ABOUT OUR STRATEGIC FRAMEWORK: The Strategic Framework is a blueprint for building on the VHL Alliance’s accomplished foundation of service to patients, families, and caregivers, and maintain its activism to broaden research and enhance public policy while evolving in new ways to expand its impact in every community. This summary is an excerpt from the full Framework the Board of Directors approved on February 1, 2022.

OUR MISSION:  Improving quality of life and health outcomes for VHL patients, families, and caregivers with inclusive community building, connections to excellent education and treatment options, and advancements in medical research.

OUR VISION:  Curing cancer through VHL research.

OUR CORE OPERATING VALUES:

Compassionate Connections: We foster friendship and collegiality so that everyone at any phase of a VHL diagnosis can seek and receive accurate answers to questions, ideas, resource links, and support from people with significant experience and perspective.

Inclusive Excellence: We embrace everyone who can benefit from access to knowledgeable community support and medical resources, emphasizing underrepresented communities of color and other underserved communities who experience marginalization.

Information Integrity: We offer the most objective, medically informed, and up-to-date information about VHL, its diagnosis, surveillance, and treatment of the manifestations it causes.

Leading Edge: We are a convening organization that continuously leads knowledge building, information gathering, and innovation to help patients, families, and caregivers to live well with VHL and the medical community to diagnose and evolve the most effective treatments.

OUR GUIDING PRINCIPLES:

1. Every person deserves access to quality healthcare for their particular healthcare needs. Quality healthcare includes healthcare providers (see the description in the supporting partners section) knowledgeable about the VHL disease and updated in the treatment approaches of tumors and cancers caused by VHL condition, including new medications, clinical trials, and experimental treatments for VHL-related illnesses.
2. Every person deserves to be part of a community of like-minded people who want to learn from each other's stories and give each other hope.
3. Every patient, family member, and caregiver has a perspective about their health and healthcare needs that decision-makers need to hear. The VHL Alliance helps build confidence to share these voices.
4. Every patient, family, and caregiver have unique interests and needs. We respect each person's situation by offering various programs and types of assistance and support and continuously looking for new opportunities to evolve what the VHL Alliance provides.
5. By listening, we expand our understanding.
6. By tapping into our community connections, we can increase access to the resources and support available to VHL patients, families, and caregivers.
Strategic Framework 2022-2025

Our 2022-2025 Strategic Direction:

- Expand our role as an educator, facilitator, and connector to support VHL patients, families, & caregivers to maintain quality of life.
- Expand the number of Clinical Care Centers and Comprehensive Clinical Care Centers, update standards of practice, and offer healthcare professionals continuing professional education and advocacy training.
- Convene audiences of the VHL community globally, to attract new resources, identify new patients, and grow advocates for VHL research and funding.
- Elevate our role in telling VHL and cancer research stories, advocating for more research funding and grants research dollars to advance knowledge about VHL and cancer.
- Invest in professionalizing all aspects of our operations and reflecting a climate of inclusion to implement our evolutionary direction.

Our 2022-2025 Goals:

Goal #1: Deliver Accessible Education and Support to all VHL Patients, Families, and Caregivers to Help Them Become Their Own Best Advocates for Their Healthcare

Goal #2: Catalyze Engagement with Culturally Competent, Adequately Trained Healthcare Professionals Who Coordinate High-Quality, Multidisciplinary Healthcare for all VHL Patients

Goal #3: Galvanizes and Mobilizes Relationships and Partnerships to Expand Education, Services, and Advocacy to Increase the VHL Community's Positive Impact

Goal #4: Progress Toward a Cure for VHL-related cancers by leveraging Clinical Care Center Partnerships and Advocating for High Mortality Manifestations and Treatment Research

Goal #5: Effectively Steward and Grow VHL Alliance Financial and Human Resources and Foster a Healthy, Inclusive Organizational Climate that Delivers High-Impact Services to the VHL Community