# Vested interests are undermining our efforts to beat cancer

## The worries of a battle-hardened German oncologist

➜ Simon Crompton

Cancer treatment is at a critical juncture, says **Dieter K Hossfeld**, veteran campaigner for the recognition of medical oncology in Germany. Future progress, he believes, depends on reasserting the interests of society at large over those of the pharmaceutical industry, the medical establishment and even individual patients.

Dieter K Hossfeld is worried about the future. Medical oncology, the specialty he helped establish in Germany, is still struggling for recognition in Europe. The chemotherapy drugs that should be saving patients are being over-prescribed and making patients ill. And drug companies and patients themselves are driving unsustainable spending on new cancer drugs.

It may sound curious that a medical oncologist, whose life-saving tool in trade is cancer drugs, should be so critical of the sweeping drug advances that have occurred in the past few decades. But Hossfeld has always had a view to the larger picture – the need to consider the lives of the many as well as the lives of the few, the need to balance the treatment and research agendas, the need to be cool as well as compassionate.

Now 71 and in semi-retirement, the man who brought Germany in from the post-war cold of cancer politics and became president of the European Society for Medical Oncology (ESMO, 1997–1999) and the Federation of European Cancer Societies (now ECCO, 1999–2001), has a sense of perspective as he looks back. Having been at the hub of progress in medical oncology, having experienced communism in East Germany and the transformation of Germany with reunification, he can see that now cancer treatment is at another major juncture. And it makes him uneasy.

We're talking at his manicured home in Hamburg, where Hossfeld was professor of internal medical oncology and haematology at the medical university for 25 years. Paintings, engravings and original prints hang on the white walls, abstract and expressionist works by the likes of Joan Miró and Alexei Jawlensky. His art, his medicine and his wife are his first loves, he says. He draws my attention to one line drawing he's particularly fond of: a sleeping woman by Jawlensky. "It reminds me of my patients," he says.

Patients have always been his driving force, says Hossfeld – the confidence and trust they placed in him, the thrill of seeing that they were "objectively better" as a result of his intervention. But paradoxically, he's also shown some impatience about patients' collective influence on the course of

medicine. In 2004, for example, at the American Association for Cancer Research meeting, he expressed concern that too many oncologists believed that clinical trials existed to benefit the study participants, not to come up with findings that would benefit society as a whole.

He's still concerned about cases where upholding patient rights seems to block medical progress generally – particularly, for example, when trials are interfered with in their early stages so that more patients can benefit from what looks like a promising treatment.

What riles Hossfeld, who has been a leading name in investigating the cytogenetics of chronic myeloid leukaemia for the past 35 years, is the way that patient pressure groups are having an influence on the cancer research agenda. "It's been particularly problematic with regard to breast cancer – women are more aggressive than men, no question," he laughs. "They hear about a new drug that is still at phase I trials, and do not hesitate to put heavy pressure on the doctor to use the drug, and if the doctor says no, they go to another, and then they go to politicians, and if they do not cooperate they go to the media. And they claim that doctors are denying life-saving medication for economic reasons. This isn't just a problem in Germany, it's certainly a problem in the United States and elsewhere – people are going to court to get drugs that are still at phase I. And you may be destroying the trial."

"Many of these patient pressure groups are supported by pharmaceutical companies who want to push their new developments as fast as possible to market," he says.

## Hijacked by big money

The influence of the pharmaceutical industry in research is generally becoming too great, he believes. The European Parliament's clinical trial directive places such workload and expense on clinical investigation that it is hard for academic institutions to finance independent research – and trials are increasingly being initiated, financed and performed by the pharmaceutical industry.

"It's almost impossible to conduct a study as a doctor without a lot of money, because of the incredible bureaucracy required, so behind it you need a pharmaceutical company. I think it's not exaggerating to say that many of us are manipulated by pharmaceutical companies. Once you have a positive result, say

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in Germany, you are not allowed to present your findings at a German cancer conference – you have to go to an international conference in America, because this is economically the most worthwhile drug market in the world."

As we talk about his concerns, there's a common theme. Money. It drives the research agenda. It drives what treatments patients get. And ultimately, patients aren't benefiting. In fact, they may be living shorter, lower-quality lives as a result of some of the financial imperatives driving cancer care.

The prime example of this, he believes, is in Germany and other European countries, where the specialty of medical oncology is being held back by healthcare structures that have a financial interest in maintaining the old medical, organ-based specialties.

"The burning problem for me, and the European Society for Medical Oncology, is getting recognition as a specialty," he says. "Medical oncology is recognised in many countries, but not in Brussels by the European Union. And in countries like Germany and Austria there are gynaecologists, urologists, gastroenterologists – you name it – who claim chemotherapy, the main purpose of medical oncology, as part of their business. They question the purpose of medical oncology."

Patients are suffering as a result, says Hossfeld. Speaking with caution, he puts it this way: "There are certainly urologists who are highly specialised in treating cancer, and know everything they should about chemotherapy. But this is not true for the general urologist, say those who tend to concentrate on surgical treatment of the prostate. So I'm convinced that you need someone who is specialised in medical oncology to do it properly – not only to do the job of giving drugs intravenously properly, but to take care of the patient as a whole."

His point is that in most countries, the speciality of medical oncology is built on the in-depth training of a physician/internist. This allows a medical oncologist to take account of other illnesses and characteristics the patient with cancer may have when planning treatment. He, with ESMO, has been fighting for this to be recognised by Europe for 20 years. Why hasn't it happened? Money again. There's resistance to the idea because it would mean reorganising old health structures that currently suit the interests of healthcare providers.

"Consider gynaecologists," he says. "They don't deliver that many babies any more. The gynaecology

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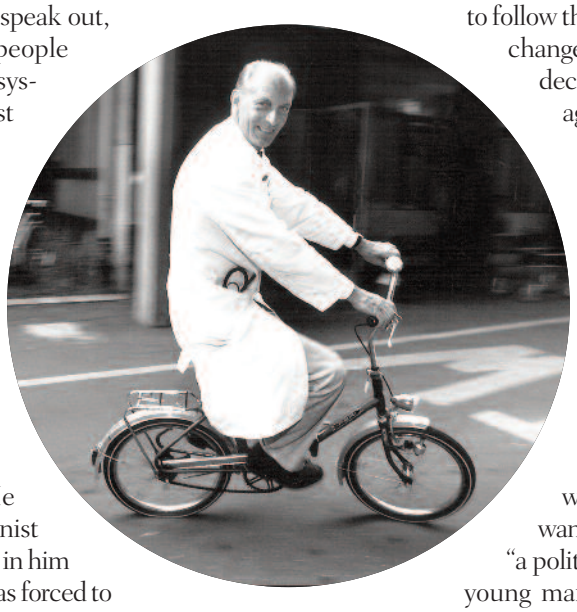
clinics are huge – with 50, 100, 200 beds, that have to be filled. They are filled with chemotherapy patients." Unfortunately, he says, a lack of understanding about chemotherapy in some clinics means that too many patients are being treated unnecessarily. Medical oncologists are increasingly recognising that cytotoxic drugs don't help many patients, and in others the traumatic side-effects may far outweigh any anti-cancer benefits. But other clinicians may simply follow past-practice and protocols.

"I mean, I became a doctor when I was young in order to heal, and then I realised there were too many diseases to heal everyone, but at least you have to help…"

## A POLITICAL STAND

The story of how Hossfeld did actually come to become a doctor may help explain his passionate views, his need to speak out, and his intolerance of people falling in with inflexible systems. He was born the eldest of four children in 1938, in Gotha, a city which in 1949 became part of communist East Germany. On the partitioning of Germany, his father, a lawyer for a large insurance company and Mayor of Gotha, took a political stand that was to change the family's future. He refused to join the Communist Party. His defiance resulted in him fearing for his life, and he was forced to escape overnight to West Germany, leaving the family behind. Hossfeld's mother, meanwhile, was threatened with jail unless she divorced her husband: she reluctantly agreed.



Two years after his father had fled, Hossfeld aged 14 and the rest of the family followed him, leaving everything they had behind in Gotha. "We took just a small bag when we left our home – all our toys and these beautiful things we had collected had to be left behind, and it was a completely new story for the six of us. We had nothing. It was not easy for my parents."

They lived in Westphalia, where Hossfeld attended high school, and by the time he finished his studies he had already decided to be a doctor. There had been a family tradition of going into the military. But as a teenager living in a post-war world where the outrages of the Nazis, including some of his own relatives, were all too evident, that was no longer something he wanted to consider.

"What our high-ranking officers from great families, and one of my own family members too, did during the Nazi regime made it unacceptable to follow this profession. I wanted to change the family tradition." He decided to be a doctor at the age of 12, though ironically he first had to complete compulsory national service with the Panzer division. "But I had a strong wish to give something back to the country where I now lived, because of the new freedom I found, where you could read the newspapers you wanted to, travel where you wanted." He became, he says, "a politically thinking and active young man". Even now, when he talks of communism, or doctors who conformed with the communist regime at the expense of colleagues, he can't conceal visceral disgust, at one point miming spitting.

He studied medicine in Münster, Westphalia,

then Würzburg, Bavaria, but his father died during his studies, making it all the more urgent that he should qualify and start earning money to support the family. He finished his studies in 1966, with the top marks of 240 students qualifying that year. "I was extremely ambitious," he explains. "I worked and worked, to be the best."

He wanted to become a surgeon. But when he tried out the work with three different surgeons, he was shocked by their rudeness and intolerance, getting angry at his questions, throwing their instruments around in theatre, pushing him out of the way. With typical self-assertiveness, he decided this wasn't the sort of behaviour he was prepared to tolerate, let alone work with.

Instead, he decided to move into internal medicine. Offered the opportunity to join a new tumour clinic at Medical University Clinic in Essen, he took it, and then in 1969 gained a scholarship from the German government to study cancer cytogenetics at Roswell Park Memorial Institute in Buffalo, New York, under Avery Sandberg. He wavered about accepting, he admits, partly because of his reservations about the American involvement in Vietnam. But for three years, he worked there – absorbing knowledge from Sandberg's expertise on haematology, chromosomal abnormalities and chronic myeloid leukaemia. They were the areas Hossfeld was to work in for the rest of his life.

## The Philadelphia story

Much of his research since then has focused on the chromosomal changes involved in CML. But, fascinatingly, if you ask him about his greatest research achievements, his first thought is of what he failed to do.

In early 1973, Janet Rowley from the University of Chicago published a paper describing her observation that a translocation of chromosomal material between chromosomes 9 and 22 explained the existence of the so-called "Philadelphia chromosome" characteristic of people with CML. The traditional explanation had been that the Philadelphia chromosome existed because chromosomal material had been lost.

"I had seen what Rowley saw earlier, in 1972," says Hossfeld. "But the opinion of famous people, much older than I, was that the genetic material was lost, so I did not realise what was behind it. But this lady, a woman again you know, she did not accept the common notion, she questioned it, and she was right."

The finding was ultimately to lead to the development of the revolutionary drug Glivec. "This was probably the biggest mistake of my medical career," says Hossfeld.

Nevertheless, Hossfeld had a distinguished research career, improving understanding of cytogenetics in CML and acute leukaemia. His findings were published in *Nature* and the *Lancet*.

Returning to Germany, he became fellow in internal medicine, oncology and haematology at the University of Essen, and then professor of medical oncology and haematology at the Medical University Clinic, Hamburg, a position he held until 2004. "Getting this position, and the fact that my wife agreed to marry me, are the two big events of my life."

Hossfeld's academic brilliance and political interest drew him into the national and international limelight. As director of the first clinic in Germany for oncology and haematology, he became an adviser to the German, Austrian and Swiss governments, and became central in the development of medical oncology in Germany.

And, after a prolonged post-war hiatus when it was difficult for Germans to gain influence in international health bodies, he made the breakthrough of being appointed chairman of the treatment programme of the UICC in 1986, and has been highly involved with that and other national and international cancer organisations ever since.

As president of ESMO and then of the Federation of European Cancer Societies, he spearheaded the push for a common, comparable educational level for oncologists in European countries, initiating an Accreditation Council of Oncology in Europe to

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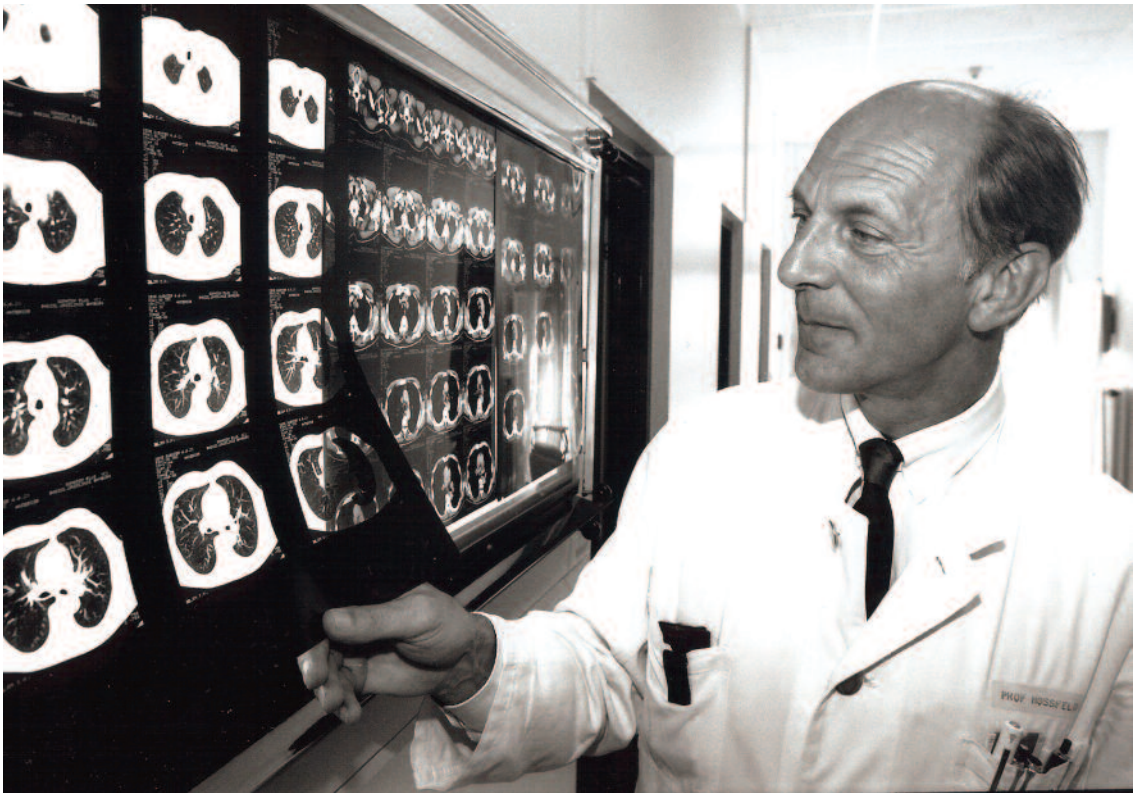

guarantee a comparable high level of education offered at cancer conferences.

His proudest achievement on the policy level has been in persuading German colleagues that passing the annual ESMO examination had to be a requirement for acceptance as a medical oncologist by the association. The exam is now also a requirement in other countries. "I think it has greatly helped increase the quality of people working as oncologists in Germany and other countries too," he says.

Now, he says, his quieter life is a good life. He looks back and marvels at the fact that until a couple of years ago, he worked 12 hours a day, often six days week, at a 60-bed clinic with more than 12,000 outpatient visits a year. He fears he neglected his responsibilities as a father, and reflects a little ruefully at the fact that neither of his two sons wanted to follow him into medicine. "They saw how much it took out of their father," he explains.

He looks – and says he indeed is – a picture of health, sustained by tennis twice a week, regular churchgoing (he's a protestant)… and his continuing medical practice. He couldn't give that up, he says. Medicine is too much part of him. He sees cancer patients privately two days a week.

As we end the interview, I ask him whether there's anything else he wants to say. Hossfeld thinks, and then returns to an earlier theme, the balance between the needs of the individual and the needs of the many. It pervades the debate over the rationing of expensive cancer drugs. Hossfeld would like to see a pan-European system duplicating the function of NICE (the National Institute for Health and Clinical Excellence) in the UK, stipulating under which circumstances new drugs can and cannot be paid for by state systems. Money, he worries, is so easily wasted on drugs that produce minimal quality of life gains for the people they are used on – money that could be far more widely and wisely spent.

"We need politicians who are courageous enough to help doctors impose a rationality on this," he says. Still political, still seeking systems based on reason not dogma. Having witnessed so much chaos in his early life, Hossfeld would love to see the cultured order he has created in his home finally reflected in European health systems.