



Ehlers-Danlos Syndrome Canada is pleased to announce that Toronto's CN Tower will light up in magnificent BLUE at sundown on February 28, 2014 in honour of RARE DISEASE DAY, a global health awareness initiative.

Greater Toronto supports Rare Disease Day annual community fundraising efforts at home, work, and school; the CN Tower lights the way in blue and shines attention on Rare Disease Day.

<http://ehlers-danlossyndromecanada.org/rare-disease-day-2014.html>

<http://www.rarediseaseday.org/event/canada/203>

www.rarediseaseday.org

www.globalgenes.org

www.cntower.ca

TORONTO, ONTARIO-(February 28, 2014)

Starting at sunset on February 28th until sunrise the following morning, Toronto's CN Tower will light up blue to raise awareness of Rare Disease Day and Ehlers-Danlos Syndrome. The CN Tower is the first Canadian monument to honour Rare Disease Day. The lights will run continuously with the exception of the CN Tower's hourly light show which will run for eight minutes at the top of every hour.

Rare Disease Day commenced in 2008 and quickly spread across the globe, to unify people with all forms of rare diseases and make an international impact. This year's theme is 'Join Together for Better Care' www.rarediseaseday.org. Notably, 80% of rare diseases are of genetic origin and the Global Genes Project aims to advocate for people with faulty "genes" by encouraging everyone to show their support and wear blue "jeans" on Rare Disease Day. This associated movement inspired blue as the lighting choice <http://globalgenes.org>.

EDS Canada spearheaded this event to raise awareness for all rare diseases! In conclusion to a week of commemorative events, on March 3rd & 4th, 2014, EDS Canada's President, Ms. Tiffany Skladan, will attend the (CORD) Canadian Organization for Rare Disorders' Conference and Parliamentary Action Day <http://raredisorders.ca>. Tiffany, an EDS patient herself, will attend the conference in order to represent the estimated 7,000 Canadians living with Ehlers-Danlos Syndrome.

-2-

Defining the Toronto skyline, at a height of 553.33m (1,815 ft., 5 inches), the CN Tower is Canada's National Tower, an engineering Wonder and Toronto's must see attraction visited by over 1.5 million people annually. With the installation of innovative, energy efficient programmable LED exterior lighting, the CN Tower literally lights up the Toronto skyline each night vividly bringing light to many great causes. www.cntower.ca

Ehlers-Danlos Syndrome Canada provides knowledge, advocacy and support to individuals and their families living with Ehlers-Danlos Syndrome. It is a difficult to diagnose chronic degenerative illness.

Remarkably, as of February 28, 2014, our EDSC's Facebook page has reached over 1500 participants! www.facebook.com/edscanada

Thank you supporting this global initiative. Please visit our website and Facebook page. We look forward to your feedback.

Contact information: info@ehlers-danlossyndromecanada.org