor checklist and advises people who find themselves at risk to consult with their physician. The brochure does not mention any specific medication.

Marion Merrell Dow, Inc., which manufactures a nonprescription calcium supplement, publishes “Calcium Communique,” a newsletter that is mailed to anyone who requests it. A 1991 issue includes articles about exercise, RDAs, and the effects of caffeine and excessive dieting on the body’s store of calcium (64). FDA regulations with respect to the promotion of prescription medications do not apply to nonprescription medications, and the newsletter explicitly promotes the company’s calcium supplement. The issue contains a testimonial that favorably compares the company’s calcium supplement to a generic calcium supplement. It also contains an article which points out that although calcium-fortified orange juice is a way of meeting one’s need for calcium, one would have to drink almost a quart of juice a day to provide the RDA for calcium. According to the article, the same amount of calcium can be obtained from two tablets of the company’s calcium supplement.

In addition to brochures, booklets, and newsletters, some pharmaceutical companies have sponsored multifaceted publicity campaigns to increase public awareness and knowledge about osteoporosis. In 1983, Ayerst Laboratories hired a public relations firm to conduct a publicity campaign focused on reaching radio, television, and magazine audiences with the message that osteoporosis is a major women’s health problem for which there are remedies and that women at risk should consult a physician. The campaign did not promote a specific medication (38). Information about osteoporosis, its risk factors, and the role of calcium, vitamin D, weight-bearing exercise, and estrogen therapy to reduce the risk of osteoporosis appeared in magazines, such as Vogue, McCall’s, Self, and Reader’s Digest (84). The campaign included a media tour of 10 cities by three osteoporosis experts to discuss osteoporosis in the context of the conclusions of the 1984 NIH Consensus Development Conference on Osteoporosis: one conclusion of the conference was that “estrogen replacement therapy is highly effective for preventing osteoporosis in women” (127).

The public relations firm developed a pamphlet, bearing Ayerst Laboratories’ name, that discussed decreased estrogen production after menopause as a cause of rapid bone loss. The pamphlet did not mention any specific medication. Ayerst Laboratories received over 100,000 requests for the pamphlet (38).

The public relations firm also arranged with the Nurses Association of the American College of Obstetricians and Gynecologists (NAACOG) to conduct “nurse to health professional” and “nurse to public” osteoporosis seminars. The firm set up an advisory panel, consisting of osteoporosis experts, NAACOG members, and a consumer representative, to develop the educational content for the seminars. The seminars used a slide/script format that discussed osteoporosis, its risk factors, and prevention strategies such as adequate calcium intake, weight-bearing exercise, and estrogen therapy. Ayerst Laboratories was not identified in the educational materials (84).

NAACOG initially presented the seminars to nurses and other health professionals in order to motivate and prepare them to present the public seminars. Thereafter, the slide/script materials for the public seminars were distributed to NAACOG members and other interested health professionals. Osteoporosis seminars were presented at adult day centers, churches, and women’s clubs. The total number of seminars presented during the campaign is not known (6,38).

In 1990, the American Osteoporosis Alliance, an association of pharmaceutical companies that had or were developing osteoporosis medications, hired a public relations firm to conduct a publicity campaign to increase public awareness and understanding about osteoporosis. The public relations firm launched the campaign by generating media
coverage of a 1990 conference “Research Advances in Osteoporosis.” The firm issued press kits, arranged press conferences and media interviews with osteoporosis experts, and developed a background videotape about osteoporosis. The firm also publicized the 1990 National Osteoporosis Prevention Week by inviting media reporters to attend a luncheon sponsored by the National Osteoporosis Foundation and issuing a press release to reporters not in attendance. During 1990 and the first half of 1991, the firm developed and distributed to the media National Osteoporosis Foundation position statements on research findings. The position statements typically referred readers to the foundation for additional information.

As noted at the beginning of this background paper, several recent commentaries have expressed concerns about some of the ways pharmaceutical companies use the mass media to promote prescription medications directly to consumers (16,45). It is said that in some instances, promotion of prescription medications through a media news event is intended to evade FDA regulations for the promotion of prescription medications, i.e., regulations requiring that promotional activities be truthful and balanced, regulations prohibiting pharmaceutical companies from promoting prescription medications that have not been approved by the FDA, and regulations prohibiting pharmaceutical companies from promoting approved medications for unapproved indications (16,45). The FDA regulations do not apply unless a promotional event is sponsored by the company that manufactures the medications in question. In some instances, however, the sponsorship of these events is unclear.

In addition to mounting publicity campaigns, some pharmaceutical companies use paid advertising to promote osteoporosis products to the public. Thus far, most of the advertising has been for nonprescription calcium supplements. One example is an advertisement that promoted a calcium supplement that “contains more calcium than a half-quart of milk” (52). Another example is an advertisement for an antacid tablet that contains calcium. The advertisement showed newspaper headlines from the Wall Street Journal, USA Today, and the New York Times citing the benefits of calcium for osteoporosis and said that two tablets of the antacid “can help prevent osteoporosis” (108). A third example is an advertisement that offered readers a free “Stand Up to Osteoporosis” booklet in return for completing a questionnaire indicating whether they use calcium supplements and, if so, what brand they use (63). Half of the 18-page booklet is devoted to a discussion of calcium and a favorable description of the company’s calcium supplement; the other half includes an osteoporosis risk assessment and a discussion of bone biology, osteoporosis, and the role of estrogen and exercise in reducing the risk of osteoporosis.

Since 1985, the FDA has allowed direct advertising of approved prescription medications. In 1991, Wyeth-Ayerst Laboratories conducted a 3-month print advertising campaign for its estrogen medication. The advertisement, which appeared in magazines, such as Better Homes and Gardens, In Health, Lears, McCall’s, Prevention, and Readers’ Digest, featured a picture of four middle-aged women and the message, “One out of four women over 50 will get osteoporosis.” The advertisement advised women that the company’s estrogen medication is the most effective way to prevent osteoporosis and urged readers to contact an “osteoporosis information center” by mail or by a toll-free telephone number for free information. Women who contacted the center received a
cover letter, an insert from the National Osteoporosis Foundation, and a brochure, “What You Should Know About Estrogen Deficiency and Osteoporosis.” The brochure briefly explains osteoporosis in the context of menopause and declining estrogen production but is essentially an advertisement for the estrogen medication. Both the magazine advertisement and the brochure included the ‘brief summary’ of contraindications and side effects that is required by the FDA. The National Osteoporosis Foundation’s insert outlined the consequences of osteoporosis and urged women over 50 to consult with their physician about steps to prevent osteoporosis. The cover letter included a certificate that offered a free exercise videotape to women who had the certificate signed by a physician indicating that a consultation had occurred. The certificate asked women to indicate whether their physician prescribed a medication and, if so, to specify the name of the product. The offer for the free exercise tape expired May 1, 1991. For proprietary reasons, the number of women who contacted the osteoporosis information center is unavailable. One in 10 women who requested information from the center returned the certificate with a physician’s signature indicating that a consultation had occurred (38).

The appropriateness of direct-to-the-consumer prescription drug advertising has been vigorously debated over the last decade. Authorities familiar with the issue describe the debate as follows:

Pharmaceutical companies argue that prescription drug advertising meets the increasing consumer demand for health information, alerts consumers to new treatments, encourages people to seek medical advice for conditions that would otherwise go untreated, and generally results in a more informed public. Others argue that advertising prescription drugs to consumers interferes with the physician-patient relationship, confuses consumers, increases the cost of drugs, puts undue emphasis on pharmacological treatments alternatives, pressures physicians to prescribe products, and results in unnecessary drug use (45).

In some instances, it may be easier for consumers to evaluate the information in an obvious advertisement than information that is presented as news but is actually promotional information sponsored by a pharmaceutical company.

**Public Information About Osteoporosis**

**Available from Federal and State Government Agencies**

Many federal agencies conduct activities to inform the public about osteoporosis. Most of these agencies—i.e., the National Institutes of Health, the Food and Drug Administration, the Centers for Disease Control and Prevention, the Office of Disease Prevention and Health Promotion, the Office of Women’s Health, and the Administration on Aging—are part of the U.S. Department of Health and Human Services. In addition, the U.S. Department of Agriculture educates the public about osteoporosis through its Cooperative Extension System. A description of these federal activities follows. Also described are the activities of several states that have conducted osteoporosis public information campaigns.

**Information Available from the National Institutes of Health**

The National Institutes of Health (NIH) are part of the U.S. Department of Health and Human Services. Four of the institutes—the National Institute of Arthritis and Musculoskeletal and Skin Diseases, the National Institute on Aging, the National Institute of Diabetes and Digestive and Kidney Diseases, and the National Institute of Dental Research—conduct public information activities related to osteoporosis. The NIH Office of Research on Women’s Health also plays a role in increasing public awareness of osteoporosis, primarily because of media coverage of issues pertaining to women’s health research.

**National Institute of Arthritis and Musculoskeletal and Skin Diseases**

The National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS) provides the majority of the federal government funding for osteoporosis research. NIAMS has sponsored numerous osteoporosis workshops and conferences,

NIAMS’ Office of Scientific and Health Communications and the National Arthritis and Musculoskeletal and Skin Disease Information Clearinghouse distribute information about osteoporosis and conduct osteoporosis education activities for health care professionals and the public. As noted at the beginning of this background paper, NIAMS expects to select an organization to function as the congressionally mandated resource center on osteoporosis and related bone disorders by September 1994. After the organization is selected, NIAMS will coordinate the functions of its information clearinghouse and the new resource center to eliminate duplication of effort between the two entities (69).

As of May 1994, the National Arthritis and Musculoskeletal and Skin Disease Information Clearinghouse maintains a database of osteoporosis education materials and publishes annotated bibliographies of osteoporosis literature for scientists, health care professionals, and the public. It also compiles osteoporosis information packets containing review articles and commentaries.

NIAMS published a booklet, “Osteoporosis: Cause, Treatment, Prevention,” that has been distributed to more than 100,000 people. As noted earlier, NIAMS also copublished a booklet, “Boning Up on Osteoporosis,” with the Food Marketing Institute. Both publications explain osteoporosis and its causes; discuss estrogen therapy, calcium, vitamin D, and weight-bearing exercise; and suggest ways to prevent falls and fractures. The former also reviews therapies, such as calcitonin, sodium fluoride, vitamin D, anabolic steroids, and parathyroid hormone, and discusses current research on osteoporosis. Both publications refer the reader to the National Osteoporosis Foundation for additional information.

NIAMS produced a videotape and booklet, “Osteoporosis,” based on a 1989 presentation by NIAMS’ director for the NIH “Medicine for the Layman” lecture series. NIAMS also prepares news releases about recent research findings and the results of scientific conferences.

The National Arthritis and Musculoskeletal and Skin Disease Information Clearinghouse and NIAMS’ Office of Scientific and Health Communications respond to written and telephone inquiries concerning osteoporosis. The clearinghouse handles general questions about osteoporosis, and the Office of Scientific and Health Communication handles questions requiring a more detailed or technical response (1 36). Between July 1 and September 30, 1990, 92 people contacted the clearinghouse for general information about osteoporosis: 30 people received NIAMS information packets, and 62 people received the booklet, “Osteoporosis: Cause, Treatment, and Prevention.” During the same interval, 38 people contacted the NIAMS Office of Scientific and Health Communication and received responses to their specific questions about osteoporosis, including questions about estrogen therapy, etidronate, calcium, calcitonin, vitamin D, and bone density testing. Both the clearinghouse and the Office of Scientific and Health Communication refer callers to the National Osteoporosis Foundation for further information.

National Institute on Aging

NIA provides the public with information about osteoporosis through its Public Information Office and a contract clearinghouse. The clearinghouse functions as the “National Institute on Aging Information Center,” responding to requests for NIA publications. The publications, which are prepared by the Public Information Office, include a 30-page booklet, “Menopause,” that describes osteoporosis and its risk factors, suggests calcium, vitamin D, and exercise to prevent it, and discusses the benefits and risks of estrogen therapy. The Public Information Office also publishes one-page fact sheets, called “Age Pages,” that offer practical advice on health promotion and preventive care for older people. One Age Page, “Osteoporosis: The Bone Thinner,” briefly describes osteoporosis and its risk factors, recommends calcium, vitamin D, and weight-bearing exercise to prevent it, mentions estrogen therapy, sodium fluoride, calcium, and vitamin D as ways to slow or stop bone loss, and suggests ways to treat osteoporosis-related fractures. Other Age Pages that mention osteoporosis include “Should You Take Estrogen?,” “Managing Menopause,” “Preventing Falls and Fractures,” “Nutrition: A Lifelong Concern,” “Dietary Supplements: More Is Not Always Better,” “Smoking: It’s Never Too Late to Stop,” and “Don’t Take It Easy—Exercise.”

NIA developed a pamphlet, “Women and Osteoporosis,” that was published by Peoples Drug Stores, Inc. as part of its “Living With Aging” pamphlet series and distributed by its 800 drug stores. The pamphlet contained a brief overview of osteoporosis and its risk factors and urged readers to seek advice from their physician about calcium, vitamin D, estrogen therapy, and sodium fluoride as possible means of prevention.

The NIA Public Information Office also prepares consensus conference statements, news releases, and articles about NIA-supported osteoporosis research. These materials are distributed to the media, other federal government agencies, and the public.

The NIA Public Information Office responds to written and telephone inquiries about osteoporosis. The office keeps no formal count of the number of requests it receives for osteoporosis information, but in 1991, an NIA spokesperson estimated it to be similar to the number received by NIAMS. If a request is for more general information, the office usually mails the inquirer NIA’s Age Page on osteoporosis and other general materials. If the request is for specific information about a new development in osteoporosis prevention or treatment, the office includes professional journal articles on the topic. If the request is for information about research being conducted by another institute, the office refers the inquirer to the appropriate institute. The office also refers inquirers to the American College of Obstetricians and Gynecologists for information about estrogen therapy and to the National Osteoporosis Foundation for information about osteoporosis diagnosis and treatment strategies.

In 1993, NIA jointly sponsored with AARP a workshop on disseminating public information about menopause, in conjunction with an NIH conference, "Menopause: Current Knowledge and Recommendations for Research." The workshop focused on problems and strategies for the dissemination of public information about menopause. Its conclusions and recommendations apply to information about the effects of menopause on bone as well as other body tissues and organs.

National Institute of Diabetes and Digestive and Kidney Diseases

Since 1986, when NIAMS became a separate institute and ceased to function as a division of
NIDDK, most inquiries about osteoporosis go to NIAMS. As of early 1991, NIDDK’s Information Office was receiving only 25 to 30 osteoporosis inquiries a year. For questions related to endocrine or metabolic effects on bone, a NIDDK spokesperson will advise the caller. Otherwise, the caller is referred to NIAMS or the National Osteoporosis Foundation (107).

National Institute of Dental Research
The National Institute of Dental Research (NIDR) conducts and supports research on bone biology and metabolic bone diseases that affect oral and facial tissues. NIDR cosponsored the 1993 workshop, “Osteoporosis and Oral Bone Loss,” and the 1994 symposium, “Osteoporosis: Research Advances and Clinical Applications.” As noted earlier, these workshops and symposiums are intended primarily for scientists and health care professionals but mass media coverage of their findings may increase public awareness and knowledge about osteoporosis.

Office of Research on Women’s Health
The NIH Office of Research on Women’s Health was established in 1990 to enhance research on diseases and conditions that affect women, ensure that women are included as subjects in clinical research, and increase career opportunities for women in scientific and clinical research (47). Providing public information about osteoporosis is not a primary function of the office, but mass media coverage of its activities—particularly its efforts to identify gaps in knowledge about women’s health and initiate and support research to address the gaps—increases public awareness of osteoporosis.

The Office of Research on Women’s Health collaborates with other offices and institutes at NIH on the “Women’s Health Initiative,” a 15-year, three-part study that will eventually involve 40 to 45 research centers nationally and cost $625 million. The study focuses on the effects of low-fat diets, calcium, vitamin D, and estrogen and progestin therapy on the incidence of cancer, cardiovascular disease, and osteoporotic fractures in women.11 Mass media reports on this study and public presentations by staff of the Office of Research on Women’s Health about the study and other NIH-funded research on women’s health issues call attention to osteoporosis as a women’s health issue and increase public awareness, if not knowledge, about the disease.

Information Available from the Food and Drug Administration
As part of its mandate to promote and protect the public health, the Food and Drug Administration within the U.S. Department of Health and Human Services produces osteoporosis information for health professionals and the public and conducts osteoporosis education programs. In 1983, the FDA initiated a “Women’s Health Initiative” to focus attention on women’s health issues—including osteoporosis. In 1986, the agency sponsored a “National Conference on Women’s Health” that underscored osteoporosis as a public health problem and laid the groundwork for the agency’s 1987 “Special Topic Conference on Osteoporosis.” The 1987 conference was intended to establish a baseline of reliable information about osteoporosis and to outline key educational messages about bone loss, bone density testing, nutrition, exercise, and other methods of prevention and treatment. Proceedings of the two conferences

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11 The three parts of the Women’s Health Initiative are: 1) a clinical trial, involving 57,000 women ages 50 to 79, that will evaluate the effectiveness of low-fat diets, calcium, vitamin D, and estrogen and progestin therapy in preventing cardiovascular disease and osteoporotic fractures; 2) an observational component, involving 100,000 postmenopausal women, that will determine the risk factors for cancer, cardiovascular disease, and osteoporotic fractures; and 3) a community intervention study that will evaluate various ways of improving health-related behaviors in women age 45 and over. Fractures will be tracked in subjects at all centers, and three of the research centers will collect information about subjects’ bone density at the hip and spine. Bone density data will be available for about 10,000 subjects.
were published as supplemental issues of Public Health Reports, the U.S. Public Health Service’s magazine for health care professionals and public health educators (1 18,120).

The FDA’s Office of Consumer Affairs handles written and phone requests for osteoporosis information. The office keeps no formal count of the number of inquiries about osteoporosis it receives, but a spokesperson estimated in 1991 that the number was considerably less than the 130 osteoporosis inquiries received in a three-month period by NIAMS (31). Most requests were for general information about osteoporosis. Requests of a more technical nature—for example, side effects of a medication used to treat osteoporosis—were referred to another FDA office that is expert in that area.

The FDA has consumer affairs officers located in field offices nationwide. The consumer affairs officers conduct health education programs throughout the year, and FDA publications that discuss osteoporosis are distributed to people who attend these programs (31).

In 1993, the FDA completed its evaluation of the relationship between calcium intake and osteoporosis and issued regulations for allowable health claims, as required by the Nutrition Labeling and Education Act of 1990 (124). The regulations allow the labels on food products that contain calcium to state that adequate calcium intake in early life contributes to low peak bone mass and that adequate calcium intake may be helpful in reducing bone loss later in life. According to the regulations, the labels must make clear that calcium intake is not the only factor that affects the development of peak bone mass or the loss of bone with age; that the risk of osteoporosis varies for different subgroups of the population; and that calcium intake above 200 percent of the recommended daily amount has no additional benefit for bone health (23, 124). To the extent that food manufacturers decide to make claims about the relationship between calcium intake and osteoporosis on their product labels, these labeling requirements are likely to increase public awareness of osteoporosis.

The labeling requirements for claims about the relationship between calcium intake and osteoporosis are only one component of the FDA’s new food labeling regulations. To help consumers understand the food labels required by the new regulations, the FDA and several other public and private organizations have initiated a public information campaign (88). The campaign will include public service announcements, the distribution of public education materials, and the establishment of consumer hotlines for food labeling information. This public information campaign is also likely to increase public awareness of osteoporosis.

Lastly, the FDA is the federal agency that evaluates prescription medications for safety and efficacy. The FDA division that evaluates medications for osteoporosis drugs has an advisory group, the Endocrinologic and Metabolic Drugs Advisory Committee. As noted in box 2 at the beginning of this background paper, in 1991 the Endocrinologic and Metabolic Drugs Advisory Committee reviewed the findings of the available research on etidronate and recommended that the FDA not approve etidronate for osteoporosis. The FDA decided to follow the committee’s recommendation.

The FDA generally does not notify the public of its decisions to approve or not approve particular medications, except in life-threatening situations. To OTA’s knowledge, the FDA’s 1991 decision not to approve etidronate for osteoporosis was not presented to the general public in any way. The decision was reported in pharmaceutical industry newsletters and has been discussed at professional meetings and conferences. Anecdotal evidence suggests, however, that some physicians who prescribe etidronate for osteoporosis may not be aware of the decision. As of May 1994, the company that manufacturers etidronate continues to meet with the FDA, and it is possible that new evidence for the efficacy of the medication could result in its approval in the future. Given this context, however, OTA believes that the claim, which has been made in some public forums, that FDA “inaction and indecisiveness” are
holding up the approval of etidronate is misleading.\(^{12}\)

In 1991, the FDA’s Endocrinologic and Metabolic Drugs Advisory Committee also reviewed the findings of a five-year post-marketing study of calcitonin, a medication that was approved by the FDA in 1984 for osteoporosis. The study found an increase in bone density and a higher rate of new spinal fractures in subjects who received calcitonin compared with subjects who did not receive calcitonin (126). The company that produces calcitonin and the Advisory Committee agreed that the study was so poorly conducted that its findings could not be used to determine the efficacy of calcitonin in reducing fracture rates. The Advisory Committee voted unanimously to recommend that the FDA revise the labeling requirements for calcitonin to reflect the lack of evidence that it prevents fractures, and the FDA followed that recommendation. To OTA’s knowledge, the revised labeling requirements and the reasons for the changed requirements were not presented to the general public in any way, although, as in the case of etidronate, the transcript of the advisory committee meeting is available to the public, and the decision was reported in pharmaceutical industry publications. As of 1994, public information about osteoporosis continues to note correctly that calcitonin is an approved medication for osteoporosis but fails to point out the revised labeling requirements with respect to the lack of evidence that calcitonin reduces fractures.

**Information Available from the Office of Disease Prevention and Health Promotion**

The Office of Disease Prevention and Health Promotion (ODPHP) within the U.S. Department of Health and Human Services coordinates federal health promotion activities. ODPHP has coordinated the development of several reports related to osteoporosis. One of these reports, *The Surgeon General’s Workshop: Health Promotion and Aging*, has a chapter on skeletal diseases and recommends increased calcium intake for girls and young women (119). A second report, *Healthy People 2000: National Health Promotion and Disease Prevention Objectives*, includes recommendations to increase public awareness of osteoporosis and ways to prevent the disease (121).

ODPHP operates a “National Health Information Center.” The center refers people who write or call with questions about osteoporosis to other organizations, including the National Osteoporosis Foundation, the National Institute on Aging, the National Institute of Arthritis and Musculoskeletal and Skin Diseases, the National Dairy Council, the American College of Obstetricians and Gynecologists, and the National Women’s Health Network (132).

In 1984, ODPHP initiated the “Healthy Older Persons Campaign” to educate older people about health practices that can reduce the risk of disabling illness. The campaign was part of a joint initiative by the U.S. Department of Health and Human Services and the Administration on Aging to encourage public and private organizations at the national, state, and community levels to work together to provide health education to older Americans. The campaign focused on six areas of disease prevention: exercise, nutrition, safe use of medicine, smoking cessation, injury prevention, and preventive health services.

To implement the “Healthy Older Persons Campaign,” ODPHP established contacts in each state and helped to develop coalitions in most of the states to implement the campaign. ODPHP developed broadcast and print materials, including public service announcements, posters, and fact sheets about disease prevention for older people and provided samples of the materials to coalition members along with technical assistance on how to use the materials. The "Healthy Older Persons Campaign" is regarded as a successful model of a public health education effort to encourage a specific group of people to adopt lifestyle habits that decrease the risk of chronic diseases. When the

\(^{12}\) See, for example, Alliance for Aging Research, May 4, 1994 (2).
campaign ended in 1988, 43 states had participated in the campaign, and every state had a lead agency to direct health education programs for older people (61).

The “Healthy Older Persons Campaign” did not address specific diseases, although the prevention messages about nutrition, exercise, and injury prevention are similar to those recommended to prevent osteoporosis. Some osteoporosis advocates point out, however, that since the campaign did not link the prevention messages to specific diseases, including osteoporosis, it probably did not increase public awareness or knowledge about the relationship between the recommended health behaviors and the diseases (95).

**Information Available from the Office on Women’s Health**

The Office on Women’s Health within the U.S. Department of Health and Human Services, Office of the Assistant Secretary for Health, was established in 1991 to advise the assistant secretary about scientific, medical, legal, ethical, and policy issues relating to women’s health. The office is a focal point for the coordination of federal activities with respect to women’s health. It was instrumental in developing the 1991 PHS Action Plan for Women’s Health, which includes research and prevention activities for osteoporosis (128). The office is also responsible for monitoring implementation of the plan (65). The office has recently begun to develop some public information materials about osteoporosis. In addition, as is true of the NIH Office of Research on Women Health, mass media coverage of the activities of the Office on Women’s Health and public presentations by its staff call attention to osteoporosis as a women health issue and increase public awareness of the disease.

**Information Available from the Centers for Disease Control and Prevention**

The Centers for Disease Control and Prevention (CDC) within the U.S. Department of Health and Human Services develops national programs for the prevention and control of communicable and chronic diseases and implements them through state and local health departments. The CDC has funded osteoporosis-related research and is currently conducting a study of the incidence of osteoporosis-related fractures.

The CDC does not publish information about osteoporosis for the public. Its public information activities are informal and limited. In 1991, public inquiries about osteoporosis were being answered by the chief of the CDC’s Enzyme Research Center, Environmental Health, who reported responding to five to 10 inquiries a year. In addition to using the CDC’s resources to provide answers to questions about osteoporosis, callers were usually sent National Osteoporosis Foundation publications and referred to the foundation’s Georgia Chapter for additional information (109).

In 1991, the CDC provided funds to two states, Colorado and New Jersey, for three-year osteoporosis projects that include public information components. The project in Colorado involves the development of an inventory of medical specialists, screening sites, support groups, and community agencies with programs for osteoporosis prevention and treatment (13). The project in New Jersey involves the provision of osteoporosis education programs for elderly people in three counties, the development of an osteoporosis resource manual, and the dissemination of osteoporosis information to the 116 local health departments in the state (72).

**Information Available from the Administration on Aging**

The Administration on Aging within the U.S. Department of Health and Human Services is the federal agency responsible for promoting the health and well-being of older Americans. The agency administers its policies and programs through a nationwide network of state and community agencies, known as *state units on aging* and *area agencies on aging*.

As previously mentioned, the Administration on Aging provides funding for the National Resource Center on Health Promotion and Aging, which is administered by AARP. The center is in-
tended to provide state units on aging and other health care planners and health educators with training, technical assistance, information, and materials to implement health education programs for older people. It maintains a clearing-house that distributes information packets on topics such as nutrition, exercise, injury prevention, smoking, alcohol use, and safe use of medications. The center also publishes a newsletter, *Perspective in Health Promotion and Aging*. Several issues of the newsletter, including one focused on men’s health, have mentioned osteoporosis and referred readers to the National Osteoporosis Foundation for additional information. The center is primarily a resource for state units on aging and other aging network agencies, and people who call with inquiries about osteoporosis are generally referred to the National Osteoporosis Foundation. The center also mails these callers a brochure and order form for National Osteoporosis Foundation publications (74).

From 1987 through 1992, the Administration on Aging provided funding to the National Osteoporosis Foundation to develop educational materials for National Osteoporosis Prevention Week. The Administration on Aging has also distributed the foundation’s educational resource kits to state units on aging, which in turn may distribute them to area agencies on aging, senior centers, and other community organizations (112).

In 1990, the Administration on Aging helped to fund public service announcements developed by the National Osteoporosis Foundation. As noted earlier, the public service announcements featured Dr. Louis Sullivan, then-secretary of the U.S. Department of Health and Human Services, who urged people to take steps to prevent and treat osteoporosis and advised them to contact the National Osteoporosis Foundation for the “Bone-wise” osteoporosis information kit, described earlier. The brochures and fact sheets in the “Bone-wise” kit were also paid for by the Administration on Aging.

Area agencies on aging, as a rule, do not function as public information agencies (22), but OTA is aware of several area agencies on aging that have conducted osteoporosis education activities either in conjunction with National Osteoporosis Prevention Week or as part of other health education campaigns. For example, in conjunction with the 1990 National Osteoporosis Prevention Week, the Area XIV Area Agency on Aging in Creston, Iowa, distributed National Osteoporosis Foundation publications and arranged for speakers from the County Extension Service agency to speak about osteoporosis and nutrition at senior nutrition sites.

In 1990, the Albuquerque Area Agency on Aging, in Albuquerque, New Mexico, sponsored a series of health education programs on a television network that serves New Mexico, Colorado, and parts of Arizona. The series included one program that featured an orthopedist who discussed osteoporosis and its prevention and treatment and a physical therapist who discussed ways to prevent falls and fractures. A second program featured a physician who discussed the beneficial effects of estrogen therapy for osteoporosis (30).

The New York City Department for the Aging, a department of municipal government and the largest area agency on aging in the country, has offered information about osteoporosis to older people through its health education program, “Project Stay Well.” The program trains older volunteers (average age 64) to conduct 12-session courses about a variety of health-related topics, including osteoporosis. Mini-courses, including one about osteoporosis, are offered for older people who do not want to participate in a full 12-session course. Educational materials from the National Dairy Council and NIA’s Age Pages are distributed to the course participants. The health education programs are conducted at libraries, senior housing complexes, and senior centers. As of January 1991, the program had 400 trained volunteers who had presented “Stay Well” programs to over 3,000 older people at 82 sites in the city (26).

### Information Available from the Department of Agriculture

The U.S. Department of Agriculture (USDA) educates the public about osteoporosis through its Cooperative Extension System, a nationwide net-
work consisting of the federal Cooperative Extension Service and state and county Cooperative Extension Service agencies. Cooperative Extension Service agencies in Colorado, Indiana, Kansas, Maryland, Minnesota, Nevada, New Mexico, New York, North Carolina, West Virginia, and Wisconsin have published fact sheets or brochures about osteoporosis (116). Because these materials are often produced for nutrition education programs, much of the information focuses on the role of nutrition, especially calcium, in reducing the risk of osteoporosis. For example, the University of Wisconsin/Madison Cooperative Extension Service offers four brochures: "Links Between Nutrition and Osteoporosis," “How To Get Enough Calcium,” “What To Do If You Are Lactose Intolerant,” and “Links Between Excessive Exercise, Weight Loss and Osteoporosis.” The last brochure discusses the increased risk of osteoporosis due to excessive exercise and notes that men, as well as women, are at risk of osteoporosis.

Information Available from State Osteoporosis Programs

As previously mentioned, Colorado and New Jersey have CDC-funded projects to develop osteoporosis public information programs. The New Jersey project involves the provision of osteoporosis education programs for elderly people at senior nutrition sites. Early experience with these programs has shown that the presentations must be shorter than originally planned since the attendees generally do not want to remain long after the meal (29). In the past year, the project has also worked with the Girl Scouts on an osteoporosis-related badge (29).

In 1986, Wisconsin conducted a one-year, public information campaign. “Osteoporosis: Stop the Ladykiller.” The campaign, developed by the Wisconsin Division of Health, consisted of three parts: a multimedia campaign to increase public awareness; training sessions for physicians and allied health professionals; and training sessions for volunteers to enable them to conduct educational outreach activities at the local level. The Wisconsin Division of Health worked with a public relations firm to develop public education messages that declared that osteoporosis is a “Hipbreaker, Humpmaker, Heartbreaker—Lady Killer” but can be prevented. The messages were targeted to women ages 18 to 65, physicians, pharmacists, nurses, dietitians, and health educators (135).

Public service announcements were distributed to 121 radio stations and 18 television stations. A follow-up survey indicated that 57 percent of the radio stations and 51 percent of the television stations aired the announcements that advised women to consult their physician for information about osteoporosis (135).

A consumer brochure was developed that discussed osteoporosis and its risk factors. The brochure was distributed by volunteers from local public health agencies, health care organizations, the University of Wisconsin-Extension Service, the Dairy Council of Wisconsin, Inc., and other agencies. Many of these agencies also conducted other public information activities, such as distributing posters, setting up information booths at shopping centers and grocery stores, speaking at community forums, and participating in workshops and health fairs (135).

Limited funding permitted the Wisconsin Division of Health to conduct the osteoporosis information campaign for only one year. The campaign cost $400,000: the Division of Health paid $20,000 for printing brochures, training volunteers, and incidental expenses, and the remaining costs were funded by individuals, companies, and foundations (135).

CONCLUSION

As described in this background paper, a large quantity of public information about osteoporosis has been and is being produced by the mass media and commercial publishers, the National Osteoporosis Foundation and other voluntary associations, individual health care organizations, dairy industry organizations, pharmaceutical companies, and federal and state government agencies. Despite the existence of this information, many people are not well informed about the disease.
Although some new and updated public information materials would be helpful, OTA does not believe that the problem of lack of public knowledge about osteoporosis will be solved by the generation of more pamphlets or videotapes. Better ways of disseminating public information materials and programs are needed. The establishment of a national resource center on osteoporosis and related bone disorders will undoubtedly improve the dissemination of these materials and programs. The resource center can collect and catalogue the existing public information materials and programs, identify materials and programs that are needed but not available, create the needed materials and programs, and respond to requests for information. Since health care professionals as well as lay persons will use the resource center, it should collect and disseminate reports and articles from the medical and scientific literature, as well as the kinds of public information materials discussed in this background paper.

The existence of an entity with primary responsibility for public information about osteoporosis should help to reduce some of the duplication of effort that currently occurs because public and private agencies and groups are not aware of the educational materials that already exist. Once one organization is designated as the national resource center, other agencies and groups will be able to contact that organization to determine whether the materials they need already exist, and, if the materials do exist, they can spend their time and resources on dissemination and other functions rather than on the development of new materials.

At present, the National Osteoporosis Foundation is functioning as a de facto national information clearinghouse for osteoporosis. The foundation considers itself a national osteoporosis resource center, and many other agencies and groups that provide public information about osteoporosis refer people to the National Osteoporosis Foundation for information they cannot provide. Although the foundation is a relatively small organization, it is currently responding to a large volume of calls and letters. Several federal agencies also respond to requests for information about osteoporosis. These agencies receive many fewer requests than the National Osteoporosis Foundation for such information. The federal agencies also do less than the National Osteoporosis Foundation to identify themselves as sources of osteoporosis information. As a result, people who want information about osteoporosis may not know that the information is available from these agencies.

Given the National Osteoporosis Foundation's current functioning as a resource center on osteoporosis, an obvious choice would be to designate the foundation as the federally mandated national resource center. It is also possible that the selection process now underway at the National Institutes of Health will produce a credible alternative to the foundation.

Most, if not all, federally mandated information clearinghouses have an advisory board to oversee their operation and advise them about the content of their educational materials and programs. The resource center on osteoporosis and other bone diseases should have such a board. The board should include representatives of the different population groups affected by osteoporosis and other bone diseases and individuals with different points of view about methods of prevention and treatment for these diseases.

In addition to better ways of disseminating existing public information, some new educational materials and programs are needed. As noted earlier, most existing public information about osteoporosis focuses on prevention of bone loss and is targeted to middle-aged and older, white women. This background paper has described some impressive educational materials and programs for children and teenagers, most of which have been produced and/or paid for by dairy industry organizations. In contrast, OTA has found very little public information about osteoporosis for men and ethnic minority persons. Although men and some ethnic minority persons are less likely than white women to have osteoporosis, no one is immune, and educational materials and programs designed for these persons should be available.
Given the increasing attention to women’s health issues and the inclusion of osteoporosis as a women’s health issue, the availability of educational materials and programs about osteoporosis in men is particularly important. More educational materials and programs are also needed for people who already have osteoporosis, particularly older people who are most likely to have the disease and to need information about how to avoid falls and fractures and how to cope with the disability and pain often associated with it.

Public education materials and programs that are designed for certain types of people are only helpful if they get to those people. The perception that the existing public information about osteoporosis is confusing may in part reflect the fact that some people are exposed to educational materials and programs designed for other types of people whose situations and information needs are different. The resource center can help to solve this problem because individuals who contact the resource center will be able to describe their particular situations and receive materials appropriate for their needs.

Ideally, public information about osteoporosis would convey a simple, accurate message about what different types of people can do to prevent and treat the disease. Such a message cannot be developed at present because of the current uncertainty about the efficacy of many of the proposed methods of prevention and treatment. Now and in the near future, most simple messages about the prevention and treatment of osteoporosis are likely to be incorrect, and conversely the correct message is likely to be complex.

OTA believes that the public would benefit from educational materials and programs that convey more of this sense of uncertainty than is conveyed by the materials and programs OTA has seen. People need to understand that simple, definitive answers about many aspects of the prevention and treatment of osteoporosis are not yet available, and that ongoing research is likely to result in findings that contradict some current ideas about the efficacy of various methods of prevention and treatment.

Many of the educational materials and programs described in this background paper list investigational medications as possible methods of prevention and treatment for osteoporosis without pointing out that these medications have not been approved for osteoporosis by the FDA. Other materials and programs point out that the medications have not been approved for osteoporosis but give the misleading impression that the medications are in the pipeline for FDA approval and that it is only a matter of time before they will be approved. This has not been the case thus far for either etidronate or sodium fluoride. Both of these medications are available on the market because they are approved for other indications, and many individuals have taken and continue to take them. Some and perhaps many of these individuals probably are not aware of the FDA approval status of the medications, or more particularly, the reasons for the FDA’s decisions thus far not to approve the medications. OTA believes that public education materials and programs that discuss investigational medications should inform people about the approval status of the medications and the reasons for FDA decisions, if any, not to approve the medications. Certainly educational materials and programs produced or disseminated by a publicly funded resource center should include this information.

Most of the educational materials and programs described in this background paper focus on what works, or is believed to work, to prevent or treat osteoporosis. For people who are interested in prevention and treatment, information about what does not work is just as important as information about what does work, and they should have access to both types of information. OTA has seen some articles in consumer magazines that describe as effective substances for which there is no scientific evidence of efficacy. More importantly, however, most of the public information materials discussed in this background paper imply or state explicitly that interventions, such as increased calcium intake and exercise, prevent osteoporosis. Although there are some people for whom this message may be correct,
there are other people for whom it is almost certainly incorrect. The latter may benefit in many other ways from increased calcium intake and exercise but are unlikely to be fully protected from osteoporosis. OTA believes that public education materials and programs should inform people about what is not likely to work as well as what is likely to work for different subgroups of the population.

Lastly, it is important to keep in mind that public information is only one way people learn about osteoporosis, and improved public information is one component of an effective system to prevent and treat the disease. Aside from the various sources of public information discussed in this background paper, the most likely other source of information about osteoporosis is physicians and other health care professionals. Some people first learn about osteoporosis from their physician or another health care professional. Others learn about osteoporosis from another source and then go to their physician or another health care professional for further information and help in devising a plan to prevent or treat the disease. Many health care professionals are not knowledgeable about osteoporosis, and improved professional education and training is another important component of an effective system to prevent and treat the disease.
Appendix A: Coverage of Osteoporosis in Consumer Magazines
For this background paper on public information about osteoporosis, the Office of Technology Assessment (OTA) contracted with Consumer Choice Unlimited, Inc., for a survey to determine what was being said about osteoporosis in consumer magazines and to whom the information was targeted. Consumer Choice Unlimited reviewed the contents of 62 consumer magazines from April 1990 through March 1991. Table A-1 lists the 26 magazines that included no osteoporosis-related articles in the one-year period of the study. The remaining 36 magazines included a total of 97 osteoporosis-related articles; table A-2 lists these magazines with the month and title of each relevant article and the category and subcategory of the article’s content. As noted earlier, Consumer Choice Unlimited used broad criteria for identifying osteoporosis-related articles, and a few articles about vitamin D, exercises, and calcium are included even though they did not specifically mention osteoporosis.

The full report of the survey, "Review and Analysis of Consumer Magazine Articles Related to Osteoporosis," is available from the National Technical Information Service, U.S. Department of Commerce, 5285 Port Royal Road, Springfield, VA 22161; telephone (703) 487-4650; rush orders 1 (800) 553-NTIS; publication no. PB 94-188042.

### Table A-1: Consumer Magazines That Did Not Publish Any Osteoporosis-Related Articles from April 1990 Through March 1991

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<tr>
<th>Magazine</th>
<th>Audience Category</th>
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<tr>
<td>Baby Talk</td>
<td>Child</td>
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<td>Canadian Child</td>
<td>Child</td>
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<tr>
<td>Eating Well</td>
<td>Health</td>
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<tr>
<td>Ebony</td>
<td>Of color, general</td>
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<tr>
<td>Essence</td>
<td>Of color, women</td>
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<tr>
<td>First for Women</td>
<td>General</td>
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<tr>
<td>Food &amp; Wine</td>
<td>Gourmet</td>
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<td>Go/den Years</td>
<td>Senior</td>
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<tr>
<td>Mature Outlook</td>
<td>Senior</td>
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<tr>
<td>Men's Fitness</td>
<td>Men</td>
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<tr>
<td>Mirabella</td>
<td>Senior</td>
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<tr>
<td>Modern Maturity</td>
<td>Over 40</td>
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<td>Consumer</td>
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<td>Parenting</td>
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<td>Teen</td>
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<tr>
<td>Southern Living</td>
<td>General</td>
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<td>American Health</td>
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<td>Sodium fluoride calc-</td>
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<td>American Health</td>
<td>March</td>
<td>*Which Supplements Should You Take?</td>
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<td>Beauty</td>
<td>April</td>
<td>Soda Addiction and Bone Fractures</td>
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<td>Better Homes &amp; Gardens</td>
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<td>Black Elegance</td>
<td>March</td>
<td>*Give Young Teeth a Good Start</td>
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<td>*Benefits and Risks of Hormone Therapy</td>
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<td>Sodium fluoride</td>
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<td>Consumer Reports</td>
<td>November</td>
<td>*Process American Slices (chart omits calcium)</td>
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<td>Low-Fat Yogurt Low-Cal Calcium</td>
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<td>Family Circle</td>
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<td>Glamour</td>
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<td>Oxalate</td>
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<td>Overview</td>
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<td>Good Housekeeping</td>
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<td>*Cram for Calcium</td>
<td>Peak bone mass</td>
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<td>July/August</td>
<td>Kale for Calcium</td>
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<td>In Health</td>
<td>May/June</td>
<td>Tracking Women’s Bone Loss</td>
<td>Exercise</td>
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<td>January/February</td>
<td><em>The Calcium Advantage</em></td>
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<td>In Health</td>
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<td>Ballerina Bones</td>
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<td>In Health</td>
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<td>Sources</td>
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<td>*HGH: Drug for the Decade?</td>
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<td>November</td>
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