

VHL Alliance Russia: Present and Future

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Although Russia is a rather large country with great financial capabilities and resources, and even though there are many multidisciplinary high-equipped hospitals currently operating, it is rather difficult for some people with rare diseases to get the necessary medical care. Since 2017, our multidisciplinary team from different cities of Russia has been trying to help patients with VHL in solving such problems. In August 2020, based on the Russian Society of Rare Diseases, a group of specialists responsible for promoting the interests of patients with VHL was formulated to organize assistance to patients, resolve problems related to obtaining disability, undergoing rehabilitation.

According to our calculations, at least 2,000 families with VHL live in Russia. At the moment, there are ~100 families under our observation. We see the task of "VHL Alliance Russia" in finding and uniting families with VHL, providing assistance in the observation and treatment of patients, and raising the awareness of doctors about VHL. We also plan to involve patients and their relatives in the work of our organization. In the future, we will try to implement the idea of creating a fund to help patients with VHL.

In our short message, we would like to present to the audience the story of the creation of our young organization, the problems our patients most often face, and the prospects of the organization.

We would be grateful to more experienced colleagues for their assessment of our work and would like to hear from the audience suggestions for improving the quality of care for patients with VHL in Russia.