

Nothing about us without us

Europe's patient advocates gather for the first time

→ Anna Wagstaff

From every corner of Europe and beyond, they descended on Milan. Patients and former patients with breast cancer, leukaemia, prostate and testicular cancers, multiple myelomas or lung cancer. Some were experienced cancer advocates and campaigners, others were active in support groups, or were in the first stages of setting up a patient association. Yet others, from countries with no history of patient organisation, came as individuals. All had one purpose in mind: to assert the voice of the patient in all decisions that might affect them, in order to improve the outlook for all cancer patients. This was the first meeting of the European Cancer Patient Coalition (ECPC), held at the European Institute of Oncology in Milan, June 12-13. Billed as a Masterclass in Patient Advocacy, it was designed to equip delegates with the information they need to campaign effectively for an end to needless suffering. Cancer patients suffer when they don't have the information they need at the right time, when their disease is picked up too late or when they are treated inappropriately by medical staff with too little specialist experience. Even as survivors, their quality of life is often blighted by a lack of understanding and support.

Using the European School of Oncology's official language ('bad English'), a procession of experienced patient activists, politicians, and medical and research professionals filled in this international gathering on everything they might ever need

to know. This stretched from the details of Europe's complex democratic, bureaucratic, legal, regulatory and consultative structures to advice on dealing with politicians and the media. There was also a focus on reaching out to other patients, working in alliance with one another, with disability groups, and with the medical profession and drugs industry.

Perhaps most valued by the delegates were opportunities, during coffee breaks and meal times, to swap anecdotes and contact details and to network: "Everyone I went to sit next to had something I could learn from," said Lia van Ginneken-Noordman, from the Multiple Myeloma and Waldenström Macroglobulinemia Patients Association in the Netherlands (CKP), after a busy evening chair-swapping at the formal dinner. ECPC Chairman Lynn Faulds Wood said: "Our first Masterclass in Cancer Patient Advocacy was an incredible experience. Over 100 cancer patients organisations were represented, from 33 countries, and every session was packed – no one seemed to want to leave the meeting to take a look at Milan! ECPC aims to be a sort of 'virtual trade union' of cancer patients, sharing ideas and best practice to help reduce inequalities within countries and across Europe, to improve access to good treatment for all.

"We are a potent force and together we can help to change our world: our mantra – 'Nothing About Us, Without Us!' – is becoming a reality."

THE PERSONAL AND THE POLITICAL

Two former Health Ministers, Italy's Umberto Veronesi and Holland's Else Borst-Eilers, contributed to a round table discussion on politics and cancer. They agreed that access to top quality treatment and screening remains shockingly unequal between and even within the countries of Europe. However, they said that politicians face pressures from many directions, and while they will always sound sympathetic behind closed doors, you must use every weapon at your disposal if you want to see real change. Public campaigns in the Netherlands helped to slash waiting lists, and in the UK gave chronic myeloid leukaemia (CML) patients access to the drugs they need free of charge. Taking test cases through the courts has also proved effective, for instance, in establishing the obligation of national health systems to pay for treatment abroad, if the patient cannot get the treatment he or she has a right to expect in their own country.

Stella Kyriakides, President of Europa Donna – The European Breast Cancer Coalition – told the story of the long campaign that led to an important breakthrough on breast cancer policy at the European Parliament. Patient advocates, she said, are uniquely powerful; they take painful personal life events and put them to use in driving political change. Speaking from the floor, Rita Rosa Martin, from the German breast cancer organisation Breast Health, argued that if national governments and European institutions want to consult and involve patients groups, then they must provide funds so that groups can buy in equipment and training to play an effective role. "I for one," she said, "am no longer prepared to be grateful simply for being asked for my opinion or advice." The example of the Netherlands, where lobbying led to 30 million euro of state funds being made available annually to patient groups, was held up as a possible lead for ECPC and national groups to follow.

WE WANT TO LIVE, NOT JUST SURVIVE

The session on Discrimination in the Workplace was like no other. Delegates who had remained

quiet and attentive throughout the weekend sprang to their feet to tell their stories. Ekke Buechler of the Austrian prostate cancer group Selbsthilfe Prostatakrebs talked about the attitude of a union rep at his workplace who had special responsibility for disabilities. "I went to this man after my prostatectomy, to ask for some help securing a less physically demanding job. He told me: 'You're looking good, you have all your arms and legs, you're not blind – perhaps



Stella Kyriakides, President of Europa Donna

you could lose some weight. So what's the problem?"

He added: "It's ironic that so many cancer patients are getting back their lives thanks to scientific research, only to find civil society then denying them their lives by excluding them."

Catherine Casserley, of the UK Disability Rights Commission, said that all but four countries in Europe have yet to introduce laws to comply with the EU Disability Rights Directive, for which there is a deadline of 2006. She urged delegates to campaign to ensure that their governments define "disability" in such a way as to include the sort of chronic, often intermittent, and almost always invisible impairments suffered by cancer patients.

Many delegates had strong feelings on whether or not cancer patients wanted to be labelled

“disabled,” but agreed that ECPC should work within the European Disability Forum, and that everyone had to stick together to promote a culture, backed by legislation, that supports cancer patients who want to remain in work.



ECPC Chairman Lynn Faulds Wood

STRATEGIC ALLIANCES

ECPC Chairman Lynn Faulds Wood spoke of the need to form strategic alliances with people working within healthcare systems, research institutions, the pharmaceutical industry, and politics. Few of these professionals, she argued,

have the single-minded determination that has motivated her ever since the day she was told that she stood only a 34% chance of surviving

both Rees, told the story of a similar strategic alliance they put together in the UK to fight for the right of all CML patients to be prescribed Glivec, free of charge. Their hard fought battle was won because they campaigned alongside their doctors and the drugs company Novartis.

How best to work with drugs companies was seen as a tricky question. Some delegates said their groups were wary of inappropriate pressure, and would never accept funding from the industry. Others said they couldn't survive without it and they didn't feel too compromised. Some of the activities of the ECPC are supported through no-strings grants from six drugs companies in accordance with the sort of transparent funding policy that is increasingly being adopted by patient groups (see www.ecpc-online.org/policy_funding.html). Lynn Faulds Wood said: “The interests of patients and the industry are by no means identical, and where they diverge we say so. But where they do coincide, it is important that we seize any opportunity to collaborate to achieve our ends.”

“Just a few patients can change the world a little bit,
if we work in alliance with others”

bowel cancer, and had to face the prospect of her three-year-old son growing up without her. “That,” said Lynn “is what we patients bring to the table.”

Before she was diagnosed, Lynn's general practitioner told her she had nothing to worry about. Later on, using her experience as an investigative journalist, she discovered that, the world over, the advice doctors are given on how to differentiate bowel cancer from other bowel disorders has little backing in research. So she formed a strategic alliance with a number of specialists, to find out more about the key warning symptoms doctors should look for. “Just a few patients can change the world a little bit,” she said, “if we work in alliance with others.”

Two patient advocates, Sandy Craine and Eliza-

The European Cancer Patient Coalition (www.ecpc-online.org) is the voice of European Cancer Patients.

It was established in 2003 to represent the views of cancer patients in the European healthcare debate and to provide a forum for European cancer patients to exchange information and share best practice experiences.

Membership is open to organisations dedicated to advocacy, support and care of cancer patients and their carers.

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Why I got involved in cancer advocacy: Four ECPC delegates tell their stories

Eoghan Cahill Men Against Cancer, Ireland

Eoghan Cahill, from County Cavan in Ireland, had to call on all his reserves of stubborn determination and his creative skills as a commercial artist, in order to get home from hospital with his self-esteem intact.

His doctor had warned him that surgery for prostate cancer risked leaving him impotent and incontinent. But he had also told him the incontinence was nothing to worry about, "You will have all the advice you need." He didn't get advice. What he got was a massive nappy that hardly fitted into his trousers, and advertised to the passing world: 'This man has lost control of his bladder'. Eoghan was having none of it. "By this time," he said, "I'd spent three weeks in hospital, and had seen how men had come in for their operation, proud and tall, and had left bewildered and humiliated, some of them leaving dribbles of urine on the hospital floor before they'd even started their journeys home."

Armed only with a pair of scissors, a roll of sticky tape, some plastic bags and the offending giant



nappy, he cut, stuck, fashioned and moulded himself an effective lining for his pants, invisible to the outside world. And he went home. In the end, it was his local chemist who led him to the advice that had been so disastrously lacking following surgery. He put Eoghan in touch with a community nurse who happened to specialise in problems of

incontinence. She brought neat absorbent pouches and showed him how to regain bladder control through strengthening his pelvic floor muscles. One man's post prostatectomy problems had been greatly alleviated. But he was still very angry.

The story of how Eoghan moved to co-founding MAC (Men Against Cancer), eventually teaming up with the European prostate cancer advocacy group Europa

Uomo and attending the ECPC conference, could match any told of a pleasant evening in a (smoke-free) Irish pub. One small part of it involved a throwaway comment by an eminent oncologist addressing a conference of support groups called by the Irish Cancer Society. The oncologist said: "We all know how backward men are about coming forward for medical treatment...". For Eoghan, who had been through a

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done that and wears the T-shirt lifts a huge load of fear off you"

personal battle to get information and who was attending this meeting uninvited, that was the last straw. "That comment just pressed my button," he said. "I stood up and shouted 'THAT IS NOT TRUE!' and the room went silent. I said: 'If men have a tendency to try to play down problems with their waterworks, it's because they don't know the dangers until it's too late. And whose fault is this?' I asked, and I pointed around the room, 'Every single one of you professionals in this room have known for years the true story and have never once made the effort to set up an awareness campaign to make men of this country aware of the dangers of prostate and testicular cancer. And shame on you!'"

Clearly Eoghan was not the only angry man in the room, because he sat down to a rousing applause – even the eminent oncologist joined in. After the meeting, the Chief Executive of the Irish Cancer Society collared Eoghan and his friend, and Men Against Cancer (MAC) was born.

Today, Eoghan and his colleagues in MAC remain a vital source of information and support. Ireland is now running its first prostate and testicular cancer awareness campaign, using plenty of humour to encourage men to think about the upkeep of their bodies the way they do the maintenance of their cars.

What did Eoghan learn from the ECPC meeting? "I learned from the experience of others about communication, about dealing with politicians and about creating powerful alliances by combining small groups together, as we did with Europa Uomo, which will soon have groups from 13 different countries."

And how will he use it? "I would like to see the current awareness campaign expanded and continual-

ly refreshed, so it's not just a one-off effort. I would like to see better training of frontline primary care staff to improve early detection, and addressing the question of over-treatment is very important. But at the end of the day, we are patient support groups, and we mustn't forget why we are here. Because I remember vividly what a dark, dark journey I travelled. It doesn't matter how loving and caring your family is. Just to talk to someone who's been there, done that and wears the T-shirt lifts a huge load of fear off you."

**Lt. Gen.
Antonio Avelino Pereira Pinto**
**Portuguese Association of Patients
with Prostate Diseases**



When General Pinto founded the Portuguese Association of Patients with Prostate Diseases one and half years ago, he did so somewhat reluctantly. As far as personal cancer journeys go, his had been relatively free of trauma. He had a good doctor, who, on diagnosis, had encouraged him to seek a second opinion (an offer General Pinto declined) and then carefully went through the options:

Surgery would deal with the cancer, but carried a 60% risk of impotence and a 15% risk of incontinence. Without surgery, because the cancer was relatively slow-growing, it could be contained for a good 10 years or so by regular medication, but in the end it would probably be fatal.

General Pinto, who was 62 at the time, took the very personal decision to forego surgery, and he set about enjoying the life he had left to him – something he does very well. "I told my wife I had a prostate problem. I never said it was cancer,

"What could I do? He has saved my life for 12 years ...

I couldn't say No. As a military man, I accepted the mission."

because I don't want her to worry. If she is going to wake up every morning and have to look closely at me to see whether her husband was dying, she would have died before me!"

Today, he has been living very happily with cancer for more than 12 years, and his illness impinges very little on his life.

So when, in 2002, his doctor begged him to start up a prostate cancer organisation in Portugal, he felt little of the sense of personal anger and injustice that motivates many cancer advocates. He did, however, recognise that many lives are being lost needlessly. "Every day, between five and six men die of prostate cancer, and there are around 140,000 currently diagnosed with the disease. Yet very few men in my country know what prostate cancer is. Most don't even know they have a prostate," he says.

General Pinto's doctor was insistent, arguing that it is crucial that patients speak out about their disease and provide a point of information for men who may be reluctant to visit their doctor. With his gregarious and optimistic outlook on life, Pinto, argued the doctor, was the man for the mission. "What could I do?" said Pinto, "He has saved my life for 12 years. I couldn't say 'No'. As a military man, I accepted the mission."

He set about the task in a systematic way. He set up the Portuguese Association of Patients with Prostate Diseases, and recruited patients via their urologists. The Association now has between 30 and 40 members, but is still at a very early stage. "When we have 100 members, we will set up proper statutes and functions." He runs a help and information line from his home, and has even fielded calls from France. He is in the process of setting up a website. But he still works very much alone, so when his doctor told him about meetings of the ECPC and of Europa Uomo (which held its founding meeting in Milan), he was curious and eager to attend. He learned a lot. For a start, he met a woman from a breast cancer organisation in Portugal that

he had never known about, and she told him about other groups, for ovarian and colon cancer. "When I return, I will contact these organisations, and we will try to decide how we can lobby together".

"I have found out so much from this meeting about how people help patients. I will take the information back with me and study it and decide how to proceed. I want to start a newsletter with information about this seminar to send to my members."

One of General Pinto's priorities has been lobbying for prostate cancer to be classified as a chronic disease for the purpose of eligibility for free treatment. His present treatment, for example, costs him around 30 euro a month.

He is also keen to spread information among Portugal's general practitioners, so that they pick up symptoms quicker and have a better understanding of treatment options. "The important thing is for people to be diagnosed and treated earlier, and for them to realise that life does not stop because you are diagnosed with prostate cancer. Life is there to be lived."

As for his personal goals, "My aim is to live three years more, so I will complete 50 years of marriage, and my wife and I can celebrate our golden anniversary."

You sense that this is a man who will accomplish his mission.



Anna Valachova
breast cancer patient,
Slovakia

Anna Valachova is a breast cancer survivor from Nitra in Slovakia. She survived because she knew someone who was able to get her seen by a specialist for a second opinion. She now wants to make sure that everyone in

Slovakia knows how to get access to good cancer treatment when they need it.

"I went to my doctor with a lump in my breast. He told me not to worry. 'Many women have lumps like this' he said. I wasn't satisfied, and I told him my

“Very few people know . . . that you can ask your general practitioner to refer you to breast screening even if there is no screening centre in your area, and that if they refuse this request, you can go elsewhere.”

sister had been diagnosed with breast cancer 10 years previously. He just told me to ‘wait and see.’” Luckily, Anna had a friend who was on good terms with a cancer specialist. She went to see him at Bratislava’s cancer hospital, and underwent all her tests on the same day under the same roof. Four days later a lump measuring 2.8 cm was surgically removed, and two weeks later she was started on a course of adjuvant treatment combining radio- and chemotherapy. That was in 1997. Because she is considered to be genetically at high risk, she still attends a check up every three months. Once a year she has tests to check for metastases.

Anna knows that not everyone is as lucky as she is, and every year people are dying simply because they did not have the information they needed when they needed it. “The most important thing,” she says, “is to inform people about all cancers. Very few people know, for instance, that you can ask your general practitioner to refer you to breast screening even if there is no screening centre in your area, and that if they refuse this request, you can go elsewhere.”

When her doctor told her about the ECPC meeting in Milan, she saw it as a great opportunity to set something up in Slovakia. “I am so glad I came,” she said. “Before coming here, I discussed with my doctor the possibility of setting up an organisation and developing a cancer information website. After this meeting, I have a lot of new ideas. I want to go to schools to raise awareness about cancer among children – they have access to the Internet at school and will be able to pass on information about prevention and treatment to

their families. I have spoken to Europa Donna about working with them.”

And her source of recruits for Slovakia’s new cancer advocacy group? – Bratislava’s oncology hospital. “It’s best if we are all patients or former patients,” says Anna, “We understand and feel things differently.”

Jan Geissler
Leukaemie-Online.de, Germany

Jan is a young information technology (IT) professional from Bietigheim. When he was diagnosed with chronic myeloid leukaemia (CML) three years ago, his doctor recommended a bone marrow transplant. Jan was not happy with the idea, and sought a second opinion. Again, he was told: if you want a cure, transplantation is the only option. However, Jan’s first doctor had mentioned a drug that was still under development – Glivec (imatinib), then known only as STI-571 and not available on the market – and Jan determined to find out more.

He turned to the Internet, and found nothing in German. Luckily, his grasp of English was just about sufficient to allow him to wade

through the rapidly increasing amount of information coming onto the Web from patients, academics and researchers. He located a paper written by a doctor in Mannheim and e-mailed him asking for more information. This doctor, who turned out to be one of the best CML experts in Germany, phoned him, and after a conversation



lasting two hours, Jan knew a great deal more.

The Mannheim university hospital was running an international trial comparing Interferon alone (the standard drug at that time) with STI-571 (now known as Glivec). The new drug was showing terrific early results, but no-one knew how it would behave in the longer term. So far it had largely been tested on patients who had failed to respond to Interferon, but never on patients like Jan who had undergone no previous treatment. As this trial was already closed, joining a small trial combining STI-571 with Interferon was his only option to get access to the new drug.

Jan, the scientist, took a hard look at the statistics and opted to join the trial: "I calculated all the probability values, and concluded that my chances of dying would have been much higher going directly into transplantation." And so far, that has turned out to be a very good choice.

"During almost three years of treatment I have pretty much lived my normal life. I have hardly any side effects, my life has returned to normal." Like so many patients involved in the Glivec trials, Jan wanted to make sure other patients benefited from the information he had. So being an IT professional, it was a simple matter to set up a new website: Leukaemie-Online.de.

And in a matter of weeks, Europe's 100 million or so German-speaking population had their first access to information on CML in a language they could understand.

With the help of a few other volunteers, Jan sifts through information he picks up from newsletters, health professionals and patients all over the world, and in particular from US and Asian online support groups, and selects the stuff most relevant to patients in Germany. He then translates it and posts it up on his site, where it is accessed by thousands of patients at a rate of 45,000 hits a month.

Jan is convinced that many German doctors are continuing to recommend bone marrow transplants to their CML patients as a first line of treatment. "Doctors are no different to any other profession," he says. "About 80% of them are just doing their job, some 10% are alarmingly ill-informed, and about 10% are brilliant and have a mission.

"The problem is among the 80%, because they don't just deal with CML, they deal with all kinds of cancer, and they are often slow to pick up on new developments which have revolutionised leukaemia treatment in recent years. The mission of Leukaemie-Online.de is therefore to inform patients about all their options, so they can challenge their doctors, and ask why they can't try this treatment or another. If the doctor has a good reason, fine. But if not, the patient should insist on exploring the options further."

Jan is a founding member of ECPC, and he got a lot of benefit from the meeting. He met in person fellow CML patients from Canada, UK and Israel whom he already knew through Internet exchanges, and he found out about international groups working in a similar field. "I had a picture of what was happening in Germany, but not Europe wide and not in other cancers." He is now convinced about the need for European cancer patients to join forces. "When I saw what happened with the EU clinical trials directive, which is now heavily damaging life-saving research in Europe, I can see that we have to work at the level of the EU and not only at national level. I think it is very important not only to have CML support groups or breast cancer support groups, and not only to have German or UK support groups, but to have a European perspective for all cancer patients.

That is why I became a founding member of ECPC."

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