

From: Fran Hickmott <fran.hickmott@gmail.com>
Sent: Monday, July 7, 2025 1:06 AM
To: City of Saint John Mayor's Office <mayor@saintjohn.ca>
Subject: Proclamation for Usher Syndrome Day

You don't often get email from fran.hickmott@gmail.com. [Learn why this is important](#)

[External Email Alert] **Please note that this message is from an external sender. If it appears to be sent from a Saint John employee, please forward the email to spamsample@saintjohn.ca or contact the IT Service Desk.**

July 7, 2025

310-9 Horizon Drive

Quispamsis, NB

E2E 0V2

Donna Reardon
Mayor of Saint John, NB

Dear Mayor Reardon,

I am writing, on behalf of the Usher Syndrome Coalition, to ask the city of Saint John, New Brunswick to proclaim the third Saturday in September, September 20, Usher Syndrome Awareness Day.

Usher syndrome (USH) is a rare inherited condition - passing from parents to children - that impacts three major senses in the body: vision, hearing and balance. It is the most common genetic cause of combined deafness and blindness.

In 2015 the Usher Syndrome Coalition, the only organization in the world working to find and support every individual and family living with USH, declared the third Saturday in September as global "Usher Syndrome Awareness Day." This day falls near the autumnal equinox in the northern hemisphere, marking the start of days that contain more darkness than light - a powerful metaphor for the threat of Usher syndrome.

There is currently no cure for Usher syndrome, but there is a growing USH community. Building a community and awareness leads to treatment and a cure. You can help raise awareness with this proclamation. I have attached a sample of the wording for a proclamation regarding Usher syndrome Awareness Day.

My grandsons, Ethan and Gavin Morrobel, have both been diagnosed with Usher syndrome. They have bravely shared their experiences in their own words, writing articles that provide valuable insights into the challenges and triumphs of living with this condition. I have included links to their articles below.

I am pleased to share that the CN Tower recognized Usher Syndrome Awareness Day in 2024 by displaying the yellow and blue colours of the Usher Syndrome Coalition on September 21, 2024 and will recognize Usher Syndrome Awareness Day again this year on September 20, 2025.

I have attached a sample Proclamation.

Thank you for your consideration,

Sincerely,
Fran Hickmott
fran.hickmott@gmail.com
506-654-7200

‘An Uncomfortable Life: Getting Comfortable with Being Uncomfortable’ by Ethan Morrobel
<https://reader.mediawiremobile.com/epmagazine/issues/208904/viewer?page=38>

‘**Speaking Up**’ by Gavin Morrobel
<https://reader.mediawiremobile.com/epmagazine/issues/209001/viewer?page=34>

Fran Hickmott
fran.hickmott@gmail.com