



SyNC Neuromodulation Symposium 2020 Symposium Summary

Novel Treatments for the 21st Century: The Rise of the Brain Computer Interface and Neuromodulation of Incontinence

Date: 25th November 2020

Meeting Location:

University of Sydney, Australia and virtual attendance from throughout the world

More information at: <u>http://www.joedusseldorp.com/sync-2020</u>

Hosted by:

Dr Joseph Dusseldorp

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About the SyNC Symposium

The goals of this SyNC symposium were to highlight advances in neuromodulation, lessons learned and challenges for the future. Researchers and Clinicians from Australia and internationally had the opportunity to interact directly with families in what was another highly productive meeting.



The Sydney Neurobionics Collaboration was founded in 2018 to address the need for communication between clinicians and biomedical engineers. Our goal is to leverage rapid technological advances to improve outcomes in neuromotor dysfunctions such as spasticity, incontinence and non-verbal communication.

More about SyNC https://www.joedusseldorp.com/sync-2020

Born out of the University of Sydney, SyNC has developed a broad network of institutes and entities, including:

- The Cerebral Palsy Alliance
- Bionics Queensland
- The ANZAC Research Institute
- Harvard University, Boston
- Global Surgical Innovations, Sydney
- Utrecht Brain Center

- Saluda Medical, Sydney
- Ingenuity Electronics, Sydney
- Cochlear, Sydney
- Synchron Inc, New York
- Inventia Life Sciences, Sydney
- Remarkable
- Brown University

Symposium Program

Session 1: Brain Computer Interfaces (BCI): Updates from the Cutting Edge Chair: Alistair McEwan, SyNC Founder

Joe Dusseldorp, Alistair McEwan, Convenors	Welcome
Mariska Vansteensel, Utrecht Brain Centre	Utrecht NeuroProsthesis: Implantable ECoG-based BCI for Home Use
Leigh Hochberg, Brown University	Update on the BrainGate Trial
Peter Yoo, Synchron Medical	Stentrode: The Australian Deep Brain Interface
Panel Discussion – Ethics and Legal Aspects of	Cameron Stewart, University of Sydney
Neuromodulation	Sascha Callaghan, University of Sydney
Speakers were joined by:	Allan McCay, University of Sydney

Session 2:

Living with Communication Challenges in Cerebral Palsy Chair: Pete Horsley, Remarkable

Lived Experience Discussion – Peter is joined by people living with functional limitations and their families		
Bob MacDonald, Google	Project Euphonia	

Session 3:

Deep Brain & Spinal Cord Neuromodulation for Movement Disorders Chair: Joe Dusseldorp, SyNC Founder

David Borton, Brown University	Responsive Neuromodulation of Spinal Cord Injuries	
Hugh McDermott, Bionics Institute	Feedback Control for Deep Brain Stimulation for Motor Disorders	
Simon Paget, Children's Hospital Westmead	A Clinical Perspective on the Future Challenges of Cerebral Palsy	
	Treatment	
John Parker, Saluda Medical	The Unlock CP Project	
Panel Discussion – Speakers are joined by joined by people living with functional limitations and their families		

Session 4: Sacral Nerve Neuromodulation for Incontinence: Future Challenges Chair: Joe Dusseldorp, SyNC Founder

Pejman Pak	Lived Experience Perspective
Janie Thompson, Continence Foundation of Australia	Support in Australia for people with continence issues
Amanda Chung, North Shore Private Hospital	Sacral Nerve Neuromodulation for urinary incontinence in adults
Danielle Delaney, North Shore Private Hospital	Sacral Nerve Neuromodulation for urinary incontinence in
	children
Margaret Schnitzler, North Shore Private Hospital	Sacral Nerve Neuromodulation for Faecal Incontinence
Gerrit Gmel, Closed Loop Medical	Closed Loop Neuromodulation of the Sacral Nerve
Panel Discussion	

See Profiles of Speakers, Chairs and Convenors at: https://www.joedusseldorp.com/sync-2020

Summary prepared by Dr Joe Dusseldorp, SyNC Co-Founder

It was my great honour to join with my SyNC Co-Founder, Professor Alistair McEwan in welcoming more than 20 distinguished speakers to the SyNC 2020 Neuromodulation Symposium. We had presenters from across Australia and from the Netherlands and the USA, including a number of clinicians, researchers, biomedical engineers, software engineers, technology innovators, community advocates, ethics and law experts, and people living with functional limitations and their family members.

We had 164 registrants from many countries including Australia, France, Germany, India, USA, UK, Argentina and the Netherlands.

All sessions were filmed and can now be watched on YouTube. Follow the link at <u>www.joedusseldorp.com/sync-2020</u>.

Session 1: Brain Computer Interfaces (BCI): Updates from the Cutting Edge

To open SyNC 2020, we were extremely fortunate to hear from three world leading researchers and medical device developers from Utrecht NeuroProsthesis, BrainGate and Synchron. Their presentations highlighted how much progress has been made in the development of a reliable implanted Brain Computer Interface (BCI) to assist people with severe communication difficulties, such as in Amyotrophic lateral sclerosis (ALS) or in Locked-In Syndrome (LIS).

Have you ever heard of a Brain Click?

Dr Mariska Vansteensel from the Netherlands described their solution, the Utrecht NeuroProsthesis, which is an implantable ECoG-based BCI for home use. Dr Vansteensel explained that they have been able to interpret brain signals of people with limited communication ability to perform a **"Brain click"** meaning that people can look at a computer screen and with their mind move the mouse and click on a keyboard or website link. She described that by combining Brain Clicks with predictive communication software tools, the speed of communication can be dramatically improved. There are challenges of course.

"Reliability and complexity are not each other's friends."

This device is already showing real world benefits for patients in their home environment and she showed us numerous examples where people had been able to use this technology to improve their daily lives.

Our second speaker was Professor Leigh Hochberg, from Brown University, USA. Prof Hochberg is a neuro-intensive care physician and treats adult patients after severe stroke or brain injury in his daily work. His passion is to restore full faculties to people in this plight and his drive is to one day be able to say to his patients:

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"You will never lose the ability to communicate."

He then proceeded to tell us how close we are to this being a reality. He showed how patients can already continue to use the same tablet device they were using prior to their diagnosis. The key to this ability is fast, real time and closed loop decoding of brain signals. And the learning curve is in the software, not the user. He is focussing his current research on decoding phonemes (the sounds of spoken syllables) rather than communicating by typing text in an effort to make decoded speech faster and more natural.

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Peter Yoo from Synchron Inc spoke next, explaining to us how an Australian team led by Neurologist, Dr Tom Oxley, a speaker at the SyNC Symposium 2018, is achieving similar results but with a minimally invasive brain implant known as the StentrodeTM. Where other BCIs require a neurosurgical procedure - opening the skull to facilitate placement of recording electrodes on the surface of the brain or actually in the brain tissue itself - the StentrodeTM is inserted exactly like any other brain stent, through a blood vessel in the neck;

"...using blood vessels as a highway into the brain."

This elegant approach is already in use in human trials and is showing promising early results.

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The panel discussion for Session 1 was a wonderful opportunity to ask these giants of research and industry some tough questions about how this technology could help people with a diverse range of problems, not only locked-in syndrome.

The threads of the discussion focussed on the importance of closed loop feedback to enable real time processing of brain signals and interpreting commands of the user accurately. There are two arms of this process. One is in the hardware solution of making brain signal recordings, and each of the three groups presenting were focussed on developing different hardware solutions to this problem. The other arm is software development. And it is clear that there were similarities in the software solutions needed by users with a diverse range of problems. BCIs could potentially be used to decode any brain signal not just by thinking about clicking a mouse but also walking, speaking, sensing, and in epilepsy prevention. We asked our speakers to think about future applications, and it is clear the field is wide open.

> "We envisage that BCIs can become a platform technology giving additional functionality for people to use in whatever way supplements their functional needs."

During the panel discussion we were also lucky to have experts in the Australian legal system and with a strong background in ethics as it relates to brain surgery in the context of diminished capacity. The session closed with a robust discussion about the risks and challenges of ensuring autonomy in decision-making for someone with limited ability to give their own consent.

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Session 2: Living with Communication Challenges in Cerebral Palsy

Disability Technology dynamo, Pete Horsley from Remarkable, led a conversation with diverse panel of people living with functional limitations and their families, along with people working to make technology more inclusive. Amongst many others we met Al and heard from his mum Penny about their amazing story of success with deep brain stimulation, helping him to live his life fully. The picture of him recently attending his school formal with a huge grin on his face was extremely powerful.

We met Chris Hills and his father Garry who told their incredible story of the life-changing influence of a Head Switch control (attached to the headrest of his wheelchair) enabling Chris to control his numerous Apple devices, of which he confesses to being a massive fan! This seemingly simple access tool has been the single biggest influence on Chris's independence and now Garry is looking forward to Chris looking after him in his old age!

Some great insights from the discussion were:

"The technological advancements that may be essential for some people, will be beneficial for all."

"Technology is just a method to help people."

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We heard from Bob MacDonald from Google, who is working to make voice to text technology more accessible via Project Euphonia. Members of the symposium gave him great suggestions of how to get voice recordings from people with all types of disability and in all different types of situations to train voice recognition algorithms and to make them more inclusive. Bob dreams of a time when technology reaches a level that we enter a **"Virtuous Cycle"**, whereby systems are trained to such a level that all people are included in its advancement regardless of their level of ability.

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There was a sign-off from Leigh Hochberg that there is

"a moral imperative to try"

and that the people who benefit most from the technology should be having a say as to what research we ultimately undertake, balancing carefully the risks and benefits of any technological advance.

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Session 3: Deep Brain & Spinal Cord Neuromodulation for Movement Disorders

In session 3 we were fortunate to have internationally renowned neuromodulation experts with over 60 years in collective experience building implanted medical devices. Professor David Borton, also from Brown University, and also part of the Braingate team, told us of his personal goal to create an

"Intelligent Spine Interface"

to bridge the gap in spinal cord injury.

He took us on a tour of the nervous system using the schematic drawings of Cajal and the fantastic multicolour brilliance of Lichtman's Brainbow. His depiction of the complexity of the nervous system was beautifully demonstrated and his advanced bionic solutions for interpreting the activity of the spinal cord and decoding these signals into movements is rapidly approaching clinical trials offering much hope for people living with spinal cord injury.

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Professor Hugh McDermott from Melbourne's Bionics Institute and Chief Technology Officer of spin out company DBS Technologies gave a wonderful presentation demonstrating the immediate benefit of Deep Brain Stimulation (DBS) for two patients living with obvious motor disorders; one a lady living with Parkinson's disease was able to show immediate benefit in her walking and tremor when the device was switched on versus when it was switched off, and the other, a young man with a progressive and severe movement disorder that made everyday life extremely difficult.

> "The moment when a young man was able to switch off his severe movement disorder to attend his high school formal with a huge smile on his face was the highlight of the day."

These brief videos captured the imagination of the audience as to what the power of implanted electronics could be for people living with neuromotor dysfunction.

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Dr Simon Paget and Professor John Parker followed up on the information presented at SyNC 2018 about the need for a bionic solution to assist with the management of spasticity in children living with cerebral palsy.

Great strides forward towards a clinical trial have been taken to investigate the use of closed loop spinal cord stimulation. The Evoke device, as it is called, is a technology developed in Australia by John Parker with his team at Saluda Medical, and it has already been shown to be transformative in treating chronic back and leg pain, something many living with spasticity of their legs already live with on a daily basis.

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The panel discussion after this session raised some important questions:

"If the effects of implanted electronics can be so transformative, like a miracle, why is it that we are not seeing a more rapid uptake of these technologies?"

The panel members had a number of theories, including issues with naming of the technologies. One of our audience members stated that all three words of Deep, Brain and Stimulation are somewhat scary! And we shouldn't dismiss the power of a name in appealing to, or deterring people from, learning more about a technology.

John Parker pointed out that existing technologies are just not quite up to scratch, and for technologies like this to be taken up they have to be automatic and smarter. He pointed to the permanent pacemaker which is implanted in millions of people, versus conventional spinal cord stimulators which are used 10-20 fold less per year. The pacemaker is a closed loop stimulator which can measure the heart rate and automatically adjust its stimulation. All the panelists agreed that some form of closed loop, automated or adaptive capability within an implant will be the future of medical devices.

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Session 4: Sacral Nerve Neuromodulation for Incontinence: Future Challenges

In the final session for the day we explored the use of sacral nerve neuromodulation for the management of incontinence. Not many people in the audience knew that incontinence was such a big problem, and certainly almost no one knew that an implanted electrical solution was available that can cure it.

Did you know that incontinence is a more common problem in the community than back pain?

We heard firsthand from Pej Pak, a young man who has a sacral nerve stimulator implanted, and he told us how it changed his life. We also heard from the Continence Foundation of Australia about the supports that are available for people with continence issues.

Three brilliant surgeons from North Shore Private Hospital presented their experiences implanting these devices in people with continence difficulty, both urinary and faecal. Dr Amanda Chung, Dr Danielle Delaney and Associate Professor Margaret Schnitzler gave us a wonderful summary of what modern SNM can achieve and what its limitations are.

When we explored why this technology is not more commonly used, we learned that:

"There is a stigma associated with talking about incontinence and many just accept it as a normal part of aging, especially after childbirth. Even GPs may not know this treatment exists."

Finally, Gerrit Gmel shared more about the potential for closed loop neuromodulation of the sacral nerve.

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Suggestions by registrants for future workshops

- Devices and commercialization
- Visual prostheses
- Neuromodulation in psychiatry
- More lived experience insights
- An overview of the model of care for cerebral palsy in each presenter's country differences may impact the viability of technologies
- Training for families and carers so they can engage with new technologies
- How to determine who will benefit most from access to brain machine interface treatments and other technologies to improve communication outcomes
- Electrical impedance tomography in biomedical research

Registrant feedback

"I could only come to the first session, but it was brilliant and very inspiring. I learned so much and am grateful to have been able to attend. Thank you to the organisers and the presenters for such cutting-edge presentations!"

"Excellent speakers who interacted in a collegial manner."

"Excellent opportunity for collaboration. Would be even better in person."

"This symposium had a great agenda! Seemed like it could have been an ANZ INS (International Neuromodulation Society) conference. I would suggest partnering with them for a future meeting."

"Very informative on advances in medical devices and cutting-edge technology available for people living with neuromuscular diseases."

"More start-up involvement would definitely help."

"The lived experiences panel was the highlight. It was fantastic to hear their valuable insights and thoughts."

"I didn't find out about this event till the day before. Maybe more ways to promote the symposium."

"Will love to attend more of these."

"The symposium was engaging, and the talks are all interesting and enlightening. I think it would be helpful if the agenda indicated which speakers were joining via Zoom or in person."

"Fantastic! I was a Zoom participant and felt like it went really well."

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It was a wonderful day and an opportunity for clinicians, and researchers and engineers from industry to openly discuss the issues each faces in coming to a solution for such difficult problems. I very much enjoyed the robust, honest and open discussions during the panel sessions, which focused on how we can make neurobionic solutions more widely known and available for people living with difficult challenges.

There was so much dedication on display from those working tirelessly to improve existing treatments and to create new ones. The future of neuromodulation looks bright indeed.

Finally, I would like to thank all of our presenters (especially those who stayed up late into the night in their respective time zones!), my co-host Alistair McEwan, Nicholas McKay and Thalia Hambides from the University of Sydney, and my support staff Melanie, Martina and Mally.

See you at the next SyNC Symposium!

For early notice of upcoming SyNC events and news, subscribe here <u>https://www.joedusseldorp.com/subscribe</u>



SyNC information is hosted on Dr Joe Dusseldorp's website.

You can find all the profiles for Symposium speakers, photos from the day, and links to all recorded presentations here.

https://www.joedusseldorp.com/sync-2020