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Activity Plan January – June 2016

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Last October 2014, the IAHRC International Consortium was created as a coordinated network of clinical centers and basic research labs, to carry out large-scale studies based on common collaboration rules and on common elements, formats and methods for the data and information sharing.

During this first year of life, the results of the first IAHRC studies have been published on prestigious journals; some new studies and initiatives have been launched and many more have been planned for this current year.

The IAHRC Common Data Elements have been defined by the Standardization Workgroups, adopted by the IAHRC Studies carried out so far, and new datasets are going to be added for more specific studies and surveys.

Now, it has become strategic for the Consortium to involve all its members more deeply in all these initiatives, to reinforce our internal collaboration and cohesion as a group and to make our role and contribution clearer towards the ATP1A3 in disease community, as well as towards the scientific and health communities for rare diseases. We would also create new collaborations with all interested research groups, supporting partners and stakeholders.

With these objectives, we have planned many activities to carry out in this first semester 2016; among them the development of the IAHRC-Cloud Service, for the on-line data collection and sharing for the collaborative studies of the Consortium. The service is developed by the IEMEST Research Institute – Italy www.iemest.eu, an IAHRC member Center.

We are also creating the on-line IAHRC Forum, to facilitate the participation to the discussions about the main topics identified by the Standardization Workgroups and the contribution to the related activities. The Forum will be accessible by all the IAHRC members and, upon invitation, also by external researchers, patients and any other stakeholders.

Finally, we have scheduled the annual General Assembly in June, as the highest expression of participation and of collaboration, for the harmonic and positive contribution of all the IAHRC members to the development of the research on AHC and all the ATP1A3 diseases.

If you need further information about the activities and studies of the Consortium, or are interested to join it, or want to propose new kinds of partnership and common initiatives, please, do not hesitate to contact us through our website www.iahcrc.net.

Alexis Arzimanoglou, Mohamad Mikati, Eleni Panagiotakaki, Rosaria Vavassori and all the members of the IAHRC Consortium