

# We're back!

How an alliance of patients and politicians put cancer back on the EU agenda

→ Anna Wagstaff

When Europe Against Cancer ended, the need for a Europe-wide strategy to tackle Europe's growing cancer problem fell off the political agenda. Now, thanks to an impressive two-year campaign by patients and their parliamentary allies, key EU bodies are starting to give this issue the attention it deserves.

An afternoon of political speeches in the Committee of the Regions in Brussels is not everyone's cup of tea. Even Alojz Peterle, founding chair of MEPs Against Cancer and vintage political campaigner, admitted that conferences like this 'can be boring'. The April 7–8 summit of the European Cancer Patient Coalition (ECPC), however, really wasn't.

The top table brought together a combination of people who have the ability to make things happen for European cancer patients. Not only were they all singing to the same tune, but the tune sounded pleasingly similar to that composed by MEPs Against Cancer when they put forward an action plan for tackling cancer in Europe at their first meeting, in 2006.

There was Georgs Andrejevs, one of the founding members of MEPs

Against Cancer. He was sponsoring a comprehensive resolution due to go before the Parliament on combating cancer in the enlarged European Union.

Marija Seljak was there representing the Slovenian Minister of Health, Zofija Kukovič, who was about to make cancer the priority item at an informal meeting of all EU health ministers, under her chairmanship, in Brdo. Slovenia holds the Presidency of the EU for the first half of 2008.

Androulla Vassiliou was present, making her first public appearance as the newly appointed European Health Commissioner. She is set to start drawing up an EC Cancer Action Plan for 2009.

Also speaking was Luc Van den Brande, president of the EU Committee of the Regions, a 'consultative' body designed to bring in the expertise and opinions of local and regional

authorities before new legislation starts its journey through Parliament and the Council.

Although the COR does not have the power to veto legislation, it is important because its members tend to be close to the delivery of services to cancer patients. The COR was about to finalise its submission on the EU's draft health strategy *Together for Health: A Strategic Approach for the EU 2008–2013*.

This was a perfect line-up to open a summit entitled Making Cancer a Priority, and testimony to three years of intensive activity and nifty political footwork led by the European Cancer Patient Coalition and their political strike force, MEPs Against Cancer.

It signals a welcome return to focusing on cancer that had been all but abandoned at European level after the ending of the Europe Against Cancer programme in 2002.



Patient power. Former ECPC president Stella Kyriakides asking the new Health Commissioner whether her Cancer Action Plan will be designed to act as a permanent lobby to pressurise governments to deliver. Seated to her left is Hildrun Sundseth, ECPC's head of EU policy, and to her right Jan Geissler, ECPC vice-president, and Sandy Craine, Secretary

PHILIPPE VELDEMAN

#### BUILDING POLITICAL WILL

Europe Against Cancer (1989–2002) was an initiative of the European Commission that provided funding for key areas of cancer control, including prevention, screening and cancer registries. However, growing resistance to EC 'interference' with national healthcare policies, pressure from other disease groups, and the lack of a coherent European voice for cancer led to the programme being aban-

doned in favour of a health strategy that moved the focus away from tackling specific diseases.

Just as countries such as France, the UK and Denmark were beginning to accept that cancer requires a strategic, patient-centred, evidence-based, quality-controlled approach, the European Commission's health directorate, DG Sanco, redirected its efforts towards generic action to reduce smoking, improve diet and promote exercise.

But despite its termination, efforts that began under the Europe Against Cancer programme continued to bear some fruit. In 2003, work conducted by the European Cancer Screening Networks generated an EC recommendation on screening for breast, cervical and colorectal cancers. In the same year, the European Parliament passed a resolution on the screening and management of breast cancer. These measures have great potential,

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## ECPC and MEPs Against Cancer became an effective double act, building support among political leaders

but their impact has been limited by lack of political will at European and Member State level. Only seven countries have so far set up cervical cancer screening programmes and only 11 provide nationwide screening for breast cancer. The EC has yet to publish a progress report, due in 2006.

### A VOICE FOR PATIENTS

The formation of the European Cancer Patient Coalition in 2004 proved a turning point. Bringing together more than 250 patient groups representing millions of survivors of many different cancers, across 30 countries, it has given Europe's cancer patients a single voice to fight for their right to good care and social inclusion, to argue for a role in policy making, and to hold national and European politicians to account.

ECPC searched out sympathetic politicians to champion the cause, and by the end of 2005, MEPs Against Cancer was launched under the co-chairmanship of Adamos Adamou, Liz Lynne and Alojz Peterle.

Peterle is himself a cancer survivor. A former Prime Minister of Slovenia, he feels strongly the need to close the wide gap in cancer mortality between 'old Europe' and the newer central and eastern European Member States.

Above all, perhaps, as one of the architects of the rejected European constitution, Peterle is conscious of the dangerous distance between the structures of the European Union and the citizens of Europe – the so-called 'democratic deficit'.

He sees delivering effective action

on cancer as a good way to reconnect the EU with its citizens – and he has put an extraordinary effort into achieving this.

At its first full meeting early in 2006, MEPs Against Cancer adopted a seven-point action plan that set out what it wanted from European and national political leaders (see [www.mepsagainstcancer.org](http://www.mepsagainstcancer.org)). Top of its list of priorities was to

- Encourage member states to draw up and implement national cancer plans
- End the socio-economic and geographic gap in cancer mortality
- Convince the Commission to create an EU cancer task force involving members of the Commission, the Parliament and the Council as a forum to exchange information and to galvanise political will to translate policy into action

ECPC and MEPs Against Cancer became an effective double act, mobilising patient advocates behind these policies and building support among political leaders and policy makers. They used the Eurocare-3 data to show the difference that good prevention policies, effective screening and high-quality care can make to mortality. They invited key players from the UK, France and Portugal to share experiences of setting up national cancer plans, and talked to patient advocates about putting pressure on political leaders to act to stem the increase in cancer cases in their own countries and to improve the experience and life chances of those diagnosed with cancer.

In November 2006, Slovenia hosted a summit on tackling cancer in the countries of central and eastern Europe, which attracted politicians and policy makers from across the region. An informal closed discussion at the start of the conference provided a rare opportunity for political leaders to hold a high-level discussion of strategies for cancer control in Europe.

Joaquim Gouveia, National Coordinator for Oncological Diseases in Portugal, took back to his government a suggestion from the Summit that the issues of cancer registries, screening and cancer plans should be singled out for a special discussion when Portugal assumed the EU Presidency in the second half of 2007.

A set of simple and clear recommendations on all three issues was agreed and are available in English (see figure opposite).

To promote active surveillance of the progress in cancer control across Europe, they included in this document a set of maps and charts showing how Member States are performing in terms of registering cancer diagnoses, screening their citizens and operating a cancer plan, which they intend to update in line with developments. They also included in their recommendations a provision that cancer should be included as a standard item on the agenda of every meeting of EU health ministers.

This was taken up with enthusiasm by Portugal's successor to the EU Presidency – Slovenia. In fact, the Slovenian government adopted cancer as the main health focus of their term of

Saints and sinners. This map, which can be viewed at [www.acs.min-saude.pt/2007/12/18/health-strategies-in-europe-workshop-sobre-cancro](http://www.acs.min-saude.pt/2007/12/18/health-strategies-in-europe-workshop-sobre-cancro) (go to Conclusões), shows how Member States are performing on cancer control plans. Similar data can be found at the same site for other key parameters such as population screening and cancer registries

### Cancer control plans in Europe



office, which started in January 2008, and senior European policy makers were invited to a conference in Brdo in February, to take an in-depth look at strategies for reducing the burden of cancer in Europe.

The Slovenian presidency also commissioned a book, *Responding to the challenge of cancer in Europe*, which brings together current knowledge about the burden of cancer across the continent, and effective strategies for collecting data, carrying out population screening, organising high-quality care, and developing comprehensive strategies for control.

A key chapter, contributed by Hildrun Sundseth and Lynn Faulds Wood of ECPC, says that Europe has shown a lack of commitment to getting to grips with the growing cancer problem. “Astonishingly,” they write, “within the EU there seems to be little political will to share and apply evenly the knowledge we do have on how to prevent, diagnose and treat cancer, and how to care for patients...”

They reiterate the call for an EU cancer task force “to provide fresh

impetus and a European framework for tackling inequalities and sharing best practice”. They also express hopes that the Slovenian government would use its presidency to “build the political will required to force through the level of change and investment in health needed to close the gaps in cancer control, both within European countries and between the countries of east and west Europe.”

#### CLOSING THE GAP

It’s still too early to make a full assessment of the Slovenian Presidency’s efforts, but the opening session of the ECPC summit in Brussels testified to significant success in pushing cancer high up on the agenda of every part of the EU’s complex decision-making machinery.

The ECPC summit in Brussels testified to significant success in pushing cancer high up on the agenda

## “Cancer patients have shown that working in partnership with political leaders can bring about change”

Luc Van den Brande of the Committee of the Regions – “good fighters, who feel the inequalities most,” according to Peterle – said the COR Opinion on the EU’s draft Health Strategy 2008–2013 prioritises action to reduce inequalities in health, since citizens “are exposed to variable levels of health services, hospitals and provision of qualified doctors”. He promised, “The Committee of the Regions fully supports all efforts in helping to close the gap in cancer care in different regions of the EU.”

The COR is pressing for stronger mechanisms to encourage those with day-to-day responsibility for organising and delivering healthcare at a regional level to cooperate with one another and exchange information, experiences and best practice.

They are also pressing for health considerations to be taken into account in developing EU policy on pharmaceuticals. Their Opinion notes that the health strategy currently fails to address this issue, “despite the far reaching impact on patients and the public if the provisions in place in this area are considered solely as a facet of industrial policy and not in connection with health.”

Two days after the Patient Summit the European Parliament adopted the 41-point cancer resolution (<http://tiny.cc/epcancerres>). Crucially, point 2 calls on the Commission to “set up an interinstitutional EU Task Force composed of Members from the Commission, the Council and the European Parliament, which shall meet on a regular basis”. Canny politician that he is, Georgs Andrejevs MEP grabbed the opportunity of having the new health

commissioner by his side in front of an audience of cancer patient advocates, to stress his “sincere hope that this Task Force will be established soon”.

Maria Seljak, Director General of Public Health in Slovenia, told the summit that recommendations from February’s Brdo conference would be discussed at the next meeting of the Social Policy, Health and Consumer Affairs Council (EPSCO), in June, which the Slovenian Minister of Health would chair.

The emphasis will be on getting action throughout all Member States on the key priorities and strategies agreed at the ministerial informal meeting. Slovenia would push the Council to recommend a comprehensive cancer control strategy across the European Union.

To patient advocates, it certainly sounded as if their concerns are now being taken seriously. And by a happy twist of fate, this seems to have coincided with the appointment of a real ally in the European Commission, in the person of Androulla Vassiliou. The Health Commissioner has a track record on supporting cancer patients. She is one of the three founding patrons of ECPC, and has long served as chairperson of the board of trustees of the Cyprus Oncology Centre. Faced with searching questions from the floor, she does seem geared up to confronting some of the obstacles in the way of getting action on cancer.

For instance, she does not accept that the EU can make policy about pharmaceuticals without reference to the impact on patients. She told the

summit that she had discussed this with Günter Verheugen, EC Commissioner for Enterprise and Industry, saying that an effort should be made to make the same types of medicines available in all EU countries, because these disparities cannot be maintained. “We are working towards it because we understand the inequity of this problem.”

She also recognises that the success of the Cancer Action Plan for Europe 2009 that she is charged with drawing up will depend on getting the plan implemented in every Member State, since healthcare is an issue of national autonomy in the EU. “Certainly we will put pressure on Member States, though we can’t force them. But if we publicise the good practices of certain states, we put other states in a difficult situation because they have to explain to their citizens why they don’t take the same measures.”

This, she says, is where patient advocates come in as partners for change, adding that any Cancer Task Force should include not only the Commission, Council and Parliament, but also the involvement of patients themselves.

As head of EU Policy for the ECPC, Hildrun Sundseth has been co-orchestrator, together with Peterle, of the two-year campaign to get cancer back on the EU agenda. She warmly welcomed the new willingness to tackle cancer more forcefully. “Cancer patients have demonstrated that working in partnership with political leaders and key players can bring about change. We’re looking forward to taking that fight forward.”