

CP QUEST RESEARCH PRIORITIES

Causal pathways

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

Early identification & intervention

Prevention of CP

Reducing incidence, severity, complications, data bases

Community engagement

Community engagement in research/sharing experiences and participatory research methods; reducing stigma around disability; 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

*Reducing pain; best technology & equipment/aids/exoskeleton for independence, access and communication; Improving quality of life; learning and CP; 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

Stem cell and cure; intensive therapy; 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

80% family members 20% people with CP

Developed and analysed by:
Natasha Garrity, Isabelle Balde, Sarah McIntyre