

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 followup 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] y 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 only 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.