

# Putting breast cancer on the political agenda

How Karin Jöns MEP is helping improve breast care across Europe

→ Mary Rice

Two years ago, the European Parliament passed a landmark resolution which set goals and standards for breast cancer services. It all started when a surgeon saved Karin Jöns MEP from an unnecessary mastectomy, and introduced her to the concept of specialist breast units. “This is what women need. You are a politician. Do something,” he said. So she did.

**K**arin Jöns has been a member of the European Parliament since 1994. In June 1999, when she had just been re-elected, she was told that she had breast cancer. Her diagnosis and subsequent treatment have made her a tenacious advocate of the rights of European women with breast cancer to have the best possible diagnosis, treatment and care. For someone who by her own admission became interested in breast cancer “by accident”, she has a remarkable record in attracting political support to the cause.

Jöns was born in Germany and brought up in Sweden. As an MEP she now works between three cities – Bremen, Brussels, and Strasbourg – and to add to the logistical problems, her husband also works abroad, currently in Tel Aviv. “He was in Warsaw when I was diagnosed,” says Jöns, who is clearly used to relying on her own resources to get her through difficult times, though she adds “during this time, we managed to see each other more often. It’s true that to meet we often have to undertake a top logistical performance, but it is always worth it!”

“At the time of my diagnosis – during a so-called routine mammography – my election posters were still up all over the region,” she says. “Therefore I managed to get an appointment with four different specialists – today I would say ‘so-called specialists’ – on the same day. They all wanted to do surgery, without any further examination, in the next four days.” But Jöns was unconvinced. She decided to ask around among friends and physicians, including some outside her region.

By the next day she had found the address of what was at the time the only hospital in Germany that specialised in breast cancer, which was a few hundred kilometres from where she lived.

“The treatment started eight days later. If I had decided to go ahead with surgery and treatment in my own region, I am convinced that I would have had a total mastectomy instead of breast-conserving surgery.

But even today many women do not have the chance to get quality treatment in a multi-disciplinary breast centre.”



LEANNE FAIRLEY

MEPs hear about the importance of implementing breast screening in accordance with European guidelines at a meeting organised by the European Parliamentary Group on Breast Cancer and Europa Donna this January

## MAKING POLICY

Jöns' greatest political achievement in the fight against breast cancer was the adoption of the resolution 'Breast Cancer in the European Union' by the European Parliament in 2003. It had to be introduced as an 'own-initiative report', through a lengthy process which Jöns says required both patience and perseverance. "It is difficult to get topics outside the general legislative process onto the agenda, however important they may be. Thus everyone who wants to introduce an own-initiative report has to point out very clearly to the different political groups why the topic is more important than others and needs to be discussed. This is even more difficult when the report targets an issue, such as breast cancer, where the European Union does not have any legislative competence."

The breast cancer resolution was the first disease-specific resolution to go through the European Parliament (since then, a resolution on multiple sclerosis has also been adopted). As

rapporteur, Jöns had to overcome numerous obstacles. Even members of the Committee on Women's Rights thought the demands were too far-reaching. "I had to find countless forms of compromise without watering down the essential requirements for screening and treatment," she says. "In the end, though, I think we had an excellent resolution, acceptable to all, and finally adopted by the European Parliament with unanimity."

It is a great achievement, but has the resolution really made a difference on the ground? Jöns is less sure about this. "We really don't know at the moment. The resolution was only adopted two years ago and therefore Member States haven't had much time to implement it." One problem is that there is no central body able to monitor implementation and assess whether national governments are complying and increasing their efforts in the fight against breast cancer. However, Jöns is encouraged by the fact that after the resolution was adopted

by the Parliament, health ministers of the 15 states then in the EU (the EU-15) adopted a recommendation on cancer prevention that advises Member States to implement screening programmes for breast, cervical and colorectal cancer.

Jöns stresses that, with regard to bringing down mortality rates, the resolution called specifically for Member States to set themselves the target of creating the conditions required for a 25% reduction in deaths from breast cancer by 2008. “Things change slowly and I was realistic enough to ask for feasible changes within a realistic timeframe.”

She also points out that many of the 10 states that joined the EU last year have very different baselines of cancer treatment to the EU-15, and have a long way to go before they can meet the targets set out in the resolution. But this makes fighting for improved breast cancer services in these countries all the more important. “I would like to encourage women in all Member States to impress on both physicians and politicians the need for more quality assurance in the early detection and treatment of breast cancer. Races for the cure and other charity events are important in awareness-raising, but even more important is the fight for structural changes in the entire care of breast cancer.”

Another aim of the resolution was to reduce the disparities in five-year survival from 16% to 5% by 2008. There is little evidence to show that this is underway, but Jöns is optimistic. She cites as examples France, where the national screening programme has been completely revised, Germany, which has met the requirements to hopefully implement a countrywide screening programme by the end of this year, and Hungary, where she says huge progress has been made in screening.

She also points out that Member States are now debating the introduction of specialist breast units, and that, despite the current lack of clear EU guidelines for the certification of breast units, a great deal of progress has been made in setting up specialist units in national hospitals. “I have great hopes in the work of the European Breast Cancer Network, which is in the process of drafting the EU guidelines based on the 2000 requirements of EUSOMA [the European Society of Mastology], which will be published by the European Commission at the end of this year.”



TRISTAN VANKANN

#### CHANGING PRACTICE

There is no doubt that, in order to improve survival rates, both quality-assured early detection and optimal treatment in multidisciplinary breast units are needed, says Jöns. However, this

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returns once more to the question of compliance by Member States. You can have all the resolutions and good intentions in the world, but if no-one is chasing up those who are supposed to implement them, there probably won't be much change.

Jöns is well aware of this problem. “As Members of the European Parliament, we need to maintain strong relationships with our colleagues in national and regional parliaments. We must pass on to them information about progress made in other countries. And we should not forget to keep breast cancer on the agenda in the European Parliament.”

She also hopes to convince the new European Commission to submit a mid-term review on the implementation of the resolution in 2006. This would provide essential information about what has been done across Europe, which could be used to identify best practice and provide reference points to measure progress across the EU – so-called ‘benchmarking’. Jöns is grateful for the support she received from David Byrne, who was Health Commissioner until last May, and says she is very hopeful that the new Health Commissioner, Markos Kyprianou, will be as good an ally.

But perhaps the most important ally in ensuring that the aims of the breast cancer resolution become reality, says Jöns, is the patient advocacy movement. “Without Europa Donna we would not be where we are today in the fight against breast cancer. They provided excellent information from their national groups in the drafting of the resolution and they are now working consistently on the dissemination of the terms of the resolution in the old and new Member States.” As rapporteur on breast cancer, she says she received support from a range of advocacy groups, and she is confident that this sort of Europe-wide collaboration will continue to influence practice at both European and national level.

### PERSONAL AND POLITICAL

Jöns acknowledges that, had she not had breast cancer herself, this subject might not be so high on her political agenda. Having had her surgery in a multidisciplinary unit, it was her surgeon who first introduced her to the EUSOMA requirements for breast units. “He gave me a copy of the first draft and said: ‘This is what women need. You are a politician. Do something.’”

In the beginning, she says, it wasn't easy. She started by working with Europa Donna to build support for a cross-party European Parliamentary Group on breast cancer, which has been key to the subsequent work. The Group also acts as a forum where there is a constant exchange of information and opinions on breast cancer issues. The topic for its next meeting is the use of structural funds for the implementation of mammography screening. This, says Jöns, is one of the most important questions in healthcare reform and setting up new programmes, especially in new Member States.

It all bodes well for the future of breast cancer treatment in Europe, but does Jöns ever feel the need to get involved in some of the less ‘fashionable’ cancers, such as lung, prostate, or colon, which receive far less media coverage and where patients seem more reluctant – or less able – to speak out?

“It is true,” says Jöns, “that breast cancer is high on the political agenda, but this has been achieved by women themselves, united in Europa Donna or other initiatives that have been working hard to raise public awareness of the disease. In the EU-25, a woman is diagnosed with breast cancer every six minutes. Every two minutes a woman dies from this disease. We ourselves have gathered together and organised, and learnt more about the fight against breast cancer. Men can do this too!”

She admits that women may find it easier to speak more openly about breast cancer than



In conversation with Lawrence von Karsa (left), coordinator of the European Breast Cancer Network, and Karl Freese, Policy Officer at the European Commission directorate general for Health and Consumer Protection

LEANNE FURLEY

men would about prostate cancer, for example, but says: “This difference is not God given. If men know how to talk about the stock market, for example, why cannot they speak about cancer?” She also argues that there are still not enough women in politics and society who are prepared to say that they are breast cancer patients or survivors. “This is one area where we can learn a lot from the USA.”

Jöns refutes the suggestion that other cancers have been forgotten at European level. She points out that screening for cervical and colorectal cancers is included in the EC recommendations on cancer prevention, and that the framework research programme includes funding for projects in prostate cancer and leukaemia. She also mentions a new European campaign against tobacco, which will help fight the increase in lung cancer.

As for breast cancer, despite the successes, Jöns argues that there is still a great deal left to

do. She is looking forward to the publication of the fourth edition of the European guidelines on mammography screening, which will include, for the first time, guidelines for digital screening, and will have integrated evidence-based requirements for breast units and criteria for their accreditation. “To have these documents at hand will be a big step forward for quality assurance in breast cancer.”

She is also looking towards a second resolution on breast cancer, once data on the implementation of the original resolution become available.

Looking back on it, rarely can the exhortation “Do something!” have been met with a more committed and effective response. And hundreds of thousands of women in Europe have cause to be thankful that Jöns not only did something, but looks set to continue fighting their corner on breast cancer services for many years to come.

“We ourselves have got together and learnt to fight against breast cancer. Men can do this too!”