CHILD NEUROLOGY FOUNDATION SYMPOSIUM

CANNABIS IN EPILEPSY: CLINICAL SCIENCE, PARENT & CAREGIVER PERSPECTIVES

WILLIAM H. TRESCHER, MD – SURVEY RESULTS
LOLLY BENTCH – PARENT AND ADVOCATE (VIA VIDEO)
ELIZABETH THIELE, PH.D., M.D. – STATE OF SCIENCE
CATHERINE JACOBSON, PH.D. – PARENTAL VIEW - PLUS
ANUP PATEL, M.D. – CANNABIS USE IN CHILD NEUROLOGY: LOOKING FORWARD
AMY BRIN MILLER – MSN, MA, PCNS-BC – ADVOCACY VOICES
CANNABIS IN EPILEPSY
UNDERSTANDING CURRENT USE AND ATTITUDES TOWARDS CANNABIS: RESULTS FROM CNS MEMBERSHIP AND PARENT/CAREGIVER SURVEYS

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Disclosures

- Mallinckrodt Advisory Board for Infantile Spasms
- State of Pennsylvania Advisory Board and Physician Working Group for Medical Cannabis
Mission of the Child Neurology Foundation

We are committed to serving as a connective center for education and support for children and families living with neurologic condition.
Goals of the Symposium
A Dialogue Between Mars and Venus

- Understand the current views of some neurologists regarding the role of medical cannabis for the treatment of epilepsy in children.
- Understand the history and science behind cannabinoids in the treatment of epilepsy.
- Review the current clinical evidence for medical cannabis in the treatment of epilepsy.
- Develop an appreciation for the position of some parents/caregivers with regards to medical cannabis and the treatment of children with epilepsy.
Survey Results of Child Neurologists and Parents/Caregivers on Cannabis Use for Epilepsy

- Survey to Child Neurology Society members in September 2016
  - 167 responses
- Survey to parents and caregivers identified through several advocacy groups (CNF, CURE, Global Genes, Lennox-Gastaut Syndrome Foundation, Dravet, TS Alliance, others) Sept. 2016
  - 479 responses
CNS Member
Survey
Responses
74% - Currently legal
14% - Not legal
10% - Legalization under consideration
2% - Did not know
47% cared for patients who had participated in an organized trial of a cannabinoid for epilepsy

49% did not have patients in any trials

4% did not know
Attitudes of Prescribing if Medical Cannabis were legal

- 27% would write a prescription for a high CBD product
- 38% do not have enough information to prescribe or recommend
- 20% support use but would refer to someone else for the prescription
- 15% would not support cannabis in any form at this time
Neurologist’s Prescribing Knowledge for Medicinal Cannabis

Do you feel you have adequate knowledge/information on proper (current) dosing?

- Yes: 15%
- No: 85%
Reasons for not writing a script for cannabis use – 73% of respondents

- It will not be effective: 16%
- It is not safe: 22%
- No available options for monitoring levels: 52%
- Inadequate knowledge of potential side effects: 58%
- Inadequate knowledge of proper dosing: 80%
- Inadequate knowledge of potential interactions with other medications: 75%
- Concern about medico-legal liability (mine or my hospital’s): 56%
71% aware of the statements/positions
71% of those aware responded that the statements were helpful
How were the statements helpful?

- Made me aware of the issue: 49%
- Validated my current position: 55%
- Educated me on the current research: 66%
- Reaffirmed the need for more research into CBD: 92%
What are the Next Steps for Cannabis Treatments for Epilepsy?

- Randomized controlled clinical trial with placebo control and a classical design
- Open-label trial restricted to a few sites with careful follow-up of patients/caregivers
- States should continue to pass legislation allowing physicians to legally prescribe CBD oil
- States should permit individuals to use CBD oil or marijuana legally for epilepsy
Parents/Caregiver Survey Responses
Parent/Caregiver Survey

Respondents

- 79% - Parent
- 6% - Grandparent
- 15% - Family member/legal guardian/other

Sources of respondents: Wide range of disease groups, advocacy organizations, and CNF (10%)
Parent and Caregiver Survey
Legal status by State of Residence

- 58% medical cannabis is legal
- 24% medical cannabis not legal
- 12% under consideration by state government
- 6% status not known
If legal, what level of access to medical cannabis would you support:

- Any type of prescribed medical cannabis: 79%
- Only to prescribed medical cannabis with high cannabidiol (CBD) content: 12%
- Not enough knowledge about medical cannabis to answer: 9%
- Do not support the use of medical cannabis in any form at this time: 1%
Parent/Caregiver Reasons for Not Using Medical Cannabis (41)

- 63% - Inadequate knowledge of interactions with other medications
- 51% - Inadequate knowledge of dosing
- 44% - Inadequate knowledge of side effects
- 27% - “other”
- 10% - Not safe
- 2% - Not effective – one respondent!
How does your physician perceive medical cannabis to treat epilepsy?

- Positive: 34%
- Negative: 7%
- Neutral: 24%
- Don’t know: 34%
32% - Medical Provider recommended cannabis use
Sources of Information
Medical Cannabis (often multiple)

- 85% - Internet search
- 61% - Epilepsy or disease specific community
- 57% - Online forum/social media channels
- 54% - Parents/caregivers
- 37% - Physicians
- 17% - Other (marijuana growers, friends, professional colleagues, documentaries such as Dr. Sanjay Gupta, other media, PubMed, etc.)
Parent/Caregiver views on what would bolster use of medical cannabis

- 77% - Research data showing efficacy
- 59% - Physician recommendation
- 58% - Parent/Caregiver positive experience
- 36% - Support group recommendation
- 13% - Other
- 1% - Do not support use
Parents/Caregivers views on what they would like from physicians

- 48% - The physician’s experience and knowledge about cannabis
- 24% - Research announcements
- 14% - Connection to other parents/caregivers
- 12% - Educational opportunities
- 8% - Informational handouts
“I have been the PI on all of GW trials and thus feel more educated than most about high CBD content products.”

“These trials have already occurred for Dravet and LGS—so unsure why CNS is asking.”

“Don’t see this as CNF priority but, if it is, focus should be on regulatory issues.”
“Support access to pharmaceutical grade, contaminant free CBD +/- THC for randomized placebo controlled trials.”

“Conduct rigorous clinical research.”

“Support scientific research regarding cannabis and cannabinoid receptors in the brain. Support re-classification by the DEA so that more research can be done. Support long-term research on the effects of marijuana use in teens.”
“Guide patients to FDA approved CBD sites. Encourage people to not use the home brew CBD oils. Encourage the FDA and companies to use the expanded access programs for the two FDA approved products so more patients could be treated with real CBD.”

“Continue to advocate for DEA rescheduling of CBD and FDA approval of Epidiolex.”

“Advocate for FDA monitoring of drug quality, purity as it does for other medications.”
“Federal decriminalization of CBD.”

“Federal law needs to be changed before my hospital will allow physicians to prescribe CBD.”

“It isn’t just a state issue—it is a Federal issue. If kid is admitted to hospital, can't administer CBD.”
“Advocate for research that addresses potential impact of cannabis on brain development in children with intractable epilepsy. Much of my concern is that while cannabis may lessen the frequency of seizures in these patients, the deleterious effect on development may actually cause a worse outcome.”

“Need to await results of clinical trials and a pharmaceutical grade product. First do no harm.”

“I am more concerned about long-term psychiatric side effects, but support the use as a palliative measure.”
“My daughter has been on cannabis oil for 3 years. She had previously failed most of the available AED's and many combinations of them. Cannabis has been the most effective for seizure control for her, with not only, no negative side effects, but positive ones, in addition to seizure control. We experienced negative side effects with the less effective results from all the AED's. Based on our experience, I believe cannabis is the most benign treatment available and should be tried first. Our life would have been very different, for the better, if we would have had that opportunity.”
“It has incredible medical value and offers a more natural alternative with fewer and less severe side effects than traditional pharmaceuticals.”

“The side effects for current epilepsy pharmaceuticals are horrendous – worse than the disease. Cannabis offers help without horrible side effects.”
“My daughter has intractable epilepsy, and a 20:1 CBD oil has done what 5 anti-epileptic drugs (AEDs) and a rescue medication had failed to do: control her seizures while allowing to thrive and catch up developmentally.”

“No one has died from an overdose of cannabis whereas there are multitude of dangerous side effects from drugs such as Tegretol, Ativan, etc. One mistaken pill can be fatal.”
“My neurologist was not open to us trying CBD due to our son's age. However, he did provide us with the opportunity to meet with another neurologist who enrolled us in a clinical trial for CBD. Because of the trial, we felt safe giving it to him due to the level of physician oversight.”

“I would like to see more studies on long-term effects both positive and negative.”
“Although our daughter is still not seizure free while using CBD she has been greatly improved. We just wish that there was more research available and that there was more "industry" oversight into quality control....it would be nice to be able to discuss this with the pharmacist like we can any other FDA approved substance and get reliable information.”
“No information from our doctors. Any information I have received was anecdotal reports from parents who moved their families to a legal state and began using it for their child. 95+% have been overwhelmingly positive.”

“From a physician? None, just deep skepticism.”
Neither survey is scientifically sound and as such open to bias.

Nevertheless, there is some disconnect between CNS member responses and the parent/caregiver responses.
Need more information on cannabinoids in the treatment of epilepsy.
Desire more research on the use and effects of cannabinoids in the treatment of epilepsy
Express desire for FDA approval and reservation about using artisanal forms of cannabis.
Summary
Parents/Caregivers

- Seem to desire more research, evidence, and support from physicians in the use of medicinal cannabis.
- Are less worried about and maybe even favorable to broader forms of cannabis.
- Are not willing to wait for the results of research in the face of the suffering of their children.
Lolly Bentch
Mother and Accidental Activist