Cannabinoids & Epidermolysis Bullosa

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Today's greatest challenge in EB is living with Pain and Itch.

A patient-driven initiative to investigate the therapeutic potential for Cannabinoid-Based Medicines in EB.

Evidence-Based Best-Practice guidelines

Cannabinoid Modulation of Pain and Itch Signalling
Our drugs are not sufficient!
Patient Discoveries

Patients, their families and friends are challenged.

Reciprocate, Assess and Improve
Endocannabinoid System

Appetite, pain-sensation, mood and memory

CB-1

CB-2

Arachidonoyl ethanolamide

2-Arachidonoyl glycerol
(Phyto-)Cannabinoids

Δ9-tetrahydrocannabinol (THC) & Cannabidiol (CBD)
The Netherlands

- 1976 Opium-act
- Ways to obtain cannabis:
  - Self Cultivation
  - Buying from a Coffeeshop
  - On prescription
- 2001 Office of Medicinal Cannabis (OMC)
- 2003 Cultivated and Distributed (prescribed)
Number of times medicinal cannabis was dispensed within the prescription program between 2007 and 2016

- It is Legal!
- Government reimbursement
- Success stories
- Until 2010, 50% used for Pain

Graphic Source: 15 december 2016, Pharmaceutisch Weekblad, Jaargang 151 Nr 50. Stichting Farmaceutische Kengetallen (data unavailable for 2017)
Why the increase?

- Reproducibility is difficult
- Standardization
- Medical/Research-grade cannabis
  - genetically identical
  - standardized oil (GMP)
- Reliable administration forms?
Administration Routes

Onset of effects after intrapulmonary and oral administration of cannabis

Time after administration of cannabis in minutes

- Intrapulmonary
- Oral
Intrapulmonary

• Most preferred around the world
• Fast effects
• Inconsistent
  – Breath hold time, depth of inhalation, puff duration; compositions; dosing.
• Safety
  – Toxicity

→ Vaporization
  • Non-toxic; consistent; temperature control; training
Oral

- Most common method of patient self-medication in the Netherlands
- Varied metabolism, location of absorption.
- Cannabinoids = Lipid Soluble

→ Sublingual oil
  - GMP
  - faster absorption
  - precise dosing
Topical?
Entourage Effect

• Synthetic, Purified, Cultivar

• Monotherapy?

• Combination of cannabinoids is more effective
Dutch Patients' Experience

- Prevalence and characterization of Cannabis-use to treat pain and itch in EB. A cross-sectional survey with 44 patients in the Netherlands. NHB Schräder, WY Yuen, MF Jonkman. Unpublished.

N = 44 Participants

N = 7 with cannabis-use

N = 3 to treat itch

N = 5 to treat pain

**Pain:**
- “Reduced severity and frequency”
- “Worsening of symptoms when not using cannabis”
- “Worked better than other medicines”

**Itch:**
- “Reduced Severity and frequency”
- “Easier to hold off from scratching”
Conclusions

- Patients use cannabis
- Pain and itch are improved
- No severe side effects
- The “entourage” improves effectiveness
- Standardization → Objectify patient perceived results
  → Optimise therapeutic use of cannabinoids