



sharing data · reducing disease
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MINUTES

International Confederation of Countries Advisory Council
2 June 2015 1200hrs GMT/UTC

MEMBERS

Present

Interim Members

Matthew Lebo	Canada
Domenico Coviello	Italy
Zilfalil bin Alwi	Malaysia
Augusto Rojas-Martinez	Mexico
Johan Rung	Sweden
Peter Taschner	Netherlands

Observers:

Celeste Bento	Portugal
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ICO:

Helen Robinson (HVPI Liaison – WHO)

Apologies

Interim Members

Graham Taylor	Australia
Martina Witsch-Baumgartner (Chair)	Austria
Thomy de Ravel	Belgium
Kathleen Claes	Belgium
Jordan Lerner-Ellis	Canada
Ming Qi	China
Andreas Hadjisavvas	Cyprus
Maria Loizidou	Cyprus
Milan Macek	Czech Republic
Sherifa Ahmed Hamed	Egypt
Mahmoud Raafat Kandil	Egypt
Maurizio Genuardi	Italy
Makia Marafie	Kuwait

Amir Feisal Merican	Malaysia
Luis Figuera-Villanueva	Mexico
Tilak Shrestha	Nepal
Rebati Man Shrestha	Nepal
Marielle E van Gijn	Netherlands
Oyekanmi Nash	Nigeria
Hadiza Mahey Rasheed-Jada	Nigeria
Raj Ramesar	South Africa
Collet Dandara	South Africa
Myungchull Rhee	South Korea
Jong Bhak	South Korea
Angel Carracedo	Spain
Maria Jesus Sobrido	Spain
Richard Rosenquist	Sweden
Andrew Devereau	UK
Sir John Burn	UK
Mike Watson	USA
Bruce Korf	USA
Aída Falcón de Vargas	Venezuela
Chí Dǔng Vĩ	Vietnam

Observers:

Peter Pearson	Brazil
Denise Brito	Mozambique

Invited Attendees:

Rosemary Ekong	Nigeria
Raj Ramesar	South Africa
Vera Lopes	Brazil

1. Welcome

As the meeting was scheduled so closely to ESHG in Glasgow, members present agreed to carry out the formal duties of the scheduled meeting – conforming the minutes – quickly, then to follow with an informal discussion and information exchange. As a result several members decided to leave the call preferring to take up issues in Glasgow. Hence the 2 June 2015 meeting is not a formal of the ICCAC and this record is provided for information only.

2. Brief reports from Council members :-

- Johan Rung from Sweden reported on current efforts to link together the network of Laboratories in Sweden saying that it was progressing well and would be likely to assist strengthening the Swedish Country Node. He would be willing to report on progress at future meetings and any members wanting to know more about what was happening should feel free to contact him directly.
- Domenico Coviello said that he was keen to learn more about what the UK Node was currently doing in terms of their efforts to align and co-ordinate laboratories, databases and focus more on health service delivery across the NHS. As this would be of interest to those attempting to do similar things in Italy. John Burn will be presenting on this topic at ESHG so those interested should try to attend. It was thought that there were likely to be several issues arising out of the this presentation that would be interesting to discuss at future meetings of ICCAC and they could be added to the agenda.
- Falil bin Alwi reported on advances in GG2020 and the preparations for the meeting in Paris at UNESCO on Saturday 13 June, saying that the meeting was scheduled to take advantage of the members present for the BRCA meeting and so was not a full GG2020 meeting so as such, rather it would be more of an information session than a working meeting. He indicated that there was a lot of interest in the project and that current effort were focused on: getting the project membership and structure right; working out the technical requirements for thalasseмии and sickle cell diseases, followed by G6PD; looking for the right partners to work with HVP; and raising funds for a planning meeting. Countries are currently completing their country check lists and this would assist in categorizing countries into groups with similar interests.
- Peter Taschner commented that the Netherlands was currently reviewing how they would handle thalasseμία patients within the public health system and it seemed difficult to raise interest from the potential carrier-status patients to be diagnosed.

3. Other matters

Helen Robinson quickly outlined the attached documents regarding the HVP Country Progress Awards for 2016 and drew attention to the key dates.

4. Next Meetings

- TBA