



# Living Beyond Cancer: A European Dialogue

President's Cancer Panel

U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES  
National Institutes of Health  
National Cancer Institute



# Living Beyond Cancer: A European Dialogue

President's Cancer Panel  
2003–2004 Annual Report  
Supplement

*Prepared by:*  
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*for The President's Cancer Panel*

May 2004

National Cancer Institute  
National Institutes of Health  
U.S. Department of Health and Human Services

**This report is submitted to the President of the United States in fulfillment of the obligations of the President's Cancer Panel to appraise the National Cancer Program as established in accordance with the National Cancer Act of 1971 (P.L. 92-218), and the Health Research Extension Act of 1987 (P.L. 99-158), the National Institutes of Health Revitalization Act of 1993 (P.L. 103-43), and Title V, Part A, Public Health Service Act (42 U.S.C. 281 *et seq.*).**

## **The President's Cancer Panel**

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# P R E S I D E N T ' S   C A N C E R   P A N E L

NATIONAL CANCER PROGRAM

NATIONAL CANCER INSTITUTE  
U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES

NATIONAL INSTITUTES OF HEALTH

The President  
The White House  
Washington, DC 20500

Dear Mr. President:

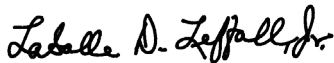
Though we have yet to eliminate cancer as a threat to Americans' health and well-being, we can be justifiably proud that a growing number of people diagnosed with cancer are overcoming the disease and joining the ranks of cancer survivors. Today, nearly ten million people in the United States are living with a cancer history, due largely to earlier detection and better treatments.

Many who have faced and conquered a cancer diagnosis, however, find they then must battle after-effects of the disease or its treatment. These effects, sometimes occurring many years after treatment ends, may include a host of physical, psychological, and social problems; insurance barriers; employment and legal issues; and financial difficulties. These long-term and late effects can be severe, unexpected, and traumatic, diminishing the quality of life for survivors and their families to a significant degree.

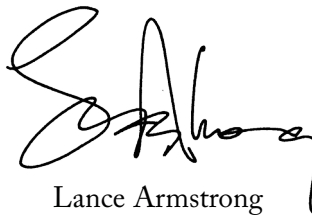
To date, our understanding of the post-treatment issues faced by cancer survivors, and our ability to intervene effectively when needed throughout survivors' lives has been limited. For this reason, the President's Cancer Panel launched a series of meetings to learn firsthand from survivors, health care providers, and insurers about these issues, unmet needs, and possible solutions.

Mr. President, as you well know, cancer is more than a national problem—it is a global issue. The attached document reports findings from the Panel's first meeting in this series, held in Lisbon, Portugal, May 27–28, 2003. A key objective of the meeting was to learn about health services and survivorship activities in diverse European nations and health systems that might benefit survivors in this country. The findings from this meeting have been included in the Panel's considerations for recommendations on how the Nation can better meet the ongoing needs of cancer survivors. These recommendations are contained in our full report, *Living Beyond Cancer: Finding a New Balance*, which accompanies this document.

Sincerely,



LaSalle D. Leffall, Jr., M.D., F.A.C.S.  
Chairman



Lance Armstrong



Margaret L. Kripke, Ph.D.



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# Executive Summary

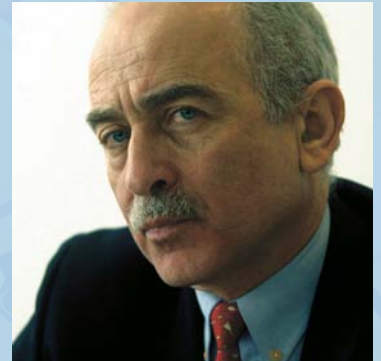
**G**lobally, an estimated 22.4 million people are living with a history of cancer. Nearly ten million live in the United States. As part of its continued analysis of issues that face people with cancer, the President's Cancer Panel launched a series of meetings in May 2003 with a European dialogue to examine survivors' issues as they manifest in the context of diverse European societies and health care systems. The Panel was interested in perspectives and attitudes that may affect the support and care received by Europeans with cancer, as well as in health care delivery and financing approaches to addressing survivors' needs that might be adapted to the health care system in the United States.

## Cancer Survival Trends in Europe

As of 1992, the most recent year for which data are available, slightly more than two percent of Europeans were living with a history of cancer; this rate may now be slightly higher. This compares with current cancer prevalence (i.e., people alive at a given point in time who have ever had a cancer diagnosis) in the United States of approximately three percent.

Cancer prevalence varies considerably throughout Europe, with higher rates in Northern Europe and lower rates in Eastern Europe. These differences primarily reflect variable access to care and quality cancer treatment. Data on prevalence by time since diagnosis show that approximately 20 percent of European survivors in 1992 had been recently diagnosed (within the previous two years); another 20 percent were diagnosed two to five years prior to 1992; 22 percent were diagnosed five to ten years prior to that date; and more than 37 percent were diagnosed ten or more years prior to 1992.

European surveillance data indicate that cancer survivors are living longer, but the risk of death from most common cancers remains as much as four times the corresponding risk in the United States. Better progress has been made in specific countries



“...whether we look soon after the diagnosis or five years after the diagnosis, the chance of [cancer] death in the United States is much lower than the corresponding chance of death in Europe. That is true for adult malignancies...For childhood malignancy, it is not true...it is possible to achieve the same results, at least for childhood malignancy, which holds out hope also for adult malignancy.”

*Michel Coleman, London School of Hygiene and Tropical Medicine, United Kingdom*

“...tobacco control in women is one of the great failures that we find in Europe in the last 10 or 15 years—and it is an obvious priority for the future.”

*Peter Boyle, European Institute of Oncology, Italy*

“[The] priority of the acute sector and less on survivorship issues, long-term effects, and other needs, including social care and support reflect, of course, an implicit priority setting and, many will say, the resource realities.”

*Odd Søreide, Norwegian Cancer Society, Norway*

and for various cancer types; most of the survival improvements are attributed to greater availability of breast and prostate cancer screening that is making earlier stage diagnosis possible. National survival differences among countries also are affected by widely varied rates of spending on health care per person, and by other factors.

As in the United States, the majority (70 to 80 percent) of European children with cancer are treated on clinical trials, and outcomes for these patients are comparable to those of U.S. pediatric survivors. Children in Eastern Europe, however, have lower survival rates compared to elsewhere in Europe due likely to reduced access to effective treatments and state-of-the-art protocols.

## European Health Care Systems

Current health care systems in Europe, designed and to varying degrees managed by government entities, have been shaped by numerous historical, environmental, demographic, cultural, political, social, and economic factors. European health care systems employ one of three basic models: (1) nationalized single payer, (2) social insurance/multiple payer systems, or (3) private insurance. However, due to rapidly escalating health care costs, aging populations, and a greater prevalence of chronic diseases including cancer, most countries, regardless of the core financing scheme, are experimenting with a variety of health system reforms. Importantly, no European health insurance system is tied to employment, as in the U.S.—losing a job does not mean one will lose health insurance.

The goal of universal access and quality health care for rich and poor alike at little or no cost to the patient is the guiding principle underlying nationalized systems. Yet, the Panel learned that certain surgical procedures, diagnostic testing, other treatments, and prescription drugs are more available in some nations than in others. In addition, cancer treatment options may differ within a country depending on the extent to which the national system is regionalized and the funds and resources available in each region or community. Follow-up care for cancer also is highly variable among countries. With some exceptions, psychosocial or other supportive care is not covered under most European health systems, and in many countries these services are not readily available. These types of care and cancer information services are provided primarily by private cancer charities.

Long waiting lists are common. Speakers stated that personal contacts, supplemental insurance, and cash payments often were

necessary to receive prompt care or continuity of care. Some who can afford it seek timely care in other countries, using private insurance or personal funds to cover the cost.

## Survivor Issues and Expressed Needs

According to survivors who testified, having cancer still carries a heavy social stigma in Europe. The term ‘survivor’ is rarely used except to refer to surviving an accident, or even one’s cancer treatment, but not to refer to life beyond a cancer diagnosis. Cancer still is a taboo subject in many countries, and many still believe a cancer diagnosis is a death sentence. In some countries, cancer seldom is discussed in public or even in many families with a member who has the disease. It is highly uncommon for a public figure to disclose that he or she has had cancer or to become a cancer advocate or spokesperson.

As a result, many Europeans with cancer hesitate to reveal that they have the disease because they do not want to be pitied or viewed as different, weak, or disabled. Speakers described fears of seeking needed psychological support, instances of workplace discrimination, resistance of educational institutions to modifying testing or other procedures to accommodate memory or other learning problems of people who have had cancer, inability to get life insurance or a home mortgage, and social difficulties.

Speakers from many nations reported that cancer-related information is difficult to find, support groups are few, and discussions about cancer, treatment options, possible side or late effects of treatment, and follow-up care requirements generally are not part of the doctor/patient interaction. However, the testimony also indicated that with a growing number of survivors, a culture of survivorship and greater openness and awareness are beginning to develop in some countries.

Other recurring themes were the desire to return to some form of “normal” life; receive support in transitioning from the intense personal care provided during treatment to self-reliant daily living; receive assistance for long-term emotional as well as physiological needs; and transform the experience of cancer into something positive through advocacy, volunteerism, or other means.

Several speakers emphasized the need to educate general practitioners (GPs), oncologists, and nurses about cancer survivors’ needs, including greater information sharing and the importance of referring patients to available psychosocial services. Speakers suggested that many oncologists are unaware of all available treatment options or possible late effects of treatment.

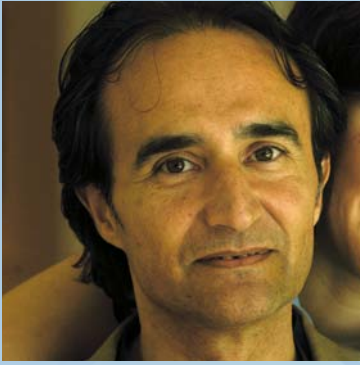
“...we have a possibility of seeking help from a psychologist but only in the first six months after you are diagnosed. And at this time, you are not capable of seeking that help—and when you need it, you do not have the possibility.”

*Karen Lisa Hilsted, 46, breast cancer survivor diagnosed 2001, Denmark*



“I asked my bank to support me and asked for loans to start a professional project creating my own company in the field of marketing counseling; and to buy a small flat for personal [use] and to carry out the projects, but my medical dossier and my physical position as a single person stopped all my projects.”

*Marie-Agnès Moulin, 50, breast cancer survivor diagnosed 1996, France*



“It was thanks to my personal research that I deepened my awareness of what it means to be a cancer patient and that this disease can come back. Accepting this condition is the fruit only of my interior work, and I am embittered by the lack of support of external structures and the great lack of rapport on the part of the professionals.”

*Antonio Toscano, 47, lung cancer survivor diagnosed 2002, Italy*



“Advocacy—it is about a culture of questioning. In Northern Ireland, we have had a culture of being accepting of what the doctor says, but I am very glad to say that that is changing, and it is changing rapidly.”

*Ruth Campbell, Ulster Cancer Foundation, Northern Ireland*

GPs in many countries also are unaware of possible late effects, either failing to notice or dismissing symptoms that may relate to a survivor’s cancer history.

## Practices and Programs with Potential for Application or Adaptation in the U.S. Health Care System

Examples of described health financing and programming mechanisms that may be applied or adapted to the U.S. health care system included:

- European countries require all citizens to have insurance; at a minimum, national health plan participation, which typically is funded through general tax revenues. Citizens in some countries have the option of purchasing supplemental private insurance to obtain complementary or other additional services, private hospital rooms, and greater continuity of care.
- Cancer patients in Europe can travel to other countries to receive care that is not available in their home country. A “health passport” (form E112) agreement covers all treatment, travel, lodging, and incidental costs for the patient, and when necessary, an accompanying relative. Costs are paid by the home country’s regional health board or equivalent agency; there is no cost to the patient.
- Sweden includes rehabilitation as a standard part of oncology treatment and recognizes that these services may be needed in different combinations and at different times both during and after treatment.
- In addition to psychosocial support provided from the beginning of inpatient cancer care, the Netherlands has added integrated psychosocial programs into outpatient cancer care. Services begin a year after a patient’s last treatment and last for three to six months at no cost to the patient.
- German cancer survivors are given a disability identification card that entitles them to free public transportation if the individual is unable to drive, preference in hiring when qualifications are equal to other candidates, and protection from insurance rate increases.

- The Swedish national insurance plan covers patient and family expenses related to travel for treatment of pediatric cancer. Family members are housed for up to a month in adjoining special rooms while a pediatric patient is receiving cancer treatment away from home. The only cost is for food provided to the adults.
- In Denmark, family caregivers, assisted by community nurses, are paid to care for family members with cancer who are dying.

**P**articipants at this meeting raised a broad range of issues, many of which warrant further investigation as they apply to cancer survivors and health care systems both in Europe and the United States. The issues and observations described in this document have been included with those from the four U.S. meetings on survivorship issues in the Panel's consideration of recommendations for improving quality of care and quality of life for people living with a cancer history.



“It seems to me that the follow-up care is very good at discovering a relapse of a disease, but it is not in my opinion good enough at seeing the whole person and seeing what else is the matter. You are supposed to be well after the completion of the treatment and if you are not then you are on your own.”

*Steinar Krey Voll, 23, testicular cancer survivor diagnosed 1996, Norway*



# Living Beyond Cancer: A European Dialogue

## Introduction

This year, more than a million Americans will be diagnosed with and treated for cancer. Most will complete their treatment and return to the daily business of living—going to school, caring for families, holding down jobs, contributing to their communities. But how are the everyday experiences of living changed after cancer treatment ends? What are the special needs of this growing population of cancer survivors—now nearly ten million strong—and how can their quality of life be enhanced?

The President's Cancer Panel, established by the National Cancer Act of 1971 (P.L. 92-218), is charged to identify barriers to optimal development and implementation of all aspects of the National Cancer Program. The Panel raises questions and explores issues chiefly, though not solely, by soliciting testimony from leaders in cancer-related medicine, academic research, industry, the advocacy community, and the public. At least annually, the Panel reports to the President its recommendations for removing identified impediments and addressing identified needs.

Many of the issues described in the Panel's recent report, *Voices of a Broken System: Real People, Real Problems*,<sup>1</sup> centered on difficulties experienced by Americans from all walks of life as they tried to access and pay for needed cancer screening,

diagnostic, and treatment services. However, some of the nearly 400 patients, caregivers, and health providers who testified also alluded to a broad range of issues that confront people after they have completed cancer treatment. The Panel's decision to further explore survivorship concerns through a new series of meetings derived in part from this compelling testimony, and is focused principally on the post-treatment period. The issues of long-term survivors were of particular interest.

Research to date reveals that survivors experience cancer differently and may have different after-effects from the disease or its treatment depending, in addition to cancer type and other factors, on the age at which they were diagnosed. For this reason, the Panel took a life span approach to this meeting series, as the schedule below indicates:

May 27-28, 2003	<i>Living Beyond Cancer: A European Dialogue</i> Lisbon, Portugal
September 5, 2003	<i>Survivorship Issues and Challenges among Pediatric Cancer Survivors</i> (aged 0-14 years) Denver, Colorado
September 22, 2003	<i>Living Beyond Cancer: Challenges for Adolescent and Young Adult Survivors</i> (aged 15-29 years) Austin, Texas

- November 4, 2003 *Living Beyond Cancer: Meeting the Challenges of Adult Cancer Survivors* (aged 30-59 years) Birmingham, Alabama
- January 5, 2004 *Living Beyond Cancer: Meeting the Challenges of Older Adult Cancer Survivors* (60 years of age and older) Philadelphia, Pennsylvania

This document summarizes findings from the first of these meetings, which focused on similarities and differences in the experiences of cancer survivors from a variety of European nations. In addition to learning about available services and support, the meeting explored differences in societal attitudes and awareness concerning cancer.

Cancer is a global problem that exacts a massive toll in individual and family suffering, lost productivity, and loss of life. Nonetheless, improvements in detection and treatment have contributed to a growing population of cancer survivors worldwide, and awareness of survivors' concerns likewise is increasing. Opportunities exist for collaboration and sharing of best practices, not only within the United States but worldwide. The Panel invited 33 speakers from 14 European nations to describe their personal experiences as cancer survivors or caregivers and/or their work related to cancer surveillance, research, cancer treatment, or patient advocacy. Survivor and caregiver speakers were selected because they had experienced different cancers and different treatments, were of varied ages, lived in urban and rural settings, and represented distinct European

cultures. Importantly, they sought and received information about their disease, cancer treatment, supportive services, and follow-up care in the context of diverse health care financing and delivery systems. A list of meeting participants and the meeting agenda are included as an Appendix.

In addition, the testimony provided in Lisbon was a major impetus for a fortuitously timed cancer awareness event held in Paris, France shortly after the Lisbon meeting and at the conclusion of the Tour de France cycling race, which was won by Panel member Lance Armstrong. Several of the survivors who testified in Lisbon also attended this event. The event was conducted in recognition of cancer as a global problem that requires increasing international collaboration to raise awareness, improve the quality of treatment and quality of life for cancer survivors, and reduce cancer mortality worldwide.







# Principal Sources of European Cancer Data

Data from several sources provide information on cancer incidence, prevalence, and mortality in Europe. These data are being used to assess progress against cancer, track survival trends, and develop programs at disease, national, and continental levels. Most countries in both Western and Eastern Europe have cancer registries, but many are relatively new and currently are of variable quality as they do not use standard definitions, data sets, quality controls, or analytic methods. These are the same issues with which U.S. cancer surveillance efforts have grappled over the past few decades and resolved to a considerable degree through collaboration between the National Cancer Institute's (NCI) Surveillance, Epidemiology, and End Results (SEER) program, and the National Program of Cancer Registries (NPCR) supported by the Centers for Disease Control and Prevention (CDC). In Europe, several efforts are underway to use existing data in a standardized fashion and enhance the quality and consistency of future cancer surveillance activities.

## **EUROCARE (European Cancer Registry-based Study of Survival and Care of Cancer Patients)**

A research project supported by the European Union (EU) since 1990, EUROCARE is the first large-scale international project to compare cancer survival across Europe using incidence and mortality data from population-based cancer registries, and employing a common protocol and standardized quality control and analysis.<sup>2,3</sup> Twenty-two European nations are involved in the

EUROCARE study, including 11 of the 15 EU member countries. In all, the study is using data from 67 cancer registries. Follow-up is current through 1999, and includes data on 42 types of adult cancer. The study is measuring survival rates in the 95 percent of European cancer patients who do not participate in clinical trials. EUROCARE data have been used to support changes in cancer care policies in several European countries, including the United Kingdom, Italy, Poland, Norway, and Denmark.

The data collection period included all cases diagnosed from 1978–1989. A follow-up study, EUROCARE II, updated and expanded the database to study variation in survival in more recent periods.<sup>4</sup> EUROCARE III will interpret the survival differences observed across time and populations to assess the effects of earlier diagnosis, differences in efficacy of treatment, and interaction of these factors.

EUROCARE and EUROCARE II data have been used to ascertain survival differences among children with cancer across Europe and in comparison with U.S. pediatric cancer survival rates.<sup>5,6,7</sup> EUROCARE researchers are conducting numerous other analyses of the data,<sup>8</sup> including detailed (“high resolution”) site-specific studies, focused on breast,<sup>9,10</sup> colorectal, and prostate cancers, for which significant differences in survivorship exist among the various European nations. Testicular cancer also is being studied because it is a highly curable disease; this study will ascertain whether patients are receiving the best available treatment. The studies are designed to interpret cancer survival data through age-adjusted comparisons;

describe and compare patterns of care for cancer patients, including the thoroughness of diagnostic staging; and quantify the prevalence of cancer recurrence and late outcomes of treatment using clinical follow-up data.

### **EUROPREVAL Project**

The EUROPREVAL project is a subsection of EUROCORE focusing on cancer prevalence in Europe. Its goals are to provide an overall picture of cancer prevalence, to use statistical modeling to estimate incidence and prevalence trends at the national level in European countries, and to study prevalence with respect to patients' health care needs. The prevalence figures must be estimated at the population level, because cancer registries in the 17 countries included in the study do not collect this information routinely. EUROPREVAL considers only person prevalence (i.e., only the first primary cancer diagnosed in each person) not tumor prevalence (i.e., all primary malignant tumors occurring in a person).

### **CONCORD Cancer Survival Study**

The CONCORD study is a large, trans-Atlantic project designed to measure and explain differences in survival of breast, prostate, and colorectal cancers between Europe and North America. Using standardized disease definitions, data quality controls, and analytic procedures, EUROCORE data are being compared with data from selected NPCR and SEER registries. Variables used in the CONCORD study include age, socioeconomic status, and stage at diagnosis. The study will examine how treatment decisions are made on both sides of the Atlantic and how diseases are defined and described. The study began with 18 European countries, 18 U.S.

states, and seven Canadian provinces. Its scope recently has been expanded to include all states in Australia and three prefectures in Japan.

CONCORD is being conducted in three phases. Phase I involves classic survival analysis, while Phase II involves detailed patterns of care studies to assess observed differences in survival. Phase III will involve a pathology review to determine whether the same diseases are being described in both Europe and the United States.

### **European Organisation for Research and Treatment of Cancer (EORTC)**

EORTC is one of the largest clinical trials organizations in Europe. Its goal is to improve cancer treatment and alleviate related problems. The organization sponsors multicenter, multinational, and intercontinental clinical trials. More than 2,000 organizations in 31 countries participate in EORTC studies. Research projects focus on methods and practices for cancer clinical trials, anti-cancer agent development, and cancer management procedures. EORTC has a quality of life unit that studies factors that improve quality of life, supervises quality of life evaluations in cancer clinical trials, and encourages physicians to pay greater attention to quality of life factors in cancer treatment. Most of these studies focus on the treatment and immediate post-treatment period; quality of life researchers in Europe are only beginning to design studies of quality of life among long-term cancer survivors.

### **Europe Against Cancer Program (EACP)**

EACP was initiated in 1985 at a meeting of the European Commission, which is comprised of EU heads of state. It is a partnership project to promote prevention, screening, education, and training activities. EACP publishes and disseminates the European Code Against Cancer,<sup>11</sup> which sets goals and associated principles and activities for

cancer mortality reductions. The Code is revised periodically; the current revision will take into consideration the diverse cultures of EU member and candidate nations.

EACP also is charged to forecast cancer mortality through 2015, taking into account a growing but aging population and an expected increase in cancer diagnoses. In addition, EACP has launched a study to compare survivorship outcomes of specialist centers with non-specialist centers. Early findings indicate that the differences are consistent and significant. The results of this study will assist in planning and implementing efforts to reduce cancer mortality across Europe.

### **International Association for Research on Cancer (IARC)**

The IARC is part of the World Health Organization. Its mission is to coordinate and conduct research on the causes of human cancer and mechanisms of carcinogenesis, and to develop scientific strategies for cancer control. The agency is involved in both epidemiologic and laboratory research and disseminates scientific information through publications, meetings, courses, and fellowships.<sup>12</sup> The IARC has published many of the papers on the EURO CARE study. In addition, IARC maintains databases on cancer epidemiology, carcinogenic risks to humans, ongoing research in cancer prevention, and research on the p53 tumor suppressor gene.



# Cancer Survival Trends in Europe

EUROCARE data for 1992 (the most recent year for which data are available) suggest that the overall cancer prevalence rate (the number of people alive at a given point in time who have ever had cancer) in Europe was slightly more than two percent of the total population, with breast and colorectal cancers the most prevalent diseases among survivors.<sup>13</sup> It is possible that prevalence now is higher. Current cancer prevalence in the United States is approximately three percent.<sup>14</sup>

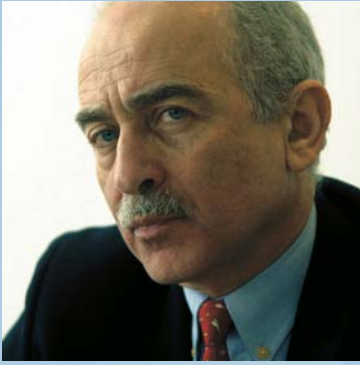
Cancer prevalence varies considerably throughout Europe, with higher rates in Northern Europe (e.g., Sweden, three percent) and lower rates in Eastern Europe, with Poland having the lowest estimated cancer prevalence of approximately one percent. These differences are attributed primarily to differences in access to care and quality cancer treatment. Data on prevalence by time since diagnosis show that approximately 20 percent of European survivors in 1992 were recently diagnosed (within two years of the index date); another 20 percent were diagnosed two to five years prior to 1992; 22 percent were diagnosed five to ten years prior to that date; and more than 37 percent were diagnosed ten or more years prior to 1992.<sup>15</sup>

A EUROCAPRE researcher<sup>16</sup> stated that when the death rate of European cancer patients becomes the same as that of the general population, patients surviving beyond that point are considered to be cured. Increased mean survival time for patients who die earlier than that point is an indicator of progress against cancer.

Although EUROCAPRE data indicate that survival duration is improving in Europe overall, a comparison of EUROCAPRE and SEER data<sup>17</sup> on selected cancers in adults shows that the risk of cancer death in Europe is up to four times the corresponding risk of death in the United States for 11 of the 12 most common adult cancers. These comparisons vary widely for specific cancers and among countries; for example, five-year colorectal cancer survival approaches 60 percent in the Netherlands, but is less than 25 percent in Poland.

“Even though we have a very small country, the offer of treatment is still not the same. It is dependent on how much money you have in the different communities—like colon cancer is treated differently in east Denmark and west Denmark—and the survival is, therefore, different.”

*Karen Lisa Hilsted, 46, breast cancer survivor diagnosed 2001, Denmark*



“...whether we look soon after the diagnosis or five years after the diagnosis, the chance of [cancer] death in the United States is much lower than the corresponding chance of death in Europe. That is true for adult malignancies...For childhood malignancy, it is not true...it is possible to achieve the same results, at least for childhood malignancy, which holds out hope also for adult malignancy.”

*Michel Coleman, London School of Hygiene and Tropical Medicine, United Kingdom*

“...tobacco control in women is one of the great failures that we find in Europe in the last 10 or 15 years—and it is an obvious priority for the future.”

*Peter Boyle, European Institute of Oncology, Italy*

Significant improvements in mortality reduction have been made for specific cancer sites in most EU nations (e.g., stomach cancer); however, deaths from some cancers (e.g., lung cancer in women) are rising in most member nations and some cancers (e.g., lung cancer) still are almost uniformly fatal in most countries.<sup>18</sup> The lung cancer death rates are believed to reflect ineffective tobacco control programs. The European Commission is dedicated to working with countries with rising lung cancer death rates, such as Portugal, to reverse this trend.

Greater availability of breast and prostate cancer screening across Europe is believed to be the major factor underlying decreased incidence and improved survival statistics, though these rates also vary considerably among countries for these diseases.<sup>19</sup> Specific to breast cancer, two consecutive high resolution studies indicate that in some countries, tumors are being detected at earlier stages, which is allowing greater use of breast conserving treatment and improving survival.

Cancer mortality rates overall are stable or falling in most EU nations, but are rising for both men and women in Spain, Portugal, and Greece.<sup>20</sup> Speakers emphasized that national survival differences in Europe must be interpreted in light of the vast differences in health care expenditure per person and as a percent of Gross Domestic Product (e.g., Poland \$400 US equivalent per person/six percent GDP versus Switzerland \$2,500 US per person/11 percent GDP in 1995).<sup>21</sup> Late-stage diagnosis was cited as an important factor in the low survival rates in some countries. Other important variables affecting cancer outcomes include the availability of specialist physicians, the number of cancer care beds, and treatment regimen. It also is expected that cancer mortality rates across Europe will be affected by rising cancer incidence rates due to an aging population. Moreover, overall EU cancer incidence, survival, and mortality rates will be affected dramatically when the ten candidate states, most of which are Central and Eastern European nations, join the Union. These countries have far higher cancer mortality rates than many of the current EU nations.

Outcomes for pediatric cancer patients generally are comparable in North America and Europe.<sup>22</sup> Speakers attributed this similarity to the fact that in both the U.S. and Europe, treatment for pediatric cancer is provided in clinical trials or highly structured settings (e.g., cancer centers, clinical networks, other facilities that provide specialized care). On average, 70 to 80 percent of European children with cancer are treated on clinical trials. However, pediatric cancer survival rates in Eastern Europe are



markedly lower than those elsewhere in Europe or the U.S., due likely to reduced access to effective treatments and state-of-the-art protocols.

In the countries covered by the EURO CARE study, approximately five percent of adult cancer patients are treated on clinical trials.<sup>23</sup> Survival rates differ between participants in clinical trials and those not treated on trials. Trial participants receive optimal care delivered under controlled conditions. Further, a speaker stated that patients with few if any comorbidities (in addition to other criteria) are most likely to be selected for trials.<sup>24</sup>

Although efforts such as the CONCORD study are improving the ability to track and compare cancer survival in Europe and the U.S., such comparisons must take into account the different maturity levels, data collection methodologies, quality control procedures, and definitions used by European and U.S. cancer registries. Within Europe, similar issues exist among cancer registries in various nations as well as among regional cancer registries in some countries. Other issues associated with calculating cancer prevalence include differences in the numbers of cases lost to follow-up, the availability of cancer mortality data only from death certificates, and difficulty in accounting for treatment of multiple tumors and patient migration. In addition, long-term survivors may be undercounted since cases diagnosed before the start of the various cancer registries are not included in the data.<sup>25</sup>

“One of the points that we should bear in mind when interpreting international survival differences in Europe is the huge disparity in health care expenditure, even among countries that do have nationally funded systems of health care.”

*Michel Coleman, London School of Hygiene and Tropical Medicine, United Kingdom*



# European Health Care Systems

Current health care systems in Europe have been designed and to varying degrees are managed by government entities. The development, operation, and evolution of these systems has been shaped by a range of historical, environmental, demographic, cultural, political, social, and economic factors.<sup>26</sup> The following sections provide a brief overview of European health care financing and delivery systems.

## Financing Systems

European nations have organized their health care systems using one of three basic models: nationalized single payer, social insurance/multiple payer, and private insurance.<sup>27</sup> However, due to rapidly escalating health care costs, aging populations, and a greater prevalence of chronic diseases including cancer, most countries, regardless of the core financing scheme, are experimenting with a variety of health system reforms. Importantly, none of the systems is tied to employment, as in the U.S.—losing a job does not mean one will lose health insurance.

### Nationalized Single Payer

Under nationalized single payer systems, health care is organized and paid for by governments at the national or regional level and is financed by income taxes. Access to health care is guaranteed, and all citizens are insured regardless of income. Nations with single payer systems include the United Kingdom, Spain, Portugal, Denmark, Norway, and the Republic of Ireland (a two-tiered benefit system). These systems face problems when the government's allocated budget

is insufficient to cover costs of needed care; the result tends to be waiting lists, rationed care, and reduced quality of care.<sup>28</sup>

### Social Insurance/Multiple Payer

In countries with social insurance/multiple payer systems (e.g., Germany, Austria, France, Belgium, the Netherlands, Luxembourg), citizens are required to join one of a number of private, non-profit organizations known in some countries as sickness funds. Individuals may choose which fund they join, but coverage is identical for everyone. In some countries (e.g., Belgium), the premium paid to the fund is calculated as a percent of wages, which is the same for everyone. In other countries (e.g., Germany, the Netherlands), the premium assessment may vary within a narrow range. Patients in sickness fund systems also face waiting lists for some services. It is illegal in some countries to leave the sickness fund and purchase private insurance.

### Private Insurance

Only Switzerland has a system based solely on private health insurance. All citizens are required to purchase basic insurance, but also may purchase additional coverage. Patients cannot be denied insurance because they have had an illness. All inpatient treatment within the patient's canton (territorial division or region) is covered; treatment in another canton requires permission from the insurance company. Under the Swiss system, patients pay copayments for primary and hospital care up to specified deductibles, which are low by most U.S. standards. The copayments cover



“Switzerland is a small but complicated country...very international but closed to the outside world [for] immigration...Now we have immigration. We have a lot of people coming on board and the situation is changing. It is changing also due to the cost of cancer, to the cost of health. And the expenses are exploding... Lymphedema [is] a complication well-known in breast cancer treatment...you [could] get a lot of sessions of physiotherapy. Now they restrict the number of sessions.”

*Georges Vlastos, Geneva University Hospital, Switzerland*

approximately one-third of all Swiss health care. Patients are responsible for ten percent of the cost of outpatient care.

Although premiums and deductibles can differ under this system, the government provides offsetting subsidies to certain risk groups. These subsidies, however, have been reduced in recent years due to Switzerland's budgetary problems. Services covered also can vary, but must include at least the services specified by the government as the minimum standard of care.<sup>29</sup>

Complementary and alternative therapies usually are paid out-of-pocket unless an individual has purchased additional insurance coverage; some such treatments, however, are covered under the national plan. To try to contain costs, some Swiss insurers are implementing health maintenance organizations similar to those in the United States.

### Hybrid Systems

Cost pressures similar to those that led to widespread implementation of managed care in the U.S. are changing many European health care financing mechanisms. Some of the countries using the multiple payer system are experiencing revenue shortfalls approaching 50 percent. These deficits are being supplemented by the government through general tax funds. As a result, differences between the multiple and single payer systems are blurring.<sup>30</sup>

In addition to this development, a growing number of citizens in some countries are becoming privately insured, at least in part. Many countries now allow citizens to purchase private insurance to augment their coverage under the national single or multiple payer system. In some cases, people are permitted to replace their national coverage with private insurance. For example, in Germany, people above a certain income level can opt out of the public system and purchase private insurance; more than ten percent of the population has done so. In return for higher quality health care, they pay a premium based on their age group at the time they join the insurance plan. Interestingly, the premium does not rise as the insured person ages; this provides a strong incentive to become privately insured at the earliest possible time.

Swedish health care is 90 percent publicly financed by a combination of taxes and social insurance. Patients pay fees for certain services and consultations, and have a medication deductible of approximately \$175 per year. If they also have supplemental private insurance, however, these costs will be reimbursed, as will any health-related travel costs and expenses. In addition, the insurance company may pay the patient a monthly stipend

for a year to cover any additional expenses that may be incurred during treatment of a serious illness such as cancer. The Italian health care system is essentially a single payer system, but is partially supported by employer and employee contributions.

In Spain, approximately nine percent of the population has private insurance in addition to national coverage, but up to a quarter of residents in the major cities have dual coverage. Private coverage of preventive services and cancer care, however, is quite limited.

In the Netherlands, more than a third of the population is privately insured. Non-catastrophic health coverage is operated through sickness funds, and people above a specified income level can choose to leave the sickness fund and buy private insurance for this part of their coverage. Catastrophic health insurance is operated as a single payer system funded by income taxes and participation is mandatory.<sup>31</sup>

The need to provide long-term follow-up care for people with cancer has been recognized relatively recently by European health systems; some are considering whether these patients should have private supplemental health insurance to cover this care.<sup>32</sup>

## Access and Referral

In countries with nationalized systems, everyone has access to care. The goal of quality health care for rich and poor alike, at little or no cost to the patient, is the guiding principle in the systems of the United Kingdom, Germany, France, Denmark, Norway, and other countries.<sup>33</sup> However, nations continue to reassess what the minimum acceptable standard of care should be, and these standards are in part cost-driven.

In some nations, general practitioners/primary care physicians serve as gatekeepers who control access to specialists (e.g., the Republic of Ireland, Italy, the Netherlands, Norway, Portugal, Spain, the United Kingdom).<sup>34</sup> By contrast, patients in France, Belgium, and Germany can consult as many types of physicians as they choose as often as they wish. Primary health care teams are most firmly established in the Netherlands, Scandinavia, Spain, and the United Kingdom.<sup>35</sup>

Certain surgical procedures and other treatments are more available in some nations than in others. This has caused some of those who can afford it to seek care in other countries and to purchase private insurance that covers such care. Speakers from Germany and Switzerland stated that tests or treatment



“...my husband was a very high executive in a big multinational company. I say this because I have private insurance...I was covered by the social system, the public system, but I have private insurance...They offered me to go to the States, to Houston. They offered me to go to Paris. I decided to stay in Madrid...”

*Pilar Suarez, 52, breast cancer survivor diagnosed 1997, Spain*

“[The] priority of the acute sector and less on survivorship issues, long-term effects, and other needs, including social care and support reflect, of course, an implicit priority setting and, many will say, the resource realities.”

*Odd Sørreide, Norwegian Cancer Society, Norway*

“We have recently moved to multiannual budgeting, so for once, our Department of Health can actually plan something on a five- to ten-year program, and this enables some of the complex areas of service provision—including survivorship issues, which are a long-term issue in terms of patient recovery and return to normality—to be addressed and funded.”

*Donal Hollywood, Trinity College, the Republic of Ireland*

obtained outside the country would not be covered by their health insurance, while a speaker from Ireland indicated that patients could apply to their regional health service for care in another country; if approved, all costs would be covered.

In addition, treatment options may differ within a country depending on the funds and resources available in each region or community. In southern Italy, for example, access to optimal care and cancer information is less than in northern Italy; though cancer incidence is lower in the South, mortality is higher, reflecting later stage at diagnosis.

In Denmark, the government has stipulated the maximum length of time that should elapse between treatment phases: diagnosis, surgical consultation and surgery, oncology consultation, and chemotherapy. To try to meet these targets, some patients are sent to other countries for treatment. However, if a patient wants to receive treatment or participate in a clinical trial in another country, permission must be obtained from the national health service.

A speaker stated that in Norway, there is growing public discontent with the health care system, which is viewed as having insufficient resources. As in many other European countries, the health system is focused on acute care, with far less attention to prevention, survivorship, and palliative care issues, which are seen as less pressing. The need to integrate palliation into hospital and home care is recognized and initiatives have been launched, but these services are hampered by competing priorities.

Coverage of prescription drugs varies among European countries. In nationalized but decentralized systems, particular medications may be covered in one area of the country but not another. In addition, some national health services have policies that restrict elderly patients' access to expensive treatments or drugs.<sup>36</sup> Access to new drugs also varies among European nations; delays are related to cost considerations, regulations imposed by the governments on pharmaceutical manufacturers, and sometimes by the political popularity of the disease for which the drug is indicated.<sup>37</sup>

Some nations are working to reorganize, integrate, and improve cancer care services for their populations. For example, Northern Ireland and the Republic of Ireland have entered into a collaborative arrangement with the NCI to improve cancer data collection, firmly establish a clinical trials infrastructure, improve quality of care in a more patient-centered system, and develop education, training, and scholarship opportunities. A similar collaboration is being developed with the Italian Ministry of Health. Across the United Kingdom, efforts are being made to

integrate palliative care into all phases of cancer treatment and improve the linkage between palliative and end of life care.

## Patient Advocacy and Support

Compared with the U.S., cancer advocacy and support organizations in Europe are few but are growing in number. According to speakers, the development of these efforts has been influenced, in part, by the extent to which volunteerism is part of the national culture. Most advocacy work is done by charity organizations that provide patient information and in some cases psychosocial services, including counseling and support groups, since these services are not included or are underfunded in many national health care systems. Advocacy activities to promote cancer awareness are increasing, but activities related to promoting national health policy or coverage changes appear to be relatively uncommon.

Advocacy and support programs are better developed in some countries compared with others. For example, the United Kingdom has established, active cancer-focused charities that conduct a wide range of patient support activities. Over 700 self-help and peer support groups (e.g., a lymphedema network, and a group for patients suffering late effects of radiation therapy) have been formed, with a total membership of more than 12,000. These groups provide peer support; some also lobby for improved treatment guidelines and other cancer care improvements.

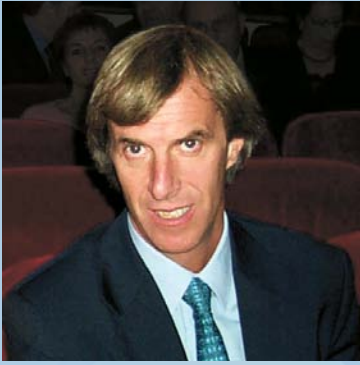
In addition, the major cancer charity in the United Kingdom is experimenting with training long-term survivors to work with those more newly diagnosed with cancer. In Northern Ireland, the charities also raise money for cancer research, provide cancer education and prevention programs, and provide cancer services (including home visits and palliative and end of life care) for patients and their families. According to a speaker, advocacy—a culture of questioning replacing a culture of accepting—is developing rapidly in Ireland, and a group of survivors has coalesced that speaks publicly and to legislators about cancer issues.

A cancer advocacy organization has been established in Denmark for 75 years. In Norway, the cancer society funds three-fourths of cancer research in the country, in addition to funding support services and providing financial assistance for the poor. In the Netherlands, about two dozen cancer patient organizations exist; these previously focused on peer support and information, but in recent years have become involved in helping to develop clinical protocols and national guidelines for cancer care.



“What are the challenges to a cancer charity in providing long-term care? Creating a climate where it is okay to ask for help. Traditionally in Northern Ireland, we have tended to keep our problems, our difficulties within the family. It is making patients, caregivers, and health care professionals aware of the services... frequently, patients are unaware of the help that is available to them.”

*Ruth Campbell, Ulster Cancer Foundation, Northern Ireland*



“The partnership with a leading organization surely helps you when you are working in cancer [advocacy]. You get more respect and attention, and you find that sometimes doors open rather than close.”

*Riccardo Masetti, Catholic University of Rome, Italy*

“Cancer care in Spain is organized without taking into account the patient’s view... families are still the main support for a cancer patient in Spain, and I must say that close family members are key decision-makers in cancer treatment, follow-up, and advanced disease in our country.”

*Josep Borràs, Institut Català d’Oncologia, Spain*

In a number of other European nations, patient advocacy activities are in early stages of development. For example, a speaker noted that because of Germany’s social and economic system, there are relatively few poor people. As a result, there has been little need of advocates for the disenfranchised; patient advocacy is a somewhat new endeavor and funding for advocacy activities through charitable organizations still is limited. Swiss patient advocacy groups, though few, are strong but they are not cancer-specific. Breast cancer advocacy organizations (e.g., Europa Donna, Susan G. Komen Foundation) are just becoming established in Switzerland. In Spain, patient groups are active only for breast, pediatric, and laryngeal cancers. Some patient support and information needs are funded, albeit unevenly nationwide, by the Spanish Association Against Cancer. Families are the main source of support for cancer patients.

Two pan-European cancer patient organizations exist: Europa Donna advocates for the rights of European women with breast cancer; the more recently organized Europa Uomo is a European prostate cancer coalition. Prostate cancer patient communities from 14 nations participate in PRONet, an organization dedicated to identifying best practices in prostate cancer care and disseminating this information to health care providers and the public. No other such pan-European coalitions of cancer patient organizations were identified.

A strong European orphan disease organization (EURORDIS) participates in the European Medicines Evaluation Agency; cancers other than those causing the highest mortality are considered orphan diseases in many European countries, and EURORDIS represents patient views on access to anti-cancer agents that are considered orphan drugs.







# Survivor Issues and Expressed Needs

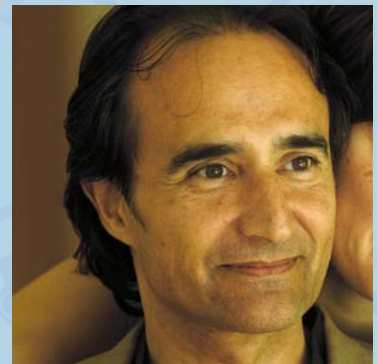
The cancer survivors, advocates, and others who testified in Lisbon identified five major areas in which specific needs were cited: (1) access to care, (2) information, (3) the transition from active cancer treatment back to daily living activities, (4) the social stigma of cancer, and (5) professional education needs.

## Access to Care

Speakers indicated that although care is guaranteed at no cost in most European countries, treatment options often are limited, and patients may be given no choice at all. Waiting lists can be long for diagnostic testing, surgery, and other cancer-related treatment. Referral to support groups or other supportive care is inconsistent, and these services are scarce or non-existent in some countries.

For example, a German athlete waited a month for surgery to remove a malignant brain tumor. A Danish prostate cancer survivor stated that he was diagnosed in August 2000, but was unable to begin treatment until late December because of waiting lists. By that time, his cancer had spread to his spleen and bladder. His family had tried unsuccessfully to arrange earlier treatment at a private hospital. The speaker was treated with radiation therapy and hormone treatment, and his cancer appears to be under control. He noted, however, that of the approximately 1,800 new prostate cancer patients diagnosed annually in Denmark, only ten percent are offered curative treatment. The speaker has since become active in a prostate cancer awareness organization in his country.

Waiting lists, particularly for cancer treatment, are a serious problem in Portugal; in addition, cancer screening, psychosocial support, and palliative care services are nearly non-existent. The Portuguese Institute of Oncology is attempting to implement a multidisciplinary approach to cancer care, but limited political support for implementing the existing national cancer plan is a barrier.



“I was also always...looking for the right ward, for the room in which to undergo the CAT scan... for scintigraphy, for x-rays, bronchoscopy, et cetera. And all of this without synergy, and often, I myself have had to explain to the doctor on duty what was wrong with me...Everything is in my hands: my fight against cancer, my fight against the treatment by the medical professionals, and lastly, my fight against the system of how patients are followed up.”

*Antonio Toscano, 47, lung cancer survivor diagnosed 2002, Italy*

An Italian surgeon acknowledged that the experience of a lung cancer survivor, described at the meeting, exemplified major problems in the Italian health care system, including lack of information, poor access to quality care, and lack of psychosocial support.

### **Private Insurance and Personal Contacts to Facilitate Access**

Speakers stated that patients often need additional private insurance to obtain timely care, more treatment options, continuity of care (seeing the same doctor or other provider), and better accommodations in the hospital. A survivor from Northern Ireland indicated that having private insurance would not have made any difference in the surgery, other treatment, and follow-up visit schedule she was provided. However, it did enable her to receive annual check-ups after the conclusion of the follow-up period designated by the national health system, to see the same doctors in a private hospital, and to have longer consultations with her physicians. She further noted that because she had private insurance, possible side effects of her treatment (e.g., a neurological problem) have been followed up on promptly and thoroughly. Another speaker stated that in the Republic of Ireland, patients can purchase private insurance to supplement the national plan, but that a cancer patient (or person with other designated diseases) with long-term medical needs can apply for a medical card that guarantees access to all forms of care at no cost. Whether or not a patient has private insurance, no one is billed for end of life care.

In the Netherlands, all citizens have access to standard medical care, but there are long waiting lists and restricted access for expensive treatments. For this reason, more than a third of the population has supplemental private insurance. In addition to private insurance coverage, out-of-pocket payments to doctors and hospitals are a common way of sidestepping waiting lists in some countries. Both strategies favor those with resources and undermine the intended equity of the state-run systems.

Having a personal contact within the system or an acquaintance with medical contacts also was cited as a great advantage for receiving prompt treatment. For example, it was only through an acquaintance that a lung cancer survivor from Italy was able to obtain an appointment with a prominent lung surgeon; though it was decided that his tumor was inoperable without presurgical chemotherapy, he was quickly taken into the system and received treatment. When he developed symptoms of concern following his surgery, he again had to prevail upon personal contacts

to help him get a recommended PET scan in a timely manner instead of waiting 45 to 60 days.

In another case, a young adult lymphoma survivor from the Republic of Ireland who suffered treatment-related bone tissue death (avascular necrosis) in both hips was told he would need hip replacements by age 50. Despite increasing pain, he received no medication for his condition until, due to a chance meeting with one of the physicians who treated him previously, he was referred to an orthopedic surgeon from whom he has received acceptable, though not complete, pain control.

### **Support Groups and Supportive Services**

As noted above, support groups and supportive services in some countries are only available through cancer charities or fledgling advocacy groups, though the number and scope of such services appears to be expanding. Support services for family members or caregivers appear to be extremely scarce.

### **Complementary and Alternative Treatments**

The limited testimony received on this topic suggests that the acceptability and availability of complementary and alternative treatments also varies considerably among nations. According to a Swiss breast cancer survivor, the country has a strong tradition and high tolerance level by the mainstream for alternative treatments, though providers may not communicate well with each other. Some patients still are reluctant to tell their mainstream providers about alternative therapies they are taking for fear of losing the physicians' support.

### **Information Needs**

Speakers, particularly those who were longer-term survivors, noted that when they were diagnosed, they were given little or no information about their disease. Further, there were no readily available information resources, and no Internet, now often the most relied upon information source by both newly diagnosed and longer-term survivors.

### **Cancer, Cancer Prevention, and Healthy Lifestyle Information**

Public education and the availability of information about cancer and its prevention appear to be uneven across Europe. Although the European Code Against Cancer, which spells out screening and prevention measures, has been in existence since



“The strain on my wife, in particular, was enormous and she had nowhere to turn.”

*Ambrose Heaney, 46, non-Hodgkin's lymphoma survivor diagnosed 1983 and 1984, the Republic of Ireland*



“My primary physician said to me, ‘Look, Claudia, I think it is fine that you are doing these [complementary] treatments. I cannot talk to these people though; they use words that I do not understand.’ So I tended to be the go-between. That was very difficult.”

*Claudia Roemers, 44, breast cancer survivor diagnosed 1997, Switzerland*

“Our main problem in the health services is the waiting lists for diagnosis and treatment. And the doctor-patient communication is sometimes a problem; we are trying to fight that. And I think the worst problem is the GP-specialist communication problem, as well as...between doctors working in different hospitals.”

*Luis d'Orey Manoel, Portuguese Institute of Oncology, Portugal*

the 1980s, the limited testimony received suggests that its recommendations may not be reaching the European public with any uniformity. A speaker from a cancer charity in the United Kingdom stated that patients increasingly are questioning the scarcity of information and services about cancer prevention. A speaker from Italy indicated that almost no cancer information is transmitted through the media; however, work is underway through a special grant to improve public awareness of the importance of early detection of breast cancer.

Activities in this area also are underway in other nations in response to patient and public demand. In the United Kingdom, the nutritionist at a regional cancer center has developed a well-received program that educates patients about healthy diets. A Swiss speaker who was referred by her oncologist to a dietitian indicated that there is such an abundance of complementary health-related regimens and treatments that it is difficult to decide which may be the most efficacious. She also noted that in Switzerland, where there are more computers per capita than in any other nation in the world, information seeking via online and other anonymous means (e.g., special telephone information lines) is preferred over counseling, education sessions, or other more public avenues.

Under the German national and private insurance systems, cancer screening is fully covered, and according to one speaker, patients are routinely referred by the general practitioner for testing. However, another speaker suggested that general practitioners and internists in Germany do not address women's cancer issues, which are considered the sole purview of the gynecologist. Thus, when older women cease going to the gynecologist, they are unlikely to be educated about the importance of early detection or referred for screening at a time when their risk for gynecologic and breast cancers is rising.

### **Information about Diagnosis, Prognosis, and Treatment Options**

An Irish survivor noted that it was some time before he realized that his diagnosis of non-Hodgkin's lymphoma meant he had cancer; none of his doctors informed him of this fact. Similarly, a breast cancer survivor from Spain stated that she did not really understand that she had cancer until after her lumpectomy.

Upon learning she had cancer, another speaker from Northern Ireland obtained information about her treatment not from her physicians, but from the local cancer charity; however, five years later, when she had a recurrence, she was gratified to have more

open communication from her new doctor, the care of a multi-disciplinary team, and the support of a breast care nurse.

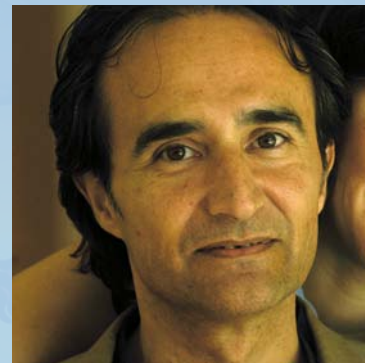
A survivor from the Netherlands stated that doctors are required by law to inform patients of their diagnosis, but that it is difficult for patients to judge the quality of their cancer treatment, in part because of insufficient communication and miscommunication by physicians. An Italian lung cancer survivor related his frustration at the minimal information about his condition provided by his physicians; he was expected to trust in them blindly, and was discouraged from seeking information on his own. It was not until his third appointment that he was given a booklet that answered some of his questions and acknowledged his anxieties, although he subsequently discovered that the scenarios described in the booklet understated the realities of his cancer treatment.

A speaker from Switzerland indicated that while there is no shortage of specialists, no central resource exists for finding their names and locations. In addition, she indicated that she was faced with widely varied medical opinions about her case that made informed decision-making difficult.

### **Information about Psychosocial and Other Supportive Care**

Several of the survivors who testified indicated that they were not given information about or referred to a support group or psychological counseling, nor were even asked if this was a service they needed. In some cases, no such services existed, particularly for longer-term survivors; in others, doctors were unaware of available services. It was suggested that providers may resist providing information on support services because they feel as if “veteran” survivors and advocates are encroaching on their practice. Others suggested that providers make decisions as to whether a support group is right for the patient, rather than letting the patient decide for him/herself. According to the testimony, lack of information about support services remains a significant issue in many nations.

Lack of psychosocial support information was cited as a particular problem in Portugal, but a speaker stated that at the hospital in which she works, attempts now are being made to integrate psychosocial support information and services into all phases of treatment and follow-up care. This approach is better established in the Netherlands, where both inpatients and outpatients with cancer meet with a team comprised of a social worker, psychologist, psychiatrist, and palliative care physician immediately upon



“The information received from doctors is merely essential. When I asked for more specific information and clarification, I was sometimes politely invited to change the types of reading I was doing. The sensation of being treated as a container of one or more organs in which to intervene was always the strongest one.”

*Antonio Toscano, 47, lung cancer survivor diagnosed 2002, Italy*



“... it is so easy to do it differently: an open attitude towards questions, interest in your personal situation, a telephone number to call in case of panic. These are really experiences that help.”

*Fenna Postma-Schuit, 60, thyroid cancer survivor diagnosed 1978, the Netherlands*



“I no longer live in fear of my cancer returning but I wonder what issues its defeat has left me.”

*Ambrose Heaney, 46, non-Hodgkin's lymphoma survivor diagnosed 1983 and 1984, the Republic of Ireland*



“Some people talk about getting back to normal, but for most people with a cancer experience, the reality is a new life with cancer.”

*Judith McNeill, Macmillan Cancer Relief, Great Britain*

diagnosis. Even if the patient does not need or desire these services at that time, a contact has been established for future needs as they arise. Likewise, in Sweden, psychosocial support information and services are made available from the outset of care.

### **Information on Possible Side or Late Effects of Treatment or Disease**

Several speakers reported that they were not told about possible side effects of their treatment. A number of survivors diagnosed during their reproductive years were not informed about the possibility of early menopause and infertility until after treatment was completed. It was suggested that this still occurs in some countries.

A survivor from Germany noted that she had to search the Internet to learn that treatment for her Hodgkin's disease may have weakened her immune system and led to the development of cervical cancer, which is caused by infection with certain strains of the human papillomavirus (HPV). A breast cancer survivor stated that she was not told that lymphedema might occur as a result of her surgery. Another breast cancer survivor from Spain indicated that she received no information about possible side effects of her upcoming radiation and chemotherapy, such as the radiation burns, menopause, and near-fatal lung complications she experienced.

### **Transition from Active Treatment to Follow-up Care, Social Reintegration, and Self-reliant Living**

#### **Post-treatment Rehabilitation Needs**

Speakers emphasized the need for post-treatment rehabilitation, however, in some countries, such services are not offered or covered by national insurance. An Irish survivor treated with extensive chemotherapy indicated that he has learned to use technology (e.g., electronic calendar, e-mail, telephone messaging) to accommodate the short-term memory loss and concentration deficits (“chemo brain”) caused by his treatment, but he did not receive any assistance with the problem from health care providers. Another survivor from Norway indicated that although he lost half of his body weight during his treatment, he was not offered physical therapy. He suggested that while the follow-up care in his country is good at detecting recurrences, it does not consider other health problems the individual may have.



A speaker from the Netherlands suggested that post-treatment fatigue is under appreciated and undertreated in her country, and that more research in this area is needed. A physical and psychosocial rehabilitation program, originally developed by a patient group, now is being implemented in the comprehensive cancer centers, but private insurance support for these services has been hard to secure. In Switzerland, rehabilitation services are available, but may not be cancer-specific.

Conversely, a German brain tumor survivor indicated that he received extensive physiotherapy following his surgery, and under the national health plan, was entitled to additional physical therapy three years later to address remaining or new issues. Ireland now offers rehabilitation services in a few select hospitals.

The Swedish health system also provides rehabilitative care. Pain control and symptom management are considered part of both the treatment and rehabilitation processes. In a pioneering project in the southern part of the country, distinct but integrated units offer psychosocial support, physiotherapy, individual and group therapy, information, pain management, and palliation (including hospice, day care, home care, and education/training). Services are available to survivors and family members both during and post-treatment. The speaker noted that while survivorship *per se* is not discussed, psychosocial oncology is of increasing importance in Sweden. It is understood that rehabilitation services may be needed in different combinations and at different times from diagnosis through long-term survival and at the end of life. The project is funded by a combination of public and private resources.

A Swiss speaker indicated that psycho-oncology services are quite limited currently, but this type of care is recognized as an area of need. Palliative care for cancer also is limited and lacks a coordinated approach both philosophically and in terms of service provided by multidisciplinary teams. In Spain, there has been a major initiative to improve the quality and availability of palliative care, which is included as part of the national health plan.

## Psychosocial Support Needs

In addition to the scarcity of psychosocial support services in many European countries, particularly post-treatment, speaker testimony suggested that survivors in the same country may have very different experiences in finding psychological or psychosocial support. According to one German survivor, psychosocial support is widely available through cancer aid associations, and a variety of web sites and self-help groups are available to

“We believe that rehabilitation of cancer patients should be considered an integral part of oncological therapy...We also believe that supportive care is extremely important for outcome of therapy.”

*Mads Utke Werner, University Hospital of Lund, Sweden*



“Since my second cancer, I often have panic attacks for no reason... and sometimes I have depression... I saw myself as a survivor after my first chemotherapy, but since my second cancer—there is no relation between the two cancer types—but since my second cancer, I am always scared of a third cancer and that I do not have any time anymore.”

*Daniela Kampmann, 25, Hodgkin's lymphoma and cervical cancer survivor diagnosed 2000 and 2003, Germany*



“When I was diagnosed with cancer—I had just gotten married about a month before, and the disease became the center of the marriage, not letting us live as a normal couple who had just got married. For the following three years, my husband and I tried to deal with this situation, most of the time individually and not as a couple. The problem got bigger as time went by.... This is why I think that it is important to have support groups not only for cancer patients, but also for the families of cancer patients...”

*Ulrika Botelho Cyrne, 28, thyroid cancer survivor diagnosed 2000, Portugal*

survivors. Another survivor from Germany, however, reported that psychological help for the panic attacks and depression she has suffered related to her two cancer diagnoses has been inadequate. Family members, though supportive, have needed her to appear strong and confident and some friends were uncomfortable talking about her illness. She found little help from the cancer aid societies, self-help groups, or cancer site-specific, citizen-initiated peer support networks. She did, however, find information and assistance online from foreign cancer organizations.

A speaker from the Netherlands noted that when she was diagnosed 20 years ago, her doctors were caring, but they never inquired as to her or her family’s emotional well-being. No psychosocial support was offered and contact with fellow patients was discouraged. Today, she stated, only five percent of doctors routinely offer psychological or social support to newly diagnosed patients, despite the fact that research in the Netherlands has shown that one in three patients has long-term psychological problems, and only one in ten gets the support needed. No guidelines currently exist concerning physician communication about psychosocial needs; guidelines and patient assessment checklists are being developed but are not near completion. The speaker stated that any such guidelines would most likely be implemented by nurses, some of whom are oncology specialists. She also expressed her belief that psychosocial needs often are not discussed by physicians for economic reasons, since doing so would prolong the visit and enable the doctor to see fewer patients.

In Denmark, cancer patients can receive free psychological services as long as they request them within the first six months following diagnosis, but cancer-related depression and anxiety frequently arise well after treatment ends. Support groups exist for patients and for family members, but many patients and family members are uncomfortable participating in such groups. A nurse who also is a breast cancer survivor expressed her belief that not enough is done to support families of people with cancer, particularly children in families in which the patient did not die. She noted that during her own treatment she chose not to wear a wig; others told her children that her appearance indicated that she would die.

A Swiss survivor indicated that support groups are rare, limited to several cancer sites, and not available nationwide. In addition, there is little or no recognition of the psychological and emotional burden borne by the families of people with cancer (e.g., that cancer is a family issue). Reluctance to speak about cancer, combined with a strong work ethic, prevents many Swiss family

members and patients from asking for help. A survivor from Portugal likewise emphasized the need for support services for family members, and for survivor support groups that are not site-specific. She also noted the severe strain on her marriage caused by her diagnosis only a month after her wedding. Female survivors from France and Spain stated that their relationships with their partner/spouse had dissolved during their treatment.

Speakers from Northern Ireland, Germany, the Netherlands, France, and Spain stated that becoming involved in cancer advocacy, support, and awareness activities had provided crucial support and been important in their transition back into society and their day-to-day lives. An Irish breast cancer survivor indicated that she works with newly diagnosed patients through the cancer charity in her area. In addition, she compiled and published the stories of 15 other survivors as a tool to give new patients hope and encouragement. Similarly, a general practitioner in the Netherlands who developed thyroid cancer subsequently authored patient information materials, led support groups at cancer centers, and became a consultant to the hospitals in her region.

In another case, a survivor from France suffering from depression first discreetly sought out a psychologist for help. Subsequently, she became aware of patient support activities in her area. With great trepidation due to the social stigma of cancer in her country, she became involved in these efforts. She has since become more open and active in her work with advocacy organizations. A survivor from Spain stated that it has only been through her volunteer work with the Spanish Association Against Cancer that she has become educated about the disease; she is gratified to provide the psychological support to other patients that was unavailable during her own cancer treatment.

### Follow-up Care Needs

Statements made by speakers suggested that follow-up care availability varies across countries and perhaps even within countries. A German brain tumor survivor who completed treatment 11 years ago indicated that he now has regular check-ups with a brain MRI every three years, but can visit his neurologist whenever he wishes. In Northern Ireland, patients may be scheduled for quarterly follow-up hospital visits for the first two years, biannual visits in the following three years, and annual visits at five years from diagnosis. The annual visits currently continue through the tenth year, but the national health care system is now considering ceasing follow-up visits after five years.



“An essential part of my recovery and transition from cancer patient to cancer survivor has been due to the opportunities afforded me by the charity when I wanted to put something back. I have become involved with the Patient Action Group...”

*Elvira Lowe, 64, breast cancer survivor diagnosed 1990 and 1995, Northern Ireland*



“[Mathilde’s brother] Jonathan is six years old today. He is a happy guy but...you can [see] that he had a rough time in childhood. He is today seeing a child psychologist to talk about the rough time he experienced with Mathilde.”

*Annica Andersson, mother of Mathilde, 8, childhood leukemia survivor diagnosed*

“We need to recognize the fact that the follow-up issues and follow-up care, I think, are subtly different depending on whether you are diagnosed as having a cancer in the pediatric age group, as an adolescent, as a young adult, or as someone somewhat older in life.”

*Donal Hollywood, Trinity College, the Republic of Ireland*



“I do not consider myself to be a cancer survivor... I consider myself to be a person who has had cancer and... human. That is what I consider myself... I think the word ‘survivor’ separates us from others.”

*Claudia Roemers, 44, breast cancer survivor diagnosed 1997, Switzerland*

According to a speaker, the primary care physician is the provider of routine care for cancer survivors in Portugal. In Switzerland, follow-up care in the German-speaking region is coordinated principally through the primary care physician after the hospital tumor board decides the patient no longer needs to see an oncologist frequently (i.e., beyond a specified post-treatment follow-up period). The primary care doctor maintains contact with the patient’s oncologists. In the rural areas of this region, physicians know the families well and assist in decision-making, including with regard to end of life care. However, cost-related pressures on the Swiss national insurance system are causing some services to be limited; people now may need supplemental insurance to obtain all of the services they require. A survivor from Italy stated that following his treatment, his abandonment by the medical system was total; he was left on his own to fight through waiting lists to obtain necessary prescriptions and appointments for follow-up tests.

As indicated above, private insurance often is necessary to ensure one’s ability to see the same health care providers both during and following treatment. A need was expressed for specialized long-term survivor clinics or services. Speakers suggested that these services should be provided in a separate department within the hospital or a separate clinic by providers experienced in addressing survivorship issues.

A speaker explained that currently, long-term follow-up care for European cancer survivors may be impeded by legal issues surrounding patients’ access to their medical records and retaining their long-term care when they move from one country to another. In addition, a lack of standard regulations exists on the exchange of patient information among health providers in different countries.

## **Stigma of Cancer in Society, Employment, and Education**

The current and former cancer patients, researchers, caregivers, and others who provided testimony to the Panel spoke about the meaning of survivorship, social attitudes about cancer, and insurance, employment, and educational issues, both from their individual experiences and as participants in the cultures and society of their respective nations. Their compelling testimony made clear that the stigma of having cancer in European societies remains far greater than it is in most parts of the United States today, permeating virtually every aspect of the cancer experience.

## Survivors and Survivorship in Europe

The meaning and acceptance of both the concept of survivorship and the term, 'survivor,' varies considerably across Europe. In some languages (e.g., German, Dutch), no word for 'survivor' exists except as in the case of the survivor of an accident or violent crime. Some speakers at the meeting identified with the concept of survivorship beginning at the day of diagnosis; others only felt like survivors after they had been told they were cured. One survivor felt that the term separates more than it binds, setting cancer apart as something worse or more deadly than other illnesses.

A speaker from Spain said that she did not feel like a survivor of cancer, but she did feel like a survivor of cancer treatment. She felt she was a "fighter" and noted the dramatic change in her outlook on life since having the disease—she takes every possible opportunity to experience and learn new things. Several other survivor speakers likewise described significant changes in their approach to life after cancer.

## Social Attitudes about Cancer

Relative to the United States, it is uncommon in most European countries to wear ribbons or logo pins indicating that one is a cancer survivor or supporter of a cancer organization. Likewise, it is still uncommon for public figures who have had cancer to speak out about the disease. This appears to be changing in some countries.

In Northern Ireland, cancer (particularly breast cancer) has come to be discussed much more openly than it was a decade ago. Much of this change can be attributed to media attention. In addition, educational programs for teenagers have been implemented to provide information on cancer and cancer prevention, and to dispel any remaining stigma and fear attached to the disease.

By contrast, a speaker stated the common Norwegian view that "you are supposed to be well when you are well and if you get cancer you are supposed to die...what people tell you is everyone they have heard of, they have died." But if one is spared death, he or she is expected to return to normal functioning without any additional assistance. Cancer also is equated with death by the majority of the Portuguese public, according to a survivor from that country.



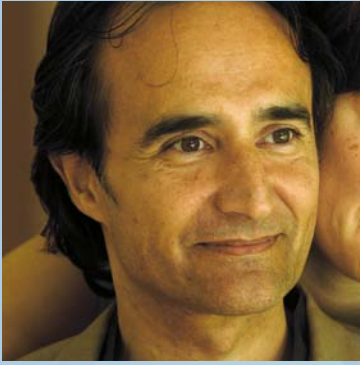
“Do I still have cancer? Well, I do not think of myself as having cancer but neither do I think that I’m cured....Am I a survivor? Yes, most definitely.”

*Elvira Lowe, 64, breast cancer survivor diagnosed 1990 and 1995, Northern Ireland*



“I do not plan things. I do not know what I am going to do this summer; I am just here. Tomorrow, I do not know where I will be. They call me: ‘Pilar, do you want to go?’ ‘Yes, I’ll go,’—even before they finish the sentence....Now I am here; maybe in five minutes I am not. And that is my thought.”

*Pilar Suarez, 52, breast cancer survivor diagnosed 1997, Spain*



“Unfortunately in my country, there is no open discussion of the problem of cancer apart from some TV commercials inviting people to buy a bonsai tree, for example, as a donation. Talking about cancer is extremely difficult. I definitely sensed a deep cultural and informational void.”

*Antonio Toscano, lung cancer survivor diagnosed 2002, Italy*



“I do know that cancer is a chronic disease, but no physicians nor media can express this reality in France. So there is a real difference in speaking about cancer through the medical practices, through society feelings, through the media, and through patient suffering.”

*Marie-Agnès Moulin, 50, breast cancer survivor diagnosed 1996, France*

A lung cancer survivor from Italy stated that in conversation, many people prefer to say ‘tumor’ rather than ‘cancer,’ which seems to engender more fear. However, another speaker from Italy reported that with funding from the U.S. Susan G. Komen Foundation, a group in Italy is working to stimulate change in this attitude, at least with regard to breast cancer. Breast cancer postage stamps have been issued, famous figures have been recruited to promote early detection, politicians are discussing cancer publicly, and a five kilometer “Race for the Cure” has been run four times in Rome. Free mammography and needed treatment have been provided to immigrant women who do not participate in the national health system. These have been major steps forward in cancer awareness and acceptance in Italy.

Cancer also remains a taboo subject in much of French society; only recently has the country attempted to make the disease a more open subject and developed a national cancer plan. Cancer survivors in France are beginning to make themselves more visible and demand full participation in social life.

The situation was reported to be similar in Spain, where cancer is not discussed openly and many patients hesitate to reveal they have had the disease. Even family members and friends may refer to the patient’s ‘problem,’ to avoid saying the word ‘cancer.’ The speaker indicated that now that she is several years past the conclusion of her treatment, she does not mention that she has had cancer, and many of her acquaintances are unaware of her cancer history.

In Germany, cancer survivors have extensive legal and social accommodations, but one survivor indicated that people with cancer may face public pity as they often are viewed as less than fully capable. A young female Hodgkin’s lymphoma and cervical cancer survivor from Germany encountered shocked reactions and occasional disgust when she revealed that she had cancer. Further, her experience was that people in Germany in general are uncomfortable talking about cancer.

According to a speaker, the Swiss are reluctant to discuss private matters with neighbors or people they know only superficially, and a cultural stoicism (less prevalent in the younger generations) dictates that life’s burdens are to be carried with grace. Some still see cancer as a death sentence, but attitudes are changing as more information becomes available through the media, brochures, and lectures. Some cancer survivors hesitate to reveal they have cancer because they do not want to be viewed as different, weak, or disabled. The speaker, a physical therapist, considered specializing in oncology-related physical therapy, but decided against promoting her practice as such because

patients might avoid her care for fear their cancer history might be revealed. Despite these cultural reservations about discussing cancer, the speaker indicated that she discussed her own disease openly and that friends and others were always available to help her, usually without being asked.

## Insurance Issues

Limited testimony was received on the impact of a cancer history on access to insurance in various European nations, but fewer problems were reported with regard to health or disability coverage compared with life insurance issues. In Germany, people with a cancer history cannot be charged higher insurance rates. A survivor from Switzerland, where the health insurance system is based on private coverage, explained that insurers are not allowed to cancel a policy because the insured develops an illness. However, she was denied a new insurance policy for self-employed persons that would cover loss of income for the first two years after diagnosis. As a result, she had to retain her old policy, but at a substantially increased premium.

As the adjacent survivor statements attest, lack of life insurance can have significant financial ramifications for people with a cancer history.

## Employment Concerns

A speaker from Denmark indicated that he was able to speak openly about his cancer at work, and that his employer offered him the use of taxis, other company resources, and economic assistance if needed. An Irish survivor noted that his employer had been very understanding and accommodating while he was in treatment and that he felt a great obligation to get back to work and prove both to his employer and himself that he was “normal” again.

In Germany, it is illegal to discriminate against a person with a cancer history. Survivors with qualifications equal to other applicants must at least be granted an interview and actually are to be given preference in hiring. But adherence to the law can be uneven, and the speaker suggested that employment discrimination lawsuits are uncommon. One German survivor lost her job because she had had cancer twice in two years; her employer said she was absent too often due to her treatment and rehabilitation.

In the Netherlands, employers are supportive of employees diagnosed with cancer, but if survivors have a recurrence or longstanding fatigue, they may be forced to give up their job.



“You cannot get life insurance and I understand that I will not get any money if I get cancer again, but I do not understand why I cannot have an insurance that gives my family money if I die in traffic.”

*Steinar Krey Voll, 23, testicular cancer survivor diagnosed 1996, Norway*



“...in Portugal, in order to buy a house, to get a mortgage, you have to have life insurance, and you have to have health insurance. But obviously, if you are ill, in order to get this credit, to get life insurance, you cannot, because it is denied to you.”

*Ulrika Botelho Cyrne, 28, thyroid cancer survivor diagnosed 2000, Portugal*



“Although the law says you cannot be discriminated against, in reality, you face the weird kind of discrimination of public pity... People would not openly state that you are, in their view, less capable, but you would still feel them thinking, ‘Hey, you had cancer; you cannot do that job even if you have come back.’”

*Dirk Schmidt, 34, brain cancer survivor diagnosed 1991, Germany*

In such cases, survivors must rely on their government-paid disability benefits. Currently, political pressure is pushing people to either work full-time or go back to unemployment benefits. Little is known about discrimination in hiring in the Netherlands; a law prohibits employers from asking a candidate’s medical status, but it is not clear to what extent the law is followed.

Due to multiple surgeries, a French breast cancer survivor reported that she was unable to work consistently for three years and finally was replaced by another worker. She negotiated an agreement with her employer that enabled her to have a mentor and training to find a new job. Ironically, the mentor died of cancer a few months later, and was not replaced. Appeals for help from the government were not successful. The survivor, then 45 years old, sought a bank loan to start a marketing business and buy an apartment in which to live and work. Because of her medical history and unmarried status, she was denied.

### **Educational Issues**

A young adult Norwegian survivor of testicular cancer affected by short-term memory and concentration difficulties indicated that while he is an excellent student, his treatment-related disability prevents him from performing well on oral examinations. He provided a letter from his doctor explaining the situation, and the school indicated that it would restructure the examination to accommodate him, but has not done so. As a result, he has had to repeat courses two years in a row. Other testimony at the meeting did not indicate whether his experience was typical of Norway or of other European countries.

### **Professional Education Needs**

Several survivors and health professionals who testified underscored the need to educate general practitioners, oncologists, and nurses about the needs of cancer patients/survivors. Specifically, speakers noted the need to educate health professionals about the importance of information sharing, both with the patient and with other health professionals. According to speakers, most health professionals treating people with cancer are unaware of, and therefore seldom make referrals to, available psychosocial or other support services. In some cases cited, physicians believed such services were of no benefit or were unnecessary.

Some survivor speakers stated that they were not informed of possible side and late effects of their cancer treatment. While in some cases this may have been an information sharing issue,



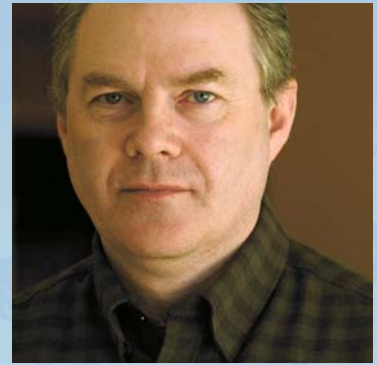
some speakers suggested that the provider did not know that such after-effects of treatment might occur, or felt that these effects were relatively unimportant if the patient was alive.

Speakers indicated that because general practitioners in many countries are unaware of possible late effects of cancer treatment, they are unlikely to recognize that symptoms presented by patients may be related to their cancer history. Side effects such as “chemo brain” tend to be discounted, though awareness of the condition may be growing in some countries.

It was further suggested that health care providers in many countries did not know the appropriate treatment options for specific cancers. Treatment guidelines, speakers stated, are needed to improve the quality and consistency of cancer care.

In Italy, all health care providers must now participate in pain management training as part of their continuing medical education. In addition, grant funding is being used to educate nurses and general practitioners in Italy about the needs of breast cancer survivors; 7,000 providers have been trained to date.

Noting the importance of doctor-patient communication on patients’ quality of life, a speaker from the Netherlands reported that doctors receive training in communication skills as part of their basic medical education, but further training in this area is not required of specialists or as part of continuing medical education. She suggested that the medical and scientific societies should take more responsibility in this area. In Sweden, however, oncology residents receive a one-year course in communication, and all oncologists now must take three years of psychotherapeutic training.



“I now have no more appointments with the hospital. The regular hospital appointments with an oncologist are too rushed with current patients to bother with long-term survivorship issues and if I go to a GP, I am way out of his league.”

*Ambrose Heaney, 46, non-Hodgkin's lymphoma survivor diagnosed 1983 and 1984, the Republic of Ireland*

“We believe that we need more specific education for health professionals and patients and a better trained workforce that can address problems faced by cancer survivors.”

*Odd Sørreide, Norwegian Cancer Society, Norway*



# Practices and Programs with Potential for Application or Adaptation in the U.S. Health Care System

In the testimony provided to the Panel, and in additional information gathered prior to and following the meeting, a number of health financing and programming mechanisms were described that could have possible application, perhaps with modification, in the health care system of the United States:

- European countries require all citizens to have insurance, at a minimum national health plan participation, which typically is funded through general tax revenues. Citizens in many countries have the option of purchasing additional private insurance to obtain complementary or other additional services, private hospital rooms, and greater continuity of care.
- Cancer patients in Europe can travel to other countries to receive care that is not available in their home country. A “health passport” (form E112) is signed by the home country provider and the provider in the country in which care would be provided; there is no cost to the patient. Travel, lodging, and incidental costs for the patient and, where necessary, an accompanying relative are paid by the home country’s regional health board or equivalent agency.
- Sweden includes rehabilitation as a standard part of oncology treatment and recognizes that these services may be needed in different combinations and at different times both during and after treatment.
- In addition to psychosocial support provided from the beginning of inpatient cancer care, the Netherlands has added integrated psychosocial programs into outpatient care for cancer patients. Services begin a year after a patient’s last treatment and last for three to six months. There is no cost to the patient.
- In Germany, cancer survivors are given a disability identification card that entitles them to free public transportation if the individual is unable to drive, preference in hiring when qualifications are equal to other candidates, and protection from increases in insurance rates. A speaker noted, however, that although cancer survivors are protected from employment or legal discrimination, social stigma remains.
- In Sweden, the national insurance plan covers patient and family expenses related to travel to treatment for pediatric cancer. Family members are housed for up to a month in adjoining special rooms while a pediatric patient is receiving cancer treatment away from home. The only cost is for food provided to the adults.
- In Northern Ireland, a few hospitals have established a six-week post-treatment rehabilitation program for breast cancer patients to help them transition from the treatment phase to life after cancer.
- In Denmark, because hospice services are scarce, family caregivers are paid by the community to care for family members with cancer who are dying. They are assisted by community nurses.



# Conclusion

Participants at this meeting raised a broad range of issues, many of which warrant further investigation as they apply to cancer survivors and health care systems both in Europe and the United States. The issues and observations described in this document have been included with those from the Panel's four U.S. meetings on survivorship issues in consideration of recommendations for improving quality of care and quality of life for people living with a cancer history.

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# Appendix

## Living Beyond Cancer: A European Dialogue

May 27–28, 2003, Lisbon, Portugal

### Agenda

#### Tuesday, May 27, 2003

**9:00 Welcome/Opening Remarks**

Dr. LaSalle D. Leffall, Jr.  
*Chairman, President's Cancer Panel*

**9:10 National Cancer Institute  
Director's Report**

Dr. Andrew C. von Eschenbach  
*Director, National Cancer Institute*

#### Surviving Cancer—An Overview

**9:20 Cancer Control in Europe**

Dr. Peter Boyle  
*Director, Division of Epidemiology  
and Biostatistics, European Institute  
of Oncology*

**9:40 European Survivor Populations**

- Mr. Michel P. Coleman  
*Head of the Cancer and Public Health  
Unit, London School of Hygiene and  
Tropical Medicine*
- Dr. Milena Sant  
*Senior Researcher, Epidemiology Unit,  
Istituto Nazionale per lo Studio e la Cura  
dei Tumori*

- Mr. Riccardo Capocaccia  
*Department of Epidemiology and  
Biostatistics, Istituto Superiore di Sanità*

- Dr. Gemma Gatta  
*Medical Doctor, Istituto Nazionale per  
lo Studio e la Cura dei Tumori*

**10:40 Question and Answer Session**

**11:00 Morning Break**

**11:10 U.S. Concept of Survivorship**

Dr. Julia Rowland  
*Director, Office of Cancer Survivorship, NCI*

**11:30 European Approach to Quality  
of Life Issues**

Dr. Andrew Bottomley  
*Coordinator, Quality of Life Unit,  
European Organisation for Research  
and Treatment of Cancer*

**11:50 Question and Answer Session**

**12:10 Lunch Break**

## **Living Beyond Cancer—Survivorship Needs Throughout Life**

### **1:30 Stories of Cancer Survivorship**

- Ms. Elvira Lowe  
*Breast Cancer Survivor and Advocate, Northern Ireland*
- Mr. Ambrose Heaney  
*Chairperson, BMT Support Group, and Non-Hodgkin's Lymphoma Survivor, The Republic of Ireland*

### **1:50 Question and Answer Session**

### **2:00 Stories of Cancer Survivorship *continued***

- Mr. Jørgen Petersen  
*Prostate Cancer Survivor, Denmark*
- Mr. Steinar Krey Voll  
*Testicular Cancer Survivor, Norway*
- Ms. Annica Andersson  
*Mother of Leukemia Survivor, Sweden*

### **2:30 Question and Answer Session**

### **2:45 Afternoon Break**

### **3:00 Stories of Cancer Survivorship *continued***

- Mr. Dirk Schmidt  
*Brain Cancer Survivor, Germany*
- Ms. Daniela Kampmann  
*Hodgkin's Lymphoma and Cervical Cancer Survivor, Germany*
- Dr. Fenna Postma-Schuit  
*Thyroid Cancer Survivor, The Netherlands*
- Ms. Claudia Rodemers  
*Breast Cancer Survivor, Switzerland*

### **3:45 Question and Answer Session**

### **4:00 Stories of Cancer Survivorship *continued***

- Mr. Antonio Toscano  
*Lung Cancer Survivor, Italy*
- Ms. Marie-Agnès Moulin  
*Breast Cancer Survivor, France*
- Ms. Ulrika Botelho Cyrne  
*Thyroid Cancer Survivor, Portugal*
- Ms. Pilar Suarez  
*Vice President, Madrid Delegation, Spanish Association Against Cancer, and Breast Cancer Survivor, Spain*

### **4:45 Question and Answer Session**

### **5:00 Closing Remarks**

Dr. LaSalle D. Leffall, Jr.  
*Chairman, President's Cancer Panel*

### **5:15 Adjournment, Day 1**

## Wednesday, May 28, 2003

### 8:00 Remarks

Dr. LaSalle D. Leffall, Jr.  
*Chairman, President's Cancer Panel*

### Care Beyond Cancer—Addressing Survivorship Needs

#### 8:15 Addressing Survivorship Needs

- Dr. Patrick G. Johnston  
*Director, Cancer Research Centre, Belfast City Hospital, Northern Ireland*
- Ms. Ruth Campbell  
*Head of Care Services, Ulster Cancer Foundation, Northern Ireland*
- Dr. Judith McNeill  
*Head of Community Links, Macmillan Cancer Relief, United Kingdom*
- Dr. Donal Hollywood  
*Marie Curie Professor of Clinical Oncology, Trinity College, Dublin, The Republic of Ireland*

#### 9:00 Question and Answer Session

#### 9:15 Addressing Survivorship Needs *continued*

- Ms. Karen Lisa Hilsted  
*Cancer Care Nurse and Breast Cancer Survivor, Denmark*
- Dr. Odd Søreide  
*Chairman of the Board, Norwegian Cancer Society, Norway*
- Dr. Mads Utke Werner  
*Director, Center of Oncological Rehabilitation and Palliative Care, Department of Oncology, University Hospital of Lund, Sweden*

#### 9:45 Question and Answer Session

#### 10:00 Addressing Survivorship Needs *continued*

- Ms. Julia Doherty  
*Health Care Consultant, United States, representing Germany*
- Dr. Jan Buter  
*Medical Oncologist, VU Medical Centre, The Netherlands*
- Dr. Georges Vlastos  
*Attending Physician, Geneva University Hospital, Switzerland*

#### 10:30 Question and Answer Session

#### 10:45 Break

#### 11:00 Addressing Survivorship Needs *continued*

- Dr. Riccardo Masetti  
*Associate Professor of Surgery, Catholic University of Rome, Italy*
- Dr. Luis d'Orey Manoel  
*Surgeon, Portuguese Institute of Oncology-Lisbon Center, Portugal*
- Dr. Josep M. Borràs  
*Director, Institut Català d'Oncologia, Spain*

#### 11:30 Question and Answer Session

#### 11:45 Closing Remarks

Dr. LaSalle D. Leffall, Jr.  
*Chairman, President's Cancer Panel*

#### 12:00 Adjournment

# Living Beyond Cancer: A European Dialogue

May 27–28, 2003, Lisbon, Portugal

## Participant List

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