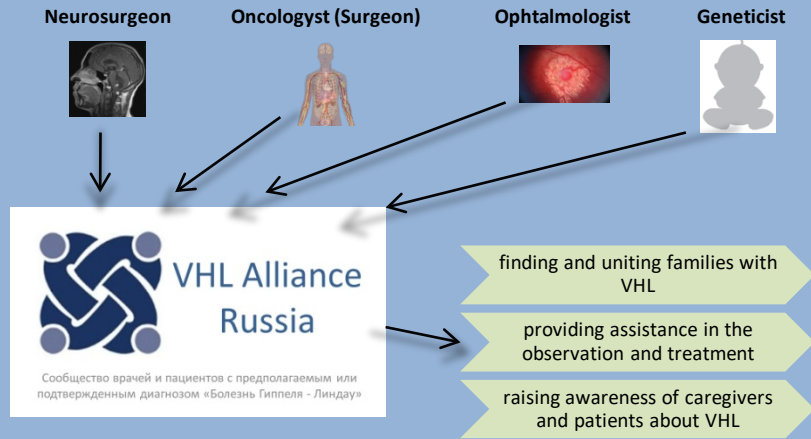


VHL Alliance Russia Present and Future

Simonyan A.S., Lepsveridze L.T., Mikhaylova A.D.

2017 Creation of initiative group



2017 – 2020 Achievements



Future directions and working plan In 2021

Collaboration with other National VHL Societies

- Involvement of patients and their families in the work of the VHL Alliance Russia
- Raising awareness of caregivers and patients about VHL
- Cooperation with doctors from remote regions for increasing quality of patient care

Creation of a charitable foundation to help patients with Von Hippel - Lindau Disease

- “VHL Handbook 2020” translating and adapting to Russian Language
- Creation of multidisciplinary teams on the basis of clinical hospitals, to help patients with rare diseases
- Providing educational events for patients and caregivers

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