MEETING SUMMARY
PRESIDENT'S CANCER PANEL

LIVING BEYOND CANCER: A EUROPEAN DIALOGUE

May 27–28, 2003
Lisbon, Portugal

OVERVIEW

The President's Cancer Panel held its first international meeting in Lisbon, Portugal, May 27-28, 2003, commencing a series of new meetings to consider challenges in living beyond diagnosis and treatment of cancer. This meeting illustrated opportunities for collaboration and sharing of best practices in many areas. Cancer is a global problem, and its burden is enormous. Surviving treatment is not the end of the story; many gaps in service and care remain for European citizens, and personal stories vividly illustrated these points. While we are "blessed" in the United States with excellent treatment for cancer, this care is not available to all citizens; access to care is not an absolute right in the United States (as it is in Europe). This is a deficiency the Panel continues to address. As with its deliberation of other matters of significance to the National Cancer Program, the Panel hopes to put a human face on the issues related to cancer survivorship and develop concrete recommendations for change.

MEETING PARTICIPANTS

President's Cancer Panel

LaSalle D. Leffall, Jr., M.D.
Margaret Kripke, Ph.D.
Lance Armstrong

National Cancer Institute

Maureen O. Wilson, Ph.D., Assistant Director, NCI, and Executive Secretary, President's Cancer Panel
Andrew von Eschenbach, M.D., Director, NCI
Harold P. Freeman, M.D., Chairman Emeritus, President's Cancer Panel
Doug Ulman, Director's Consumer Liaison Group, NCI

Speakers

Annica Andersson, Community Representative, Sweden
Josep Maria Borràs, M.D., Institut Català d'Oncologia, Spain
Ulrika Botelho Cyrne, Community Representative, Portugal
Andrew Bottomley, Ph.D., Coordinator, Quality of Life Unit, European Organisation for Research and Treatment of Cancer
Peter Boyle, Ph.D., Director, Division of Epidemiology and Biostatistics, European Institute of Oncology
Jan Buter, M.D., Ph.D., Medical Oncologist, VU Medical Centre
Ruth Campbell, Head of Cancer Care Services, Ulster Cancer Foundation
Riccardo Capocaccia, M.Sci., Department of Epidemiology and Biostatistics, Istituto Superiore de Sanità
Michel Coleman, M.Sci., Head, Cancer and Public Health Unit, London School of Hygiene and Tropical Medicine
Julia Doherty, Health Care Consultant, United States (representing Germany)
Gemma Gatta, M.D., Division of Epidemiology, Istituto Nazionale per lo Studio e la Cura dei Tumori

Ambrose Heaney, Community Representative and Chairperson, Bone Marrow Transplant (BMT) Support Group, Ireland
Karen Lisa Hilsted, Community Representative, Denmark
Donal Hollywood, M.D., Marie Curie Professor of Oncology, Trinity College Dublin
Patrick G. Johnston, M.D., Ph.D., Professor of Oncology, Director of Cancer Research, Belfast City Hospital
Daniela Kampmann, Community Representative, Germany
Elvira Lowe, Community Representative, Northern Ireland
Luis d'Orey Manoel, M.D., Surgeon, Portuguese Institute of Oncology–Lisbon Center
Riccardo Masetti, M.D., Associate Professor of Surgery, Catholic University of Rome
Judith McNeill, Ph.D., Head of Community Links, Macmillan Cancer Relief
Marie-Agnès Moulin, Community Representative, France
Jørgen Petersen, Community Representative, Denmark
Fenna Postma-Schuit, M.D., Head of Patient Education and Psychosocial Care, Comprehensive Cancer Center, Amsterdam; Community Representative, The Netherlands
Claudia Rodemers, Community Representative, Switzerland
Julia Rowland, Ph.D., Director, Office of Cancer Survivorship, NCI
Milena Sant, M.D., Senior Researcher, Epidemiology Unit, Istituto Nazionale per lo Studio e la Cura dei Tumori
Dirk Schmidt, Community Representative, Germany
Odd Søreide, M.D., FRCS, Professor, Chairman of the Board, Norwegian Cancer Society
Pilar Suarez, Community Representative, Spain
Antonio Toscano, Community Representative, Italy
Georges Vlastos, M.D., Attending Physician, Department of Gynecology and Obstetrics, Geneva University Hospital
Steinar Krey Voll, Board Member, Norwegian Cancer Society Youth Group; Community Representative, Norway
Mads Utke Werner, M.D., Ph.D., Director, Center of Oncological Rehabilitation and Palliative Care, Department of Oncology, University Hospital of Lund, Sweden

MAY 27, 2003
OPENING REMARKS—DR. LaSALLE D. LEFFALL, JR., CHAIRMAN

- Dr. Leffall acknowledged the presence of his fellow Panel members, Dr. Margaret Kripke and Mr. Lance Armstrong; NCI Director Dr. Andrew von Eschenbach; Former PCP Chair Dr. Harold Freeman; and Mr. Doug Ulman, representing the NCI Director's Consumer Liaison Group. He stated that the purpose of the meeting was to examine challenges of living after cancer diagnosis and treatment, including access to long-term care, employment, economics, and social issues.

- Dr. Leffall outlined the agenda, which would include an overview of cancer survivorship statistics and concerns in the United States and Europe, followed by testimony from cancer survivors, care providers, and advocates. He said that the meeting's goal would be to generate discussion, ideas, and recommendations for follow-up by the Panel and others committed to managing and overcoming cancer.

- Dr. Leffall provided a brief overview of the mission and composition of the President's Cancer Panel, explaining that the Panel meets four times each year to gather information on cancer-related issues and presents its findings and recommendations to the U.S. President, the Congress, and the rest of the nation in its annual reports. Understanding that there are nine million cancer survivors in the United States alone, and that the number of cancer survivors throughout the world will continue to increase, the Panel decided to focus its 2003-2004 series of meetings on the following questions: How do patients and the public view cancer and cancer care at various stages of disease? Is cancer viewed as a chronic disease or an acute disease? What are the medical, social, and economic issues faced by people living beyond cancer diagnosis and treatment?

- Dr. Leffall stated that the Panel is also interested in learning from participants about other questions that need to be addressed.

- Dr. Leffall introduced Dr. Andrew C. von Eschenbach, Director of the National Cancer Institute.

NCI DIRECTOR'S REPORT
DR. ANDREW C. von ESCHENBACH

- Dr. von Eschenbach began by highlighting the qualifications and experience of the current members of the President's Cancer Panel. Dr. Leffall is a renowned clinical and surgical oncologist, former President of the American Cancer Society, and Chair of the Steering Committee of the National Dialogue on Cancer; he is a world leader in the development of state-of-the-art care for cancer patients. Dr. Kripke, an accomplished basic scientist whose career has focused on skin diseases and melanoma, is the Executive Vice President and Chief Academic Officer at the M. D. Anderson Cancer Center. Mr. Armstrong has become a champion of cancer survivors through his own accomplishments as a survivor and through efforts of the Lance Armstrong Foundation to better understand and improve cancer survivorship.

- At a recent White House ceremony honoring cancer survivorship, President Bush stated that "We can say for the first time with certainty that the war on cancer is winnable." We are beginning to understand the fundamental genetic, molecular, and cellular mechanisms that underlie cancer, and we now have the opportunity to exploit that understanding to develop better interventions. Therefore, the NCI has established a Challenge Goal to eliminate the suffering and death due to cancer by the year 2015. This Goal does not envision eliminating cancer altogether by that date but looks toward a day when the process of cancer can be preempted at multiple points.

- Dr. von Eschenbach explained that cancer can be described as a disease process that begins with susceptibility and progresses through malignant transformation, development of clinically apparent disease, metastasis, and, ultimately, death. This pathway offers multiple opportunities to preempt this process by intervening at specific steps in the progression of biologic mechanisms that promote the growth and spread of cancer, thus preventing cancer from developing, detecting it as early as possible, or controlling its ability to cause suffering and death. We can essentially turn cancer into a chronic disease, so that people who do develop cancer live with the disease rather than die from it.

- The NCI is developing a balanced portfolio of discovery, development, and delivery designed to meet the 2015 Challenge Goal. Dr. von Eschenbach acknowledged the fact that cancer is a global problem and stressed NCI's commitment to work closely with international partners to foster scientific exchange and develop global programs for education and information dissemination.

- Dr. von Eschenbach concluded by stating that the Panel had come to Lisbon to gain a global perspective on the problems and challenges of cancer survivorship. The PCP and the NCI, he added, will continue to seek opportunities to work with individuals and organizations outside the United States to continue the collaborative effort to eliminate suffering and death caused by cancer throughout the world.

EUROPEAN SURVIVOR POPULATIONS

Presenters

Dr. Michel Coleman
Dr. Milena Sant
Mr. Riccardo Capocaccia
Dr. Gemma Gatta
Dr. Peter Boyle (rescheduled to day 2)

DR. MICHEL P. COLEMAN

Background

In addition to his work at the Public Health Unit in London, Dr. Coleman is Deputy Chief Medical Statistician at the United Kingdom (UK) Office for National Statistics. In this capacity, he has been involved in research on cancer survival patterns across the European continent as part of the EUROCARE Study on Survival and Quality of Care of Cancer Patients in Europe, a research project supported by the European Union since 1990 that uses incidence and mortality data from European cancer registries.

Key Points

- Survival rates differ between participants in clinical trials and the population as a whole. In trials, optimal care is provided under controlled conditions to patients who have been selected, among other criteria, for lack of comorbidity. The EUROCARE study is measuring survival rates in the 95 percent of cancer patients who do not participate in clinical trials. All cancer patients are included, regardless of disease stage or whether they receive treatment.

- When the proportion of patients surviving after cancer diagnosis becomes stable, indicating that their death rate is the same as that for the general population, those surviving beyond that point are considered to have been cured. Measures of the mean time of survival for patients who die earlier than that point are an indicator of progress against cancer. Data from the EUROCARE study show that survival time is improving over time.

- Twenty-two European nations are involved in the EUROCARE study, including 11 of the 15 members of the European Union. The study is using data from 67 cancer registries.

- A comparison of EUROCARE data on a selected group of cancers with similar data from the NCI's Surveillance, Epidemiology, and End Results (SEER) program shows that the risk of death in Europe is up to four times the corresponding risk of death in the United States for adults (whereas outcomes for pediatric cancer were comparable in North America and Europe). The differences are so large, the project has questioned whether the same diseases are being diagnosed and treated in North America and in Europe. The CONCORD Cancer Survival Study was established several years ago to explore and attempt to explain survival differences between Europe and North America using standardized definitions of disease, data quality control, and analytic procedures. Variables used in the CONCORD study include age, socioeconomic status, and stage at diagnosis. The study will look at how treatment decisions are made on both sides of the Atlantic and how diseases are defined and described.

- Phase I of the CONCORD study involves classic survival analysis; Phase II involves patterns-of-care studies to examine observed differences in survival; and Phase III will involve a pathology review to determine whether the same diseases are being described. The study began with 18 European countries, 18 U.S. states, and 7 Canadian provinces; its scope has more recently expanded to include each state in Australia and 3 prefectures in Japan. Substantial numbers of patients with breast, large bowel, and prostate cancer have contributed data for Phase I analyses, and Phase II data collection has begun.

- The CONCORD study is developing new methodologies and approaches for exploring cancer survival. These include period survival techniques that may be more effective than classical survival analysis for predicting survival rates for patients diagnosed recently; incorporation of stage and treatment information into survival comparisons; and examination of health care delivery factors that may affect probability of survival and cure.

DR. MILENA SANT

Background

Since 1990, Dr. Sant has served as Scientific Coordinator and a member of the EUROCARE Steering Committee. She works with the project's data analysis group and is responsible for breast and testicular cancer studies. Dr. Sant is also a member of the Steering Committee for the CONCORD project. For the European Breast Cancer Network, she is Project Leader for several breast cancer survivorship studies.

Key Points

- Two high-resolution studies within the EUROCARE project are designed to interpret cancer survival data through age-adjusted comparisons; describe and compare patterns of care for cancer patients; and quantify prevalence of cancer recurrence using clinical follow-up data. Detailed information is collected on both stage of disease and the specific diagnostic method used to determine stage, since the determination of stage category can be influenced by the thoroughness of the diagnostic investigation. These studies focus on breast, colorectal, and prostate cancers, for which significant differences exist in survivorship among the various European countries. Testicular cancer is also included because it is a curable disease and the project wanted to ensure access to the best available treatment.
- Analysis of breast cancer survival data suggests that most of the differences in survival depend on stage at diagnosis, although differences in treatment and delivery of care are also associated when adjusting for stage.
- The project has compared patterns of breast cancer care for patients diagnosed in 1992 with those diagnosed in 1996 and 1998. The probability of receiving breast-conserving surgery plus radiotherapy was estimated for each group, adjusting for age and stage at diagnosis, both of which are determinants of the likelihood of receiving breast-conserving treatment, and it was found that this probably increased for the second group.
- The study has concluded that differences in survival among women diagnosed with breast cancer were associated with differences in stage at diagnosis and that the persistence of high risk of death in several regional groups, after stage adjustment, is associated with less-than-optimal treatment in those regions. The proportions of women diagnosed at early stages and women receiving breast-conserving treatment have increased over time.

MR. RICCARDO CAPOCACCIA

Background

Mr. Capocaccia is a senior biostatistician on the EUROCARE and CONCORD project Steering Committees and is an expert in cancer prevalence estimation, on which he is a direct collaborator with the NCI.

Key Points

- Prevalence, when studied in the context of variables such as disease severity, time elapsed since diagnosis, and age, is the most useful tool in estimating the burden of cancer in a population and in planning for future health services.
- The EUROPREVAL project, a subsection of the EUROCARE project, has three main objectives: provide an overall picture of cancer prevalence in Europe; use statistical modeling to provide an estimation of incidence and prevalence trends at the national level in European countries; and study prevalence with respect to the health care needs of patients.

- To address the first objective, the project studied data from cancer registries in 17 countries. Because these registries are relatively young, numbers of long-term survivors diagnosed before the start of registration must be estimated through statistical modeling.
- In 1992, the most recent year for which such data are available, overall cancer prevalence in Europe was slightly more than 2 percent. Breast and colorectal cancers were the most prevalent diseases among cancer survivors.
- Data on European cancer prevalence by geographical area show that 1992 prevalence was highly variable throughout Europe, but it was higher in Northern Europe due to higher incidence and higher survival rates. Data on prevalence by time since diagnosis show that approximately 20 percent of the 1992 cases were recently diagnosed; about the same number diagnosed 2 to 5 years prior to 1992; 22 percent were diagnosed 5 to 10 years prior to that date; and over 37 percent, over 10 years previously.
- As an example of the estimation of the proportion of cured patients compared with those expected to die as a result of their disease, 1992 data show that between 85 and 91 percent of colon cancer patients in Europe can be considered cured. This range takes into consideration an estimate of the number of survivors who can be expected to experience a relapse of the disease.
- As an example of the use of statistical modeling to predict trends in prevalence rates, the project estimates that, based on increasing incidence and survival levels, colorectal cancer prevalence increased 50 percent between 1992 and 2000.

DR. GEMMA GATTA

Background

Dr. Gatta has been involved in collaborative research with the Lombardy Cancer Registry, EUROCARE, and EUROPREVAL. Her research interests include the methodology of case-control studies for screening evaluation; evaluation of educational programs on tobacco, diet, and breast-feeding; comparisons of cancer survival in North America and Europe; descriptive epidemiology of rare tumors; and childhood cancer incidence and survival.

Key Points

- It is very important to study prevalence by time of diagnosis, because health care and health surveillance requirements vary with time. In the first few months after diagnosis, care generally consists of primary and adjuvant treatment. Subsequently, care consists of follow-up to monitor recurrences or side effects and, if necessary, treatment of recurrences.
- Prevalence can be divided into four subgroups. The "initial care" subgroup includes patients diagnosed in the past year who are in primary treatment. The "prevalence with recurrence of disease" subgroup includes patients with diagnosed cancer recurrence; the "intensive surveillance" subgroup includes recurrence-free patients diagnosed within the past 5 years; and the "mild surveillance" subgroup includes recurrence-free patients diagnosed over 5 years ago.
- It is useful to know how many patients can be considered cured—with risk of death equal to that of the general population—and those whose risk of death is greater than that of the general population. Information needed to qualify prevalence data in this way is easily obtained from clinical trials, but must be estimated at the population level, because cancer registries do not routinely collect such information.
- In collaboration with the Federation of European Cancer Societies (FECS), Dr. Gatta's group conducted a pilot study on the health and social needs of colorectal cancer patients. Its principal aim is to learn whether

the general practitioner can be relied upon to accurately analyze late outcomes of cancer treatment. The study collected data on early and late stoma, bowel function, urinary problems, sexual function, and secondary tumor development.

- Preliminary findings show a significant difference between physicians and patients in perceptions of bowel dysfunction. Patients with problems did not report them to their doctors.

- In order to qualify prevalence data and make them more useful, it is important to collect more clinical follow-up data, particularly regarding cancer recurrence and late outcomes of treatment. This is being done in the EUROCARE high-resolution studies. It is equally important to collect data on the costs and effectiveness of intensive versus less intensive follow-up.

DISCUSSION—DRS. COLEMAN AND SANT, MR. CAPOCACCIA, AND DR. GATTA

- EUROCARE has been important in changing policies on cancer care in a number of European countries. In the UK, for example, the Department of Health convened an international workshop to which both proponents and critics of the EUROCARE project were invited; the EUROCARE workshop findings have been taken into account in developing a national cancer plan and providing additional funding for treatment to address cancer survival deficits.

- When two or more populations that receive comparable treatment have different outcomes, it is likely that these populations differ in terms of health care access and/or delivery.

- In the EUROCARE high-resolution studies designed to investigate the thoroughness of diagnostic staging, a direct relationship was found between the number of lymph nodes examined and the accuracy of detection of metastases.

- Although most Europeans have no-cost or low-cost health care, either through government-provided services or compulsory insurance, geographical disparities in cancer outcomes among countries still exist. Significant factors contributing to these disparities include variations in stage at diagnosis and unequal access to optimal treatment, and disparities in health care expenditures.

- The CONCORD study is not designed to address differences in health care systems or the degree of development of models of cancer care between Europe and North America; however, the EUROCARE project is incorporating information about European health care system access and expenditures into its efforts to understand differences in cancer outcomes.

- Consistency in pediatric outcomes can be partially explained by the fact that pediatric cancers are a more homogeneous group of diseases than adult cancers, which are much more likely to vary in genetics and etiology among populations.

- In both the United States and Europe, treatment for pediatric cancers is provided in very structured settings—either comprehensive cancer centers or within clinical networks—which has resulted in comparable outcomes across all countries that provide specialized cancer care. If a similar approach to adult cancers could be established, real progress could be made in equalizing outcomes. Although not all adult cancers can be treated in specialized centers, it should be possible to ensure that all patients have access to optimal care delivered in collaboration with cancer centers.

- In some cases, cancer outcomes differ between Europe and the United States because cancers occurring in several sites are grouped together as a single disease. Stomach cancers, for example, can occur in different parts of the stomach, but all are lumped together statistically as stomach cancers, even though there are geographic variations in the prevalence of cancer in the different parts of the stomach.

- EUROCARE does not have data comparing outcomes of public- and private-sector care; most patients in Europe receive public support for health care and also, at some point, receive care in private-sector settings. The project does have data indicating that patients treated in comprehensive cancer center settings have higher survival rates than the general population.
- Most cancer survival data focus on 5-year survival rates. Public health surveillance should, like the EUROCARE project, also estimate cure rates and identify the point in time at which the risk of death for patients becomes identical with that for the general population.
- In the EUROCARE project, approximately 70 percent of international differences in survival for several major cancers can be attributed through regression analysis to several variables related to public expenditures—for example, proportion of gross domestic product spent on health care, number of beds available for cancer care, number of physicians, and similar measures used by the Organization for Economic Cooperation and Development (OECD) to assess the economics of health care.
- The EUROCARE and CONCORD projects would be interested in receiving advice and assistance from the NCI on research methodologies or economic models that could be used to support the hypothesis that improving cancer survival reduces overall costs associated with cancer care.
- Variations in caseloads and degree of expertise among physicians and institutions account for some of the variation in outcomes. Compliance with published treatment guidelines is not universal. Equitable outcomes will not be achieved without requiring clinicians to deliver optimal care.

U.S. CONCEPT OF SURVIVORSHIP—DR. JULIA ROWLAND

Background

Dr. Rowland has been Director of the Office of Cancer Survivorship (OCS) since 1999. Before that, she was Director of the Psycho-Oncology Program at the Lombardi Cancer Center at Georgetown University. Dr. Rowland's research has focused on both pediatric and adult cancer survivors; she has published extensively on women's reactions to breast cancer as well as on the role of coping, social support, and developmental stages in a patient's adaptation to cancer. Dr. Rowland is active in championing public awareness of cancer survivorship issues.

Key Points

- The years prior to 1950s could be called a period of "presurvivorship" during which cancer outcomes were very poor. Beginning in that decade, researchers began to look at psychosocial factors and quality-of-life issues among people living with cancer. Early studies focused on pediatric survivors. During the 1960s, and especially after passage of the National Cancer Act in 1971, both patients and physicians became more open about discussing cancer. New informed consent requirements also served to bring cancer "out of the closet."
- At the beginning of research into psychosocial issues, investigators used the medical model to look at distress, dysfunction, and disability outcomes. This paradigm has changed over time. In the late 1970s, psycho-oncology training programs became available for those working with cancer patients and their families. Patient and professional educational materials were developed on living with and beyond cancer. Attention to survivorship issues increased through the efforts of a vocal advocacy community. Intervention studies began to explore ways to help patients minimize problems associated with cancer treatment. However, although the majority of American cancer survivors are in older age groups, most behavioral research in survivorship has continued to focus on younger survivors. Little is known about the effect of comorbidity, for example, on survivorship among older Americans.

- Around the time of the establishment of the OCS in 1996, an era of resilience and health promotion had begun—it became apparent that cancer patients were living long enough that life after cancer had to be addressed. The population of cancer survivors has continued to grow. The percentage of children surviving 5 years has increased from 20 percent to nearly 80 percent. Among adults diagnosed with cancer today, 62 percent will be alive after 5 years. Based on SEER data, it is estimated that there are 9.6 million cancer survivors in the United States, and the World Health Organization (WHO) has placed the worldwide figure at 22.4 million. Cancer is beginning to be perceived as a chronic illness.

- Estimates of long-term survival in the United States indicate that 14 percent of the prevalent population was diagnosed over 20 years ago. The largest groups among these survivors are breast, prostate, and colorectal cancer survivors; although lung cancer's prevalence is high, its survival rate is not. Survival rates for women are somewhat higher than for men, primarily because women are more likely to be diagnosed with treatable cancers (e.g., breast cancer), not because they receive better treatment.

- As further advances are achieved in diagnosis and treatment, cancer survival rates will continue to rise. However, at least in the United States, increases in survivorship are not uniformly shared by all members of the population. African Americans and Native Americans, for example, are not benefiting from increased breast and prostate cancer survivorship at the same level as the general population. Asian Americans have survivorship rates that are higher than average.

- About 80 percent of U.S. cancer patients are treated in facilities other than comprehensive cancer centers. Cancer care is increasingly provided in the outpatient setting, and family members are becoming involved in the primary care of cancer patients. The American Cancer Society (ACS) estimates that one in four families will be affected by cancer. About one-quarter of adult cancer patients live in households with small children; little is know about the impact on children of the experience of living with adult cancer patients.

- Cancer survivors are becoming more visible. As a result of advocacy and public education, the definition of survivorship has begun to evolve. Advocates have been a powerful force for change in the health care system; they were directly responsible for the establishment of the OCS. Advocates wanted to know how many of the almost ten million Americans with cancer were newly diagnosed, how many had recurrent disease, how many were dying, how many were cured, and how many were living with cancer-related disabilities. It remains an enormous challenge to answer these questions.

- In the medical arena, a cancer survivor has been defined as a person diagnosed with cancer who has lived disease-free for 5 years. Personal definitions among cancer patients vary widely, from victim to thriver to advocate to warrior. The OCS defines a cancer survivor as anyone with cancer, from the moment of diagnosis until the end of his or her life. The Office also views caregivers, family members, and loved ones as "secondary survivors."

- The OCS research portfolio is concerned with finding ways to prevent or reduce adverse late-term consequences of treatment and other cancer-related outcomes and developing outreach methods to teach the health care community and the public about challenges faced by cancer survivors and their loved ones. The Office also supports studies on long-term follow-up of cancer patients, addressing questions such as who should receive this type of service, how intense it should be, and who should deliver it.

- The Office is also concerned with optimizing health care after cancer treatment. Instead of being returned to their "premorbid condition," cancer survivors want to know how to make their lives healthier by paying attention to such issues as diet, exercise, and stress management. Cancer survivors, in fact, are now demanding a type of prevention-oriented health care that is not being delivered to the rest of the population.

- Every year, the OCS reviews survivorship-related research funded by the National Institutes of Health (NIH). In 1996, 24 studies were looking at posttreatment outcomes, including epidemiologic, descriptive, and intervention studies. In FY2002, 183 survivorship-related studies were identified. Many addressed multiple

tumor sites, but among single-site studies, breast cancer has been the largest focus. Several other tumor sites with high prevalence are understudied.

- About 40 percent of NIH-funded survivorship studies are conducting intervention research. The NIH hopes to increase this proportion to 50 percent to create a balance with discovery-related research.

- Surveys of survivorship research findings make it clear that no cancer treatments are completely benign; they all have an impact on a patient's physical and psychological well-being. Physical side effects include hair loss, nausea, pain, fatigue, lymphedema, and cardiotoxicities. Psychological consequences range from depression, stress, anxiety, and fear of recurrence to altered body image, social problems, changes in relationships, and concerns about employment and health or life insurance.

- The OCS has learned about the resilience of cancer survivors and the powerful messages they can convey to others with cancer about how to get through treatment and move on with life. The Office has also learned that standard cancer care must be supplemented with psychosocial and behavioral interventions to improve outcomes for survivors.

- Future directions in survivorship research include reducing the impact of emerging late effects of new treatments, such as cognitive deficits following intensified chemotherapy; addressing the economic and emotional burdens placed on family caregivers; promoting overall health following treatment; developing guidelines for long-term follow-up; eliminating health disparities among cancer survivors; and examining creative methods of care delivery, including European models. Survivorship research will also need to consider developmental issues among adults, such as how treatment and its consequences will affect family and career plans over the lifespans of survivors. Cancer care should continue to be tailored, as in the case of Lance Armstrong, to enable each individual to have the richest possible life.

EUROPEAN APPROACH TO QUALITY-OF-LIFE ISSUES—DR. ANDREW BOTTOMLEY

Background

Dr. Bottomley is Coordinator of the Quality of Life (QOL) Unit of the European Organisation for Research and Treatment of Cancer (EORTC) in Brussels, Belgium. The QOL Unit's objectives include: (1) examining factors that improve quality of life; (2) supervising evaluation of quality of life in cancer clinical trials; and (3) encouraging physicians to pay greater attention to quality-of-life factors in the treatment of cancer.

Key Points

- Historically, most clinicians and health care workers were concerned only with treating disease. Over the past two decades, more attention has been focused on treating the patient as a person. As numbers of cancer survivors and the length of survivorship have increased, quality of life has become a key issue.

- The results of a recent Medline search for peer-reviewed literature on cancer-related quality of life yielded more than 2,000 articles published over the past two decades. The rate of publication of these articles doubled in the past 5 years.

- Quality-of-life clinical trials are moving away from traditional disease-level measures—such as hemoglobin levels and tumor response—and toward patient-level measures, as well as moving from short-term to long-term assessments.

- Because quality of life is subjective, clinicians, nurses, and even family members are not in a position to assess quality of life for individual patients; they often underestimate or overestimate the importance of specific symptoms and issues. These issues are multidimensional and go beyond pain, fatigue, and physical

functioning to include social and spiritual issues. Quality of life also changes over time for individual patients and survivors.

- The drug approval process is only beginning to consider issues related to quality of life. The EORTC is working with the U.S. Food and Drug Administration (FDA), the European Agency for the Evaluation of Medicinal Products, the International Society for Quality of Life Research, and the International Society for Pharmacoeconomics to encourage the incorporation of quality-of-life considerations into this process.

- The EORTC supports large-scale, multinational clinical trials in collaboration with more than 2,000 organizations in 31 countries. Routinely, EORTC trials on a variety of subjects address quality-of-life issues during Phase III. More than 15,000 individuals have been recruited into more than 120 EORTC studies focusing on quality-of-life issues.

- Key quality-of-life issues facing individual cancer survivors depend on their disease stage, cancer site, and treatment options. For example, a breast cancer patient treated at an early stage may be greatly concerned about body image, whereas a late-stage breast cancer patient may be facing a shorter length of survival and may have primary concerns about pain and related issues.

- The methodology of quality-of-life assessment is unknown to many clinicians and is not taught in medical schools. The EORTC and the European School of Oncology (ESO) are developing training programs to educate clinicians about quality-of-life measures and how to use them. Assessing quality of life requires good doctor-patient communication and close collaboration among health care professionals, statisticians, and researchers.

- Cultural challenges also make quality-of-life research difficult. There is little in the published literature on cultural factors that must be taken into account when pooling data from different parts of Europe. Comparisons of existing international quality-of-life studies present additional challenges. Few measurement tools are available. In the United States, the Functional Assessment for Cancer Therapy (FACT) system has been used in measuring quality of life, whereas in Europe, the EORTC Quality of Life Questionnaire has been used. Culture-specific issues in measuring quality of life need to be studied, and measurement tools need to be refined to address the right questions.

- Study design is another challenge for quality-of-life research. Many existing studies are cross-sectional, and this may not be the optimal design. Response rates for mailed surveys may be too low and involve selection bias. Studies should be designed to facilitate long-term follow-up of patients.

- Quality-of-life research is a relatively new area in the context of the long history of cancer treatment. Increasing the number of studies in this area will make it possible to better address methodological issues and understand the cultural factors involved in cancer survivorship.

DISCUSSION—DRS. ROWLAND AND BOTTOMLEY

- In developing measures of quality of life, the EORTC works with cancer patients and survivors to learn which key factors should be taken into account. Studies in the United States have compared physicians' and patients' perceptions; there can be a disconnect between these two ways of looking at observed functional outcomes.

- Measures of quality in the acute phase of disease are widely available, but measures are needed for long-term posttreatment issues, such as distinguishing between comorbid conditions and the effects of cancer on organ function. One important challenge is to develop measures for comparing cancer survivors with individuals without cancer who match them in age and share other characteristics.

- Recent European studies have shown that doctor-patient communication improves when both groups receive education about survivorship and are questioned about quality-of-life factors. Other studies recently presented at a meeting of the American Society of Clinical Oncology (ASCO) demonstrate the clinical utility of quality-of-life measures.

- Survivorship research should pay attention to issues associated with stress and anxiety associated with cancer screening and detection.

- To help promote standardization of measurement tools for assessing quality of life, the NCI has supported the Cancer Outcomes Measurement Working Group (COMWG). This group of investigators is reviewing the literature to determine what tools are being used, collect data on their reliability and validity, and make recommendations regarding standardization. The group will soon publish its findings.

- To fully understand quality-of-life issues, long-term follow-up of patients is required. The EORTC tries to follow clinical trial patients as long as is necessary to get a full understanding of the consequences of new treatments compared with standard treatments. The NCI is looking for ways to develop more long-term studies within its clinical trial groups, as well as finding methods for conducting long-term studies of people treated outside clinical trials.

- Many people with a cancer history who are now cancer-free prefer not to be called cancer survivors. However, the definition of *survivor* used by the OCS, which was originally framed by the National Coalition for Cancer Survivorship, was intended to help destigmatize cancer survivorship and to emphasize the importance of well-being for patients both before and after treatment. How people identify themselves is a personal decision, but knowing who has had cancer is important in terms of getting the right information to the right people about long-term consequences of cancer and its treatment.

- The often-used analogy comparing the fight against cancer to warfare can be misleading, because cancer will continue to exist. Instead of debating whether the war against cancer is being won or is winnable, the cancer community should focus on making progress against cancer. Advances in science and medicine have made it possible to understand cancer as a chronic disease. The elimination of suffering and death due to cancer depends on understanding this shift in thinking about cancer. It is natural to want the fight against cancer to be a war in which there is a decisive victory; however, a person who has had cancer, even if cancer is no longer present, will always be a cancer patient.

STORIES OF CANCER SURVIVORSHIP—GROUP I

Presenters

Ms. Elvira Lowe
Mr. Ambrose Heaney

MS. ELVIRA LOWE

Key Points

- In 1990, at the age of 41, Ms. Lowe discovered a breast lump through self-examination. Her primary care physician, a specialist, and a radiologist who administered a mammogram all assured her that there was nothing to worry about. After a 5-week delay, a biopsy was performed and a malignancy was discovered, which came as a terrible shock—until that time, the word *cancer* had never been mentioned.

- Ms. Lowe talked openly with family and friends and gathered information about lumpectomy and radiation therapy from the Ulster Cancer Foundation. She kept a diary during her 5 weeks of radiation therapy to

record her experiences and emotions. She returned to her teaching job after treatment and put thoughts of cancer at the back of her mind, determined not to let it cast a shadow over her life.

- In 1995, Ms. Lowe was diagnosed with breast cancer for the second time. She discovered that cancer treatment had improved in the 5 years since her first diagnosis. This time, her consultant surgeon had prepared her for the possibility of a cancer diagnosis. She was placed under the care of a multidisciplinary team, including a breast care nurse. She was offered reconstructive surgery at the time of her mastectomy, which helped her cope with this procedure. She felt that she was being treated as a whole person, not just a cancer case. Ms. Lowe received excellent follow-up care, with monthly reviews for 2 years, semiannual reviews for 3 years, and then 5 years of annual reviews. Although some hospitals stop reviewing patients 5 years after diagnosis, Ms. Lowe is reassured by receiving the annual checkups.

- In the UK, all cancer treatment is covered by the National Health Service. Ms. Lowe has additional private health insurance that provides continuity of care by the same specialists and allows her to receive follow-up review at a private hospital. She has great respect for her surgeon and radiologist.

- Ms. Lowe was fortunate in receiving loving support from her family. Her cancer experience was very hard on her two teenage daughters, but her willingness to discuss her experiences has made it easier for family and friends to ask questions.

- When she was diagnosed in 1990, Ms. Lowe said, her cancer was referred to as "your little problem." The word *cancer* was not spoken aloud. Today, people are much more open about the topic. Breast cancer, in particular, has been very visible in the media, and schools are making information available; Ms. Lowe has spoken to 16-year-old girls about her experiences to help remove the stigma from the diagnosis and treatment of breast cancer.

- A difficult time for breast cancer patients comes when treatment ends, because the regular visits to the hospital have added structure to their lives. When this structure is removed, patients are expected to resume their everyday lives while faced with cancer-related anxieties. Every cancer patient should be offered a period of rehabilitation to bridge the time after treatment. Ms. Lowe has visited hospitals in Northern Ireland that have such programs to encourage patients to understand that life goes on again. Rehabilitation should be followed by ongoing encouragement, information, and friendship; Ms. Lowe received this type of assistance from a support group operated by the Ulster Cancer Foundation.

- Because this group's support was an essential part of her recovery, Ms. Lowe wanted to give something back by becoming part of the Patient Action Group, an advocacy organization that works to improve cancer care systems and make politicians aware of the need for cancer-related services. The group was involved in establishing a new cancer center at Belfast City Hospital.

- Ms. Lowe understands that not all cancer patients have had experiences as positive as hers. Due to immense pressures on resources, many patients experience unacceptable delays in receiving treatment. The Patient Action Group is speaking on behalf of these patients.

- Through her work as a volunteer working with breast cancer patients, Ms. Lowe interviewed 15 women in Northern Ireland and incorporated their stories into a book called *Ribbons of Life.* (Proceeds from book sales benefit the Ulster Cancer Foundation.) Each woman has faced her cancer journey in a different way, but each would agree that her experience with cancer has changed her outlook on life for the better. Ms. Lowe feels that her own experience has led her to a heightened awareness of life itself and strengthened her spiritually and emotionally. She sees her diagnosis and treatment as steps along the road of survivorship. She is determined not to live a smaller life because of cancer, but to live a more fulfilling life.

MR. AMBROSE HEANEY

Key Points

- Mr. Heaney visited his doctor in 1983, at the age of 26, with what appeared to be symptoms of pneumonia. Although nothing unusual appeared to be involved, he was referred for a second opinion. Following a biopsy, Mr. Heaney learned that he had non-Hodgkin's lymphoma. He had never heard of this disease, and he was not told until much later that it was a form of cancer. His only concern was how long he would be away from work. At that time, and throughout his treatment, he did not have access to patient information or support groups.

- His 3 months of treatment with CHOP (Cytoxan, Adriamycin, Oncovin, and Prednisone) ended in November 1983 with remission. His reaction to chemotherapy was severe, and he was unable to receive treatment as an outpatient. He was unable to attend to household concerns due to loss of concentration, pain, and mood swings. His wife had to take over the family's finances in addition to taking care of him and their young son.

- Mr. Heaney eagerly returned to work. He and his wife worried about each routine pain or cough. At one point, he was sure he had relapsed, but tests showed he only had the flu. However, in June 1984, he went to the hospital with what he thought was another case of the flu but found that he had relapsed. He underwent 6 months of therapy and by December was again in remission.

- Because of the strong likelihood that he would relapse again, Mr. Heaney's doctors recommended autologous bone marrow transplant (ABMT), using his own marrow instead of marrow from a donor. In January 1985, he began a course of radiotherapy to keep the cancer at bay. He chose to have the transplant in Dublin, where he had faith in the team that had brought him this far, rather than travel to a hospital in the UK that had more experience.

- The bone marrow harvest was performed in early April 1985 and the autograft at the end of May, followed by high-dose chemotherapy. His reaction to the chemotherapy was again severe, and he did not leave isolation until June 12. When he saw his son for the first time in weeks, the boy did not recognize him. However, tests showed he was free of cancer, checkups became less frequent, his hair grew back, and life returned to normal.

- Mr. Heaney's cancer has not returned, but things are not the same as before. No one mentioned long-term issues—such as fertility problems—during his treatment, because the problem at hand was so much more important. He had leg pain that went unexplained during treatment, and it was found afterward that his hips were damaged as a result of treatment and would probably have to be replaced by the time he reached the age of 50. There were no follow-ups on this problem until a year ago, when he arranged for a consultation and learned that he had avascular necrosis (AVN), which was caused by exposure to steroids. Mr. Heaney researched AVN on the Internet and, in consultation with his oncologist, obtained medication that manages the pain for the time being.

- Mr. Heaney learned only recently that oncologists are beginning to believe patients when they complain of short-term memory loss, difficulty in concentrating, and other neurological problems often referred to as "chemo brain." Because nothing can be done about these deficits, he uses e-mail, online calendar software, and phone messages to keep track of details that he may not remember.

- Oncologists are too busy with patients undergoing treatment to worry about long-term survivorship issues, Mr. Heaney feels, and general practitioners are out of their depth in addressing them. Mr. Heaney no longer fears the return of his cancer, but he worries about health issues that remain after its defeat.

- Mr. Heaney hopes to give something back to society through his work with support groups for survivors but finds it unfortunate that these long-term survivorship issues are not something that can be addressed in working with patients currently being treated.

DISCUSSION—MS. LOWE AND MR. HEANEY

- Advocacy groups and support groups are increasingly available to provide cancer patients and survivors with referrals to assistance with psychosocial issues, but they have been frustrated in their efforts to encourage doctors and hospitals to provide this information to patients.
- Even if Ms. Lowe had not had private insurance, it would not have affected her access to surgery or follow-up reviews. Private insurance meant shorter waiting periods and being able to see the same physicians each time.
- Oncology units should have separate services devoted to long-term cancer survivorship, so that patients who have concluded treatment can see specialists instead of residents or trainees when they return for regular follow-up visits.

STORIES OF CANCER SURVIVORSHIP—GROUP II

Presenters

Mr. Jørgen Petersen
Mr. Steinar Krey Voll
Ms. Annica Andersson

MR. JØRGEN PETERSEN

Key Points

- In July 2000, Mr. Petersen entered an emergency room due to severe pain and an inability to urinate. He was catheterized to relieve the pain, and a blood sample was taken. The next day, he was told that his prostate-specific antigen (PSA) value was 47—a very high level. In late August, following a biopsy, he was diagnosed with prostate cancer.
- Following MRI and CT scans, for which there were waiting lists, it was determined that the cancer was limited to the prostate, and hormone treatment was initiated in late August to reduce his PSA levels.
- Paperwork was initiated to approve surgical removal of his prostate pending further tests to determine whether the cancer had spread. By the time these tests were finally performed, in December, cancer cells were found in his spleen and bladder, making surgery impossible. Radiotherapy was proposed if it was determined that the cancer had not spread to his lymph nodes. In January 2001, it was ascertained that this had not occurred, so radiotherapy, accompanied by hormone therapy, was initiated in February. Mr. Petersen received hormone therapy through November 2002 and radiotherapy through April 2003. He worked part-time throughout his treatment.
- Radiotherapy caused intestinal problems that were not very well handled by medical personnel. Because their advice was not useful, Mr. Petersen experimented with eating oatmeal three times a day, and this was very helpful. He lost some weight, but it was recovered after treatment. His PSA is checked every 6 months and has been constant at a value of less than 0.1.

- Of the 1,800 new prostate cancer patients diagnosed in Denmark each year, only 10 percent are offered curative treatment. Mr. Petersen has joined the Community of PROPA, an organization of Danish prostate cancer patients and survivors, to help address this issue by encouraging doctors to provide patients with information and to emphasize constant care instead of watchful waiting. PROPA cooperates nationally and locally with the Danish Cancer Society as well as internationally to increase global awareness of prostate cancer. The group works to increase prostate cancer research; contributes to the dialogue between the medical community and patients; endeavors to protect the rights of patients; and uses the knowledge and experience of members to influence policies that will improve conditions for patients and their families.

MR. STEINAR KREY VOLL

Key Points

- Mr. Krey Voll was diagnosed with testicular cancer in 1996. He had two surgeries and a series of chemotherapy treatments; he feels that he is now in better physical shape than ever.
- However, Mr. Krey Voll was never told by his surgeons or other doctors that there might be problems after treatment. As a result of treatment, he is unable to father children. More importantly from his perspective, he has had problems with short-term memory and concentrating. This has affected his life as a student because he cannot perform well on oral examinations. His school was contacted by his doctor and has promised to make accommodations in his testing, but so far, this has not happened. He has been able to postpone his examinations, but this has left him 2 years behind in his studies.
- Mr. Krey Voll serves on the Board of the Norwegian Cancer Society Youth Group, through which he has met many cancer patients and survivors, and they have reported similar experiences in school and work situations. These difficulties can lead to economic setbacks. Cancer, according to Mr. Krey Voll, is heavily stigmatized in Norway. It is perceived as a death sentence.
- Follow-up care is good at detecting relapse but not, in Mr. Krey Voll's opinion, very good at addressing the needs of the whole person. Although he lost half his body weight during treatment, he was never offered physiotherapy. He was told that if he ever became active again, he would develop lymphedema. He ignored this advice and later learned by studying physiotherapy that the advice was erroneous.

Ms. ANNICA ANDERSSON

Key Points

- Ms. Andersson's 8-year-old daughter, Mathilda, was diagnosed with acute lymphocytic leukemia (ALL)—one of the more common forms of leukemia in children—at age 2, when Annica was pregnant with her second child. Her son, Jonathan, was born 5 weeks later. Mathilda received aggressive chemotherapy for several weeks, during which the hospital to which she had been transferred provided housing for the whole family. The diagnosis of cancer came as a shock for the family, which believed that cancer always resulted in death.
- After 1½ years, Mathilda and Jonathan came home and were enrolled in daycare. A doctor came to the school and explained that if any children became sick, their parents should notify the school so that Mathilda and Jonathan could temporarily stay at home.
- Ms. Andersson was pleased with the medical treatment her daughter received. Social workers at the children's hospital were also extremely helpful. The family received assistance, including field trips, from the Child Cancer Foundation. Medical care for children up to age 18 is free in Norway, and insurance pays for many expenses associated with obtaining treatment, such as travel.

- Today, Mathilda is a happy 8-year-old. She is healthy, but vulnerable to infections. Jonathan is 6 years old and also a happy child, but he sees a child psychologist to talk about the rough times he experienced. Ms. Andersson showed signs of depression after her daughter's treatment was completed and has received medication to alleviate this problem. She is grateful for the medical care available in Norway but worries about whether Mathilda will be sick again, although her daughter's chances of growing up and having a healthy life and family are very good.

DISCUSSION—MR. PETERSEN, MR. KREY VOLL, AND MS. ANDERSSON

- There is no social stigma in Europe associated with wearing lapel pins or other symbols to signify a concern for cancer awareness, but the use of such symbols is not a tradition. Mr. Krey Voll wears a pin with the logo of the Norwegian Cancer Society, which has received positive responses.

- Prostate cancer advocacy in Denmark has had a positive effect on utilization of the PSA test; PROPA encourages men to see their doctors at the first sign of prostate cancer symptoms.