Amyloidosis Awareness Month declared at recent Dufferin County Council meeting

Written By PAULA BROWN

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Dufferin County has proclaimed March as Amyloidosis Awareness Month to help bring awareness to the rare, incurable and fatal disease.

During their meeting last Thursday (Feb. 13), Dufferin County Council received a presentation from Keith Dares, a board member and secretary from the Canadian Amyloidosis Support Network (CASN), regarding awareness of the disease.

?I'm happy to report that our awareness efforts in Canada, in conjunction with other international organization efforts, are making a difference here and abroad. In the past year, since I addressed Council, there has been a lot of activity to bring amyloidosis into view in Canada,? said Dares.

?We are achieving greater awareness, more clinicians are more informed about this disease and its symptoms, the time to diagnose is slowly becoming shorter, clinical trials are starting to take place and more treatments and drugs that help manage the disease are being approved for use. All of these achievements confirm awareness is vitally important and it makes a difference in the lives of our citizens who are challenged with this disease,? he continued.

Amyloidosis is a rare disease caused by the accumulation of clumps of ?misfolded? proteins, called amyloid fibrils, in organs and tissues in the body leading to organ impairment or failure.

Dares, who is an amyloidosis patient himself, explained that the amyloid fibrils circulate in the bloodstream and become lodged in between smooth muscle cells. When the fibrils accumulate over time, they become a stiff plaque-like substance and cause organ impairments, which eventually leads to organ failure.

?It's a complicated disease,? said Dares. ?It's a systemic multi-system disease and depending on the type of amyloidosis it can affect individual or a combination of organs or tissues in the body.?

According to the CASN, amyloidosis affects a small percentage of Canada's population with approximately eight in one million people diagnosed with the disease.

Due to the rarity of the disease, the diagnosis process varies, taking anywhere from six months to five years because symptoms of amyloidosis often present as other more common diseases.

Described as the ?great masquerader,? Dares added that it is suspected that due to the delay in diagnosis some patients die before even getting a diagnosis.

?Having a rare disease and being unwell for up to five years or more with limited life expectancy places a heavy toll on families, who must care and support patients through this process,? said Dares. ?To relieve these burdens, the successful pathway is very simple; awareness leads to early diagnosis, early diagnosis leads to sustaining treatments, treatments lead to better outcomes, prolong life and hopefully in the future [provide] a cure.?

The Canadian Amyloidosis Support Network (CASN) is a federally registered, not-for-profit organization formed by amyloidosis patients that is committed to making a difference in the lives of amyloidosis patients and families by promoting awareness, offering patient support and funding research projects.

?Our project is to bring awareness of this disease to the general public and the medical community in hopes that more people can be diagnosed earlier, treated earlier, and with treatments can resume some level of normalcy and balance in life until a cure can be found,? said Dares. ?Amyloidosis can only be treated if it's diagnosed, and that is why awareness is so very important.?