

WORKING GROUP ON RARE CANCERS – MEETING MINUTES

21st October 2016, 10:30-16:30

ECPC Office, Rue Montoyer 40, 1000 Brussels

Organised by the European Cancer Patient Coalition

ATTENDEES

The meeting was attended by 27 participants.

Organisation	Country	Rare Cancer
AEAS	Spain	Sarcoma
AMMF	UK	Cholangiocarcinoma
Brain Tumour Charity	UK	Brain
Diagnoza leukemie	Czech Republic	Haematological
Društvo onkoloških bolnikov Slovenije	Slovenia	All rare cancers
ECPC	European	All rare cancers
FIALPO	Italy	Head and neck
GIST Contact group	Netherlands	GIST
Gynsam Sweden	Sweden	Rare gynaecological cancers
Italia - Glioblastoma Multiforme - cancro al cervello	Italy	Brain
KEFI	Greece	All rare cancers
MIELOPRO	Romania	Myeloproliferative neoplasms
Myeloma Euronet Romania	Romania	Haematological
Patients with GIST Aid Association	Poland	GIST
Polish Cancer Patient Coalition	Poland	All rare cancers
Pseudomyxomasurvivor	UK	Appendix
Romanian Leukemia Association	Romania	Haematological

Sănătate pentru Comunitate/ Community Health	Romania	Head and neck
Sarcoma Ireland	Ireland	Sarcoma
Slainte an Chlair	Ireland	All rare cancers
The Cyprus Association of Cancer Patients and Friends (PASYKAF)	Cyprus	All rare cancers
Thyroid Bulgaria	Bulgaria	Thyroid

ATTENDED VIA SKYPE

Organisation	Country	Rare Cancer
Nationwide Association for CML Patients Aid	Poland	Haematological

APOLOGIES (CONTACTING ECPC PRIOR TO THE MEETING)

Organisation	Country	Rare Cancer
A.I.G. Associazione Italiana GIST Onlus	Italy	GIST
Associação Portuguesa Contra a Leucemia	Portugal	Haematological
Everything for her	Croatia	All rare cancers
Group of Volunteers Against Cancer "Agkaliazo" Municipality Of Achaia	Greece	All rare cancers

INVITED SPEAKER

Dr. Annalisa Trama from the Fondazione IRCCS Istituto Nazionale dei Tumori, Milano, JARC Coordination Team

SUMMARY

On the 21st October 2016, ECPC held the first meeting of the Working Group on Rare Cancers (WGRC) in the ECPC premises.

The WGRC was first established in June 2016, at the ECPC AGM, following the formal request of several ECPC members to guarantee that a large number of rare cancer patient organisations, representing different European countries and rare cancer types, will be able to contribute to the activities of the Joint Action on Rare Cancers (JARC).

The meeting, chaired by Jana Pelouchova, ECPC Board Member and CML patient, gathered 25 participants from 21 organisations representing 13 countries. Among the participants was Dr. Annalisa Trama, invited to talk about the Joint Action on Rare Cancers. The meeting was also attended by ECPC President Prof De Lorenzo, Director Dr. Lydia Makaroff and ECPC's previous Project Coordinator Miss. Kalliopi Christoforidi.

During the meeting, members of the WGRC introduced themselves and their organisations and shared with ECPC their priorities and challenges they face in their respective countries with regards rare cancers.

ECPC director, Dr. Lydia Makaroff, shared with the participants an overview of the activities going on in rare cancers in Europe, namely introducing the [European Reference Networks](#) (ERNs), [Rare Cancers Europe](#) (RCE) and the Joint Action on Rare cancers, explaining the relationship within the different initiatives.

Dr. Annalisa Trama presented an overview of the Joint Action on Rare Cancers, from the [definition of a Joint Action](#) to the overall objectives of the JARC.

The JARC will produce recommendations about rare cancers to improve the following: 1) epidemiological surveillance of RCs; 2) quality of healthcare; 3) the availability of clinical practice guidelines on RCs; 4) innovation; 5) medical and patient education; 6) health policy measures on RCs at the EU and national level; 7) patient empowerment. JARC will building on the experience of the RARECARE and RARECAREnet project, ranging from producing an operational definition of rare cancers, to improvement of care and research, to public policy solutions.

Dr. Trama's presentation was followed by the presentation of Kalliopi Christoforidi on the ECPC specific activities within the JARC in each of the 10 Work Packages. Taking each Work Package at a time, WGRC members started a discussion on the tasks to be carried out. In order to facilitate the discussion, WGRC members were advised to think from two different perspectives: their personal experience and their country experience. At the end of the meeting the WGRC agreed on some action points (page 5).

AGENDA

The Agenda of the meeting can be found under Annex 1.

OBJECTIVES

The overall aim of the Working Group meeting was to identify main challenges, priorities and speak in one voice for rare cancer patients.

In order to achieve the overall aim, this meeting had the specific objectives to:

- Bring all participants up to date with the situation in Europe.
- Generate capacity building and networking between rare cancer patient organisations in order to give them the tools to become contact points for the [Cross Border Healthcare Directive](#) (CBHD) and the ERNs.
- Share the work of ECPC within the JARC.
- Agree on the role and tasks of the WGRC.

PRIORITIES

During the meeting, each participant was asked to share with the group their challenges and priorities for rare cancer patients.

Following an extensive discussion, the identified priorities have been regrouped as indicated below:

- Raise awareness among GPs on rare cancers to improve early, timely and correct diagnosis
- To ensure that correct ICD codes are used to accurately diagnose rare cancers
- Empower rare cancer patients all over Europe by providing them with adequate information
- Ensure that patients are referred to centres of excellence rather than remaining with a non-specialist
- Ensure affordable and sustainable access to treatment, innovation, and psychological support
- Ensure that country-level decisions are made on pricing and reimbursement as soon as possible after [EMA](#) approval of new treatments
- Ensure collaboration among healthcare professionals through a multidisciplinary approach to guarantee expertise and sharing of best practices
- Agree on a common Pan-European definition of rare cancers
- Increase funds for rare cancer research to improve treatments and diagnostic tests
- Establish co-ordinated biobanking to have access to tissue samples
- Ensure equal access to biomarker testing
- Ensure availability and harmonisation of epidemiological data on rare cancers
- Include rare cancers in national cancer plans (EPAAC - <http://www.epaac.eu/national-cancer-plans>)

ECPC TOOLS

In order to facilitate communication among the WGRC but also provide support to the members within their own organisations and countries ECPC has proposed to provide the following tools:

Online Platform for the members, including a helpline – ECPC will create an online platform, dedicated to the members of the WGRC. The platform will allow sharing of documents and timely feedback and encourage discussion among members. Within this platform, ECPC will also provide helpline that members can use in case of questions they have been asked that they are not able to answer with regards to the rare cancer situation in Europe.

Information Toolkit – ECPC will provide to the WGRC members an information toolkit including key definitions (ERNs, [CHCD](#), JARC, Rare Cancers), major problems and epidemiological figures. ECPC will also provide a template presentation on what is happening in Europe with regards to rare cancers that members can use during meetings.

Contact Points at National Level – Upon approval from the JARC partners, ECPC will share with the WGRC members the contact details of the country representatives within the JARC, when applicable.

Advocacy Help at National Level – Upon invitation, ECPC will travel the countries of the WGRC members to explain what the Joint Action is and raise awareness on rare cancers. ECPC will also pass on invitations to the JARC coordinators should the WGRC members want to invite them to an event.

ECPC Calendar – Considering the multitude of activities and initiatives related to rare cancers, ECPC will ensure that WGRC members can share their own events on the ECPC online events calendar, and also include conferences, trainings and workshops on rare cancers all over Europe both addressed to patients and healthcare professionals.

ACTION POINTS

The WGRC decided on a few action points.

JARC - WORK PACKAGE 4 - EPIDEMIOLOGY

OBJECTIVE

There is a need for a common definition of rare cancers potentially based on more than just incidence (also prevalence and survival). This is important because rare cancer patients face different issues from patients affected by more common types (late or incorrect diagnosis, lack of treatment, no access to specialists). GPs and patients are not aware about the definition and do not know which cancers are considered rare. It is time that rare cancers are recognized.

Therefore, a simplified list of the 198 rare cancers needs to be available, supported by the JARC.

ACTION 1

ECPC to circulate the list of rare cancers with the WGRC members.

ACTION 2

WGRC members to provide feedback on the current list of rare cancers stating the main issues with the list and suggesting ways to improve it.

ACTION 3

WGRC members to identify target groups that need to be informed about rare cancers (GPs, patients, endocrinologists etc.)

JARC – WORK PACKAGE 5 – ASSURING QUALITY OF CARE

OBJECTIVE

In order to increase awareness of patients and healthcare professionals of centres available for referring rare cancer patients it is important to identify expert centres and networks for all 12 families of rare cancers in Europe. It is also crucial to raise awareness about the creation and function of the European Reference Networks.

Additionally, the JARC has to propose system-based standards for all families of rare cancers and the networks serving them whilst identifying gaps and inequalities of patient access to resources.

ACTION 4

WGRC members to disseminate information about European Reference networks and advocate at national level so that Member States nominate more centres (hospitals) to join the Networks.

ACTION 5

WGRC members to share with ECPC good or bad stories that they have experienced during the healthcare pathway.

WGRC members to also share what they believe is a best practise in terms of quality of care.

ACTION 6

In order to be able to propose quality standards for all families of rare cancers in all countries, ECPC should enlarge the WGRC scope with the help of the current WGRC members. ECPC will therefore send out a table with the 12 families of rare cancers and each EU country.

ACTION 7

WGRC members to populate the table, identifying and recruiting patients or patient representatives to join our effort in their respective countries or rare cancer types when these are missing. These members will liaise with the country or rare cancer representative of the WGRC when required.

JARC – OTHER WORK PACKAGES

ACTION 8

WGRC members to provide feedback on the tasks presented by Kalliopi in WP6, WP7, WP8, WP10.

TERMS OF REFERENCE

Before the meeting, ECPC circulated Terms of Reference for the WGRC.

- Members are invited to provide feedback on the Terms until the 15th of November 2016.
- Elections will take place in early 2017 in order to nominate two Chairs for the WGRC. Interested members should contact ECPC at rarecancers@ecpc.org until the 25th of November 2016.

OTHER ACTIONS

- Share [ECPC position](#) (click link) on draft report on EU options for improving access to medicines

NEXT STEPS

The discussions of the current meeting will ensure that ECPC truly reflects the patient perspective at the Launch of the Joint Action on Rare Cancers, taking place on the 7th of November 2016 in Luxembourg

SAVE THE DATE- The next WGRC face-to-face meeting will be during the ECPC AGM 2017 in June (preliminary date: 16th of June).

ANNEX 1

AGENDA

- 10.30 – 10.45 **Welcome by Chair and Introduction**
Why an ECPC Working Group on Rare Cancer (WGRC)?
Jana Pelouchova, ECPC Board Member
- 11.00 – 11.10 **Roundtable presentations**
All participants to introduce themselves and their organisation
- 11.10 – 11.30 **What's going on in rare cancers in Europe? Setting our priorities.**
Lydia Makaroff, ECPC Director
- 11:30 – 11:40 **Questions from floor**
- 11.40 – 12.30 **Each representative to share their top three priorities and challenges with regards to their work on rare cancers**
- 12.30 – 13.15 **Lunch**
- 13.15 – 13.30 **Joint Action on Rare Cancers**
Annalisa Trama, JARC Coordinating Team
- 13:30 – 13:45 **Questions on the Joint Action on Rare Cancers**
- 13.45 – 14.00 **ECPC activities within the Joint Action on Rare Cancers**
Kalliopi Christoforidi, ECPC Project Coordinator
- 14:00 – 14:30 **Discussion on the involvement of the WGRC members on the all JARC tasks**
- 14.30 – 14.45 **Communication and dissemination activities**
- 14.45 – 15.15 **Discussion on the definition of Rare Cancers**
Raising issues and sharing experiences of problems in the recognition of rare cancers in your country
- 15.15 – 15:45 **Discussion on function of the WGRC**
- 15.45 – 16.30 **What's next and concluding remarks**