

## **CANADIANS WITH EPILEPSY FACE SERIOUS HEALTH AND SOCIAL IMPACTS: NEW SURVEY**

### **Stigma, independence, social and work barriers among top challenges to be addressed**

**TORONTO, Ont. (February 27, 2012)** – Results released today from *The Impact of Epilepsy on Canadians* survey reveal that Canadian adults struggling to control the common seizure disorder face serious health obstacles, including access to specialized care and treatment options, as well as numerous social impacts. They list stigma, independence, and social and work barriers among the top challenges that need to be addressed. Conducted by Leger Marketing in late 2011, *The Impact of Epilepsy on Canadians* survey is the first of its kind in Canada to explore the impact on life and health among adults living with the disorder.

“We are grateful to the many Canadians from St. John’s to Victoria who shared their experiences living with epilepsy through this important survey,” says Gail Dempsey, President of the Canadian Epilepsy Alliance (CEA). “Their insights confirm that many are still struggling to live well with epilepsy, and importantly, they point to where changes are needed most across the country to improve lives.”

#### **Restricted independence and discrimination**

Every day, many Canadians living with epilepsy experience social isolation, work barriers and relationship issues, according to *The Impact of Epilepsy on Canadians* survey. Over half of respondents (56 per cent) say that restricted independence due to epilepsy is their number one challenge. Stigma, discrimination and a lack of awareness about epilepsy is cited by 38 per cent as the number two challenge, along with the impact of the disorder on their social life. The third biggest challenge facing Canadians with epilepsy is maintaining employment, with half saying their job choices are restricted, and just under 40 per cent unable to get a job if they disclose their condition.

“Since I was diagnosed with epilepsy more than 28 years ago, I have learned to cope with the many challenges of this disorder, including the effects of seizures and the feeling of isolation which comes as a result of stigma and discrimination,” says Terri Beaton, who lives in Victoria, B.C. “This survey, as well as connecting with my local epilepsy society, has given me a voice – a way to share my experiences with epilepsy, in the hopes of overcoming the obstacles faced by all those who are touched by it, including our family, friends and colleagues.”

#### **Access to medical care, community services**

Beginning at diagnosis and throughout their lives, *The Impact of Epilepsy in Canada* survey indicates that Canadians living with epilepsy need improved access to specialized medical care. On average, respondents waited nearly four years to be diagnosed with epilepsy, and almost one year to be seen for the first time by an epilepsy specialist. About 60 per cent of the respondents who were candidates for surgery waited up to five years to undergo surgery for epilepsy. For ongoing treatment of epilepsy, 40 per cent report seeing their General Practitioner or family doctor regularly, and only 30 per cent have ever been to see an epileptologist, a neurologist who specializes in epilepsy.

The survey findings also show that access to community-based government support services and disability programs is lacking, according to some respondents. Although social services exist for people with epilepsy, two-in-ten Canadians living with epilepsy say they are not available in their communities. And with just over three quarters (77 per cent) of respondents believing that uncontrolled epilepsy

should be classified as a disability, 41 per cent report that government disability programs are not available to them.

### **Frequency and treatment of seizures**

*The Impact of Epilepsy on Canadians* survey confirms that the majority of Canadian adults living with epilepsy continue to endure seizures which have profound physical, psychological and emotional consequences. Nearly all (96 per cent) of those who responded to a question about seizure frequency indicated that they suffer from seizures, with only four per cent reporting being seizure free.

The survey also underscores that access to new and better treatment options is needed to minimize the impact of epilepsy on all Canadians touched by the disorder. Most respondents (82 per cent) say they rely on medications to manage seizures, and that they have been prescribed an average of four different drugs since they were diagnosed.

### **Taking a stand for epilepsy**

“In light of these survey results, it is time for Canadians to take a stand in support of people living with epilepsy,” urges Dempsey. “Together, we must strive to eliminate stigma through greater public education, expect and demand the best specialized care and social supports, and ensure better access to all safe and effective treatment options for optimal seizure control,” concludes Dempsey.

The *Impact of Epilepsy on Canadians* survey, conducted by Leger Marketing, was funded by UCB Canada Inc., and completed by 671 Canadian adults living with epilepsy in both official languages, online or on paper, between August 9 and October 14, 2011. A probability sample of the same size would yield a margin of error of +/-3.8 per cent, 19 times out of 20.

Please visit [www.epilepsymatters.com](http://www.epilepsymatters.com) for more information and to locate your community epilepsy support organization.

### **About Epilepsy in Canada**

*Epilepsy is a chronic neurological disorder that affects approximately 300,000 people in Canada., Epilepsy is characterized by a tendency to have recurrent seizures caused by abnormal, excessive electrical discharges of the nerve cells, or neurons, in the brain. Living with the condition can have severe impacts on a person’s independence, productivity and overall quality of life. It can also cause significant challenges including difficulty finding employment, loss of driving privileges in some provinces, cognitive decline, memory impairment and higher mortality rates. People living with epilepsy also face significant social stigma associated with seizures.*

### **About the Canadian Epilepsy Alliance**

*The Canadian Epilepsy Alliance (CEA) is a Canada-wide network of grassroots organizations dedicated to the promotion of independence and quality of life for people with epilepsy and their families, through support services, information, advocacy and public awareness. The CEA network includes rural, urban, local and provincial incorporated Epilepsy Associations from coast to coast in Canada and currently has member associations in Newfoundland and Labrador, Nova Scotia, Quebec, Ontario, Saskatchewan, Alberta and British Columbia. Visit [www.epilepsymatters.com](http://www.epilepsymatters.com) for more information.*

### **About UCB Canada Inc.**

*UCB Canada Inc. was officially incorporated in 2006 with the objective of bringing new-generation therapies to the Canadian market for auto-immune and central nervous system diseases. As a patient-focused organization, the company is dedicated to bringing new and innovative programs to patients, and to the specialists who treat them, to help improve the lives of people living with severe diseases.*



The Impact  
of Epilepsy on  
Canadians

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