



Summary of Activities in 2012 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 June 21, 2013.

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 **Thursday, August 22, 2013**, in Milan, Italy

Chairperson: **BOBBY GASPAR** e-mail: h.gaspar@ucl.ac.uk

Total amount received (in Euro): **6.081 €**

Total amount spent (in Euro): **6.081 €**

Justification of expenditures (in Euro):

The activities of the Committee in 2012 were centered on the following topics: dissemination of the new 2011 Classification of PID with editorials, development of a simplified version for Clinicians and the ICD-11 Codes revision for the WHO, amongst others. In addition, the Committee worked out an agreement with Kenes, a management agency located in the UK that is providing administrative and logistic support for the Committee.

The 2011 PID Classification

The 2011 PID Classification tables published in 2011 were put together in the article entitled "**Primary Immunodeficiency Diseases: an update on the classification from the International Union of Immunological Societies Expert Committee for Primary Immunodeficiency**" published in the Official Journal of IUIS Frontiers in Immunology. Several members of the Committee worked out on publishing editorial reviews to disseminate this article around the world in 2012:

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, 144: 24-25.

A simplified version of the PID tables was developed as an initiative led by Dr. Aziz Bousfiha from Morocco and some of his coworkers as well as all members of the Committee. This initiative was intended to provide a practical reference tool for diagnosis to physicians, scientists and patient organizations. This article was accepted in the Journal of Clinical Immunology in December of 2012.

3. Bousfiha AA, Jeddane L, Ailal F, Al-Herz W, Conley ME, Cunningham-Rundles C, Etzioni A, Fischer A, Franco JL, Geha RS, Hammarström L, Nonoyama S, Ochs HD, Roifman CM, Seger R, Tang MLK, Puck JM, Chapel H, Notarangelo LD, Casanova JL. **A Phenotypic Approach for IUIS PID Classification and Diagnosis: Guidelines for Clinicians at the Bedside**. J Clin Immunol. DOI 10.1007/s10875-013-9901-6.

Special attention was put to publish the tables in color and the article is available online ahead of print (<http://www.ncbi.nlm.nih.gov/pubmed/23657403>). Plans are on the way to make this article widely available with the help of PID continental organizations such as ESID, LASID, ASID, CIS and APIIEG, and Patient Organizations such as the Jeffrey Modell Foundation and IPOPI, amongst others. A mobile and interactive version of these tables is in the works and funds are being sought to develop this project.

Other Activities

The PID Committee was involved in the establishment of the first PID meeting in Peru (InmunoPeru 2012), and José Franco (Latin American Society for Immunodeficiencies (www.lasid.org), participated in the activities of the PID symposium sponsored in part by the PID Committee. Initiatives to attend these meetings as well as others from Africa and Asia are being promoted by the PID committee through Mary-Ellen Conley, the Education liason. Jose Franco represented the committee on the 59th IUIS Council meeting that took place on May 29, 2012 in Lima, Perú. Funds from the IUIS were provided to support part of the expenses incurred by Dr. Franco to attend the meeting in Lima. Dr. Franco will represent the Committee again in the 60th Council Meeting to be held on the ICI2013 Congress in Milan, Italy on August 22nd of this year.

The Committee unveiled an initiative to invite non-members and Professional Organizations devoted to PID including: The European Society for Immunodeficiencies (www.esid.org), the clinical immunology society (www.clinimmsoc.org), The African Society for Immunodeficiencies (www.asid.org), The Latin American Society for Immunodeficiencies (LASID), Asian Pacific Immunoglobulins in Immunology Expert Group (APIIEG), as well as patient organizations, to work on specific tasks with the Committee such as Diagnostic Criteria, consensus recommendations, etc. The International Patient Organization for Primary Immunodeficiencies –IPOPI- (www.lpopi.org) is organizing the First International Primary Immunodeficiencies Congress (IPIC2013) in Lisbon (Portugal) on November 7 and 8 of 2013. Dr. Franco is currently the Medical Liason of the PID Committee to IPOPI and in 2012 he worked out the endorsement of IUIS of this meeting in the form of Scientific Support. This year, Dr. Franco is working out the endorsement of IUIS in the form of scientific support for the III Meeting of the Latin American Society for Immunodeficiencies (LASID2013). This meeting will take place in Santiago de Chile (Chile) in October 16-18 of 2013.

Work on the ICD-11 Codes

The committee worked throughout 2012 in the ICD code revision on “Disorders of the Immune System” for the new ICD-11 that should be available for 2015. A first revision was submitted in June of 2010 then a second revision was submitted in December of 2012, to Bertrand Bellet and Segolene Ayme of the Rare Diseases Advisory Group (Orphanet). All comments were well received and the draft is available on the web for further work as indicated by them. (<http://apps.who.int/classifications/icd11/browse/f/en>). Dr. Mimi Tang continues to be the ICD codes liason for the Committee. Dr. Franco worked out the 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, however no changes were implemented.

PID Committee Meetings in 2012

A business meeting was held on October the 3rd during the biannual meeting of the European Society for Immunodeficiencies (ESID) in Florence, Italy. The main topics of this meeting were the presentation of the Management Agency Kenes (see below for further information) and the planning of the next biannual meeting of the Committee on Primary Immunodeficiencies (PID) for the year 2013. In addition, it was agreed that several members would leave at the beginning of 2013, and that an election would have to be held early on 2013 to replace them (Chairman and 5 members). The following members left the Committee: Luigi Notarangelo, Chaim Roiffman, Alain Fischer, Helen Chapel and Lennart Hamarstrom. Previously in 2011, another member (Raif Geha) had left the Committee.

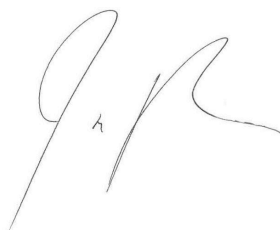
The newly elected members are:

Steven Holland, MD	Head of the Laboratory of Clinical Infectious Diseases, National Institutes of Health, Bethesda, MD (United States)
Bobby Gaspar, MD	GOSHCC Professor of Paediatrics and Immunology. Molecular Immunology Unit. UCL Institute of Child Health, London (England)
Erik Oksenhendler, MD	Service d'immunologie Clinique. CHU Paris-GH St-Louis Lariboisière F.Widal - Hôpital Saint-Louis, Paris (France)
Capucine Picard, MD, PhD	Centre d'étude des déficits immunitaires, Pavillon Kirmisson, Hôpital Necker-Enfants Malades. Laboratoire de Génétique Humaine des Maladies Infectieuses, Université Paris Descartes, Paris (France)
Kathleen E. Sullivan, MD, PhD	Chief, Division of Allergy and Immunology. The Children's Hospital of Philadelphia. University of Pennsylvania, Philadelphia, PA (United States)
Chatila Amine Talal, MD	Denise and David Bunning Professor of Pediatrics. Department of Pediatrics, Harvard Medical School. Division of Immunology, The Boston Children's Hospital, Boston, MA (United States)

In addition, the new Chairman of the Committee is Bobby Gaspar. The rest of the Executive board includes Charlotte Cunningham-Rundles from Mount Sinai School of Medicine (United States) and the secretary José Luis Franco from the University of Antioquia, School of Medicine (Colombia, South America). The web page of the PID Committee was updated last year and currently reflects the composition of the Committee.

At the meeting in NYC plans were established to host a PID Satellite meeting during ICI2013. Dr. Luigi Notarangelo and Dr. José Franco teamed up with Dr. Isabella Quinti, who kindly volunteered to become the liaison in Italy for the organization of this meeting. Unfortunately, due to logistic reasons it was not possible to organize the meeting in Italy.

In 2012, the Committee decided to explore the possibility that a Management Services Agency could provide assistance to the Committee in order to assist on the administrative issues and to provide logistic support for our initiatives. The Agency Kenes has been coordinating the ESID meetings and Drs. Helen Chapel and Charlotte Cunningham-Rundles contacted them in April of 2012. A formal presentation of Kenes was done at the ESID meeting in Florence in October of 2012 and an agreement was reached between the Committee and Kenes by December of 2012. The services provided by them include: a dedicated manager that works with the Committee to provide project management and administrative support. Previously, Dr. Franco has been involved generating additional funding for the Committee with the industry. From now on, the manager will fundraise on behalf of the Committee for its activities and is providing a set of Financial Services as well. Kenes will also assist the Committee on its actions and publication efforts. Funding for this agreement is being provided by sources independent of the IUIS budget as established in the Request for IUIS funds 2013 report. With the aid of Kenes and the assistance of the members of the Committee, Drs. Chapel Franco developed an information pack that will provide the necessary information for all the Organizations that might become interested in closed interactions with the PID Committee (attached).



Date: June 22, 2013 Signature: Jose Franco, Secretary

For further information, please contact the IUIS Central Office or the Treasurer:

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