

# RESEARCH CP

SETTING A PATIENT-CENTERED RESEARCH AGENDA FOR CEREBRAL PALSY



## Comparative Effectiveness of Interventions

Research	<b>2</b>	Which interventions [surgeries, injections, medications and therapies (orthotics, equipment, training)] are associated with better functional outcomes (important to child/ family) controlling for GMFCS level, age and co-morbidities?
Research	<b>5</b>	What are the best methods and ways to reduce pain, falling, lack of stamina, and deterioration of function that can have a negative impact on the quality of life for people with CP especially in adulthood?
Research	<b>13</b>	Research the effectiveness of intensive physical therapy programs, bursts of services, combined protocols (i.e. botox with intensive PT, etc.) Evidence of efficacy is needed to get ALL insurers to fully cover the treatment options that work.
Care Treatment	<b>13</b>	Evaluating the intensity of physical therapy and other therapies that is needed for condition, age, GMFCS level, function, and other individual characteristics.
Care Treatment	<b>18</b>	Identify biomarkers (neuroimaging, blood, CSF, amniotic fluid) to help determine which individuals respond best to which interventions (therapy, medical, surgical) so that treatment approaches can be tailored to each individual person with CP

## Exercise, Physical Activity and Chronic Disease Risk

Research	<b>1</b>	What are the best long term exercise/strength training strategies to improve activity, participation and health, minimize pain, and maximize function in each GMFCS category across the lifespan?
Care Treatment	<b>6</b>	Research effective ways to build and maintain strength, flexibility & cardiovascular health in children and adults with CP. How can we find better ways to successfully integrate these into daily living?

Research	7	Develop and test effective methods for exercise and increased physical activity for individuals who are less ambulatory (Some GMFCS III, and GMFCS IV and V) including techniques, proper dosing, and information on effects on strength and health.
Care Treatment	8	Exercising to improve general health is a challenge for people with CP. Study interventions that promote effective exercise techniques and/or adapted equipment for home/gym to enable effective cardiovascular and strength training for all ages/levels.

## Understanding Aging

Care Treatment	1	Research the issues around aging with CP, to understand not only how to treat adults now, but also to update our treatments & therapies with children who have CP to prevent some of the secondary impairments such as pain, fatigue, and functional loss.
Research	11	What are effective treatment methods to address differential outcomes in adolescents and adults related to pain, fatigue, and early functional loss?
Care Treatment	11	Have large-scale studies that follow children with the various types of cerebral palsy throughout adulthood to discover how the aging process affects individuals with different types of CP & severity levels.
Research	19	How do we optimize and streamline transitional care services and support for teens with CP transitioning into and through adulthood? Once a person reaches the age of 18, access to all of the above is often removed or limited.

## Complementary and Alternative Medicine

Care Treatment	12	Study the outcomes of complementary and nontraditional therapies, i.e. hyperbaric oxygen, hippo, swimming/aquatic, Feldenkrais, massage, yoga, Tai Chi, music, recreational, acupuncture, etc. Reviewing efficacy, costs, insurance support probabilities.
Research	20	Research neurosensorimotor reflex integration for dysfunctional reflexes in children and adults with CP to improve function, mobility and flexibility and decrease pain, startle and obligatory movement.

## Other Ideas

Research	4	Increasing age is related to pain and fatigue in people with CP, regardless of GMFCS level. What variables are important to monitor / treat early on in life to prevent the development of pain and fatigue later on in life?
Research	8	How can we best leverage the brain's neuroplasticity to retrain neural pathways for improved motor function, speech function and mobility?
Care Treatment	15	How do we best maximize functional independence and life participation of children and adults with CP? (Inclusion beyond the CP community)
Research	18	Quality of life is an important goal for a number of questions related to CP. How do we quantify that so that we can really answer which interventions produce the greatest benefit to quality of life?
Research	21	not much work has been done on the cognitive impairments including difficulties with math and any subject with spatial orientation