Proceedings:
National Strategic Planning Conference for the Prevention and Control of Oral and Pharyngeal Cancer

August 7-9, 1996

Conference Sponsors

The American Dental Association,
Centers for Disease Control and Prevention, and
National Institute of Dental Research, National Institutes of Health

Acknowledgments

The following organizations and individuals devoted numerous hours to planning the 1996 oral cancer strategic planning conference. Without their tireless efforts, the conference would not have been possible.

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CHAPTER 1: INTRODUCTION

Background

One American dies from cancers of the oral cavity and pharynx every hour. This translates into an estimated 8,000 deaths each year. Some 30,000 individuals are diagnosed annually with these cancers.

Oral cavity and pharyngeal cancer account for 2-4% of all cancers diagnosed annually in the United States. They occur twice as often in men as in women; the average age at diagnosis is 60 years. Approximately 75% of oral cancers[1] are attributed to the use of tobacco, either smoked or smokeless (spit). Using tobacco in combination with alcohol significantly increases the risk of developing oral cancer.

Despite advances in surgery, radiation, and chemotherapy, only about half of all persons diagnosed with oral and pharyngeal cancer survive more than 5 years. Although the survival rates for many other cancers (e.g., breast, colorectal, and prostate cancer) have improved over the past 20 years, the long-term prognosis for oral and pharyngeal cancer has not changed significantly; in fact, the survival rates for minorities with oral cancer have worsened. Most oral cancers are not detected at a localized stage. Persons with oral cancer who survive are more likely than other cancer patients to develop new oral cavity or other cancers. Associated morbidity, physical disfigurement, mental anguish, and economic cost add considerably to the challenge of living with this disease.

High-priority goals for public health are to lower the number of new cases of oral cancer as well as its associated morbidity and mortality. Prevention and early diagnosis assume critical roles in achieving these goals and can be accomplished by:

- Understanding cause and effect and modifying associated risks.
- Recognizing and controlling precancerous conditions and lesions.
- Establishing the earliest possible diagnosis and administering adequate therapy.
- Effectively managing the complications of treatment.

In 1992, a consortium of health agencies — led by the Centers for Disease Control and Prevention (CDC) and the National Institute for Dental Research of the National Institutes of Health (NIDR/NIH) — initiated a major planning effort to establish objectives, goals, and programs for reducing oral cancer morbidity and mortality. The first key step in this effort occurred in December 1992, when the Oral Cancer Workgroup was convened to advise CDC on ways to facilitate a coordinated effort for the prevention and control of oral and pharyngeal cancer. This group developed both long-term and short-term goals, which were published in 1993 and disseminated to a broad range of organizations and individuals interested in preventing

[1] The term “oral cancer” includes cancers of the lips, tongue, floor of the mouth, palate, gingiva and alveolar mucosa, buccal mucosa, and oropharynx.

and controlling this disease.

One of the group's recommendations called for the development of position papers on the state of the science of oral and pharyngeal cancer. Toward that end, CDC's Division of Oral Health (DOH) commissioned nine background papers intended to provide an overview of the science related to the prevention, control, and treatment of the disease — from epidemiology through rehabilitation — and to address current knowledge, emerging trends, and opportunities and barriers to further progress. Each paper was prepared by a different set of authors, who represented a variety of specialties and expertise and were backed by personal experience, current literature reviews, and in-depth critiques.

The Oral Cancer Workgroup further recommended that CDC convene a strategic planning conference to develop a set of national strategies for action to make oral cancer prevention and control a higher priority in this country. In anticipation of this conference, CDC, in partnership with the NIDR and the American Dental Association (ADA), formed an Oral Cancer Conference Advisory Group that, during 1995 and 1996, worked closely with DOH to plan the meeting. The members of this group, along with a larger cadre of oral cancer experts, also developed a draft set of strategies for consideration during the conference. The draft strategies and a working conference version of the background papers were mailed to participants before the conference so that they could be used as a springboard for discussion.

Conference Agenda

The conference was held on August 7-9, 1996, at the ADA Headquarters building in Chicago. A deliberate effort was made to invite individuals representing a broad range of health care and human services disciplines, as well as experts in the areas of oral cancer prevention, treatment, and research to facilitate cross-fertilization during the strategic planning process. The exchange among individuals who seldom have the opportunity to work together was a positive component of the conference.

The meeting began with brief welcoming remarks by the sponsors: ADA, CDC, and NIDR. The chief dental officer of the U.S. Public Health Service then conveyed his congratulations to the sponsors for the excellent planning and organization of the meeting. Presentations from four nationally recognized experts in oral cancer followed; they covered the epidemiology of oral cancer, its etiology, ongoing and needed research, lessons learned from experience with five other cancers (breast, lung, prostate, and cervical cancer as well as leukemia), and the human impact of oral cancer from a survivor's perspective.

After the opening plenary session, participants were divided into five working groups, each focused on a different area:

- Data collection, evaluation, and research
- Professional education and practice
- Public education
- Public health policy

- Advocacy, collaboration, and coalition building

Assignments were based on preferences expressed by participants before the conference or by participants' expertise. Each working group was led by a chair and co-chair, preselected from among the conference participants; their charge was to develop recommendations and strategies for action in their assigned area. The working groups convened Wednesday afternoon and most of the day on Thursday; a short break on Thursday morning gave chairs an opportunity to share progress to that point. On Friday morning, the entire group gathered to hear the chairs present their respective groups' recommended strategies. Participants had a chance to provide oral or written comments, some of which stimulated further discussion and revision in the strategies.

Post Conference Activities

Following the conference, CDC mailed the draft strategies to all participants for formal review and comment. These proceedings summarize the presentations comprising the opening and closing sessions of the conference and the final strategies recommended by the working groups. DOH plans to publish a summary of the conference and recommended strategies in a summer 1997 issue of the CDC *Morbidity and Mortality Weekly Report — Recommendations and Reports*.

It is the conference sponsors' hope that the strategies will stimulate an effective national campaign to prevent and control cancers of the oral cavity and pharynx. Toward this end, DOH is pursuing the establishment of a multidisciplinary and multiorganizational National Oral Cancer Steering Committee. The committee will explore the development of a National Oral Cancer Plan, with each of the agencies or organizations represented on the committee assuming responsibility for moving a specific recommendation or strategy forward. DOH, working through this committee, will then be able to track progress and disseminate information related to oral cancer prevention and control to interested groups and organizations.

CHAPTER 2: OPENING SESSION

WELCOMES AND OPENING REMARKS

Dr. Donald Marianos

Director, Division of Oral Health, CDC

Dr. Donald Marianos welcomed participants to the first National Strategic Planning Conference for the Prevention and Control of Oral and Pharyngeal Cancer. (See Appendix A for the conference agenda.) He noted that the conference represented the culmination of nearly 4 years of planning and coordinated effort involving CDC's Division of Oral Health (DOH), the National Institute of Dental Research (NIDR), and the American Dental Association (ADA). He also thanked the more than 75 individuals who had served as expert consultants, authored and reviewed the background papers, developed the draft strategic planning document, and helped to plan the meeting.

Dr. Marianos summarized the chronology of events leading up to the conference, beginning in December 1992 when CDC convened the Oral Cancer Workgroup. He noted that one of the suggestions that had emanated from the 1992 meeting was for CDC to convene a strategic planning conference to develop a set of national strategies for the prevention, early detection, and control of oral cancer. The overarching goal of the meeting, he told the audience, would be the development of an action plan and policy recommendations that would make oral cancer a higher priority in this country. Toward that end, DOH had commissioned nine background papers on the state of the science of oral and pharyngeal cancer. Dr. Marianos thanked the many individuals who had spent countless hours writing, editing, and reviewing this document. In particular, he thanked Dr. Sol Silverman, Jr., and Dr. Deborah Winn, who had served as the science editors for the document, and Ms. Susan Toal, who had served as technical editor.

Dr. Marianos then recognized the Oral Cancer Conference Advisory Group, which had worked closely with CDC, NIDR, and ADA to plan the meeting. He also thanked the cadre of dedicated and talented individuals who had agreed to develop a draft set of strategies for consideration during the conference and to serve as chairs and co-chairs for conference deliberations (the Oral Cancer Conference Strategic Planning Working Group Chairs and Members). (See Appendix B for a listing of the chairs and co-chairs.)

Next he thanked the conference co-sponsors: NIDR, for its staff time and financial support over the past 3 years, and the ADA, for graciously allowing the use of its headquarters building for the conference. In particular, he recognized Jane Forsberg Jasek of the ADA's Council on Access, Prevention and Interprofessional Relations; Jim Sweeney and his staff in the Department of Conference Services; and the staff in the Department of Media Relations. He also noted the efforts of the ADA Health Foundation staff, who had acquired funding from the Robert Wood Johnson Foundation to support the food functions during the conference and funding from Zila Pharmaceuticals, Inc. The American Cancer Society was also recognized for awarding a Cancer

Control Grant to the ADA Health Foundation; the grant supported travel for several experts and process consultants as well as publication of the proceedings. Finally, Dr. Marianos thanked Barbara Park and Dolores Malvitz, DOH staff, for their work in organizing the conference.

Dr. William Ten Pas

President, American Dental Association

Dr. William Ten Pas welcomed conference participants on behalf of the ADA's board of directors and officers. He stressed the potential power of the group to learn, work, and plan toward a common goal — the prevention and control of oral cancer. Dr. Ten Pas suggested several strategic areas for consideration during the conference, including a focused effort to enhance health professionals' ability to diagnose and treat oral cancer and expanded education of professional athletes to change their "spitting" habits. He expressed concern about the decreasing age of oral cancer victims but urged participants to draw strength and renewed commitment from the courage of oral cancer survivors.

Dr. Reuben Warren

Associate Director, Office of Minority Health, CDC

Dr. Reuben Warren welcomed participants on behalf of CDC; its director, Dr. David Satcher; and its 7,000 employees. He extended a special welcome to a friend and colleague, Dr. Clement Luhanga, founding dean of the dental school in Tanzania, Africa. Dr. Warren noted the reputation that the city of Chicago has earned for "moving a national agenda" and cited a concurrent meeting in the city at which African-American groups were developing an agenda for addressing key health care issues. He expressed confidence that the conference on oral cancer would "move the oral cancer agenda" despite the complexity of the challenge.

Dr. Warren recalled the Secretary's Task Force on Black and Minority Health, convened in 1985, as the federal government's first official acknowledgment that health problems could be chronicled by race and ethnicity. He urged participants to consider the impact that racial and ethnic issues have on oral cancer prevention and control. Dr. Warren noted with excitement the collaboration of CDC, NIH, and ADA in the area of oral cancer and told the conference that he was looking forward to the upcoming deliberations and outcomes.

Dr. Sherry Mills

Director, Extramural Research Branch, Division of Cancer Prevention and Control, National Cancer Institute

Dr. Sherry Mills greeted participants on behalf of the National Cancer Institute (NCI) and briefly described several new NCI initiatives in the areas of youth access to spit tobacco and the development of programmatic approaches to public health education. She expressed particular interest in conference outcomes related to research, which she hoped would complement NCI's current and planned research efforts.

Dr. Stephen Corbin

Chief of Staff, Office of the Surgeon General, and Chief Dental Officer, U.S. Public Health Service

Dr. Stephen Corbin extended the greetings of Acting Surgeon General Dr. Audrey F. Manley and congratulated the three conference sponsors for convening the "who's who" of health professionals involved in fighting oral cancer, including those in dentistry and public health, basic research, and medical and rehabilitation specialties. He expressed optimism that the conference objectives would be achieved and that oral cancer would be elevated on the national agenda as a major health problem. He recounted the lack of progress in changing the epidemiologic patterns of oral cancer, despite what is known about its etiology and the value of early diagnosis. He urged participants to use the Healthy People 2000 Objectives related to oral cancer as a template for identifying specific strategies.

Dr. Corbin then presented two awards. He presented the Chief Dental Officer's Exemplary Service Award to Dr. Sol Silverman, Jr., for his contribution to the mission of the chief dental officer and the Surgeon General's Exemplary Service Award to the ADA for its national leadership in the fight against tobacco use and oral cancer. Dr. William Ten Pas accepted the second award on behalf of the ADA.

PANEL PRESENTATIONS

Dr. Harold Slavkin

Director, National Institute of Dental Research, NIH

Dr. Harold Slavkin began his presentation by comparing the oral cancer conference to his favorite Olympic event, the 4-by-400 relay race. In both activities, he explained, individuals are united by a common goal that can only be achieved through mutual respect and cooperation. He asserted that high U.S. mortality from oral cancer (one death every hour) was more than sufficient impetus for the development of new diagnostic and therapeutic tools and techniques. He cited collaboration, partnership, and leveraging of finite resources as keys to lowering prevalence and improving mortality patterns and prognostic statistics for oral cancer.

To set the stage for a closer examination by conference participants of critical policy decisions and their implications for prevention and control of oral cancer, Dr. Slavkin summarized trends in oral cancer etiology; he highlighted the clear association between the disease and tobacco and alcohol consumption. He noted that the risk changes as a function of the amount of tobacco or alcohol consumed; heavy drinkers who smoke more than one pack of cigarettes a day are 24 times more likely to develop oral cancer than individuals who do not use either substance. He also reviewed trends in the 5-year survival rate for oral cancer, which has not improved much over the past decade and commented that African Americans are at particularly high risk for this disease. Over the past decade the incidence of oral cancer among young people has tripled.

Dr. Slavkin then summarized the research areas that he believed need to be pursued. The areas include behavioral research that integrates the sciences of human behavior, the environment, and human biology in a creative fashion; molecular research, particularly on biomarkers for early detection, diagnosis, and prognosis; and basic research to explore the relationship between stem cell biology and the neoplastic process. All of this research, he noted, requires an integrated, interdisciplinary approach with well-defined, common goals and true partnerships.

Dr. Slavkin said he was particularly pleased to announce the upcoming funding of Centers for Oral Cancer (in partnership with NCI) which will focus on the molecular basis of therapeutic approaches. Another new initiative, Centers of Discovery, will award 1-year planning grants to academic institutions for the design of thematic approaches to cancer by integrating biology, behavior, and the environment. At the end of the first year, recipients will submit specific project proposals to test their designs, which will receive careful peer review before being considered for funding.

In closing, Dr. Slavkin reiterated the Healthy People 2000 Objectives related to oral cancer and challenged conference participants to consider creative ways of enlisting support from the "drivers" of success: managed health care entities and health maintenance organizations, which can help make preventive care a reimbursable service; the educational system which can enhance the knowledge of children in grades K-12 about healthy behaviors; and the media, which can influence public perception and knowledge about this critical health problem.

Dr. Sol (Bud) Silverman, Jr.

Professor and Chairman, Department of Oral Medicine, University of California, San Francisco

A clinician and academician with extensive experience in oral cancer, Dr. Sol Silverman congratulated CDC, NIDR, and ADA for convening the myriad experts at the conference. He summarized the planning process that CDC had initiated in 1992 and lauded the background papers. Dr. Silverman reported that the process, involving more than 75 persons, compiled what is currently known about oral cancer epidemiology, etiology, precancerous lesions, early detection, diagnosis, treatment, rehabilitation, complications of treatment, and behavioral aspects.

Dr. Silverman suggested that the practice of prevention could best be improved if the nation focused on gaining a better understanding of four major areas: the etiology of oral and pharyngeal cancer, diagnosis and control of precancerous lesions, early detection, and treatment to prevent or modify complications. He emphasized the importance of concentrating on very specific priorities for action within these four broad areas.

He concluded by showing three slides that highlighted the difficulties clinicians have in differentiating benign from malignant lesions and in recognizing cancer in its very early stages (when it can be controlled completely and result in little or no morbidity). He noted that two-thirds of all patients have advanced disease by the time they present for treatment. This statistic, he said, can and must be improved through effective education of health care professionals and the general public.

KEYNOTE SPEAKERS

Rick Bender

Oral Cancer Survivor

Mr. Bender, the owner of a hobby shop in Round Up, Montana, opened his presentation by stating that it was more than 5 years since he had been diagnosed with oral cancer. He was in his mid-20's at the time of diagnosis, and now speaks to groups around the country about his personal experience with this disease and its physical and psychological toll. He estimated that he had reached more than 100,000 children in the past year.

Mr. Bender noted the two types of spit tobacco — chewing tobacco and snuff — and cautioned participants to avoid using the term "smokeless" tobacco because it implies that spit tobacco is not harmful. He told the audience that when he first began using spit tobacco as a 12-year-old, he was influenced by three factors: peer pressure, advertisements by tobacco companies that billed spit tobacco as a safe alternative to cigarettes, and professional baseball players who used spit tobacco. He chronicled his increased usage throughout high school and his experience with recurring sores on his tongue. He first sought a clinical evaluation in 1988, when one sore persisted and became painful; the diagnosis was undifferentiated squamous cell carcinoma. Surgery revealed a tumor much larger than expected, and one-third of his tongue as well as his lymph glands were removed. He was expected to live only 2 more years.

Radiation effectively controlled the cancer but caused an infection that resulted in three more operations and removal of the right half of Mr. Bender's jaw bone. Although the infection and cancer have not recurred, he said he cannot lick his lips, has limited movement on the right side of his neck because of nerve damage, and is unable to throw a ball to his young son. In addition, he has lost all the teeth on the right side of his mouth. He said he feels fortunate that he can still speak.

Mr. Bender showed a series of slides he uses during his presentations to young children. The slide show pointed out the increased use of spit tobacco among young males and its emerging use by young female athletes, the slick marketing approaches used by the tobacco industry, and the adverse health effects caused by spit tobacco (e.g., mouth cancer, nicotine addiction, gum recession, and gum disease).

In closing, Mr. Bender expressed his strong belief that education is the key to combating spit tobacco use in this country. His educational philosophy is to tell young people what will happen to them if they use spit tobacco, then hope they will make the right personal choice for their health and their future.

Dr. Harold Freeman

Director of Surgery, Harlem Hospital Center; and Professor of Clinical Surgery, Columbia University College of Physicians and Surgeons, New York City

After thanking Mr. Bender for his inspirational message, Dr. Harold Freeman related a chronicle of oral cancer that began with the hushed diagnosis of President Grover Cleveland, who was treated on his yacht, away from the public eye. Decades later, on December 23, 1971, President Richard Nixon signed the National Cancer Act, declaring war against cancer. The act appropriated funds for cancer research and anticipated the discovery of a "magic bullet" to cure the disease.

Dr. Freeman then cited several statistics to prove how far the United States still is from being cancer-free. By the year 2000, he stated, it is anticipated that cancer will cause more U.S. deaths than will heart disease. He shared data on cancer cases and deaths by site in males and females, differences in incidence and death rates among racial and ethnic groups, person-years of life lost for various types of cancer, and types of cancers related to tobacco use.

With these data as background, Dr. Freeman discussed his perception of what has occurred to raise five cancers to national visibility and prominence: breast, lung, cervix, and prostate cancer, and leukemia. He discussed the experience with breast cancer in the greatest detail, as efforts to give this cancer visibility and prominence have been deemed most successful. Factors contributing to the success of these efforts include:

- A sophisticated database that can supply data on morbidity and mortality, economic costs, and human and emotional costs.
- Prominent, well-respected role models with breast cancer, including the wife of a vice-president.
- Development of active advocacy organizations, initiated by women on their own behalf, sometimes with great anger.
- Promulgation of screening guidelines for breast cancer diagnosis, which provided a template for both health professionals and women.
- Discovery of new techniques in surgery, radiation, and chemotherapy that could be applied by clinicians in lieu of radical mastectomies.
- Public education on the need for women to have regular mammograms.
- Federal funding, through the Breast and Cervical Cancer Mortality Prevention Act of 1990, to support breast cancer screening.

Dr. Freeman listed the factors contributing to success in efforts on lung cancer: the Surgeon General's report of 1964, which concluded that smoking causes lung cancer; statements discouraging smoking by all the major medical groups in the country discouraging smoking; and media attention to recent legal issues. Dr. Freeman noted that the greatest single obstacle to reducing the incidence of lung cancer is the country's continued investment in the tobacco industry.

Prostate cancer, Dr. Freeman said, is on the national agenda because of the prostate-specific

antigen (PSA) test, which allows early detection and diagnosis, and because of well-organized advocacy groups such as Us Too. For cervical cancer, the key was the Pap test, which would greatly reduce deaths from this disease if applied appropriately and effectively for all women. As for leukemia, recent treatment research has resulted in development of a combination of drugs that has increased survival rates for certain types of leukemia to 80% (compared with very low survival rates in the 1940s). The human element has also been a factor in leukemia, as everyone is sympathetic to the survival of children.

To apply the nation's experience with these five cancers to oral cancer, Dr. Freeman suggested several key strategies:

- Improve the database, particularly in the areas of economic cost, human cost, years of productivity lost, and profile of cases (e.g., by race, economic status, culture, and lifestyle factors).
- Develop a stronger, better-organized advocacy movement.
- Deliver more education on oral cancer in relation to other cancers.
- Develop early detection guidelines and share them widely with the public and relevant professionals.
- Collaborate with anti-tobacco groups and "piggyback on their efforts" so that oral cancer is added to the list of diseases nationally recognized to be caused by tobacco.
- Work with managed care organizations to ensure they offer oral examinations as part of their prevention package, particularly for those at risk.
- Develop educational information that is culturally and linguistically appropriate for the intended audience.
- Urge the media to stress the importance of regular oral cancer examinations.

Dr. Freeman challenged conference participants to identify actions that can change the nation's approach to this disease. Drawing an analogy to the sinking of the Titanic, he said we must not merely "rearrange the furniture" but instead must change our course.

Finally, Dr. Freeman discussed the impact of poverty on oral cancer specifically and on overall health in general. Poor Americans experience greater pain and suffering because they are diagnosed later than better-off Americans, encounter a variety of barriers when they attempt to negotiate the health care system, must make tremendous personal sacrifices to obtain medical care, engage in lifestyle behaviors and practices that may be hazardous to their health, and often find educational materials and activities irrelevant and insensitive to their needs and priorities. African Americans, he said, represent a disproportionate share of the 35 million Americans who are poor.

Dr. Freeman said he believes that the problem of oral cancer will not be solved until all Americans have universal access to the full array of health care services — including prevention, early detection, diagnosis, and treatment. Currently, 40 million Americans are uninsured for health services.

Dr. Freeman urged conference participants to involve individuals who are most at risk for oral

cancer in the planning and implementation of prevention strategies. He cited the following adage to support this recommendation: "Tell me and I will forget. Show me and I will remember. Involve me and I will understand." He also quoted Albert Einstein, saying, "What you see depends on where you stand." Applying this adage to oral cancer, he urged participants to seek ways of making the public, researchers, policy makers, and scientists see this problem in a way that will help reduce death and increase survival.

CHARGE TO THE WORKING GROUPS

Dr. Myron Allukian, Jr.

Assistant Deputy Commissioner and Director of Community Dental Programs, Boston Department of Health and Hospitals

As chairman of the Conference Advisory Group, Dr. Allukian expressed his pleasure in seeing the conference become a reality. He complimented the two keynote speakers for setting the stage for the deliberations by both humanizing oral cancer and outlining strategies to put oral cancer on the national agenda.

Dr. Allukian acknowledged that many people in the audience had been working long and hard to improve oral cancer outcomes, but often in isolation. He asked participants to be thoughtful in examining the draft strategies that had been prepared, to be creative but practical, and to identify the strategies that would make a difference over the next 4 to 5 years.

It is unacceptable, Dr. Allukian said, that only 14% of surveyed Americans have reported that they had ever had an oral cancer examination. Improving this statistic, he said, will take a concerted effort by all components of the health care system. Just as it takes a village to raise a child, he noted that it takes a community to make an impact on a disease that causes so much tragedy and suffering. He closed with a challenge: "If you don't take the lead, you can't complain that you're being led."

Dr. Jim Feldt

Institute of Community and Area Development, University of Georgia

A consultant to the conference sponsors, Dr. Jim Feldt described the process that he had designed in collaboration with the Conference Advisory Group for use by the working groups. The chairs and co-chairs of each working group had been trained to guide their groups to

- Share their expectations about the conference with each other.
- Clarify the purpose of the working group activity: to focus on one topic and develop a short list of strategies to prevent and control oral and pharyngeal cancer.
- Identify the draft strategies they believe are most "on target."
- Generate a list of additional strategies.

Dr. Feldt said the Wednesday evening reception would provide an opportunity to learn about the strategies being discussed by other working groups and to make suggestions for other groups to consider the following day.

The entire group would reconvene on Thursday morning for a description of progress followed by a question-and-answer period. The working groups would then meet to resolve unfinished business and identify the highest-priority strategies. It was hoped that the top five to nine items would be selected by lunchtime, with the afternoon devoted to discussion of the potential opportunities and barriers to implementation of each priority strategy.

Dr. Feldt said that during the Friday morning session the working group chairs would share with the entire group the priority strategies identified, along with any other major recommendations or issues they wished to raise. Participants would have an opportunity to comment on the working group's reports, both verbally and in writing.

Dr. Feldt emphasized the important role of the chairs and co-chairs, noting that these individuals were the colleagues of participants, not "hired guns." He urged participants to work with them and support them as they tried to keep the group on task and move discussion toward consensus. He clarified the difference between "participants" and "observers"; participants were expected to participate actively in discussion and stay involved and focused. Observers would sit around the outer rim of the room, pay close attention to the discussion, share thoughts and comments when asked by the chair or co-chair, and help the group look at issues from a broader perspective.

Dr. Feldt then distributed and reviewed the ground rules for the sessions and encouraged participants to abide by them. After calling for questions or comments, he asked participants to join their assigned working groups.

CHAPTER 3: WORKING GROUP REPORTS

This chapter presents the strategies for action recommended by conference participants. The strategies were initially drafted by the individual working groups during break-out sessions scheduled for the first two days of the conference; they were revised to incorporate comments raised by participants during a general session on the final morning. Following the conference, the draft strategies were disseminated to all conference participants for a final review to ensure they accurately captured the intent.

ADVOCACY, COLLABORATION, AND COALITION BUILDING

Introduction

Because tobacco use contributes so significantly to morbidity and mortality from oral cancer, its reduction (especially among individuals who consume large amounts of alcohol) must be an essential component of any national strategy to reduce the burden from oral and pharyngeal cancers. To facilitate increased awareness of the connection between combining tobacco use with heavy drinking and the risk for oral cancer, new partnerships must be formed between the oral health community and persons and groups that are working to prevent and control tobacco and alcohol use.

Major gains in oral cancer prevention, intervention, early diagnosis, treatment, research, and funding depend on strong, effective advocacy by the oral cancer community in collaboration with powerful coalitions and interest groups from outside that community. Existing tobacco-control coalitions working at the national, state, and local levels must be made aware that the oral health community is already working in the area of tobacco use prevention and control and wishes to expand its role and impact. Opportunities for involving the oral health community with the ongoing work of these coalitions should be identified. Additionally, third-party payers and health maintenance organizations (HMOs) should reexamine their recommendations and guidelines on the provision of oral cancer examinations for patients at risk for developing cancers of the oral cavity and pharynx so that they better support efforts in early detection and treatment.

Recommended Strategies

Advocacy and coalition building can be accomplished more effectively if the following areas are pursued:

1. Establish an ongoing, institutionalized mechanism to monitor and implement the conference outcomes.

2. Urge oral health and other health professionals to become more actively involved in community health issues, especially tobacco and alcohol abuse, by:

- Developing a comprehensive advocacy training program for a core group of oral health professionals.
- Recruiting and enrolling individuals from the health community in a national database for tobacco and oral cancer advocacy.
- Designing outreach programs to encourage local and state dental societies to become pro-active in oral cancer coalitions and other coalitions to promote oral cancer issues.
- Establishing a network of oral cancer survivors to advocate for change.
- Developing a speakers bureau of sports figures and other prominent, highly visible individuals.

3. Promote the publication and dissemination of the Department of Health and Human Services' biennial *Report to Congress on Tobacco Control Activities in the United States.* This document, mandated by the Comprehensive Smoking Education Act of 1984 (Public Law 98-474) and the Comprehensive Smokeless Tobacco Health Education Act of 1986 (Public Law 99-252), should be a complete review of the health effects of tobacco and trends in its use and serve as an advocacy tool to update policy makers, the media, and the public on key issues.

PUBLIC HEALTH POLICY

Introduction

Although the product of the conference is intended to be strategy-oriented and to stimulate action by the health community, a sound basis for the strategies is fundamental. Good science and sound epidemiology, along with effective education and committed individuals and organizations, are keys to success. Updated knowledge, skills, and attitudes of both health professionals and the public will help attain the goals of lowering the incidence of oral cancer in the United States and reducing morbidity and mortality from this disease.

Recommended Strategies

The major public health policy strategies the working group recommended were organized into four categories: prevention and control of tobacco and alcohol use, professional knowledge and behaviors, compensation, and national programs. These strategies are summarized below.

A. Strategies Related to Prevention and Control of Tobacco and Alcohol Use

1. Increase excise taxes on alcohol and tobacco products to provide funding targeted for prevention programs.

2. Strengthen and enforce youth access laws regarding alcohol and tobacco.

3. Give the Food and Drug Administration regulatory authority over tobacco, because

nicotine is an addictive drug.

4. Prohibit all advertising and promotional activities by the tobacco industry and conduct a well-funded counteradvertising campaign that focuses on smoked and spit tobacco, cigars, and pipe tobacco.

5. Deny federal health and medical research funding to organizations that accept health research funding from the tobacco industry or its "research" institutes.[2]

6. Increase excise taxes on spit tobacco at least enough to make them equal the taxes on cigarettes.

7. Promote a ban on the use of tobacco products among members of all professional sports teams during practice and games.

8. Add strong warnings about the risk for oral cancer to tobacco and alcohol warning labels. In general, tobacco warning labels should cover 25-30% of the front or back of a product's package as well as of advertising copy. Warnings should be modeled after those used in Australia and Canada.

B. Strategies Related to Professional Knowledge and Behaviors[3]

1. Require training in tobacco- and alcohol-use prevention and control, including tobacco cessation, at all levels of training in dental, medical, nursing, and other appropriate health care disciplines.

2. Ensure that clinicians learn to perform oral cancer detection procedures that are appropriate to their professional practice.

3. Urge health professionals to conduct tobacco and alcohol intake assessments routinely on their patients. Certification agencies should ensure that questions on these high risk factors are asked.

4. Encourage appropriate agencies and professional organizations to recommend that all clinicians delivering primary health care routinely perform oral cancer examinations.

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[2] This strategy generated considerable discussion among conference participants. While the working group recognized the strategy's potential impact on research support, it believed strongly that the strategy should be included.

[3] These strategies complement those developed by the Professional Education and Practice Working Group but are listed here because of their public policy implications.

C. Strategies Related to Compensation

1. Work with the American Dental Association and the American Medical Association to reaffirm that existing codes used for reimbursement (e.g., CPT, ICD-9, CDT) appropriately identify the oral cancer examination as a component of the standard oral examination.

2. Ensure that Medicaid, Medicare, traditional insurance plans, and managed care entities consider oral cancer examinations an integral part of a comprehensive physical and/or oral examination.

3. Base reimbursement for oral cancer examinations on the service provided rather than the academic degree of the provider.

D. Strategies Related to National Programs

Designate federal funding for a national program of oral cancer prevention, early detection, and control that includes support for outcomes assessment and policy-based research.

E. Other Strategies

Additional strategies considered important by the working group included:

- Increase public protection from involuntary tobacco smoke by strengthening clean indoor air laws to cover all public and work places.
- Ensure that public policy research on the role of the tobacco industry in subverting public health efforts is an integral aspect of public and private grantmaking activities.
- Further develop comprehensive cancer registries.
- Ensure that individuals being treated for oral cancer are eligible for (and receive) reimbursement by public or private insurance carriers for tobacco and alcohol cessation treatment.
- Assist appropriate groups (e.g., U.S. Preventive Health Services Task Force, Canadian Task Force) to develop screening, early detection, referral, and treatment guidelines for oral cancer.
- Include a strongly worded section on oral cancer prevention, early detection, and control in the Surgeon General's Report on Oral Health.
- Incorporate a focus on oral cancer into CDC's September 1997 "comprehensive integrated" cancer control conference.
- Sponsor a White House conference on oral health, to include oral cancer, and an NIH consensus development conference on oral cancer prevention, early detection, and control.
- Unite major health organizations in support of the National Spit Tobacco Education Program (NSTEP) — a public education and awareness effort that uses professional baseball players to promote oral health and educate young people, parents, and coaches about oral cancer prevention and the dangers of using spit tobacco.
- Issue a joint policy on oral cancer examinations by stakeholder organizations.

- Urge the ACS to develop a policy on oral cancer and to take a leadership role among voluntary organizations.
- Identify alternative sources of income for groups and publishers that accept tobacco money.
- Develop a standardized continuing medical education/continuing dental education (CME/CDE) course on oral cancer examinations and interventions and work with the appropriate licensing agencies to certify it as fulfilling a licensure requirement.
- Increase advocacy efforts to prevent the passage of laws that preempt regulatory and control activities and policies at the local and state levels.
- Encourage major national dental organizations to include mention of oral cancer examinations in their public service announcements promoting dental care.
- Increase efforts to promote oral health awareness among the general public and include information on the ability of oral health and other health professionals to prevent oral cancer through early detection and counseling on the prevention and cessation of tobacco use.
- Urge collaboration among federal agencies and other key organizations to incorporate an oral cancer module into school health education.
- Educate health policy makers about the lack of access to oral health services for vulnerable populations and provide evidence documenting the effect on prevention, early detection, and treatment of oral cancers.

PUBLIC EDUCATION

Introduction

The major risk factors for oral and pharyngeal cancer and their signs and symptoms have been established. As with most cancers, it is known that the earlier these cancers are detected, the more likely the patient will survive. For several decades, exam procedures have existed to detect oral lesions suspicious of cancer, and the ACS recommends that all persons 40 years of age and older have such an examination annually. However, survival rates for oral and pharyngeal cancer remain at about 50% and essentially have not changed over the past three decades.

Recent evidence suggests that the majority of U.S. adults 18 years of age and older are ill-informed about risk factors for oral cancer and its signs and symptoms. Reportedly, only 14% have had an oral cancer examination. Also disturbing are results of other studies that suggest many dentists and physicians are not well informed about oral cancers in general. Thus, a large gap exists between what is known about the prevention and early detection of these cancers and what members of the public and health professions practice.

Health promotion, which includes health education, influences knowledge and behavior at all levels of social organization. It can help bridge the gap between knowledge and practice. Educating public groups, including consumers, high-risk groups, health care providers, and

legislators and other decision makers using appropriate educational approaches is necessary to improve awareness of methods of prevention and early detection, gain their acceptance by these groups, and increase their routine use.

Members of the public need to know that an examination for oral cancer exists and that they can and should request one routinely from a variety of health care providers. The public also needs to know the signs and symptoms of oral cancer, the risk factors for this disease, and ways to reduce risk. This is particularly important for high-risk groups of tobacco and alcohol users.

Recommended Strategies

The major recommendations that emerged from the conference in the area of public education were the following:

1. Develop and disseminate guidelines and lists of resources to assist communities (e.g., states, counties, cities, towns, members of organizations and institutions) in developing, evaluating, and implementing models for oral cancer education. This effort would include an inventory of guidelines, literature, processes, and models.

2. Based on locally assessed needs, develop, implement, and evaluate statewide models to educate all relevant groups. These models should be practical, culturally appropriate, and user-friendly and should include, but not be limited to, the following content areas:
   a. risk factors for oral cancer (tobacco and alcohol use, a diet low in fruits and vegetables),
   b. signs and symptoms of oral cancer,
   c. procedures for a thorough oral cancer exam that show the ease with which it can be performed, and
   d. methods of public advocacy.

3. Persuade (educate) relevant CDC and NIH decision makers, members of Congress, and members of other organizations to secure funding for statewide oral cancer model demonstration projects and to establish an oral health component for integration into the IMPACT program of CDC's Office of Smoking and Health.

4. Develop and conduct a national promotional campaign to raise public awareness of oral cancer and its link to tobacco use (cigarettes, spit tobacco, pipes, and cigars) and alcohol abuse. The campaign might include a mascot or logo, sports figures or other distinguished people as spokespersons, and a national awareness week or month.

5. Ensure that behavioral and educational research is included in the oral cancer budget of research institutes (e.g., NIH, universities, foundations).

6. Increase the representation of educators, behavioral scientists, and oral cancer specialists on the grant review committees of cancer and dental research institutions.

7. Ensure that a national research agenda is developed that includes:
    - Ongoing surveillance to monitor knowledge, opinions and attitudes, and practices of the public, especially high-risk populations.
    - Surveys of the knowledge, opinions, and practices of all relevant health care providers regarding oral cancer.
    - Evaluations of the effectiveness of educational interventions among targeted populations.
    - Changes in existing survey instruments, such as the National Health Interview Survey, to include items on oral cancer comparable to those for other cancers.
    - Inclusion of oral cancer questions in state Behavioral Risk Factor Surveillance System (BRFSS) surveys.
    - Determination of the proficiency of individuals taught to perform an oral cancer self-examination.
    - Assessment of the quality (e.g., reading level, scientific accuracy), quantity, and availability of educational materials directed to the public about oral cancer.

The working group proposed the following additional recommendations:

1. Create and disseminate a tobacco education and oral cancer component for inclusion in elementary-level health curricula.

2. Ensure that target groups include high-risk individuals and their families, low income communities, blue-collar workers, and elderly populations.

3. Include survivors and survivor groups in all public education efforts. Consider using the Internet and existing support groups to identify interested individuals.

4. Compile an inventory of allies in public education (including tobacco and alcohol prevention and control groups, health maintenance organizations, and insurance companies) to support advocacy efforts.

PROFESSIONAL EDUCATION AND PRACTICE

Introduction

For years, the incidence of squamous cell carcinoma of the mouth and throat has remained steady despite wide agreement on the principal risk factors and our ability to characterize the high-risk patient. Moreover, the mouth is readily accessible for rapid, painless visual and digital examination by health care professionals; before many oral cancers are diagnosed, clinical abnormalities often can be detected, biopsied, and diagnosed as premalignant lesions. In addition, current biopsy techniques are simple, inexpensive out-patient office procedures with virtually no untoward sequelae. Yet the majority of oral cancer patients present with relatively advanced

disease requiring extensive therapy; prognosis for their 5-year survival is little better than it was 25 years ago. To reverse this dreary statistic, to drastically reduce incidence, and to improve the prognosis of oral and pharyngeal cancer patients are the goals of the oral health community and other primary health care providers.

Oral health care professionals at all levels nationwide have a principal responsibility for detection and diagnosis of pre-malignant oral lesions (PMOLs) and oral squamous cell carcinoma. They must know the high-risk sites for those lesions and how to properly perform a complete, thorough oral soft tissue examination. This procedure should be incorporated into their routine clinical practice. They must also be able to develop a realistic differential diagnosis and must understand management approaches.

Furthermore, dentists and dental hygienists should know the risk factors for PMOL and oral squamous cell carcinoma (tobacco and alcohol use) and recognize the high-risk patient. As a corollary, they must also be willing and able to counsel patients regarding the adverse health consequences associated with use of tobacco and alcohol products and either perform in-office interventions or direct patients to community resources for assistance.

Last, other health care professionals (physicians, nurses, physicians' assistants), while not sharing the level of training and expertise in oral anatomy and oral pathology required for dental professionals, nonetheless share a responsibility to be cognizant of oral cancer. They, too, must know its risk factors, assess their patients routinely for tobacco and alcohol use, and provide appropriate counseling. They should also know the high-risk sites for oral cancer and be able to examine all other oral cavity sites properly. They should know the general normal appearance of the oral cavity and have established referral patterns for evaluation of patients in whom they detect abnormalities.

Prevention includes not only approaches for reducing tobacco and alcohol risks and for identifying premalignant lesions but also for early detection of oral cancers. Success in these areas will reduce morbidity and mortality. Finally, all health professionals should advise patients about the benefits of good nutrition, because diets low in fruits and vegetables appear to increase the risk of developing oral cancers.

Recommended Strategies

The recommended strategies in the area of professional education included the following:

1. Develop health care curricula that require competency in prevention, diagnosis, and multidisciplinary management of oral and pharyngeal cancer, including the prevention and cessation of tobacco use and alcohol abuse.

2. Promote soft tissue examination for detection of oral cancer as a standard part of a complete patient examination by health care professionals.

3. Develop, promote, and maintain an information base of all professional education materials related to oral cancer.

4. Define, identify, develop, and promote centers of excellence in oral cancer management.

5. Sponsor and promote continuing education for health care professionals on guidelines for the multidisciplinary management of all phases of oral and pharyngeal cancer and its sequelae.

The working group identified several elements that must be in place to facilitate the achievement of the recommended strategies. These elements pertain to all appropriate health care disciplines and include:

- Educational standards and standards of care for oral and pharyngeal cancer.
- Standardized oral cancer examination techniques implemented consistently in clinical practice.
- A national speakers bureau with standardized educational materials.
- An oral cancer home page on the World Wide Web.
- Guidelines for developing oral cancer screening and detection programs.
- Self-instructional materials on oral cancer for health professionals to cover such topics as risk factors, early detection, and counseling of high-risk patients.
- Identification of sources of and deficits in professional education materials related to oral cancer, a catalogue of these materials, and strategies to ensure access to the catalogued materials.

DATA COLLECTION, EVALUATION, AND RESEARCH

Introduction

Although much is known about the causes, prevention, detection, and treatment of oral and pharyngeal cancer, many of the critical research efforts needed to conquer this disease have only just begun. This introduction to strategies for data collection, evaluation, and research is intended to suggest how far we have come and how far we have yet to go.

Compelling evidence from basic research and human population studies shows that the two most important causes of oral cancer are tobacco use and heavy alcohol consumption. Public health efforts to change these behaviors have met with some success; for example, the percentage of U.S. adults who had never smoked increased from 44% in 1965 to 50.2% in 1991. During the twentieth century, mortality from oral cancer has been fairly stable, as use of spit tobacco declined but smoking increased. Mortality for white males and for all females has been dropping recently, as these groups reached their peak rates of tobacco use many decades ago. Oral cancer mortality has declined slightly in the past few years among black men after increasing rapidly for decades. However, disturbing shifts in behaviors have the potential to reverse these trends. Cigarette smoking and use of spit tobacco and alcohol are rising among adolescents and young adults in the

United States. In both Europe and the United States, oral cancer rates are rising among younger men for reasons that are as yet unclear but may be related to these behavioral changes. New strategies for addressing these serious epidemics of adverse health behaviors must be developed and tested.

Alcohol and tobacco use together are responsible for about 75% of oral cancers; the remaining 25% of oral cancers are caused by other factors. The etiology of these other cancers is not well understood, and methods for preventing them need to be developed. Nutritional and other factors appear to play a role in the development of these cancers, but more work is needed to understand whether these factors interact with other contributing causes of oral cancer. We also need to know how to use this information to prevent new oral cancers and reduce the risk of additional primaries in those who already have the disease.

Oral and pharyngeal cancer patients generally have a relatively low socioeconomic status. How socioeconomic status as well as the other health problems they may experience as a result of tobacco and excessive alcohol use affect their diagnosis, treatment, and treatment outcomes has received little attention. In addition, estimates of the costs of treatment and other costs (e.g., productivity, social costs) of oral cancer are needed.

Oral cancer patients experience a very high rate of second primary cancers. Recent findings of discordance in p53 mutations in patients with multiple primary oral cancers offer some insight into the process by which this occurs. The tendency for oral cancer patients to have multiple primaries needs to be considered in developing approaches to prevent new primaries and treat individuals with additional primary cancers. One promising avenue involves chemopreventive agents, that is, pharmacologic therapies designed to prevent disease. Chemopreventive agents, particularly retinoids, have shown promise in preventing oral cancer among persons with leukoplakia lesions and also in preventing second oral cancer primaries. However, further research is clearly needed because toxicity and long-term compliance may be a problem, and many other critical research questions remain. In addition, not all chemopreventive trials have yielded positive results. Finally, there may possibly be only a very narrow dosage range in which the patient might benefit.

The term “oral cavity and pharyngeal cancer” is often used in the scientific and public health literature to refer to cancers that share some features but affect multiple anatomic sites and are disparate in other respects. Salivary gland cancers, lip cancers, and nasopharyngeal cancers differ from cancer of the oral cavity in etiology, histologic type, and many other characteristics; research issues for the treatment and rehabilitation of these cancers differ as well.

Oral cancers frequently are preceded by clinically evident soft tissue lesions, which offer major opportunities for early detection. Only 37% of oral cancers are diagnosed at a localized stage, however. The public’s knowledge of the signs of oral cancer is inadequate, and medical and dental personnel need training to detect oral cancer early. Detection of early oral cavity lesions can be improved through regular examination by qualified providers and greater public awareness of the need for such exams. Lesions which are less accessible to visual inspection, such as those found on the base of the tongue and on the pharynx, will continue to pose problems.

Stage-for-stage, pharyngeal cancers have a worse prognosis than oral cavity cancers.

Our understanding of the molecular events that lead to the development of cancer and influence its prognosis has increased rapidly in recent years. Tumor suppressor genes, oncogenes, apoptosis-related genes, and many other regulatory genes both contribute to the multistage process leading to cancer and help determine its aggressiveness. It has recently been shown that the types of mutations in the p53 tumor suppressor gene are different and more heterogeneous in oral cancer patients who smoked than in those who did not smoke. This information provides a lead about disease etiology and hints at the potential importance of the interactions of genetic and environmental factors. In the future, mutations in p53 in the margins of oral cancer tumors may aid treatment planning. However, the work of identifying, refining, and integrating the many cascading molecular events of a paradigm that can be used to test preventive and therapeutic approaches remains in the earliest stages.

Recommended Strategies

The strategies developed by the working group are intended to facilitate research to address all of these critical scientific questions about disease etiology, prevention, and treatment. The strategies are also concerned with translating research findings into public health action that benefits the public.

1. Increase funding or targeting of funding to initiate and sustain research on oral cancer. NIDR and NCI will award funding for centers for oral cancer research. Other mechanisms could be developed to help direct funding to oral cancer research.

2. Improve the capacity of individual health practitioners and small medical centers to participate in research. To reduce morbidity and mortality from oral cancer, the contributions of a variety of professions are important. Researchers in the areas of basic, clinical, and population-based research are making progress in understanding the carcinogenic process and in developing and testing therapies and preventive measures. In addition to major research centers, individual practitioners and small medical centers need to be enlisted to participate in some of these clinical preventive and therapeutic trials, for several reasons. First, multicenter studies are often needed to recruit sufficient numbers of cases to allow for more generalizable findings and adequate statistical power. Second, the growing trend toward treating oral and pharyngeal cancers in ambulatory settings and managed care delivery systems dictates inclusion of such settings in future clinical and health services research for these neoplasms. Finally, differences in treatment outcomes under various delivery systems and settings can be assessed only if these venues are included in research studies. Curricula and continuing education training for many types of health professionals should be developed to improve knowledge of the nature, value, implementation, and importance of well-designed and well-conducted studies.

3. Improve access to study populations, tissues, and data sources. Population-based cancer registries that can be used for follow-up studies of patients are becoming increasingly common

and can provide excellent sources of subjects for research. However, registries and good sources of patients with nonmalignant oral and pharyngeal lesions are lacking.

Investigation should be made of existing sources of data that can be used, singly or in combination, to address a wide range of questions about cancer care, consequences, and costs. An example is the database that combines the Surveillance, Epidemiology, and End Results (SEER) cancer incidence and survival data with Medicare claims for the same persons. By using existing data resources, researchers can save both time and money.

CDC is working with states throughout the nation to develop high-quality, state-based cancer registries. Combining information from these databases could provide a unique opportunity to conduct research on oral cancer, particularly among smaller subpopulations not sufficiently represented in SEER or single-state registries. At a minimum, it would allow greatly enhanced descriptive epidemiology of oral and pharyngeal cancer.

Basic science research using tissue banks, biopsied lesions, and archival material from surgical pathology laboratories has pointed to the critical role of acquired and genetic mutations and of carcinogen metabolism pathways and alleles. To develop a paradigm to describe the complex sequence of the molecular and behavioral events and interactions that take place in the development of oral cancer, researchers must have access to tissue specimens and detailed information about the behavioral and medical characteristics of large numbers of persons at high risk of oral cancer, of persons with premalignant lesions, and of persons with oral cancer. Researchers should also develop creative ways to share sources of appropriate research subjects and patients, biopsy specimens, and research findings so that they can maximize the information gained from biological studies. Laboratory assays that conserve specimens and allow for different assessments to be made on the same tissue would be valuable.

In addition, researchers should evaluate innovative approaches for identifying individuals known to be at greatest risk and recruiting them for research studies. One such approach may be to form partnerships with organizations that serve persons at potential high risk (e.g., homeless shelters, alcohol and substance abuse treatment centers).

4. Develop valid and reliable patient-oriented indices of health, quality of life, and functioning.

5. Obtain input from user groups about how research or training in research issues can best be accomplished. Persons who are the subjects of research, surveillance, or treatment; professional school students; and clinical practitioners can provide valuable information that can be used in designing effective research studies and research training efforts. Focus groups and other methods can be used to refine the research questions and to formulate effective ways to elicit information from research subjects and gain their cooperation and compliance. Similarly, plans for training of practitioners to participate in research need to be developed with the input of potential students.

6. Facilitate movement from basic to applied research. Strategies that bring together

multidisciplinary groups facilitate this type of cross-fertilization and movement toward real-life application. The cyclical nature of research should also be recognized. Getting findings from research in the clinical sciences, epidemiology, and health services delivery to basic scientists will help focus basic research efforts and enhance their value.

Once scientific discoveries have been made, information about the discoveries and their implications must be diffused rapidly to persons who can apply it to reduce morbidity and mortality from oral and pharyngeal cancer. Strategies to enhance diffusion could include innovative approaches to using the Internet. Basic and clinical researchers need to identify ways of describing complex biological processes to clinicians, students, and the public. Behavioral scientists should address in a more focused way how the public and practitioners understand and act on the concept of risk of disease and its consequences.

7. Strengthen organizational approaches to reducing oral and pharyngeal cancer through organized cooperative and collaborative arrangements, formal centers, and commercial firms.

    a. *Organized cooperative and collaborative arrangements*. One valuable strategy to encourage sharing of research resources and facilitation of research could be a formal collaborative arrangement. NCI has multicenter cooperative groups that conduct therapeutic clinical trials. Such a group could also improve the study of the molecular biology of the disease by sharing patient resources, increasing communication, and attaining greater efficiency in understanding complex therapeutic pathways. A cooperative group could achieve adequate sample sizes for clinical studies and help standardize clinical protocols. A cooperative group of scientists using standardized protocols could also achieve adequate power (sample sizes) for clinical studies and research focused on understanding disease risk and behavioral and genetic interactions.

    Consortia of researchers and medical and dental practitioners also could enhance science transfer and recruit patients and at-risk individuals for research studies. Professionals and organizations (e.g., alcohol treatment centers) that serve populations at risk for oral cancer or its sequelae could be a source of study subjects.

    b. *Formal centers.* NIDR and NCI jointly fund oral cancer research centers. Other formal centers could be envisioned.

    c. *Commercial interest.* Commercial firms could use their marketing and distribution systems to enhance science transfer, health promotion, and disease prevention activities. They also could join with academic or governmental groups to fund or otherwise facilitate research.

CHAPTER 4: CLOSING REMARKS

The closing session of the conference began with brief presentations by each of the working group chairs on their proposed set of recommended strategies. Participants then were given an opportunity to comment on these strategies, pose questions to the chairs, or suggest additional strategies. Dr. Wallin (Wally) McMinn, Chairman of the ADA's Council on Access, Prevention and Interprofessional Relations, moderated the session.

Following the session, Dr. Myron Allukian and Dr. Donald Marianos delivered brief closing remarks and adjourned the conference.

Dr. Myron Allukian, Jr.

Assistant Deputy Commissioner and Director of Community Dental Programs, Boston Department of Health and Hospitals

Dr. Myron Allukian thanked Dr. McMinn for moderating the session and soliciting so many useful comments from participants. He then thanked a few key individuals for their help and support in planning and conducting the conference, including the chairs and co-chairs of the working groups, the recorders for these groups, the Oral Cancer Conference Advisory Group, Dr. Jim Feldt, and the ADA. He extended special thanks to Jane Forsberg Jasek and Barbara Park. He also thanked the three federal agencies — NCI, NIDR, and CDC — for their growing commitment to oral cancer, singling out Dr. Donald Marianos for having the foresight to begin the process nearly 4 years earlier.

Dr. Allukian commended members of the audience for their hard work and dedication during the past two days, which resulted in a meaningful list of strategies for putting oral cancer on the national agenda. He cautioned that the list of strategies should be viewed as a living document that can change over time. He reviewed the myriad changes taking place in the health care system and urged participants to view them as opportunities to approach oral cancer differently. He noted that although tobacco use prevention is the key to primary prevention, a broad approach to oral cancer must not neglect early detection and control of the disease.

Dr. Allukian marveled at the diversity of the audience and stressed that progress in oral cancer will only occur if the entire health and human services community becomes involved — at the national, regional, state, and community levels. He singled out one of the recommendations that emerged from the conference: to establish an ongoing mechanism for monitoring conference outcomes. He applauded this recommendation and noted the need for a work plan to define "who must do what by when" to implement the recommended strategies. He commended CDC for committing the resources to publish and disseminate the proceedings but emphasized that more is needed to ensure effective implementation. He suggested that another conference be held within 1 to 2 years to examine progress in improving oral cancer rates and outcomes and to adjust the course of action accordingly.

After thanking the participants for a very personally enriching learning experience, Dr. Allukian expressed confidence that the "right" strategies were identified and that, with compassion and commitment, the participants collectively could make a major impact on oral cancer in this country. He also said he hoped that the conference would serve as a model for other nations.

He closed with a few adages: "To know the difference is to make a difference." "Knowledge is power." "In America, what you do is what you are. To do little is to be little. To do something is to be something."

Dr. Donald Marianos

Director, Division of Oral Health, CDC

Dr. Donald Marianos began by stating that he had learned early in his management career that "if you surround yourself with good people, they make you look good." He cited the conference as an example of this lesson and commended the dedication of the conference participants and the quality of their recommendations as "nothing short of outstanding." He reminisced about the "humble beginnings" of the conference, when the initial small group met in 1992 at CDC. At that time, the challenge of oral cancer loomed, but the course was not clear.

Dr. Marianos noted his pleasure that a clear road map for the prevention and control of oral and pharyngeal cancer had now been prepared. For the first time, he said, the nation will be able to monitor progress and measure success. He committed CDC to preparing the proceedings and disseminating them to all participants for review prior to publication. He also expressed the agency's dedication to the elimination of oral and pharyngeal cancer. He noted two factors critical to success:

- The personal commitment, skills and competencies, connections and linkages, and enthusiasm that all the conference participants can bring to bear on this disease.
- Coordination and communication among all the disparate parties working to improve oral cancer trends and outcomes.

Dr. Marianos expressed his personal and professional pleasure in being associated with a group of such high caliber and reiterated that progress can be made only with the participants' continued support and assistance.

APPENDIX A

PROGRAM

National Strategic Planning Conference for the Prevention and Control of Oral and Pharyngeal Cancer

August 7-9, 1996
American Dental Association Headquarters Building
Chicago, Illinois

WEDNESDAY, AUGUST 7

8:00 - 8:45 a.m.	**Registration and Continental Breakfast** - Hillenbrand Auditorium Foyer
8:45 - 9:15 a.m.	**Opening Session** - Hillenbrand Auditorium **Welcomes and Opening Remarks** Moderator: *Dr. Donald W. Marianos* - Director, Division of Oral Health, CDC *Dr. William Ten Pas* - President, American Dental Association *Dr. Reuben Warren* - Director, Office of Minority Health, CDC *Dr. Sherry Mills* - Cancer Prevention and Control Branch, NCI *Dr. Stephen B. Corbin* - Chief of Staff, Office of the Surgeon General, and Chief Dental Officer, U.S. Public Health Service *Dr. Harold Slavkin* - Director, National Institute of Dental Research, NIH
9:15 a.m. - 12:15 p.m	**Panel Presentation** *Dr. Harold Slavkin* - Oral Cancer: Trends, Research Needs, and Policy Development *Dr. Sol Silverman, Jr.* - Scientific Evidence Presented in Background Papers: Overview **Keynote Speakers** *Mr. Rick Bender* - Oral Cancer: One Survivor's Perspective *Dr. Harold Freeman* - Chairman, The President's Cancer Panel Policy Development Strategies: A Call to Action
12:00 - 12:30 p.m.	**Charge to the Working Groups** *Dr. Myron Allukian, Jr.* - Charge to the Working Groups *Dr. James A. Feldt* - Working Group Process to Meet the Charge
12:30 - 1:30 p.m.	**Break into Working Groups** (Working Group Members and Observers) **and Working Lunch**
1:00 - 5:00 p.m.	**Working Group Meetings** (Working Group Members and Observers)
5:00 - 7:30 p.m.	**Reception** - Hillenbrand Auditorium

THURSDAY, AUGUST 8

8:00 - 8:30 a.m. **Continental Breakfast**

8:30 - 9:30 a.m. **Plenary Session**
Moderator: *Dr. Myron Allukian, Jr.*
Working Group Chairs - Status Report on Progress

9:30 a.m. - 12:00 p.m. **Working Group Meetings** (Working Group Members and Observers)

12:00 - 1:00 p.m. **Working Lunch** (Working Group Members and Observers)

1:00 - 4:00 p.m. **Working Group Meetings** (Working Group Members and Observers)

4:00 - 5:30 p.m. **Wrap-up and Preparation for Closing Session**

FRIDAY, AUGUST 9

8:00 - 8:30 a.m. **Continental Breakfast**

8:30 - 10:30 a.m. **Closing Session**
Panel Discussion: Recommendations for Action to Prevent and Control Oral and Pharyngeal Cancer - Reports from Working Groups
Moderator: *Dr. Wallin (Wally) McMinn* - Chairman, ADA Council on Access, Prevention and Interprofessional Relations

1) Professional Education and Practice
2) Public Education
3) Public Health Policy
4) Advocacy, Collaboration, and Coalition Building
5) Data Collection, Evaluation, and Research

10:30 - 11:00 a.m. **Closing Remarks**
Dr. Myron Allukian, Jr. - Chairman, Oral Cancer Conference Advisory Group
Dr. Donald W. Marianos - Director, Division of Oral Health, CDC

APPENDIX B

WORKING GROUP CO-CHAIRS

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APPENDIX C

CONFERENCE PARTICIPANTS

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