

# 2nd International LiS Webinar

## 12th June 2023



**Time:** Monday June 12, 2023 09:30am UK time (check your local time)

### **Join Zoom Meeting**

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## **Presentations:**

In order of appearance on 12th June 2023

Introduction by **Host, Shannan Keen**; I am Shannan, the founder of these International LiS Webinars (with IT help from Emmanuel Ribeiro and input and encouragement from Dawn Faizey-Webster). I hold a BA in Psychology and Philosophy and a Masters in Neuroscience. In 2011, I founded and continue to run the Australian Register for Disorders of Consciousness (ARDoC) at the Australian Brain Foundation. My neuroscience work and PhD was halted in 2013 when I developed bacterial meningitis from which I am still recovering. In early 2023, I launched the LiSA online Community Forum. I'm Australian and am very happily married to my husband, Max. We live part of each year in Sydney and part of each year in England.

**Co-host, Bouke J van Balen**; Bouke is a PhD candidate in the Ethics and Philosophy of Technology at the University Medical Centre Utrecht, TU Eindhoven, and TU Delft. His research is about the (potential) effects of Brain Computer Interfaces (BCIs) on the lives of people with Locked In Syndrome, their caregivers, and the medical practice around them. BCIs are communication devices that can be controlled with brain activity, and thus circumvent the need for muscle control. The promise of BCIs is to provide people with LIS with a good alternative for natural speech. In his research, Bouke asks how BCIs **can** and **should** change the lifeworlds of people with LIS. An integral part of the answer to this question lies in the perspectives of people with LIS and their caregivers. Bouke lives in Amsterdam.

[Brief resume of Presenters for 2023 LiS Webinar](#) including outline for each of their presentations. It is with pleasure that, for the first time, we welcome four people who are living locked-in, to tell their own story today.

[LiS Tracey Gibb](#); When Tracey was 19 years old, she was having trouble with severe headaches. This was out of the norm for her, because she simply didn't get headaches. She told her doctor this but he kept treating her for migraines. She suffered an unexpected stroke went to hospital and was found unconscious. After an MRI, she and her family were told that she had experienced a brainstem stroke, caused by an abscess on the brainstem pons. Tracey lived a full life, taking part in many organisations including being the Ambassador for ARDoC and doing great work with the Stroke Foundation. Sadly Tracey died a month after last year's LiS Webinar. She was very happy that it had taken place.

Presentation;

Tracey would be proud to be having Tracey's Story, a YouTube video, shown as her Presentation today.

[Coralie Graham](#); Coralie is an Associate Professor in the School of Nursing & Midwifery at the University of Southern Queensland (USQ) and Adjunct at Griffith University's School of Pharmacy and Medical Science. She is dually registered as a Registered Nurse and Psychologist and has worked in a number of roles in both professional capacities. Coralie's research interests include resilience, equity, and fatigue related to neuro-injury and for chronic stroke.

Presentation; Ensuring all people in health care are treated individually and without bias defines cultural safety. In recognition of this, Australia's Health Practitioner Regulation Agency (AHPRA) has mandated that all regulated health practitioners are required to complete cultural safety training. Recognising that people with a disability are people - with the same individual healthcare needs as everyone, who need to be treated and communicated with without bias - is what culture safety is about.

[LiS Benedicte Origer](#); Benedicte is 42 years old and has been locked-in since 2016. She is married and has two children of 11 and 8 years; one boy and one girl.

Presentation; Benedicte will give us insights into her life living locked-in. She is working hard to establish a Belgian Locked-in Syndrome Association, in part with the aim of improving social and health care for those living LiS in Belgium.

[Dorothee Lule](#); Since 2018 Dorothee has been Professor for Neuropsychology and Experimental Neurology, University of Ulm. She is both Head of research in Neuropsychology and a Neuropsychologist at the University and Rehabilitation clinics Ulm. She has more than 100 peer-reviewed scientific papers to her name and multiple research projects. Additionally Dorothee is on the editorial board of the journal 'Neurology' and is reviewer for more than 35 national and international journals, grant offices and conferences.

Presentation; Dorothee will present research findings regarding the well-being of subjects with progressive immobility up to the locked-in state of differing neurological origin.

Among others, she will refer to quality of life and depression as measures of psychosocial adaptation in the course of Motor Neurone disease. She will add findings from other conditions, including coma. Furthermore, Dorothee will report on resources which facilitate satisfactory well-being in these conditions.

**LiS Bram Harrison;** Bram (AKA DJ Eye Tech) wrote and presented the International Eye Life radio show with his Eye-controlled computer. He uses his DJ Eye Tech Facebook page to voice his opinions, review films, TV and music as well as share jokes. Additionally he shares charity information and is keen to use his platform, and thought from his healthy brain, for the good of the planet. Bram is English. He's been living Locked-in for roughly 25 years. He had a bicycle accident which resulted in the condition.

Presentation; Bram will talk to us today about his life living locked-in.

**Lisa Paling;** Lisa qualified as a Physio from University of Brighton in 2002. Since 2003, Lisa has worked in Neurophysiotherapy at Cannock hospital, part of The Royal Wolverhampton NHS trust. She works across the service in inpatient rehab, day unit and outpatient services.

Lisa believes that everyone deserves the opportunity to work to maximise their potential despite what life may have thrown at them.

She lives in Staffordshire with her husband (who is also a Physio) and their three children.

Presentation;

Lisa will be examining different approaches to physiotherapy, ensuring the best possible outcome.

She will demonstrate some methods to help you achieve improvements, with a little help. Lisa focuses on the importance of being you and on defining, with you, the therapy that works to achieve the best outcome for you.

## **Lunch break; James Brinton's 'Eyegaze Edge Promotion'**

**LiS Dawn Faizey-Webster;** Dawn had her son on 15th June 2003 at 27 weeks due to severe pre-eclampsia. Two weeks later she had, in her words, 'the mother of all strokes', leaving her living locked in for the past 20 years.

Prior to this Dawn gained a BSc in Psychology and Computing. She had been a Financial Adviser, a motorcycle salesperson and finally an ICT teacher at a private grammar school, which was a job she loved.

Since becoming locked-in, she has written a short book, taken a BA in History, an MA in History of Art and is currently in the final year of her PhD in Architectural History.

Presentation;

Dawn will be discussing 'a day in the life of someone with LIS', the day to day challenges and how to overcome them, where possible. She will also discuss the pros and cons of running your own care team.

**Phil Kennedy;** Philip Kennedy, MD, PhD has been developing brain computer interfacing since 1986. He has been instrumental in six patient implantations, the two most recent for developing a speech prosthesis. He obtained a PhD from Northwestern University in Chicago in 1983, having obtained his MD from the University of Ireland in Dublin in 1972. He works in his Neural Signals lab in Duluth, Georgia, USA. [www.neuralsignals.com](http://www.neuralsignals.com).

#### Presentation;

The Neurotrophic Electrode (NE) consists of a hollow glass cone with recording wires inside. Nerve growth factors (NGF) entice the neuropil to grow inside the cone. Neural signals have been recorded for many years until the participants died and as long as a decade in one human (ER) (1) whose histological analysis when he died at 13 years after implantation indicated no gliosis and numerous myelinated axons (2). His histological analysis is the same as the histological analyses in rats and monkeys (3). A criticism of this early version of the (NE) is that the number of neural signals that can be recorded is too low, usually 20 per electrode. However, neurons grow neurites from a diameter of almost 2 mm in rat studies (4) so the single units cover a wide area and can be conditioned (5). Nevertheless, histological analysis of so many myelinated axons in ER suggested we should attempt to record from more of them, and hence we teamed with NeuroNexus Inc. to develop a 16-channel electrode based on the same principle of growing the neuropil into the electrode tip without increasing the size of the tip.

Early results from vibrissa cortex implantations in three rats indicate about 300 single units (SUs) were recorded from each. Inter Spike Interval Histograms (ISIHS) confirmed the SUs when there was adequate firing to perform the ISIH. Further analysis will define these SUs more precisely using autocorrelation that is expected to reveal which SUs are related and hence redundant, thus reducing the count of functionally active SUs. Studies using a switch closure wand that deflects the vibrissae will determine the SUs that fire in response to the deflection of the vibrissae. These responses are expected to have different firing patterns depending on which vibrissae are being deflected. Hence different words can be attached to the different firing patterns, thus producing 'rat speech'. The pattern recognition system is identical to what we expect to use in future human implantations for producing speech. We have teamed with Arctop Inc. to develop the real-time software system for rat data that can ultimately serve us directly on human speech.

#### **Steven Laureys;**

Prof Dr Steven LAUREYS MD PhD FEAN, is Neurologist, keynote speaker, author and FNRS Research Director. He is Head of GIGA Consciousness at the University & University Hospital of Liège, Belgium and visiting professor at CERVO Brain Research Centre, Quebec

[www.drstevenlaureys.org](http://www.drstevenlaureys.org)

#### Presentation;

Locked-in syndrome and the power of the mind – a neurologists' view.

Dr Steven Laureys here briefly explains his research on locked-in syndrome and brain injury. He also exposes the effects of mindfulness on our body and mind. Through this team's research on the brains of Buddhist monks such as Matthieu Ricard, interpreter of the Dalia Lama, he illustrates how meditation stimulates brain function and modifies it in a positive way. But you don't have to be a Zen master to experience the positive changes in meditation. The resulting benefits for our mental health - less stress, better sleep, more focus, less anxiety, antidepressant and pain relieving effects ... - are within our grasp. During this conference, Steven explains our current knowledge of the action of meditation

on our neurons, and offers simple and effective meditation exercises. Yes, meditation can change our lives, just as it has changed the lives of Steven Laureys and many of the patients he follows!

Based on the international bestseller :

[The No-Nonsense Meditation Book](#), A scientist's guide to the power of meditation, Steven LAUREYS, Bloomsbury Publishing, 2021

**Ujwal Chaudhary**; During Ujwal's eight years of research in academia and industry after his Ph.D., he developed several different kinds of brain-computer interfaces (BCIs) for communication with individuals in LIS and Complete LIS (CLIS). He and his colleagues pushed the limit of BCIs; for the first time in history, they enabled complete sentence formation by someone in CLIS (published in Nature Communications). Several of Ujwal's publications have been highly cited. His Nature Communications publication is among the TOP 25 health articles of the year 2022.

Ujwal is co-founder of "ALS Voice" a non-profit organisation providing customised communication solutions to individuals with paralysis and he is the Co-founder and CEO of ARN Labs, Germany a Neurotechnology company

Presentation;

1. Non-invasive BCI-based communication for patients in transition from LIS to CLIS
2. Invasive BCI-based communication for a patient in CLIS.

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Host, Shannan, and Co-host, Bouke, chair open discussion.

**\*\*\*The day's Presentations will be recorded in full.** The link for the recording will be sent to every Registrant as soon as it is ready.

New members are always warmly welcomed to the [LiSA online Community Forum](#).

Simply follow this link and apply to join;

<https://www.facebook.com/groups/1243149376305687>

If you have any questions, would like further information or are interested in Presenting at the 2024 3rd International LIS Webinar, to be held on 10th June 2024, please contact Shannan; shannan@brainfoundation.org.au