



A summary of the Advancing Innovation in Assistive Technology Summit 2018

Report authored and edited by Cerebral Palsy Alliance



Report of the Summit

Background

On May 3-4, 2018 the Cerebral Palsy Alliance, hosted the Assistive Technology Innovations for Communication and Mobility **in San Francisco**. The event was the 8th international research summit organized and facilitated by Cerebral Palsy Alliance's International Summit Committee.

The objectives of the summit were to:

- Bring together experts on cerebral palsy and innovative technologies from around the world to share their knowledge, enhance trans disciplinary thinking and establish new networks and collaborations
- Build and execute carefully-designed roadmaps that accelerate development and delivery of new accessible technologies to consumers the market that challenge previous barriers, leverage new advances in computer science, embrace universal design and drastically improve the lives of people with disabilities around the globe
- Prioritise novel research, collaborations and financial support moving forward

The delegates represented companies such as Apple, Microsoft, Amazon and Facebook. They also came from institutions such as the National Science Foundation, Brown University, Cornell University, Harvard University, University of California, Berkeley, Vanderbilt University, University of California, Los Angeles, University of Kansas, University of Pittsburgh, University of Michigan, University of Sydney, Utrecht University, University of Calgary, University of Bremen, University of Tsukuba, Imperial College London, University College London and the Indian Institutes of Technology. Importantly, people with cerebral palsy and their families were also among the delegates.

The two-day summit featured both plenary presentations and facilitated workshops and was organized around three streams: **Thought-to-Speech, Mobility and Communication**.

Seventy four delegates attended from 12 countries. This global interdisciplinary research summit featured collaborations with a distinguished group of world-class experts in the fields of brain-computer interface, robotics, exoskeletons, virtual reality, cerebral palsy, neuroscience, brain stimulation, rehabilitative medicine, language development, speech recognition, assessment and access solutions.



Key Messages from the Summit

There are clear breakthrough opportunities in providing long-term, rapid, intuitive, useful communication and mobility for people with cerebral palsy – using technology such as artificial intelligence, flexible technology and robotics will allow us to reach the goals to:

- By 2021, have five people with cerebral palsy participating in today's ongoing clinical trials of implantable BCI to restore communication
- By 2021, have children less than two years of age having access to devices that enhances their mobility
- By 2021, have children and adults, with severe complex communication needs, skills accurately assessed for use and learning

Cerebral palsy imposes a severe physical, emotional and economic burden on affected individuals, their families and the communities in which they live

- Researchers were urged by a parent to make sure that no innovations were left sitting on the shelf and not be shared with user groups who could potentially make the product commercially available, after they have been appropriately evaluated for efficacy and cost-effectiveness, if they only knew about it
- Every person with cerebral palsy deserves technology that is personalised to their needs
- Families want devices that have consolidated functions so they don't need as much equipment
- Both non-invasive and surgery-requiring brain-computer-interface approaches were believed to be of potential value
- Good design is essential to complement technology

Strategic investments in innovation and research are required to accelerate progress

- Increased investment in research with standardized data elements including harmonized outcomes will facilitate meta-analysis
- Seed funding to bridge the gap between start-up and research evaluation or commercialisation

There can be no progress without partnership

- Some of the **highlights of this summit have been the** connections that were made between different researchers, industry partners and family representatives. The families who participated in the summit and told their story had an influence on the direction of many of the potential future projects that were discussed. This has resulted in an increased awareness among researchers and industry partners new to cerebral palsy, about the challenges many children and adults face

Summit Action Plan

Immediate next steps

1. Develop a consumer advisory panel available to all companies to better understand and prioritize technology needs and ensure we are responsive to them as well as achieving good user-device fit
2. Pilot test a “y-combinator-style accelerator” that catalyses new tech development by identification of talent, enables user test and runs an investment model that returns profit from devices back to new investment in devices to benefit those who have cerebral palsy

The development of the following **Road maps for Thought-to-Speech, Mobility and Communication.**

Thought-to-Speech

Despite significant progress in the development and evolution of computerized augmentative and alternative communication devices, for someone with severe motor impairments, use of these systems remains exceedingly cumbersome and time-consuming. We are proposing a revolutionary new communication process utilizing recent advances in brain-computer interface technology and by-passing many of the impediments of currently available communication systems.

The Thought-to-Speech track provided a review of current knowledge regarding communication neuroscience and the status of brain-computer interface technology. While the goal is to develop a real-time thought-to-speech brain-computer interface communication system, the delegates recognized that many intermediate steps will be required. The elements of an aggressive research roadmap, including timeframe, were identified, see figure 1.

Priorities

- Define projects/collaborations, leveraging existing efforts and apply for funding
- Underpinning ethical principles and framework
- Define standardized measures of assessment and output measures

...The fact that I am unable to vocalize for myself where people can always understand me has been a frustrating part of my life. Such things as telling a beautiful girl I love her with my own voice.”

– Bill Jnr., 44 years old

Action step

- Explore local solutions for recruitment
- Explore funding opportunity through the National Institute of Health award to study language areas in Alternative and Augmentative Communication speakers
- National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR) Rehabilitation Engineering Research Center (RERC) on Brain Computer Interface
- Develop partnerships with: National Institutes of Health (NIH) National Institute of Neurological Disorders and Stroke (NINDS), National Institute on Deafness and Other Communication Disorders (NIDCD), National Center for Medical Rehabilitation Research (NCMRR), Department of Defense (DOD)/ Defense Advanced Research Projects Agency (DARPA) funds for imaging studies, implant technologies

- Seek opportunities for proof of concept proposals from the National Science Foundation
- Develop Cerebral Palsy Alliance Research Foundation partnerships with funding agencies

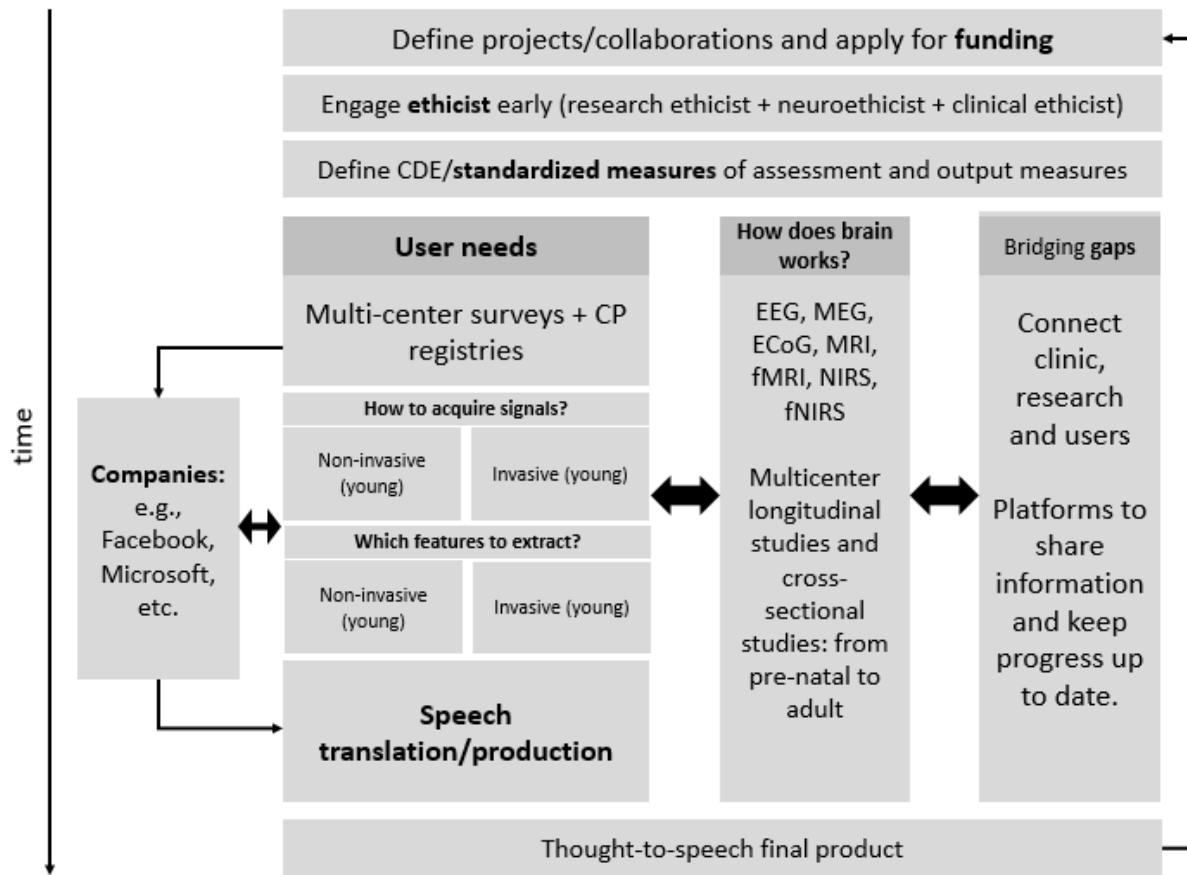


Figure 1: courtesy of Dr. Mariana Branco

Mobility Technology

Discoveries in robotics, driven mainly via machine learning advanced manufacturing and computational modelling are set to transform the mobility technology available across a wide range of disabilities. Exoskeletons, rehabilitation robots and orthosis should be personalized and adjustable to age, goals and capabilities, whereas in the past they mainly focused on adult populations and conditions such as spinal cord injury where there is no rigidity or large uncontrolled movements. Gamification and mixed/virtual reality may provide improved motivation and rehabilitation outcomes. Progress will be more rapid by bringing together globally disparate projects, communicating the potential of machine learning and defining a common strategy and research priorities as proposed at the technology summit.

Priorities

- Devices to enhance mobility and activity in children less than two years of age
- Devices that provide training (personalized solutions to tailor training to individualized abilities and goals). Works when worn and when off
- Devices that provide greater access, participation and independence

“I’d like to be able to go to school without an aid...If I could improve my wheelchair, I would have just one that has all features instead of three. And, the wheels would light up!...”

– Lily, 11 yrs old

Action step

- Involve consumers, children, and clinicians
- Develop software modelling, personalized platforms, hardware modularity, standards, common data elements, data collections, young techies, and health economics
- Know FDA pathways to design approval e.g. new computational design and modelling pathway
- Organizational support to invest in development: y combinator, Investors or corporate partners, crowd sourcing, NSF and other funders – encourage them to consider new models
- Bring all device companies together; change training model for device developments (business people, academics, automotive companies), find mechanisms to work collaboratively

Communication Technology

The most common access solutions for communication for people with cerebral palsy are pressure sensing micro-switches, autonomic nervous system sensors, accelerometers, video cameras used for image processing, thermal cameras and eye-track technology. However, these access pathways may not meet the needs of many people with severe disabilities, such as cerebral palsy, who do not have voluntary control of their movements and cannot successfully and reliably operate these access solutions.

Through a novel and multidisciplinary approach, researchers, people with lived experiences, clinicians, engineers and industry partners joined forces to stimulate development that leverages newly available technologies, such as virtual reality, voice recognition and modern software, to design solutions that hold the key to unlock vast potential in people with severe disabilities, who today have limited means to learn, play and communicate.

Priorities

- Develop standardized assessment for foundational communicational skills for use and learning of personalised assistive technology
- Develop a global fund for commercialisation and communication solutions to realise the human right of communication
- Identify large gaps in existing technology and implementation

“There are issues with the computer program I use for communication. Often, when I do business calls, the person on the other end of the phone cannot understand me and will talk over me....”

– Bill Jnr., 44 years old

Action step

- Develop partnerships with International Society of e.g. the International Society for Alternative and Augmentative Communication (ISAAC), the Association for the Advancement of Assistive Technologies in Europe (AAATE), Australian Rehabilitation and Assistive Technology Association (ARATA), Microsoft, Apple, Amazon, Google and non-for profit organizations

- Seed funding to bridge the gap between start-up and research evaluation or commercialisation (governance, criteria)
- Develop and plan for maintenance of a Wiki resource to collect and maintain current assistive technology that has been developed to support communication

Immediate activities from the Summit

- A request from the organizing committee in regards for a letter of support for a grant for Dr. Eduardo Rocon
- Professor Hochberg and Professor Cash provided a proposal from Brain gate
- Dr. Mariana Branco provided a summary of the discussion and offered continued collaboration
- Professor Sunil Agrawal, Columbia University and Professor Tom Chau, Holland Bloorview Research Institute have extended invitations for site visits to their labs
- Microsoft announced a \$25 million disability technology initiative

About Cerebral Palsy Alliance

For the 17 million people with cerebral palsy worldwide and others living with a disability, the world's largest minority group, technological advances that could enhance participation such as mainstream technology can be a challenge to access. With one in three people with cerebral palsy unable to walk and one in four unable to talk, innovative assistive technology addressing solutions such as walkers for toddlers; voice recognition for people with dysarthric speech; access to Apps on smart phones and computers are urgently needed.

The Cerebral Palsy Alliance has almost 70 years' experience serving people living with cerebral palsy and their families. Beginning as a small family-based organization, we now employ more than 1800 staff from a range of disciplines in support of our clients' needs.

At Cerebral Palsy Alliance, our clinical service provides intervention to over 5000 clients annually to support their full inclusion. Our research program focus on prevention and cure of cerebral palsy as well as finding innovative new treatments and interventions.

Our purpose: Building futures for people with cerebral palsy whilst working for a future without cerebral palsy.

Our values: Integrity, Respect, Courage, Passion, Excellence

In 2005, the Cerebral Palsy Alliance, in response to the expressed concerns of our clients, launched the world's first Research Foundation focused on the prevention and cure of cerebral palsy and interventions to improve the life of people with cerebral palsy. In a few short years, the Alliance has developed an international reputation as a world leader in cerebral palsy research. Fifty-eight percent of the most effective cerebral palsy treatments being used worldwide have been discovered in the past 10 years thanks to the efforts of researchers around the globe working with the Cerebral Palsy Alliance.

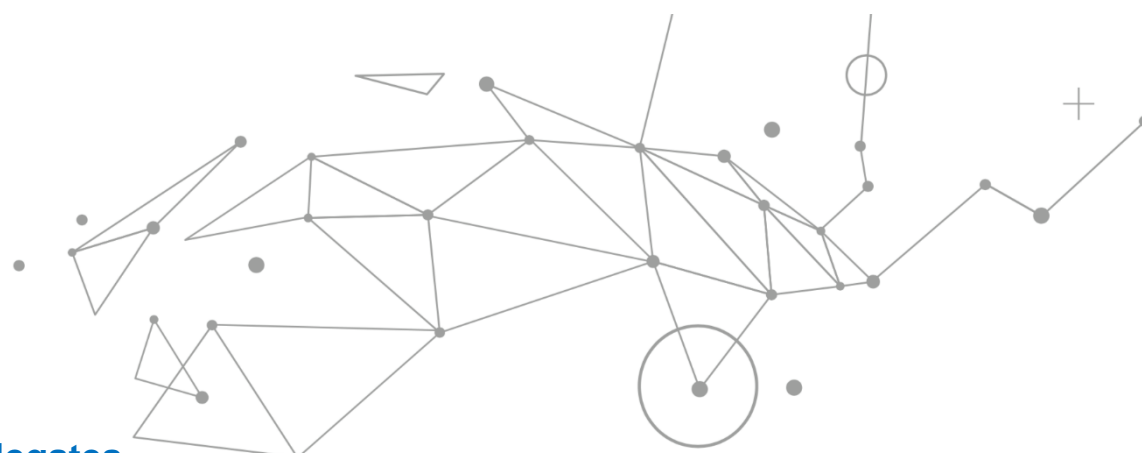
In just over ten years, the Research Foundation has awarded more than US \$30 million, supporting more than 300 Cerebral Palsy research projects worldwide. The Research Foundation has a strong on-going commitment to funding high-quality research into the

prevention, treatment and cure of cerebral palsy. Each year, Cerebral Palsy Alliance's Research Foundation invites researchers to submit funding applications to its Grants Program.

Sponsors



Miller Family



Delegates

Sunil	Agrawal	Columbia University	New York, USA
Gopala	Anumanchipalli	UCSF	USA
*Nadia	Badawi	Cerebral Palsy Alliance	Sydney, Australia
*Isabelle	Baldé	Cerebral Palsy Alliance	Sydney, Australia
Anupam	Basu	National Institute of Technology Durgapur	Durgapur, India
*James	Blackman	Cerebral Palsy Alliance Research Foundation	New York, USA
Kristofer	Bouchard	University California Berkeley	Berkeley, USA
Mariana	Branco	Utrecht Medical Center	Utrecht, The Netherlands
Cameron	Brown	Cerebral Palsy Alliance Research Foundation	New York, USA
Jonathan	Brumberg	University of Kansas	Kansas, USA
Thomas	Bulea	National Institutes of Health Bethesda	Maryland, USA
Etienne	Burdet	Human Robotics Group, Imperial College	London, UK
Sarah	Caplener	Amazon	USA
Sydney	Cash	Massachusetts General Hospital, Harvard University	Cambridge, USA
Edward	Chang	University of California, San Francisco	San Francisco, USA
Josh	Chartier	UCSF	USA

*Tom	Chau	Holland Bloorview Kids Rehabilitation Hospital	Toronto, Canada
Mark	Chevillet	Facebook	San Francisco, USA
Michael	Clarke	University College London	London, UK
Ted	Conway	Florida Institute of Technology	Melbourne, USA
*Diane	Damiano	National Institutes of Health Bethesda	Maryland, USA
*Donna	Ferriero	University of California, San Francisco	San Francisco, USA
Antonio	Frisoli	Scuola Superiore Sant'Anna Pisa	Pisa, Italy
Deborah	Gaebler-Spira	Ability Lab, Northwestern Memorial Feinberg School of Medicine	Chicago, USA
*Dawn	Gano	University of California, San Francisco	San Francisco, USA
Johanna	Geytenbeek	VU University Medical Center Amsterdam	Amsterdam, The Netherlands
Bernadette	Gillick	University of Minnesota Medical School	Minnesota, USA
Michelle	Grimm	National Science Foundation	Washington, USA
Paul	Gross	Cerebral Palsy Research Network	Seattle, USA
Frank	Guenther	Boston University	Boston, USA
Disha	Gupta	Burke Medical Research Institute	New York, USA
Meghan	Hadlock	Carer Josephine	New York, USA
Masato	Hasegawa	University of Tsukuba, Cyberdyne	Tokyo, Japan
Christian	Herff	University of Bremen	Bremen, Germany
Katya	Hill	University of Pittsburgh	USA
Leigh	Hochberg	Brown University, Massachusetts General Hospital, Harvard Medical School	USA
*Pete	Horsley	Cerebral Palsy Alliance	Sydney, Australia
Christopher	Howson	Howson & Partners for Global Health	Santa Fe, New Mexico
*Jane	Huggins	University of Michigan	New York, USA
*Petra	Karlsson	Cerebral Palsy Alliance	Sydney, Australia
Hoymahoon	Kazerooni	University of California, San Francisco	San Francisco, USA
Hiroki	Kimura	Cyberdyne	Tokyo, Japan
Adam	Kirton	University of Calgary	Alberta, Canada
Harish	Kulkarni	Microsoft Corporation	San Francisco, USA
Jean Louis	Lelogeais	Cerebral Palsy Alliance Research Foundation	New York, USA
Daniele	Leonardis	Scuola Superiore Sant'Anna Pisa	Pisa, Italy
David	Lloyd	Griffith University Queensland	Gold Coast, Australia
Stephanie	Martin	Swiss Federal Institute of Technology	Lausanne, Switzerland
*Alistair	McEwan	Cerebral Palsy Alliance	Sydney, Australia
Maria	McNamara	Cerebral Palsy Alliance	Sydney, Australia

*Bronya	Metherall	Cerebral Palsy Alliance Research Foundation	New York, USA
*Nina	Miller	Cerebral Palsy Alliance Research Foundation	New York, USA
Josephine	Miller	Daughter Nina	New York, USA
Zac	Miller	Husband Nina	New York, USA
*Cathy	Morgan	Cerebral Palsy Alliance	Sydney, Australia
David	Moses	UCSF	USA
Emily	Mugler	Facebook	San Francisco, USA
Dina	Nikitina	Trexo Robotics	Toronto, Canada
*Iona	Novak	Cerebral Palsy Alliance	Sydney, Australia
Silvia	Orlandi	Holland Bloorview Kids Rehabilitation Hospital	Toronto, Canada
Nader	Pouratian	University of California, San Francisco	San Francisco, USA
Eduardo	Rocon	CSIC, Spanish National Research Council	Madrid, Spain
Rosalind	Sadleir	Arizona State University	USA
Lana	Shekim	National Institutes of Health Bethesda	Maryland, USA
Michele	Shusterman	CP NOW	Greenville SC
Sara	Smolley	Voiceitt	Tel Aviv
Walid	Soussou	Wearable Sensing & QUASAR	California
Lucie	Wade	Jewish General Hospital, McGill University Health Centre	Montreal, Canada
*Karen	Walker	Cerebral Palsy Alliance	Sydney, Australia
Seth	Warschausky	University of Michigan	USA
Danny	Weissberg	Voiceitt	Tel Aviv
Leila	Whebe	University California Berkeley	Berkeley, USA
*Rob	White	Cerebral Palsy Alliance	Sydney, Australia
Dean	Hodson	Apple	USA
Frances	van Ruth	Consul and Trade & Investment Commissioner	San Francisco, USA
Sheila	Bangalore	Legal Assist General counsel	Aristocrat Technologies

*Organising Committee

