The story begins in November 2008 in Brussels, with the conference “Rare Tumours in Europe: Challenges and Solutions” marking the beginning of the Rare Cancers Europe (RCE) partnership initiative. The conference was hosted by the European Society for Medical Oncology (ESMO) and organised in partnership with several stakeholders active in the fields of rare diseases and cancer. It offered an opportunity for EU policy-makers and regulators to meet with cancer researchers, healthcare professionals, rare disease and rare cancer patients and patient advocates, government representatives and the pharmaceutical industry to discuss ways to address the key challenges linked to rare cancer research, treatment and care in Europe.

The conference participants publicly called for awareness and prioritisation of rare cancers and agreed on 39 political and stakeholder recommendations, addressing:
- regulatory barriers in rare cancer care
- methodological barriers to rare cancer care
- the need for centres of expertise and European reference networks
- barriers to patients’ access to care
- the education of healthcare professionals
- access to information on rare cancers.

A CALL TO ACTION
Based on these recommendations, the partners involved in the conference launched a public “Call to Action Against Rare Cancers” (which you can sign at www.rarecancerseurope.org). This calls on European governments, the European Union institutions and other international governmental organisations, the research community, the pharmaceutical industry, medical professionals and members of civil society to give a high priority to addressing the specific challenges associated with rare cancers. It wants to see all work towards:
- substantially improved equity of rare cancer care across borders

**Rare Cancers Europe:** Joining forces for action
Robert Schaefer describes the journey that led to a unique multi-stakeholder initiative to address the key challenges linked to rare cancer research, treatment and care in Europe.
the development of new effective therapies for rare cancers
facilitating more clinical studies in rare cancers with greater flexibility
balanced, timely and transparent assessment of new therapies
building a knowledge-base through clinical database networks, rare cancer registries and tissue banks
increased knowledge-sharing across borders through centres of expertise and reference networks
timely and accurate detection and provision of care through appropriate referral of patients to centres of expertise and reference networks.

The “Call to Action” and the 39 recommendations both build the framework for the ongoing activities of the RCE multi-stakeholder initiative, which aims to place the issue of rare cancers firmly on the European policy agenda and advocate for the implementation of the recommendations. By summarising these recommendations under the following overarching goals, the initiative has agreed on a series of meaningful and manageable joint projects and activities:

1. To improve the methodology of clinical research on rare cancers.
2. To improve the organisation of health care in rare cancers.
3. To improve access of rare cancer patients to new therapies in the EU.

REACHING A CONSENSUS

The first activity under goal 1, is to reach a multi-stakeholder consensus on ways to improve the methodology of clinical studies in rare cancers, focusing on the following aspects: design of clinical studies, end-points of clinical studies, methods for combining available evidence, and organisational and regulatory aspects of clinical studies.

To facilitate this process, an online consensus discussion has been set up, involving various stakeholders, to develop a consensus document. A follow-up consensus meeting and a related Rare Cancers Conference in Brussels were organised by ESMO and RCE in early February 2012. The consensus discussion is still ongoing, and once a final agreement is reached and the consensus paper published, a targeted advocacy campaign will encourage the swift implementation of the proposed recommendations and action steps.

Projects related to goal 2 include an exemplary survey on existing clinical practice guidelines for selected rare cancers. The survey will enable us to better understand the reasons for discrepancies and explore the potential for harmonisation of those guidelines across Europe to ensure optimal care for rare cancer patients. This will be done in close coordination with related activities carried out by the European Partnership for Action Against Cancer (EPAAC). In addition, consensus guidelines for quality criteria of collaborative networks in rare cancers will be developed.

Rare Cancers Europe will also provide input to the new EU Commission-funded three-year RARECARENet project, which aims to identify clinical centres of expertise for rare cancers and establish a related information network across Europe. In collaboration with ESMO, the project also envisions the development of additional clinical practice guidelines on rare cancers currently not addressed.

In collaboration with the European Society of Pathology (ESP), RCE and ESMO are organising a consensus meeting in autumn 2013 focusing on the issues around the pathologic diagnosis of rare cancers. Pathology is one of the most significant aspects for the accurate diagnosis of rare cancers. This meeting will provide an opportunity for identifying the existing challenges, as well as enabling stakeholders to put forward recommendations for action both at EU and national level.

Activities on behalf of goal 3 include a series of comparative text and video case studies on haematological and childhood cancers. These aim to illustrate key issues and opportunities in the rare cancers arena concerning access to treatment and care within the EU.

Since its inception in 2008, the RCE multi-stakeholder initiative has grown from 12 founding partners to 32 cooperating organisations. The campaign is moreover supported by additional corporate supporters. For more information, please visit www.rarecancerseurope.org.

Together we can ensure that policy-makers and all other relevant stakeholders give high priority to quality treatment and care for patients with rare cancers.

Caption: Picture on the facing page shows the Rare Cancers Europe (RCE) partnership meeting, Stockholm, 23 September 2011.

Standing (from left to right): Jan Geissler (Chronic Myeloid Leukaemia Advocates Network), Susanna Leto di Priolo (Novartis Oncology Region Europe), Gracemarie Bricalli (European Society for Medical Oncology, ESMO), Anita Margulies (European Oncology Nursing Society, EONS), Antoni Gelonch Viladegut (Sanofi), Alan J. Howard (ESMO), Prof. Dr. Gilles Vassal (European Society for Paediatric Oncology, SIOP Europe), Prof. Dr. Paolo G. Casali (ESMO and Fondazione RICCS Istituto Nazionale dei Tumori, ConticcoNet, EuroBoNet and World Sarcoma Network, WSN), John Bean (European Organisation for Research and Treatment of Cancer, EORTC), Prof. Dr. Ruth Lodenstein (SIOP Europe), Dr. Clair Watts (ECNS), Kathy Oliver (International Brain Tumour Alliance, IBTA and Cancer 52).

Seated (from left to right): Edel Fitzgerald (SIOP Europe), Christina Clausen (Pfizer Oncology), Prof. Dr. Nicholas Pavlidis (European School of Oncology, ESO), Robert Schaefler (Rare Cancers Europe).