

Meeting report series

Report of the 1st Funders Committee Meeting

Teleconference

August 22, 2016

Participants

Dr Christopher Austin, National Center for Advancing Translational Sciences, NCATS/NIH, USA
Dr Takeya Adachi, Agency for Medical Research and Development (AMED), Japan
Prof Hugh Dawkins, Western Australian Department of Health, Australia
Dr Ruxandra Draghia-Akli, European Commission, DG Research and Innovation, EU
Dr Adam Hartman, National Institute of Neurological Disorders and Stroke, NINDS/NIH, USA
Dr Daria Julkowska, E-RARE-3 Consortium, EU
Dr Lucia Monaco, Telethon Foundation, Italy
Dr Katherine Needleman, Food and Drug Administration, USA
Dr Irene Norstedt, European Commission, DG Research and Innovation, EU
Dr Jeffery Schloss, National Human Genome Research Institute (NHGRI), NIH, USA
Dr Makoto Suematsu, Agency for Medical Research and Development (AMED), Japan
Dr Santa Tumminia, National Eye Institute, NEI/NIH, USA
Dr Lu Wang, National Human Genome Research Institute, NHGRI/NIH, USA
Dr Sonja van Weely, The Netherlands Organisation for Health Research and Development

Ms Christine Cutillo, National Center for Advancing Translational Sciences, NCATS/NIH, USA
Dr Anneliene Jonker, Paris, France – Scientific Secretariat (Sci Sec)

Apologies

Prof Paul Lasko, Canadian Institutes of Health Research, Canada
Dr Cindy Bell, Genome Canada
Dr Pedro Cortegoso Fernández, Carlos III Health Institute, Spain
Dr Bertrand Schwartz, Agence National de la Recherche, ANR, France
Dr Marie-Christine Ouillade, AFM- French Association against Myopathies, France
Dr Roseline Favresse, Fondation Maladies Rares, France
Prof Willem Ouwehand, National Institute for Health Research, UK
Dr Melissa Parisi, National Institute of Child Health and Human Development, NICHD/ NIH, USA
Dr Gualtiero Ricciardi, Istituto Superiore de Sanita, Italy
Dr Ralph Schuster, Federal Ministry of Education and Research, Germany
Dr Edward Trimble, National Cancer Institute, NCI/NIH, USA
Dr Heikki Vilen, Academy of Finland, Finland

Dr Yoshihiro Yoneda, National Institutes of Biomedical Innovation, Health and Nutrition (NIBIOHN),
Japan

Dr Hyun-Young Park, Korea National Institute of Health, South Korea

Dr Lilian Lau, Scientific Secretariat, France

Dr Ana Rath, Scientific Secretariat, France

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

Document history

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