Jan Geißler:

We, the patients

Marc Beishon

Keeping your life together when you have cancer is hard. To achieve this and still find the energy to work with other patients to influence decisions that shape the services and treatments you rely on is asking a lot from anyone. The ECPC was set up to help Europe's cancer patients take on this ambitious role. Jan Geißler, an Internet-savvy young dad living with leukaemia, is its first director.

When one looks back at the dark days of cancer – the fear, lack of support and information, societal taboo and an aloof medical community – we have come a long way towards meeting the needs of patients and families. Arguably, the main force for breaking down barriers has been patient advocacy – often from well-known people with cancer who have commanded attention in the media and helped raise awareness.

But as Jan Geißler, director of the European Cancer Patient Coalition (ECPC – www.ecpc-online.org) points out, while there has been great success in raising both funds and awareness by high-profile celebrities, such as the tenor José Carreras and his International Leukemia Foundation, patient groups have been – and mostly still are – small, fragmented operations run mainly by volunteers.

"Many struggle to work with their local health authorities and politicians to influence policy for their patients," he says. "What they need is help with organisation and information about a wide range of cancer issues to help them build capacity for their campaigning and support activities – which is one of the key aims of the ECPC."

With more than 300 patient organisations in 41 countries now members of ECPC – and many more that could join – there is already considerable pooled knowledge about effective advocacy work to hand, notably communicated at well-attended masterclasses and with 'toolkits' on how to organise patient meetings, develop and run patient-friendly websites and media campaigns, as well as on more heavyweight subjects such as understanding the health technology assessments government health bodies conduct on new drugs.

"The other major plank of our work is at European policy level – working to influence politicians and the wider oncology community on issues such as the Clinical Trials Directive, access to patient information on treatments and trials, patient safety, cross-border healthcare, patient rights, issues specific to rare cancers, and much more. So much of this directly affects our members, as it will be enacted at national level. We must help them see the big picture in Europe to prepare better for local action."

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ECPC is itself a small organisation. Geißler has been director since 2008, and has one other full-time colleague, who works as a policy expert in Brussels. His wife Michi runs the office on a part-time basis. But it has a heavyweight board, comprising leading figures from a wide range of national cancer patient groups, many of whom are also active in the growing number of international patient groups for specific cancers, such as Europa Uomo (prostate) and the CML Advocates Network. As a Europe-wide patient body, ECPC gets support from the European Commission, the European School of Oncology and a number of 'sustaining partners' from industry.

Support from industry, meaning mainly pharmaceuticals, does raise concerns about conflicts of interest and indeed direct accusations about being a 'front' for drug companies – a charge that tends to be levelled at advocacy organisations and patient groups that raise money from industry to run their projects. In *CancerWorld* recently (Masterpiece, September/October 2009), German oncologist Dieter Hossfeld criticised patient groups for contributing to a perceived takeover of trial work by the pharmaceutical industry.

"But the big issue for us is resources," says Geißler. "We look at the oncology community, which is increasingly networked internationally, as too is the pharmaceutical industry and indeed the regulatory authorities, certainly at European level in bodies such as EMEA (the European Medicines Agency). If we are to sit at the same table as equal partners, we need funds to

attend meetings across Europe, do research, and develop and run websites. Those criticising industry funding need to demonstrate viable alternatives."

National patient groups, he argues, can raise funds through charitable donations and in some countries even have access to government grants, but pan-European bodies can't attract that sort of money – and of course government money carries its own risk of undue influence: "Some patient groups hesitate to speak up against their politicians so as not to put their funding at risk." EU funding, meanwhile, is available only on a project-by-project basis, and is notoriously complex and time-consuming to apply for. "It requires a level of dedicated project staffing which volunteer-driven organisations don't have."

That said, Geißler recognises that to preserve the integrity and credibility of the organisation, transparency, good governance and professionalism are essential, and it is up to him as director to ensure the highest standards. "When patient groups lose credibility and funding they are dead – the medical community, in contrast, is much less vulnerable to criticism." The collapse of Cancer United, he adds (a European campaign launched in 2006), provided a salutary lesson to everyone involved in cancer advocacy. "It was killed off by the media because there was a perception that it was the tool of a pharmaceutical company."

Geißler stresses that patient groups differ from other types of advocacy group in that solidarity and support for individual patients is their *raison d'être*. For some of them, access to drugs and trials is an issue, but this doesn't mean they are cheerleaders for the industry. Fairer access programmes to experimental therapies, greater transparency about new drugs being trialled, greater support for the many (non-commercial) clinical trials comparing variants of existing therapies, as well as better patient information – not least within the context of seeking 'informed consent' – are some of the many issues being taken up with increasing stridency by the ECPC and its member groups.

He emphasises too the broad agenda that ECPC is working to. Among the key initiatives are

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A patient's right to know. Geissler provided the patient perspective in a panel discussion on access to information, held at a meeting in Munich last September. He is pictured here with Antje-Katrin Kühnemann (far left), a well-known broadcaster who chaired the session, together with the other panel members

"There is huge emotion in our work. But we must earn our seat at the table with a professional approach"

providing the secretariat for MEPs Against Cancer (the 70-strong group of European Parliament members – see also Masterpiece page 36), and playing a major role in the launch of the new European Partnership for Action Against Cancer, which aims to coordinate research and spread best practice among the EU countries.

Geißler knows more than most just what a life-saver a new drug can be, as he joined one of the early trials of Glivec (imatinib) in Germany after he was diagnosed with chronic myeloid leukaemia (CML). "We must remember that many patient representatives like me have had to fight for their lives. There is huge emotion involved in our work. But of course we must earn our seat at the table with a professional approach."

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Geißler's background has certainly equipped him to handle the challenges of present-day communications, which is so much part of the job. "My studies were in business and I joined the media giant Bertelsmann to work in a think-tank on media innovation, especially new Internet technologies, well before any commercial introduction. I then moved to Vodafone, working in R&D, and also managed a multinational team of business developers, which has helped me acquire the skills to run a non-governmental start-up like ECPC."

Being a self-professed 'technology geek' has proved to be more than useful in Geißler's move into cancer advocacy work – enabling him to rapidly develop a website and online community for leukaemia patients in Germany. That came after he was diagnosed with CML at the age of 28.

"I went for a standard health check in 2001 and found my blood white cell counts were way out of range – and a bone marrow biopsy revealed I had cancer." After the huge shock, Geißler propelled himself into researching CML and the treatment options, and quickly found there was hardly any German-language information and little consistent guidance from local oncologists. Having studied in the UK, his English was good, so he was in a much better position than many to find out more.

"Being a young patient, rather than being recommended interferon I was referred to a bone barrow transplant centre, on the grounds that this was the treatment of choice and my only chance for a cure. Step by step I found out that, not only was the mortality rate at my risk group still around 20%–30%, but a further 30% of patients would become severely ill for the rest of their lives. Nor was the important issue of my fertility ever mentioned [for more on this, see Patient Voice, page 58]. I even looked into alternative medicine such as mistletoe, but was told it was not an option

We, the patients. Delegates from cancer patient groups across Europe learn how to influence policies that make a difference to their own members at gatherings like this ECPC Members in Action meeting in Munich, October 2009. (Inset) In conversation with Alojz Peterle, co-chair of MEPs Against Cancer, at the same meeting

"As patients we must make our voices heard to encourage collaboration and speed things up"

for leukaemia. But luckily I found out on the Internet about a new targeted therapy, Glivec, which was at the experimental stage, and I managed to get on a small phase II trial in Germany."

Glivec, of course, turned out to far exceed expectations, for which Geißler and others on the trial are living proof. "I was travelling 800 kilometres a week to participate in the trial, and no-one at work knew of this except my line manager. But without the efforts of engaged clinicians like Andreas Hochhaus [the principal investigator on the German trial] and others, and particularly the key investigator, Brian Druker in the US, Glivec may never have come to market, as Novartis did not think at first it would be commercially viable." Hochhaus, now at Jena in central Germany, has since become one of Geißler's closest oncology contacts.

CML is just one of many less common cancers that Geißler and colleagues are keen to highlight. He would like to see more resources and support given to speed up similar, if probably less dramatic, progress in other rare cancers, where industry interest is scant because of the small size of the market. As he adds, Glivec was not expected to work in CML in the long term. "I thought I'd be on it for a few years and then still have to go for a transplant. But my blood count stabilised quickly and I've now stopped taking Glivec at all – instead I'm taking low-dose interferon as a maintenance therapy, as are 19 out of 25 people who were on my trial, who are all in stable remission with just a single injection every fortnight."

While there were initial reservations about Glivec – at least from the commercial side – it might seem that its use and follow-up research are now in full swing. That certainly is not the case, and reinforces Geißler's contention that without patient group input and pressure, sufferers could still be left by the wayside.

"The low-dose interferon I'm on now is a case in point – it's very controversial, as many oncologists saw the suffering that high doses used to cause before Glivec came along. There are also the second-line drugs for treating those who develop resistance to Glivec and for those who cannot tolerate it. However, for those who respond well, the question is whether a life-long therapy is necessary and tolerable. It takes seven or eight years for significant research findings to translate into clinical practice, and as patients we must make our voices heard to encourage collaboration and speed things up."

As he says, this is not just about personal survival, but also about the huge burden that increasing availability of very expensive drugs will have on society. "Of course, the new second-line drugs, even though approved by EMEA, are not always made available. In England, for example, NICE has rejected reimbursement of drugs that have shown astonishing efficacy as second-line CML therapy and are the last resort for patients with resistance, but you can get them if you live in Scotland."

Ending such regional and postcode lotteries between and within countries is a key role for patient groups, he adds, as is countering prescribing practices that discriminate against certain groups. "For instance, an oncologist here in Munich has found that less than half of CML patients aged 70 and older in Bavaria are being given Glivec – there seems to be an odd view that older people don't need expensive but life-saving treatments, so they are given something that will keep them alive for only two to three years. But with a 70-year-old having an average life expectancy of 14 years, that's ridiculous. If we are seeing this level of suboptimal care in western European countries, imagine what it's like in less well-off nations."

Geißler left Bertelsmann and joined Vodafone, but this time he told no one about his condition as he did not want to jeopardise his career. "If you were a human resources manager looking at two equal candidates, but one with cancer and one who, say, played amateur football, who would you pick, even though the footballer may be off sick more with injury?"

He started leading a double life, having launched the Leukämie-Online website for fellow German leukaemia patients, making use of his command of English to translate key materials on latest treatments

for an audience that was getting very limited information in German. "Improving patient information is one of the key aims of ECPC and we are faced with big variations about what the authorities will allow in certain countries. Germany, for example, has very strict laws about providing information on prescription medicines, and a recent ruling of the European Court of Justice has made things even worse. As a result, we patient groups don't even get access to non-commercial information like medical journals and prescription information. You must ask doctors, but even they have trouble keeping up if their English is not so good."

Where government agencies and others do provide information in local languages – and there are 23 languages in Europe – inevitably it is the rarer cancers that tend to get left behind in priority on translations of the latest material, he adds.

After attending a CML meeting in Switzerland, where his organising and technology skills were spotted, Geißler was asked to be a co-founder of ECPC, and his patient work starting growing until he had to make a choice between a commercial career and advocacy. "I was still hiding my advocacy work from colleagues at Vodafone. I wouldn't let my photo appear on websites and I had to say I was doing something else in Barcelona when the ECCO [European CanCer Organisation] meeting was on. Luckily there is a doctor called Jan Geißler in Munich who would come up in Google searches on me."

By 2008, now married with two young children, he opted to take on the full-time position at ECPC, and has carried on running Leukämie-Online – a very lively online platform for leukaemia patients – and the CML Advocates Network, which he helped set up in 2007, and which now includes 42 CML patient groups across five continents. He sees social media tools such as Facebook, YouTube and Twitter central to future communication strategies, and indeed the top floor of his house in Munich is already a nerve centre of e-advocacy.

"Yes, older people are more likely to have cancer and do not use the Internet so much, but I'm now getting a lot of younger relatives on Leukämie-Online. I'm looking also at what's happening in the US, where they are far ahead. For example, the site PatientsLikeMe, which collects stories that include patient-made reports on side-effects, seems now to be attracting industry interest, as this information about how their therapies behave cannot always be observed in the streamlined environment of clinical trials."

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The way other health groups are using social media is instructive, he adds. "EURORDIS (the European umbrella organisation for rare diseases) used Facebook, Twitter and YouTube to great effect for Rare Disease Day last year. I see these new channels as great ways for patients to get to know each other and as very powerful tools for campaigning and knowledge sharing."

Geißler was in Dublin last August for the Livestrong Global Cancer Summit, run by the Lance Armstrong Foundation. "I heard that some 70 volunteers were recruited to support the event using Facebook. And during the conference, Lance Armstrong sent out a tweet saying he was going for a bike ride – and more than 1200 people turned up in Dublin's Phoenix Park to ride with him."

Groups that focus on other disease types can also provide much guidance on other ways to work more effectively, says Geißler. "I'm astonished by what the HIV/AIDS patient community has achieved, for example – the way groups have united to work with

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researchers and industry to achieve what is turning from a killer to a chronic disease is a great model."

One topic he says AIDS speakers have addressed at meetings is how to build a trusted organisation – how to apply good governance principles such that funders and other parties feel comfortable that they are dealing with a professional group.

Also growing in importance, he adds, is the Patients' and Consumers' Working Party of EMEA, on which ECPC, EURORDIS and others such as the European AIDS Treatment Group, the European Myeloma Platform and Myeloma Euronet currently sit. "As well as medical issues, this group has published a code of practice on how patient groups should work with industry, which we helped draft. It sets out minimum standards of transparency and best practice that are essential if a patient group is to grow."

But he stresses that 'red tape' should not stifle the many grassroots groups that are run by volunteers in their spare time. "I started Leukämie-Online out of my own pocket, and had I needed a scientific advisory board, charitable status, a certified website and so on at the beginning, I may never have launched it."

Meanwhile, breaking down – and interpreting – red tape at European level is one of the key goals for Geißler and colleagues. The EU's Clinical Trials Directive – so much criticised in the cancer world for loading excessive bureaucracy on research – is now open to revision, and ECPC is one of the groups that will contribute to a consultation. "We must make our views known about the need to accelerate safe research and stop trials moving to the US, China and other countries. We are pressing, for example, to reduce the complexity of trial approval procedures and ethics reviews around Europe, to cut delays as protocols are batted to and fro like a game of ping pong."

He adds that a critical stage in a drug coming to market after approval is health technology assessment – which can be a prolonged process where government agencies decide on reimbursement, if at all. "We need to look at conditional approaches and innovative reimbursement schemes to speed up availability to patients in urgent need, while more data are collected. And patient representatives definitely need training in how to engage with health technology assessment."

He notes too that patients could have more say on the efficacy/safety balance. "Those who may be dying are often prepared to take on more risk. And we need to monitor closely the move to personalised medicine through targeted therapies. Are researchers setting the cut-off points for eligibility for trials at the right points? Changing designs may speed up recruitment and results. Increasingly, if patient groups are not convinced about a trial's design we may advise people not to take part. It is another likely outcome from the power of the Internet and social media and it's no exaggeration to say patient groups are able to make or break trials today."

Naturally, Geißler is keen to avoid confrontation and to show oncologists, such as his compatriot Hossfeld, that patient involvement at this level can be beneficial. "We need to show oncologists that by working with well-educated patient representatives they can recruit patients faster, improve informed consent and change public perception about trials, which is often poor.

"Another issue that I spoke on recently at a European Commission meeting on translational research is compliance when taking oral cancer drugs. In the next five years the proportion of cancer drugs taken orally will rise from 10% to 25% and patient groups will have a vital role in helping with compliance away from the clinic." There are also issues about what not to take: Geißler notes that two-thirds of people with cancer take some sort of alternative medicine, and often do not disclose it to their doctor, raising the potential for counteracting mainstream medication.

Other initiatives and information Geißler highlights include ECPC's involvement with RARECARE, pooling data from more than 88 cancer registries across Europe to build an accurate database on rare cancers, and the European colorectal cancer screening guidelines – ECPC received funding for both from the European Commission. "We also worked with the European Society for Medical Oncology at

their conference on rare cancers in 2008, and generally we are pleased to report that the oncology community at European level is happy to involve us more as an equal partner."

He mentions also the approach in the UK, where the National Cancer Research Institute has around three dozen patient representatives in training to be partners in research, with their expenses paid to attend the meetings. "I was amazed to see this, but I recognise that researchers are wary of patient representatives who do not have the training to understand issues such as trial design and outcomes, side-effect management and so on. We need training to have an informed opinion."

Patient involvement in both research and treatment is crucial, he feels, and is undoubtedly more difficult in countries such as Germany, where even younger oncologists suffer from a strict medical hierarchy, and where interest groups such as urologists hold much power. He says he felt a sense of *déjà vu* recently when his mother was diagnosed with ovarian cancer – "I've found the same problems I had, such as doctors not communicating with each other, and a lack of relevant patient groups – there is not one specifically for ovarian cancer in Germany to my knowledge."

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A beacon of light for CML and related cancers is undoubtedly the European Leukemia Net (ELN), which is run from Germany, and which he says is rightly viewed as one of the world's leading cooperative research networks in rarer cancers. "Initially funded by the European Commission and with public–private partnership on certain projects, it is one of the cancer networks I've seen working well – others have funding problems and rivalry between oncologists." But he has mixed feelings as, despite patient group involvement being one of the work packages, so far there has been limited evidence of it, he says.

Much of Geißler's frustration – shared by colleagues at ECPC and other groups – is lack of information with which to approach health authorities. "We have to get our facts right on issues such as screening, clinical excellence, survival and so on. But it is getting easier now to compare data across countries and so make stronger cases for improvements."

At a little over a year into the ECPC job, Geißler is strongly focused on the task of generating more resources to tackle the huge agenda on the organisation's plate. Now travelling every week to various events, the ECPC message – 'Nothing about us without us' – is moving up a gear.

And for those yet to meet him, check out the ECPC website (ecpc-online.org), Leukämie-Online (leukaemie-online.de) and CML Advocates Network (cmladvocates.net) to see just what this Internet advocate has achieved in cyberspace to help patients in the real world. "And bear in mind that I basically owe my life to the Internet," he says.