

# Prevention and Cure Cerebral Palsy Summit 2011



Supported by the Balnaves Foundation



## Background

The Prevention and Cure Cerebral Palsy Summit was held on October 18-19<sup>th</sup> 2011 in San Francisco, USA. The summit was hosted by the Cerebral Palsy Alliance Research Foundation and proudly supported by the Balnaves Foundation. Professor Donna Ferriero from the University of California San Francisco chaired the event.

The purpose of the summit was to invite a selection of the world's leading researchers in cerebral palsy to inform the development of a cerebral palsy research network, which will seek to: cure and reduce birth prevalence and severity of cerebral palsy.

Thirty-two delegates attended the summit. The delegates were chosen to represent the broad number of specialities actively involved in cerebral palsy research. At the summit, each participant gave a presentation reflecting their expertise, and group work devoted to objectives set through a pre-summit survey was completed.

## Objectives

The objectives of the summit were to:

- Support the formation of a new cerebral palsy network committed to accelerating breakthroughs for cerebral palsy
- Focus international research on cerebral palsy prevention, cure, early identification and intervention
- Identify critical knowledge gaps and recommend research priorities
- Develop a statement for action on knowledge gaps and research priorities to form a roadmap for collaboration and future research partnerships

## **OUTCOME ONE: Support the formation of a new cerebral palsy network committed to accelerating breakthroughs for cerebral palsy**

Summit delegates agreed that the formation of an international research network aiming to prevent and cure cerebral palsy would be a valuable next step in building momentum toward the prevention and cure of cerebral palsy. Delegates agreed that the network should include all international researchers who have the same over-arching aims and are interested in joining.

The suggested name for the new network was:

### **IMPACT for CP**

*International Multidisciplinary Prevention And Cure Team for Cerebral Palsy*

The following mission of the **IMPACT for CP** Network was proposed:

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A network committed to preventing and finding a cure for cerebral palsy

The network would be an open collaboration of scientists, researchers, clinicians, families, patients, philanthropists, industry, policymakers, and funders.

Delegates proposed the following **IMPACT for CP** Network aims, to:

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- Develop a shared research plan outlining goals and research priorities with well-defined research end-points
- Support efforts to promote a smoother continuum of cerebral palsy research from basic science studies to clinical trials and to expedite research translation
- Provide a forum for informal mentoring and support between cerebral palsy researchers

Delegates proposed the following **IMPACT for CP** Network strategies:

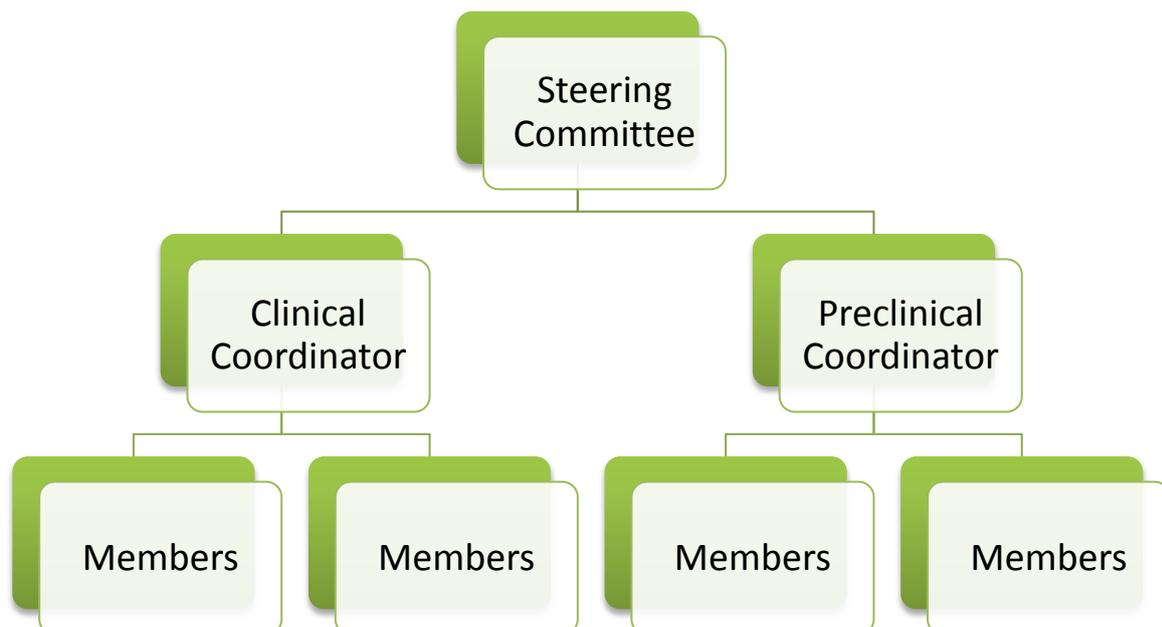
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- Provide seed funding for priority projects
- Assist the work of cerebral palsy registries via:
  - ▶ Development and use of standardised definitions
  - ▶ Data sharing

- ▶ Pooling and linking data, e.g. MRI's linked to Registries or other bio-specimen repositories such as placenta banks, or a standardised video-clip of each child
- Support efforts towards network-led coordinated data collection that is both prospective and longitudinal
- Agree on a range of standardised data collection tools and outcome definitions so that data can more easily be shared, compared and pooled for future meta-analyses
- Develop strategies to support the sharing of raw data between network researchers [not only aggregated data points]
- Explore opportunities for collaborative research [e.g. research register, multi-centre/multi-site studies and prospective meta-analysis], because these methodologies provide increased participant numbers and statistical power and therefore lend themselves to a collaborative network
- Leverage network members research outputs by collaborative efforts to expedite or expand research efforts
- Seek funding for research as a collaborative group

The following organisational structure was proposed:

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## Partnerships

The benefits of partnering with existing networks and organisations were also discussed in terms of raising the profile of cerebral palsy with current researchers and networks, supporting excellent work already being done and not wasting valuable resources in replicating systems that are already working well. Presentations from attendees highlighted that many current organisations or networks would be pleased to collaborate with a cerebral palsy network with a prevention and cure focus e.g. ACOG, AACPDM and AusACPDM, cerebral palsy registers, International Pediatric Stroke Study (IPSS), the CP CPR group described by Sid Tan, neonatal intensive care research groups, CIRM, cerebral palsy service providers and advocacy groups.

It was also noted by the attendees that families and individuals with CP are great advocates for the vision of a future where cure and prevention of cerebral palsy is a reality. Families of children with autism have demonstrated a great capacity for research advocacy and this network should support any efforts of this kind within the cerebral palsy or wider community. Attendees of the summit noted that families and individuals with cerebral palsy are a powerful group in their ability to support research efforts both in terms of advocating for better research funding or supporting individual participation in research studies.

## ACTIONS:

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1. Cerebral Palsy Alliance to identify and obtain the funding for a full-time Network Coordinator to advance the collaborative efforts of the network
2. Seek Network endorsements from key bodies, e.g. UCP, CPIRF, ACOG, AACPDM, AusACPDM, EACD, PSANZ, AAP, CNF

## **OUTCOME TWO: Focus international research on cerebral palsy prevention, cure, early identification and intervention**

Delegates identified that rates of cerebral palsy have not changed significantly in decades. Delegates were in agreement that in order to accelerate progress in research and the clinical application of research findings a greater international research focus on the prevention and cure of cerebral palsy was imperative.

### **Prevention:**

Prevention research would include primary prevention of cerebral palsy inclusive of public health strategies [e.g. folate prior to pregnancy to reduce birth defects?] and other strategies directed at preventing distal components on a causal pathway to cerebral palsy [e.g. melatonin for SGA during pregnancy], as well as strategies closer to the proximal cause of brain damage [e.g. magnesium for neuro-protection when very preterm birth is imminent].

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### **Cure:**

Cure research would include strategies aimed at ameliorating early brain damage as close as possible to the proximal timing of the brain injury [eg cooling and cooling with other strategies]. The network would also focus their research efforts on finding interventions to cure long-standing brain injuries associated with cerebral palsy, as well as epilepsy and intellectual, vision and hearing impairments. Cure efforts would also be aimed at lessening the severity of motor impairment and other disabilities.

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### **Early identification:**

Early identification research would include efforts towards strategies for identifying cerebral palsy as early as possible, with a focus on implementation of MRI advances in combination with other predictive tools [e.g. General Movements] in order to provide opportunity for implementation of secondary prevention strategies or curative treatments as soon as possible.

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### **Early intervention:**

Early intervention research would refer to intervention strategies for reducing the severity of the condition and prevention of secondary deformities and complications.

### **Outcome Measures and Study End-Points**

A detailed overview of the measures and terminology in use in the prevention and cure of cerebral palsy field was presented. The data from this presentation was acquired by systematically abstracting data from trials published in the Cochrane library that used the

word cerebral palsy in the review or was applicable to cerebral palsy but did not use the word but was published in the Pregnancy and child birth or Neonatal Cochrane groups. The group concurred that research outcomes would be accelerated if consistent terminology and consistent use of a core-set of measures for future studies could be agreed upon. Delegates engaged in an active dialogue about the operating principles that should apply when choosing measures and end-points for future collaborative studies. The guiding principles recommended included:

- Development of or acquisition of a shared data dictionary
- Use of continuous variables wherever possible
- Agreement to share raw data freely
- Use of agreed upon definitions and measures already endorsed by leading bodies (NB it is noted that not all endorsed documents are completely agreed on).
- Use of tools with sound psychometric properties
- Coding of data in consistent and agreed upon formats to expedite pooling

## **ACTIONS:**

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1. Cerebral Palsy Alliance to complete and publish the data abstraction and synthesis of measures in use.
2. Sub-committees to be formed to carry on the work commenced at the summit regarding a core data set. Diane Damiano, Jan Brunstrom and Mijna Hadders-Algra volunteered to help with this Network task.

## **OUTCOME THREE: Identify critical knowledge gaps and recommend research priorities**

A structured and facilitated research priority setting activity was undertaken during the summit. The aim of the activity was to update and build on the cerebral palsy research priorities already published in the literature<sup>1</sup>. Delegates used a 7-point Likert scale to rate the priority of fifty-four research questions identified in literature and from delegate pre-summit survey responses. A rating of seven meant the delegate rated the issue as a very high priority. A rating of six denoted high priority, a rating of five denoted fairly high priority, and a rating of four denoted a topic area that was neither low nor high priority. Ratings of 1-3 referred to low/non-priorities and are not reported here. Twenty-six questions were rated as a priority. The research priority areas are listed below in topic themes and are ranked in order of priority agreement, with the highest priority first.

### **RESEARCH PRIORITIES**

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#### **Neuroprotection/regeneration/repair**

- How can endogenous repair pathways be enhanced?
- Experimental research addressing the importance of the delayed phase (days-weeks) and the possibilities of intervention in the delayed/tertiary phase
- What are the mechanisms of neuroregeneration?
- What neuroregeneration strategies can be developed?
- What value can stem cells have for this population?
- What new strategies for term babies will augment hypothermia?

#### **Intervention:**

- What are the most effective early intervention strategies?
- Can early intervention (therapy) augment cellular therapies following discharge from hospital?

#### **Research tools:**

- Do we have the tools (registers) to identify reductions and increases in the frequency of CP? How can we best combine databases to increase accurate surveillance?
- What tests can be developed to identify placental abnormalities?

- What strategies are available [e.g. a research network] to promote collaboration across disciplines [e.g. animal models, obstetrics, neonatal, epi] and to share data when/if appropriate?
- Can a gold standard classification system of cerebral palsy based on underlying pathology be developed and agreed on?
- Can a consensus be reached on placental procedures, terminology and interpretation of pathology?
- Can a classification system/set of comprehensive definitions be developed to provide consistency of reporting of neuroimaging data, to promote better collaborative research opportunities and analysis?
- How do we ensure translation of research findings to practice?
- What strategy can be used to drive forward aetiological research by combining epidemiology with genetics, basic science and other disciplines to identify causal pathways?

### Focus on timing:

- What are the pathways to CP for those born at term without NE?
- How can we maximise neurodevelopmental outcome for babies born with perinatal hypoxic-ischaemic injury secondary to intrapartum asphyxia?
- Do risk factors in the antenatal period reduce a baby's tolerance to perinatal asphyxia?
- What are the most effective public health strategies to reduce postnatal CP?
- To what extent can CP be prevented in developing countries through the improved management of childhood illness?
- How can perinatal stroke be prevented?

### Other:

- What can be done to enhance our understanding of the aetiology of cerebral palsy?

■ How can we identify cerebral palsy earlier?

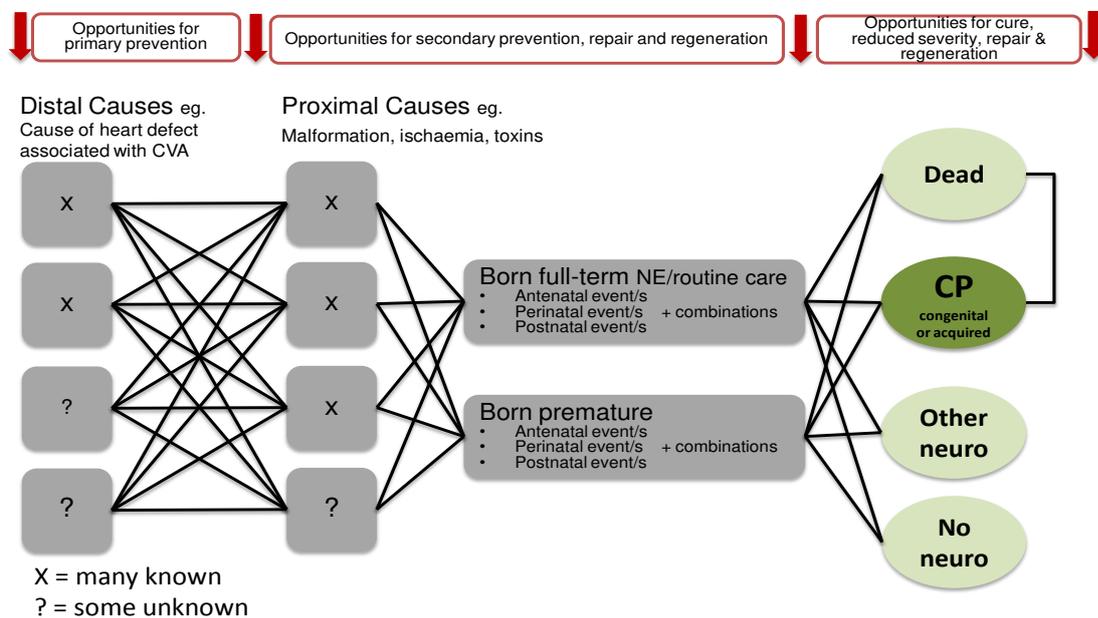
1. McIntyre, S., Novak, I., & Cusick, A. (2010). Consensus research priorities for cerebral palsy: a Delphi survey of consumers, researchers, and clinicians. *Developmental Medicine and Child Neurology*, 52(3): 270-275.

**OUTCOME FOUR: Develop a plan of action to address knowledge gaps, establish research priorities and a roadmap for collaboration and future research partnerships**

**Road Map for Cerebral Palsy Research**

A road map for cerebral palsy prevention and cure research will be developed by the network. Below is a general starting point for the network to further develop.

**Road Map for Cerebral Palsy Prevention and Cure Research**



Knowledge gaps were identified by those presenting, and research priorities were also further developed. A subsequent statement for action was not completed during the summit, it is thought that this could be one of the first tasks once the network was formally established.

**Thank you from the Chair and Organising Committee**

We would sincerely like to thank the summit delegates for their attendance, active participation and collaboration in seeking to build a future without cerebral palsy. We look forward to continuing to work with you as part of the **IMPACT for CP** Network to accelerate breakthroughs for cerebral palsy.

*The final thank you goes to the Balnaves Foundation. Without their vision, this summit and the first steps toward "IMPACT for CP" would not have taken place.*

