

LH

Deborah Liske

Subject: proclamation and info on our cause and event
Attachments: Rare Disease Day 2017 Proclamation_Esquimalt.docx; RareDiseaseDay2017_Poster Feb 03 2017 FINAL.pdf

From: CarterSim, Jocelyn N. [mailto:Jocelyn.CarterSim@viha.ca]
Sent: February-14-17 3:17 PM
To: Deborah Liske

CORPORATION OF THE TOWNSHIP OF ESQUIMALT		
For Information:		
<input type="checkbox"/> CAO	<input type="checkbox"/> Mayor/Council	
<input type="checkbox"/>		
RECEIVED: FEB 15 2017		
Referred:		
<input type="checkbox"/> For Action	<input type="checkbox"/> For Response	<input type="checkbox"/> COTW
<input type="checkbox"/> For Report	<input checked="" type="checkbox"/> Council Agenda	<input type="checkbox"/> IC

As per out telephone conversation please find attached a request for the proclamation of Rare Disease Day on February 28, 2017 and the request to fly a flag for Rare Disease Day.

I have also attached an invitation for our Rare Disease Day event at the Gorge Vale Golf Club on Feb 28, 2017 at 7pm (doors open at 6:30 pm with talks at 7:30 pm) which we extend to Mayor Desjardins, the Council and any other staff and community members who would be interested in attending.

We are really hoping to spread awareness about Rare Diseases that affect the children in our communities. Please feel free to refer to the organisations website: <https://www.rarediseasefoundation.org/>

As you can read from the proclamation Rare Disease Day is to bring about awareness of these diseases and the impact they have on the children and their families. There is lots of rare out there....

Thank you for your consideration.

Sincerely,
Jocelyn

Jocelyn Carter-Sim, MSc., CCGC
Genetic Counsellor | Vancouver Island Medical Genetics | Island Health
Victoria General Hospital | 1 Hospital Way Victoria | British Columbia | Canada | V8Z 6R5
E: Jocelyn.CarterSim@viha.ca | T: (250) 727.4507 | F: (250) 727.4295



Confidentiality Notice: This e-mail, including any attachments, is for the sole use of the intended recipient(s) and may contain private, confidential, and privileged information. Any unauthorized review, use, disclosure or distribution is prohibited. If you are not the intended recipient or this information has been inappropriately forwarded to you, please contact the sender by reply e-mail and destroy all copies of the original.

RARE DISEASE DAY

February 28, 2017

WHEREAS, the Rare Disease Foundation and its Victoria Parent-2-Parent Network provides a forum for families in our community for mutual support, mentoring and knowledge sharing regardless of a child's diagnosis; and

WHEREAS, the last day of February is recognized as Rare Disease Day internationally, with the purpose to bring about awareness of rare diseases and their impact on patients' lives amongst the general public and decision-makers; and

WHEREAS, on February 28th the Victoria Parent-2-Parent Network will collectively recognize and promote awareness of Rare Disease Day throughout the greater Victoria region;

THEREFORE, I, Barb Desjardins, Mayor of the Township of Esquimalt, do hereby proclaim **February 28, 2017 Rare Disease Day** in Esquimalt.

Barb Desjardins
Mayor

Rare Disease Day 2017

RESEARCH BRINGS HOPE

TO PEOPLE LIVING WITH A RARE DISEASE

Researchers and Families Fighting Rare Diseases Together
FREE EVENT

7:00-9:30pm, February 28, 2017 *Doors open at 6:30pm*

Gorge Vale Golf Course, 1005 Craigflower Road

Appetizers, tea, coffee and cash bar (1st beverage complimentary)

Speakers to commence at 7:30pm

Owen Underhill

Parent, Board Member Rare Disease Foundation

Introduction to the Rare Disease Foundation

o

Dr. Patrick Walter

University of Victoria Researcher

Iron Metabolism and the 3 Aspects of My Research that Investigates Rare Disease

o

Dr. Patrick MacLeod

Clinical Geneticist

Progress I've Seen Over the Last Five Years in Clinical Research

o

Simone Conner

Parent, Vancouver Island Make-A-Wish Foundation Coordinator

Our Story with NF2

Official book launch of *Rare is Everywhere!* Copies available to purchase

*You are invited to join us on this special day to hear stories from families affected by and specialists working with rare diseases. Please **RSVP** to victoriafamilies@rarediseasefoundation.org by **February 22nd***

SPACE IS LIMITED PLEASE RSVP

Reception to follow



RARE DISEASE
FOUNDATION





CORPORATION OF THE TOWNSHIP OF ESQUIMALT

Municipal Hall, 1229 Esquimalt Road, Esquimalt, B.C. V9A 3P1
Website: www.esquimalt.ca Email: info@esquimalt.ca

Voice: (250) 414-7100
Fax: (250) 414-7111

PROCLAMATION

"RARE DISEASE DAY"

February 28, 2017

WHEREAS

The Rare Disease Foundation and its Victoria Parent-2-Parent Network provides a forum for families in our community for mutual support, mentoring and knowledge sharing regardless of a child's diagnosis; and

WHEREAS

The last day of February is recognized as Rare Disease Day internationally, with the purpose to bring about awareness of rare diseases and their impact on patients' lives amongst the general public and decision-makers; and

WHEREAS

On February 28th the Victoria Parent-2-Parent Network will collectively recognize and promote awareness of Rare Disease Day throughout the greater Victoria region.

THEREFORE,

I, Barbara Desjardins, Mayor of the Corporation of the Township of Esquimalt, do hereby proclaim February 28, 2017 as

Rare Disease Day

In the Municipality of Esquimalt, Province of British Columbia.

Barbara Desjardins
Mayor