

From unwanted interference to indispensable partner

The patient advocate who helped open the minds of Europe's cancer doctors

→ Simon Crompton

As founding president of Europa Donna, the European Breast Cancer Coalition, **Gloria Freilich** helped transform attitudes towards patient advocacy. She would like to see further progress, particularly in regions that have been slow to accept a patient role, and advises that her softly softly approach – building confidence and allaying suspicions – is the way to go.

Three years after taking up the presidency of Europe's first international breast cancer coalition, Gloria Freilich faced her most embarrassing moment. It was 1997 and she had started to address a major meeting of oncologists in Lisbon, talking about her new organisation, designed by women for women, called Europa Donna. Then a doctor stood up and challenged her. What right did a layperson, he asked, have to address a thousand oncologists at a medical meeting?

Freilich was flabbergasted. Many of the doctors there were too. She gathered herself, and answered that she had a right to be there because she was representing the other side of the medical equation – the patient viewpoint. Then she carried on with her presentation, uninterrupted.

Recalling the event 13 years later, her presidency of Europa Donna now in the past, it still makes Freilich's toes curl. Nowadays, such an incident would be unthinkable. It's a mark of how much Europa Donna has helped change attitudes that the

patient viewpoint is now intrinsic to top-level international discussions about breast cancer. Under Freilich's leadership, a European breast cancer organisation representing the interests of patients earned a place at the scientific table not by confrontation, but by instilling respect among medical colleagues. The process hasn't always been easy.

So Freilich's proudest moment came three years later when, after the end of her presidency, she stood up again to speak, this time in Strasbourg to 90 Members of the European Parliament and the then European Health Commissioner David Byrne. When Europa Donna had been set up, its instigator, surgeon Umberto Veronesi, told Freilich that its aspiration should be to address the European Parliament and gain its support for improving diagnostic and treatment services across the whole continent.

Now, by a strategy of making the patient voice indispensable rather than an unwanted interference, it had achieved this aim. In her Strasbourg address, Freilich emphasised the need for a European breast



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cancer registry, rapid access to treatment, multidisciplinary breast units and equalisation of services throughout Europe. This prepared the ground for major developments that have followed, such as the European guidelines for quality assurance in breast cancer screening and diagnosis – now a fundamental tool that Europa Donna coalition members use to advocate for better services in their countries.

Appropriately enough, Freilich's role in this transformation started from her own distressing experiences of cancer. It all began with an error. In 1983, living in London, she decided she should have a general health check-up and mammogram. Her mother had died of breast cancer 10 years earlier, and her

cousin and aunt had also died of the disease shortly after diagnosis. So there was good reason for having a check, even though there was as yet no national screening programme in the UK. When she arrived at the hospital, the mammogram machine had broken down. So she had to go to another, where the machinery had a peculiar balloon contraption instead of a plate to hold the breast in place.

"I must say, I remember it very well because it was very difficult not to laugh while it was happening," says Freilich. "You were kind of squashed down under this balloon, and it was only a single view of each breast, not two views as one would expect now. And I was told that everything was fine."

"That summer I went away on holiday with my husband to Italy. It was two months after I'd had the mammogram, and pulling my swimsuit up I found a lump about the size of a plum in my left breast. I said nothing at the time, but when we got back to London I rang the breast surgeon's secretary and made another appointment. When I went in, I had a needle put into the lump. Shortly afterwards, I was telephoned at my office – I was working as the fundraising officer for the

National Autistic Society at the time – and I was told there and then, on the telephone, that it was cancer."

It was a terrible blow. It felt like a family destiny that she should die of cancer too. Freilich remembers being in such a state that she accidentally set fire to her dressing gown – thankfully she was unhurt. Her husband and her twin son and daughter, who were 15 years old and studying for their 'O' level exams, were "desolate". So she returned to hospital and had a segmental mastectomy and complete axillary node clearance. Histology came back with its analysis. It was not cancer.

At the time, Freilich was overjoyed at the news, but nowadays, she reflects, patients might sue under

Cancerkin, Hyde Park, 2005. Every other year, patients, families, friends, health professionals and celebrity supporters gather in London's most famous park for a 10km walk to raise funds for the breast cancer advocacy group



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similar circumstances. She had to perform an enormous psychological turnaround and was left with conflicting emotions – a knowledge of how grueling a diagnosis of cancer was, an awareness of the inadequacies of some services, but also a deep gratitude at being spared.

GETTING INVOLVED

To this point, almost every experience she had had of cancer had been negative. The one thing that had impressed her was the care given to her at the Royal Free Hospital (the misdiagnosis had been a laboratory error). She stayed in touch with her surgeon, Santilal Parbhoo, and offered to help with a breast cancer research appeal he was setting up. Freilich set about raising money, not only for clinical research but

for a new clinic for women at high risk of breast cancer, and a new computerised call and recall system. On the basis of her success with this, she was invited to help set up and run new patient services, as a full-time, professional job.

With a background in music – she had studied to be a pianist and opera singer before starting a family – she was aware of gaps in her scientific knowledge and attended lectures for medical students. “I was allowed to build up my knowledge and confidence,” she says. “So I started to suggest, there’s little here to inform or support patients. Couldn’t we do something about that? I took a counselling course and prepared to set up this organisation for patients, which in 1987 became Cancerkin.”

Cancerkin, which Freilich led as chief executive

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until two years ago, was the first hospital-based, dedicated breast cancer charity in the UK, concerned with treatment, supportive care, education and research. “Treat the patient, not just the cancer” was, and still is, its philosophy.

It was one of the first manifestations in Britain of what started to become known as breast cancer advocacy. Its services were, in part, inspired by the American Reach to Recovery Programme, which Freilich visited in 1986 as part of her personal research into how best to offer support to women with breast cancer. It trained carefully selected volunteers – women who had had breast cancer themselves – as counsellors to visit patients in their own homes and support them, their families and friends.

Soon the charity outgrew the one room it had been allocated in the Royal Free Hospital – so another Freilich-coordinated fundraising push resulted in a new Cancerkin centre being opened at the hospital in 1990. It was the first on-site dedicated breast cancer support centre in the UK.

Freilich speaks fondly of the medical staff at the Royal Free – the way doctors supported her ventures throughout, invited her to multidisciplinary meetings and gave seminars to patients and volunteers. But the fact is that in her national work, and the international work that followed, she has had to address a problem that was rife 20 years ago, and still common: doctors did not provide information to cancer patients or involve them in decision-making. More than anything, women like her, and her mother, needed someone to talk to. Freilich acknowledges that it was personal experience that drove her on to correct this.

“The kind of support we offered was completely missing for my mother and

me. If you don’t have information about a condition, you can build pictures in your mind that can be so harmful and so negative and can affect the way you recover or the way you respond to treatment. But it was unusual for hospital doctors to have much time to spend with patients beyond the hospital environment. The role of the breast care nurse was not very well developed at that time. So I considered it important that patients had someone else to turn to for support.

“I think it’s about cooperation. In the past, patients have traditionally deferred completely to doctors, which I believe is wrong. But I don’t go along with the idea that women are equipped to make their own independent decisions. They need to be informed sufficiently to be able to make sensible decisions in collaboration with doctors.”

EUROPA DONNA

If it was an error that contributed to the founding of Cancerkin, it was a chance meeting that led to Freilich becoming Europa Donna’s first president. Her valuable work at the Royal Free led to her being invited onto a Reach to Recovery international advisory committee, under the auspices of the UICC (International Union for Cancer Control) in Geneva. After attending a Reach to Recovery conference in Trieste in 1992, she shared a taxi back to the airport with Umberto Veronesi, and asked him what had happened to his plans to set up a European



With renowned concert pianist Alfred Brendel. Having trained as a pianist and opera singer herself, Freilich put her musical connections to good use, organising fundraisers for Cancerkin. This picture was taken following a Gala Concert featuring Brendel with London’s Philharmonia Orchestra, at the Royal Festival Hall, September 2004

breast cancer coalition along the lines of the American National Breast Cancer Coalition. Veronesi admitted that things had not got off the ground as rapidly as he'd wished. Freilich said she was interested in becoming a representative in London, and they exchanged addresses.

Three weeks later, she received a box full of all the papers relating to the proposed organisation. She was kept informed of all correspondence, but didn't have any official role. But a year later, in 1993, she was invited to attend a conference of EUSOMA, the European breast cancer specialists, in Paris. At the end, Veronesi made a surprise announcement: a new breast cancer coalition called Europa Donna was to be formed, and its first president would be Gloria Freilich.

Nobody was more surprised than Freilich. It took some backtracking – establishing a working party and organising elections – for the body to actually come into being, with Freilich formally at the helm. With enthusiastic representatives of breast cancer patient groups in Italy, Germany, Belgium, Austria, Switzerland and the UK, the objectives were agreed: enhancing the role of women in controlling breast cancer; promoting improvements in the standards of diagnosis and management across Europe; promoting equality of access; making partnerships with clinicians and scientists; influencing European and national politicians. “From the earliest days, we were greatly helped by the valuable support of Alberto Costa and the European School of Oncology, with whom Europa Donna has worked closely throughout its history,” stresses Freilich.

The launch conference was held at the Euro-



A milestone in patient advocacy. The European Breast Cancer Conference is the first European scientific cancer conference to include patient advocates as equal partners. As Europa Donna president, Freilich was a co-founder of EBCC, and is pictured here at its first conference, September 1998

pean Institute of Oncology in Milan in 1994. “At that time the advocacy concept was barely understood,” says Freilich. “Immediately, we had to overcome suspicion of our motives and establish a clear understanding of our mission. We began to make our presence felt through involving ourselves in breast cancer public education, holding conferences and patient meetings, lobbying decision makers, publishing newsletters, holding media campaigns and generally coalition building.”

One of Europa Donna's early undertakings – a 15-country survey of women's experiences of breast and gynaecological cancers carried out in 1996 – confirmed the absolute legitimacy of what it was trying to do. “Some of their experiences were pretty ghastly. I think many women felt able, for the first time, to vent feelings they would never have shared with a medical expert. You could tell that people had suffered psychological angst, damage, and the survey drew attention to aspects of treatment and care across Europe where improvements could or should be made.”

The fact that Europa Donna – the name is Italian for ‘European woman’ – was envisaged as a ‘sisterhood’ is important, says Freilich. It isn't that the organisation has excluded men – supporting male family members and friends is an important objective, and many male clinicians, most importantly Veronesi and Costa, have been influential in driving the organisation forward. “But I suppose that women, by virtue of our biology, have various times of our lives when important events and diseases happen to us alone, and because we have the child

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bearing responsibility, all the gynaecological side of it is more or less out in the open. We're used to communicating with each other about these issues, and even in countries where topics like cancer are not openly discussed, women do get together and support each other in many different ways.”

Nevertheless, the fact that breast cancer – and even the breast itself – is still a taboo subject in some countries, has been a consistent hurdle. The original logo design for Europa Donna was a breast, but was vetoed because of sensitivities – instead, it became a map using women's silhouettes. The very word cancer is still barely spoken publicly in some regions – an additional barrier to getting patients to feel confident about talking to others about their condition.

“In some countries, if it becomes widely known that there is cancer in the family, it can cause all sorts of problems, influencing marriage prospects, for example. I suppose it starts with the assumption that if you have cancer, you have an untimely end. That's not necessarily the case any more, and I think that as people acquire confidence about a diagnosis of cancer being properly treated and the possibility of making a good recovery, then fears and superstitions will gradually subside. We are already making a difference.”

There have been other significant problems: creating objectives to work towards on a European level has been immensely difficult, given the cultural disparity and variations in health care systems and economies between EU Member States. The idea of patients having a say in their own care is still anathema to some doctors – like the oncolo-

gist who stood up to challenge Freilich in 1997.

“Not all countries are readily accepting of laypersons' involvement,” says Freilich. “But you change things by driving up levels of understanding and confidence, by encouraging more interplay between the layperson and the medical profession. The medical professionals have to feel confident that they're not going to be overrun by women wildly making demands they can't meet. You change things by showing examples of what has been already achieved, and which they can emulate.”

The merits of a professional multidisciplinary approach to breast cancer, which Europa Donna advocates, are still not always appreciated. Wherever this is the case, Europa Donna has had to work hard to persuade medical professionals to link with their colleagues to found multidisciplinary breast units.

But Freilich assesses the organisation's achievements over 16 years as considerable: its influence in the setting of European standards of breast cancer care; its planting of the patient perspective firmly in the centre of high-level clinical and political discussions; the growing acknowledgement of the need for multidisciplinary breast units.

A powerful alliance. Breast care nurse Sylvia Denton (right) was among the first advocates for patients to be treated by a multidisciplinary breast team, including a specialist breast nurse – key issues for Europa Donna. President of the UK Royal College of Nursing (2002–2006), she is pictured here with Freilich at the Europa Donna conference, Paris 1999, where she led a one-day course on endocrine therapy aimed at nurses from Europa Donna's member states



EUROPA DONNA



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A royal occasion. HRH the Duke of Gloucester joined other distinguished patrons, major donors, medical experts and dedicated volunteers for the launch of Cancerkin's 20th anniversary, in Goldsmiths' Hall, the City of London, April 2007

ONE AIM, MANY CULTURES

She is proud that Europa Donna membership now extends to 44 countries. She's proud too of the link that she forged with EORTC (the European Organisation for Research and Treatment of Cancer) and EUSOMA to found the biennial European Breast Cancer Conference. And she's certainly proud of the coalition's relationship with the European Parliament.

But she is also realistic. "We wanted to equalise the standard of diagnosis and treatment right across Europe, and one has to acknowledge it's going to be a long time before that happens. We've lately embraced countries like Kazakhstan, Kyrgyzstan and Georgia, and our Russian-speaking Europa Donna Ukraine Forum is able to help them with training and education. But things are going to happen more quickly in some countries than others. Because of these variations, I think there could be more regionalisation within Europa Donna in the future in order to concentrate help where it can be given most effectively."

She sees improving screening as key to sparking developments in all areas of cancer services. "Where good screening programmes have been established, those standards have tended to carry through into surgery and oncology as well," she says. Though there are questions being raised in the UK about how many lives a national breast cancer screening programme really does save, Freilich believes that if the programmes are established to a high standard, and women are provided with quality information about the pros and cons of screening, the benefits outweigh the risks.

Though she is no longer in full-time employment in the cancer world, full retirement doesn't seem an option. The set of oil paints, brushes and canvases she was presented with when she left Cancerkin remain largely untouched, awaiting a day when she has time on her hands. Her work with Europa Donna continues in her capacity as founding president. She remains involved with ESO and

many cancer projects, such as the Look Good... Feel Better programme, which provides women affected by cancer with access to cosmetics to address the effects some cancer treatments can have on one's appearance. In 2008 she was appointed a trustee of the Bowel and Cancer Research Trust at the Royal London Hospital, and she would love to see some of the growth in interest and resources that breast cancer has experienced in recent decades spill over into these less well publicised fields.

Was it really chance, luck, mistakes that led her guiding role in these influential breast cancer bodies, as she implies? Her modesty is misleading. The reason behind Freilich's rise in the cancer world becomes clearer when I ask her exactly what it was that Veronesi saw in her, after that conversation in a taxi – what made him want to invest such responsibility and trust in her. She thinks carefully before answering.

"I think he had made some enquiries about my work in London and probably heard a few good reports. I tend to make things happen. I'm a very entrepreneurial person, and I think that if I want to make something happen, and work hard enough at it, I will make it happen. I did have a very strong feeling about Europa Donna. I thought it would be wonderful to do it."

Skill at fundraising, organising people and making alliances, driven by personal conviction. It's a potent combination, which has significantly driven on the cause of user involvement in Europe. It is a combination still vitally needed in cancer organisations around the world.