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Belzutifan Gets Positive CADTH Recommendation

On August 3rd, 2023 the Canadian Agency for Drugs and Technologies in Health (CADTH) made a positive recommendation regarding the Merck VHL drug [Belzutifan](#).

For VHL patients in Canada this is the best news we have received regarding therapies!

Dr. Maryam Soleimani, CVHLA Scientific and Medical Advisory Council Chair, BC Cancer said the following about the CADTH recommendation: "Belzutifan represents a true paradigm shift in the management of von-Hippel Lindau (VHL) disease. With the recent positive recommendation from CADTH, the next step is ensuring equitable access across Canada for all patients with VHL disease. This is an exciting time in VHL care and I believe it is the beginning of many more advancements to come"

The complete recommendation can be found on the [CVHLA Website](#).

We need VHL representatives in each province to advocate for this drug now!

Please contact info@CVHLA.ca !!

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Warrior Walk 2023

On May 28, 2023, the first National Canadian VHL Alliance Warrior Walk took place! Almost 100 people participated in PEI, Nova Scotia, Ontario and British Columbia! The weather was fantastic in all locations, and everyone had a great time raising funds for this important cause.

Thanks to our generous donors and all of the walk participants, over \$36,000 was raised!!! What a **HUGE SUCCESS!!!**

Money raised through all fundraising efforts have been used to help fund research and supporting VHLers in Canada.

The CVHLA has given \$120,000 to research in Canada over the past 5 years.

Through our partner, the Cancer Research Society, this donation has turned into \$480,000 in Canadian VHL research.

Keep an eye out for future updates outlining how all money raised is helping to fund important Canadian research and other projects to support Canadian VHL patients!!



Chilliwack Walk



Halifax Walk



Whittby Walk





Belzutifan Gets Positive CADTH Recommendation

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The next step in the process is the pan-Canadian Pharmaceutical Alliance (pCPA) price negotiation and then each province will identify if it will pay for this drug, based on the price negotiated.

The CVHLA in partnership with the Canadian Organization for Rare Diseases, Kidney Cancer Canada, Pancreatic Cancer Canada and the Canadian Neuroendocrine Tumour Society have responded to the CADTH recommendation with five main points:

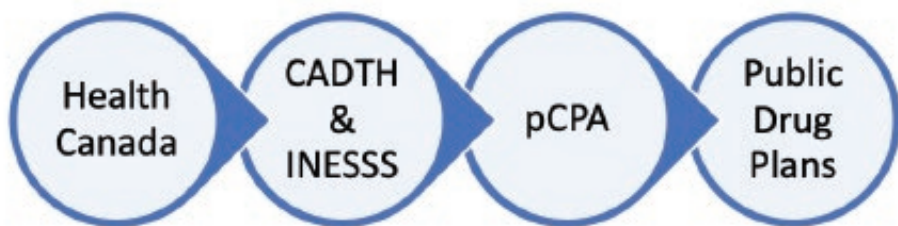
1. We appreciate the recommendation and application of section 9.3.1, the “Considerations for Significant Unmet Need”.
2. We applaud the pan-Canadian Oncology Drug Review Expert Review Committee (pERC) for taking the very positive step to evaluate belzutifan through the complex rare disease lens, including the significant unmet need for VHL patients. However, we are extremely concerned that this step forward could still result in significantly delaying or even denying access if the current economic cost utility (re)analysis stands.
3. To ensure fair, timely, and equitable access to belzutifan, we strongly urge CADTH to include in its recommendations that public drug plans, in addition to providing timely access, must put in place strategies to assure patients not adjacent to specialist centres, have access to this therapy. The recommendation should include a process for the development and dissemination of best practice guidelines for screening, genetic testing and diagnosis to identify patients that need this drug immediately and those who might need it in the future.
4. Again, the community supports pERC’s efforts to find the difficult balance for the rare disease therapy approval process and your conclusion regarding the significant value of this therapy.
5. On behalf of the VHL patients that are suffering today, we implore pERC to unequivocally state in its recommendation, the absolute urgency to make this new therapy available to Canadian patients as soon as possible. Please use this recommendation and your position as clinical leaders to recommend including a pathway for immediate access to those in critical need, even while the price is being negotiated. The recommendation should be clear: negotiations between the pan Canadian Pharmaceutical Alliance (pCPA) and public drug plans should be initiated and concluded as quickly as possible.

**We need VHL representatives in each province
to advocate for this drug now!**

Please contact info@CVHLA.ca !!

Here is a quick overview from the pan-Canadian Pharmaceutical Alliance (pCPA) website of the drug approval process in Canada, with links for more information.

The following information gives an overview of the drug review process in Canada:



Health Canada

[Health Canada](#) reviews drugs for safety, efficacy and quality before authorizing them for sale in Canada.

CADTH & INESSS

In Canada there are two health technology assessment organizations which review the clinical and cost-effectiveness of a drug product; the [Canadian Agency for Drugs and Technologies in Health](#) (CADTH) and in Quebec, [l'Institut national d'excellence en santé et en services sociaux](#) (INESSS). CADTH and INESSS provide a recommendation to public drug plans on whether or not a drug should be reimbursed for public funding.

pCPA

The pCPA [negotiation process](#) begins for the majority of new drugs, once a recommendation is published by CADTH and/or INESSS. pCPA uses the recommendations from CADTH and INESSS and other factors to determine whether or not it will enter into a negotiation for a drug. Following a successful negotiation, pCPA will issue a letter of intent which sets the terms of the agreement between pCPA and the drug manufacturer.

Public Drug Plans

Public Drug Plans make a final decision to fund a drug once a negotiation has been successfully completed and enter into a product listing agreement with the drug manufacturer.

pCPA Office

The pCPA office is hosted and staffed through Ontario and works closely with the jurisdictions providing support in negotiations, administration, communications, standardization, analytics, process design, and policy related to brand and generic products.

<https://www.pcpacanada.ca/about>



Jess Pearson “My Family Legacy”



The spoken word poem was originally written by Jess Pearson for the virtual November 2022 [VHL International Medical Symposium](#), co-hosted by the CVHLA. Medical experts from around the world were assembled virtually to review the latest in medical research and share best practices. Jess, a CVHLA Board Member, was asked to be one of two Canadian patients presenting their perspective on living with VHL. The poem highlights the generational resilience built despite living with hardship and illness.

[My Family Legacy](#) – a 3 minute spoken word poem with a time lapse drawing of one of the themes.

Stories from the frontlines of the fight for access to innovative therapies

Our Chair Steve Parrott was featured in [Macleans.ca](#) this past week. The article is about his family, his nephew and bit about his journey with VHL.

“In March of 2023, the Government of Canada announced the National Strategy for Drugs for Rare Diseases to help bring innovative #raredisease therapies within reach for patients across the country. Now, as patients and their families continue to wait for a tangible plan to be implemented, we’d like to introduce you to 3 Canadians whose lives hang in the balance.” (source: [@patientvoiceca](#))

Read the entire [Macleans.ca](#) story at [macleans.ca](#)



(photo source: [macleans.ca](#))

FOR SALE — Canadian VHL Alliance Swag!!



T-SHIRTS: Cost \$25 plus shipping

- Available in either the VHL Logo or Butterfly image
- Sizes: Adult Small, Medium, Large, X-Large or Youth Medium.

REUSABLE BAGS: Cost \$10 plus shipping

- With VHL Logo

Email info@cvhla.ca with your order!