

PRIORITIES FOR RESEARCH

Research dollars for cerebral palsy are scarce and competitive. The CP Institute conducted a Delphi study in 2007 with the aim to identify questions for future research directions.

The study used the well established Delphi survey which involves asking an independent expert panel of consumers, researchers and clinicians, a recurring progression of questions, via a series of questionnaires. It is a way of structuring a group communication between experts, where individual participants give feedback that contributes to emerging consensus.

Research priorities will change as evidence is established; however the following themes were identified by consumers and professionals.

Consumers identified questions in the themes:

- Prevention/Cure
- Quality of Life/Community participation
- Service provision/Intervention

Intervention researchers and clinicians identified questions in the themes:

- Effective outcomes
- Effective Research/Services

Aetiology and prevention researchers identified questions in the themes:

- Infection/Inflammation
- Focus on Timing
- Haematology
- Research Tools
- Neuro-regeneration
- Genetics

Reference

McIntyre, S., Novak, I., & Cusick, A. (2009). Consensus research priorities for cerebral palsy: A Delphi survey of consumers, researchers and clinicians. Developmental Medicine and Child Neurology, in press.

HIGH PRIORITY QUESTIONS FOR CONSUMERS

Consumers ranked preventing CP as their highest priority for research and were the only group to identify exploring the therapeutic impact of stem cells. Pain is an important focus for consumers, so too is the effectiveness of individual interventions including alternative therapies, physiotherapy and parent education.

Consumers identified questions in the themes:

- Prevention/Cure
- Quality of Life/Community participation
- Service provision/Intervention

Prevention/Cure

- How can CP be prevented?
- What are the causes of and casual pathways to CP?
- What potential does the brain have to repair injury?
- Can stem cells have a therapeutic effect for CP?

Quality of Life/Community participation

- What policies are needed to improve quality of life for families caring for Australians with severe disabilities?
- What factors have the greatest impact on improving the lifestyle and quality of life of individuals with CP?
- What are the barriers to employment that exist for people with CP?
- How can people with CP be better trained with the necessary skills to enter the workforce?
- What is the relationship between CP and poverty?
- Can people with CP equitably access the community?

Service provision/Intervention

Service models

- What can be done to address the mismatch between what services parents and people with CP need and what they actually receive?
- What is the optimal intensity of therapy programs?
- What is the most efficient service model so that maximal services reach people with CP and their families?

Effectiveness and Outcomes

- What are the optimal treatments for CP?
- What are the long term outcomes of treatment?
- What is the effectiveness of alternative therapies for the treatment of CP?
- What early intervention (dependent on CP type) will prevent and minimise structural impairments?
- Does physiotherapy benefit people with CP?
- What are the most effective methods of pain management so the secondary complications can be reduced?
- What is the effectiveness of hydrotherapy with CP?

Role of families in intervention

- What are the most effective methods of educating parents to help improve their child's independence and function?
- What is the impact of therapy type and duration on parents of a child with CP?
- Is hands-on treatment by therapists a more effective method than guided therapy by parents?

HIGH PRIORITY QUESTIONS FOR INTERVENTION RESEARCHERS AND CLINICIANS

Half of the consumer generated questions were reflected in the professional's priority questions. Consumers were interested in policies at a societal level that may improve their quality of life, whereas professionals were still focusing on health interventions aimed at improvements in families' quality of life.

Intervention researchers and clinicians identified questions in the themes:

- Effective outcomes
- Effective Research/Services

Effective outcomes

Function and Participation

- What are the most effective interventions for improving participation and quality of life?
- What interventions deliver the biggest functional gains?

Relationships

- What strategies assist people with CP to develop friendships and relationships?

Long Term Outcomes

- What interventions produce the best long-term outcomes?
- What are the most effective equipment and devices for improving independence and quality of life long-term?
- What is the long-term safety and impact on function; participation and quality of life of medical interventions that reduce spasticity?

Coping

- What family support strategies best reduce family stress and promote coping?
- What interventions promote self-esteem?

Employment

- What service factors improve the likelihood of people with CP gaining employment?

Prevention of Deformity

- What are the safest and most effective surgical interventions to improve skeletal alignment and function?
- What is the effectiveness of orthoses for improving function and preventing secondary deformity?

- What is the most effective way to prevent hip dislocation?
- What are the best ways to prevent the secondary impairments and injuries?

Physical Potential

- What is the best way to maximise mobility?
- What physical activity programs best improve function and fitness?

Effective Research/Services

Service models

- What is the optimal intensity of therapy programs?
- What models of service, policies and education program best support transition from paediatric to adult services?
- What are the differences in outcomes, when services are provided by allied health versus parent versus community volunteers?
- What affects client satisfaction and service uptake?

Measurement and Methodologies

- What is the best research method to evaluate the relative contributions of the therapies, orthoses and medical interventions?
- What instruments measure the effectiveness of cerebral palsy intervention and what is the sensitivity of these measures?
- What are the most efficient ways to establish and maintain CP registers to facilitate research?
- What are the most efficient ways to establish and maintain CP registers to facilitate research?

HIGH PRIORITY QUESTIONS FOR AETIOLOGY AND PREVENTION RESEARCHERS IDENTIFIED QUESTIONS

The intervention and aetiology/prevention survey had a slightly lower degree of stability. The aetiology/prevention survey had a number of questions with the full range of possible answers, suggesting low convergence.

Aetiology and prevention researchers identified questions in the themes:

- Infection/Inflammation
- Focus on Timing
- Haematology
- Research Tools
- Neuro-regeneration
- Genetics

Infection and Inflammation

- What is the association between altered fetal inflammatory response in CP mothers and infants and CP?
- Are cytokines markers of infection or ischaemia?
- What are the infectious agents involved in pregnancy that are strongly linked to CP?
- Does earlier recognition of maternal infection lead to reduced incidence of HIE?
- Does cytokine elevation correlate with severity of injury?
- What are the molecular and cellular mechanisms that explain the epidemiologically observed association between chorioamnionitis and greater risk of CP?
- How can TORCH infections be reduced?
- How can chorioamnionitis in pregnancy be identified, treated and prevented? Who is most at risk?
- Does intra-uterine infection and fetal inflammatory response affect the fetal brain?
- Do viral and bacterial exposure/infection interact with genetic factors or know major risk factors IUGR, prematurity, multiple birth, ante partum haemorrhage on a pathway to CP?
- What are cytokines roles in brain development, pregnancy and inflammatory homeostatis?

Focus on Timing: Preterm, Term and Postnatal

- Do pathways to pre-term birth differ in the ways they predispose to brain injury?
- To what extent can CP be prevented in developing countries through the improved management of childhood illness?

- What are the predictors and risk factors of CP in term infants (from socio economic to neonatal health)?
- How can severe encephalopathy be reduced to moderate and moderate be reduced to mild?
- Is both infection and acidosis required in term infants to cause CP?
- What are the most effective public health initiatives to reduce post natal CP?
- What therapeutic drugs reduce the severity, if not stop the destruction of oligodendrocytes in PVL?
- What are the causes of neonatal encephalopathy?

Haematology

- How do disorders of coagulation (fetal and maternal) affect the fetal brain?
- What postnatal medications best reduce the risk of severe IVH?
- What are the underlying mechanisms of prenatal hypoxia/inflammation that result in brain damage?
- How can perinatal stroke be prevented?

Research tools

- Do we have the tools (registers) to identify if we start to prevent CP? How can we best combine data bases to increase accurate surveillance?
- Can a gold standard classification system of CP based on underlying pathology be developed and agreed on?
- How can the timing of lesions be most accurately identified?
- What strategy can be used to drive forward aetiological research by combining epidemiology with genetics, basic science and other disciplines to identify causal pathways?

Neuro-regeneration

- Do neuroprotective interventions change severity and functional outcomes?
- What are the mechanisms of neuro-regeneration?
- How can we maximise neuro-developmental outcome for babies born with perinatal hypoxic-ischaemic injury secondary to intrapartum asphyxia?

Genetics

- What are the maternal and fetal immune, clotting, and immune response genetic factors predisposing to CP?
- Do genetic factors play a role in neonatal encephalopathy?
- What role do thrombophilic risk factors have in the pathogenesis of CP?