

## ESPE Rare Disease Advisory Group Remit

Committee Composition	
<b>Members</b>	<ol style="list-style-type: none"> <li>1. Chair</li> <li>2. Deputy Chair</li> <li>3. Endo-ERN representative</li> <li>4. ERN-BOND representative</li> <li>5. Non-clinical scientist</li> <li>6. Representative outside Europe</li> <li>7. ESPE Secretary General (ex officio)</li> <li>8. ESPE Corporate Relations Manager (ex officio)</li> <li>9. ESPE Senior Operating Officer (ex officio)</li> </ol>
<b>Co-opted members</b>	<ol style="list-style-type: none"> <li>1. ESE representative</li> </ol>
<b>Other considerations</b>	<ul style="list-style-type: none"> <li>• All members should have experience of cross-border collaboration in the field of any rare disease.</li> <li>• All members should be members of ESPE; co-opted members do not need to be ESPE members</li> <li>• Only RDAG members should attend the meetings; no representatives should attend unless expressly agreed by the Chair.</li> </ul>
<b>Quorum</b>	5 members, including Chair or Deputy Chair
<b>Duration of Service</b>	2 years
<b>Reporting</b>	The RDAG shall report to the ESPE Council
<b>Meetings</b>	At least 4 meetings per year. There will be at least one face to face meeting and it will take place at the Annual Meeting
<b>Minutes</b>	Bioscientifica
<b>Administrative Support</b>	<ul style="list-style-type: none"> <li>• Bioscientifica</li> </ul>
<b>Remit</b>	<ul style="list-style-type: none"> <li>• Review the current activities of ESPE (committee by committee) in the field of rare diseases and identify gaps and overlaps between ESPE committees and with other organisations involved in the field of rare diseases</li> <li>• Over the first year, provide recommendations to ESPE Council on following aspects:- <ul style="list-style-type: none"> <li>- fostering collaboration with all ERNs including Endo-ERN and ERN-BOND, focussing on opportunities for knowledge exchange in Europe as well as beyond Europe and which would include activities such as webinars, guideline development, research</li> <li>- the role and remit of ESPE representatives in ERNs and other rare disease organisations</li> <li>- collaboration with international rare disease patient organisations</li> <li>- improving awareness and engagement of researchers and clinicians with rare-disease registries. Specifically, the RDAG should advise how ESPE should act as a stakeholder in the EuRECa project.</li> <li>- promoting rare disease research through its existing activities</li> <li>- acting as an advocate for rare diseases by raising public awareness of rare-diseases through collaboration with European institutions and other relevant national and international organisations</li> <li>- engaging with industry that have a focus on rare diseases</li> <li>- engaging with other professional scientific societies esp ESE</li> </ul> </li> <li>• Over the second year, assess how ESPE has progressed with the recommendations</li> <li>• Advise Council on its long-term strategy after 2 years for maintain a focus on rare diseases</li> </ul>
<b>Additional notes</b>	<ul style="list-style-type: none"> <li>• All RDAG members should make every effort to attend all meetings.</li> <li>• Any member who attends less than 50% of the scheduled meetings in any given year will be asked to step down, other than in extenuating circumstances (e.g. maternity/paternity leave, illness etc.).</li> <li>• All papers and minutes must be treated in strictest confidence.</li> </ul>

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|  | <ul style="list-style-type: none"><li>• All members must act in the best interest of the Society.</li><li>• Any passwords and logins provided to members to enable their roles should not be shared with anyone.</li><li>• Any potential conflicts of interest should be declared at the start of the meeting or as they arise, and the member concerned should take no part in the discussion.</li><li>• All members can serve a second consecutive term of office or extend their term for one year if it is decided that the RDAG exists for longer beyond the two years.</li><li>• Members may be asked to take ownership of specific projects being managed by the RDAG.</li><li>• Co-opted members do not have voting rights</li></ul> |
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