This brochure is destined to those who deal with the management and care of patients with disorders of consciousness.

We wish to provide caregivers and policy makers with general information about noncommunicating severely brain-injured patients and how we can use electrical technology to promote their level of consciousness.

After many years in research we came to realize that the families and the direct environment of patients are in need of reliable information and access to state of the art options for treatment. Brain research is currently advancing to create a full understanding of how consciousness is created, lost, and restored.

One way to restore consciousness is by stimulating the brain. This is because we know that consciousness emerges through numerous cerebral areas and connections (links) between different regions of the cerebral cortex. Therefore, when a person has brain damage some of these connections can be damaged.

Research protocols on altered states of consciousness are now the reality all over the globe. Studies aim to better understand the emerging medical conditions, to develop precise diagnostic and prognostic tools and to develop treatments that can facilitate the recovery of these patients.

During the past years the LUMINOUS Project was serving those aims. Although most of the involved researchers might tell you that these interventions most likely will not help your loved one directly, they will all agree that we have nevertheless advanced greatly. We have now the ability to design better experiments with cutting-edge technology aiming at pertinent questions. The results feed-back theoretical models and enrich our understanding of consciousness in an unprecedented way.

Definition guidelines for **Disorders of Consciousness**



opening even with intense stimulation No evidence of awareness of self and their environment Duration: at least one hour Leads either to death, to recovery of consciousness or to transition to UWS/VS Bad outcome: absence of pupillary or corneal reflexes wakefulness stereotyped or absent motor response to noxious stimulation bilateral absent incontinence cortical responses of somatosensory evoked potentials hypothalamic and brainstem functions biochemical permitting survival with markers (i.e., high levels of serum

medical and nursing care neuron-specific enolase for anoxic Variably preserved coma) cranial nerve and spinal reflexes

evidence of awareness of self or awareness of self environment and an or environment inability to interact with others Purposeful behaviors (visual No evidence of pursuit of moving sustained. objects or visual reproducible fixation on objects) purposeful, or voluntary behavioural Smiling or crying in responses to visual. response to verbal auditory, tactile and or visual emotional noxious stimuli Reaching for No evidence of objects language

expression

Intermittent

wake cycles

Preserved

comprehension and Touching or holding objects Vocalizations or aestures in direct manifested by the response to the presence pf sleep linguistic content of questions Bowel and bladder

Command following

Gestural or verbal ves/no response (regardless of accuracy)

Intelligible verbalization

Diagnosis guidelines for Disorders of Consciousness

The diagnosis of patients with disorders of consciousness is facilitated by focusing on specific behaviors after repeated clinical assessments.

IMPORTANT: Prior to assessment, the patient needs to be properly awaken.

Eye movements To assess for signs of voluntary eye movements it is crucial to first open the eyes of the patients. The examiner should probe for both vertical and horizontal eye movements. If the patients do not show eye movements on command, the examiner should probe for visual tracking using a mirror. If the mirror does not evoke a response, other stimuli may be used (e.g. pictures showing the patient's or relatives' faces or personal objects). Regular reassessment is important because levels of consciousness may fluctuate rapidly. Resistance to passive eye opening may be a sign of preserved consciousness.

Spontaneous behaviors These refer to tube pulling, nose scratching, grabbing sheets, leg crossing and localizing behaviour. Observation of spontaneous motor behaviors that may or may not be intentional could help diagnose covert consciousness. The examiner should be mindful of confounding factors, such as cranial nerve palsies, central and peripheral causes of quadriplegia, severe spasticity, hypokinesia and bradykinesia, and hypertonus or hypotonus.

Standardized evaluation of consciousness Provided sedation is stopped, the Coma Recovery Scle-Revised (CRS-R) is the most sensitive tool for detecting signs of consciousness. It includes all criteria for MCS. The CRS-R can be used for both subacute and patients in the intensive care unit. The examiner should report the CRS-R subscale scores or use the modified score because the total score is inadequate to distinguish VS/UWS from MCS patients. Confounding factors: intubation, sedation, setting (presence or absence of relatives), motor, visual, auditory and/or cognitive impairments (language, memory, flexibility, attention). The classification of consciousness levels should never be made based on an isolated assessment

Standardized evaluation of pain The Nociception Coma Scale - Revised (NCS-R) can be used for regular monitoring of signs of discomfort. Physicians and nursing staff should screen for signs of discomfort both during manipulation/ daily care and at rest. It should be kept in mind that the NCS-R is highly dependent on motor abilities, preserved sensory function and whether the patient is intubation

Kondziella D. Bender A. Diserens K. van Erp W. Estraneo A. Formisano R. et al, European Academy of Neurology guideline on the diagnosis of coma and other disorders of consciousness, Eur J Neurol 2020; :ene.14151.

Electrical treatment

The brain is the most complex organ in the human body. It is formed by billions of nervous cells called **neurons**. Neurons control and react to nearly everything that is happening in our body. They communicate with each other with tiny electric impulses. This current is how messages are dispatched in the brain.

Transcranial current stimulation (tCS) is way to modulate neuronal activity using a device on a person's head which delivers low electric currents (max 4 mA, comparable to a battery used for home electronic devices). It is safe, relatively inexpensive, easy to administer and non-invasive, meaning that it does not need chirurgical intervention for its application.

The electric current circulates from two electrodes which are placed over specific areas of the head.

in red and blue.

over specific areas of the head. These electrodes are small sponges soaked in salt water or tiny thin metal clips with conductive gel, here shown

tCS can create some itching sensations and skin redness on the stimulated areas. Other than that it is a painless to administer.

In the last years, tCS has been used to promote consciousness and responsiveness in noncommunicating severe brain-injured individuals. Currently, a full understanding of the working mechanisms and efficiency, remain under development. The LUMINOUS Project aims at providing explanations and ways of how to restore consciousness of severely brain-injured patients and therefore promote the wellbeing of those individuals and the families and carers that surround them.

NOTE The severity of brain damage and the associated deficits can differ greatly from one individual to another. For this reason, it is necessary to communicate with the doctor and the nursing staff who are in charge of your loved one, as they will be the most able to give you details about their condition and give you specific advice concerning treatment.

The type of treatment your loved one will receive varies depending on the type of injury they have suffered. In addition to the medical team and nurses in the department, your loved one can be followed by physiotherapists, occupational therapists, speech therapists and psychologists. Do not hesitate to ask the healthcare teams for more information on the specific treatment given to your loved one.

Thibaut A, Schiff N, Giacino J, Laureys S, Gosseries O. Therapeutic interventions in patients with prolonged disorders of consciousness. Lancet Neurol 2019; 18:600–14.



