Memorandum of Agreement for Investigators Participating in the
Canadian Rare Disease: Models & Mechanisms Network (RDMM)
Réseau de Maladies Rare: Modèles et Mécanismes de Canada (MRMM)
"the Network"

I: Purpose of Memorandum

This memorandum of agreement sets out the arrangements of the Network for investigators who wish to collaborate and receive funding. The **objective** of the Network is to expedite collaboration between basic scientists and clinicians in functional studies of rare disease genes with the ultimate goal of expanding and improving the understanding of rare disease pathogenesis to generate new insights into biological pathways and novel therapeutic avenues.

II: Guiding Principles

The collaboration is based on certain values as outlined below:

1. **Trust and Confidentiality:** Any memorandum of agreement is fundamentally based on a sense of mutual trust and respect among the participating investigators. Findings and results generated by the collaborative efforts of a team will be treated on a confidential basis and cannot be used in grant applications or papers without the prior consent of all of the investigators involved.

2. **Timeliness of activities/research:** There is a commitment to adhere to reasonable timelines in carrying out analyses and publishing papers.

3. **Role of the governance, scientific steering and advisory committees:** The collaboration needs strong governance and responsive steering and advisory committees to run the everyday tasks of the project. However, the collaboration can only be successful if it also makes maximum use of the creativity and energy of the participating investigators.

4. **Adherence to the research program of the Network:** Participants are expected to establish collaborations to conduct, complete and report on experiments in accordance with the research program as outlined below.

III: Requirements for Participation

1. **Consent**: The original gene discovery investigations in a patient(s) were conducted after appropriate consent had been obtained using the clinician investigator's institution-specific Research Ethics Board approval (or approved designate) which included:
    - the application of exome or whole-genome sequencing approaches for gene discovery
    - return of results, including actionable incidental findings in childhood, to participants
2. **Canadian patients**: At least one patient for the gene being studied is a resident of Canada at the time of the study.
3. **Return of results**: The investigator/team is not required to return results to the patient/their family at the study's conclusion, however, this is encouraged as a means to promote the value of the Network and to emphasize the need for model organism research platforms to put disease-causing genes into a biological context.

4. **Exclusivity of funding**: The members will not use Network funding to perform experiments for which they already have funded from another source.

IV: Publication Policy

1. Authorship will be determined by the individual gene-specific research teams according to standard academic guidelines of making an important intellectual contribution to the study (such as clinicians providing samples, informaticians, scientists etc). The Network will also be listed as an author where allowed by the journal and the Scientific Steering and Clinical Advisory Committee members listed in a supplementary table.

2. All publications will comply with Genome Canada's policy on *Access to Research Publications* in section 3.5.5 of the *Guidelines for Funding Large-Scale Genomics Research Projects* and CIHR's policy on *Access to Research Outputs*. Under this policy, grant recipients must make every effort to ensure that research papers and bio-molecular data generated from CIHR funding are freely accessible online.

3. Investigators are required to acknowledge Genome Canada, the Canadian Institutes of Health Research, and, if applicable, other organizations such as rare disease societies who have funded Network projects, in any communication or publication related to the project.

V: Intellectual Property (IP)

The IP will fall under institutional rules of the lead site (University of British Columbia) as dictated by the agreements signed with the current (CIHR, Genome Canada) and future funders of this project. Further information will be provided concerning the specifics of UBC IP policies and how these will be applied consistent with requirements of the academic institutions of individual investigators. It is not anticipated that many projects will entail development of novel IP as part of the current Network portfolio, although it is potential.

VI: Signature

Signature means an agreement in principle with this document and a commitment to abide by the terms of the memorandum.

Name:	Date:
Affiliation:	Signature: