



## MEDIA RELEASE

# Ontario Family Organizes 'Slide for SUDEP':

## Event to Call Awareness to Sudden Unexpected Death in Epilepsy (SUDEP)

MARKDALE, ONTARIO (January 24, 2012) - On February 24, with the help of their local community and Beaver Valley Ski Club, Deb and Dave Fawcett are hosting a fun-filled day on the slopes in memory of their daughter, Jordan. Registration is now open for Jordan's Slide for SUDEP: an action-packed event with Olympian and World Cup champion Todd Brooker that includes skiing, snowboarding & snowshoeing, indoor activities, a buffet lunch, bucket prize draws, an auction and an après ski social with live band.

This fundraiser is to celebrate Jordan's life and to also improve awareness and understanding of sudden unexpected and unexplained death in epilepsy (SUDEP) through supporting the work of the not-for-profit organization **SUDEP Aware**. Co-founder Dr Elizabeth Donner, a pediatric neurologist at SickKids Hospital in Toronto, will be at the event to share her knowledge of epilepsy and SUDEP.

In November 2010, the Fawcetts lost their 15 year old daughter to SUDEP. It was just twelve months after Jordan's first seizure. Through this tragedy, the Fawcetts have come to understand that the possibility of SUDEP cannot be discounted for those, such as Jordan, who are considered at low risk. They are determined to prevent this from happening to others and strongly advocate for people with epilepsy to discuss SUDEP and seizure reduction with their healthcare provider.

**What:** A day of skiing, snowboarding, snowshoeing and other fun activities in memory of 15 year old Jordan Fawcett.

**Why:** To celebrate Jordan's life and to raise awareness about SUDEP.

**When:** **Friday, 24 February, 2012.**

**Where:** Beaver Valley Ski Club, 100 Pioneer Drive, RR#4, Markdale, Ontario.

**Who:** Everyone is welcome.

### Contact details:

Event registration: Cheryl Crowther, Beaver Valley Ski Club, (519) 986-2520 x224, [cheryl.crowther@beavervalley.ca](mailto:cheryl.crowther@beavervalley.ca)

Event information: Deb/Dave Fawcett, (519) 924-3142, [deb@fishlady.ca](mailto:deb@fishlady.ca)

SUDEP information: Tamzin Jeffs, SUDEP Aware, (416) 556-8770, [tcieffs@sudepaware.org](mailto:tcieffs@sudepaware.org)

Make a donation: [www.sudepaware.org](http://www.sudepaware.org)



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### BACKGROUND

#### **About SUDEP:**

One in 100 people have epilepsy, the neurological condition characterized by recurrent seizures. These individuals face an increased risk of death compared to the general population. The main causes include epilepsy-related accidents, status epilepticus (where a seizure or cluster of seizures continue for more than 30 minutes), suicide and instances of sudden death that occur without warning or explanation, known as SUDEP.

Recent studies estimate the rate of SUDEP among people with all types of epilepsy at approximately one death per 1000 people per year. Due to the nature of SUDEP, it is very difficult to know exactly how often it occurs. Identification of SUDEP cases is hindered by a general lack of awareness and by the fact that age-related factors cannot be excluded as causes of death in the older population.

Research shows the rate of SUDEP varies greatly according to the group of people being studied. For example, in general, children tend to have lower rates of SUDEP than adults. Individuals with seizures poorly controlled by medication tend to have higher rates of SUDEP than those with seizures under better control.

The risk factors for SUDEP include frequent generalized tonic-clonic (grand mal) seizures and younger age of epilepsy onset. Individuals with epilepsy may reduce their risk by working with their healthcare team to have as few seizures as possible. For some people this could mean adjusting medications or lifestyle factors, for others it could mean exploring different avenues of treatment, such as surgery.

#### **About SUDEP Aware:**

SUDEP Aware is a not-for-profit organization founded by Tamzin Jeffs, an active member of the epilepsy community who lost her sister to SUDEP and herself has epilepsy, and Dr Elizabeth Donner, a pediatric neurologist and researcher at Toronto's SickKids Hospital. It is run by volunteers who recognize that awareness is the first step in determining the cause and prevention of SUDEP. Through education, research, support and collaboration, and its Making Sense of SUDEP campaign, SUDEP Aware works to improve knowledge and understanding of SUDEP. Further information is available at [www.sudepaware.org](http://www.sudepaware.org).

#### **SUDEP information:**

Tamzin Jeffs, SUDEP Aware, (416) 556-8770, [tcjeffs@sudepaware.org](mailto:tcjeffs@sudepaware.org)



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Jordan Fawcett skiing



Jordan Fawcett