

A GLOBAL PURSUIT FOR ANSWERS

Advances in Cerebral Palsy Research, A Primer for UCP Affiliates



Dear Colleagues:

UCP is pleased to provide you with “A Global Pursuit for Answers,” a brief piece that summarizes the latest research and work being conducted in the field of cerebral palsy (CP) research and shows ways that UCP affiliates can become involved. This effort was led by UCP’s Research Leadership Committee, which wanted to provide a concise summary of CP-related research for UCP affiliates and the individuals and families that they serve.

Below are acknowledgements for everyone involved. Special thanks must go to Dr. Gary Edwards, Chair of UCP’s Research Leadership Committee, and Dr. James Blackman, Medical Director of the Cerebral Palsy International Research Foundation (CPIRF) and Medical Consultant for UCP. I am proud of the work that was done and hope this is a helpful tool for the UCP Network that fosters increased enthusiasm to become involved with research.



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OVERVIEW

United Cerebral Palsy's (UCP) Research Leadership Committee recently came together in Washington, DC, at the UCP national office, to meet with other disability organizations and government agencies to understand the scope of research being conducted in the field of cerebral palsy (CP) and to explore ways for UCP affiliates to become involved with CP-related research. The group received updates from representatives from the following organizations and agencies:

Cerebral Palsy International Research Foundation (CPIRF)

Dr. James Blackman, CPIRF Medical Director and Medical Consultant to UCP, reviewed the current research grants in the country and around the world that CPIRF is funding. These research projects include studying pain among adults with CP, the efficacy of deep brain stimulation in CP, and white matter injury and repair in premature infants. New CPIRF research projects for 2013 focus on prevention of loss of mobility across the lifespan, innovative therapeutic approaches that take advantage of brain plasticity, and functional connectivity of the deep gray nuclei in the dystonic form of CP. CPIRF is exploring the feasibility of establishing Centers of Cerebral Palsy Research Excellence (CCPRE). For a detailed list of these projects or more information, please visit www.cpirf.org or contact Dr. Blackman at jblackman@cpirf.org.

National Institute on Disability and Rehabilitation Research (NIDRR)

NIDRR is a part of the U.S. Department of Education and a funder for CP-related research. Dr. Charlie Lakin, Director of NIDRR, and Dr. Ruth Brannon, Director of NIDRR's Research Sciences Division, outlined the types of funding given by the agency. NIDRR annually distributes nearly \$110 million in funding for disability-related research, including research about CP. The main focus areas of NIDRR grants for developmental and intellectual disabilities include home and community living, employment supports, social inclusion, health, direct support workforce and technology. If you would like more information, please visit www2.ed.gov/about/offices/list/osers/nidrr/index.html or call (202) 245-7640.

Association of University Centers on Disabilities (AUCD)

Dr. George Jesien, Executive Director of AUCD, discussed the organization's University Centers for Excellence in Developmental Disabilities (UCEDD) and Leadership Education in Neurodevelopmental and Related Disabilities (LEND) programs. UCEDDs and LENDs can consist of medical schools, graduate schools, research centers, pediatric departments and independent service agencies. There are 67 UCEDDs and 43 LENDs in the country, all of which welcome collaboration with disability-service providers,



such as UCP affiliates. There are benefits on both sides for a partnership. UCEDDs and LENDs offer research knowledge, interdisciplinary trainees, instruments and evaluation, and grant-writing skills. UCP affiliates offer research opportunities for leveraging resources and meeting education requirements, community placements, access to clients and service-provider and public policy experience. If you would like to find a UCEDD or LEND near you, please visit www.aucd.org/directory/directory.cfm?program or call (301) 588-8252.

Centers for Disease Control and Prevention (CDC)

Dr. Marshalyn Yeargin-Allsopp, Chief of the Developmental Disabilities Branch at CDC’s National Center on Birth Defects and Developmental Disabilities, provided an overview of the work being done by the CDC to better understand cerebral palsy. This agency, part of the U.S. Department of Health and Human Services, is conducting multiple population-based surveillance programs to track CP prevalence. Its Metropolitan Atlanta Developmental Disabilities Surveillance Program (MADDSP) is using data from multiple school systems and clinical sources to track autism spectrum disorder, CP, and other developmental disabilities among eight-year-old children in metropolitan Atlanta, Georgia. MADDSP serves as the model for the Autism and Developmental Disabilities Monitoring (ADDM) CP Network, funded by CDC, which is tracking CP prevalence in areas of Alabama, Georgia, Missouri and Wisconsin. These surveillance projects are helping researchers learn more about the number and characteristics of children with CP, including information on overall, sex-specific and race-specific prevalence, CP subtypes, walking ability and co-occurring conditions.

According to a 2011 study, which utilized data from 2006, CP prevalence was about 3.3 per 1,000 children of the

population.¹ In addition, prevalence was lower among Hispanic children compared to white and black children and higher among boys. Spastic CP was the leading subtype of CP, existing in more than 75 percent of CP cases, and slightly more than half of individuals with CP were reported to be able to walk independently. Among children with CP, about 35 percent had epilepsy and 8 percent had an autism spectrum disorder. Another study published in 2012 found that, among Medicaid-enrolled children, medical costs for children with CP were 10 times higher than for children without CP or another intellectual disability². Updated prevalence estimates from CDC’s ADDM CP Network are forthcoming. For more information about the CDC’s latest data on CP, please visit www.cdc.gov/cp or call (800) 232-6348.

STATE OF RESEARCH

There are still many questions about the root cause of CP and even more debates about the best path forward in treatments and therapies. A survey of the latest research has identified five top causes of CP:

- 1) periventricular leukomalacia
- 2) intrapartum asphyxia*
- 3) cerebral dysgenesis
- 4) intracranial hemorrhage
- 5) vascular abnormalities³

Top 5 Causes of Cerebral Palsy	Summary	Cause Percentage
Periventricular leukomalacia	Injury to the white matter of the brain	25%
Intrapartum asphyxia	Lack of oxygen to the brain during labor and/or delivery	22%*
Cerebral dysgenesis	Abnormal brain development	17%
Intracranial hemorrhage	Bleeding inside of the brain	13%
Vascular abnormalities	Abnormality of the blood vessels of the brain	13%

**Recent epidemiological studies and improved diagnostic methods suggest that true asphyxia as a cause of CP may be much lower than 22 percent.*

Researchers in the field have focused their efforts on three main areas in CP-related research: prevention and cure, therapeutics, and quality of life. At the 2011 *Prevention and Cure Cerebral Palsy Summit* hosted by the Cerebral Palsy Alliance, UCP's Australia affiliate, emerging topics included stem cell research, perinatal infection and inflammation, neuroprotection and distal risk factors.

PREVENTION AND CURE

Stem cells are cells that have not yet specialized, giving them the ability to develop into multiple cell types and make identical copies of themselves. When one examines the top causes of cerebral palsy, all of them involve some aspect of brain injury or development. Researchers in this area are attempting to see if stem cell treatments can be used to replace damaged tissues in the body, including brain cells, aiding in dramatically more effective treatments for individuals with CP. While this area of research holds great promise, caution remains as there is risk of stem cells developing into tumors. Currently, no reliable stem cell treatment for CP exists. Duke University and Georgia Health Sciences University are the only sites in the U.S. conducting human clinical trials of cord blood stem cells for treatment of CP.

Perinatal Infection and Inflammation and Neuroprotection

Perinatal infection and inflammation have been widely associated with CP. Researchers believe a reduction of infection would reduce the incidence of CP. Studies are

focusing on neuroprotection, focusing on strategies to protect the central nervous system (CNS). For example, researchers are giving mothers allopurinol prenatally to protect the fetus with potential intrauterine hypoxia. Melatonin and morphine are also being researched for neuroprotection. In some of the more advanced hospitals, brain cooling is being used in asphyxiated newborns. Researches are finding that brain cooling performed within six hours of birth can help reduce the effects of asphyxia in newborns.

Distal Risk Factors

Distal risk factors are environmental or behavioral factors that have an influence on a disease outcome. Studies are evaluating the effects that preconceptual health, prenatal care and industrial pollutants have on the incidence of CP.

THERAPEUTIC RESEARCH

Another major focus in CP-related research lies with various therapies, such as brain stimulation and constraint-induced movement therapy. New methods of brain imaging—including conventional, functional and three-dimensional volumetric magnetic resonance imaging (MRIs) and proton magnetic resonance (MR) spectroscopy—are helping to uncover relationships between successful therapies and structural/functional changes in the brain. Constraint-induced movement therapy (CIMT) is being explored with children having hemiparesis, or an affected upper limb. With CIMT, a person performs focused tasks, training the affected limb for up to six hours each day for 10 days, all while the unaffected limb is constrained for most of the time. Studies have shown CIMT to be effective for individuals with hemiplegic CP; however, at least one study in Australia found it to be no more effective than intensive occupational therapy. Studies of variation in the intensity of therapy are currently underway.

QUALITY OF LIFE AND PARTICIPATION

Researchers are focusing on the quality of life and participation in life activities of individuals with CP. Children with CP have been found to typically engage in activities alone or at home and in a smaller range of activities than in children without CP. The effects of exercise on individuals with CP is being studied, such as the University of North Carolina's Project ACT NOW, which looked at the effects of aquatic exercise on fitness and participation of adults with CP. If you would like to learn more about Project ACT NOW, please contact Dr. Deborah Thorpe, Associate Professor, Division of Physical Therapy, The University of North Carolina at Chapel Hill, at deborah_thorpe@med.unc.edu.





FUTURE RESEARCH

While a tremendous amount of work is being done around these top five causes of CP, the direction of CP-related research is moving toward issues of aging, including a focus on pain, as more individuals with CP are growing older. Other future directions of research involve robotics, other assistive technologies, and public policy.

Aging & Pain and Other Disabilities

Pain is a growing concern among individuals, particularly adults, with CP.⁴ Common sites of pain include the back, hips, lower extremities, mouth and jaw. Pain can come from biological causes, such as movement impairments, and environmental factors, such as limited access to healthcare and dental services. Below is a table that lists some of the known causes of pain:

Biological Factors:	Environmental Factors:
Orthopedic and movement impairments (musculoskeletal factors, joint deformity, spasticity)	Access to health and dental care
Poor low-bone mineral density	Assistive technology (example: poorly-fitting wheelchair)
Nutrition (underweight and obesity issues)	Living environment and availability of personal-care attendants

Medication Interventions	Healthcare and Health-Promotion Approaches
Antispasmodics	Counseling
Anti-reflux agents	Biofeedback
Laxatives	Relaxation training
Oral baclofen	Cognitive therapy
Botulinum toxin A	Exercise

Fortunately, there are known medication and healthcare interventions that have shown some effectiveness with managing pain. While none have been proven to be absolutely effective, the following medications and approaches have been reported to have some limited success. For more information, please contact Dr. Laura K. Vogtle, Professor and Director at the University of Alabama at Birmingham, at lvogtle@uab.edu.

BECOMING INVOLVED

UCP affiliates are known for their steadfast commitment to those they serve. Often, people with disabilities and their families have questions about the kinds of research going on related to CP and other disabilities. Developing a connection with research in the affiliate’s community allows an affiliate to answer these kinds of questions. It also allows for more training of direct care staff, the use of the latest technologies and a possible new funding stream for the affiliate.

If you would like to stay abreast of the latest research, Cerebral Palsy Alliance, UCP’s affiliate in Australia, offers a free bulletin, *CP Research News*, that features the latest research about CP, as indexed each week in the National Center for Biotechnology Information (NCBI), PubMed (Medline) and Entrez (GenBank) databases. Covering a wide range of topics, including therapeutic interventions and management, etiology and prevention, the newsletter is a valuable resource for health professionals and service providers. To subscribe, please complete the online subscription form found at www.cpresearch.org/subscribe/researchnews. For inquiries about CP Research News, please email Robyn Cummins, Manager Knowledge Brokerage at Cerebral Palsy Alliance, at RCummins@cerebralpalsy.org.au.

If you would like to learn more about other ways to become involved with research, please find the research team’s “Recognizing Research” template enclosed in this publication. This template was developed by affiliates for affiliates to have an understanding of the types of questions to answer when exploring opportunities for collaboration. If you would like extra copies of this template, please contact O’Ryan Case, Executive Assistant to the President & CEO of UCP National, at (202) 973-7104 or ocase@ucp.org.



International Leadership: Cerebral Palsy Alliance's Research Foundation

Cerebral Palsy Alliance's Research Foundation was formed in 2005 to coordinate and fund research projects around the world into cerebral palsy (CP) prevention, cure and intervention. For too long, cure and prevention of CP had been largely ignored by the international research community. Cerebral Palsy Alliance knew that had to change for answers to be found, and so began its mission to put CP under the international research spotlight.

What began, thanks to the generosity of a donor's bequest and a one-time grant from the Australian federal government, is now supported by visionary philanthropists, foundations and companies that share the long-term commitment to finding the answers to the challenges of CP. The Foundation's aim is to raise a sustainable funding pool of \$50 million so that groundbreaking research projects can be supported until prevention and cure strategies are found. In seven short years, they are more than halfway there, having secured grants totaling more than \$25 million.

It is the Foundation's three-tier approach to supporting research into CP that has seen it gain an international reputation as a leader in this field. That approach includes:

- With a core team of researchers, the Foundation is directly involved in numerous research projects within Australia and around the world.
- Just as importantly, though, it also grants funds to budding researchers around the world to enable them to continue their important work. So far, it has funded 72 research projects across the globe, valued at more than \$5.8 million.
- Its third tier of work, and arguably its most crucial, is its commitment to promoting coordination and collaboration between international research teams to maximize findings and outcomes.

The Foundation is working with top researchers around the world to develop and refine a road map of research direction and priorities. This will reduce research duplication, promote sharing of results and encourage research collaboration. It is this enhanced learning that will ultimately take us closer to finding strategies for prevention and cure.

In 2011, the Foundation hosted the inaugural World Cerebral Palsy Prevention and Cure Summit in the United States. This year, it will again bring together the world's best minds in CP research to further develop research projects and priorities.

There is confidence that this ongoing collaboration between world researchers, coupled with the support of the Foundation's generous philanthropists and donors, will one day enable the answers to CP prevention and cure to be found.

For more information on the Foundation, visit www.cpresearch.org.au.





Embracing Research: UCP of Orange County - CVI Early Intervention Program

Cathy Collins, CEO of UCP of Orange County (UCP-OC), has become involved with research at the local level by building a strong relationship with the Gavin Herbert Eye Institute at the University of California, Irvine, and addressing cortical visual impairment (CVI), a leading cause of bilateral visual loss. At least 60 percent of children with neo-natal brain injuries due to lack of oxygen, such as with CP, experience CVI. As diagnoses are often too late to benefit rehabilitation and treatments, new measures are critically needed.

Under the guidance of a non-voting Advisory Medical Board she developed, Collins began discussions with Dr. Jennifer Simpson, Associate Clinical Professor at the Department of Ophthalmology at UC Irvine, about a collaboration to improve the diagnosis and rehabilitation of infants at risk for CVI. With funding from multiple grants, including support from UC Irvine Institute for Clinical and Translational Research, the project launched a CVI screening and treatment program at UCP-OC's Life Without Limits Therapy Center. The project aims to demonstrate that early diagnosis and intervention can maximize the use of functional residual vision.

Collins has and continues to foster a philanthropic culture at UCP-OC, engaging individuals, corporations, foundations and grateful families interested in making a difference in the lives of children. Her Board of Trustees and Advisory Medical Board consist of individuals who truly care about UCP's mission and gladly assist as ambassadors and connectors in the community. The entire staff at UCP-OC is engaged in fund development, and the center provides daily tours to supporters and interested community members. Collins works diligently to engage the local medical and academic community to advance the mission of UCP-OC and recently received \$100,000 of Proposition 10 funds from the Children and Families Commission of Orange County to support the vision collaboration with UC Irvine. UCP-OC now raises an average of \$1.3 million annually to support its comprehensive care model for children with disabilities. For more information about this and other programs, please contact Collins at (949) 333-6400 or ccollins@ucp-oc.org.

REFERENCES:

1. Kirby, RS, Wingate MS, Van Naarden Braun, K, et al. Prevalence and functioning of children with cerebral palsy in four areas of the United States in 2006: A report from the Autism and Developmental Disabilities Monitoring Network. *Research in Developmental Disabilities* 2011;32(2):462-469.
2. Kancherla V, Amendah DD, Grosse SD, et al. Medical expenditures attributable to cerebral palsy and intellectual disability among Medicaid-enrolled children. *Research in Developmental Disabilities* 2012;33(3):832-840.
3. Shevell MI, Majnemer A, Morin I. Etiologic yield of cerebral palsy: A contemporary case series. *Pediatric Neurology* 2003;28(5):352-359.
4. Vogtle, LK. "Pain in adults with cerebral palsy: impact and solutions." *Developmental Medicine & Child Neurology* 2009;51:113-121.

1) PROFILE YOUR AFFILIATE:

Programs/services/areas of expertise: _____

How/what research could enhance the delivery of services: _____

Research-related issues that consumers and family members have identified: _____

Champions in the affiliate who have expertise/interest in research: _____

2) IDENTIFY POTENTIAL SOURCES FOR COLLABORATION:

Hospitals in the community: _____

Research Projects: _____

Clinics/research centers in your community: _____

Research Projects: _____

To find a University Center for Excellence in Developmental Disabilities (UCEDD) or Leadership Education in Neurodevelopmental and Related Disabilities (LEND) near you, please visit:

UCEDD: <http://www.aucd.org/directory/directory.cfm?program=ucedd>

LEND: <http://www.aucd.org/directory/directory.cfm?program=lend>

Local UCEDD(s): _____

Director(s) and Contact Information: _____

Research Projects: _____

Local LEND(s): _____

Director(s) and Contact Information: _____

Research Projects: _____

3) FUNDING:

Local corporations and/or foundations that would be interested in funding research: _____

Possible county grants: _____

Possible state grants: _____

Possible federal grants: _____

Events/fundraisers to use and or create: _____

4) Brainstorm how a Collaboration may Look:

Affiliate's role with the collaboration: _____

Timeframe affiliate can commit to remain involved: _____

Staff member(s) to oversee the management of the collaboration: _____

Any additional staff needed to be hired: _____

Board Members who would play a strong role: _____

Amount of staff/volunteer time required: _____

Budget for the collaboration: _____

Benefits the affiliate and consumers receive: _____

Ways this collaboration helps the affiliate fulfill its mission: _____

Any other UCP affiliates that may be interested in the collaboration with whom you might partner: _____

Any negative consequences to consider: _____

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