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Issue n°7 – January 2021

Dear SIOOPEN members,

We are happy to provide you with the 7th SIOOPEN Flash news.
Key points of the last EC&AB meeting from January, 29th, 2021:

- Update on SIOOPEN High-risk Neuroblastoma 2 opening
- Primage project
- Research and Innovation Finance Steering Group
- Ymab and SIOOPEN data
- SIOPE 2021

Best wishes,
Maja Beck Popovic, SIOOPEN President



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SIOPEN High-Risk Neuroblastoma 2 - Update on HR-2 opening in other countries:

- The HR-2 protocol is currently open in France and in The Netherlands and is close to be opened in Greece, Italy, Denmark, UK and Israel.
- The protocol will be amended to include Lorlatinib. It is anticipated that many countries will open the initial protocol first, and then consider the protocol amendment and regulatory approvals. Currently the sponsor is working with Pfizer to get the product.

Primage project

Some countries have difficulties to get the autorisation from their regulatory authorities to submit imaging data to the Primage project from HR-NBL1 participants. Some additional documents (the arguments presented to the ethics committee in Vienna) will be shared in orther to help these countries in the submission of the project.





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- **Research and Innovation Finance Steering Group** : This group has the task to decide on financial support for approved projects (evaluated by CTC and validated by Ex Com), based on quality, innovation and priority. Many opinions and thoughts have been exchanged. A final document is in elaboration and will allow, after approval, to form this group composed of 3-4 EC-members, a non-EC member and a parents/charity representative.
In parallel, the set-up of a larger strategic group to brainstorm and reflect upon future direction of SIOOPEN is in discussion.
- SIOOPEN is working on a document for a **protection/privacy statement** for all members, to be in accordance with the General Data Protection Regulation (GDPR).



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- **Ymabs and SIOPEN:** Ymabs expressed interest in collaboration with SIOPEN by 2 requests: a) the possibility to refer to the published data from the recent SIOPEN publication on CNS relapse of HR1 patients, for their regulatory needs on Omburtumab. SIOPEN agreed on that. b) comparable patient data for their patient cohort on Naxitamab. SIOPEN will ask for additional and precise information before considering any collaboration in this field.
- **SIOPEN 2021 virtual meeting (28-30 April 2021)** – SIOPEN EC&AB members, National Deputies and specialty committee chairs will be invited to work on a scientific program for the spring SIOPEN meeting that will be integrated into the SIOPE meeting.





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SIOOPEN members website <http://members.siopen.org/>
SIOOPEN public website <https://www.siopen.net/>



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