4th International LiS Webinar

9th June 2025

Presentations;

In order of appearance;

Introduction by **Host, Shannan Keen**; I am Shannan, the founder of these annual International LiS Webinars. 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. In early 2023, I launched the LiSA online Community Forum (on Facebook). In 2024, I was commissioned by Routledge to write a book about LiS entitled; 'Giving a Voice to Those Living Locked-in'. It contains chapters written by twelve people living LiS plus three professionals working in this field some of whom are presenting or with us today. It is available to purchase through Routledge or order through any book shop, or as an ebook. I'm Australian and am 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 Ethics and Philosophy at the University Medical Centre Utrecht, TU Eindhoven, and TU Delft. He researches how communication Brain Computer Interfaces (cBCIs) can and should shape the lived experience of people with Locked In Syndrome, their caregivers, and the medical practice around them. He interviews people with LIS, their caregivers, and medical professionals to study their experiences of communication, well-being, and personhood. These experiences form the basis of his philosophical analysis and ethical recommendations. Bouke lives in Amsterdam.

LiS Wenche (Norway; spoken by Shannan on behalf of Wenche)

Wenche Løseth comes from Ulsteinvik, a small town in Norway. She is 65 years old and has three children and six grandchildren. She used to work in an elementary school, as a student assistant.

On March 8, 2000, at the age of 39, Wenche suffered a serious brain stem stroke that led to Locked-in syndrome. She became paralysed throughout her body and needed help with everything. She could blink her eyes, for yes or no.

For two years, she was hospitalised in various rehabilitation institutions. During that time, her house was rebuilt and adapted with assistive technology. The goal was for her to continue her life and live in her house together with her children and family.

Afterwards, computers became key tools for her and she was able to communicate with others. Wenche has written a book about her rehabilitation process and worked as a web editor in a kindergarten.

Presentation;

This Presentation explains Wenche's LiS, her life and experiences.

Bouke van Balen

Bouke van Balen is a philosopher from Amsterdam. He works at the University Medical Center Utrecht, Technical University of Eindhoven, and Technical University of Delft. He researches lived experiences of communication and personhood between people with LIS, their loved ones, and medical professionals. He tries to bridge the gap between his research and practice by connecting to medical practice and technology development.

Presentation; In his talk, he will share insights from an interview-study he conducted about lived experiences of communication of people with LIS, their loved ones, and medical professionals.

LiS Isabelle Lauberthe (Paris, France)

Isabelle is 51 years old. She was born in Paris and has always lived there, despite a few moves related to the evolution of her personal life.

Presentation;

Isabelle hadn't anticipated what would happen in her 35th year.
The arrival of the LIS was a radical change from the life she had imagined. This is what she's going to try to explain to you, even though words can never truly describe the intensity of this upheaval.

Vincente Hitabatuma & Jean Baptiste Leyh, BALiS (Belgium);

A political scientist by training, Vincent Hitabatuma has over 10 years of experience in the public sector, particularly in social security, health, human rights and equal opportunities. Throughout his career, Vincent has worked in various ministerial offices and parliamentary assemblies. Vincent is one of the founding members of the non-profit organisation BALIS, the Belgian Association of Locked-in Syndrome.

Jean-Baptiste Leyh is a graphic designer living in Liège (Belgium). He´s an old friend of Vincent and when they founded BALIS with Bénédicte and her then husband Alexandre, they asked him to design the logo. From there, he quickly joined the team to help with whatever is needed for this essential project.

BALIS Presentation;

BALIS, the Belgian Association of Locked-In Syndrome, is a non-profit organisation launched on September 22, 2022, on the initiative of Bénédicte and Alexandre Origer. Bénédicte has been suffering from Locked-In Syndrome (LiS) since November 2016. BALIS is the first association in Belgium dedicated specifically to Locked-in Syndrome This presentation will outline the objectives and missions of their association.

Lunch break (approx 45 minutes);

Music by Dick van der Heijde, living LiS
Talk by expert, James Brinton; Communication devices
Stefan Carmien about the tool he created that enables eye blinking to initiate conversation for people with LIS

Afternoon session;

Dr Roy Kohnen
Roy Kohnen is currently a nursing-home physician specialist at the long-term care organisation Livio in the Enschede and Haaksbergen area of the Netherlands. He successfully defended his PhD Thesis ‘Conscious patients with severe chronic acquired brain injury in Dutch nursing homes’ in October 2021. In one of his studies he established the prevalence and characteristics of patients with classic Locked-in Syndrome in Dutch nursing homes. The results of this study have been published in Journal of Neurology.

Presentation:
Roy Kohnen will talk about LiS in general, the prevalence and characteristics of patients with LiS in Dutch nursing homes, the implications of the results, and their long-term care in general and in the Netherlands in particular.

Andre Heid (Rio de Janeiro and Yale, USA)
Andre is a Mechanical Engineering student at Yale College. His co-author of this presentation is Kieran O’Keefe, an Electronics Engineering student at the University of Limerick.

Presentation:
This work presents a cost-effective electro-oculography (EOG) front-end that employs a gamut of signal-processing circuits; pre-amplification, drift compensation, band-limiting, and final amplification—built from easy-to-access, low-cost components. By outputting a clean digital signal, their system reduces inherent measurement bias and sampling uncertainty while minimising overhead expenditure and lowering entry barriers for adopters. In testing, the prototype sustained under 0.5 ms end-to-end latency and achieved a 38.65 dB signal-to-noise ratio, demonstrating its suitability for real-time communication applications.
Ultimately, this design paves the way for accessible, affordable EOG-based devices to restore communication in individuals with Locked-in Syndrome and ALS.

MD Phil Kennedy (USA)
Philip Kennedy received his MD degree from University College Dublin, Ireland in 1972 and his PhD from Northwestern University Chicago in 1983. In 1996, he was the first to implant the brain of a paralysed and mute human for communication with a computer. In 2004, he was the first to implant locked-in participant 'ER' for speech restoration. As we can reveal, 'ER' is Eric Ramsey whose father will be giving a Presentation immediately after Phil today.
In 2014 Phil's own speech cortex was implanted to better understand decoding of speech. The implanted electrode is unique in that it grows the brain into the tip of the electrode and hence is more long-lasting than metal tipped electrodes.

Presentation;
Phil will present the advances in implantable BCI that he and others have achieved including restoring movement to a limb and restoring speech. He will also discuss the

disadvantages of the speech prostheses such as the 3-second latency between the participant trying to speak and the speech output.
Phil and his team have a long-lasting electrode whose signals persist. They have a different way of training the speech output by using the inherent computing power of the brain to train the output. The steps in implantation and training will be discussed in detail. For example, it takes three months for the brain to grow into the electrode tip. The signals are stable at that point in time so training will begin. Training may take months. Phil will explain how Individual units would be attached to phonemes, words, phrases and musical notes. There are only 39 phonemes in the English language and these are the building blocks of words. We will learn how controlling phonemes allows the participant to produce words.

Eddie Ramsey, father of LiS Eric (USA)
Presentation;
Eddie's son, Eric, was the recipient of the BCI that we've just heard about from Phil Kennedy. He will tell us about Eric and about the BCI experience. There will be a discussion between Phil Kennedy and Eddie Ramsey and you can ask questions.

Close of Webinar

New members are always warmly welcome to the LiSA online Community Forum. Simply follow this link and 'Request' to join;
https://www.facebook.com/groups/1243149376305687

If you have any questions, would like further information or are interested in Presenting at the **5th International LiS Webinar, to be held on Monday 8th June 2026**, please contact the organiser, neuroscientist Shannan Keen; shannan@brainfoundation.org.au

Register here to attend the 2026 LiS Webinar;
https://05nykaus.forms.app/5th-international-lis-webinar-8th-june-2026-registration