



AGENDA  
STRATEGIC ADVISORY GROUP MEETINGS | JAN/FEB 2022  
REGISTRATION LINK

VIRTUAL | FEBRUARY 15, 2022  
19.00 – 20.00 CET

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**RARE DISEASES**

Chairs: Risto Lapatto & Liesbeth Siderius

- 1. Welcome and approval of the agenda**  
Risto Lapatto
- 2. Approval of the Minutes of the EAP Spring Meeting**  
Liesbeth Siderius
- 3. “Dad, can you create a light that turns on when my brain switches off?”**  
Tim Buckinx, Epihunter ([www.epihunter.com](http://www.epihunter.com))
- 4. UEMS Multidisciplinary joint committee on rare and undiagnosed diseases**  
Risto Lapatto
- 5. News from the European Reference Network’s (ERN’s)**  
Risto Lapatto
  - Final approval of new ERN members
  - ERN Expert platform on newborn screening: Towards European Recommended Uniform Screening Panel (ERUSP)
- 6. Proceedings on digital child health : the HL 7 community**  
Liesbeth Siderius
  - International Patient Summary
  - Child Health Scheme (UK:  
<https://theprsb.org/standards/healthychildrecordstandard/>, Australia  
<http://build.fhir.org/ig/hl7au/au-fhir-childhealth/>)
- 7. Other Business and General Discussion**  
Risto Lapatto & Liesbeth Siderius

Please send any questions, remarks or proposals in advance to both:

Risto: [risto.lapatto@hus.fi](mailto:risto.lapatto@hus.fi)

Liesbeth: [e.siderius@kpnplanet.nl](mailto:e.siderius@kpnplanet.nl)