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Committee on Social Affairs, Health and Sustainable Development

Minutes

of the hearing on "Women and breast cancer" held in Strasbourg, on Monday, 9 October 2017, from 2 to 3 pm

The Committee held a joint hearing with the Committee on Equality and Non-Discrimination.

Ms Kyriakides opened the meeting and welcomed the participants. She recalled that since 2013 the Social Affairs Committee had been organising an event to raise awareness of breast cancer during each October part session. This year, in addition to this joint meeting, the Palais de l'Europe would be illuminated in pink at nightfall and pink ribbons would be distributed. Ms Kyriakides encouraged all members to take part in these different events. She then welcomed the two experts: Ms Donata Lerda, who worked for the European Commission Joint Research Centre (ECJRC) and Ms Elizabeth Bergsten Nordström, President of the Swedish Association against Breast Cancer and former President of Europa Donna. She thanked Ms Centemero for having involved the Committee on Equality and Non-Discrimination in this awareness-raising event.

Ms Centemero, Chairperson of the Committee on Equality and Non-Discrimination, thanked **Ms Kyriakides** for this initiative and the two experts for attending the meeting.

Ms Lerda briefly presented the work of the ECJRC, which was not aimed solely at European Union (EU) member states but also at non-member states. With a view to ensuring equality in access to quality care, the ECJRC endeavoured to ensure the implementation of Council of Europe texts, including Resolution 2021(2014) of the Parliamentary Assembly "Towards optimum breast cancer services across Europe". To this end, it established standards relating to care services, in particular by drawing up guidelines. The ECJRC adopted an inclusive approach. It took account of the opinions of the states, the experts and the patients, who had played a major part from the very outset. It did not issue a certificate to any care centre which did not abide by its recommendations, in particular with regard to screening, treatment and rehabilitation. Ms Lerda concluded that, given the limited jurisdiction of the EU with regard to care, the main problem was to ensure member states' firm commitment in this area.

[Ms Lerda's full presentation is available in PowerPoint on the Extranet.]

Ms Bergsten Nordström said that in labour and insurance legislation women with breast cancer were the weak party and they needed to be protected. Social security coverage and the duration of that coverage varied considerably from one European country to the next. Most patients continued to work while they were receiving treatment. Nevertheless, after a certain period of time, it was no longer possible to work full time and most patients needed an adjustment of working hours. Every employer should have appropriate insurance which would cover the costs when female employees with breast cancer were no longer able to work. However, insurance rules often stipulated that patients had to be in hospital, whereas that was not always necessary in the case of breast cancer. Patients often had to choose between giving up their jobs, asking for leave for personal reasons, or coming to an agreement with their employer, an agreement which often meant having to accept a less senior post on a much lower salary. Employment and insurance systems

¹ Minutes approved and declassified by the Committee on Social Affairs, Health and Sustainable Development at its meeting on 6 December 2017 in Paris.

were therefore not flexible enough. The more complicated the treatment, the more difficult it was to negotiate special working arrangements with employers. In the long run, 75% of women who recovered from breast cancer took up a completely different job from the one they used to do. Women who had or had in the past had breast cancer had great difficulty in taking out private insurance. Since 2006, insurance companies in Sweden were obliged to provide insurance. Although there were many reasons for refusing to provide insurance to women with breast cancer, the only valid reasons for refusing were those based on risk analysis.

[Ms Nordström's full presentation is available in PowerPoint on the Extranet.]

Baroness Massey said that in the United Kingdom, there was a 5-year strategy for combating breast cancer. Recent reports had revealed various key problems, including access to preventive and therapeutic treatment. There was also the question of how to manage the problem in a period of austerity. It was necessary to have a genuine discussion on the effectiveness of treatment and its cost. She asked whether other member states had encountered such problems.

Ms Dalloz focused on the problems encountered by patients with regard to their insurance. She wondered how many member states had adopted the right to be forgotten, the right which made it possible for a person who had suffered from an illness in the past to enter into a contract with another person without informing that person of the past illness.

Ms De Sutter mentioned a recent dispute in Belgium concerning a private insurance company which proposed specific insurance to women who had or had had breast cancer. She said she would like to have the experts' opinion on this subject. She also asked if there were associations of patients suffering from other types of chronic disease.

Ms Pruidze said that, in addition to the problem of access to healthcare, the emphasis should be placed on awareness-raising and prevention so as to lift the taboos that still existed in society. She wondered what impact there might be if more women were involved in decision-making bodies in this field and whether any data was available on this subject.

Mr Wojtyła thought that it was necessary to address the need for early diagnosis but also the numerous factors which increased the risk of having breast cancer, such as smoking, obesity and even the fact that some women did not breastfeed their babies.

Mr Thiéry thought that when patients discovered that they had breast cancer they should receive psychological assistance, as well as during and after treatment. He asked whether there were any guidelines on this. With regard to financial problems, he mentioned the case of a colleague with breast cancer who wanted to come back to work far too soon because in Belgium employees were no longer entitled to their full salary after a certain time. The fact that she had come back to work too soon had led to complications and she had suffered from burn out. Her state of health had finally obliged her to stop working altogether. He asked for the experts' opinion on such cases. He wondered if it might not be a good idea to establish a one-stop shop solution for breast cancer patients. He also stressed the fact that prevention advice should be provided in the person's mother tongue.

Ms Higgins underlined the importance of screening. It should be encouraged and the age-discrimination that existed with regard to screening had to stop.

Ms Lerda stressed the fact that general practitioners should be responsible for proper prevention. She recommended screening for all women every two years as from 50 years of age and evidence-based treatment. However, she pointed out that the ECJRC could only "recommend" and that its only tool was certification.

Ms Bergsten Nordström said that there was not enough data on insurance at European level. Specific insurance contracts for women who had or had had breast cancer were currently being debated in Sweden. In her opinion, this was simply a way for insurance companies to make money. Early screening had saved many lives and it was necessary that each member state have proper screening systems, while making monitoring less compulsory for women with fewer risks.

Committee on Social Affairs, Health and Sustainable Development Commission des questions sociales, de la santé et du développement durable

Joint meeting with the Committee on Equality and Non-Discrimination Réunion jointe avec la commission sur l'égalité et la non-discrimination

Hearing on "women and breast cancer" Audition sur « les femmes et le cancer du sein »

PRESENCE LIST / LISTE DE PRESENCE Monday 9 October 2017 / Lundi 9 octobre 2017

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