

Diagnosing VHL in Brazil

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Joyce is just back from the 9th International Medical Symposium on VHL in Rio de Janeiro. One day of basic science, one day devoted to optimal treatments for the various kind of VHL tumors, and one day designed specifically for the families. We had 40 people from all over Brazil, and representatives from the patient organizations in four European countries, US, and Argentina. What has this meeting accomplished? Why is it important to get an accurate diagnosis of a rare disease like VHL? Why do we need to convene people worldwide in order to make progress in understanding and treating rare diseases?

