



Epilepsy Trials and Treatment

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Outline

- I'd like to talk today about 3 topics:
- EpLink – New in Epilepsy Research
- The EpLink PUFA Trial
- The EpLink CBD Trial

EpLink

- In TSC, seizures are common and hard to control.
- There is a new epilepsy/seizure research program in Ontario.

EpLink

- **EpLink is the Epilepsy Research Program of the Ontario Brain Institute.**



EpLink

- **The OBI provides EpLink with 1.5 million per year to do epilepsy research.**
- **That makes EpLink one of the largest epilepsy research program in Canada.**

EpLink

- **EpLink consists of more than thirty epilepsy researchers.**
- **They work in Ottawa, Toronto, Hamilton and London.**

EpLink

- **They work at 6 different institutions, including:**

- The Children's Hospital of Eastern Ontario (Ottawa)
- The University of Toronto
- The Hospital for Sick Children (Toronto)
- The Toronto Western Hospital
- Hamilton Health Sciences Centre
- University Hospital (London)
- Western University (London)

EpLink

- **The Co-Directors of EpLink are:**
 - **Mac Burnham, PhD (Toronto) and**
 - **Jorge Burneo, MD (London)**
- **The Program Manager is Kathryn Hum, PhD (Toronto).**

EpLink

- **EpLink's research is “translational” research.**
- **It is designed to improve clinical epilepsy care in the near future.**

EpLink Partners

- **The Epilepsy Associations**
- **An industry advisory board**

EpLink Research

- **Drugs**
- **Diet**
- **Surgery**
- **Brain Stimulation**
- **Quality of Life**

Contact Us

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Epilepsy Trials – PUFA and CBD

- I'd like to talk today about two of our clinical trials.
- These trials might offer help for people with seizures in the near future.

The EpLink **PUFA** Trial

- It has been known for many years that special diets can help to control seizures.
- The traditional ketogenic diet, however, is very restricted and hard to maintain.

The EpLink PUFA Trial

- We are now testing an entirely new diet approach at the Toronto Western Hospital.
- It involves adding fish oil to a normal diet.

The EpLink PUFA Trial

- Fish oil is a rich source of the n-3 PUFAs.
- PUFAs are the “good” fats that improve health.

The EpLink PUFA Trial

- Research in our laboratories has shown that adding fish oil to a normal diet raises seizure threshold in rats.
- We are now trying to see whether it will work in people.

The EpLink PUFA Trial

- 15 adult patients are getting fish oil supplement s– 15 others are getting placebo capsules (double blind)
- Both groups are keeping seizure diaries.

The EpLink PUFA Trial

- The trial will last for 6 months.
- We are about half-way through.
- We will have data to report next spring.

The EpLink PUFA Trial

- **We are hopeful. A similar trial in Egypt has reported positive results in children.**
- **We will let you know the results of our study as soon as we have them.**

What Can You Do?

- **Omega 3 PUFA can be bought without a prescription at any health food store.**
- **We are giving our adults 3 grams per day.**

What Can You Do?

- **The only known side effects are diarrhea and bruising/bleeding.**
- **The effects take more than a month to occur.**

What Can You Do?

- **Crucial: You want DHA, not EPA.**
- **Many preparations contain both.**
 - EPA: Eicosapentaenoic Acid
 - DHA: Docosahexaenoic Acid

The EpLink **CBD** Trial

- A second trial will begin next summer.
- It will be a test of “medical marijuana” for seizure control.

The EpLink CBD Trial

- It has been known for thousands of years that cannabis (marijuana) suppresses seizures.
- Unfortunately, it also makes you “high”.

The EpLink CBD Trial

- **There are two major extracts from cannabis:**
- **Tetrahydrocannabinol (THC) which stops seizures and makes you “high”.**
- **Cannabidiol (CBD) which stops seizures but doesn’t make you “high”.**

The EpLink CBD Trail

- **EpLink is working with Tilray – a grower in BC – to start a trial of CBD in adults.**
- **We are currently working getting the necessary permissions from Ottawa.**

The EpLink CBD Trial

- **Adults will get either placebo, CBD or CBD with a little bit of THC (double blind).**
- **They will record their seizures in a seizure diary. The trial will last 3 months.**

The EpLink CBD Trial

- **We are hopeful. An adult trial in 1980 reported positive effects.**
- **An ongoing trial in children in the US is reporting positive results.**

What Can You Do?

- **CBD is already available in Canada under the “medical marijuana” regulations.**
- **A doctor must fill out a form. A patient can then get CBD from a grower.**

What Can You Do?

- **The dose we will be testing in adults will be about 1600 mg per day. (about 1.5 grams).**
- **The side-effects are unknown, but probably involve some sleepiness.**

What Can You Do?

- **Details of how to obtain and use CBD can be obtained from a variety of contracts.**
- **Ask me if you're interested.**

What Can You Do?

- **Crucial:** You would want to use a cannabis strain high in CBD.
- **Not THC.**



o QUESTIONS?