Sarcoma: EU needs policy response to rare cancers

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Opinion

We need to work together to address the challenges facing sarcoma patients, writes Marlene Mizzi.

Sarcomas represent less than one per cent of all cancers, yet two per cent of total cancer-related mortality. There are nearly 28,000 new cases of sarcoma per year in EU27 alone, and patients report some of the poorest experiences of any cancer type.

Patients with sarcoma face particular challenges in terms of poor information availability, limited professional expertise, and lack of access to specialised care and treatment. As a result, misdiagnosis is common, and patients' chances of survival are severely impacted.

There have been a number of important efforts to improve research and care for rare cancers in recent years. The EU-funded joint action on rare cancers was recently launched to enhance
In addition, in December the Commission announced that rare adult cancers (such as sarcoma) will now be covered by the European reference networks. The Commission will also support the development of up to four new registries on rare diseases to improve collection and exchange of data and information on rare diseases within the scope of the third health programme.

I am also pleased that Malta has prioritised cross-border collaboration in rare diseases as part of its health programme. Increasing access to innovative health technologies is a key focus.

A ministerial conference on 'Developing medicines for rare diseases' will be held on 21 March in Malta, in association with key stakeholders from the rare disease community. This is an important policy milestone for rare cancers.

Despite these important efforts, we cannot afford to be complacent. The challenges faced by rare cancer patients are very real. Close collaboration between all stakeholders is needed to improve the care received by patients across Europe.

This is why, on 8 February, I will be hosting a debate on the European policy response to rare cancers, showcasing the case of sarcomas, so that, jointly with all interested parties we address the issue at EU level. Together, we will discuss what can be done to improve the lives of people with sarcoma, as well as showcase the policy recommendations of the group of experts.

European health Commissioner Vytenis Andriukaitis will be participating and will underline the importance of the issue, present the work of the Commission on rare cancers and reflect on the recently established European reference networks.

A group of experts, including patient representatives, clinical experts and industry representatives will present their work, the sarcoma policy checklist.

The checklist proposes policy recommendations aiming to improve the care of sarcoma patients across Europe. I am committed to advancing policy action to help improve the current situation related to sarcomas in Europe.

The experts, as well as myself, hope that as care structures, research knowledge and access to appropriate therapies improve, so will the lives of sarcoma patients.

I truly hope that these latest initiatives will pave the way for further work among healthcare professionals, patients, experts, health advocates, industry and policymakers at European and national levels, to drive change for the benefit of sarcoma patients across Europe.
About the author

Marlene Mizzi (S&D, MT) is a Vice-Chair of Parliament's petitions committee

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