



Cerebral Palsy:

Accelerating breakthroughs in prevention, treatment and cure

A summary of the Prevention of Disability following Premature Birth Research Summit

Report authored and edited by:
Howson C, Walker K, Novak I, Badawi N,
Keogh J, McIntyre S, Morgan C, Ferriero D,
Blackman J, de Vries LS, Brunstrom-Hernandez J, White R (2017).

CPA IMPACT for CP: Cerebral Palsy Alliance

San Francisco, CA
May 3-5, 2017



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

At CPA, our priority is to help babies, children, teenagers and adults living with cerebral palsy lead the most comfortable, independent and inclusive life possible. Our therapy teams work with individuals and families to maximise their participation in the community. We know that every person with a disability is an expert in his or her own life. So we aim to guide and support – not to direct. Collaboration and partnerships with our clients are key.

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 CP. 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 258 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, CPA's Research Foundation invites researchers to submit funding applications to its Grants Program

KEY MESSAGES FROM THE SUMMIT

There are 17 million people with cerebral palsy worldwide

More than 268,000 babies are born with cerebral palsy every year

- Cerebral palsy is the most common motor disability in childhood. Population-based studies from around the world report prevalence estimates of CP ranging from 1.5 to more than 4 per 1,000 live births or children of a defined age range.
- Babies born preterm and/or with low birthweight have a significantly higher risk of developing cerebral palsy

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

- Cerebral palsy is the most common physical disability in childhood
- Children with cerebral palsy may have a range of associated physical and cognitive impairments, including inability to walk or talk, constant pain, epilepsy, behavioral disorders, intellectual impairment, severe problems with the eyes and vision, bladder control problems and sleep disorders
- Cerebral palsy costs national economies billions each year in lost income and the costs of care
- Cost-effective feasible interventions already exist that can prevent many cases of cerebral palsy and reduce the severity of disability in affected children
- Family planning, ensuring optimal nutrition before and during pregnancy and improved quality of care both antenatally and postnatally can help prevent preterm birth and reduce cerebral palsy incidence and disability rates
- Magnesium sulphate, cooling of the newborn and other treatments around the time of birth can prevent or reduce the severity of cerebral palsy in affected children
- Early diagnosis and intervention can maximise mobility, preserve cognitive function and ensure that all children with cerebral palsy can live productive and fulfilling lives

Strategic investments in innovation and research are required to accelerate progress

- Increased investment in descriptive, discovery, development and delivery research will allow us to better assess and monitor cerebral palsy incidence and outcomes, advance the science of prevention and improve early diagnosis and care of the affected newborn and child, especially in low- and middle-income countries where rates are high

There can be no progress without partnership

- Preventing cerebral palsy and improving the care of affected children will require coordination and, ideally, collaboration among all stakeholders, including government policy makers at national and local levels, donors and philanthropic organizations, academic and research institutions, the business community, health care workers and their professional organizations and civil society, including parent/patient organizations. Working together at last the answers are within our grasp.

Report of the Summit

Background

On May 3-5, 2017, the Cerebral Palsy Alliance of Australia, in an inaugural collaboration with IMPACT for CP, the UCSF Preterm Birth Initiative and March of Dimes Foundation, held a ground-breaking summit on the *Prevention of Disability following Preterm Birth* in San Francisco, CA. Participants included over 40 delegates from the co-sponsoring agencies, the World Health Organization, Bill & Melinda Gates Foundation and Global Alliance to Prevent Prematurity and Stillbirth (GAPPS), along with international researchers and clinicians working to improve the prevention and care of preterm birth and cerebral palsy. Attendees hailed from Australia, the United States, Europe, Bangladesh and Canada.

The objectives of the Summit were to:

- Bring together experts on cerebral palsy and preterm birth from around the world to share their knowledge, enhance transdisciplinary thinking and activity and establish new networks and collaborations;
- Determine what we currently know about how to prevent cerebral palsy during and following a preterm birth and what strategies are required to implement and translate these best practices in prevention and care into clinical practice; and
- Prioritise novel research, collaborations and financial support moving forward.

The two-day summit featured both plenary presentations and facilitated workshops. Twenty-two experts presented on a variety of plenary topics, including environmental and genetic factors in the aetiology of preterm birth and cerebral palsy; best clinical practices in the prevention of cerebral palsy following preterm birth; evidence-based early detection and intervention to minimise impairment, maximise healthy outcomes and improve quality of life; and strategies for harmonization of definitions and the collection of data on cerebral palsy incidence, prevalence, time trends, impairment and long-term outcomes in high-risk infants following preterm birth, especially in low- and middle-income countries (LMIC) where rates are high.

Five workshops provided an opportunity to review and discuss a number of pressing issues, including current gaps in knowledge about environmental and genetic causes and the research needed to improve the prevention of cerebral palsy in premature newborns, especially in LMIC. The workshops were also action oriented, with participants devising and agreeing upon action plans with next steps that they, their institutions and partner organisations could take to improve obstetric care, strengthen capacities for early detection and management of cerebral palsy in premature infants, stimulate research to close existing gaps in knowledge and promote the effective translation of new research findings into clinical care. They focused on enhancing collaboration and coordination of international efforts in ways that build upon rather than duplicate existing programs and on identifying joint sources of funding in support of global research activities.

For readers interested in more information on the Summit, including its agenda and participant bios, please visit: <https://impact.cerebralpalsy.org.au/>

An important announcement was made by the Cerebral Palsy Alliance on the first day of the summit, with the goal of accelerating action on the next steps summarised in this report. Mr. Rob White, CEO of the Cerebral Palsy Alliance in Australia, announced a gift of \$1 million dollars in support of research and programs directed to the prevention, detection, care and cure of cerebral palsy.

Summit Declaration

We, the delegates of the “Prevention of Disability following Premature Birth Research Summit” commit to working together to ensure that preventing cerebral palsy and disability following premature birth are a major focus for our collaborative research and partnerships.



Summit Action Plan

Research

There remain significant gaps in our understanding of the causes and outcomes of cerebral palsy following preterm birth and what can be done to strengthen prevention and minimise disability, especially in LMIC with high preterm birth rates. To close these gaps, participants discussed research needs and the priority action steps required to address these needs across the four “D’s” of research—description, discovery, development and delivery.

Description research

The need for better data. Participants agreed that comprehensive data on the global toll of cerebral palsy are lacking, especially in low-income regions like sub-Saharan Africa and South Asia where preterm birth rates are high. Given evidence in the U.S. that at least 50% of cases of cerebral palsy are due to prematurity (Schieve et al., 2016), it can be expected that rates of cerebral palsy in countries with high preterm birth rates will also be elevated especially as more preterm babies in these countries survive with improved care. Available data from Australia and Bangladesh support this contention where their rates of preterm birth are 7.6 and 14 per 100 live births, respectively (Born Too Soon, 2012), and the corresponding rates for cerebral palsy are 2.0 and 14.1 per 1,000 live births (ACPR, 2016; BCPR, 2016; Khandaker et al., 2015). However, country-level data on cerebral palsy incidence, prevalence, sub-types, severity of disability and outcome are almost completely lacking for other LMIC. There is, thus, an urgent need to collect robust data on the toll of cerebral palsy at national and subnational levels, especially in populations with high rates of preterm birth. Such data will allow for a better understanding of the particular causes of cerebral palsy in different populations, inform research directions and improve prevention, detection and treatment, especially in LMIC.

Action step:

There is a need to collect, evaluate and monitor robust data on the incidence, prevalence, types, severity and outcomes of cerebral palsy, especially in countries where preterm birth rates are high. These efforts should build on existing data collection efforts for preterm birth where feasible, including Demographic and Health Surveys (DHS), demographic surveillance sites and programs such as the Preterm Birth Initiative-East Africa funded by Marc and Lynne Benioff and the Bill and Melinda Gates Foundation. Hospital-based information systems collecting data on newborn outcomes such as preterm birth, low birthweight and congenital disorders could also be helpful as data sources as long as potential selection and other biases are taken into account. Better assessment will also require simpler and more accurate methods for the early detection and diagnosis of cerebral palsy and assessment of its severity and long-term outcome in affected children.

Discovery research

Identifying epigenetic factors that increase cerebral palsy risk. The prenatal environment has become increasingly recognised as an important predictor of birth outcome, but there are few biological markers that can identify mothers at risk of going into preterm labour or of premature infants at increased risk of developing cerebral palsy. Research into epigenetic factors in the intrauterine environment may help in the identification of biomarkers that can more accurately predict the risk of cerebral palsy in premature newborns. Such research could include identification and evaluation of genes that regulate biological pathways important to pathogenesis and the interaction of those genes with environmental factors that may contribute to cerebral palsy risk, including exposure to stress, under- or over-nutrition, neurotoxins and smoking, infectious agents and markers of placental function. Early identification of at-risk mothers and newborns could also help in identifying targeted interventions to prevent or delay preterm birth, allow in utero transfer to specialist centres and minimise subsequent disability in the premature newborn with cerebral palsy.

Action step:

Participants called for increased funding for research into the identification and characterisation of epigenetic factors and related biomarkers that can predict women at increased risk of preterm labour and premature newborns at elevated risk of cerebral palsy and severe disability. Funding should be given to research that builds on existing studies and trials funded by international granting agencies such as the US National Institutes of Health, European Commission and UK Medical Research Council.

The importance of biobanks in research on cerebral palsy. Biobanks play a crucial role in biomedical research. They can contain a wide array of biospecimens, including blood, saliva, plasma, and purified DNA, and catalogue these using genetic and other traits, such as age, gender, blood type, and ethnicity. Samples can also be categorised according to environmental factors, such as whether the donor had been exposed to radiation, asbestos, or other environmental toxins that can affect human genes. Biobanks are valuable resources as they give researchers access to data on large numbers of people allowing for investigation of rare traits or of combinations of traits that might not otherwise be feasible with smaller numbers of people typically enrolled in individual or even national studies. Many conditions—for example, cerebral palsy and preterm birth—may be associated with single-nucleotide polymorphisms (a variation in a single nucleotide that occurs at a specific position in the genome); thus, performing genome-wide association studies (GWAS) using large collections of biobanked samples representing tens or hundreds of thousands of individuals could help to identify biomarkers demonstrating risk of these conditions. Experience to date has proven the value of biobanking in the study of cerebral palsy. For example, in 2015, the Australian Cerebral Palsy Biobank overseen by the Australian Collaborative Cerebral Palsy Research Group at the University of Adelaide's

Robinson Research Institute reported the finding that at least 14 percent of cerebral palsy cases are likely caused by genetic mutations (McMichael et al., 2015). In light of this and other findings discussed at the Summit, participants agreed that biobanking is an under-appreciated and underfunded resource for discovery research into the causes and prevention of cerebral palsy and disability following preterm birth.

Action step:

Participants call for greater funding and support of biobanking that can help researchers better understand the causal relationship between genetic factors and environmental exposures in increasing risk of cerebral palsy and disability in preterm infants. Emphasis in funding should be placed on the establishment of new biobanks in regions where preterm birth rates are high, such as sub-Saharan Africa and South Asia. Established biobanks should collect a broad array of biologic specimens as well as donor data from medical records and patient questionnaires, where feasible. Funders should encourage researchers to pool specimens and information from multiple related studies. A good model for the pooling of data is the NIH Biobank on Prematurity, Preeclampsia and Other Pregnancy Complications which combines information on and biological specimens of women from three original studies: the PREDICTION, PEARL and PREDICTION2 studies (NIH, 2017).

Development research

The use of smartphones for early detection of cerebral palsy. For the past decade, smartphone technology has been at the forefront of health innovation in LMIC, as well as high-income countries. With sales of smartphones surpassing one billion units in 2014 and most shipping to emerging markets (Gartner, 2015), global health entrepreneurs in LMIC have been finding novel ways to harness the technology for a broad range of purposes, from medical education to improving point-of-service care. Summit participants discussed the potential of smartphone technology to improve early detection, diagnosis and care of babies with cerebral palsy. Currently, the average age of diagnosis for a child with spastic diplegia, a very common form of cerebral palsy, is 18 months (ACPR, 2016). However, new screening tools such as the General Movements Assessment (GMA), which can be used to identify absent or abnormal general movements in infants, can now with a high degree of certainty predict cerebral palsy by three months of age. Detecting and diagnosing cerebral palsy early in life, a period of greater neuroplasticity, would provide the potential for intervention at a younger age that could help children in mastering everyday tasks and increase their mobility and immediate and long-term quality of life. Participants recognised the promise of smartphone technology in revolutionising the early detection and diagnosis of cerebral palsy, especially in highly rural and low-resource regions.

Action step:

Participants called for increased funding to develop smartphone technology that could incorporate new software and algorithms allowing point-of-care-providers in rural and resource-poor regions to harness new generation screening tools like the GMA in the detection and diagnosis of cerebral palsy in the first months after birth.

Delivery research

Prevention

Assessing the effectiveness and safety of IM versus IV administration of magnesium sulphate (MgSO₄) in the prevention of cerebral palsy. MgSO₄ has been shown to be a neuroprotective agent, decreasing rates of cerebral palsy among children born to women at high risk of early preterm delivery by 32% (Rouse and Gibbins, 2013). While MgSO₄ can be administered by both continuous intravenous (IV) infusion and intramuscular (IM) injection, most health centres in the world administer

MgSO₄ by IV as it is less painful to the patient and magnesium levels can be more easily controlled. The latter is important as high levels of magnesium in the blood can be toxic. However, in LMIC, IV administration is often impractical because of the lack of availability of infusion sets, trained clinical staff and means of taking periodic blood samples to monitor serum magnesium levels. IM administration in these settings is generally considered preferable. However, there have been relatively few studies in LMIC that have compared the safety and efficacy of IM versus IV administration of MgSO₄ for the prevention of cerebral palsy. These are needed because, if effective, they will make a proven preventative agent easily available to all.

Action step:

Rigorously controlled studies of the safety and effectiveness of IM versus IV administration of MgSO₄ and of its impact on incidence, severity and outcome of cerebral palsy in babies born to women at high risk of preterm delivery in LMIC are needed.

Safety of antenatal corticosteroid (ACS) therapy in low-resource settings. Even the most well-established ACS therapies lack the comprehensive pharmacokinetic and dose–response data necessary to optimise dosing regimens. There is growing evidence that some foetal corticosteroid treatments are either ineffective, or may result in adverse outcomes as well as causing lasting epigenetic changes in a variety of homeostatic mechanisms. The Antenatal Corticosteroid Trial (ACT), which assessed the feasibility, effectiveness, and safety of a multifaceted intervention to increase the use of ACS in mothers at risk of preterm birth at all levels of care in LMIC, found that the intervention effectively increased the use of ACS, but was associated with an overall increase in neonatal deaths (Althabe et al., 2015).

Action step:

Participants agreed on the urgent need for further studies of the effectiveness and safety of ACS on neonatal mortality and health outcomes in LMIC. These studies should be conducted in a variety of low-resource sites worldwide and their findings and other data pooled to identify common clinical elements and procedures that decrease risk of neonatal death and morbidity following ACS as well as those that increase risk.

Assessing the impact of preconception care in reducing the rate of cerebral palsy following preterm birth. Babies born preterm are at higher risk of cerebral palsy than babies born at term, with cerebral palsy rates increasing inversely with gestational age (ACPR, 2016). Born Too Soon, the Global Action Report on Preterm Birth called for accelerated action on the prevention of preterm birth, including widespread administration of priority packages and evidence-based interventions to adolescent girls and women during the preconception and inter-conception periods. Proven interventions need to be scaled up, integrated and implemented in large studies of adolescent girls and women in the preconception period to assess their relative benefit in reducing both preterm birth rates and rates of cerebral palsy incidence and disability following preterm birth.

Action step:

Summit participants agreed that increased attention to addressing preconception health needs in adolescent girls and women, especially in LMIC with high rates of preterm birth, is needed to assess impact on both preterm birth rates as well as on incidence and disability rates from cerebral palsy following preterm birth. These interventions should include those currently recommended by WHO in the preconception period—family planning and prevention and treatment of sexually-transmitted infections (WHO, 2012)—as well as the promotion of adequate nutrition, education on restricting tobacco use and the diagnosis and management of chronic diseases known to increase preterm birth risk such as hypertension and type 2 diabetes.

The promise of community-based approaches to prevent cerebral palsy and disability following preterm birth. Reducing the burden of maternal, newborn and child mortality and morbidity requires a combination of interventions tailored to the target population. To ensure that the interventions delivered are cost-effective, sustainable and acceptable to those receiving them, an integrated approach that includes community-based care as an essential component is key (Lassi et al., 2016). Community-based care—where the community plays an active role in improving its own health outcomes—is an increasing mainstay in the delivery of health care for mothers, newborns and babies, both in LMIC and high-income countries (WHO, 2011). Community-based care, in which community health workers (CHW) play a vital role through home visits and sustained individual contact, can be instrumental in increasing service delivery, healthy behaviours and community demand for services. Community-based approaches also include implementation of intervention care packages which have shown to be effective, for example, in reducing neonatal mortality and increasing rates of early breastfeeding and health seeking behaviour both during pregnancy and in the neonatal period (Lassi et al, 2010).

Action step:

Community-based approaches that have shown success in reducing maternal, newborn and child mortality and morbidity should be scaled up, implemented and evaluated in a larger number of LMIC settings. These programs should include, where possible, measures of impact on cerebral palsy incidence and disability following high-risk pregnancies, including preterm birth.

Early detection and intervention

The need for early detection. It is essential that motor delays be identified at as young an age as possible to allow for early diagnosis and referral to developmental intervention that can promote optimal cognitive and motor development. Strategies for identifying high-risk infants are still being debated in high-income countries. Given that cerebral palsy is a heterogeneous entity, it can be expected that effective early diagnostic and intervention methods may differ for various subgroups of affected children. The problem of early detection is compounded in LMIC where clinical capacities and facilities may be limited. In addition, available evidence from LMIC suggests that in addition to the burden of following preterm birth there is a higher incidence of CP due to complications at term and post-term such as asphyxia, hyperbilirubinemia and infections like meningitis (Haders-Algra 2014). These differences in aetiologies may result in a different presentation of cerebral palsy in LMIC than in high-income countries requiring different diagnostic approaches.

Action step:

There is a need to determine what early diagnostic exams for cerebral palsy are most accurate and feasible in LMIC. Neurological and neuromotor exams that should be tested include the general movement assessment (GMA) and other motor assessments to predict cerebral palsy in infancy. Assessment of the many possible tools such as the Dubowitz assessment for neonates and its adaptation for older infants, the Hammersmith infant neurological examination [HINE], the Prechtl assessment for newborns and its adaptation for older infants, the Touwen infant neurological examination [TINE] and the assessment according to Amiel-Tison needs to be made to see which are most adaptable to particular country environments to allow training of staff in their use and interpretation.

The need for early intervention. Early intervention in infants at high risk for cerebral palsy is of proven benefit and critical both to primary prevention and to reducing the severity and extent of disability in affected children. A number of early interventions to reduce neonatal mortality and maximise health outcomes in premature infants in regions where preterm birth and neonatal mortality and morbidity rates are high have been evaluated for effectiveness, feasibility and safety, with several showing considerable promise. These include the training of nurses, midwives and traditional birth attendants in neonatal resuscitation; kangaroo mother care; and the benefit of delayed cord clamping. Other potential interventions that show promise but require additional evaluation in a variety of LMIC settings include the administration of prophylactic oral dextrose gel to newborns at risk of neonatal hypoglycaemia and the use of erythropoietin and hypothermia (cooling) therapy in infants exposed to oxygen deprivation during birth as well, as the use of creatine and melatonin in foetuses with identified intrauterine growth restriction.

Action step:

Studies evaluating the effectiveness, feasibility and safety of early interventions to prevent neonatal mortality and morbidity in regions where preterm birth and newborn death rates are high are ongoing, with many of the interventions showing effect and considerable promise. Funding for these studies should be increased and promising interventions scaled up and implemented in a greater variety of settings. These studies should include, where possible, cerebral palsy incidence and disability as outcomes. Promising interventions should be packaged, where feasible, so that their effects can be studied individually and in the aggregate.

Collaboration and Funding

There can be no progress without partnership. The Summit over its two days demonstrated convincingly that there is a need for concerted action to prevent cerebral palsy and minimise disability following preterm birth. Like preterm birth, cerebral palsy has a heterogeneity of genetic and environmental causes and understanding its natural history and pathogenesis following preterm birth will demand continued vigorous investigation. Likewise, while capacities in high-income countries to detect, diagnose and treat cerebral palsy have advanced considerably in the past couple of decades because of organisations like CPA and its partner researchers worldwide, the screening tests, interventions to minimise disability and improve quality of life and the expert training required to employ these diagnostic tools and interventions need to be tested in a variety of LMIC settings to determine their feasibility, cost-effectiveness and safety. Strengthening prevention and care worldwide will, therefore, require an innovative and vigorous research agenda across the “Four D’s,” where coordination and collaboration among all stakeholders will be essential to ensure that research and funding are complimentary, not duplicative, and that solutions found in one setting are immediately available to clinicians and researchers in other parts of the world. Through its IMPACT for Cerebral Palsy network, CPA has demonstrated that successful international collaboration is not only possible, but strongly desired by cerebral palsy researchers. This is evidenced by the success of the six international summits on cerebral palsy organised by CPA and the global collaboration that has led to the development of a common set of internationally-adopted clinical guidelines for early diagnosis and detection rather than a series of differing single country guidelines.

Action step:

Future collaboration and funding for research to advance the prevention of cerebral palsy and early detection and care of affected children must engage stakeholders at all levels, including governments at local, regional, national and global levels; the United Nations and other multilateral organisations; donors and philanthropic institutions; the business community; academic and research institutions; health care workers and their professional organisations; and civil society, including parent-patient organisations. Important next steps should include the establishment of international research consortia between organisations like CPA and countries like China and India that have large numbers of cerebral palsy patients and the scientific capacity to conduct world-class collaborative research trials on such topics as the aetiology of CP, prevention, early diagnosis, early intervention, treatments including stem cell therapy and cure. Emphasis should also be placed on the funding of programs that scale up and evaluate in LMIC, what is currently known to work in high-income countries, identify the specific needs of LMIC by identifying common causal pathways active in those countries, while supporting description, discovery, development and delivery research to fill in knowledge gaps. These programs should build, where appropriate, on existing international efforts directed to improving adolescent, maternal, newborn and child health in target LMIC. To promote coherence and transparency in collaboration and funding, a website should be set up that can monitor and track current research activities and serve as a repository for peer-reviewed publications, data and other information that can be accessed by those interested in conducting new and innovative research in prevention and care.

CO-SPONSORS



IMPACT for CP (International Multidisciplinary Prevention and Cure Team) is an international research network for the prevention and cure of cerebral palsy. The network includes scientists, researchers, clinicians, families, people with CP, philanthropists, industry, policymakers and supporters.



The UCSF Preterm Birth Initiative (PTBi) is a multi-year research effort working to reduce the burden of prematurity in California and East Africa. PTBi engages in holistic, place-based research and respectful care across the reproductive life course.



March of Dimes Foundation, USA, is a not-for-profit organisation with a mission to prevent birth defects, preterm birth and infant mortality. Internationally, March of Dimes has overseen a rapidly growing portfolio of cost-effective, transparent and accountable in-country partnerships and programs in over 35 low- and middle-income countries. These partnerships and programs have emphasized capacity building to improve the health of women to prevent adverse maternal and newborn outcomes.

DELEGATES

Professor Nadia Badawi Cerebral Palsy Alliance Australia
Mr David Berman CPRAF - Board member USA
Professor James Blackman CPRAF USA
Professor Jan Brunstrom Washington University School of Medicine in St. Louis USA
Professor Caroline Crowther The Liggin Institute NZ
Dr Paul Dawson University of Queensland Australia
Professor Linda de Vries UMC Utrecht Brain Center Rudolf Magnus The Netherlands
Professor Donna Ferriero University of California, San Francisco USA
Dr Linda Franck UCSF USA
Dr Jonathan Fuchs UCSF USA
Dr Dawn Gano UCSF USA
Anne & Kel Geddes USA
A/Professor Andrea Guzzetta Univeristy of Pisa Italy
Dr Chris Howson Howson & partners for global health USA
A/Professor Laura Jeliffe-Pawlowski UCSF USA
Professor Sandra Juul UW Medicine, Seattle USA
Professor Carole Kenner COINN USA
Dr Gulam Khandaker Cerebral Palsy Alliance AU
Professor Shoo Lee Mount Sinai NYC Canada
Dr Joe Leigh Simpson March of Dimes USA
Dr Ornella Lincetto WHO
Dr Sarah McIntyre Cerebral Palsy Alliance Australia
Dr Maria McNamara Cerebral Palsy Alliance Australia
Professor Steve Miller Hospital for Sick Kids Canada
Dr Cathy Morgan Cerebral Palsy Alliance Australia
Professor Michael Msall Univeristy of Chicago USA
Professor Louis Muglia Cincinnati childrens hospital USA
Dr Jeff Murray Gates foundation USA
Professor Iona Novak Cerebral Palsy Alliance Australia
Dr Colleen Peyton University of Chicago USA
Dr Larry Rand UCSF USA
A/Professor Liz Rogers UCSF USA
Dr Craig Rubens GAPPS USA
Dr Barbara Sargent UCSF USA
A/Professor Anne Stroustrup Mount Sinai NYC USA
Dr Salimah Walani March of Dimes USA
A/Prof Karen Walker Cerebral Palsy Alliance Australia
Professor Euan Wallace Ritchie Centre Australia
Mr Rob White Cerebral Palsy Alliance Australia

References

- Althabe F, Belizán JM, McClure EM, Hemingway-Foday J, Berrueta M, Mazzoni A, Ciganda A, Goudar SS, Kodkany BS, Mahantshetti NS, Dhaded SM, Katageri GM, Metgud MC, Joshi AM, Bellad MB and Honnugar NV. A population-based, multifaceted strategy to implement antenatal corticosteroid treatment versus standard care for the reduction of neonatal mortality due to preterm birth in low-income and middle-income countries: the ACT cluster-randomised trial. *The Lancet*. 385; 9968, p629–639, 14 February 2015.
- Bhutta ZA, Lassi ZS. 2010. "Empowering Communities for Maternal and Newborn Health." *The Lancet* 375 (9721): 1142–44.
- Born Too Soon: The Global Action Report on Preterm Birth. 2012. Howson CP, Kinney MV, Lawn JE, eds. March of Dimes, PMNCH, Save the Children, WHO. World Health Organization, Geneva.
- Gartner Report. 2015. Gartner Says Smartphone Sales Surpassed One Billion Units in 2014. Press release. Egham, UK, March 3, 2015. <http://www.gartner.com/newsroom/id/2996817>
- Hadders-Algra M. 2014. Early Diagnosis and Early Intervention in Cerebral Palsy. *Front Neurol*. 2014; 5: 185. Published online 2014 Sep 24. Prepublished online 2014 Jul 23. doi: 10.3389/fneur.2014.00185
- Khandaker G, Smithers-Sheedy H, Islam J, Alam M, Jung J, Novak I, Booy R, Jones C, Badawi N, Muhit M. Bangladesh Cerebral Palsy Register (BCPR): a pilot study to develop a national cerebral palsy (CP) register with surveillance of children for CP. *BMC neurology*. 2015 Sep 25;15(1):173.
- Lassi ZS, Kumar R, Bhutta ZA. 2016. Community-Based Care to Improve Maternal, Newborn, and Child Health. In *Reproductive, Maternal, Newborn, and Child Health: Disease Control Priorities, Third Edition (Volume 2)*. Black RE, Laxminarayan R, Temmerman M, et al., eds. Washington (DC): The International Bank for Reconstruction and Development / The World Bank; 2016 Apr 5.
- McMichael G, Bainbridge MN, Haan E, Corbett M, Gardner A, Thompson S, van Bon BWM, van Eyk CL, Broadbent J, Reynolds C, O'Callaghan ME, Nguyen LS, Adelson DL, Russo R, Jhangiani S, Doddapaneni H, Muzny DM, Gibbs RA, Geck J and MacLennan AH. 2015. Whole-exome sequencing points to considerable genetic heterogeneity of cerebral palsy. *Molecular Psychiatry* 20, 176-182 (February 2015) | doi:10.1038/mp.2014.189
- NIH (National Institutes of Health). 2017. Biobank on Prematurity, Preeclampsia and Other Pregnancy Complications. ClinicalTrials.gov Identifier: NCT02744365. <https://clinicaltrials.gov/ct2/show/NCT02744365>
- Report of the Australian Cerebral Palsy Register, Birth Years 1993-2009. September 2016.
- Rouse DJ, Gibbins KJ. 2013. Magnesium sulfate for cerebral palsy prevention. *Semin Perinatol*. 2013 Dec;37(6):414-6. doi: 10.1053/j.semperi.2013.06.025
- Schieve LA, Tian LH, Rankin K, Kogan MD, Yeargin-Allsopp M, Visser S and Rosenberg D. 2016. Population impact of preterm birth and low birth weight on developmental disabilities in US children. *Annals of Epidemiology*. 26; 4, 267–274
- WHO (World Health Organization). 2011. Rio Political Declaration on Social Determinants of Health. Rio de Janeiro: WHO.
- WHO (World Health Organization). 2012. Meeting to develop a global consensus on preconception care to reduce maternal and childhood mortality and morbidity: World Health Organization Headquarters, Geneva, 6–7 February 2012: meeting report

Did you know that:

- Cerebral palsy results in life-long disability which can increase in severity with age
- People with cerebral palsy age earlier than those without
- Cerebral palsy is more common in children than cancer, eating disorders, Type 1 diabetes and spinal cord and other life-long injuries from road traffic accidents (individually or combined?)
- People with cerebral palsy have markedly worse health than their age matched peers
- Cerebral palsy is the 5th highest cause of childhood death in Australia
- Amongst children with cerebral palsy: 3 in 4 experience chronic pain; 1 in 3 cannot walk; 1 in 3 have a hip displacement; 1 in 4 cannot talk; 1 in 4 have epilepsy; 1 in 4 have a behaviour disorder; 1 in 5 have a sleep disorder; and 1 in 10 are blind
- 50% of infants with cerebral palsy in high-income countries get no early intervention before one year of age
- Cerebral palsy has no cure
- The average age of cerebral palsy diagnosis in Australia is 19 months
- 50% of people with CP have normal intelligence
- Cerebral palsy respects no borders or social boundaries

But...

- Cerebral palsy is not too hard to solve, like other conditions research holds the key to unlocking its secrets
- New tools in genetics, stem cells, new technologies and new collaborations provide new ways forward that provide previously undreamed-of pathways for the prevention, amelioration and even cure of cerebral palsy. This common but neglected condition demands or urgent and committed attention