

# Nordic von Hippel-Lindau meeting 2019

## Venue and date:

Clarion Hotel Copenhagen Airport, Friday the 26th of April 2019, 12-18

## Participants:

The meeting is for medical professionals working with von Hippel-Lindau disease (vHL) as well as for vHL patients and their families. The purpose of the meeting is to:

- Increase and spread the knowledge about vHL – for doctors as well as vHL families
- Promote collaboration between the Nordic countries, especially with regard to screening and treatment of vHL patients as well as research collaborations

## Registration and fee:

It is free to participate, however, the dinner after the meeting will have to be paid for by the participant, if you want to join us. The price for the dinner will be DKK 195 + beverages to be paid directly to the hotel.

Registration to [info@vhl.dk](mailto:info@vhl.dk) no later than Monday 15 April 2019.

Please indicate whether you will participate in the dinner after the meeting.

## Programme:

12.00-13.00: Welcome and lunch

13.00-15.30: Talks

13.00-13.30: **Dr. Marie Louise Binderup**, Department of Cellular and Molecular Medicine, University of Copenhagen, Denmark: *The Danish vHL coordination group, the national vHL Database, and overview of recent Danish vHL research*

13.30- 14.10: **Prof. Karl-Heinrich Link**, Asklepios Tumor Center and Visceral Surgery, APK, Wiesbaden, Germany: *Pancreatic Neuroendocrine Tumors in vHL: The individualized indication for surgical treatment after appropriate diagnosis and staging*

14.10 - 14.40: Break

14.40- 15.00: **Dr. Hans Ulrik Møller**, Department of Ophthalmology, Viborg hospital and Aarhus University hospital, Denmark: *An ophthalmologist's personal experiences with vHL through 30 years*

15.00 - 15.30: Information from the Danish vHL patient organization

15.30-16.00: Coffee break

16.00-17.00: **Panel discussion: Recommendations for and coordination of vHL surveillance**

Moderator: Dr. Marie Louise Binderup

Panelists:

**Prof. Lone Sunde**, Clinical Genetics department, Aarhus University hospital

**Dr. Anders Palmstrøm Jørgensen**, Section for Specialized Endocrinology, Oslo University hospital

**Dr. Staffan Welin**, Oncological Endocrinology department, Uppsala University hospital

17.00-18.00: **Conclusion and next steps: Marie Louise Binderup and Vibeke Harbud**

After the meeting, it will be possible to participate in dinner.