Meeting report series

Report of the 1st Funders Committee Meeting
Teleconference
August 22, 2016

Participants

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Apologies

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**Agenda**

1. Introduction of Funders Committee
2. Purpose of Committee
3. Analysis and discussion of impact of IRDiRC Policies and Guidelines
4. Discussion of Funders Committee
REPORT

Actions and deliverables

- All: Send additional ideas/thoughts to Sci Sec re:
  - Overlap and gaps in RD research funding
  - Coordination of funding agency priorities / opportunities to minimize duplication and fill gaps
  - Opportunities and challenges that IRDiRC should address

- All: Review the impact of IRDiRC policies and guidelines on your constituency’s work

Conference notes

- Introduction of Funders Committee
  - Historically, IRDiRC is a gathering of funders, with common goals, but while Funders are IRDiRC’s biggest group, no formal coordination re rare disease funding has been done so far
  - Growth of IRDiRC requires structure that is more manageable
  - Once governance issues are resolved, a Funders Committee representative will participate in OpComm

- Purpose of Committee
  - Provide common forum specific to constituency areas and discuss problems that can only be solved by that constituency
  - The main initial goals of this group are to identify:
    - Landscape analysis of overlap and gaps in RD research funding
    - Contribute to better awareness of different (funding) initiatives in the field
    - Coordination of funding agency priorities / opportunities to minimize duplication and fill gaps
    - Opportunities and challenges that IRDiRC should address
    - Definition of further recommendations and guidelines in RD
  - Would like to use that information to:
    - Determine appropriate goals for IRDiRC in the funding space for the next 5 years
    - Identify how the funders will contribute to that new set of goals

- 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

- Discussion
  - Diagnostics
    - Cutting the time period it takes for a patient to be correctly diagnosed
    - Dealing with undiagnosed population
    - [post-meeting note: potential collaboration with AMED with UDNI (Undiagnosed Diseases Network International), which 4th conference will be held in Tokyo, 16-17 November 2016. Information can be shared to IRDiRC]
  - Therapeutics
Perhaps placing a numerical goal on this area is not as enticing as when previous goals were being set.

- Assure that therapies actually reach the patients
- Linking to diagnosis
- Enhancing participation in clinical trials

○ Data sharing
  - Enhancing data sharing capabilities (e.g., Orphanet, Orphacodes)
  - Coordinate or share funding pipelines across agencies (e.g., European Reference Network)
  - Creating database of orphan designations and market authorizations
  - Enhancing registries for use as feasibility tools
  - Sharing knowledge and experiences of funding management to facilitate data sharing to overcome N-of-1 problem.

○ Regulatory and operational
  - Medical coding – ensure capturing rare diseases appropriately so that patients don’t disappear once diagnosed
  - Real-time tracking of research initiatives and research networks to ensure coordination and information exchange
  - Discussion with regulatory agencies concerning clinical trial framework, to assure faster approval

○ Funding
  - Funding coordination, awareness of different calls in a very early stage to make joint calls possible

Constituency committee meetings will be held during the Catania CA meeting.