**Walking and its Effects on Health and Function in Individuals with Cerebral Palsy as they Transition to Adulthood: A Health Outcomes Study**

James Carollo, PhD, PE, David Robertson, BS, Allison Frickman, BA, Patricia Heyn, PhD, FACRM

Center for Gait and Movement Analysis (CGMA) - Dept. of Physical Medicine & Rehabilitation
Children’s Hospital Colorado - University of Colorado SOM

---

**Background**

While cerebral palsy (CP) is considered a childhood disorder, it is of course a lifelong disease that presents challenges at every stage of development. In recent years, there has been growing evidence that young adults with CP can develop a variety of secondary conditions associated with aging that typically occur later in life for those without the disease.

These secondary conditions may be mediated by pain or chronic fatigue, exacerbated by poor biomechanics or energy inefficiency, and often contributes to loss of independent ambulation or development of a sedentary lifestyle at a much earlier age than the general population.

---

**The CPAT Study**

The Cerebral Palsy Adult Transition Study (CPAT) is a federally funded effort to understand the relationship between walking ability, overall health status, and the risk for secondary health conditions in a cohort of 72 adults with CP who previously underwent Instrumented Gait Analysis (IGA) as children. The general hypothesis is that reduced walking ability is associated with risk factors for secondary health conditions; suggested by this proposed model.

**Mechanism of Health Decline due to Decreased Walking Performance**

---

**Objectives**

- Examine critical health issues that affect individuals with CP during and after their transition to adulthood.
- Understand the relationships between changes in gait performance (measured as children and adults) and measures of current health condition.
- Explore the importance of screening for cardiovascular risk factors and metabolic syndromes in young adults with CP.
- Analyze how mood and cognitive status in adults with CP may be related to other biomarkers of function.
- Assess how “person-focused research” principles and a “health passport” can improve subject awareness of their personal responsibility for their own health.

---

**Design**

- Prospective, longitudinal cohort study of ambulatory and physical performance, using comprehensive IGA comparison to the same measures collected as children
- Prospective cross-sectional cohort study evaluating current associations between walking ability, cognition, overall health status, QoL, and participation
- Phone health screening with subset recruited for main study
- Follow-up survey to assess impact of “health passport” visit

**Site:** Nationally accredited clinical motion laboratory at a regional children’s hospital

**Participants**

- Cohort of 72 adults with spastic CP
- Ambulatory, > 18 yrs.
- GMFCS I – III
- Previous IGA at the same Center
- Minimum 5 year follow-up

**Main Outcome Measures (tools)**

- 3D IGA: kinematics (Vicon), kinetics, GDI, temporal-spatial, physical exam
- Health status (Medical History, Lifestyle and Physical Exam, PROMIS)
- Pain assessment
- Metabolic and inflammatory panels (blood labs)
- Cognitive status & mood (STMS, WMS-IV, NIH Toolbox, CES-D, PROMIS)
- Quality of life and participation (PROMIS)

**Health Passport**

- Each participant receives a novel multimedia “health passport” that summarizes their test results in a format that can be shared with their healthcare provider.
- The passport includes a 2-hour health consultation/coaching session to empower the participant to take control of their own health, and local health resources.

---

**Results**

- This ongoing study is in the final phase of data collection for the original 72 subject cohort. Recruitment profile and demographics are shown in the diagram and tables below.

---

**Discussion / Conclusion**

Presently, this is the only study relating longitudinal IGA data with health and functional outcomes in adults with CP. The inevitable transition to adult care often leads to unmet healthcare needs as the young adult with CP separates from their pediatric providers. Results from this study will provide significant insight into the ramifications of our pediatric gait interventions, and will support our goal to develop guidelines for individualized walking prescriptions that maximize function and decrease the chance of premature aging. This study is also uncovering many inherent flaws in the way pediatric conditions are managed in the adult health care system, that may contribute to the decline in overall health and quality of life sometimes seen in this fragile and neglected population.

---

**Acknowledgments**

The authors wish to acknowledge the significant contributions of the CPAT investigator team (Heather Baer, Amy Baldwin, Tom Boyd, Meghan Coyle, Tina Cameron, Mariana Oliveira, Zhaoming Pan, Tim Reinstein, Alex Tagava, Suthi Thomas, and Pam Wilson) and the faculty/staff of CGMA. This research was supported by grants from the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR H113130130202, NIDILRR H901F000051), in the Administration for Community Living (ACL) of the Department of Health and Human Services (HHS). Additional support provided from the J. Tai & Company Foundation.