#### **Cannabinoids & Epidermolysis Bullosa**

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#### Our drugs are not sufficient!



## **Patient Discoveries**

Patients, their families and friends are challenged.









Reciprocate, Assess and Improve



# Endocannabinoid System





Arachidonoyl ethanolamide



<sup>2-</sup>Arachidonoyl glycerol

Appetite, pain-sensation, mood and memory

# (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

# Why the increase?

- Reproducibility is difficult
- Standardization
- Medical/Research-grade cannabis
  → genetically identical
  - $\rightarrow$  standardized oil (GMP)

• Reliable dministration forms?



## **Administration Routes**

Onset of effects after intrapulmonary and oral administration of cannabis



# Intrapulmonary

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

#### $\rightarrow$ Vaporization

 Non-toxic; consistent; temperature control; training







# Oral

- Most common method of patient self-medication in the Netherlands
- Varied metabolism, location c absorption.
- Cannabinoids = Lipid Soluble
- $\rightarrow$  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-٠ sectional survey with 44 patients in the Netherlands. NHB Schräder, WY Yuen, MF Jonkman. Unpublished. 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  $\rightarrow$  Objectify patient perceived results

 $\rightarrow$  Optimise therapeutic use of cannabinoids