



EUROPEAN  
**CANCER**  
**PATIENT**  
COALITION



Slovenian Summit  
3-5 November 2006

# **"United Against Cancer" CEE Cancer Patient Summit 2006**

**November 3 - 5 2006  
Ljubljana, Slovenia**

**Under the Auspices of the President  
of the Republic of Slovenia**

**The Patronage of Mr Janez Potočnik,  
European Commissioner for Science and Research**

**The Patronage of the Ministry of Health of Slovenia**

# CONFERENCE BOOK

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Dear Friends and Supporters,

I want to share with you my excitement and whole-hearted commitment for the first Cancer Summit for Central, Eastern and South Eastern European countries which will take place in Slovenia 3 – 5 November 2006. With this Summit we wish to draw attention to the urgent need to fight cancer across Europe, especially in the new EU Member States and future accession countries.

Together we will examine how best we can tackle the existing inequalities in cancer outcomes, how we can reduce the gap in cancer prevention treatment and survival and what we can learn from each other.

Since I have been elected to the European Parliament, I have become committed to support European citizens in their fight against cancer. Together with 50 members of the European Parliament we have formed a cross-party Forum of **MEPs Against Cancer – MAC** for short. As a cancer survivor myself, I know from personal experience how hard it is to live with the disease for those who are directly affected or those who are close to them.

The Conference will take place under the Auspices of the President of the Republic of Slovenia and with the support of the Slovenian Ministry of Health. Under the title “**United Against Cancer**”, we hope to unite key stakeholders from eastern and western Europe: health policy makers, politicians, cancer patient advocacy groups and the professional oncology community behind the fight against cancer.

Did you know that across Europe the sad statistics are that every third person will, at one time in their life, be diagnosed with cancer. Cancer is a disease which concerns us all. And we, new member states and CEE countries have worse outcomes. Twice as many people die from lung cancer in Hungary than in Finland.

By joining forces in the fight against cancer we can all contribute our expertise, will and energy to tackle cancer and share best practice across Europe.

Please help us in making the United against Cancer Summit a success. Together we can make a difference.

I very much look forward to welcoming you at the Slovenian Cancer Summit in November.

Lojze Peterle  
(MEP and First Prime Minister of Slovenia)



Dear Delegates,

A very warm welcome to all “**United Against Cancer**” delegates. We hope you share with us the excitement of this unique Cancer Summit. This is the European Cancer Patient Coalition’s first strategic initiative to bring together - under the auspices of the President of Slovenia - the leading voices amongst politicians, health ministers, the European Research Commissioner, medical professionals and patient advocates from across the Central & Southeastern European region - and wider Europe - to discuss how we can improve the poorer survival rates and quality of life of cancer patients in CEE, the Baltic countries and beyond.

It is surely a scandal that some European citizens will be dying unnecessarily of cancer as you read this. And the EUROCARE data showed that people living in CEE countries had worse chances of survival than those living in Northern and Western Europe.

Cancer in the 21st Century for most of us is **preventable, treatable and beatable**. Many more lives could be saved every day, thousands of families spared the trauma of watching people we love dying when - if they lived in another region, they would have been screened for common cancers, received better medical care, or lived in a country able to afford the latest treatments - they might have lived.

As President of the European Cancer Patient Coalition, representing over 200 patient organizations across Europe, we have been delighted to have taken on the planning and organization of the “**United Against Cancer**” Summit with Mr. Alojz Peterle. We believe this groundbreaking Summit really does have the opportunity to improve all of our lives. We very much hope to welcome you in great numbers at our Summit – it will be your meeting, come and help us make it a success.

**Lynn Faulds Wood**  
**ECPC President**



## **Slovenian Summit Supporters and Sponsors**

**ECPC IS GRATEFUL FOR THE OFFICIAL SUPPORT OF  
THE PRESIDENT OF SLOVENIA,  
THE MINISTRY OF HEALTH  
AND THE EUROPEAN COMMISSIONER FOR SCIENCE AND  
RESEARCH.**

**OUR WARM THANKS GO TO MR ALOJZ PETERLE, MEMBER OF THE  
EUROPEAN PARLIAMENT, WHO HAS BEEN OUR INSPIRATION FOR  
THE SUMMIT.**

The **European Cancer Patient Coalition** is honoured to host this important Summit. It has invested a lot of its own resources, time and effort to make this conference happen and to ensure that as many patient groups as possible are part of it.

The Summit was organised by the **ECPC Brussels office**, headed by **Hildrun Sundseth**, who volunteered her time and expertise.

She was assisted by **Nataša Hace**, European Public Affairs Officer and **Lea Wongsoredjo**.

**WE WISH TO EXPRESS OUR THANKS TO THE FOLLOWING  
SPONSORS WHO HAVE SUPPORTED THE SUMMIT WITH AN  
UNRESTRICTED GRANT**



**NOVARTIS ONCOLOGY (Major Founding Sponsor)**





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Education Et knowledge through people Et facts

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

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## Cancer in Europe: Key Facts and Figures

- Cancer is a major public health problem in Europe - **1 in 3** Europeans will be diagnosed with cancer in an average lifetime, and **1 in 4** deaths is attributable to cancer. Cancer is the second most common cause of death, after cardiovascular disease.
- In 2004, an estimated 2.9 million Europeans were diagnosed with cancer (54% men, 46% women), and 1.7 million died of cancer (56% men, 44% women). In other words, some 7,900 Europeans are diagnosed with cancer every day, and 4,700 die from the disease.
- Among citizens of the 25 EU member states, the corresponding estimates for 2004 are 2.1 million new cases and 1.2 million deaths each year, equivalent to some 5,600 new cases and 3,200 deaths every day.
- *New cases:* Lung cancer is the most common (381,000 cases, 13.2% of all new cases), followed closely by cancers of the large bowel (13.0%) and breast (12.8%). These three cancers account for almost two-fifths (39%) of all new cancers diagnosed in Europe each year.
- *Deaths:* Lung cancer is more lethal than bowel or breast cancer, and it accounts for 20% of all cancer deaths (bowel, 12%; breast, 8%). Stomach cancer is falling, but still causes 8% of cancer deaths. Together, these four cancers cause half (48%) of all cancer deaths in Europe.
- The annual numbers of new cases and deaths will continue to increase - even if cancer risks in each age group do not change - simply because the European population is ageing.

**Public health measures are already available to reduce the numbers of new cases and deaths from cancers of the lung, bowel and breast, through tobacco control (lung), earlier diagnosis (all cancers), screening (breast, cervix, bowel) and better access to optimal treatment.**

**A concerted, long-term and Europe-wide effort against the four big cancer killers - lung, colorectal, breast and stomach cancer - would enable great progress within 10 years.**

A comparison between the EU-15 Member States and the 10 new Member States who joined the EU in 2004:

- Death rates are higher in the new member states\* than in the EU-15 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.

- Trends in both survival and mortality from most cancers over the last 20 years have been less favourable in the new member states than in the EU-15 states.
- For men, the annual death rate from all cancers combined averaged 166 deaths per 100,000 population in EU-15 countries, but it ranged from 195 (Lithuania) to 269 (Hungary) among the new member states in central and eastern Europe.\*
- For women, the annual all-cancers death rate averaged 95 per 100,000 in the EU-15, but among the new member states of central and eastern Europe, it ranged from 97-98 in Latvia and Lithuania up to 120 in the Czech Republic and 138 in Hungary.
- 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 than in the EU-15 states. Lung cancer death rates in Hungary are double those for the EU-15.
- Survival from most cancers at five years is lower in eastern European EU states than in the EU states 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 cancer prevention, diagnosis and treatment could substantially reduce the disparities in cancer incidence, survival and mortality between the 8 largest new EU member states in central and eastern Europe and the EU-15 member states.**

#### **Notes**

*EU-15 (to 2003): Austria, Belgium, Denmark, Finland, France, Germany, Greece, Ireland, Italy, Luxembourg, Portugal, Spain, Sweden, The Netherlands, United Kingdom.*

*EU-25 (from 2004): EU-15 plus Cyprus, Czech Republic, Estonia, Hungary, Latvia, Lithuania, Malta, Poland, Slovakia, Slovenia.*

*\*Cancer death rates in Malta are generally similar to those in EU-15 countries; data for Cyprus were not available. These two countries have much smaller populations than the other 8 new member states (1.2 million cf. 74 million).*

*Europe (40 countries): EU-25 plus Iceland, Liechtenstein and Norway (European Economic Area); plus Albania, Belarus, Bosnia and Herzegovina, Bulgaria, Croatia, Macedonia, Moldova, Romania, Russian Federation, Serbia and Montenegro, Switzerland and Ukraine.*

**Data sources - derived from the European Network of Cancer Registries and the International Agency for Research on Cancer (incidence), WHO (mortality), and the EURO CARE study (survival)**

*Boyle P, Ferlay J. Cancer incidence and mortality in Europe, 2004. Ann Oncol 2005; 16: 481-8.*

*Levi F et al. Trends in cancer mortality in the European Union and accession countries, 1980-2000. Ann Oncol 2004; 15:1425-31*

*Sant M et al. EURO CARE-3: survival of cancer patients diagnosed 1990-94 - results and commentary. Ann Oncol 2003; 14 (suppl\_5): v61-v118.*



# **CONFERENCE PROGRAMME**



Slovenian Summit  
3-5 November 2006



**Under the Auspices of  
The President of the Republic of Slovenia**

**The Patronage of Mr Janez Potočnik,  
European Commissioner for Science and Research**

**The Patronage of the  
Ministry of Health of Slovenia**

**CONFERENCE PROGRAMME**

***“United against Cancer”***

***Making Cancer a Priority – CEE Cancer Patient Summit***

Hotel MONS Conference Centre, Ljubljana, Slovenia  
<http://www.unitedagainstcancer.eu>

**Friday, 3 November 2006**

**Arrival and Registration**

**19:30 Welcome Buffet**

**Saturday, 4 November 2006**

**OPENING SESSION**

**9:30 Welcome**

- *Mr Alojz Peterle, Member of the European Parliament*

**9:40 Opening address**

- *Welcome note from Dr Janez Drnovšek, the President of the Republic of Slovenia*
- *Mr Andrej Bručan, the Slovenian Minister of Health*

**10:10 Combating cancer in the CEE Region**

- *Mr Václav Havel, First President of the Czech Republic*

## SESSION 1 – IMPROVING CANCER SURVIVAL

*Chairs: Mr Alojz Peterle, MEP and Mrs Lynn Faulds Wood, President the European Cancer Patient Coalition (ECPC)*

- 10:15**                    **Setting the Scene:  
Differences in the Outcome in Cancer Care across Europe**
- *Prof Michel Coleman, London School of Hygiene & Tropical Medicine*
- 10:35**                    *(Coffee break and Exhibition)*
- 10.50**                    **The need for national Cancer Plans**
- *Slovenian Cancer Plan, Dr. Marija Seljak, Director General, Public Health Directorate, Ministry of Health Slovenia*
  - *UK Cancer Plan, Prof Mike Richards, National Cancer Director, Department of Health, UK*
  - *France Cancer Plan, Mrs Brigitte Guillemette, Institut National du Cancer, France*
- 11:40**                    **Prevention of Cancer - Making Cancer Screening a Priority**
- *Cervical Cancer Screening, Dr Magdalena Bielska-Lasota, M. Sklodowska-Curie Cancer Center, Warsaw*
- 12: 00**                    **Discussion**
- 12:30 – 14:00**            **LUNCH**

## SESSION 2 – CANCER RESEARCH AND GOOD PRACTICES

*Chairs: Dr. Irena Belohorská, MEP and Dr Dorjan Marušič, Slovenian Deputy Health Minister*

- 14:00**                    **KEYNOTE: Making Cancer Research a priority for Europe**
- *Commissioner Potočnik, DG Research*
- 14:20**                    **Academic Cancer Research in CEE countries**
- *Prof. Dr. Tanja Čufer, EORTC General Board*
- 14:35**                    **Training experts in oncology - Learning to care**
- *Dr Alberto Costa - European School of Oncology*
- 14:50**                    **Making Cancer Prevention a priority for Europe**
- *Dr Adamos Adamou, MEP and co-chair of MAC*
- 15:10**                    **Healthy Lifestyle –**
- *Mr Marjan Videnšek, founding President of 'Revival'-Movement for Healthier Lifestyle*
- Followed by Questions and Answers

15:30 (Coffee Break)

### SESSION 3 – ACCESSING NEW ANTI-CANCER TREATMENTS

*Chairs: Dr Sanja Rozman, EuropaDonna Slovenia and Dr Janez Remškar, Director-General, Health Care Directorate, Slovenian Ministry of Health*

- 15.45 **Access to Treatment – Why is it so difficult?**
- *Mrs Lynn Faulds Wood, President ECPC*
- 16:00 **EU Approval of Cancer Medicines**
- *Prof. Dr. Stanislav Primožič, Director of Slovenian Agency for Medicinal Products and Medical Devices*
- 16:15 **Less Patients and more Survivors**
- *Dr Mojca Senčar, EuropaDonna Slovenia*
- 16:30 **Personal experience – My Cancer Journey**
- *Mr Jaka Jakopič, Slovenian Footballer and Cancer Survivor*

Followed by Questions and Answers

### SESSION 4 – CREATING THE POLITICAL WILL ACROSS EUROPE

*Chairs: Mr Alojz Peterle, MEP and Mrs Jolanta Kwaśniewska, founder of the Jolanta Kwaśniewska's Foundation, Warsaw*

- 17.00 **Portuguese Health Plan and EU Presidency Agenda**
- *Dr Joaquim Gouveia, National Coordinator for Oncology Diseases, Ministry of Health Portugal*
- 17:10 **The Warsaw Declaration : the Polish experience**
- *Mrs Magda Bojarska, Institute for Patients' Rights and Health Education, Poland*
- 17.20 **PANEL DISCUSSION: How do we implement the Warsaw Declaration on combating cancer?**
- Panel:
- *Dr Dorjan Marušič, Deputy Minister of Health, Slovenia*
  - *Dr Emil Raynov, Deputy Minister of Health, Bulgaria*
  - *Prof Maja Primic-Žakelj, Head of Epidemiology and Cancer registries, Slovenia*
  - *Prof Dr Borut Štabuc, President of Slovenian Cancer League*
  - *Mrs. Štefka Kučan, Former First Lady of Slovenia*
  - *Dr Irena Belohorská, MEP*
  - *Mrs Lynn Faulds Wood, President of ECPC*
  - *Prof Michel Coleman, London School of Hygiene & Tropical Medicine*
  - *Dr Sanja Rozman, EuropaDonna Slovenia*
  - *Prof Mike Richards, Department of Health, UK*
  - *Mrs Hiltrun Sundseth, Head ECPC Brussels Office*

**Recommendation - Call for European Cancer Task Force**

18.30

Close of day and cocktail party

Sunday, 5 November 2006

10:00 – 14:00

United Against Cancer Rally

Venue: Congress Square, city centre

WWW.UNITEDAGAINSTCANCER.EU

# PREMAGAJMO RAKA!

Z NAMI BODO TUDI:

- Nuša Derenda
- Parlament Dixie Band
- Vill Resnik
- skupina Victory
- Marjan Novina
- slovenski športniki

**EUROPEAN CANCER PATIENT COALITION**

Vabljeni na prireditev "Premagajmo raka!", ki bo  
**V NEDELJO, 5. NOVEMBRA, OD 10. DO 14. URE, NA KONGRESNEM TRGU**  
v Ljubljani.

**TAM BOSTE LAHKO:**

- Vprašali vas, kar vas zanima o bolezni.
- Spoznali družbo onkoloških bolnikov.
- Prebrskali dobrote slovenskih obolih bolnikov.
- Prebrskali pričevanje obolevanj in odnosa ljudi.
- Srečali na gel in vodni na kol z avtorici Slovenski športniki.

**VSE! BREZPLAČEN ČAJIN KOSTANJ ZA VSE!**

V so delo vezja iz:

- centro za onkološki skrbni svet
- Evropska unija
- EUROPA DOMNA

# **OPENING SESSION**

## **Dr Janez Drnovšek**

### **President of the Republic of Slovenia**

#### **Biography**



Dr Janez Drnovšek was sworn in as President of the Republic of Slovenia at the National Assembly on 22 December 2002, after he had presided for ten years over both the Government of the Republic of Slovenia and the leading parliamentary party, the Liberal Democracy of Slovenia. As president of the Liberal Democracy of Slovenia, he succeeded in leading the party to victory at the parliamentary elections three times, in 1992, 1996, and 2000.

Dr Janez Drnovšek was born on 17 May 1950 in Celje. He graduated in economics at the University of Ljubljana's Faculty of Economics. In 1986, he finished his doctoral studies in economic science at the Faculty of Economics and Business in Maribor. In

1994, he received an honorary doctorate from the University of Boston, and in 1999, an honorary doctorate from the Illinois Wesleyan University. In 2004 he also received the honorary functions of Protector and Honorary Senator of the European Academy of Sciences and Arts from Salzburg.

Until 1989, he held various positions in the economic sector and was involved in credit and monetary policy. After a successful career in banking, Dr Drnovšek was elected as the Slovene representative in the collective presidency of the former Yugoslavia at the first free and democratic elections in April 1989. From May 1989 to May 1990 he was the Head of the Presidency of the former Yugoslavia. In September 1989, he presided over the Summit of the Non-Aligned in Belgrade. During Slovenia's independence negotiations, Dr Drnovšek was the principal negotiator between the Slovene leadership and the leaders of the former Yugoslavia and the high command of the Yugoslav People's Army. In July 1991, he successfully negotiated the final withdrawal of the Yugoslav Federal Army from Slovenia. In recognition of his outstanding merit in defence of the freedom and sovereignty of the Republic of Slovenia, on 24 July 1992 Dr Drnovšek received the highest state decoration, the Golden Order of Freedom of the Republic of Slovenia.

During his years of political activity, Dr Drnovšek has taken part in many international meetings, conferences and forums with participants from the highest levels. For his political, economic and humanitarian achievements and personal contribution to Slovenia's successful transition to democracy and its development into a democratically and economically stable country, as well as towards its inclusion into the European and international communities, Dr Drnovšek has received a number of international awards, such as Le prix de la Méditerranée (Crans Montana Forum, Malta, October 1995), the Public Leadership Award (Hubert H. Humphrey Institute of Public Affairs, University of Minnesota, May 1997), the award of the Fund for American Studies (American Institute of Political and Economic Systems, Prague, August 1998), the Diálogo Europeo award (Madrid, November 1998), and the Ramón Trias Fargas award (Barcelona, November 2003).

Dr Drnovšek is a frequent guest of honour and lecturer at prestigious international establishments and universities all over the world. He is also the author of many articles in the fields of credit control and monetary policy, as well as on international financial relations, in which he has focused on the world loan crisis. In 1996, his book was published, *Moja resnica* (Escape from Hell), in which Dr Drnovšek described his experiences and views of the break-up of the then Yugoslavia. In recent years, Dr Janez Drnovšek has been publishing his analyses of and commentaries on topical international questions, in the most important world media. As President of the Republic of Slovenia, Dr Drnovšek has promoted a debate on the future of the Republic of Slovenia and has invited Slovene experts in various fields, academicians, scientists, economists, and various other representatives of Slovene society to participate in a wide public debate in order to highlight the topics that are of vital importance to the future of the Slovene state.

Dr Drnovšek is fluent in English, French, Spanish, and German.

## **Minister Andrej Bručan**

### **Slovenian Minister of Health**

MSc, M.D.

Andrej Bručan was born in Kranj on 10 February 1943. He completed his grammar school studies in Ljubljana in 1961 and graduated from the Faculty of Medicine, University of Ljubljana in 1967. He completed specialist studies in internal medicine in 1974, undertaking further postgraduate studies in cardiology in 1976 and 1977 in Warsaw and Ljubljana. He was given the title of lecturer at the Ljubljana Faculty of Medicine in 1981 and elected to the post in 1986. He completed his specialist cardiology studies in 1992 at the Faculty of Medicine in Ljubljana.

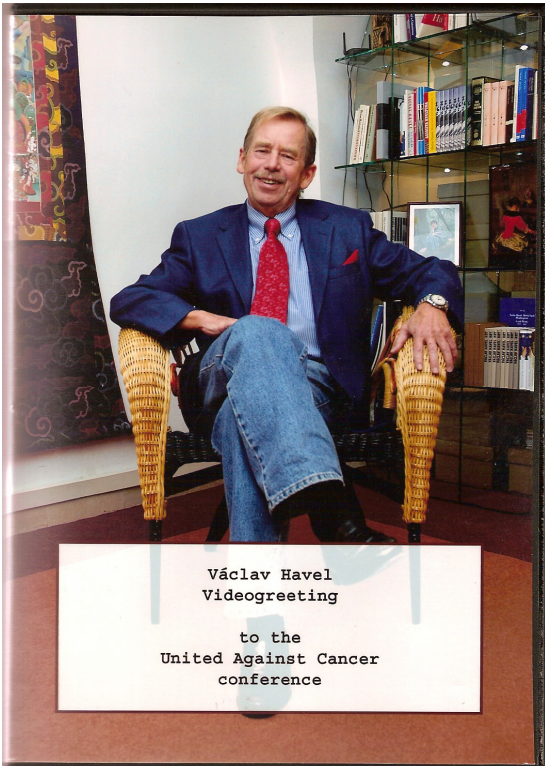
Mr. Bručan was employed at University of Ljubljana Medical Centre from 1969, first at the Clinic for Infectious Diseases and Fevers and then, from 1974, at the Zaloška Internal Medicine Clinics, where he was made head of the emergency internal medicine service and coordinator of the Clinics in 1979, as well as supervisory mentor for junior doctors on probation and interns at University of Ljubljana Medical Centre. Mr. Bručan has taken part in numerous international projects and lectured at a variety of seminars and conferences in Slovenia and abroad, chiefly in the fields of emergency medicine and cardiology. Since 1994 he has organised an annual international emergency medicine symposium; it has since become one of the largest specialist healthcare gatherings in Slovenia. In 1998 he was co-organiser of the 1.st European emergency medicine congress in San Marino. He is a member of a large number of international professional associations, president of the Slovenian Society for Emergency Medicine, member of the executive committee of the European Society for Emergency Medicine, member of the executive committee of the European Resuscitation Council and elected coordinator of these institutions. He is also a member of the Slovenian Society for Intensive Internal Medicine and the Slovenian Society of Cardiology.

Mr. Bručan speaks English and German, and has a passive knowledge of French.



# Václav Havel

## First President of the Czech Republic



***President of the Czech Republic, prominent playwright and poet, one of the leading intellectual figures and moral forces in Eastern Europe. Havel's role as a public figure has now somewhat overshadowed his record as a dramatist and political essayist.***

Václav Havel was born into a well-to-do family in Prague. His father owned Prague's cliff-top Barrandov suburb and his mother, Božena Havlová, the daughter of an ambassador and journalist, encouraged her son's intellectual and artistic ambitions. Because of his 'bourgeois' background he was denied the right to attend university.

In 1951-55 Havel worked as a laboratory technician. He studied at a technical college (1955-57) and served in the Czechoslovak Army (1957-59). Havel had joined Group 42, and after challenging the older generation of writers in their magazine *Kveten* (May), he was for the first time noticed as a writer. In 1964 Havel married Olga Šplíchalová (1933-1996). They bought a small farm near the Polish border, where the happy couple was visited by a number of their friends. After his wife's death Havel married an actress, the former Dagmar Veskrnová.

In the 1960s Havel made his way in the theater, first as a stagehand, and then becoming resident writer for the Prague "Theatre on the Balustrade" from 1960 to 1969. During this time he continued his education at the Prague Academy of Art. His first play as the dramatic consultant of the theater Na Zábřahách, *The Garden Party* (1963), was a satire of modern bureaucratic routines. It was a success both at home and abroad. Havel was subsequently enrolled at the Academy of Dramatic Arts and he graduated in 1967. Prague Spring was crushed by Soviet-led Warsaw Pact forces in 1968. A few years earlier he had joined the editorial board of the literary magazine *Tvarin*, which was soon in conflict with the conservative Writers' Association. The magazine ceased to appear in 1969. In the same year Havel's passport was confiscated because his writings were considered subversive.

During the 1970s and 1980s Havel was repeatedly arrested, and he served several years in prison for his dissident activities (1977, 1978-79, 1979-83, 1989). After the communist regime sentenced Havel in 1979 to 4 1/2 years in prison for subversion, he was given the opportunity to emigrate, but he chose imprisonment. In the 1980s Havel became the undisputed unofficial leader of the Czechoslovak human rights movement. In November 1989 he formed a new opposition group, Civic Forum. Following the fall of communism, Alexander Dubček (1921-92), who had launched a series of reforms in 1968 and was subsequently expelled from the Presidium, was elected chairman of the parliament. Havel was elected in 1989 by direct popular vote as president of the Czech and Slovak Federal Republic, following Gustav Husák.

Havel's first great defeat was the 1992 break-up of Czechoslovakia. He resigned but was elected president of the new Czech Republic in February 1993. Havel promoted reconciliation with Germany, and lobbied for the Czech Republic's entry into Nato and the European Union. Havel has said that as soon as his homeland does not need him, "I will with great appetite devote myself to my original profession." Before stepping down as President, Havel became the target of smear campaigns by the tabloid media and he was criticized by communists. However, he remained for most citizens in his country among the most popular politicians.

**SESSION 1:**  
**IMPROVING CANCER SURVIVAL**

**Alojz Peterle**  
**Member of the European Parliament (Slovenia)**  
**and co-chair of the MEPs against Cancer (MAC)**

**CURRENT FUNCTIONS AT EUROPEAN LEVEL:**

- **Member, European Parliament since 2003**
- **Vice-President, European People's Party**
- Vice-President, UEF (Union of European Federalists)
- Leader, Slovenian Delegation, European Peoples Party - European Democrats (EPP-ED) Group
- Full member, Committee on Foreign Affairs, European Parliament
- EPP-ED Coordinator for the Religious Dialogue with the Orthodox Church
- Member, Delegation for Relations with the Countries of Southeast Asia and the Association of Southeast Asian Nations (ASEAN)
- Substitute member, Delegation to EU-Russia, Parliamentary Cooperation Committee
- Substitute member, Committee on Environment, Health, and Consumer Protection
- Founder and co-chair of the informal all-party forum "MEPs Against Cancer" in the European Parliament
- Member of the board of the Schuman Foundation

**PREVIOUS FUNCTIONS AT THE EUROPEAN LEVEL:**

- Personal Representative of Chairman-in-Office of the OSCE for Central Asia 2004-2005
- **Member of the Presidium of the Convention for the Future of Europe, on behalf of the candidate countries, April 2002.**
- Chairman, European State Legislative Leaders Foundation, since 2000 (board member since 1999)
- **Vice-President, European Union of Christian Democrats, 1996-1999**

**PREVIOUS FUNCTIONS AT THE NATIONAL LEVEL:**

- **1990-1992 Prime Minister of the first democratically elected Slovene Government**
- 1990, 1992, 1996, and 2000 elected member of Slovene National Assembly
- **1993-1994 Deputy Prime Minister and Minister of Foreign Affairs**
- 1996-2004 Chairman, Parliamentary Commission for European Affairs
- **1990-2000 President, Christian Democratic Party of Slovenia**

**EDUCATION:**

- BA (Honours), Geography and History
- BA (Pass Degree), Economics

## **Lynn Faulds Wood** **ECPC President**

Lynn Faulds Wood is an award-winning TV presenter and health campaigner.

A graduate in French and Spanish from Glasgow University, Lynn and her husband John Stapleton were the first married couple TV presenters in the UK, presenting the BBC peak time consumer programme Watchdog for many years.

In 1991, when her son was three, Lynn was diagnosed with colorectal cancer (also known as bowel and colon cancer), the second biggest cancer killer in the UK and the commonest cancer across Europe. She had never even heard of the disease at that time. Due to nearly a year of medical delay, Lynn had advanced cancer and was lucky to survive.

Lynn left Watchdog to concentrate on making medical programmes, with the first - "Doctor Knows Best" - focusing on family doctor training in cancer symptoms, attracting an audience of over 10 million. It was followed by a woman's health series called "The Ladykillers" and an award-winning investigation into colorectal cancer called "Bobby Moore and Me" – Bobby, who died of bowel cancer, was the UK's finest footballer. The "Bobby Moore & Me" programme brought in 28,000 letters and Lynn decided to take a break from TV to concentrate on saving lives from bowel cancer. Her personal experience of misdiagnosis inspired her to help produce new research-based symptoms' advice for this common cancer. This advice has now been officially adopted by the UK Department of Health.

She has also helped to change the way doctors learn to use sophisticated equipment with the setting up of formal national diagnostic training programmes for doctors and nurses, organised "Patient Feedback Parties" for bowel cancer patients, among other initiatives. She is a judge of the ACE Cancer Writers Award, created and run by the European School of Oncology in Milan.

Lynn has encouraged people at the highest level to get involved with this neglected cancer – people like the UK heir to the throne, the Prince of Wales and many celebrities. Two years ago she was invited to the Vatican to meet the Pope, to help launch the world's first global awareness campaign for this common cancer. In 2004 she was given an honorary doctorate for services to bowel cancer.

Lynn is President of the European Cancer Patient Coalition, launched in 2003, still works part-time in television and runs a voluntary cancer charity (Lynn's Bowel Cancer Campaign – [www.bowelcancer.tv](http://www.bowelcancer.tv)). John & Lynn have an 18 year old son Nick.

**Michel Coleman**  
**Professor of Epidemiology and Vital Statistics**  
**London School of Hygiene & Tropical Medicine**  
[michel.coleman@lshtm.ac.uk](mailto:michel.coleman@lshtm.ac.uk)

**BA BM BCh MSc MFPHM**

***Background***

Since 1995, he has been Professor of Epidemiology and Vital Statistics at the London School of Hygiene & Tropical Medicine. He was Deputy Chief Medical Statistician at the Office for National Statistics, 1995 to 2004 and Head of the Cancer and Public Health Unit at the School, 1998 to 2003. He has previously worked for the World Health Organisation at the WHO's International Agency for Research on Cancer in Lyon (1987-1991), and was Medical Director of the Thames Cancer Registry in London (1991-1995). His main interests include trends in cancer incidence, mortality and survival, and the application of these tools to the public health control of cancer.

***Teaching***

He has been teaching epidemiology and public health since 1981, mainly at postgraduate level and has directed and/or taught on national and international intensive courses in advanced epidemiological methods in English, French, Portuguese and Spanish. He is on the ***Examination board*** of the MSc Epidemiology (London, 1997-) and was ***External examiner*** Diploma in Public Health (Cambridge, 1997-2000).

***Research***

We are carrying out a wide range of projects to quantify, describe and explain patterns and trends in cancer survival by socio-economic group, geographic area and ethnicity, as well as extending the methodology and tools for survival analysis, in collaboration with many research partners in the UK and around the world. We develop (and maintain on the web) a STATA program for relative survival analysis. This study commenced in April 2005. We recently updated national estimates of the socio-economic gradient in cancer survival in England and Wales among four million adults diagnosed with one of 20 major cancers between 1971 and 1999 and followed up to December 2001. We produce survival estimates for patients with one of 8 major cancers in English Health Authorities for use as NHS High-Level Performance Indicators. We are co-ordinating the CONCORD project to compare survival up to 1999 among over 2 million patients diagnosed with cancer of the breast, bowel or prostate during 1990-94 and followed up to 1999 in over 30 countries on five continents. With the Childhood Cancer Research Group in Oxford and the UK Children's Cancer Study Group, we aim to measure trends in the cure rate for UK children with leukaemia between 1971 and 2000.

***Committees and research groups (current)***

Project Management Group of EURO CARE [cancer survival] 1989-); Comité national des registres (France, 1991-); Cancer Registry Advisory Group (Childhood Cancer Research Group, Oxford, 1994-); Advisory Committee on Cancer Registration (DH, 1995-); Conseil scientifique (Public Health Department, Université de Montpellier, France, 1995-); Scientific Adviser, Northern Ireland Cancer Registry (1998-); Scientific Adviser, Children with Leukaemia (1999-); Steering Committee, EUROCHIP [cancer health indicators] project (EU) (2002-); Scientific Adviser, West Midlands Cancer Registry (2004-); Advisory Group on Ionising Radiation, National Radiological Protection Board (2004-); Bowel cancer treatment working group, DH NHS Bowel Cancer Programme (2005-)

***Editorship***

British Journal of Cancer (Epidemiology section) (1995). International Encyclopedia of Public Health (Editor, Cancer Section) (2004-)

### ***Scientific programme reviews***

Childhood Cancer Research Group (Department of Health); Europe Against Cancer Programme (EEC); National Institutes of Health (USA); Scientific Policy Directorate (Belgium); Scientific Commission on INSERM Cancer Epidemiology Unit (France); Cancer Research UK Population and Behavioural Sciences Committee; Department of Health Research and Development, Investing for Health; Scientific Commission of the Swiss Cancer League; INSERM (Institut national de la santé et de la recherche médicale), (France).

### ***Learned societies***

American Association for the Advancement of Science (USA); British Association of Surgical Oncology (UK); International Epidemiological Association; Public Health Association (UK); Société française de santé publique (F); Society for Epidemiologic Research (USA); Society for Social Medicine (UK)

Co-founded with Dr Jacques Estève (IARC) and Dr Ole Jensen (Denmark) the ***European Network of Cancer Registries*** in 1989 and co-founder with other UK registry directors of the ***UK Association of Cancer Registries*** (chairman 1991-95).

**Dr. Marija Seljak**  
**Ministry of Health of the Republic of Slovenia**  
**General Director of the Public Health Directorate**

Ms Marija Seljak first work experience was at the Regional Institute of Public Health in Kranj, where she started to work as medical doctor epidemiologist in the Department of epidemiology. Dealing with outbreaks control and communicable diseases surveillance she gained experiences in communication, teamwork and decision-making.

In 1990 Ms Marija Seljak started her career as a director of that Institute. During these years she participated in quality system introduction. She also became an assessor of the quality systems on the Standards ISO 9000.

Looking for additional knowledge in management she finished MBA at the IEDC School of Management Bled. She graduated with the project The Future of the Public Health Institutes in Slovenia.

In 2002 she moved to the National Institute of Public Health in Slovenia where she worked as the Head of the Centre for Environment and Health.

In the period 2004 - 2005 she worked as a Director General of the University Clinic of Pulmonary and Allergic Diseases Golnik.

In the 2005 she became a General Director of the Public Health Directorate at the Ministry of Health of the Republic of Slovenia.

**Professor Mike Richards**  
**National Cancer Director**  
**Department of Health, UK**

**CBE MA MD FRCP FFPH FRCPath (Hon) FRCR(Hon) FFPH DSc(Hon)**

Professor Richards was appointed as the first National Cancer Director in October 1999. In 2000 he led the development of the NHS Cancer Plan, the first comprehensive strategy to tackle cancer in England and since then has been responsible for overseeing its implementation. He works closely with ministers, parliamentarians, civil servants, clinicians, managers, patient groups, charities, researchers and industry to achieve the objectives of the plan.

Prior to his appointment to the Department of Health, Prof Richards was a Consultant Medical Oncologist at Guy's Hospital specialising in breast cancer (1986 - 1995) and Sainsbury Professor of Palliative Medicine at St Thomas' Hospital (1995 - 1999). He was also Clinical Director of Cancer Services at Guy's and St Thomas' from 1993 to 1999.

In 2001 he was appointed CBE in the New Year's honours. In 2003 he was awarded the Hambro Macmillan Fellowship for his contribution to cancer services.

Mike was closely involved in the establishment of the National Cancer Research Institute in 2001 and has been a board member throughout its first five years. In April 2006 he took on the post of Chairman of the NCRI Board in addition to his role as National Cancer Director.



**Mrs Brigitte Guillemette**  
**Head of European Affairs**  
**French National Cancer Institute**

Doctor of Economics, Head of European Affairs at the French National Cancer Institute

**Abstract**

**ON THE NATIONAL LEVEL,  
A GLOBAL VIEW OF THE FIGHT AGAINST  
CANCER**



The French National Cancer Institute is responsible for providing a global view of the fight against cancer in France. One of its main duties is therefore to monitor the implementation of the Cancer Plan. As a coordinating body, the National Cancer Institute is intended as a benchmark centre in terms of expertise and resources for researchers, healthcare professionals and government bodies.

Patients are at the heart of its operations. They participate in every aspect of the National Cancer Institute's actions. Efforts such as setting up a system to announce the disease to patients, prevention, screening, access to innovation and quality treatment are inconceivable without patient involvement. Moreover, the National Cancer Institute works in direct contact and in close collaboration with central healthcare and research administrations, health-related agencies and major scientific bodies. It therefore forms a bridge between the various institutions and their specific areas of expertise, and in so doing, has brought down barriers.

On the research front, the National Cancer Institute works in partnership with the existing research structures to avoid overlaps and to foster complementary lines of investigation and synergies. Its role is to define a coherent, coordinated strategy, and to support programmes that promote research by bridging the gap between the research lab and the hospital room, by providing additional funding and rigorous, objective and independent evaluations.

**◆ The missions of the National Cancer Institute**

- ❖ Define benchmarks for good practice and care in the field of oncology and the criteria for certifying institutions and professionals in the field of oncology.
- ❖ Inform professionals and the public.
- ❖ Participate in the implementation and validation of continuing education for doctors and paramedical personnel.
- ❖ Implement, finance and coordinate research projects in collaboration with the relevant public research organisations and charitable associations.
- ❖ Develop and monitor public/private actions in the areas of prevention, epidemiology, screening, research, education, care and evaluation.
- ❖ Participate in developing European and worldwide actions.
- ❖ Prepare expert reports on oncology and cancer issues at the request of the relevant ministries.

**◆ An innovative, interdisciplinary Institute**

The National Cancer Institute brings a new organisational model to the French public healthcare landscape: a disciplinary approach focusing on a disease and its victims. Researchers, healthcare professionals and patients are closely involved in the Institute's operations. Its long-term objective is to coordinate the efforts by all players in French oncology in an open atmosphere of humanity and national cooperation. The Institute comes as a response to the unaddressed problem observed by patients and professionals: the fragmentation of information and responsibilities in the fight against cancer.

The National Cancer Institute covers the entire spectrum of the fight against cancer and in particular, prevention, treatment and research. This integrated approach is relatively new to French healthcare, where existing bodies focus either on non-targeted cognitive research or research concerning pathologies as a

whole. This unique operational structure fosters cross-cutting policies and continuity from the lab to the hospital bed, even tackling the patient's complete social reintegration.

### **◆ Promote and coordinate French cancer care policy**

The National Cancer Institute's comprehensive view of the cancer care system puts it in a position to stimulate existing healthcare structures (without exercising any supervisory authority). In the area of care, the Institute's main objective is to ensure that all cancer patients in the healthcare system have equal access to quality care that meets existing clinical practice standards, thereby maximising their chances of recovery.

The National Cancer Institute's goals must contribute to this objective by:

- coordinating the implementation and assessment of healthcare organisations to ensure the coordination and continuity of cancer care from one healthcare facility to the next, both in space (geography) and time (throughout the illness).
- optimising the organisation of oncology networks
- promoting the intra-regional organisation of cancer care in each region,
- devising clinical practice recommendations and their dissemination
- promoting the quality of healthcare both in the hospital and community
- establishing quality criteria for the certification of cancer care units, and monitoring their implementation.
- certifying regional cancer care networks
- assessing the national care system for cancer patients and its impact on public health.
- establishing a summary chart to track this system.
- creating a database of authorised cancer structures and provide criteria to help direct patients both regionally and nationally.
- implementing monitoring and evaluation measures for therapeutic innovations, and providing advice on access to these innovations in conjunction with the scientific advisory board.

### **◆ Define and unite cancer research policy**

The National Cancer Institute manages the "Canceropôles", defines overall research strategy and validates plans of action with them. It also carries out certain research activities directly, particularly in the humanities and social sciences, and acts as a flagship for French cancer research. In this area, the National Cancer Institute's goals are to:

#### **▶ Lend impetus to fundamental research.**

The seven Cancéropôles, which were created as part of the Cancer Plan and have been in place in France since 2003, were specifically devised to foster fundamental cancer research. The National Cancer Institute will continue to organize and direct these units by:

- issuing tender invitations to select and finance projects;
- financing post-doctoral programmes;
- participating in national programmes;

#### **▶ Lend impetus to research in the social sciences and humanities.**

#### **▶ Lend impetus to clinical research and translational research**

The National Cancer Institute aims to ensure the participation of 10% of patients in clinical trial protocols as soon as possible and to promote the transfer of knowledge from fundamental research to clinical research. To accomplish this mission, the National Cancer Institute will, in practice:

- provide financial support to existing clinical research structures by issuing four invitations to tender for major national research projects every year;
- create and coordinate unifying structures for clinical research with:
  - the certification of a national network by strengthening regional means for clinical research in order to promote patient participation in research protocols, and the creation of clinical research groups specific to each type of tumour, including rare and orphan tumours.
  - the certification of data processing centres in order to work together on defining a strict and coherent clinical testing methodology.
- create coordinating taskforces with the pharmaceutical and biotech industries, as well as patient committees,
- provide regulatory expertise to assist the Cancéropôles with the legal aspects of their clinical trials, and,
- assess research protocols.

**Magdalena Bielska-Lasota, MD PhD**  
**Assistant Professor (Adiunkt)**  
**Maria Sklodowska-Curie Memorial Cancer Center**  
**and Institute of Oncology, Warsaw (Poland)**

**Present position:**

1989-2006 Assistant Professor (Adiunkt) in the Maria Sklodowska-Curie Memorial Cancer, Center and Institute of Oncology, ul. W.K. Roentgena 5, 02-781 Warszawa, Poland e-mail: [mbielska@coi.waw.pl](mailto:mbielska@coi.waw.pl)

**Main professional activities:**

Co-ordination of multi-centre research projects on cancer epidemiology and the quality of care in Poland  
Co-ordination of EUROCARE and EUROCHIP studies in Poland  
Participating investigator in several multi-centre research projects in clinical epidemiology and the quality of life of cancer patients, in collaboration with European Organization for Research and Treatment of Cancer (EORTC) Quality of Life Study Group, Belgium  
Participation in activity of the Public Health Committee of Polish Academy of Science  
Teaching cancer epidemiology to medical students, Medical University of Warsaw

**Academic Degrees/Diplomas:**

1973 - MD, Medical Academy of Warsaw, Poland  
1981 - PhD in Medicine, Pomeranian Medical Academy of Szczecin, Poland  
Specialization: 1st degree in Internal Medicine; 2nd degree in Epidemiology

**Complementary vocational qualifications:**

Numerous training courses in cancer epidemiology, cancer registration and clinical trials held variously with WHO, IARC, ESO and Finnish Cancer Registry

**Previous appointments:**

1973-88 - Physician in the National Health Service, Warsaw, Poland  
1982-84 - Senior Registrar, Health Service Management Board, Kano, Nigeria

**International fellowships:**

1976 - Endocrinology Department, Erasmus University, Rotterdam, the Netherlands  
1993-94 European Organization for Research and Treatment of Cancer, Brussels, Belgium  
1995 Visiting Research Fellow, Cleveland Clinic Foundation, Cleveland OH, USA

**Society Memberships:**

Polish Chamber of Physicians 1994-  
International Epidemiological Association 1996-  
Polish Epidemiological Association 2004-

**Publications:**

Over 50 publications and abstracts in Polish and English

**SESSION 2:  
CANCER RESEARCH  
AND GOOD PRACTICE**

**Dr Irena Belohorskà**  
**Member of the European Parliament (Slovakia)**  
**Member MEPs Against Cancer (MAC)**

**Member of European Parliament**

- Conference of Presidents, Member
- Committee on the Environment, Public Health and Food Safety, Member
- Subcommittee on Human Rights, Member
- Delegation for relations with the countries of Central America , Member
- Committee on Foreign Affairs, Substitute

**Curriculum vitae**

- Certificate of postgraduate study, grade one, in gynaecology and obstetrics (1976). Certificate of postgraduate study in clinical oncology (1982). European School of Oncology (1992). Doctor's assistant (1973-1976). National Oncological Institute (1977-1983). Expert doctor, Tunis (1983-1986). Head doctor of the Preventive Centre at the National Oncological Institute (1986-2002). Head of a faculty hospital (1992-1993).
- Head of the Office of the Ministry of Defence (1993). State Secretary at the Ministry of Foreign Affairs (1993). Minister of Health (1993-1994).
- Member of HZDS (Movement for a Democratic Slovakia) (1993). Chairwoman of a town organisation of HZDS (1996). Member of the European Democrat Group at the Council of Europe (1999)..
- Member of the Federal Assembly of the Czechoslovak Federal Republic (1992). Member of the National Council of the Slovak Republic (1994-2004).
- Vice-Chairwoman of the Foreign Affairs Committee (1994-1998). Vice-Chairwoman of the Committee for European Integration (1994-1998). Vice-Chairwoman of the Human Rights Committee (2002-2004). Member of the Permanent Delegation of the National Council of the Slovak Republic to the Council of Europe (1994-2004). Member of the Delegation to the Western European Union (1994-2002). Member of the Delegation to the NATO Parliamentary Assembly (1994-2002).
- Chairwoman of the Subcommittee on Health of the Council of Europe (1997-1999). Chairwoman of the Social, Health and Family Affairs Committee of the Council of Europe (2003).
- Awarded the decoration 'Rad A. Hlinka I stupňa' (Order of Andrej Hlinka, First Class) in 1994.

## **Dr Dorjan Marušič** **Deputy Minister of Health, Slovenia**

Dorjan Marušič was born on June 13, 1957 in Koper, Slovenia, where he completed his primary and secondary education. Upon graduation from the Koper High School in 1976 he enrolled at the University of Ljubljana, Faculty of Natural Sciences and Technology. He graduated in 1981 majoring in Pure Mathematics.

Shortly after that he became a medical student at the Faculty of Medicine at the University of Ljubljana and graduated in 1989. In 1989 he worked as a doctor trainee at the Primary Health Care Center in Koper. He specialized in internal medicine and served his internship at the Izola General Hospital, University Hospital Groningen and at the University Clinic for Internal Medicine in Ljubljana. In 1995 he earned his specialist degree in internal medicine. During the 1991 and 1998 period he took a number of graduate and advanced courses in the field of Internal Medicine. Between 1998 and 2000 he was the Head of the Unit of Intensive Care in the Izola General Hospital. In May 2000 he was appointed Medical Manager of the Izola General Hospital. In 2004 he became a Master Candidate in the field of Management of Non-profit Organizations at the Graduate School of Social Sciences at the University of Ljubljana.

Dorjan Marušič is the author or co-author of more than 100 titles of scientific works published in scientific journals and collections of scientific papers. In addition, he has published more than 200 other articles of miscellaneous topics and presentations. He gave several presentations and lectures at a number of conferences and experts meetings. He is the Head Expert of the Association of Coronary Diseases of Istra in Slovenia, Deputy president of the Experts Council of the Associations and Clubs of Coronary Diseases. He is also a member of the Slovenian Association of Urgent Medicine, Slovenian Association of Intensive Care and Association of Cardiologists of Slovenia.

Dorjan Marušič was appointed State Secretary at the Ministry of Health of the Republic of Slovenia in December 2000 and reappointed State Secretary at the Ministry of Health of the Republic of Slovenia in December 2004.

**Dr Janez Potočnik**  
**European Commissioner for Science and Research,**  
**European Commission**

**EDUCATION**

1993	Ph.D. degree in Economics Faculty of Economics at the University of Ljubljana Slovenia
1983	Bachelor's degree in Economics Faculty of Economics at the University of Ljubljana Slovenia
1989	Master's degree in Economics Faculty of Economics at the University of Ljubljana Slovenia

**PROFESSIONAL EXPERIENCE**

2002 - 2004	Minister for European Affairs
June 2001 - Jan 2002	Minister Councillor at the Prime Minister's Cabinet
June 2000 - Dec 2000	Acting director of Government Office for European Affairs
1993 – 2001	Director Institute of Macroeconomic Analysis and Development, Ljubljana
April 1998	Head of Negotiating Team for Accession of the Slovenia to the European union
1988 – 1993	Senior Researcher, Institute for Economic Research, Ljubljana
1984 – 1987	Assistant Director, Institute of Macroeconomic Analysis and Development, Ljubljana
1983 – 1984	Economic Analyst, former SDK (APP) Agency, Kranj

**CURRENT POSITION**

As a European Commissioner I belong to a [team of 25 Commissioners](#), one from each Member State, who will work together from 22 November 2004 to 31 October 2009.

Each Commissioner has his or her own field of responsibility. A rather unique aspect of the Commission is that it acts as a collective body, as a team. This means that when I present a proposal, all 25 Commissioners decide on it together. Equally, when another Commissioner presents a proposal in his or her field of responsibility, I take part in the decision. Legislative proposals are thereafter forwarded to the [Council of Ministers](#) and the [European Parliament](#).

**My field of responsibility is Science and Research.** My objective is to improve the situation for research and researchers in the EU. Research leads to knowledge and Europe needs new knowledge for growth and for enhanced quality of life in a globalised world.

I am supported by two Commission Departments responsible for science and research, the [Directorate-General for Research](#) and the [Joint Research Centre](#). Each Department is led by a Director-General who is responsible for implementing the science and research policy and supervising the day-to-day work. I work closely together with the Directors-General in setting out the priorities and providing the necessary political advice and guidance.

Although I come from Slovenia and was nominated to this post by the Slovenian Government, in my job as Commissioner I am completely independent from any national government and look to the interests of the Union as a whole.

**Prof. Tanja Čufer M.D., Ph.D.**  
**Board Member of the**  
**European Organization for Research and Treatment of Cancer (EORTC)**

Tanja Čufer, MD, PhD is Professor of Oncology at Medical Faculty, University of Ljubljana, Slovenia and she also serves as a senior consultant at the Institute of Oncology in Ljubljana. Dr. Čufer earned medical degree and PhD in oncology from the University of Ljubljana. Afterwards she completed her medical oncology training at the Stanford University and at The Netherlands Cancer Institute in Amsterdam. In the year 2004 she spent three months at the Jules Bordet Institute in Brussels as a visiting professor. She has been involved in various scientific societies, advisory boards and cooperative groups.

Currently she serves as the elected member of the General Board of the European Organization for Research and Treatment of Cancer (EORTC). She is also a member of the following medical societies: Slovenian Medical Society, European School of Oncology (ESO), European Society of Medical Oncology (ESMO) and the American Society of Clinical Oncology (ASCO). From 1998 she serves as a co-chair of the Central Eastern Oncology Congress.

Dr. Čufer's major scientific interest is breast cancer, bladder cancer, and prognostic and predictive factors with the focus on proteases. She plays an active role in new drug development and she has been principal investigator in more than 20 multi-national clinical trials. She is very active in academic research in oncology. Her fruitful professional work resulted in 57 papers published in peer-reviewed journals, including Journal of Clinical Oncology, Journal of National Cancer Institute and Cancer. She has contributed to many books on cancer, mainly with the articles on breast cancer, prognostic and predictive factors, proteases and bladder cancer. She is also a member of several editorial boards and a reviewer for numerous international medical journals.

Dr. Čufer has been an invited speaker at the European Society for Medical Oncology (ESMO) congress, European School of Oncology (ESO), Central European Oncology Congress (CEOC) and European Breast Cancer Conference (EBCC). Dr. Čufer is the recipient of the national anti-cancer society award.

**EDUCATION:**

Undergraduate: Elementary and High School, Celje, Slovenia.  
Medical Faculty, University of Ljubljana, Slovenia; graduated in January 1979.

Postgraduate:  
Residency and Board Exam. in Internal Medicine, Medical Faculty, University of Ljubljana; Nov. 1986.  
Master's Degree in Oncology (Title of thesis: Salvage Chemotherapy in Metastatic Breast Cancer), University of Zagreb, Croatia; November 1990.  
Ph. D. in Oncology (Title of thesis: The influence of primary tumor characteristics on the prognosis of breast cancer patients - stage I and II ), University of Ljubljana, July 1995.

**POSTDOCTORAL TRAINING:**

Residency in Internal Medicine: University Clinical Center, Ljubljana; 1982- 1986.  
Clinical Observer: Stanford University Medical Center, Division of Oncology, Stanford, USA, Sept.- Dec. 1992  
Visiting professor, Institute Jules Bordet, Free University of Brussels, Sept.-Dec. 2004



## **POSITION AND APPOINTMENTS:**

Specialist in Internal Medicine and Medical Oncology, Department of Medical Oncology, Institute of Oncology, Ljubljana, Slovenia – from 1986 to 1997

Head of Medical Oncology Department, Institute of Oncology, Ljubljana, Slovenia - from 1997 to 2003

Assoc. Professor, Faculty of Medicine, Chair of Oncology, University of Ljubljana, Slovenia – since 2001

Senior consultant, Medical Oncology Department, Institute of Oncology, Ljubljana, Slovenia-since 2003

Permanent Professor, Faculty of Medicine, Chair of Oncology, University of Ljubljana, Slovenia – since 2006

## **ORGANIZING ACTIVITIES AT INTERNATIONAL LEVEL**

- ◆ Co-chairman of the Central European Oncology Congress (1st, 2nd , 3rd, 4th )Opatija 1998, 2000, 2002,2004.
- ◆ Member of the organizing committee – 10th Reach to recovery UICC international conference, Ljubljana 1998.
- ◆ Member of the advisory committee – 2nd ,3rd , 4th, 5th European breast cancer conference, Brussels 2000, Barcelona 2002, Nice 2006.
- ◆ Chairman ESO course on Organ sparing treatment in oncology, Bled 1999.

## **RELEVANT EXPERIENCE:**

15 years experience as a medical oncologist mainly involved in breast cancer treatment. Active work on clinical research in the field of breast cancer, member of the EORTC BCG, EORTC IDBBC Group and IBCSG. 51 published papers in peer-reviewed journals, main themes: breast cancer, prognostic and predictive factors, proteases, bladder cancer. Assoc. Prof of oncology, 10 years of teaching experience, 7 monographies and co-authorship on chapters in books.

## **MEMBERSHIP IN INTERNATIONAL MED. SOCIETIES:**

Slovenian Medical Society, Ljubljana/Slovenia; member since 1979.

European School of Oncology (ESO) Alumni Club, Milan/Italy; member since 1988.

European Organization for Research and Treatment of Cancer (EORTC), Breast Cancer Group; member since 1989.

European Society of Medical Oncology (ESMO); member since 1992.

American Society of Clinical Oncology (ASCO); member since 1996.

## **MEMBERSHIP AND POSITION IN INTERNATIONAL SCIENTIFIC SOCIETIES**

EORTC General Board member since 2006

European organization for research and treatment of cancer (EORTC). Active member and representative for Slovenia since 1989.

## **AWARDS**

Recipient of the national anti-cancer society award for 1993.

## **Abstract**

### **Academic Cancer Research in CEE Countries**

**Prof. Tanja Čufer M.D., Ph.D.**

The burden of cancer is constantly increasing all over the world, and cancer rates could further increase to 15 million new cases in the year 2020, according to the World Cancer Report issued by the WHO. Due to better early detection and improved treatment strategies the survival of cancer patients is on a steady rise, people are living longer and better after cancer diagnosis. Main contributor to these is cancer research which led to improved cure rates, earlier diagnosis and less toxic treatments for many types of cancer. Clinical research is essential to translate new discoveries into clinical practice, to define state of the art treatment and by this guarantee the best medical practice.

The large scale multi-national trials are extremely important for progress in cancer because in common malignancies even a small improvement in survival will have a major impact on public health while; in rare tumors multi-national effort is necessary to ensure participation of an adequate number of patients in the trials; the participation in multi-national trials also discourages national/small sized trials, which are inconclusive, unethical and unnecessarily concomitantly conducted in several countries. High quality clinical research, which aims at developing new state of the art treatments, and not at registering new drugs alone is vital for improving the quality of patient care, therefore multi-national academic clinical trials oriented at evaluating multi-disciplinary treatment strategies as well as screening, prevention, diagnostic and quality of life issues on independent objective evaluation are to be strongly supported.

The European Organization for Research and Treatment of Cancer (EORTC) is one of the leading organizations promoting and conducting academic cancer research in Europe. Through conduct of large scale randomized phase 3 trials and meta-analysis, EORTC studies have had a major impact on establishing new standards of patient care, with trials exploring concomitant chemotherapy and radiotherapy after surgery in head and neck cancer, temozolomide with radiotherapy as adjuvant treatment in glioblastoma and targeted therapy in GIST, being the recent examples. Collaboration in academic international clinical trials is extremely important for small or less developed countries. It provides the patients with access to highest quality of care and to new treatment modalities and the health professionals with knowledge and expertise, thus leading to better national cancer care and quality of research. CEE countries are lately quite involved in EORTC led research, Poland, Slovenia, Slovak Republic, Czech Republic and Croatia being the most active ones, while on the other hand most central European countries have also been involved in clinical research conducted in the frame of Central and East European Oncology Group (established in 1983).

The major threat for academic research in Europe comes from increased bureaucratic and administrative work, high regulatory burden and increased costs, mainly originating from the new EU legislation, which is supposedly intended to harmonize and promote clinical research in Europe. To overcome these obstacles and promote independent academic clinical research in Europe the rules for clinical trials should be harmonized and simplified and funding for this kind of research should be increased. To improve cancer control in CEE countries we must ensure that a higher percentage of cancer patients (so far less than 5% of cancer patients participate) will have the option to participate in academic clinical trials in the future.

**Dr. Alberto Costa**  
**Director European School of Oncology (ESO)**

**RELEVANT PROFESSIONAL DETAILS**

- 2006- Coordinator of the Breast Unit at the Maugeri Foundation, Pavia.
- 2005- Coordinator of the Breast Unit of the Italian Speaking region of Switzerland (Canton Ticino).
- 2005- Chairman of the VI European Breast Cancer Conference, Nice 2006.
- 2001- Member of the Committee for Cancer Prevention of the European Commission:
- 2000-2002 Member of the Commission of the Italian Ministry of Health for the “Continuing Medical Education” and Advisor of the Italian Minister of Health.
- 2000-2005 Director of the Breast Surgery Unit at the Maugeri Foundation, Pavia.
- 1998-2000 Director, Scientific Communication and International Affairs - European Institute of Oncology, Milan
- 1998- Trustee of the “Challenge Fund, fighting cancer in developing countries”, London.
- 1997- Treasurer of the Southern - Europe New Drug Development Organisation (SENDO), Milan.
- 1995-1997 Secretary General of the Federation of European Cancer Societies (FECS), Brussels.
- 1994-1997 Deputy Director of the Breast Cancer Division and Head of the Training and Communication Unit - European Institute of Oncology, Milan.
- 1992-1993 Assistant Scientific Director of the National Cancer Institute of Milan.
- 1989-1994 Secretary General of the European Organisation for Research and Treatment of Cancer (EORTC), Brussels.
- 1986- Member of the European Commission Programme “Europe Against Cancer”, Luxembourg.
- 1984- Founding Member of the Italian School of Senology.
- 1982- Co-founder with Prof. Umberto Veronesi and Director of the European School of Oncology (ESO), Milan. Trustee of the European School of Oncology Foundation, Lugano, Switzerland.
- 1980 Medical Assistant as surgical oncologist at the National Cancer Institute of Milan.
- 1976 Graduated from the University of Milan with a thesis prepared at the National Cancer Institute of Milan.

**Dr Adamos Adamou**  
**Member of the European Parliament (Cyprus)**  
**and co-chair of MEPs against Cancer (MAC)**

**Member of European Parliament**

- Confederal Group of the European United Left - Nordic Green Left, Member
- European Parliament, Member
- Conference of Delegation Chairmen, Member
- Committee on the Environment, Public Health and Food Safety, Member
- Committee on Culture and Education, Substitute
- Delegation to the EU-Chile Joint Parliamentary Committee, Substitute
- Delegation for relations with the Palestinian Legislative Council, Chairman

**Curriculum vitae**

- Graduate in medicine (Athens, 1976); specialised in pathology (1982) and pathological oncology (2001).
  - Doctor with the Hellenic Anticancer Society (1976-1979).
  - Specialist doctor and pathologist at Pathology Clinic I of the Hellenic Red Cross Hospital (1979-1984).
  - Lecturer and deputy director of Pathological Oncology Clinic I of the Agioi Anargyroi Hospital (Athens, 1984-1985).
  - Deputy Director of the Clinical Oncology Department of Nicosia General Hospital (1988-1998).
  - Consultant Oncologist at the Bank of Cyprus Oncology Centre (1998-2003) and at the Medical 'Prevention' Centre (from 2004).
  - AKEL-Left - New Powers Member (from 2003).
  - Member of the parliamentary Health, Environmental, European Affairs and Audit Committees.
  - Representative of Cyprus in the European Society for Medical Oncology (ESMO) (from 1998).
  - Member of the Cyprus Medical Association and chairman of its Bioethics Committee.
  - Member of the Cyprus Anticancer Association and chairman of its information committee.
  - Chairman of the Scientific Committee of the Karaiskakio Foundation.
  - Elected member of the Pancyprian Medical Association for three continuing terms
  - Honourable mention from the Hellenic Breast Cancer Research Society.
  - Honourable mention and plaque from the Hellenic Psychosocial Oncology Society
  - Member of the American Society of Clinical Oncology (ASCO)
- 
- He is the author and co-author of many scientific articles about cancer published in local and international magazines.

**APPLYING GOOD PRACTICE**  
**Making Cancer Prevention a priority for Europe**  
Dr Adamos Adamou (MEP and co-chair of MAC)

**INTRODUCTION**

As we all know, the provision of healthcare is primarily a responsibility for national and regional authorities. However, the European role in health matters has progressively emerged within the last decades, in 2 main areas:

1° to help co-operation between Member States,

- to share and promote best practice in health across the European Union;
- to learn from each other;
- to look at successes in one part of the Union and to examine how this success can be replicated somewhere else.

2° to analyse the impact that other policy areas may have on health:

- environment policy,
- enterprise policy and its pharmaceutical legislation,
- regional policy and the Union's structural fund which rather than to focus on traditional infrastructure project should include greater scope for investment in health infrastructure because health is a vital component of economic success,
- the internal market rules which apply to health services, etc

The European action on health must add value to the work of the member States. The primary responsibility for health lies with member States as 99% of the funds.

Often the most effective form of action is to help Member States to work better together. In the area of health services, the 'open method of coordination' is helping Member States reflect on how best to respond to the common challenge of:

- demographic ageing,
- accessibility of care for all,
- high quality of care,
- long term financial sustainability of care.

The high level Group on health services and medical care is facilitating concrete cooperation on issues such as

- centre of reference
- patient safety,
- cross border healthcare purchasing and provisions,
- health impact assessment and health systems,
- health Technology assessment, etc.

By working together on these issues, the quality and efficiency of health services throughout the European Union may be improved.

**MAKING CANCER PREVENTION A PRIORITY FOR EUROPE:**

For many years, the European Union has already developed and funded several initiatives in the field of cancer. In addition to the funding for cancer research projects and the development of EU pharmaceutical legislation with specific provisions for anti cancer-drugs and the development of specific guidelines, the EU Institutions have mainly worked on issues like:

- epidemiological surveillance,
- screening,
- prevention,
- exchange of good practices

One very important action funded by the European Commission was the development of the European Code against cancer.

This project took place under the funding of the "Europe against cancer programme". The long term objective of which was to decrease by 15 % the number of cancer deaths by the year 2000 in Europe. Despite the fact that this objective was not entirely achieved, between 1987 and 2000 the annual mortality related to cancer decreased by 10% in Europe.

Under the Europe against cancer programme, another important funding was given to the European Cancer Registries network established in 1989 with the following objectives:

- to improve the quality, comparability and availability of cancer incidence data,
- to create a basis for monitoring cancer incidence and mortality in the European Union,
- to provide regular information on the burden of cancer in Europe,
- to promote the use of cancer registries in cancer control, health-care planning and research.

In terms of secondary prevention, the Council released on December 2003, the Council recommendation on cancer screening (cervical, breast, and colorectal cancer):

- pap smear screening for cervical cancer starting not before the age of 20 and not later than the age of 30;
- mammography screening for breast cancer in women aged 50 to 69 in accordance with the European guidelines on quality assurance in mammography;
- faecal occult blood screening for colorectal cancer in men and women aged 50 to 74.

The 2003-2008 FWP is now supporting the European cancer Network, a project aimed at analysing how these recommendations are implemented

## I. THE EUROPEAN CODE AGAINST CANCER

In 2002, the European Commission gave a new funding to re-evaluate and recast the previous version of the European code against cancer, resulting in the development of the 3<sup>rd</sup> version of the Code against cancer.

Many aspects of general health can be improved, and certain cancer avoided, if you adopt a healthier lifestyle

**1.Do not smoke**; if you smoke, stop doing so. If you fail to stop, do not smoke in the presence of non-smokers

**2.Avoid Obesity**

**3.Undertake some brisk, physical activity every day**

**4.Increase your daily intake and variety of vegetables and fruits**: eat at least five servings daily. **Limit your intake of foods containing fats from animal sources**

**5.If you drink alcohol**, whether beer, wine or spirits, **moderate your consumption** to two drinks per day if you are a man and one drink per day if you are a woman

**6.Care must be taken to avoid excessive sun exposure**. It is specifically important to protect children and adolescents. For individuals who have a tendency to burn in the sun active protective measures must be taken throughout life

**7.Apply strictly regulations aimed at preventing any exposure to known cancer causing substances**. Follow all health and safety instructions on substances which may cause cancer. Follow advice of national radiation protection offices

There are public health programmes that could prevent cancers developing or increase the probability that a cancer may be cured

8. Women from 25 years of age should participate in **cervical screening**. This should be within programmes with quality control procedures in compliance with European Guidelines for Quality Assurance in Cervical Screening

9. Women from 50 years of age should participate in **breast screening**. This should be within programmes with quality control procedures in compliance with European Union Guidelines for Quality Assurance in Mammography Screening

10. Men and women from 50 years of age should participate in **colorectal screening**. This should be within programmes with built-assurance procedures

11. Participate in **vaccination programmes against Hepatitis B** virus infection.

## II. THE FIGHT AGAINST TOBACCO

The Commission has always supported many anti-tobacco campaigns and has launched on 1 March 2005 a new anti-smoking campaign. Young people are the primary target of this Commission's new anti-smoking campaign. The Commission will spend 72 million euros until 2008 on promoting tobacco-free lifestyles, primarily among adolescents (15-18) and young adults (18-30)

**But all these initiatives do not represent a guarantee for all Europeans to profit from the best cancer programmes.**

For example, while screening programmes can help reduce deaths from certain cancers, in some Member States these programmes are poorly implemented or non-existent despite the Council recommendation.

## SO WHAT CAN WE DO?

We know that:

- Cancer is the second biggest cause of mortality in Europe and accounts for four out of ten deaths in the 35-65 age groups.
- In 2004, 2 millions of new cancer cases have been diagnosed, and 1.2 million deaths have been monitored in the 25 EU member states.
- Every day, 5214 Europeans are diagnosed with cancer and 3185 die from their disease.
- Cancer will affect 1 in every 3 Europeans and will kill 1 in 4.
- The number of Europeans with cancer will increase dramatically over the next 20 years due to the ageing of the European population.

And we also know, that in the field of health, the power of the EU Institutions is limited!

## GOVERNMENTS need to take urgent actions!

### 1° INFORMATION- COMMUNICATION CAMPAIGNS

Not everybody is aware about

- the basic prevention measures to be applied
- the extent of inequalities in health status and incidence of diseases across EU
- as about the significant discrepancies in cancer outcomes both within and between different EU member States

Governments need to develop communication campaigns to raise awareness among their citizens about cancer and the key measures to be applied to prevent as much as possible cancer.

**If we look at the 7 first measures listed in the code against cancer**, we can conclude that the EU citizens can apply these measures at **very low cost** or even in saving money (eg tobacco). But our citizens are probably not really aware about the risks linked to alcohol, obesity, lack of physical exercise, sun exposure, etc!

**This is the duty of each national Health Authority to develop a campaign to inform its citizens. Europe may help in developing a broad campaign, but in any case it will have to be adapted/tailored by individual governments for national implementation.**

## **2° CANCER SCREENING/ IMPLEMENTATION OF THE COUNCIL RECOMMENDATIONS**

The last 4 points of the code against cancer are dealing with the screening of cervical, breast and colorectal cancer, as well as with the vaccination against Hepatitis B.

The challenge we face to improve the discrepancies existing in Europe concerning cancer prevention (primary and secondary) and treatment is huge. But:

- we cannot accept that thousands of EU citizens are dying every year because their treatment is below standard or is given too late.

**We have to work very hard at national level to ensure that governments will put in place the Council recommendations.**

Of Course the implementation of screening as well as the development of a national cancer plan that each country should do, represent an **investment**.

We can anticipate that in the new Member States funds for the setting up of cancer plan and of population-based screening programmes will not be readily available.

But as it is known that **25 % of the difference in the mortality rates** between East and Western Europe is attributed to inadequacies in healthcare (Institut de la science et de la santé, Paris), we cannot just accept that the chance of surviving cancer is affected by where one lives, where one is treated and whether one has the necessary information.

The New Member States **can have access to the EU Structural Funds**, in order to accelerate improvement in health care and try to bridge the gap which is existing between the 15 old and the 10 new member States.

**Healthcare professionals, citizens and patients groups should campaign for mobilizing EU funds to set up cancer screening programmes and to improve cancer treatment services in their country. National authorities have to be lobbied in order to make sure that they will develop an explicit national framework for health improvement, without which they will never be able to be selected for any EU funding for health.** (For more information, please visit the ECPC website).

## **THE EUROPEAN PARLIAMENT, THE VOICE OF EU CITIZENS, IS WITH YOU**

In order to act as a driving force in all the complex issues related to cancer , a group of MEPs has decided to create in 2005, an initiative called **MAC**, "**MEPs against cancer**".

**MAC** is an all-party informal group of 51 MEPs committed to promoting action on cancer as an EU priority and harnessing European Health policy to that end.

**Mac members are calling on the Health Ministers to consider the following:**



1. Urgently to develop and, where existing, improve **national plans**, setting priorities and effectively allocating resources for improving cancer control and research across the European Union.
2. Firmly to **tackle the socio-economic and geographic divide**, that leads to inequalities in cancer control.
3. To make high quality and up to date **prevention, treatment and care attainable for all** cancer patients in each European Member State.
4. Vigorously to **promote cancer awareness** in the general public through the existing Europe against Cancer Code, making a special effort in new Member States.
5. To **invest in cancer prevention** in Member States through implementing the Council Recommendation on Cancer Screening of December 2003 and setting up national high quality screening programmes
6. To **oppose discrimination** because of age, race, gender and domicile in respect of the latest cancer treatments.
7. To **set up a Cancer Task Force at European level**, to exchange best practice and to highlight once again that tackling cancer is a priority and sending a strong political signal that immediate and concerted action is needed now.

MAC members are very committed and share the concept that altogether we will be able to make the difference. Patients, Healthcare professionals, policy makers, politicians and other interested parties **should work together to promote joint actions** in order to further increase the effectiveness of national measures and campaign for equal access to quality cancer screening programmes, early diagnosis, best quality treatment and care for cancer patients living in the EU Member States.

I thank you for your attention.

**SESSION 3:  
ACCESSING NEW  
ANTI-CANCER TREATMENTS**

**Dr Sanja Rozman**  
**EuropaDonna Slovenia**

**EDUCATION:**

- DOCTOR OF MEDICINE, UNIVERSITY OF LJUBLJANA, November 1979
- SPECIALIST IN OCCUPATIONAL HEALTH, UNIVERSITY OF LJUBLJANA, May 1989
- Postgraduate course in Traditional Chinese Medicine and Acupuncture, 1989
- Postgraduate course in Transactional Analysis (TA 101, TA 202, Advanced) 1993-1997
- Postgraduate course in Group Analytical Psychotherapy, 2000
- Postgraduate course in Behavioral and Cognitive Psychotherapy, 2002

**ACHIEVEMENTS:**

*1. BOOKS*

- **Sanje o rdečem oblaku** (Meditating on the Red Cloud), 282 pg., 1994, a bestselling book on personal development issues and life with a dying cancer patient ([http://www.emka.si/article.asp?article\\_id=9788611140995](http://www.emka.si/article.asp?article_id=9788611140995))
- **Zaljubljeni v sanje**, (People Who are in Love With Dreams), 344 pg., 1995, a monographic book on healing relationships
- **Peklenska gugalnica**, (The Swing of Hell), 346 pg., 1997, a bestselling book on non-chemical addictions and healing
- **Sprememba v srcu** (The Change in Heart), 270 pg., 2004, a bestselling book on relationships

*2. LECTURES*

- “**Just sitting and talking is not enough**” EASG Conference in Warsaw, 2000 ([http://www.easg.org/Warsaw/Presentations/sanja\\_rozman.htm](http://www.easg.org/Warsaw/Presentations/sanja_rozman.htm))
- “**Addiction – a disease or just a way of life**”, Theological Faculty Ljubljana, 2002 ([http://www.mic.si/mic-02/02/mic\\_02-02.htm](http://www.mic.si/mic-02/02/mic_02-02.htm))
- “**Character of Contemporary Spirituality**” Congress Center Ljubljana, 1995, round table ([http://www.cdk.si/om\\_gosti.htm](http://www.cdk.si/om_gosti.htm))
- “**Doctor-patient relationship, Patient’s point of view**”, ESMO, Vienna, 2004.
- “**Centering Care**”, ECCO 13, Nurses Seminar, Paris 2005
- “**Patient’s experience on Cancer**”, ESO seminar “Controversies in CAM”, Brussels, 2006
- “**Why patients Use CAM**”, ESMO, Nice, 2006
- over 100 public lectures for various audiences (medical doctors, social workers, parents and relatives of patients, people in distress, cancer patients and treatment personnel) on personal development, holistic medicine, addiction prevention and treatment, spiritual issues in healing, relationships, doctor-patient relationship etc. (<http://www.utrip.net/arhiv/html/dec01/17.htm>)

*3. PUBLICATIONS*

- “**Everybody makes his own love**”, an article in a women’s monthly health magazine VIVA on relationship problems, January 2003
- “**Should I Stay or Should I Go**”, an article in a women’s monthly health magazine VIVA on relationship problems, September 2003
- “**Do something for yourself**”, an article on holistic approach to cancer treatment in Europa Donna News Magazine, No5, 2001
- several interviews and articles in various magazines on relationships, group therapy, self-help groups
- since 1997 runs a column in a women’s monthly magazine on relationship issues, answering the readers’ questions (<http://www.viva.si/aktualna.asp>)

#### 4. NOMINATIONS

- nominated the **Samaritan of the year 2001 in Slovenia**

#### CURRENT OCCUPATION:

- **Doctor of medicine**, occupational health specialist, working in a team for Vocational Rehabilitation in the Institute for Rehabilitation (vocational assessment, finding suitable jobs for the handicapped population): 24 years of practice
- **President** of the society: "A Change in heart" ([http://med.over.net/telefonske\\_stevilke/drustvo.htm](http://med.over.net/telefonske_stevilke/drustvo.htm)) which provides help and psychotherapy for its members (over 600 in the last 9 years)
- **Member of honor** of Slovenian institution "Odsev se sliši" (The Sound Of Reflection) that promotes life free of addictions

#### SPECIAL FIELDS OF INTEREST:

- **self-help and therapeutic groups**, has initiated a network of groups for therapeutic purposes and support
- **group and individual psychotherapy**
- **relationships** : 8 years of experience in answering readers' questions on relationships, addictions and health issues in a woman's magazine. Recently emphasis on doctor-patient relationship
- **non-chemical addictions** such as bulimia, anorexia, sexual addiction, gambling, codependency
- **holistic approach to health** or "what else can you do besides going to a doctor to improve your physical, psychological, social as well as spiritual well-being", meditation, use of complementary medicine

#### EUROPA DONNA ISSUES:

- member since 2001
- several **public lectures** on holistic approach to cancer treatment since 2001 (the use of meditation, physical activation, diet, group support and therapy in cancer treatment). Chairman of several ED teaching lectures
- an article on holistic approach in **Europa Donna News Magazine**
- **breast cancer patient** since 2002, surgically treated, currently asymptomatic, working part time
- **Europa Donna Slovenia National Delegate and Board Member**
- **Since 2003 Europa Donna European Breast Cancer Coalition Board Member**
- **Advocacy training in Milan**
- **In 2004 represented ED on AACR meeting in Orlando, USA**
- **In 2005 and 2006 visited Latvia on behalf of ED to promote awareness**

#### LANGUAGE SKILLS:

- Slovenian, English, Croatian, French, German

**Dr Janez Remškar (Primarius)**  
**Director General Health Care Directorate**  
**Slovenian Ministry of Health**

Primarius Janez Remškar, M.D., was born on 11 June 1947 in Ljubljana.

In 1966 he enrolled at the Faculty of Medicine, Dept. of General Medicine and graduated in 1972. After completing internship, he was employed at the Institute of Pulmonary Diseases and Tuberculosis, Golnik, where he worked until May 1994.

Between 1975 and 1976, he completed postgraduate study in pulmonology, and in January 1980 passed his board exam in internal medicine. From 1980 to 1987, he worked as specialist in internal medicine at the Intensive Care Unit of the Institute; in 1987 he started to work in the Cardiovascular Rehabilitation Unit and became Head of that unit the following year (from 1988-1994). He has been a member of the Institute's Professional Board since 1985.

His Bibliography comprises 26 articles published in national and international professional journals, and 45 registered presentations at professional conferences in the country and abroad; in 1992 he received an AARC fellowship in the USA. He gives lectures on pulmonology within the regular postgraduate program, as well as lectures for physicians – residents in general medicine. Until 1990, he led a practicum in internal medicine for undergraduate students of the Faculty of Medicine. In the same period, he was mentor to two physicians preparing theses within their postgraduate studies. In 1993 he was awarded the title of Primarius.

In May 1994, in response to public tender, he was selected for the position of Director (executive and medical director) of the General Hospital Jesenice with a four-year mandate. While holding that function he attended a study course on health management at GEA College. I was re-elected to the position of Director in 1998. In the same period, he undertook additional education for the needs of hospital management in order to upgrade my knowledge of financial management as well as other managerial skills (documentation management, "Excellence in the public sector" project management). In 1999, the General Hospital Jesenice joined the latter project for the first time, with the aim of laying the foundations for future work and to test our current position. During that period, he twice represented the Republic of Slovenia at meetings of the European Association of Hospital Managers (Krakow 1997, Rome 1998).

In the period 1999-2000, he was appointed President of the Management Board of the Association of Health Institutions of Slovenia, and soon after that President of the Assembly of the same Association. For four years he functioned as a representative of healthcare service providers in negotiations with the Ministry and Health Insurance Institute of Slovenia regarding the Collective and Sectoral Agreement on Hospital Activities. Owing to a professional blunder by a subordinate physician (gynaecologist), in July 2001 he accepted strict liability for the event in question, and in October of the same year resigned from the post of hospital director. He continued to work as Acting Director until 5 June 2002. From that date on, he has been employed at the Health Insurance Institute of Slovenia as supervisory physician – adviser. In 2000 and 2001, he was editor of *FanBakon*, a journal that publishes unbiased objective reports on the effectiveness and adverse side effects of medicines (EU member states are obliged to maintain such a journal covering the sectors of healthcare and particularly pharmaceuticals, which should not be sponsored by the pharmaceutical industry or producers of medical-technical equipment).

From 1980 to 1984, he was President of the Municipal Board of the Red Cross in Kranj. In that period, assisted by Prof. Štangelj, MD, he organized a meeting with friendly municipal boards from other towns of Yugoslavia on the topic of blood-donation, which met with a

wide response. The meeting was attended by representatives from Leskovac, Zemun, Osijek, Hercegnovi, Zadar and Rijeka. Later, for a number of years he gave lectures in primary and secondary schools of the former municipality of Kranj, in the framework of the Red Cross. The conducting thread of all those lectures was "unhealthy lifestyles". He participated in the organization of blood-donation campaigns, which were based on an outreach principle, and thus brought closer to potential donors. Since 4 April 2004 he has been the President of the Slovenian Red Cross.

From 1990-1992, he was delegate of the Assembly of the Socialist Republic of Slovenia, in which he was appointed representative of healthcare in the Chamber of Associated Labour. He was vice-president of two committees and a member of five committees of the then Assembly. He took an active part in the preparation of new legislation in the fields of healthcare and social policy. In the period 1990-1994, he was an external, non-paid member of the Executive Council of the Municipality of Kranj, responsible for healthcare, labour, family and social affairs. There he would like to stress that in Kranj, there has never been any problems due to irresponsible approaches to solving healthcare and privatisation related problems. Further, he served two mandates as municipal councillor of the urban municipality of Kranj. In the last two years, as supervisory physician-adviser and president of the Slovenian Red Cross, he has become well acquainted with the problems of the elderly (including their personal, social and financial distress), while in the field of internal medicine, he has learned more about the work and differences between individual hospitals in this particular area of their activity.

Since 1 July 2005 appointed to the function of Director-General of the Directorate for Health Protection.

**Professor Dr Stanislav Primožič,**  
**Director of Slovenian Agency for Medicinal products and Medical Devices**

Prof. Primožič took the position of the Director of the Agency for Medicinal Products in 2001. Prior to his present appointment, he pursued an academic career at the University of Ljubljana, Faculty of Pharmacy. While his scientific background is in pharmacokinetics and pharmacoepidemiology, his regulatory experience prior to joining the Agency included work on several national regulatory Committees. He took part in the Pan-European Regulatory Forum (PERF) in the areas of Telematics, Pharmacovigilance and Acquis Communautaire. Since EU enlargement, he has participated in the work of EMEA Management Board, and European Commission bodies including the Transparency Committee. He is a member of the Pharmaceutical Forum Steering Committee.

His principal tasks as the Director include the development of the Agency's structure, services and activities into a modern national regulatory authority by integrating new areas of activity, in the first place pharmaceutical inspection and veterinary medicinal products regulatory affairs. He sees potentials for the competency of the Agency in mobilizing the internal and external expertise and intensifying international cooperation. As part of the Ministry of Health, the Agency also takes part in the policy issues such as reference pricing of medicinal products. In the area of medical devices, the inclusion of the Agency in the international information datasources and materiovigilance are the key priorities.

**Mojca Senčar, M.D.**  
**Europa Donna Slovenia**

**PERSONAL INFORMATION**

Born: April 4, 1940 in Slovenia

Citizenship: Slovenian

Breast cancer: surgery in 1981

**EDUCATION**

- 1964 graduation from the Faculty of Medicine,
- specialisation in anaesthesiology, specialist exam in Dec. 1970

**WORK EXPERIENCE**

- From October 1964 to April 2000 anaesthesiologist at the Oncological Institute, in the last years head of the department;
- In April 2000 retirement;
- Member of ED Slovenia since 1997;
- President of the Slovenian ED since February 2001;
- National representative of ED;
- Participation in the editorial board of NEWS ED;
- SOS telephone;
- Personal counselling;
- Organisation of lectures and giving lectures across Slovenia and participation in other projects.



## EUROPA DONNA, Slovenian breast cancer coalition:

### LESS PATIENTS AND MORE SURVIVORS

#### Let me quote some statistical data:

- June 30, 2003:
  - population in Slovenia (number of inhabitants): 1,996.773
  - older than 65 years 277.143

Source: Statistical Office of the Republic of Slovenia

- In 2003
  - In 2003 affected by cancer in Slovenia 9997 people
  - In 2003 died of cancer in Slovenia: 5058 people

Source: Cancer incidence in Slovenia 2003, Cancer registry in Slovenia, Institute of Oncology Ljubljana, Slovenia

- In 2003 affected by.
  - **breast cancer:**
    - women: 1083
    - men: 13
  - **colon- and rectum cancer:**
    - women: 525
    - men: 673
  - **cervix uteri cancer:**
    - women: 208

Five-year surviving period of patients (period 1993-97) in Slovenia compared with the same surviving space of time in EU in %:

	Slovenia	EU
• <b>breast</b>	<b>65,6 %</b>	<b>74,8 %</b>
• <b>colon</b>	<b>36 %</b>	<b>48 %</b>
• <b>rectum</b>	<b>30 %</b>	<b>44 %</b>
• cervix uteri:	56,2 %	59,9 %

Source: The EURO CARE-3 Study

I have intentionally presented these three localizations in order to make it clear that by a well organized screening the death rate could be reduced.

#### Which are in our opinion the reasons for worse surviving chances in Slovenia?

One of the key reasons is obviously insufficient cancer awareness of people. Many patients are still today visiting a doctor for the first time with already locally spread or metastatic disease.

Too few people realize that cancer is a curable disease if diagnosed at an early stage. And these facts should be therefore adequately explained and made clear already to young people at high schools. Yet just raising awareness of people is not enough. The necessary conditions for early

diagnosis of disease, immediate and efficient treatment and rehabilitation should be prepared and improved without delay. And here is where the health politics, professional dept. and health insurance scheme have to move and act.

We do have a state programme ZORA for early diagnosing cancer of cervix uteri cancer but it has not yet been able to completely fulfil its task as the women's response is not as good as we expected.

The state programme for early breast cancer diagnosing DORA is still at its infant stage. We still lack organized and specific primary and secondary centres according to the European and Slovene professional guidelines.

### **Why am I stressing this?**

Cancer, not only breast cancer, is such a disease that its diagnosing, treatment and rehabilitation belong to and should be run by specialized institutions which are additionally adequately equipped (furnished) and employ experts with improved oncological knowledge. Treatment of cancer requires a complex approach and must be performed by multidisciplinary - and multiprofessional teams.

And the experts – oncologists themselves are lecturing at congresses that better surviving is achieved with cancer patients treated at specialized institutions.

We are happy to know that cancer is getting more and more curable. Increasingly more people are after successful treatment returning home to their families and also to their working places. However joy over recovery from cancer is often marred by difficulties caused by the aftermath of treatment. They manifest themselves in impaired fitness for work, either psychological or physical. Unfortunately only a few employers are willing to take this into consideration. Furthermore commissions for the disabled are also reluctant to listen to these arguments when considering to grant part time work or possibilities for modified qualification so that the survivors could remain professionally active as long as possible. In case the troubles get too severe immediate measures should be taken to give the survivors the rights they are entitled to. Today we patients – the survivors are no longer satisfied just to survive but we want to live – we want to lead after the illness a full and decent life.

### **And what else do we require?**

Most people – when encountered with cancer – the disease which used to be not so long ago only whispered about – feel terribly hurt. First they seek comfort from their beloved ones, from their dear friends. But it is at that time certainly most important that we see a doctor who is an excellent expert – oncologist and at the same time a good person who is willing to listen and to help us overcome the worst problems, who can explain to us in an understandable language everything important in connection with our disease and about the available treatment possibilities, who does not hesitate to talk to us about changes in our life that we can expect after the treatment, who does not reject us if we wish to acquire second opinion from some other expert or do not wish to accept the suggested treatment. Someone we can trust and feel sure that he/she will help us choose the best treatment possible.

And in this sense already young medical students should be educated. They should be taught about pristine principles of communication, they should learn about the fears and troubles the cancer patients have to endure when attacked by this increasingly occurring disease.

Furthermore the responsible people should see that the normative provisions for the work of doctors and other medical staff are changed so as to provide the doctors with more time that should be dedicated to every single cancer patient.

### **And where is here the role of the civil society organizations ?**

I would like to quote a free version of the slogan of the European Coalition EUROPA DONNA:  
Equal chances for all cancer patients regardless of their place of birth, their financial status,

education or confession. Only organized groups of patients know and understand in detail what the various needs of every single patient are. For this reason they should take part in designing an efficient health system for individuals as well as the society as a whole. We the survivors, who are able, wish and are willing to collaborate voluntarily, are only seldom invited to take part.

However we are making efforts to raise the cancer awareness, promote healthy way of life stressing also the importance of including patients into clinical research studies. We organize lectures all around Slovenia, issue publications and brochures, appear in media, organize self-help groups, personal counselling, SOS telephones. We also offer our help in overcoming all sorts of problems, selection of proper treatment, acquirement of second opinions and much much more.

Surely it is our most important task to constantly remind the health politics that numerous lives depend on the organization of a complex cancer treatment in Slovenia which also includes a well organized palliative care. We wish to be involved here as well. Our organizations are performing an important work and if we could achieve closer ties through or common work our voice could be louder. Consequently the professional field and the health politics should more frequently pay attention to our suggestions and seek a more intensive cooperation with us.

#### Sources:

1. Cancer Incidence in Slovenia 2003:  
Cancer registry in Slovenia, Institute of Oncology Ljubljana, Slovenia 2006
2. 5th ESMO Patient Seminar Istanbul, Turkey, 30 Sept. – 1 Oct. 2006
3. Survival of Cancer Patients in Europe: The EURO CARE-3 Study

# **Jaka Jakopič**

## **Slovenian Footballer and Cancer Survivor**

### **EDUCATION**

- **1985-1993** Elementary School (France Bevk Ljubljana)
- **1993-1997** Secondary School (Sport Gymnasium Ljubljana-Šiška)
- **1998-** Faculty of Law

### **MY SPORTS CAREER**

- **NK Factor (1<sup>st</sup> division):** 2006 -
- **NK Factor (2<sup>nd</sup> division):** 2004 – 2006
- **Cancer survivor (1 year break from football)**
- **NK Domzale (1<sup>st</sup> division):** 2000 - 2002
- **NK Era Smartno (1<sup>st</sup> division):** on loan (second half 2001)
- **NK Dravograd (1<sup>st</sup> division):** 1999 - 2000

### **OTHER ACTIVITIES**

- Member of SPIN Committee
- Member of Slovenian oncology patient committee
- One of initiators of HEADS UP project
- One of initiators of CIRCLE OG LIFE project
- Active in a lot of oncology projects (FOR LIFE, PINK OCTOBER...)
- Member of editor committee of OKNO magazine
- Column writer
- Still professional football player

**SESSION 4:**  
**CREATING THE POLITICAL WILL**  
**ACROSS EUROPE**

**Dr Joaquim Gouveia,  
Ministry of Health, Portugal**

Joaquim Gouveia, born in Funchal on September 14, 1943.  
He obtained his medical degree at Lisbon University in 1970.  
Internship and residency at Hospitais Cívicos de Lisboa (HCL).

Trained at Institut de Cancérologie et Immunogenetique -Villejuif, France from 1977 to 1982, with Prof. Georges Mathé. His main interest was Clinical Pharmacology.

Post graduated in Clinical Haematology (Paris VII) and Experimental Oncology (Paris Sud). Board certified in Clinical Haematology and Medical Oncology.

Head of Haematology at HCL.

President of the Board of Directors of the Lisbon Center of Instituto Portugues de Oncologia.

Member of the National Board of Medical Oncology, represented Portugal at the European Society of Medical Oncology.

Member of the NATO panel "Life Science and Technology"

Former Clinical Director and Head of the Oncology Department of the Hospital CUF Descobertas in Lisbon.

National Coordinator for Oncology Diseases since April 2006.

**Magdalena Bojarska**  
**Institute for Patients' Rights and Health Education, Poland**

Graduated from Warsaw University, Spanish Philology. For several years she worked for the State administration - at the Chancellery of the Senate of Poland and at the Office of President Wałęsa. She also has long experience in political consultancy and lobbying - she worked for GJW Polska, a PR and lobbying Polish-British joint venture, and for CEC Government Relations. She has been involved in the activity in the III sector in Poland. She is the president of the Aid Foundation for Disabled Children in Warsaw and a member of the Board and a co-founder of the Institute for Patient's Rights & Medical Education – a not-for profit patient advocacy NGO.

**Assistant Professor Borut Štabuc, MD. PhD**  
**President of Slovenian Cancer League**

**Education:**

1979: graduated from the Faculty of Medicine, University of Ljubljana; general medicine

1987: Board Exam in Internal Medicine

1993: Ph.D. degree in the field of oncology and radiotherapy; Faculty of Medicine, University of Ljubljana

1994, 1999: Assistant Professor of Oncology

2002: Assistant Professor of Internal medicine

**Appointments and jobs held:**

1981-2000: Department of Medical Oncology, Institute of Oncology, Ljubljana

2000-: University Clinical Center Ljubljana, Department for Gastrointestinal Internal Medicine.

2006-Head of Gastroenterology department; University Medical Centre Ljubljana

2006: part-time assignment as Teaching Assistant at the Chair of Internal Medicine, Faculty of Medicine, University of Ljubljana

**Membership in professional associations:**

1988: European Society of Medical Oncology (ESMO), 1995-6: national representative

1992: President of "Doc Dr.J.Cholewa" Cancer Foundation

1997: President of Slovene Cancer Liege

1998 American Society of Clinical oncology (ASCO)



**Assoc. Prof. Maja Primic Žakelj, MD, DSc**  
**Head of Epidemiology and Cancer Registries, Slovenia**

Born in 1952, I have graduated from the Medical Faculty in Ljubljana in 1979 and then started to work at the Institute of Oncology Ljubljana, since 1981 at its Epidemiology Unit, being its head in last years. During my first case-control study on breast cancer and oral contraceptives, started by the late prof. Ravnihar, I did my postgraduate studies in occupational medicine and public health in Ljubljana and epidemiology and biostatistics in London. In 1987 I obtained MSc degree, in 1991 finished specialisation in epidemiology and in 1995 DSc study with the thesis on population based case-control study on breast cancer and oral contraceptives. Additionally I attended several courses in cancer epidemiology in Europe. Since 1992, I am actively involved in teaching cancer epidemiology, starting as Assistant, and being currently Assistant Professor at Ljubljana Medical Faculty (employed 80% at the Institute of Oncology and 50 % at medical Faculty). I am also the national coordinator for specialisation in public health, nominated by medical Chamber of Slovenia that is in charge of specialisations for medical doctors. During my collaboration with European Institute of Oncology in Milan I was nominated Senior Research Associate at its Division of Epidemiology and Biostatistics in 1996.

My main fields of interest are cancer descriptive and analytical epidemiology (especially breast cancer and oral contraceptives, colorectal cancer, occupational cancer), cancer prevention and public education on cancer prevention, teaching graduate and postgraduate students, organisation of screening programmes and cancer control in general as I am also national cancer control coordinator. Since 2003, I am the head of the Epidemiology and Cancer Registry Unit at the Institute of Oncology Ljubljana, the service that comprises The Cancer Registry of Slovenia (founded in 1950), Epidemiology Unit and Screening Unit, where currently organised cervical cancer screening is coordinated and pilot project on breast cancer screening developing.

I have been involved in several national and international epidemiological studies (currently EURO CARE IV, EUROCHIP II, EUROCAN+PLUS), but beside research and teaching I am also involved in public education on cancer prevention, working for our Cancer League and some other NGO's.

## **EMPLOYMENT AND PROFESSIONAL CAREER**

- Since 1981 Department of Epidemiology at The Institute of Oncology, Ljubljana, since October 1981, head of the Department since 1996.
- Since 2003, head of Epidemiology and Cancer Registry, the Unit that comprises:
  - Cancer Registry of Slovenia and Cancer Registry of the Institute of Oncology Ljubljana
  - Screening Unit, coordination of national screening programme for cervical cancer and starting to establish organised breast cancer screening
  - Epidemiology Unit – epidemiological studies
- Since 2003, partially employed as Assoc. Prof. in Public Health at Ljubljana Medical Faculty (University).
- Since 1991, National Coordinator for Cancer Control (Ministry of Health), since 1998 national coordinator for organised cervical and since 2002 also for breast cancer screening.
- Since 2000, president of the Committee for Education of Association of Slovenian Cancer Societies.
- Since 2002, the President of Professional Committee of Europa Donna Slovenia.
- Since 2005, the national coordinator of specialisation in public health (Medical Chamber of Slovenia)

## **PROFESSIONAL EXPERIENCE & FIELDS OF INTEREST:**

- Cancer analytical epidemiology (especially breast cancer and oral contraceptives, colorectal cancer, occupational cancer).
- Cancer descriptive epidemiology (Collaboration with the Cancer Registry of Slovenia).
- Cancer prevention and public education on cancer prevention.
- Teaching graduate and postgraduate students in cancer epidemiology and public health.
- Organisation of screening programmes and cancer control in general.

## **COLLABORATION IN INTERNATIONAL STUDIES:**

- With International Agency for Research on Cancer in the study: Second primary cancers among 5446 women treated for cancer or carcinoma in situ of the cervix uteri in Slovenia 1950-1969 (published in 1983).
- In the international study EUROGAST- Geographic correlation of biological risk factors with gastritis and gastric cancer, organised by Commission of the European Communities, COMAC-EPI in collaboration with Imperial Cancer Research Fund, Oxford and IARC, Lyon.
- Member of Collaborative group on Hormonal Factors in Breast Cancer at Imperial Cancer Research Fund, Oxford, UK.
- Since 2003, as the head of the Cancer Registry, involved in international studies and groups: EUROCARE IV (member of Steering Committee), EUROCHIP II, EUROCAN+PLUS, ECN, EUNICE etc.

## **MEMBERSHIP:**

- International Epidemiology Association
- International Association of Cancer Registries
- Zdravniško društvo
- Sekcija za preventivno medicino
- Zdravniška zbornica

## **MAIN POSTGRADUATE COURSES:**

- Southampton, UK, April 17-23, 1983: The British Council course on Industrial Cancer and its Epidemiology
- London, UK, October 1983-March 1984: Combined Course in Epidemiology and Medical Statistics on London School of Hygiene and Tropical Medicine
- Ljubljana, Slovenia, October 7-12, 1985: UICC Postgraduate Course on Clinical Cancer Chemotherapy at The Institute of Oncology
- Heidelberg, Germany, June 15-26, 1987: IARC Advanced Epidemiological Methods Course at the German Cancer Research Centre
- Ljubljana, Slovenia, September 18-23, 1989: IARC International Course on the Epidemiological Aspects of Occupational Cancer at The Institute of Oncology
- Venice, Italy, October 12-14, 1992: European School of Oncology course on Mechanisms in Nutrition and Cancer
- Budapest, Hungary, November 7-9, 1992: UICC Central European Workshop on Cancer Education in School
- Lyon, France, March 1-12 1993: International Agency for Research on Cancer (IARC) Course on the Epidemiology of Nutrition and Cancer, IARC
- Banff, Canada, September 26 - October 2, 1993: WHO Workshop on National Cancer Control Programmes
- Ljubljana, Slovenia, 1996-1997: Course on Management in Healthcare organised by GEA College
- IARC, Lyon, France – 1998-2002 .- several shorter courses in cancer epidemiology

# Monitoring the effectiveness of cancer control in Slovenia

By Maja Primic Žakelj

## Abstract

Population-based cancer registries are an essential component of a fully developed cancer-control programme. In addition to providing information on current and future needs for services, they are used to monitor programmes of prevention, early detection and treatment. In Slovenia, there is the oldest obligatory population based Cancer Registry in Europe, founded in 1950, so besides mortality, data on cancer incidence, prevalence and survival of cancer patients are available to monitor the cancer burden in our country. In 2003, there were nearly 10.000 new cancer cases diagnosed and 5058 deaths registered. As in other central and eastern European countries, lung is still the most frequent cancer site in males and breast in females. The lung cancer incidence started to decline in males, reflecting decreasing smoking prevalence in the last three decades, but not in females.

In females, cervical cancer is ranked the sixth, but compared to other western European countries, the incidence is among the highest; that's why the national organised screening programme has started in 2002. The results from the screening registry show that in some regions the goal of 70% of women having a smear in the last three years has already been achieved and preliminary data from the Cancer Registry do not show an upward trend of cervical cancer any more.

Increasing trend in breast cancer is followed by slow decreasing mortality in ages 40-69, but not in older women. Currently, the breast screening is opportunistic and no official data are available on its extent. The organised programme according to European guidelines for quality assurance in breast cancer screening and diagnosis is in preparation and a pilot will start in 2007.

The most worrying in Slovenia is an increasing trend in colorectal cancer in both sexes that can be ascribed to unhealthy lifestyle (diet, obesity and lack of physical activity). No organized screening is available currently.

Systematic screening is a public health intervention, often performed in primary health care. For its sustainability it should receive political support, supporting legislation and professional education. The key for success of such a programme is organisation, existence of national standards for quality assurance and control and constant monitoring of short- and long-term indicators. Financial support for implementation of evidence based screening programmes in central and eastern European countries could be found in EU Structural Funds, while professional support could come from experiences of European Cancer Screening Network (ECN).

The Registry follows the survival of cancer patients and contributes the data to international comparisons studies (EUROCORE II-IV). At European level, the survival of Slovenian cancer patients is somewhere between western and eastern European countries, especially in the most common cancers (breast, colorectal, prostate). One of reasons is not only diagnosis at a later stage, but also lack of national guidelines and different standards of treatment in several hospitals.

Not all of the indicators, as agreed in EUROCHIP-I, are available to monitor the effectiveness of cancer control programme in Slovenia, so it is hoped that in the following years they will be gathered and the national cancer control programme formally developed.

## **Marjan Videnšek** **President of Preporod**

Studied at Life Science Institute (Canada)  
Established Preporod (1996), Association For Healthy Living  
With the help of natural, raw food conquered **my own** serious health problems  
Therapist for hydrocolon therapy

### **My work**

Adviser in the field of healthy food, fasting and a healthy way of life  
Lecturer on these topics in Slovenia  
Chief editor of magazin Preporod V sožitju z naravo  
Author of numerous articles about health  
Moderator of numerous TV and radio emissions about health

### **My interests**

Causes and evolution of illness  
The importance of freeing the body of toxic matters  
Fast, natural and effective ways to clear up the body  
Safe fasting  
Harnessing the body's power for self healing, how everyone can build their health  
Wholesome nutritional and natural food to build vital capacity of the body  
Detoxification of body

**Hildrun Sundseth**  
**Head of EU Policy, European Cancer Patient Coalition**  
**Board Member European Institute of Women's Health**

Over the last 20 years Hildrun had the responsibility for the political and policy work with the EU institutions as Director of European Community Affairs for one of the world's leading pharmaceutical companies. She pioneered improved communication with patient/health NGO groups based on shared interest, transparency and respect and helped to develop the European Pharmaceutical Industry and Associations' Guidelines for working with patient groups. Initiated the company's healthy ageing strategy which led to the setting up of an Institute of Ageing and Health under the Company Foundation.

After retiring in early 2004, was elected Board member of the European Institute of Women's Health based in Dublin and became Head of Policy for the European Cancer Patient Coalition, an umbrella organisation bringing together cancer patient groups from across Europe to speak with one voice. Responsible for ECPC's strategy on all EU policies, legislation and measures that affect cancer patients and their care. Initiated and now provides the Secretariat for the Forum **MEPs against Cancer - MAC** in the European Parliament with the aim to make combating cancer once more a priority in the EU.

**Education**

- Degree in Political Science and modern European Languages

**Committee work**

- EMEA Working Group with Patients and Consumer Organisations
- Commission DG Sanco Health Policy Forum
- Commission DG Sanco Rare Disease Task Force
- Expert for European Institute of Women's Health at Bundeszentrale fuer gesundheitliche Aufklaerung, Germany "Media competence and knowledge management for women's health in midlife and beyond"
- EFPIA/Patient Think Tank

**Publications:**

*European Cancer Patient Coalition*

- ECPC leaflet
- ECPC position papers on public health strategy, paediatrics, cancer screening, patient information, etc
- ECPC press releases

*European Institute of Women's Health*

- Women in Europe - **Toward Healthy Ageing**
- The Internet and Health information for Older Women
- Women's Health - Facts and Figures across Europe



# LEAFLET

## EUROPEAN CANCER PATIENT COALITION (ECPC)

### *Nothing About Us, Without US !*

#### **Who are we?**

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 policymakers, 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 enrol in them
- To call for improved multi-disciplinary training of health professionals

#### **ECPC Aims**

- Promoting the fundamental rights of European cancer patients
- Increasing cancer patients influence over all European policies that affect our health
- Ensuring timely access to appropriate prevention, screening, early diagnosis treatment and care
- Promoting the advancement of cancer research

## **ECPC Members**

We derive our mandate to speak with "**one voice**" for **all** cancer patients from our membership and our democratic structure. ECPC is growing steadily. Currently we have over 170 members from across the 25 Member States of the European Union representing the big cancers such as lung, breast, colon and prostate as well as the rarer cancers whose voice is seldom heard. In addition we have over 35 associate members from across the world.

## **How is ECPC organised and governed?**

We are an independent, non-profit "umbrella" organisation registered under Dutch charity law. Governed by an elected Board of nine members most of whom must be cancer patients, survivors or carers. ECPC's executive powers are vested in the President, two Vice Presidents, Treasurer and Secretary. We hold regular Board meetings and inform our membership through the Annual General Assembly, our website, newsletters, discussion fora and yearly Masterclasses. We have a Brussels office close to the European institutions and our Secretariat is based in Munich.

## **What are our activities?**

ECPC maintains links with EU institutions: Commission, Parliament, Council, and the European Medicines Agency (EMA). ECPC monitors political developments at EU level, identifies those which could impact on cancer patients, informs its member societies and contributes the cancer patient perspective to European health issues. ECPC produces position papers on a range of priority issues and is involved in the promulgation of Quality Screening Guidelines for colon cancer.

## MAC - MEPs Against Cancer

The European Parliament has set up an informal all-party forum called "**MEPs Against Cancer**" (MAC); ECPC provides the Secretariat. MAC currently brings together 45 Members of the European Parliament who are committed to making the fight against cancer once again a EU priority.



## EMA/CHMP Working Group with Patients

The new Community legislation requires the EMA, its Management Board and committees to develop contacts with patient groups and consumers. ECPC has been approved as a member, giving cancer patients an opportunity to interact with the European Agency on important regulatory issues. (<http://www.ema.eu.int>)

## Commission DG SANCO Health Policy Forum

ECPC is a member of the Health Policy Forum. The Forum aims to ensure that the European Community's health strategy is made clear to the public. ECPC is thus able to contribute at an early stage to health policy development, its implementation and the setting of priorities for action.

([http://europa.eu.int/comm/dgs/health\\_consumer/index\\_en.htm](http://europa.eu.int/comm/dgs/health_consumer/index_en.htm))

## Major Cancer Conferences

To live up to our motto "Nothing about us, Without us", ECPC is involved in organising patient seminars at major cancer conferences, e.g. European Society of Medical Oncology (ESMO), European Cancer Conference (ECCO), European School of Oncology (ESO).

## Central and Eastern European Cancer Patient Advocacy Summit

ECPC has partnered with the Polish Res Humanae Foundation and the Polish Institute for Patients' Rights and Health Education, to organize Advocacy Summits for CEE cancer patient groups. Summit delegates produced and endorsed **The Warsaw Declaration**, highlighting inequalities in cancer control in CEE countries and stressing the urgent need to make high-quality prevention, treatment and care attainable in CEE countries.

***How to join ECPC***

If you are a EU cancer patient organisation, we hope you will join us in the fight against cancer. To become a member please contact [info@ecpc-online.org](mailto:info@ecpc-online.org) or see the ECPC website for the application form.

**ECPC President**

Lynn Faulds Wood

Member organisation: Lynn's Bowel Cancer Campaign (UK)

[www.bowelcancer.tv](http://www.bowelcancer.tv)

**ECPC Head of EU Policy (Brussels Office)**

Hildrun Sundseth

e-mail: [hildrun.sundseth@ecpc-online.org](mailto:hildrun.sundseth@ecpc-online.org)

[www.ecpc-online.org](http://www.ecpc-online.org)

**ECPC Administrator (Munich Administrative Office)**

Michaela Geissler

e-mail: [info@ecpc-online.org](mailto:info@ecpc-online.org)

[www.ecpc-online.org](http://www.ecpc-online.org)





PARLAMENTO EUROPEO EVROPSKÝ PARLAMENT  
EUROPA-PARLAMENTET EUROPÄISCHES PARLAMENT EUROOPA PARLAMENT  
ΕΥΡΩΠΑΪΚΟ ΚΟΙΝΟΒΟΥΛΙΟ EUROPEAN PARLIAMENT  
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EUROPOS PARLAMENTAS EURÓPAI PARLAMENT  
IL-PARLAMENT EWROPEW EUROPEES PARLEMENT PARLAMENT EUROPEJSKI  
PARLAMENTO EUROPEU EURÓPSKY PARLAMENT  
EVROPSKI PARLAMENT EUROOPAN PARLAMENTTI EUROPAPARLAMENTET



## ***MEPs Against Cancer - Statement***

Members of the European Parliament from all parties have joined forces to promote action on cancer as a priority in the European Union. MEPs are keen to harness the health policies of the European Member States towards improving cancer control for Europe's citizens.

We are painfully aware that there are considerable inequalities in health status and cancer survival rates within Member States and across the European Union. Commissioner Kyprianou recently pointed out that the male life expectancy in Estonia and Latvia is a full 12 years shorter than in Sweden. Lung cancer kills twice as many people in Hungary as in Finland.

We are extremely concerned that, according to warnings from WHO, there will be a "cancer epidemic" as the disease rate increases dramatically in Europe's ageing population.

There are significant inequalities in cancer within and between Member States across the EU. The chance of surviving cancer is affected by where one lives, where one is treated and whether one has the necessary information.

Every year thousands of people die unnecessarily from cancer because their treatment is below standard or is given too late.

Cancer survival is significantly lower in eastern European countries, including the 10 new Member States compared with the EU 15.

The ***European Code against Cancer*** was developed before the new countries joined but it could help to promote cancer awareness in them.

The ***Europe against Cancer*** programme, which finished in 2002, helped encouragingly to raise awareness and achieve good data collection.

Europe has been aware of the problems for more than a decade. It is time to put knowledge and understanding to good use and provide timely and effective information, prevention, screening, treatment and care for all EU citizens.

## MAC Recommendations

We call upon Health Ministers to consider the following:

1. Urgently to develop and, where existing, improve national plans, setting priorities and effectively allocating resources for improving cancer control and research across the European Union.
2. Firmly to tackle the socio-economic and geographic divide, which leads to inequalities in cancer control.
3. To make high quality and up to date prevention, treatment and care attainable for all cancer patients in each European Member State.
4. Vigorously to promote cancer awareness in the general public through the existing **Europe against Cancer Code**, making a special effort in new Member States.
5. To invest in cancer prevention in Member States through implementing the **Council Recommendation** on Cancer Screening of December 2003 and setting up national high quality screening programmes
6. To oppose discrimination because of age, race, gender and domicile in respect of the latest cancer treatments.
7. To set up a **Cancer Task Force** at European level, to exchange best practice and to highlight once again that tackling cancer is a priority and sending a strong political signal that immediate and concerted action is needed now.

*Presented at*



**MAC**

**1<sup>st</sup> MAC Conference**

**“Making Cancer a Priority”**

**in the European Parliament**

**22 March 2006**

**[www.mepsagainstcancer.org](http://www.mepsagainstcancer.org)**

**49 MEPs signed the Statement**



***The MAC Secretariat is provided by the European Cancer Patient Coalition representing the views of cancer patients in the European healthcare debate. Under the motto : “ Nothing about Us, without Us!” ECPC speaks with a single voice for all cancer patient groups from the major to the rare cancers.***



## **“United Against Cancer”**

### ***Making Cancer a Priority for Action***

## **How to reduce the gap in cancer prevention, treatment and survival in CEE countries**

### **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 EU.
- Prevalence and 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 lifestyles 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.

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
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 attending the Warsaw Summit November 2005*

*Adopted and signed by 120 delegates attending the ECPC Milan Masterclass May 2006*

*→ → Adopted and signed at the Slovenian Cancer Patient Summit November 2006 ← ←*