LINKING LIS ALL OVER THE WORLD

INTERNATIONAL SYMPOSIUM ON LOCKED-IN SYNDROME

IN ASSOCIATION WITH

HOPE UNLOCKED

MONDAY 13TH JUNE

11:30 AM – 2:45 PM CEST
10:30 AM – 1:45 PM BST
6:30 PM – 9:45 PM AEST
5:30 AM – 8:45 AM EDT

FOR MORE INFORMATION, EMAIL INFO@HOPEUNLOCKED.ORG

LINKING LIS ALL OVER THE WORLD

Locked-in syndrome is a rare condition. There are relatively few people - fortunately - with locked-in syndrome. Likewise, there are also relatively few experts on this condition. So it is important that patients and professionals who work with people with LIS are vocal and know each other.

The current webinar was initiated by Dawn Faizey Webster (LIS patient in the UK and well known after her TEDx Talk on LIS), Tracey Gibb (LIS patient in Australia, disability activist) and Shannan Keen (Founder Australian Register for Disorders of Consciousness). The three of them searched and found several people in the field of LIS throughout the world and asked them to give a presentation at the webinar. Mariska Vansteensel (Assistant Professor at the University Medical Center of Utrecht) and Femke Nijboer (Assistant Professor at the University of Twente) later joined in to help organize a conference in the form of an online webinar. We are hoping to make this an annual or biannual event.

The aim of the first webinar is to give an overview of some big topics related to LIS; clinical prognosis and therapy, quality of life and living with chronic LIS, existing assistive technology, technological innovations from the field of neuroscience.

In addition, we want to make sure that people with experience and knowledge on LIS can more easily find one another. To this end, we encourage you all to make use of the chat function to network and make yourself visible.

Finally, it would be nice if the first webinar on LIS ever was not the last. Together with you we'd like to talk about how to repeat this symposium annually or biannually in order to maintain momentum for our aims.

We hope to welcome you on the 13th of June to the online webinar.

How do you join?

- Sign up through this link: https://my.forms.app/hopeunlocked/zoom-webinar-registration-form
- You will receive a link to a Zoom meeting

PROGRAM – MONDAY JUNE 13 (TIME IN CEST)

INTRODUCTION 11:30 AM - 11:40 AM

CORALIE GRAHAM 11:40 AM - 12:00 PM

Placebo-controlled randomized Clinical Trial of Perispinal Etanercept in Australian patients with chronic stroke 2020: Fatigue & muscle spasticity study (PSE-2020)

AURORE THIBAULT 12:00 PM - 12:20 PM

LIS: is there a place for non-invasive brain stimulation?

FEMKE NIJBOER 12:20 PM - 12:40 PM

A life worth living - perspectives of people with chronic LIS on quality of life and inclusion

IAN FOULGER 12:40 PM - 1:00 PM

Amego – A communication and access system for people with LIS

BREAK 1:00 PM - 1:30 PM

JAMES BRINTON 1:30 PM - 1:50 PM

T.B.D.

MARISKA VANSTEENSEL 1:50 PM - 2:10 PM

At-Home Testing of an Implanted Brain-Computer Interface for Communication

PHILL KENNEDY 2:10 PM - 2:30 PM

Restoration of conversational speech using single units recorded from the speech motor cortex.

QUESTIONS AND CLOSURE 2:30 PM - 2:45 PM

SPEAKERS

Coralie Graham

Associate Professor (Nursing & Midwifery), University of Southern Queensland and Visiting Scholar: Griffith University School of Pharmacy and Medical Sciences

"Placebo-controlled randomized Clinical Trial of Perispinal Etanercept in Australian patients with chronic stroke 2020: Fatigue & muscle spasticity study (PSE-2020)"

A new treatment for chronic stroke repurposing a TNF inhibiting medication (Etanercept/ Enbrel) currently used to treat Rheumatoid arthritis, is being trialled at Griffith University in Australia to treat post-stroke neuroinflammation. Following stroke, the area around the damaged area becomes inflamed and remains inflamed - expanding the area of stroke damage. The perispinal etanercept treatment(PSE) is delivered in a way that bypasses the Blood Brain Barrier and reduces the area of inflammation surrounding the original stroke damage and the function in the inflamed area is often regained. The current clinical trial is the second internationally and is close to completion, following on from the world-first study published in January 2020 that showed that PSE is safe and effective in treating post-stroke neuropathic pain and improving muscle spasticity. The current clinical trial is testing the efficacy of PSE in reducing often debilitating post-stroke fatigue and improving affected shoulder mobility. Despite the placebo-controlled double-blind measures on the current study, we are seeing some wonderful improvements in many participants. To date we have completed 70 of the 80 participants required to complete this study and are planning a larger Phase 3 study with the plan to apply for government approval of PSE initially to treat stroke.

Aurore Thibaut

Co-director of the Coma Science Group, Associate Professor & FNRS Research Associate, Coma Science Group, GIGA-Consciousness, Centre du Cerveau; University & University Hospital of Liege, Belgium

"LIS: is there a place for non-invasive brain stimulation?"

The majority of patients with locked-in syndrome (LIS) will be able to recover head movement, which may allow them to use a letter board or computer keyboard with their mouth or head. Despites these improvement, most patients will remain with severe motor disabilities and might also suffer from mood or emotional disorders such as depression or anxiety. In this context, non-invasive brain stimulation techniques may represent valuable therapeutic options for patients in LIS. They have been studied for years in attempts to modulate brain activity to treat several neurological diseases. In this presentation, we will expose how these novels techniques, such as transcranial direct current stimulation (tDCS) and transcranial magnetic stimulation (TMS) could be applied to improve not only motor functions but also pain or anxiety based on what has been already extensively studied in other populations of patients. We hope that in the near future, non-invasive brain stimulation techniques can be employed in patients with LIS to enhance their recovery and improve their quality of life.

Femke Nijboer

Assistant Professor at the University of Twente, Research Fellow at the Design Lab, The Netherlands

"A life worth living - perspectives of people with chronic LIS on quality of life and inclusion"

A common assumption of healthy people is that a life with LIS is not a life worth living. Also people with LIS, in the acute phase, and their family can hardly imagine what it is like to live with LIS. In a small, qualitative study in the Netherlands (unpublished) we asked seven persons with chronic LIS about their quality of life, the extent to which they felt included in society and their satisfaction with assistive technology. Five out of seven persons reported a good quality of life and tended to focus on things they can still do. Inclusion is more difficult. One can live with LIS, but not with being excluded from society or being perceived as someone you are not. Some people reported feeling locked-out, rather than locked-in. Most people were happy with their assistive technology which is quickly and easily reimbursed in the Netherlands and allows mobility and access to communication and internet. Maintenance service could be better; having to wait for repairs when you are dependent on your assistive technology is frustrating. We conclude that life can certainly be worth living with LIS although exclusion from society remains a problem.

James Brinton

Director of Business Development & Clinical Education, EYEGAZE

TBD

Ian Foulger

AAC Manager, Jabbla UK

"Amego – A communication and access system for people with LIS"

Ian Foulger from Jabbla UK, will demonstrate the Amego vocabulary package used by people with LIS. Amego has 2 main uses, communication and access. Any access method can be used; touch, keyboard, switch, joystick and eye gaze. As an access system it acts as an interface to allow a user to control a Windows-based computer system. Communication can be speech output using voice synthesizers, text messaging, phone calls and social media platforms. Other uses that Amego can be used for are environmental control, playing games, reading books and taking photographs. Calendar and alarm features are also available.

Mariska J Vansteensel

Assistant Professor, UMC Utrecht Brain Center, The Netherlands

"At-Home Testing of an Implanted Brain-Computer Interface for Communication"

Brain-Computer Interfaces based on implanted electrodes may present a solution for the communication impairment of people with Locked-In Syndrome. Before these devices can be widely implemented, however, important steps need to be taken. One such step is the demonstration that implanted BCIs can be used independently by people with LIS in their daily life at home. In this presentation, I will discuss findings from the ongoing Utrecht Neural Prosthesis (UNP) study, which addresses exactly this question. I will show that an implanted BCI may offer a reliable signal to control communication software, but also discuss the significant challenges that arise when BCIs are tested in real-world situations.

Phil Kennedy

Neural Signals Inc., Duluth, GA, USA

"Restoration of conversational speech using single units recorded from the speech motor cortex"

Our research effort is aimed at restoring conversational speech to those who are locked-in. Two patients have been implanted in the motor speech cortex with long-lasting electrodes (one produced recordings for a decade). Off-line single unit analysis indicates that phonemes, words and phrases can be decoded. The single units can be conditioned, suggesting that those single units not related to the task can be conditioned to the task. These results strongly suggest that conversational speech for locked-in people is possible.