

World Congress on

NEUROSCIENCE AND EPILEPSY

November 16-17, 2018 Tokyo, Japan

Attitudes and experience of cannabinoid-based therapies for epilepsy in the Australian community**Carol Ireland and Lisa Todd**

Epilepsy Action Australia, Australia

Purpose: Epilepsy Action Australia (EAA) sought to understand the attitudes toward and lived experiences of adults and parents of children living with epilepsy of cannabinoid-based therapies in an ever-changing climate of public opinion, government legislation and clinical trials in Australia.

Method: Two studies were undertaken with the first informing the second study. A nationwide online survey was conducted assessing demographics, clinical factors, including diagnosis and seizure types and experiences with and opinions towards cannabis use in epilepsy. The second study (PELICAN) focused on experiences of 61 families of children with epilepsy under the age of 16 years who desired, were currently or had previously administered cannabinoid-based therapies to their children to manage seizures. Semi-structured interviews were conducted; samples collected with subsequent laboratory analysis.

Results: 976 responses met the inclusion criteria of the initial survey. 15% of adults with epilepsy and 13% of parents/guardians of children with epilepsy were currently using, or had previously used, cannabinoid-based products to treat epilepsy. Of those with a history of cannabis product use, 90% of adults and 71% of parents reported success in reducing seizure frequency. 41 of the 65 families participating in the second study (PELICAN) were currently or had previously administered cannabinoid-based therapies to their children. Analysis of the products highlighted a wide variability of cannabinoid content and low concentration of Cannabidiol (CBD) while $\Delta 9$ -tetrahydrocannabinol (THCA9) was present in nearly every sample.

Conclusion: The survey provides insight into the use of cannabis products for epilepsy, in particular some of the likely factors influencing use, as well as novel insights into the experiences of and attitudes towards medicinal cannabis in people with epilepsy in the Australian community while the PELICAN study highlighted the profound variation in the illicit cannabis extracts being utilized as therapies in epilepsy in Australia warranting further investigation.

Biography: Carol Ireland & Lisa Todd

Carol Ireland, CEO and Managing Director of Epilepsy Action Australia (EAA), Carol has an extensive background spanning 35 years in the not-for-profit human services sector, holding a variety of executive positions. She has been at the forefront of the medical cannabis movement in Australia. In her role at Epilepsy Action Australia she has had significant contact with many individuals and families faced with managing very challenging forms of medication resistant epilepsy, with few or no options left in the conventional treatment bucket. Carol has heard and seen the changes in people's lives, including reduction in the severity and frequency of seizures, resulting from use of medicinal cannabis. Carol serves on the Australian Advisory Council for the Use of Medicinal Cannabis, Advisory Board of The Lambert Initiative for Cannabinoid Therapeutics, Steering Committee for the NSW government's Pediatric Epilepsy Trials (MC Research), and is a founding Director of the Medicinal Cannabis Council. She is a strong and active advocate for people living with epilepsy.

Lisa Todd is a Clinical Nurse Consultant in Epilepsy and Clinical Governance Manager for Epilepsy Action Australia. She is a Registered Nurse with a Post Graduate Certificate in Neuroscience Nursing and Masters of Education. Lisa is a trained cannabis nurse, having attended numerous educational seminars, conferences and master classes for health care professionals in the United States and Australia. She was the lead investigator and co-author on 'An Australian nationwide survey on medicinal cannabis use for epilepsy: History of antiepileptic drug treatment predicts medicinal cannabis use' published in *Epilepsy & Behaviour* (2017) and Co-investigator in the PELICAN study (Pediatric Epilepsy Lambert Initiative Cannabinoid Analysis) with the University of Sydney. Prior to her work in the field of Medicinal Cannabis Lisa was seconded to the George Research Institute for Global Health for several years as Research Fellow for the SEMISIC study (Sydney Epilepsy Incidence Study to Measure Illness Consequences).

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