Navigate to: vhl.org/MyVHL and click “Participate” at bottom of page.

Register for MyVHL by clicking “Register” in top right corner and follow the instructions.

Complete and submit the appropriate consent form:
- VHL Informed Consent Agreement, if entering your own information.
- VHL LAR Informed Consent Agreement, if entering information for somebody else.

At any time, patients can withdraw their consent to participate in MyVHL and their data will be removed from the registry.

Complete and submit ALL applicable surveys at least ANNUALLY.
Submit any scans and reports, through the “Upload Survey” and/or complete Records Release Form.

All non-medical and genetic data is curated by trained VHLA staff.
All medical data is curated by a trained medical professional.

Researchers and Institutions will request access to DE-IDENTIFIED data.

If the data request is denied, no data will be provided.
If the data request is approved, the researcher/institution will be provided with the requested data AFTER it has been de-identified, or stripped of any patient identifying information.

At any time, patients can withdraw their consent to participate in MyVHL and their data will be removed from the registry.