

## IPOPI 11<sup>th</sup> PID Forum

### Access to paediatric medicines: the case of PIDs Towards the revision of Paediatric Regulation

Wednesday 27 June 2018 – 16:30-18:30

Room JAN 2Q2, European Parliament Brussels

16:30	Welcome by <b>Jose Drabwell</b> , IPOPI
16:35	Welcome video by <b>Mr Jose Inacio Faria MEP</b> (EPP, Portugal)
16:40	Introduction by <b>Mr Tomáš Zdechovský MEP</b> (EPP, Czech Republic)
16:45	Setting up the scene, <b>Martine Pergent</b> , IPOPI
	<b>Paediatric Medicines Development Process</b>
16:55	<ul style="list-style-type: none"> <li>• <b>Industry perspective</b> <ul style="list-style-type: none"> <li>- Clinical trials for therapies for children with PIDs – <b>Dominika Misztela</b>, PPTA</li> </ul> </li> </ul>
17:05	<ul style="list-style-type: none"> <li>• <b>Researchers perspective</b> <ul style="list-style-type: none"> <li>- What it means to perform bone marrow transplantation in children? – <b>Prof Isabelle Meyts</b>, ESID President elect</li> </ul> </li> </ul>
17:15	<ul style="list-style-type: none"> <li>• <b>Researchers perspective</b> <ul style="list-style-type: none"> <li>- Research projects to develop new gene therapies for children with SCID – <b>Prof Frank Staal</b>, RECOMB coordinator</li> </ul> </li> </ul>
17:25	<ul style="list-style-type: none"> <li>• <b>Patients perspective</b> <ul style="list-style-type: none"> <li>- Representing patients at Enpr-EMA – <b>Jose Drabwell</b>, IPOPI</li> </ul> </li> </ul>
17:35	<ul style="list-style-type: none"> <li>• <b>Patients perspective</b> <ul style="list-style-type: none"> <li>- The need for a holistic approach when treating children with PIDs: <ul style="list-style-type: none"> <li>- <b>Ellen Desmet</b>, mother of a patient,</li> <li>- <b>Edith Klapwijk</b>, mother of three patients</li> <li>- <b>Jonas Bukowski</b>, patient</li> </ul> </li> </ul> </li> </ul>
17:55	Discussion
18:20	Conclusions by <b>Dr Gentile MEP</b> (S&D, Italy)

