



Introduction

Williams Journey – Part 1

Cannabidiol Research

Campaigning & Fundraising

Findings

Williams Journey – Part 2

Current Developments

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Current Developments



make william well



www.makewilliamwell.com

Website/ Facebook Page

- Terminology reassurance

- Focal point for fundraising and campaigning

- Advice for other parents

- Story

- Keto recipes

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Current Developments



Persistent/recurrent headache



Balance/co-ordination/walking problems



Persistent/recurrent vomiting



Abnormal eye movements



Blurred or double vision/loss of vision



Behaviour change



Fits or seizures



Abnormal head position such as wry neck, head tilt or stiff neck

2013 Signs & Symptoms

Headsmart

RCPCH

TBTC

CBTRC

2014 - Diagnosis

Surgery, Chemo

Hearing Loss

2015 - Recurrence

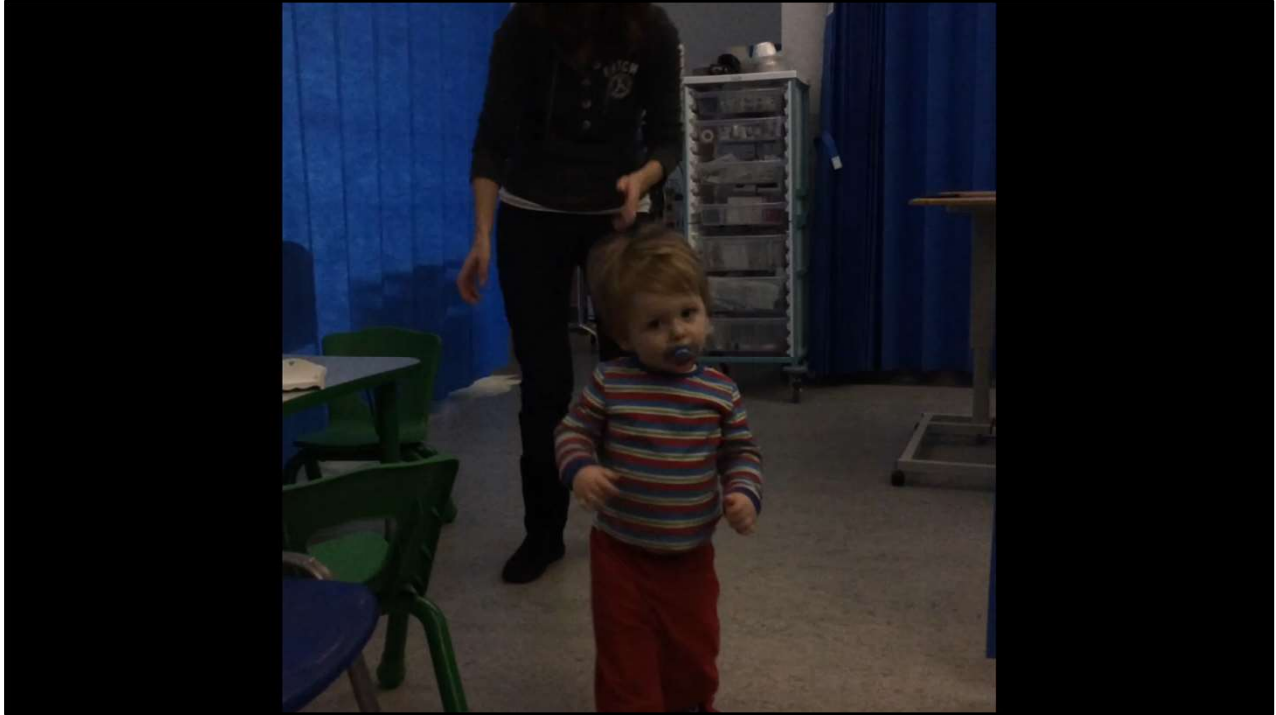
Surgery

Trachy

Radiotherapy – proton/ photon

2016 - Hospice Referral

Start to question medical establishment



VIDEO – William's Head Tilt

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Current Developments



- Project Storm
- Research
- Discussion with oncologist
- Ketogenic Diet
 - Enzymatic Profile
- Search for legitimate supply
- Tumour shrinkage
- Trachy removed
- Prescription Request
 - Prescription Process
 - Clinical Trial Process
 - Specific drug per cancer
 - Pre-clinical explanation
 - Gold standard RCT

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Research Proposal

Pam White & confidence to propose
£100,000 target 18 month project

Fundraising

Local media and BBC
BTA & ABTF

Early 2018 Project Started

Completed this year with more research following on

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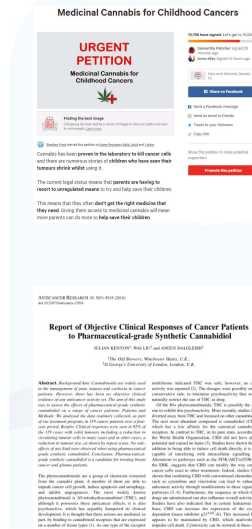
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Event Attendance

2 x cannabis

APPG

Petitions

Medicinal Cannabis

Fundraising Events

Three Peaks x2, Hadrians Wall

Case Published

Kenyon, Liu & Dalglish

Changes in Law

NICE Stakeholder

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**Brain tumour
research
receives less
than 1% (0.7%)
of national cancer
research spending
in the UK**

In the last 40 years,

ONLY 3

NEW CANCER DRUGS

have been developed
specifically to treat children.



Statistics

Filter down from adult treatments

Pre-clinical research

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2019 – Recurrence

Surgery & Chemo

No radiotherapy

Side effects

Metronomic Chemo

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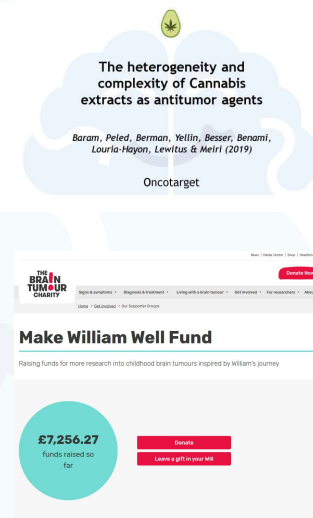
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Requirement for THC

Case for more research – pre-clinical/ legality/ public perception

Move away from RCT towards Adaptive Clinical Trials



make william well

#ACureCantWait

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