

IRDiRC Memo

Roles and responsibilities of the Scientific Secretariat

June, 2019

Composition of the Scientific Secretariat (Sci Sec) team members

Scientific Coordinator: Daria Julkowska, Ph.D. (part-time dedication)

Daria provides overarching supervision of IRDiRC Scientific Secretariat projects as part of the EJP RD from the administrative, financial and scientific point of view. She provides scientific and organizational support to the team when needed and follows up on the team activities through internal meetings planned by the Project Managers. She attends the Consortium Assembly and Operating Committee meetings, and she is involved in the exchange with the IRDiRC Consortium Assembly, Constituent Committees and Scientific Committees to ensure efficient communication between the team and the Committees.

Senior Project Managers: Carla d'Angelo, Ph.D. and Galliano Zanello, Ph.D.

Carla and Galliano are responsible for the project management and reporting of the IRDiRC Scientific Secretariat as part of EJP RD. They prepare the work plan of the team according to the requests and needs of IRDiRC Committees, manage the day-to-day work of the team, follow up on the team activities, report to the Chair of the IRDiRC Consortium, and prepare activity reports in accordance to the Scientific Secretariat contract. They support the activities of IRDiRC Committees and Task Forces through preparation and distribution of meeting documents as well as additionally requested documents, and reporting of conference calls and meetings. They plan and draft the annual State-of-Play report. They also review the budget and financial reports. They will assist, on request, in the organization of an IRDiRC Conference.

Communication Manager: Eleonora Passeri, Ph.D.

Eleonora is responsible for the dissemination of the IRDiRC research project to the public at large, as well as the dissemination of IRDiRC achievements as a consortium. She produces information for the IRDiRC website and the IRDiRC newsletter, and manages the social media account. She prepares presentations, posters and leaflets, and contributes to the production of documents related to the activities of the IRDiRC Committees and Task Forces. She supports the drafting of the annual State-of-Play report. She will assist, on request, in the

organization of an IRDiRC Conference.

Data Manager (located at Orphanet): Driss El-Moustaine, Ph.D.

Driss, who was part of the previous IRDiRC Scientific Secretariat and works at Orphanet, continues to ensure the collection of expert resources related to research activities from the funding agencies members of IRDiRC, according to the Orphanet database procedures, and highlights these sources in the Orphanet database. He is responsible for the coordination of monitoring the progress towards IRDiRC objectives, using Orphanet data on the count of rare diseases, the number of genes linked to rare diseases, the number of rare diseases for which there is a genetic test available, and the count of approved therapies. He provides the clinical research data for the annual State-of-Play report.

Assistant: Katerina Tzima

Katerina assures the secretarial and administrative work of the team. She organises meetings logistics, provides travel organization support including reimbursement claims processing, and keeps track of expenses.

Contact information

For general enquiry:

carla.dangelo@ejprarediseases.org

galliano.zanello@ejprarediseases.org

scisec-irdirc@ejprarediseases.org (Carla d'Angelo and Galliano Zanello)

For general scientific support (email to the Chair and Vice Chair, their assistants, and the Sci Sec team):

scientificsupport@irdirc.org

For scientific coordination issues

Daria.julkowska@ejprarediseases.org (cc: scientificsupport@irdirc.org)

For communication-related items:

leonora.passeri@ejprarediseases.org

carla.dangelo@ejprarediseases.org

galliano.zanello@ejprarediseases.org

For supplying info on funded projects:

driss.el-moustaine@irdirc.org (cc: scientificsupport@irdirc.org)

For travel support/administration:

Katerina Tzima (katerina.tzima@ejprarediseases.org)