International Epilepsy Day – Making Artisan Soap to Raise the ‘Bar’ for Those Living with Epilepsy

To bring awareness to SUDEP and ultimately help reduce epilepsy deaths, Maria DiPietrantonio-Lambert is honouring her daughter by launching a new line of artisan soap.

Worldwide an estimated 65 million people live with recurrent seizures, known as epilepsy\(^1\). Each year, on the second Monday of February, people celebrate International Epilepsy Day and highlight the problems faced by people with epilepsy, their families and carers\(^2\).

Maria DiPietrantonio-Lambert of Hastings County, Ontario, is marking the occasion by launching a handcrafted, all vegan, soap line called ‘Soap for SUDEP’. By debuting this new line and sharing her daughter’s story, Maria hopes to encourage learning about epilepsy and SUDEP.

People living with epilepsy are at heightened risk of premature death compared to the general population. The main causes include injuries sustained during a seizure, status epilepticus (when a seizure is continuous and unremitting) and suicide. However, there are cases where no cause of death can be found and the person with epilepsy who died suddenly was otherwise healthy. This is known as Sudden, Unexpected Death in Epilepsy (SUDEP). It is estimated to occur in one in a thousand people with epilepsy, but this rises to 1 in 150 for people with seizures that are poorly controlled with medication.

Maria’s 17-year old daughter, Alecia, was lost to SUDEP on 3 February, 2009. “I’m determined to prevent other families from being left in the dark about SUDEP, as we were,” says Maria. “With ‘Soap for SUDEP’ we want to raise public awareness and generate funds for SUDEP research. We need to find out the causes of these deaths and how to stop them.” With each ‘Soap for SUDEP’ bar purchased, Alecia’s Artisan Soapery\(^3\) will donate $1.00 to SUDEP research via the Canadian charity SUDEP Aware\(^4\).

Tamzin Jeffs, cofounder of SUDEP Aware adds, “Sadly, too many people living with epilepsy are unaware of SUDEP, how they may reduce their risk and the importance of discussing this with their healthcare provider. Initiatives like ‘Soap for SUDEP’ help to bring much needed public attention to the leading cause of epilepsy-related death and vital funds for research. We are extremely grateful to Maria and her family for their support.”

More information about SUDEP and the work of SUDEP Aware can be found at www.sudepaware.org.

‘Soap for SUDEP’ bars are available for purchase online at: www.aleciasoapery.com/shop
PRESS RELEASE
Toronto, Ontario, Canada - Monday, 12th February 2018

AVAILABLE ONLINE
WWW.ALECIASOAPERY.COM

$1 TO SUDEP RESEARCH
WITH EACH BAR SOLD

Sudden, Unexpected
Death in Epilepsy (SUDEP)

HAPPY SOAPING!
IN ALECIA’S HONOUR

Learn more @
SUDEP Aware.org
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Further notes/reading:

- For information about epilepsy and to connect with your local Canadian epilepsy organization visit: the Canadian Epilepsy Alliance.
- International Epilepsy Day is a joint initiative created by the International Bureau for Epilepsy (IBE) and the International League Against Epilepsy (ILAE).
  - IBE was founded in 1961 and is an international organisation for national epilepsy organisations representing people with epilepsy around the world.
  - ILAE was founded in 1909 and is a federation of more than 100 national chapters, with one chapter per country. Its membership mainly consists of medical professionals working in the field of epilepsy worldwide.

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1 https://epilepsy.org/about-epilepsy/
2 https://epilepsy.org
3 https://www.aleciasonapery.com
4 https://www.sudepaware.org