

# May E-Newsletter

## A month of celebration and recognition

### WORLD LUPUS DAY – MAY 10, 2017



World Lupus Day is sponsored by the World Lupus Federation, a coalition of lupus patient organizations from around the world, united to improve the quality of life for people affected by lupus. Through coordinated efforts of its global affiliates, the World Lupus Federation works to create greater awareness and understanding of lupus, provide education and services to people living with the disease, and advocate on their behalf.

World Lupus Day serves to call attention to the impact that lupus has on people around the world. The annual observance focuses on the need for improved patient healthcare services, increased research into the causes of and cure for lupus, earlier diagnosis and treatment of lupus, and better epidemiological data on lupus globally.

World Lupus Day serves to rally lupus organizations and people affected by the disease around the world for a common purpose of bringing greater attention and resources to efforts to end the suffering caused by this disabling and potentially fatal autoimmune disease.

Since 2004, lupus organizations around the globe have conducted activities on May 10 to raise awareness and educate the public about the symptoms and health effects of lupus.

Together we can make lupus an international health priority and to ensure that people with lupus around the world are diagnosed and treated effectively.

On May 10, 2017, the World Federation will release a report on the global impact that lupus has on individuals and families around the world. Developed with the support of GlaxoSmithKline, the report will:

- Provide first-hand stories from individuals directly impacted by lupus
- Identify and understand public misconceptions about the disease
- Describe the emotional support needs of those living with lupus

If you are in either the Niagara, Ontario area check out the Falls as they will be illuminated in purple at 10pm in support of World Lupus Day! Or should you be in Toronto, go down to the CN Tower as it will also be illuminated in purple.

To learn more about World Lupus Day please visit [worldlupusfederation.org](http://worldlupusfederation.org).

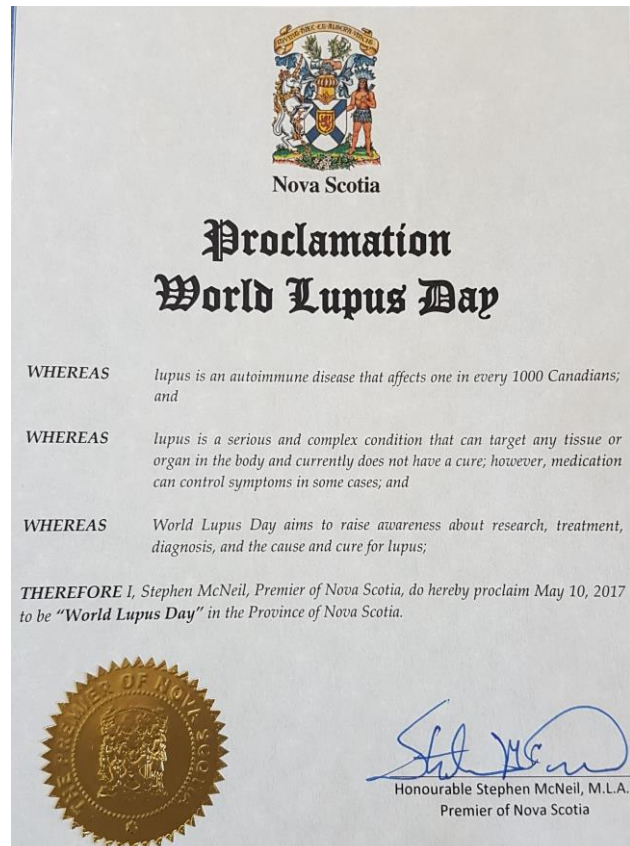
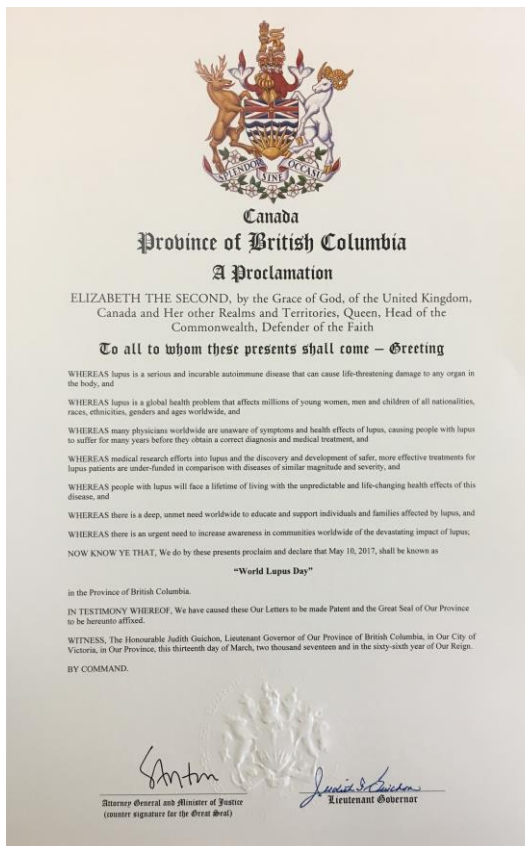


**PUT ON PURPLE – FRIDAY MAY 19,**

Show your support in finding a cure and help those living with lupus by wearing **purple** on **May 19**. Help raise awareness and rally public support for this under-funded and under-recognized disease. Mobilize individuals, corporations, physician offices, hospitals, people with a connection to lupus and the general community to get the word out about **Put On Purple** day and build excitement and interest.

Share your photos or videos on Twitter, Instagram or Facebook. Don't forget to send us your photos, email them to [info@lupuscanada.org](mailto:info@lupuscanada.org).

# A Special Note of Thanks . . .



In addition to both World Lupus Day and Put on Purple day we also celebrate all the mothers around the world this month who dedicate their lives to loving and caring for their family. Happy Mother's Day!

## New Twitter Survey

Thank you to those who participated in our Twitter Survey Poll. The new twitter survey reveals most people have serious misconceptions about lupus. Raising awareness of lupus and improving understanding of the challenges that people living with the disease face is an important goal of the new World Lupus Federation, a coalition of global lupus patients. **Results to be posted by May 10.**

# Twitter Chat

The World Lupus Federation is working with GlaxoSmithKline (GSK) and Tiffany Peterson, host of the Twitter Channel, [#LupusChat](#). Together they will host a Twitter Chat on **Sunday, May 7 beginning at 3:00 p.m. EDT** (1900 hours UTC). We encourage everyone to join the conversation online. During the chat, the results of the Twitter polls that measured how lupus impacts the lives of people living with lupus will be presented.

Please join us for the #LupusChat on May 7.

## Research Update

### **MyLupusGuide receives support from the Lupus Clinical Investigators Network (LuCIN)**

Congratulations to the *MyLupusGuide* team, for receiving recognition by the Lupus Clinical Investigators Network (LuCIN)! LuCIN is coordinated by the Lupus Research Alliance (LRA), who is interested in the results of the study, and potential expansion to the United States.

The purpose of the *MyLupusGuide* study is to test how the needs of people living with lupus are being met by the newly developed website. This study will be conducted in many CaNIOScentres across Canada, with approximately 2,000 persons with lupus invited to take part. Lupus Canada is pleased to partner on this study by taking a lead role on the Patient Advisory Committee for the project.

## Lupus Canada Update

For more information on all our Board members please visit <http://www.lupuscanada.org/board-of-directors/>.

Lupus Canada recently welcomed Kerry Johnson to our Board of Directors. Kerry has considerable health care experience. He has been involved with various health care and education-related boards and advisory councils at the local and national levels. As you will read in his journey with lupus below he is also a lupus patient. Welcome to the Board Kerry!

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## My Lupus Journey by Kerry Johnson

Having lived with SLE for 45 years, lupus is a huge part of me; but I have made a conscious effort to not let it define who I am. Diagnosed in 1973 in my early teens, a life with lupus is really all I know. Certainly, it affected my plans as to where I went to high school, completed my university education, my career choices, as well as decisions about married life and family. Yet, through a life with lupus and the various other medical issues and associated conditions, I have done my best not to let SLE define who I am as a person; rather, it is a challenge that I need to work around. I have been blessed insofar that although I have had bouts with the lupus that have put me on the "disabled list" for a short period of time, I have been able to work full time throughout my life.

Fortunately, after a career as a secondary school teacher was thwarted by a lupus flare, I stumbled upon a career in health information management (HIM), which allowed me to work in an environment that met my physical needs, but also challenged me intellectually by working in health care.

As Canadians, we are fortunate to live in an age and country where “school” is not necessarily defined by “bricks and mortar”. As such, I was able to complete my education with college-level certificates through to doctoral studies via distance-learning formats—both through the postal service in the early days and later by way of Internet technology. Taking advantage of these options as an individual with chronic illness allowed me to do much of my study from the comfort of my home (usually in my “jammies”!). As a result, I have been able to enjoy a full career in health care and finally get back to my first love of teaching.

Of course, I did not (and could not) do this on my own. My wife and family have been of immense support to me in my endeavours. With me, a life with chronic illness is all they have really ever known. But, the importance of a supportive family (and in my case church community) have been foundational to my life with lupus. Of course, there is also my amazing rheumatologist (of 30 years!) and his support staff.

As I begin my tenure as a Board member for Lupus Canada, my encouragement to others living with lupus is that it is not a disease that defines who we are! Yes, it is a significant portion of and consideration in our lives. But, hopefully with the support of our families, physicians, and communities we can rise above the challenges and demonstrate to others “we shall overcome”.

## RECIPE:

### Greek Potato Salad



#### ➤ **Ingredients:**

- 12 red potatoes
- ¼ cup chopped green onion
- ¼ cup olive oil
- ¼ cup red wine vinegar
- ½ teaspoon fresh lemon juice
- ½ teaspoon garlic powder
- ½ teaspoon onion powder
- ½ teaspoon coarse salt
- ½ teaspoon ground black pepper
- ¼ teaspoon dried oregano
- ¼ teaspoon white sugar
- ¼ teaspoon dried rosemary, crumbled
- 1 pinch ground pepper

#### Directions:

Prep 30 m Cook 25 m Ready In 1 h 25 m

1. Place red potatoes into a large pot and cover with salted water; bring to a boil. Reduce heat to medium-low and simmer until tender, about 25 minutes. Drain and chill in freezer until cold, about 30 minutes.
2. Slice potatoes and place into a large salad bowl; toss potatoes with green onion. Whisk olive oil, red wine vinegar, lemon juice, garlic powder, onion powder, salt, black pepper, oregano, sugar, rosemary, and red pepper in a bowl. Pour the dressing over the potatoes and toss. Serve immediately or chill until serving time.

source:

<http://allrecipes.com/recipe/223380/light-and-easy-greek-potato-salad/?internalSource=previously%20viewed&referringContentType=home%20page>