UNITED AGAINST CANCER

Slovenian Summit
3-5 November 2006

Making Cancer a priority

CEE Cancer Patient Summit Report

EUROPEAN
CANCER
PATIENT
COALITION

Slovenian Cancer Summit

The European Cancer Patient Coalition hosted this important Summit. We invested a lot of our own resources, time and effort to make this conference happen and to ensure that as many patient groups as possible were part of it. The Summit was organised by the ECPC Brussels office, headed by Hildrun Sundseth with support from her team.

For more information please visit the Summit website where conference material and presentations can be found.

www.unitedagainstcancer.eu

Acknowledgements

We wish to thank the following sponsors who have supported the Summit with an unrestricted grant -

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Report

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Nothing About Us,
Without US !

About the EUROPEAN CANCER PATIENT COALITION

Established in 2003, ECPC is the voice of the European cancer patient community, uniquely representing the interests of all cancer patient groups from the major to the rarer cancers. The Coalition is committed to improving cancer prevention, screening, early diagnosis and best treatment, reducing disparity and inequity across the EU. ECPC seeks to ensure that policy makers, politicians, health professionals, the media, and the general public recognize the serious nature of cancer and the need for concerted action to reduce unnecessary death and suffering.

ECPC Objectives

- To ensure that the rights of cancer patients are upheld and enforced.
- To increase cancer patients' representation and influence at the highest level of decision making, nationally and Europe-wide, in all areas that affect their health.
- To empower patients to become true partners in the healthcare system.
- To obtain for patients certain and timely access to appropriate and accurate prevention, medical diagnosis, treatment and care, including psycho-social care.
- To encourage population-based screening programmes according to European quality guidelines.
- To promote the advance of cancer research, to include all applicable information on well-designed clinical trials and where possible the right to enroll in them.
- To call for improved multi-disciplinary training of health professionals.

For more information visit www.ecpc-online.org.

ECPC is grateful for the patronage of

THE PRESIDENT OF SLOVENIA
THE MINISTRY OF HEALTH *and*
JANEZ POTOČNIK, EUROPEAN COMMISSIONER FOR RESEARCH.

Our warm thanks go to

ALOJZ PETERLE, MEMBER OF THE EUROPEAN PARLIAMENT

who has been our inspiration for the Summit.

About MAC – MEPs Against Cancer

MAC is an all-party informal group of Members of the European Parliament committed to promoting action on cancer as an EU priority and harnessing European health policy to that end.

MAC objectives

Cancer rates are set to increase dramatically in part due to Europe's ageing population. MAC supports citizens and cancer patients by

- Sending a strong political signal that immediate and concerted action is needed to reduce cancer rates and improve cancer outcomes across Europe.
- Harnessing Community policies and instruments such as the EU Health Strategy and Programmes, the Framework Research Programmes to the fight against cancer. We want to prevent those cancers that can be prevented and give patients the best chance with early detection and best quality of treatment and care.
- Promoting publicity and information campaigns around the European Code against Cancer.
- Ensuring that best practice is shared across the EU and gaps that exist in prevention, diagnosis, treatment and care between and within Member States are eradicated.
- Insisting that the Council Recommendation on Cancer Screening is implemented at national level and good practice guidelines are developed.
- Promoting cancer research.

Hildrun Sundseth, Head of EU Policy, European Cancer Patient Coalition, Alojz Peterle, MEP and Lynn Faulds Wood, President, European Cancer Patient Coalition.

For more information visit www.mepsagainstcancer.org.

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Dear Friends and Supporters,

I want to share with you my excitement and satisfaction at the success of the first Slovenian Cancer Summit for the countries of Central, Eastern and South Eastern Europe. As this report shows, our meeting in Ljubljana was a significant milestone - forcefully broadcasting the urgent need to fight cancer across the European Union, especially in the new Member States and future accession countries where so much needs to be done.
Our aim was an appeal to all Europeans - to health policy makers, politicians, patient advocacy groups, the professional oncology community and to the general public - to put their collective energy and knowledge behind the battle against cancer.

The alarming estimate that one in three of our people will be diagnosed with cancer during their lifetime unquestionably calls for a new impetus to reduce Europe's cancer rates and brighten the outlook for us all. It has been shown that around 50 per cent of cancer can be prevented through robust programmes such as tobacco control, healthier lifestyles, population-based screening and early diagnosis. If we apply current knowledge NOW we can forestall a future cancer epidemic in Europe as our citizens age. Nor must we forget patients for whom prevention comes too late: for we need to invest in research, and to organise our healthcare systems efficiently to provide the best treatment and care.

Our Summit examined how best to tackle the existing inequalities in cancer outcomes; how to reduce the gap in prevention, treatment and survival; and what we can learn from each other. We based our discussions on the Warsaw Declaration of 2005, the policy tool which has been widely endorsed. I am most grateful to my own government, to the Slovenian Ministry of Health and to the European Commissioner Janez Potocnik, who gave their support unstintingly and helped to make the Summit such an important policy event. All who took part will feel both privileged and satisfied if it duly leads to the humanitarian results we seek.

As a survivor of cancer myself, I know from personal experience how hard it is to live with - both for those directly affected and for those close to them. Since I was elected to the European Parliament, I have committed myself to support people across the European Union in their struggle against the disease. Together with now 56 Members of the European Parliament we have formed a cross-party forum of MEPs Against Cancer – MAC for short.

Let us join forces against cancer at every level. Cancer control is such a complex matter that no single organisation or discipline can tackle it on its own. We need everyone's will and energy, and we need to stay on the course. The health agenda is full of urgent issues; but this disease has been with us for a long time and is too often viewed with fatalism. Therefore we need continuity and solidarity in our approach. Many cancers are now preventable; and the treatments are there which allow patients to survive. We must put those capabilities to good and immediate use.

Please help us to take the cancer agenda forward across Europe. Everyone can help in the fight. Nothing less than the health and well-being of our family, friends and neighbours is at stake.

Lojze Peterle
MEP and First Prime Minister of Slovenia

Dear Reader,

This report of the "United Against Cancer" Summit provides a useful summary of the wide-ranging and stimulating discussions. It was my pleasure to welcome delegates to the meeting in Ljubljana and to provide our Ministry's patronage. As Slovenian Minister of Health I was especially interested that the Summit highlighted the cancer gaps between Eastern and Western Europe; and we fully intend to focus on these differences during our EU Presidency in the first half of 2008. We will examine the causes of lower survival rates of cancer patients in Central and Eastern Europe.

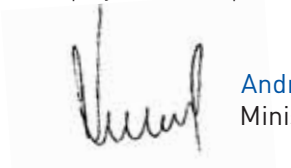
Cancer has been and remains one of the most serious issues in public health, affecting every society and healthcare system in the world. In spite of numerous activities and measures undertaken in the Member States and the European Union, the incidence of cancer and cancer mortality is growing in most European countries and according to data the burden of this disease will increase further. It is estimated that by 2010, 3 million Europeans will suffer from cancer and this disease will kill almost 2 million of them. The forecast for 2020 is even more worrying; almost 3.4 million of our European citizens will be diagnosed with cancer, with more than 2.1 million deaths. We can easily see why we need to improve the prevention and treatment of cancer to lessen the financial burden on healthcare systems and our economies and moreover the devastating personal burden that cancer patients, their family and carers carry.

Currently prevention and screening are one of our most effective weapons against the most frequent cancers. In Slovenia, as elsewhere, the most common form of cancer in men is that of the lungs. In women it is breast cancer and cervical cancer ranks in the 5th place. This is why we have introduced national screening programmes. A worrisome fact is the rise in the occurrence of colorectal carcinoma in both genders, which to a high degree may be attributed to unhealthy lifestyles such as bad diet, obesity and lack of physical exercise and smoking.

During the EU presidency, Slovenia will highlight the "Gap in Healthcare and Cancer" as a priority theme. Within this scope we will focus on the European dimension of an integrated approach to cancer management.
I believe that we will gain extensive support for further endeavours that will greatly contribute towards improvements in managing all aspects of this disease; from primary prevention, early detection and screening to effective treatment, rehabilitation and palliative care. At the same time we will concentrate on joint approaches, harmonised activities and measures at EU level to improve the conditions for reducing the risk of cancer diseases.

I firmly believe in the added value of cooperation at the level of the European Union and in the possibility of improved cancer control and management.

Finally, let me say that we are aware of the invaluable cooperation of civil society, both in raising awareness in the general public and responding to patient's need for support. As such you patient groups are an important partner to the State and to local communities. And the individual cancer patient can take heart from your example and support. Slovenia will strive to promote solidarity, equity and the equal availability of cancer treatment during our presidency.



Andrej Bručan, MD
Minister of Health, Slovenia

LJUBLJANA

The European Cancer Patient Coalition (ECPC) organised a landmark meeting in November 2006 to buttress Europe's flagging fight against cancer. The Slovenian Cancer Summit took place over three days in Ljubljana with the direct encouragement of the President of the Slovenian Republic, Janez Drnovšek, and under the patronage of the Slovenian Ministry of Health and the European Commissioner for Science and Research, Janez Potočnik.

With **Alojz Peterle,** founding member and co-chair of **MEPs Against Cancer (MAC)**, its moving spirit, and ECPC's resolve to bring a truly patient-centred focus, the Summit drew together more than 160 delegates including government health officials, oncological and public health researchers, and the patient community.

Slovenia will hold the EU Presidency in the first half of 2008; and here was a fine opportunity for all interested parties to provide early input to the EU health agenda. The ECPC umbrella covers all cancer patient groups across Europe, from the big diseases such as lung, breast, colon and prostate to the rarer types. Thus patients were squarely in the centre of policy formulation and action - no longer merely standing on the sidelines or being at the receiving end of other people's decisions. Their advocates were having their say alongside national and European politicians, medical experts involved in cancer prevention and screening programmes, and the administrators of some of Europe's most comprehensive cancer projects. In short, delegates representing 20 countries stretching from the Baltic to Eastern and Western European states, including candidate countries waiting at the European Union's doors, united in an effort to elaborate a common cancer strategy.

Despite their diverse background and nationality, and although many meeting one another for the first time, Summit delegates quickly agreed to tackle jointly the very complex and immensely burdensome range of cancers that exist and to mobilise all society behind a common effort of solidarity.

The Summit's programme included

- a Political Roundtable,
- the United against Cancer Conference and, finally,
- a Cancer Rally to alert and involve local groups and the general public in the campaign.

Major issues – improving cancer control and reducing Europe's East-West gap

Speakers produced alarming figures showing the higher cancer mortality rates in countries in Central and Eastern Europe [CEE] relative to the rest of the EU, and explored several key issues:

- **How, in view of the growing ageing population, the numbers of people developing cancer could be reduced more effectively;**
- **How limited healthcare budgets should best be used for prevention, treatment and care;**
- **How already established best cancer practice could be better shared across the EU; and**
- **How European research could be harnessed to improve cancer outcomes.**

Opening Addresses signal high-level political commitment

The opening addresses embodied the spirit of the conference and showed that, in one way or another, cancer spared few of us. Four leading political figures pledged their commitment to the EU fight against the disease.

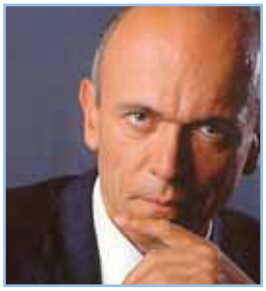


Foto: Arhiv UPRS

Dr. Janez Drnovšek
Slovenia's President

Slovenia's President, *Dr. Janez Drnovšek,* who has survived cancer, sent a message of welcome, "especially to those of you who have personally faced cancer, and now on the basis of your own experience are generously helping those who are still struggling.... Through your activities you have given great hope to many patients and their carers."

Slovenia's Minister of Health, *Andrej Bručan, MD* pledged his country's support in fighting cancer as a health priority of the Slovenian EU presidency. Slovenia, he said, would examine the causes of lower survival rates of cancer patients in Central and Eastern Europe, marshall support for improving cancer outcomes and tackle the existing cancer gaps and inequalities. He felt that measures against cancer were all too often carried out in isolation and lacked a comprehensive strategic approach. What was needed was better management of all aspects of the disease from primary prevention, early detection and screening to effective treatment, rehabilitation and palliative care.

Andrej Bručan, MD
Minister of Health, Slovenia

" In the first half of 2008, during the EU presidency, Slovenia will highlight the "Gap in Health Care and Cancer" as a priority theme. Within this scope we will focus on the European dimension of the integral approach to cancer management. "

" I believe that your organisation will have the energy and capacity to take such steps. "

Václav Havel
First President of the Czech Republic congratulated the European Cancer Patient Coalition for organising the conference

The former President of the Czech Republic, *Václav Havel,* one of the great personalities and political leaders of Central Europe, himself a survivor of lung cancer, in a video contribution encouraged all cancer patients in their struggle: "I have particular sympathy for your activity because my first wife and my mother both died of cancer. I am co-founder of the VIZE 97 Foundation, and one of our programmes has very successfully focused on the prevention of colon cancer."
Václav Havel made the case for volunteers, independent organisations and the non-profit sector to join forces with commerce and governments to cooperate in such an important common cause.

***Alojz Peterle,* MEP, first Prime Minister of Slovenia and now Vice President of European People's Party, Europe's largest political group**, welcomed delegates to his home country. He was proud, he said, that Slovenia, the first new Member State to hold the EU presidency, had chosen tackling cancer as its primary task for the EU health agenda. This Summit, he felt, was a step to building the political will to act across national boundaries, government departments and disciplines thus mobilising and including all resources within our society. To that end he called for the EU to create an inter-institutional Cancer Working Group.

Alojz Peterle
First Prime Minister of Slovenia, co-chair of MEPs Against Cancer

"Nobody combating cancer in Europe should be left on their own. No physician, no politician, and no patient. I believe we have shown this solidarity today"

The East – West cancer gap – Key cancer facts and figures

A comparison between the EU15 and the 10 new Member States who joined the EU in 2004

HIGHER DEATH RATES Death rates are higher in the new Member States than in the EU15 countries for most cancers, including lung and other tobacco-related cancers, but also stomach, bowel and liver, and a few cancers amenable to treatment, such as testis, Hodgkin's disease and the leukaemias.

LESS FAVOURABLE TRENDS Trends in both survival and mortality from most cancers over the last 20 years have been less favourable in the new Members than in the EU15.

FOR MEN the annual death rate from all cancers combined averaged 166 deaths per 100,000 population in EU15 countries, but it ranged from 195 (Lithuania) to 269 (Hungary) among the new Members.

AND WOMEN For women, the annual all cancers death rate averaged 95 per 100,000 in the EU15, but it ranged from 97-98 in Latvia and Lithuania up to 120 in the Czech Republic and 138 in Hungary.

IN SOME CANCER CASES For cancers of the stomach (both sexes), the testis and the uterine cervix (neck of the womb) death rates are substantially higher in the new Member States. Lung cancer death rates in Hungary are double those for the EU15.

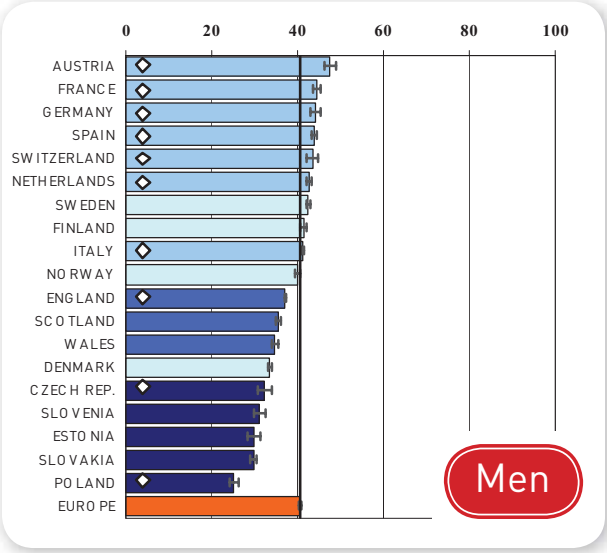
LOWER SURVIVAL Survival from most cancers at five years is lower in Eastern European EU States than in Northern, Western and Southern Europe.

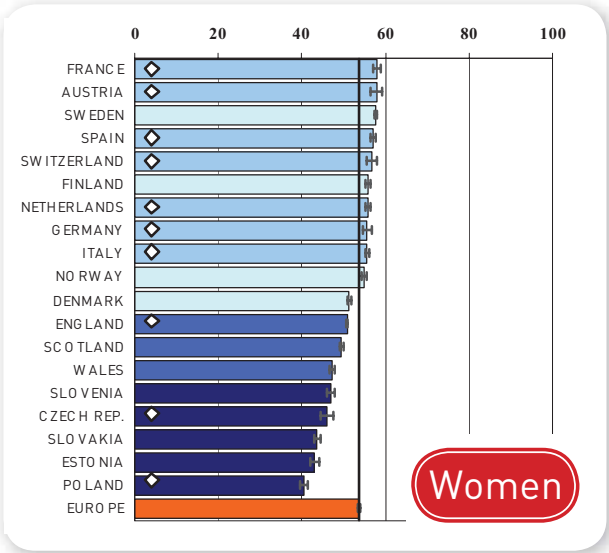
Most of the unfavourable patterns and trends in cancer in the new Member States are **DUE TO POTENTIALLY AVOIDABLE CAUSES**, including tobacco, alcohol, diet and hepatitis, as well as absent or inadequate screening (breast, cervix and bowel cancers) programmes, and inadequate diagnostic or treatment services.

Application of what we already know about prevention, diagnosis and treatment could substantially reduce the disparities in cancer incidence, survival and mortality between the 8 largest new Members and the EU15.

ALL CANCERS FIVE-YEAR SURVIVAL INDEX (%)

Patients diagnosed 1990 - 94, followed up to 1999





Nordic countries
South and West Europe
UK (England, Scotland, Wales)
Eastern Europe
◇ Data covering less than 100 % of country

Differences in cancer control across Europe - The urgent need to forestall a new divide

Prof. Michel Coleman

" Even if tomorrow we applied everything we knew about cancer prevention, it would take a generation for most of those effects to be seen and we still don't know what causes other cancers and therefore cannot act logically to prevent them. For the foreseeable future, therefore, cancer will remain a major global public health problem in Europe."

Professor Michel Coleman, Professor of Epidemiology at the London School of Hygiene and Tropical Medicine, a leading author of the EUROCARE report into cancer survival in Europe, described why the Warsaw Declaration and the Slovenian Summit were so important.

He explained that cancer control could be measured in a number of ways by looking at trends in the occurrence of the disease, and in mortality and survival rates. These were all interrelated and, to make it more complex, across Europe they were interrelated in very different ways.

In West Europe there was a fairly high burden of disease, due to higher risks and large and older populations. Death rates had been going up until the mid-1970s, but now in many Western European countries they were going down - not only for lung cancer. This positive trend in the West essentially reflected tobacco control.

In eastern parts of Europe almost the reverse could be found: cancer rates increasing, particularly for tobacco-related cancers. And because many of the tobacco related malignancies - lung, pancreas and others - had such poor survival rates and were difficult to treat effectively, trends in occurrence of the disease were mirrored, very shortly thereafter, by trends in mortality. So if the numbers of cases were rising, so were the numbers of deaths. That was because, for lung cancer and those especially lethal smoking-related malignancies there had been little progress in treatment and early diagnosis. Survival rates had hardly improved.

Professor Coleman startled his audience by calling this difference "a new divide across Europe": where the Iron Curtain had long since vanished one saw discrepancies in the burden of cancer related to its control, not just in primary prevention (tobacco, alcohol, etc.) but also in outcomes, once patients were diagnosed with the disease.

On the positive side, Professor Coleman asserted that we could prevent at least half of all cancers if we applied everything known worldwide, and if we controlled all the key risk factors appropriately. But it had been 50 years since we knew about tobacco as a risk factor for major malignancies; we had still only recently managed a commendable level of tobacco control; and that did not cover all of Europe. And here he delivered a shocking message to Summit delegates: "It will take another century or more before we have the kind of control over cancers that we would all see as desirable".

Therefore he urged that the other side of the coin must also be addressed. Prevent, yes, but where we could not prevent, we had to treat - and if possible cure - cancer where we found it. That meant early diagnosis and most effective treatments.

Survival rates for Western, Northern and Southern Europe, he said, had been increasing according to the EUROCARE study over the past 10, 15 years. However, in Eastern Europe (for the five countries with solid data) those survival rates were broadly speaking static - going up for some, but not for others. There was a very clear, widening difference between rich and poor countries in terms of cancer control, and the differences were getting worse, not better. The survival gap was widening.

Professor Coleman argued that through **primary prevention** Europe could start tackling the cancer burden now, instead of waiting for another century. He argued for political measures such as robust tobacco control, better diet, adoption of healthier lifestyles and reduction of alcohol abuse.

He cited some more factors contributing to the East-West gap. Health services had not always been given the attention they needed during the period of transition from State-run economies. Freedom of movement had led to an exodus of well-trained cancer physicians and nursing staff to better paid jobs elsewhere in Europe. The EU15 countries had benefited from important initiatives under the **Europe Against Cancer** programme, including financial help for developing cancer registries. That programme had stopped in 2002, before CEE countries joined, and vital help had therefore been denied to the countries that needed it most. ■

Cancer in Slovenia - Monitoring the effectiveness of cancer control

Maja Primic Žakelj

"Most worrying is that in Slovenia we see an increasing trend in colon cancer in both men and women. This is ascribed to unhealthy lifestyles such as diet, obesity and lack of physical activity. No organised screening is currently available."

Associate Prof. Maja Primic Žakelj, Head of Epidemiology and Cancer Registries at the Slovenia Institute of Oncology confirmed the trends outlined by Michel Coleman for her country. Slovenia was aware of them - having one of the oldest obligatory population-based Cancer Registers in Europe to monitor the cancer burden. Although Slovenia was doing better than most new Member States, improvement was needed. **Lung cancer** incidence had started to decline in men, reflecting less smoking during the last 3 decades, **but this was not true for women.**

Cervical cancer was ranked sixth, but compared to other Western countries was among the highest - which was why the national cervical screening programme had been started in 2002. Currently breast cancer screening was opportunistic, but Prof. Primic-Žakelj was optimistic that an organised programme, according to European quality assurance guidelines, was in preparation and that a pilot would be launched in 2007. She argued that systematic screening was a public health intervention; and therefore that financial support for evidence-based screening programmes in CEE countries could be found through the EU Structural Funds - as called for in the Warsaw Declaration - while professional support could come from the collective experience of the European Cancer Screening Network (ECN). ■

The Warsaw Declaration – The policy tool to close the gap

The basis for discussion was the Warsaw Declaration, the policy document developed with advice from the ECPC, formulated and signed by cancer patient groups at the Cancer Advocacy Summit in Warsaw - the meeting hosted a year earlier by the Polish Foundation for Humanitarian Aid "Res Humanae", the Institute for Patients' Rights and Health Education, and ECPC.

The Warsaw Declaration is a good example of how to use the ammunition of statistics to build a broad political campaign. The Declaration draws attention to the situation of cancer patients in Central and Eastern Europe with less chance of survival than similar patients in the rest of Europe. It makes eight broad recommendations, embracing the need for national cancer control plans, prevention, screening, high-quality treatment, equal access, patient participation, patients' rights, and using health-related grants from the European Structural Fund to invest in cancer control.

The overall aim is to close the gap between East and West by pressing politicians at national and European level, opinion leaders and patient groups to sign up to the Declaration; then persuading governments to take action. ■

EUROPEAN CANCER PATIENT COALITION

2nd Summit Cancer Patients Advocacy Groups in Central and Eastern Europe

UNITED AGAINST CANCER
Slovenian Summit
3-5 November 2006

WARSAW DECLARATION

Five years after The Charter of Paris Against Cancer was adopted at the first World Cancer Summit the situation of cancer patients in CEE countries is still dramatic.

Whereas

Total health expenditure as proportion of GDP in CEE countries is less than in the European Union.

Survival rates for every type of cancer are lower than in the rest of Europe.

Inadequate health prevention measures such as opportunistic screening, delay in early diagnosis and innovative treatment, lack of best quality care account for the poor cancer control in CEE countries.

Public awareness and understanding of cancers and their prevention, robust anti-smoking campaigns, promotion of healthier life-styles are low or fragmented.

According to WHO predictions, cancer is expected to increase to epidemic proportions due to the ageing population all across Europe, including CEE and Accession Countries.

Recommendations

Because good health is a basic human aspiration;

Because all European Governments share the goal of protecting and improving their citizens' health and well-being;

Because the right to health protection is enshrined in the European Treaties;

We, the signatories call on policy makers, politicians and key stakeholders urgently to:

1. Develop national cancer plans, setting priorities and allocating resources, for improving cancer control and research in all CEE countries and assure patients' groups monitoring over the implementation of these plans.

2. Invest in cancer prevention by promoting awareness, information and education campaigns about the risk factors of cancer, building on the European Code against Cancer.

3. Invest in national screening programmes as recommended by the European Union; and implement high quality EU standards to support early diagnosis.

4. Make high quality up-to-date treatment, rehabilitation and care attainable for all cancer patients throughout Europe.

5. Encourage and ensure patient participation in all decisions on health policy and health care affecting cancer.

6. Advance cancer control as a priority for action where necessary to qualify for grants from the EU Structural Funds.

7. Oppose discrimination because of age, race, gender, domicile and economic status in respect of the latest cancer treatment.

8. Encourage and adopt national Charters of Patients' Rights according to European guidelines.

ADOPTED AND SIGNED UNANIMOUSLY BY 143 PATIENT GROUP REPRESENTATIVES, WHO ATTENDED THE WARSAW SUMMIT, NOVEMBER 2005, BY THE DELEGATES ATTENDING THE ECPC MASTERCLASS IN MAY 2006 IN MILAN AND THE SLOVENIAN CANCER SUMMIT IN NOVEMBER 2006.

YOUR SIGNATURE:

For more information about the WD campaign please see Resource Section.

Patient advocacy - Fewer patients, more survivors

Sanja Rozman

"Patients are no longer satisfied just to survive. After the illness we want to live – to lead a full and decent life."

Mojca Senčar

Sanja Rozman and **Mojca Senčar** spoke about patient advocacy, explaining that it was thriving in Slovenia, driven by organisations such as EuropaDonna and the Cancer Patient Coalition. The profile of cancer had thus been raised at the political level and brought it to general attention. The Breast Cancer Coalition's agreed slogan was ***"Equal chances for all cancer patients regardless of nationality, financial status, education or religion."*** To put it into practice in Slovenia, Mojca argued that patient groups must have a part in designing an efficient health system for individuals as well as for society. Through their own experience, patient groups had become expert in knowing and understanding what the real needs of cancer patients were. Survivors, able and willing to volunteer their services, could contribute the patients' perspective and make health service more patient friendly. It was up to advocacy groups such as EuropaDonna and Cancer Patients Association to constantly remind the system that so many lives depended on the organisation of a complex range of cancer treatments and that additionally it was a measure of humanity how our societies organised their palliative care.

Reflecting what delegates felt in the conference room, Mojca held that well-organised screening programmes could reduce the death rate. The state-run DORA programme for early breast cancer diagnosis was still at its infant stage and Slovenia lacked organised and specific primary and secondary centres working according to agreed European quality assurance guidelines.

Mojca argued that, to improve cancer awareness, health information and education must start early - at high school with young people. One of the key reasons why people did not seek prompt medical help was lack of knowledge. Even today many patients were visiting their doctors when their cancer had already begun to spread or metastatise.Too few people realised that many cancers were curable or amenable to treatment if diagnosed early.

However, just raising people's awareness was not enough: it had to be flanked with the necessary healthcare infrastructure to permit early diagnosis, immediate and efficiant treatment and speedy rehabilitation. This was where health policy makers, professionals, and those in charge of health insurance schemes had to act together. Experts in oncology **knew** that survival was better achieved by treating patients at specialised institutions.

Cancer, and not only breast cancer, was such a complex disease. Its diagnosis, treatment and care had to be run by specialised institutions appropriately equipped and employing experts with the very latest oncological knowledge. Treatment of cancer requires a comprehensive approach and must be performed by multidisciplinary and multiprofessional teams.■

Jaka Jakopič - My cancer journey

The well-known young Slovenian footballer and cancer survivor, **Jaka Jakopič** then addressed the Summit. His personal example demonstrated how fame, youth, commitment and energy could be harnessed to appeal to and galvanise the general public.

Jaka's Story

"I am a professional footballer and when I was diagnosed with cancer (Hodgkin's Lymphoma) this has given me strength and stamina to go through operation, chemotherapy and treatment. I have always been positive about it, saying to myself: I'm a 100% person and I have 100% chance of recovery. But during my cancer journey I missed others to share my experience and thoughts. I missed someone who has overcome the same disease; someone I could talk to about it - a role model, like Lance Armstrong. I got the impression that everybody in Slovenia was hiding the disease, no one really dared to speak about it. I felt alone until I got engaged with more outspoken women of the **Cancer Patient Association in Slovenia.** There we started with ***Heads Up*** and ***Cycle of Life campaigns*** - and were successful in raising awareness among healthy people about the disease. There is hope and there are ways to treat it successfully. Cancer can be conquered! I did it. We should not be afraid to speak out and share our cancer journey – and make other patients roads to recovery easier."

How cancer medicines are approved in the EU

"To protect the health of patients and ensure that the medicines they take are of highest quality, safety and efficacy, all cancer medicines are now centrally approved in the European Union by the European Medicines Agency (EMEA)."

Prof Stanislav Primožič,
Director of the Agency for Medicinal Products and Medical Devices of the Republic of Slovenia

Regulated by EU legislation the EMEA undertakes the scientific evaluation - a rigorous assessment of the safety, efficacy and quality of new cancer drugs - to ensure that the therapeutic benefit of a new medicine outweighs the disadvantage of any risk or side effects. Slovenia, along with other EU Member States has its own Medicines Agency called JAZMP that interacts closely with the EMEA.

When assessing new medicines, regulators rigorously assess the Clinical Trials data prove the pharmaceutical company applying for the marketing authorisation. At EMEA the Committee for Human Medicinal Products (CHMP) is the body that coordinates the scientific evaluation of new drugs and makes recommendations for approval. It must give its opinion within 210 days which is then followed by an official Commission Decision that can take up to 3 months.

Crucially, for cancer patients with serious or life threatening conditions who can't afford to wait, regulatory agencies have 3 additional more rapid procedures at their disposal:

- **Accelerated assessment procedure**
promising new drugs can be fast tracked
- **Conditional procedure**
came into force in April 2006 and will allow for fast track approval
- **Exceptional circumstances**
A medicine can be authorised although comprehensive information about it is lacking. The conditions for this are clearly defined: the disease is so rare that there are not enough patients for the clinical trials, the present state of scientific information is not comprehensive, or it would be unethical to collect this information by subjecting seriously ill patients to extensive testing. The pharmaceutical company has to continue the testing of the medicine to proof the therapeutic benefit. These authorisations are reviewed every year to assess the risk-benefit ratio.

Once the cancer medicine has been approved it receives a European Marketing Authorisation which stipulates the indications and other conditions of use for which it is accessible Europe-wide. This authorisation must be accompanied by an approved Summary of Product Characteristics (SPC) and Patient Information Leaflet (PIL) that the lay public can easily understand, using a question-and-answer format. Importantly for the patient, the medicine must be accompanied with an approved package leaflet which provides relevant information. In addition, according to recent legislation, the European Public Assessment Report is available on the EMEA website for each centrally approved medicine containing relevant information on the authorization process and regulatory decision taking.

In order to make information more patient-friendly, EMEA has set up a Consumer Patient Working Party through which it consults with patient groups to ensure the information leaflet that accompanies the medicine explains its use and major safety issues in a way patients will find easy to understand.

EMEA is developing a public database on approved medicines, starting with the centrally approved products and later on for all medicines approved EU wide to make medicines information more widely available. For more information please consult the website of EMEA www.emea.europa.eu, the website of the EU Heads of Agencies Group www.medagencies.org and the Slovenian Agency http://www.jazmp.si.

While the authorization process of cancer medicine has been centralized, the consequent decision which make particular medicine available in the national health care systems, remains the competence of each Member State. Decisions on pricing and reimbursement are taken according to the national legal acts which need to be aligned to the "Transparency" Directive 89/105/EEC , but which in practice have often led to substantial differences in the availability of the medicine for pharmaceuticals among all the Member States. More effort to recognize best practices and achievements in this area had initially started by the so-called G10 process. Recently the Pharmaceutical Forum, bringing together key stakeholders, was set up to continue the work and find an optimal balance between promotion or reward for innovation and cost containment measures. The European Commission coordinates, the Forum. ■

Agency for Medicinal Products and Medical Devices of the Republic of Slovenia

Agencija RS za zdravila in medicinske pripomočke

In January 2007 a new Agency for Medicinal Products and Medical Devices (JAZMP) has replaced the former Agency for Medicinal Products and Medicinal Devices of the Republic of Slovenia (ARSZMP). Whereas the former ARSZMP was a constitutive body of the Ministry of Health, the new Agency is a legal person of public law and performs regulatory, professional and inspection activities related to the testing, production and trade of medicines and medical devices for human and veterinary use. It issues marketing and corporate activity authorizations for the above areas. The Agency has a major role for pharmacovigilance and shares this information on a regular basis with the EMEA to ensure patient safety. It also performs the tasks of the Official Medicines Control Laboratory.

JAZMP takes part in the surveillance of pricing of medicinal products and provides professional support to the implementation of pharmaceutical policy of the Ministry of Health. It publishes the national list of authorized medicinal products and semi-annual list of mutually interchangeable products, as well as the register of nationally registered medical devices. The content and scope of the Agency's activities are set out in the Medicinal Products and Medical Devices Act, and other national and EU regulations. ■

Recommendation of the Warsaw Declaration – National Cancer Plans

Having heard from Professor Coleman about the need for good data to develop national cancer plans, several experts gave national examples of what such plans could achieve for patients and society at large. It was made obvious that it would be difficult to sustain the battle against cancer without political will and leadership at the highest level, driven by continuous pressure from patients' advocates and the media, or without total commitment from health professionals.

The United Kingdom

"During the 1990s, advocacy, particularly from patient groups, got stronger, and in response to that the media saw that we needed to do something about cancer. All of that contributed to getting the political will."

Mike Richards, architect of the UK Cancer Plan

Professor Mike Richards, the UK's National Cancer Director, explained the decision by his government to institute a national cancer plan to deal with inequalities, create a cancer service infrastructure, set solid targets and improve outcomes.

Echoing Professor Coleman's message, he said that without good evidence, it was difficult to persuade governments to invest more in cancer control. Although it was blindingly obvious from the EUROCARE study that action was needed.

In Britain, the focus had been on increased investment in cancer prevention and care and on creating the service structure most likely to deliver the best care across the country. Mike Richards told delegates that in practice this had meant dividing the country into a network of cancer services each covering populations of one to two million, with well-equipped specialist cancer centres where patients could have their treatment planned by specialists working in multidisciplinary teams. The actual treatment was often shared by the centre and staff in cancer units based at hospitals closer to the patient's home.

The British plan also included specific commitments on prevention, screening, waiting times, equal access to best treatment and palliative care. ■

Slovenia

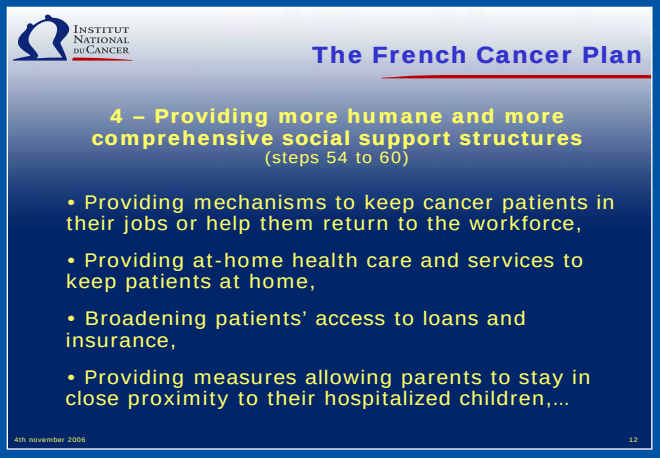
Marija Seljak, head of Slovenian public health directorate

Dr. Marija Seljak, who heads the Slovenian Public Health Directorate, said that in Slovenia the emphasis had so far been on prevention and early detection. Legislation on tobacco control passed in 1996 had led to a drop in smoking from 42% to 28% in men and from 27% to 24% in women. Public health messages now focused on diet and exercise. She described how an opportunistic screening programme for cervical cancer had failed to stem a worrying rise in the number of cases. The implementation of an organised national screening system in 2003, however, had increased the uptake from less than 35% to 68% and the incidence curve had now stopped rising. The present plan was to create a similar national programme for breast cancer screening. Only days before the Slovenian Summit, a decision had been taken to start screening for colorectal cancer, the most rapidly increasing cancer in Europe. ■

France

Brigitte Guillemette, French National Cancer Institute

Brigitte Guillemette of the French National Cancer Institute, INCa, described the French cancer plan which had perhaps been the most comprehensive of all. Summit delegates heard that the French plan, launched in 2002, included psychosocial support - and about what making it easier for patients to return to "normal life". Again it was the political leadership of President Chirac, whose global call for action against cancer as "one of the greatest challenges of our century", that had made the difference. INCa was founded in 2005 to oversee the implementation of the plan. Mme Guillemette went through the 70 steps of the plan. They dealt with prevention (steps 1–20), screening (21–28), delivery of the best quality patient-centred care (29–53), social support for cancer patients (54–60), training (61–65) and research (66–70). The social support provisions, she said, were the first in Europe to tackle the discrimination – by employers, insurance companies and mortgage brokers – that can blight the lives of cancer patients and survivors. ■



Implementing comprehensive cancer plans

The Summit agreed that comprehensive national cancer plans were a good way forward: any country with no national cancer strategy urgently needed one, while countries who had plans on paper needed to ensure that they were swiftly implemented with clear targets and budgets. All too often plans remained paper aspirations. Those whose governments had already put plans in place were reminded that plans were living documents in constant need of updating and improvement. It was suggested that one way to keep abreast was to have some political oversight or audit over a plan to keep it from growing stale.

In response to requests from delegates for assistance in developing cancer plans for their own countries, Professor Richards said he would be delighted to help, but stressed that the major obstacle was not developing a plan - in Britain it took no longer than six months - but creating the will among politicians, clinicians and patients to carry it out. Many delegates felt that the EUROCARE data could be used to equally powerful effect in their own countries. They had been unaware that the gap in survival between East and West was so conclusively documented, and asked how they could get hold of copies of the report. They were directed to the EUROCARE site www.eurocare.it where graphs showing survival differences between countries for all cancers and separately for each of the main cancers could be found and downloaded. ■

The European Research Agenda

Dr. Janez Potočnik,
European Commissioner for Science and Research

"A major message from today's initiative is that, regarding cancer, Eastern European and new EU countries are facing specific and serious problems."

Dr. Janez Potočnik, European Commissioner for Science and Research, started the afternoon session lighting the torch of research. The title of his speech, "Cancer is everybody's business", struck at the heart of Europe's cancer burden. Almost no family in Europe, he said, was spared this disease. He told delegates that cancer was a European issue: it affected about 2.9 million people each year, costing the lives of 1.7 million people. Lung, colorectal and breast cancers were Europe's most common forms of cancer and with the ageing of the European population, cancer rates were expected to continue to increase. The Commissioner assured the Summit that cancer could be addressed "in a European way, at European level and in a European framework".

He said that **Europe Against Cancer** had been an all-encompassing programme, addressing the disease in all its dimensions: prevention, research, information, regulation, and the campaign against tobacco addiction. It had led to real results such as the **European Code against Cancer** which recommended 10 ways in which the most common cancers could be avoided. An estimated 92,000 cancer deaths each year had been averted, he said. Another Commission's initiative was the production of EU guidelines for breast cancer screening to help detect cancers earlier. These have been implemented by several EU countries and were updated in Spring 2006. Delegates were reassured to hear the Commissioner say that cancer was one of the major research priorities of the EU's health and medical research policy and programmes. It is targeted for EU research along with other major diseases such as CVD and brain disease.

Framework Programme (FP7) would look into the following areas.

- Development of new methods for detection, diagnosis and monitoring
- Assessment of new innovative therapeutic approaches
- Identification of best clinical practices

Given that cancer survival rates in the new EU countries were lower, Mr Potočnik called for increased participation of the newcomers in FP7. The new Research Framework Programme, running from 2007 to 2013, would promote world-class collaborative research in health issues. (see FP7 website address for more information)
Epidemiologists at the Summit were pleased to hear the Commissioner's statement that as part of FP7's first call for proposals, a network would be launched "on the optimisation of the use of cancer registries for cancer research purposes". This would be designed to network all national and regional screening programmes in the EU and help the exchange of best practices, improve data collection and support epidemiological and clinical research in EU countries.

Mr Potočnik also spoke warmly of such initiatives as the Slovenian Cancer Summit, MEPs against Cancer and the work of the European Cancer Patient Coalition. He welcomed the chance to address such a diverse audience, including so many cancer survivors - *"We need to make sure that we learn as much from them as they have learnt about cancer."*

"I look forward to the proposals coming out of this Summit. These initiatives and others such as MEPs Against Cancer and the European Cancer Patient Coalition can provide a united, European front to tackle cancer." ■

Academic Cancer Research in CEE countries

Professor Tanja Čufer, Professor of Oncology at the University of Ljubljana and board member of the European Organisation for Research and Treatment of Cancer (EORTC), addressed the importance of cancer research for patients needing the best quality treatment immediately. Supporting the Commissioner's research message, she argued that it was essential that cancer treatment centres in CEE countries took on more of a research role.Participating in clinical trials, she said, was an important way for cancer patients to get access to experimental therapies or protocols. Furthermore, innovative treatments that had proved themselves in trials tended to be adopted by all cancer treatment centres far quicker in countries and regions participating in the trials. More generally, participating in clinical trials had been shown to raise the quality of oncology departments as a whole, improving adherence to protocols, subjecting pathology labs to quality control and fostering a more analytical approach among staff. Helping cancer centres to get involved in clinical trials was therefore one important way that CEE governments could help close the survival gap between the East and West. ■

Prof. Tanja Čufer

The need for Continuing Medical Education

Dr Alberto Costa, Director of the European School of Oncology, Breast Cancer Surgeon

"Fifty percent of the medical knowledge that students receive at university is obsolete after seven years."

Dr Costa forcefully argued for the need to agree on a Europe-wide system of independent Continuing Medical Education based on a set of agreed guidelines. His presentation covered the complex and often difficult area of training doctors in oncology: from the role of universities, the need of clinical experience for doctors, the concept of Continuing Medical Education to the need for independent teaching.

He surprised his audience with the startling fact that fifty percent of the medical knowledge that students receive at university was obsolete after seven years.

Universities had a crucial role training future doctors. Medicine was not like for example philosophy; clinical experience had to be added. This training took place in hospitals, was difficult to organise because it involved the professor and students visiting patients at the bedside, sometimes several times a day. It included multi-disciplinary teaching which again was a complex area, rife with professional jealousies between surgeons, gynaecologists and radiologists - to take an example from the breast cancer field. The clinical experience is an essential component of a doctor's training. However, once the doctor had received his degree, the university did not offer any further medical education. This was mostly left to business interests.

Continuous Medical Education is especially important in oncology as was critical mass - the number of operations a surgeon performs a year had an important influence on patient survival. Communication was not taught in medical schools, indeed some people, including doctors, were better communicators than others. Factors such as time pressure, communication skills, and privacy of place, all played a role. However, a patient felt and did better and was a more empowered partner, engaged in conquering his/her illness if the relationship with his doctor was good.

Continuous Medical Education originated in the US with its typical consumer style approach. The US system forced doctors to continue to study. Every 5 years the doctor's medical training was rechecked before he could continue to practice. This meant that doctors had to attend training courses and earn credit points. If a doctor did not gain enough points, his licence was not renewed. The cost of studying was tax deductible. This "consumer protection" approach was hard to push through in Europe. Some time ago a European

pilot accreditation system was established, but failed as Member States could not agree on the mobility of credit points across Europe. Instead the gap in Continuous Medical Education was filled by business interests.

In the absence of any European regulation, this had become a big business for organisers of scientific conferences. It meant that doctors are away from their hospital job to attend congresses, organised by companies whose sponsors supported educational events that were relevant to their market.

Dr Costa argued for the independence of teaching to avoid interference by third parties. The European School of Oncology of which he has been the director for over 20 years, was one of the few places in Europe to provide independent teaching. ESO was lucky to receive funding from two private foundations to carry out its teaching work. He ended his presentation with the plea for a renewed effort in Europe to agree on a Continuous Medical Education system that allowed for the mobility of credit points, provided fiscal incentives and included the universities. ■

BUILDING THE POLITICAL WILL - CAMPAIGNING FOR CHANGE

The closing session of the conference dealt with the issue key to everything else: building the political will to force through the level of change and investment needed to close the gap between East and West - and indeed to improve cancer control across Europe.

Magda Bojarska

Mme Magda Bojarska from the Polish Institute of Patients Rights outlined the strategy her Institute was pursuing together with patient groups to get the Warsaw Declaration into the public eye, onto the political agenda and implemented by the Polish government. Together with ECPC and the Polish Foundation for Humanitarian Aid "Res Humanae", her organisation had been responsible for organising the Warsaw Summit in 2005 when the Declaration was adopted.

Once again evidence from the EUROCARE survival data had shown Poland to be at the bottom of the league tables, with rates around 25% lower than elsewhere in the EU. This had created the drive for action. The data on healthcare spending today was equally damning: Poland spent 3.8% of GDP compared with 6.7% in the Czech Republic, 5.5% in Hungary and 5% in Slovakia. The Warsaw Declaration had given the necessary consensus and focus and helped to equip cancer patient groups across all regions of Poland to draw up action plans for their own local and regional campaigns. ■

Summit Conclusions - CONTINUITY AND SOLIDARITY

"Solidarity is the other key to success", said Alojz Peterle. "Nobody combating cancer in Europe should be left on their own. No physician, no politician, and no patient. I believe we have shown this solidarity today, and I'm sure this commitment will continue."

Alojz Peterle and Jolanta Kwaśniewska

Alojz Peterle, chairing the closing session with Mme **Jolanta Kwaśniewska**, patroness of the two preceding Warsaw Patient Summits and former First Lady of Poland, praised the energy and dynamism of ECPC and pledged continued support for a European cancer campaign and around the Warsaw Declaration. He welcomed the commitment made by the politicians at the Roundtable of the previous day that "patients need to be put at the centre" and said that that sentiment should be a guideline for all future work.

Looking ahead, Mr Peterle emphasised two important concepts that had been strengthened by the Slovenia Summit: *continuity and solidarity.*

Continuity is vital because Slovenia can only ensure cancer is an EU priority during the six months of its presidency, whereas tackling cancer required a long-term strategic approach with national governments working together with the European Parliament and Commission. ■

Slovenia Takes the lead

Dorjan Marušic, Deputy Health Minister of Slovenia

" Politicians should be well aware that they will have to listen to patients and experts on how to solve our problems. I wish that all positive energy and conclusion from the Summit will help to be all more efficient and more successful in fighting cancer, not just in Europe, but worldwide."

Dorjan Marušic, Deputy Health Minister of Slovenia, confirmed that the reason Slovenia chose cancer to be the main Presidency theme for health was the increasing disparity in cancer control. The Ministry of Health would strive to promote solidarity, equality and the equal availability of cancer treatment. He hoped political will would be mobilised across Europe to strengthen the battle against cancer. He reminded the Summit that following the Paris Cancer Charter in 2000, there had been a first EU ministerial cancer meeting in 2005 under the Luxembourg presidency and supported by the French government. Now such meetings could be stepped up by the fresh drive coming from the European Parliament's MEPs against Cancer initiative, their call to form a European cancer task force. Many heads in Europe were thinking along the same lines: how to close the gap within a country, and between countries, how to step up prevention campaigns and how to eliminate some of the worst inequalities between East and West, rich and poor.

He encouraged Summit delegates that the recommendations coming out of the meeting would fit well into the preparation of Slovenia's EU Presidency in 2008. He feared – and trends were going that way - that with present and future EU enlargement the differences in cancer control would continue to widen across Europe.

It was urgent that Europe found an effective and forceful approach to strengthen prevention through tobacco control, healthy lifestyles and screening programmes and to make our health systems as efficient as possible. There was hope that with continued pressure from all quarters - patient groups, politicians and the media - we would generate enough positive energy to tackle cancer together at regular ministerial meetings. Slovenia was pleased to play a leading role in providing a new impetus to the cancer challenge, but help was needed from all.

In an unprecedented show of solidarity between East and West, North and South

Europe, Summit delegates joined the previous signatory groups from the Warsaw Patient Summit and the ECPC Masterclass and added their names to the Warsaw Declaration.

Irena Belohorska, MEP, former Health Minister of Slovakia, **Andrej Bračun,** Health Minister of Slovenia and **Alojz Peterle,** MEP

Delegates committed themselves to unite and bring sustained pressure at EU and national level through every possible channel. Patient groups understood that it was up to them to gather support for the Declaration from a wide circle to bring about change: realising full well that fighting cancer was a long haul, small consistent steps as recommended by Václav Havel in his video address could make a difference to setting comprehensive national cancer plans in motion. The time to act against cancer was now - to forestall a future cancer epidemic brought about by an ageing population. Nothing less than the health of European citizens was at stake.

Now everyone's hopes are pinned on Slovenia's leadership to continue the fight against cancer. However, Slovenia is not alone in the struggle: support was coming from the Roundtable of EU and national health politicians, who wished to deepen their discussions at further meetings.

Dr Joaquim Gouveia, the National Coordinator for Oncology Diseases at Portugal's , Ministry of Health suggested greater continuity through an EU cancer strategy could be in sight. One idea might be to place Europe's fight against cancer as a regular item on the agenda of every EU Health Ministers meeting.

The rich discussions of the day confirmed and strengthened the Warsaw Declaration whose recommendations had been purposefully broad to ensure that the complexities of cancer control were well covered. Cancer is not one disease but a multifaceted set of over 200 diseases, difficult and expensive to treat. The message was clear – we must prevent what can be prevented NOW, and we must have robust programmes that bring about change, invest in early diagnosis and treat those patients for whom prevention comes too late with the best quality of patient-focused care. And we must engage everyone in this endeavour. It is not possible for any one institution or interested party on its own to deal with cancer's complexity. Cancer, the greatest challenge of our century can and should be faced at a European level and in a European framework learning, harnessing, uniting Europe's strong and resourceful diversity. As the European Community celebrates its 50th Birthday in 2007 Europe's citizens can only hope that fighting cancer now will be one of our biggest achievement for future generations. ■

Dr Joaquim Gouveia,
the National Coordinator for Oncology Diseases at Portugal's Ministry of Health

Slovenian Summit
3-5 November 2006

The Summit Recommendations:

- Whenever and wherever possible - to prevent cancer through robust anti-smoking campaigns, creating greater public awareness and motivation to act against the dangers of cancer, and wider and sustained promotion of the Europe against Cancer Code.

- Urgently to implement the EU Cancer Screening Recommendation along with EU quality assurance guidelines. Member States will be asked to send their national progress report to the European Commission in 2007.

- To use FP7 to look into the development of new methods of detection, diagnosis and monitoring of cancer.

- To enlist cancer treatment centres in CEE countries to take on a research role and actively participate in FP7.

- To establish an EU standard for the assessment of new innovative therapeutic approaches and identification of best clinical practices.

- As a first step to national cancer plans, to continue support for cancer registries across the EU to create an evidence base from which to move forward, set targets and measure progress.

- To employ patient expertise to ensure policies and plans are patient-centred.

- All interested parties to unite in an effort of solidarity and continuity to build the necessary political will for action across national boundaries, government departments and disciplines, thus mobilising and including all resources within our society.

- To set up an inter-institutional EU Cancer Task Force to provide drive and leadership.

WWW.UNITEDAGAINSTCANCER.EU

DEFEATING CANCER RALLY...

EUROPEAN CANCER PATIENT COALITION

...has been held on Sunday, November 5th, 2006 on Congress Square in Ljubljana.

WE JOINED FORCES WITH:

Nuša Derenda
Vili Resnik
Marijan Novina
Parliament Dixie Band
Victory Band
Slovenian athletes

PEOPLE WERE ABLE TO:

Ask questions about the disease.

Get to know the cancer patient organisations.

Taste the specialities of Slovenian eco farms.

Witness the stories of people who defeated cancer.

Enjoy the sporting activities with Slovenian athletes.

Defeating Cancer Rally

Declaring the Summit closed, Mr Peterle invited all delegates to attend the Cancer Rally the next day in the centre of Ljubljana.

The Rally sent a strong message of solidarity between cancer patients and their local communities. Entering into the spirit of the celebration, the Slovenian Parliament's Dixie Band set the note of optimism that today it is possible for many patients to survive cancer.

Hildrun Sundseth, Head of the ECPC Brussels office, delivered a message of solidarity at the Cancer Rally in Ljubljana's main square.

Prof Borut Štabuc
Cancer League of Slovenia

"In 2005 our League issued a number of flyers on colorectal cancer and, in collaboration with prominent experts, we prepared also other publications on colorectal cancer that appeared in different media. In 2006 we studied the feasibility of colorectal cancer screening in Slovenia…Eventually, we all agreed that we have plenty of willpower, sufficient capacity, medical doctors and other potentials to carry out the screening programme at the national level. The screening programme was presented to the national professional boards for different medical specialties and to the Health Council. As this is a substantial financial load, it is up to the Ministry of Health and the Health Institute to decide whether resources will be provided for the implementation of the programme."

"It is easy to estimate that this approach could save more than six thousand female lives in Central and Eastern Europe alone. Population-based, organized cervical cancer screening should be considered as a priority in European cervical cancer prevention to enable each woman to be protected by having an easy access to standard prevention allowing an effective treatment".

Magdalena Bielska-Lasota
Maria Skłodowska-Curie Cancer Center and Institute of Oncology, Warsaw, Poland

Fatmire Mulhaxha-Kollçaku,
Chair of the Committee on Health, Labour and Social Welfare in the Assembly of Kosova

"I have changed during this Conference. I see many optimistic people here. I see that our patients must be organised in some sort of patient coalition. If nobody pushes the government, they see the problem but they don't feel under pressure to take urgent action."

"We invite the next Summit to take place next year in Bulgaria, because it will help our politicians and government bodies to focus on cancer and listen more attentively to their citizens and patients."

Evgenia Adarska
Bulgarian cancer patients group, APOZ

"I felt clearly from the Conference that patients want more empathy from the profession. Many are excellent researchers and doctors, but they keep a certain distance from the patients."

Mihály Kökény
Chair of the Health Committee in the Hungarian Parliament and former Minister of Health

"It was helpful to learn about the UK and French national cancer plans. I can now make some proposals for the Romanian cancer plan. For example, psycho-oncology, rehabilitation and insurance – these are very important for the patients but are not included in the Romanian cancer plan. "

Simone Ene
Association of Cancer Patients in Romania

"I really liked this issue of the patient-oriented aspect of the French cancer plan, because there are some problems that people tend to overlook. I will certainly try to raise it when we work further on the development of our cancer plan."

Ariana Znaor
Croatian National Institute of Public Health

"The Cancer Patients Association of Slovenia unites cancer patients and everyone willing to participate in solving the many issues facing cancer patients and their families. Established more than two decades ago the Association works through volunteers and self help groups to educate people about cancer, raise awareness of the importance of engaging patient's active cooperation in their treatment and rehabilitation by informing them of their rights or acting as their advocates if necessary. Our work, based on the principle of self help, aims to complement medical treatment and support patients on their way to recovery. It is of great personal satisfaction to me to know that our voluntary work and campaigns have succeeded to reach thousands of people in need."

Štefka Kučan,
Honorary Member of Cancer Patients Association of Slovenia and Former First Lady of Slovenia

Marjan Videnšek
founding President of 'Revival'- Movement for Healthier Lifestyle

Advice for improving and promoting our own health came from Marjan Videnšek: "Many cancers are preventable through adopting healthier lifestyles and behaviour. It sounds like a difficult task as there are so many potential cancer-causing agents in your food and your environment. However, the answer is a relatively simple one.

Yes, live simply and follow the laws of life:

1. Stop smoking and drink only in moderation.
2. Procure adequate daily rest.
3. Drink plenty of water.
4. Try to eat mostly foods to which we are biologically adapted to eat: wholesome fresh vegetables, fruits, nuts, seeds and fruit juices. Whenever possible, purchase these foods organically grown or grow your own.
5. Exercise daily.
6. Spend some time each day in the fresh air, but guard your skin against too much sun shine. If possible, move to the country where the air is freer from pollution.
7. Avoid as much as possible the use of chemicals on your skin or hair and in your house.
8. Strive to procure a job in a safe workplace free of toxic chemicals.
9. When you feel "below par", try fasting for a day and then resume a rawfood diet.

"I strongly believe that the Warsaw Declaration will give a fresh impetus to Slovenia's health policy agenda. As a member of the National Health Committee, I fully agree and support initiatives signed by numerous patient groups at the Warsaw Summit and the ECPC Masterclass and the Slovenian Summit".

Mojca Kucler Dolinar,
Member of the Parliamentary Health Committee of the Slovenian Assembly

"Cancer patients very much look forward to a time when we will be dying in fewer numbers and fewer of us will get the disease. A lot of that will be down to the step we have taken with this Summit. ECPC is very grateful for the support from the Slovenian Ministry of Health, Mr. Alojz Peterle, MEP and Commissioner Potočnik and all of our delegates who have helped us to make this meeting a success."

Lynn Faulds Wood,
President of European Cancer Patient Coalition

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Hill and Knowlton

Mrs. Evgenia Adarska, BULGARIA
APOZ

Dr. Anna Achileoudi, CYPRUS
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Mrs. Corina Alexandru, ROMANIA
ONCOLOGIC ROM Association

Mrs. Victoria Asanache, ROMANIA
Renasterea Foundation

Mr. Žarko Avdalovič, CROATIA
HULL

Mr. Roger Bacon, UNITED KINGDOM
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Društvo onkoloških bolnikov Slovenije

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Stowarzyszenie Urszuli Jaworskiej

Rt. Hon. Kevin Barron, UNITED KINGDOM
House of Commons Chair of Health Committee

Mrs. Gordana Bednaš, SLOVENIA
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Ms. Dragica Bošnjak, SLOVENIA
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Warsaw Declaration

The document has been voluntarily translated by patients into several languages: Polish, English, German, Greek, Dutch and Slovenian.

It is available on the ECPC website www.ecpc-online.org and open for signature to all interested parties. Please sign!

Warsaw Declaration Communication package

At its May 2006 Masterclass, ECPC organised an advocacy workshop to promote the Warsaw Declaration and distributed a communication package. This package is available in English from the ECPC office on request info@ecpc-online.org.

Websites

European Institutions & Associations

European Parliament
http://www.europarl.europa.eu/

MEPs Against Cancer Forum
http://www.mepsagainstcancer.org/

European Commission
http://ec.europa.eu/index_en.htm

DG Research
http://ec.europa.eu/research/

Commissioner Potočnik's website
http://ec.europa.eu/commission_barroso/potocnik/indexfl_en.htm

Health-EU Portal from the European Commission (in 20 languages)
http://ec.europa.eu/health-eu/index_en.htm

European Commission - Enterprise DG - Pharmaceuticals
http://pharmacos.eudra.org/F2/home.html

European Commission - Public Health
http://ec.europa.eu/health/index_en.htm

European Medicines Agency
http://www.emea.eu.int/

European Code Against Cancer
http://www.cancercode.org/

European Commission FP7: The Future of EU Research policy
http://ec.europa.eu/research/fp7/home_en.html

Local links Slovenia and others

Website MEP Alojz Peterle
http://www.peterle.si/

Slovenian Ministry of Health
http://www.mz.gov.si/en/

Institute of Oncology Ljubljana
http://www.onko-i.si/en/

French Cancer Plan
http://www.e-cancer.fr/

UK Cancer Plan
http://image.guardian.co.uk/sys-files/Society/documents/2003/08/26/cancerplan.pdf#search=%22Cancer%20Plan%20NHS%22

Slovenian Cancer Patient Association
http://www.onkologija.org/sl/domov/

Slovenian Cancer League
http://www.protiraku.si/

Europa Donna-Slovenian Association against Breast cancer
http://www.europadonna-zdruzenje.si/index.php

Nataša Hace, ECPC, Alojz Peterle, MEP, Hildrun Sundseth, ECPC, Thomas B. Robertson, U.S. Ambassador to Slovenia with his wife, Dorjan Marušič, Deputy Health Minister and Lynn Faulds Wood, ECPC

Programme for implementing the promotion of eating vegetable and fruit 5 times per day and of exercise, started by Slovenian Ministry of Health on the World Food Day, 16th October 2004
ECPC is grateful to the Slovenian Ministry of Health for kindly allowing us to use the image.

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THANK YOU TO ALL WHO HAVE HELPED US TO ORGANISE THE 'UNITED AGAINST CANCER' SUMMIT

ECPC is registered in The Netherlands, Reg.-Nr. 30211815