

*Supplementary Material*

*Questionnaire*

*Cannabidiol for Treatment of Childhood Epilepsy*  
*– a cross-sectional Survey*

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This is the PDF-Version of a stratified and responsive digital online-Survey. Skip logic is not depicted.

\* 1. Are you treating children or adolescents with epilepsy ?

- ☐ Yes and I am a paediatrician
- ☐ Yes and I am a neurologist
- ☐ No

## ***Professional qualification***

2. Are you a board certified Neuropaediatrician ?

- ☐ Yes
- ☐ No
- ☐ Other (please specify)

3. Have you completed a formal curricular training in Epileptology?

- ☐ Yes
- ☐ No
- ☐ Other (please specify)

4. I am affiliated with / I am working in a

- ☐ Private practice / doctor's office
- ☐ Neuropaediatric/Neurological Department
- ☐ Epilepsy Center
- ☐ other (please specify)

### ***Previous experience with the use of Cannabidiol***

\* 5. Have you ever prescribed Cannabidiol (CBD) for treating epilepsy in children or adolescents?

☐ Yes

☐ No

## ***Previous experience with the use of Cannabidiol***

6. What were the treatment goals in your patients treated with Cannabidiol ? (Multiple answers possible)

- ☐ Seizure freedom
- ☐ Seizure reduction of  $\geq 50\%$
- ☐ Reduction of potentially harmful seizures ("Grand mal seizures", drop seizures)
- ☐ Reduction of epileptiform activity in EEG
- ☐ Improving patients' quality of life
- ☐ Reducing dose or number of other antiepileptic drugs
- ☐ others (please specify)

7. How many patients have you treated with Cannabidiol to date ?

Number of patients  
treated with Cannabidiol:

8. In which year did you start treating patients with Cannabidiol ?

Year

## Application of Cannabidiol

9. Which Cannabidiol preparations are you using ? (Multiple answers possible)

- ☐ Preparations manufactured by a pharmacy only available on prescription
- ☐ Preparations manufactured by a licensed pharmaceutical company only available on prescription
- ☐ Over the counter preparations (e.g. dietary supplements)
- ☐ other (please specify)

10. Have you ever used Cannabinoids other than Cannabidiol (CBD) to treat epilepsy in children or adolescents? (Multiple answers possible)

- ☐ No
- ☐ Tetrahydrocannabinol (THC, e.g. Dronabinol)
- ☐ Combination of Tetrahydrocannabinol + Cannabidiol
- ☐ Hemp (oil)
- ☐ Homeopathic cannabinoid preparations
- ☐ Vaporized medical cannabis
- ☐ Others (please specify)

## Dosing of Cannabidiol

11. What is your final target dose when treating epilepsy with Cannabidiol (mg/kg bodyweight) ?

- ☐ < 10 mg/kg
- ☐ 10 - 25 mg/kg
- ☐ > 25 mg/kg
- ☐ other (please specify)

12. This is divided into how many single doses of Cannabidiol per day ?

- ☐ 1
- ☐ 2
- ☐ other (please specify)

13. Do you gradually increase the Cannabinidiol dose ?

- ☐ Yes, gradually increase
- ☐ No, start with final target dose
- ☐ Other (please specify)

14. In your opinion is there a maximum permissible Cannabidiol dose ?

- ☐ Yes
- ☐ No, dosage should be based on body weight
- ☐ others (please specify)

## ***Dosing of Cannabidiol***

15. The maximum permissible daily dose of Cannabidiol is

dose in milligrams (mg)



## Monitoring & management of side effects

16. Do you perform liver function tests during Cannabidiol treatment ?

- ☐ No
- ☐ Routinely
- ☐ Only in case of clinical signs indicating adverse effects
- ☐ Only in case of a co-medication with Valproate
- ☐ Other (please specify)

17. Do you consider one of the following conditions to be contraindications for the use of Cannabidiol?

	No contraindication	Relative contraindication	Absolute contraindication
Failure to thrive	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Elevated liver enzymes	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Psychiatric comorbidities	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
History of or current substance abuse	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Obesity	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

18. How do you proceed with preexisting anticonvulsive medications ?

	Discontinue Drug	Maintain dose unchanged	Reduce dose	Increase dose
Valproate	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Clobazam	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Phenobarbital	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Phenytoin	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Carbamazepine	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Topiramate	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Zonisamide	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

other (please specify)

19. Do you measure serum levels of Cannabidiol to adjust treatment dose ?

☐ Yes

☐ No

☐ Other (please specify)

## Indication for the use of Cannabidiol

20. Would you consider using Cannabidiol as

- ☐ First-line treatment ?
- ☐ Second-line treatment ?
- ☐ after proven pharmcoresistancy only (definition according to ILAE) ?
- ☐ other (please specify)

21. On what basis did you or would you decide to commence a Cannabidiol treatment ? (Multiple answers possible)

- ☐ As part of a standardized departmental treatment protocol (SOP)
- ☐ Individual decision
- ☐ Only in clinical trials
- ☐ others (please specify)

22. Is the use of Cannabidiol for seizure treatment justified by the current body of evidence on this topic (as of December 2017) ? (Multiple answers possible)

- ☐ Yes, without question
- ☐ Data are limited, but current evidence from clinical experience justifies its use
- ☐ Despite limited data, Cannabidiol may be used as a last resort only
- ☐ No, current evidence does not justify its use; but my patients may start self medication therefore I would rather commence a supervised Cannabidiol treatment
- ☐ Other (please specify)

## Limitations and contraindications for the use of Cannabidiol

23. After how long should Cannabidiol be discontinued if treatment goals have not been achieved ?

weeks

months

24. In your opinion, which forms of epilepsy should **NOT** be treated with Cannabidiol? (Multiple answers possible)

- ☐ Dravet syndrome
- ☐ other genetic epilepsy
- ☐ Lennox-Gastaut syndrome (LGS)
- ☐ structural epilepsy without LGS
- ☐ other (please specify)

25. Which age group(s) should **NOT** be treated with Cannabidiol due to potential **safety** issues ?  
(Multiple answers possible)

- ☐ Neonates (day of life 0-28)
- ☐ Infants (day of life 28 - 1 year of age)
- ☐ Toddlers ( 1 - 5 years of age)
- ☐ School children ( 6 - 12 years of age)
- ☐ Adolescents ( 13 - 18 years of age)
- ☐ All of the above could be treated with Cannabidiol
- ☐ Other (please specify)

## ***Interaction with patients / parents***

26. How often do you receive enquiries concerning Cannabidiol treatment from parents / patients ?

- ☐ Very often (at least weekly)
- ☐ Often (at least monthly)
- ☐ Occasionally (several times yearly)
- ☐ Rarely (less than above)
- ☐ Never
- ☐ Other (please specify)

27. Do you actively suggest to parents / patients to start a treatment with Cannabidiol ?

- ☐ Yes, I may suggest treatment to parents / patients
- ☐ No, I only discuss this treatment option if parents / patients enquire about Cannabidiol
- ☐ Other (please specify)

## Regulation and Reimbursement

28. What is the legal basis for the medical use of Cannabidiol in your country / jurisdiction ?

- ☐ Available for medical purposes
- ☐ Available for medical purposes after individual application and official approval of authorities
- ☐ Freely Available (without a prescription)
- ☐ Possession and use prohibited
- ☐ Other (please specify)

\* 29. How is reimbursement for the costs of Cannabidiol treatment regulated ?

- ☐ Reimbursed by the health insurance
- ☐ Reimbursed by the health insurance after individual application
- ☐ No reimbursement provided (guardians/patient have to pay out-of-pocket)
- ☐ Not applicable
- ☐ Other (please specify)

30. How often do you receive enquiries concerning Cannabidiol treatment from parents / patients ?

- ☐ Very often (at least weekly)
- ☐ Often (at least monthly)
- ☐ Occasionally (several times yearly)
- ☐ Rarely
- ☐ Never
- ☐ Other (please specify)

\* 31. What is your motivation not to use Cannabidiol to treat intractable epilepsy in children or adolescents ? (Please provide the answer that applies most)

- ☐ Not available in my country / jurisdiction
- ☐ Cannabidiol treatment will be commenced by other colleagues within my team or department
- ☐ No medical need to use Cannabidiol in my patients so far
- ☐ No personal experience
- ☐ Not enough evidence to support the use of Cannabidiol
- ☐ I do not condone the use of cannabinoids for medical purposes
- ☐ Other (please specify)

\* 32. If it was available within your country / jurisdiction would you consider using it ?

- ☐ Yes
- ☐ No, not enough evidence to support the use of Cannabidiol
- ☐ No, there is generally no indication for Cannabidiol when treating epilepsy
- ☐ No personal experience
- ☐ I dont condone the use of cannabinoids for medical purposes
- ☐ Other (please specify)



\* 33. If you had the chance to become familiar with this drug, would you then consider using it?

- ☐ Yes
- ☐ No medical need to use Cannabidiol in my patients
- ☐ Not enough evidence to support the use of Cannabidiol
- ☐ I dont condone the use of cannabinoids for medical purposes

34. Could you provide us with the contact details of the respective colleague ?

### ***Previous experience with Cannabinoids***

35. Have you ever used Cannabinoids for other conditions? (Multiple answers possible)

- ☐ No
- ☐ Epilepsy
- ☐ Spasticity
- ☐ Anorexia
- ☐ Self-regulation disorder
- ☐ Multiple sclerosis
- ☐ Other (please specify)

# **Thank you very much for participating in our survey !**

Please let us know if you have any questions concerning this survey:

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