

## Bancroft council shines spotlight on rare disease

By Kaitlin Sylvester

Bancroft council recognized March as Amyloidosis Awareness Month at the Feb. 14 council meeting. The council unanimously voted to raise awareness of amyloidosis, a rare disease characterized by the accumulation of abnormal proteins (known as amyloid) in various organs. The impact of amyloidosis can lead to organ dysfunction, and in severe cases, can be fatal. Amyloidosis (am-uh-loi-DO-sis) Awareness Month aims to educate Canadians about the diverse manifestations of amyloidosis and the consequences. By reaching out to city councils the Canadian Amyloidosis Support Network (CASN) aims to raise awareness across Ontario. Councils recognizing the month fosters awareness of the disorder, promotes early detection, and increases understanding of the disease. Amyloidosis encompasses a group of diseases where abnormal amyloid proteins accumulate in organs, such as the heart. Mimicking symptoms of more common medical conditions, diagnosing amyloidosis can be challenging, particularly in rural communities where healthcare can be limited by access to medical services. Since amyloidosis can be difficult to catch, early diagnosis is crucial for better outcomes, specifically in rural communities where access to treatment can be a struggle. Timely intervention can mitigate the progression of the disease and improve the quality of life for patients. Often, rural patients do not know to advocate for themselves, choosing to delay visits to a physician or accepting incomplete diagnosis. Those living in rural or northern communities face additional healthcare shortages that make accessing regular and thorough healthcare difficult. Coe Hill resident, Thomas Sinclair said, "I don't have a family doctor here in town, and I'm not going to drive two plus hours over a minor complaint." Comprehensive testing and treatment are often not available at the regional hospitals, which requires residents to go to Bellville, Kingston, or even Toronto for treatment. With symptoms resembling those of more prevalent diseases, this disease can go undiagnosed when physicians don't know the signs to look out for. By promoting March as Amyloidosis Awareness Month the CASN hopes to increase education around the disease, ultimately removing obstacles to early detection and proper management of the disease. Not-for-profit groups like CASN will lobby local governments to declare 'awareness months' as an affordable method of reaching wider audiences. Amyloidosis presents with a diverse range of symptoms that can impact various organs and systems in the body. Symptoms may include shortness of breath, weight loss and fatigue, swelling in the ankles and legs and numbness in the hands and feet may occur due to nerve damage caused by deposits. Foamy urine, carpal tunnel syndrome, bruising around the eyes, and an enlarged tongue are all potential manifestations of this complex condition. In 2023 the towns of Welland, Collingwood, and Amherst recognized Amyloidosis Awareness month, while this year the province of British Columbia joined Bancroft in recognition of the disease. "Citizens can use Amyloidosis Awareness month to learn about the disease and symptoms, as an early diagnosis can lead to better outcomes for patients and their families." said Andra Kauffeldt, general manager of Bancroft. Local governments have issued statements across Canada in order to bridge the information gap around rare conditions like amyloidosis. By dedicating March to raising awareness of the disease, the Bancroft council hopes to give residents information to support their access to healthcare. The treatment of amyloidosis varies depending on the type, with treatments ranging from supportive therapies aiming to manage symptoms, to disease-modifying therapies that target the amyloid protein buildup. Ongoing clinical trials exploring advanced treatments, such as monoclonal antibodies and gene-editing technologies, offer hope for more effective interventions in the future. The Town of Bancroft recognizes the importance of bringing awareness to this rare disease. Increased awareness, early diagnosis, and ongoing research efforts are crucial in the treatment and management of amyloidosis. Communities across Canada are being asked to work together to build a healthier society.