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#700 Abstract

Hereditary angioedema in Canada: preliminary demographic and treatment results from the second national survey

Immune deficiencies and autoimmunity / Primary Immunodeficiency

Badeau J.¹, Cooper M.¹, Dumbrille D.¹, Bick R.², Dao M.¹, Kelly S. M.³, Yang W.⁴

1. HAE Canada, Ottawa, Canada
2. Consultant, Ottawa, Canada
3. Red Maple Trials, Ottawa, Canada
4. Ottawa Allergy Research Corporation, Ottawa, Canada

Background

Hereditary angioedema (HAE) results from rare genetic disorders leading to, low C1 inhibitor (C1INH), lack of control of bradykinin production and unpredictable, painful episodes of angioedema affecting the abdomen, extremities and, of great concern, the face and larynx. HAE Canada is a patient organization representing HAE patients and caregivers in Canada.

Method

In December 2020 a comprehensive 144 question on-line survey was sent to all members of HAE Canada in order to gather updated information on demographics, burden of illness and treatment of HAE in Canada. A snapshot of the questionnaires completed by January 28th, 2021 was analyzed for information about patient demographics and treatment. Data is reported as a percent of the responses to each question.

Results

By the cut-off, there were 167 respondents. Of these, 85.6% were adults or parents of children with HAE and 12% were caretakers of patients with HAE. The majority (78.3%; 108/138) were female; 68.2% (92/135) had Type I or II HAE, 25.9% (35/135) had HAE with normal C1INH and 2.2% (3/135) had acquired angioedema. Most respondents (87.1%; 115/132) used medication to treat HAE in the past year. Acute treatments included C1INH intravenous (66.7%) and subcutaneous (20.5%) and icatibant (37.1%). Long-term prophylaxis treatments included C1INH intravenous (35.2%) and subcutaneous (27.2%), lanadelumab (8.0%), androgen (4.8%) and tranexamic acid (4.0%). Thirty-three percent did not use prophylactic treatment.

Conclusion

Like the previous survey done in 2017, the majority of respondents were female and a high proportion were diagnosed with HAE with normal C1INH. C1INH remains the most common treatment but subcutaneous injection is used more commonly, particularly for long-term prophylaxis. Newer medications like lanadelumab are beginning to be used for treatment.