
*MJC RUD meeting notes
on possible collaboration of
Multidisciplinary Joint Committee of Rare
& Undiagnosed Diseases
(MJC RUD)
&
Joint Action for Rare Cancers
(JARC)
20 October, 2017*

Attendees: Ulf Kristofferson, Section of Clinical Genetics (acting chair), Liesbeth Siderius (acting secretary),

1. Welcome and introductions

UK welcomed the participants, introduced himself in more depth, including short summary of his research interest related with the relevant topics

2. Discussion objectives

The aim of the discussion was:

- Secure a detailed understanding of the scope and activities of the JARC, including the goals of the JARC WP8, that could be relevant for MJC RUD colleagues
- To explore the potential areas of collaboration between MJC RUD and the JARC.

3. Joint Action for Rare Cancers Overview

Using the official cartoon slides of Paolo G Casali (JARC coordinator) UK explained the aims of the JARC. He also highlighted that the goals includes the partnering of the three Rare Cancer ERNs: EUROBlood ERN (Hematology / Non-Solid Rare Cancers); PaedCan ERN (Paediatric Oncology), and; EUROCAN ERN (Adult Solid Rare Cancer). The specific, key items include topics of:

- Clinical Practice Guidelines for rare cancers
- Medical Education and Training
- Education policy issues
- eHealth including virtual healthcare, IT tools

The main outputs of the JARC WP8 will be recommendations in the above areas, building consensus in the rare cancer community and exploiting these recommendations..

The JARC is a 3yr action and is coming to the end of 1yr.

4 MJC RUD & JARC Potential Areas of Collaboration

4.1 Collaboration Aims:

The key aims of the collaboration between MJC RUD & NRNs was initially identified as:

- To try to foster collaboration between MJC RUD & 3 RC ERNs
- Securing consensus between MJC RUD & 3 RC ERNs on clinical practice guidelines.

Action: MJC RUD meeting participants agreed to identify MJC RUD members working under initiative and to connect these experts up.

4.2 Training & Education

BM was identified as the education and training lead that 'bridge' GENTURIS and the JARC. He agreed to coordinate the education and training activities between the 3 RC ERNs, GENTURIS and the JARC.

Action: BM to coordinate medical education and training between the JARC and the 3 RD ERNs & GENTURIS.

4.3 Policy Areas

To identify how a network can be shape to provide the best for both community.? (*Not sure what we identified here ...*)

6. Next Steps

The JARC is arranging a joint meeting in the new year with the 3 RC ERNs and extended the invitation to GENTURIS. The scope of the meeting would be a broader scope than just treatment and will also cover network collaboration, policy, guidelines and diagnosis.

On confirmation of this agenda for the meeting, GENTURIS leads would confirm their attendance to the joint meeting.

Action Points

No.	Action	Lead
1.	JARC leads & GENTURIS agreed to identify experts working under initiative and to connect these experts up.	ALL
2.	To share the priority list of CPGs and the clinical leads with GENTUIRS.	PC
3.	To identify expertise in GENTURIS who can liaise with JARC clinical leads on the CPG.	NH
4.	To share rare cancers list with GENTURIS	AT
5.	Bela to coordinate medical education and training between the JARC and the 3 RD ERNs & GENTURIS.	B