Rare Cancers Europe (RCE) is a partnership dating back to November 2008. Six years have gone by and it is time to appraise what we have achieved together and, of course, to look at the challenges still ahead, and they are many.

The aim of our multi-stakeholder initiative is to work to overcome the particular challenges that rare cancers pose to patients and their caretakers, physicians and other healthcare workers, the research community, governments and industry. These challenges were summarised in our 2009 Call to Action, which built the framework for RCE activities.

We are particularly proud of our consensus documents on the methodology of clinical studies in rare cancers and the consensus process we launched on improving the pathological diagnosis of rare cancers.

From twelve founding members we have grown to 32 partners. As our motto “joining forces for action” says, none of the goals we have set will be attained without a concerted effort.

Together we will continue working to ensure communication and proactive sharing of information between stakeholders. We will continue to lobby for a more efficient infrastructure to be set up in Europe for the diagnosis and treatment of rare cancers.

We need better information networks, we need recognised centres of excellence easily available to all patients through efficient cross border healthcare agreements, we need more registries, more cancer biobanks, more educational courses and an improvement in the methodology of clinical trials for rare cancers.

So as we look to the past in this report, we keep in mind what remains to be done. Numbers indicate that there are over 4 million people suffering from rare cancers in Europe today. But patients are not statistics. To each one of them their cancer is a unique and personal battle and they are looking to the community for answers and a reason to hope.

Dr. Paolo G. Casali
Coordinator of Rare Cancers Europe
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Call to Action: http://www.rarecancerseurope.org/About-the-Campaign/Call-to-Action
Rare Cancers –
More common than you think

What is a “Rare Cancer”?

Rare cancers are infrequent cancers, affecting small groups of patients. They have been defined by their incidence (number of new diagnoses per year). A rare cancer affects less than 6 in 100,000 people per year, i.e. 30,000 new cases per year in Europe.

Despite being uncommon, rare cancers put together make up 10-20 percent of all cancers diagnosed in the EU annually.

Rare Cancers in figures

20% of all cancers are "rare"

500,000 people are newly diagnosed with a rare cancer each year, 30,000 in Europe alone

186 cancer types are considered “rare”

100% of solid paediatric cancers are “rare”

47% is the survival rate for rare cancers, versus 65% for common cancers
Milestones

2008
- Rare Tumours
- Brussels Meeting
- 39 Recommendations
- 12 founding members

2009
- Call to Action Against Rare Cancers
- European Action Against Rare Cancers (EAARC) signature
- 13 members

2010
- ESMO Press Conference
- European Parliament Meeting: Orphan Drugs
- EAARC secretariat
- 15 members

2011
- European Parliament Meeting
- Challenges of Rare Cancers
- Workshop on Rare Cancers
- The Value of Closer Cooperation
- Relaunching Rare Cancers Europe (RCE)
- New RCE website
- Awareness initiatives
- Political meetings
- "The Challenges of Rare Cancers" advocacy session (September) at European Multidisciplinary Cancer Congress (EMCC)
- Collaboration with European Partnership for Action Against Cancer
- 7 new members

2012
- February: Workshop on Methodology of Clinical Trials
- Rare Cancers Pathology Survey Report
- Rare Cancers Round Table
- Launch Rare Cancers EU Access Index
- Comparative Rare Cancers EU Access text
- Video case studies
- Rare Cancers Pathology with European Society of Pathology (ESP)
- Awareness raising initiatives (articles, ads, participation meetings)
- Collaboration with European Partnership for Action Against Cancer
- September: Advocacy session on Rare Cancers at ESMO Patient Seminar
- Joint statement on “Proposal for EU Regulation on Clinical Trials”
- 22 members

2013
- Workshop
- European School of Oncology (ESO) ESMO Masterclass
- New governance structure
- Steering committee election
- Access index report and related video cases
- Web: new management system
- Case studies on chronic myeloid leukemia (CML) and central nervous system (CNS) paediatric tumours
- 32 members

2014
- Workshop on Pathological Diagnosis
- European Parliament Meeting on Rare Cancers Centre of Excellence
- Consensus Statement on Pathology
- Consensus Statement on Methodology
- Clinical Trial Workshop
- ESMO 2014: Press Conference on Rare Cancers
- RCE session at ESMO Congress and Meeting with European Medicines Agency (EMA) in October in London to discuss Clinical Trials for Rare Cancers
- 32 members
The need

Rare Cancers pose more challenges that you think

Because of the “small” number of patients involved, rare cancers present a unique set of problems, which can be summarised as follows:

» Late or incorrect diagnosis
» Difficulties finding clinical expertise and accessing appropriate treatments
» Difficulties in carrying out clinical studies due to the small number of patients
» Difficulties in funding research for innovative therapies due to small markets
» High uncertainty in clinical decision-making
» Scarcity of available registries, guidelines and tissue banks

A group of twelve motivated partners (32 today) decided to get together to address these challenges. They were aware that the hurdles to diagnosis, research, treatment and care of rare cancers in Europe could not be addressed by one society alone. The group first gathered in November 2008 in Brussels, at a meeting hosted by the European Society for Medical Oncology (ESMO) and organised with other stakeholders.

The “Rare Tumours in Europe: Challenges and Solutions” meeting brought together 150 participants representing patients, physicians, researchers and the industry. Together they drafted 39 political recommendations, which were made public at a press conference held in the European Parliament in December 2008 and are the basis for our activity now. The mission of Rare Cancers Europe is to implement these 39 recommendations.

39 Recommendations on stakeholder actions and public policies

8 addressing regulatory barriers in rare cancer care
11 addressing barriers to patients’ access to care
9 addressing the need for centres of expertise and European reference networks
2 on education of healthcare professionals
6 addressing methodological barriers to rare cancer care
3 on access to information on rare cancers

Our main goals are:

» To improve the methodology of clinical research on rare cancers
» To improve the organisation of health care for rare cancer patients across Europe
» To improve access of rare cancer patients to innovative therapies in Europe
» To encourage knowledge sharing and networking on a pan European scale

For each goal, here’s what we have achieved to date and what is in the pipeline for the future:

1. Methodology of clinical research on Rare Cancers:

» Consensus Meeting: “Improving the Methodology of Clinical Research on Rare Cancers”. Brussels, 10 February 2012
» Consensus Paper on “Improving Methodology of Clinical Research on Rare Cancers”, published in Annals of Oncology in October 2014
» RCE/EMA meeting on 3 October 2014: Oncologists, statisticians and methodologists met EMA officials in London. Starting from the Rare Cancers Europe consensus position paper on the methodology of clinical studies in rare cancers, the goal is to further discuss and analyse the set of recommendations elaborated by RCE and find fertile and constructive ground for implementation of shared methodological solutions
» A joint RCE/ESMO/EMA working group will plan and implement the next steps

2. To improve the organisation of health care for rare cancer patients across Europe:

» Survey on Pathology (2012) and production of summary report
» Workshop on Pathological Diagnosis of Rare Cancers, February 2014
» Rare Cancers Roundtable on the organisation of rare cancer care and research, with a special focus on France and Italy (12 March 2012)
» White Paper on Rare Cancers, sent in 2014 to an appropriate political audience in the EU
» MEP Meeting on European Reference Networks for Rare Cancers (February 2014)
» Consensus document on Pathology in preparation, to be published in 2015
» Consensus Statement on Pathological Diagnosis to be finalised in 2015

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3. To improve access of rare cancer patients to innovative therapies in Europe:
   - RCE commissioned the Swedish Institute for Health Economics to collect data about the status of rare cancer patients’ access to diagnosis and treatment in each European country. The 2013 report includes data on:
     - Resource endowment
     - Reimbursement
     - Reimbursement of second opinion
     - Access to information
     - Existence of Cancer Registries
     - Existence of National Cancer Plan
     - Availability of Practice Guidelines
     - Use of multidisciplinary teams
     - Timely access to cancer drugs
     - Availability of compassionate use programmes

4. To encourage knowledge sharing and networking on a pan European scale:
   - RCE website (http://www.rarecancerseurope.org) created in 2012 and regularly updated by the ESMO web team
   - Dedicated press conferences at ESMO annual congress (2010, 2014…) which hope to create awareness about the difficulties facing rare cancer patients and highlight actions needed to be undertaken by European health authorities
   - Social Media: creation of Twitter account to spread our news and retweet relevant news sent out by our partners (@_rarecancer)
   - Press: sending out of press releases for each important event (http://www.rarecancerseurope.org/News)
   - Collaboration with other initiatives
     - European Partnership for Action Against Cancer
     - RARECARENet
     - EPAAC (WP7)
     - European Society of Pathology (ESP)
   - This activity report, which will be updated on an annual basis

A summary of Rare Cancers Europe “Call To Action”

We call on all relevant stakeholders to work towards:

- **Substantially** improved equity of care in rare cancers
- **Development** of new effective therapies for rare cancers
- **Facilitating** clinical studies in rare cancers
- **Balanced** timely and transparent assessment of new therapies
- **Building** a knowledge base
- **Timely and accurate** detection and provision of care

If you haven’t yet, please sign the Rare Cancers Europe Call to Action today, here

Show your support and sign the Call to Action Against Rare Cancers:
http://www.rarecancerseurope.org/
Rare Cancers: More joint action than you think

Rare Cancers Europe is a multi-stakeholder initiative including physicians, patients, industry partners, research institutes, advocacy organisations and government bodies.

Together we call on society to commit resources to support effective research in the field of rare cancers and to provide the best and equal care to patients suffering from rare cancers in Europe.

Today we are 32 members, but if you care about Rare Cancers and are based in Europe, we still have space for you. Come and join us!

Who’s Who?

Steering Committee:

Paolo Casali
European Society for Medical Oncology (ESMO) / Fondazione IRCCS Istituto Nazionale dei Tumori

Sandrine Marreaud
European Organisation for Research and Treatment of Cancer (EORTC)

Markus Wartenberg
Sarcoma Patients EuroNet Association (SPAEN) / International Kidney Cancer Coalition (IKCC)

Susanna Leto Di Priolo
Novartis Oncology

Nicholas Pavlidis
European School of Oncology (ESO)

Joining forces for action
We thank our Corporate Supporters

Benefits for Supporters

> *Industry Partner*: Two face-to-face meetings and two teleconferences each year with all cooperating organisations; participation in joint decision-making; regular progress reports; recognition on information materials; recognition on the website

> *Gold Industry Supporter*: Regular progress reports; recognition on information materials; recognition on the website

> *Silver Industry Supporter*: Recognition on information materials; recognition on the website

> *Bronze Industry Supporter*: Recognition on the website

If you are interested in supporting Rare Cancers Europe, please contact us: rarecancerseuropenews@esmo.org

Where next?

Our 39 recommendations and the Call to Action are our roadmap.

Much remains to be done.

We count on you to see them implemented ASAP!

If you have any questions or want to join us, please write to us at: rarecancerseuropenews@esmo.org

Or check out our website: www.rarecancerseurope.org