

Real world data of Canadians living with Hereditary Angioedema (HAE): Attributes of new medications.

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Background: Hereditary angioedema (HAE) is a chronic spontaneous life-threatening disease. Until recently, treatment options for HAE have been limited and required infusion. New treatment options would be beneficial to this population.

Methods In 2019, HAE Canada conducted an online survey of patients and caregivers to assess the challenges patients and caregivers face as a result of hereditary angioedema and to gain insight into their experience and expectation with therapies used to treat hereditary angioedema.

Results: Of 73 respondents to the questions, 68 were living with HAE and 6 were providing care to a patient with HAE. Of the respondents, 43/50 (86%) indicated that access to new treatments is extremely important. Attributes for new medications that were considered extremely important were: more convenient dosing interval -38/58, reduction in edema attacks - 47/57, easier mode of delivery 44/58, prophylactic administration – 44/56. Eight participants (13%) had received treatment with lanadelumab a newly approved medication. On a scale of 1 to 5, five participants rated its effectiveness preventing attacks at 5 and 1 each rated it a 3 or 4. Reported adverse events were headache (2/8) and pain at injection site (7/8) scored as tolerable to very tolerable. The majority (5/8) indicated their quality of life while taking lanadelumab to be comparable to normal living. Access to lanadelumab was predominantly through participation in a Canadian clinical trial (5/8), a compassionate access program (1/8) or through private insurance (1/8).

Conclusion: The data collected indicates that newer, more effective and more convenient treatments for are wanted by Canadian HAE patients. The newest approved treatment, lanadelumab, which is given by subcutaneous injection every 2 weeks fulfils some of these requirements according to a limited number of patients. It is important that Canadian HAE patients have access to multiple treatments to address the unpredictable nature of this disease.

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