

Dear Mr/Mrs X

The European Cancer Patient Coalition (ECPC) is an active participant of CANCON, the new Joint Action against Cancer. Our partners within CANCON have agreed to share your details for the purposes of an important project.

The RARECAREnet (information network on rare cancers www.rarecarenet.eu) is an EU funded project that started in 2012 with the aim of building a pan-European information network to provide comprehensive information on rare cancers to the community at large (e.g. oncologists, general practitioners, researchers, health authorities and patients). RARECAREnet is working to contribute to ameliorate diagnosis and treatment of rare cancers, to foster research on rare cancers, to support the establishment of centres of expertise and to empower patients. This is important due to the challenges faced by rare cancer patients, among which we could mention: late or incorrect diagnosis, lack of access to appropriate clinical expertise, and a dearth of clinical trials.

Rare cancers are those that affect less than 6 people every 100,000 individuals (**examples of rare cancers follow: tumours of the head and neck, sarcomas, neuroendocrine tumours, tumours of testis, penis, central nervous system, thymus, vulva and vagina, some tumours of ovary and of the haematopoietic system such as leukaemias and lymphomas, multiple myeloma. All childhood cancers are rare**).

A major deliverable of the RARECAREnet project is the identification of Centres of Expertise for the diagnosis, treatment and follow-up of rare cancers. To reach this objective we are working with Orphanet, the portal for rare diseases and orphan drugs, which has developed a list of Centres of Expertise for many rare diseases (including some rare cancers). We did a bibliographic search on relevant specific legislation on rare cancers in Europe, and we have started a collaboration with CANCON. Now, we would like to have more detailed information on the way rare cancers are managed and cared of in each EU country, with particular reference to specific measures included in the National Cancer Control Plans (NCCP). We are writing to you as you were identified as the *Country X* representative for CANCON. Your help would be very important to understand the state of art of rare cancer activities in *Country X*.

In the framework of the EPAAC a survey was undertaken to give a comprehensive picture of where different countries are in relation to the development of NCCP. Many countries participated to the survey and some included information also on rare cancers however, the information provided on rare cancers were often scattered and/or limited. Thus, we would appreciate if you could answer the following questions in order to provide some clarifications:

QUESTIONS

- 1. In a few words, please describe your NCCP priorities with regards to rare cancers.**
 - 2. Where are rare cancer patients treated in your country?**
- Do you have **specialised units/department** for rare cancer patients within general hospitals? If yes, would you please list the hospitals and which type of cancer is treated in each hospital? **For your convenience we have created a table with the rare cancers on interest. Please fill in the spaces when applicable.**

- Do you have **cancer dedicated hospitals** which treat also rare cancers? If yes, would you please list the hospitals and which type of cancer is treated in each hospital? For your convenience we have created a table with the rare cancers on interest. Please fill in the spaces when applicable.
 - How these hospitals have been identified? Did you use any criteria? If yes, we would appreciate if you could list the criteria used (the RARECAREnet project is working on the definition of quality criteria for Centres of Expertise for selected rare cancers thus your experience would be extremely important to share)
- 3. If no centres or units of an already existing hospital dedicated to rare cancer are identified, how is your National Health System planning to proceed to refer rare cancers patients for diagnosis and treatment?**
 - 4. Patients are mainly asking to have information on where they have to go when diagnosed with a rare cancer. Can we make the list of centres provided to us publicly available?**

Thank you for your collaboration! Your answers will help us develop a complete image of the situation and ultimately share this information with patients in need (if agreeable with you).

Kind regards,

The ECPC team