

CP QUEST

RESEARCH PRIORITIES

Causal pathways (6)

Genetics, term babies – no risk factors + pathways at birth

Early identification & intervention (8)

Prevention of CP (13)

Reducing incidence (3) severity (2) complications (2) data bases

Community engagement (13)

Community engagement in research/sharing experiences and participatory research methods (3); reducing stigma around disability (2); societal effects of discrimination and effect on self and self worth, social and community participation; increasing awareness; transparency with funding; expanding research units (SA); increasing funding; informing NDIS of needs for people with CP; knowledge translation to medical community (early id & intervention) and families; decision aids e.g. lift (independence) v stairs (challenge)

Daily living (30)

*Reducing pain (7); best technology & equipment/aids/exoskeleton (6) for independence, access and communication; Improving quality of life (5); learning and CP (2) best practice education approaches; increasing experiences and opportunities; social and community participation; sport & leisure; best housing for adults with mod/severe disability; employment; aging; psychological well being; fitness; adults with mild CP in the community
Counselling/exercise for parental well being; balance between hours doing therapy and living*

Interventions & potential interventions across the lifespan (21)

Stem cell (7) and cure (5); intensive therapy (2) benefits (+GMFCS III-V); Btx-A efficacy and long term outcomes; better dystonia management; more progressive orthopaedic interventions; treatments aimed at everyday functions; alternative options e.g. music, acupuncture; a range of adolescent and adult treatment options for physical, emotional & lifestyle

N=30 responders

80% family members 20% people with CP

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