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# MINUTES

International Confederation of Countries Advisory Council  
2 December, 2014 – 11:00PM Melbourne, Australia time  
Via Calliflower

## ATTENDEES

Graham Taylor	Australia	<b>Apologies</b>	
Martina Witsch-Baumgartner (Chair)	Austria	Thomy de Ravel, Kathleen Claes	Belgium
Ming Qi	China	Milan Macek	Czech Republic
Maurizio Genuardi	Italy	Andreas Hadjisavvas, Maria Loizidou	Cyprus
Augusto Rojas-Martinez	Mexico	Sherifa Ahmed Hamed	Egypt
Tilak Shrestha	Nepal	Mahmoud RaafatKandil	Egypt
Peter Taschner, Marielle E van Gijn	Netherlands	Domenico Coviello	Italy
Oyekanmi Nash	Nigeria	Myungchull RHEE, Jong Bhak	South Korea
Hadiza Mahey Rasheed-Jada	Nigeria	Makia Marafie	Kuwait
Richard Rosenquist, Johan Rung	Sweden	Zilfalil bin Alwi, Amir Feisal Merican	Malaysia
Mike Watson	USA	Augusto Rojas-Martinez	Mexico
		Luis Figuera-Villanueva	Mexico
<b>Observers:</b>		Rebati Man Shrestha	Nepal
Peter Pearson	Brazil	Angel Carracedo, Maria Jesus Sobrido	Spain
Denise Brito	Mozambique	Andrew Devereau, Sir John Burn	UK
		Bruce Korf	USA
<b>ICO:</b>		Aída Falcón de Vargas	Venezuela
Richard Cotton (HVPI Founding Patron)		Chí Dǔng Vǔ	Vietnam
Heather Howard (HVPI Operations Manager)			
Helen Robinson (HVPI Liaison – WHO)		<b>Observers</b>	
Timothy Smith (HVPI Communications Officer)		Celeste Benta	Portugal
Fan Li (Liaison Officer)		Jordan Lerner-Ellis	Canada
<b>Invited Attendees:</b>			
Rosemary Ekong	Nigeria		
Raj Ramesar	South Africa		
Vera Lopes	Brazil		

## AGENDA

### 1. Welcome

### 2. Apologies

See list above.

### 3. Welcome new Members

ICCAC welcomes two new Interim Country Nodes: Netherlands (represented by Peter Taschner and Marielle E van Gijn) and Sweden (represented by Richard Rosenquist and Johan Rung). The ICO also reported on progress of recent discussions with Argentina.

#### 4. Confirmation of minutes of previous meeting – 23 September, 2014

The minutes were approved without modification.

#### 5. Issues arising from previous meeting

Note that all issues arising from the previous meeting have been taken up in the items below.

#### 6. Horizon 2020 project

The group of Country Nodes involved in putting together a multi-country application for an EC Horizon 2020 grant reported on their progress to date. Building on Martina's preliminary proposal outline for discussion (under PHC-30-2015: Digital representation of health data to improve disease diagnosis and treatment - deadline is April 2015) Maurizio Genuardi and Domenico Coviello have been enthusiastic and put together a proposal based on six work packages for discussion (draft circulated to members). This proposal has made a valuable contribution to progress the thinking of those involved and to clarify the various complex issues that would need to be addressed by the project. All those involved to date are to be thanked as their efforts have advanced the thinking of the group and help focus on the key challenges. With regard to the important component of linking of phenotypic information with genotypic, Martina reported on her discussions with Peter Robinson in Berlin. He has made his own grant application and raised the possibility of working with HVP members if the project is successful; and in the case that his grant proposal is not successful he is willing to be involved in our grant application for H2020.

Peter Taschner informed the Council that he had been made aware that there would be another call from the EU during 2015, and that it will focus more on disease registries and related activities; he suggested that this may be more easily aligned to the development of Country Node infrastructure and addressing the concrete practicalities of data sharing between countries. Given the significant amount of time and effort required to develop a quality application, the selection of the call is very important. Members asked Peter Taschner to seek more information on their behalf and also agreed that those Council members who are interested in participating in this project should form a sub-group with a view to holding a tele-conference within 1 – 2 weeks to make a final decision on whether to pursue the current call or work towards applying for the later round. The sub-group would report back to the Council on their progress.

Key group at the moment: M. Genuard, D. Coviello, P. Taschner, P. Pearson, M. Claustres, M. van Gijn, R. Ekong, M. Macek, M. Vihinen, M. Witsch-Baumgartner

#### **ACTION**

- Interesting individuals to communicate in email exchanges to discuss the issue
- A meeting to be held on H2020 **before 16 Dec** to make a final decision on whether to pursue the current call
- Coordinator role to be decided if a decision is made to pursue the current call

#### 7. Country node development – plans for 2015

Helen Robinson introduced several issues related to developing the concept of HVP Country Nodes. The new definition and process for becoming a Country Node has been in place for the last 12 months and

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appears to be working well. There has been a marked increase in the number of enquiries received from individuals and groups wanting to establish national nodes during 2014. The HVP Strategic Plan makes reference to developing a process for Nodes to move from *interim* to *full* status to be in place by the end of 2016. This latter issue is likely to require a lot of discussion and debate. As well the new HVP web-site needs up-dating with relevant information about each interim node. With this in mind several documents were sent out with the agenda to stimulate some action.

Before a *Guide to becoming an HVP Country Node* can be developed for use in 2015, members were asked to review the slide package. This slide package is a shorter version of the package used in the HVP one-day workshop – *How to establish and operate an HVP Country Node*. This workshop was run several times in 2014 and is scheduled to be offered in conjunction with 2 or 3 major conferences during 2015. Preliminary comments on the package revealed some omissions and suggested changes of emphasis, including making clearer the ‘why’ of data collection and sharing. Once agreed, these slides can be made available to be used by Council members to promote HVP Node activities

With regard to idea of creating a series of awards for HVP Country Nodes – the ‘most improved node’ was suggested as a place to start. This could be awarded at HVP6 in 2016 at UNESCO. The 4 X 5 draft matrix might provide some ideas for assessing nodes for such an award. Members were asked to give some thought in preparation for a fuller discussion at the next meeting.

#### **ACTION**

- Members to provide their feedback on the introductory slides by **31 December 2014**
- Members to review the information on the HVP website for their Node using the link provided and provide the following minimum information to the ICO by email by **Friday 9 January 2015**:
  - A) contact information for national Node in form of email address
  - B) contact name, title and telephone number for information on Node activities
  - C) links to Node’s web address
- Discussion of the 4 X 5 matrix will be put on the agenda of the next meeting – **3 February**; members are asked to review the document in preparation for the discussion

#### **8. Global Haemoglobinopathies Initiative**

Most recent activities regarding this project have been related to discussions with potential funders and planning future meetings. Members will recall that Raj Ramesar and Zilfalil bin Alwi have agreed to lead this project on behalf of the ICCAC and HVP.

The project will be the theme of the HVP session at HUGO in KL, Malaysia scheduled for 17 March 2015. Those attending HUGO 2105 should try to attend the session. Details of the panel session are currently being finalized.

A working meeting of those involved in the project is scheduled for **Sunday 26 April 2015** at Leiden, Netherlands, as a satellite of *Mutation and Detection 2015*. This Global Haemoglobinopathies Initiative meeting will be by invitation only and for those Nodes and observers directly involved in the project. The details of the meeting, agenda and funding are still being discussed.

**9. Recommendations to the Scientific Advisory Committee**

None

**10. Items for information**

None

**11. Other matters**

None

**12. Next Meetings - all via Calliflower unless otherwise indicated**

- 3 Feb 2015
- 7 Apr 2015
- 2 June 2015

Meeting closed 12:15AM 3 Dec 2014 Melbourne time.