

Therapeutic Cannabis Medical Oversight Board
June 21, 2023, DHHS Offices, 29 Hazen Drive, Concord (with Remote Teams option)
Meeting Minutes

Members Present: Virginia Brack, Heather Brown, Jerry Knirk (Chair), Richard Morse, Tricia Tilley, Lisa Withrow

Members Absent: Corey Burchman, Jill MacGregor, Molly Rossignol, Seddon Savage,

DHHS Staff: Michael Holt, DPHS Program Administrator

Note: In-person quorum met

Meeting convened at approximately 5:35 pm

Public Hearing – Epilepsy as a qualifying condition in children and adults under age 21

The public hearing on the reconsideration of epilepsy as a qualifying condition for therapeutic cannabis in children and adults under age 21 was held.

The first person to testify, Scott S. (Manchester), has an 11 year old son with intractable seizures. They see a neurologist at Dartmouth. Fifteen different medications have failed to control the seizures. They tried therapeutic cannabis as a “rescue” and found that it reduced the numbers of seizures but did not stop them. It also shortens the duration of seizures. He recommended keeping epilepsy as a qualifying condition for children, and said that there are sufficient checks and controls on minors becoming cannabis patients to prevent any abuses.

A board members asked if any developmental problems were noted since using therapeutic cannabis. He responded that his child already has significant developmental delays He has not regressed since using therapeutic cannabis, and he has improved, but can’t say if the cause of improvement is therapeutic cannabis.

A board member asked about the other drugs which were used before therapeutic cannabis. He stated that they did not decrease the number of seizures and had side effects of lethargy (eg, comatose, zombie-like).

A board member asked whether Epidiolex was being used. He stated that his child is currently on Epidiolex. Therapeutic cannabis is used only for “rescue” situations. Epidiolex was started about 18 months ago, and therapeutic cannabis started about four or five years ago. The therapeutic cannabis product used is a high-CBD/low-THC product.

A board member asked if he tried pure CBD for “rescue” situations, and he said yes, but it was not as effective as products with THC. The delivery method is tincture. He said they tried Diazepam as a rescue medication, but that would fully sedate his son.

A board member asked about his experience with the ATCs. He reported that the ATCs were a great experience, positive, pleasant, educated, professional. His child is certified by his PCP and his neurologist, as is currently required by program rules.

A board member asked if intended to continue to use therapeutic cannabis for his child. He responded “yes” and asked that it not be taken away, as it’s the only option that works.

The second person to testify was Lee C., former administrator of Sanctuary ATC. She stated that she was concerned about removing the condition. This would set a precedent for removing other conditions. She stated that Epidiolex is very expensive, especially for off-label uses, for which Medicaid would not pay. She emphasized the high quality products produced by the ATCs, as regulated by the TCP, including requirements for a robust quality control and improvement program. She stated that her biggest concern was about the message that removal of the condition would give.

A board member noted that Medicaid does cover Epidiolex.

The public was given another chance to provide final comments. Scott S. stated that his son needs products that contain THC.

Chair closes the Public Hearing at 6:26.

Board Discussion

Brown stated that a family member had seizures (not from epilepsy), and that she is fully functional because of using therapeutic cannabis.

Morse read his personal statement regarding what he felt should be done with epilepsy as a qualifying condition in children and adults under age 21. He noted that 1/3 of children are medication resistant.

Knirk suggested there may be non-dichotomous options to consider, like limiting products and percentages of THC. A member disagreed with that approach.

Tilley suggested that scope and scale are important factors to consider on whether to make a recommendation for a change. What is the role of the medical community? Are there already sufficient controls considering there are only 4 minor patients with epilepsy. A member responded, no, decades later, who knows the consequences, people are desperate for relief.

Brown said that the use of therapeutic cannabis should be the individual choice of the parent and their medical providers. The response is too variable to use a classical medication-dosing model. Leave it up to parents and their providers.

Withrow referred to email testimony submitted by a patient and the testimony by Scott S. and stated that their experiences with therapeutic cannabis helping when other medications did not

work indicated that epilepsy should not be removed as a qualifying condition for this population. The anxiety and panic over the potential loss of something that works for their children should be considered. The stories shared show that parents are doing their due diligence for responsible use.

Brack noted that there is no evidence that THC has a role but that whole plant extract does, and asked what is available at the ATCs. Brown answered that nearly all products are whole plant extract. Holt responded that all ATCs have low THC products, and these options were increasing based on TCMOB request for more CBD rich products. Holt showed the menu from Prime ATC demonstrating various products.

Knirk pointed out that there are several different choices as to how this could be pursued:

1. Not allow new pediatric patients to be qualified for epilepsy, but grandfather the existing ones.
2. Allow certification only if certified by the treating neurologist (guardrails).
3. Allow certification only for patients who failed standard medications, including Epidiolex.
4. A requirement for “low THC only” could be added to any of those options.

Brown pointed out what she felt was an inconsistency of removing barriers for pain certification, but adding barriers for epilepsy.

Scot S. asked what does “low” THC mean; asked why more guardrails would be necessary considering the small number of minor patients with epilepsy.

Holt reminded that the Board had recommended, and could use again, the models for allowing opioid use disorder and autism spectrum disorder.

Morse suggested the gold standard of treatment would include a pediatric epilepsy specialist or a pediatric neurologist, treated at center for epilepsy. Knirk asked Morse if all of the 1200 kids children with intractable epilepsy see a neurologist and Morse responded yes, nearly all of them do. Knirk observed that it therefore would not be an insurmountable barrier to require certification by the treating neurologist as a guardrail.

No vote was taken as the written public comment period needs to remain open for 5 days after the public hearing.

Minutes

Minutes from 4/5/23 meeting were approved
Motion: Withrow; Second: Brack; Vote: 6-0

2023 Legislative Update

None provided

TCMOB Slide Deck

No updates

Public Comments

None

Meeting adjourned at 7:36pm