



MyVHL: Promise Statement

By participating in the MyVHL: Patient Natural History Study, you become part of a community created to energize, inform, engage and support VHL, BHD, and HLRCC research. We come together to help find better treatments, more quickly. When you add your voice, VHLA makes a steadfast promise:

- We promise to safeguard your information and protect your privacy.
- We promise that you own your health information, forever.
- We promise that you control who can access your health information.
- We promise not to share your contact information or identifying information, unless you tell us to reveal it.
- We promise to honor your preferences about the types of information we send you.
- We promise that you can stop participating in MyVHL at any time and have your information removed from the registry.
- We promise to do everything we can to ensure patient voices are heard.