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Dufferin County declares March as Amyloidosis Awareness Month

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Local Journalism Initiative Reporter

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

During their meeting last Thursday (March 14), Dufferin County Council received a delegation from Keith Dares, a board member and secretary from the Canadian Amyloidosis Support Network (CASN), regarding the disease.

?We are extremely pleased that more and more communities are assisting us to bring awareness to this rare, incurable and fatal disease,? said Dares.

?We're certainly happy to proclaim the month of March 2024 the Amyloidosis Awareness Month in the County of Dufferin to help get the word out on behalf of the organization,? said Dufferin County Warden, Darren White.

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, that is why awareness is so very important.?

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 very complicated disease,? said Dares. ?It's a systemic multi-system disease, meaning that depending on the amyloid type it can affect any organs and 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.

?A diagnosis of amyloidosis places a heavy weight on the patient, their caregivers, their families as well it creates burdens on the public health care system, human resources and financial resources,? said Dare. ?If we can shorten the diagnosis time of amyloidosis, we can mitigate these costs and bring a higher quality of life to patients and families.?

Dares said the simplest pathway to helping relieve the burden on amyloidosis patients and their families is to draw awareness to the disease.

?Awareness leads to early diagnosis, early diagnosis leads to life-sustaining treatments, treatment leads to better outcomes, prolongs life and hopefully in the future; a cure,? said Dares.