

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

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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 "Bonewise" 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

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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 Health Network is an affiliate 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 net work 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 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

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 spe-

cialized 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

osteoporosis 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



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

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 (101).

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

center, and osteoporosis research at the center and elsewhere.

***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.

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.

### 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 sever-

al 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

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.
- “Super You: A Guide to Getting Fit and Staying Fit,” for 9- to 11-year-olds, offers a 24-page “Super You” booklet with games, activity ideas, nutrition information, nutrition puzzles, snack recipes, and a “Superkids” poster.
- “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.
- “Food Power: A Coach’s Guide to Improving Performance,” for coaches, particularly of athletes in grades 11 and 12, discusses training diets, pre-competition meals, carbohydrate loading, and effects of dehydration on performance.
- “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 (77).

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 (77).

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

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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 is

appeared in magazines, such as *Vogue*, *McCalls*, *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.<sup>9</sup>

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.<sup>10</sup> 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*, *McCalls*, *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 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

<sup>9</sup> Beginning in the fall 1991, the publicity efforts of the National Osteoporosis Foundation and the American Osteoporosis Alliance were conducted separately. The American Osteoporosis Alliance went out of existence in 1994.

<sup>10</sup> As noted earlier, pharmaceutical companies also use paid advertising, particularly in medical journals, to promote medications for osteoporosis to physicians.