

The Illuminated Self



The CANDO (Controlling Abnormal Network Dynamics using Optogenetics) project is a world-class, multi-site, cross-disciplinary project to develop a cortical implant for optogenetic neural control in people with focal epilepsy.

The implant will modulate abnormal activity and prevent the development of epileptic seizures, providing precisely timed stimulation by continuously monitoring brain waves via implanted electrodes and modifying them via implanted light sources. This requires that some cells within the brain are genetically altered using a safe virus to make them sensitive to light. The goal is to create a first-in-human trial in patients with focal epilepsy.

Operating Theatre has been making work about health and well being for 15 years, working with medical schools, health care providers, charities, researchers and industry to deliver heartfelt drama that aims to change how people think about health.

Their aim in the project is to respond, as theatre practitioners, to the challenges and opportunities that the CANDO project presents.

Operating Theatre will be producing a full length piece, created through extensive research and collaboration with people living with epilepsy as well as the CANDO project.

We would like to that everyone who has contributed thus far including:

Alexander, Alina, Charles, Craig, Edgar, Emily, Fyodor, Gaius, Irene, John, Julius, Michael, Neil, Rhys, Vicky, Vincent

The CANDO Public Engagement project is supported by Wellcome and Newcastle University



www.cando.ac.uk www.operatingtheatre.org.uk

Operating Theatre is a registered charity No:1100963

# **Shedding Light**

We would not be here today without having passed through the evil spirits of ages past, the ignorance, the mythology, the pain of countless people...

I'll be honest, my mother struggled to come to terms with what she called my 'trouble'. I remember sitting there, waiting to see the consultant. Something terrible was apparently wrong with me but no one could explain it...

All these years later, I can see there is a positive aspect. In many ways you are unique. It's extraordinary the way the firing of the neurons can affect you, physically, emotionally. It can affect your personality too. Maybe it makes me live more in the moment. I believe that.

I wouldn't be the same person without it.

## **The Illuminated Self**

Written by Operating Theatre

2 lecterns

#### 2 Characters: Voice 1 and Voice 2

- V1: In Alice in Wonderland, Lewis Carroll wrote...."WHO IN THE WORLD AM I? AH, THAT'S THE GREAT PUZZLE"
- V2: "Men ought to know that from the brain, and from the brain only, arise our pleasures, joys, laughter and jests, as well as our sorrows, pains, griefs and tears.
- **V1:** Through it, in particular, we think, see, hear, and distinguish the ugly from the beautiful, the bad from the good, the pleasant from the unpleasant....
- V2: It is the same thing which makes us mad or delirious, inspires us with dread and fear, whether by night or by day, brings sleepnessness, inopportune mistakes, aimless anxieties, absent-mindedness, and acts that are contrary to habit."
- V1: Good afternoon everyone and welcome to the Illuminated Self, the first in our series of occasional lectures. Today we will consider the disease called sacred.
- V2: "It is not, in my opinion, any more divine or more sacred than any other disease, but has a natural cause, and its' supposed divine origin is due to men's inexperience and to their wonder at its peculiar character."
- V1: In 400BCE, this turn from the supernatural to the naturalistic explanation, what Hippocrates described as the flux of phlegm flowing from the brain into the veins, is now considered a major shift in the history of medicine. However it can be argued that we are as far from a universal understanding of... what? ....What to call it?

#### V2: Condition:

Complaint Disorder Defect Disease Affliction Ailment Weakness Infirmity Indisposition Malaise Malady.

Peter Mark Roget...lexicographer... and interestingly also a physician

V1: "Diseases exist to remind us that we are not made of wood, and it seems to me this is the bright side of it all".

Vincent Van Gogh

- V2: I remember the first time I saw a Van Gogh painting. I mean, really saw a Van Gogh painting. I stood in front of it and I wondered about him. About his life. About his painting. About his anxiety, synaesthesia, and depression. About how it all came together in brilliant colour on a piece of canvas. When my son was first diagnosed I searched for famous people who had it. The first name I noticed was his, Vincent.
- V1: "The brain within its groove runs evenly and true But let a splinter swerve, T'were easier for you To put the water back When floods have slit the hills And scooped a turnpike for themselves, And blotted out the mills."
  Emily Dickinson

#### V2: Seizure: OED

Capture Conquest Occupation Takeover Annexation Invasion Subjection Subjugation Colonization.

V1: For example... Napoleon's seizure of Spain.

The question of whether the Emperor was a sufferer or not has always been a matter of controversy. Opponents of the theory argue that none of the many doctors who attended him ever mentioned it. Those in favour reply that such doctors would need to be very careful about how they worded any diagnoses when it came to their Imperial patient.

- **V2:** "I am sometimes a fox and sometimes a lion. I can no longer obey; I have tasted command and I cannot give it up."
- **V1:** "The best cure for the body is a quiet mind".

"There was an old man who when little Fell casually into a kettle But growing too stout he could never get out So he passed all his life in that kettle"

- V2: Edward Lear, painter and limerician, kept a diary for 40 years but never mentioned what he called his 'heartstopping and braintwisting' incidents. He merely placed the letter X on days on which they occurred and a score of between 1 to 10 to mark their severity.
- **V1:** He congratulated himself saying it was 'wonderful' that as far as the world was concerned his 'Demon' had never been discovered.

**V2:** In Powell and Pressburgher's film 'A Matter of Life and Death', the escalator which carries Peter up towards the Other World is lined by large statues of historically prominent men.

A list of the names of the statues appears in Michael Powell's handwriting on Pages 49 and 50 of his script. The statues include Alexander the Great, King Solomon, Plato, Confucius, Abraham Lincoln and Jonathan Swift. At the time, 1945, they were all believed to have had epilepsy.

**V1:** Epilepsy is like a thumbprint, everyone is different. No two cases are alike.

**V2:** "For several instants I experience a happiness that is impossible in an ordinary state, and of which other people have no conception. I feel full harmony in myself and in the whole world, and the feeling is so strong and sweet that for a few seconds of such bliss one could give up ten years of life, perhaps all of life."

Fyodor Dostoyevsky

V1: We're very near the end of our time together. I do hope that you have been galvanised by what you have heard. And if you have, you owe it to Luigi Galvani.

Known as the 'the frog's dancing master' Galvani, an 18<sup>th</sup> century surgeon and lecturer in anatomy, stimulated the legs of frogs to demonstrate that biological cells have electrical properties.

Reports of this early research into electric signals and patterns emitted by nerves, muscles and the brain, circulated widely reaching the shores of Lake Geneva and the Villa Deodati, firing the imagination of a certain Mary Shelley....

"I'm not strange, weird, off... nor crazy. My reality is just different from yours"

Charles Lutwidge Dodgson ...

### "WHO IN THE WORLD AM I? AH, THAT'S THE GREAT PUZZLE."

Lewis Carroll.