



THE  
**HUMAN VARIOME**  
PROJECT

sharing data · reducing disease  
an NGO Official Partner of UNESCO

# MINUTES

International Confederation of Countries Advisory Council  
23 September, 2014 – 10:00PM Melbourne, Australia time  
Via Calliflower

## ATTENDEES

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

## AGENDA

### 1. Welcome

### 2. Apologies

See list above.

### 3. Welcome new Members

ICCAC welcomes Peter Pearson from Brazil and Centre for Biotechnology of the Eduardo Mondlane University in Mozambique (representative: Denise Brito) to formally become ICCAC Observers.

#### **4. Confirmation of minutes of previous meeting – 5 August, 2014**

The minutes were approved without modification.

#### **5. Horizon 2020 project**

It was agreed at the May council meeting that a multi-country application for an EC Horizon 2020 grant would be developed. Martina developed a preliminary proposal outline for discussion (under PHC-30-2015: Digital representation of health data to improve disease diagnosis and treatment). The grant application deadline is April 2015.

Martina informed the council that she cannot continue to act as the coordinator for this proposal due to her full-time workloads and available time restriction. The council needs to look for a new coordinator urgently. Mireille Claustres and Peter Taschner are suggested candidates. Peter Pearson is willing to assist with the application.

Please see attached Martina's summary for discussion details and Mireille Claustres' bio.

#### **ACTION**

- Martina to contact with Mireille Claustres and Peter Taschner for the coordinator role; she remains as coordinator until her replacement is found

#### **6. Global Haemoglobinopathies Initiative**

Helen reported that the countries involved are working on a description of the project, a work plan and budget. One of the first items will be to plan a meeting for early 2015.

#### **7. Country node updates**

This item was skipped due to time restriction.

#### **8. Recommendations to the Scientific Advisory Committee**

None

#### **9. Items for information**

- 9.1 WHO relationship – there is nothing new to report, we are still waiting for the negotiated agreement to be signed.

#### **10. Other matters**

None

#### **11. Next Meetings - all via Calliflower unless otherwise indicated**

- 18 Nov 2014
- 20 Jan 2015

Meeting closed 11:15PM 23 Sep 2014 Melbourne time.