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## Orphanet Network Management Board members

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February 2025

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### Members

| Orphanet Network coordinator              |
|-------------------------------------------|
| <b>France</b> Inserm,<br>US14 Ana<br>Rath |

| Orphanet National Teams coordinators                                                               |
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| <b>Austria</b><br>Medizinische Universität Wien<br>Till Voigtlander                                |
| <b>Belgium</b><br>Sciensano<br>Annabelle Calomme                                                   |
| <b>Bulgaria</b><br>Bulgarian association for Promotion and Education and Science<br>Rumen Stefanov |
| <b>Switzerland</b><br>Geneva University Hospital<br>Loredana D'Amato Sizonenko                     |
| <b>Czech Republic</b><br>Charles University Prague<br>Milan Macek                                  |
| <b>Georgia</b><br>GeRaD<br>Oleg Kvividze                                                           |
| <b>Germany</b><br>Bfarm<br>Carina Thomas                                                           |

| Orphanet National Teams coordinators |                                                                                                             |
|--------------------------------------|-------------------------------------------------------------------------------------------------------------|
| <b>Estonia</b>                       | University of Tartu<br>Vallo Tillmann                                                                       |
| <b>Spain</b>                         | CIBERER<br>Francesc Palau                                                                                   |
| <b>Finland</b>                       | THL<br>Helena Kääriäinen                                                                                    |
| <b>France</b>                        | Inserm US14<br>Ana Rath                                                                                     |
| <b>Greece</b>                        | National Agency for Quality Assurance in Health (ODIPY S.A.)<br>Eleftherios<br>Thireos                      |
| <b>Iceland</b>                       | Landspítali<br>Ingolfur Einnarson                                                                           |
| <b>Japan</b>                         | Translational Research Center for Medical Innovation<br>Atsuhiko Kawamoto                                   |
| <b>Ireland</b>                       | National Centre for Medical genetics<br><b>TBD</b>                                                          |
| <b>Israel</b>                        | Chaim Sheba Medical Center<br>Annick Raas-Rotshild                                                          |
| <b>Italy</b>                         | The Bambin Gesù Children's Hospital<br>Bruno Dallapiccola                                                   |
| <b>Kazakhstan</b>                    | Scientific Centre of Obstetric, Gynecology and perinatology<br>Gulnara Salavatovna Svyatova                 |
| <b>Latvia</b>                        | Children's University Hospital Coordination Center of Rare Diseases<br>Madara Auzenbaha                     |
| <b>Lithuania</b>                     | Center for Medical genetics-Vilnius University Hospital<br>Birute Tumiene                                   |
| <b>Luxembourg</b>                    | Ministry of Health<br>Silvana Masi                                                                          |
| <b>North Macedonia</b>               | Research Centre for Genetic Engineering and Biotechnology "Georgi D.Efremov"<br>Dijana Plaseska-Karanfilska |

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| <p><b>Netherlands</b><br/>NFU/Radboudumc<br/>Wendy van Zelst-Stam</p>                                                                                                |
| <p><b>Norway</b><br/>Oslo University Hospital Trust<br/>Stein Are Aksnes</p>                                                                                         |
| <p><b>Poland</b><br/>Instytut Pomnick Centrum Zdrowia Driecka<br/>Krystyna Chrzanowska</p>                                                                           |
| <p><b>Portugal</b><br/>DGS<br/>Carla Pereira</p>                                                                                                                     |
| <p><b>Romania</b><br/>Universitatea de Medicina si Farmacie Iasi<br/>Cristina Rusu</p>                                                                               |
| <p><b>!! Russia -Temporary Suspension</b><br/>Federal State Budgetary scientific Institution Research Centre for Medical Genetics<br/>Sergey Kutsev</p>              |
| <p><b>Serbia</b><br/>Institute of Molecular Genetics and Genetic Engineering- Belgrade University<br/>Maja Stojiljkovic</p>                                          |
| <p><b>Sweden</b><br/>Karolinska Institutet<br/>Rula Zain</p>                                                                                                         |
| <p><b>Slovenia</b><br/>University Medical Center Ljubljana<br/>Luca Lovrecic</p>                                                                                     |
| <p><b>Turkey</b><br/>Institute for Public Health<br/>Ugur Ozbek; Ilham Satman and Onur Burak Dursun-General Directorate of Healthcare System, Ministry of Health</p> |
| <p><b>Orphanet contact points</b></p>                                                                                                                                |
| <p><b>Armenia</b><br/>Center of Medical Genetics and Primary Health Care of Armenia<br/>Tamara Sarkisan</p>                                                          |
| <p><b>Chyprus</b><br/>Ministry of Health<br/>Marios Antoniadis</p>                                                                                                   |
| <p><b>Malta</b><br/>Ministry of Health<br/>Neville Calleja</p>                                                                                                       |
| <p><b>Slovakia</b><br/>Gabriela Hrková</p>                                                                                                                           |
| <p><b>Morocco</b><br/>Institut National D'Hygiène<br/>Abdelaziz Sefiani</p>                                                                                          |

**Tunisia**

Farhat HACHED University Hospital  
Dorra H'mida-Ben Brahim