



Summary of Activities in 2011 supported by IUIS Funds

IUIS Committee on Primary Immune Deficiencies

Please complete this form and email to: iuis-central-office@medacad.org

2 months prior to the annual council meeting of the IUIS, at the latest April 30th, 2012.

If this summary is not received in time, there will be no consideration of requests for future financial support. If possible, please attach documentation of expenditures.

Please note: the next IUIS council meeting is **Tuesday, May 29, 2012,** in Lima, Peru

Chairperson: **Luigi NOTARANGELO** e-mail: luigi.notarangelo@childrens.harvard.edu

Total amount received (in Euro): **2.418,70**

Total amount spent (in Euro): 2.418.70

Justification of expenditures (in Euro):

An IUIS PID Expert committee was held on May 31st of 2011 in New York City. For this meeting it was defined that the new treasurer of the committee would be Dr. Charlotte Cunningham-Rundles (Mount Sinai School of Medicine, USA) and the new secretary Dr. José Luis Franco (University of Antioquia School of Medicine (Colombia, South America).

The agenda included a revision of the 2009 PID Classification tables and considerations for a new publication in 2011, along with possibilities of dissemination of this information. From this meeting and from additional work following the NY meeting (via email), a manuscript was put together and submitted to the IUIS official journal *Frontiers of Immunology* in November of 2011. The article entitled "**Primary Immunodeficiency Diseases: an update on the classification from the International Union of Immunological Societies Expert Committee for Primary Immunodeficiency**" was published in 2011 (*Front. Immunol*, 2011. 2: 1-26; 10.3389/fimmu.2011.00054). Arrangements were made to create a link on the IUIS web page under the section of committees, and this link allows free download of the article.

Current efforts by several members of the committee on behalf of the entire committee, are now focused on publishing editorial reviews to disseminate this article around the world:

1. Chapel H. **Classification of primary immunodeficiency diseases by the International Union of Immunological Societies (IUIS) Expert Committee on Primary Immunodeficiency 2011.** *Clin Exp Immunol*, 2012. 168(1): 58.

2. Al-Herz W and Notarangelo LD. **Classification of Primary Immunodeficiency Disorders: One-Fits-All Does Not Help Anymore.** *Clin. Immunol*, 2012. To be submitted.

An additional editorial review is being prepared by Jose Franco for the Journal *Allergologia and Immunopathologia*.

A simplified version of the PID tables has been developed as an initiative of Dr. Aziz Bousfiha from Morocco and member of the Committee, and it is intended to provide a practical reference tool for diagnosis to physicians, scientists and patient organizations. Plans are on the way to make them widely available with the help of PID continental organizations and Patient Organizations. Dr Bousfiha, Dr Chapel and Dr Franco attended the 2011 Global Leaders Meeting of the International Patient Organization for Primary Immunodeficiencies in October and Dr Bousfiha presented the tables there. An online and mobile version will be developed by Dr Jose Franco from Colombia to provide full accessibility to them.

The PID Committee was involved in the establishment of the first PID meeting in Peru (ImmunoPeru 2012), and Dr José Franco who is also on the board of the Latin American Society for Immunodeficiencies (www.lasid.org), will participate in the activities of the PID symposium, sponsored in part by the PID committee. Taking into account the suggestions of the Council Meeting of 2010 to promote attendance to these meetings from Africa and Asia, the PID committee elected Dr. Mary-Ellen Conley to become the Education liason. Dr Jose Franco was also elected to represent the committee on the 59th IUIS Council meeting that will take place on the 29 of May of 2012.

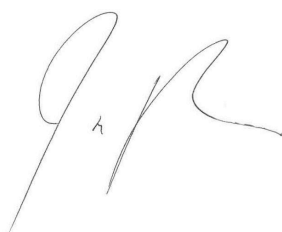
The committee has also been working on the ICD code revision on "Disorders of the Immune System" for the new ICD-11 that will be available for 2015. The revision was submitted in June of 2010, comments were well received and the draft has been available on the web since last year for further work. (<http://apps.who.int/classifications/icd11/browse/f/en>). Dr

Mimi Tang of Australia is the current ICD codes liason for the Committee. Feedback has been provided to Dr. Segolene Ayme, Chairman of the Rare Diseases Advisory Group and most changes were updated on the current version. In addition, Dr Jose Franco was commissioned by the PID committee to follow issues raised by IPOPI's CEO (Johan Prevot) related to the WHO essential medicines list related to the new concentrations of gammaglobulins in the list and ICD code issues that would be addressed by both organizations to try to provide uniform feedback.

The meeting in NYC also served as a discussion forum to plan a PID Satellite meeting during the next International Congress of Immunology to be held in Milan in October of 2013. Dr Isabella Quinti kindly volunteered to become the liason in Italy for the organization of this meeting along with the chair of the PID committee and she has been working out the details and providing feedback to the committee. A scientific committee has been formed to organize the program and they have been in contact with the organizers of ICI 2013 to coordinate this as well.

A new PID Committee meeting is being planed alongside the ICI 2013 Congress in order to reduce costs. The preliminary agenda will include a new revision of the PID classification tables for publication in 2014, continue the process of revision of the ICD codes and ways do continue dissemination of this information, etc, educational activities, guidelines and consensus recommendations from continental societies, etc. To provide broader input into the tasks of the Committee, it has been suggested to invite non-members and Professional Organizations devoted to PID such as the European Society for Immunodeficiencies (www.esid.org), the clinical immunology society (www.clinimmsoc.org), The African Society for Immunodeficiencies (www.asid.org), LASID, and others with additional expertise, to work on specific tasks with the Committee such as Diagnostic Criteria, consensus recommendations, etc.

Funding for these meetings is in progress and Drs Chapel and Cunningham-Rundles have been exploring new possibilities of funding with the industry and coordinated with the European Agency Kenes through Michael Foreman, who already assist ESID.



Date: April 28, 2012 Signature: Jose Franco, Secretary

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