MyVHL Data Journey

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.**

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

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

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

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

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

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.

If the data request is denied, no data will be provided.