



ERN-Skin Board Meeting

Hôpital Necker Enfants Malades - 149 rue de Sèvres - 75015 PARIS, France

October 3

Registration - Amphithéâtre Robert Debré Lobby

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| 08:30 | Registration & Welcome Coffee |
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SPOT App test - Amphithéâtre Robert Debré

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| 09:00 | SPOT app test | Amphithéâtre Robert Debré |
| 10:30 | Break | Amphithéâtre Robert Debré |

Thematic group meetings - Parallel sessions

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| 11:00 | Thematic group meetings + Orphanet | |
| | Epidermolysis bullosa | Amphithéâtre Robert Debré |
| | Cutaneous mosaic disorders | Kirmisson |
| | Hidradenitis suppurativa | Imagine 221 B |
| 13:00 | Lunch | Amphithéâtre Robert Debré |
| 14:00 | Thematic group meetings + Orphanet | |
| | Severe cutaneous drug reactions | Kirmisson |
| | Ectodermal dysplasias | Amphithéâtre Robert Debré |
| | Mendelian causes of connective tissue disorders | Imagine 221 B |
| 16:00 | Break | Amphithéâtre Robert Debré |
| 16:30 | Thematic group meetings + Orphanet | |
| | Autoimmune bullous diseases | Kirmisson |
| | Ichthyosis & palmoplantar keratoderma | Salle de Staff |
| | Cutaneous diseases related to DNA repair disorders | Imagine 221 B |

Executive committee meeting – Salle de Staff

This meeting is open to the ERN-Skin executive committee members

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| 18:30 | Executive committee meeting | Salle de Staff |
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October 4

Registration - Amphithéâtre Robert Debré Lobby

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| 08:30 | Registration & Welcome Coffee Posters (achievement of thematic and transversal groups + ePAG) |
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ERN-Skin at a glance – Plenary session - Amphithéâtre Robert Debré

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| 09:00 | Welcoming – Christine BODEMER, Hôpital Necker Enfants Malades, Paris, France ERN-Skin at a glance & 2019-2022 events |
| 09:15 | Registry – Johann BAUER, EB Haus, Salzburg, Austria - Catherine CHAMPSEIX, Hôpital Necker Enfants Malades, Paris, France |
| 09:35 | European Joint Programme on Rare Diseases – Daria JULKOWSKA, Inserm |
| 10:00 | Orpha codes – Houda ALI, Orphanet |
| 10:20 | Discussion |

Skin ePAG – Plenary session - Amphithéâtre Robert Debré

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| 10:30 | e-PAG |
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New classifications and guidelines – Plenary session - Amphithéâtre Robert Debré

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| 11:00 | New classification of epidermolysis bullosa and skin fragility disorders - Cristina HAS, Universitätsklinikum Freiburg, Germany |
| 11:20 | New classification of ectodermal dysplasia - Holm SCHNEIDER, Universitätsklinikum Erlangen, Germany |
| 11:40 | Mosaic abnormalities of the skin: review and guidelines from the European Reference Network for Rare Skin Diseases – Veronika KINSLER, Great Ormond Street Hospital for Children NHS Foundation Trust, United Kingdom |

Lunch - Amphithéâtre Robert Debré

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| 12:00 | Lunch + Posters (achievement of thematic and transversal groups + ePAG) |
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Training course – Plenary session – Amphithéâtre Robert Debré

| Vascularisation & Dermatology | |
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| Interventional radiology | |
| 13:00 | Regulation of dermis vascularisation by growth factors and microenvironment - Laurent MULLER - CIRB - CNRS/UMR7241 - INSERM U1050 Collège de France |
| 13:20 | The benefit from a multidisciplinary approach (clinical situations) Experience from an Italian ERN-Skin healthcare provider - Massimo ROLLO, Ospedale Pediatrico Bambino Gesù, Rome, Italy |
| 13:40 | The benefit from a multidisciplinary approach (clinical situations) Experience from a French ERN-Skin healthcare provider - Grégoire BOULOUIS, Interventional Radiologist, Hôpital Necker Enfants Malades, Paris, France |
| 14:00 | Round Table & Discussion |
| Ophthalmology & Dermatology | |
| ERN-Skin/ERN-Eye joined session | |
| 14:20 | Eye and skin: overview of anatomy and pathophysiological pathways - Daniel BÖHRINGER, Universitätsklinikum Freiburg, Germany |
| 14:40 | Innovation in ocular surface impairment associated with skin diseases - Dominique BREMOND-GIGNAC, Hôpital Necker Enfants Malades, Paris, France |
| 15:00 | Ocular surface involvements in acquired and congenital skin blistering diseases: semiology and management - Eric GABISON, Fondation Ophtalmologique Adolphe de Rothschild |
| 15:20 | Round Table & Discussion |
| Oral medicine & Dermatology | |
| 15:40 | Oral manifestations and management of children with rare skin diseases - Bothild KVERNELAND, Hôpital Necker Enfants Malades, Paris, France |
| 16:00 | Oral manifestations and management of autoimmune blistering diseases and SJS-TEN spectrum - Jane SETTERFIELD, Guy's and St Thomas' NHS Foundation Trust, United Kingdom |
| 16:20 | Round Table & Discussion |
| 16:45 | End of the meeting |