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MINUTES

International Confederation of Countries Advisory Council
 16th Apr, 2013 - 10PM Melbourne, Australia time
 Via GoToWebinar

ATTENDEES

Martina Witsch-Baumgartner (Chair)	Austria
Augusto Rojas-Martinez,	Mexico
Sir John Burn	UK

Richard Cotton (HVP Scientific Director)
 Heather Howard (HVPI Operations Manager)
 Helen Robinson (HVPI Liaison – WHO)
 Fan Li (Liaison Officer – China)

Apologies

Graham Taylor, John Coghlan	Australia
Helene Antoine-Poirel	Belgium
Milan Macek	Czech Republic
Ming Qi	China
Andreas Hadjusavvas, Maria Loizidou	Cyprus
Sherifa Ahmed Hamed, Mahmoud Raafat Kandil	Egypt
Fahd Al Mulla, Makia Marafie	Kuwait
Zilfalil bin Alwi, Amir Feisal Merican	Malaysia
Luis Figuera-Villanueva	Mexico
Tilak Shresta, Rebati Man Shreshta	Nepal
Angel Carracedo, Maria Jesus Sobrido	Spain
Chí Dững Vũ	Vietnam
Andrew Devereau	UK
Mike Watson, Bruce Korf	USA
Aída Falcón de Vargas	Venezuela

Timothy Smith (HVPI Communications Officer)

AGENDA:

Meeting Opened 10pm Melbourne, Australia time

1. **Welcome**
2. **Chair**

It was with regret that Fahd's resignation was accepted and Martina informed the committee that she was asked by Dick to take on the role of the Interim Chair of ICCAC as she was the only other person who was on the ballot in Paris. She thought that the ICCAC was important, regardless recent disagreement on some issues, and decided to accept the offer. She also thought at there are three important topics which need to be worked on:

- Attract more country nodes
- Develop written description about HVP node

- Help countries to get funding

We should establish working groups to achieve these objectives. Let us work together to meet challenges.

3. Welcome new Members

ICCAC welcomes Venezuela to formally become HVP node. Dick, Martina and Helen informed the council that India, Singapore, Philippines, Sri Lanka, Chili. Brazil have also expressed intention to start node.

It was with regret that Greece and George Patrinos had withdrawn their membership and support.

Augusto raised funding issue. He approached the university in Mexico for possible funding support. Martina commented that the funding situation is different in Austria where universities focus on research only. Therefore we should explore variety of ways to get funds in different countries.

4. Confirmation of minutes of previous meeting – 19th February, 2013

The minutes were approved without modification.

5. Issues arising from previous meeting

None

6. Working Groups under the purview of the Council

There are currently no working groups allocated to the Council.

Martina suggested form a working group of funding to generate good ideas regarding how to raise funds. Heather clarified that it should be an interest group for this purpose, whereas working groups are for standard development.

7. HVP Country Node Baseline report

Helen thanked those who had submitted their baseline reports. It was a lot of work and very much appreciated. She indicated that a lot of information had been submitted including both published and unpublished reports and articles. There was also a lot of valuable information from countries that had not yet taken the formal step to become an HVP country node. ICO would like to make this information available to members but as it was given in confidence, the ICO must first seek permission from each relevant CN manager to make it available. It is also proposed that additional information be sought from countries to add to this electronic database. The ICO will work with each member of the ICCAC to ensure that their country file is up-to-date, to collect any more information and to produce a simple country summary in a standard format.

It was further proposed that a small number of working groups of Council members be established to prepare short discussion papers for Council meetings on key aspects of CN activity, for example:

- a. How to group and describe various types of testing being done
- b. How to present changes in the nature of tests being performed
- c. Analysis of who pays for tests in various parts of the world – public, private households
- d. Patterns in testing and data collection over time in various regions
- e. Analysis of national differences in approaches to quality standards

Helen and Tim will be in touch with each member individually before the next meeting. In the meantime, any feedback or comments on this proposal would be very welcome.

ACTION: ICO to send message to each country regarding permission to share the information they have provided and seeking further co-operation

8. Human Variome Project/China Country Development Program

Two proposals are approved. Funding Agreement yet to be negotiated, pending funds from China.

- Austria, Czech Republic and India
- Belgium & Democratic Republic of Congo – Approved

There are 3-4 proposals in the process of being put in the form that will be reviewed by the International Scientific Advisory Committee. Augusto informed that Mexico was in discussion with Spain and Chili to put together a proposal. He was encouraged to continue working on it since it took considerable amount of time to put together such a proposal and seek for other sources of funds.

Funds from China have not arrived. Martina asked if ICO could issue a letter of approval, despite no funds available yet. ICO agreed.

ACTION: ICO to send approval letter to successful applicants

9. Standards Development Process/Activity Proposals

No Working Groups currently chartered.

No Activity Proposals received.

ICO will draft a list of the standards required and discuss with Martina and then circulate to ICCAC members.

ACTION: ICO to draft the standard list

10. Recommendations to the Scientific Advisory Committee

None

11. World Health Organization consultations

Helen reported that this joint project with the Foundation for Genomics and Population Health (PHG Foundation) and WHO. HUGO has also expressed interest in joining the project. This will be followed up by ICO. To date consultations have been conducted in San Francisco, Kuala Lumpur, Singapore, and Canada. Further ones are planned for France, Mexico and Boston. Approximately 20 interviews have also been completed and about another dozen have been planned in the next few months. So far the results indicate an overwhelming support for an international program on genomics and public health to be established but there is less agreement on the exact nature of the program, its priorities and its mandate. Helen asked that anyone wanting further information on this project or wanting to have input should please contact her directly.

Helen also reported that she is a member of a WHO working group representing HVP that is preparing a report on the outcomes of the Grand Challenges in Genomics and Global Health.

12. Other matters

Dr Fan Li at ICO will act as the point of communication with ICCAC members.

13. Next Meeting

7th June, 2013, face to face at UNESCO Headquarters, Paris

Meeting Closed 10:40PM Melbourne, Australia time