

<p>Mission:</p> <ul style="list-style-type: none"> <li>• Provide an up-to-date classification of all primary immunodeficiency diseases (PID)</li> <li>• Assist with the identification, diagnosis and management of patients with these uncommon conditions</li> <li>• Support diagnostic and therapeutic guidelines developed by national societies and others, to assist healthcare providers</li> <li>• Promote awareness, diagnosis and treatment of PIDs in all regions of the world</li> <li>• Produce ad-hoc reports on any aspect of PIDs and to assist in the welfare of patients with these conditions</li> </ul>	<p>Objectives:</p> <ul style="list-style-type: none"> <li>• Provide and publish up to date reports of new primary immunodeficiencies.</li> <li>• Provide and publish simplified versions of primary immunodeficiencies classification tables for the general public.</li> <li>• Promote the participation of members of the Committee in continental meetings around the globe on initiatives related to education in PID.</li> <li>• Continue the work to update the Classification of PID by the Committee. The pace of which inborn errors of immunity are being described and characterized on a yearly basis requires a more frequent update from our part.</li> <li>• Develop working parties for the update of the templates for national and international guidelines.</li> <li>• Develop a new tool for a therapeutic approach to the treatment of PID highlighting current approved therapies as well as potential new treatments for these diseases.</li> <li>• Develop an accurate online database of primary immunodeficiencies that can be updated in real time and includes key information regarding investigation and management of these rare conditions, and can be accessed by clinicians through a search platform that assists with diagnosis and management, supporting excellence in clinical care of patients with these rare conditions.</li> </ul>
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	Name	Country	Responsibilities	Term	Photo	cv
Committee:	Primary Immunodeficiency					
Chair:	Bobby Gaspar	UK	<ul style="list-style-type: none"> <li>• Responsible for coordinating the completion and revision of the classification of Primary Immunodeficiency Diseases, typically every two years.</li> <li>• Initiates and leads the Committee's annual report, budget and financial statement to the IUIS Council.</li> <li>• Responsible for coordinating revision of the ICD codes that pertain to Primary Immunodeficiency Diseases. In this task, the Chair will be assisted by the Secretary and by all Committee members.</li> <li>• The Chair shall represent the Committee with other scientific organizations and patient advocacy groups.</li> <li>• The Chair shall be responsible for calling and chairing all meetings of the Committee, assigns work to the Committee members, sets the agenda and runs the meetings, and ensures distribution of meeting minutes.</li> <li>• The Chair shall serve as the official spokesperson of the Committee at the IUIS Council meeting. The Chair may delegate to be represented by the Secretary or by another Committee member, upon approval by the majority of the Committee.</li> <li>• Provides leadership and direction for Committee activities.</li> <li>• Sets tone for the Committee work.</li> <li>• Oversees the logistics of Committee's operations.</li> <li>• Builds an effective team and inspires the members to actively participate.</li> <li>• Ensures that members have the information needed to do their jobs.</li> <li>• Works to ensure succession planning of the members and the chair.</li> <li>• Initiates and leads the Committee's annual evaluation.</li> <li>• Performs other duties as determined by the IUIS Council</li> </ul>	Please see accompanying spreadsheet on members for 2015		
Secretary:	José Luis Franco	Colombia	<ul style="list-style-type: none"> <li>• Works with the Treasurer to generate income for the PID-EC.</li> <li>• Maintains accurate records of the work of the PID-EC.</li> <li>• Reports to the IUIS Council yearly as required, ahead of the Council meeting.</li> <li>• Liaises sub-committees of the IUIS PID-EC with other IUIS Committees.</li> <li>• Liaises with IPOPI and other organizations.</li> <li>• Ensures that activities of members are carried out, implemented and concluded in a timely manner.</li> <li>• Oversees the arrangements of committee meetings and manages the minute taking and record keeping of the meetings and ensure their distribution in a timely manner.</li> <li>• Generate the annual report of activities for the IUIS annual Council meeting and with the Treasurer provide feedback to the financial report in a timely manner.</li> <li>• Ensures that the Chair has the information needed to make decisions about the PID-EC's future strategy.</li> <li>• Keeps accurate records to ensure succession planning of the Secretary role.</li> <li>• Provides information for the Committee's annual evaluation.</li> </ul>			
Co-Chair	Kathleen Sullivan	USA	<ul style="list-style-type: none"> <li>• Supports the activities of the chair to initiate the Committee's annual report, budget and financial statement to the IUIS Council.</li> <li>• Assist the chair with coordinating revision of the ICD codes that pertain to Primary Immunodeficiency Diseases.</li> <li>• The Co-Chair shall represent the Committee with other scientific organizations and patient advocacy groups in case the Chair is absent.</li> <li>• The Co-Chair shall be responsible for assisting the Chair in all meetings of the Committee, as well as to assign work to the Committee members, sets the agenda and runs the meetings, and ensures distribution of meeting minutes.</li> <li>• Ensure that all the members are attending the meetings.</li> <li>• The Co-Chair shall represent the Chair and serve as an official replacement spokesperson of the Committee at the IUIS Council meeting.</li> <li>• Provide support and direction for Committee activities as the Chair is absent.</li> <li>• Oversees the communication of Committee's operations.</li> <li>• Participate in the Chair's task to build an effective team and inspire the members to actively participate in any activities of the committee.</li> <li>• Ensures the supervision of members' tasks and provide them with the information needed to do their jobs.</li> <li>• Works to ensure succession planning of the members and the chair.</li> <li>• Performs other duties as determined by the PID-EC Chair or the IUIS Council.</li> </ul>			
Treasurer	Charlotte Cunningham-Rundles	USA	<ul style="list-style-type: none"> <li>• Works with the Secretary to generate income for the PID-EC.</li> <li>• Oversees the financial impact of the Committee's activities.</li> <li>• Sends requests for funds for the following year with Secretary's annual report to IUIS.</li> <li>• Claims financial allocation from IUIS in a timely manner.</li> <li>• Ensures that the Chair has the information needed to make financial decisions about the PID-EC's future strategy.</li> <li>• Keeps accurate records to ensure succession planning of the Treasurer role.</li> <li>• Provides financial information for the Committee's annual evaluation.</li> <li>• Performs other duties as determined by the PID-EC Chair or IUIS Council.</li> </ul>			
Members:	Amos Elzoni	Israel	<ul style="list-style-type: none"> <li>• Makes a serious commitment to participate actively in Committee work. He/she must commit the time, energy and creativity needed to assist the Committee in realising its goals and objectives.</li> <li>• Regularly participates in Committee conference calls and attends i meetings; if s/he fails to attend two meetings consecutively, s/he will be deemed to have resigned</li> <li>• Stays informed about Committee matters; is well prepared for meetings and reviews and comments on minutes and reports.</li> <li>• Actively participates in planning and implementing short and long-range goals and projects of the Committee.</li> <li>• Leads a particular project at the request of the committee</li> <li>• Is responsible for responding to communications from the Executive Committee in a timely manner and accepting and performing tasks assigned to him/her by the Chair.</li> <li>• Promotes the IUIS and the PID-EC to colleagues and other organisations. Serves as an advocate of the IUIS.</li> <li>• Takes a genuine interest in other Committee members and builds a collegial working relationship that contributes to consensus.</li> <li>• Brings concerns to the Committee's table if they could negatively impact any work of the IUIS and/or the IUIS PID-EC</li> </ul>			
Members:	Aziz Boussifa	Morocco	As above			
Members:	Capucine Piccard	France	As above			
Members:	Iatal Chatila	USA	As above			
Members:	Christoph Klein	Germany	As above			
Members:	Erik Oksenhendler	France	As above			
Members:	Hans Ochs	USA	As above			
Members:	Jean-Laurent Casanova	USA	As above			
Members:	Jennifer Puck	USA	As above			
Members:	Mimi Tang	Australia	As above			
Members:	Shigeaki Nonoyama	Japan	As above			
Members:	Steven Holland	USA	As above			
Members:	Waleed Al Herz	Kuwait	As above			
Members:	Yanick Crow	UK	As above			
Members:	Stuart Tangye	Australia	As above			
Members:	Troy Torgerson	USA	As above			
Other stakeholders:						

		research	scientific / educational products	teaching/training courses	conferences	conferences		publishing	networking / community activities	public awareness	external relations
Activities			Educational Product: Primary Immunodeficiency Disease: an update on the classification from the International Union of Immunological Societies Expert Committee for Primary Immunodeficiency. Front. Immunol. 2014 vol. 5 (162) pp. 1-33. Corrigendum: Front		funding of the PID Committee for a 1-day executive meeting in 2014 to continue the work on the ICD codes, discuss the initiatives for templates, diagnostic criteria, etc and administrative issues	To provide financial assistance of some members of the Committee to the next PID-EC business meeting to be held in Prague, Czech Republic on October 28 of 2014 alongside the 16th Biennial Meeting of the European Society for Immunodeficiencies (ESID)		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.	Publication of editorials to highlight the new 2013 revised PID Classification.	To work on the simplified version of the 2013 Classification Tables.	Kenes Management Fee
Budget (in USD)	*IUIS funding				2000	1000		3000	1000	1000	19435,75
	Non-IUIS funding				5365,7				130,5		
	Non-IUIS funding details				Coverage of the rest of the meeting expenses						
	Resources										
	Funding challenges										
	Type of expenses				Compensation to Committee Members/Food &	Flight			Cost of publishing - the report highlights over 230 primary immune	Publishing Cost	
	Expenses										
	Cost Management Challenges										
	Financial Objectives										
Communication	Target Audience		Medical and Research Community							Medical and Research Community	
	Media used (mail, email, event, newsletter)							Journal Frontiers of Immunology		Journal of Clinical Immunology	
Partners / Agents											

Expenditures and corresponding receipts for the funds received from the IUIS.

		research	scientific / educational products	scientific / educational products	teaching/training courses	conferences	conferences	conferences	publishing	networking / community activities	public awareness	external relations
Activities				To support and help develop an initiative for advocacy and education in PID in one region of the world		To continue the funding of the next biannual meeting of the Committee to update the Classification of PID and to work on future educational projects in March 2015 in London	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 Colombia	Reimbursement of Financial assistance to cover expenses of Amos Ezioni, member of the Committee to attend the Council Meetings of the IUIS in Colombia	Publication of an updated version of the 2013 Classification tables. Publication of an updated version of the Phenotypic Approach for IUIS PID Classification and Diagnosis: Guidelines for Clinicians at the Bedside		Formation and Printing of Brochure for Awareness and sponsorship opportunities	Kenes Management Fee
Budget (in USD)	*IUIS funding			1000		4000	1000	1000	1000			
	Non-IUIS funding					20580		1260			750	19.435,75
	Non-IUIS funding details			Not yet done for 2015			Not yet done for 2015		Articles accepted		Not yet done for 2015	
	Resources											
	Funding challenges											
	Type of expenses							Flight				
	Expenses											
	Cost Management Challenges											
	Financial Objectives											
Communication	Target Audience			Regional Meeting					Medical and Research Community		Sponsorship Companies	
	Media used (mail, email, event, newsletter)								Journal of Clinical Immunology		mail at IUIS event and other relevant congresses	
Partners / Agents												

nditures and corresponding receipts for the funds received from the IUIS.

		research	scientific / educational products	scientific / educational products	teaching/training courses	Conference	Conference	Conference	publishing	networking / community activities	public awareness	external relations
Activities			Develop an accurate online database of primary immunodeficiencies that can be updated in real time and includes key information regarding investigation and management of these rare conditions, and can be accessed by clinicians through a search platform would greatly assist with diagnosis and management, supporting excellence in clinical care of patients	To work on simplified versions of the 2015 Classification Tables. Printed cards of the tables to distribute in meetings		Funding of the PID Committee for a 1-day executive meeting in 2016 to continue the work on the ICD codes, discuss the initiatives for templates, diagnostic criteria, etc and administrative issues	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.	Financial assistance to cover expenses of one member to attend the IUIS Council Meeting.	Publication of editorials to highlight the new 2015 revised PID Classification.			Kenes Management Fee
Budget (in USD)	*IUIS funding		15000			5000	1500	500	1000			
	Non-IUIS funding		5000	1000					1000			19435.75
	Non-IUIS funding details		Will be applying for sponsorship opportunities	Costs for publishing								
	Resources					meeting costs are lower due to meeting at ESID						
	Funding challenges		Large initial cost for setup and development/programm									
	Type of expenses		See attached project proposal									
	Expenses											
	Cost Management Challenges						Increasing costs of flights versus value - brochures help with awareness		Publishing costs are expensive but gain exposure of the tables			
	Financial Objectives											
Communication	Target Audience		See attached project proposal	Medical and Research Community								
	Media used (mail, email, event, newsletter)								Editorials in Scientific Journals			
Partners / Agents												

\*IUIS funding - Please include an itemized list of expenditures and corresponding receipts for the funds received from the IUIS.