

Summary of Activities in 2013 supported by IUIS Funds

Primary Immunodeficiency Expert Committee (PID)

Committee Leadership

Bobby Gaspar– Committee Chair
José Luis Franco– Committee Secretary
Charlotte Cunningham-Rundles- Treasurer

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

PLEASE NOTE that you must complete the form “**Summary of Activities in 2013 Supported by IUIS Funds**”. Evidence of expenditures is required.

The summary form must be submitted annually, 2 months prior to the IUIS Council Meeting = **September 30, 2014**
If this summary is not received in time, there will be no consideration of requests for future financial support.

The next IUIS Council Meeting will take place in Nairobi, Kenya, November 30, 2014

Sent to: Bobby Gaspar, PID Expert Committee Chair

h.gaspar@ucl.ac.uk

Total amount received 2013: \$8,000

Total amount spent 2013: \$8.000

Please include:

1. Mission and objectives:

- Provide an up-to-date classification of all primary immunodeficiency diseases (PIDs)
- Assist with the identification, diagnosis and management of patients with these uncommon conditions
- Support diagnostic and therapeutic guidelines developed by national societies and others, to assist healthcare providers
- Promote awareness, diagnosis and treatment of PIDs in all regions of the world
- Produce ad hoc reports on any aspect of PIDs and to assist in the welfare of patients with these conditions

2. Activities:

- Provide up-to-date reports of new primary immunodeficiencies in the form of a classification that is being published biannually in the Journal Frontiers of Immunology since 2011. The most recent classification was published in April of this year (Front. Immunol, 2014 vol. 5 pp. 162) with a recent corrigendum in September. This current report highlights over 230 primary immune deficiencies and provides important definitions for clinical management and standardized research, as well as for patients.
- Revision of national and international guidelines for the diagnosis and or management of immune deficiencies by expert groups on request.
- Assistance with the revision of diagnostic criteria for primary immunodeficiencies with the IUIS Clinical Immunology committee and the European Society for Immune Deficiencies.
- Production of simplified versions of the PID Classification Tables for the general public.
- Assistance to Orphanet and the World Health Organization in the revision of the International Classification of Diseases (ICD) codes for the primary immune deficiencies, version 11, due to be published in 2015.
- Assurance of continued inclusion of therapeutic immunoglobulin in the World Health Organization Essential Medicines Lists.
- To encourage, with the International Patient Organisation for Primary Immunodeficiencies (IPOP), the implementation of the recommendations from the IUIS PID position paper on the Safety and Availability of Immunoglobulin (1999) including: the avoidance of blood donation by individuals who have received blood or blood products in the past; recording of all batch numbers for tracing in the event of any pathogen transmission; to attempt (with the patient organizations) to obtain ante-mortem permission for post-mortem examination in all patients with primary immune deficiencies in countries in which post-mortem examinations are permitted. Advice on the routine immunisations needed for patients with primary immune deficiencies.

3. Results:

- **Election of new members for replacement of those that stepped down and elections for the new executive committee.**
- New members:
- **Bobby Gaspar.** GOSHCC, Professor of Paediatrics and Immunology, Molecular Immunology Unit, UCL Institute of Child Health, 30 Guildford Street, London, WC1N 1EH, UK
- **Capucine Piccard.** Laboratoire de Genetique, Humaine des Maladies Infectieuses, Universite Paris Descartes, 98 rue Didot, Batiment Leriche, Porte 9, 75014, Paris, France
- **Talal Chatila.** Professor of Pediatrics, Department of Pediatrics, Harvard Medical School, Harvard University, Karp Family Building, Room 10-214, 1 Blackfan Street, 2115 Boston, Massachusetts, USA
- **Christoph Klein.** Medical Director. Department of Pediatrics, University Children's Hospital Dr. von Haunersches Kinderspital, Lindwurmstrasse 4, D-80337 Munich, Germany
- **Erik Oksenhendler.** Service d'immunologie Clinique, CHU Paris – GH St Louis Lariboisiere F Widal, 1 Avenue Claude Vellefaux, CEDEX 10, 75475, Paris, France

- **Kathleen Sullivan.** Chief, Division of Allergy and Immunology, University of Pennsylvania, 34th St and Civic Centre Boulevard, Philadelphia, USA
- The new executive committee was defined as follows: Bobby Gaspar (Chairman), Jose Franco (secretary), Charlotte-Cunningham-Rundles (treasurer)
- **Committee meetings:** Expert Committee in Primary Immunodeficiency biannual meeting, April 2013, New York (USA). Workshop to establish the new classification of Primary Immunodeficiencies for the year 2014.
- **Administrative:** Biannual contract with Kenes Association for the Management of the Committee for the next 2 years. Aimed at: providing assistance for committee meetings, development of a plan for funding for the committee's activities, budget management.
- **Information pack:** document to socialize the committee and its activities in the scientific and medical community
- **Publication:** Al-Herz W, Bousfiha A, Casanova JL, Chatila T, Conley ME, Cunningham-Rundles C, Etzioni A, Fischer A, Franco JL, Gaspar HB, Holland SM, Klein C, Nonoyama S, Ochs HD, Oksenhendler E, Picard C, Puck JM, Sullivan K, Tang MLK. Primary immunodeficiency diseases: an update on the classification from the international union of immunological societies expert committee for primary immunodeficiency. *Front. Immun.* (2014) vol. 5 pp. 162.
- **Publication:** 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*, 2013 vol. 33 (6) pp. 1078-87.
- **Activities with other committees:** Continued assistance to Orphanet and the World Health Organization in the revision of the International Classification of Diseases (ICD) codes for the primary immune deficiencies.

4. Financials:

For the year 2013 the Expert Committee requested 8.000 USD to cover the following activities:

- 1.000 USD. Financial assistance to cover expenses of one member to attend the IUIS 61th Council Meeting.
- 3.000 USD. To support assistance from members of PID committees to continental meetings on initiatives that include diagnostic criteria and template guidelines and other issues related to education in PID.
- 2.000 USD. Continue funding of the PID Committee for a 1-day executive meeting in early 2014 to continue the work on the ICD codes, discuss the initiatives for templates, diagnostic criteria, etc and administrative issues.
- 1.000 USD. Publication of editorials to highlight the new 2013 revised PID Classification.
- 1.000 USD. To work on the simplified version of the 2013 Classification Tables.
The money provided by the IUIS Council for these activities was 6.111.00 € (16-07-2013), and was used to cover the following activities:
- 1.000 €. Reimbursement of Financial assistance to cover expenses of Jose Luis Franco, the Secretary of the Committee to attend the Council Meetings of the IUIS in Milan, Italy.
- 1.130.50 €. Reimbursement to Dr Azizz Boushifa for the publication of the article titled: **Approach for IUIS PID Classification and Diagnosis: Guidelines for Clinicians at the Bedside.** *J Clin Immunol*, 2013 vol. 33 (6) pp. 1078-87. This article was developed to include a set of colored

tables for a simplified version of the Classification of primary immunodeficiency diseases of the 2011 classification.

- The rest of the money was used to cover reimbursements for some expenses for the Biannual Meeting of the Committee held in April of 2013, administrative issues and bank charges.

5. Perspectives for next year:

- Promote the participation of members of the Committee in continental meetings around the globe on initiatives related to education in PID.
- Continue the work to update the Classification of PID by the Committee. The pace at which inborn errors of immunity are being described and characterized on a yearly basis requires at least a biannual update from our part.
- Develop working parties for the update of the templates for national guidelines for diagnosis and treatment.
- Develop new online tools for diagnosis and discuss the possibility of including later therapeutic information related to the treatment of PID highlighting current approved therapies as well as potential new treatments for these diseases.



Date of Request: October 30, 2014

Signature: _____