Purple Day[®] raises awareness of sudden death in epilepsy and promotes the SUDEP Global Conversation

The <u>Anita Kaufmann Foundation</u> together with the editor organizations of the newly launched online resource '<u>SUDEP Global Conversation</u>' (<u>SUDEP Aware Canada</u>, <u>SUDEP Action UK</u> and <u>Epilepsy Australia</u>) have joined forces to bring greater awareness of mortality in epilepsy around the world, through Purple Day[®].

Nine-year-old Cassidy Megan created the idea of Purple Day[®] in 2008, to bring better understanding to epilepsy and to reassure people with epilepsy, and their families, that they are not alone. Now she plans to do the same for families impacted by death in epilepsy, via new Purple Day[®] SUDEP materials and by promoting the SUDEP Global Conversation website www.sudepglobalconversation.com as a recommended resource for reliable SUDEP information.

Sudden Unexpected Death in Epilepsy (SUDEP) refers to the death of a person with epilepsy that occurs without warning, and where no other cause of death can be determined. SUDEP risk varies from person to person but there are simple measures that can be taken to lower the risk. The first step is an honest, open discussion between a person with epilepsy and their doctor.

Cassidy Megan says, "SUDEP is still not talked about enough. By highlighting it as part of Purple Day's global awareness effort, we hope to encourage conversation around the world. We need to learn more about it, find its cause and how to prevent it."

According to SUDEP Aware's Executive Director Tamzin Jeffs, "Through partnering with Purple Day[®] and with the help of their *Purple Day Every Day initiative* the increased global reach will bring better awareness to SUDEP. SUDEP is a vital risk that must be assessed with all other epilepsy-related risks when making daily lifestyle decisions. Keeping fully informed and aware of all the facts about epilepsy is important, not just on Purple Day but *Every Day*."

New Purple Day® SUDEP materials are now available from:

http://www.purpledayeveryday.org/

ENDS, 26 March 2015

About Purple Day®

Purple $\mathsf{Day}^{\$}$ is an internationally recognized grassroots effort dedicated to raising awareness

of epilepsy around the globe. Every year, on March 26th, people from countries far and wide

wear purple and hold events in their communities to help bring better understanding to

epilepsy.

Purple Day® was founded in 2008 by nine-year-old Cassidy Megan of Nova Scotia, Canada,

and is run in partnership with the Epilepsy Association of Nova Scotia and the Anita

Kaufmann Foundation in the United States.

An initiative called 'Purple Day Every Day' has been launched to expand the impact and

reach of Purple Day® and encourage epilepsy awareness 365 days per year!

For more information, visit:

Anita Kaufmann Foundation http://www.akfus.org/

Epilepsy Association of Nova Scotia http://www.epilepsyns.org/

Purple Day[®] http://www.purpleday.org

Purple Day Every Day http://www.purpledayeveryday.org/

About SUDEP Global Conversation

SUDEP Global Conversation is a unique SUDEP knowledge resource created by a three-way

collaboration between SUDEP Aware Canada, SUDEP Action UK and Epilepsy Australia. It

combines the latest research and insight of nearly 60 experts with the powerful accounts of

over 35 bereaved families from around the world.

This new, web-based resource was launched last December and follows the success of two

earlier books (created in 2005 and 2011) that have been widely distributed, in both hard

copy and electronically, between 2005 and 2014.

For more information, visit:

SUDEP Global Conversation website http://www.sudepglobalconversation.com

Epilepsy Australia http://www.epilepsyaustralia.net/

SUDEP Action http://www.sudep.org/

SUDEP Aware http://www.sudepaware.org/