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CEREBRAL PALSY RESEARCH



Main Sources of Federal Funding for Cerebral Palsy and Disability Research

- Health & Human Services
 - National Institutes of Health
 - Centers for Disease Control & Prevention
 - Agency for Healthcare Quality & Research
- Department of Education
 - National Institute on Disability and Rehabilitation Research
- National Science Foundation

Cerebral Palsy Research at the NIH

- FY 2008 - \$16 million
 - 0.05 % of total NIH funding
 - 86 active studies among institutes
 - National Institute of Child and Human Health Development (NICHD) - 42%
 - National Institute of Neurological Disorders and Stroke (NINDS) - 47%
 - National Institute of Biomedical Imaging and Bioengineering (NIBIB) - 3 %
 - Other Institutes - 8%

NIH Funding Trends for 4 Childhood Conditions in Millions

	FY06	FY07	FY08	FY09	\$/new case annually
■ CP	\$18	\$16	\$16	\$16	\$1,000
■ MD	\$40	\$47	\$47	\$47	\$78,000
■ CF	\$85	\$82	\$81	\$81	\$81,000
■ Ped AIDS	\$276	\$262	\$263	\$266	\$1.5 M

Types of NIH –funded CP studies active in FY 08

- NINDS

- Basic Research
 - Mechanisms of Pre and Perinatal Brain Injury
 - Stem cell therapy
 - Neurophysiology
 - Neurodevelopment
- Clinical Research
 - Diagnostic - Imaging
 - Early Clinical Trials of Neuroprotective Therapies
 - Outcome Measurement Development
 - Assistive Technology Development
 - Rehabilitation Intervention Development
- Career Awards

NINDS Research Program Areas

- **Channels, Synapses and Neural Circuits**
- **Clinical Trials**
- **Neural Environment**
- **Neurodegeneration**
- **Neurogenetics**
- **Repair and Plasticity**
- **Systems and Cognitive Neuroscience**
- **One Program Announcement Related to CP Motor Disorders in FY08**
 - Understanding and Treating Generalized and Focal Dystonias

Types of NIH –funded CP studies active in FY 08

- NICHD

- Bench

- Mechanisms of Pre and Perinatal Brain Injury
 - Mechanisms of Pre-term birth

- Clinical

- Early Treatment /Prevention of Brain Injury
 - Clinical Evaluation Methods
 - Early Diagnosis
 - Neurorehabilitation
 - Small Clinical Trials of Rehabilitation interventions
 - Outcome Measurement Development
 - Prevention/Treatment of Secondary Complications

- Observational – Risk factors, Genetics

- Career Awards

NICHD Research Program Areas

- Developmental Medicine & Perinatal Medicine
 - Developmental Biology, Genetics, & Teratology
 - Mental Retardation & Developmental Disabilities
 - Pregnancy & Perinatology
- Population Research
 - Contraception & Reproductive Health
 - Demographic & Behavioral Sciences
 - Reproductive Sciences



NICHD Research Program Areas

- Research for Mothers and Children
 - Child Development & Behavior
 - Endocrinology, Nutrition & Growth
 - Obstetric & Pediatric Pharmacology
 - Pediatric, Adolescent & Maternal AIDS
- National Center for Medical Rehabilitation Research
 - Improve mobility
 - Promote behavioral adaptations to functional losses
 - Assessing the efficacy and outcomes to medical rehabilitation
 - Develop improved technology
 - Understand whole body system responses to physical impairments and functional changes
 - Develop more precise methods of measuring impairment, disability and societal and functional limitations
 - Training research scientists in the field of rehabilitation



FY08 NICHD Program

Announcements related to CP

- **Understanding and Treating Generalized and Focal Dystonias (R01 and R21)**
- **Focal Cognitive Deficits in CNS Disorders (R01, R03 and R21)**
- **The Science and Ecology of Early Development**

Other Public Sources...

- CDC
 - Funds public health studies
 - Epidemiological/surveillance
 - Health Promotion
 - 2 Active studies related to CP in FY 08
 - Epidemiological study of reproductive and health outcomes in Denmark
 - Health promotion study to prevent obesity in persons with cerebral palsy, SCI and MS
 - No program announcement for CP from the National Center on Birth Defects and Developmental Disabilities in FY08
- Agency for Healthcare Quality & Research
 - Funds research evaluating health care policy, practice and delivery
 - Has a focus on improving care of the disabled
 - 1 active study in FY 08
 - Surgical outcomes in CP patients

Other Public Sources..

- National Science Foundation
 - Annual \$5 billion research budget
 - RAPD program – Research to Aid Persons with Disabilities
 - 10 studies in FY08 for severely disabled
 - Brain computer interface
 - Tongue-driven AT
 - Shape/memory AFO
 - Voice Recognition of Dysarthric Speech
 - Robot assisted movement



Other Public Sources...

- Department of Education -National Institute on Disability and Rehabilitation Research
 - Has a special emphasis on vocational rehabilitation and AT that makes work possible for the disabled
 - Annual \$100 million research budget
 - 10 Active Studies related to CP in FYo8
 - Assistive Technologies
 - Cognitive Assessment
 - Motor Assessment
 - Rehabilitation Technology
 - Orthotics
 - Prevention of secondary conditions in adolescents

Prevalence vs. Annual Private Funding

- Leukemia – 1 in 25,000/\$315 million
- Muscular Dystrophy – 1 in 20,000/\$175 million
- Pediatric AIDS – 1 in 8000/\$394 million
- Juvenile Diabetes – 1 in 500/\$130 million
- Autism – 1 in 150/\$15 million
- *Cerebral Palsy – 1 in 278/\$2 million*

Sources of Private Funding for Cerebral Palsy and Disability Research

- United Cerebral Palsy Research and Educational Foundation
 - Funds Investigator-Initiated grants at \$50K per year for 2 years
 - Priorities Include
 - Improved diagnosis and/or clinical management of cerebral palsy.
 - Effects of aging on persons with disabilities due to cerebral palsy and the prevention and treatment of increasing disability
 - Development of interventions/therapies to prevent developmental brain damage
 - Mechanisms of brain injury resulting in Cerebral Palsy and other Developmental Disabilities
 - Evaluation of interventions to mitigate disability and improve mobility and function
 - Development and evaluation of research methodologies for use in studies of Cerebral Palsy
 - Funds Career Awards at \$75K per year for 3 years

Other Private Sources...

- Dana Foundation
 - Supports brain research in neuroscience and immunology and their interrelationship in human health and disease.
 - Funding is available for
 - Brain and immunoimaging projects
 - Clinical Neuroscience Research
 - One CP research project is currently funded
- American Academy of Cerebral Palsy and Developmental Medicine
 - Scientific society devoted to the study of CP
 - Clinical Research Planning Grant
 - Student & International Scientist Travel Grants

Other Private Sources...

- March of Dimes
 - A non-profit organization for pregnancy and baby health
 - 2009 RFP
 - basic biological processes governing development, genetics
 - clinical studies,
 - studies of reproductive health
 - environmental toxicology
 - social and behavioral studies
 - *Research that advances understanding of – and therefore our ability to prevent – the cognitive and behavioral risks that affect outcomes of pregnancy, the perinatal period, and subsequent child development*
 - Up to \$120k per year for 3 years
 - Basil O'Conner Starter Scholar Research Award Program
 - Salary for technical support for beginning a research career in birth defects - \$75k per year for 2 years

Other Private Sources...

- March of Dimes cont
 - RFP for the Prematurity Research Initiative
 - Up to \$215k per year for 3 years
 - Research proposals of new paradigms based on strong conceptual frameworks are invited. The intent is to provide new insights into the large, and increasing, proportion of preterm deliveries in which the cause remains elusive. The proposals need to consider especially, but not be limited to, genetics, gene-environment interactions, and animal models.
 - Applicants must be members of not-for-profit institutions.

Other Private Sources...

- Thrasher Research Fund
 - A private non profit research foundation that funds clinical/translational pediatric medical research
 - Emphasis is placed on projects with potential findings that would be clinically applicable in a relatively short period of time for the prevention, diagnosis and/or treatment of pediatric medical problems.
 - Investigator –initiated awards up to \$400k for 3 years
 - Early Career Awards up to \$25 k for 2 years
 - 30 awards made per year
 - Current projects related to CP
 - In vivo assessment of quadriceps muscle plasticity in children with Cerebral Palsy
 - Phase I multicenter clinical trial of early high-dose erythropoietin in term infants with hypoxic-ischemic encephalopathy
 - Hand-Arm Bimanual Intensive Therapy (HABIT) in children with Cerebral Palsy
 - Prevention of immobilization-induced osteoporosis in children
 - A new diagnostic standard for the assessment of swallowing disorders in children
 - Assessing antenatal biomarkers of preterm delivery

Clinical Trials in CP

- 64 active clinical trials listed in NIH Clinical trial registry
 - 25 % are fully or partially funded by Federal sources
 - 10% are fully or partially funded by Shriners' Hospitals
 - 28% are funded by foreign entities
 - 22% are fully or partially funded by Universities
 - 10% are fully or partially funded by Private Foundations
 - <1% are funded by Private companies

Some of the interventions in the registry..

- Treatment of Spasticity
 - 8 Botox Trials
 - Oral baclofen
- Improvement of Motor Function
 - Combination therapies trials
 - Botox + PT
 - Botox + PT + Electrical Stimulation
 - 2 Constraint Induced Movement Therapy trials
 - Neuromuscular Stimulation
 - Body-weight supported treadmill training
- Early Prevention Therapies
 - 2 Magnesium Sulfate trials
 - Erythropoietin



Research Gaps...

- Prevention of CP
 - Mechanisms of neurological damage
 - Studies of neuro-protective pharmacological agents and strategies
 - Studies of agents that encourage neural regeneration
 - Large epidemiological studies examining environmental and/or practice factors that may be contributing to brain damage in newborns
 - Genomic and biomarker studies to identify babies at –risk for CP before symptoms are manifested

Research Gaps...

- Improving motor and cognitive function
 - Studies of Mass Practice and Robotic Therapy
 - Exploring Virtual Reality Technologies in conjunction with motor and intellectual learning
 - Studies of functional neuromuscular stimulation in combination with
 - Mass practice/robotics
 - Focal anti-spasticity treatment
 - Virtual reality/computer environment stimulation
 - Non-invasive Neuroimaging



Research Gaps...

- Adults with CP
 - Long –term health outcomes studies of interventions from childhood
 - Methods to keep adults ambulatory and improve cardiovascular fitness
 - Epidemiological studies to ascertain the magnitude of medical and orthopedic complications in this population
 - Health services research to ascertain best practice of care as children with CP transition to adulthood

Thank you for your attention

- Founded in 1955, United Cerebral Palsy Research and Educational Foundation (UCPREF) has always stood for “hope through research” for all affected by cerebral palsy. UCPREF has supported research that has had international impact, including developing the vaccine for rubella, virtually eradicating one cause of CP throughout the world. Visit our website www.ucpresearch.org to learn more.