

Outcomes report

“European policy response to rare cancer: the case of sarcoma”

8th February 2017, European Parliament

On the 8th of February 2017, Ms Marlene Mizzi, Member of the European Parliament (MEP) hosted a policy debate on the *“European policy response to rare cancer: the case of sarcoma”* in the European parliament in partnership with the Group of Experts¹ of the Sarcoma Policy Checklist. The Group consists of multi-stakeholder sarcoma experts whose aim is to help policy-makers close the gap in access to high-quality information and care for patients across Europe. The policy report they have produced, called ‘the **Sarcoma Policy Checklist**’,² was launched during this event.

The Checklist describes five key areas (see below) on which EU policy-makers should focus to bring improvements in sarcoma care, and outlines to what extent its recommendations are being implemented in six countries (France, Germany, Italy, Spain, Sweden, and the UK).

-  **1** Designated and accredited centres of reference for sarcoma in each country
-  **2** Greater professional training for all health care professionals involved in sarcoma care
-  **3** A multidisciplinary approach to care for every patient with sarcoma
-  **4** Greater incentives for research and innovation
-  **5** More rapid access to effective treatments

The debate highlighted a key issue: inequalities in access to expertise and care persist despite policy advances in many countries, contributing to suboptimal outcomes for patients.

MEP Marlene Mizzi opened the discussion by introducing sarcomas, a particularly challenging family of rare cancers. Sarcomas make up 5% of rare cancers and 1% of all cancers, however they account for 2% of total cancer mortality.³ Sarcomas present themselves in approximately 70 subtypes, and can occur anywhere in the body. This heterogeneity means that it may be difficult for patients to find specialist knowledge for both diagnosis and treatment – and equally challenging for researchers to find effective treatments that work across all types of sarcomas.

EU Health Commissioner Vytenis Andriukaitis⁴ then shared his personal experience as a surgeon. “Helping people with rare cancers get the best possible diagnosis and care – across the European Union – is our common goal” he said. The Commissioner also reaffirmed his commitment to leading the European Commission’s effort to address social inequalities with regard to access to cancer prevention, screening and care. He welcomed the Sarcoma Policy Checklist as providing

¹ For details on the group see at the end of this document.

² The Sarcoma Policy Checklist is available at www.sarcoma-patients.eu in five languages.

³ Sharma S, et al. Efficacy and safety of pharmacological interventions in second- or later-line treatment of patients with advanced soft tissue sarcoma: a systematic review. BMC Cancer 2013;13(1):1-21.

⁴ The full speech of EU Health Commissioner Andriukaitis is available on his official blog [here](#).

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“valuable guidance on what is needed to improve sarcoma care and thus the lives of many people.” The Commissioner noted that the Joint Action on Rare Cancers (JARC) aims to facilitate research and contribute to prioritising rare cancers in national cancer plans. He also outlined how the European Reference Networks (ERNs) and EU research programmes can help improve transfer of knowledge on sarcomas between countries.

Ms Estelle Lecointe-Artzner, President of the French sarcoma patients group (Info Sarcomes) and co-chair of Sarcoma Patients EuroNet (SPAEN), stressed the many challenges faced by sarcoma patients, including: late and incorrect diagnosis; lack of access to appropriate treatment and clinical expertise; high rates of morbidity and recurrence of the disease. She also highlighted that access to treatment and care in Eastern Europe is especially problematic. Estelle presented both the recommendations of the Sarcoma Policy Checklist as well as the SPAEN Paper on “Sarcoma Patient Pathway Analysis and Recommendations for Service Development”⁵, which was developed to help improve the situation for sarcoma patients across Europe.

Professor Paolo G. Casali, Coordinator of the JARC and sarcoma domain leader of the European Reference Network (ERN) on Rare Adult Cancers (EURACAN), then spoke of the role of EURACAN and JARC in addressing the challenges posed by rare cancers, through disseminating knowledge, empowering patients, supporting research and promoting a multidisciplinary approach to care across Europe. Professor Casali underlined the importance of designating national reference centres with formal links to ERNs, to make sure the excellence and knowledge from these European networks are disseminated within each country to all centres which treat sarcoma patients.

Other experts who joined the debate were Antoni Montserrat, Senior Expert for Cancer and Rare Diseases at the European Commission’s Directorate General for Health, Dr Peter Naredi, President of the European CanCer Organisation (ECCO) and Dr Nora Drove, EU Regional Medical Lead for Soft Tissue Sarcoma at Eli Lilly & company.

In a panel debate moderated by MEP Mizzi, speakers were invited to suggest ways for how to drive policy change in sarcoma. Noting the critical importance of good quality care, Dr Naredi presented the recently published “ECCO Essential Requirements for Quality Cancer Care: Soft Tissue Sarcoma in Adults and Bone Sarcoma. A critical review”⁶ which aims to identify an EU standard of care that should be implemented across all centres that treat sarcoma patients. Mr Montserrat stressed the role that patient advocacy groups and initiatives such as the Sarcoma Policy Checklist can play to drive EU policy action. Dr Nora Drove emphasized the need to collect clinical data at the European level and to allow more flexibility in HTA and regulatory frameworks to address the unique nature of rare cancers.

⁵ SPAEN Sarcoma Policy Paper Available Online here: <http://www.sarcoma-patients.eu/en/sarcoma-reports2/position-papers>

⁶ ECCO Essential Requirements Available Online here: <http://www.sarcoma-patients.eu/en/docman/policy-checklist/35-ecco-essential-requirements-for-quality-cancer-care-soft-tissue-sarcoma-in-adults-and-bone-sarcoma-a-critical-review/file>

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Among the conclusions of the discussion was that European networks and multi-stakeholder collaboration are vital for improving patient outcomes in rare cancers. Sarcomas provide a good model of how this can be achieved. It was also highlighted that whilst the role of the EU is important, change also needs to occur at the level of each Member State. In particular, we need to encourage investment in research and development of new treatments, improve access for and reimbursement of cross-border care for patients who cannot access care in their own country, and encourage the collection and use of real-world data from patients at country level.

About the Group of Experts of the Sarcoma Policy Checklist:

The Group of Experts of the Sarcoma Policy Checklist is an independent multi-stakeholder group including leading patient representatives, clinical experts, politicians and industry representatives set in 2016 with the aim to develop a Policy Checklist for Sarcoma. The group of experts maintains full editorial control of the final document.

Members of the expert group include: Paolo Casali, Istituto Nazionale Tumori, Italy; Nora Drove, Eli Lilly & company; Sarah Dumont, Institut Gustave Roussy, France; Mikael Eriksson, University of Lund, Sweden; Alessandro Gronchi, Istituto Nazionale dei Tumori, Italy and EORTC Soft Tissue and Bone Sarcoma; Bernd Kasper, University of Heidelberg, Germany; Estelle Lecointe, Info Sarcomes, France and SPAEN; Claudia Valverde, University Hospital Vall’ Hebron, Spain; Markus Wartenberg, SPAEN & das Lebenshaus e.V., das Wissenhaus GmbH, Germany; Roger Wilson, SPAEN.

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