

## **Nordic von Hippel-Lindau meeting 2019**

The meeting was held at Clarion Hotel Copenhagen, just by the airport make it easy for participants from Norway and Sweden. As the meeting was on Friday the 26<sup>th</sup> of April, the day SAS's pilots started they strike, this unfortunately prevented some participation, so we ended up being only 34 people.

The program for the day is attached.

Take away points from the first three talks were:

- In Denmark, vHL management and guidelines are coordinated by the national vHL coordination group consisting of doctors from multiple medical specialities, vHL researchers as well as patient representatives
- All Danish vHL patients are asked to be registered in the national VHL database, in which 96 individuals with vHL are currently registered.
- vHL neuroendocrine tumors (NETs) alone accounts for about 1% of all NETs
- An NET size above 24 mm is still an indicator for operation, however, doubling time should also be considered. The limit for doubling time is 22 months.
- 20% of the vHL NETs will develop metastases – most often liver metastases.
- For vHL NETs organ preservation surgery is to be preferred
- In vHL patents spinal anesthesia should be avoided as the is a risk of hemangioblastomas
- Retinal hemangioblastomas may look different in children compared to adults and diagnosis requires examination by a specialist
- Ophthalmoscopic examination should be carried out by a trained ophthalmologist

After the coffee break two different forms of MDTs (multi disciplinary teams) were presented. The approaches for the teams were different: In the Uppsala setup you as a patient were in a meeting where several doctors were present, in the Danish setups (both the one in Århus and in Odense) you met with one doctor at the time, the doctors had held a conference in the morning before the patients arrived.

Following the presentations there was a lively discussion as to what was preferred by the patients, no conclusion was reached, however, it gave several insights for the doctors and the patients became (more for some) aware of how they experienced the meetings.

It was agreed that the meeting gave an excellent forum for interactions, exchanging experiences and "braining". So great that it was agreed that a new meeting would be held in two years time and "Norway" would host the meeting – Anne Grethe Myrhr and Vibeke Hovland will be chairmen.

It was agreed that if we manage to get the international medical symposium to Denmark, it would be hosted by all three countries.