



Declassified¹
AS/Soc (2019) PV 07 add
5 December 2019
Asocpv07add_2019

Committee on Social Affairs, Health and Sustainable Development Committee on Equality and Non-Discrimination

Minutes

Joint public hearing on “Life after treatment”, held in Strasbourg on Monday, 30 September 2019, from 2.15 to 3 pm

In the framework of the breast cancer awareness day in the Parliamentary Assembly, the Committee held a public hearing – jointly with the Committee on Equality and Non-Discrimination – with the participation of:

- ✓ Ms Liz Egan, Team leader – Macmillan Working Through Cancer Programme (United Kingdom);
- ✓ Ms Julie Daul, Occupational psychologist, *Ligue nationale contre le cancer*, Strasbourg.

Mr Schennach, Chairperson, welcomed members, experts, and other guests to the joint hearing which was convened to speak about the problems that hit predominantly women as breast cancer patients after they finished treatment. Through discussion with experts, it was important to assess developments in the situation of breast cancer patients when they sought to return to “normal life” but often faced the adverse social impacts on their families, social life, professional career and insurance cover. According to the World Health Organization’s statistics, in Europe, one in eight women might develop cancer before the age of 85; about 20% of breast cancer patients were younger than 50, and about 36% were at age 50 to 64. This meant that many women were confronted with the disease during their years dedicated to work and family. Over half-a-million women in Europe were concerned. Ms Kyriakides, the former rapporteur on breast cancer, had launched the breast cancer awareness events at PACE four years ago and had been very closely involved in preparations for this year’s awareness day including a pink stand with pins and lanyards, the pink MediaBox, this hearing and the pink lighting of the Council of Europe building.

Ms Elvira Kovács, Chairperson of the Committee on Equality and Non-Discrimination, in turn welcomed the participants and thanked both the Committee on Social Affairs, Health and Sustainable Development and its Chairperson, Mr Schennach, for the initiative of organising the joint hearing. Women’s rights and health continued to be in the focus of the work of the Committee on Equality and Non-Discrimination. Next Thursday for example, the Assembly would debate the report on “Obstetrical and gynaecological violence” to raise awareness around issues related to this little-known form of violence against women. Although an early-stage breast cancer could be very effectively treated, obstacles persisted in terms of patients’ access to adequate information, health care and insurance, as well as reintegration in the labour market, where women continued to face discrimination. Discussing good practice to overcome such obstacles and end discrimination was highly pertinent for law makers.

Mr Schennach introduced Ms Liz Egan, who would share her findings on the social consequences of breast cancer treatment, in particular problems related to workplace and labour markets, in her capacity as team leader of the “Working through cancer programme” at Macmillan UK.

Ms Egan² started her presentation by explaining that cancer was increasingly considered as a chronic disease rather than a cause of death, with rates of survival growing each year. In the United Kingdom (UK), one in two persons born after 1960 were likely to get cancer at some point in their lives and the number of people living with cancer was projected to grow by about one million per decade from 2010 to 2040. Thus some 4 million people could be living with cancer in 2030. As from 2010, cancer was increasingly about living with the condition. The

¹The minutes were approved and declassified by the Committee on Social Affairs, Health and Sustainable Development at its meeting on 5 December 2019, in Paris.

² Ms Egan’s full presentation is available on the Extranet.

Macmillan programme's research showed that many people with cancer wanted to work and for 87% of them staying employed gave a sense of normality, positive impetus in life and a source of revenue.

However, these persons also needed support to keep working. Over a quarter of cancer patients lacked essential support to return to work and a fifth of those who did return to work faced discrimination of some sort. In the UK, more than 890,000 people of working age were living with a cancer diagnosis and about 700,000 people in work were caring for someone with cancer. It was essential to advise cancer patients on their rights at work, ways to talk to employers about their health conditions, adjustments in working time to be able to follow treatments or rehabilitation. Similarly, care-takers needed support and advice, and line managers had to be better equipped to support employees with cancer.

The Macmillan programme offered the public free "Essential work and cancer toolkits", access to free e-learning modules for line managers, occupational health professionals and trade union representatives. It also published e-newsletters and information about work and cancer.

Mr Schennach referred to an example of a nurse in Austria diagnosed with breast cancer who had been coerced into early retirement (at the age of 57) by her employer and had been genuinely shocked by such attitude.

Ms Kovács also evoked an example of her friend working in a kindergarten who was eager to continue working despite the diagnosis of cancer.

Ms Egan stressed the importance of exploring the existing alternatives and options for cancer patients.

Ms Kovács thanked Ms Egan and introduced Ms Julie Daul, Occupational psychologist at the French league against cancer (*Ligue nationale contre le cancer*) who would share her expertise on measures to support both individuals and companies in anticipating and supporting patients' return to work and full integration into the professional environment. She would also explain the difficulties faced by cancer survivors as regards access to bank loans and insurance.

Ms Daul presented France's *Ligue Contre le Cancer*. Established in 1918, it supported people with cancer and their families and contributed to enforcing the government's action plans on cancer. In France, three million people were cancer patients or cancer survivors. For many of them, going back to work felt like returning to normal life, but the consequences of cancer were heavy and included fatigue and lack of concentration and memory problems. Patients often lacked knowledge of the procedures and regulations that might help to adapt their work to their specific needs. Some survivors needed to learn a completely new job, as cancer had left them unable to perform their previous tasks. Some managers and colleagues felt uncomfortable dealing with cancer patients, which might end up isolating them. The *Ligue* therefore organised awareness raising events, which had proved effective. Cancer patients also faced financial challenges (reconverting one's skills or initiating new activities had a cost, and access to funds and insurance was more difficult) and psychological challenges which required specific professional support.

Lord Touhig appreciated the pertinence of the expert speakers' remarks and the most valuable support that mentoring services by women for women brought for patients and their families.

Mr Amraoui pointed to a delicate balance to be found in each country between laws, practice and the local culture which combined together and impacted cancer patients' lives. Younger generations should be better educated about living and working with chronic diseases, and the accessibility of medical treatments should be improved. Counselling and support services for patients should not be viewed as luxuries but rather as essential elements of the healing and caring process.

Ms Hadri spoke of her experience of battling with cancer and the need to stay involved in professional terms.

Ms Sayek Böke stressed the importance of support networks for patients and wondered how the State could best support them.

In reaction to members' comments and questions, **Ms Egan** explained that a "job carving" exercise could help adapt existing jobs to patients' needs and would give patients more space to adapt to evolving health conditions. Networks were important to help fight the stigma affecting cancer patients and played a crucial role in informing persons concerned about existing rights and choices. The voluntary sector could be a starting point for networks.

Ms Daul added that after the treatment, patients often questioned themselves on their role in the workplace. Stigmatisation and prejudice affected their opportunities and needed to be addressed.

Ms Kovács thanked the guest speakers and participants and closed the meeting.

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

List of members (84 seats) / Liste des membres (84 sièges)

Chairperson / Présidente :	
Mr Stefan SCHENNACH	Austria/ Autriche
Vice-Chairpersons / Vice-Président(e)s :	
M. Luís LEITE RAMOS	Portugal
Ms Carina OHLSSON	Sweden/ Suède
Ms Nina KASIMATI	Greece / Grèce

Mr Tritan SHEHU	Albania / Albanie	ZZ...
M. Pere LÓPEZ	Andorra / Andorre	Mme Mònica BONELL
M. Mikayel MELKUMYAN	Armenia / Arménie	Mr Ruben RUBINYAN
Mr Franz Leonhard ESSL	Austria / Autriche	Mr Roman HAIDER
Mr Stefan SCHENNACH	Austria / Autriche	Ms Doris BURES
Ms Sevinj FATALIYEVA	Azerbaijan / Azerbaïdjan	Mr Nagif HAMZAYEV
Ms Ganira PASHAYEVA	Azerbaijan / Azerbaïdjan	Ms Ulviyye AGHAYEVA
Mr Bob DE BRABANDERE	Belgium / Belgique	Ms Els VAN HOOF
M. Simon MOUTQUIN	Belgium / Belgique	ZZ...
ZZ...	Bosnia and Herzegovina / Bosnie-Herzégovine	ZZ...
Mr Nikolay ALEKSANDROV	Bulgaria / Bulgarie	Mr Krasimir BOGDANOV
Ms Aneliya KLISAROVA	Bulgaria / Bulgarie	Ms Ivelina VASSILEVA
Ms Marijana BALIĆ	Croatia / Croatie	Mr Mihael ZMAJLOVIĆ
Ms Stella KYRIAKIDES	Cyprus / Chypre	Ms Christiana EROTOKRITOU
Ms Zdeňka HAMOUSOVÁ	Czech Republic / République tchèque	Ms Alena GAJDŮŠKOVÁ
Mr Jaroslav KYTÝR	Czech Republic / République tchèque	Mr Jiří STRÝČEK
Ms Mette GJERSKOV	Denmark / Danemark	Mr Jan E. JØRGENSEN
Mr Jaak MADISON	Estonia / Estonie	Ms Marianne MIKKO
Ms Minna REIJONEN	Finland / Finlande	Ms Tarja FILATOV

M. Bernard CAZEAU	France / France	M. François GROSDIDIER
Mme Yolaine de COURSON	France / France	Mme Martine WONNER
Mme Jennifer DE TEMMERMAN	France / France	Mme Nicole TRISSE
Mme Laurence TRASTOUR-ISNART	France / France	Mme Sophie AUCONIE
Ms Irina PRUIDZE	Georgia / Géorgie	ZZ...
Ms Sybille BENNING	Germany / Allemagne	Mr Josef RIEF
Mr Andrej HUNKO	Germany / Allemagne	Ms Cornelia MÖHRING
Mr Matern von MARSCHALL	Germany / Allemagne	Ms Doris BARNETT
Mr Ulrich OEHME	Germany / Allemagne	Mr Christoph HOFFMANN
Ms Nina KASIMATI	Greece / Grèce	Mr Theodoros ROUSOPOULOS
Mr Sokratis FAMELLOS	Greece / Grèce	Mr Kyriakos VELOPOULOS
Ms Mónika BARTOS	Hungary / Hongrie	Mr Jenő MANNINGER
Mr Tibor BANA	Hungary / Hongrie	Mme Zita GURMAI
Mr Bergþór ÓLASON	Iceland / Islande	Mr Birgir THÓRARINSSON
Mr Joseph O'REILLY	Ireland / Irlande	Mr Thomas PRINGLE
Mr Fabio DI MICCO	Italy / Italie	Mr Gianluca PERILLI
Mr Emilio FLORIS	Italy / Italie	Ms Maria RIZZOTTI
Mr Gaspare Antonio MARINELLO	Italy / Italie	Ms Barbara GUIDOLIN
Mr Gianfranco RUFA	Italy / Italie	Mr Manuel VESCOVI
Ms Linda OZOLA	Latvia / Lettonie	Ms Dana REIZNIECE-OZOLA
Ms Susanne EBERLE-STRUB	Liechtenstein / Liechtenstein	ZZ...
Mr Virgilijus PODERYS	Lithuania / Lituanie	Mr Kęstutis MASIULIS
Mme Françoise HETTO-GAASCH	Luxembourg / Luxembourg	M. Marc SPAUTZ
Mr Etienne GRECH	Malta / Malte	Ms Rosianne CUTAJAR
ZZ...	<i>Republic of Moldova / République de Moldova</i>	ZZ...

M. José BADIA	Monaco / Monaco	M. Guillaume ROSE
Ms Marija Maja ČATOVIĆ	Montenegro / Monténégro	Mr Predrag SEKULIĆ
Ms Reina de BRUIJN-WEZEMAN	Netherlands / Pays-Bas	ZZ...
Ms Ria OOMEN-RUIJTEN	Netherlands / Pays-Bas	ZZ...
Ms Silje HJEMDAL	Norway / Norvège	Ms Emilie Enger MEHL
Mr Nikola POPOSKI	North Macedonia / Macédoine du Nord	Mr Antonijo MILOSHOSKI
Ms Margareta BUDNER	Poland / Pologne	Mr Cezary TOMCZYK
Mr Maciej MASŁOWSKI	Poland / Pologne	Mr Krzysztof PASZYK
Mr Jarosław OBREMSKI	Poland / Pologne	Ms Agnieszka POMASKA
Mme Edite ESTRELA	Portugal / Portugal	ZZ...
M. Luís LEITE RAMOS	Portugal / Portugal	ZZ...
M. Cezar Florin PREDA	Romania / Roumanie	M. Viorel Riceard BADEA
Mr Ionuț-Marian STROE	Romania / Roumanie	Ms Cristina-Mădălina PRUNĂ
Ms Adriana Diana TUȘA	Romania / Roumanie	Mr Valeriu Andrei STERIU
Mr Sergey KALASHNIKOV	Russia/ Russie	Mr Aleksandr BASHKIN
Ms Alfiia KOGOGINA	Russia/ Russie	Mr Andrey EPISHIN
Mr Sergey PAKHOMOV	Russia/ Russie	Mr Igor KAGRAMANYAN
Ms Irina RODNINA	Russia/ Russie	Mr Sergey LISOVSKIY
Mr Roger ZAVOLI	San Marino / Saint-Marin	Ms Vanessa D'AMBROSIO
Ms Elvira KOVÁCS	Serbia / Serbie	Ms Dubravka FILIPOVSKI
Mr Aleksandar ŠEŠELJ	Serbia / Serbie	Mr Miljan DAMJANOVIĆ
Mr Ján MAROSZ	Slovak Republic / République slovaque	Ms Renáta KAŠČÁKOVÁ
Ms Andreja ZABRET	Slovenia / Slovénie	Mr Andrej ŠIRCELJ
Ms Susana SUMELZO	Spain / Espagne	Mr José CEPEDA
Mr César SÁNCHEZ	Spain / Espagne	Ms Carmen LEYTE

Mr Antón GÓMEZ-REINO	Spain / Espagne	Ms Melisa RODRÍGUEZ HERNÁNDEZ
Mr Alexander CHRISTIANSSON	Sweden / Suède	Mr Ola MÖLLER
Ms Carina OHLSSON	Sweden / Suède	Ms Annicka ENGBLOM
M. Pierre-Alain FRIDEZ	Switzerland / Suisse	M. Filippo LOMBARDI
Mr Hannes GERMANN	Switzerland / Suisse	M. Jean-Pierre GRIN
Ms Selin SAYEK BÖKE	Turkey / Turquie	M. Haluk KOÇ
Ms Emine Nur GÜNAY	Turkey / Turquie	Mr Mehmet Kasim GÜLPINAR
Mr Hişyar ÖZSOY	Turkey / Turquie	Ms Felekna UCA
Mr Ali ŞAHİN	Turkey / Turquie	Ms Sena Nur ÇELİK
Mr Oleksandr BILOVOL	Ukraine / Ukraine	Mr Vladyslav GOLUB
Mr Serhii KIRAL	Ukraine / Ukraine	Mr Boryslav BEREZA
Mr Viktor VOVK	Ukraine / Ukraine	Mr Oleksii GONCHARENKO
Mr John HOWELL	United Kingdom / Royaume-Uni	ZZ...
Baroness Doreen E. MASSEY	United Kingdom / Royaume-Uni	Mr Conor McGINN
Ms Kerry McCARTHY	United Kingdom / Royaume-Uni	Mr Steve DOUBLE
Mr John PRESCOTT	United Kingdom / Royaume-Uni	Lord Don TOUHIG

OTHER PARLIAMENTARIANS / AUTRES PARLEMENTAIRES

Ms / Mme Eglantina GJERMENI.....	Albania / Albanie
Ms / Mme Sahiba GAFAROVA	Azerbaijan / Azerbaïdjan
Mr / M. Fourat BEN CHIKHA	Belgium / Belgique
Mr / M. Goran BEUS RICHEMBERGH	Croatia / Croatie
Mr / M. Jussi SARAMO	Finland / Finlande
Ms / Mme Maryvonne BLONDIN	France / France
Mr / M. Frank HEINRICH	Germany / Allemagne
Ms / Mme Josephine ORTLEB	Germany / Allemagne
Ms / Mme Béatrice FRESKO-ROLFO	Monaco
Ms / Mme Petra STIENEN	Netherlands / Pays-Bas
Ms / Mme Shpresa HADRI.....	North Macedonia / Macédoine du Nord
Ms / Mme Erika BENKŐ	Romania / Roumanie
Ms / Mme Ann-Britt ÅSEBOL.....	Sweden / Suède
Mr / M. Momodou Malcolm JALLOW	Sweden / Suède
Mr / M. Manuel TORNARE	Switzerland / Suisse

PARTNERS FOR DEMOCRACY / PARTENAIRES POUR LA DEMOCRATIE

Ms / Mme Haya MUFLIHJordan / Jordanie
 Mr / M. Allal AMRAOUIMorocco / Maroc
 Ms / Mme Aïcha LABLAKMorocco / Maroc

**EMBASSIES / PERMANENT REPRESENTATIONS AND DELEGATIONS
 AMBASSADES / REPRESENTATIONS ET DELEGATIONS PERMANENTES**

Mr / M. Abudov JAVIDAN, intern, Permanent Representation of Azerbaijan to the Council of Europe / *stagiaire, Représentation permanente de l'Azerbaïdjan auprès du Conseil de l'Europe*

Mr / M. Alibala KHALILOV, intern, Permanent Representation of Azerbaijan to the Council of Europe / *stagiaire, Représentation permanente de l'Azerbaïdjan auprès du Conseil de l'Europe*

Mr / M. Valentyn SKURATOVSKYY, Deputy to the Permanent Representative, Permanent Representation of Ukraine to the Council of Europe / *Adjoint du Représentant Permanent, Représentation permanente de l'Ukraine auprès du Conseil de l'Europe*

**SECRETARIAT OF DELEGATION OR OF POLITICAL GROUP /
 SECRETARIAT DE DELEGATION OU DE GROUPE POLITIQUE**

Mr / M. Semih Emre ÖZER, Delegation Secretary, Turkish delegation to PACE / *Secrétaire de délégation, délégation de la Turquie à l'APCE*

ALSO PRESENT / EGALEMENT PRESENTS

Ms / Mme Julie DAUL, Occupational psychologist, National league against cancer / *psychologue du travail, Ligue nationale contre le cancer, Strasbourg*

Ms / Mme Liz EGAN, Team leader – Macmillan Working Through Cancer Programme, United Kingdom / *cheffe d'équipe – Programme Macmillan « Working Through Cancer », Royaume-Uni*

**SECRETARIAT OF THE PARLIAMENTARY ASSEMBLY /
 SECRETARIAT DE L'ASSEMBLÉE PARLEMENTAIRE**

Ms / Mme Tanja KLEINSORGE Head of the Secretariat / *Cheffe du Secrétariat*
 Ms / Mme Aiste RAMANAUSKAITE Secretary to the Committee / *Secrétaire de la commission*
 Ms / Mme Yulia PERERVA Secretary to the Committee / *Secrétaire de la commission*
 Ms / Mme Prisca BARTHEL Europe Prize section / *Section Prix de l'Europe*
 Ms / Mme Bogdana BUZARNESCU Principal Assistant / *Assistante Principale*
 Ms / Mme Melissa CHARBONNEL Assistant / *Assistante*
 Ms / Mme Françoise SCHIR Assistant / *Assistante*
 Ms / Mme Anne-Sophie PALSTERMAN Trainee / *Stagiaire*