

**Agreement of Cooperation in
Investigations on
Molecular Epidemiology of Head and Neck
Paragangliomas**

Partners:

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and

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Patients with Paragangliomas of the Head and Neck (HNP) run a risk to have germline mutations of the succinatdehydrogenase gene subunits B, C and D. These susceptibility genes are named SDHB, SDHC and SDHD. All together are named SDHx. About 25% of patients with HNP have an SDHx mutation.

- We in Freiburg offer to test such patients free of charge.
- The results are transferred as written reports.
- The results can be used for scientific purposes and for genetic counselling of the patients. In case of scientific reports, Prof. Neumann has to be a co-author.

The Iranian partner sends EDTA anticoagulated blood to Freiburg. Alternatively DNA extraction can be performed and sent to Freiburg, but whole EDTA blood is the preference.

The DNA samples are used only for molecular analysis of SDHx as per the written consent form taken from the patients. Further extension of analyses depends on acquiring written consent from the patients.

The Iranian partner provides with clinical key information: Age, sex, tumor location, tumor number, biology (benign/malignant), information regarding clinical symptoms before and after operation and treatment, other tumors in the patient previously and during follow up as well as family history for HNP and other tumors.

The Freiburg partner will use the molecular genetic results for scientific reports mainly together with results obtained by other cooperation. The Iranian partner will be co-author, if this is adequate for the contribution to the report.

The Iranian partner has taken the acceptance of local ethical committees. The Freiburg partner has already obtained the positive ethical committee vote in Freiburg.

This agreement is valid for one year from the time of signatures and extension beyond that requires the agreement of both parties.

Teheran and Freiburg, June 3, 2008

Masoud Motasaddi Zarandi, MD and Hartmut P.H. Neumann, MD

Masoud MZ
Jun, 10, 2008

H. Neumann
July 5, 2008

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