



CANADIAN
VHL
Alliance



THE CURE FOR CANCER IS IN OUR GENES
LE REMÈDE CONTRE LE CANCER EST DANS NOS GÈNES

Canadian VHL Alliance (CVHLA)

My story

VHL and CVHLA

Future coalition of partners

My daughters

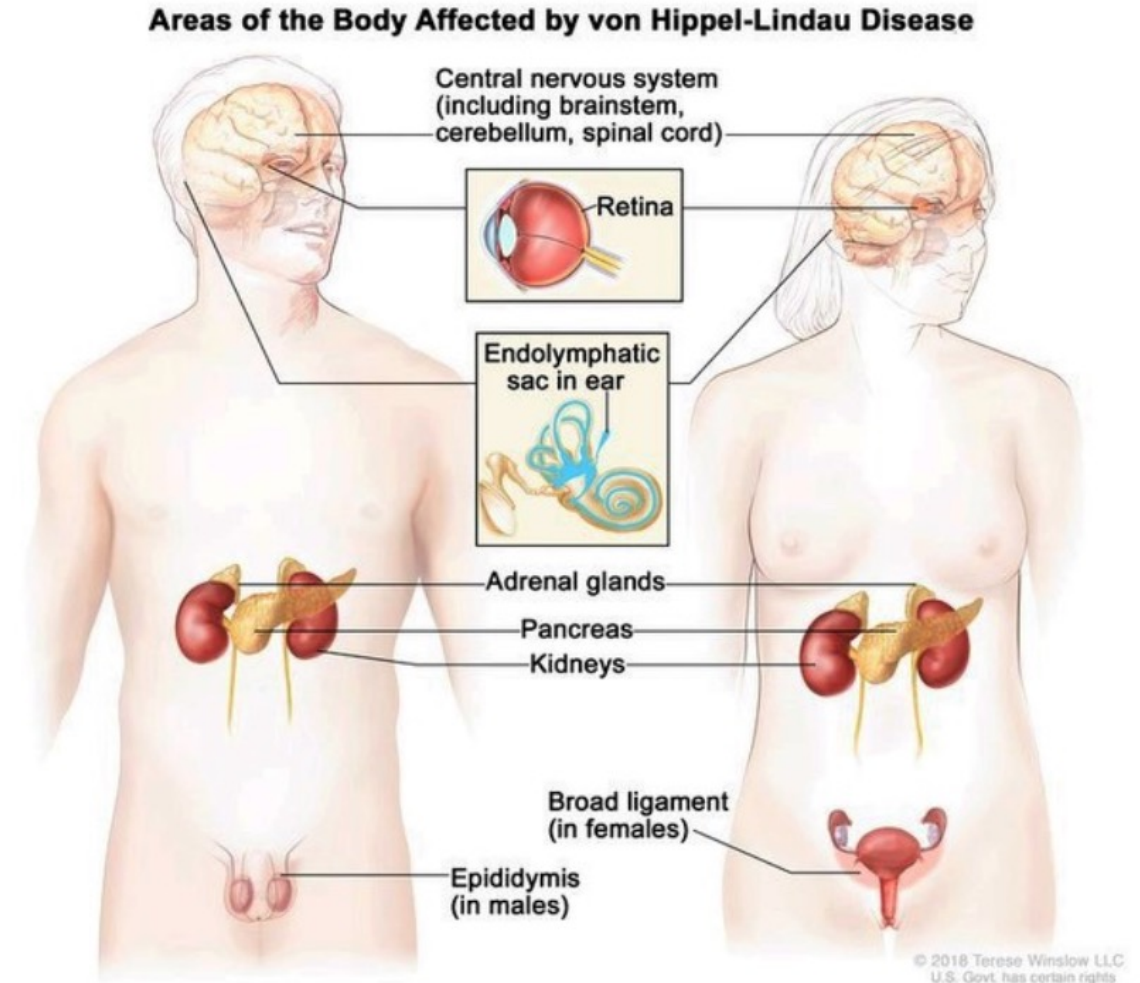


CVHLA Board Members



von Hippel-Lindau

- Von Hippel-Lindau (VHL) is most often a hereditary condition associated with tumors arising in multiple organs.



CVHLA Background

VHL in Canada:

- Approximately 1 in 36,000; 1100 VHLers in Canada

CVHLA

- Organization over 20 years old
- Mission: Research, Education and Support

Research

- \$120k in Cancer Research Society partnership
 - Became \$480k in Canadian Research on VHL

CVHLA Background

Patient Education and Support:

- Information: email newsletter, website, social media

Current Fundraising:

- Walk, Canada Helps – \$20-30k per year

CVHLA Background

- Nov 2022 – International Symposium with VHL Alliance
 - Merck sponsorship

Belzutifan/Welireg

- July 2021 HC Approval – HOPE: Belzutifan/Welireg
- Sept. 2023 CADTH, Nov. 2023 INESSS positive rec.
 - CORD, KCC, Bob Bick, PCC, CNET, RQMO
- ? Early 2024: pCPA Price Negotiation
- ? Summer 2024: Provincial Coverage

CVHLA Today

Current Patient Support:

- Volunteer working board of 7 (2 patients, 5 family/friends)
- Scientific and Medical Advisory Council
 - Dr. Maryam Soleimani – BC Cancer – VHL Clinic
 - Renee Hofstedter, Alexandra Volenik – Gen. Coun. UHN
- Information: newsletter, 5 Brochures by U of T: VHL intro, questions, genetics

Cannot do more without professional staff!

Must partner with other Rare Disease organizations!

CVHLA Future Coalition of Partners

Future Patient Support:

- Belzutifan Videos (partner with VHLA?)

I-Rare: RQMO/Quebec Coalition of Orphan Disorders, CanPKU+

- 1-800 Number and disease information
- Registries, clinical trials
- Regional Communities

CVHLA Future Coalition of Partners

I-Rare/RQMO/CanPKU+, CORD + CRDN?

- Connections to specialists in each province
- Support
 - Community: BIPOC, Psychosocial,
 - Events, fundraising
 - Mental Health
 - Coordination of appointments etc.
- More information:
 - Screenings, genetic, trials

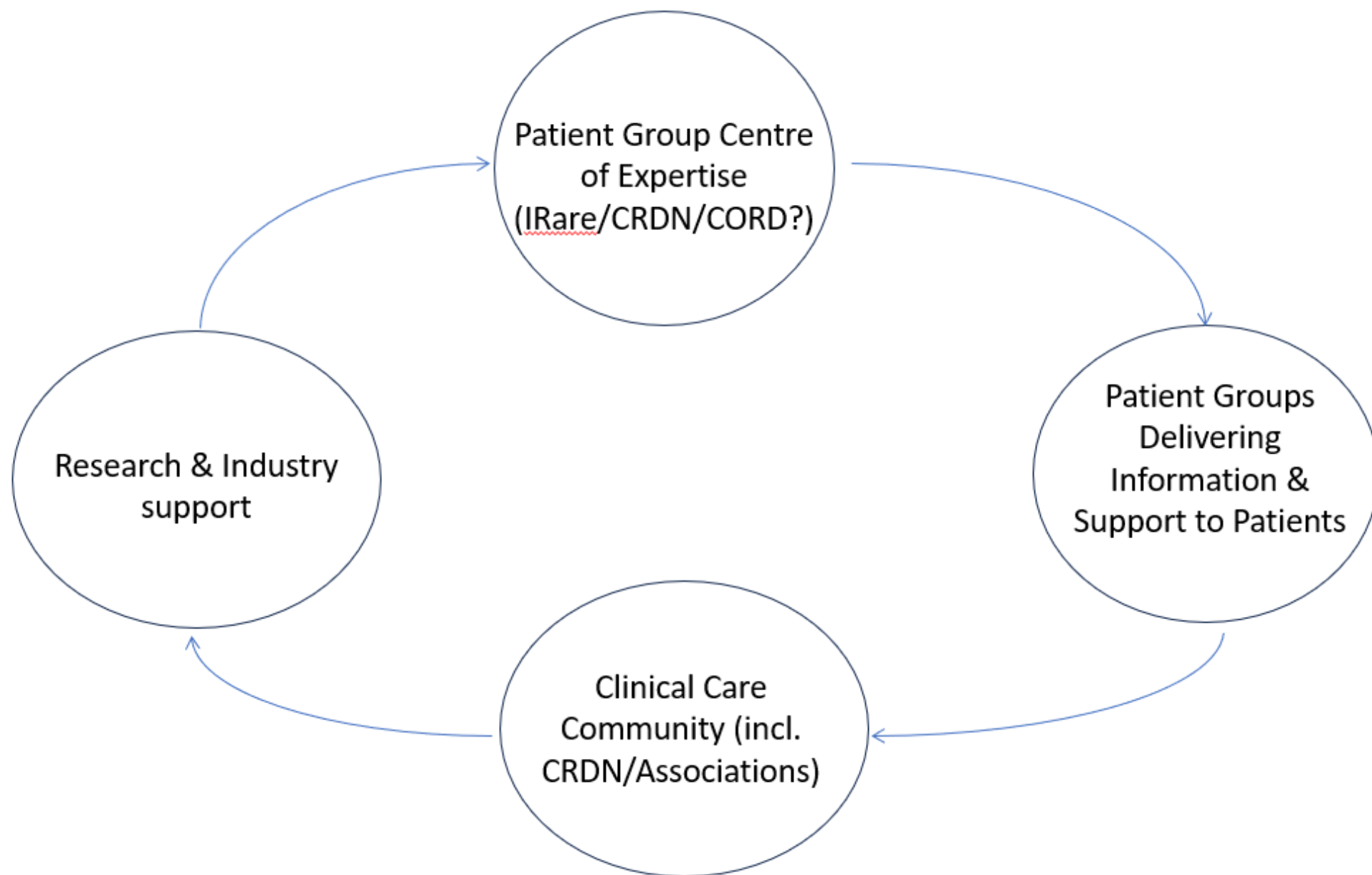
CVHLA Future Coalition of Partners

Patient Group Support

I-Rare/ RQMO/CanPKU+, CORD + CRDN?

- Structure, processes, Tools
- Education and training:
 - Leadership training
 - Operations, governance, strategy
 - Advocacy (CORD),
 - Fundraising for research and operations
 - Standard Registry consent/privacy
- Partners: Pharma, clinicians, researchers, government

Patient Group Centre of Expertise



Build Bridges from

The Rare Disease Patient Community

to

The Healthcare Ecosystem



Most groups are barely surviving

Vast/complex