



PRESS RELEASE

13 January 2011

“Let us do it together, not just for ourselves, but for all future European patients.” – Prof. Henk Van daele

On Wednesday 12th January 2011, the Forum Against Cancer Europe (FACE) launched its 2011 programme with a workshop bringing together MEPs, patient groups, and representatives from the pharmaceutical industry, the European Commission, researchers and the oncological community. Entitled “Rare Cancers: An Urgent Need for Policy”, the event was chaired by MEP Marisa Matias, a member of the ITRE Committee, who welcomed speakers representing stakeholder groups from across Europe.

The European Commission defines a ‘rare cancer’ as a cancer affecting less than 5 people per 10,000, and they are often overlooked. However, rare cancers are not as rare as they sound – RARECARE estimates that there are 2.7 million patients with rare cancers in the EU, constituting 23% of all cancer cases. As the numbers affected by each cancer are small, availability of specialised healthcare, range of effective treatments and opportunities to participate in clinical trials are much lower than for more common cancers.

The chair, **MEP Marisa Matias**, set the tone for the workshop by combining personal stories with policy imperatives. “I am sick and tired of losing people, it is our lives which are at stake”, she said, calling on policy makers to address the urgent needs of rare cancer patients across Europe. **Petru Luhan, MEP**, began by observing that there are massive differences between availability and quality of care for rare cancer patients between EU member states. He emphasised the importance of communication between policy makers and those who experience cancer treatment ‘on the ground’ in working towards the primary goal of providing equal care to all patients. ECPC President **Tom Hudson** read a speech on behalf of **Dr Adamos Adamou, former MEP**, outlining some of the difficulties faced by rare cancer patients, which include delayed or incorrect diagnosis, lack of understanding about the development of the disease, difficulties accessing appropriate treatment or clinical trials, and insufficient access to registries of tissue banks. Rare cancers are cancers, but require a different approach to more well-known types.

The Head of the ECPC Rare Cancers Action Group, **Kristina Andrekute**, showed the need to place rare cancers in a pan-European context for a pan-European solution. Rare cancers fall under the category of rare diseases, rather than cancers, but neither group fully reflects the reality of living with such a disease and “without a strategy, rare cancer patients will deal again and again with the same problems”. **Kathy Oliver**, from the International Brain Tumour Alliance, shared her experiences of her son’s illness and some of the new challenges she faced in adapting to “the new normal”, and passionately articulated the great need for patient advocacy in order to prevent those with rare cancers from being left in “the shadows of the map.”

The issue of investment in and access to clinical trials, which emerged as one of the key themes of the workshop, was introduced in a video message by **Prof. Jean-Yves Blay**, from the European Organisation for Research and Treatment of Cancer (EORTC). He deplored the standards of care

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many experience and emphasised the importance of clinical trials in addressing this. Demonstrating the European Commission's commitment to improving treatment for rare cancer patients, **Dominika Trzaska** from DG Research outlined the funding available under the Seventh Framework Programme and spoke of the work of some of the projects they support. **Prof. Paolo Casali**, from the Istituto Nazionale Tumori, outlined some of the weaknesses and obstacles in the path from conception to available drug, assessing the risks posed by regulator standards, suggesting collaborative ways to fund studies and urging a new approach to medical statistics. A successful method for joint funding of studies was explained by the Head of Clinical Trials from Cancer Research UK, **Julie Hearn**, who spoke of the need to attract more research applications for available funding, and commended the beneficial impact CRUK has experienced from involving patients in clinical study groups and committees. The medical researcher's perspective was offered by **Dr Filippo De Braud** from the Istituto Europeo di Oncologia. Looking forward to a time when all cancers will be rare diseases, he spoke of some of the difficulties involved in developing new drugs and called for "an exceptional approach in exceptional circumstances". The patient's point of view was offered by **Prof. Henk Van daele**, an ECPC Board Member, who has survived the little-known male breast cancer and highlighted the difficulties and dangers of experiencing a rare variant of a more common cancer.

Experts from three countries shared some of the successes and obstacles encountered in implementing their national cancer plans. From Belgium, **Prof. Simon Van Belle** from Gent University Hospital and **Frank Boeye** from Study Group Brain Tumour emphasised the potential benefits of a fully comprehensive and accessible National Cancer Registry, which would constitute a "virtual centre of expertise" and could be used as a resource by researchers. They highlighted the challenges of working within a system where federal legislation was implemented at a local level, suggesting that a European Cancer Plan might face similar challenges. Jeanne Marie Brechot from the National Cancer Institute in France spoke of the importance of communication, including publishing guidelines covering every stage of the disease from diagnosis to after-care. From the Czech Republic, Jana Pelouchova from Diagnoza CML offered a metaphor: the political and administrative decision-makers are one island, the medical professions are another island and the patients are swimming in the sea of uncertainty between the two. She illustrated how doctors face a conflict of interest between the patient's needs and the hospital finances.

Turning the issues raised into suggestions for action, **Andras Fehervary** from Novartis Oncology Europe showed that the budget impact of orphan drugs on healthcare systems is not as high commonly thought, constituting 1-3% of pharmaceutical spending. The need for policy is more urgent now than ever before, as economic pressures urge government cuts, and Andras illustrated a number of innovative pricing models and policy changes which could expand early access to orphan drugs and make them more affordable. ECPC Board Member **Sandra Craine** delivered a moving personal account entitled 'The End of Benign Neglect', addressing the frustrations of living with a cancer that is classified as a 'rare disease'. Urging the inclusion of rare cancers under cancer policy areas, she observed that the current classification encourages policy developments which "detach us from the place where we, as cancer patients, feel we belong." The division between two groups has left rare cancer patients in a "cul-de-sac", "forced into a policy ghetto as a result of administrative decisions to house our community under the word rarity, rather than under the more potent and meaningful word 'cancer'". **Marisa Matias, MEP**, closed the conference by emphasising that there can be no 'collective good' in which marginal communities are sacrificed, and that rare cancer patients do not have the luxury of time, as many politicians and policy-makers do.

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