



Rare cancers in Europe – tackling a common problem

→ Kathy Redmond ■ EDITOR

A campaign to tackle the particular problems posed by rare cancers was launched this summer. European Action Against Rare Cancers (www.rarecancers.eu) is determined to put this neglected set of diseases firmly on the European health agenda and to bring some much-needed attention to the challenges faced not only by patients living with rare cancers, but also clinicians and researchers working in this field.

Many cancers can be defined as ‘rare’ according to the EU criteria. Yet while rare cancers are actually quite common when viewed as a group, the vast majority occur very infrequently, and therein lies the problem.

Because of their rarity, lack of awareness and knowledge often leads to diagnostic delays and misdiagnosis. Centres of excellence do not exist for every rare cancer. Where they do exist, patients are not always referred to them as quickly as they should be.

Living with rare cancers can be very difficult. Some patients have to travel long distances, sometimes abroad, to get the care they need. Many struggle to find up-to-date and comprehensive information about their disease, and getting hold of advice and support from other patients can be difficult when there are so few other patients with the same condition.

Researchers also face unique challenges with rare cancers, because it is hard to conduct adequately powered, controlled trials in

small patient populations. This means that evidence underpinning practice is often sketchy, leaving doctors and patients to make treatment decisions with a high degree of uncertainty. Given the small size of the potential market, few companies are willing to risk investing in developing drugs for rare cancers, despite the incentives associated with EU Orphan Drug legislation. The challenge of meeting the efficacy and cost-effectiveness requirements of regulatory and reimbursement agencies makes drug development in this group of cancers even less financially attractive.

European Action Against Rare Cancers, which is led by a coalition of patient and professional groups, including the European Cancer Patient Coalition and the European Society for Medical Oncology, wants to level the playing field for rare cancers. Innovative solutions are needed. Health authorities and insurers could do a lot more to ensure that patients are referred to specialist centres in time. Given the very high levels of off-label prescribing in this patient population, facilitating studies to formally extend the indication of these drugs to rarer cancers could also make a big difference.

Raising awareness about the problems faced is an important first step; however, much more needs to be done to improve rare cancer outcomes and address the burdens faced daily by people living with a rare cancer. You can find out more about the campaign and add your support by going to www.rarecancers.eu.