

Consultation Workshop:

Engaging Patient Organizations in Funding Research (draft model)

Stephanie Robertson

Assistant Director, Institute of Genetics

Canadian Institutes of Health Research



On behalf of E-Rare-3

Mandate

To excel, according to internationally accepted standards of scientific excellence, in the creation of new knowledge and its translation into improved health for Canadians, more effective health services and products and a strengthened Canadian health care system

CIHR Institute of Genetics

Mandate

Supports research on the human and model genomes and on all aspects of genetics, basic biochemistry and cell biology related to health and disease, including the translation of knowledge into health policy and practice, and the societal implications of genetic discoveries

Patient Organizations:

Partnering with CIHR on E-Rare Calls

E-Rare-2 - 2013 Joint Transnational Call



E-Rare-2 - 2014 Joint Transnational Call



The FOUNDATION
FIGHTING BLINDNESS



E-Rare-3 - 2015 Joint Transnational Call



Cystic Fibrosis
Canada



E-Rare-2 Joint Transnational Call (2014): Muscular Dystrophy Canada (MDC) Story

- Patient organizations co-funding can be more fluid than national funders as their mandates are not always restricted to research being conducted within a specific country

MDC partnered with national funder in France & CIHR funded the work being undertaken in Canada

- **Impact:** *allowed the funding of an additional grant which would otherwise not have been possible*





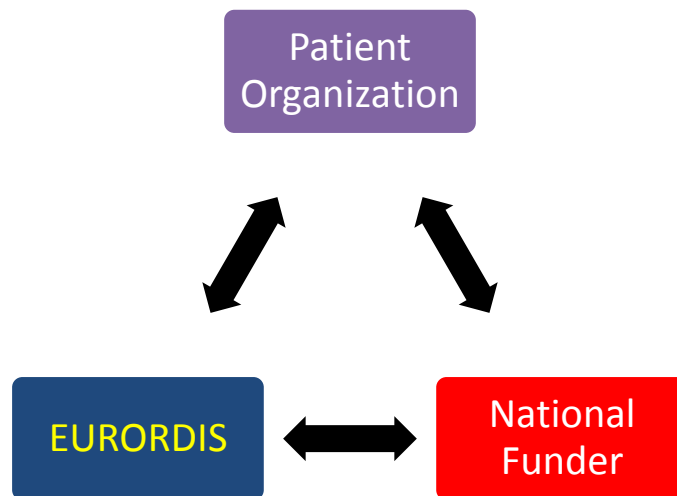
Consultation: Draft model for
engagement of Patient Organizations
as funding partners in
E-Rare-3 Joint Transnational Calls (JTC)

*Working together to advance the rare diseases research
agenda*



Engaging Patient Organizations

- EURORDIS/National funder reaches out to POs to establish interest in co-funding research projects **within their organizations mandate**



- Initiate as soon as possible to allow for POs to seek board approval
- Can become a partner up until the peer review of the full application
 - e.g., some POs may want to participate if there is a project within their mandate going to full application



Approach & Tools

Approach

- Method of communication depends on relationship with PO
- “Flexibility” is a key requirement when engaging with POs
- Robust communication strategy will be developed

Tools

Two-page communication document (under development):

- E-Rare overview
- How to become a research partner



Becoming a Research Funder on an E-Rare-3 JTC

Intent to Partner

PO will confirm the area(s) of research interest, anticipated level of support, & primary contact through an *Intent to Partner* statement

Coordination

Both the Intent to Partner Statement & the PO Funder table will be sent to EURORDIS who will work with the JTC Secretariat to coordinate with national funders in the overall JTC



Areas of Interest:

Advance research within a POs Mandate

JTC
Materials

POs will be asked to complete a table modeled after the JTC “funder table”, in partnership with national funders (where appropriate)

It is in the “patient organization table” where POs will include information such as:

- Outline their areas of interest
- Indicate level of funding available & the duration
- Identify other terms/requirements/preferences as needed such as research must be conduct in XXX (name of country)
- Provide a contact name



Relevance Review

Review

POs determine which applications are within their area of interest to fund through the review of anonymized one-page research summaries

Timing

Anonymized one-page research summaries will be provided at the full application stage. PO relevance review results must be finalized prior to the review of the full applications

Coordination

EURORDIS coordinates the relevance review process & represents the POs at the E-Rare-3 CSC meetings



Finalizing Competition Results

Applications are funded in rank order

Step 1

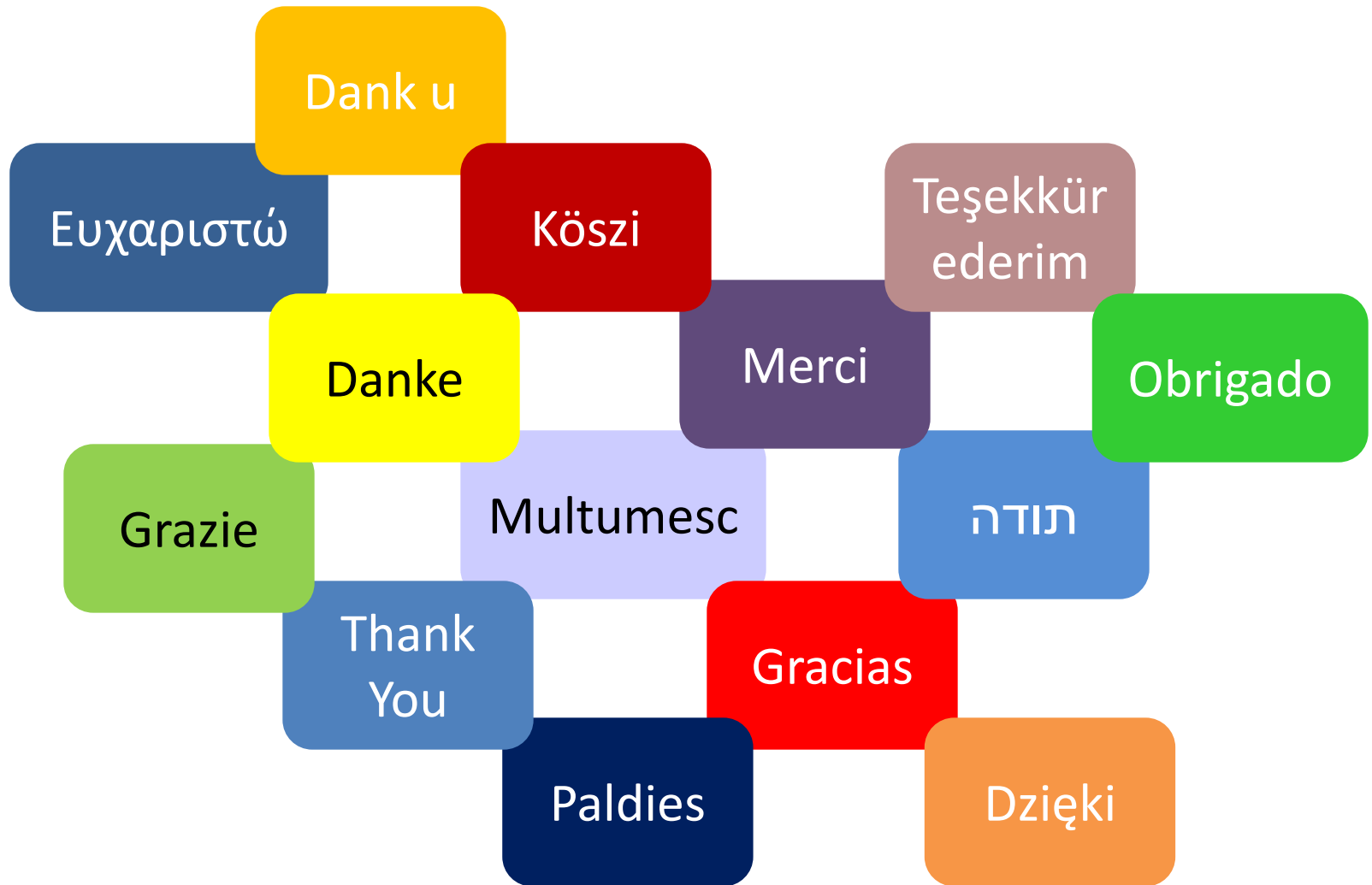
EURORDIS will participate at the CSC meeting to develop the funding scenario on behalf of POs based on the relevance review results & anticipated level of funding

Step 2

EURORDIS will confirm the funding scenario with POs & will connect them with the appropriate national funder

Step 3

Collaborative Agreements are established with the national funder



Benefits and Potential Impact of Co-Funding Research: ARSACS

Economic value

- When you are a patient organization for a rare disease raising funds is not an easy task. Partnering with CIHR enables a direct source of funding leveraged to the funds invested into research by the patient organization.

Public Awareness & Credibility Values

- Partnering with an important partner such as CIHR adds credibility to the organization's overall work with respect to the scientific and philanthropic communities. It also raises public awareness towards the specific rare disease.

Benefits and Potential Impact of Co-Funding Research: ARSACS

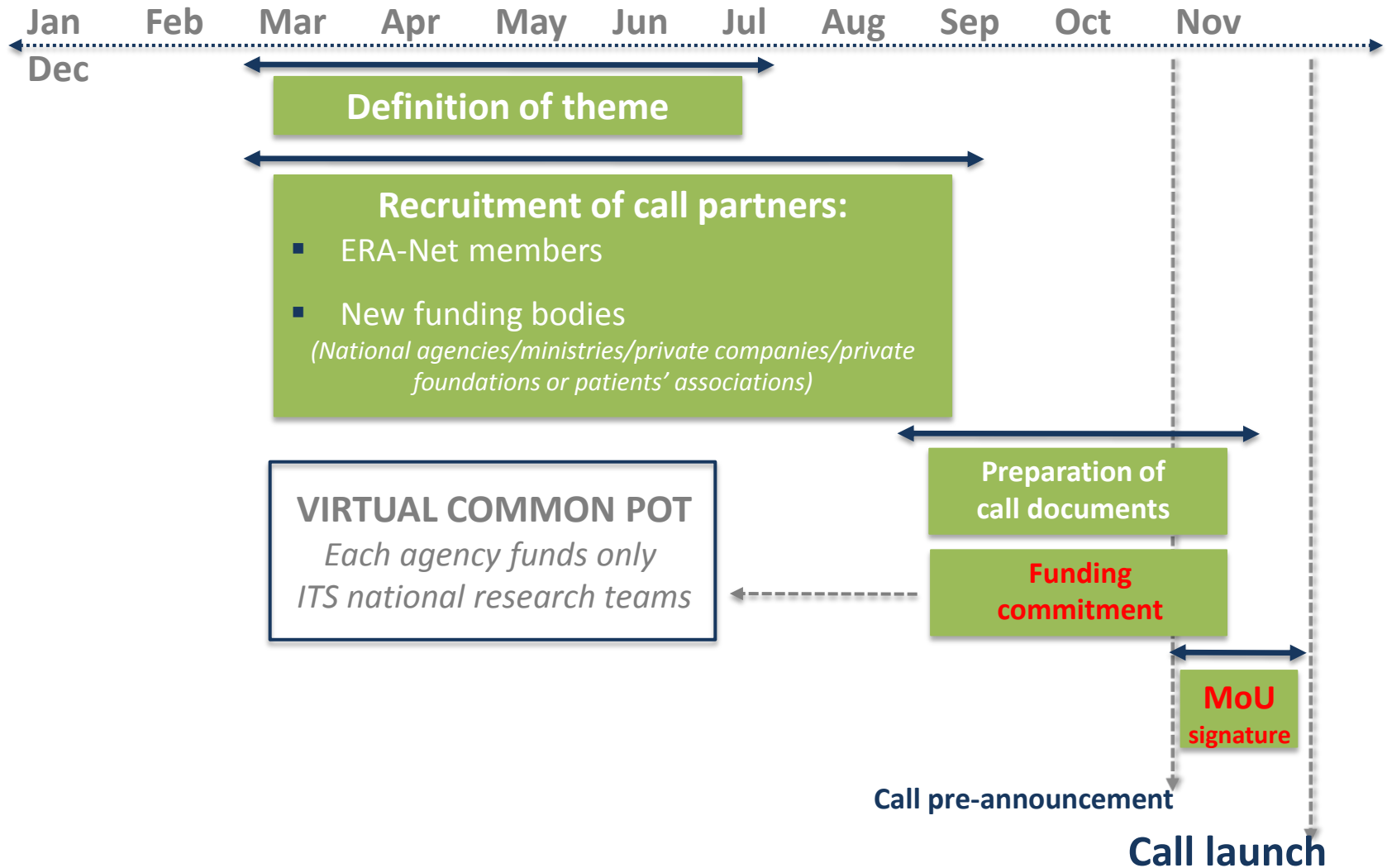
Scientific Value

- Partnering brings together new researchers (nationally and internationally) and new participants such as pharma to the existing research project. As a patient organization devoted to a rare disease, it can be difficult to reach out to new researchers and to new research projects nationally and internationally.

Hope Value

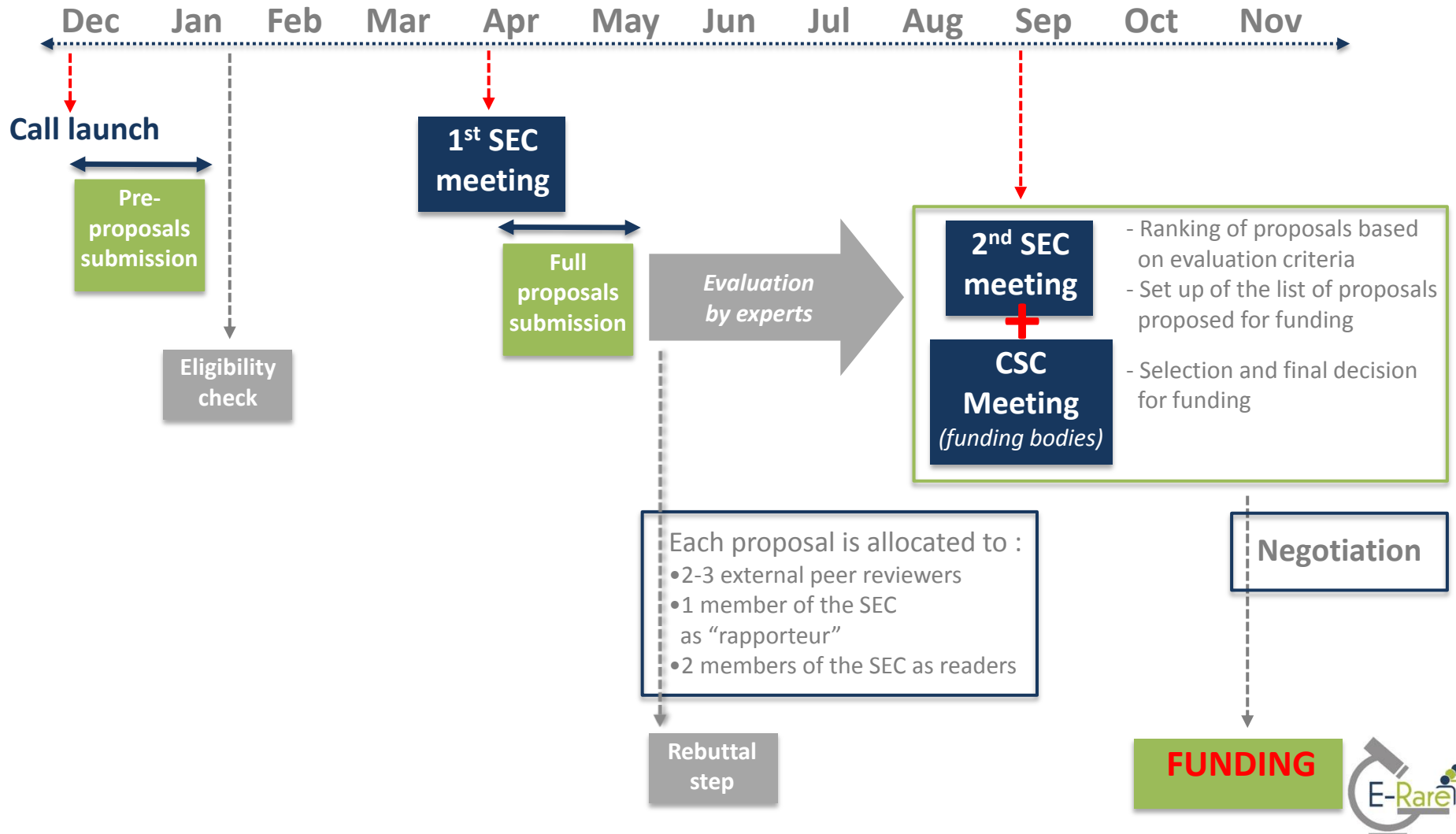
- Individuals and their families afflicted with a rare disease often feel isolated. Partnering with CIHR sends a message of hope to the families who are affected by the disease by letting them know that they are not left to themselves and that organizations are actively working together to improve their quality of life.

Joint Transnational Calls: PREPARATION



Joint Transnational Calls: CALL SCHEDULE

2-STEP PROCESS



Areas of Interest: to advance research within a POs Mandate

JTC Materials

POs will be asked to complete a table modeled after the JTC “funder table”, in partnership with national funders (where appropriate)

CANADA, CIHR-IG

Country	Canada
Funding organisation	Canadian Institutes of Health Research Institute of Genetics (CIHR-IG)
National contact person	Marilyn Desrosiers Deputy Director, Strategic Program Design and Analytics Canadian Institute of Health Research Telephone: 613-954-6242 Email: marilyn.desrosiers@cihr-irsc.gc.ca
Funding commitment	The total amount available from CIHR-IG is \$500,000 (CAD) per year for a term of three years. The maximum amount that can be requested in support of a Canadian component is \$150,000 (CAD) per year for up to 3 years from all Canadian funding sources (CIHR-IG, Genome Canada, FRQS and their funding partners).
Anticipated number of fundable research partners	It is anticipated that funding will be available to support up to 6 to 8 from all Canadian funding sources (CIHR-IG, Genome Canada, FRQS and their funding partners). CIHR-IG is providing funding for up to 3 to 4 teams as outlined in the call text. Canadian funders will be working together to maximize participation from the Canadian research community
Eligibility of project duration	Up to three years
Eligibility of a partner as a beneficiary institution	Refer to the Individual Eligibility Requirements (http://www.cihr-irsc.gc.ca/e/22630.html#1-D2) regarding the eligibility requirements for institutions.
Eligibility of principal investigator or other research team member	Refer to the Individual Eligibility Requirements (http://www.cihr-irsc.gc.ca/e/22630.html#1-D1) regarding the eligibility requirements for individuals.
Eligibility of costs, types and their caps	The maximum amount per grant from CIHR-IG is \$150,000 per annum for a term up to three years. Applicants should review the Use of Grant Funds (http://www.nserc-crsng.gc.ca/Professors-Professeurs/FinancialAdminGuide-GuideAdminFinancier/FundsUse-UtilisationSubventions_eng.asp) section of the Tri-Agency (CIHR, NSERC and SSHRC) Financial Administration Guide for a complete listing and description of allowable costs and activities.
Submission of the proposal at the national level	Additional application material is required to be submitted to CIHR at the full application stage . This information can be obtained from the national contact person identified above.
Submission of financial and scientific reports at the national level	Successful applicants funded through this funding opportunity and any other persons working on the project must comply fully with the CIHR Funding Policies (www.cihr-irsc.gc.ca/e/204.html). Policies and guidelines cover areas such as Applicant Responsibilities, Official Languages policy, Access to Information and Privacy Acts, and Acknowledgement of CIHR's Support. Successful applicants will be informed of any special financial requirements prior to the release of funds or when they receive CIHR's Authorization for Funding (AFF) document.
Further guidance	See national call available on the CIHR website: <i>will be available shortly</i>