

# Stella Kyriakides: the torch bearer

→ Marc Beishon

When Dolly Triantafyllides, a prominent member of Cypriot society, contracted breast cancer in the late 1960s, she broke with traditional taboos and went public, becoming one of the island's first advocates. Many years after her death, her daughter Stella faced the same diagnosis. She took up the torch of advocacy and has been running with it ever since.

**M**any runners who carried the Olympic torch on its long journey to the Athens games last year publicised important causes – and none more so than Stella Kyriakides, president of Europa Donna, the European breast cancer advocacy organisation. She bore the torch as part of its leg through her home city of Nicosia, Cyprus, with supporters, wearing Europa Donna T-shirts, lining the route.

It was, she says, symbolic of her own journey as a woman who has experienced breast cancer both personally and in her family. Her mother was diagnosed with the disease in the late 1960s, when Kyriakides was a schoolchild – a time, she adds, when cancer was very much a taboo subject. “Even now it is still common to see reports of people losing their fight against the ‘terrible disease’, and not to see it by name,” she says.

But starting with her mother, and later on in breast cancer awareness campaigns in Cyprus, Kyriakides says openness in society about the disease has slowly improved. “My mother and

father were well-known people in what is still a small community, and she never tried to hide her condition,” she says. “Right to the end of her life – and she lived with breast cancer for 10 years – she attended functions and got on with things. She was certainly, unknowingly, one of the first breast cancer advocates in Cyprus.”

Today, thanks to Kyriakides and other Cypriot women, the country has an active national Europa Donna forum, while Kyriakides has become increasingly involved in the organisation at European level, first as vice-president, and then president in 2004. She sees Europa Donna as first and foremost a political, campaigning organisation that has done much to shape standards for breast cancer treatment and care – but still has a huge agenda on its plate.

In 2003 the European Parliament passed its first ever disease-specific resolution, laying down a ‘gold standard’ for pan-European breast cancer diagnosis, treatment and care. But as Kyriakides says, major variations in facilities and approaches among countries – and at regional and hospital level within countries – means that advocates



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At home  
with her husband  
Kikis and her sons  
Yiannis (centre-  
right) and Mihalis  
(centre-left)

## “I remember waking up believing it would not be there – but of course it was”

and medical authorities need to engage in a complex picture of prioritisation and national ‘politicising’ if consistent improvements across Europe are to be realised.

It is an engagement that Kyriakides is well equipped to help lead. Her career to date – her ‘day job’ in other words – is as a child psychologist at the Archbishop Makarios hospital in Nicosia. But when she started out in 1979, psychology services for adults – let alone children – were virtually non-existent. Over 25 years, she has helped develop the shift in care of people with mental health problems from institutions to community-based rehabilitation, and set up the first child psychiatric department on the island.

But first, like many Cypriots of her generation, Kyriakides had to travel abroad to gain a university education to establish her credentials. At school, she worked as a volunteer with children to fulfil her community service requirement. “I knew then I wanted to work with children,” she says. “It is fun and fascinating to see how they grow and develop, and how painfully honest they can be.”

Eschewing a family tradition to study law – but with family encouragement – she duly went to the University of Reading in England to complete a degree in psychology, and then to Manchester for a Masters in Child Maladjustment. It was during her Masters that her mother died. “She was diagnosed with breast cancer when I was 11,” says Kyriakides. “I often wonder if my choice of psychology is related to living through the experience of my mother’s breast cancer during adolescence, and wanting to learn more about how people function. I do know I have never regretted studying psychology.”

After her mother’s death, she still had to complete her dissertation, which with the support of friends in England she did, and returned to Cyprus to begin work as a clinical psychologist in the Ministry of Health. “I was one of the first psychologists in Cyprus and a founder of the Cyprus Psychological Society – we were considered a strange breed at the time,” she says.

Working in a mental health hospital for a number of years, she and her colleagues also helped set up the first rehabilitation programmes

and community homes for patients – sometimes using their own cars to drive them away from institutions. “I lived through the transition from institutionalisation to community mental health services. It was wonderfully exciting, but my heart was always in working with children.”

Kyriakides went back to England – this time on a World Health Organization fellowship on child psychiatry at the Institute of Psychiatry – and then set up a small outpatients clinic for children in Cyprus. “I don’t like to call myself a pioneer but the child psychiatry department where I now work was built from plans I held in my hand. We lobbied hard for this service. At first the department had no psychiatrists, only one psychologist – myself – and two nurses. Now we have 22 nurses, four child psychiatrists and eight psychologists. I’ve seen it grow day by day.”

At first, Kyriakides did not expect to encounter the problems she saw while training in England, such as child abuse, thinking that Cypriot society was more close knit, with strong family ties. “But there were the same problems, although much more hidden,” she says, adding that notification of abuse has now become more common since appropriate services have been in place.

Kyriakides and colleagues have also addressed the needs of children with serious medical as well as social problems. “I started working on paediatric oncology at a time when there was no children’s cancer ward – they were given a room in the paediatric hospital and sometimes left there for months,” she says. Now there is a range of children’s specialisms at the Archbishop Makarios children’s hospital, including oncology, and Kyriakides and colleagues are involved with diagnosis and care from day one.

Again, child cancer has been a taboo subject in Cyprus – and she has had to tread a careful pathway between protecting the child and the wishes of parents, and a strong belief that children do have a right to know about their disease. “Cancer takes children out of their normal journey – out of school, away from peers and affects their body image. They need to go through their treatment and also be psychologically healthy.”

It is all very important and richly rewarding work that has been a cornerstone of Kyriakides’

life – along with marriage and two sons, now 18 and 22.

But given her background and experience, what happened in 1996 – when she was diagnosed with breast cancer – still came as a great shock.

She wasn’t unwell. Like many women, she felt a lump in her breast while showering, although because of her mother’s history, she had also been having regular check-ups. It was her 40th birthday. “I chose to do what a lot of women do – nothing. I decided it would go away on its own. I remember waking up believing it wouldn’t be there – but of course it was.”

A visit to a doctor followed – but, as a friend, he could not believe it either, and said: forget it. “Then I was told it was a cyst and had a fine-needle aspiration – but there was no liquid and no one sent anything for biopsy. I visited a surgeon, who was complacent too. Then I called an oncologist friend in London who said it’s probably nothing, but we don’t leave palpable lumps in women with your history.”

Back with the surgeon, Kyriakides had the lump removed – and a fast biopsy revealed that she did have breast cancer. Although she went through some denial, the whole process actually took only two weeks, but she involved only her husband and brother at the time of surgery – “I regret not telling my children earlier now,” she says.

Determined to be open about her condition after the diagnosis – “I knew I had to come out with it immediately” – she went back to the hospital where she worked to see people before flying to England for a course of radiotherapy. “I could not have disappeared from hospital life for months with everyone thinking the worst was happening. But people were frozen – they couldn’t believe it was happening to their Stella, whom they’d known for 15 years.”

Despite her position in the medical world and her mother’s breast cancer, there was a huge amount to learn. “Having a scientific background enabled me to read a lot of articles and understand the options, but to start with I didn’t know what ‘hormone receptor positive’ was, what tamoxifen was, or what a linear accelerator was and why it was a good idea to spend three

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months in London on that machine and not with the cobalt option at the hospital in Cyprus.”

In short, the doctors were speaking a foreign language of medical jargon – “I was surprised how little information there was in Greek, and I don’t know what I would have done if I hadn’t been fluent in English.”

Her treatment was successful – although as she points out, being away from home having radiotherapy was a lonely time. “I spent hours walking in London, and saw so many movies. And I wondered how women in Cyprus without my level of expertise would have coped.”

The seeds of her advocacy role were sown then, but it was to be a couple of years before she started. “I knew from my experience the frustration of women in Cyprus, and didn’t have the European experience I have now,” she says. “But first I needed to complete my treatment and focus on my family and work. I needed to integrate the experience into my self and not act emotionally, and wanted people to see me in my professional role – not a mixed front – and needed also to protect my family from what had happened.”

Then, with a small group of other Cypriot women, Kyriakides formed a breast cancer awareness movement. Some 20,000 signatures were collected and presented to the country’s president – “We stood in supermarkets and on the streets” – with the aim of lobbying for a national breast cancer policy.

“I’d been reading a lot about standards of excellence and what we needed to do to improve treatment,” she says. “It was also about making people aware that the disease can be treated very effectively if you have early diagnosis and good care. And the message was that it affects us all – we found sponsors for advertising that actually used the words ‘breast cancer.’” After also giving media interviews, Kyriakides is now well known in Cyprus for her advocacy work.

At this time, the island was building its first

oncology centre, and one of the consultants on the project encouraged Kyriakides to find out more about European work, in particular Europa Donna. So in 1998 she flew to the 1st European Breast Cancer Conference in Florence, where she encountered reality and shock – talks from doctors, for example, about five-year and seven-year survival rates. “I had thought: two years on and I’m cured,” she says.

But there were also women standing up and asking questions, and of course the presence of Europa Donna, which has been one of the three partners behind each of the two-yearly European Breast Cancer conferences – the co-partners are the European Society of Mastology (EUSOMA) and the European Organisation for Research and Treatment of Cancer (EORTC). “Once I’d got hold of my personal feelings I was able to see the importance of putting over the views of the ‘other side’, and wanted to know more about Europa Donna.”

Kyriakides quickly discovered that Europa Donna has a clear mission as an advocacy organisation – turning personal experience into political expertise, as she puts it – and it was not a support agency for breast cancer patients and their families. “But at times you need to advocate for change in order to safeguard basic breast care,” she notes, adding that support groups are very important.

But the 10 pan-European goals formulated by Europa Donna in 1994 – which Kyriakides says remain unaltered today – have certainly proved to be agents for change, not least in the European Parliament’s breast cancer resolution, which is a highly detailed call for minimum standards of screening and treatment, and ambitious targets “of creating, by 2008, the conditions required for a 25% reduction in the average breast cancer mortality rate in the EU and of reducing to 5% the disparity between the Member States in the five-year survival rate.”



Carrying the torch for breast cancer patients. Supporters wearing Europa Donna T-shirts lined the route as Kyriakides carried the eternal flame through the streets of her home town, Nicosia, at last year's Olympic games

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As Kyriakides points out, the resolution is just the beginning. Getting national implementation is the key, and the realities for each of the countries in Europa Donna can vary from having few or obsolete mammographic machines up to proper screening programmes in dedicated breast units. “As for the targets, if we come out and say they are too ambitious we have shot ourselves in the foot. We are going to try – it’s about putting the pressure on at European and national level.”

Objections to the resolution, she says, have come from some authorities in states that feel the bar has been set too high. “But the resolution was not put together by taking the crème de la crème of two or three healthcare systems – it did take into account variabilities in Europe, and laid down the minimum standards for women with breast cancer.”

Together with other advocates – in particular Karin Jöns, the Member of the European Parliament (MEP) who was rapporteur on the resolution (and who is also president of Europa Donna Germany) – Kyriakides says they will not let up the pressure, especially as there has been a large influx of new

MEPs after the last round of elections. At a European level, Europa Donna has instigated an annual training programme to equip advocates with the skills and knowledge needed to lobby effectively for service improvements. The programme takes 2.5 days – the most recent was in Milan in November – and comprises a packed agenda of science and communications training and workshops.

“It’s a very tight programme. We need to give information about breast cancer as a disease – its science and epidemiology – and about how to be effective as lobbyists,” says Kyriakides. The toughest part of the course for most delegates – and there were 27 at Milan, each from a different Europa Donna country – is the basic science. “But if you are an advocate for, say, better screening you need to know about the biology of cancer,” she says.

“It’s fine to ask for a seat at the table, but your emotion can only get you so far. You’re in danger of being seen as a breast cancer patient talking about your personal experience, and that’s not the point. We have to put forward an educated and responsible voice. But it takes training and time.”

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For national service improvements, it is also not enough to know about effective treatments without doing a lot of research about the resources available. Out of the European Parliament’s resolution, Kyriakides says screening is clearly a priority for countries yet to introduce programmes. “But if you pick up cancer at a very early stage and you don’t have the right histopathology and surgery set up, it may not be effective,” she says. Likewise, all the machinery in the world makes little sense without trained radiographers. Surveys of services are crucial first-line research. At home in Cyprus, a national screening programme is now in place, but Kyriakides and colleagues have recently turned to another key issue. “Unfortunately, we do see cases of surgery that women are very unhappy about – it’s a Pandora’s box we had to open and we got the reaction we expected.”

In 2004, Europa Donna in Cyprus went public with criticism that too many surgeons were carrying out small numbers of breast cancer surgery – and the Surgeon’s Association responded with a statement along the lines of “who operates on whom is not a matter for public dialogue.”

“Women should have a complete picture of their tumour type and the options available, including the type of surgery they require,” says Kyriakides. “We have women – not just in Cyprus – coming out of surgery with mastectomies they may not need. I am an advocate for surgeons doing a minimum number of new cases, as the Resolution specifies. We have excellent surgeons in Cyprus – but too many are doing breast cancer operations.”

It is a stand-off that surgeons are unlikely

to win in the long run, as Kyriakides says the essential plank of advocacy has been laid – namely they have been collecting outcomes over a number of years. “When you decide to open up an issue, you must get your facts right.” The most desirable outcome, from her viewpoint, would be the establishment of one or two dedicated breast units to handle the relatively small number of cases in the country (about 300 a year) staffed by multidisciplinary teams.

In a wider context, that Europa Donna has a ‘seat at the table’ is now a given – its full title, after all, is the European Breast Cancer Coalition – and it is also involved at the cutting edge of research on the global stage. Kyriakides mentions ‘TransBIG’, a worldwide translational research consortium run by the Breast International Group (BIG); Europa Donna sits on its steering, ethics and spreading of excellence committees.

“Our role is to help disseminate information that comes out of trials to women as quickly as possible,” she says. “I think trials are much misunderstood, which is why a lot of women do not take part. They often think it’s a choice between a placebo or new treatment. We have a booklet on trials in English, which we encourage national forums to translate into local languages. We certainly want more women enrolled in trials.”

Breast cancer research and treatments are changing very rapidly, and progress certainly provides another powerful reason for Europa Donna’s work, as all country activists, from those struggling to establish basic services up to those with well-developed infrastructures, need access

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to latest information. But it is sometimes said that breast cancer receives more than its fair share of resources.

“People should realise it is getting the share it should have,” says Kyriakides. “There is one new diagnosis every 2.5 minutes in the European Union and a woman loses her life every six minutes. We should always be top priority on the political agenda.

“I think too that what we have achieved in breast cancer is benefitting other types of cancer. It’s not that we will make it more difficult for others to move on – they will move on with us.”

That breast cancer mainly affects women (fewer men also contract the disease) has been part of the reason why advocacy has been successful, adds Kyriakides.

“I think that women organise themselves more effectively, and breast cancer affects us mainly when we are involved in multiple roles – as a mother, at work. So it has a great impact on

of the Year in Cyprus, and was also runner-up as European Woman of the Year.

Early last year, shortly after being elected president of Europa Donna, Kyriakides suffered a second breast cancer, which required more radical treatment than before. “People say it must have been more difficult for you – it was not harder, just different as I knew what questions to ask and what to do, and I did not have the feelings of panic I had then.” Crucial advice for a woman facing breast cancer, she adds, is to take your time and research the options properly.

The treatment was short enough for her to resume her work – but for a while she considered relinquishing the Presidency, as she was concerned she would not be able to effectively fulfil her role. Kyriakides spends the mornings and early afternoons as a child psychologist, catching up with e-mails and Europa Donna work later on. As the current President she has cut down her involvement in the Cyprus forum somewhat.

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society in general – and that means that many men have also become our strongest voices and advocates.”

She comments that the first breast cancer advocacy groups evolved from the women’s movement in the US – while Europa Donna itself was initially the idea of famous Italian surgeon Umberto Veronesi.

As the most recent Europa Donna president, Kyriakides’ main concern is to maintain the momentum that organisation has generated, and she feels a great responsibility for advocacy work, especially as a representative at European Union level. A personal vision she has is to cater specifically for the needs of younger women with breast cancer, a group she feels face some very different issues from older women.

She has also been widely recognised for her advocacy work – in 2001, she was voted Woman

Free time she likes to keep unstructured – “I like to relax, chat with my sons, walk the dog and pass the time of day. Generally I’m a happy bouncy person.”

She finds advocacy work tremendously rewarding. “If someone had said when I had breast cancer in 1996 I would be doing this now, I would have said ‘no way’. It has brought out a positive and creative side in me I never knew I had, and I have also met many wonderful people.

“Someone said in one of our workshops, ‘Breast cancer is the best thing that ever happened to me because it made me change my priorities,’ and I see what she means. I remember after my first cancer experience seeing sunflowers outside the hospital and thinking how beautiful they were – of course, they were always like that. But you shouldn’t have to go through breast cancer to feel like that.”