

## Meeting report series

### Report of the 5<sup>th</sup> Funders Constituent Committee Meeting

Teleconference

April 20, 2018

#### Participants

Dr Daria Julkowska, E-RARE-3 Consortium, France (Chair)

Dr Takeya Adachi, Japan Agency for Medical Research and Development (AMED), Japan

Dr Cindy Bell, Genome Canada, Canada

Ms Christine Cutillo, National Center for Advancing Translational Sciences, NCATS/NIH, USA

Dr Iiro Eerola, European Commission, DG Research and Innovation, Belgium

Dr Oleg Kvlividze, Children's New Hospitals Management Group, Georgia

Dr Teri Manolio, National Human Genome Research Institute, NHGRI/NIH, USA

Dr Alexandre Mejat, AFM Telethon, France

Dr Lucia Monaco, Telethon Foundation, Italy

Dr Katherine Needleman, Food and Drug Administration, USA

Dr Ralph Schuster, Federal Ministry of Education and Research, Germany

Dr Sonja van Weely, The Netherlands Organisation for Health Research and Development (ZonMW), the Netherlands

Dr Marlène Jagut, Paris, France – Scientific Secretariat (SciSec), France

Dr Anneliene Jonker, Paris, France – Scientific Secretariat, France

#### Apologies

Dr Christopher Austin, National Center for Advancing Translational Sciences, NCATS/NIH, USA

Prof Hugh Dawkins, Western Australian Department of Health, Australia (Vice Chair)

Dr Adam Hartman, National Institute of Neurological Disorders and Stroke, NINDS/NIH, USA

Dr Paul Lasko, Canadian Institutes of Health Research, Canada

Dr Daniel Lavery, Loulou Fondation, USA

Dr Jean-Louis Mandel, French Foundation for Rare Diseases, France

Dr Irene Norstedt, European Commission, DG Research and Innovation, Belgium

Prof Willem Ouwehand, National Institute for Health Research, UK

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

Dr Melissa Parisi, National Institute of Child Health and Human Development, NICHD/NIH, USA

Dr David Pearce, Sanford Research, USA

Dr Manuel Posado, Carlos III Health Institute, Spain

Dr Gualtiero Ricciardi, Istituto Superiore de Sanità, Italy

Dr Sultan Turki AlSedairy, Saudi Human Genome Project, Kingdom of Saudi Arabia

Dr Edward Trimble, National Cancer Institute, NCI/NIH, USA

Dr Heikki Vilen, Academy of Finland, Finland

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

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## **Agenda**

1. Suggestions from Funders Constituent Committee (FCC) members on which topics members would like to discuss in Vienna
2. Start current funding data collection
3. Future collaboration for funding calls: questionnaire

## REPORT

The Chair of the Funders Constituent Committee (FCC) thanked and welcomed participating members to the teleconference, aimed to discuss the agenda for the Vienna meeting, the start of the current funding data collection and the questionnaire on future collaboration for funding calls.

### 1. Suggestions from FCC members on which topics members would like to discuss in Vienna

The CA meeting in Vienna will have a half-day breakout session dedicated to the FCC. Several topics are suggested for the agenda for this face-to-face meeting of the FCC.

- ▶ Ethical/Legal (ELSI) aspect of RD research funding, RD healthcare and therapies
  - FCC members filled out a survey, results compiled by the Sci Sec
  - Discuss results of survey, and determine next steps
- ▶ Future collaboration for funding calls
  - Will be an occasion to discuss the first results of questionnaire that will be discussed later on the call
  - Determine next steps for funding cooperation and collaboration
- ▶ Call for tenders for funding project database
  - Once the Sci Sec contract amendment has been accepted, the Sci Sec coordinator will write a call for tenders for a funding project database
  - The meeting could be an occasion to discuss the deliverables that should be included in this call for tenders
- ▶ International collaboration with developing countries
- ▶ The European Conference for Rare Diseases, taking place before the IRDiRC Consortium Assembly (CA) meeting, is organizing a session on international collaboration and developing countries
  - Take advantage of this session and discuss with invited speakers on how do they see the support and collaboration with IRDiRC (what would be the most pertinent for them),
  - We could ask to provide a summary of the outcomes of this session
- ▶ Possible activities for IRDiRC Roadmap 2019
  - This topic can be in the main CA meeting agenda, but if not, FCC can start discussion for funders

### 2. Start current funding data collection

- ▶ In the past, we collected IRDiRC funded projects data via email. Action A, for which we are currently amending the SUPPORT-IRDiRC contract, necessitates the creation of a new Task Force/Working Group to determine the data fields/elements, methodology, and structure required of the new DB/tool.

- Until the new DB/tool has been developed, we will need to continue to collect the data via Excel spreadsheet.
- ▶ Data will be used to:
  - Fulfill contractual obligations
  - For the implementation of Action A
- ▶ The data that will be collected for each project are:

Official title	State the full title of the project
Description of project	Provide a brief summary of project, indicating the main goals of the project or the url where it can be found
Category	Several project categories are provided. Please select one or more categories that fits best the project out of the list in the excel sheet
Funding body	Please state the funding body that funds the project
Funding call	Please state the funding call that funds the project
Disease	State the disease or group of diseases of the project
Effective date start and end of project funding	State the date that the project effectively starts and ends
Name and email of researcher	State the full name and email address of the researcher
Institution and department of researcher	State the institution and affiliation of the researcher
Total budget	State the budget of the project
National/Multinational	State the partners and their affiliation

- ▶ Comments on data collection:
  - Categories are extended with additional categories, such as registries, biobanks and databases
    - It is possible to indicate multiple categories for each project
    - Sci Sec will inquire if it is possible to sort categories in a more systematic matter
  - Costs: in US, the total costs of a funded project include overhead
    - Needs to be indicated in the email and field that costs are total costs, not indirect costs
  - What to do with non-traditional funding?
    - Should we add intramural and extramural funding?
    - Excel will have the possibility to add comments if necessary
  - Overlap Orphanet and Sci Sec data collection
    - In countries where there is an Orphanet team in place, Sci Sec can provide you with an extraction of the existing data, and ask you for validation/ completion of that data

- In countries where there is no Orphanet team, the Sci Sec will ask you to directly provide all data

→ Sci Sec will send out a call for data collection shortly

### **3. Future collaboration for funding calls: questionnaire**

In parallel to the data collection and the funding database, FCC would like to do a first step towards stronger funding collaboration. In order to do so, the Working Group of Activity A has started working on question for a funding collaboration questionnaire. This questionnaire mostly investigates procedures, different functioning modes and possibilities and constraints for future collaboration.

The questions will be updated with the discussion of this teleconference. Questions concerned funding instruments, type and timeline of calls, eligibility criteria and constraints for grants and evaluation criteria for grants.

In addition, it should be clarified that the outcomes of this questionnaire are confidential, and can only be shared within the FCC.

- The questionnaire will be updated with the comments of the FCC discussion
- The questionnaire will be send to all FCC members to fill out prior to Vienna

### **Action Items and deliverables**

- ▶ Send out a call for funding data collection
- ▶ Finalize agenda for Vienna
- ▶ Update questionnaire funding collaboration with FCC comments
- ▶ Provide answers to funding collaboration questionnaire