

Meeting report series

Report of the 1st Patient Advocates Committee Meeting

Teleconference
August 22, 2016

Participants

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Ms Sharon Terry, Genetic Alliance, USA

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Apologies

Mr Peter Saltonstall, National Organization for Rare Diseases, NORD, USA
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Dr Lilian Lau, Scientific Secretariat, France
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Agenda

1. Introductions of Patient Advocates Committee
2. Purpose of Committee
3. Analysis and discussion of impact of IRDiRC Policies and Guidelines
4. Potential additional Patient Advocates organizations

REPORT

Actions and deliverables

- ▶ All: Send thoughts via email to group and Sci Sec re:
 - Overlap and gaps in patient advocacy group priorities
 - Common roadblocks across patient advocacy groups worldwide that IRDiRC should address
 - Other people in the patient space who would benefit the committee or benefit from the committee
- ▶ All: Review the impact of IRDiRC policies and guidelines on your group's work

Conference notes

- ▶ Introduction of Patient Advocates Committee
 - With growth of IRDiRC a new era has come around, with different subgroups that are not only asked to comment, but also to be involved in setting both the goals and actions, but also involved in attributing to these goals.
 - Growth of IRDiRC requires new structure
 - What role should patient advocacy play in research, both inside and outside of IRDiRC?
 - Patient groups need to be at the same level as funders, companies, and scientists
 - Once governance issues are resolved, a Patient Advocates Committee representative will participate in OpComm
- ▶ Purpose of Committee
 - Constituency groups will be analogous to the scientific committees in terms of their structure and level in the organization
 - The main initial goals of this group are to identify:
 - Overlap and gaps in patient advocacy group priorities; find common ways to addressing problems, no matter the patient advocacy group
 - Common roadblocks across patient advocacy groups worldwide that IRDiRC should address, in order to achieve their vision
 - Find other people in the patient space who would benefit the committee or benefit from the committee
 - Would like to use that information to:
 - Determine appropriate goals for IRDiRC in the patient advocacy space for the next 5 years; it will be the occasion to redefine how and where to have an influence
 - Identify how the patient advocacy groups will contribute to that new set of goals
 - The committee would like to ruminate on these common issues/goals and send around thoughts to the group via email
 - Constituency committee meetings will be held during the Catania CA meeting
- ▶ Analysis and discussion of impact of IRDiRC Policies and Guidelines
 - Paper on IRDiRC Policies and Guidelines currently being written up

- Members asked to think about impact on their organization and ask to send to Sci Sec
- ▶ Potential additional members to invite to participate:
 - Which other patient advocates should be invited to participate, and could benefit from or to the Patient Advocates Committee?
 - Take into account cultural differences; some groups might not have same history or similar representatives
 - Should we focus on umbrella groups?

Document history

Version 1. Report drafted by Christine Cutillo and Anneliene Jonker
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