



SIOOPEN Flash News 11

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Issue n°11 – May 2021

Dear SIOOPEN members,

We are happy to provide you with the 11 th SIOOPEN Flash news. Key points:

- SIOOPEN pathology and bone marrow committee presentation to EC&AB
- SIOOPEN Strategy Meeting
- Finance Steering Committee
- PASS study
- SIOOPEN AGM dates reminder
- Survey for LINES Group 1 patients

Best wishes,
Maja Beck Popovic, SIOOPEN President



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SIOPEN Pathology and Bone Marrow Committee – presentation to EC&AB

- Klaus Beiske, chair of the SIOPEN pathology committee presented the work of the group to the board.
- A request has been made **that national coordinators identify pathologists to support the group in performing central review of bone marrow trephines in HR-NBL2.** Contact Klaus Beiske.

SIOPEN Strategy Meeting:

- The SIOPEN strategy meeting will now take place in late November 2021, rather than September 2021.
- There will be a “brain-storming” session at the SIOPEN AGM October 2021, which will be open to all members, to inform an agenda and key questions for the focussed strategy meeting in November 2021.



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Finance Steering Committee:

- First meeting held on 21.5.21.
- EC&AB and finance steering committee have agreed:
 - Transfer SIOOPEN funds to Bank of Liechtenstein
 - Plans to release €1 million for current SIOOPEN projects, invest €1 million for 2-3 years and invest €1 million longer term

PASS Study

- SIOOPEN sponsored post EMA approval registry study of dinutuximab beta is open in limited SIOOPEN countries and centres, but not recruiting well.
- Success of this study is vital for EUSA and SIOOPEN.
- SIOOPEN will support EUSA to identify blocks and explore options to improve recruitment.



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SIOPEN AGM 6-8 October 2021 – Barcelona – reminder.

- The AGM dates are fixed – please add to diaries.
- Remains to be decided if this will be a face to face or virtual meeting.

LINES Group 1 survey – request to national coordinators

To participate in a **short survey that has been sent out on March 24th 2021**. This survey should help to understand why the randomization between chemotherapy and observation for patients in the LINES study Group 1 (Stage L2, <18 months, MYCN non-amplified with a NCA genomic profile, with no life threatening symptoms) failed. The number of Study Group 1 patients that entered the LINES study was very small with very few patients going into the randomization and so this treatment group was closed early due to a failure to recruit. As it remains unclear both why the randomization failed and how these patients were and are currently treated, we would like your response to this questionnaire. Please complete it whether or not you had the LINES clinical trial open at your site. The collected information should help to plan future trials and treatments effectively.

Please could you distribute this questionnaire to all clinicians looking after NB patients even if the LINES trial was not open in your centre.

The questionnaire will only take about 3 MINUTES.



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



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