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1-28-98: 3:23PM; AMERICAN CANCER SOC.
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American Cancer Society

Facsimile

To: Jerry Mande
@Fax: 456-6027
From: Susan L. Polan
Director, Government Relations
Date: January 28, 1998
Re: Relevant lists
Pages: 1, including this

Attached are the membership lists for NCCR and the Ad Hoc Group. Call if you have questions.

with Research!America's Board of Directors. The Ad Hoc Group participated in a Coalition for Health Funding press briefing that coincided with the release of the President's budget. The Ad Hoc Group expressed disappointment with the meager increase the President proposed for the NIH.

The Ad Hoc Group for Medical Research

Executive Committee - The activities of the Ad Hoc Group for Medical Research Funding are led by an active Executive Committee.

The 1996-1997 Executive Committee

Chairman

Richard Knapp, Ph.D.

Executive Secretary

Dave Moore

Permanent Members

American Psychiatric Association	Jay Cutler/Cathy Brady/William Bruno
American Society for Microbiology	Janet Shoemaker
Association of American Medical Colleges	David Blake, Ph.D.
Association of American Universities	Maureen Byrnes
Federation of American Societies for Experimental Biology	Howard Garrison, Ph.D./ Michael Stephens/Bonnie Litch
National Association of State Universities and Land Grant Colleges	Jerold Roschwalb
CR Associates	Nicholas Cavarocchi
Capitol Associates	Marguerite Donoghue

Elected Members (term expires)

American Academy of Dermatology	Cheryl Hayden (1998)
American Academy of Pediatrics	Karen Hendricks (1998)
American Association of Immunologists	Patrick White (1998)
Association of Professors of Medicine	Tod Ibrahim (1997)
American Society for Reproductive Medicine	Sean Tipton (1997)

Juvenile Diabetes Foundation International
National Organization for Rare Diseases
American Academy of Physical Medicine
and Rehabilitation, American Academy of Neurology

Bill Schmidt (1997)
Michael Langan (1997)
Richard Verville (1998)

Ex officio Members

Coalition for Health Funding
National Health Council
Biotechnology Industry Organization

Alan Kraut
Stephanie Marshall
Seth Radus

Working Groups - Much of the planning and execution of Ad Hoc Group programs and publications are led by ad hoc working groups composed of members of the Ad Hoc Group Executive Committee. The following working groups were active in 1996-1997.

Policy Breakfast Working Group

Patrick White, chair
Karen Hendricks

White House Briefing Working Group

Marguerite Donoghue, chair
William Bruno
Pat White

Retreat Planning Group

Maureen Byrnes, chair	Bonnie Litch
Karen Hendricks	Colleen McCabe
Tod Ibrahim	Pat White

Scientific Advisory Committee - During 1996-1997, the Science Advisory Committee contributed to the production of a variety of Ad Hoc Group advocacy documents including the *fact sheets* and the testimony before the House Appropriations Subcommittee. The Scientific Advisory Committee is comprised of the following individuals.

Steven C. Beering, M.D.
Purdue University

Kenneth I. Berns, M.D., Ph.D.
Cornell University Medical College

Joseph R. Bertino, M.D.
Memorial Sloan-Kettering Cancer Center

Ralph A. Bradshaw, Ph.D.
University of California at Irvine College of Medicine

Gail H. Cassell, Ph.D.
University of Alabama at Birmingham

Joseph T. Cuyte, M.D.
McLean Hospital

Eric G. Neilson, M.D.
University of Pennsylvania School of Medicine

Ora H. Pescovitz, M.D.
Indiana University School of Medicine

Richard R. Ranney, D.D.S.
University of Maryland Dental School

Michael R. Rosen, M.D.
Columbia University

Jess G. Thoenes, M.D.
University of Michigan Medical Center

Membership - As each Ad Hoc Group document and activity is scheduled, societies and organizations are free to join in to the extent possible. The following organizations participated in one or more of the Ad Hoc Group's activities in 1996-1997. Those organizations marked with an * provided financial support to the Ad Hoc Group.

Academy of Orscointegration
Academy of Radiology Research
Alliance for Eye and Vision Research*
Alzheimer's Association
Ambulatory Pediatric Association
American Academy of Allergy, Asthma & Immunology*

American Academy of Child and Adolescent Psychiatry
American Academy of Dermatology
American Academy of Directors of Psychiatric Residency Training
American Academy of Neurology*
American Academy of Ophthalmology

American Academy of Orthopaedic Surgeons*
American Academy of Otolaryngology-Head and Neck Surgery, Inc.
American Academy of Pediatrics*
American Academy of Physical Medicine and Rehabilitation
American Association for Cancer Education
American Association for Cancer Research
American Association for Dental Research
American Association for the Study of Liver Disease
American Association for the Surgery of Trauma
American Association of Academic Physicians
American Association of Anatomists
American Association of Blood Banks
American Association of Chairmen of Department Psychiatry
American Association of Colleges of Nursing*
American Association of Colleges of Osteopathic Medicine
American Association of Colleges of Pharmacy*
American Association of Colleges of Podiatric Medicine
American Association of Dental Schools
American Association of Immunologists*
American Association of Pharmaceutical Scientists
American Cancer Society
American Chemical Society
American College of Cardiology
American College of Chest Physicians
American College of Clinical Pharmacology*
American College of Medical Genetics*
American College of Neuropsychopharmacology
American College of Preventive Medicine
American College of Psychiatrists
American College of Rheumatology*
American College of Surgeons
American Congress of Rehabilitation Medicine
American Dental Association*
American Federation for Medical Research

American Foundation for AIDS Research*
American Gastroenterological Association
American Geriatrics Society
American Heart Association*
American Liver Foundation
American Lung Association
American Medical Association
American Neurological Association
American Optometric Association*
American Parkinson's Disease Foundation
American Pediatric Society
American Physiological Society*
American Podiatric Medical Association
American Psychiatric Association*
American Psychological Association
American Psychological Society*
American Rehabilitation Association
American Sleep Disorders Association
American Social Health Association
American Society for Biochemistry and Molecular Biology
American Society for Bone and Mineral Research*
American Society for Cell Biology
American Society for Clinical Nutrition
American Society for Clinical Pharmacology and Therapeutics
American Society for Dermatologic Surgery
American Society for Investigative Pathology
American Society for Microbiology*
American Society for Nutritional Sciences
American Society for Pharmacology and Experimental Therapeutics
American Society for Reproductive Medicine
American Society for Therapeutic Radiology and Oncology
American Society for Tropical Medicine Hygiene
American Society for Virology
American Society of Addiction Medicine
American Society of Animal Science

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American Society of Clinical Nutrition
 American Society of Clinical Oncology*
 American Society of Hematology
 American Society of Human Genetics
 American Society of Nephrology*
 American Society of Pediatric Hematology/Oncology
 American Spinal Injury Association
 American Speech-Language-Hearing Association
 American Surgical Association
 American Thoracic Society
 American Veterinary Medical Association
 America's Blood Centers
 Americans for Medical Progress*
 Arthritis Foundation
 Association for Behavioral Sciences and Medical Education
 Association for the Cure of Cancer of the Prostate
 Association for Medical School Pharmacology
 Association for Research in Vision and Ophthalmology
 Association of Academic Chairmen of Plastic Surgery
 Association of Academic Health Centers
 Association of Academic Health Sciences Libraries
 Association of Academic Physicians
 Association of Academic Surgery
 Association of American Cancer Institutes
 Association of American Medical Colleges*
 Association of American Universities*
 Association of American Veterinary Medical Colleges*
 Association of Anatomy, Cell Biology and Neurobiology Chairs
 Association of Anesthesiology Program Directors
 Association of Departments of Family Medicine
 Association of Independent Research Institutes
 Association of Medical and Graduate Departments of Biochemistry

Association of Medical School Microbiology and Immunology Chairs*
 Association of Medical School Pediatric Department Chairmen
 Association of Minority Health Professions Schools
 Association of Pathology Chairs
 Association of Pediatric Oncology Nurses
 Association of Population Centers
 Association of Professors of Dermatology*
 Association of Professors of Medicine*
 Association of Schools and Colleges of Optometry
 Association of Schools of Public Health
 Association of Subspecialty Professors
 Association of Teachers of Preventive Medicine
 Association of University Anesthesiologists
 Association of University Environmental Health Sciences Centers
 Association of University Professors of Neurology
 Association of University Professors of Ophthalmology
 Association of University Programs in Occupational Health and Safety
 Association of University Radiologists
 Autism Society of America
 Biophysical Society*
 Biotechnology Industry Organization
 CJ Foundation for SIDS
 CR Associates*
 Cancer Research Foundation of America*
 Candlelighters Childhood Cancer Foundation
 Citizens for Public Action on Blood Pressure and Cholesterol, Inc.
 Coalition for American Trauma Care
 Coalition of Patient Advocates for Skin Disease Research
 College on Problems of Drug Dependence
 Consortium of Social Science Associations
 Cooley's Anemia Foundation
 Corporation for the Advancement of Psychiatry
 Cushing's Support and Research Foundation

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Cystic Fibrosis Foundation*
 Dermatology Nurses Association
 Digestive Disease National Coalition
 Dystonia Medical Research Foundation
 Dysmorphic Epidermolysis Bullosa Research Association of America
 Endocrine Society
 Families Against Cancer Terror
 Federation of American Societies for Experimental Biology*
 Federation of Behavioral, Psychological and Cognitive Sciences
 Foundation for Ichthyosis and Related Skin Types
 Friends of the National Library of Medicine
 General Clinical Research Center Program Directors Association
 Genetics Society of America
 Genome Action Coalition
 Glaucoma Research Foundation
 Health, Safety and Research Alliance of New York State, Inc.
 Human Rights Campaign
 Immune Deficiency Foundation
 Institute of Electrical and Electronics Engineers
 Jeffrey Modell Foundation
 Joint Committee for the Advancement of the Dermatologic Health of Women
 Joint Council of Allergy, Asthma and Immunology
 Juvenile Diabetes Foundation International*
 Lupus Foundation of America
 Mary Woodward Lasker Charitable Trust*
 Medical Library Association
 National Alliance for the Mentally Ill
 National Alopecia Areata Foundation
 National Association for Biomedical Research
 National Association for Pseudoexanthoma Elasticum, Inc.
 National Association of Children's Hospitals*

National Association of State Universities and Land Grant Colleges*
 National Campaign to End Neurological Disorders
 National Caucus of Basic Biomedical Sciences Chairs
 National Coalition for Cancer Research
 National Committee to Preserve Social Security and Medicare*
 National Council on Spinal Cord Injury*
 National Depressive and Manic-Depressive Association
 National Foundation for Ectodermal Dysplasias*
 National Health Council
 National Marfan Foundation
 National Multiple Sclerosis Society
 National Organization for Rare Disorders*
 National Osteoporosis Foundation*
 National Periphagus Vulgaris Foundation
 National Perinatal Association
 National Psoriasis Foundation
 National Rehabilitation Association
 National Vitiligo Foundation, Inc.
 New England Biomedical Research Coalition
 Oncology Nursing Society*
 Orthopaedic Research Society
 Osteogenesis Imperfecta Foundation
 The Paget Foundation*
 Parkinson's Action Network
 Parkinson's Disease Foundation
 Parkinson's International
 Paralyzed Veterans of America*
 Pharmaceutical Research and Manufacturers of America
 Population Association of America
 PXE International, Inc.
 Radiation Research Society
 Renal Physicians Association
 Research Society on Alcoholism
 RESOLVE*

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Scleroderma Research Foundation
Society for Academic Emergency Medicine
Society for Education in Anesthesia
Society for Inherited Metabolic Disorders
Society for Investigative Dermatology
Society for Investigative Pathology
Society for Neuroscience*
Society for Pediatric Research
Society for Research in Child Development
Society for the Advancement of Women's
Health Research*
Society of Academic Anesthesiologists
Society of Gynecologic Oncologists
Society of Medical College Directors of
Continuing Medical Education

Society of Surgical Chairmen
Society of Toxicology
Society of University Otolaryngologists
Society of University Surgeons
Society of University Urologists
Sturge-Weber Foundation
Sudden Infant Death Syndrome Alliance
Susan G. Komen Breast Cancer Foundation
Tourette Syndrome Association, Inc.
United Scleroderma Foundation, Inc.
The V Foundation
Wilson's Foundation
Women's Dermatological Society

For more information about the National Institutes of Health; medical research,
or the Ad Hoc Group for Medical Research Funding, as well as copies of Ad Hoc
Group documents, contact Dave Moore, executive secretary, 202-828-0525,
adhoc@aamc.org.

THE
NATIONAL
COALITION
FOR
CANCER
RESEARCH

*Albert and Mary
Lasker Foundation*

*American Association
for Cancer Education*

*American Association
for Cancer Research*

American Cancer Society, Inc.

*American College
of Radiology*

*American Society for
Therapeutic Radiology
and Oncology*

*American Society
of Hematology*

*American Society
of Pediatric
Hematology-Oncology*

*Association of American
Cancer Institutes*

*Association of Pediatric
Oncology Nurses*

*American Society
of Pediatric
Hematology-Oncology*

*Association of American
Cancer Institutes*

*Association of Pediatric
Oncology Nurses*

*Cancer Research
Foundation of America*

*Cancer Treatment
Research Foundation*

*Candlelighters Childhood
Cancer Foundation*

*CoP CURE —
Association for the Cure
of Cancer of the Prostate*

*FACT: Families
Against Cancer, Inc.*

*International Foundation for
Anticancer Drug Discovery*

*National Childhood
Cancer Foundation*

Oncology Nursing Society

Radiation Research Society

*The Society of
Gynecologic Oncologists*

*The Susan G. Komen
Breast Cancer Foundation*

*The V Foundation for
Cancer Research*

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**AMERICAN CANCER SOCIETY: SOCIETY-WIDE
RECOMMENDATIONS FOR COMMUNITY CANCER CONTROL**

**BLUE RIBBON ADVISORY GROUP
ON COMMUNITY CANCER CONTROL**

REPORT TO THE NATIONAL BOARD OF DIRECTORS

November, 1997



NATIONAL HOME OFFICE

October 13, 1997

Dear Colleagues:

We are pleased to enclose the completed report of the Blue Ribbon Advisory Group on Community Cancer Control. This report has also been sent to the National Assembly for their information. If the recommendations are approved by the Board at the November meeting, you will receive a formal, bound copy of the report.

We will also send you a version of the report that takes into consideration your requests for additional information, direction, and/or clarification during our recent meetings. We believe that implementation of these recommendations will help us move forward boldly, and make huge, new contributions in the battle against cancer.

It has been--and will continue to be--most helpful for us to have your practical suggestions and understanding of this enormous undertaking. Thank you in advance for your continuing support of this process.

Best regards,

A handwritten signature in dark ink, appearing to read "Nancy Lins", written over the printed name.

Nancy Lins

Table of Contents

	Page
I. Executive Summary	1
Recommendations At-A-Glance.....	2
II. Blue Ribbon Advisory Group Report on Community Cancer Control	14
The Charge to the Blue Ribbon Advisory Group.....	14
Preamble.....	15
Recommendations.....	17
2015 Goals.....	17
Principles of Cancer Control.....	18
Programs.....	20
Prevention.....	20
Early Detection.....	23
Treatment.....	26
Support Services to Individuals with Cancer, their Families and Caregivers	28
The Way We Work.....	31
Planning, Research, and Development Opportunities.....	31
Socio-Economically Disadvantaged, Underserved, and High Risk.....	33
Working with Systems.....	34
Collaboration.....	35
Promotion of Public Understanding of Community Cancer Control.....	36
Cancer Control Education for Health Care Providers.....	37
Capacity.....	38
Development and Recruitment of Staff.....	38
Development and Recruitment of Volunteers.....	41
Resource Acquisition and Allocation.....	43
Implementation Plan.....	45
Development of Business Plan.....	45
III. Appendices.....	46
1. Strategic Directions of the American Cancer Society	
2. Tying It All Together: Moving Through Mission 2000 and Core to 2015 Goals	
3. Year 2015 References	
4. Members of the Blue Ribbon Advisory Group	
5. Process of Fulfilling the Charge to the Group	
6. Executive Summary of the Unit/Division Inventory of Cancer Control Activities	
7. Survivorship Initiatives Addendum	
8. Glossary of Selected Cancer Control Terms	

EXECUTIVE SUMMARY

BLUE RIBBON ADVISORY GROUP ON COMMUNITY CANCER CONTROL

EXECUTIVE SUMMARY

In January, 1997, the American Cancer Society appointed a Blue Ribbon Advisory Group and asked them to examine community cancer control both inside the Society and throughout the nation. This group was charged to recommend the role and future actions of the Society in community cancer control through the year 2015 and beyond.

Several forces triggered the formation of this advisory group: first, as we close in on the Year 2000, it is time for the Society to reevaluate our goals and Core priorities and to establish additional goals for work beyond the Year 2000. Second, our knowledge about how to prevent, detect, and treat cancer has evolved, as have organizational systems that could employ that knowledge. Third, we are currently witnessing an unprecedented downturn in cancer incidence and mortality rates. We must seize the opportunity to build on this trend. Finally, the American Cancer Society itself stands on the threshold of a new era in which structural reorganization and resource realignment offer the opportunity to improve dramatically the way the Society does business and to maximize our impact on community cancer control.

The Blue Ribbon Advisory Group has proposed a set of eight underlying Principles for Community Cancer Control with thirteen major recommendations that will guide our programs, change the ways we do our work, and measurably improve our capacity to achieve community cancer control.

In formulating our recommendations, the Blue Ribbon Advisory Group gathered input from many sources. In particular, input from Staff and Volunteer leaders in Divisions and Units and from the Unit/Division Survey of Cancer Control Activities was critical to the development of the recommendations. In addition, the Blue Ribbon Advisory Group considered how the five Strategic Directions of the American Cancer Society (Appendix 1) are linked, and how the American Cancer Society might collaborate with outside systems and organizations as well.

This opportunity to plan for the Year 2015 was set before the Blue Ribbon Advisory Group at an auspicious point in history. The Society is, by definition, a cancer control organization, and we have made our own unique contribution in the history of community cancer control. With the implementation of these recommendations, we will move forward into an ever stronger, more vigorous future.

Following is a brief outline of the Blue Ribbon Advisory Group on Community Cancer Control's recommendations.

BLUE RIBBON ADVISORY GROUP ON COMMUNITY CANCER CONTROL RECOMMENDATIONS AT-A-GLANCE

2015 GOALS

The American Cancer Society should:

In addition to reducing age-adjusted cancer mortality by 50%, adopt Year 2015 Goals for incidence and quality of life, and tie these goals to level of effort.

Facilitate the development and coordination of a collaborative National Cancer Program Plan for this country.

PRINCIPLES

The following principles were adopted by the Blue Ribbon Advisory Group on Community Cancer Control to guide the specific recommendations included in this document. Over time these principles should be institutionalized throughout all levels of the Society so that they undergird all American Cancer Society community cancer control activities.

1. **Our interventions should be based on scientific evidence.** Evidence should be drawn from basic, epidemiologic, clinical, behavioral, and psycho-social research. Where scientific evidence is incomplete or inadequate, organized expert opinion should be used. All of our activities, programs, and interventions should be focused on achieving outcomes, and must be subject to planned evaluation. Interventions that are ineffective, that show no relationship to outcomes, or that science does not support, should be abandoned in a planned fashion. At a time when science has provided us with proven cancer prevention and control strategies, we cannot afford to allocate resources or implement programs simply on the basis of tradition or feelings. We should make ourselves accountable, and be willing to be measured against our mission statement, goals, principles, and the recommendations articulated in this report.
2. **Prevention should be the primary goal and focus.** This does not lessen the importance of early detection, treatment, or support services. Instead, this principle recognizes that, even if treatment becomes 100% successful, the public would rather never develop cancer. The Society should shift greater resources to prevention as scientific advances allow and the Society's capacity for prevention increases.

3. **Our mission is to serve everyone.** This includes every age group, with a special responsibility to identify and help those in greatest need. Those greatest in need include: socio-economically disadvantaged populations; the underserved; and those at high risk medically, including various ethnic populations. We must intervene where problems exist, with data driving both our planning and our selection of interventions.
4. **We recognize our interdependence.** No major cancer control issue can be addressed by the American Cancer Society alone, by medical care alone, or public health alone. Most organizations and individuals generally recognize that if services and interventions are to be improved, critical gaps in information and knowledge are to be filled, and unnecessary duplication eliminated, we must cooperate with others in productive ways. In fact, the future of American Cancer Society organizational effectiveness depends on collaboration and partnerships--both internally and externally.
5. **Our cancer control efforts should be primarily focused on working with systems.** Our effectiveness in reaching many individuals can be enhanced by working through systems like schools and managed care plans, that in themselves work with large numbers of people.
6. **We must focus our efforts and resources on the strategies for which the Society is best equipped.** The American Cancer Society is uniquely qualified to fulfill certain roles in cancer control, but cannot meet every need. The Society should work with others to insure that all cancer control needs are met. An important decision then is how we deploy our limited resources--both financial resources and the time and talents of our Volunteers and Staff. We must make hard choices and set priorities among our community cancer control activities based on the outcomes of our programs and interventions, our potential resources, and our capacity. Moreover, cancer control strategies should be consistent throughout all levels of the Society. As we make good decisions that effect a positive difference in community cancer control, these choices will in turn enhance the visibility of the American Cancer Society in the communities where we are at work.
7. **Informed decision making by the public and health care providers is critical to improved community cancer control.** American Cancer Society interventions must enable the general public and health care providers to make informed decisions about lifestyle, early detection (screening), treatment, patient outcomes, and quality of life choices. We must deliver accurate, unbiased information in a timely fashion and in a form easily accessed and understood.

8. **Advocacy at all levels of the Society is an essential tool for community cancer control.** As we shift our emphasis to working with systems, advocating for a variety of issues, programs, and policies will play an increasingly important role in community cancer control. The Society at all levels should strengthen its capacity to accomplish these diverse types of advocacy. Use of advocacy tools such as information, media access, persuasion of decision/policy makers, and collaborations with others, will help create or change policies that affect community cancer control.

SUMMARY OF PROGRAM RECOMMENDATIONS

PREVENTION

1.0 Accelerate movement of resources toward prevention

Tobacco

- 1.1 Advocate for laws and policies to curb tobacco use
- 1.2 Continue the Great American Smokeout with focus on at-risk audiences
- 1.3 Advocate for state, community, and school programs
- 1.4 Adopt new role of cessation advocacy and referral instead of direct provider/payor

Nutrition

- 1.5 Increase nutrition interventions
- 1.6 Promote and advocate for adoption of nutrition guidelines
- 1.7 Advocate for state, community, and school programs
- 1.8 Adhere to nutrition guidelines at American Cancer Society-sponsored events

Other

- 1.9 Promote awareness of UV exposure as a cancer risk factor
- 1.10 National should monitor and determine the role of the American Cancer Society in environmental carcinogen issues

Children and Youth

- 1.11 Advocate for policies and resources to support school health programs
- 1.12 Discontinue emphasis on developing and delivering Society school prevention curriculum
- 1.13 Implement efforts through other channels, in addition to school systems

Guidelines

- 1.14 Develop and promote an evidence-based approach to guideline development

Managed Care

- 1.15 Advocate for coverage in indemnity and managed care plans

EARLY DETECTION

- 2.0 Allocate resources consonant with potential for reducing mortality and suffering from cancer**

Breast Cancer

- 2.1 Continue to promote early detection of breast cancer
- 2.2 Advocate for and participate in state and community programs
- 2.3 De-emphasize Breast Self Examination as an activity promoted by Units

Colorectal Cancer

- 2.4 Increase efforts to promote screening for early detection of colorectal cancer

Cervical Cancer

- 2.5 Continue to promote early detection of cervical cancer

Prostate Cancer

- 2.6 Continue to promote early detection of prostate cancer with emphasis on informed decision making

Skin Cancer

- 2.7 Continue to promote early detection of skin cancer

Testicular Cancer

- 2.8 De-emphasize Testicular Self Examination as an activity promoted by Units

Early Detection and Screening Services

- 2.9 Encourage the provision of early detection and screening services, but not as a direct provider/payor
2.10 Advocate for coverage in indemnity and managed care plans

Guidelines

- 2.11 Develop and promote an evidence-based approach to guideline development

TREATMENT

- 3.0 **Advocate for quality state-of-the-art treatment, and promote treatment guidelines developed by others**

Guidelines

- 3.1 Encourage the integration and analysis of outcomes data in guidelines
3.2 Develop criteria to evaluate guidelines developed by others
3.3 The American Cancer Society should not formulate treatment guidelines

Treatment Information

- 3.4 Help people in making appropriate treatment choices
3.5 Monitor availability and accessibility of effective treatments
3.6 Provide information about nonstandard therapies

Advocacy for Treatment

- 3.7 Provide information and advocate for open access to clinical trials.
3.8 Advocate for access to pediatric oncologists in children's care and follow-up

**SUPPORT SERVICES TO
INDIVIDUALS WITH CANCER, THEIR FAMILIES AND CAREGIVERS**

- 4.0 Allocate resources consonant with the potential for enhancing quality of life, addressing end of life issues, and reducing morbidity**

Existing Programs

- 4.1 Enhance effective support programs
- 4.2 Maximize use of Call Centers as a point of access
- 4.3 End role as direct provider of financial assistance, home care equipment, CanSurmount and nutritional supplements

Programs in Development

- 4.4 Develop a survivorship initiative
- 4.5 Support educational programs addressing end of life
- 4.6 Assist patients in making informed decisions
- 4.7 Assess needs, long-term costs and benefits before development of any Hope Lodge, children's camp, or other new program or service
- 4.8 The American Cancer Society should not engage in licensing or operating hospice facilities

Advocacy

- 4.9 Provide information and advocate for making the health care system easy to use
- 4.10 Advocate for policies supportive of end-of-life care

SUMMARY OF RECOMMENDATIONS FOR THE WAY WE WORK

PLANNING, RESEARCH, AND DEVELOPMENT OPPORTUNITIES

- 5.0 Base planning, interventions, and evaluation on appropriate data and expert opinion**
- 5.1 Identify quality data
- 5.2 Develop a process for evaluating effective interventions
- 5.3 Develop common sets of cancer control standards and guidelines
- 5.4 Identify emerging issues and promising trends
- 5.5 Conduct market research to identify population needs
- 5.6 Link intramural/extramural research to cancer control

SOCIO-ECONOMICALLY DISADVANTAGED, UNDERSERVED, AND HIGH RISK

- 6.0 Identify SED, poor, underserved and high risk populations**
- 6.1 Allocate resources consonant with identified target populations
- 6.2 Create a Unit-based incentive program
- 6.3 Support model programs and demonstration sites for best practices
- 6.4 Advocate for improved access for services
- 6.5 Develop expertise in addressing cultural diversity

WORKING WITH SYSTEMS

- 7.0 Promote policy and practice changes in social systems**
- 7.1 Identify priority systems to promote cancer control activities
- 7.2 Work with identified systems to change policies, programs, and services
- 7.3 Identify opportunities to provide incentives for change within identified systems
- 7.4 Advocate for coverage by indemnity and managed care plans

COLLABORATION

- 8.0 Increase collaborative efforts at all levels**
- 8.1 Create guidelines regarding collaboration
- 8.2 Implement a skill-building training program
- 8.3 Evaluate the success of collaborative efforts

PROMOTION OF PUBLIC UNDERSTANDING OF COMMUNITY CANCER CONTROL

- 9.0 Enhance public understanding of cancer control and what the Society does in cancer control**
- 9.1 Planned approach for communication
- 9.2 Promote cancer control as a part of overall media campaigns
- 9.3 Communicate progress toward achieving Year 2015 goals
- 9.4 Focus community attention on cancer control opportunities

CANCER CONTROL EDUCATION FOR HEALTH CARE PROVIDERS

- 10.0 Target professional education to primary care and other frontline health care providers**
- 10.1 Use new educational technology in collaborative programs
- 10.2 De-emphasize stand-alone professional education programs
- 10.3 Assure cancer control in health care provider curricula

SUMMARY OF RECOMMENDATIONS FOR CAPACITY

DEVELOPMENT AND RECRUITMENT OF STAFF

11.0 Increase the quantity and quality of staff time dedicated to cancer control

Staff Training

11.1 Identify skills and institute training

Staff Recruitment

11.2 Hire skilled community cancer control staff

11.3 Hire cancer control specialists in large population areas

Staff Accountability

11.4 Identify structures and procedures most effective for delivering cancer control interventions

11.5 Link work of cancer control and fundraising

Staff Compensation and Recognition

11.6 Adjust pay ranges for recruitment and retention of staff

11.7 Develop a system of recognition

DEVELOPMENT AND RECRUITMENT OF VOLUNTEERS

12.0 Attract and retain volunteers of high capability

Volunteer Training and Recruitment

- 12.1 Plan approach to volunteer recruitment and retention
- 12.2 Ensure skills essential to volunteer implementation of cancer control strategies
- 12.3 Attract academics and other experts on sabbaticals
- 12.4 Institute a Management Information System
- 12.5 Develop new volunteer structures that are project-based
- 12.6 Recruit specific volunteers for well-defined tasks

Volunteer Retention and Recognition

- 12.7 Develop a system of recognition

RESOURCE ACQUISITION AND ALLOCATION

13.0 Provide appropriate and sufficient resources

Resource Development

- 13.1 Hire specialized staff to acquire additional outside funding
- 13.2 Link fundraising with community cancer control product

Resource Allocation

- 13.3 Shift field expenditures toward programmatic development and capacity-building

Technology/Information Infrastructure

- 13.4 Increase access to management technologies

Capacity Development

- 13.5 Monitor progress on capacity and resources to deliver effective community cancer control

SUMMARY OF RECOMMENDATIONS FOR THE IMPLEMENTATION PLAN

Development of Business Plan

Develop a business plan for implementation of recommendations as well as progress towards Year 2015 goals.

**BLUE RIBBON ADVISORY GROUP
REPORT ON COMMUNITY CANCER CONTROL**

AMERICAN CANCER SOCIETY

BLUE RIBBON ADVISORY GROUP REPORT ON COMMUNITY CANCER CONTROL

THE CHARGE TO THE BLUE RIBBON ADVISORY GROUP

The genesis of the Blue Ribbon Advisory Group on Community Cancer Control can be traced to two simultaneous, yet distinct forces: the continuing drive to attain the Society's Mission 2000 Goals, and a pressing need to consider how the Society must approach community cancer control in order to reach past the Year 2000 toward the Year 2015 mortality goal and beyond.

In January, 1997, the American Cancer Society National President and Chairman of the Board appointed the Blue Ribbon Advisory Group on Community Cancer Control. The group was charged to present at the November, 1997 Board meeting a set of recommendations for American Cancer Society activities and leadership in the area of community cancer control. The specific charge to the Blue Ribbon Advisory Group follows:

Assess the current state-of-the-practice of community cancer control within the American Cancer Society and externally review the state-of-the-art of community cancer control and discuss what could/should be done.

Recommend the practical American Cancer Society role in community cancer control and subsequent actions the American Cancer Society should implement to fulfill this role with measurable outcomes by the Year 2015.

PREAMBLE

The Society's Mission Statement is a constant reminder of both who we are and where we are headed.

Mission: **The American Cancer Society is the nationwide community-based voluntary health organization dedicated to eliminating cancer as a major health problem by preventing cancer, saving lives from cancer, and diminishing suffering from cancer through research, education, advocacy, and service. (1987)**

For the first time in history, we are able to discern a sustained decline in cancer mortality and incidence. The key actions that are driving this downturn--prevention, early detection, and improvements in cancer therapy--are fundamental to the mission of the American Cancer Society. Certainly this decline is a milestone to celebrate, and it is due in no small part to the work of the Society. Nevertheless, we are still losing too many lives from cancer. We are challenged to forge ahead with more commitment, more energy, and more focus than ever, if we are to see this trend continue and to extend these benefits toward the Year 2015 Goal.

To guide the Society toward the future, five strategic directions were established--Cancer Control, Advocacy, Information, Research, and Resource Acquisition (Appendix 1). Designed to be complementary in nature, these strategic directions work in harmony to support community cancer control efforts, and ultimately to prevent cancer and to improve cancer control outcomes. Advocacy, Information, Research, and Resource Acquisition--each of these improves the reach and impact of Cancer Control.

Community cancer control is defined as the broad array of organized activities at local, state, regional, and national levels that have an impact on reducing the human burden of cancer. Community cancer control encompasses prevention, early detection, effective treatment, support services, survivorship, and end-of-life issues.

Current and emerging knowledge about how to prevent and control cancer, recent mergers of Divisions, and resource alignment within the Society present us with tremendous opportunities to move forward boldly and to make huge, new contributions in the battle against cancer. The gap between where we are now in preventing and controlling cancer and where we could be is real. The good news is that the gap can be narrowed based on existing knowledge, and in some instances, closed. In order for this to happen, we must change significantly the way we do business, and we must, over time, shift our precious resources to the effective delivery of proven cancer control interventions.

While there is much we can do today, we need to build aggressively toward the long term solutions in which we all believe. Now is the time for us to rethink our cancer control delivery systems, our capabilities, and our capacities. We must become more strategic in our planning,

and more skilled and collaborative in our efforts. Now is the time for us to raise the standards for consistent development and delivery of cancer control services. If we are to effect a fundamental shift in resources, if we are to change the way we work to implement effective and proven cancer control strategies, if we are to reach underserved and high risk populations, every level of the American Cancer Society must make a firm commitment. This document provides a blueprint for beginning the fundamental changes that all levels of the Society must be willing and able to make.

As we look carefully and realistically at what we do and how we work, each level--National, Divisions, Units--has different and complementary roles to play in effecting cancer control. It is primarily in families, neighborhoods, and communities where change must occur if we are to have a positive impact on cancer prevention and control. The support and leadership that enables Units and communities to embrace sustained, long-term cancer control efforts may be the most important thing National and Divisions can do.

The leadership task at all levels is to employ the principles and the recommendations in this report for the development and delivery of community cancer control. Core and Mission 2000 plans extend to the Year 2000. The recommendations from the Blue Ribbon Advisory Group on Community Cancer Control comprise a blueprint for the Years 2000-2015 and beyond. This process allows us to extend our reach into the future, while continuing the work on current Mission 2000 plans.

How bold we are about seizing these opportunities, how thoughtful we are in changing the ways in which we work, how wise we are in translating current knowledge into every day community-level practice, will make all the difference in the progress we make in the future.

RECOMMENDATIONS

2015 GOALS

Recommendation: In addition to the Year 2015 Goal of a 50% reduction in age-adjusted cancer mortality, the Blue Ribbon Advisory Group on Community Cancer Control recommends that the Board of Directors adopt Year 2015 Goals for incidence and quality of life, and that these goals be tied to level of effort.

Recommendation: The American Cancer Society should take a major leadership role working with the Centers for Disease Control and Prevention, the National Cancer Institute, and other appropriate organizations in facilitating the development and coordination of a renewed collaborative National Cancer Program Plan (NCP) for this country. The previous National Cancer Program Plan, for all practical purposes, is no longer in effect. Community cancer control in the United States will benefit from a common vision and related strategies for addressing the disease Americans fear most.

PRINCIPLES OF CANCER CONTROL

The following principles were adopted by the Blue Ribbon Advisory Group on Community Cancer Control to guide the specific recommendations included in this document. Over time these principles should be institutionalized throughout all levels of the Society so that they undergird all American Cancer Society community cancer control activities.

1. **Our interventions should be based on scientific evidence.** Evidence should be drawn from basic, epidemiologic, clinical, behavioral, and psycho-social research. Where scientific evidence is incomplete or inadequate, organized expert opinion should be used. All of our activities, programs, and interventions should be focused on achieving outcomes, and must be subject to planned evaluation. Interventions that are ineffective, that show no relationship to outcomes, or that science does not support, should be abandoned in a planned fashion. At a time when science has provided us with proven cancer prevention and control strategies, we cannot afford to allocate resources or implement programs simply on the basis of tradition or feelings. We should make ourselves accountable, and be willing to be measured against our mission statement, goals, principles, and the recommendations articulated in this report.
2. **Prevention should be the primary goal and focus.** This does not lessen the importance of early detection, treatment, or support services. Instead, this principle recognizes that, even if treatment becomes 100% successful, the public would rather never develop cancer. The Society should shift greater resources to prevention as scientific advances allow and the Society's capacity for prevention increases.
3. **Our mission is to serve everyone.** This includes every age group, with a special responsibility to identify and help those in greatest need. Those greatest in need include: socio-economically disadvantaged populations; the underserved; and those at high risk medically, including various ethnic populations. We must intervene where problems exist, with data driving both our planning and our selection of interventions.
4. **We recognize our interdependence.** No major cancer control issue can be addressed by the American Cancer Society alone, by medical care alone, or public health alone. Most organizations and individuals generally recognize that if services and interventions are to be improved, critical gaps in information and knowledge are to be filled, and unnecessary duplication eliminated, we must cooperate with others in productive ways. In fact, the future of American Cancer Society organizational effectiveness depends on collaboration and partnerships -- both internally and externally.

5. **Our cancer control efforts should be primarily focused on working with systems.** Our effectiveness in reaching many individuals can be enhanced by working through systems like schools and managed care plans, that in themselves work with large numbers of people.
6. **We must focus our efforts and resources on the strategies for which the Society is best equipped.** The American Cancer Society is uniquely qualified to fulfill certain roles in cancer control, but cannot meet every need. The Society should work with others to insure that all cancer control needs are met. An important decision then is how we deploy our limited resources--both financial resources and the time and talents of our Volunteers and Staff. We must make hard choices and set priorities among our community cancer control activities based on the outcomes of our programs and interventions, our potential resources, and our capacity. Moreover, cancer control strategies should be consistent throughout all levels of the Society. As we make good decisions that effect a positive difference in community cancer control, these choices will in turn enhance the visibility of the American Cancer Society in the communities where we are at work.
7. **Informed decision making by the public and health care providers is critical to improved community cancer control.** American Cancer Society interventions must enable the general public and health care providers to make informed decisions about lifestyle, early detection (screening), treatment, patient outcomes, and quality of life choices. We must deliver accurate, unbiased information in a timely fashion and in a form easily accessed and understood.
8. **Advocacy at all levels of the Society is an essential tool for community cancer control.** As we shift our emphasis to working with systems, advocating for a variety of issues, programs, and policies will play an increasingly important role in community cancer control. The Society at all levels should strengthen its capacity to accomplish these diverse types of advocacy. Use of advocacy tools such as information, media access, persuasion of decision/policy makers, and collaborations with others, will help create or change policies that affect community cancer control.

Programs

Prevention

Recommendation 1: **There should be an accelerated movement of American Cancer Society resources toward prevention.** At all levels of the organization, the American Cancer Society should allocate prevention resources consonant with the potential for reducing incidence of cancer.

Tobacco

The American Cancer Society should:

- 1.1 Advocate for laws and policies that :**
 - assure clean indoor air
 - prohibit youth access to tobacco
 - end tobacco advertising directed at children and youth
 - increase excise taxes
 - promote strict enforcement of FDA regulations and control of nicotine content (and other addictive elements) in all tobacco products
 - increase research into behavior modification and tobacco use addiction
- 1.2 Continue the Great American Smokeout with major emphasis on engaging at-risk audiences.**
- 1.3 Continue to advocate for and support school and community programs for tobacco control, and state programs such as ASSIST, IMPACT, and Smokeless States. We should focus activities on youth, women, poor, underserved, and other high risk populations.**
- 1.4 Remain actively involved in tobacco cessation by:**
 - moving from its role as a direct provider/payor of smoking cessation programs to one of cessation advocacy and referral
 - maintaining a directory of cessation resources
 - collaborating with and referring to other organizations that provide cessation assistance
 - collaborating in a nationally coordinated cessation network to respond to tobacco addiction

Nutrition

The American Cancer Society should:

- 1.5 Increase nutrition interventions as they are required to change nutrition-related behavior.** Nutrition related interventions include changing eating behaviors as well as physical activity and alcohol consumption. The American public needs to be more aware of nutrition as it relates to cancer and of the lifestyle choices that can decrease the risk of cancer.
- 1.6 Continue to promote the Society's nutrition guidelines, and advocate for their widespread adoption by not only the general public, but also systems such as schools, worksites, and the food industry.**
- 1.7 Continue to advocate for and support school and community programs for nutrition education, and state programs such as 5-A-DAY.**
- 1.8 Adhere to current American Cancer Society nutrition guidelines at all American Cancer Society-sponsored events where food is served.**

Other

The American Cancer Society should:

- 1.9 Address UV exposure as a cancer risk factor by promoting awareness of the need to limit direct exposure to sunlight and the need to use sunscreens and protective clothing when outdoors.**
- 1.10 At the National level, monitor the role of environmental carcinogens as cancer risks. Divisions and Units should not give high priority to environmental carcinogens except in selected instances of well-established and heavy exposure, such as industrial/occupational exposure to asbestos.**

Children and Youth

The American Cancer Society should:

- 1.11 Assume a primary role in advocating for policies and resources required to implement effective school health programs, including comprehensive school health education.** The Society also should advocate for schools to employ adequately trained school health personnel. American Cancer Society training should be carried out in coordination with other education and health organizations.

- 1.12 Discontinue its current emphasis on developing and delivering Society school cancer prevention curricula.**
- 1.13 Implement efforts through other channels, in addition to school systems, that can reduce risk behaviors among children and youth.** Work with media, churches, and other youth-serving organizations to establish policies, resources, and programs that will help young people avoid cancer risks.

Guidelines

The American Cancer Society should:

- 1.14 Continue to develop and promote an evidence-based and consensus approach to the establishment of prevention guidelines.** The approach should include specific guidance for high risk groups, should consider cost effectiveness, and should provide a strategic plan for their promotion.

Managed Care

The American Cancer Society should:

- 1.15 Advocate for the provision and coverage of cancer prevention interventions in both indemnity and managed care plans.**

Rationale: Current knowledge indicates that up to 70% of all cancers may be considered preventable given widespread implementation of effective interventions. Known precursors of cancer, primarily tobacco use and diet, should receive the most emphasis, since they cause the vast majority of all preventable cancer. Such precursors impose a double burden on our people and our health care system--they affect patients and families directly, and they consume resources that we could otherwise devote to problems for which reliable preventive strategies are not yet known.

If we are to achieve the mortality and incidence goals established for Year 2015 and beyond, the Society must be willing to embrace prevention as a long-term focus. If we are to take advantage of the role prevention efforts can play in reducing premature mortality and unnecessary suffering, then there must be an accelerated shift of time, money, staff, and volunteers focused on prevention, with particular emphasis on addressing the needs and behaviors of the poor and underserved.

Early Detection

Recommendation 2: At all levels of the organization, allocate early detection resources consonant with the potential for reducing mortality and suffering from cancer. The allocation of resources should take into consideration the Society's capacity to carry out interventions and the needs of the population affected.

Breast Cancer

The American Cancer Society should:

- 2.1** Continue to promote and facilitate early detection of breast cancer, according to American Cancer Society guidelines.
- 2.2** Continue to advocate for and participate in state and community programs for breast and cervical cancer, such as the Centers for Disease Control Breast and Cervical Cancer grants.
- 2.3** De-emphasize breast self examination (BSE) as an activity promoted by Units, as scientific evidence does not support its impact on cancer control.

Colorectal Cancer

The American Cancer Society should:

- 2.4** Promote our new guidelines for early detection of colorectal cancer, and make a substantial effort to promote screening for early detection of colorectal cancer.

Cervical Cancer

The American Cancer Society should:

- 2.5** Continue to promote and facilitate early detection of cervical cancer according to American Cancer Society guidelines, with emphasis on high risk and underserved populations.

Prostate Cancer

The American Cancer Society should:

- 2.6 Continue to promote and facilitate early detection of prostate cancer, according to American Cancer Society guidelines, with emphasis on informed decision making by both the public and providers, since the science is unclear.**

Skin Cancer

The American Cancer Society should:

- 2.7 Continue to promote and facilitate early detection of skin cancer.**

Testicular Cancer

The American Cancer Society should:

- 2.8 De-emphasize testicular self examination (TSE) as an activity promoted by Units, as scientific evidence does not support its impact on cancer control.**

Early Detection and Screening Services

The American Cancer Society should:

- 2.9 Collaborate with other entities and organizations to encourage the provision of early detection and screening services, but should not have a substantial role as a direct provider or as a direct payer for screening services such as fecal occult blood testing.**
- 2.10 Advocate for the provision and coverage of cancer screening tests and exams in both indemnity and managed care plans.**

Guidelines

The American Cancer Society should:

- 2.11 Continue to develop and promote an evidence-based and consensus approach to the establishment of early detection guidelines.** The approach should include specific guidance for high risk groups, should consider cost effectiveness, and should provide a strategic plan for guideline promotion.

Rationale: Current scientific evidence indicates that the wider application of available screening and early detection techniques can significantly reduce the number of deaths attributable to breast, cervical, and colorectal cancers.

Although screening for colorectal cancer has not been a priority in the past, science now supports a substantial emphasis on colorectal cancer at all levels of the Society. Because current screening rates for colorectal cancer are so low, we can make significant progress toward reducing suffering and mortality from colorectal cancer.

If significant progress toward the mortality and incidence goals established for breast, cervical, and colorectal cancers for the Year 2015 and beyond is to be made, the American Cancer Society must promote and facilitate early detection programs for those in greatest need. By reaching the socio-economically disadvantaged populations, we can achieve the greatest impact on reaching the Year 2015 goal for a 50% reduction in age-adjusted cancer mortality.

Advocacy efforts should substantially increase, particularly as they relate to increased accessibility for the high risk and underserved populations through payment for these services by insurance companies and existing entitlement programs.

Treatment

Recommendation 3: The primary role of the American Cancer Society regarding treatment should be to advocate for quality, state-of-the-art treatment for all people, and to interpret, translate, and promote awareness of treatment guidelines that meet acceptable evidence-based standards.

Guidelines

The American Cancer Society should:

- 3.1 Encourage the integration and analysis of outcomes data to inform the development of treatment guidelines by other organizations and entities.**
- 3.2 Develop criteria to evaluate and identify acceptable treatment guidelines developed by others. The Society should then promote the guidelines that meet these criteria with the public and with health care professionals.**

The American Cancer Society should NOT:

- 3.3 Formulate treatment guidelines.**

Treatment Information

The American Cancer Society should:

- 3.4 Provide unbiased information regarding treatment guidelines, what constitutes good treatment, and the availability of local resources to help people in making appropriate treatment choices. The Society's National and Regional Call Centers should be a primary source of information about treatment and treatment resources.**
- 3.5 Develop the capacity to monitor effective treatments, their availability, their accessibility, and the extent to which they are used in communities, and to provide this updated information to the National and Regional Call Centers. This should be a National responsibility.**
- 3.6 Provide current information about nonstandard therapies, including those considered alternative, complementary, or unproven.**

Advocacy for Treatment

The American Cancer Society should:

- 3.7 Provide information on clinical trials, and advocate for open access to clinical trials.**
The Society should advocate for health care plan coverage of participation in clinical trials.
- 3.8 Advocate for access to pediatric oncologists in children's care and follow-up, given the special problems associated with cancer in children.** This is particularly important as the health care system continues to evolve.

Rationale: We will achieve our mortality goal for the Year 2015 and beyond only if individuals with cancer receive timely and appropriate treatment. In fact, many of the gains we anticipate from early detection and screening will not occur if quality treatment isn't widely available and accessible. Therefore it is critical that the American Cancer Society advocate for quality treatment for all people in an evolving health care system. The Society is well-positioned to play a strong role in advocating that health care provider systems, particularly managed care and indemnity plans, base provision of their services on state-of-the-art treatment information. The American Cancer Society can also provide accurate and complete information on current care and referrals to appropriate health care providers.

Support Services to Individuals with Cancer, their Families and Caregivers

Recommendation 4: At all levels of the organization, allocate patient services resources consonant with the potential for effectively enhancing the quality of life of patients, their families and caregivers, addressing end-of-life issues, and reducing morbidity. The allocation of resources should take into consideration the Society's capacity to carry out interventions and the needs of the populations affected.

Existing Programs

The American Cancer Society should:

- 4.1 Enhance effective support programs--Reach to Recovery, Man To Man, I Can Cope, Road to Recovery, Look Good . . . Feel Better--whose impact is proven by past evaluations, by exploring new models and methods of delivery such as:**
 - creating multiple delivery approaches (e.g. telephone, one-to-one, face-to-face, telephone groups, Internet groups)
 - designing a single training model that includes the common elements of all programs accompanied by program-specific modules
- 4.2 Maximize the use of the National and Regional Call Centers as a point of access for individuals with cancer, their families and caregivers.** Appropriate follow-up should accompany this initial telephone call.
- 4.3 End its role as a direct provider of financial assistance, CanSurmount, home care equipment, and nutritional supplements.** While these services are important, the Society's role should be to coordinate the provision of these services with other community organizations rather than assuming responsibility for providing them directly.

THE WAY WE WORK

Planning, Research, and Development Opportunities

Recommendation 5: The American Cancer Society should base cancer control program planning, selection of interventions, and evaluation of effectiveness of interventions on appropriate data and expert opinion that establishes the state-of-the-science and the state-of-the-art in practice.

The American Cancer Society should:

- 5.1 Identify quality data from national, state, and/or local sources, and collect (or work with other organizations to collect) data and information for use in making decisions on goals, target populations, and interventions. This is a responsibility for all levels of the Society.**
- 5.2 Develop a process for evaluating and recognizing interventions that have proven effective in cancer control, and the conditions under which they are successful. In addition, the Society should:**
- develop a process for continuing to identify quality programs across Divisions
 - disseminate these best practices nationwide and facilitate the networking and sharing of these best practices throughout the Society
 - continue to monitor scientific results for emerging opportunities for cancer control applications
 - support and fund targeted demonstration sites and model programs where best practices can be researched, highlighted, and disseminated
- These activities are a responsibility of the National Home Office.
- 5.3 Move toward a common set of cancer control standards and guidelines for:**
- **program planning, development, and delivery**
 - **outcomes-based evaluation of interventions**
 - **accountability assessments**
- Within these standards, Divisions and Units should have the flexibility to select and prioritize proven interventions based on their unique local needs and capacities, taking into consideration 2015 Goals and site-specific data.

- 5.4 Develop the capacity and infrastructure to monitor experimental and population-based research to identify emerging issues and promising trends that present opportunities for applications in cancer prevention, early detection, treatment, patient services, and patient quality of life.** Promising opportunities should then move into the appropriate areas for development of future interventions with nationwide applications. These actions are the responsibility of the National Home Office.
- 5.5 Conduct market research that not only identifies needs of special populations, but also assesses potential for proposed interventions to be effective in meeting the needs of the special populations.**
- 5.6 Link our intramural and extramural research to our cancer control programs.** The rapid dissemination of cancer control advances to all those in need is a fundamental part of the American Cancer Society mission. Similarly, the research needs of cancer control programs should influence the American Cancer Society's research agenda.

Rationale: Certainly we all want to decrease the burden of cancer in every community, but we haven't all been in agreement about how to do this. With current resource realignment and Division mergers, we have an opportunity to change the way we select, implement, and evaluate cancer control interventions at all levels, so that the Society as a whole speaks with one voice.

The American Cancer Society must commit to an organization-wide, data-based planning system that achieves critical cancer control outcomes in the community. This requires the development of a comprehensive, integrated planning, budgeting, delivery, and evaluation cycle, based on clearly articulated organization priorities and on relevant data available at the local, state, and national levels. Adherence to quality standards should also guide this planning cycle. Quality standards for planning, intervention delivery, and assessment are critical to the achievement of community cancer control objectives that are the bridge to the Year 2015 goals.

At the same time, we must recognize new opportunities that are relevant to the mission of the Society. For example, National must move effective interventions such as those noted in the Wilder Report into widespread application in the field. The Society also needs to anticipate and recognize trends in basic science, translational research, epidemiology, behavioral, and clinical science, disease burden, and the expressed needs of the population. We must find ways to "see" into the future so that we are prepared. Ideally the Society should be a catalyst for new directions in cancer control as soon as opportunities emerge.

Socio-Economically Disadvantaged, Underserved, and High Risk

Recommendation 6: The American Cancer Society should identify socio-economically disadvantaged, poor, underserved, and high risk populations and their specific needs and systematically move toward allocating resources consonant with opportunities.

The American Cancer Society should:

- 6.1 Allocate community cancer control resources consonant with the target populations identified in specific geographic areas. The data are clear that certain populations have disproportionate risks for cancer, therefore the identified populations should be targeted.**
- 6.2 Create a Unit-based incentive program to facilitate working with hard-to-reach populations.**
- 6.3 Support and fund targeted demonstration sites and model programs where best practices for reaching underserved populations can be researched, highlighted, and disseminated.**
- 6.4 Advocate for improved access for services across the cancer control continuum for identified populations.**
- 6.5 Identify and develop expertise in addressing cultural diversity and apply that expertise throughout the cancer control continuum.**

Rationale: The American Cancer Society has a special responsibility to those in great need--the communities that are the hardest to reach tend to have rates of cancer at or above the general population. Furthermore, these hard-to-reach communities consist of a disproportionately large number of persons of color, poor individuals, and people who are otherwise disadvantaged and underserved.

Although working with identified populations has been a priority for many years, we still do not know how to reach these populations effectively and lack Volunteers and Staff who represent these populations. The American Cancer Society is unknown in many of these communities and is viewed with suspicion in some. Building on such successful programs as those cited in the Wilder Report, the American Cancer Society must develop competence and devote resources to reaching these populations effectively. Currently there is a serious and unacceptable gap between their need for cancer control services and our ability to reach these populations with effective cancer control services.

Working with Systems

Recommendation 7: The American Cancer Society should develop strategies that promote policy and practice changes in a variety of societal systems.

The American Cancer Society should:

- 7.1 Identify priority systems such as health care systems, school systems, political systems, worksites, and payor systems for cancer control activities.**
- 7.2 Work with identified systems to change policies, programs, services, and methods of reimbursement in ways that improve cancer control .**
- 7.3 Identify opportunities to provide incentives for the implementation of cancer control interventions in these priority systems.**
- 7.4 Advocate for the provision and coverage of services that address opportunities for cancer control in both indemnity and managed care plans.**

Rationale: Traditionally, the American Cancer Society has focused on controlling cancer through working with individuals. The Society can be more productive by acting as a catalyst for change in the way systems approach or include cancer control as part of their agendas. Our effectiveness, our reach, and our resources will be leveraged by working through systems that in themselves work with large numbers of people. Not only should the American Cancer Society shift toward working with systems, but we should enhance advocacy efforts that enable these systems to support and address high impact opportunities along the cancer control continuum. Systems interventions will be different for different levels of the Society, but are a necessary strategy for effectively meeting Core goals and supporting community cancer control.

Collaboration

Recommendation 8: The American Cancer Society should increase efforts at all levels for working with other organizations and agencies to achieve our common cancer control goals.

The American Cancer Society should:

- 8.1 Create guidelines to use in identifying partners and coalitions with whom collaboration would be most effective and guidelines for negotiating those partnerships and coalitions.**
- 8.2 Design and implement a practical skill-building training program so that both staff and volunteers collaborate with others more effectively.**
- 8.3 Evaluate the success of collaborative efforts toward achieving specific cancer control outcomes. This is a responsibility for all levels of the Society.**

Rationale: The reality is that no major cancer control issue, no major gains in reaching established cancer control goals, and no comprehensive cancer control intervention can be addressed by the American Cancer Society alone. This means that partnerships and collaborations, particularly with systems and hard-to-reach populations are increasingly important for the American Cancer Society.

Making collaboration work for the American Cancer Society is a difficult issue to resolve. What is not generally recognized, or at least articulated, is that most people are not very good at collaborating as individuals within organizations, much less between organizations. Working with others no matter who they are or what you are doing has challenges. However, the cost of not effectively collaborating is really too high. More people will go unserved, more resources will be expended than necessary, and most importantly, more problems will be left unresolved.

Promotion of Public Understanding of Community Cancer Control

Recommendation 9: The American Cancer Society should work to enhance public understanding of what people can do to prevent and control cancer and what the Society does in community cancer control.

The American Cancer Society should:

- 9.1 Develop a planned approach for communicating with the public, the field, and donors, all American Cancer Society position statements, guidelines, new program interventions, and nationwide plans for cancer control.**
- 9.2 Promote cancer control activities as a part of the Society's overall media campaigns.**
- 9.3 Develop a planned approach for systematically and regularly communicating progress toward achieving Year 2015 goals.**
- 9.4 Focus community attention on cancer control problems and opportunities, using local data.**

Rationale: All too often the public does not actually know or understand how to control cancer, nor does the public understand what the American Cancer Society does in community cancer control. If the public is to have better understanding of cancer control, as well as have access to the full range of American Cancer Society services, Volunteers and Staff must be able to articulate what it is we do in community cancer control (our Core activities, Mission 2000 plans, cancer control results, Year 2015 goals).

This will aid in giving the public, potential volunteers, and potential donors a clear view of the dynamic nature of American Cancer Society efforts to prevent cancer and to improve cancer outcomes. There is also a need to communicate our alliances and cooperative efforts with various agencies toward common cancer control goals, with a specific need to show with exact data where Society money goes and what results are achieved.

Cancer Control Education for Health Care Providers

Recommendation 10: **The American Cancer Society should target its medical education efforts to primary care practitioners and other frontline health care providers.** Education efforts should encompass prevention, early detection, and quality of life considerations, including end-of-life issues. Actual delivery of education should be carried out, as much as possible, in coordination with discipline-specific professional organizations. The Society's role in education of health professionals should emphasize ways to facilitate cancer control education for their patients, including how to refer to a menu of the Society's services.

The American Cancer Society should:

- 10.1 Work to educate health professionals in ways other than traditional conferences, such as collaborative programs using new educational technology.**
- 10.2 De-emphasize American Cancer Society stand-alone professional education programs; instead work in collaboration with others to educate health professionals.**
- 10.3 Advocate for the inclusion of cancer control opportunities and issues in health care provider curricula.**

Rationale: In the past, the American Cancer Society has relied on conferences to educate health care professionals about cancer control and about American Cancer Society programs and services. These conferences have been unsuccessful in encouraging health care providers to refer their patients to American Cancer Society services and programs, and they have had limited impact on improving cancer control knowledge and practice of health care professionals.

The American Cancer Society cannot continue to take on the role of being a major source of education for health care specialties. We must instead work with the entities that do the training to ensure that the cancer control concepts we believe important are taught. In particular, we need to emphasize the delivery of programs and not continuing education for professionals. The Society can obtain a greater effect by changing the way general health care providers include cancer control strategies routinely in their practices.

CAPACITY

Development and Recruitment of Staff

Recommendation 11: At all levels of the organization, the American Cancer Society should increase the quantity of the Staff time and the quality of the Staff effort dedicated to cancer control. This can be done by more detailed identification of job skills, strategic hiring, extensive training, and the establishment of clear lines of cancer control accountability for program outcomes.

Staff Training

The American Cancer Society should:

- 11.1 Identify the specific skills necessary for cancer control work and institute clear and consistent systems of training.** These skills include, but are not limited to, applying public health strategies, community organization, working with minorities and low income populations, volunteer recruitment, collaboration, and a systems approach to cancer control.

Staff Recruitment

The American Cancer Society should:

- 11.2 Give priority to hiring Staff who are committed to the American Cancer Society mission, skilled in public health, community organization, advocacy, or health education, and representative of diverse segments of the population.**
- 11.3 Hire cancer control specialists for work in large population areas. Their work should be targeted to cancer control priorities. In small Units, the Society should evaluate the role of the field generalist to assure an appropriate level of cancer control activity.**

Staff Accountability

The American Cancer Society should:

- 11.4 Evaluate current and emerging staffing patterns, lines of authority, and accountability structures in Divisions and identify the structures and procedures most effective for delivering cancer control interventions. The Society should share best practices widely among Divisions and Units.**
- 11.5 Assure that cancer control and fundraising Staff work in a team approach with cooperative planning and clear recognition of interdependence. Cooperative planning should emphasize the value of effective cancer control at the community level in securing and maintaining income.**

Staff Compensation and Recognition

The American Cancer Society should:

- 11.6 Adjust current pay ranges for cancer control Staff to recruit and retain the personnel needed to implement the Blue Ribbon Advisory Group Recommendations and to achieve the Year 2015 goals and objectives.**
- 11.7 Develop a system of recognition that motivates Staff, sustains momentum, and improves program effectiveness. The system should recognize Staff for accomplishments toward cancer control outcomes, especially effective programs to reach targeted populations, including those programs conducted in collaboration with other organizations.**

Rationale: As planning for community cancer control at all levels becomes data driven, the face of cancer control at the local level will change. We must also change our expectations for our Staff. The recent survey of Unit practice clearly indicates that cancer control is understaffed and that there is a strong need to increase Staff ability to implement effective cancer control. Our current and future Staff must be better trained, bring a better set of skills to the tasks at hand, and be able to devote significant and focused time to the job.

Currently, many Staff members are generalists who lack sufficient background in public health to efficiently carry out cancer control activities. Staff turnover is a moderate to major problem in most Divisions, preventing consistency in effort and hindering the impact of any systematic training program. The Unit practice survey also revealed a widespread perception that the number of Staff and amount of resources within the organization are disproportionately devoted to income development. Cancer Control Staff report feeling compelled to drop cancer control activities to work on fundraising. The reality is that income development and cancer control can

both be enhanced by better interaction between the two.

A recurring theme in the national surveys was the need for training both for Volunteers and Staff. Respondents asked for National/regional training meetings in cancer control, and voiced specific interest in the increased use of technology for ongoing training/information. Units and Divisions noted the need for sharing best practices and for highlighting special or effective efforts at the Division level as part of a new system of training mechanisms.

Development and Recruitment of Volunteers

Recommendation 12: **The American Cancer Society should assure that it attracts and retains volunteers of high capability for cancer control. The Society must commit itself to programs of training and recognition, and to making sure each volunteer has a clear sense of accomplishment.**

Volunteer Training and Recruitment

The American Cancer Society should:

- 12.1 Support a planned approach to Volunteer recruitment, development, and retention. Systematic training for Volunteers should be implemented at all levels of the organization.**
- 12.2 Identify the skills essential to Volunteer implementation of cancer control strategies. In addition, the Society must ensure Volunteer competencies by further developing skills for the implementation of a more science-based, systems approach to cancer control.**
- 12.3 Attract academics on sabbaticals, industry experts on short term assignments, and young investigators whose work ties to Society cancer control activities.**
- 12.4 Institute a strong, organization-wide Management Information System (MIS) to determine current Volunteer capacity and future Volunteer needs for delivery of community cancer control.**
- 12.5 Develop new Volunteer structures that are project-based with a focus on clear Volunteer expectations and increased accountability for achieving cancer control outcomes.**
- 12.6 Develop a plan that recruits specific Volunteers for well-defined tasks. These Volunteers should be representative of diverse segments of the population.**

Volunteer Retention and Recognition

The American Cancer Society should:

- 12.7 Develop a system of recognition that motivates Volunteers, sustains momentum, and improves program effectiveness.** The system should recognize Volunteers for accomplishments toward cancer control outcomes, including effective programs to reach targeted populations, especially those conducted in collaboration with other organizations.

Rationale: The diversity and number of our community Volunteers is both the basis for our strength and the driving force behind our work. It is only through effective use of this incredible pool of Volunteers that we will be able to reach our Year 2015 goals. In this, as in other areas of the Society's organization, we now have an opportunity to rethink the ways we recruit, train, and utilize Volunteers.

Currently, there are no systematic records available on the numbers and kinds of volunteers working in cancer control for the American Cancer Society. Volunteers are increasingly needed to perform a wide variety of cancer control tasks, although they have not been trained for many of these activities. Clearly we need to match Volunteer talents and abilities to the strategies that will accomplish community cancer control, and we need to provide the training that will enable them to carry out these strategies.

In addition, the American Cancer Society should commit to a system of recognition that gives each Volunteer a clear sense of accomplishment. We must be realistic and creative in the ways we ask our volunteers to contribute their time and talents to the Society.

Resource Acquisition and Allocation

Recommendation 13: The American Cancer Society should provide appropriate and sufficient resources to support cancer control recommendations to meet the goals for the Year 2015 and beyond.

Resource Development:

The American Cancer Society should:

- 13.1 Initiate innovative and aggressive actions to secure outside funding through contractual and grant mechanisms by hiring Staff with skills in this area.**
- 13.2 Work with income development to link fundraising more efficiently with the cancer control product at the community level.**

Resource Allocation

The American Cancer Society should:

- 13.3 Shift resource expenditures in the field toward programmatic development and capacity-building initiatives by significantly decreasing expenditures in publications, materials, and direct financial assistance as recommended in the field surveys and in the wake of resource realignment.**

Technology/Information Infrastructure

The American Cancer Society should:

- 13.4 Increase to 100% the access of cancer control Staff to:**
 - computer and other support technologies**
 - data systems that provide current science, surveillance, and marketing data**
 - management information tracking systems**
 - the latest information on best practices in cancer control**

Capacity Development

The American Cancer Society should:

- 13.5 Regularly monitor progress on increasing the Society's capacity and resources to deliver effective community cancer control.** The Society should monitor this progress with regular surveys of the state of cancer control in the Society.

Rationale: Changes in our Staff and Volunteer capacity will contribute immeasurably toward our progress in reaching Year 2015 goals. However, we won't fully realize American Cancer Society potential to effect community cancer control unless we are able to devote more financial resources to the development of skilled people and of our infrastructure. Whether we reallocate current resources or acquire new sources of income, we must spend available dollars differently if we are to make new inroads in the war against cancer.

According to the recent Unit practice survey, over half of Executive Vice Presidents report that the largest direct expenses in cancer control after salaries are materials, printing and publications, and direct patient assistance. Twenty percent of Divisions provide direct financial assistance to everyone who applies. Obviously these figures represent an enormous amount of resources that can be shifted, for the most part, to expense areas directly related to cancer control program and delivery--including funding for cancer control Staff and Volunteer capacity development.

Additionally, many Staff and Volunteers do not have adequate access to computers, and those who do have access to computers lack training necessary to use them effectively as a tool of cancer control.

IMPLEMENTATION PLAN

DEVELOPMENT OF BUSINESS PLAN

Recommendation: Immediately after the approval of this document, a small group consisting of American Cancer Society National, Division, and Unit Volunteers and Staff should be convened to develop a business plan for the implementation of the recommendations in this document. The charge to the National Office is to:

- devise the means for communicating the recommendations to the field
- develop surrogate indicators for mortality, specific roles, and interim measures based on Year 2015 goals
- assess progress toward Year 2015 goals
- convene an advisory group to evaluate progress on the business plan within two years

APPENDICES

APPENDICES

- 1. Strategic Directions of the American Cancer Society**
- 2. Tying It All Together: Moving Through Mission 2000 and Core to 2015 Goals**
- 3. Year 2015 References**
- 4. Members of the Blue Ribbon Advisory Group on Community Cancer Control**
- 5. Process of Fulfilling the Charge to the Group**
- 6. Executive Summary of the Unit/Division Inventory of Cancer Control Activities**
- 7. Survivorship Initiatives Addendum**
- 8. Glossary of Selected Cancer Control Terms**

Appendix 1. Strategic Directions of the American Cancer Society

**Strategic Directions of the American Cancer Society
(Adopted by the Board of Directors, November, 1995)**

***Strategic Direction #1:* Establish leadership in the delivery of cancer information**

***Strategic Direction #2:* Provide local leadership in cancer prevention and control nationwide through enhanced collaboration with others transforming state of the science and state of the art into state of the practice**

***Strategic Direction #3:* Develop, support, and market a focused, high impact cancer research health professional training program which compliments, but does not duplicate others**

***Strategic Direction #4:* Advocate aggressively at both the local and national levels in behalf of cancer patients and cancer control**

***Strategic Direction #5:* Adopt best practices, with built-in accountability for the acquisition and development of resources, both human and financial**

**Appendix 2. Tying It All Together:
Moving Through Mission 2000 and Core to 2015 Goals**

Tying It All Together

Moving Through Mission 2000 and Core to 2015 Goals

There have been many new directions--**Mission 2000, Core, strategic directions, role delineation, resource realignment, business planning, and the Blue Ribbon Advisory Group Recommendations on Community Cancer Control**. How do they all fit together?

Mission 2000 and Core represent the American Cancer Society's basic program of work and its focus toward applying the most productive interventions to reach the corporate goals we have set out for the Year 2000. **Measures of Success**, a part of Mission 2000, are the measurable outcomes in each of the Core areas, which direct us to meeting our Mission 2000 goals.

Strategic directions, adopted by the National Board of Directors in November 1995, represent the "super highways" that we are using to travel to Mission 2000 and beyond. We call them super highways because they are broad strategic avenues believed to be the most direct routes to achieve our mission.

The **role delineation** initiative helps clarify and resolve the distinctive roles to be played by the various entities that make up the American Cancer Society. The recommendations from role delineation will help form and direct resource realignment.

Resource realignment, at its base, is about reconfiguring our field structures and operations so that each of our Divisions is empowered with maximum resources to change the course of cancer at the community level. This is important because it is grassroots cancer control that Mission 2000 aims to effect.

Our contemporary **business planning process** is an effort to work out the details of our corporate action plans for the next two to five years. Specifically, the business planning process will spell out the strategic and action plans, with resources then allocated to carry out these plans.

While Mission 2000 and Core plans extend to the Year 2000, the recommendations from the **Blue Ribbon Advisory Group on Community Cancer Control** comprise a successor document looking to the Year 2015 and beyond. This process allows us to plan for the future, while continuing to work on our current Mission 2000 programs.

Appendix 3. Year 2015 References

Year 2015 References

Introduction

The Board of Directors of the American Cancer Society has adopted the goal of a 50% reduction in age-adjusted cancer mortality for the Year 2015 to guide the American Cancer Society into the future. In addition, the Blue Ribbon Advisory Group on Community Cancer Control recommends that the Board of Directors adopt Year 2015 goals for incidence and quality of life, and that these goals be tied to level of effort. To this end, the Chair of the Blue Ribbon Advisory Group on Community Cancer Control, Dr. Gerald Woolam, invited a number of outside scientists to serve as members of a workgroup that would address incidence and quality of life goals. The workgroup was charged to:

- develop primary goals, interim goals, and outcome measures through the Year 2015
- develop an evaluation plan for long term goals, and a plan for evaluating those goals on an interim basis
- identify the relationship between Mission 2000 and the goals for Year 2015

The workgroup recognizes that the American Cancer Society cannot address these enormous tasks alone, but must collaborate with other health organizations on the work that will achieve these goals. Certainly the Year 2015 goal of a 50% reduction in age-adjusted cancer mortality is ambitious, but it is clearly useful in that it serves as a “vision statement” and helps the Society in setting direction and priorities.

The initial labor of the workgroup was to develop a framework and process by which to proceed throughout the process of establishing goals for incidence and quality of life. The workgroup approved the following guidelines for our work:

- objectives should closely model those of the Department of Health and Human Service’s Healthy People 2000 Objectives
- objectives should be ambitious but realistic
- objectives need to be measurable
- objectives need to be tied to a level of effort
- data for tracking the objectives need to be comparable to existing surveillance systems
- objectives should include separate components for minority and underserved populations

In order for the workgroup to fulfill its charge, it will be necessary to develop cancer mortality and incidence projections by cancer site for the Year 2015. These projections are complicated and fraught with scientific issues not easily resolved. It will also be necessary to develop Year 2015 objectives by cancer site as well as to identify the relevant databases to track progress.

The workgroup needs to do more work on the objectives related to quality of life and survivorship. Specifically, we must develop objectives relating to long-term survivors, and

develop databases to track quality of life data.

Several significant issues make it difficult to develop projections for the goals and objectives we wish to establish. For example, in primary prevention, it is difficult to obtain the population prevalence of modifiable risk factors. For early detection, it is hard to get information about the dissemination of new technologies and translate the results of clinical trials into state-specific survival benefits.

Statistical Profile and Trends for Incidence and Mortality

In establishing goals and objectives, the workgroup will consider only the major cancer sites in women and men. Major cancer sites related to mortality for men are lung, prostate, colon, pancreas, and non-Hodgkin's lymphoma, in order. Major cancer sites related to mortality in women are lung, breast, colon, pancreas, and ovary, in order.

Estimated new cancer cases and deaths by sex for all sites, United States, 1997, is presented in Table 1. To fully understand the trends in cancer data, it is important to understand that from 1973 to 1994, cancer increased as the leading cause of death from 17.3 percent to 23.4 percent, Figure 1. Figure 2 reflects the fact that cancer is a disease of older persons. Mortality rates for cancers for persons less than 65 years of age have shown a steady decline since 1984. However, cancer mortality rates for persons 65 and over have been increasing since 1974. From 1973 to 1994, mortality rates for lung (female), non-Hodgkin's lymphoma, liver, multiple myeloma, melanomas of the skin, prostate, kidney/renal, brain, and lung (male) have been increasing with an overall 5.4 percent increase for all cancers. Decreases in U.S. cancer mortality rates from 1973-1994 have occurred for breast, colon/rectum, corpus and uterus, stomach, and cervix uteri (Figure 3).

About 1,382,400 new cancer cases are expected to be diagnosed in 1997 with 560,000 Americans expected to die of the disease. One of every four deaths in the United States is from cancer. The National Cancer Institute estimates that approximately 7.4 million Americans alive today have a history of cancer with a portion of them being "cured," and others still showing evidence of cancer. It is estimated that from 50 to 70 percent of all cancer can be prevented, largely through changes in individual behavior such as not using tobacco products, eating a diet high in fiber and low in fat, seeking appropriate cancer early detection examinations such as mammography, and protecting oneself from ultraviolet exposure.

Quality of Life Issues for 2015

Quality of life and survivorship issues occur along a continuum that begins with diagnosis and ranges through long-term survival and effects on cancer patients, their families and caregivers. The problem inherent in improving quality of life for cancer survivors is that we lack a standardized tool for measuring quality of life and we do not have a national database to monitor quality of life. Research into quality of life has expanded over the last two decades, but has been

somewhat limited to patients currently receiving treatment. If the American Cancer Society is to capitalize fully on the recommendations of the Blue Ribbon Advisory Group on Community Cancer Control, the Society must develop the infrastructure for research and services related to quality of life and survivorship. The workgroup will identify existing databases that can be used to monitor progress on objectives and will make recommendations to create new databases for surveillance.

Next Steps

Because Year 2015 objectives will, in essence, set the framework for action, all levels of the Society, as well as the National Cancer Institute and Centers for Disease Control, must reach consensus on the objectives. The consensus process will take time, but is critical if the Society is to move ahead as a part of a concerted effort.

TABLE 1

ESTIMATED NEW CANCER CASES AND DEATHS FOR 1997

All Races, By Sex

Primary Site	Estimated New Cases			Estimated Deaths		
	Total	Males	Females	Total	Males	Females
All Sites [□]	1,257,800	661,200	596,600	560,000	294,100	265,900
Oral Cavity and Pharynx	30,750	20,900	9,850	8,440	5,600	2,840
Tongue	6,400	4,200	2,200	1,820	1,200	620
Mouth	11,000	6,700	4,300	2,500	1,400	1,100
Pharynx	8,800	6,400	2,400	2,030	1,500	530
Other Oral Cavity	4,550	3,600	950	2,090	1,500	590
Digestive System	225,900	120,000	105,900	127,070	67,440	59,630
Esophagus	12,500	9,400	3,100	11,500	8,700	2,800
Stomach	22,400	14,000	8,400	14,000	8,300	5,700
Small Intestine	4,900	2,600	2,300	1,140	540	600
Colon	94,100	45,500	48,600	46,600	22,600	24,000
Rectum	37,100	20,900	16,200	8,300	4,400	3,900
Anus, Anal Canal, and Anorectum	3,400	1,400	2,000	410	150	260
Liver and Intrahepatic Bile Duct	13,600	9,100	4,500	12,400	7,500	4,900
Gallbladder and Other Biliary	6,900	2,500	4,400	3,500	1,300	2,200
Pancreas	27,600	13,400	14,200	28,100	13,500	14,600
Other Digestive	3,400	1,200	2,200	1,120	450	670
Respiratory System	194,600	111,400	83,200	165,920	98,490	67,430
Larynx	10,900	8,900	2,000	4,230	3,300	930
Lung and Bronchus	178,100	98,300	79,800	160,400	94,400	66,000
Other Respiratory	5,600	4,200	1,400	1,290	790	500
Bones and Joints	2,500	1,300	1,200	1,410	750	660
Soft Tissues	6,600	3,700	2,900	4,100	1,900	2,200
Melanomas of Skin	40,300	22,900	17,400	7,300	4,600	2,700
Breast	181,600	1,400	180,200	44,190	290	43,900
Genital Organs	424,800	343,000	81,800	68,870	42,370	26,500
Cervix Uteri	14,500		14,500	4,800		4,800
Corpus and Uterus, NOS	34,900		34,900	6,000		6,000
Ovary	26,800		26,800	14,200		14,200
Vulva	3,300		3,300	800		800
Vagina and other genital organs female	2,300		2,300	700		700
Prostate [□]	209,900	209,900		41,800	41,800	
Testis	7,200	7,200		350	350	
Other Male Genital	1,300	1,300		220	220	
Urinary System	85,400	58,000	27,400	23,520	15,060	8,460
Urinary Bladder	54,500	39,500	15,000	11,700	7,800	3,900
Kidney and Other Urinary	30,900	18,500	12,400	11,820	7,260	4,560
Eye and Orbit	2,100	1,100	1,000	250	140	110
Brain and Other Nervous System	17,600	10,100	7,500	13,200	7,200	6,000
Endocrine Glands	17,560	5,530	12,030	2,070	870	1,200
Thyroid	16,100	4,700	11,400	1,230	450	780
Other Endocrine	1,460	830	630	840	420	420
Lymphomas and Myelomas	74,900	42,100	32,800	36,180	18,720	17,460
Hodgkin's Disease	7,500	3,900	3,600	1,480	820	660
Non-Hodgkin's Lymphoma	53,600	30,300	23,300	23,800	12,400	11,400
Multiple Myeloma	13,800	7,900	5,900	10,900	5,500	5,400
Leukemias	28,300	15,900	12,400	21,310	11,770	9,540
Lymphocytic Leukemias	10,400	5,900	4,500	6,310	3,570	2,740
Myeloid Leukemias	13,500	7,100	6,400	8,700	4,800	3,900
Other Leukemias	4,400	2,900	1,500	6,300	3,400	2,900
All Other Sites	35,500	16,500	19,000	34,300	17,400	16,900

Source: Cancer Facts & Figures - 1997, American Cancer Society (ACS), Atlanta, Georgia, 1997.
 Excludes basal and squamous cell skin and in situ carcinomas except urinary bladder.
 Incidence projections are based on rates from the NCI SEER Program 1979-1993.

□ Estimates revised 4/97. Original ACS prostate cancer estimate may be too high due to the unavailability of 1994 and preliminary 1995 incidence rates at estimation time. With the additional information, NCI and ACS estimate that there will be less than 210,000 new cases of prostate cancer in 1997.

Leading Causes of Death in U.S. Percent of All Causes of Death 1973 vs. 1994

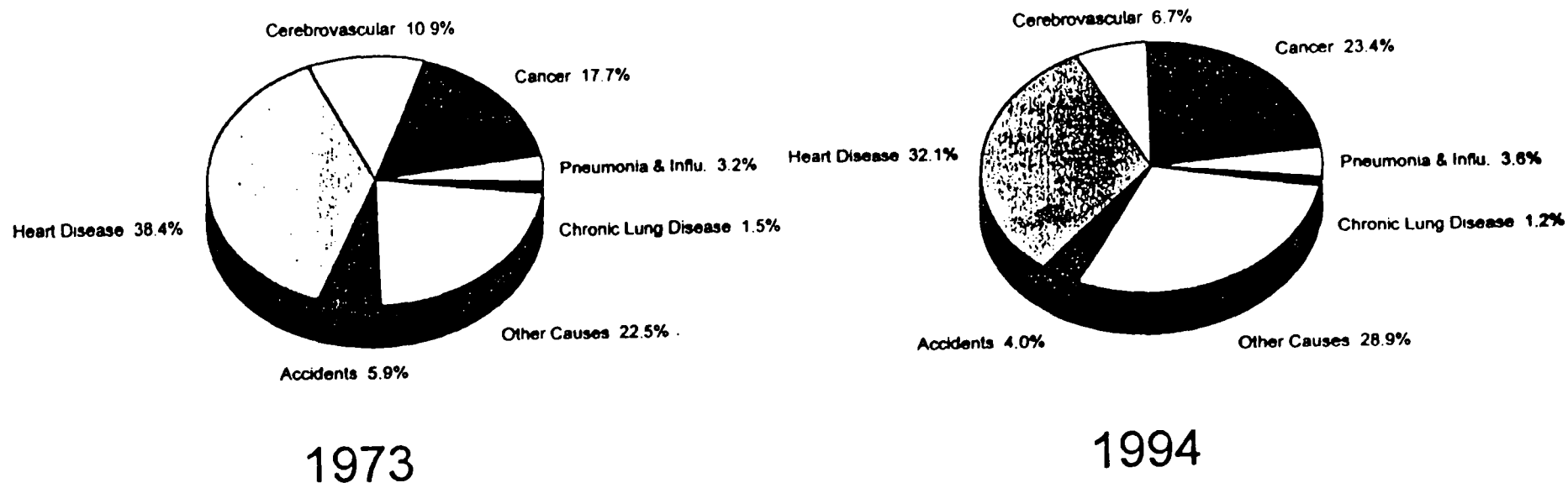
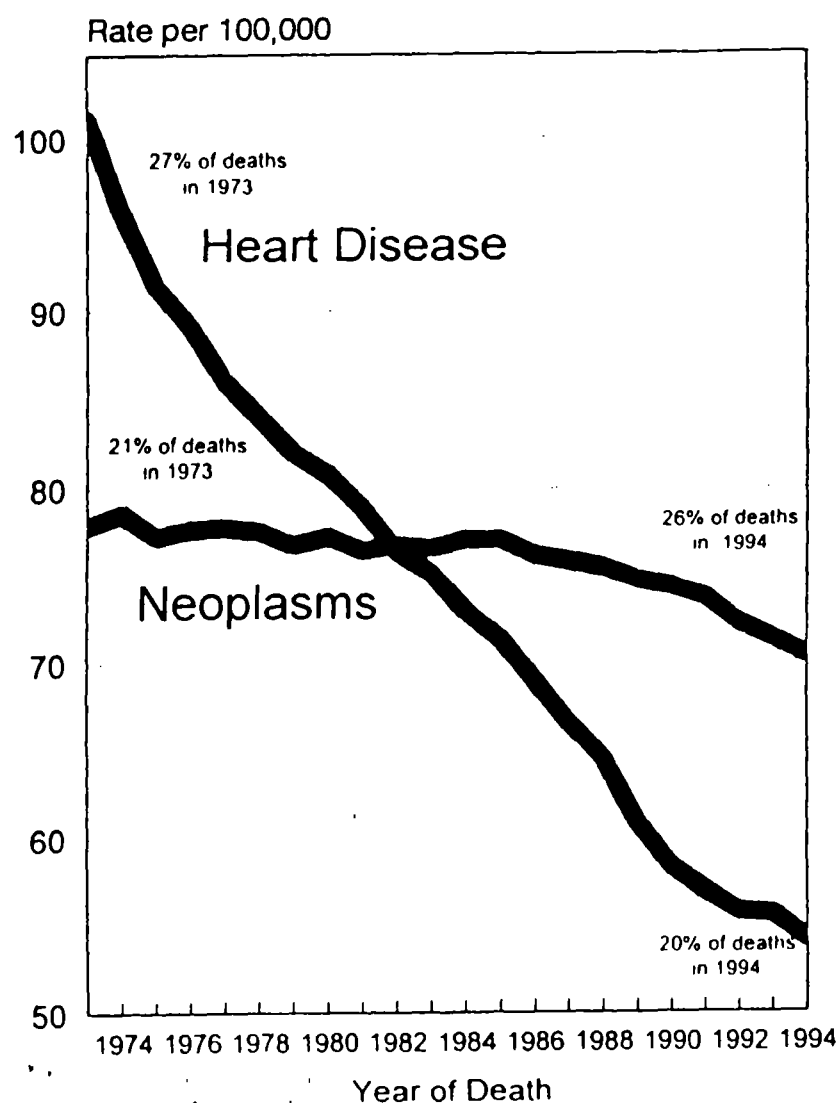


FIGURE 1

U.S. Mortality Rates 1973 - 1994

Ages Less Than 65



Ages 65 and Over

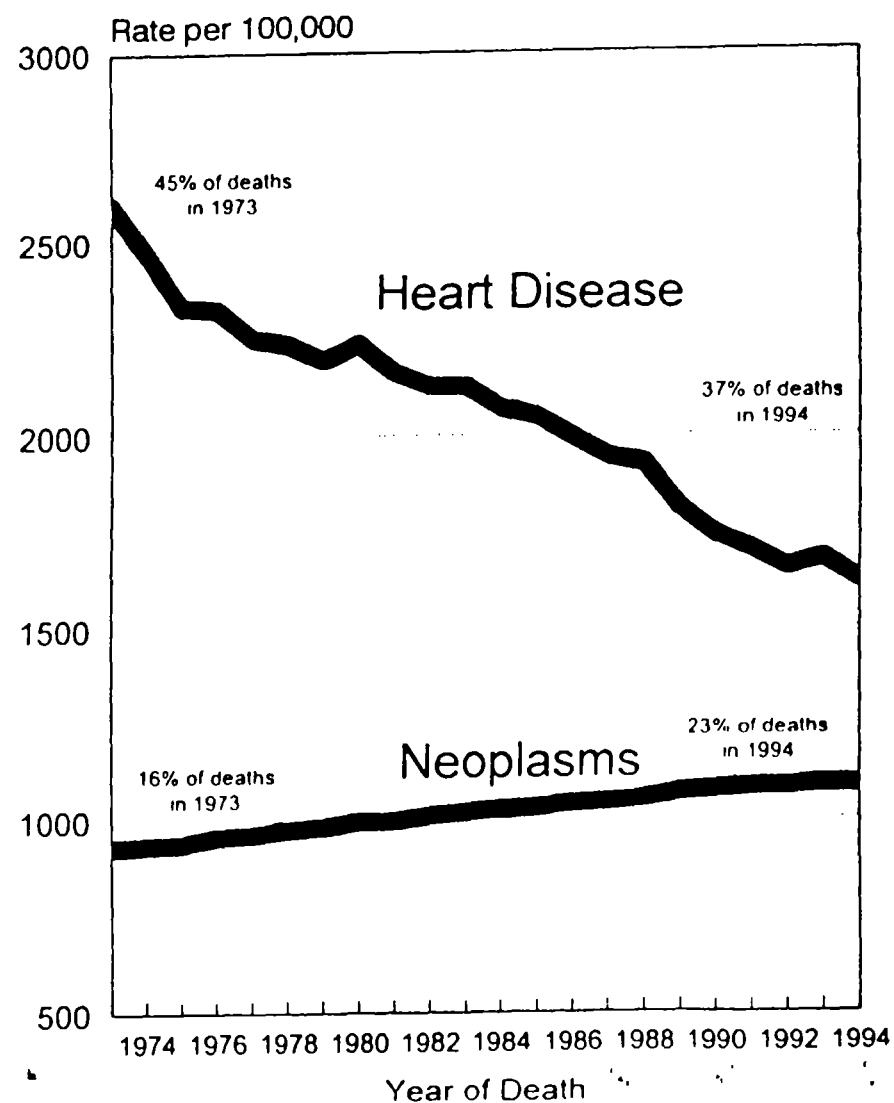
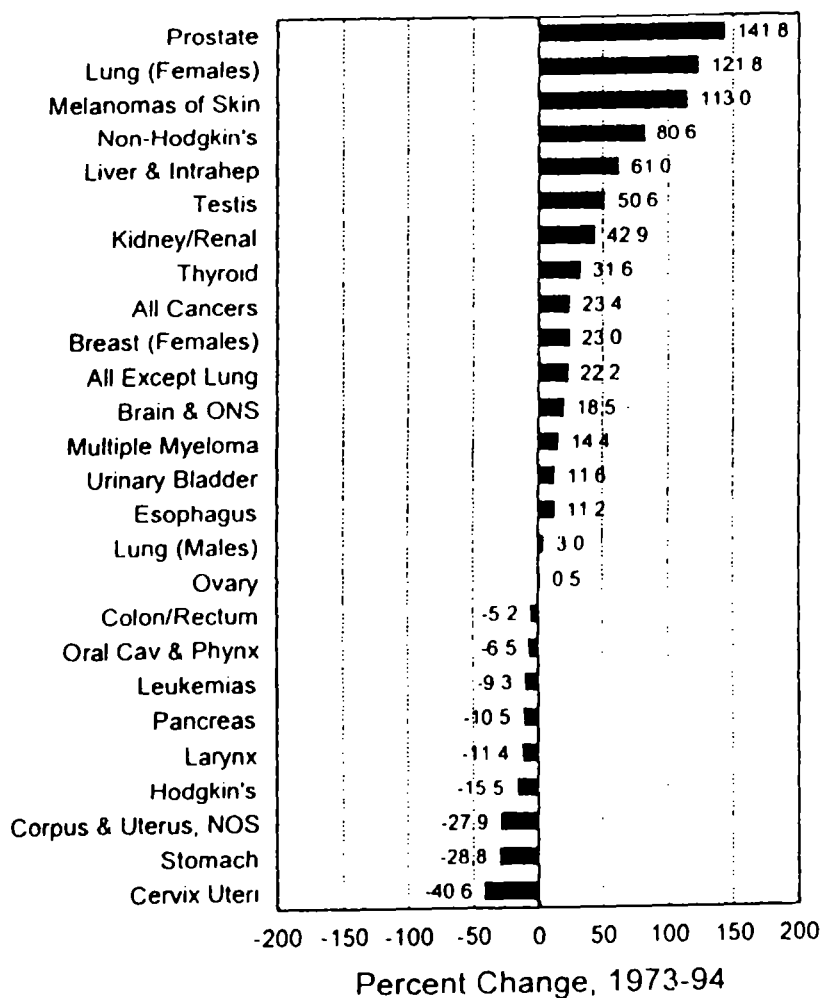


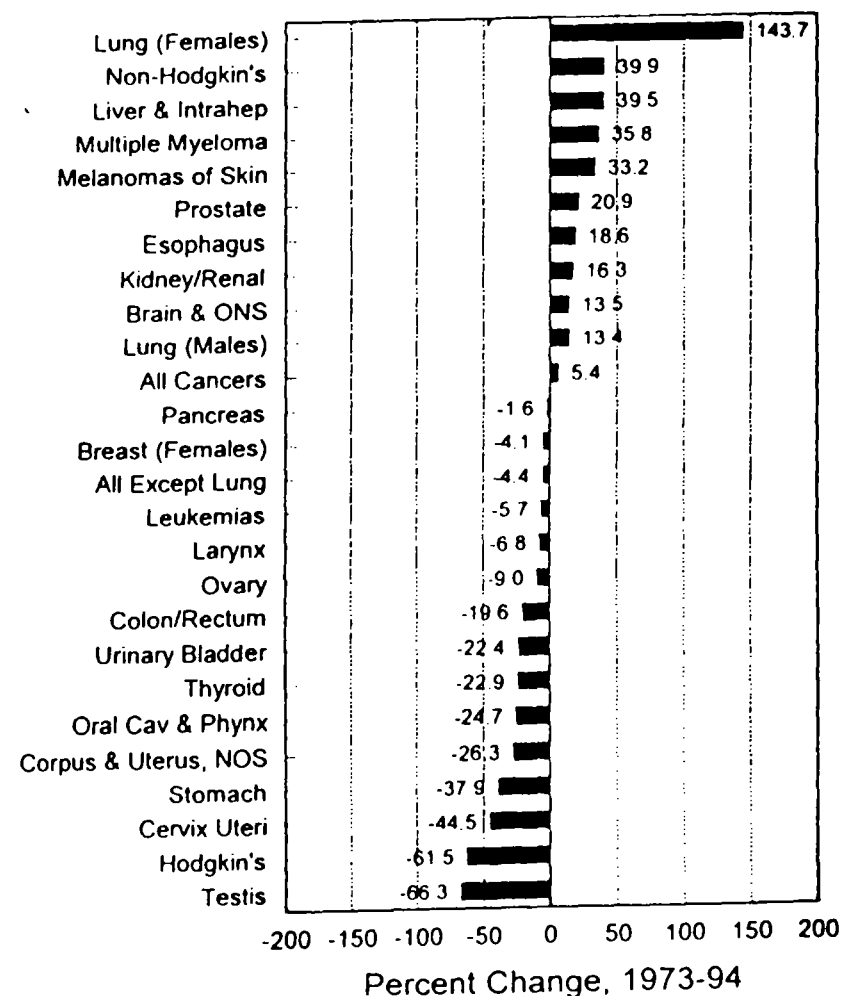
FIGURE 2

Trends in SEER Incidence & U.S. Mortality Rates by Primary Cancer Site 1973-1994

Trends in SEER Incidence Rates



Trends in U.S. Cancer Mortality Rates



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Appendix 5. Process of Fulfilling the Charge to the Group

Process of Fulfilling the Charge to the Committee

November, 1996: President and Chairman of the Board of Directors recommend that the American Cancer Society review the state-of-the-science, state-of-the-art, and state-of-the-practice in community cancer control and make recommendations regarding the American Cancer Society's role in community cancer control.

January, 1997: Blue Ribbon Advisory Group for Community Cancer Control is appointed. Leadership of the group includes Gerald Woolam, MD - Chair; Dileep Bal, MD - Co-Chair; Harmon Eyre, MD - Co-Staff; and Nancy Lins, Co-Staff.

March, 1997: First meeting of Blue Ribbon Advisory Group. Six workgroups are formed:

- Prevention
- Detection
- Treatment
- Patient Issues
- Delivery
- Infrastructure

Each workgroup consists of one Volunteer Chair and one National Home Office Staff, national and division level volunteers and staff, and outside experts who have special knowledge and interest in the workgroup area. Workgroups begin gathering information on which to base their recommendations.

Blue Ribbon Advisory Group and Workgroups meet March 6 and 7 to discuss the charge, the recommendation process, sample recommendations, and the time line for the recommendation process. The Workgroups meet individually to develop a work plan, establish conference call dates, set parameters for the work, and review the known resources.

March - May, 1977: Workgroups carry out their workplan and develop draft recommendations for consideration by the Blue Ribbon Advisory Group.

June, 1977: Blue Ribbon Advisory Group meets June 6-7 to review the draft recommendations. Workgroups meet to refine the recommendations, and the Blue Ribbon Advisory Group approves (in concept) the Workgroup recommendations. Volunteers are asked for input at the June Board of Directors Meeting.

A workgroup of outside scientists is convened to develop incidence and quality of life goals for the Year 2015

July, 1977: Draft recommendations (with evaluation form) are sent to the Blue Ribbon Advisory Group, the National Board of Directors, Standing Committee Members, Division and National Volunteers and Staff, and Program Advisory Groups for comment and evaluation. At a meeting of the writing group, the draft recommendations are revised based on input from these evaluations.

August, 1997: Blue Ribbon Advisory Group meets August 9-10 to review newly drafted recommendations. In addition to reviewing the recommendations and suggesting revisions, the group discusses the potential audiences for the report and the format of the final report.

Revisions are made and circulated to the writing group.

September, 1997: Blue Ribbon Advisory Group meets September 13-14 to revise and approve the final recommendations.

October, 1997: Final preparation and printing for presentation to the Board of Directors.

November, 1997: Presentation to the Board of Directors.

Appendix 6. Executive Summary of the Unit/Division Inventory of Cancer Control Activities

EXECUTIVE SUMMARY

An Inventory of Cancer Control Activities within the Divisions and Units of the American Cancer Society

Paul W. Mattessich, Ph.D.

Prepared at the Request of the
Blue Ribbon Advisory Group on Cancer Control

Managed by
The Departments of Cancer Control and
Evaluation Services
National Home Office

Under Contract with
Wilder Research Center
Suite 210
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July, 1997

AN INVENTORY OF CANCER CONTROL ACTIVITIES WITHIN THE DIVISIONS AND UNITS OF THE AMERICAN CANCER SOCIETY

Wilder Research Center¹
July 29, 1997

INTRODUCTION

The American Cancer Society established a Blue Ribbon Advisory Group on Community Cancer Control. A major goal of the Advisory Group is to make recommendations on the best strategy for the Society to do community cancer control.

The Advisory Group commissioned Wilder Research Center to develop an inventory of cancer control activities within Units and Divisions of the American Cancer Society to help inform its assessment of the state of the practice of community cancer control and to assist in the development of recommendations.

Wilder Research Center prepared this report.² It is organized as follows:

- ◆ Introduction
- ◆ Major Themes from Site Visits, Unit Interviews, and Unit Mailed Survey
- ◆ Types of Activities Among Units
- ◆ Planning Process
- ◆ Appendices

Each of these sections builds upon the findings of three information-gathering activities:

Site visits to eight Divisions of the Society.

A mailed survey of 568 Units of the Society.³

A phone interview of 146 Units of the Society.

¹ Contact Paul W. Mattessich, Ph.D., Wilder Research Center, Suite 210, 1295 Bandana Boulevard North, St. Paul, MN 55108. (612) 647-4600.

² The report has benefited from the contributions of a number of staff in Wilder Research Center and the American Cancer Society. These include Eden Avery, Bruce Black, Don Compton, Rebecca Glover, and Kim Sawyer at the American Cancer Society, and Marilyn Conrad, Phil Cooper, Louann Graham, Barb Monsey, Kent Treichel, and Karen Ulstad at Wilder Research Center. We thank the Unit and Division staff and volunteers who participated in the surveys that provided the inventory data.

³ Details on the methods used for the mailed survey, phone interview, and site visits appear in Appendix E.

MAJOR THEMES FROM SITE VISITS, UNIT INTERVIEWS, AND UNIT MAILED SURVEY

Review of the results of the site visits, the Unit interviews, and the Unit mailed survey led to the identification of a number of themes. This section of the report presents these themes in a common, succinct format:

Explanation: A description of each theme, including major points raised, major findings from survey data, and/or examples.

Opportunities/Suggestions for Addressing this Theme: Ideas presented by volunteers and/or staff from Units and Divisions, as well as thoughts from the Wilder Research Center staff.

For ease of discussion, the themes are grouped into four categories:

- Program Quality
- Resources
- Planning
- Relationships Inside and Outside the Society

Program Quality

➤ Need for Training and for Information about New Approaches

Explanation:

- Volunteers and staff want more opportunities to learn what others in the Society are doing in their program activities and in their planning efforts. They have an interest in the kinds of issues and challenges their counterparts face, and the approaches they use to face them.⁴
- Volunteers and staff want more opportunities to learn what is effective, so that they can apply this knowledge in their Units. In general, Units lack information on the effectiveness of many or all of their own programs.⁵ They also lack access to information on the effectiveness of similar or identical programs elsewhere.

⁴ A very active, long time volunteer in one of the Divisions said: "I never know what other Divisions do, unless I work hard to find out."

⁵ This is described in more detail in the section on "Need for Measures of Success/Evaluation."

- Sharing of information needs to occur vertically (National/Division/Unit) and horizontally (Division/Division; Unit/Unit). Unit staff and volunteers report that they value National as an information source. However, they also find great value in learning from their peers in other Divisions and Units. In addition, the wisdom accumulated within Divisions sometimes surpasses that of National, especially with respect to the development of materials and technology to improve cancer control program activities (e.g., outreach to the underserved).

Opportunities/Suggestions for Addressing this Theme:

- Training programs, such as National Core Team Meetings, which brought together staff and committee chairs from around the country, were often identified as very positive sources of information and mutual support among people dealing with similar issues. Continuation of this type of training might be beneficial. If cost considerations, or other factors, prohibit this type of training, videoconferencing might be an alternative.
- Units could benefit from a system developed on Lotus Notes which identifies: (a) the new activities Units are trying; and (b) the level of effectiveness (or lack of effectiveness) of what's been tried.⁶

➤ Reaching Persons of Color, Disadvantaged, and Underserved Populations

Explanation:

- The hardest to reach communities tend to have rates of cancer at or above the general population. Hard to reach communities disproportionately consist of persons of color, poor individuals, and the otherwise disadvantaged and underserved.
- The American Cancer Society is unknown in many hard to reach communities. It is viewed with suspicion in some. It takes a long time to gain the recognition and trust of communities. Even staff and volunteers of color have to spend time overcoming a negative image of the Society in some locales.
- Many Divisions of the American Cancer Society lack volunteers from communities with large numbers of persons of color, disadvantaged, and underserved people. This lessens the ability of the Society to make progress in these communities. It also increases the likelihood that dollars and volunteer hours contributed in one community will have to go to another community – which creates stress for some Divisions when donors ask where their money goes.

⁶ In our review of Mission 2000 (September, 1996), we recommended that this system should have at least the following characteristics: It should be accessible. It should have clear indexing, clear terminology, and complete information. It should systematically categorize the level of effectiveness and strength of evidence regarding a particular practice. (Examples were provided.) It should indicate special circumstances which may influence effectiveness, or which make a practice more or less suitable in certain situations or with certain populations.

- The American Cancer Society needs to develop competence serving different cultures. Brochures, materials, speakers, outreach workers, etc., need to present the programs of the Society in different languages and with images appealing to different cultures.

Opportunities/Suggestions for Addressing this Theme:

- Divisions are developing new programs intended to appeal to underserved populations. Some Divisions have, for a long time, been taking effective steps at outreach to underserved populations. Some have translated materials. Some Divisions have increased their impacts on poor and underserved communities. The work of these Divisions could serve as models for others. A number of them have offered to be training sites, or to educate others who are interested in their work.⁷
- Units in geographic areas with large populations of color may serve as models for recruitment of volunteers and successful implementation of cancer control activities.⁸
- Demonstrations are occurring in some Divisions, to test collaborative approaches to working with poor and underserved populations. The results of these demonstrations can become available to other Divisions, to help them plan programming.⁹
- State and County Health Departments appear to be willing to collaborate with the American Cancer Society on this issue.

➤ **Need for Measures of Success/Evaluation**

Explanation:

- Divisions and Units lack ways to understand their effectiveness (both short term accomplishments and long term impacts). Mechanisms to evaluate programs do not exist in most cases. Divisions point to this as a serious deficiency.
- Information on results is not available in most cases. Only very rarely can Units understand what the ultimate impacts of their community cancer control efforts are. Data do not exist at a community level to indicate rates of smoking, mammography

⁷ For example, Virginia overcame language and cultural barriers in bringing mammograms to Cambodian immigrant women. Minnesota has developed multi-language brochures and will develop more. Southwest has collaborated with a hospital serving low income persons of color. Massachusetts has incorporated a diversity strategy into the fabric of its planning process. The Division brings people from underserved communities into its committees; it targets high risk sites for programming; and it takes other proactive steps to increase its service to the poor and underserved.

⁸ Staff and volunteers pointed to examples of such units in Florida, Hawaii, California, and New York City, among others.

⁹ A current National initiative involves projects in South Carolina, Texas, Minnesota, and Southwest Divisions.

screening rates, early detection, and so on.¹⁰ Other organizations that collaborate with Divisions and Units (e.g., School Districts) also report that their work suffers from a lack of this information.

- Pilot testing of programs and evaluation as soon as they are implemented would improve the ability of Divisions and Units to make decisions about what programs to offer.
- Units need information on effectiveness to motivate people and sustain momentum. They would like the ability to set goals, to orient activities to meet those goals, and to celebrate the achievement of goals. Currently, they cannot do this, except in limited ways.
- Divisions and Units need information on effectiveness to make improvements in programs. Since volunteers and staff can now only develop impressions on how well their efforts pay off, they lack reliable data to inform decisions about changing and/or improving their programs.
- Divisions and Units need information on effectiveness to satisfy funders, donors, and other organizations. Financial contributors have increasingly called for accountability – including the demonstration that their money helps to achieve important goals. Providing information on accomplishments to potential funders is not merely reactive. It can also be a proactive way to market the work of the American Cancer Society and to obtain donations.
- Volunteers and staff generally recognize the wisdom of discarding the PAR system for recording activities. However, they often feel that nothing exists to replace it.

Opportunities/Suggestions for Addressing this Theme:

- Establishment of the Evaluation Services Unit at National during the past two years is viewed positively. Many Divisions want to work more closely with Evaluation Services; and some of them have already developed projects.¹¹
- Some Divisions¹² have expressed interest in working on “Accomplishment-Based Reporting” which would help both in understanding effectiveness and in improving the planning process.

¹⁰ That is, data on such important behaviors as the number of people who smoke, or the proportion of women over 40 who receive mammograms, are often accurate only for the U.S. as a whole, or for a State. Such statistics do not enable a community to know its specific characteristics.

¹¹ Southwest, Texas, Florida, and Massachusetts, for example, mentioned projects. On a related note, in the case of Southwest, the Division's approach to planning includes requirements for an implementation plan, a marketing plan, and an evaluation plan.

¹² For example, Texas and Virginia.

- National could routinely evaluate new program ideas tried in one or a few Divisions, to assess whether they should be continued and/or adopted by others. This role is frequently identified as an important role for National – one which the Divisions, for a variety of reasons, cannot assume on their own.
- National could support the standardization of evaluations of similar programs across Units.
- In any new program it develops, National could at least include a self-assessment tool for minimal evaluation purposes. For example, CSHE programs could have pre/post measurement procedures, for teachers to administer.
- Information on what the Society does, including demographics which portray work with minority groups, when it occurs, could help with efforts to reach more persons of color and underserved populations.
- Recognition of programs that succeed, based on evaluation with reliable measures of success, could help National to encourage Divisions/Units to adopt more effective programs and shed those that are less effective.
- The MAXX system might be helpful for some tracking of activities; but it will not, at least as currently designed, help with tracking long term impacts.
- National might engage in advocacy for resources to do data collection at a local level, at least every few years, to provide a picture of the health behaviors of the population. This information would be valuable for a number of organizations in addition to the American Cancer Society.¹³

➤ Competition: Program vs. Fund Raising

Explanation:

- Cancer control staff are often expected to drop cancer control activities to work on fund raising. Staff with dual job duties (income development and cancer control) often express frustration that income producing activities take a disproportionate share of their time.
- The number of staff and amount of resources seem disproportionately devoted to income development (in the eyes of cancer control staff, as well as some others). This affects the morale of many cancer control staff who question why the major business of the Society (saving lives through cancer control) receives less priority than the support or resource function (income development).¹⁴

¹³ Working with the National Center for Health Statistics, to expand their survey capacity, might be a possibility.

¹⁴ Everyone understands the importance of raising funds. However, many question the priority it seems to receive relative to cancer control. In addition, staff in one Division asserted that increases in financial resources are disproportionately channeled into income development, rather than into programs. They said that, ironically, this forced program staff to do fund raising to support their own work.

- Salaries are reportedly higher for income development staff than for cancer control staff. This causes morale problems among cancer control staff. Some managers speculate that it also contributes to high turnover.¹⁵
- Income development staff are often perceived as unwilling to communicate with cancer control staff, other than to recruit them for income development support. This impedes the development of joint programming, where the same activity can serve both cancer control and income development purposes. It also increases confusion among people outside the Society, as when Income Development and Cancer Control staff independently contact the same employer without coordinating their calls.
- Income development staff and cancer control staff sometimes compete for volunteers, with income development getting priority.
- Cancer control staff report that, at the same time they are denied funds for publishing brochures in different languages, to address the needs of underserved populations, the printing budgets of income development staff are increased to produce fund raising materials.

Opportunities/Suggestions for Addressing this Theme:

- Some volunteers and staff expressed the opinion that, if the mission of the American Cancer Society is to save lives by eliminating cancer, cancer control must be positioned as the major product of the Society. Everything else should then be planned and implemented to support this product.
- Many cancer control staff would like to blend the activities and strategies related to cancer control with the activities and strategies related to income development (e.g., coordinating approaches to employers, doing public education at Relay for Life, doing patient services presentations during fund raising talks, etc.). They feel that income development could be enhanced through better interaction between the two sets of activities.¹⁶
- Divisions with more cancer control specialists (in contrast to Divisions with many staff who have dual income development/cancer control responsibilities) seem to report less stress.¹⁷ This might be examined.

¹⁵ This work for this report did not include a comparison of salaries between income development and cancer control staff. Nonetheless, the perception exists among cancer control staff that they receive less pay; and this perception decreases their positive feelings and commitment to the Society. The perception may also affect turnover, as some speculate. However, in some Divisions, managers reported higher rates of turnover for cancer control staff than for income development staff.

¹⁶ For example, Western Pacific, Virginia, Massachusetts, and Southwest Divisions reported that they increased their efforts to do this, with beneficial results.

¹⁷ The newly merged Heartland Division had the opportunity to hire a large number of new, cancer control staff. This Division might provide some insight into whether the cancer control specialization is beneficial. Western Pacific is trying to see whether their new model of cancer control specialists is better than cancer control generalists.

➤ Lack of Control Over “End Product”

Explanation:

- Some cancer control activities rely upon other people – who are not formally part of the American Cancer Society – for their actual implementation. For example, teachers must actually do the school health education, doctors must actually follow American Cancer Society recommendations, etc. – for programming to be effective.
- Divisions and Units need information on what activities are most likely to produce behavior change among the actors expected to undertake cancer control activities, and ultimately among the general public. With this, they can maximize the likelihood that their efforts will produce the desired result, even if that result depends on the behavior of “the last link in the chain” and that link is not a part of the Society.

Opportunities/Suggestions for Addressing this Theme:

- Sharing of information across Divisions and the development of a data base which includes evaluation information could be helpful. It would enable volunteers and staff to learn about and select the activities which will most likely lead to desired outcomes in their communities.

➤ Materials Inadequate, Inappropriate, or Out of Date

Explanation:

- The day to day representation of the American Cancer Society and its programs relies very much on “materials”. These include posters in hospitals and schools, medical displays, brochures distributed to the general public, cancer patients, survivors, and so on.
- Some materials are not available. The Society has not developed written information to support some activities; or it has developed the information, but it is now out of print. Staff pointed to some school health materials as examples.
- Some materials are outdated. They contain visual images, terms, references, or statistics which no longer apply. (For example, staff often cited smoking cessation materials as outdated.)
- Many materials are not available in non-English languages. This seriously impedes programming in communities with a large number of non-English speakers. (This relates to the issue mentioned earlier -- service to persons of color and to the underserved.)
- Some materials have an old, unattractive style. Staff report that materials from other organizations are often preferred over those of the Society.

- Policy and advocacy materials have not yet been developed. It would be useful if National developed something that Divisions could use, with or without additional customization.
- The perception exists that Income Development receives resources for producing modern, effective materials, but that Cancer Control does not.

Opportunities/Suggestions for Addressing this Theme:

- Many Divisions have begun to produce new and better materials. Some have done this for quite a while. An improved mechanism for sharing ideas across Divisions would assist Divisions to overcome the lack of materials.
- National could collaborate with Divisions that have already successfully produced new materials. This would provide at least two benefits. First, it could speed up the communications across Divisions, by offering a clearinghouse of materials produced to meet the needs of special populations. Second, it could increase the learning at National regarding models and approaches – so that National could better incorporate these into its new product development.
- National could develop a publications plan, which covers: type/content of materials; timeliness (e.g., a schedule for updating to make sure they reflect the latest thinking, as well as that they convey a modern message); cultural diversity (language, image, etc.); distribution; etc.

➤ **Advocacy Perceived as Important and Effective**

Explanation:

- Many volunteers and staff have come to believe that the Society can increase its impact through advocacy. They feel it is more efficient and effective to influence laws, change systems, and so on (when possible), rather than to promote individual lifestyle changes.
- Divisions and Units have increasingly included advocacy activities in their work.¹⁸

Opportunities/Suggestions for Addressing this Theme:

- The American Cancer Society could clarify the “state of the science” with respect to the relative advantages of advocacy, and why it might be more effective than approaches which seek to influence decision-making or lifestyle practices among individuals.¹⁹

¹⁸ The Western Pacific Division, for example, strategically identifies several types of advocacy, including personal advocacy, community meetings and awareness raising, lobbying, etc. Massachusetts reported that advocacy has made the Division more attractive to government. For example, the Mayor of Boston took action to get \$200,000 devoted to breast cancer.

¹⁹ For example, if a major reason why women don’t obtain mammograms is that their health care provider didn’t recommend them, advocacy to influence health care providers, improve their training, etc., may be more productive than attempts to influence women directly through education, distribution of brochures, and so on.

- Advocacy activities at the National level should be coordinated with advocacy activities at the local level.

Resources

➤ Staff Turnover

Explanation:

- Turnover of cancer control staff appears to be a moderate to major problem in most Divisions.
- Turnover increases costs (more training time, time spent on recruitment, etc.).
- Turnover upsets continuity of programming. It also makes collaboration difficult, since the American Cancer Society does not have one, consistent representative participating in joint activities with other organizations.

Opportunities/Suggestions for Addressing this Theme:

- National could work with Divisions to determine the extent to which turnover can and should be reduced. Then, National and Divisions could develop a strategy to reduce turnover to an "acceptable" level.
- Reduction of the "competition" between income development and cancer control might reduce turnover. It might increase the job satisfaction of cancer control staff who currently feel the ill effects of this competition. It would enable staff to specialize; and it would help them to solidify relationships with others in the community – relationships that are often difficult to nurture if cancer control staff cannot devote all their time to cancer control.²⁰
- Changes in some Divisions which reduce travel time and time away from home may lead to reduced turnover. These changes should be monitored; and if they are successful, National could communicate the results to Divisions.

²⁰

Recall, however, that many cancer control staff see opportunities for blending income development and cancer control activities, in certain situations. In fact, they would like to do so. Therefore, elimination of the "competition" does not imply that cancer control staff would do no income development work, nor that they would increase their independence from income development staff. Blending these two sets of activities, and forging collaborative efforts between the two sets of staff may provide ways to eliminate the competitive pressures experienced by cancer control staff.

➤ Workload/Staff Shortage

Explanation:

- Work expectations in any voluntary, nonprofit organization are usually heavy; and the American Cancer Society is no exception. Saving lives through cancer control is an ambitious, overwhelming task. Field staff are expected to do a lot. They are often expected to work long hours, as well as to cover a large geographic area. Most Divisions report that they have more than enough for staff to do. Consequently, many people feel overworked; and some jobs have to go undone.
- This situation influences turnover (as noted above) In addition, it places huge demands on management personnel for coordination.
- The combination of a heavy workload, plus staff turnover, may impair the ability of staff to become as knowledgeable as they should in specific topics, because they have to spread their time and attention to so many issues.
- Some staff feel that, although Mission 2000 helped by defining a focus, the American Cancer Society still has not “learned how to say no” to projects that probably should not be undertaken, given limited resources.

Opportunities/Suggestions for Addressing this Theme:

- Development of challenging, but realistic, work expectations might help. Staff should be able to experience a sense of accomplishment, for work completed – and not feel continually that, no matter how much they do, the list of assignments can never be completed.
- Management at National and Division levels should think carefully about requests for additional work, making sure that staff have adequate time to get this work done. Discussions at site visits revealed situations where National had requested participation in activities, with very little lead time. They also revealed requests from National for information that afforded the responding Divisions only a few days to comply. (In one case, the requested information was “due” prior to the date of receipt of the memo requesting the information.)

➤ Changes in Types of Volunteers Needed

Explanation:

- Increasingly, Divisions and Units need volunteers to do “advocacy” or to represent programs to public officials, community leaders, etc. Volunteers sometimes need to be “activists.” Many, existing volunteers are not comfortable doing this.

- Some Divisions report that the types of issues faced by some of their committees are not compatible with the interests and skills of current volunteers.

Opportunities/Suggestions for Addressing this Theme:

- Divisions and Units will have to look to sources of volunteers who have skills and experience related to advocacy.
- Staff could benefit from the development/distribution of a written guide, as well as from training, on the recruitment and retention of volunteers. The training should give staff skills in the ongoing management of volunteers.

➤ **Changes in Availability of Volunteers**

Explanation:

- Obtaining enough volunteers is a problem. The American Cancer Society, like all organizations seeking volunteers during the 1990's, increasingly faces difficulty recruiting enough volunteers. The reasons include both demographic changes in the American population, as well as changes in attitudes and preferences regarding volunteering.
- Volunteers have less time to donate. For example, communities have more two-earner households. Many elderly households are available only during summer months, etc.
- More volunteers "just want to do one or two defined things". They don't want to make a continuous commitment.

Opportunities/Suggestions for Addressing this Theme:

- As part of the effort to develop a community cancer control plan, the American Cancer Society needs to incorporate an accurate vision of today's volunteers.
- Divisions and Units need to recognize that volunteers are busy with jobs, families, and other pursuits. There needs to be a way to define and limit the work expected of volunteers.

➤ **Differences Between Large and Small Units**

Explanation:

- Larger, generally urban, Units often appear to have more staff and resources. Consequently, they have a better ability to use the talents of volunteers and to carry out work.

- Small Units, often rural, have fewer staff and resources. Staff are more often generalists; and they feel that they must devote more attention to fund raising than to cancer control. (This relates to the “competition” issue discussed earlier.)
- Some of the smaller, more isolated Units have not kept up with changes occurring in the American Cancer Society as a whole.²¹

Opportunities/Suggestions for Addressing this Theme:

- Divisions are exploring ways to overcome the challenges of trying to work with small units, many of which are quite distant from field offices.

➤ Technology Access

Explanation:

- Where computer systems are working as they should, staff and volunteers perceive benefits. However, many American Cancer Society staff and volunteers don't feel they have computer access.²²
- Volunteers may actually have started to receive less information, rather than more, as a result of Lotus Notes, since they have much less access to computers than the staff do.
- Many who have computer access lack training. They don't understand how to use equipment, how to access available information, etc.
- Software is not available for some needs, such as support for policy and advocacy activities (for example, the MAXX system is not yet doing all that people thought it might).

Opportunities/Suggestions for Addressing this Theme:

- National could develop a framework for establishing computer competencies within Units. This could specify the types of hardware and software to be installed, the types of competencies expected of volunteers and staff, and the types of training necessary for developing these competencies. Then, a system for training could be set up.
- Divisions and Units need to get “on line,” with computer hardware and software functioning as they should.
- Divisions that have used technology successfully in cancer control efforts could serve as showcases/trainers for other Divisions.²³

²¹ One Executive Vice President described a few of his rural Units as “living in the 1950's. They still use the terms and approaches of the American Cancer Society of 40 years ago.”

²² One staff member, who does not have computer access, stated bluntly, “Since the Executive Notices went on Lotus Notes, we stopped getting them.”

²³ Western Pacific, for example, feels that it has used technology quite effectively to keep volunteers and staff informed of the latest announcements related to cancer control from National and other organizations, to get access to items from National, and to communicate with others.

Planning

➤ Logistics of Division/Unit Planning Process Generally Satisfactory

Explanation:

- Divisions and Units within the American Cancer Society use slightly different approaches to planning; but all these approaches seem to have common, basic elements: careful examination of Core recommendations; discussion of how these recommendations relate to the specific Division/Unit; involvement of volunteers and staff in the process; etc.
- Increasingly, Units are using formats that enable them to develop objectives that are specific, feasible, and measurable.
- No major dissatisfaction seems to exist with the planning process.
- In Divisions merging with others (or Divisions recently merged), some ambiguity exists about how planning will occur. However, staff seem to feel that this will be resolved within a year or so of each merger.

Opportunities/Suggestions for Addressing this Theme:

- Volunteers and staff should feel good about their success at doing planning. This success could be recognized and reinforced.
- The process of strategic planning for community cancer control should focus some attention on planning techniques, including training and technical assistance to enable Divisions and Units to use these techniques.

➤ Lack of Data for Planning

Explanation:

- Divisions and Units lack data on community conditions, health and lifestyle trends, etc. – at a level useful for planning. When data are available, they are typically estimates for the United States population, or for the population of a specific state. Communities have difficulty obtaining information on their specific conditions.
- Therefore, Divisions, and especially Units, don't have important tools for developing cancer control plans, monitoring progress, and revising plans over time. (A later section of this report also discusses this issue.)
- In addition, the attempt to translate goals from National becomes a futile exercise. For example, National may request a "20 percent reduction" in something, but there is no way to calculate this target, since no baseline exists.

Opportunities/Suggestions for Addressing this Theme:

- The process of strategic planning for community cancer control should focus some attention on the activities to develop data bases, and access to those data bases, to improve the ability of Divisions and Units to do good planning.
- Divisions which have managed to make good use of information could be identified and their work can inform other Divisions.²⁴

➤ **Lack of Current, Written Plans**

Explanation:

- Many Units do not have current cancer control plans. That is, they may have no plan for a specific area, or they have a plan, but it is quite old.²⁵
- The practice of updating written cancer control plans is not consistent across all Divisions and Units. (More on this appears in a later section of this report.)

Opportunities/Suggestions for Addressing this Theme:

- National can play an important role standardizing expectations for planning and providing assistance, as needed.

➤ **Lack of Overall, Coordinated Plan for Cancer Control**

Explanation:

- No system currently exists for coordinating the approach to cancer control among Units/Divisions/National.
- Within Divisions, often no system exists to ensure that Units are all moving toward one, common end, to meet objectives at a Division level.

²⁴ Southwest, for example, has made great efforts to blend together in their planning and decision-making process: epidemiological data; data on community resources other than A.C.S.; community sense of priorities; and volunteer and staff defined priorities. They use this to make decisions customized to each of their seven market areas.

²⁵ For example, in the phone survey, 84 percent of Units had a Breast Cancer plan; 71 percent had a Breast Cancer plan less than two years old. For CSHE, 61 percent had a plan; only 49 percent had a plan less than two years old.

Opportunities/Suggestions for Addressing this Theme:

- The work of the Blue Ribbon Advisory Group is expected to address this.

➤ **Flexibility Needed in National Plan**

Explanation:

- A nation-wide approach to cancer control is good, but it must allow for flexibility, local customization to fit the community.
- A nation-wide plan should include guidelines for planning, implementing, evaluating programs.
- A nation-wide plan needs to recognize the different capacities of Units and to set realistic expectations for smaller Units with fewer resources. If a plan expects too much, volunteers will become discouraged.
- A nation-wide plan needs to take into account the work already being undertaken by Units.

Opportunities/Suggestions for Addressing this Theme:

- Obtaining input from a wide array of Divisions and Units may strengthen a nation-wide plan proposed for the American Cancer Society. It will lead to incorporation of flexibility and realistic goals. It will also lead to better “buy in” when it comes time to implement the plan.

Relationships Inside and Outside the Society

➤ Extent of Collaboration

Explanation:

- Much collaboration occurs between the American Cancer Society and other organizations.²⁶ Volunteers and staff increasingly recognize collaboration as a necessary strategy for effectively meeting Core goals and doing community cancer control.
- Volunteers and staff have learned the advantages and disadvantages of collaboration. Generally, it is viewed more positively than negatively.
- Collaboration not only offers the opportunity to increase effectiveness. It also avoids the image of duplication and waste among organizations working on the same goals.

Opportunities/Suggestions for Addressing this Theme:

- Divisions/Units with successful collaborative efforts can make information about their work available to others.²⁷ Sharing of information could include identification of the types of partners with whom Divisions and Units work, their actual experiences (positive and negative), tips for effective collaboration, and so on.²⁸
- A work group, comprised of representatives from National, Divisions, and Units could address and resolve some of the issues that arise in collaborations between the American Cancer Society and other organizations – for example, to what extent the Society must have independent recognition, how to handle signature programs, policies on what activities are permissible, etc. In addition, this group could look at opportunities for National to set up more collaborative work with the Centers for Disease Control.

²⁶ Results of the surveys conducted for this cancer control inventory document this.

²⁷ As examples, in Virginia, the State Parent Teachers Association may offer a major boost to CSHE efforts by working with the American Cancer Society throughout the state. In Texas, work with the Urban League on women's health, and with the Chamber of Commerce, on CSHE, has proven worthwhile. Minnesota has had success working with the State Department of Education (The Department of Families, Children, and Learning).

²⁸ Volunteers and staff sometimes have to be creative. For example, they may have to work around slow moving school boards or other governing groups and communicate directly with teachers or other staff to bring about collaboration.

➤ Ways National Could Support Units/Divisions

Explanation:

The following roles were commonly identified as useful for National:

- **Evaluation/Measurement:** Evaluating programs produced by National; assisting/guiding Divisions/Units with their own evaluation design; establishing an information bank that indicates the effectiveness (or lack of effectiveness) of programs that have been evaluated.
- **Information Broker:** Identifying new approaches; knowing what's going on around the country and making that knowledge easily accessible; making scientific data available. Putting information into a form that enables Divisions to recognize how the latest research relates to best practices.
- **Information Producer:** Developing systems for producing information that Divisions/Units cannot produce on their own. Conducting or financing surveys.
- **Consensus Builder:** Getting Division Executive Vice Presidents to share information, opinions, and come to consensus on the future direction of activities in their Divisions.
- **Consultant, troubleshooter:** Being available to provide advice on issues, respond to questions. Assisting Divisions when crises arise.
- **"Champion for Core:"** Providing visible leadership to promote Core both inside the American Cancer Society and with others.
- **Setter of Standards:** Determining the standards for programs, for collaborative relationships, etc., that will guide Divisions.
- **Creator of Alliances at National Level, with Local Opportunities:** Joining with national organizations that have local chapters, to pave the way for collaboration at the local level.
- **Planning guidelines and training:** Establishing principles, techniques, forms that will assist Divisions and Units to do better planning.
- **Producer of quality materials:** Using ideas generated in Units/Divisions as well as by others, National can develop resources.
- **Developer of new programs.**

Opportunities/Suggestions for Addressing this Theme:

- Sponsoring conferences (in person, or videoconferencing) is generally considered very valuable by staff and volunteers who want to learn more.
- Developing staff accountabilities around the functions listed above is, obviously, appropriate.

➤ **Communication Problems with National**

Explanation:

- National is sometimes perceived as “abandoning” Core. This perception develops from such things as: lack of clearly designated staff assigned to some Core areas; greater attention focused on some Core areas than others, lack of materials supporting some Core areas; attention to non-Core issues; and so on.
- Staff at National are sometimes difficult to reach.
- Volunteers and staff sometimes feel that inconsistencies exist in the messages received from National.
- Volunteers and staff report that it is not uncommon for National to provide information which is incomplete or make commitments to Divisions for information and then fail to honor the commitments.²⁹
- National is often thought to have unrealistic expectations (e.g., expecting immediate turnaround for requested information). Also, National is often described as unwilling to accept that it takes at least a year, sometimes three to five years, for ideas to move from the National Home Office to all of the Units.
- National often fails to inform Divisions of significant items (e.g., major media events, release of new guidelines, etc.).³⁰
- National sometimes makes commitments for things Divisions have to implement, without understanding all the implications of those decisions, without adequately informing Divisions about the commitments, and/or without allowing adequate lead time for implementation.

²⁹ Volunteers in one Division recounted that they attended a meeting of Core Breast Teams and were told that “everything they needed to know would be covered.” Then, shortly thereafter, things showed up from National that they knew nothing about. They also reported that they felt they were promised technical support and communications assistance from National, but they never received it.

³⁰ One EVP reported, “I have no idea what our relationship is with National. There is no mechanism for joint planning of advocacy and the legislative agenda. We are not working as one organization.”

Opportunities/Suggestions for Addressing this Theme:

- National could consider multiple means of distribution of important information, at least until computer access is reliable and universal throughout the Society.
- National should clarify the purpose of “cause-related marketing” and other National initiatives. Before committing Divisions to work on such initiatives, there should be a time for discussion, and if the decision is made to go ahead, adequate time should be devoted to training, providing information, etc., about the initiative and the specific expectations for a Division.³¹
- A volunteer suggested: “The strength of cancer control is *grass roots efforts* – people in their own families, in their own way, do cancer control education, get screened, and influence policy. National isn’t learning right now from the grass roots. It should set up a way to learn from the grass roots.”³²

TYPES OF ACTIVITIES AMONG UNITS

A total of 568 Units returned a survey questionnaire indicating the types of activities they had completed during a one year period.³³ The complete results appear in Appendix A. They provide:

- A snapshot of current activities.
- A baseline against which to assess change. This may have particular importance if the Blue Ribbon Advisory Groups recommends changes.

Note that these statistics indicate only the “presence” or “absence” of an activity in a Unit during the past year. They do not reflect volume or intensity.

The following table indicates the most common and least common activities among American Cancer Society Units during the twelve months preceding the survey.³⁴

³¹ This discussion should also include the image and “political” implications of alliances forged at the national level. One Division reported, for example, that National had set up a cooperative arrangement with a retail chain that is a principal competitor of another retail chain which supports the Division with money and volunteers. This, understandably, causes a problem for the Division.

³² The field of Public Health has made much progress in this regard; and many members of the American Cancer Society do have expertise in Public Health. So, paying more attention to the grass roots, in a systematic way, should be feasible.

³³ The questionnaire contained a checklist, organized into seven categories. It was developed by Bruce Black, with input from others at the National Home Office.

³⁴ This would be approximately May, 1996, to April, 1997. The column marked “%” in the table indicates the percentage of the 568 Units in the survey sample that did the specified activity at least once during the year.

Most Common	%	Least Common	%
Prevention: Comprehensive School Health (15 items) • Provide posters, brochures, stickers. • Provide curriculum kits. • Provide volunteer speakers.	92 82 78	Prevention: Comprehensive School Health (15 items) • Do local CSHE assessments. • Evaluate quality and effectiveness. • Physical activity and exercise activities.	25 24 9
Prevention: Tobacco Activities and Programs (15 items) • Great American Smokeout • Tobacco Education activities • Advocate to stop illegal sales to kids.	90 89 74	Prevention: Tobacco Activities and Programs (15 items) • Evaluate quality and effectiveness. • ASSIST activities. • IMPACT activities.	44 25 4
Other Prevention Activities (only 3 items) • Skin cancer prevention activities. • Nutrition education and promotion for adults. • Physical activity and exercise activities.	69 59 11		
Detection (19 items) • National Breast Cancer Awareness Month • Provide educational materials (for breast and/or cervical cancer screening). • Provide volunteer speakers	88 83 82	Detection (19 items) • Cervical cancer detection activities. • Tell-a-Friend mammography program • Colorectal cancer detection activities.	35 29 22
Patient Services (21 items) • Reach to Recovery • Wig banks. • Home care items • Self-help and support groups.	93 80 78 78	Patient Services (21 items) • Man to Man • Camps for children • CanSurmount	35 31 22

Most Common	%	Least Common	%
Treatment (7 items) • Provide information on cancer treatment. • Referral to other resources for information on treatment • Help patients understand the health care system	86 84 54	Treatment (7 items) • Referral for treatment. • Information on complementary treatment, such as relaxation... • Involved in State Pain Initiative.	34 31 13
Advocacy (5 items) • Advocate for state and local restrictions on tobacco use. • Participate in tobacco advocacy coalitions. • Develop grass roots constituency for advocacy efforts.	73 67 59	Advocacy (5 items) • Participate in breast cancer advocacy coalitions. • Advocate for state and local requirements for School Health Education.	58 35
Working with Organizations in the Community (22 items) • Schools • Hospitals • Local Businesses	92 91 84	Working with Organizations in the Community (22 items) • Susan Komen Foundation • American College of Surgeons Hospital Physician Liaison • 100 Black Men	18 12 5

For every activity undertaken by a Unit, the survey respondent(s) indicated the importance of that activity to the overall cancer control effort. As would be expected, virtually all Units that do an activity consider it to be at least "Moderately Important." Complete figures appear in Appendix A. Activities considered "Very Important" by at least 80 percent of the Units involved in the activity during the past year appear in the following table.

Activity	% Rating "Very Important"
Reach to Recovery	96
Sponsorship of low-cost or free breast cancer screening.	92
Advocate to stop illegal sales to kids.	91
Working with hospitals	91
Tobacco education activities	90
Recruit health care providers (for screening).	90
Recruitment and education for state's breast and cervical cancer program.	89
Updated local resource directory	89
Participate in coalition or partnership (for screening).	88

Activity	% Rating "Very Important"
Transportation program	88
Participate in tobacco advocacy coalitions	88
Advocate for state and local restrictions on tobacco use	88
Evaluate quality and effectiveness of detection activities.	87
Evaluate quality and effectiveness of patient services programs	87
Man to Man	87
Working with schools	87
Recruit participants (for screening).	86
Provide educational materials (for screening).	86
Self-help and support groups	86
Provide information on cancer treatment	85
Participation in breast cancer advocacy coalitions	85
Develop grass roots constituency for advocacy efforts	85
Provide on-site BSE instruction (for screening).	84
Advocate for increased tobacco excise taxes.	84
Breast Health Education/Group BSE instruction.	84
National Breast Cancer Awareness Month.	84
Financial assistance	83
Working with local tobacco control coalitions	83
ASSIST activities.	82
Patient callback activities	82
Working with prostate cancer groups	82
Development of grass roots advocacy constituency.	81
Partnership with local health departments.	80
Great American Smokeout	80
Advocate for Clean Indoor Air...	80
Other peer interpersonal activities to persuade women to get Mammograms (not Tell-a-Friend).	80
Prostate cancer detection activities.	80
Look Good... Feel Better	80
Referral to other resources for information on treatment	80
Working with social workers	80
Working with local county health departments	80

PLANNING PROCESS

The three approaches to gathering information – Division site visits, Unit mailed survey, and Unit phone interviews – obtained information about the community cancer control planning process. Each approach looked at the planning process from a different vantage point. This section presents highlights from the site visits and the Unit phone interviews. Complete details from the phone interviews and the Unit questionnaires appear in the Appendices.

Site Visits

The site visits explored the mechanics of the planning process in each of the eight Divisions visited. The site visitors obtained information on how planning occurs, who is involved, how objectives are set, whether any problems exist in the process, and so on.

Each of the eight Divisions³⁵ has a well developed process for establishing Division plans. Elements of the process common to most or all of the Divisions include:

- Alignment of the plans with Core goals. (Including use of the primary and enabling goal framework.)
- Committees of volunteers and staff organized around Core areas, and usually one or more additional areas.
- An examination of available information on community needs and the services being delivered by other organizations. (The completeness and accuracy of this information varies across the Divisions; but all seven of them at least look at what they have.)
- A sequence of steps in which goals are developed for a Division, then passed on to Units, for their comments, prior to the final development of Division goals.
- Use of Division goals, by Units, for setting Unit goals and/or establishing work plans. (Unit planning is often a process of picking activities for the year, based on a “menu” provided by the Division.)
- A standard format for stating goals, objectives, activities, other items.

As noted earlier, virtually everyone expressed satisfaction with the overall process, with their opportunity to participate, and with the plans that are developed.

Comments, issues, and suggestions which arose in the conversations with volunteers and staff about the planning process include:

- In Divisions experiencing mergers, volunteers and staff expressed some ambiguity about exactly how planning would occur. They felt that it may take a few years until the planning process settles into a new pattern.

³⁵ These are Florida, Heartland, Massachusetts, Minnesota, Southwest, Texas, Virginia, and Western Pacific.

- For some Units, the process is really not “planning” in the sense of making significant decisions based on an understanding of needs, the availability of resources, etc. It is rather a discussion between staff and volunteers about what projects or activities to select. Often, Units do not set specific goals.
- Some Unit Boards still organize around the old system. They don’t have Core committees.
- A great deal of data that would support the planning process is not available.
- Any changes expected to be made in the planning process itself, or in the contents of plans, take at least two to three years to fully make their way from a Division to all of its Units.
- Divisions differ in what they expect from Units. Some Divisions accept a statement of goals and activities; other require more specific information on marketing and implementation.

Unit Phone Survey

The phone interviews with 146 Units ascertained:

- Whether Units have written plans in the areas of Breast, Tobacco, Comprehensive School Health Education, and Patient Services.
- How long ago the plans were written.
- Whether the plans were developed by a committee.
- Whether the plans have targets for short term accomplishments.
- Whether the Units obtain information on how well they reach these targets.
- Whether the plans have targets for results.
- Whether the Units obtain information on how well they accomplish those results.

The table below summarizes the information on these topics. (Cell entries indicate the percent of all Units.)

Characteristics of Unit Plans	Breast	Tobacco	CSHE	Patient Services
Unit has written plan.	84%	84%	61%	85%
Plan was written in 1996 or 1997	71%	67%	49%	66%
Plan was developed by a committee in Unit.	71%	71%	49%	71%
Plan has targets for short term accomplishments.	51%	63%/49%	31%	58%

Characteristics of Unit Plans	Breast	Tobacco	CSHE	Patient Services
Some information received on short term accomp.	38%	43%33%	26%	52%
Information received on <u>all</u> short term accomp.	24%	22%/14%	16%	38%
Plan has targets for results.	47%	44%	39%	62%
Some information received on results.	27%	28%	27%	55%
Information received on <u>all</u> results.	14%	13%	12%	32%

APPENDIX A

**American Cancer Society
Unit Inventory Survey
for the
Blue Ribbon Advisory Group
on Cancer Control
(Conducted during April – June, 1997)**

This appendix contains data from the Inventory Questionnaire completed by 568 Units/Offices of the American Cancer Society throughout the United States. A description of the method used to select respondents appears in the Methodology Appendix.

The first two pages of the appendix contain tables and a map summarizing information on who responded to the survey. The remaining pages contain the inventory questionnaire, in a modified form, to show the number and/or percent of Units that selected each response.

PERSONS COMPLETING SURVEY:

Completion of Survey (N=568)

By 1 Person	58%
By 2 People	26%
By 3 People	9%
By 4+ People	5%
Total	100%

By Staff Only	68%
By Volunteer Only	9%
By Staff and Volunteer	21%
Not Recorded	2%
Total	100%

Types of Units/Office

Single Unit	39%
Area Office	35%
District Office	11%
Regional Office	11%
Not Recorded	4%

Number of Units Served by Area, District, Regional Offices

	1	2-5	6-10	11+	Total
Area	4%	58%	22%	12%	100%
District	3%	39%	31%	20%	100%
Regional Office	9%	44%	23%	22%	100%

LOCATION OF COUNTIES SERVED BY UNITS/OFFICES

(See Map on Separate Page)

Total Population for Unit/Office

Under 15,000	4%
15,001 to 75,000	26%
75,001 to 250,000	32%
250,001 to 500,000	16%
500,001 to 1,000,000	11%
Over 1,000,000	9%
Not Recorded	3%

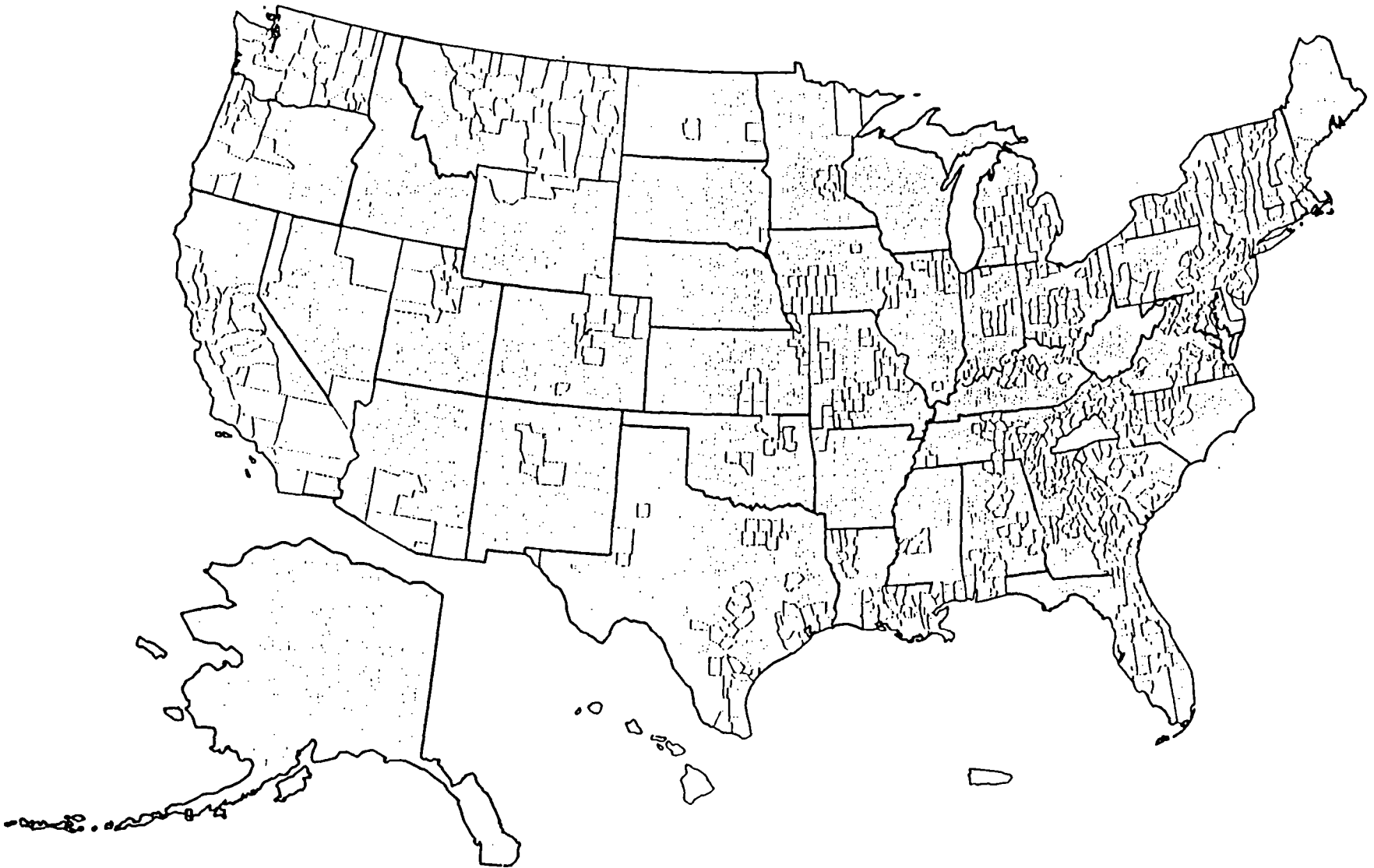
Urban/Suburban/Rural

(Could check more than one.)

Urban	29%
Suburban	39%
Rural	35%
Other	10%
Not Recorded	2%

Counties Included in Unit Inventory

Spring 1997



Appendix 7. Survivorship Initiatives Addendum

Survivorship Initiatives Addendum

At the turn of the century, very few survived cancer. Now many of the nearly 8 million people living with cancer in the United States today have survived over five years. Long-term survivorship is a realistic expectation for approximately 56% of those diagnosed with cancer today. While some are "disease free," others continue to struggle with active disease, and many are affected by long-term and late side effects. The number of persons directly affected by someone else's cancer (family, friends, etc.) is another emerging concern.

Until recently, primary emphasis was placed on the problems and needs of persons newly diagnosed with cancer or under active treatment. These persons were called "patients" and our focus was on "curing." In the past several decades there has been a fundamental shift in the structure of the American family, new population trends, and major changes in our health care system. These have added another significant dimension to today's emerging cancer care issues.

Growing numbers of long-term cancer survivors, families, and others have come forward to identify important issues. They are no longer passive "patients" or cancer "victims." They have become "survivors" who are active participants and consumers of health services as well as strong advocates. Defining someone as a cancer survivor "from the time of discovery and for the balance of life" stresses the importance of quality in the quantity of life. First and foremost, people want to prevent cancer. If cancer is diagnosed, a cure is needed. But whether or not a cure is found, quality of life is essential for survivors and their families. This underscores the need for the American Cancer Society to reevaluate its traditional approach to serving the needs of people with cancer and their families.

Families are an integral part of the cancer experience. As such, the survivorship continuum can be conceptualized to include concerns about risk factors and end-of-life issues. Loss and bereavement are also unfortunate realities for many families as well as survivors.

Survivorship is much more than the traditional "patient" focus that targets individual needs and concerns. We must also focus on systems changes. Survivors and survivorship must become a more visible part of the American Cancer Society's corporate culture. Survivors lend the face, the voice, and the passion to survivorship initiatives and must be the driving force behind them. This will ensure that programs, services, and activities will be relevant to their diverse needs, easy to access, and offered within an appropriate cultural context.

Appendix 8. Glossary of Selected Cancer Control Terms

Glossary of Selected Cancer Control Terms

Advocacy - Advocacy consists of actions that influence or change policy. In cancer control, for example, it can range from one individual discussing with one member of a school board the implementation of comprehensive school health education through to the introduction and passage of legislation at the national level.

Alternative Therapy - Alternative treatments are defined as remedies in popular use that are under study or otherwise unproven. On the other hand, the American Cancer Society defines questionable methods as lifestyle practices, clinical tests, or treatment methods that are promoted for **general** use for the prevention, diagnosis, or treatment of cancer and which, on the basis of careful review by scientists and/or clinicians, are deemed to lack real evidence of value.

Clinical Trials - In cancer research, a clinical trial is a study conducted with cancer patients, usually to evaluate a new treatment. Each study is designed to answer scientific questions and to find new and better ways to help cancer patients. Not all clinical trials use new anti-cancer drugs. For example, some clinical trials compare the best known standard therapy with a newer therapy to see if one produces more cures and causes fewer side effects than the other. The search for good cancer treatments begins with basic research in laboratory and animal studies. The best therapies identified in basic research are studied in patients, hopefully leading to findings that may help many people.

Collaboration - Collaboration is the process by which several organizations or individuals make a formal, sustained commitment to work together to accomplish a common mission. Collaboration requires a commitment to participate in shared decision-making and joint allocation of resources in response to mutually identified needs. Collaboration implies a sense of community in which members see themselves as complimentary and mutually supportive contributors to the whole and not primarily as competitors.

Community Cancer Control - The broad array of organized activities at local, state, regional, or national level that have a positive impact on reducing the human burden of cancer. Community cancer control encompasses prevention, early detection, effective treatment, support services, survivorship, and end-of-life issues.

Complementary Therapy - Complementary treatments are defined as those used to supplement, or are used in conjunction with, conventional cancer treatments. On the other hand, the American Cancer Society defines questionable methods as lifestyle practices, clinical tests, or treatment methods that are promoted for **general** use for the prevention, diagnosis, or treatment of cancer and which, on the basis of careful review by scientists and/or clinicians, are deemed to lack real evidence of value.

Comprehensive School Health Education - Comprehensive school health education is the component of school health programs that provides planned and sequential, pre-school through grade twelve instruction designed to educate young people about health, and to reduce critical, often inter-related, health risk behaviors. These behaviors include: tobacco use; dietary patterns; physical inactivity; behaviors that result in unintentional injuries (e.g., motor vehicle crashes) and intentional injuries (e.g., violence, homicide, suicide); alcohol and other drug abuse; and sexual risk behaviors that result in HIV, other sexually transmitted diseases, and unintended pregnancy.

Early Detection - Early detection refers to the discovery of an abnormality by health professionals through a special effort designed to screen for asymptomatic disease, or by people themselves who become aware of a sign or symptom.

End-of-Life Care - End-of-life care refers to a set of discrete activities including, but not limited to, pain management, respite care, psycho-social support, and bereavement preparation. These activities occur during a period of transition from aggressive treatment of the disease to preparation for end of life, and are not limited to hospice care.

Managed Care - Managed care is a broad approach to health care that aims to lower costs by arranging for care at predetermined or discounted rates, specifying which doctors and hospitals a person can use and overseeing physicians' treatments and referrals.

Managed Health Care - Managed health care is a system that uses financial incentives and management controls to direct patients to providers who are responsible for giving appropriate care in cost-effective treatment settings. Such systems are created to control the cost of health care.

Oncology - Oncology is the study of tumors.

Outcomes Research - Outcomes research is dedicated to the evaluation of outcomes for a variety of conditions. The specific aims of outcomes research are to measure clinically relevant outcomes and evaluate treatment effectiveness. The data collected may also be used in the process of continuous quality improvement within a treatment setting.

Patient Support - Patient support is the range of emotional and practical help the American Cancer Society offers for patients, their families, their caregivers, and the community from the time of diagnosis throughout life to life's end. All patient support issues can be located along a continuum of survivorship that begins in prevention and extends through the end of life and bereavement.

Prevention - Primary prevention is the absence of disease. It is the steps taken to prevent a disease from ever developing. It refers to efforts to reduce or eliminate exposures to carcinogens in order to prevent the initiation or promotion of the fundamental carcinogenic process.

Quality Standards - Quality standards set a level of excellence, or attainment regarded as a measure of adequacy. They are established as the basis for comparison in judging capacity, content, value, or quality.

School Health Programs - School health programs consist of eight interactive components, including: (1) comprehensive school health education; (2) school health services; (3) a healthy psychosocial and biophysical environment; (4) counseling, psychological, and social services; (5) school food service; (6) school physical activity; (7) health programs for school faculty and staff; and (8) integrated efforts of schools, students, families, and communities to improve the health of young people.

Screening - Screening refers to the mass examination of the population to detect the existence of a particular disease, as breast or colorectal cancer. Screening is done in order to detect the existence of pre-cancerous changes early enough so that cancer can be prevented. Additionally, screening is done to detect cancers in early stage so that early treatment can be given to cure the cancer, or to prevent it from worsening or spreading.

Survivorship - Cancer survivorship is a term used to represent the state of living with the challenges of the cancer experience.

Systems - A system is set of things that are so related or connected as to form unity in purpose, such as school systems or health care systems.

Treatment - Treatment refers to that which is done to help rid the body of or control cancer, or enable individuals to live with the cancer. "Treatment" encompasses diagnosis and staging of disease, application/delivery of appropriate therapeutic modalities, and the management of symptoms related to the disease and its treatment.