

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 EURO CARE 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 EURO CARE 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 EURO CARE study show that survival time is improving over time.
- Twenty-two European nations are involved in the EURO CARE study, including 11 of the 15 members of the European Union. The study is using data from 67 cancer registries.
- A comparison of EURO CARE 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 EUROCORE 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 EUROCORE 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 EUROCORE 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 EUROCORE 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, EURO CARE, 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 EURO CARE 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

- EURO CARE 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 EURO CARE project were invited; the EURO CARE 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 EURO CARE 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 EURO CARE 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 known 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 (Cytosan, 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.

STORIES OF CANCER SURVIVORSHIP—GROUP III

Presenters

Mr. Dirk Schmidt

Ms. Daniela Kampmann

Dr. Fenna Postma-Schuit

Ms. Claudia Rodemers

MR. DIRK SCHMIDT

Key Points

- Mr. Schmidt, a university student and professional swimmer in East Germany, was scheduled to take part in the 1992 Olympic Games in Barcelona. In September 1991, after experiencing a seizure, he was diagnosed with a malignant brain tumor that could not be treated with chemotherapy or radiation. In October 1991, the tumor was removed surgically, resulting in paralysis of the left side of his body.
- Mr. Schmidt received excellent physiotherapy between January and March 1992. His doctors predicted that he would always use a wheelchair, but he did not accept this opinion. The combination of therapy and the body's ability to transfer lost neurological functions to other sections of the brain led to substantial recovery from his paralysis. He resumed his university studies and eventually earned an M.B.A.
- Germany, Mr. Schmidt said, has an excellent cancer system, from detection through treatment and posttreatment care and rehabilitation. He receives an MRI every 3 years and can visit his neurologist whenever he wants to. He can also have physiotherapy every 3 years.
- Cancer patients and survivors receive financial support through the use of an ID card available to persons with disabilities. For example, because Mr. Schmidt is still unable to drive, his ID entitles him to free public transportation. Under German law, disabled individuals are entitled to receive preference in hiring (when their qualifications are equal to those of other job applicants) and are protected from increased insurance rates.
- German law requires that everyone be covered by health insurance. There are two kinds of health insurance in Germany: private and national. Private insurance provides access to certain privileges, such as private rooms in the hospital.
- Financial aid is also available from groups such as the German Cancer Association, and self-aid groups help survivors overcome the side effects and psychological consequences of cancer treatment. Germany also has an abundance of Web sites for cancer patients and survivors.
- Although there is no legal discrimination against cancer survivors in Germany, there is some social stigma attached to having had cancer. The public feels pity for cancer patients, and many feel that cancer survivors are less capable than others.

Ms. DANIELA KAMPMANN

Key Points

- Although it has been said that a survivor is someone with cancer from diagnosis on, Ms. Kampmann considered herself a survivor only from the day her doctor told her she was cured.

- When Ms. Kampmann was diagnosed with Hodgkin’s disease at the age of 22, the reactions she received from others ranged from shock to disgust. No one believed someone so young could have cancer. Most people, she said, do want to talk or hear about cancer.
- In addition to Hodgkin’s disease, Ms. Kampmann was diagnosed with cervical cancer 3 months ago; she also lost her job. She was told that she was ill too often.
- Ms. Kampmann has experienced panic attacks and depression since her second cancer diagnosis. Although the medical care she has received has been excellent, she has been frustrated by having no one to talk with about psychological problems. She has had to be strong for her friends and family at times when she needed their strength more, but overall, most of them have been supportive. She does not blame the few friends who turned away, describing them as helpless in the face of cancer.
- No one told Ms. Kampmann that her immune system had been weakened by her treatment for Hodgkin’s disease, leaving her vulnerable to infection. Her cervical cancer was probably caused by the human papillomavirus (HPV), to which her compromised immune system may have been susceptible.. Her only source of information on this problem, obtained after the fact, was the Internet.
- Ms. Kampmann did not obtain much useful help from the many cancer-related resources available in Germany. She found government resources to be very bureaucratic; she characterized self-help group activities as “sitting around waiting for the worst story”; and citizen-initiated groups frustrated her because they focused only on specific cancers. The most useful resources she found were foreign, including the Lance Armstrong Foundation, which promptly responded to her e-mail with abundant resources and referrals.

DR. FENNA POSTMA-SCHUIT

Key Points

- Dr. Postma-Schuit was a general practitioner 20 years ago when, at the age of 35, she was diagnosed with thyroid cancer. She found that she did not know very much about the treatment she needed.
- While her family went through a period of confusion, fear, and anxiety, she became extremely dependent on her doctor to put the information she had collected into perspective. As with many patients who count on professionals for unconditional support, she experienced the disappointment and anger that comes when anything goes wrong. Dr. Postma-Schuit eventually learned to overcome this dependency and regain the initiative.
- She found many interactions with hospital staff frustrating and humiliating. For example, a doctor came to her room, aspirated blood from the swelling in her neck, said “That is what I thought,” and quickly left the room. He made no effort to explain his actions or thoughts and made it clear he was not open to questions. During treatment, patients were discouraged from interacting with doctors and nurses.
- Stories of miscommunication reported by many patients and families led Dr. Postma-Schuit to become involved in cancer care, first as a volunteer writing informational materials and later as a leader of support groups at the Netherlands Cancer Institute. When the Comprehensive Cancer Center in Amsterdam invited her to develop patient education and psychosocial care programs for 18 hospitals in the region, she accepted and changed her specialization to psycho-oncology. Although patients cannot judge the quality of treatment, they can judge the quality of communication with health care professionals; this is the area on which Dr. Postma-Schuit wanted to concentrate.
- Cancer care in the Netherlands is well organized, and health insurance is almost universal, but waiting lists for treatment are sometimes long, and access to new, expensive medications is limited. Cancer is discussed

more openly in the Netherlands than in the past; doctors are more likely to communicate directly about diagnoses, and patient education is supported by law. Nevertheless, complaints about miscommunication continue.

- Quality-of-life studies have shown that doctor-patient communication has a great impact on outcomes, but communication training is minimal. Doctors who are sensitive to psychosocial needs have limited knowledge of resources and do not have the time or expertise to provide these services themselves. Professional societies could take a more prominent role in making improvements in this area.
- Twenty years ago, none of the doctors who treated Dr. Postma-Schuit offered any kind of psychosocial support, and contact with fellow patients was discouraged. Today, the situation is much the same. Although three of four cancer patients in the Netherlands have long-term psychological problems, only one in ten receives needed support. There is no law requiring psychosocial support, and no structural system exists to address such needs. Also, health care financing does not support rehabilitative care after cancer treatment has ended.
- Small projects are developing psychosocial checklists to be used during treatment and follow-up. The growing specialty of oncology nursing is beginning to take responsibility for patient education and psychosocial support, but many cancer patients still have no contact with oncology nurses.
- Comprehensive Cancer Centers in the Netherlands have started a “Restore the Balance” program to help patients overcome fatigue, return to prediagnosis activities of daily living, and restore quality of life. Financial support for these services remains a barrier to access.
- Most cancer-free survivors in the Netherlands receive adequate support in returning to work, but those with recurring cancer or long-term effects, such as fatigue, have a harder time. Although employers are not legally permitted to ask about medical status, it is not clear that this is always respected.
- There are 25 cancer-related organizations in the Netherlands. They began by providing patient-to-patient support but have become more powerful in recent years. Advocacy organizations have been involved in the development of standards such as the *National Cancer Treatment Guidelines*.

CLAUDIA RODEMERS

Key Points

- At the age of 38, Ms. Rodemers was diagnosed with breast cancer. Based on her Internet research, she asked whether stereotactic biopsy would be performed, and was told this procedure was not usually available in Switzerland; now, 6 years later, there are at least a dozen facilities that offer it. She had a bilateral mastectomy and did not have reconstructive surgery. She was offered tamoxifen after surgery, but she chose not to take it.
- At the time of her diagnosis, Ms. Rodemers found that her problem in choosing among treatment options was not lack of information, but the way information was presented. It was difficult for her to distinguish between statements of opinion, statements based on experience, and statements based on scientific evidence. If the opinions she was given had been characterized in this way, she probably would have limited herself to a second opinion instead of consulting four different surgeons.
- As a physical therapist, Ms. Rodemers was aware that alternative medicine and complementary care are widely available in Switzerland. After her surgery, she was treated for 2 weeks in a clinic that used alternative therapies, but she did not respond well to the treatment provided by that clinic. Although mainstream physicians are tolerant of alternative medicine, they do not know much about it and do not

communicate well with its practitioners. The patient must act as the go-between, and this role can be difficult to play.

- Cancer patients can continue to see their oncologists, but follow-up care is usually coordinated by the primary care physician. Patients sometimes have trouble finding out whether specialists are available; there is no central source of information on specialists.
- Ms. Rodemers does not consider herself a cancer survivor because she feels that this terminology separates persons who have had cancer from other people. Everyone has in common the capability of suffering and the inevitability of death—not just people with cancer.
- The Swiss are very private, reserved people. When they talk about cancer, a subject they seldom discuss, they do so in a nonconfrontational way. The needs of cancer patients' families are largely unseen and unmet. The Swiss people have a strong work ethic, prefer to take care of themselves, and are reluctant to seek assistance. Patients do not want to be viewed as different or weak.
- Although there are few self-help groups in Switzerland, the country ranks high among European countries in survival rates. Ms. Rodemers attributes this to the fact that so many people in Switzerland have computers and gather information using the Internet. People prefer to get their information anonymously. Ms. Rodemers once considered setting up an oncological physical therapy practice, but she decided not to because she found that most patients would worry that everyone would know they had cancer.
- One-on-one support is more common than support groups. A breast cancer advocacy group is getting started in Switzerland, but there are few disease-specific groups. Instead, people who feel they have a problem with discrimination contact a general patient advocacy organization.

DISCUSSION—MR. SCHMIDT, MS. KAMPMANN, DR. POSTMA-SCHUIT, AND MS. RODEMERS

- Ms. Rodemers felt that her most serious postoperative problem was an inadequate belief by health care practitioners in healing. She would like to see a shift in perspective from curative to healing care. Healing is not simply a physical process. Survivorship is a healing process even for patients who will die from their disease.
- In Switzerland and Germany, the costs of diagnostic procedures and treatment obtained outside the country are not covered by national health insurance.
- It is possible that lack of attention to the quality of dying for cancer patients is jeopardizing the quality of living.

STORIES OF CANCER SURVIVORSHIP—GROUP IV

Presenters

Mr. Antonio Toscano

Ms. Marie-Agnès Moulin

Ms. Ulrika Botelho Cyrne

Ms. Pilar Suarez

MR. ANTONIO TOSCANO

Key Points

- In August 2002, Mr. Toscano underwent surgery for lung cancer. He experienced this event as an opportunity to begin living one day at a time and come to terms with the small things in life. He quit smoking and left his job as a fine art restorer because the work exposed him to harmful chemicals. He managed to remain emotionally calm even as the situations he faced became harder and harder.
- Mr. Toscano entrusted technical aspects of his medical care to his doctors as he focused his efforts on fighting the bureaucracy of the National Health Service and problems in communicating with health care professionals. He received only basic information from his doctors and felt that the health care system treated him merely as a container for his organs.
- Mr. Toscano's care involved many hours of waiting in grim hospital corridors and explaining his problems repeatedly to each doctor he was passed on to. He was forced to exploit personal connections to shorten the customary 60-day waiting period to receive a PET scan.
- It was through his own research that Mr. Toscano developed an understanding of what it means to be a cancer patient. He has been embittered by the lack of structured psychosocial support and the inability of health care providers to develop rapport with patients. He was even treated with disrespect by a doctor who had written an encouraging booklet called *Me, the Patient*.
- Having finished his therapy, Mr. Toscano felt a sense of abandonment. He described the process of obtaining follow-up appointments and medication as an exhausting journey.

MS. MARIE-AGNÈS MOULIN

Key Points

- Ms. Moulin is the seventh person in her family to be diagnosed with cancer. Over a period of 3 years in the mid-1990s, she underwent eight operations, including a double mastectomy, operations to correct surgical mistakes, and reconstructive surgery. After the fourth operation, she lost her job. Appeals to government agencies for support in occupational retraining or establishing a small business were unsuccessful, primarily due to her medical history and the fact that she was 45 years old.
- Ms. Moulin received a great deal of support from family and friends at the beginning of her treatment, but this support dwindled over time. She became depressed and sought psychological counseling. She also started a small support group for women with cancer who were living alone. Through this work, she came into contact with the French Cancer League. The League and the National Federation of Cancer Centers asked her to establish a Patients' Committee, which reviews protocols of the Federation Clinical and Therapeutic Trials and verifies abstracts patients are asked to sign indicating that they accept the objectives, processes, treatments, and effects involved in trials in which they are being asked to participate. She is an active volunteer in the League's cancer patient network.
- After her experience with cancer, Ms. Moulin began to realize her childhood dream of learning art history and creating art in the studio. She hopes to establish a studio devoted to art therapy for cancer patients.
- France now has an ambitious cancer plan, and French people are trying to break the taboo against talking about cancer.

MS. ULRIKA BOTELHO CYRNE

Key Points

- Three years ago, at the age of 25, Ms. Cyrne was diagnosed with thyroid cancer. She underwent two surgeries and three treatments with radioactive iodine. She now takes medication every day because she has no thyroid gland. She still has nodules in her neck and is not yet completely cured. Ms. Cyrne has had no problems in obtaining follow-up care; she visits the Portuguese Institute of Oncology every 4 months for checkups and addresses other health problems with her physician.
- In Portugal, cancer is thought of as synonymous with death, and open discussion of the disease is rare. However, she has not experienced discrimination as a cancer patient. Her treatment in public hospitals has been free, and her care has been supplemented through private health insurance. The one disadvantage of having cancer is the inability of obtaining life insurance, which is required to get a mortgage.
- Cancer has affected Ms. Cyrne's family life. She had been married only a month before her diagnosis, and the disease has made it impossible for her and her husband to live as a normal couple. Ms. Cyrne sought the assistance of a private therapist to help her avoid depression. The availability of a support group for cancer patients and family members would have made dealing with the disease easier. Some support groups exist for very specific groups of patients, but Ms. Cyrne believes that more people would be better served by general cancer support groups.

MS. PILAR SUAREZ

Key Points

- In 1997, following a mammogram, Ms. Suarez was told she had "something that had to be taken away." It was not serious, she was told, so she could take a planned trip to Paris first. Ten days later, she had the operation and again was told it was not serious. However, after a week, she was told to come to the doctor's office with her husband. This time, she learned that she needed another operation. The word *cancer* was not mentioned.
- Ms. Suarez underwent conservative surgery, and lymph nodes were removed from her right side. She was told that everything had been taken away, and she needed to see the oncologist. She had the opportunity, through her husband's company, to travel to Houston or Paris, but she had confidence in the Spanish doctors and chose to stay in Madrid to receive radio- and chemotherapy. The consequences of these treatments were not explained to her. During her treatment, she was hospitalized and almost died from pneumonia and other complications.
- She now has lymphedema, which no one had ever explained to her. They told her about types of physical activities she should avoid but provided no help in finding ways to carry out the activities of daily living.
- Ms. Suarez never received psychosocial support. No one in her family ever said the word *cancer*. Instead of calling her to find out how she was doing, people contacted her husband or family members.
- Ms. Suarez is now separated from her husband. She is now healthy, and no one knows that she had cancer. She does not talk about cancer, because no one believes her.
- For 2½ years, Ms. Suarez has worked as a volunteer with the Spanish Association Against Cancer. She has learned a lot about cancer, its prevention and treatment, and the value of helping others through support groups. It is important for advocacy groups to pressure politicians to provide not only medical treatment but also psychosocial support, because people with cancer are not only patients, they are also people.

- Ms. Suarez does not think of herself as a survivor but as a fighter. She no longer plans very far ahead, and she is willing to participate in any endeavor that will help her learn.

DISCUSSION—MR. TOSCANO, MS. MOULIN, MS. CYRNE, AND MS. SUAREZ

- Dr. Leffall said that all of the speakers heard today are warriors of the highest caliber who are fighting a terrible foe. When you bring a man hope, he said, you bring him one of the greatest of all human joys, and that is the joy of anticipation.

CLOSING REMARKS—DR. von ESCHENBACH

- Dr. von Eschenbach stated that after hearing today's testimony, he has been made proud of the fact that he is a prostate cancer and melanoma survivor. These stories have made it clear that the problem is not with cancer patients or cancer survivors, but with the system.
- Dr. von Eschenbach expressed confidence that through these stories, the President's Cancer Panel will gain significant insights into the directions that need to be followed not only to change the U.S. system, but to collaborate with other governments and private organizations to change systems throughout the world.

MAY 28, 2003

OPENING REMARKS—DR. LaSALLE D. LEFFALL, JR., CHAIRMAN

Dr. Leffall explained that a speaker listed on the first day's agenda, Dr. Peter Boyle, would be today's first speaker, providing his contribution to the overview on surviving cancer. He then introduced panelists invited to discuss cancer control in Europe.

CANCER CONTROL IN EUROPE

DR. PETER BOYLE

Background

Professor Boyle is Director of the Division of Epidemiology and Biostatistics at the European Institute of Oncology; Professor of Cancer Epidemiology at Birmingham University, UK; Scientific Advisor to the Imperial Cancer Research Fund (ICRF) on Prevention and Control; Chairman of the ICRF Prevention and Control Groups; honorary Principal Scientist at the ICRF; and Director of the World Health Organisation Collaborating Centre for Statistical Modeling in Chronic Diseases. His presentation focused on the Europe Against Cancer Program.

Key Points

- The European Union (EU) currently comprises 15 member states; within the next year 10 new states will join the Union, and two additional states have applied for membership. In addition, the European Economic Area, comprising Norway, Switzerland, Liechtenstein, and Iceland, participates in some European Union activities.
- The Europe Against Cancer Program was launched in 1985 at a meeting of EU heads of state. It was described as a partnership project to promote prevention, screening, education, and training activities. The first-stage goal was a 15 percent reduction in cancer deaths by the year 2000. The European Code Against Cancer was published in 1986 and revised in 1993 and 1994. Tobacco control is a strong focus of the Program.
- Data on cancer mortality show a slight increase through 1990, followed by substantial reductions in some countries. There was an overall decrease across the EU of about 9 percent compared with projected rates for 2000 (940,000 deaths, compared with just over a million deaths projected); this fell short of the 15 percent goal but represents about 92.5 thousand cancer deaths avoided. Reductions in cancer mortality among women have been somewhat greater than reductions in the general population. Countries that met the 15 percent target included Finland and Austria, and the UK almost reached that goal. There were, however, increases in cancer mortality in Greece, Spain, and Portugal.
- Overall, mortality rates for lung cancer among men have begun declining, although some countries have not shared in this success. In addition, tobacco control among women in Europe has not been a success. Substantial increases in lung cancer mortality in women have been found throughout Europe.
- The Europe Against Cancer Program has been charged with creating a third version of the European Code Against Cancer. Numerous working groups are developing recommendations for sections of the Code, which will then be presented to the European Commission. One objective of this revision is to take into consideration the addition of Central European populations to the European Union. The EU can no longer be perceived as a homogenous entity and must recognize cultural differences among member nations. As part of the new Code, the Program has been asked by the European Commission to address the issue of citizens'

rights. Another aspect of the new Code is establishment of a goal to reduce cancer mortality in 2015 by 20 percent; using mortality rates from the year 2000; this would keep the total number of cancer-related deaths below the number of deaths recorded in 2000.

- The second stage of the Program is designed to forecast cancer mortality through 2015. A serious challenge for the future is the aging of the population, with dramatic increases in the number of people over the age of 65 as well as increases in the number over 80, a population that has received little attention. Due to the increase in the total population, as well as the increased cancer risk associated with aging, the number of cancer diagnoses in Europe is expected to increase. When mortality rates from 2000 are applied to the projected 2015 population, the result is about 1.4 million cancer deaths. When predicted declines in cancer mortality rates are taken into consideration, the result is about 1.25 million deaths in 2015. The projection of 1.25 million deaths, based on trends in declining mortality rates, represents a decrease of about 12 percent. Heightened efforts in screening, tobacco control (especially among women), and other public health interventions will be required to achieve the targeted 20-percent reduction.
- The new Code will contain specific recommendations to the public on smoking, obesity, nutrition, alcohol consumption, sun exposure, and occupational and environmental exposures. It will include detailed guidelines concerning screening for cervical, breast, and colorectal cancers and will recommend participation in hepatitis B vaccination programs to reduce risk of liver and cervical cancers.
- Civil rights recommendations under consideration include guaranteed access to mammography screening with audited quality-control standards; the right to a tobacco-free environment; and the right of employees to a workplace free of carcinogens.
- The Europe Against Cancer Program has launched a study to compare survivorship outcomes of specialist centers with nonspecialist centers; early findings indicate that the differences are remarkable and consistent. Results of this research are expected to assist the Program's efforts to reduce mortality.

ADDRESSING SURVIVORSHIP NEEDS—GROUP I

Presenters

Dr. Patrick Johnston

Ms. Ruth Campbell

Dr. Judith McNeill

Dr. Donal Hollywood

DR. PATRICK G. JOHNSTON

Background

Dr. Johnston was appointed Professor of Oncology at Queen's University of Belfast in July 1996 and Director of the Cancer Research Centre, Queen's University, in April 1999. From 1986 to 1996, he was a Senior Investigator at the NCI. He received his M.D. and Ph.D. degrees from University College, Dublin and is the author of nearly 98 scientific articles and several textbooks. His recent research has focused on understanding the mechanisms of molecular resistance to therapeutic agents.

Key Points

- Health care in the United Kingdom is delivered as part of the National Health Service; in Northern Ireland, it is run by the Northern Ireland Department of Health. The governing structure includes four health boards and a Chief Medical Officer. Care to patients is free at the point of delivery. Health care is delivered and

managed by hospitals or community trusts and supported heavily by volunteers through organizations such as the Ulster Cancer Foundation, Action Cancer, and Macmillan Cancer Research, UK.

- Northern Ireland has a population of 1.65 to 1.7 million, and there are approximately 8,800 new cancers and about 3,850 deaths from cancer per year. In Ireland, males have a higher rate of cancer than females; however, one of every nine cancers diagnosed is in women 45 years of age or younger. As recently as 6 years ago, Ireland had some of the worst outcomes for cancer in Europe. Clinical care was outdated; old radiation equipment was being used; and many surgeons performing cancer operations only did one or two operations per year. No ovarian cancers were treated with taxanes. The total chemotherapy budget was £850,000, and only 40 percent of cancer patients saw an oncologist.
- In 1996, Dr. Etta Campbell, the Chief Medical Officer for Northern Ireland, released a report that started a restructuring of cancer services in Northern Ireland. The report, *Cancer Services: Investing in the Future*, made several recommendations, including the following: develop cancer centers like the Comprehensive Cancer Centers found in the U.S.; improve palliative care; deliver cancer care using a multidisciplinary approach with teams of professionals; develop day hospital (outpatient) services; and invest in training and development of and research by cancer professionals.
- As a result of the *Cancer Services* report, cancer care was consolidated from 17 centers to 5, with a sixth, the Northern Ireland Cancer Centre, under construction. There has been a 30 percent increase in the number of patients seeing oncologists, and the chemotherapy budget has increased to 5.5 million. Patients are seeing the benefits of more multidisciplinary teams; an increase in the number of specialists; and onsite access to a full range of acute services. A new dynamic infrastructure has been created with more than 200 clinical and basic researchers who will work together in two new clinical cancer and cancer research centers
- Clinical trials, not historically conducted in Ireland, have appeared in the last 3 or 4 years. The cancer clinical trials unit is currently activating, executing, and monitoring clinical trials. Patients in clinical trials report more satisfaction with the health system, and the trials also increase professional satisfaction.
- In 1999, the NCI-All Ireland Consortium was initiated. The Consortium is a mechanism that enables both Northern Ireland and the Republic of Ireland to learn from the programs of the NCI. Initial programs set up by the Consortium included cancer registries, informatics for clinical trials, exchange programs, and the All-Island Cancer Clinical Trial Group.

MS. RUTH CAMPBELL

Background

Ms. Campbell has been with the Ulster Cancer Foundation for 18 years. She initially worked on the Cancer Helpline, a free telephone service, and has also worked as a bereavement counselor.

Key Points

- The Ulster Cancer Foundation has been working in Northern Ireland for 30 years. The Foundation, which receives no government funding, raises money for cancer research, provides cancer education and prevention programs, and provides cancer-related services for patients and their families.
- Recently, regional guidelines for clinicians have been developed covering how to handle the issue of telling a patient he or she has cancer. In the past, doctors were given no training in how to deliver such a potentially devastating diagnosis. As a result of the palliative care review, this is changing.

- Northern Ireland is beginning to develop a cohort of specialist nurses working in oncology. These nurses specialize in head-and-neck cancers, colorectal cancer, gynecological cancers, breast cancer, and lung cancer.
- In a new trial in rural areas of Northern Ireland, experienced oncology nurses are handling the review of cancer patients. The oncology nurse is able to fast-track the patient to a consultant if any problems are detected during the review.
- Cancer charities provide services that are either underfunded or not funded at all by the government. These services include cancer education and prevention, including a Smokebusters program to make school-aged children aware of the dangers of smoking. Charities also provide information and support services for patients and their families, as well as palliative and terminal care services and fundraising for cancer research. Counseling services are offered in each of the cancer units free of charge to both patients and their families. Disease-specific support groups facilitated by nurses or counselors are also provided by charities. A patient-volunteer visiting service, in which physically and emotionally well-adjusted survivors are selected and trained to visit newly diagnosed patients, is also run by the charity. In addition, a cancer helpline and complementary therapies are provided by the Ulster Cancer Foundation, which is funded entirely through community donations.
- Volunteerism is very active in Northern Ireland. Four hospices are funded by volunteer efforts, and palliative care teams based in hospitals and in the community, hospice daycare, home nursing for terminally ill patients, and bereavement support are all provided by the volunteer sector.

DR. JUDITH McNEILL

Background

Dr. McNeill joined Cancerlink as Chief Executive in 1997. In 2001, Cancerlink merged with Macmillan Cancer Relief, and Dr. McNeill is now leading programs working with patients, caregivers, and those close to them to provide social and practical support for people living with cancer at home. She has worked extensively with a network of more than 700 cancer self-help and support groups across the UK and has played a key role in developing the CancerVOICES network, an independent group dedicated to improving cancer services. Dr. McNeill chairs the Steering Group of the Department of Health/Macmillan Cancer Relief Cancer Partnership Project and is a member of the National Cancer Taskforce and the Department of Health's Supportive and Palliative Care Coordinating Group.

Key Points

- The notion of survivorship has been used in the UK in the past, but with respect to the mental health system and abuses within that system, as well as in relation to women and domestic violence—particularly in the 1970s. Survivorship has not been a concept used in the UK in conjunction with cancer, and the word *survivor* is rarely used in that context now.
- For people living with cancer and its treatments it means living with the physical impact of cancer, the emotional and psychological impacts, the social impact, the impact on finances and lifestyle, and the spiritual impact.
- Self-help initiatives are flourishing in the UK. There is an extensive lymphedema support network for women who have been treated for breast cancer as well as a group called RAGE, Radiotherapy Action Group, for women who have been damaged by radiation. Clinicians are looking to patients, particularly breast cancer patients, to be partners in their follow-up care by having the women check for signs and symptoms themselves—an effective way for them to gain a feeling of control over their treatment. Self-management is a concept that is gaining wider acceptance in the UK. The Chronic Disease Self-Management

Programme, devised for people living with long-term conditions such as arthritis, may have some applicability to cancer. In addition, people are looking to complementary therapies and diet and exercise to maintain health. Art therapy is a method being looked at to help maintain survivors' emotional and spiritual balance.

- Helping others through cancer self-help and support groups is popular in the UK. There are more than 700 groups with more than 12,000 active members. Macmillan Cancer Relief publishes a directory of these groups to ensure that everyone living with cancer has the opportunity to learn about a group and become involved if they wish.
- Macmillan is supporting an independent grassroots network of people affected by cancer—patients, caregivers, and those close to them—who want to have their say as equal partners in the system. The network is called CancerVOICES.

DR. DONAL HOLLYWOOD

Background

Dr. Hollywood played a major role in drafting a report on the national strategic development of cancer services for the Republic of Ireland. He was also involved in developing a report on the future structure of radiation/oncology services for the Republic of Ireland that included a significant patient study.

Key Points

- Ireland has the youngest population in Europe and is, therefore, expecting a significant increase in cancer incidence by the year 2015 due to the aging of the population. The funding of the health care system is centralized, and the Department of Health and Children funds all aspects of cancer care. There are 8 health boards and 12 difference administrative structures. The country spends 8.4 percent of its gross domestic product on health care. There is a mix of publicly and privately funded hospitals. All patients over the age of 65 have free health care, and all patients have access to free hospital care. Some elements of the health care system are not free of charge, and that is income-dependent. There is also private health insurance, used by about 40 percent of the population.
- The *National Cancer Strategy*, written in 1996, articulates Ireland's response to cancer. The *Strategy* is being revised and the revision will be published later this year. The updated *Strategy* will address more sophisticated aspects of care, including existing practices and patterns of care. The updated *Strategy* will also address the fragmented current structure of cancer service delivery. It will recognize recovery and survivorship as well as the implementation of new technologies and new strategies as priority issues. In addition, the new *Cancer Strategy* will move Ireland from a focus on individual hospitals to the concept of local or national clinical networks. The revised document also acknowledges the central role of research in oncology care.
- Health care portability is an important issue in Europe. Patients within Europe can access free health care in another part of Europe that is not available in their home country or region by using the E112 form, a medical care "passport."
- Challenges to providing long-term follow-up care to people with cancer will be in adhering to evidence-based practice guidelines and published recommendations. Sophisticated pre- and posttreatment care pathways and support structures need to be developed. There is also a need for functional rehabilitation of patients who undergo major surgery or endure the consequences of high-dose multimodal therapy, including personal, family, and employment issues.

DISCUSSION—DR. JOHNSTON, MS. CAMPBELL, AND DRs. McNEILL AND HOLLYWOOD

- Prevention efforts have failed to control tobacco use in Portugal. A new tobacco directive will become law in Portugal in 2003; it will include warning labels on cigarette packs, require limitations on tar, nicotine, and carbon monoxide in cigarettes, and mandate statements as to additives and proof of safety on packages.
- The European Commission did not recommend annual PSA testing because they felt that the adverse effects of radical treatment would offset any gains by reducing mortality.
- The European Cancer Code recommends hepatitis B vaccinations because it is widely believed that infections or bacteria cause 15 to 20 percent of cancers and there is a strong association between hepatitis B infection and cervical cancer. The cervical cancer screening guidelines call for women 25 years of age or older to be screened. While hepatitis B is a sexually transmitted disease, and many women will become sexually active before age 25, it was decided that setting 25 as the age to start screening would be the most effective strategy for Europe.
- In the Republic of Ireland, the Department of Health has identified cancer as a disease with a prolonged impact on patients. Cancer patients can apply for a medical card that will guarantee them access to free health care. Some patients decide to use private insurance to expedite their health care in situations in which the free health care is not available quickly enough.
- Within Great Britain and Northern Ireland, there has been a focus on developing open-access palliative care services. Historically, this has been accomplished through charitable donations, but recently, the government has provided some funding for hospices. Cancer charities have been active in providing services to cancer patients to allow them to live in their own homes and die with dignity. England has developed supportive and palliative care guidelines with input from people who have experienced cancer. These guidelines help ensure a holistic and continuous approach to cancer health care and not just at certain delivery points (e.g., diagnosis, treatment).

ADDRESSING SURVIVORSHIP NEEDS—GROUP II

Presenters

Ms. Karen Lisa Hilsted

Dr. Odd Søreide

Dr. Mads Utke Werner

MS. KAREN LISA HILSTED

Background

Ms. Hilsted is a former oncology nurse. She was diagnosed with breast cancer in May 2001. After receiving lumpectomy, chemotherapy, and radiation therapy, she is fully recovered.

Key Points

- Health care is free in Denmark regardless of age or income; however, the taxes are high to help pay for it. There are five cancer centers in Denmark, two of which are located in the capital city of Copenhagen. In 1999, Denmark created a new cancer program that included mandatory treatment schedules for cancer. For example, women diagnosed with breast cancer must consult with a surgeon within 14 days of their diagnosis, have their operation within 14 days of the first consult, consult with the oncologist again within 14 days after the operation to discuss follow-up treatment, and begin chemotherapy within 14 days of the follow-up

consult. Within 6 weeks of completing chemotherapy, women receive radiation treatment. A drawback to this rapid schedule of treatment is that Denmark lacks sufficient facilities to handle the patient load. Often, patients are sent to neighboring countries (Sweden or Germany) for treatment, and many others end up waiting for an opening in Denmark.

- Palliative care is lagging in Denmark due to a lack of cancer pain centers. Denmark does not have a history of hospice care (Copenhagen has only two hospices), and most cancer patients still die in ordinary hospitals.
- Danish law provides certain benefits to cancer patients. Some of these benefits include paid sick leave and psychological services. However, the psychological benefits are available only during the first 6-month period after cancer diagnosis—a period during which many patients are not ready or capable of seeking assistance.

DR. ODD SØREIDE

Background

Dr. Søreide is Chairman of the Board of the Norwegian Cancer Society (NCS), a volunteer organization with 170,000 members. He is also a professor at the Center for Health Administration, University of Oslo. Dr. Søreide chaired the committee that established the Norwegian Cancer Plan in 1997.

Key Points

- The Norwegian Cancer Plan was commissioned in 1996 and published in 1997 as an official report.
- The latest statistics in Norway show that there are two groups of survivors: those with survival of greater than 5 years and those with survival less than 5 years. Currently, both of these groups are growing faster than the incidence of cancer, creating a great challenge for Norway's health care system.
- Health care in Norway is based on a national health care system, which is free and organized on a regional basis. Over the years, many health care reforms have been enacted; however, there is currently a feeling in Norway that health care resources are capped and that the health care system is failing.
- A great challenge in Norway is that acute care seems to take priority over survivorship issues although the Norwegian Cancer Plan includes a call for a sustained focus on palliative/end-of-life issues.
- The Norwegian Cancer Society plays a strong advocacy role for cancer patients in Norway.

DR. MAD S UTKE WERNER

Background

Dr. Werner, an anesthesiologist, is the Director of the Center of Oncological Rehabilitation and Palliative Care in the Department of Oncology at the University Hospital of Lund, Sweden.

Key Points

- Palliative and supportive care can be viewed as rehabilitative measures if one defines rehabilitation as “a targeted, sometimes recurrent, process aimed at restoration of the patient's physical, psychological, and social functions based on the patient's perceived disability, needs, and interests.” Using this definition, rehabilitation should be a standard part of oncological therapy.

- The University of Lund Department of Oncology has four individual units: a psychosocial oncology unit, a cancer rehabilitation unit, and a palliative care unit run by the Oncology Department as well as a cancer pain unit run by the Anesthesiology Department. The psychosocial oncology unit is staffed by nurses, psychiatrists, psychologists, social workers, and physiotherapists. If patients or family members feel that they are in need of psychosocial support, they can call and be admitted to the unit. Physiotherapy is an important aspect of the psychosocial oncology unit's care for cancer patients because physical well-being promotes positive mental health and enhances coping strategies. Staff are also supervised carefully to identify professional fatigue or "burnout." All residents receive a 1-year course in communication managed by the psychosocial unit. All new residents undergo an extensive 3-year training in psychoanalysis and psychotherapy.
- The rehabilitation unit offers patients a 1-week posttreatment residential stay during which they receive information about cognitive, physiological, psychological, and therapeutic aspects of cancer. Physical therapy and creative arts are also offered.
- The oncological pain unit uses both conventional pharmacological therapies and specialized techniques such as pumps for subcutaneous morphine administration and spinal administration of local anesthetics and opioids.
- The palliative care unit includes an inpatient hospice, a daycare facility, and an extended home-care service.
- Supportive care is also very important for a good therapeutic outcome. Pain is treated aggressively, so that acute pain does not turn into chronic pain.

DISCUSSION—MS. HILSTED AND DRS. SØREIDE AND WERNER

- In Denmark, there has been a greater focus on patients dying at home, but decisions are often made by the caregivers, often without consulting the patients themselves. There is some question as to whether it would be better to have a homelike facility available within a hospital or hospice setting.
- In Sweden, there has been a focus over the past 10 years on a variety of issues related to palliative care and symptom management. Many new units (pain, psychosocial, home care, hospices) have been formed, but they are all independent programs with no continuity. These programs need to be offered to the patient in a comprehensive and combined way.
- In Norway, palliative care has taken a back seat to acute care, and a framework needs to be developed in which palliative care is an equal to acute care.

ADDRESSING SURVIVORSHIP NEEDS—GROUP III

Presenters

Ms. Julia Doherty

Dr. Jan Buter

Dr. Georges Vlastos

MS. JULIA DOHERTY

Background

For the past 5 years, Ms. Doherty has been involved in a comprehensive community needs assessment for the German affiliate of the Komen Foundation to learn why Germany has the fifth highest breast cancer mortality

rate in the world. The study collected information from health care providers, breast cancer survivors, and healthy women.

Key Points

- Many Europeans feel ambivalent about the term *survivor* as it is defined in the United States. Cultural differences between Americans and Europeans may play a large role in the way the term is used in relation to cancer and in health care in general. Most Europeans do not question their physicians, and since health care is free, they do not interact with their doctors as consumers or customers.
- In Germany's social system, in which 50 percent of each person's income goes toward the services the country provides, health care is mandated at the national level, and benefits and coverage are legislated at the national level, but care is provided locally. Much like the American system, physicians are reimbursed on a fee-for-service basis. The roots of the current system go back hundreds of years. Therefore, things like palliative care, which is a relatively new concept, are not accounted for.
- The German health care system is currently under extreme financial pressure. One response to this pressure would be to institute DRGs (direct reimbursement grants), which pay a flat rate to the hospital based on the patient's diagnosis regardless of the actual treatment and needs. Two people with the same diagnosis could have a \$10,000 difference in the cost of their care, but under the proposed system, the hospital would be reimbursed at the same flat rate for both. This system could be implemented for 100 percent of hospitals within the next 3 years.
- Germany differs from other European countries in many ways. For example, the health care delivery system in Germany is decentralized, which has some ramifications with respect to the European *Guidelines*. The *Guidelines* call for screening centers to perform at least 5,000 mammograms a year—a reasonable number in a centralized system. However, in Germany's system, with smaller practices, only three centers perform that many mammograms a year. Using this standard, many women would have to travel long distances to obtain a mammogram. The benchmark number is not evidence-based and may be discouraging women from getting screened at geographically closer centers that do not meet the guidelines but provide adequate screening. Until the systems across Europe become more homogeneous, the focus should be on national, not European guidelines.
- Another key difference between Germany and other European countries is that in Germany, there is a legislative break between inpatient and outpatient care, which discourages physicians on the inpatient side from talking with outpatient physicians, creating a continuity-of-care problem.
- In Germany the primary provider of women's cancer care is the gynecologist. Oncologists in Germany do not generally treat women's cancers. A recent study found that only 12 percent of German women had clinical breast exams performed by a general practitioner or an internist. Therefore, as women age and stop going to the gynecologist, this becomes a major problem.
- In Germany, 47,000 women a year are diagnosed with breast cancer—and at a significantly later stage than in other industrialized countries.
- Due to the German social system, there are very few poor people in Germany; thus, they have few people who might be considered disenfranchised. Advocacy, therefore, has not been an issue in the past, and consequently, there are few effective advocacy groups.

REMARKS

At this point, due to time constraints, Dr. Leffall asked Panel member Lance Armstrong and Dr. von Eschenbach to offer remarks prior to the resumption of the proceedings.

Presenters

Mr. Lance Armstrong

Dr. Andrew C. von Eschenbach

MR. LANCE ARMSTRONG

Mr. Armstrong discussed the differences in the Americans and European approaches to cancer. Americans are much more open about cancer and willing to talk about it and ask questions, whereas Europeans are more reserved and less likely to talk about cancer and issues related to the disease. He stated that when he goes to events or races in the United States, fans routinely speak to him about cancer; in Europe, however, very few people who approach him mention cancer.

DR. ANDREW von ESCHENBACH

Dr. von Eschenbach thanked Lance Armstrong for his tremendous leadership. He noted that in addition to great leadership in the scientific, patient advocacy, and community arenas, Lance Armstrong represents another kind of leader: one who demonstrates through his own experiences that it is possible to live an even fuller and more successful life after cancer.

DR. JAN BUTER

Background

Dr. Buter has worked as a medical oncologist at the Free University Medical Center in Amsterdam for 3 years. Before that, he completed his medical training at various hospitals around the country.

Key Points

- The Netherlands has mandatory basic health care insurance, and people can purchase private insurance as a supplement. There are eight university cancer centers and two categorical cancer hospitals. Patients are also treated in community hospitals. Visiting consultants, coordinated by nine regional cancer registries, travel from the cancer centers to the community hospitals to consult on cases. The registries also provide patient information and coordinate patient advocacy groups.
- Recently, outpatient care has received additional psychosocial support.
- In 1998, six centers were assigned by the government to provide education and coordination of palliative care initiatives. This resulted in regional differences in palliative care. Currently, there are regional networks with hospitals, hospices, and nursing homes to address end-of-life issues and provide care. The Netherlands has a program entitled Restore and Balance, which begins the year after a patient's last treatment and lasts for 3 to 6 months. This program offers physical and psychological support, information, and some tools to help patients get back to normal.
- Two problems the Netherlands faces are waiting lists for surgery and expensive drugs. Both of these problems are being addressed.

DR. GEORGES VLASTOS

Background

Dr. Vlastos, a specialist in breast cancer care and research who has practiced in Switzerland for several years, completed a breast cancer fellowship at the M.D. Anderson Cancer Center in Houston between 1998 and 2000. Recently, Dr. Vlastos initiated a cancer information campaign.

Key Points

- Switzerland is a small, wealthy country comprising 26 cantons or states. The country, with a population of 7 million, has cultural influences coming from France, Germany, and Italy, but it maintains a unique Swiss cultural identity. The country has four official languages. One in three Swiss will develop some kind of cancer in his or her lifetime; 40,000 new cases of cancer are reported each year. There are five major university centers and other, regional centers. Several factors, including the mountainous terrain and a military requirement, influenced how the system was set up.
- The Swiss have a strong commitment to research, prevention, treatment, and palliative care, and the 5-year survival rates are good. However, the system is quite expensive. The country spends more than US\$2 billion every year for health care. Health care costs in Switzerland have been rising rapidly, causing the government to reassess the extent of cancer care for which it reimburses.
- The Swiss have recently formed a new organization called Oncosuisse, which is a collaborative network of cancer organizations working to achieve excellence in cancer care and research.
- Switzerland lacks guidelines for cancer care; thus, patients may receive completely different treatments depending on where they are treated. This is an issue on which the Swiss are working.
- Insurance is mandatory in Switzerland, with everyone paying a monthly fee; this provides the insured with guaranteed access to treatment. This mandatory public insurance can be supplemented with private insurance to obtain additional benefits such as single rooms and private clinics.
- There is little specialization in Switzerland, so the physiotherapists who treat cancer patients are the same ones that treat orthopedic patients. A similar situation exists with psychology: There are no specialized psycho-oncology units.
- Advocacy is in its infancy in Switzerland, with very few advocacy groups. Breast cancer advocates are leading a movement toward advocacy activity.

DISCUSSION—MS. DOHERTY AND DRs. BUTER AND VLASTOS

- The Restore and Balance program started out as a patient group and was picked up by the cancer registries and is beginning to be funded by the government, but is still underfunded.
- Each country needs to use different models that fit in its particular cultural context. For example, in Germany, volunteerism is not typical, so a model like the Komen Foundation, with its reliance on volunteers, may have to be adapted to work in Germany.

ADDRESSING SURVIVORSHIP NEEDS—GROUP IV

Presenters

Dr. Riccardo Masetti

Dr. Luis d'Orey Manoel
Dr. Josep Borràs

DR. RICCARDO MASETTI

Background

Dr. Masetti is a surgical oncologist and an Associate Professor of Surgery at the Catholic University of Rome. He has taught surgery in the university setting for 22 years and has extensive experience in adapting the American model for cancer outreach in Europe. Dr. Masetti chaired a committee that conducted a nationwide community needs assessment to explore standards of care in breast cancer diagnosis and treatment, evaluate existing facilities, and describe unmet needs.

Key Points

- Italy has approximately 250,000 to 300,000 new cancer cases each year and some 159,000 cancer deaths per year. There are more than 1.5 million Italians living with cancer. Breast cancer is the leading cause of death in women over 40 in Italy, claiming about 11,000 lives per year. Each year, 31,000 new cases of breast cancer are diagnosed. Regional differences are seen in both incidence and mortality, with southern Italy having a lower incidence of breast cancer but a higher mortality rate. This is because in southern Italy, breast cancer is diagnosed at a later stage due to decreased access to care, stronger cultural barriers, and less information and awareness than in northern Italy.
- For the last 20 years, cancer has been a prominent target of the national health plan, and the current national plan specifically addresses cancer pain management and end-of-life care—two major survivorship issues. The Ministry of Health recently created a national committee on pain therapy. The committee will be looking at barriers to the use of proper pain control strategies. With respect to end-of-life issues, the new national health plan fosters the creation of a regional network of palliative care units to improve the availability of in-home, in-hospice, and in-hospital services for terminally ill patients.
- In 1999, Italy received a grant from the Komen Foundation to create an education program. A year later, they were ready to start an Italian affiliate of the Foundation to provide health care providers with free opportunities for continuing medical education, promote awareness and early detection, raise funds for research, provide educational and support opportunities to women, and try to change the attitude toward cancer in Italy.
- The Italian Komen Foundation affiliate has offered more than 150 free mammogram training sessions in 41 cities, allowing more than 7,000 health care providers to update their skills and knowledge. A major Italian telephone company released a telephone card calling attention to the importance of mammography, and a famous Italian actress developed a promotional movie trailer about mammography that played in more than 100 movie theaters. In 2000, the Italian post office issued two Breast Cancer Awareness stamps. Four Races for the Cure[®] have been held in Italy, the most recent one drawing a crowd of 17,000 participants.
- The sale of 4 million copies of the semi-postal stamps has raised US\$800,000 and may, by the end of 2003, raise as much as \$2 million. The Race for the Cure[®] has also raised money and helped fund 37 projects in central and southern Italy.
- Early Detection Day is another event the Foundation sponsors. In this event, 30 breast cancer specialists volunteer their time to work for a day in mobile mammographic units and breast ultrasound stations providing underserved populations with the opportunity to get high-quality mammograms and breast ultrasound.

DR. LUIS d'OREY MANOEL

Background

Dr. Manoel is a surgeon at the Portuguese Institute of Oncology, Lisbon Center.

Key Points

- Portugal has a National Health Service, which is publicly funded and provides universal coverage for all citizens.
- Portugal's main problems with respect to cancer-related health care include waiting lists for both diagnostic services and treatment and poor communication among doctors—either between the general practitioner and the specialist or between doctors at different hospitals.
- Portugal has few cancer screening programs, and chronic care facilities are also rare, resulting in acute care hospitals providing the bulk of the palliative care services.
- The Portuguese Institute of Oncology is tailoring its oncology practice to meet the needs of cancer patients. A “One Patient–One Team” approach is being put into practice.

DR. JOSEP M. BORRÀS

Background

Dr. Borràs is Director of a small cancer center in Barcelona, Spain. The center employs 45 medical personnel, 95 nurses, and 10 scientific researchers. Dr. Borràs was active in developing a cancer plan for Catalonia and serves on the region's Cancer Advisory Board.

Key Points

- Spain, with a population of 40 million, provides cancer care primarily through university hospitals. There are three comprehensive cancer centers. Health care in Spain is free, financed through taxes. Nine percent of the population, who are concentrated mostly in metropolitan areas, have additional insurance. Spain is in the process of decentralizing health care and will delegate health care to 17 regions.
- Patient advocacy groups are not very active, except in breast, pediatric, and laryngeal cancers.
- Families provide the main means of support for cancer patients in Spain and are integral to patients' decision-making process in treatment, follow-up, and advanced disease.
- Palliative care has received a lot of attention in Spain in the last 10 years. There is a national palliative care plan and different regional plans. A variety of palliative care support options are available, including home care and hospital care teams. For example, Catalonia, with a population of 6 million, has 50 palliative care units. It is estimated that 67 percent of cancer patients who die in Catalonia are covered by either palliative care or home care support teams. In the 10 years since the beginning of the palliative care program, there has been a reduction in the overall length of hospital stay for cancer patients; reduction in overall use of emergency departments for cancer patients with advanced and terminal disease; and reduction in the percentage of patients who die in the hospital.
- Improvements in training and psychosocial support for cancer patients need to be made.

DISCUSSION—DRS. MASETTI, MANOEL, AND BORRÀS

- In Italy, the Komen Foundation works closely with other advocacy organizations in a collaborative spirit. For example, Europa Donna works more in the areas of lobbying and political action, while Komen works more in community services.
- The Spanish Association Against Cancer is a private, nonprofit organization that assists cancer patients in ways that the public health system does not, which vary from region to region.
- Psychosocial support for cancer patients appears to be a need that requires additional attention across Europe.

CLOSING REMARKS—DRS. KRIPKE, FREEMAN, AND von ESCHENBACH

- Dr. Kripke noted the many important pieces of information she learned from this meeting, including the differing survival statistics across Europe and between the United States and Europe; the importance of psychosocial support after cancer treatment; the new cancer-related initiatives spreading across Europe to fill gaps in the health care system; and the value of high-quality cancer treatment, care, and prevention made possible to most Europeans through free public access to health care.
- Dr. Freeman also noted the inherent strength of having universal free health care coverage and contrasted that with the U.S. system with its 41 million uninsured and 35 million underinsured. He also commented on the communications issues that arise when talking about cancer, especially when there is no equivalent word for *survivor* in other languages and cultures.
- Dr. von Eschenbach announced that the NCI will soon be starting discussions with the Ministry of Health in Italy about starting a program similar to the NCI-All Ireland Consortium. He closed the meeting by stating that he hoped everyone had come away with additional insights into opportunities for collaborations and cooperative efforts that would benefit all.

I certify that this summary of the President's Cancer Panel meeting, *Living Beyond Cancer: A European Dialogue*, held May 27–28, 2003, in Lisbon, Portugal, is accurate and complete.

Certified by: _____ Date: 11/12/03

LaSalle D. Leffall, Jr., M.D.
Chair
President's Cancer Panel